DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 2005

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

NONDEPARTMENTAL WITNESSES

[CLERK'S NOTE.—The subcommittee was unable to hold hearings on nondepartmental witnesses. The statements and letters of those submitting written testimony are as follows:]

DEPARTMENT OF LABOR

PREPARED STATEMENT OF THE ASSOCIATION OF FARMWORKER OPPORTUNITY PROGRAMS

Good morning Chairman Specter and members of the subcommittee. My name is David Strauss and I represent the 50 nonprofit and public agencies that provide job training and related services to our nation's migrant and seasonal farmworkers.

About 3 million people labor in the fields and farms of America, from Hawaii to Florida and Puerto Rico, from Maine to California. Estimates are that 85 percent of the fruits and vegetables we eat are hand harvested by farmworkers. The pay is extremely low: most farmworkers earn less than $12,000 per year. Few farmworkers receive the job-related benefits, such as health insurance and sick pay, which we all take for granted. In most states, agricultural workers are not even eligible for unemployment compensation. They live a tough life. Many workers travel hundreds, sometimes thousands of miles in search of work. They get paid only when they perform the work: if the weather is bad or the crop is not as plentiful as the farmer had hoped, they simply do not receive wages. They typically cannot afford decent housing. Their children have to struggle mightily to even complete their public school education. The dropout rate for farmworker youth, especially those who migrate with their parents, is enormous.

For over 33 years the federal government has made and kept a commitment to these hardworking people. Special federal programs were created to recognize the reality that farmworkers often cross state lines to work and live. Thus, we have migrant head start, migrant health, migrant education, and the job training effort called the National Farmworker Jobs Program. These all are federally funded and have guidelines that acknowledge that Governors should not be placed in a position of deciding whether or not agricultural workers qualify for these services under state residency or other localized requirements.

Today, I want to talk with you about the last program I mentioned: the National Farmworker Jobs Program, referred to in the budget as the migrant and seasonal farmworker job-training program. This program serves about 25,000 farmworkers each year, a very small percentage of the eligible total. Most of the customers are Hispanic; all must be American citizens or possess valid work authorization documents.

It is an extraordinary program on several counts: it is the most successful program that the Department of Labor funds. In its most recent national report, this program outperformed all others, including the Job Corps, the Dislocated Workers program, the Older Americans program, and so on. The program is operated by non-

profit and public organizations that typically have to serve an entire state with ever-diminishing funds. In fact, they have to compete for the grants.

Yet, they are able to hire staff who are bilingual, are culturally sensitive, and are skilled at serving people with significant barriers to career advancement. Characteristics such as low English proficiency, low education levels, and extreme poverty present significant challenges to case managers who must help farmworkers find a path to a more stable and better paying career. And they do. Staff of the National Farmworker Jobs Program reach out to farm laborers in camps, fields, churches, community centers: wherever necessary to meet the needs of these hardworking people. The hours they work and the locations in which they provide services must be flexible, for during a harvest, farmworkers may toil from sunup to after sundown.

The results are excellent: over 83 percent of farmworkers who wanted training and a new job got one, and their average wage gains exceeded $4,400 per year. That data comes from the Department of Labor, not from our Association. Despite this excellent performance, despite the incredible efforts of dedicated staff and despite the commitment of program operators to achieve their goals with diminishing resources, the Department of Labor (DOL) seeks to eliminate this program in its budget request for 2005. DOL contends that the program is ineffective, that it duplicates the services available to farmworkers in the One Stop Career Centers, and that it spends too much time and money on supportive services. They are incorrect.

Now, DOL stated the same rationale in its 2003 and the 2004 budget requests, and you rejected it. Instead, you funded the program at just under the 2002 level in those years. Members of the Association of Farmworker Opportunity Programs and I have met with Department leaders on several occasions to educate them on how the program works and to explain how effective it is. Now we have DOL's own report that illustrates that it is their best job-training program. Yet they continue to resist your instruction to maintain the National Farmworker Jobs Program.

Since I can only speculate on why the Department persists in this stance, I will answer their three claims. First, as I said earlier the program is amazingly effective, especially when you also consider that many programs operate in counties with some of the highest unemployment rates in the country. I would like to submit relevant portions of the Workforce System Results as of September 30, 2003 issued in mid-January of this year as proof of our success.

Secondly, this program does not duplicate services in the One Stop Career Centers. The One Stop system created in the Workforce Investment Act of 1998 represents an improvement in training and placement services for job seekers. In fact, NFJP agencies are mandated partners in that system. Labor Secretary Elaine Chao may not be aware that most of our members have memoranda of agreement with their state's workforce boards, and participate in the One Stop Centers. But many rural areas do not have One Stop centers that are easily accessible to those who work in the fields. Further, these centers seldom operate outside normal business hours, and they have no program of outreach to hard to serve agricultural workers. One Stops are held to program measures that work against serving people with less than 10th grade educations. And many rural One Stop Centers simply do not have staff who can converse in Spanish, Creole, Vietnamese or other languages that farmworkers in particular areas may speak. It would be a great mistake to assume that removing the NFJP agency from the One Stop partnership would improve services to farmworkers, as DOL has suggested. In fact, ending the NFJP would, I am certain, end job-training services to farmworkers in most of this nation. And that would be a great tragedy, for this program represents access to the American Dream for migrant and seasonal farmworkers. Whether they choose to build their careers in agriculture or in another industry, they deserve the opportunity to achieve a better life through training and job placement.

Finally, DOL claims that our members spend too much time and money on what we call related assistance—services that help a farmworker prepare for training or stabilize their economic situation while they continue to work in agriculture. First, the data: last year, about 8.5 percent of grant funds were spent on related assistance, while over 81 percent went for job training and placement services. Now, it is true that a majority of the farmworkers nationwide who participated in our program received such assistance and no training. However, in states such as California, Texas, Washington, and Arizona you will find that a healthy majority of customers received job training and placement. In states to which farmworkers migrate and work for relatively brief periods, they tend to receive more life-sustaining services such as emergency shelter, car repair vouchers, or food. Again, I remind the committee that farmworkers do not have the same safety net as the rest of us: no unemployment insurance, for example. And when they migrate, they are often in places that have residency requirements for assistance.

I dwell on this point because this seems to me to be a particularly cruel and insensitive criticism of our members' activities—they are charged by the Section 167 of the Workforce Investment Act with providing related assistance, and for good reason. And I think members of the agricultural industry would be unpleasantly surprised to learn that DOL thinks it is wrong to help a worker who plans to harvest a crop. Sometimes that help prevents homelessness. Sometimes the help consists of English language training so the farmworker can better understand the job he/she must perform. Sometimes it consists of pesticide safety training, which enables farmers to legally employ people who must be certified in such safety before they can work amidst dangerous chemicals.

The Office of Management and Budget has issued an "analysis" of the NFJP that is as flawed as the Department of Labor's statements. Rather than going into it in detail today, I will instead ask you to accept our analysis and rebuttal of their Performance Assessment Rating Tool.

In closing, I reiterate: the National Farmworker Jobs Program does an excellent job by the Department's own assessment. More importantly, the program operators are keeping faith with the charge that you gave them when you enacted the Workforce Investment Act in 1998. This program represents a path to the American Dream for our country's lowest paid and hardest working people. Please don't let them down. Maintain the National Farmworker Jobs Program in the appropriation for the Department of Labor for 2005. Thank you for this opportunity to present testimony today.

For more information contact: David Strauss, AFOP, 4350 N. Fairfax Drive, Suite 410, Arlington, VA 22203 Telephone: 703–528–4141, ext. 101 email: strauss@afop.org

---

PREPARED STATEMENT OF RURAL OPPORTUNITIES INC.

Honorable Chairman, Senator Arlen Specter, and Honorable Committee Members: I would like to sincerely thank you for this opportunity to present testimony to the Senate Appropriations Subcommittee for Labor, Health and Human Services, and Education.

I am submitting this testimony on behalf of Rural Opportunities Inc., provider of the National Farmworker Jobs Program (NFJP) services to Migrant and Seasonal Farmworkers in Pennsylvania, New York, New Jersey and Ohio. NFJP is funded under Section 167 of the Workforce Investment Act (WIA). I am requesting that the Subcommittee recommend full restoration of funding for this initiative at $80 million for Federal fiscal year 2005.

Historically, Congress has recognized the need for a nationally-administered program to serve Migrant and Seasonal Farmworkers. The mobility and unique socioeconomic characteristics of these workers leave them unserved or under-served by any other workforce program convention. This fact is clearly evident, as each Congress since 1973 has passed an Act designating specific programs to serve Farmworkers: the Comprehensive Employment and Training Act (CETA), the Job Training Partnership Act (JTPA) and most recently, the Workforce Investment Act (WIA). WIA was passed as a direct result of the work done by you and your colleagues, and we thank you.

Today, although almost 6 years have passed since WIA was implemented, nothing has changed that should alter the intent demonstrated by the establishment and continuation of this program effort to serve the Farmworkers of this nation. Unfortunately, as grantees—and foremost as advocates—for Farmworkers and their needs, we have found ourselves continuously defending the Farmworker program and advocating for adequate funding. We also have recognized that, although Congress has clearly demonstrated its wishes in EVERY jobs program since 1973, the U.S. Department of Labor continues to zero out funding for this vital program, while at the same time hailing it as one of their most successful.[1]

Although it may seem cliché in 2004, we are still forced to ask the question: "Are Farmworkers better served today than they would be if no program existed?" The answer is an unqualified "Yes." NFJP nationally had an 84.6 percent successful placement rate (Entered Employment Rate) for Farmworkers who entered training in PY 2002 (July 2002 to June 2003).[2] According to USDOL statistics as of 30 September 2003, ROI—across our entire service area—had a 100 percent success rate in placing Farmworkers in jobs after training.

---

[1] Workforce System Results, www.dol.gov, page 6.

[2] PY 2002 Preliminary Grantee performance for the NFJP, wdsc.doleta.gov/msfwPY02.

Why does the Office of Management and Budget in their program analysis question the actions of Congress in establishing emergency and supportive services? We are directed by Section 167 of the Workforce Investment Act to provide emergency and supportive services to stabilize the agriculture workforce. Ensuring that our nation's agricultural employers continue to have access to a stable agricultural workforce required less than 9 percent of the total funds appropriated for the NFJP. Agricultural stabilization services that meet the short term emergency needs of Farmworkers enable them to be available for work in our nation's fields at peak harvest times.

With regard to the impact of NFJP job placement, ROI statistics[3] for PY 2002 show an average wage gain of $5,611 in Pennsylvania, $4,372 in New York, $6,519 in New Jersey and $3,925 in Ohio. The national average across all NFJP programs for the same wage measure is $4,413.[4] Ironically, the average wage gain reported by the One Stop system for the same period was only $3,094,[5] while serving a population confronted by far fewer barriers to employment.

As compelling as this economic information is, nothing speaks louder than the words of the participants, your constituents, who have begun to experience the American dream. I have requested and received permission from some of our participants to use their stories in this testimony.

To set the background for these stories, let me describe the typical Farmworkers served in the NFJP programs Rural Opportunities Inc. operates. The average participant is a young Hispanic male or female. Of those served in PY 2002, 91.6 percent were Hispanic, 64.7 percent were 21–44 years old, 71.5 percent had limited English speaking skills and 84.8 percent dropped out during or before high school. Most were members of families who had been working in agriculture since their birth. In fact, over 69 percent knew agriculture as their only work experience. These are the very characteristics that would preclude our program participants from being served by the local One Stop.

Ofelia Carmona is an Hispanic woman aged 41. She was born into a Farmworker family. At age 6, she began working in the fields with her 13 brothers and sisters. Married at age 14, Ofelia dropped out of school and began migrating with her husband, and soon children, to the fields and orchards of the Northeast. While pregnant with her 4th child, she and her husband decided they wanted more for their children. With the help of Rural Opportunities Inc., Ofelia pursued her GED. She attended GED class in the morning and work experience at a Migrant Health Clinic each afternoon. After completing her GED, Ofelia was hired full-time by the Clinic. But she was not through with her efforts; Ofelia returned to Community College and, while continuing her full-time employment, obtained a Nursing Assistant Associates Degree. Today, Ofelia is the Director of a Migrant Head Start Center and is working to achieve a Bachelors Degree in Early Childhood Education.

Juan Luna's story is not unlike that of Ofelia; Juan is a 36-year-old Hispanic male. He dropped out prior to completing high school, had limited English speaking skills and no transportation, and his only work experience had been as a migrant following the crops. He was not in a position to enter the traditional job market. ROI began by helping Juan access English as a Second Language classes. Then, when his English skills had begun to improve, ROI assisted him in entering Occupational Skills Training at the Metal Working Institute, where he learned the skills to become a Machinist. Today, Juan is employed with the Hauser Corporation as a machine operator and will soon complete his second year on the job.

Cipriano Rodriguez migrated from Mexico 12 years ago to pick apples. Discouraged by the poor pay, he finally left farm work after many years for a factory job, although his interest in agriculture remained strong. Learning of the services provided by Rural Opportunities, Inc., he established the goal of obtaining his Commercial Driver License and returning to agriculture—and his love for the land. He completed training and passed the required tests, and was able to obtain year-round employment at a large farm in the Hudson Valley, driving produce to processing and storage facilities. Four years ago, he became a United States citizen.

Ofelia, Juan, Cipriano . . . these are not the customers of the traditional One Stop system. These are the customers of the National Farmworker Jobs Program grantees. They are not unlike the 328 participants ROI assisted to gain full-time, year-around employment in PY 2002.[6]

---

[3] Rural Opportunities Inc. Management Information System, PY 2002.
[4] Workforce System Results, www.dol.gov, page 6.
[5] Workforce System Results, www.dol.gov, page 7.
[6] www.workforceatm.org

NFJP program served 5,612 Farmworkers in PY 2002 nationwide.[7] Without NFJP, who would serve these individuals? The One Stop system? The same system that served less than 1 percent of this population in PY 2002? The One Stop system does not have language or culturally appropriate staff and cannot be expected to develop appropriate staffing in a few short months. The One Stop system does not do outreach to overcome Farmworkers' barriers to services, such as lack of transportation, isolation, and sunrise to sunset workdays. Nor can Farmworkers, if they somehow manage to access the One Stop system, be expected to use a computerized system for job search assistance and labor market information—a system targeting high school graduates, an education level far beyond that attained by the average Farmworker.

Throughout our history, Rural Opportunities Inc. has always sought to assist Farmworkers in achieving their dreams by placing them in jobs of their choosing—within or outside of agriculture. Often Farmworkers wish to upgrade skills to stay on the farm and find a full-time job in agriculture or an agriculture-related industry. In PY 2002, agricultural upgrades accounted for 30 percent of all of the jobs in which ROI assisted Farmworkers to find placements. In Pennsylvania, we have achieved significant success in the past by working with the Mushroom Industry to design and implement job training. In New York, we have done the same with the Dairy Industry. ROI continues to experience high demand from Farmworkers for training in welding and in obtaining Class I Licenses, both of which secure higher paying year-round employment on the farms. Ironically, a concern we often hear from those in Agriculture and Ag-related Industries is that their interests are not met by the primarily urban or village-based One Stop System. Although as a case management and individual skills-based effort NFJP does not train as many Farmworkers for skilled farm positions as the Industry would like, NFJP does address the Industry's needs.

In his March 2004 presentation to the ROI Board of Directors, George Lamont, a New York State Grower and Executive Director of the New York State Horticultural Association, presented his hierarchy of needs for the Farmworkers he employs: Job Skills Training and English as a Second Language were two of the top three.

The One Stop Delivery System often has recognized how under-equipped it is to meet the needs of the Farmworker population and supports the continuation of the National Farmworker Jobs Program, as evidenced in the following excerpts:

—Your agency's interaction with migrant and seasonal farmworkers, a population that is traditionally underserved by other agencies, is integral to their well-being.[8]

—We realize that without the services provided by the NFJP, farmworkers would not have access to training and job placement outside of agriculture due to the multi-barriers many of them possess. The removal of these barriers requires staff that has the skills and cultural sensitivity to assist this special population as well as those who can provide services evenings and weekends to meet the critical demand of migrant and seasonal farmworkers.[9]

—You have provided these services and truly changed the lives of hundreds of farmworkers by providing needed tools that lead to self-sufficiency for them and their families.[10]

—Your agency staff has the needed skills and cultural sensitivity to assist this population to overcome barriers pertaining to self-sufficiency for themselves and their families.[11]

The National Farmworker Jobs Program grantees have developed a sophisticated service delivery infrastructure in the past 30+ years, capable of meeting farmworkers' needs and generating high levels of success. As an NFJP grantee, Rural Opportunities Inc. has built a support structure of additional resources that allows us to leverage NFJP dollars—for every $1 provided by NFJP, we can bring an additional $3 to bear on the host of problems faced by Farmworkers in each state we serve. The NFJP is more successful because of this and the Farmworker population

---

[7] www.workforceatm.org

[8] Joseph Kuchere, Workforce Investment Board Chair, Niagara County Workforce Investment Board, letter of support, 2003.

[9] Ana Maria Murabito, Council of Industry of Southeast New York, letter of support, 2003.

[10] Ibid.

[11] Glenn L. Decker, Commissioner of Social Services, Ulster County, letter of support, 2003.

is far better served. ROI has been recognized for the fact that 96 cents of every funding dollar go to client services.[12]

In closing, ROI requests that the Subcommittee recommend an appropriation of $80,000,000—restoring the NFJP program to full funding and recognizing the enormous potential of the NFJP program grantees. Though this appropriation will not ensure that every eligible Farmworker receives the services needed, it will enable the program to hold its ground in providing high quality, culturally appropriate services to this population so desperately in need.

PREPARED STATEMENT OF THE CALIFORNIA WORKFORCE INVESTMENT BOARD

My name is Morgan Clayton, Chairman of the Kern County California Workforce Investment Board. I whole-heartedly support the continued funding of the National Farmworkers Jobs Program, as authorized in section 167 of the Workforce Investment Board (WIA). While our Board represents a Grantee for this program, we also serve as the Local Area for the WIA formula-funded programs in the California counties of Kern, Inyo and Mono. From this unique perspective we have come to appreciate the need for the National Farmworker Jobs program and urge its continued full funding in fiscal year 2005 and beyond.

In providing services to both Farmworkers and the general population for more than 20 years, it has become clear that the farm workers have unique needs in the areas of basic skills, Vocational English-as-a-Second Language, job training and access to available services. A separate program ensures that these needs continue to be addressed. While we continue to enjoy many successes in serving farm workers through our network of rural one-stop career centers, those one-stops simply could not exist without a serious commitment of federal funding to targeted rural workers, especially farm workers.

On behalf of the Workforce Invest Board of Kern County, I am adding our support for the continued, full funding of the National Farmworker Jobs Program.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF STATE WORKFORCE AGENCIES

Chairman Specter, Senator Harkin, and distinguished Members of the Subcommittee. On behalf of the National Association of State Workforce Agencies, I thank the Subcommittee for the opportunity to share information on the contributions our members provide in strengthening our nation's economy by linking workers and jobs. The members of our association constitute state leaders of the publicly-funded workforce investment system vital to meeting the employment needs of business and workers. It is the funding you appropriate that makes much of the workforce system services and infrastructure possible.

Mr. Chairman, the nation's publicly-funded workforce system continues to build on the critical link between businesses in need of employees and workers in need of employment. The state agencies administering job training and employment assistance programs throughout our country are cognizant of the need to provide effective services. We recognize it is no longer enough to wait for a dislocated worker to walk through the door of our one-stop offices, or for the phone to ring from a prospective employer in need of skilled workers. Instead, the workforce system is transforming its operations to meet employer demands for skilled workers in the 21st century.

One can look at the latest Workforce System Results report published by the Employment and Training Administration (ETA) for evidence of our workforce system's performance and continued improvement. This report shows state workforce programs "are either meeting their Government Performance and Results Act (GPRA) goals, or have improved their performance from the previous year." These results were achieved while our nation's economy continues its recovery with sustained high demand on our system. Although the system continues to improve, we are concerned the upward trend in performance might level off in the near future if it does not obtain sufficient resources to meet an ever-growing demand.

A recent survey of state workforce agency administrators yields a consistent concern that the infrastructure needed to maintain services business and workers have come to expect is aging and in need of repair. We are becoming increasingly aware of limitations to the expectation that we can do more with less and the effect of level

---

[12] Rochester Business Journal, Non-profit Agencies Vary Widely in Outlay for Overhead Expenses. January 4, 2002; Volume17; Number 40.

or reduced funding on the quality and quantity of our services. Although we strive to continue improving our service levels regardless of our annual appropriations, under funding of our programs makes state decision-making harder and ultimately can lesson the quality and quantity of services we will be able to provide.

STATE UNEMPLOYMENT INSURANCE ADMINISTRATION GRANTS

The Social Security Act requires the Secretary of Labor to allocate grants to states that are necessary for proper and efficient administration of their unemployment insurance programs. However, the President's budget has not proposed sufficient amounts and Congress has often appropriated less than the President's insufficient request for many years. The result is states often receive less than is necessary for proper and efficient administration of their unemployment compensation programs.

Insufficient funding has forced many states to delay indefinitely technological upgrades. Many states are unable to automate their aging benefits and tax systems. The inability to improve infrastructure hampers states ability to combat fraud, such as identity theft and unemployment tax evasion.

NASWA's request for state administration of unemployment compensation in fiscal year 2005 exceeds the Administration's request by $439 million, totaling $3.140 billion. This amount is estimated to be necessary for the states to operate their unemployment compensation programs properly. We believe this amount is necessary because a new budget formulation and allocation system, known as the Resource Justification Model (RJM), provides estimates of the amounts states need for proper and efficient administration of the UI program.

NASWA also requests Congress enact an immediate transfer of $9 billion as a special Reed Act distribution to state trust fund accounts to improve trust fund solvency, avoid employer tax hikes, and improve UI administration, employment services and unemployment benefits. Unemployment trust fund solvency has continued declining during the past year. State unemployment trust fund balances fell from $51.57 billion on September 30, 2001 to $28.13 billion on September 30, 2003. Benefits increased from $27.35 billion in fiscal year 2001 to $41.8 billion in fiscal year 2003. Six months ago, one state borrowed to maintain trust fund solvency. Today eight states are borrowing. Many other states are planning to borrow or substantially increase state unemployment taxes or cut unemployment benefits to maintain trust fund solvency.

If a transfer of $9 billion as a Reed Act distribution does not occur in the next five months, many states will be forced to borrow, cut benefits, or collect additional revenue through state unemployment payroll taxes on employers. Collection of additional employer taxes is unnecessary given the $19.9 billion balance credited to the federal unemployment trust fund accounts. Using already-paid employer unemployment taxes for the UI and ES programs is a far better purpose during this period of high unemployment than merely maintaining balances in federal trust fund accounts.

Mr. Chairman, as you know the workforce system received an $8 billion Reed Act distribution in 2002. Some in Congress and the Administration have said states are "sitting" on these funds, not using them in valuable ways. We can assure you that this is not the case. A recent survey of NASWA members found states have used all of the 2002 distribution for economic stimulus, improved UI benefits and administration and employment services. The $8 billion allowed states to cut unemployment payroll taxes for employers by more than $4 billion and improve state unemployment trust fund solvency, unemployment insurance administration and employment services. A Reed Act distribution in 2004 would stimulate further the economy by allowing many states to avoid raising employer taxes that will increase the cost of hiring new employees and slow the rate of job creation.

WORKFORCE INVESTMENT ACT & EMPLOYMENT SERVICE PROGRAMS

ETA Assistant Secretary DeRocco recently said in her testimony before this subcommittee, the WIA programs that are delivered by the state and local workforce partners continue to meet or substantially meet the majority of their established performance targets this past year. Some 83 percent of adults and 89 percent of dislocated workers were still working in the third quarter following receiving services against respective GPRA targets of 80 percent and 88 percent respectively. After receiving services, adults increased their annual earnings on average by $3,030 and dislocated workers averaged 88 percent of their pre-dislocation earnings.

For older youth ages 19 to 21 receiving services by the publicly-funded workforce system, 70 percent were employed in the first quarter after receiving services. Sixty-three percent of younger youth (ages 14 to 18) who entered the program without

a high school diploma or equivalent, attained a diploma or equivalent by the first quarter after receiving services.

In order to meet the needs of both workers and businesses over the coming year, NASWA recommends the following funding levels for WIA programs for fiscal year 2005: $1.5 billion for dislocated worker state allocations; $950 million for adult training; and $1.128 billion for youth training activities. These amounts represent the funding levels allocated for the system in fiscal year 2002.

Our members are concerned about the Administration's proposed funding cut of $91 million to Employment Service (ES) programs and the elimination of the $35 million for Reemployment Services. Funding for employment services has not been increased in over 8 years. However, most states have supplemented their budget with state or Reed Act funds. While NASWA members can support funding for new initiatives proposed by the Administration ($250 million for Community Colleges, $50 million for piloting Personal Reemployment Accounts, and $35 million for the Prisoner Reentry Initiative), they are concerned about reductions to existing programs.

NASWA requests $330.5 million more than was requested by the Administration for fiscal year 2005 employment service state allotments for a total of $991.7 million. In many parts of the country, the one-stop career centers are built on the ES program. The Administration, state workforce agencies, and local One-Stop centers have accepted a new focus on the business customer. The majority of services provided to the business community have been provided with ES funds. During the period ending December 31, 2003, the ES provided service to 9.2 million applicants.

TRADE ACT FUNDING

Each year, many states deal with a shortfall of funding for worker training benefits under the Trade Act. States have been forced to freeze spending and turn many workers away. Turning workers away has become especially prevalent over the past few years as the number of trade impacted workers rises. We look forward to working with Congress on finding sufficient spending levels for trade programs in fiscal year 2005.

LABOR MARKET INFORMATION

NASWA supports a return to ETA's earlier investment levels of $150 million for one-stop/America's Labor Market Information System (ALMIS) funding. The importance of adequate funding to state agencies for labor market information has intensified as states attempt to work with the Administration on its new "high growth job training initiative." State and local labor market information and high quality employment projections are critical to the identification of industry sectors and occupations where the employment growth will occur and ensure that training dollars are wisely invested.

NASWA also calls for the Administration's leadership and support for funding of the new collaborative effort between the Bureau of Labor Statistics and the Bureau of Census to develop a unified wage record program. This new effort will afford better measurement of program performance and improved understanding of the labor market.

VETERANS EMPLOYMENT AND TRAINING PROGRAMS

Two year's ago, Congress approved the Jobs for Veterans Act, giving states greater flexibility to serve their veteran populations. NASWA supported many provisions in this legislation, especially those that gave states more flexibility in integrating the veterans' employment and training programs into the one-stop career center system.

The Jobs for Veterans Act requires states to submit to the Secretary of Labor, "a plan that describes the manner in which the state shall furnish employment, training, and placement services required under this chapter for the program year." NASWA members believe the annual plan required by the Jobs for Veterans Act will be greatly improved by moving the funding for these programs from a fiscal year to a program year funding cycle. By transitioning funding to a program year (July 1 to June 30) and aligning it with most other employment and training programs, the plans that state workforce agencies submit to the Department will reflect future program year services based on established budget outlays. Program year funding supports integrating VETS-funded programs into WIA one-stop career center systems and planning and performing on the same cycle as other one-stop partners. The workforce system looks forward to another year of high performance and improvement. NASWA greatly appreciates your support. Thank you for considering our request.

PREPARED STATEMENT OF THE NATIONAL YOUTH EMPLOYMENT COALITION

On behalf of the National Youth Employment Coalition (NYEC) and its more than 270 members, I am writing to thank you for being the champion for the Department of Labor's Reintegration of Young Offenders program. If not for your heroic efforts, this small, yet important program would have ceased to exist years ago.

As you know, the Administration's fiscal year 2005 budget proposes to supplant the $49 million Reintegration of Young Offenders program with a new $90 million Prisoner Reentry Program. While NYEC applauds the Administration for its commitment to helping adult prisoners successfully return to society, details are still vague about how or whether this new program would involve young offenders. Additional resources to help reintegrate adult prisoners to society should not come at the expense of existing programs that help reintegrate incarcerated youth and prevent other court-involved youth from recidivating and being incarcerated.

According to the Bureau of Justice Statistics, approximately 120,000 youth under the age of 18 are currently incarcerated in juvenile detention centers, state prisons, and local jails. Most will be released in the next few years. While youth in general are being hard hit by the sluggish economy, court-involved youth face additional barriers to employment. There is a growing consensus among youth development experts that youth who come under court supervision have multiple issues that must be addressed in comprehensive and coordinated ways, if they are to attain employment at wages that will sustain a constructive life path. DOL's Youth Offenders Demonstration grantees provide coordinated services to young offenders, gang-involved youth, and at-risk youth to help them find employment, reduce dependency, and break the cycle of crime and recidivism. Court-involved youth who are at-risk of being incarcerated, and youth already in secure facilities receive training and employment opportunities in addition to education; substance abuse treatment as needed; mental health services; aftercare; housing assistance and family support services; and juvenile justice supervision. Several of our members have received competitive grants through the Reintegration of Young Offenders program in the past and many others plan to apply when the Department of Labor announces that funds are available for the fiscal year 2003 grant cycle.

We must sustain our national investment in services and support for court-involved youth to enable these youth to positively contribute to their communities. Without resources such as the Responsible Reintegration of Young Offenders program, many more will fail to successfully transition into productive employment and instead will join the more than 2 million people currently incarcerated.

Again, thank you so much for your long-standing commitment to court-involved youth.

PREPARED STATEMENT OF THE NATIONAL YOUTH EMPLOYMENT COALITION

The National Youth Employment Coalition (NYEC) is a network of over 270 youth employment, education, and development organizations dedicated to promoting policies and initiatives that help young people succeed in becoming lifelong learners, productive workers and self-sufficient citizens. We urge you to increase federal funding for youth employment/development programs under the Workforce Investment Act (WIA). In addition, we urge you to restore funding for the Reintegration for Young Offenders Program to its fiscal year 2003 level of $54 million, and ensure that these funds continue to be targeted at helping reintegrate incarcerated young offenders and prevent court-involved youth from recidivating or being incarcerated.

We understand that this year's federal budget is particularly tight and we face a historically large deficit. However, our nation is facing a silent crisis—hundreds of thousands of youth are not being provided the opportunities they need to develop the academic and job skills they need to succeed in the 21st century workplace. We continue to hear reports that youth are having difficulty finding jobs in this sluggish economy because many employers are hiring adults for jobs for which they would hire youth in a tighter labor market. These reports are confirmed by the Bureau of Labor Statistics' January 2004 data, which shows that youth (age 16 to 19) have lost more than one million jobs since January 2000; and only 34 percent of youth were employed (part- or full-time) in January 2004—marking the lowest youth employment rate for the month of January since 1965.

Despite record levels of youth joblessness, combined federal funding for the WIA youth formula and the Youth Opportunity Grant Program has been cut by more than 26 percent—from $1.352 billion in fiscal year 2002 to $995 million in fiscal year 2004. The Administration's fiscal year 2005 budget proposes a slight increase to $1.001 billion for the WIA youth formula; however, the House WIA reauthorization bill and the President's reauthorization plan propose using 25 percent of the

formula funds to launch a new National Challenge Grant program. While we support new programs that help youth prepare for jobs and careers and prevent them from dropping out of school, funding for such a new program should not come at the expense of current programs that are already stretched to the breaking point.

We cannot afford to allow our nation's youth development/employment system to erode further. Therefore we were very pleased to learn that the Senate's fiscal year 2005 budget resolution includes an amendment, sponsored by Senators Enzi (R-WY) and Cantwell (D-WA), that would increase WIA funding by $250 million in fiscal year 2005. We urge you this year to begin increasing funds for the WIA youth formula to restore funding to the $1.4 billion level. An additional $250 million should be provided in the event that the new National Challenge Grant program is authorized as a result of WIA reauthorization.

The Administration's fiscal year 2005 budget also proposes to supplant the $49-million Young Offenders program with a new $90-million Prisoner Reentry Program. While NYEC applauds the Administration for its commitment to helping prisoners successfully return to society, details are still vague about how or whether this new program would involve youth. Additional resources to help reintegrate adult prisoners to society should not come at the expense of existing programs that help reintegrate incarcerated young offenders and prevent court-involved youth from recidivating or being incarcerated. At minimum, funds currently targeted at court-involved youth under the Reintegration for Young Offenders Program should be maintained to fiscal year 2003 levels ($54 million) and set aside for young offenders within the structure of the new prisoner reentry program.

According to the Bureau of Justice Statistics, approximately 120,000 youth under the age of 18 are currently incarcerated in juvenile detention centers, state prisons, and local jails. Most will be released in the next few years. While youth in general are being hard hit by the sluggish economy, court-involved youth face additional barriers to employment. There is a growing consensus among youth development experts that youth who come under court supervision have multiple issues that must be addressed in comprehensive and coordinated ways, if they are to attain employment at wages that will sustain a constructive life path. DOL's Youth Offenders Demonstration grantees provide coordinated services to young offenders, gang-involved youth, and at-risk youth to help them find employment, reduce dependency, and break the cycle of crime and recidivism. Court-involved youth who are at-risk of being incarcerated, and youth already in secure facilities receive training and employment opportunities in addition to education; substance abuse treatment as needed; mental health services; aftercare; housing assistance and family support services; and juvenile justice supervision.

We understand that you face difficult decisions this year as you seek to spread limited federal resources for a range of national needs. Yet we must sustain our national investment in services and support disadvantaged youth to enable these young people to positively contribute to their communities. Without resources such as the WIA youth formula and the Responsible Reintegration of Young Offenders program, many more will fail to successfully transition into productive employment.

We thank the Committee for its attention to these important programs for our youth and our emerging workforce.

PREPARED STATEMENT OF THE NATIONAL COALITION FOR HOMELESS VETERANS

INTRODUCTION

The National Coalition for Homeless Veterans appreciates the opportunity to submit recommendations on fiscal year 2005 appropriations for and program management issues related to the U.S. Department of Labor (DOL).

The National Coalition for Homeless Veterans (NCHV), established in 1990, is a nonprofit organization with the mission of ending homelessness among veterans by shaping public policy, promoting collaboration, and building the capacity of service providers. NCHV's nearly 250 member organizations in 42 states and the District of Columbia provide housing and supportive services to homeless veterans and their families, such as street outreach, drop-in centers, emergency shelter, transitional housing, permanent housing, recuperative care, hospice care, food and clothing, primary health care, addiction and mental health services, employment supports, educational assistance, legal aid and benefit advocacy.

The VA estimates that more than 299,000 veterans are homeless on any given night; more than 500,000 experience homelessness over the course of a year. Conservatively, one of every three homeless adult males sleeping in a doorway, alley, box, car, barn or other location not fit for human habitation in our urban, suburban,

and rural communities has served our nation in the Armed Forces. Homeless veterans are mostly males (2 percent are females); 54 percent are people of color. The vast majority are single, although service providers are reporting an increased number of veterans with children seeking their assistance; 45 percent have a mental illness; 50 percent have an addiction.

America's homeless veterans have served in World War II, Korea, the cold war, Vietnam, Grenada, Panama, Lebanon, anti-drug cultivation efforts in South America, Afghanistan, and Iraq. 47 percent of homeless veterans served during the Vietnam Era. More than 67 percent served our nation for at least 3 years and 33 percent were stationed in a war zone.

Male veterans are twice as likely to become homeless as their non-veteran counterparts, and female veterans are about four times as likely to become homeless as their non-veteran counterparts. Like their non-veteran counterparts, veterans are at high risk of homelessness due to extremely low or no income, dismal living conditions in cheap hotels or in overcrowded or substandard housing, and lack of access to health care. In addition to these shared factors, a large number of at-risk veterans live with post traumatic stress disorders and addictions acquired during or exacerbated by their military service. In addition, their family and social networks are fractured due to lengthy periods away from their communities of origin. These problems are directly traceable to their experience in military service or to their return to civilian society without appropriate transitional supports.

Contrary to the perceptions that our nation's veterans are well-supported, in fact many go without the services they require and are eligible to receive. One and a half million veterans have incomes that fall below the federal poverty level. Neither the VA, state or county departments of veteran affairs, nor community-based and faith-based service providers are adequately resourced to respond to these veterans' health, housing, and supportive services needs. The VA plays only a limited role in providing employment services to veterans, administering just one small supported employment program for veterans with serious disabilities.

The U.S. Department of Labor and state and local workforce agencies bear primary responsibility for ensuring that veterans are provided opportunities to prepare for and obtain productive employment. Accordingly, we urge Congress to provide full funding for the programs of the Department of Labor Veterans Employment and Training Service (VETS) in order to ensure that our nation's workforce services system is equipped to fulfill their obligations to our nation's veterans.

FISCAL YEAR 2005 APPROPRIATION RECOMMENDATION—HOMELESS VETERAN REINTEGRATION PROGRAM

The Homeless Veterans Reintegration Program (HVRP), within the Department of Labor's Veterans Employment and Training Service (VETS), provides competitive grants to community-based, faith-based, and public organizations to offer outreach, job placement and supportive services to homeless veterans. HVRP is the primary employment services program accessible by homeless veterans and the only targeted employment program for any homeless subpopulation. Homeless veterans have many additional barriers to employment than non-homeless veterans due to their lack of housing. HVRP grantees remove those barriers through specialized supports unavailable through other employment services programs. Grantees are able to place HVRP participants into employment for $2,100 per placement, a tiny investment for moving a veteran out of homelessness, and off of dependency on public programs.

DOL estimates that 16,800 homeless veterans will be served through HVRP at the fiscal year 2004 appropriation level of $19 million. This figure represents just 3 percent of the overall homeless veteran population, which the Department of Veterans Affairs estimates numbers more than 500,000 over the course of a year. An appropriation at the authorized level of $50 million would enable HVRP grantees to reach approximately 44,000 homeless veterans.

HVRP grants are funded on a 3-year cycle. DOL representatives have indicated that if funding is not increased for the program this year, it is unlikely there would be a competition for new start grants in fiscal year 2005. Additionally, HVRP is being used as the account to fund a joint Department of Labor and Department of Veterans Affairs initiative authorized by Congress to assist veterans incarcerated in their reentry to the community. This decision essentially adds a new purpose to the HVRP program, for which additional funds are needed.

We urge Congress to appropriate at least $50 million for HVRP in fiscal year 2005 Labor-HHS-Education appropriations legislation.

[In millions of dollars]

	Fiscal year			
	2003	2004	2005 administration	2005 NCHV
Funding for Homeless Veterans Reintegration Program	18.2	19.0	19.0	50.0

FISCAL YEAR 2005 APPROPRIATION RECOMMENDATION—VETERANS WORKFORCE INVESTMENT PROGRAM

The Veterans Workforce Investment Program (VWIP), within the Department of Labor's Veterans Employment and Training Service (VETS), provides grants to states and community-based, faith-based, and local public organizations to offer workforce services targeted to veterans with service connected disabilities, with active duty experience in a war or campaign, recently separated from the service, or facing significant barriers to employment (including homelessness). VWIP grants last for twelve months and currently have a limit of $255,000. The fiscal year 2004 appropriation for VWIP is $7.5 million.

At least 80 percent of total VWIP funds is distributed via competition. State governments have traditionally been the exclusive eligible applicant for competitive funds. The states then publish requests for proposals, to which local governments, workforce investment boards, and community organizations may respond. The states monitor the projects and frequently provide matching funds to increase opportunities. While matching funds are not required, applicants can gain up to ten points on their application if they demonstrate effective leveraging. In 2003, VWIP competitive funds were awarded to state agencies in AL, CA, HI, IN, ME, MA, PA, TN, and TX.

VETS may reserve 20 percent of total VWIP funds for discretionary grants. VETS uses discretionary funds for studies, demonstration projects, and additional funding to supplement competitive grants. Discretionary grant applications are accepted directly from local governments, workforce investment boards, community-based, and faith-based organizations. In 2003, VWIP discretionary funds were awarded to organizations in CA, DC, FL, MS, NY, SC, OH, PA, and VA.

Both those agencies that receive VWIP funds and those hoping to apply face the problem of resource scarcity. Due to funding limitations, agencies and organizations receive VWIP funds in only 16 states. The need for the type of targeted assistance that VWIP offers is clearly needed in all states. Additionally, caps on the size of grant awards make it difficult for existing grantees to recruit and retain staff. This limits program effectiveness and the collaborative process.

We urge Congress to appropriate at least $33.5 million for VWIP in fiscal year 2005 Labor-HHS-Education appropriations legislation.

[In millions of dollars]

	Fiscal year			
	2003	2004	2005 administration	2005 NCHV
Funding for Veterans Workforce Investment Program	7.5	7.5	7.5	33.5

PROGRAM MANAGEMENT RECOMMENDATION—PRIORITY OF SERVICE FOR VETERANS IN DOL JOB TRAINING PROGRAMS

The Jobs for Veterans Act (Public Law 107–288) establishes a priority of service for veterans in the receipt of employment, training, and placement services provided under qualified job training programs of the Department of Labor. We request the Committee's assistance in ensuring that qualified job training programs fully extend priority of service for veterans as required by this law.

We recommend that the Committee, through report language, urge the Secretary of Labor to ensure that states, localities, and nonprofit organizations receiving workforce investment funds from the Department of Labor screen all applicants for services for military service status and implement the priority for those qualified. Further, we recommend that the Committee urge the Secretary of Labor to develop and disseminate a guide for veterans in accessing workforce investment services.

In addition, we recommend that the Committee encourage the Secretary to develop and disseminate a guide for assisting veterans service organizations and homeless veteran service providers in accessing workforce investment funds and workforce investment planning processes. Also, we recommend that the Committee

encourage the Secretary to develop and disseminate a technical assistance guide to inform state and local workforce systems on the workforce services needs of veterans, the current limitations of veteran-specific programs in meeting those needs, and the responsibility of mainstream workforce systems to prioritize veterans for services and to collaborate with homeless veteran service providers and veterans service organizations.

Finally, we recommend that the Committee urge the Secretary to compel state workforce agencies to increase their outstationing of disabled veterans outreach program specialists and local veterans employment representatives in locations where homeless veterans congregate, including grantees under the homeless provider grant and per diem program and the homeless veterans reintegration program.

TRANSITION ASSISTANCE PROGRAM

Individuals leaving the military are at high risk of homelessness due to a lack of job skills transferable to the civilian sector, disrupted or dissolved family and social support networks, and other risk factors that preceded their military service. Separating service members must be made aware of the factors that contribute to homelessness and receive information about sources of preventive assistance before they exit the military. The Transition Assistance Program (TAP) has been established to ease the transition of separating service members to the civilian sector. We are concerned that the TAP curriculum, which is developed and administered by the Department of Labor, does not currently include a component on homelessness.

We urge the Committee, through report language, to instruct the Secretary of Labor to ensure that a module on homelessness prevention be added to the TAP curriculum. The module should include a presentation on risk factors for homelessness, a self-assessment of risk factors, and contact information for preventative assistance associated with homelessness.

CONCLUSION

The National Coalition for Homeless Veterans appreciates the opportunity to submit recommendations to Congress regarding the resources and activities of the U.S. Department of Labor. We look forward to continuing to work with the Appropriations Committee in ensuring that our federal government does everything within its grasp to prevent and end homelessness among our nation's veterans. They have served our nation well. It is beyond time for us to repay the debt.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF HOME BUILDERS

On behalf of the over 215,000 members of the National Association of Home Builders (NAHB), as well as our workforce development arm, the Home Builders Institute (HBI), we thank you for the opportunity to submit this statement for the record on the Responsible Reintegration of Youth Offenders program, as well as the newly-proposed Prisoner Re-entry Initiative.

NAHB members are involved in home building, remodeling, multifamily construction, property management, subcontracting, design, housing finance, building product manufacturing and other aspects of residential and light commercial construction. Known as "the voice of the housing industry," NAHB is affiliated with more than 800 state and local home builder associations around the country. NAHB's builder members will construct about 80 percent of the more than 1.6 million new housing units projected for 2004, making housing one of the largest engines of economic growth in the country.

One of the most pressing problems confronting our industry has been a shortage of skilled workers. Record numbers in the construction of new homes, retirements and lackluster interest in the construction trades by younger generations, compounded by insufficient training opportunities for those interested in construction, are among the many factors contributing to the shortages. According to the Bureau of Labor Statistics, some 240,000 workers are needed each year to meet the nation's demand for housing.

HOME BUILDERS INSTITUTE (HBI) PROGRAM BACKGROUND

Each year, the Home Builders Institute (HBI) works through various programs to train and place several hundred youth in residential construction jobs. Through real-life, hands-on training, some of our nation's most at-risk youth learn a skill, and a second chance at a productive and successful life and career. Since 1994, HBI has focused a significant portion of its effort and resources on one particular targeted population, adjudicated youth, through its Project CRAFT (Community Res-

titution Apprenticeship-Focused Training) program. Project CRAFT is targeted solely to adjudicated youth and was piloted in 1994 through a Department of Labor demonstration grant. This program has successfully combined employers, the juvenile justice system, workforce development and other systems, in one overall approach, and has been implemented at 12 sites in nine states (Colorado, Ohio, Florida, Maryland, New Jersey, North Dakota, South Carolina, Tennessee, and Texas). Funding for HBI's work on this program has come largely through funds provided under the Responsible Reintegration of Youth Offenders budget line.

Project CRAFT incorporates the apprenticeship concept of hands-on training and academic instruction, utilizing its Pre-Apprenticeship Certificate Training (PACT), numeracy, literacy and employability skills curricula. Under the supervision of journey-level trade instructors, students learn residential construction skills while completing community service construction projects. More than 90 percent of Project CRAFT graduates achieve success through industry jobs each year. Since 1994, Project CRAFT has helped more than 2,000 high-risk youth, and in addition to offering adjudicated youth trade skills and job placement, community service projects by students saved taxpayers more than $225,000 in labor costs alone in 2002–2003. During 2002, Project CRAFT graduates were placed in jobs with an average wage of $8.29/hour, and performed over 28,000 hours of community service. Recidivism rates for Project CRAFT have averaged between 10–15 percent, with the Nashville, Tennessee program and Orlando, Florida programs experiencing impressive recidivism rates of 9 percent and 6 percent respectively. Additionally, students in the program tend to evidence one grade level of improvement in math and language skills attributable largely to the formal education component that includes contextual learning. Math and communication skills are continually reinforced as students are challenged to apply these skills to everyday situations in the field and in the classroom.

Project CRAFT efforts were recognized by the Department of Labor and the National Youth Employment Coalition when in September 2002, the program received a PEPNet (Promising and Effective Practices Network) Award. We are also grateful to the Senate Subcommittee on Labor, Health and Human Services and Education for its acknowledgement of Project CRAFT in fiscal year 2004 Report Language, and its years of dedicated support for the Responsible Reintegration of Youth Offenders program.

RESPONSIBLE REINTEGRATION OF YOUTH OFFENDERS PROGRAM

NAHB and HBI's encouraging experience with Project CRAFT is an example of the enormous success of the Responsible Reintegration of Youth Offenders pilot program, and the reason why we very strongly support the continuation of funding for a youth-focused program targeting adjudicated youth with training that provides this at-risk population with important job- and life-skills. The Responsible Reintegration of Youth Offenders Program has helped to bring together industry and government in a partnership with tangible positive outcomes. Since 1994 the program has earned a reputation as a worthwhile investment of taxpayer dollars, a significant and important resource to the nation's building industry, and a major contributor to the future success of hundreds of young people. It is a demonstration model that works, and as such deserves to be touted and replicated. We hope that its proven success and recognition as a model intervention will help enable it to receive continued funding.

PRISONER RE-ENTRY PROGRAM

In its fiscal year 2005 budget proposal, the White House introduced a new program called the "Prisoner Re-entry Initiative," with a stated focus to "support activities to help individuals exiting prison make a successful transition to community life and long-term employment." (See fiscal year 2005 Budget Appendix, page 706) This program appears to have a focus only on adult offenders, and the budget does not clearly state whether youth-focused programs would be eligible to participate in the Prisoner Re-entry Program.

NAHB and HBI support goals of the Prisoner Re-entry program, and agree that there is undoubtedly enormous potential for successful programming targeting adult offenders. However, we also strongly believe that it would be short-sighted policy to exclude adjudicated youth from the Department's workforce development efforts, and ill-advised to bring its notable successes such as Project CRAFT to an end. We believe that any funding targeted to training those who are re-entering society must include a component targeted to the youth offender population. We believe that the Prisoner Re-entry program, as laid out by the Department of Labor, has failed to

clarify whether youth and youth-focused programs would be eligible for participation in the new program.

As we have stated, the president's newly proposed Prisoner Re-entry program has significant potential for helping the adult offender community receive important training and job skills. And we believe that HBI is well-positioned to participate in an adult-focused program through its Project TRADE (Training, Restitution, Apprenticeship, Development and Education) program—which is the sister program to the youth-focused Project CRAFT. Designed to train and place adult offenders in employment in the home building industry, TRADE is currently being implemented in Colorado Springs. Project TRADE has trained over 500 adult offenders in the residential construction trade since 1995 through programs in Maryland, North Carolina, Oregon, Pennsylvania, Virginia, Washington, Tennessee and Colorado. We believe that Project TRADE's emphasis on adult offenders complements the work done by Project CRAFT's emphasis on youth offenders.

CONCLUSION

NAHB and HBI continue to strongly support the goals of the Responsible Reintegration of Youth Offenders program. We also support the Department of Labor's interest in targeting a program to adult offenders. However, we are concerned that the Department of Labor has not clearly laid out which populations would be served by the new program. Our own effort to secure from DOL a definitive understanding of the eligible populations has resulted in differing opinions and further confusion over the program's goals and targets. We believe that the Responsible Reintegration of Youth Offenders demonstration program has been highly successful, as evidenced by our own success with Project CRAFT, and we fervently hope that any proposal supported by congressional appropriators will take into account the needs of both the youth and adult ex-offender populations, and will clearly lay out congressional intent to continue serving the youth ex-offender population. We believe it would be an error to overlook the tremendous success achieved by the Responsible Reintegration of Youth Offenders program, and while we hope that such a move is not the intent of the Department of Labor, we urge appropriators to clarify the goals of the Prisoner Re-entry program, and to continue supporting those programs that target adjudicated youth.

Again, we thank the subcommittee for this opportunity to share our views on the Responsible Reintegration of Youth Offenders program, and Prisoner Re-entry Initiative, and look forward to working with you to promote training programs that help America's at-risk youth acquire the skills they need for successful and productive careers.

Prepared Statement of the Southern California Elderly Nutrition Partnership

Chairman Specter, Ranking Member Harkin, Members of the Subcommittee: The Southern California Elderly Nutrition Partnership (SOCALENP) is submitting this written testimony in support of a 5 percent increase in funding for the Older Americans Act Nutrition Programs as part of the fiscal year 2005 appropriations bill for the Departments of Labor and Health and Human Services.

SOCALENP is a regional partnership formed by six major providers of elderly services in southern California, which serve nearly 2,500,000 meals annually to 80,000 seniors. We are funded by a grant from the Altria Corporation. We came together to strengthen our advocacy voice not only on behalf of the seniors we serve in Southern California but also for all seniors who benefit from the Older Americans Act nutrition programs. It is important to note that these programs are more than a meal. They provide an essential link between seniors and their communities.

California has not only the highest population in the nation but also the largest number of older citizens of any state. For example, California has 10 percent of all persons in the United States over the age of 65. California serves the second highest number of both congregate and home delivered meals of any state in the nation.

The President's budget for fiscal year 2005, while providing a $3 million increase for the nutrition programs, represents only a .2 percent increase from fiscal year 2004. This means that funding did not even come close to keeping up with inflation. In fact, this is a chronic problem facing the nutrition programs. Whereas inflation has increased by more than 45 percent since 1990, funding for the elderly nutrition programs has increased by only 23.8 percent with an especially woeful 9 percent increase for the congregate nutrition program in that time.

Furthermore, data for fiscal year 2002 indicates that the programs, while serving more seniors, are serving them fewer meals. This defeats a primary purpose of the

program, which is to be able to provide these seniors with one third or more of their RDA's through the program. Data provided by AARP indicates that without any adjustment in the President's budget just over 5 million congregate and home delivered meals nationwide would have to be eliminated in fiscal year 2005. Since the underlying Older Americans Act calls for services to be targeted to the elderly especially those with the greatest economic need, the loss of a meal for this sector of seniors is far more devastating.

We seek this modest increase primarily to ensure that we and other service providers can maintain our commitments to eligible seniors and avoid adding to waiting lists either in the congregate or home delivered meals program.

Each member of this Subcommittee knows of Older Americans Act nutrition programs operating in their state. They probably have taken time to visit one of the sites where meals are served, which we are sure left a lasting memory of the need for these services. This program has enjoyed tremendous success over more than 30 years. It is a value-added proposition providing essential services to seniors and doing so in an efficient and localized manner. These highly leveraged federal dollars are invested in maintaining the nutritional health and independence of our nation's seniors, which helps to reduce institutionalization, shorten hospital stays, and allow seniors to remain active in their communities.

We hope you can commit the necessary $30 million to allow this 5 percent increase to be achieved in fiscal year 2005. We believe our request is modest and fiscally responsible when one considers the return on these funds both in terms of its preventive value to the seniors and the ability of service provider to leverage other support for the programs. These programs are truly more than a meal.

Prepared Statement of the Association for Professionals in Infection Control and Epidemiology

Thank you for this opportunity to submit testimony on behalf of the Association for Professionals in Infection Control and Epidemiology (APIC).

All of us will at some point be admitted to a hospital—or will visit our loved ones while they receive care at a health care facility. Our hospitals, the very institutions we depend upon to save our lives, are fighting for their survival. In recent years, only the highest risk patients are admitted—those individuals that require the highest level of care. Unfortunately, many facilities are facing severe nursing shortages; we have patients waiting for days in Emergency Departments . . . not for lack of beds, but for lack of personnel to staff the beds.

At the very same time, we are being asked to prepare for the unthinkable—not just natural disasters but intentional terrorist acts against our citizens. As a partner in public health preparedness, we are dedicating resources to create the capacity to respond effectively. At the very time we are working with our public health partners at the local, state and federal levels, we are also being asked—or rather, required—to use our extremely limited and precious resources to meet unproven, unnecessary regulatory mandates. The most flagrant, and one that we thought we had proven had no scientific merit is the recent decision by the Administrator of the Occupational Safety and Health Administration (OSHA) to enforce the General Industry Respiratory Protection Standard (or GIRPS) for potential exposures to patients with Mycobacterium tuberculosis (MTB).

On December 31, 2003, New Years Eve, Assistant Secretary Henshaw placed two notices in the Federal Register. The first notice stated that due to the fact that TB is at the lowest incidence level in recorded history, thanks to CDC guidelines and public health efforts, OSHA was withdrawing the proposed rule for preventing occupational exposure to tuberculosis. We commended the agency for this decision.

The second notice stated, however, that OSHA intended to apply the General Industry Respiratory Protection Standard to exposure to patients with potentially infectious M. tuberculosis.

OSHA altered its normal course of rulemaking by effecting significant regulatory changes without providing any opportunity for public review and comment. This decision was not necessary, nor was it precipitated by any preexisting requirement. It appears to have been done completely at the discretion of the OSHA Administrator.

It has never been understood or assumed by the health care community that the General Industry Respiratory Protection Standard would apply to exposure to patients with potentially infectious TB. In fact, when the GIRPS was revised in 1998, the language in the standard specifically stated that these requirements did not apply to health care or to exposure to TB. The health care community therefore re-

lied upon the proposed TB rulemaking for public comment regarding respiratory protection, instead of commenting on the revision of the GIRPS.

Assistant Secretary Henshaw contends that he cannot reopen a final rule for comment, as we are requesting. It is our understanding that the OSHA Administrator can, at any time, choose to reopen a rule for further consideration, regardless of whether that rule is proposed or final. In fact, Secretary Henshaw chose to open the rule on December 31, 2003, by announcing his decision to include exposure to TB under this regulation. It therefore stands to reason that he can open the rule again, to allow for public review and comment, as is the normal course of action.

APIC respectfully requests that OSHA delay application and enforcement of this standard for occupational exposure to patients with potentially infectious TB until at least January 2005, and meanwhile pursue avenues to open the rule for public review and comment. It is vital that OSHA ensure that its decisions are based on sound scientific evidence, and allow for the affected parties to voice their concerns about the implications of these actions. We hope the Subcommittee will assist us by confronting OSHA on this decision, and require the agency to reopen the rule for adequate public consideration and comment.

We thank you for this opportunity to provide testimony to the Subcommittee.

Prepared Statement of the Mexican-American Opportunity Foundation and the Career Services Center, Kern County, CA

In Jalisco, Mexico in the year 1976, Roberto and Maria Sanchez had a little girl they named Maria. When I was 4 years old my dad brought our family of twelve to the USA where they worked as farmworkers to support us while my oldest brother took care of us. A year later I started kindergarten. I remember my first day. My sister took me to school. I grabbed her leg because I didn't want to stay. I attended Carl Clemens Elementary School, then Thomas Jefferson Junior High School for 3 years. I graduated from there in 1991 and went on to Wasco Union High School where I graduated in 1995.

Three days after I graduated, I married Francisco Yerena. I thought, now with my new name, life will be different. In 1999, I gave birth to a boy. I named him Francisco. Everything seemed perfect. Being a young couple it was hard financially. My husband struggled as a seasonal farm worker trying to provide for us. I tried to attend Bakersfield College, but due to financial hardship, I had to quit school and get a job. I remember when I had my first job at Richland pre-school as a substitute teacher's aide and my husband left for Mexico to see about his papers. This made it harder for me and my son to survive. I knew something had to change.

I decided to go to the Career Services Center to get a better job. I went to my appointment and they gave me a basic skills test. Dinorah Castro of Employers' Training Resource called me back about a work experience program at the Mexican-American Opportunity Foundation training center. I worked there as a receptionist for four months. During these four months it was hard on us financially. I traveled everyday from Wasco to Bakersfield. At the end of my work day, I picked up my son from the babysitter and by the time I got home, it was very late. I fixed dinner and spent what time I had with my son. My husband finally returned after being gone for eight months and he had to find employment which only took him a couple of days.

I was so happy that the Mexican-American Opportunity Foundation's Administrator, Magda Menendez, referred me to the Mexican-American Opportunity Foundation pre-school for an interview. It was very exciting for me and I was so nervous waiting to hear from them. On February 9, 2004, they hired me as a substitute teacher and while I am working full time, I also attend Bakersfield College so I can get my teaching degree.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Prepared Statement of the Blue Cross and Blue Shield Association

The Blue Cross and Blue Shield Association (BCBSA), which represents 41 independent, locally operated Blue Cross and Blue Shield Plans throughout the nation, is pleased to submit written testimony to the subcommittee on fiscal year 2005 funding for Medicare contractors.

Blue Cross and Blue Shield Plans play a leading role in administering the Medicare program. Many Plans contract with the federal government to run much of the daily work of paying Medicare claims accurately and timely. Blue Cross and Blue

Shield Plans serve as Part A Fiscal Intermediaries (FIs) and/or Part B carriers and collectively process most Medicare claims.

This testimony focuses on three areas:

I. Background, including a description of Medicare contractor functions;

II. Current financial challenges facing Medicare contractors; and

III. BCBSA recommendations for Medicare contractor fiscal year 2005 funding.

I. BACKGROUND

Blue Cross and Blue Shield Medicare contractors are proud of their role as Medicare administrators. While workloads have soared, operating costs—on a unit cost basis—have declined about two-thirds from 1975 to 2004. In fact, contractors' administrative costs represent less than 1 percent of total Medicare benefits.

Medicare contractors have four major areas of responsibility:

1. *Paying Claims*.—Medicare contractors process all the bills for the traditional Medicare fee-for-service program. In fiscal year 2005, it is estimated that contractors will process over 1.1 billion claims, nearly 4 million every working day.

2. *Providing Beneficiary and Provider Customer Services*.—Contractors are the main points of routine contact with Medicare for both beneficiaries and providers. Contractors educate beneficiaries and providers about Medicare and respond to over 50 million inquiries annually.

3. *Handling Hearings and Appeals*.—Beneficiaries and providers are entitled by law to appeal the initial payment determination made by carriers and FIs. These contractors handle nearly 8 million annual hearings and appeals.

4. *Special Initiatives to Fight Medicare Fraud, Waste, and Abuse*.—All contractors have separate fraud and abuse departments dedicated to assuring that Medicare payments are made properly. Few government expenditures produce the documented, tangible savings of taxpayers' dollars generated by Medicare anti-fraud and abuse activities. For every $1 spent fighting fraud and abuse, Medicare contractors save the government $14.

II. CURRENT FINANCIAL CHALLENGES

Of utmost importance to attaining outstanding performance is an adequate budget. Medicare contractors have been underfunded since the early 1990's, however, and the largest portion of the contractor budget—Medicare operations—faces particularly severe funding pressures. Medicare operations activities include claims processing, beneficiary and provider education and communications, hearings and appeals of claims initially denied, and systems maintenance and security.

The underfunding of CMS and its Medicare contractors has gotten even more acute since the passage of the Health Insurance Portability and Accountability Act (HIPAA) and other legislation that places new responsibilities on contractors, without sufficient resources to perform those duties. For example, between 1992 and 2002, Medicare benefits outlays increased 97 percent; claims volume increased 50 percent; yet Medicare operations funding increased a mere 26 percent. Contractor staffing only increased by 6 percent during this time even though many new responsibilities were added and claims volume continued to rise. Clearly funding has not kept pace with additional work. In addition, the recently enacted Medicare reform legislation includes significant changes that will require additional resources for contractors to implement.

Whenever possible, contractors respond to reduced funding by achieving significant efficiencies in claims processing, but it is not enough to keep pace with rising Medicare claims volume and diminishing funding levels. It should be noted that contractors are already extremely efficient. Currently, contractors' administrative costs represent less than 1 percent of total Medicare benefits.

Inadequate budgets for Medicare operations also impact Medicare's fight against fraud and abuse. While many think of Medicare operations activities as simply paying claims, these activities are Medicare's first line of defense against fraud and abuse and are critically linked to activities under the separately-funded Medicare Integrity Program (MIP). As an example, many of the front-end computer edits (e.g., preventing duplicate payments and detecting inaccurately coded claims or claims requiring additional screening) are funded through Medicare operations.

Inadequate funding impacts different functions at different times, but always disrupts the integration of all the functional components needed to "get things right the first time." It thus results in inefficiency and higher costs.

III. BCBSA FISCAL YEAR 2005 FUNDING RECOMMENDATIONS FOR MEDICARE CONTRACTORS

BCBSA is pleased that many Members of this subcommittee recognize the need for adequate administrative resources at CMS. We are concerned the Administration's fiscal year 2005 budget does not appropriately reflect the expected costs to cover Medicare contractor workloads and it relies on a proposal for $205 million in new user fees from providers. BCBSA urges Congress to take the following steps to allow Medicare contractors to meet increased workloads as well as beneficiary and provider needs:

A. Increase Medicare Contractor Operations Funding to $1.81 Billion for Fiscal Year 2005

Medicare contractors continue to face increases in Medicare claims volume. Further reductions in administrative costs, as proposed in the President's budget, would seriously jeopardize contractors' ability to administer Medicare. BCBSA recommends:

1. Claims processing funding must be maintained

The President's budget would decrease Part B claims processing costs by $0.02 per claim to $0.63 under the assumption that standardized electronic transactions under HIPAA will provide savings. Part A claims payment remains the same at $0.87. Available contractor data through the first quarter of fiscal year 2004 show the HIPAA transactions rule has not resulted in lower claims processing costs. In fact the average cost for contractors to process a Part B claim is $0.73, and over $1 for a Part A claim. Medicare electronic claims submission rates were already high prior to HIPAA implementation—98 percent of Medicare Part A and 84 percent of Medicare Part B. The current unit costs for processing Medicare Part B claims must be maintained in fiscal year 2005, requiring an additional $15.4 million.

2. Appeals funding must be enhanced

The President's budget provides no increase to handle ongoing appeals, even though CMS projects the appeals volume will rise in fiscal year 2005. Adequate funding is imperative for contractors to sufficiently handle the nearly 8 million appeals that providers and beneficiaries are expected to submit. BCBSA recommends an additional $5.5 million for these important activities.

B. Increase Medicare Integrity Program (MIP) Funding to $740 Million

Congress created Medicare Integrity Program (MIP) under HIPAA to provide a permanent, stable funding authority for the portion of the Medicare contractor budget that is explicitly designated as fraud and abuse detection activities. Funding was capped at $720 million for fiscal year 2003 and subsequent years, however, despite continuing increases in claims volume (15 percent increase in claims is projected in fiscal years 2004–2005). This freeze in funding concurrent with increases in workload seriously erodes contractors' ability to fight fraud and abuse and ensure the accuracy and appropriateness of Medicare payments.

Contractors' enhanced anti-fraud and abuse efforts due to MIP funding have contributed to the significant decline in improper claims and deficient documentation submitted by providers. In addition, MIP saves money. HHS data shows a $14:1 return on the investment.

1. MIP Funding Should Be Increased

BCBSA urges Congress to authorize an immediate increase in the MIP appropriation to $740 million for fiscal year 2005, with provision for automatic increases in future years. Medicare contractors need these resources to effectively combat Medicare waste, fraud and abuse and to keep pace with rising workloads. MIP contributes to the decline in improper claims submissions and it saves Medicare money. HHS data show a $14:1 return on the investment.

C. Reject New User Fees

BCBSA is very concerned that once again CMS recommends new user fees of $205 million from doctors, hospitals and other providers to support contractor operations. History has shown user fees to be an unpredictable stream of funding. In order for contractors to maintain performance, funds must be consistent and reliable.

Congress has consistently rejected user fees similar to those recommended in the President's budget. Congress should reject them again and provide $1.81 billion in appropriated funds for Medicare contractors and $740 million for MIP.

MEDICARE CONTRACTOR BUDGET

[In millions of dollars]

	Fiscal year		
	2004	2005 administration recommendation	2005 BCBSA recommendation
Medicare Operations	1,701	1,704	1,814.7
Medicare Integrity Program	720	720	740.0
Total Contractor Budget	2,421	2,514	2,555.0

PREPARED STATEMENT OF THE AMERICAN DIABETES ASSOCIATION

Thank you for the opportunity to submit testimony on the important issue of funding the diabetes program at the Centers for Disease Control and Prevention (CDC) and diabetes research at the National Institutes of Health (NIH). Our government needs to significantly increase diabetes funding at these agencies not only for the 18 million Americans who currently have diabetes, but also for the 40 million who are at high risk for developing diabetes in the immediate future.

The Association is aware that the Subcommittee is in a particularly difficult economic position this year. For that reason, the Association is asking the Subcommittee to adopt one request that is feasible even under the proposed budget numbers: the American Diabetes Association strongly urges the Subcommittee to add an additional $10 million to the budget of the Division of Diabetes Translation at CDC.

Diabetes is a serious disease, and is a contributing and underlying cause of many of the diseases on which the federal government spends the most health care dollars. Diabetes is a significant cause of heart disease (which costs our nation $183.1 billion each year), a significant cause of stroke ($43.3 billion each year), the leading cause of kidney disease ($40.3 billion). Diabetes is also the leading cause of adult-onset blindness and lower limb amputations. Additionally, aside from all of these related conditions, diabetes alone costs our nation $132 billion a year.

Approximately 42,000 people suffering from diabetes live in each congressional district. The following illustrates how diabetes affects your district in realistic terms:

—177 of your constituents will develop heart disease this year because of diabetes.
—154 of your constituents will develop end stage renal disease this year because of diabetes.
—129 of your constituents will lose a foot or leg this year because of diabetes.
—55 of your constituents will go blind this year because of diabetes.

Given the systemic damage diabetes imposes throughout the body, it is no surprise that the life expectancy of a person with the disease averages 10–15 years less than that of the general population.

Unfortunately, the spread of diabetes will only get worse in the coming years unless we see a significantly larger funding commitment by the federal government. Indeed, a CDC report issued in January of this year finds that the prevalence of diabetes nationwide increased by over 60 percent between 1990 and 2001. If diabetes keeps increasing at this rate, its prevalence will double in just over 15 years.

The Association hopes that an additional $10 million this year for the Division of Diabetes Translation—a request strongly supported by the Congressional Diabetes Caucus, comprised of 280 Members of Congress—would simply be the first step in a 5-year effort to double to budget of the Division. Although the medical research community has made tremendous strides in the area of diabetes over the past two decades, the benefits of this research have not been fully realized by a majority of the Americans affected by this disease. The federal government must commit more resources to ensure that important research findings are effectively and adequately translated into public health interventions. To this end, we believe strongly in the work funded by the Division of Diabetes Translation.

However, the Division's fiscal year 2004 budget of $67 million—and the President's $67 million request for fiscal year 2005—represents a miniscule commitment to diabetes prevention and control. Indeed, for every $1 that diabetes costs this country, the federal government currently invests less than $.01 to help Americans prevent and manage this deadly disease.

In 2003 the Division provided support for more than 50 state- and territorial-based diabetes control programs to reduce the complications associated with diabetes. However, funding constraints required the Division to provide severely limited support to 26 states, 8 territories, and D.C. for capacity-building diabetes programs. Slightly more substantive support was provided to the other 24 states for basic implementation programs. Although every state and territory has at least a capacity-building program, unfortunately these programs do not even come close to addressing the needs statewide. Instead, they simply serve as a rudimentary framework upon which a more comprehensive program can be built.

CDC also conducts other activities to help people currently living with diabetes. For example, CDC works with NIH to jointly sponsor the National Diabetes Education Program (NDEP), which seeks to improve the treatment and outcomes of people with diabetes, promote early detection, and prevent the onset of diabetes. In addition, CDC funds work at the National Diabetes Laboratory to support scientific studies that will improve the lives of people with diabetes.

Even while the Division of Diabetes Translation conducts a number of activities to help people with diabetes, it suffers a similar problem as its NIH counterpart, NIDDK. Compared to other diseases, diabetes remains significantly underfunded at CDC. If adequately funded, the Division would be able to fund a basic implementation program in every state as well as conduct and fund additional projects to assist people with diabetes. Without fully-funded diabetes programs and projects in all parts of the country, it will be exceedingly difficult—if not impossible—to control the escalating costs associated with diabetic complications and to stem the epidemic rise in diabetes rates.

The American Diabetes Association supports the President's support for the Steps to a Healthier U.S. Initiative, and is encouraged that this program focuses—among other things—on obesity and diabetes. We strongly believe, though, that funds made available for this new Initiative should not take away from funds that would otherwise be made available to the Division of Diabetes Translation. State Diabetes Prevention and Control Programs—when provided with enough funding—are proven commodities that have been extremely successful in helping Americans prevent and manage their diabetes. Americans in every state should have access to such quality programs.

Chronic diseases, including diabetes, account for nearly 70 percent of all health care costs as well as 70 percent of all deaths annually. However, less than $1.25 per person is directed toward public health interventions focused on preventing the debilitating effects associated with chronic diseases, demonstrating that federal investment in chronic disease prevention remains grossly inadequate. We cannot ignore those Americans who are currently living with diabetes and other diseases.

RECENT FUNDING INCREASES

The American Diabetes Association appreciates that Congress has begun to give greater attention to diabetes research at NIH in recent years and that the current Administration has proposed an overall increase in the NIH budget. However, during much of the past decade, diabetes funding has stagnated even while the burden has grown significantly. Indeed, from 1987–2001, appropriated diabetes funding as a share of the overall NIH budget has dropped by more than 20 percent (from 3.9 percent to 2.9 percent) while the death rate due to diabetes has increased by more than 40 percent. Thankfully, the past 4 years have brought larger increases in diabetes funding than we had seen over the majority of the decade. Only over these years did the growth in diabetes research funding finally keep pace with the growth of the overall NIH budget. At a time when diabetes is exploding across our nation, it remains essential that we increase the research funding levels for diabetes.

Mr. Chairman, we appreciate the increases of the last few years. Congress should be proud of the bi-partisan support for the effort to double the NIH budget. But this should not equate to an automatic institute-by-institute doubling.

Some institute budgets are larger not only due to scientific opportunities, but due to special consideration in years past. Unfortunately, across-the-board percentage increases make it difficult, if not impossible, to address funding shortfalls for diseases that now have promising scientific opportunities. Diseases like diabetes that have not received funding commensurate with their national burden, as well as with existing scientific opportunities, continue to fall behind as a result of this funding strategy.

Across-the-board increases for all institutes simply do not allow the Congress, or the nation, to deal with the serious problem of diabetes anytime soon. While on the surface across-the-board increases appear equitable to everyone, it actually perpetuates inequity in absolute dollar terms. In reality, a 15 percent increase means

much more for diseases and institutes with large budgets, and far less for diseases and institutes with small budgets.

Continuing with an across-the-board approach for Institute funding means that these discrepancies in funding will continue to grow. This is not inherently bad so long as the difference accurately reflects the scientific opportunities and health impact of disease on the nation. But in the case of diabetes at least, it does not.

The net effect of an across-the-board approach is that past funding legacies still affect the funding priorities at NIH to this day. By not constantly making an honest assessment of the health challenges faced by our nation and by not looking harder at the scientific opportunities facing the research community, NIH has perpetuated an inequality in funding based on decisions made many years before.

CONCLUSION

I firmly believe that we could rapidly move toward curing, preventing, and managing this disease by increasing funding for diabetes programs and research both at CDC and NIH. Your leadership can help accomplish this goal.

The American Diabetes Association strongly urges the committee and Congress increase the budget of the Division of Diabetes Translation by $10 million in fiscal year 2005 as the first step in a 5-year doubling plan. A doubling of the Division's budget would allow the Division to finally implement a Basic Implementation Diabetes Prevention and Control Program in every state and territory, thus moving the government in the direction of truly helping all Americans with diabetes. Additionally, we urge the Subcommittee to increase funding at NIH for diabetes research as much as possible in these strict economic times.

Speaking on behalf of the 18 million Americans with diabetes—a disease that crosses gender, race, ethnicity and political party; a disease that is among the most costly, debilitating, deadly and prevalent in our nation; and a disease that is exploding throughout our nation—I appreciate the opportunity to submit this testimony. The American Diabetes Association is prepared to answer any questions you might have on these important issues.

PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

The American Society for Microbiology (ASM), the largest single life science society with 43,000 members, is pleased to submit testimony on the fiscal year 2005 budget for the Centers for Disease Control and Prevention (CDC). The CDC is the nation's lead agency for protecting the health and safety of the public, both nationally and globally. Threats to public health and security have steadily increased in number and complexity over time, despite medical successes and technical innovation. The work of the CDC is of unprecedented importance in safeguarding public health.

The ASM is concerned that funding for CDC is not keeping pace with its growing responsibilities to address new health threats. The $6.9 billion fiscal year 2005 request for the CDC is a 2.8 percent reduction below last year's $7.1 billion. The ASM endorses the CDC Coalition's recommendation of $8.1 billion in fiscal year 2005 for CDC, followed by annual increases to achieve $15 billion for the agency by fiscal year 2008. Increased support is crucial to the CDC's primary goals for protecting public health: surveillance and response, basic and applied research, training and education, and prevention and control.

The CDC's ability to mobilize rapidly to prevent or contain disease is an urgently needed line of defense against the economic and social havoc that can result from public health threats. In 2003, the CDC was essential in identifying the cause of the Severe Acute Respiratory Syndrome (SARS) epidemic in Asia and the first case of human monkeypox in the United States. Agency personnel also trained approximately 8,800 U.S. clinical laboratory staff in terrorism preparedness and response, while others investigated numerous outbreaks of infectious and food-borne diseases, as well as chronic disease diagnoses among diverse populations. Proposed cuts to a number of CDC programs could jeopardize the agency's activities to address health threats.

The ASM is concerned that the proposed fiscal year 2005 budget represents no or only slight increases in CDC programs such as emerging and re-emerging infectious diseases, antimicrobial resistance and domestic HIV/AIDS programs. The ASM also recommends that new bioterrorism preparedness initiatives be funded without redirecting resources from needed on-going state and local programs, as proposed in the fiscal year 2005 budget. By adequately enlarging the CDC appropriation, Congress would strengthen significantly our defenses against naturally and intentionally caused disease in the United States and elsewhere.

INFECTIOUS DISEASES AND PUBLIC HEALTH

The National Center for Infectious Diseases (NCID) supports programs to prevent and control endemic, new and reemerging infectious diseases in the United States and abroad. The proposed fiscal year 2005 budget for the CDC includes $400.8 million for infectious diseases, an increase of $31.3 million over fiscal year 2004 funding. Most of the increase benefits two CDC programs: $27.5 million to expand the CDC's Global Disease Detection Initiative to $51 million, and $2 million to increase West Nile virus (WNV) research as well as state and local health department WNV surveillance and response capabilities. Because of increased world trade and travel, nations can no longer ignore any type of infectious disease and global strategies have become fundamental to CDC's public health activities. The ASM supports the budgetary increases proposed for these two programs, but is concerned that critical components of the CDC infectious diseases mission also need additional resources in the fiscal year 2005 budget.

In 2003 the Institute of Medicine (IOM) released a strongly worded, cautionary report on Microbial Threats to Health. The IOM report points out that infectious disease public health needs have been and will continue to increase. Between 1973 and 2003, more than three dozen newly emerging diseases were identified. Most recently, hantavirus, West Nile virus, SARS, bovine spongiform encephalopathy (BSE), and monkeypox became known enemies to public health in the United States. In the 1990s, the CDC revitalized its infectious disease programs to better reflect the emergence of new infectious diseases. By investing in partnerships with local and state health departments, academic research and teaching institutions, private industries, other federal agencies, world health organizations, and health agencies and researchers in other nations, the CDC expanded its ability to detect and contain infectious disease, as it intensified its own research and training programs. The vital need for CDC programs was emphasized dramatically last year with the SARS epidemic and hundreds of human WNV infections. The need remains as urgent today with concern about BSE and avian flu now in the United States.

Experts predict a major pandemic during this century and the most likely source remains influenza. A hallmark of pandemics and many small scale emerging infectious diseases is that they are zoonoses. Zoonotic diseases, infections which are naturally transmitted between animals and man, represent one of the leading causes of illness and death from infectious diseases and nearly all emergent episodes of the past 10 years have involved zoonotic infectious agents. In the United States alone, an influenza pandemic could cause an estimated 89,000 to 207,000 deaths and cost the nation from $71–167 billion in health care costs and lost productivity. Additional budgetary resources are needed to address issues such as zoonoses and influenza, which were highlighted in the IOM report. CDC infectious diseases should be increased by an additional $50 million.We recognize that significant investment will be required to enhance efforts to address the threat of pandemic influenza in order to develop a newer generation influenza vaccine that can be quickly produced and deployed, to strengthen the public health infrastructure at the state and local levels, and to ensure needed vaccines and antiviral medicines are readily available. We recommend that the Department of Health and Human Services (DHHS) assess the needs for resources to address pandemic flu within the NIH, CDC and FDA and coordinate the planning activities.

The goal of the CDC's new Global Disease Detection Initiative within its epidemic services and infectious disease control programs is to work faster and better in recognizing and controlling any infectious disease threatening public health. The CDC operates in a global arena, establishing myriad programs and collaborations beyond the nation's borders and sending quick-response assessment teams around the world. It recently funded five university schools of public health and three non-government organizations to assist malaria-endemic African countries, where the disease kills and disables millions. CDC personnel provide consistent epidemiological expertise and lab support to nations under siege, most recently the Congo (Marburg virus disease), Uganda and Gabon (Ebola hemorrhagic fever), Saudi Arabia and Yemen (Rift Valley fever), and more. CDC programs will be expanded in five countries including Brazil and China and new sites will be created in six others, most of them in Africa. The CDC also will continue to be a major implementing agency for the U.S. Department of State's Mother to Child HIV Prevention Initiative inaugurated last year. The new Global Disease Detection initiative includes improvement of the existing international surveillance network for influenza, to bolster the early warning system for identifying more uncommon viruses.

The multi-faceted network of disease surveillance in the United States expands and changes annually. The CDC last year enhanced its surveillance of prion diseases and responded to the first confirmed U.S. case of BSE in cattle. Food-borne

illness surveillance has grown into one of the most extensively used networks: 76 million Americans suffer from contaminated foods each year at an estimated cost of over $1 billion. The CDC's PulseNet is credited with revolutionizing food-borne surveillance in this country and overseas; recently it was expanded to incorporate a total of 21 participating countries. In 2003, it was critical in identifying U.S. outbreaks of salmonellosis from tomatoes and eggs, E. coli O157 infection from beef, and listeriosis from raw milk cheese. The CDC coordinates U.S. influenza surveillance and recently expanded its sentinel surveillance sites through one of many data-collecting networks. The 891 influenza sites will not only alert officials to impending flu epidemics, but also to other respiratory diseases.

Effective as surveillance networks are in preventing further spread of disease, protecting the public must stress prevention through effective education and science-based efforts. For instance, the CDC supplies funding to most states to promote appropriate use of antibiotics and thus limit the rising medical costs associated with antibiotic resistance. The agency has implemented a National Hepatitis C Prevention Strategy by establishing coordinators in all 50 state health departments. It developed guidelines for the prevention of perinatal group B streptococcal disease that have resulted in a 70 percent reduction since 1993. An initiative begun last year expects to increase HIV testing in this country and enhance prevention, in recognition that the rate of new infections (about 40,000 each year) has remained stable despite education efforts over the past two decades. The "Advancing HIV Prevention" approach shifts strategies to reduce even further the barriers to early HIV diagnosis and quality medical care.

In response to the 2001 Public Health Action Plan to Combat Antimicrobial Resistance (AR), the CDC announced a new extramural applied research grant program in 2003, to fund research in the areas of mechanisms of dissemination of AR genes, resistance in specific human pathogens of public health concern and the characterization of strains of community-associated methicillin-resistant Staphylococcus aureus (MRSA). The goal of the applied research program is to prevent and control the emergence and spread of antimicrobial resistance in the United States. Approximately $25 million is being requested for antimicrobial resistance research, surveillance, prevention and control activities. Considering the magnitude of the problem of antimicrobial resistance, additional new funding should be provided in the CDC budget to address the alarming issue of antimicrobial resistance.

Each year about 48,000 Americans die from vaccine-preventable diseases; worldwide, these diseases cause an estimated 2.4 million childhood deaths. The fiscal year 2005 CDC budget request includes $1.9 billion for a number of significant vaccination programs. Some, like a stockpile of all routinely recommended childhood vaccines, already are in progress. Others are new, like an inventory of childhood influenza vaccine. The immunization budget will continue to provide global immunization activities ($151 million), including the goal of global polio eradication by 2005.

NATIONAL SECURITY AND BIODEFENSE

Intentional release of biological weapons troubled the CDC well before events of 2001, but the enormity of those attacks brought home the grave potential of bioterrorism. The attacks also forced the CDC to shift much of its mission focus to bioterrorism preparedness, in collaborations with other federal, state, and local health organizations. The agency quickly formed emergency response teams, established extensive state-of-the-art communication systems, and concentrated on basic and applied research related to possible bioweapons. The fiscal year 2005 request of $1.1 billion would continue CDC efforts related to terrorism preparedness and emergency response at a funding level identical to that implemented so effectively in fiscal year 2004. The ASM recognizes the dire consequences of bioterrorism and supports extensive funding of CDC preparedness programs. However, the programmatic impact of removing $105 million from state/local programs and $25 million from internal CDC activities to subsidize CDC's component in a new cross-agency Biosurveillance initiative deserves evaluation.

The new Biosurveillance Initiative was designed by a coalition of federal agencies after the Homeland Security Council identified early bioattack warning and surveillance as top priority areas in need of improvement. The CDC's contribution, funded at $130 million in the proposed fiscal year 2005 budget, includes three new program activities, the BioSense surveillance system ($100 million), real-time laboratory reporting ($20 million), and expanded border health inspection and quarantine capability ($10 million). The BioSense program represents a new and largely untested generation of infectious disease surveillance that does not rely upon mandatory or voluntary case reporting from healthcare providers. Instead, sets of anonymous health data will be automatically and electronically gathered from pre-determined

sources like over-the-counter retail sales of home health remedies and visits to emergency rooms. This system is intended to provide public health officials with "a near real-time sense" of the community's health status and to reduce the time needed to detect threats from days or weeks to hours.

The ASM strongly supports two programs of the new initiative which build on the importance of trained personnel who respond locally but work together within the national goal of preventing bioterrorist attacks. One program will expand the CDC's existing Laboratory Response Network (LRN) by adding animal diagnostics and food safety capabilities to public health, clinical, and private commercial laboratories. The other program recognizes that every day more than 2 million people travel to or through this country by air, sea or land, and that each year, more than 350,000 new immigrants arrive. It adds new, strategically placed quarantine stations and creates multidisciplinary teams able to respond to infectious disease emergencies at U.S. seaports, border crossings, and airports.

By the end of fiscal year 2004, over $3 billion will have been allocated by the CDC to upgrade state and local health departments since the 2001 terrorist attacks. Supporting this nationwide community of anti-terrorism capability extends the CDC's own efforts and provides a greater return on funding investments. CDC support also comes from the many wide-ranging communication networks used by the CDC to disseminate new scientific information, health risk alerts, and population- or disease-specific updates. An example is the Epidemic Information Exchange, Epi-X, which provides swift exchange of information among more than 2,000 key public health officials nationwide. The Public Health Information Network sends health alerts and advisory messages to one million recipients, including 90 percent of all county public health departments. The Laboratory Response Network, to be expanded under the new Biosurveillance Initiative, already includes 113 members in the United States and elsewhere; an increasing number of these labs could confirm the presence of anthrax, tularemia, and smallpox, and more than half are qualified to handle some of the most dangerous pathogens.

The complex CDC infrastructure used to prevent bioterrorism also incorporates the training of specialized personnel, the stockpiling of crucial supplies needed in mass emergencies, and the careful monitoring of pathogens and other toxic agents used in research. Management of the Strategic National Stockpile has been returned to the HHS from the Department of Homeland Security, as a source of smallpox vaccine and other medical supplies shippable to any scene of mass trauma in the United States. The Epidemic Intelligence Service grew from 148 officers in 2001, to 167 in 2003; 49 of these first-line responders are assigned to local or state health departments. With the U.S. Department of Agriculture, this year the CDC will inspect 300 laboratories using potential bioagents in research, through the Select Agent Program that controls the possession and transfer of infectious agents. The SAP program should have adequate resources.

BUILDINGS AND FACILITIES

A total of $81.5 million is proposed in the fiscal year 2005 budget for CDC buildings and facilities. CDC is undertaking and has made substantial progress in a 10-year effort to rebuild its physical infrastructure and replace and upgrade decrepit out-dated buildings and facilities. State of the art, safe and secure laboratories and facilities, as well as modern equipment, are essential to an effective CDC response to the broad range of public health threats facing the country and the world. The ASM recommends that Congress appropriate $250 million for CDC's critical infrastructure needs.

PREPARED STATEMENT OF THE INTERTRIBAL BISON COOPERATIVE

INTRODUCTION AND BACKGROUND

My name is Ervin Carlson, a Tribal Council member of the Blackfeet Tribe of Montana and President of the InterTribal Bison Cooperative. Please accept my sincere appreciation for this opportunity to submit testimony to the honorable members of the Appropriations Subcommittee on Labor, Health and Human Services and Education. The InterTribal Bison Cooperative (ITBC) is a Native American nonprofit organization, headquartered in Rapid City, South Dakota, comprised of fifty-three (53) federally recognized Indian Tribes located within 18 States across the United States.

Buffalo thrived in abundance on the plains of the United States for many centuries before they were hunted to near extinction in the 1800s. During this period of history, buffalo were critical to survival of the American Indian. Buffalo provided

food, shelter, clothing and essential tools for Indian people and insured continuance of their subsistence way of life. Naturally, Indian people developed a strong spiritual and cultural respect for buffalo that has not diminished with the passage of time.

Numerous tribes that were committed to preserving the sacred relationship between Indian people and buffalo established the ITBC as an effort to restore buffalo to Indian lands. ITBC focused upon raising buffalo on Indian Reservation lands that did not sustain other economic or agricultural projects. Significant portions of Indian Reservations consist of poor quality lands for farming or raising livestock. However, these wholly unproductive Reservation lands were and still are suitable for buffalo. ITBC began actively restoring buffalo to Indian lands after receiving funding in 1992 as an initiative of the Bush Administration.

Upon the successful restoration of buffalo to Indian lands, opportunities arose for Tribes to utilize buffalo for tribal economic development efforts. ITBC is now focused on efforts to assure that tribal buffalo projects are economically sustainable. Federal appropriations have allowed ITBC to successfully restore buffalo the tribal lands, thereby preserving the sacred relationship between Indian people and buffalo. The respect that Indian tribes have maintained for buffalo has fostered a serious commitment by ITBC member Tribes for successful buffalo herd development. The successful promotion of buffalo as a healthy food source will allow Tribes to utilize a culturally relevant resource as a means to achieve self-sufficiency.

FUNDING REQUEST FOR PREVENTATIVE HEALTH CARE INITIATIVE

The InterTribal Bison Cooperative respectfully requests an appropriation for fiscal year 2005 in the amount of $3,000,000 in the form of an earmark to the Department of Health and Human Service Department's budget. ITBC intends to utilize the funds to conduct a national demonstration project focused on the delivery of bison meat to Native Americans suffering from diet related diseases.

The Native American population currently suffers from the highest rates of Type 2 diabetes. The Indian population further suffers from high rates of cardio vascular disease and various other diet related diseases. Studies indicate that Type 2 diabetes commonly emerges when a population undergoes radical diet changes. Native Americans have been forced to abandon traditional diets rich in wild game, buffalo and plants and now have diets similar in composition to average American diets. More studies are needed on the traditional diets of Native Americans versus their modern day diets in relation to diabetes rates. However, based upon the current data available, it is safe to assume that disease rates of Native Americans are directly impacted by a genetic inability to effectively metabolize modern foods. More specifically, it is well accepted that the changing diet of Indians is a major factor in the diabetes epidemic in Indian Country.

Approximately 65–70 percent of Indians living on Indian Reservations receive foods provided by the USDA Food Distribution Program on Indian Reservation (FDPIR) or from the USDA Food Stamp Program. The FDPIR food package is composed of approximately 58 percent carbohydrates, 14 percent proteins and 28 percent fats. Studies have shown that the FDPIR food package has not been compatible with the genetic compositions of Native Americans and has been a major factor in the high incidence of diet-related disease among Native Americans. Indians utilizing Food Stamps generally select a grain based diet and poorer quality protein sources such as high fat meats based upon economic reasons and the unavailability of higher quality protein food sources.

Buffalo meat is low in fat and cholesterol and is compatible to the genetics of Indian people. ITBC intends to develop a health care initiative that would educate Indian Reservation families of the benefits of incorporating buffalo meat into their diets. In conjunction with educating Reservation families on the benefits of buffalo meat, ITBC intends to develop methods to make buffalo meat accessible for Indian families and to promote incorporation of buffalo into their diets. ITBC intends to coordinate with Reservation health care providers in nutritional studies of Reservation populations that incorporate buffalo meat into diet packages.

ITBC believes that incorporating buffalo meat will positively impact the diets of Indian people living on Reservations. A healthy diet for Indian people that results in a lower incidence of diabetes and other diet related illnesses will reduce Indian Reservation health care costs and result in a savings for taxpayers.

FUNDING REQUEST FOR ITBC TRAINING AND LABOR PROGRAM

The InterTribal Bison Cooperative respectfully requests an appropriation for fiscal year 2005 in the amount of $500,000. This amount is $400,000 above the fiscal year 2004 appropriation for ITBC and is critical to maintain last years funding level and to develop ITBC's training and labor program.

In fiscal year 2004, the ITBC and its member Tribes were funded at $100,000, a decrease of $200,000 from the previous year. ITBC is now requesting $500,000 for fiscal year 2005 for job training as part of ITBC's labor initiative. To insure the success of ITBC's buffalo restoration efforts to Indian lands, training for the various jobs related to the buffalo projects is essential. Most member Tribes of ITBC have reservation unemployment rates of 72 percent. Jobs opportunities on most Indian Reservations are limited, low-paying, and often seasonal and temporary. The jobs created by buffalo restoration to Indian lands will positively impact Tribal unemployment rates and the overall Reservation poverty levels. Raising buffalo as an economic development effort requires skilled labor in permanent employment. ITBC has developed a job training program incorporating on-the-job training and work experience for youth that specifically addresses the unique needs of managing and maintaining buffalo. ITBC's training program further focuses on strengthening the economic development opportunities of buffalo restoration with training specific to meat processing, veterinary science, wildlife and biological services, infrastructure development, business and management training, and the overall development of a skilled workforce.

Sufficient funding for job training is critical to the success of the buffalo restoration projects. The increase in funding will ensure that ITBC can provide job training, job growth training to ITBC member tribes. Without funding at the requested level, the buffalo restoration projects have less assurance of success.

ITBC GOALS AND INITIATIVES

In addition to developing a preventative health care initiative, ITBC intends to continue with buffalo restoration efforts and the Tribal buffalo marketing initiative.

In 1991, seven Indian Tribes had small buffalo herds, with a combined total of 1,500 animals. The herds were not utilized for economic development but were often maintained as wildlife only. During ITBC's relatively short 10-year tenure, it has been highly successful at developing existing buffalo herds and restoring buffalo to Indian lands that had no buffalo prior to 1991. Today, through the efforts of ITBC, over 35 Indian Tribes are engaged in raising over 15,000 buffalo. All buffalo operations are owned and managed by Tribes and many programs are close to achieving self-sufficiency and profit generation. ITBC's technical assistance is critical to ensure that the current Tribal buffalo projects gain self-sufficiency and become profit-generating. Further, ITBC's assistance is critical to those Tribes seeking to start a buffalo restoration effort.

Through the efforts of ITBC, a new industry has developed on Indian reservations utilizing a culturally relevant resource. Hundreds of new jobs directly and indirectly revolving around the buffalo industry have been created. Tribal economies have benefited from the thousands of dollars generated and circulated on Indian Reservations.

ITBC has also been strategizing to overcome marketing obstacles for Tribally raised buffalo. ITBC is presently assisting the Assiniboine and Gros Ventre Tribes of the Fort Belknap Reservation, who recently purchased an USDA approved meat-processing plant, with a coordination scheme to accommodate the processing of range-fed Tribally raised buffalo.

CONCLUSION

ITBC has proven highly successful since its establishment to restore buffalo to Indian Reservation lands to revive and protect the sacred relationship between buffalo and Indian Tribes. Further, ITBC has successfully promoted the utilization of a culturally significant resource for viable economic development.

ITBC has assisted Tribes with the creation of new jobs, on-the-job training and job growth in the buffalo industry resulting in the generation of new money for tribal economies. ITBC is also actively developing strategies for marketing Tribally owned buffalo. Finally, and most critically for Tribal populations, ITBC is developing a preventive health care initiative to utilize buffalo meat as a healthy addition to Tribal family diets to reduce the incidence of diet-related illnesses.

ITBC strongly urges you to support its request for a $3,000,000 earmark to the Department of Health and Human Service Department's budget to develop the critically needed preventative health care initiative utilizing Tribally produced buffalo.

PREPARED STATEMENT OF THE MEDICARE PAYMENT ADVISORY COMMISSION

The Medicare Payment Advisory Commission (MedPAC) was created by the Congress to provide it with independent policy advice and technical assistance con-

cerning the Medicare program and other aspects of the health care system. To carry out its responsibilities MedPAC requests a budget appropriation of $9.905 million for fiscal year 2005. This request for a $605,000 increase over the Commission's fiscal year 2004 appropriation reflects the expanded responsibilities assigned to the Commission by the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (MMA) (Public Law 108–173), including 16 additional reports and the requirement to advise the Congress on the new prescription drug benefit. The most significant increases in MedPAC's fiscal year 2005 budget will fund data analysis and research contracts to meet those requirements.

WHO WE ARE

MedPAC is a federal advisory commission authorized under section 1805 of the Social Security Act (42 U.S.C. 1395 b-6), as added by section 4022 of the Balanced Budget Act of 1997 (BBA) (Public Law 105–33). Broadly defined by statute, the Commission's responsibilities are to:

—consider Medicare payment policies for private plans and traditional fee-for-service Medicare,
—determine the effects of Medicare payment policies on the delivery of health care services, and
—analyze the implications for Medicare of changes in the broader health care system.

MedPAC is a small efficient operation. The Commission consists of 17 Commissioners, appointed by the Comptroller General of the General Accounting Office, who possess expertise in biomedical, health services, and health economics research and who draw on their experiences as consumers, providers, employers, and payers. The Commission meets publicly throughout the year as it develops its recommendations. An executive director, analytic and administrative personnel staff the Commission. Staff are highly trained health policy analysts and economists. The Commission has less than 40 staff and outsources 40 percent of its budget for tasks such as data analysis, programming, printing, editorial work, and selected research projects to maintain efficiencies. We have also achieved efficiencies by migrating data analysis to personal computers and moving from printed to electronic reports.

The MMA requires that the expertise of the Commission's membership be expanded to include pharmaceuticals, and we expect that to occur when new commissioners are appointed in 2004. Over the coming fiscal year, MedPAC will make a significant investment in resources to be able to provide advice on the implementation of the prescription drug benefit and other program changes introduced by the MMA. Judging from our experience during consideration of the legislation, we also anticipate a significant use of resources to respond to Congressional inquiries about the new benefit and program changes.

WHAT WE DO

Each year, our annual appropriations provide the resources necessary to complete the Commission's required activities, including:

—March report to the Congress. Delivered on March 1 of each year, this report includes recommendations on the appropriate levels of payment for Medicare providers and policies to address the distribution of payments within each payment sector.
—June report to the Congress. Delivered on June 15 of each year, these reports have addressed issues such as Medicare in rural America, innovations and variations in the Medicare program, and a variety of other topics.
—Reports required by other legislation. The new Medicare legislation requires MedPAC to issues 16 reports on a variety of topics—12 of which are due during fiscal year 2005.
—Comments on administrative actions. MedPAC is required to comment on payment-related reports that the Secretary submits to the Congress and other proposed rules issued by the Centers for Medicare & Medicaid Services (CMS).

To support the Congress, MedPAC also anticipates Congressional requests for the following projects not specifically mandated by law:

—Policy briefs on topics of interest, including issues such as a primer on prescription drug formularies, descriptive information on beneficiaries eligible for both Medicare and Medicaid, information about employer-sponsored insurance benefits, and other issues that generate interest throughout the year.
—A Medicare data chartbook in June 2004, similar to the one produced in 2003 in response to requests by health committee staff.
—Requests for data and analysis from the health committee staff (more than 100 last year).

MEDPAC REPORTS PROVIDE INFORMATION AND RECOMMENDATIONS

MedPAC's fiscal year 2003 reports informed the Congress on wide range of Medicare issues. During the past year, the Commission completed our annually mandated March and June reports, eight reports mandated under the BBRA and BIPA, and other reports and studies as requested by the Congress. In addition, six reports were developed for MedPAC by external contractors and issued during 2003, and the Commission has submitted written comments to the Secretary of the Department of Health and Human Services on nine proposed rules.

In a program that spends $272 billion, MedPAC's payment update recommendations have important implications for the beneficiaries, the medical delivery system, and the federal budget. The March 2004 report focuses on payment policies and presents recommendations to Congress on updating payments to hospitals, physicians, and other providers, as well as refinements to their payment systems. It also includes refinements to the payments for private plans as well as recommendations to add quality incentives to the payment systems for end-stage renal disease patients and private plan enrollees.

The June 2004 report will address a range of issues of importance to the Congress as it considers both future legislation and CMS implementation of the MMA. The report will address a broad range of policy issues, including disease management, the dual eligible population, information technology, and an overview of issues surrounding implementation of the new drug benefit. It will also include analyses of long-term care hospitals, innovations in purchasing, and hospices.

We anticipate production and submission of a Medicare data chartbook in June 2004, similar to the one produced in 2003 and as requested by health committee staff—although publication will depend upon our assessment of those resources we must commit to studies mandated by the MMA.

During the rest of fiscal year 2004 and into 2005, MedPAC will also be working on the 16 studies mandated by the MMA. These reports cover issues such as the effect of new provisions to aid rural hospitals, analysis of the volume of physician services, changes in use of Part B drugs by oncology patients, and beneficiary cost sharing in plans. In addition, the Institute of Medicine is required to consult with the Commission on a study about quality incentives in the payment system, and GAO and CMS will collaborate with us on an analysis of specialty hospitals.

MedPAC will also comment on CMS administrative actions and review new payment systems for providers such as long-term care hospitals and inpatient rehabilitation facilities. The MMA assigned the Secretary more than 30 reports on which MedPAC will comment. Given the volume of rules and reports the Secretary must promulgate in the coming year to implement the new drug benefit and other MMA provisions, we anticipate that reviewing those actions will require a substantial amount of resources.

MEDPAC PROVIDES TESTIMONY, BRIEFINGS, AND ASSISTANCE TO HILL STAFF

During calendar year 2003, the Commission testified before three Congressional committees. The Commission chair testified before the House Ways & Means, Subcommittee on Health, on the Commission's March Report to the Congress (March 6, 2003) and on Medicare cost-sharing and supplemental insurance (May 1, 2003). The Commission's executive director testified before the Senate Special Committee on Aging on disease management in traditional Medicare (November 4, 2003). In March 2004, the Commission chair testified on improving quality through Medicare payment policy before the House Ways & Means, Subcommittee on Health.

The Commission has provided additional support to the Congress. From February through April 2003, the Commission briefed the Senate Committee on Finance on selected payment systems. On separate occasions, the executive director also briefed the members of the House Energy and Commerce Committee and the House Rural Caucus. In addition, the executive director briefed staff of the rural health caucus on rural Medicare provider payments.

MedPAC staff regularly brief the health committee staff on ongoing work by the Commission. This includes a series of conference calls and face-to-face meetings prior to each public meeting to discuss research, gather feedback, and provide information about Commission deliberations and upcoming recommendations. Commission staff has also responded, both orally and in writing, to numerous requests from Congressional staff on a wide variety of topics. Not including minor requests, Commission staff has filled over 100 direct requests for information from Congressional staff, involving providing data and other substantive analyses or explanations. Staff have also had more than 20 meetings with or briefings for Congressional staff on related topics.

We anticipate our level of support to the Congress including testimony, briefings, and technical assistance will increase in the next year as issues concerning the implementation and implications of new provisions in the MMA become more apparent.

OUTREACH

During 2003, as in previous years, MedPAC has exchanged information and advice with other government entities involved in crafting and assessing Medicare policy. We have met and conferred with staff from the General Accounting Office, the Centers for Medicare & Medicaid Services, the Congressional Budget Office, the Congressional Research Service, the Agency for Healthcare Research and Quality, and the Assistant Secretary for Planning and Evaluation. Exchanges with these government entities will continue so that we coordinate our work and minimize redundancy.

As in past years, MedPAC has continued to gather input to its policy deliberations through meetings with outside groups. Members of the Commission and staff will continue to meet with outside interest groups in order to gather information for MedPAC's findings and recommendations. In addition, in order to increase our understanding of the health care market and the impact of Medicare payment policy on providers, staff have made site visits to gather information. Such efforts will continue this year.

During 2003, Commission staff extended its public outreach through speaking at a number of conferences. Another venue for public outreach has been staff publication of original articles based on Commission research. Members of the staff will continue to reach out to external groups through attendance at and presentations to academic and professional conferences, as well as publication of articles based on work at the Commission. Such efforts increase staff knowledge of the broader Medicare policy context and expand public understanding of the work of the Commission.

MEDPAC RECOMMENDATIONS HAVE BEEN ADOPTED

The Congress and CMS have adopted MedPAC's recommendations on a range of issues. For example, the MMA reflected several of the Commission's recent recommendations on dialysis payments, the update for home health services, the home health rural add-on, updates to payments for services provided at ambulatory surgical centers, increases for physician services, and inpatient hospital payments.

OUR APPROPRIATION REQUEST FOR FISCAL YEAR 2005

For fiscal year 2005, MedPAC requests $9,905,000, which is $605,000 more than the amount requested for fiscal year 2004. Medicare, a more than $270 billion program, represents one of the Congress' highest priorities. The requested budget of just over $9.9 million to better understand the policy concerns for this vital program is both justifiable and reasonable. This amount is necessary not only to maintain but to increase the current level of analysis, hold Commission meetings, develop data, and meet our mandated responsibilities to the Congress.

Our fiscal year 2005 request is driven by several factors. As required by our authorizing legislation, during fiscal year 2005 we will submit our March and June reports. In addition, we will complete a significant number of new tasks, including:

—Complete 12 mandated reports included in the MMA. In addition, MedPAC is required to consult with the IOM, GAO, and CMS on other reports mandated in the legislation.

—Respond to more than 30 payment-related reports submitted to the Congress by the Secretary.

—Increase the analytic scope of the commission to include prescription drugs.

The majority of the increase in MedPAC's budget is for research contracts, computer programming, and commercial contracts to accomplish these new tasks. External research contracts enhance our efficiency by providing access to areas of expertise and additional work force on an as-needed basis. Because of MedPAC's increasing workload, access to external research contractors is critical to providing timely advice to Congress on key Medicare policy issues.

The increased funding will also enable us to respond to the growing volume of informal Congressional requests for information. In addition, it has become increasingly clear that the data available to assess the Medicare program is inadequate and that we must strive to expand data sources and analysis. Fulfilling Congressional requests and expanding data sources requires increased staff time and increased computer costs for data analysis.

While we do have significant increases in the expenses discussed above, MedPAC has achieved certain economies. We have significantly decreased spending on main-

frame computer costs by moving data to personal computers. In addition, continued migration away from printed to electronic reports and internet-based resources has saved a significant amount of money for printing and reproduction. We anticipate these expenses will decline even further in fiscal year 2005 even though we will be delivering 12 additional reports to the Congress during the fiscal year.

More reports, more requests for information, and more timely data lead to an increase in our budget request. Small size, efficient operations, and increased economies enable us to take on increased responsibilities within, what is by any measure, a small budget in relation to the increased leverage it gives the Congress on the Medicare program.

PREPARED STATEMENT OF RESEARCH TO PREVENTION

Since June 2003, the Centers for Disease Control and Prevention (CDC) has undertaken a strategic planning effort to prepare the agency to address the health challenges of the 21st century. The Futures Initiative has involved gathering information from thousands of partners, stakeholders and the public regarding CDC's organization, scope and reach. Key findings include a need to strengthen CDC's role in health promotion and prevention of disease, disability, and injury. To accomplish this, one overarching goal was identified—"All people will achieve their optimal lifespan with the best possible quality of health in every stage of life."

Research to Prevention, a national coalition committed to improving the nation's health through prevention, wholeheartedly concurs with this goal and urges Congress to provide sufficient resources to permit CDC to maximize its chronic disease prevention efforts throughout the country. The coalition's members include the nation's premier voluntary health organizations and health provider organizations, including: the American Association of Diabetes Educators, the American Cancer Society, the American Diabetes Association, the American Heart Association, the Arthritis Foundation, the Chronic Disease Directors, the Epilepsy Foundation, the Lance Armstrong Foundation, Partnership for Prevention, Prevent Blindness America and the National Health Council.

Research to Prevention aims to make prevention and control of chronic diseases and disability a national policy and funding priority by educating policymakers and advocating for vital funding increases for comprehensive public health programs that address the nation's leading causes of death and disability. Research to Prevention is seeking a $340 million increase in funding in fiscal year 2004 for State-based chronic disease prevention and control programs at the Centers for Disease Control and Prevention (CDC). We also support an increase in funding for the Youth Media Campaign, Racial and Ethnic Approaches to Community Health (REACH), the Preventive Health and Health Services Block Grant, as well as Secretary Thompson's Steps to a Healthier U.S. initiative. The attached chart provides detail on the specific requested funding levels.

Chronic diseases are responsible for more than 70 percent of all U.S. deaths and more than 75 percent of all health care expenditures in the United States. The number of deaths alone, however, fails to convey the full picture of the toll of chronic disease. More than 125 million Americans live with some form of chronic disease, and millions of new cases are diagnosed each year. These serious conditions are often treatable but not always curable. Thus, an even greater burden befalls Americans from the disability and diminished quality of life resulting from chronic disease.

One-third, or approximately $300 billion, of the nation's health care budget is spent on older Americans who often have preventable or controllable chronic diseases and conditions. Much of the disability in old age can be delayed or prevented altogether, potentially improving quality of life and saving the nation billions of dollars in health care expenditures and the costs of long-term care.

Chronic disease is not just an issue among older adults. One-third of the years of potential life lost before age 65 is due to chronic disease. The obesity epidemic in this country is taking its toll on young people. Since 1980, obesity rates have doubled among children and tripled among adolescents. Unhealthy diet and physical inactivity play an important role in many chronic diseases and conditions. As our lead prevention agency, CDC needs additional resources to work with states, schools and local communities to implement promising approaches for preventing obesity.

To curb the excessive burden of chronic diseases, both in human and economic terms, the nation must ensure that research advances are applied, evaluated and implemented at the state and local level with comprehensive, sustainable prevention programs. CDC plays an essential role in translating and delivering at the community level what is learned from research—especially ensuring that those populations

disproportionately affected by chronic disease and disabilities receive the benefits of our nation's investment in medical research. Effective interventions need to be developed and implemented to reduce the disabling consequences of these diseases, including blindness, kidney failure, paralysis, fractures, joint deterioration, and limb loss.

Research to Prevention stands ready to work with the Members of this Subcommittee to help make it possible for every state in the nation to develop and deliver health promotion, health education and disease prevention programs to address chronic diseases and disability. By committing a minimum increase of $340 million in fiscal year 2005 for state-based chronic disease programs, we can work to make this a reality.

All states need and deserve statewide implementation grants for the leading causes of death and disability (heart disease and stroke, diabetes, cancer and arthritis) and their risk factors (physical activity, nutrition, obesity, and tobacco use). Emerging chronic conditions, such as epilepsy and complications associated with chronic disease, such as vision loss and oral disease must also be addressed. States also need to track progress statewide through disease registries and behavioral surveys, including the stroke and cancer registries and the Behavioral Risk Factor Surveillance System (BRFSS). The BRFSS information is essential for planning, conducting and evaluating public health programs at the national, state and local levels. Additionally, private organizations rely on the survey data to develop health promotion programs to reduce the prevalence of unhealthy behaviors and to document their effectiveness.

YOUTH MEDIA CAMPAIGN

Research to Prevention supports a $89 million increase above fiscal year 2004 to restores funding to its $125 million level in fiscal year 2001. This campaign—known as VERB—is designed to give kids a positive advertising message about being physically active through paid media, partnerships, and community efforts. In February 2004, the CDC released the first survey results that indicate physical activity among the nation's youth is increasing as a result of the VERB campaign. A 34 percent increase in weekly free-time physical activity sessions among 8.6 million children ages 9–10 in the United States. R2P believes that VERB should be expanded so that even more children will be exposed to healthy messages and increase their chances of becoming more physically active.

REACH

Research to Prevention supports a $12.7 million increase in the REACH program for a total of $50 million in fiscal year 2005. Launched in 1999, the REACH 2010 is the cornerstone of CDC's efforts to eliminate racial and ethnic disparities in health. This project is designed to eliminate health disparities in cardiovascular disease, immunizations, breast and cervical cancer screening and management, diabetes, HIV infections/AIDS, and infant mortality. The racial and ethnic groups targeted by REACH 2010 are African Americans, American Indians, Alaska Natives, Asian Americans, Hispanic Americans, and Pacific Islanders. REACH 2010 is unique because it works across public and private sectors to conduct community-based prevention research to identify the causes of health disparities. Culturally appropriate, community-driven programs are critical for eliminating racial and ethnic disparities in health. A $50 million allocation would support expansion of community-driven programs and evaluation of successful efforts to build capacity; target action; conduct community/systems change; eliminate health disparities; and translate and disseminate results.

PREVENTIVE HEALTH AND HEALTH SERVICES BLOCK GRANT

Research to Prevention supports an increase of $76.7 million to additional clinical services, preventive screening, laboratory research, outbreak control, workforce training, public education, data surveillance, and program evaluation. The funds are used to target the 265 national health objectives in Healthy People 2010 which address cardiovascular disease, cancer, diabetes, emergency medical services, injury and violence, infectious disease, environmental health, community fluoridation, and sex offenses. Because of the allowed flexibility in the use of the funds, states allocate their block grant resources to address areas of greatest need and target populations. A strong emphasis is placed on programs for adolescents, communities with limited health care services, and disadvantaged populations. Since so many states lack funding to address many of the chronic diseases, states have used much of their block grant money to address the leading killers. This program facilitates coordination between states and their local governments since approximately 43 percent of

PHHS block grant funds were distributed by the states to meet county and local public health needs.

THE ADMINISTRATION'S HEALTHY STEPS INITIATIVE

Research to Prevention supports the Secretary's goals of reducing the burden of chronic diseases and applauds him for his continuing commitment to chronic disease prevention. The requested increase of $81.3 million to support the Steps to a Healthier U.S. Initiative can assist the states, local governments and community organizations to increase their efforts to improve health and well being. While the states already distribute approximately 75 percent of their CDC resources directly to community programs, they still lack the resources necessary to reach many of their communities. States are the engine to reach those communities and the Secretary's Steps Initiative provides the gas for the engine. State-based chronic disease funding and the Steps Initiative need to advance together if we are to reduce death and disability and enhance quality of life.

Research to Prevention thanks the Subcommittee for the opportunity to submit testimony and stands ready to work with all Members to reduce and prevent the economic and social burden of chronic disease on our nation.

RESEARCH TO PREVENTION MEMBERS

American Association of Diabetes Educators; American Cancer Society; American College of Preventive Medicine; American Dental Association; American Diabetes Association; American Heart Association; American Public Health Association; American School Health Association; Arthritis Foundation; Association of State and Territorial Chronic Disease Program Directors; Association of State and Territorial Directors of Health Promotion and Public Health Education; Coalition of National Health Education Associations; Center for Science in the Public Interest; Eli Lilly and Company; Epilepsy Foundation; Lance Armstrong Foundation; Missouri Primary Care Association; National Health Council; National Kidney Foundation, Inc.; Oncology Nursing Society; Partnership for Prevention; Prevent Blindness America; Society for Public Health Education; and YMCA of the USA.

CDC CHRONIC DISEASE PROGRAMS—FISCAL YEAR 2005 RECOMMENDATIONS

[In millions of dollars]

	Fiscal year			Increase over fiscal year 2004
	2003 enacted	2004 enacted	2005 R2P targets	
NATIONAL CENTER CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION	963.1	1,024.4	1,613.5	589.0
Chronic Disease Line	790.5	853.8	1,353.5	499.6
Arthritis	15.6	15.8	25.0	9.2
Lupus	1.0	1.0	.....	.....
Cancer Prevention and Control	287.8	313.6	410.0	96.4
B&C Mort Prev	199.4	209.5	250.0	40.5
WISEWOMAN	14.0	14.0	20.0	6.0
Comprehensive Cancer	9.4	11.9	25.0	13.1
Ovarian	4.4	4.9	10.0	5.1
Prostate	14.0	15.5	20.0	4.5
Colorectal	13.4	14.9	25.0	10.1
Skin	1.6	2.2	10.0	7.8
Registries	45.6	49.7	65.0	15.3
Community Health Promotion	22.1	24.0	37.3	13.3
BRFSS	6.9	8.1	18.0	10.0
Com Health Promotion	8.9	8.3	8.3	.....
Compl/Alt Med	1.7	1.8	2.0	0.2
Glaucoma/Vision Screening	4.7	5.8	9.0	3.2
Diabetes	63.3	66.9	150.0	83.1
Epilepsy	7.5	8.2	13.2	5.0
Heart Disease and Stroke	43.0	45.7	80.0	34.3
Paul Coverdell Stroke Registry	5.0	5.0	5.0	.....
Nutrition/Phys Activity/Obesity	34.1	44.7	75.0	30.3
Micronutrients	5.0	0.4	.....	.....
Iron Overload	0.4	0.4	.....	.....
Oral Health	11.7	12.4	20.0	7.6
Prevention Research Centers	26.8	26.7	26.7	.....
Safe Motherhood /Infant Health	54.0	53.9	53.9	.....

CDC CHRONIC DISEASE PROGRAMS—FISCAL YEAR 2005 RECOMMENDATIONS—Continued

[In millions of dollars]

	Fiscal year			Increase over fiscal year 2004
	2003 enacted	2004 enacted	2005 R2P targets	
School Health	57.8	62.4	82.4	20.0
Coordinated School Health	10.8	15.7	35.7	20.0
HIV	47.0	46.7	46.7	.....
Tobacco	99.9	99.7	130.0	30.3
ADDITIONAL TARGETS:				
STEPS	15.4	43.7	125.0	81.3
Youth Media Campaign	51.0	35.8	5.0	89.2
PHHS BLOCK GRANT	135.0	133.3	210.0	76.7
REACH	37.6	37.3	50.0	12.7

PREPARED STATEMENT OF THE ASSOCIATION OF UNIVERSITY PROGRAMS IN OCCUPATIONAL HEALTH AND SAFETY

Thank you for the opportunity to present testimony to the Subcommittee in support of funding for the National Institute for Occupational Safety and Health (NIOSH) and for the NIOSH-funded Education and Research Centers (ERCs). My name is Jackie Agnew, and I am the Director of the Education and Research Center at Johns Hopkins University Bloomberg School of Public Health.

I am testifying on behalf of the Association of University Programs in Occupational Health and Safety (AUPOHS), the organization that represents 16 multi-disciplinary, NIOSH-supported, university-based Education and Research Centers (ERCs). The ERCs are regional resources for all parties involved with occupational health and safety—industry, labor, government, academia, and the general public. The ERCs play the following roles in helping the nation reduce losses associated with work-related illnesses and injuries:

—*Prevention Research*.—Developing the basic knowledge and associated technologies to prevent work-related illnesses and injuries.

—*Professional Training*.—Graduate degree programs in Occupational Medicine, Occupational Health Nursing, Safety Engineering, and Industrial Hygiene to provide qualified professionals in essential disciplines.

—*Research Training*.—Preparing doctoral-trained scientists who will respond to future research challenges and who will prepare the next generation of occupational health and safety professionals.

—*Continuing Education*.—Short courses designed to enhance professional skills and maintain professional certification in occupational health and safety disciplines. These courses are delivered on-campus at the 16 ERCs as well as through distance learning technologies.

—*Regional Outreach*.—Responding to specific requests from local employers and workers on issues related to occupational health and safety.

THE SCOPE OF THE PROBLEM OF OCCUPATIONAL INJURY AND ILLNESSES

The many causes of occupational injury and illness represent a striking burden on America's health and well-being. Yet, despite significant improvements in workplace safety and health over the last several decades:

—There were 5,524 occupational fatalities in 2002, for an average of 15 workers per day who died from work-related injuries; and

—More than 4.7 million workers sustained work-related injuries and illnesses in the private sector alone in that same year.

—The economic toll of work-related illness and injury on the nation's employers, workers and their families, and society overall reached an estimated $45.8 billion in 2001, with $137.4 to $229 billion more in indirect costs.

This is an especially tragic situation because most work-related fatalities, injuries and illnesses are preventable with effective, professionally directed, health and safety programs. Although our nation has made tremendous progress in reducing occupational illnesses and injuries during the past 30 years, leading to a decline in the rate of total recordable cases from 11.0 to 7.1 cases per 100 full-time workers between 1973 to 1997, the burden of occupational illnesses and injuries remains unacceptably high.

Furthermore, we do not live in a static environment. The rapidly changing workplace continues to present new health risks to American workers that need to be addressed through occupational safety and health research. For example, by the year 2005, an estimated 33 percent of the U.S. workforce will be 45 years or older. Work-injury fatality rates begin increasing at age 45, with rates for workers 65 years and older nearly three times as high as the average for all workers. Despite being the primary federal agency for occupational disease and injury prevention in the nation, NIOSH receives only about $1 per worker per year for its mission of research, professional education, and outreach.

HOMELAND SECURITY

The heightened awareness of terrorist threats, and the increased responsibilities of first responders and other homeland security professionals, illustrates the need for strengthened workplace health and safety in the ongoing war on terror. The NIOSH ERCs play a crucial role in preparing Occupational Safety and Health (OSH) professionals to identify and ameliorate vulnerabilities to terrorist attacks and other workplace hazards and increase readiness to respond to biological, chemical, or radiological attacks.

Thanks to the Subcommittee's support for occupational health and safety research, NIOSH developed more effective methods to test for anthrax contamination in congressional offices. These procedures were quickly adopted by the Coast Guard, the FBI, and government building contractors.

In addition, occupational health and safety professionals have worked for several years with emergency response teams to minimize losses in the event of a disaster. NIOSH took a lead role in protecting the safety of emergency responders in New York City and Virginia, with ERC-trained professionals applying their technical expertise to meet immediate protective needs and conducting ongoing activities to safeguard the health of clean-up workers.

In the face of the growing concerns surrounding homeland security, ERCs have rapidly upgraded research coordination and expanded training opportunities, including sponsoring national and regional forums on response to bioterrorism and other disasters.

THE NEED FOR OCCUPATIONAL SAFETY AND HEALTH MANPOWER

The NIOSH ERCs were reviewed by the DHHS Office of the Inspector General in 1995. The resulting report affirmed the efficacy of the ERCs in producing graduates who pursue careers in occupational safety and health. Since the ERCs are regional, they are ready to respond to various trends in industries throughout the country. And because they provide training that is multi-disciplinary, ERCs graduate professionals who can protect workers in virtually every walk of life. Despite the recognized success of the ERCs in training qualified occupational health and safety professionals, the country continues to have ongoing shortages. The manpower needs are especially acute for doctoral-level trained professionals who can conduct research and help in implementing the National Occupational Research Agenda.

In May 2000, the Institute of Medicine issued its final report on the education and training needs for occupational safety and health (OSH) professionals in the United States. This report concluded that "the continuing burden of largely preventable occupational diseases and injuries and the lack of adequate OSH services in most small and many larger workplaces indicate a clear need for more OSH professionals at all levels." Specific needs identified by the IOM report include:

—An insufficient number of doctoral-level graduates in occupational safety, thus limiting the nation's capacity to perform essential research and training in traumatic injury prevention.

—An inability to attract physicians and nurses into formal OSH academic training programs, thus limiting the resources needed to deliver occupational health services.

NEW NIOSH INITIATIVE: MOVING RESEARCH INTO PRACTICE

The health of the U.S. economy depends upon a healthy and productive workforce. Through its targeted research and prevention programs, as well as its programs of tracking diseases, injuries, and hazards; capacity building; and rapid dissemination of useful information, NIOSH contributes to the nation's progress in reducing workplace injuries and illnesses and enhancing the health and safety of U.S. workers.

In 1996, NIOSH established the National Occupational Research Agenda (NORA), a framework to guide and promote occupational safety and health research through a consensus-building process with more than 500 outside organizations and individ-

uals. The NORA process identified the top 21 research priorities for occupational safety and health for the nation.

NIOSH has long been committed to translating research results into practical recommendations and disseminating them through its publications. For example, "Alerts" help employers and workers identify and respond to work-related health hazards, and "Workplace Solutions" provide practical advice on hazard control. NIOSH is now building even further on these efforts by launching Research to Practice, or r2p, a new initiative to transfer research findings, technologies, and information into effective prevention practices and products and to promote their adoption in workplaces.

The goal of the NIOSH r2p initiative will be to increase the use in the workplace of effective NIOSH and NIOSH-funded research findings. NIOSH will achieve this goal by translating its research findings into practice as quickly as possible, targeting its dissemination efforts, and evaluating and demonstrating the effectiveness of these efforts in improving worker health and safety. ERCs will play a prominent role in this process.

In addition, in coordination with the HHS Secretary's *Steps to a HealthierUS* initiative, NIOSH is introducing *Steps to a HealthierUS Workforce* to encourage workplace health programs that effectively integrate or coordinate efforts to promote both personal health and workplace health. Through NORA, r2p, and *Steps to a HealthierUS Workforce*, NIOSH will continue to work to achieve its goal of preventing work-related illnesses and injuries. These efforts will continue to be enhanced through partnerships, outreach, and capacity-building to enable NIOSH to leverage resources and expertise.

RECOMMENDATION FOR FISCAL YEAR 2005

AUPOHS requests an increase of $5 million for ERCs, and we are supporting a $30 million total increase over the $277 million appropriated in fiscal year 2004 for NIOSH.—This would provide $307 million for NIOSH and $24.7 million for ERCs in fiscal year 2005. Given that much of NIOSH's extramural research program is carried out by our institutions, sustaining the academic infrastructure provided by the ERCs is essential to the success of NORA, r2p, and *Steps to a HealthierUS Workforce.* Our recommendation would ensure that our nation's universities have the capacity and manpower to implement these initiatives and expand training programs to improve the health and productivity of American workers.

Funding for NIOSH and the ERCs would reduce the staggering burden of occupational illnesses and injury on the American economy, recently estimated at $240 billion. To put this number in perspective, these costs dwarf the $33 billion for AIDS and the $67 billion for Alzheimer's disease, and they are greater than the $164 billion economic cost for all circulatory diseases and the $171 billion cost of cancer. Yet federal support for occupational safety and health research pales in comparison—for example, cancer research receives 17 times as much federal funding.

Thank you for the opportunity to report the great need for research and training in occupational safety and health.

NIOSH-SUPPORTED EDUCATION AND RESEARCH CENTERS (ERCS)

Deep South ERC (University of Alabama at Birmingham and Auburn University); Harvard University; Johns Hopkins University; New York /New Jersey ERC (Mt. Sinai Medical Center and Hunter College); Northern California ERC (UC Berkeley, UCSF); Southern California ERC (UCLA and UC Irvine); Texas ERC (University of Texas and Texas A&M University); University of Cincinnati; University of Illinois at Chicago; University of Iowa; University of Michigan; University of Minnesota; University of North Carolina at Chapel Hill; University of South Florida; University of Utah; and University of Washington.

PREPARED STATEMENT OF ROTARY INTERNATIONAL

Chairman Specter, Senator Harkin, members of the Subcommittee, Rotary International appreciates this opportunity to submit testimony in support of the polio eradication activities of the U.S. Centers for Disease Control and Prevention (CDC). The effort to eradicate polio has been likened to a race—a race to reach the last child. This race requires the dedication to make the sacrifices necessary to achieve success. Like some great relay team, the major partners in the global polio eradication effort have joined with national governments around the world in an unprecedented demonstration of commitment to cross the finish line of this historic public health goal. We cannot allow the great distance we have traveled to diminish our

resolve. Though we may be weary, our adversary is weakening. The victory over polio is closer than ever!

PROGRESS IN THE GLOBAL PROGRAM TO ERADICATE POLIO

I would like to take this opportunity to thank you Chairman Specter, Senator Harkin, and members of the Subcommittee for your tremendous commitment to this effort. Without your support of CDC's polio eradication activities, the battle against polio would be impossible. Thanks to your leadership in appropriating funds, the international effort to eradicate polio has made tremendous progress.

—The number of polio cases has fallen from an estimated 350,000 in 1988 to less than 800 in 2003—a more than 99 percent decline in reported cases (see Exhibit A). More than 200 countries and territories are polio-free, including 4 of the 5 most populous countries in the world (China, United States, Indonesia, and Brazil).

—Transmission of the poliovirus has never been more geographically confined. The Western Hemisphere, the Western Pacific and the European regions are certified polio-free. Wild poliovirus transmission is confined to a limited number of polio "hot-spots" within six countries.

—More than 2 billion children worldwide have been immunized during NIDs in the last 5 years, including more than 150 million in a single day in India.

—All polio-endemic countries in the world have conducted NIDs and established high quality surveillance of Acute Flaccid Paralysis (AFP). The eradication of polio in the Democratic Republic of Congo, Sudan, and Somalia shows that polio eradication strategies are successful even in countries affected by civil unrest.

From the launch of the global initiative in 1988, to the eradication target date of 2005, 5 million people who would otherwise have been paralyzed will be walking because they have been immunized against polio. Tens of thousands of public health workers have been trained to investigate cases of acute flaccid paralysis and manage massive immunization programs. Cold chain, transport and communications systems for immunization have been strengthened. A network of 147 polio laboratories has been established to analyze suspected cases of polio and monitor transmission of polio. This network will continue to support the surveillance of other diseases long after polio has been eradicated.

Give the tremendous progress that has been made in reducing the incidence of polio and diminishing the areas in which the virus circulates, the world currently faces an unprecedented opportunity to stop the transmission of wild poliovirus. However, significant challenges remain as obstacles to the ultimate achievement of our goal of a polio-free world. In 2003, Nigeria surpassed India to become the country with the highest number of polio cases. The surge in polio cases in Nigeria also resulted in importations of cases into several of the countries that neighbor Nigeria. The risk of importations into west and central African countries, and around the world, is magnified by financial constraints that limit the scope of immunization activities.

Continued political commitment is essential in all polio endemic countries, to support the acceleration of eradication activities. The ongoing support of donor countries is essential to assure the necessary human and financial resources are made available to polio-endemic countries. Access to children is needed, particularly in Nigeria, where political and financial differences between key states and the federal government were unexpectedly given voice in the form of untrue rumors about the safety of the oral polio vaccine. As a result, immunization activities in the states that need them most were delayed and/or suspended during the effort to address local concerns. Polio-free countries must maintain high levels of routine polio immunization and surveillance. The continued leadership of the United States is critical to ensure we meet these challenges.

THE ROLE OF ROTARY INTERNATIONAL

Since 1985, Rotary International, a global association of more than 30,000 Rotary clubs, with a membership of over 1.2 million business and professional leaders in 166 countries, has been committed to battling this crippling disease. In the United States today there are nearly 7,700 Rotary clubs with some 400,000 members. All of our clubs work to promote humanitarian service, high ethical standards in all vocations, and international understanding. Rotary International stands hand-in-hand with the United States Government and governments around the world to fight polio through local volunteer support of National Immunization Days, raising awareness about polio eradication, and providing financial support for the initiative. In 2003, members of Rotary clubs around the world announced the results of their second polio eradication fundraising campaign. Rotarians far exceeded the U.S. $80

million goal they had set by raising U.S. $119 million in cash and commitments. Rotary firmly believes that the vision of a world without polio can be realized and that the time for action is now. By the time the world is certified polio-free, Rotary's contribution to the global polio eradication effort will exceed U.S. $600 million.

Rotary International's commitment to the global polio eradication represents the largest contribution by an international service organization to a public health initiative ever. These funds have been allocated for polio vaccine, operational costs, laboratory surveillance, cold chain, training and social mobilization in 122 countries. More importantly, tens of thousands of Rotarians have been mobilized to work together with their national ministries of health, UNICEF and WHO, and with health providers at the grassroots level in thousands of communities.

In the United States, Rotary has formed and leads the United States Coalition for the Eradication of Polio, a group of committed child health advocates that includes Rotary, the March of Dimes Birth Defects Foundation, the American Academy of Pediatrics, the Task Force for Child Survival and Development, the United Nations Foundation, and the U.S. Fund for UNICEF. These organizations join us in expressing our gratitude to you for your staunch support of the international program to eradicate polio. For fiscal year 2004, you appropriated a total of $106.4 million for the polio eradication efforts of the CDC. This investment has helped to make the United States the leader among donor nations in the drive to eradicate this crippling disease.

FISCAL YEAR 2005 BUDGET REQUEST

For fiscal year 2005, we respectfully request that you maintain the level of funding that was provided in fiscal year 2004 ($106.4 million) for the targeted polio eradication efforts of the Centers for Disease Control and Prevention. It is important to meet this level of funding due to the increased costs of the accelerated eradication program, and to respond to the increase in supplementary immunization activities in endemic countries, the need to maintain immunity in polio-free areas and maintain certification standard surveillance. This will ensure that we protect the substantial investment we have made to protect the children of the world from this crippling disease by enabling us to conduct the necessary eradication activities to eliminate polio in its final strongholds—the Indian sub-continent and sub-Saharan Africa.

THE ROLE OF THE U.S. CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

Rotary commends CDC for its leadership in the global polio eradication effort, and greatly appreciates the Subcommittee's support of CDC's polio eradication activities. For fiscal year 2004, the Subcommittee appropriated a total of $106.4 million for the CDC's global polio eradication activities. Due to Congress' unwavering support, in 2004 CDC is able to:

—Support the international assignment of more than 200 long-term epidemiologists, virologists, and technical officers to assist the World Health Organization and polio-endemic countries to implement polio eradication strategies, and 16 technical staff to assist UNICEF and polio-endemic countries. This includes 19 CDC staff on direct assignment to WHO and UNICEF.

—Provide $50 million to UNICEF for approximately 540 million doses of polio vaccine and $9 million for operational costs for NIDs in all polio-endemic countries and other high-risk countries in Asia, the Middle East and Africa. Most of these NIDs would not take place without the assurance of CDC's support.

—Provide over $18 million to WHO for surveillance, technical staff and NIDs' operational costs, primarily in Africa. As successful NIDs take place, surveillance is critical to determine where polio cases continue to occur. Effective surveillance can save resources by eliminating the need for extensive immunization campaigns if it is determined that polio circulation is limited to a specific locale.

—Train virologists from all over the world in advanced poliovirus research and public health laboratory support. CDC's Atlanta laboratories serve as a global reference center and training facility.

—Provide the largest volume of both operational (poliovirus isolation) and technologically sophisticated (genetic sequencing of polio viruses) lab support to the 147 laboratories of the global polio laboratory network. CDC has the leading specialized polio reference lab in the world.

—Serve as the primary technical support agency to WHO on scientific and programmatic research regarding: (1) laboratory containment of wild poliovirus stocks following polio eradication, and (2) when and how to stop or modify polio vaccination worldwide following global certification of polio eradication in 2005.

OTHER BENEFITS OF POLIO ERADICATION

Increased political and financial support for childhood immunization has many documented long-term benefits. Polio eradication is helping countries to develop public health and disease surveillance systems useful in the control of other vaccine-preventable infectious diseases.

Already all 47 countries of the Americas are free of indigenous measles, due in part to improvements in the public health infrastructure implemented during the war on polio. The disease surveillance system—the network of laboratories and trained personnel established during the Polio Eradication Initiative—is now being used to track measles, rubella, yellow fever, meningitis, and other deadly infectious diseases. NIDs for polio have been used as an opportunity to give children essential vitamin A, which, like polio, is administered orally, saving the lives of 1.25 million children since 1998. The campaign to eliminate polio from communities has led to an increased public awareness of the benefits of immunization, creating a "culture of immunization" and resulting in increased usage of primary health care and higher immunization rates for other vaccines. It has improved public health communications and taught nations important lessons about vaccine storage and distribution, and the logistics of organizing nation-wide health programs. Additionally, the unprecedented cooperation between the public and private sectors serves as a model for other public health initiatives. Polio eradication is a cost-effective public health investment, as its benefits accrue forever.

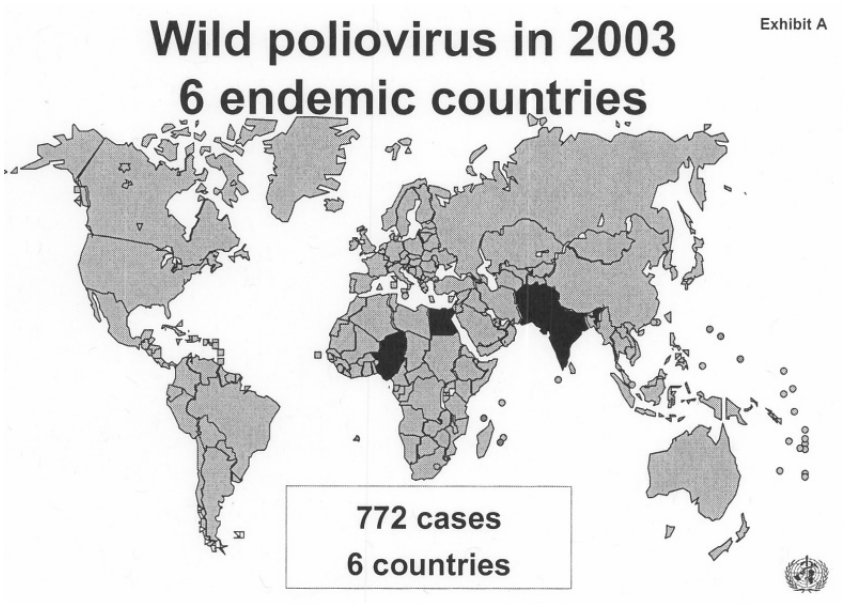
RESOURCES NEEDED TO FINISH THE JOB OF POLIO ERADICATION

The World Health Organization estimates that $765 million is needed from donors for the period 2004–2005 to help polio-endemic countries complete the polio eradication strategy. In the Americas, some 80 percent of the cost of polio eradication efforts was borne by the national governments themselves. However, as the battle against polio is taken to the poorest, least-developed nations on earth, and those in the midst of civil conflict, many of the remaining polio-endemic nations can contribute only a small percentage of the needed funds. In some countries, up to 100 percent of the NID and other polio eradication costs must be met by external donor sources. We ask the United States to continue its financial leadership in order to see this initiative to its successful conclusion as quickly as possible.

The United States' commitment to polio eradication has stimulated other countries to increase their support. Other countries that have followed America's lead and made special grants for the global Polio Eradication Initiative include the United Kingdom ($425 million), the Netherlands ($112 million), and Canada ($85 million). Japan, which has contributed $231 million, recently expanded its support to polio eradication efforts in Africa. Even the tiny country of Luxembourg has invested in global polio eradication by contributing $4.2 million. In both 2002 and 2003 the members of the G8 committed to provide sufficient resources to eradicate polio as part of its Africa Action Plan. In addition to the ongoing contributions made by historic donors such as United States, the United Kingdom, and Canada, new commitments of $37 million and $4 million were made by France and Russia in response to the G8 pledge.

Intense political commitment on the part of endemic nations is also essential to ensuring polio eradication is achieved. In January 2004, health ministers of the six remaining endemic countries (Afghanistan, Egypt, India, Niger, Nigeria, and Pakistan) gathered at a meeting convened at WHO in Geneva to declare their commitment to supporting intensified supplementary immunization activities in the "Geneva Declaration for the Eradication of Poliomyelitis." In addition, resolutions supporting polio eradication were taken by the African Union and the Organization of the Islamic Conference. Each of these resolutions encourages member states to place a high priority on completing the job of polio eradication.

Your discipline, commitment and endurance have brought us to the brink of victory in the great race against this ancient scourge. Polio cripples and kills. It deprives our children of the capacity to run, walk and play. Other great health crises loom on the horizon. Your continued support for this initiative helps ensure that today's children possess the strength and vitality to grow up and fight against the health threats of future generations.



PREPARED STATEMENT OF THE NATIONAL COUNCIL ON FOLIC ACID

The National Council on Folic Acid (NCFA) is a partnership of over 80 national organizations and associations, state folic acid councils and government agencies whose mission is to improve health by promoting the benefits and consumption of folic acid. Our goals are to reduce folic acid preventable birth defects by recommending that women of childbearing age take 400 micrograms of synthetic folic acid daily, from fortified foods and/or supplements, in addition to consuming food folate from a varied diet and to communicate and promote emerging and new science on folic acid, especially that relate to maternal and child health. The undersigned members of NCFA respectfully recommend that at least $5 million be appropriated in fiscal year 2005 for the Centers for Disease Control and Prevention's Folic Acid Education Campaign.

FOLIC ACID AND BIRTH DEFECTS

Folic acid, a B-vitamin, is critical for proper cell division and growth. It is especially important during the early weeks of pregnancy when the embryonic neural tube, which later becomes the brain and central nervous system, is forming and closing. Defects in closure of the neural tube result in the development of a group of birth defects commonly referred to as neural tube defects (NTDs). The two most common NTDs are spina bifida and anencephaly. Closure of the neural tube occurs early in the development, before most women know that they are pregnant. The consumption of only 400 micrograms of folic acid daily taken prior to conception and early in gestation can prevent as many as 70 percent of NTDs.

The birth defects such as anencephaly and spina bifida, have a great social and economic impact on our nation. The average total lifetime cost to society for each infant born with spina bifida is approximately $532 thousand, while estimated annual medical and surgical costs for persons living with spina bifida in the United States exceed $200 million.[1] Fortification of the grain supply is a significant factor in the 32 percent decline in the rates of spina bifida. In order to continue this trend, however, considerable effort is still needed to increase the number of reproductive aged women who consume 400 micrograms of folic acid each day. But, due to the growing popularity of low-carbohydrate diets many women are abandoning bread and other grains, thereby reducing their intake of folic acid.

[1] Centers for Disease Control and Prevention, MMWR, 1989.

FOLIC ACID AWARENESS AND COUNSELING

Only 20 percent of women know that folic acid can prevent birth defects.[2] Consequently, women generally are low consumers of folic acid, with only 30 percent of all women consuming a vitamin supplement with folic acid every day. Of those who take a daily multi-vitamin, 25 percent forget to take it every day.

We know that health care providers should screen women of childbearing age for folic acid consumption in an effort to promote taking a daily multi-vitamin and to prevent neural tube defects. We also know that 53 percent of women not taking a daily multi-vitamin indicated that they would likely do so if their health provider simply encouraged them.[3]

Following that logic, the undersigned NCFA members recommend that at least $5 million be appropriated to fund the Centers for Disease Control and Prevention's Folic Acid Education Campaign, which is housed with the National Center on Birth Defects and Developmental Disabilities. This funding is necessary to continue the Center's programming devoted on raising folic acid public awareness and training of health professionals on how to discuss folic acid consumption with their patients.

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF FAMILY PHYSICIANS

The 93,700-member American Academy of Family Physicians submits this statement for the record in support of the Section 747 Primary Care Medicine and Dentistry Cluster. The Academy also supports the Agency for Healthcare Research and Quality (AHRQ) and rural health programs.

Section 747 is the only national program that funds family physician training and includes dollars for general internal medicine/general pediatrics; physician assistants and general/pediatric dentistry. The fiscal year 2004 spending bill provides only $82 million to Section 747, a figure that is $10 million below the fiscal year 2003 levels. The Congressionally established Advisory Committee on Training in Primary Care Medicine and Dentistry (ACTPCMD) recommends $198 million for Section 747.

SECTION 747 PRIMARY CARE MEDICINE AND DENTISTRY CLUSTER

Background

Section 747 supports family medicine training programs in medical school and in residency programs. It is specifically designed to meet two goals: increase the number of primary care physicians, and boost the number of people who will provide care to the underserved. The Institute of Medicine defines primary care physicians as family physicians, general internists and general pediatricians.

Family physicians provide comprehensive, coordinated and continuing care to patients of both genders and all ages and ethnicities, regardless of medical condition. These residency-trained, primary care specialists treat babies with ear infections, adolescents who are obese, adults with depression and seniors with multiple, chronic illnesses. And because they focus on prevention, primary care, and integrating care for patients, they are able to treat illnesses early; cost-effectively and when necessary, help patients navigate our complex health system and find the right subspecialists.

Section 747 funding has led thousands of physicians to go into primary care and family medicine and serve millions of patients. A study by the Robert Graham Center for Policy Studies showed that medical schools that received Section 747 family medicine funds produced more medical students who:

—Practiced in family medicine or primary care;
—Practiced in a rural area; or
—Practiced in a whole county Primary Care Health Professions Shortage Area (HPSAs) (i.e., counties with inadequate numbers of family physicians, general pediatricians, general internists or obstetrician/gynecologists).

The study showed that continued funding during the years of medical school training had more of a positive impact than intermittent funding.

Another Graham Center report revealed that more Americans depend on family physicians than any other medical specialty: without family physicians, the majority of U.S. counties would become Primary Care Health Professions Shortage Areas. Of the 3,142 counties in the United States, 1,184 (38 percent) are full or partial county HPSAs, which includes more than 41 million Americans.

---

[2] March of Dimes, June 2002.
[3] March of Dimes, June 2002.

Funding for Programs Historically Under Threat

However, the health professions programs have been under fire for many years, and, as a result, funding has been threatened during several fiscal cycles. For example, the Administration's fiscal year 2005 budget would eliminate funding for Section 747 and cuts funding severely for Title VII. Reasons differ for these cutbacks, but center mainly around disagreements regarding the long-term role of the federal government in training physicians, and uncertainty about program outcomes and effectiveness.

Most recently, the Office of Management and Budget (OMB) attempted to express these arguments in the 2003 Program Assessment Rating Tool (PART). In that document, OMB criticized all of the Title VII Health Professions programs as lacking a focused objective. However, Section 747, in particular, has a clear purpose and has been successful in achieving its goals. The OMB evaluation lumps all of the programs together and does not evaluate them individually. By definition, these programs will have different goals, different levels of effectiveness and different histories, making the PART evaluation unsophisticated, at best. Additionally, since the federal government has been struggling with a budget shortfall, programs with the slightest amount of negative attention have been tempting targets for budget cutbacks.

Nonetheless, these training programs still enjoy a great deal of support from members of the Appropriations Committees in both the Senate and House, which the Academy appreciates. And, with the exception of the fiscal year 2004 spending bill, Congress has consistently restored funding for these programs.

The Academy strongly believes that the federal government must maintain appropriate funding for Section 747 family medicine training programs. The rationale for this comes from two sources: the steady reliance on family physicians in the current U.S. healthcare system and the Academy's new proposal to restructure future Section 747 family medicine training programs for the coming healthcare system. In short, family physicians are key to a modern healthcare system and more money is needed to modernize their training.

Preserve the U.S. Health Care Safety Net

The Academy supports the Administration's commitment to funding increases to build more Community Health Centers (CHC) and supplement the National Health Service Corps (NHSC). However, we believe that increasing funding for CHCs and the NHSC is only a partial solution. Without support for family physician training, there will be fewer of the physicians who work in these centers or practice in underserved areas. Thousands of family physicians will be needed if the growth in the number of CHCs sites and NHSC staff is to be realized.

Specifically, nearly half of the physicians who staff the nation's Community Health Centers are family physicians. And, since 1971, the National Health Service Corps has placed more than 18,000 health care providers in underserved areas: almost half of the NHSC doctors were family physicians. Finally, according to data from the National Association of Community Health Centers, in 2002, the majority of CHC employees were primary care physicians who were responsible for almost 22 million patient visits.

Invest in Cost-Effective, Quality Care

Unlike all other developed countries, the United States does not have a primary care-based health care system. While other developed countries have about equal numbers of primary care doctors and subspecialists, less than one-third of the U.S. physician workforce is primary care doctors (including family physicians). As a result, about two thirds of the U.S. physician workforce is made up of subspecialists.

In addition, compared to those in other developed countries, we spend the most per capita on healthcare but have the worst healthcare outcomes. More than 20 years of evidence have shown that a primary care-based health system produces greater health and economic benefits. Boosting support for Section 747, which funds training for family physicians and for other primary care disciplines, could allow patients in the United States to enjoy those benefits.

Specifically, research reveals that primary care is effective: leading to reduced all-cause mortality and mortality due to cardiovascular and pulmonary diseases; less emergency department and hospital use; better preventive care; better detection of breast cancer, and reduced incidence and mortality due to colon and cervical cancer. Studies have also shown proof of efficiency: fewer tests; higher patient satisfaction; lower medication use and lower care-related costs. Finally, the data indicates that primary care promotes equity among different populations: health disparities are reduced, particularly for areas with the highest income inequality, resulting in improved vision, more complete immunization, better blood pressure control, and bet-

ter oral health. Supporting Section 747 family medicine training would produce more family physicians, physicians who are cost-effective and provide high quality care.

AGENCY FOR HEALTHCARE, RESEARCH AND QUALITY

The Academy recommends $443 million for the Agency for Healthcare, Research and Quality (AHRQ). AHRQ conducts primary care and health services research geared to physician practices, health plans and policymakers that helps the American population as a whole. In short, the agency translates research findings from basic science entities like the National Institutes of Health (NIH) into information that doctors can use every day in their practices. Another key function of the agency is to support research on the conditions that affect most Americans.

AHRQ Translates Research into Everyday Practice

Congress has provided billions of dollars to the National Institutes of Health, which has resulted in important insights in preventing and curing major diseases. AHRQ takes this basic science and produces information that physicians can use every day in their practices. AHRQ also distributes this information throughout the health care system. In short, AHRQ is the link between research and the patient care that Americans receive.

For example, research shows that that beta blockers reduce mortality. AHRQ supported research to help physicians determine which patients with heart attacks would benefit from this medication.

AHRQ Supports Research on Conditions Affecting Most Americans

Most typical Americans get their medical care in doctors' offices and clinics. However, most medical research comes from the study of extremely ill patients in hospitals

AHRQ studies and supports research on the types of illness that trouble most people. In brief, AHRQ looks at the problems that bring people to their doctors every day—not the problems that send them to the hospital.

For example, AHRQ supported research that found older antidepressant drugs are as effective as new antidepressant medications in treating depression, a condition that affects millions of Americans.

Provisions in the Medicare Modernization Act

In addition, the new Medicare law also directs the agency to study the "clinical effectiveness and appropriateness of specified health services and treatments." While the law authorizes $50 million for this effort, the Academy supports the $75 million figure that is included in the Senate budget resolution.

Moreover, the law asks the agency to establish a new "Citizens' Health Care Working Group," to initiate a nationwide public debate about improving the health care system with the goal of providing every America high quality and affordable health care coverage. The AAFP also supports funding for this new commission.

RURAL HEALTH PROGRAMS

Continued funding for rural programs is vital to provide adequate health care services to America's rural citizens. We support the Federal Office of Rural Health Policy; Area Health Education Centers; the Community and Migrant Health Center Program; and the NHSC. State rural health offices, funded through the National Health Services Corps budget, help states implement these programs so that rural residents benefit as much as urban patients.

CONCLUSION

The Academy urges Congress to increase funding for Section 747 family medicine training (the Advisory Committee on Training in Primary Care Medicine and Dentistry $198 million for Section 747); $443 million for AHRQ and support for rural health programs. Federal support is vital to sustain and improve America's health care system.

PREPARED STATEMENT OF THE TRI-COUNCIL FOR NURSING

The Tri-Council for Nursing appreciates the opportunity to comment on fiscal year 2005 appropriations for nursing programs. The Tri-Council for Nursing is an alliance of four national nursing organizations—the American Association of Colleges of Nursing (AACN), the American Nurses Association (ANA), the American Organization of Nurse Executives (AONE), and the National League for Nursing (NLN).

The Tri-Council is focused on leadership and excellence in nursing. Together, we represent the breadth and scope of nursing; including practicing nurses, nurse executives, nurse educators, and nurse researchers.

The Tri-Council gratefully acknowledges this Subcommittee's support for nursing education and research. We appreciate your continued recognition of the important role nurses play in the delivery of health care services and the increased need to fund nursing education programs, nursing research, and innovative practice models. Unfortunately, the nursing shortage continues to worsen, therefore we are again urging you to invest in nursing.

Today, the burgeoning nursing shortage is impacting health care delivery throughout the nation. The increasing health care demands of the aging U.S. population and changes in the nurse workforce have combined to create a shortage unlike any other. A fundamental shift has occurred in the registered nurse (RN) workforce over the last two decades. As occupational opportunities for young women have expanded, and the changing health care environment has increased stresses on nursing, the number of young people entering nursing has declined. The lack of young people in nursing has resulted in a steady and dramatic increase in the average age of the U.S. nurse. Today, the average working RN is over 43 years old. The average nurse educator is over 50 years old.

This shortage is growing just as the need for nursing services is mounting. America's demand for nursing care is expected to balloon over the next 20 years as a result of the aging of the population, advances in technology, and various economic and policy factors. On February 11, 2004, the Bureau of Labor Statistics reported that registered nursing will have the greatest job growth of all U.S. professions in the time period spanning 2002–2012. During this ten-year period, health care facilities will need to fill more than 1.1 million RN job openings. The Division of Nursing at the Health Resources and Services Administration projects that, absent aggressive intervention, the supply of nurses in America will fall 29 percent below requirements by the year 2020.

The nursing shortage is already having a detrimental impact on the health care system. Numerous recent studies have shown that nursing shortages contribute to medical errors, poor patient outcomes, and increased mortality rates. A study published in the May 30, 2002, *New England Journal of Medicine* reported that higher levels of nursing care correlate with better patient care. And a Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) study published in 2002 shows that nearly one-quarter of all unanticipated deaths or injuries result from nurse shortages. Another study published in the October 23, 2002 Journal of the American Medical Association found that among the surgical patients studied, there was a pronounced correlation between nursing shortages and both patient mortality and failure to rescue.

This growing nursing shortage has effects well beyond domestic health care. Nurses are integral in everything from adequate terrorism preparedness, to veterans' health delivery, to disaster response. In addition, the activation of military reserves is drawing nurses out of the domestic labor market. Therefore, this shortage threatens our very strength as a nation.

NURSING WORKFORCE DEVELOPMENT

Federal support for Nursing Workforce Development in Title VIII of the Public Health Service Act (PHSA) is unduplicated and essential. Recognizing the impact of the nursing shortage, the 107th Congress took the visionary step of passing the Nurse Reinvestment Act (Public Law 107–205). This law improved the programs of Title VIII to meet the unique characteristics of today's shortage. It contained public service announcements, geriatric training grants, and a nurse faculty loan repayment program. It also expanded existing programs in Title VIII to include a scholarship program, career ladder programs, and retention grants for enhancing patient care delivery systems.

In fiscal year 2004, the hard work of this Subcommittee resulted in $142 million in funding for Title VIII programs. We strongly urge you to increase funding for Title VIII programs by at least $63 million to a total of $205 million in fiscal year 2005. The Tri-Council believes that the need for this increase is borne out by the HRSA information for 2003 indicating that only 2 percent of the applications for nursing scholarships were funded, and a mere 8 percent of the nurse education loan repayments were funded.

The Title VIII authorities are:

Nurse Education, Practice, and Retention Grants

This section, formerly known as the Basic Nurse Education and Practice, was expanded and reorganized by the Nurse Reinvestment Act. Education grant areas

were reorganized to include: expanding enrollments in baccalaureate nursing programs; developing internship and residency programs to enhance mentoring and specialty training; and providing new technologies in education including distance learning.

Practice grant areas include: expanding practice arrangements in non-institutional settings to improve primary health care in medically underserved communities; providing care for underserved populations such as the elderly, HIV/AIDS patients, substance abusers, homeless, and domestic abuse victims; providing skills necessary to practice in existing and emerging health systems; and developing cultural competencies.

Retention grant areas include career ladders and improved patient care delivery systems. The career ladders program supports education programs designed to assist individuals in obtaining clinical and theoretical education required to enter the profession, and to promote career advancement within nursing. In fiscal year 2003, HRSA received 301 applications for career ladder grants. Unfortunately, funding levels allowed HRSA to award a total of 12 grants.

Enhancing patient care delivery system grants encourage nurses to remain in patient care by providing grants to facilities to enhance collaboration and communication among nurses and other health care professionals, and to promote nurse involvement in the organizational and clinical decision-making processes of a health care facility. Best practices for these nurse administration programs have been identified by the American Nurse Credentialing Center's Magnet Recognition Program. These best practices have been shown to double nurse retention rates, increase nurse satisfaction, and improve patient care. In fiscal year 2003, HRSA received 122 applications for enhanced patient care delivery systems; HRSA was able to fund 14.

Nurse Education, Practice, and Retention Grants received $31.8 million in fiscal year 2004 appropriations.

National Nurse Service Corps

The nurse service corps is comprised of a loan repayment program and a scholarship program, the Secretary of HHS has the authority to allocate funds between the two areas. The Nurse Education Loan Repayment Program (NELRP) repays nursing student loans in return for at least 2 years of practice in a facility with a critical nursing shortage. For the first 2 years of service, the NELRP will repay 60 percent of the RN's student loan balance. If the nurse elects to stay for another year, an additional 25 percent of the loan will be repaid. Within 3 years, a nurse can pay off 85 percent of his/her student loans.

The NELRP has benefited from the support of this Subcommittee, as well as the administration. It boasts a proven track record of delivering nurses to facilities hardest hit by the nursing shortage. HRSA has given NELRP funding preference to skilled nursing facilities, disproportionate share hospitals, and departments of public health. However, lack of funding has hindered the full implementation of this program. In fiscal year 2003, HRSA received more than 8,300 applications for the NELRP. Due to lack of funding, only 602 loan repayments were awarded. Therefore, 92 percent of the nurses willing to immediately begin practicing in facilities hardest hit by the shortage were turned away from this program.

The nursing scholarship program offers funds to nursing students who, upon graduation, agree to work for at least 2 years in a health care facility with a critical shortage of nurses. Preference is given to students with the greatest financial need. Like the loan repayment program, the nursing scholarship program as been stunted by a lack of funding. For fiscal year 2003, HRSA received more than 4,500 applications for the nursing scholarship. Due to lack of funding, a mere 94 scholarships were awarded. Therefore, 98 percent of the nursing students willing to work in facilities with a critical shortage of nurses were also denied access to the corps.

The National Nurse Service Corps received $26.7 million in fiscal year 2004 appropriations.

Nurse Faculty Loan Program

This program establishes a loan repayment fund within schools of nursing to increase the number of qualified nurse faculty. Nurses may pursue a master's or doctoral degree. They must agree to teach at a school of nursing in exchange for cancellation of up to 85 percent of their educational loans, plus interest, over a 4-year period. Loans may cover the costs of tuition, fees, books, laboratory expenses, and other reasonable education expenses.

This program is critical given the worsening shortage of nursing faculty. Last year, schools of nursing were forced to turn away tens of thousands of qualified applicants due largely to the lack of faculty. In fiscal year 2003, HRSA awarded 55 nurse faculty loan repayments.

The Nurse Faculty Loan Program received $4.9 million in fiscal year 2004 appropriations.

Nursing Workforce Diversity

This program provides funds to enhance diversity in nursing education and practice. It supports projects to increase nursing education opportunities for individuals from disadvantaged backgrounds—including racial and ethnic minorities, as well as individuals who are economically disadvantaged. Racial and ethnic minorities currently comprise more than 25 percent of the nation's population and will comprise nearly 40 percent by the year 2020. Only 12 percent of the RNs in the United States come from diverse backgrounds. Increasing the number of RNs from diverse races and cultures allows them to address the prevention, treatment, and rehabilitation needs of an increasingly diverse population. For fiscal year 2003, HRSA received 122 submissions for nursing workforce diversity grants. HRSA was only able to fund 20.

Nursing Workforce Diversity received $16.4 million in fiscal year 2004 appropriations.

Advanced Nurse Education

Advanced practice registered nurses (APRNs) are registered nurses (RNs) who have attained advanced expertise in the clinical management of health conditions. Typically, an APRN holds a master's degree with advanced didactic and clinical preparation beyond that of the RN. Most have practice experience as RNs prior to entering graduate school. Practice areas include, but are not limited to: anesthesiology, family medicine, gerontology, pediatrics, mental health, midwifery, neonatology, and women's & adult health. Title VIII grants have supported the development of virtually all initial state and regional outreach models using distance learning methodologies to provide advanced study opportunities for nurses in rural and remote areas.

These grants also provide traineeships for masters and doctoral students. Title VIII funds more than 60 percent of U.S. nurse practitioner (NP) education programs and assists 83 percent of nurse midwifery programs. Over 45 percent of advanced nursing graduates go on to practice in medically underserved communities, and in areas with large Medicaid populations. Many provide care to minority or disadvantaged patients. In fiscal year 2003, HRSA funded 35 advanced education nursing grants, 335 advanced education nursing traineeships, and 69 nurse anesthetist traineeships.

Advanced Education Nursing received $58.6 million in fiscal year 2004 appropriations.

Comprehensive Geriatric Education Grants

This authority awards grants to train and educate nurses in providing health care to the elderly. Funds are used to train individuals who provide direct care for the elderly, to develop and disseminate geriatric nursing curriculum, to train faculty members in geriatrics, and to provide continuing education to nurses who provide geriatric care. The growing number of elderly Americans and the impending health care needs of the baby boom generation make this program critically important. In fiscal year 2003, HRSA received 92 applications for the comprehensive geriatric training program, 17 grants were funded.

Comprehensive Geriatric Education Grants received $3.5 million in fiscal year 2004 appropriations.

NATIONAL INSTITUTE OF NURSING RESEARCH (NINR)

The Tri-Council also urges the Subcommittee to increase funding for the NINR, one of the institutes at the National Institutes of Health (NIH). Nursing research is an integral part of the effectiveness of nursing care. Advances in nursing care arising from nursing and other biomedical research improves the quality of patient care and has shown excellent progress in reducing health care costs. Research programs supported by the NINR address a number of critical public health and patient care questions. The research is driven by real and immediate problems encountered by patients and families. Study results offer the clear prospect of improving health, reducing morbidity and mortality, and lowering costs and demand for health care.

Recent studies have focused on the effects of hospital restructuring, such as changes in nurse staffing, on patient care; the incidence and risk factors for uterine rupture in pregnancies following cesarean section; and the means to help family caregivers provide high-quality long, term care for loved ones with chronic health care needs. In addition, NINR is leading the NIH research on end-of-life and pallia-

tive care. The NINR is the second-lowest funded institute at NIH and provides vital health care research for the nursing community. The Tri-Council recommends increasing funding for the NINR in fiscal year 2005.

CONCLUSION

While the Tri-Council is encouraged by a recent resurgence of interest in the nursing profession, we are concerned by the fact that Title VIII funding levels have not been sufficient to assist qualified students enter the nursing profession. The nursing shortage will continue to worsen if significant investments are not made in nursing workforce development programs. Recent efforts have shown that aggressive and innovative recruitment efforts can help avert the impending nursing shortage—if they are adequately funded.

Thirty one years ago, this committee invested $153.6 million in the fiscal year 1974 programs of Title VIII. Inflated to today's dollars, this long-ago appropriation would equal $574 million (more than four times the fiscal year 2004 appropriation). Today's shortage is more dire and systemic than that of the 1970's. The Tri-Council asks you to meet today's shortage with a relatively modest investment of $205 million in Title VIII programs. Additionally, an investment in the NINR will help assure that these nurses are equipped with the information needed to provide the best care possible.

PREPARED STATEMENT OF THE NATIONAL AREA HEALTH EDUCATION CENTERS ORGANIZATION

SUMMARY OF FISCAL YEAR 2005 RECOMMENDATIONS

—Increase funding for the health professions and nursing education programs under Title VII and Title VIII of the Public Health Service Act to at least $550 million for fiscal year 2005.
—Restore funding for Area Health Education Centers (AHECs) to fiscal year 2003 level of $33.1 million.
—Restore funding for Health Education Training Centers (HETCs) to fiscal year 2003 level of $4.3 million.

Mr. Chairman, and members of the subcommittee, I am pleased to present this testimony on behalf of the National AHEC Organization (NAO).

By way of brief introduction, my name is Linda Kanzleiter. I am an Assistant Professor at the Pennsylvania State University College of Medicine and the Associate Director for the dual state Pennsylvania-Delaware Area Health Education Center Program (PA-DEL AHEC).

As a member of NAO, the professional organization representing the national network of Area Health Education Center Programs (AHECs) and Health Education Center Programs (HETCs), I come to you today to demonstrate the AHEC/HETC network as a well-established national system of community and academic partnerships that increases access to quality health care services for our nation, especially the growing number of uninsured and underinsured populations by improving the supply and distribution of our health professions workforce.

Three essential strategies were developed: the Neighborhood Health Centers, later to be named Community Health Centers (1964); the National Health Service Corps (NHSC) established in 1970; and the Carnegie Commissions Report establishing the AHEC program (1970) and HETC program, established for Border and non-border areas (1989). The three programs were created in different acts and at different times, but were brought together within the Public Health Service within a 3-year period.

The Community Health Centers are dedicated to providing preventative and ambulatory health care to the most uninsured and underinsured populations by placing point-of-service facilities in these areas; and the NHSC is committed to placing health professionals to the areas which have the most difficult time recruiting and retaining health professionals. However, it is the AHEC & HETC organization that recruits, trains and retains a health professions workforce committed to working with the underserved. This goal is accomplished through bridging the resources of academia to communities.

THE NATIONAL AHEC AND HETC ORGANIZATION

The effectiveness of the AHEC & HETC organization rests with its community and academic leadership, collaborative practices and committed partnerships of numerous community-based organizations representing 48 AHEC & HETC programs, which direct 180 centers housed in 43 states.

Fundamental to the health care infrastructure of the nation is the recruitment and retention of a qualified health professions workforce. The strategic functions of the AHEC & HETC programs is to facilitate the recruitment and retention of the current and future health care professions workforce as a means to increase access to health care services, and to provide a vehicle to access community-based and academic-based health professionals integral to the promotion, development, dissemination and management of public and community health issues. Claude Earl Fox, former Administrator of HRSA, said it so well: "AHEC programs are a catalyst in both the communities they bridge—spurring the academic enterprise to attend to the needs of the underserved people—and sparking the community of people served to involve themselves in the training of health professionals. This is a necessary first step in addressing the health needs of any community."

The strength of the national AHEC & HETC organization is their cultural diversity and scope of work. The key functions of the AHEC & HETC network rests with access and building capacity, which:

—Creates community-based education and training networks that are developed through linking health professionals and their practices in underserved areas with academic centers and programs to create clinical training experiences for primary care residents, medical students, dental medicine students, nurse practitioners, physician assistants, nurses and other allied health students.

—Recruits practitioners from the incumbent health professions workforce to medically underserved communities through established recruitment programs and special placement opportunities. Special re-entry programs offered to retrain nurses and other health careers for return to the workforce, and job re-training offered to adult learners interested in developing a career ladder or career change.

—Retains practitioners working with disenfranchised populations and medically underserved communities through innovative and traditional continuing medical education programs, building linkages between the community practitioners and academic centers, providing telemedicine initiatives and self directed educational modules to maintain knowledge and skills of health professionals, and fostering telemedicine programs for clinical consultation in some areas.

—Prepares interested primary and secondary students from rural, urban and cultural diverse communities for college and/or career programs in the health professions through academic readiness programs. With a cultural and ethnic diversity blending the nation, emphasis is placed on preparing under-represented minority students into the health careers through science, math, and English preparatory programs.

—Retains the commitment of high school students, medical students, health professions students and residents through the pipeline of health professions education and training through selective mentoring, shadowing and special interest programs.

—Builds capacity within the health care community to address community and public health issues such as bioterrorism, Healthy People 2010 objectives.

THE PA-DE AHEC PROGRAM

The PA-DE AHEC Program is celebrating its 10th Anniversary this year. Although Delaware is new to the Commonwealth's and national AHEC organization, the leadership of the Delaware region brings an in-depth understanding of its state's health professions needs and a commitment to the mission of the national organization and Pennsylvania AHEC program.

The PA-DE AHEC Program houses an innovative dual state system that integrates and bridges academic centers with communities to strengthen and increase access:

—To health care services, especially in underserved communities,

—To communities and health care personnel integral to the public health infrastructure,

—To the academic and community-based health professions workforce,

—To the vital educational resources required to maintain the skills and knowledge of those vested with safe-guarding the health of Pennsylvania and Delaware,

—To the primary and secondary educational systems fostering interests in health careers, especially for cultural and ethically diverse schools students,

—To the medical, dental and mental health practice communities facilitating and responding to community and public concerns.

THE PA-DE AHEC ORGANIZATION

The PA-DE AHEC Program has developed a dual state infrastructure that includes: the University of Pittsburgh Schools of Medicine, Nursing, Dentistry, Pharmacy and Public Health; the Pennsylvania State University College of Medicine, School of Nursing and Agromedicine Program; the Philadelphia College of Osteopathic Medicine; Temple University Schools of Medicine, Pharmacy, Nursing and Dentistry; Thomas Jefferson University, Jefferson Medical College and College of Nursing; Drexel University School of Medicine, University of Pennsylvania School of Dental Medicine and Midwifery Program, and Delaware University, School of Nursing.

Our medical education and training infrastructure also includes over 90 health science institutions, and a community-based teaching network of over 1,000 physicians and health professionals representing 12 medical, oral and public health disciplines, and numerous community organizations inclusive of Pennsylvania's 67 counties and Delaware's three counties.

About Pennsylvania and Delaware

Pennsylvania and Delaware, like the rest of the nation, share the problem of maldistribution of health care providers and limited access to essential health care services. Pennsylvania houses a population of over 12 million people within a geographic range of 46,000 square miles, and supports one of the largest aging populations in the nation. Traditional market forces have not been very effective in making health care available to rural and inner city residents. It is estimated that 21 percent or greater have no health care coverage and a significant proportion remain underinsured. Primary care access and provider shortage in the state have resulted in areas of 55 of 67 counties being designated as Health Professional Shortage Areas (HPSA), Medically Underserved Areas (MUA) or both. Dental Health Professions Shortage Areas and Mental Health Shortage Areas are representative of an increased number of counties without oral and mental health services.

Increasing Access to Health Care

The PA-DE AHEC has facilitated placement of over 31,000 students, representing 78,500 clinical training weeks. These students are primarily recruited to train in underserved communities. Working with 51 community health centers, federally qualified centers, and NHSC designated centers, the PA-DE AHEC fosters clinical training experiences that teach students the rewards and challenges of working with at-risk populations and the special knowledge and skills required to provide quality health care in communities with limited resources.

HEALTH PROFESSIONS RECRUITMENT AND RETENTION

Promoting the NHSC and State Loan Repayment and Scholarship programs are important first steps to introducing providers to Pennsylvania and Delaware. Developing and implementing math, science and English programs for students in disadvantaged school districts facilitates entrance into the health careers through a Grow Your Own approach to the health professions crisis. Special initiatives are also promoted in areas of nursing with re-entry programs (refresher courses for licensed nurses not practicing for five or more years), retraining programs that offer promotional and career advancement, and remedial programs that are targeted to the special adult learner seeking admission to the health careers. All AHEC regions look to facilitate nursing programs focused on recruitment, re-entry, retraining and retention initiatives.

In addition, the PA-DE AHEC Program provides self-directed study programs as way for practitioners to access continuing professional education programs in respect to the increasing professional and practice demands of their office and community. For example the most recent program, PA-DE AHEC is offering a self-directed learning program on the screening, diagnosing and treatment of endocrine disease, psychiatric disorders and co-morbidity. Web-based learning in areas of tobacco cessation and tobacco cessation pharmacopeias are also venues of self directed programs. In addition, statewide satellite broadcasts with capabilities to over 520 down link sites within the system add another venue for continuing professional education.

PUBLIC HEALTH INFRASTRUCTURE

Responding to the national, state and local needs of preparedness teams and public health workers, the PA-DE AHEC Program is an integral partner to the emerging public health infrastructure. The PA-DE AHEC provides, through its academic and community partnerships, program development as well as critical access to com-

munities, at-risk populations and the health professions workforce for emerging public health issues, such as bioterrorism preparedness training to health professionals, especially to agricultural and migrant communities. In addition we work with public health officials in areas of health promotion and disease prevention programs, which focus on minority health disparities and cultural sensitivity training for safety net providers. Many community and public health programs are also delivered to respond to the Healthy People 2010 objectives.

CRITICAL WORKFORCE ISSUES

Regardless of the 30 years of well-intended efforts by countless health professionals and policy makers, the nation's health care "safety net" program is not able to meet the growing health care needs of the country's uninsured and underinsured populations. Young adults no longer see clinical nursing as an acceptable career path, In fact, other health professions are at-risk; pharmacy is another example. Rural hospitals and health systems are also closing frequently; which adds another dimension to limiting access to health care services. The impact of hospital and system closures contributes to the unemployment rate in local communities and decreases the economic base. This fractured health care system looks to address the health care needs of an aging nation, which requires much of its health professions workforce.

Pennsylvania and Delaware are faced with similar concerns. Only 13 percent of Pennsylvania primary care physician workforce practice in rural areas. Furthermore, 25 percent of primary care physicians in the Commonwealth are 55 or older indicating a large number of potential retirees. Equally troublesome is documentation indicating that 20 percent will leave primary care practice in the state because of lack of practice coverage, reimbursement issues, lack of technology in rural areas, and professional isolation. Time is of the essence, and the important message is that AHEC is the foundation for recruiting, retaining and distributing a health professions workforce for the nation.

Mr. Chairman, I respectfully ask the Subcommittee to support our recommendation to increase funding for the Health Professions and Nursing Education programs under Title VII and Title VIII of the Public Health Service Act to a minimum of $550 million for fiscal year 2005. Our recommendations are consistent with those of the Health Professions and Nursing Coalition.

PREPARED STATEMENT OF THE NATIONAL LEAGUE FOR NURSING

The National League for Nursing (NLN)—representing more than 1,300 schools of nursing, 14,000 faculty and individual members, and 18 constituent leagues—appreciates the Subcommittee's past support for nursing education and your continued recognition of the important role nurses play in the delivery of our nation's health care services. NLN is concerned, however, that the advancements made by Congress to help alleviate the nursing shortage will be lost during the fiscal year 2005 appropriations process unless additional resources are expended. We urge your continued support for Title VIII—Nursing Workforce Development Programs by ensuring that these programs are funded at a minimum level of $205 million for fiscal year 2005.

Today's nursing shortage is very real and very different from any experienced in the past. The new nursing shortage is evidenced by an aging workforce; acute nursing shortages in certain geographic areas; and a shortage of nurses and nurse educators adequately prepared to meet patient need in a changing health care environment. As a result, the supply of appropriately prepared nurses and nursing faculty is inadequate to meet the needs of a diverse population. This shortfall will grow more serious over the next 5 years.

Congress did an admirable job of passing the Nurse Reinvestment Act in 2002. The new monies used to fund loans and scholarships are appreciated. However, it has become abundantly clear that significantly more funding is required to meet the existing need. In fiscal year 2003, for example, only 55 nurse faculty loans were awarded. Yet last year, schools of nursing were forced to turn away 29,284 qualified nursing students because of a lack of prepared nurse educators to teach them. This number is significantly greater than the 18,476 students who were turned away in 2002.

Schools of nursing are suffering from a continuing and growing shortage of faculty, which prevents these institutions from admitting many qualified students who are applying to their programs. NLN's 2002 Faculty Survey concludes that not enough qualified nurse educators exist to teach the number of nurses needed to ameliorate the nursing shortage. According to the Survey, this situation is not ex-

pected to improve in the near future, since an adequate number of nurse educators are currently not in the education pipeline.

The NLN Survey found three trends impacting the future of nursing education over the next decade:

The aging of the nurse faculty population

An average of 1.3 full-time faculty members per program left their positions in nursing education in 2002. About half the Survey respondents had at least one unfilled budgeted full-time faculty position and some have as many as 15 such positions.

Approximately 1,800 full-time faculty members leave their positions each year. About 10,000 master's level nurses graduate per year, 15 percent of whom would have to go into teaching just to maintain the status quo. Since this is highly unlikely, the gap between unfilled positions and the candidate pool will widen significantly.

The increasing number of part-time faculty

The number of part-time faculty has increased since 1996—nearly 17 percent in baccalaureate programs and 14 percent in associate degree programs. Approximately 23 percent of the estimated number of faculty FTEs is now provided by part-time faculty.

Part time employees are often not an integral part of the design, implementation, and evaluation of the overall nursing education program. Many may hold other positions that often limit their availability to students. Further, many part-time faculty have not been prepared for the faculty role.

The large number of nursing faculty who are not prepared at the doctoral level

Approximately half the full-time faculty in baccalaureate and higher degree programs holds a doctoral degree. In associate degree programs, doctorally-prepared faculty account for only 6.6 percent and the number is slightly more than 5 percent in diploma programs. Only 350 to 400 nursing students receive doctoral degrees each year and the pool of doctorally-prepared candidates for full-time nursing professorships is very limited.

Educators without doctoral degrees may lack credibility within a university setting and have limited opportunities to assume leadership positions. Institutions with low numbers of doctorally-prepared educators may be less likely to get funds to support research or educational innovations.

As important as educational incentives for future practicing nurses are the scholarships for doctoral students, who will instruct the next generation of nurses. Please do not allow us to lose ground in the fight against the nursing shortage—fund Title VIII nursing programs at a level commensurate with the severity of the health care crisis facing the nation today.

Your support will help ensure that nurses exist in the future who are prepared and qualified to take care of you, your family, and all those in this country who will need our care. If you have any questions about NLN's position or we can be of further assistance to you, please feel free to contact Kathleen Ream, NLN Manager of Government Affairs, at 703–241–3974.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS

The National Association of Children's Hospitals (N.A.C.H.) is pleased to have the opportunity to submit the following statement for the hearing record in support of the Children's Hospitals' Graduate Medical Education (CHGME) Payment Program in the Health Resources and Services Administration (HRSA).

On behalf of the nation's 60 independent children's teaching hospitals, we thank the Subcommittee for the remarkable achievement that Congress made last year in continuing to provide full, equitable GME funding for these hospitals, giving them a level of federal support for their teaching programs that is comparable to what all other teaching hospitals receive through Medicare. We urge the Subcommittee to continue to provide equitable funding for Children's Hospitals GME in fiscal year 2005 so that these institutions will have the resources to train and educate the nation's pediatric workforce.

N.A.C.H. is a not-for-profit trade association, representing more than 120 children's hospitals across the country. Its members include independent acute care children's hospitals, acute care children's hospitals organized within larger medical centers, and independent children's specialty and rehabilitation hospitals.

N.A.C.H. seeks to serve its member hospitals' ability to fulfill their four-fold missions of clinical care, education, research, and advocacy devoted to the health and

well being of all of the children in their communities. Children's hospitals are regional and national centers of excellence for children with serious and complex conditions. They are centers of biomedical and health services research for children, and they serve as the major training centers for future pediatric researchers, as well as a significant number of our children's doctors. These institutions are major safety net providers, serving a disproportionate share of children of low-income families, and they are also advocates for the public health of all children.

BACKGROUND: THE NEED FOR CHILDREN'S HOSPITALS GME

While they account for less than 1 percent of all hospitals, the independent children's hospitals train nearly 30 percent of all pediatricians, half of all pediatric specialists, and a majority of future pediatric researchers. They also provide required pediatric rotations for many other residents. They train about 4,000 residents annually, and the need for these programs is even more heightened by the growing evidence of shortages of pediatric specialists around the country.

Prior to initial funding of the CHGME program for fiscal year 2000, these hospitals were facing enormous challenges to their ability to maintain their training programs. The increasingly price competitive medical marketplace was resulting in more and more payers not covering the costs of care, including the costs associated with teaching.

The independent children's hospitals were essentially left out of what had become the one major source of GME financing for other teaching hospitals—Medicare—because they see few if any Medicare patients. They received only 1/200th (or less than 0.5 percent) of the federal support that all other teaching hospitals received under Medicare. This lack of GME financing, combined with the financial challenges stemming from their other missions, was threatening their teaching programs, as well as other important services.

In addition to their teaching missions, the independent children's hospitals are a significant part of the health care safety net for low-income children. On average, they devote nearly half of their patient care to children who are assisted by Medicaid or are uninsured. More than 40 percent of their care is for children assisted by Medicaid, and Medicaid covers only about 84 percent of the cost of that care. Without the Medicaid disproportionate share hospital (DSH) payments, Medicaid would cover only about 76 percent of children's hospitals' patient care costs. Further, these hospitals provide many important services from dental care to child abuse programs that are either uncovered or very underpaid.

The independent children's hospitals also are essential to the provision of care for seriously and chronically ill children in this country. They devote more than 75 percent of their care for children with one or more chronic or congenital conditions. They provide more than 40 percent to 75 percent of the inpatient care to children with many serious illnesses—from children with cancer or cerebral palsy, for example, to children needing heart surgery or organ transplants. In some regions, they are the only source of pediatric specialty care. The severity and complexity of illness and the services and resources that these institutions must maintain to assure access to this quality care for all children are also often inadequately reimbursed.

The CHGME program, and its relatively quick progress to full funding in fiscal year 2002, came at a critical time. Between 1997 and 2000, independent children's hospitals on average experienced declining operating margins and total margins. By fiscal year 2000 more than a quarter of the hospitals were not able to cover their operating costs with operating revenues, and nearly 20 percent were not able to cover their total costs with total revenues. Thanks to the CHGME program, these hospitals have been able to maintain and strengthen their training programs.

Continuing this critical CHGME funding is more important for these hospitals than ever in light of state budget shortfalls in many states and the resulting pressures for significant reductions in state Medicaid programs. Because children's hospitals devote such a substantial portion of their care to children of low-income families, they are especially affected by cutbacks in state Medicaid programs.

The pediatric community, including the American Academy of Pediatrics, Association of Medical School Pediatric Department Chairs, and others, has recognized the critical importance of the GME programs of the independent children's teaching hospitals, not only to the future of the individual hospitals and their essential services but also to the future of the nation's pediatric workforce and the provision of children's health care and advancements in pediatric medicine overall.

Lastly, many of the independent children's hospitals are a vital part of the emergency and critical care services in their communities and regions. They are part of the emergency response system that must be in place for bioterrorism other public

health emergencies. Expenses associated with preparedness will add to their continuing costs in meeting children's needs.

CONGRESSIONAL RESPONSE

In the absence of any movement towards broader GME financing reform, Congress in 1999 authorized the Children's Hospitals' GME discretionary grant program to address the existing inequity in GME financing for the independent children's hospitals and ensure that these institutions could receive equitable federal support to sustain their teaching programs. The legislation was reauthorized in 2000 through fiscal year 2005 and provided for $285 million through fiscal year 2001 and such sums as may be necessary in the years beyond.[1] Congress passed both the initial authorization (as part of the "Healthcare Research and Quality Act of 1999") and the reauthorization (as part of the "Children's Health Act of 2000").

With the support of this Subcommittee, Congress appropriated initial funding for the program in fiscal year 2000, before the enactment of its authorization. Following that enactment, Congress moved substantially toward full funding for the program in fiscal year 2001 and completed that goal, providing $285 million in fiscal year 2002, $290 million in fiscal year 2003, and $303 million in fiscal year 2004. This represents an extraordinary achievement for the future of children's health care as well as for the nation's independent children's teaching hospitals.

The $285 million appropriated in fiscal year 2002 was distributed at the end of the fiscal year through HRSA to 59 children's hospitals according to a formula based on the number and type of full-time equivalent (FTE) residents trained, in accordance with Medicare rules as well as the complexity of care and intensity of teaching the hospitals provide. Consistent with the authorizing legislation, HRSA allocates the annual appropriation in bi-weekly periodic payments to eligible independent children's hospitals.

FISCAL YEAR 2005 REQUEST

N.A.C.H. respectfully requests that the Subcommittee continue equitable GME funding for the independent children's hospitals by providing $303 million for the program in fiscal year 2005—the level of funding requested by President Bush and equal to the fiscal year 2004 appropriation enacted in January 2004. We are grateful for the administration's recognition of the significance of the CHGME program.

Adequate, equitable funding for CHGME is an ongoing need. Children's hospitals continue to train new pediatric residents and researchers every year. Children's hospitals have appreciated very much the congressional support they have received, including the attainment of the program's authorization in fiscal year 2002 and continuation of full funding with an inflation adjustment in fiscal year 2003 and fiscal year 2004. Now, N.A.C.H. asks Congress to maintain this progress by enactment of the President's request.

Support for a strong investment in GME at independent children's teaching hospitals is consistent with the repeated concern the Subcommittee has expressed for the health and well being of our nation's children—through education, health, and social welfare programs. It also is consistent with the Subcommittee's repeated emphasis on the importance of enhanced investment in the National Institutes of Health (NIH) overall, and in NIH support for pediatric research in particular, for which we are very grateful.

The CHGME funding has been essential to the ability of the independent children's hospitals to sustain their GME programs. At the same time, it has enabled them to do so without sacrificing support for other critically important services that also rely on hospital subsidy, such as many specialty and critical care services, child abuse prevention and treatment services, poison control centers, services to low-income children who have inadequate or no coverage, mental health and dental services, and community advocacy, such as immunization and motor vehicle safety campaigns.

In recommending an fiscal year 2005 appropriation of $303 million for CHGME, the Bush administration specifically cited the both the program's clear purpose and its impact on the financial health of children's hospitals.

In conclusion, the Children's Hospitals GME Payment Program is an invaluable investment in children's health. The future of the pediatric workforce and children's access to quality pediatric care, including specialty and critical care services, could

[1] The Lewin Group, an independent health policy analysis firm calculated in 1998 that independent children's teaching hospitals should receive approximately $285 million in federal GME support for nearly 60 institutions to achieve parity with the financial compensation provided through Medicare for GME support to other teaching hospitals.

not be assured without it. Again, N.A.C.H. thanks this Subcommittee and Congress for your continuing leadership and support.

For further information, please contact Peters D. Willson, vice president for public policy, N.A.C.H., at 703/797–6006 or pwillson@nachri.org.

PREPARED STATEMENT OF THE COMMUNITY MEDICAL CENTERS, FRESNO, CA

With over 43 million people in the United States lacking health insurance, the situation is reaching a crisis. National polls of Americans have ranked affordable health care as a leading concern behind the economy and jobs, and national security and terrorism. The issue is of greater concern for those of us who live in the Central San Joaquin Valley in California.

In the San Joaquin Valley, we face even greater challenges with the delivery of health care. While the national average for uninsured hovers around 15 percent, the Central San Joaquin Valleys sees a figure closer to 20 percent. As the region poises itself to address the chronic double-digit unemployment (from 14 percent-17 percent) and an equally high rate of poverty (20 percent-30 percent) through aggressive economic development and work force training initiatives, we cannot ignore the need for accessible health care for the uninsured.

The health statistics also point to the need to develop a pro-active and aggressive approach to the situation. They are:

—The third highest asthma mortality rate in the nation
—The highest incidence of diabetes among the Hispanic population
—The highest rates of teen pregnancy in the state
—The lowest immunization rates in the nation (62 percent at age 2 vs. 79 percent nationally)
—Late or no prenatal care for pregnant women

Community Medical Centers is a $574 million locally owned, not-for-profit health care corporation based in Fresno, California and is committed to improving accessibility to health care in the area. As a result of a landmark decision by the Fresno County Board of Supervisors in 1996, the County of Fresno and Community Medical Centers embarked upon a 30-year partnership obligating Community to provide care to the uninsured and underinsured residents of Fresno County.

Community, along with other health care providers such as Sequoia Community Health Foundation, a Federally Qualified Health Center, has been committed to developing a network of outpatient clinics throughout the county with a hub facility to be located on the campus of the Regional Medical Center in downtown Fresno. This outpatient clinic is to be adjacent to the UCSF Fresno Medical Education and Research Center, which is currently under construction, and in-patient hospital services as well. It is only by enhancing access to health care through multiple primary care sites can we begin to address the many health care needs of a burgeoning population, both young and old.

This Outpatient Care Clinic will serve as a hub to a network of clinics throughout the County of Fresno housing primary and specialty care including a children's clinic, a women's clinic focusing on obstetrical and gynecological needs, asthma treatment and education, diabetes treatment and education as well as surgical follow-up.

We would like to ask for your assistance in securing $1 million in funding for the purposes of constructing an outpatient care clinic on the campus of the Regional Medical Center in Fresno. We understand that this request would require a special earmark under the Health Resources Services Administration account in the Labor/Health and Human Services appropriations bill. We are also aggressively pursuing funding through multiple private foundations to secure the bulk of the funding for this $24 million facility. We believe that this facility and a comprehensive approach to addressing the need for health care services in our region is the best option to improve the quality of life in the Central San Joaquin Valley.

PREPARED STATEMENT OF THE AMERICAN MUSEUM OF NATURAL HISTORY

ABOUT THE AMERICAN MUSEUM OF NATURAL HISTORY

The American Museum of Natural History [AMNH] is one of the nation's preeminent institutions for scientific research and public education. Since its founding in 1869, the Museum has pursued its mission to "discover, interpret, and disseminate—through scientific research and education—knowledge about human cultures, the natural world, and the universe." It is renowned for its exhibitions and collections, and with nearly four million annual visitors—approximately half of them chil-

dren—its audience is one of the largest, fastest growing, and most diverse of any museum in the country. Museum scientists conduct groundbreaking research in fields ranging from all branches of zoology, comparative genomics, and informatics to earth, space, and environmental sciences and biodiversity conservation.

Today more than 200 Museum scientists with internationally recognized expertise, led by 46 curators, conduct laboratory and collections-based research programs as well as fieldwork and training. Scientists in five divisions (Anthropology; Earth, Planetary, and Space Sciences; Invertebrate Zoology; Paleontology; and Vertebrate Zoology) are documenting changes in the environment, making new discoveries in the fossil record, and describing human culture in all its variety. In the Museum's Institute for Comparative Genomics, established in 2001, researchers are mapping the genomes of non-human organisms as well as creating new computational tools to retrace the evolutionary tree.

The Museum is also a distinguished training institution, which serves up to 80 undergraduates, doctoral, and postdoctoral trainees annually. These training programs support doctoral and postdoctoral scientists with highly competitive research fellowships, and offer talented undergraduates an opportunity to work with Museum scientists. The Museum's doctoral and post-doctoral training program, dating from 1908, is the oldest and largest of any such program at a scientific museum. The Museum currently has collaborative programs with Yale University, Columbia University, Cornell University, New York University, and CUNY. The training encompasses the entire range of science covered in the Museum's mission, which includes astrophysics, earth sciences, evolutionary biology, zoology, paleontology, comparative genomics, biodiversity sciences, and anthropology.

The AMNH collections of some 32 million natural specimens and cultural artifacts are a major scientific resource, providing the foundation for the Museum's interrelated research, education, and exhibition missions. They often include endangered and extinct species as well as many of the only known "type specimens," or examples of species by which all other finds are compared. Within the biological collections are many spectacular individual collections, including the world's most comprehensive collections of dinosaurs, fossil mammals, North American butterflies, spiders, Australian and Chinese amphibians, reptiles, fishes, and one of the world's most important bird collections. Collections such as these provide vital data for Museum scientists as well as for more than 250 national and international visiting scientists each year.

The Museum interprets the work of its scientists, highlights its collections, addresses current scientific and cultural issues, and promotes public understanding of science through its renowned permanent and temporary exhibits (such as the *Genomic Revolution* in 2001) as well as its comprehensive education programs. These programs attract more than 400,000 students and teachers and more than 5,000 educators for professional development opportunities. The Museum also takes its resources beyond its walls through the National Center for Science Literacy, Education, and Technology, launched in 1997 in partnership with NASA.

COMPARATIVE GENOMICS RESOURCES

The American Museum shares with DHHS a fundamental commitment to improving the nation's health and education and advancing the research, training, facilities, and technology that support them. The Museum is deeply engaged in the area of comparative genomics; a partnership between the Museum and DHHS/HRSA would further mutual goals for improving the nation's health and welfare through research and training in genomic science.

Genomic Science and Training Resources

DHHS leads the nation's health-related research and genome science, advanced sequencing technologies, instrumentation, and facilities. The American Museum, in turn, is home to a preeminent molecular biology research and training program and leads science education and outreach efforts. In the era of genomics, museum collections have become critical baseline resources for the assessment of genetic diversity of natural populations; studying genomic data in a natural history context makes it possible to more fully understand the impacts of new discoveries in genomics and molecular biology. Genomes of the simplest organisms provide a window into the fundamental mechanics of life, and understanding their natural capabilities can help solve challenges in biodefense, medicine, and health care. In the Museum's molecular laboratories, in operation now for 11 years, more than 40 researchers in molecular systematics, conservation genetics, and developmental biology conduct genetic research on a variety of study organisms. The labs also nourish the Museum's distinguished training programs that serve up to 80 undergraduates, doctoral, and postdoctoral trainees annually.

Frozen Tissue Collection

The Museum offers unique resources in support of its molecular program. These include an expansion of its collections to include biological tissues and isolated DNA preserved in a super-cold storage facility. Because this collection preserves genetic material and gene products from rare and endangered organisms that may become extinct before science fully exploits their potential, it is an invaluable resource for research in many fields including genetics, comparative genomics, and biodefense. Capable of housing 1 million specimens, it will be the largest super-cold tissue collection of its kind. In the past 3 years, 22,000 specimens not available at any other institute or facility have already been accessioned. At the same time, the Museum is pioneering the development of collection and storage protocols for such collections. To maximize use and utility of the facility for researchers worldwide, the Museum is also developing a sophisticated website and online database that includes collection information and digitized images.

Cluster Computing

The Museum also has exceptional capacity in parallel computing, an essential enabling technology for phylogenetic (evolutionary) analysis and intensive, efficient sampling of a wide array of study organisms. Museum scientists have constructed an in-house 700-processor computing cluster—the fastest parallel computing cluster in an evolutionary biology laboratory and one of the fastest installed in a non-defense environment.

Museum investigators have taken a leadership role in developing and applying new computational approaches to deciphering evolutionary relationships through time and across species; their pioneering efforts in cluster computing, algorithm development, and evolutionary theory have been widely recognized and commended for their broad applicability for biology as a whole. The bioinformatics tools Museum scientists are creating will not only help to generate evolutionary scenarios, but will also inform and make more efficient large genome sequencing efforts. Many of the parallel algorithms and implementations (especially cluster-based) will be applicable in other informatics contexts such as annotation and assembly, breakpoint analysis, and non-genomic areas of evolutionary biology as well as in other disciplines.

COMPARATIVE GENOMICS RESEARCH AND TRAINING INITIATIVE

Building on these unique strengths in comparative genomics, and in concert with the health, education, and training goals of DHHS, in 2001 the Museum launched an ambitious initiative—*The Institute of Comparative Genomics.* Equipped with the parallel computing facility, molecular labs with DNA sequencers, ultra-cold storage units, vast biological collections, and researchers with expertise in the methods of comparative biology, as described above, the Institute is positioned to be one of the world's premier facilities for mapping the genome across a comprehensive spectrum of life forms.

The Institute is establishing a distinguished research and training record. Museum scientists have pioneered theoretical and analytical approaches and are leading major new international research projects in assembling the "tree of life." They have developed efficient software for the interpretation of microarray data, which can be used to support more accurate diagnosis of pathogens, and novel methodologies and algorithms for analyzing genomic, chromosomal, and other data to discern evolutionary relationships among organisms. Current projects include sequencing pathogens and, with NIH and DOE support, tracing the evolution of pathogenicity and transfer of disease-causing genes over time and between species.

The Museum is also successfully promoting public understanding of genomic science. The landmark exhibition, *The Genomic Revolution,* seen by approximately 500,000 visitors in New York and now touring nationally, examined the revolution taking place in molecular biology and its impact on modern science and technology, natural history, biodiversity, and our everyday lives. The Museum has also hosted several conferences on important topics related to genomics: *Sequencing the Human Genome: New Frontiers in Science and Technology,* an international conference featuring leading scientists and policymakers in Fall 2000; *Conservation Genetics in the Age of Genomics* in Spring 2001; and *New Directions in Cluster Computing* in June 2001, which explored how parallel computing enables genomic science and other fields. In June 2002, the Museum hosted an international conference examining current knowledge of life's history, *Assembling the Tree of Life: Science, Relevance, and Challenges.*

As it moves forward, the Institute, working in cooperation with New York's outstanding biomedical research and educational institutions, is focusing on molecular and microbial systematics, on constructing large genomic databases, and on expand-

ing our understanding of the evolution of life on earth and the evolution of critical organismal form and function through analysis of the genomes of selected microbes and other non-human organisms. Development of Institute activities entails expanding expertise in microbial systematics and the molecular laboratory program that now trains dozens of graduate students every year; utilizing the latest sequencing technologies; employing parallel computing applications that allow scientists to solve combinatorially complex problems involving large real world datasets; and continuing to advance public understanding of genomic science through educational materials, scientific conferences, and exhibits.

So as to contribute its unique capacities to the nation's genomics research and training efforts, the Museum seeks to partner with DHHS/HRSA in a facilities/instrumentation initiative. We request $1 million to equip our National Research and Training Laboratory for Comparative and Microbial Genomics, a state-of-the-art molecular laboratory. When equipped, the expanded facility will provide up-to-date instrumentation for graduate and postdoctoral trainees as well as for senior scientists. The Museum will contribute its participatory share to this project with funds from nonfederal as well as federal sources.

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS

On behalf of the more than 51,000 clinically practicing physician assistants in the United States, the American Academy of Physician Assistants (AAPA) is pleased to submit comments on fiscal year 2005 appropriations for Physician Assistant (PA) education programs that are authorized through Title VII of the Public Health Service Act.

A member of the Health Professions and Nursing Education Coalition (HPNEC), the American Academy of Physician Assistants supports the HPNEC recommendation to provide at least $550 million to support the Titles VII and VIII programs in fiscal year 2005, including $18 million to support PA educational programs, as recommended by the Advisory Committee on Primary Care Medicine and Dentistry.

The Academy believes that the recommended increase in funding for the Title VII health professions programs is well justified. The programs are essential to the development and training of primary health care professionals and contribute to the nation's overall efforts to increase access to care by promoting health care delivery in medically underserved communities.

The Academy is very concerned with the Administration's proposal to eliminate funding for most Title VII programs, including zero funding for training in primary care medicine and dentistry. As Members of the Subcommittee are aware, these programs are designed to help meet the health care delivery needs of the nation's Health Professional Shortage Areas (HPSAs). By definition, the nation's more than 3,800 HPSAs experience shortages in the primary care workforce that the market alone can't address. We wish to thank the members of this subcommittee for your historical role in supporting funding for the health professions programs, and we hope that we can count on your support for these important programs in fiscal year 2005.

OVERVIEW OF PHYSICIAN ASSISTANT (PA) EDUCATION

PA programs provide students with a primary care education that prepares them to practice medicine with physician supervision. Physician assistant programs are located at schools of medicine or health sciences, universities, teaching hospitals, and the Armed Services. All PA educational programs are intensive education programs that are accredited by the Accreditation Review Commission on Education for the Physician Assistant.

The typical PA program consists of 111 weeks of instruction. The first phase of the program consists of intensive classroom and laboratory study, providing students with an in-depth understanding of the medical sciences. More than 400 hours in classroom and laboratory instruction are devoted to the basic sciences, with over 70 hours in pharmacology, more than 149 hours in behavioral sciences, and more than 535 hours of clinical medicine.

The second year of PA education consists of clinical rotations. On average, students devote more than 2,000 hours or 50–55 weeks to clinical education, divided between primary care medicine and various specialties, including family medicine, internal medicine, pediatrics, obstetrics and gynecology, surgery and surgical specialties, internal medicine subspecialties, emergency medicine, and psychiatry. During clinical rotations, PA students work directly under the supervision of physician preceptors, participating in the full range of patient care activities, including patient

assessment and diagnosis, development of treatment plans, patient education, and counseling.

Physician assistant education is competency based. After graduation from an accredited PA program, the physician assistant must pass a national certifying examination jointly developed by the National Board of Medical Examiners and the independent National Commission on Certification of Physician Assistants. To maintain certification, PAs must log 100 continuing medical education credits over a 2-year cycle and reregister every 2 years. Also to maintain certification, PAs must take a recertification exam every 6 years.

PHYSICIAN ASSISTANT PRACTICE

Physician assistants are licensed health care professionals educated to practice medicine as delegated by and with the supervision of a physician. In all states, physicians may delegate to PAs those medical duties that are within the physician's scope of practice and the PA's training and experience, and are allowed by law. Forty-seven states, the District of Columbia, and Guam authorize physicians to delegate prescriptive privileges to the PAs they supervise.

PAs are located in almost all health care settings and in every medical and surgical specialty. Nineteen percent of all PAs practice in non-metropolitan areas where they may be the only full-time providers of care (state laws stipulate the conditions for remote supervision by a physician). Approximately 41 percent of PAs work in urban and inner city areas. Approximately 44 percent of PAs are in primary care. Nearly one-quarter practice in surgical specialties. Roughly 80 percent of PAs practice in outpatient settings. In 2003, an estimated 192 million patient visits were made to PAs and approximately 236 million medications were prescribed or recommended by PAs.

CRITICAL ROLE OF THE TITLE VII, PUBLIC HEALTH SERVICE ACT, PROGRAMS

A growing number of Americans lack access to primary care, either because they are uninsured, underinsured, or they live in a community with an inadequate supply or distribution of providers. The growth in the uninsured U.S. population increased from approximately 32 million in the early 1990s to nearly 44 million today. Simultaneously, the number of medically underserved communities continues to rise, from 1,949 in 1986 to more than 3,800 today.

The role of the Title VII programs is to alleviate these problems by supporting access to quality, affordable, and cost-effective care in areas of our country that are most in need of health care services, specifically rural and urban underserved communities. This is accomplished through the support of educational programs that train more health professionals in fields experiencing shortages, improve the geographic distribution of health professionals, and increase access to care in underserved communities.

The Title VII programs are the only federal education programs that are designed to address the supply and distribution imbalances in the health professions. Since the establishment of Medicare, the costs of physician residencies, nurses and some allied health professions training has been paid through Graduate Medical Education (GME) funding. However, GME has never been available to support PA education. More importantly, GME was not intended to generate a supply of providers who are willing to work in the nation's medically underserved communities. That is the purpose of the Title VII Public Health Service Act Programs, which support such initiatives as loans and scholarships for disadvantaged students, scholarships for students with exceptional financial need, centers of excellence to recruit and train minority and disadvantaged students, and interdisciplinary initiatives in geriatric care and rural health care.

Furthermore, now that there is compelling evidence that race and ethnicity correlate with persistent, and often increasing, health disparities among U.S. populations, increasing the diversity of health care professionals is essential. Title VII programs are unique in that they seek to recruit providers from a variety of backgrounds. This is particularly important, as studies have found that those from disadvantaged regions of the country are 3 to 5 times more likely to return to those underserved areas to provide care versus other areas.

TITLE VII SUPPORT OF PA EDUCATION PROGRAMS

Targeted federal support for PA education programs is currently authorized through section 747 of the Public Health Service Act. The program was reauthorized in the 105th Congress through the Health Professions Education Partnerships Act of 1998, Public Law 105–392, which streamlined and consolidated the federal health

professions education programs. Support for PA education is now considered within the broader context of training in primary care medicine and dentistry.

Publi Law 105–392 reauthorized awards and grants to schools of medicine and osteopathic medicine, as well as colleges and universities, to plan, develop, and operate accredited programs for the education of physician assistants and faculty, with priority given to training individuals from disadvantaged communities. The funds ensure that PA students from all backgrounds have continued access to an affordable education and encourage PAs, upon graduation, to practice in underserved communities. These goals are accomplished by funding PA education programs that have a demonstrated track record of: (1) placing PA students in health professional shortage areas; (2) exposing PA students to medically underserved communities during the clinical rotation portion of their training; and (3) recruiting and retaining students who are indigenous to communities with unmet health care needs.

The program works. A review of PA graduates from 1990–2002 reveals that students graduating from PA programs supported by Title VII are 84 percent more likely to be from underrepresented minority backgrounds and 32 percent more likely to practice in underserved settings, than students graduating from PA programs that were not supported by Title VII.

The PA programs' success in recruiting and retaining underrepresented minority and disadvantaged students is linked to their ability to creatively use Title VII funds to enhance existing educational programs. For example, a PA educational program in Iowa uses Title VII funds to target recruitment efforts to disadvantaged students, providing shadowing and mentoring opportunities for prospective students, increasing training in cultural competency, and identifying new family medicine preceptors in underserved areas. PA programs in Texas use Title VII funds to create new clinical rotation sites in rural and underserved areas, including new sites in border communities, and to establish non-clinical rural rotations to help students understand the challenges faced by rural communities. One Texas program uses Title VII funds for the development of web based and distant learning technology and methodologies so students can remain at clinical practice sites. A PA program in New York, where over 90 percent of the students are ethnic minorities, uses Title VII funding to focus on primary care training for underserved urban populations by linking with community health centers, which expands the pool of qualified minority role models that engage in clinical teaching, mentoring, and preceptorship for PA students. Several other PA programs have been able to use Title VII grants to leverage additional resources to assist students with the added costs of housing and travel that occur during relocation to rural areas for clinical training.

Without Title VII funding, many of these special PA training initiatives would not be possible. Institutional budgets and student tuition fees simply do not provide sufficient funding to meet the special, unmet needs of medically underserved areas or disadvantaged students. Nevertheless, the need is very real, and Title VII is critical in meeting it.

NEED FOR INCREASED TITLE VII SUPPORT FOR PA EDUCATION PROGRAMS

Increased Title VII support for educating PAs to practice in underserved communities is particularly important given the market demand for physician assistants. Without the Title VII funding to expose students to underserved sites during their training, PA students are far more likely to practice in the communities where they were raised or the communities in which they attended school. Title VII funding is a critical link in addressing the natural geographic maldistribution of health care providers by exposing students to underserved sites during their training, where they frequently choose to practice following graduation. Currently, 36 percent of PAs met their first clinical employer through their clinical rotations.

Changes in the health care marketplace reflect a growing reliance on PAs as part of the health care team. Currently, the supply of physician assistants is inadequate to meet the needs of society, and the demand for PAs is expected to increase. A 1994 report of a workgroup of the Council on Graduate Medical Education (COGME), "Physician Assistants in the Health Workforce," estimated that the anticipated medical market demand and the estimated workforce requirements for PAs would exceed supply. Additionally, the Bureau of Labor Statistics projects that the number of available PA jobs will increase 49 percent between 2002 and 2012. Title VII funding has provided, and continues to provide, a crucial pipeline of trained PAs to underserved areas. One way to assure an adequate supply of physician assistants, especially PAs likely to practice in underserved areas, is to continue offering financial incentives, such as funding preferences, to PA programs that emphasize recruitment and placement of people interested in primary health care in medically underserved communities.

Despite the increased demand for PAs, funding has not proportionately increased for the Title VII programs that are designed to educate and place physician assistants in underserved communities. Nor has the Title VII support for PA education kept pace with increases in the cost of educating PAs. A review of PA program budgets from 1984 through 2002 indicates an average annual increase of 6.5 percent, a total increase of 218 percent over the past 18 years; yet, federal support has remained relatively static.

RECOMMENDATIONS ON FISCAL YEAR 2005 FUNDING

A recent report by the Advisory Committee on Training in Primary Care Medicine and Dentistry quotes a study in the Journal of Rural Health: "In 1997, Title VII funded programs increased the rates of graduates entering health profession shortage areas (HPSAs), resulting in 1,357 providers . . . Doubling the funding of these programs . . . could decrease the time for HPSAs elimination to as little as 6 years." The Advisory Committee concluded that ". . . Title VII remains a modest investment, but, as has been demonstrated, one with substantial future payoffs in terms of system quality, access to care, and a culturally competent system of care for the entire population."

The American Academy of Physician Assistants urges members of the Appropriations Committee to consider the inter-dependency of all the public health agencies and programs when determining funding for fiscal year 2005. For instance, while it is important to fund clinical research at the National Institutes of Health (NIH) and to have an infrastructure at the Centers for Disease Control (CDC) that ensures a prompt response to an infectious disease outbreak or bioterrorist attack, the good work of both of these agencies will go unrealized if the Health Resources and Services Administration (HRSA) is inadequately funded. HRSA administers the "people" programs, such as Title VII, that bring the cutting edge research discovered at NIH to the patients—through providers such as PAs who have been educated in Title VII-funded programs. Likewise, CDC is heavily dependent upon an adequate supply of health care providers to be sure that disease outbreaks are reported, tracked, and contained.

The critically important programs administered by NIH, HRSA, and CDC are integral components within the nation's public health continuum. One component is not more important than another, and no one component can succeed without adequate support from each of the other elements.

Furthermore, while the Academy applauds the Administration's proposal to strengthen national security by increasing support for health emergency preparedness initiatives, it should not do so at the expense of Title VII programs. Training is the key to preparedness, and Title VII, section 747, is an ideal mechanism for educating primary care providers in public health competencies, facilitating population based and community-based skills and training, and increasing the alliance between public health and primary care providers. This is particularly important for our Nation's most disadvantaged and underserved populations, because they are the most vulnerable during medical emergencies because of a lack of resources and access to care.

The Academy respectfully requests that the Title VII and VIII health professions programs receive $550 million in funding for fiscal year 2005, including $18 million to support PA educational programs, as recommended by the Advisory Committee on Primary Care Medicine and Dentistry.

Thank you for the opportunity to present the American Academy of Physician Assistants' views on fiscal year 2005 appropriations.

PREPARED STATEMENT OF THE NATIONAL ALLIANCE FOR THE MENTALLY ILL

Chairman Specter, Senator Harkin and members of the Subcommittee, I am Margaret Stout of Johnson, Iowa. I current serve as President of the National Alliance for the Mentally Ill (NAMI) and Executive Director of NAMI's statewide Iowa affiliate. I am pleased to offer NAMI's view on the Subcommittee's fiscal year 2005 bill.

NAMI is the nation's largest grassroots advocacy organization, 220,000 members representing persons with serious brain disorders and their families. Through our 1,200 chapters and affiliates in all 50 states, we support education, outreach, advocacy and research on behalf of persons with serious brain disorders such as schizophrenia, manic depressive illness, major depression, severe anxiety disorders and major mental illnesses affecting children.

Mr. Chairman, for too long severe mental illness has been shrouded in stigma and discrimination. These illnesses have been misunderstood, feared, hidden, and often ignored by science. Only in the last decade have we seen the first real hope for peo-

ple with these brain disorders through pioneering research that has uncovered both a biological basis for these brain disorders and treatments that work.

The cost of mental illness to our nation is enormous. President Bush's White House Mental Health Commission—which completed its work in 2003—found that the direct treatment cost exceeds $71 billion annually. This does not include the $79 billion in estimated indirect costs of benefits and social services (including 35 percent of SSI benefits and 28 percent of SSDI benefits). These direct and indirect costs do not measure the substantial and growing burden that is imposed on "default" systems that are too often responsible for serving children and adults with mental illness who lack access to treatment. These costs fall most heavily on the criminal justice and corrections systems, emergency rooms, schools, families and homeless shelters. Moreover, these costs are not only financial, but also human in terms of lost productivity, lives lost to suicide and broken families. Investment in mental illness research and services are—in NAMI's view—the highest priority for our nation and this Subcommittee.

FUNDING FOR SERVICES PROGRAMS AT SAMHSA & CMHS

The Center for Mental Health Services (CMHS)—part of the Substance Abuse and Mental Health Services Administration (SAMHSA)—is the principal federal agency engaged in support for state and local public mental health systems. Through its programs CMHS provides flexible funding for the states and conducts service demonstrations to help states move toward adoption of evidence-based practices. Funding for all SAMHSA and CMHS programs is part of the Fiscal Year 2005 Labor-HHS-Education Appropriations bill that Congress will soon consider.

CMHS Programs and the Crisis Confronting the Public Mental Health System

During the recent economic downturn and resulting crisis the state budgets are facing, we are witnessing widening of gaps in the public mental illness treatment system in many states. This is resulting in unprecedented cuts being enacted by states in both direct spending on mental illness treatment and supportive services, and in Medicaid funding of such services. Deep cuts to front-line clinics and providers in the public mental health system, curbs on access to newer more effective medications and closure of acute care beds in the community are just a few of the misguided strategies that states are employing to close their widening budget gaps. The consequences of these emerging cracks in the service system are readily apparent, not just to NAMI's consumer and family membership, but also to the public: increased risk of suicide, the growing number of chronic homeless adults and the growing trend of "criminalization" of mental illness and the stress it is placing on state and local jails and prisons.

The Need to Focus on Recovery-Oriented Evidence-Based Practices

As states continue to cut funding for mental illness treatment and supportive services, CMHS programs are becoming an increasingly important source of funding for the states. First and foremost, states should be encouraged to use their CMHS Block Grant funds to prevent further cuts in services for children and adults with severe mental illnesses. NAMI also supports targeting of CMHS dollars toward investment in evidence-based, outreach-oriented service delivery models for persons with severe mental illness in the community. The need to focus limited resources on evidence-based models (such as Programs of Assertive Community Treatment (PACT) and integrated treatment for co-occurring disorders) was recommended in 2003 by the President's "New Freedom Initiative" Mental Health Commission Report. This landmark report called for a reform of the public mental health system to eliminate system fragmentation and better reflect the priorities of recovery and community integration.

NAMI Supports the Bush Administration's Request for a "Mental Health System Transformation" Initiative

The President's fiscal year 2005 budget includes a request for $44 million at CMHS for a new state incentive grant program for "Mental Health System Transformation." This initiative is intended to help states follow through on the July 2003 recommendations in the White House "New Freedom Initiative" Mental Health Commission report. Under the proposal, funds would be allocated to states on a competitive basis to support the development of comprehensive state mental health plans to reduce system fragmentation and increase access to evidence-based services that promote recovery from mental illnesses. States would be required to use funds to develop plans that cut across multiple systems such as housing, criminal justice, child welfare, employment and education. In subsequent years, up to 85 percent of funds could be used to support community-based programs, with the remaining 15

percent available for state planning and coordination. NAMI strongly supports this proposal as critical to the effort to reform our nation's fragmented and underfunded public mental health system and bridge the gap between scientific advances and practice.

NAMI Supports the "Samaritan" and "ELHSI" Initiatives to End Chronic Homelessness

The President's fiscal year 2005 budget proposes $70 million to continue the "Samaritan Initiative" to end chronic homelessness over the next decade, with funding spread across SAMHSA, HUD and the VA. In addition, the Bush Administration is seeking a $5 million increase for the Projects for Assistance in Transition from Homelessness (PATH) program—boosting fiscal year 2005 funding to $55 million. PATH is a formula grant program to the states that funds outreach and engagement services for homeless individuals with severe mental illnesses. CMHS estimates that this increase in the PATH program will result in 154,000 homeless individuals with severe mental illnesses being served by state and local PATH grantees. NAMI also urges additional funding in fiscal year 2005 for the PATH program to address inequities in the program's interstate funding formula that have the allocation for many smaller rural states frozen since the mid-1990s.

NAMI urges full funding of the "Samaritan Initiative" in fiscal year 2005 and the proposed increase for PATH. Individuals with severe mental illnesses and co-occurring substance abuse disorders make up the largest share of the more than 150,000 people who experience chronic homelessness—those who stay homeless for a year or more. In addition to supporting the Administration's Samaritan Initiative and the recommended increases for PATH, NAMI also supports funding for the Ending Long-Term Homeless Services Initiative (ELHSI) program at SAMHSA to assist states and localities in funding services for new permanent supportive housing being developed through HUD's McKinney-Vento program. Funding at SAMHSA for Samaritan and ELHSI is critical to producing and sustaining 150,000 units of permanent supportive housing that will all but eliminate chronic homelessness. Ending chronic homelessness through permanent supportive housing will pay for itself, as communities save hundreds of millions of dollars in that communities are relieved of the costs related to keeping people homeless—including those associated with shelters, emergency rooms and jails.

Funding for CMHS Programs in the President's fiscal year 2005 Budget

In addition to the initiatives noted above, NAMI also supports ongoing activities at CMHS:

—*Mental Health Block Grant*.—CMHS's largest program, the Mental Health Block Grant (state formula grant program), would receive a $2 million increase under the President's fiscal year 2005 budget proposal (boosting funding to $436 million).

—*Children's Mental Health program at CMHS*.—The President is requesting a $4 million increase for the Children's Mental Health program, increasing funding to $106 million.

—*Programs of Regional and National Significance*.—CMHS's own discretionary budget—known as Programs of Regional and National Significance (PRNS)—would increase under the President's budget to $271 million. This includes the $44 million mental health system transformation initiative noted above.

—*Co-Occurring Disorders*.—The request for fiscal year 2005 for the PRNS program includes $15.2 million in ongoing and new funding for best practices and targeted capacity expansion grants to foster increased access to integrated treatment for individuals with co-occurring mental illness and substance abuse disorders. SAMHSA has an important leadership role to play on this issue. NAMI strongly urges this Subcommittee to support expansion of SAMHSA's activities on this critical priority.

—*Jail Diversion*.—NAMI is disappointed that the President's budget does not request continued funding for the $7 million Jail Diversion program at CMHS. NAMI strongly supports the Jail Diversion program and urges continuation of funding in fiscal year 2005.

—*Suicide Prevention*.—NAMI strongly supports continuation and expansion of CMHS's best practices grants and contracts to support suicide prevention. The President's "New Freedom Initiative" Mental Health Commission report contains important recommendations on making suicide prevention a national priority. NAMI supports these recommendations as critical to addressing the estimated 30,000 suicides that occur every year in our country—90 percent of which involve a victim with a mental disorder.

NATIONAL INSTITUTE OF MENTAL HEALTH (NIMH) RESEARCH FUNDING

The National Institute of Mental Health (NIMH) is the only federal agency with the main objective of funding biomedical research into serious mental illnesses. Increased funding and focus is needed to achieve the promise of exciting gains in understanding the brain in upcoming years.

NIMH—Smallest Proposed Increase in 8 Years

For fiscal year 2005, the President is proposing a $1.421 billion budget for the NIMH. This is a $39 million increase—2.2 percent—over the amount Congress appropriated for NIMH for fiscal year 2004 ($1.39 billion). While this exceeds the average 0.5 percent increase for all domestic discretionary spending, it is below the 2.7 percent increase proposed for all of the National Institutes of Health (NIH)—which would increase to $28.805 billion under the President's budget. In addition, this proposed increase for NIMH for fiscal year 2005 is below the 3.6 percent increase that Congress enacted for fiscal year 2004 and far below the 8 percent and 9 percent annual increases that were achieved between fiscal year 1998 and 2003.

This minimal budget increase is expected to have a serious impact on the ability of NIMH to sustain ongoing multi-year research grants that have been initiated over the past 3–4 years and fund new grant proposals relevant to serious mental illness. This is especially the case if Congress accepts a proposal being floated by NIH to limit annual "cost of doing research" adjustments to individual grants to 1 percent per year. NAMI remains very concerned that this coming fall-off in budget increases for NIH does not wipe out the new research that has been undertaken at NIMH in recent years, and take advantage of the significant opportunities to advance treatments and cures for serious mental disorders.

Mr. Chairman, NAMI is deeply grateful for your leadership on this Subcommittee in seeking a strong budget for NIH and NIMH. The bipartisan commitment to scientific research that you and Senator Harkin continue to demonstrate is an example to your colleagues in Congress and in the Administration. We commend you for your amendment on the Senate floor during debate on the fiscal year 2005 budget resolution to increase NIH funding above the President's request. NAMI urges you and your colleagues to make every effort to fund in NIMH at the "professional judgment" recommendation for fiscal year 2005—$1.555 billion, or $172.8 million above the fiscal year 2004 level.

"Roadmap to Recovery and Cure"—NAMI's Advocacy Goals and Strategies on Mental Illness Research

This month, the NAMI Policy Research Institute is releasing a new report, Roadmap to Recovery and Cure, urging significant increases in the NIMH budget for basic, clinical and health services research focused on serious mental illness. The reality is that dramatic improvements in the lives of individuals with mental illness can be achieved over the next decade if research is expanded and the treatment system reformed and brought into closer alignment with research.

Among the conclusions in *Roadmap to Recovery and Cure* are that serious mental illness research has been underfunded, compared to other chronic, disabling illnesses, and is insufficiently prioritized at NIMH. The task force also found that psychiatric research has only begun to enter the modern era of biomedical research and requires the development of a strong base of basic and interdisciplinary research, large, policy-relevant clinical trials and services research directly tied to service delivery. It is important to note that all of these are integral to the Bush Administration's Roadmap to Medical Research initiative that is currently driving research priorities at NIH.

Among the recommendations in this report are:

—Significant and accountable increases in NIMH funding of basic, clinical and services research focused on serious mental illness—$1 billion over 5 years,

—Increased application of the NIH's Roadmap to Medical Research initiative to serious mental illness,

—Continuation and expansion of clinical trials focused on serious mental illness,

—Coordination of serious mental illness research, dissemination, and service system policy efforts by the federal government, and

—Increased training and support of researchers and mental health care providers.

The Case for Increased Federal Investment in Mental Illness Research

Further research is imperative if we are to prevent the next generation from suffering. Much has to be learned. The causes and mechanisms of diseases such as schizophrenia and bipolar disorder are mostly unknown. We do not yet have laboratory tests that can diagnose these illnesses. There are no side-effect free treatments. And, of course, there is no primary preventive measure or cure currently available.

Treatment is imperfect; it does not work well for all individuals living with these brain diseases. There are no cures for severe mental illnesses, and existing treatments and services shown to be effective are all too often not available to the people who need and deserve them. While steady research-funding gains have been achieved, NAMI believes that severe mental illness research, from the most basic to services research, remains underfunded, given the tremendous scientific opportunities that exist and the severe burden that these diseases present to the public as well as to our families.

The public health burden associated with severe mental illness is enormous, accounting for a large percentage of costs imposed by all illnesses in the United States. An independent study by the World Bank and World Health Organization (DALY: Disability Adjusted Life Years) found that four of the top ten causes of disability worldwide are severe mental illnesses: major depression, bipolar disorder, schizophrenia, and obsessive-compulsive disorder, accounting for 25 percent of the total disability resulting from all diseases and injuries.

Where Should Funding at NIMH Be Directed?

Greater Focus & Accountability on Severe Mental Illness.—NAMI believes that more focus is needed at NIMH on severe mental illness research. NAMI therefore urges Congress to require NIMH to provide an accounting of new and existing research grants broken down by specific illnesses.

Basic Neuroscience.—NIMH needs to continue progress that has been made in unraveling the mysteries of molecules, genes, and brain interconnections related to higher brain functioning in brain health and serious disease.

Treatment Research.—Currently there is a lack of understanding about which treatments work best for which patients, in what combination, and with what risks and costs. NIMH has invested in significant research to improve this understanding and it should be continued and expanded in the current budget. Importantly, new treatments must be developed as well.

Services Implementation.—There are many important, even crucial research questions relevant to the treatment system that serves individuals with severe mental illnesses—ranging from improving the provision of evidence-based care to identifying exactly how much public monies are being spent on a treatment system that more often than not is failing.

Consumer and Family Involvement in Research.—All of these efforts at NIMH must be done with a greater involvement with and accountability to those patients with severe illnesses and their families. Recent efforts at NIMH have moved in this direction, but more needs to be done to integrate families and patients into annual reporting and strategic planning on research investments and accomplishments.

CONCLUSION

Chairman Specter, Senator Harkin and members of the Subcommittee, thank you for the opportunity to offer NAMI's views on your fiscal year 2005 bill.

PREPARED STATEMENT OF THE ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS

Mr. Chairman and members of the subcommittee, the Association of Maternal and Child Health Programs (AMCHP) is pleased to submit testimony on the Maternal and Child Health Services Block Grant as you consider the fiscal year 2005 funding request for the Department of Health and Human Services. AMCHP is a national non-profit organization representing the leaders of state public health programs for maternal and child health, and children with special health care needs in all 50 states, the District of Columbia, and eight additional jurisdictions. AMCHP appreciates the subcommittee's continued support of the MCHBG, the common source of funding for our members.

I urge you to provide $807 million for the Maternal and Child Health Services Block Grant (MCHBG) in fiscal year 2005. This funding level is necessary to maintain at least fiscal year 2003 levels of service in every state. Additionally, continued funding ($5 million) within the Special Projects of Regional and National Significance (SPRANS) set-aside for MCH oral health grant activities is critical. As I will explain below, these funds are needed to help state MCH programs that have been hit hard by state budget cuts, rising demand for services, and years of federal flat funding.

Maternal and child health programs help to increase immunization and newborn screening rates, reduce infant mortality, prevent childhood accidents and injuries, and reduce adolescent pregnancy. Each year, more than 27 million women, infants,

children and adolescents, including those with special health care needs, are served by MCH Block Grant funds. Half of the 4 million women who give birth annually receive some prenatal or postnatal services made possible by the MCHBG.

State maternal and child health programs need strong financial support to meet the challenges ahead. Unfortunately, this year 31 states (Alabama, Arkansas, Colorado, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, New Mexico, North Dakota, Ohio, Oklahoma, Pennsylvania, South Carolina, South Dakota, Tennessee, Texas, Utah, Vermont, West Virginia, Wisconsin, Wyoming) receive less in MCH block grant funding than in fiscal year 2003. These cuts range from a few thousand dollars to over $1.6 million. Please see the chart at the end of this testimony.

The President's fiscal year 2005 budget flat funds the MCH Block Grant at $730 million again. The President also proposes to add the Universal Newborn Hearing Screening/Trauma Programs to the MCHBG without the $13 million that the programs received in fiscal year 2003. This would force states to cut other worthy MCH programs in order to continue important hearing screening activities or to scale back their hearing screening activities. According to a recent report, thanks to the HRSA funding, the number of infants screened for hearing loss at birth rose almost 20 percent in 2003. Today, 86 percent of infants born in hospitals nationwide are screened for hearing loss, up from 25 percent in 1999.

The need for increased funding is clear and I urge you to provide $807 million for the Maternal and Child Health Services Block Grant in fiscal year 2005. This increase assures that every state receive at least the amount that they received from the MCH Block Grant in fiscal year 2003. Without this funding, states' ability to serve the millions of American women, children, and their families who rely on these programs (approximately 27 million in 2002) would be jeopardized. In every state, Title V is a safety net program for low-income women and children, often the payor of last resort for needed medical services when other sources of payment (either public or private) are not available.

State programs funded through the MCH Block Grant make a difference. Without sufficient funding, over 18 million children will be without the vital health care they need, over 2 million pregnant women will not receive prenatal and postnatal care and have a healthy pregnancy, and almost 1 million children with special health care need will have to battle a fragmented health care system on their own to get the services they require.

Below are specific examples of how reductions at the state and federal levels have affected state maternal and child health programs. Please keep in mind that the actual effect of the cuts will not be fully felt until fiscal year 2005. That's why it is important that you provide sufficient funding in the fiscal year 2005 for the Maternal and Child Health Services Block Grant.

OHIO

Ohio received one of the steepest cuts in aid, losing $1.5 million (or 6 percent) between fiscal year 2003 and fiscal year 2004 in federal MCH funding. Combined with a $7.5 million decline in the state funds available to support MCH, the ability for the program to maintain services to the 266,000 women, infants, and children who received services in 2002 has been severely compromised. Ohio's Children with Special Health Care Needs (CSHCN) program, because of both state cuts and cuts in the Ohio MCH Block Grant, has had to decrease the number of diagnoses covered by the CSHCN Treatment Program and to change the eligibility rules to reduce the services provided. Three diagnosed conditions (Tonsils/adenoids, Serous otitis media, Hernias—except diaphragmatic) were eliminated from the list of those eligible to receive services, affecting almost 600 children.

Other changes may reduce, by as much as 25 percent, the 5,000 children who rely on the program. Co-payments are increased for families. Children with special health care needs require more frequent office visits. Raising co-payments can significantly impact the financial and physical health of these families and their children if they are unable to pay them. These families turn to Title V when insurance (either private or public) cannot provide the services. The Ohio Specialty Field Clinic Program received a 20 percent decrease in MCH block grant and other funding support. The Specialty Clinic Program provides access to pediatric specialists for children in Ohio. The number of clinics will be cut, all in rural Ohio where the greatest need for services are. This will affect the access to care for 300 children in Ohio's rural areas. Cardiac Specialty Clinics will be closed as of July 1, 2004. Funding reductions also slow the ability to respond to emerging issues, such as an increase in Ohio's infant mortality rate.

ALABAMA

Alabama lost $450,000 in federal funding. Combined with state cuts, the MCH program has had to significantly cut back services and staff. Funding for the Monsky Developmental Clinic was slashed by 50 percent. The Monsky Developmental Clinic provides developmental assessments of children with suspected or documented developmental delay (primarily for children from low income families). The clinic maintains a highly specialized multi-disciplined staff of professionals. Monsky is one of two clinics in Alabama that provides this service for children with special health care needs and serves the South Alabama region. The MCH program is the largest financial supporter of the clinic. MCH also lost a public health nurse position that had been working to engage the growing Hispanic community. Without funding to fill the position, it will be difficult to pro-actively address perinatal issues in the growing Hispanic/Latino population in Alabama. There were 2,630 live births to Hispanic/Latino Alabama residents in CY 2002: a 14.7 percent increase over the number in CY 2001.

IOWA

Iowa lost approximately $355,000 in fiscal year 2004. These cuts forced the Iowa Children with Special Health Care Needs program (Iowa Health Specialty Clinics program at the University of Iowa) to cut nutrition services to all children with special needs across Iowa, close the regional specialty clinic in Waterloo, cut the Dubuque clinic by 80 percent, and cut two other clinics by 20 percent. Scores of parents, teachers and educators who teach children who receive services through these clinics have written letters to the CSHCN program protesting the closures and/or reductions at these sites citing the devastating effect on those in need of the services.

TEXAS

Texas received a reduction of $753,000 (3 percent) in federal MCH funds. That reduction along with a reduction in state funds for MCH in 2004–2005 will drastically increase the unmet needs of the MCH population in Texas. Currently, the MCH program addresses less than 10 percent of the MCH population-in-need. For example, Title V MCH fiscal year 2004 contracts funding for population-based services (i.e., initiatives directed toward teen pregnancy, childhood obesity, immunization, etc) was decreased by 33 percent and by 13 percent for direct services (prenatal care, child well-check visits, dental, family planning, etc.). In 2001, the Texas Children with Special Health Care Needs program instituted a waiting list that has grown to 1,200 families and is expected to continue to increase.

WISCONSIN

Wisconsin loses $776,600 (or 6 percent). Options being considered to address this shortfall include applying an across-the-board cut to local projects as well as at the state and regional offices. A reduction to local projects translates to less activities and services received by the maternal and child health population. This will translate to children and families not receiving necessary services. In light of these cuts and the many more that I am unable to include in this testimony, I strongly urge you to provide states increased resources through the MCH block grant in fiscal year 2005 to protect services to low income pregnant women, infants, children with special health care needs and their families. $807 million in fiscal year 2005 does just that.

Again, thank you for this opportunity to testify.

State	Fiscal year		Difference
	2003 actual	2004 conference	
Alabama	$12,866,149	$12,415,309	−$450,840
Alaska	1,146,370	1,180,409	34,039
Arizona	7,406,094	7,842,357	436,263
Arkansas	7,785,008	7,524,664	−260,344
California	44,341,423	48,441,501	4,100,078
Colorado	7,794,869	7,603,353	−191,516
Connecticut	4,946,958	4,998,766	51,808
Delaware	1,982,247	2,034,791	52,544
District of Columbia	7,050,811	7,170,736	119,925
Florida	20,017,388	20,994,684	977,296
Georgia	17,316,887	17,348,033	31,146

State	Fiscal year		Difference
	2003 actual	2004 conference	
Hawaii	2,281,433	2,392,416	110,983
Idaho	3,373,874	3,387,761	13,887
Illinois	23,969,437	23,027,020	−942,417
Indiana	12,665,552	12,318,758	−346,794
Iowa	7,115,676	6,760,133	−355,543
Kansas	5,151,370	4,963,545	−187,825
Kentucky	12,553,023	11,948,246	−604,777
Louisiana	15,533,194	14,293,453	−1,239,741
Maine	3,546,787	3,518,418	−28,369
Maryland	12,212,800	12,367,885	155,085
Massachusetts	12,046,095	11,968,951	−77,144
Michigan	21,596,187	19,903,294	−1,692,893
Minnesota	9,845,406	9,427,666	−417,740
Mississippi	11,169,460	10,337,878	−831,582
Missouri	13,318,533	13,030,039	−288,494
Montana	2,609,133	2,560,004	−49,129
Nebraska	4,270,142	4,183,264	−86,878
Nevada	1,581,541	1,996,035	414,494
New Hampshire	2,023,344	2,071,712	48,368
New Jersey	12,102,033	12,348,050	246,017
New Mexico	4,798,959	4,723,796	−75,163
New York	42,726,728	43,708,310	981,582
North Carolina	17,183,075	17,522,028	338,953
North Dakota	2,007,580	1,882,687	−124,893
Ohio	24,889,019	23,310,577	−1,578,442
Oklahoma	8,041,242	7,791,761	−249,481
Oregon	6,484,811	6,579,878	95,067
Pennsylvania	26,051,877	25,621,198	−430,679
Rhode Island	1,768,713	1,890,246	121,533
South Carolina	12,151,811	11,952,796	−199,015
South Dakota	2,469,092	2,357,003	−112,089
Tennessee	12,693,368	12,419,315	−274,053
Texas	38,661,981	37,908,796	−753,185
Utah	6,336,960	6,222,721	−114,239
Vermont	1,746,907	1,742,951	3,956
Virginia	12,947,026	13,001,114	54,088
Washington	9,364,663	9,613,745	249,082
West Virginia	7,058,712	6,712,857	−345,855
Wisconsin	11,916,084	11,261,938	−654,146
Wyoming	1,333,642	1,309,374	−24,268
Subtotal	572,251,474	567,892,222	−4,359,252

Prepared Statement of the National Treasury Employees Union

Chairman Specter, Members of the Subcommittee: My name is Colleen M. Kelley and I am the National President of the National Treasury Employees Union (NTEU). NTEU represents more than 150,000 federal employees across 29 agencies and departments of the federal government, including employees in a number of divisions of the Department of Health and Human Services.

NTEU represents employees in the following divisions of the Department of Health and Human Services: the Health Resources and Services Administration (HRSA), Substance Abuse and Mental Health Services Administration (SAMHSA), Administration for Children and Families (ACF), Administration on Aging (AoA), Office of the Secretary (OS), Office for Civil Rights (OCR), Program Support Center (PSC) and the National Center for Health Statistics (NCHS). NTEU also represents employees in the Social Security Administration's Office of Hearings and Appeals (OHA).

As the Chairman knows, for several years now, most federal agencies have struggled to accomplish their missions to the best of their abilities within tight fiscal constraints. Many federal agencies have not had the necessary funds to adequately train their employees, others have been forced to downsize to the point where they are not staffed appropriately for their missions and still other agencies have not had

the resources to use the tools at their disposal to attract and retain the workforces they know they need for the future. These tools include recruitment and retention bonuses as well as the ability to help employees with student loan expenses—tools that the private sector knows are imperative to attracting and retaining the best employees.

The federal government faces an unprecedented recruitment and retention crisis. In addition to adequately funding agencies to perform their missions, NTEU believes that a major step toward making the federal government an employer of choice is a commitment by Congress and the Administration to establish a fair process for setting federal salaries. As you know, Mr. Chairman, for 2 years in a row now, despite a bipartisan and bicameral commitment to pay parity between the Nation's military and civilian employees, the President has chosen to implement a smaller pay raise for civilian employees only to see that raise overturned by subsequent Congressional action.

The message this sends federal employees is that they are not as important as their military counterparts, that they are somehow not as deserving of a fair pay raise. Here it is March 2004 and the pay raise these employees should have received the first pay period in January has still not reached their paychecks. While the full 4.1 percent pay raise is retroactive to January, agencies are still struggling to update their payroll systems and implement the full amount of the pay raise. We are told it may be several more months before all federal employees receive the full pay raise Congress approved.

Adequate and stable agency funding coupled with appropriate federal pay and benefits are the keys to ensuring that the government is able to attract and retain the federal employees it requires. The need for the federal government to hire and maintain a highly skilled workforce has never been more clear. Federal employees protect our Nation's medical supplies, they help secure our borders and they provide important services and information to their fellow taxpaying citizens every day.

The Administration's fiscal year 2005 budget request continues to hold federal agencies to unrealistic funding levels. We cannot continue to ask our agencies to do more while ignoring their requests for appropriate funding.

The Administration's fiscal year 2005 request for program management funding at the Health Resources and Services Administration (HRSA) is $158 million. Although this figure represents a $3 million increase in administrative funds over the fiscal year 2004 funding level, it is important to remember that HRSA's 2004 funding level represented a reduction of $9 million from the prior year. For an agency charged with insuring access to quality health care, especially to underserved populations—services that are in desperate need of expansion—a considerably larger increase in program management funding is called for. HRSA cannot effectively accomplish its mission without additional resources.

The President's budget proposes a substantial increase in funding for the National Center for Health Statistics (NCHS) for fiscal year 2005, a budget increase that is long overdue. As you know, the work NCHS undertakes is critical to ensuring that national health care initiatives are effective and the agency has been held to unrealistic funding levels for too many years now. NTEU hopes the fiscal year 2005 budget request will be enacted for NCHS.

The budget request for program management funds in 2005 at the Substance Abuse and Mental Health Services Administration (SAMHSA) is $92 million, the same as the agency's funding level for fiscal year 2004. SAMHSA is the federal agency charged with improving the quality and availability of treatment and intervention programs for those suffering from substance abuse and mental illness. It is discouraging to see this important agency held to an unrealistic funding level for the coming fiscal year and I am hopeful that program management funding for SAMHSA in fiscal year 2005 can be increased.

The President's budget proposal for fiscal year 2005 for the Administration for Children and Families (ACF), represents an increase of $12 million for federal administration of the programs ACF oversees. Funding restrictions in past years have hampered this agency's ability to accomplish its missions and NTEU strongly supports increased funding for the federal administration of ACF programs.

However, at the same time, we must continue to state our strong opposition to legislation pending in Congress to reauthorize the Head Start Program. As you know, the Head Start Program allows many children from low-income families to access a package of educational and social services that supplement the student's learning. Under the direction of the federal government, the Head Start Program has enhanced the opportunities of millions of American children since its inception. Legislation that seeks to limit the involvement of the federal government with the Head Start Program, such as H.R. 2210, is shortsighted and threatens to move the program in the wrong direction. Similarly, S. 1940, which encourages contracting

out the oversight of the Head Start Program to profit-driven firms in the private sector, must be reconsidered. I hope that the Committee will carefully review the Head Start reauthorization legislation before it is voted on by the full House and Senate.

The President's budget recommends only a slight improvement in funding for program administration for the Administration on Aging (AoA), holding the agency's program administration funding level to $18 million for 2005. With our country's rapidly growing older population, this is particularly troublesome. The Administration on Aging helps older Americans remain independent and productive and offers nutrition, caregiver support and preventive health programs. These are precisely the type of programs desperately in need of expansion, yet the fiscal year 2005 budget proposal, like the 2004 budget before it offers little in the way of new funding for these critical areas. The AoA funding level, too, requires the careful scrutiny of this Subcommittee.

The Office of the Secretary (OS) of the Department of Health and Human Services is slated to receive increased funding in fiscal year 2005. Federal employees working in the Office of the Secretary help administer all of the programs operated by the Department of Health and Human Services. It is critical that this office be effectively funded and NTEU is pleased to see a significant funding increase for this division. We urge the Committee to approve this request.

The President's budget recommends a small increase in program funding for the Office for Civil Rights (OCR). The recommendation would increase this agency's resources from their 2004 funding level of $34 million to $35 million in 2005. The HHS Office for Civil Rights helps to ensure that all individuals have proper access to the services and programs the Department offers. Moreover, this agency helps promote the privacy of medical information. In past years, OCR has been woefully under funded and NTEU urges this body to carefully review their funding needs for 2005.

The Department of Health and Human Services' Program Support Center (PSC) offers a range of administrative services both to HHS agencies and other federal departments that seek out its services. The President's fiscal year 2005 budget, which requests an increase in expenses for this key agency over their fiscal year 2004 funding level, deserves to be adopted by this body.

NTEU also represents employees in the Office of Hearing and Appeals (OHA) of the Social Security Administration. As the Chairman knows very well, OHA's mission is to assist those claimants who have been found ineligible for Social Security disability benefits by providing a due process hearing on their cases. The continuing backlog of cases before OHA prevents a fair and timely hearing for the thousands of individuals whose disability cases must be heard there. One of the problems facing OHA is that it lacks sufficient decision makers to handle its continuing and rapidly growing workload.

For almost a decade, SSA's disability program has been in crisis. In 1995, SSA introduced a program called the Senior Attorney Program that was instrumental in reducing the backlog and improving processing times. The agency's experienced staff attorneys were given the authority to decide and issue fully favorable decisions—without the time and expense of a full hearing—in those cases where the evidence clearly identified an individual as disabled. In every respect, the Senior Attorney Program was a success. Unfortunately, SSA chose to terminate this innovative program as it undertook its Hearings Process Improvement (HPI) plan, a plan SSA now admits was unsuccessful.

On a more positive note, current Social Security Commissioner Barnhart has undertaken an objective review of the entire disability system. Finally, senior SSA officials truly understand the strengths and deficiencies of the current system. This insight combined with the Commissioner's commitment to create a process which serves the needs of the public rather than the dictates of the bureaucracy, have led her to propose a plan for implementing fundamental process changes that will provide a level of service of which we all can be proud.

The plan is comprehensive and involves extensive changes such as the eventual replacement of paper folders with electronic folders, elimination of the Reconsideration Determination, elimination of the Appeals Council, a completely revamped quality assurance system, and the creation of the Reviewing Official position to provide an intermediate step between the State Agency and the ALJ. NTEU is convinced that this plan, if implemented, will result in an efficient, effective, and most importantly, a fair adjudicatory process.

In a particularly important initiative proposed by the Commissioner, a Reviewing Official, or RO position, will be created. This individual will be an attorney and will apply the same adjudicatory standards to the disability determination process, as will the Administrative Law Judges. Past experience from the Senior Attorney Pro-

gram indicates that the creation of this position in conjunction with the other improvements the Commissioner seeks to put in place will result in many disabled claimants being awarded benefits in as little as 30 days.

The President has recognized the importance of providing SSA with sufficient resources to enable SSA to implement the Commissioner's plan to improve the Social Security disability program. NTEU asks that the Congress approve the budget requests of the President regarding the funding of the Commissioner's Approach to Disability Adjudication.

However, as good as the Commissioner's plan is, it does not provide immediate relief for those currently waiting for a disability decision. Unfortunately, it will be October 2005 at the earliest before the Commissioner's recommendations can be implemented. In the meantime, the backlog will continue to grow.

Given the present state of resources, the current workload, and the direction that the Commissioner's Approach is taking the Agency, the Commissioner should immediately reinstate the original Senior Attorney Program. In addition to making a positive, immediate, and effective impact on the backlog, it would act as a good transition to the Reviewing Official. All qualified OHA Attorney Advisors should be empowered to issue fully favorable on-the-record decisions. During the period from 1995 to 1999 Senior Attorneys issued over 220,000 fully favorable on-the-record decisions, and the cases pending at OHA hearing offices fell from over 550,000 cases to 311,000 cases. A well designed and well managed Senior Attorney program should be able to process at least 60,000 fully favorable reversals in a year without reducing the number of ALJ decisions or affecting the overall reversal rate at OHA.

Implementing the original Senior Attorney Program would require limited new hiring and the impact on the backlog would be swift and striking. I strongly recommend that this Committee both carefully review and embrace the Commissioner's new disability plan and also encourage SSA to implement the original Senior Attorney Program once again without delay.

Thank you very much for your attention to these issues. I very much appreciate the opportunity to share this testimony with you.

PREPARED STATEMENT OF THE ONCOLOGY NURSING SOCIETY

The Oncology Nursing Society (ONS) appreciates the opportunity to submit written comments for the record regarding funding for cancer and nursing related programs in fiscal year 2005. ONS, the largest professional oncology group in the United States composed of more than 30,000 nurses and other health professionals, exists to promote excellence in oncology nursing and the provision of quality care to those individuals affected by cancer. As part of its mission, the Society honors and maintains nursing's historical and essential commitment to advocacy for the public good.

This year more than 1.3 million Americans will be diagnosed with cancer and more than 560,000 will lose their battle with this terrible disease. Despite these grim statistics, significant gains in the War Against Cancer have been made through our nation's investment in cancer research and its application. Research holds the key to improved cancer prevention, early detection, diagnosis, and treatment but such breakthroughs are meaningless unless we can deliver them to all Americans in need. One barrier to ensuring that all people benefit from breakthroughs in cancer research is that recent studies have reported 126,000 registered nurse vacancies in hospitals and 13,900 registered nurse vacancies in nursing homes.

To ensure that all people with cancer have access to the comprehensive, quality care they need and deserve, ONS advocates ongoing and significant federal funding for cancer research and application, as well as programs to help ensure an adequate oncology nursing workforce to care for people with cancer. The Society stands ready to work with policymakers at the local, state, and federal levels to advance policies and programs that will reduce and prevent suffering from cancer and sustain and strengthen the nation's nursing workforce.

SECURING AND MAINTAINING AN ADEQUATE ONCOLOGY NURSING WORKFORCE

Over the last 10 years, the setting in which treatment for cancer is provided has changed dramatically. An estimated 80 percent of all Americans receive cancer care in community settings including cancer centers, physicians' offices, and hospital outpatient departments. Treatment regimens are as complex, if not more so, than regimens given in the inpatient setting a few short years ago. Oncology nurses are on the front lines in the provision of quality cancer care for individuals with cancer—administering chemotherapy, managing patient therapies and side-effects, working

with insurance companies to ensure that patients receive the appropriate treatment, providing counseling to patients and family members, and engaging in myriad other activities on behalf of people with cancer and their families.

Overall, age is the number one risk factor for developing cancer. Approximately 77 percent of all cancers are diagnosed at age 55 and older. Currently, Medicare beneficiaries account for more than 50 percent of all cancer diagnoses and 64 percent of cancer deaths. Of serious concern is that over the next 10 to 15 years the number of Medicare beneficiaries with cancer is estimated to double while more than 1.1 million registered nurse job openings will need to be filled by 2012 to meet growing patient demand and replace retiring nurses. With an increasing number of people with cancer needing high quality health care coupled with an inadequate nursing workforce, our nation could quickly face a cancer care crisis of serious proportion with limited access to quality cancer care, particularly in traditionally underserved areas. A study in the New England Journal of Medicine found that nursing shortages in hospitals are associated with a higher risk of complications—such as urinary infections and pneumonia, longer hospital stays, and even patient death. Without an adequate supply of nurses, there will not be enough qualified oncology nurses to provide the quality cancer care to a growing population of people in need and patient health and well being could suffer.

Further, of additional concern is that our nation also will have a shortage of nurses available and able to conduct cancer research and clinical trials. With a shortage of nurses in cancer research, our war against cancer will take longer because of unfulfilled staffing needs coupled with the reality that in some practices and cancer centers resources could be funneled away from cancer research to pay for the hiring and retention of oncology nurses to provide direct patient care. Without a sufficient supply of trained, educated, and experienced oncology nurses, our nation will falter in its delivery—or application—of the benefits from our federal investment in research.

ONS has joined with others in the nursing community in advocating $205 million as the fiscal year 2005 funding level necessary to support implementation of the Nurse Reinvestment Act and the range of nursing workforce programs housed at the U.S. Health Resources and Services Administration (HRSA). Enacted in 2002, the Nurse Reinvestment Act included new and expanded initiatives, including loan forgiveness, scholarships, career ladder opportunities, and public service announcements to advance nursing as a career. Despite the enactment of this critical measure, HRSA fails to have the resources necessary to meet the current and growing demands for our nation's nursing workforce. For example, in fiscal year 2003 HRSA received 8,321 applications for the Nurse Education Loan Repayment Program but only had funding to award 602—a rate of 7.2 percent. Also in fiscal year 2003, the agency received 4,512 applications for the Nursing Scholarship Program but only could fund 94—a rate of 2.1 percent. Further exacerbating the current situation is that nursing programs turned away more than 11,000 qualified students last fall, in part due to a shortage of faculty. If funded sufficiently, the components and programs of the Nurse Reinvestment Act would help address the multiple factors contributing to the nationwide nursing shortage, including the shortage of faculty, decline in nursing student enrollments, and poor public perception of nursing as a viable and worthwhile profession.

ONS strongly urges Congress to provide HRSA with a minimum of $205 million in fiscal year 2005 to ensure that the agency has the resources necessary to fund a higher rate of Nurse Education Loan Repayment and Nursing Scholarship applications as well as implement other essential endeavors to sustain and boost our nation's nursing workforce. Nurses—along with patients, family members, hospitals, and others—have joined together in calling upon Congress to provide this essential level of funding. One Voice Against Cancer (OVAC)—a collaboration of more than 50 national nonprofit organizations representing millions of Americans—has added a request of $205 million for the Nurse Reinvestment Act funding to its fiscal year 2005 appropriations advocacy agenda. ONS and its allies have serious concerns that without full funding, the "Nurse Reinvestment Act" will prove an empty promise; the current and expected nursing shortage will worsen and people will not be have access to the quality cancer care they need and deserve.

BOOST OUR NATION'S INVESTMENT IN CANCER PREVENTION, EARLY DETECTION, AND AWARENESS

Approximately two-thirds of cancer cases are preventable through lifestyle and behavioral factors and improved practice of cancer screening. Although the potential for reducing the human, economic, and social costs of cancer by focusing on prevention and early detection efforts remains great, our nation does not invest sufficiently

in these strategies. While as a nation we spend almost $1 trillion a year on our health care system, we only allocate about 1 percent of that amount for population-based prevention. By the year 2020, cancer and other chronic disease expenditures will reach $1 trillion or 80 percent of health care costs. The nation must make significant and unprecedented federal investments today to address the burden of cancer and other chronic diseases and to reduce the demand on the healthcare system and diminish suffering in our nation both for today and tomorrow.

As the nation's leading prevention agency, the Centers for Disease Control and Prevention (CDC) plays an important role in translating and delivering at the community level what is learned from research—especially ensuring that those populations disproportionately affected by cancer receive the benefits of our nation's investment in medical research. Therefore, ONS joins with our partners in the cancer community—including One Voice Against Cancer—in calling on Congress to provide additional resources for physical activity, nutrition, and tobacco control programs and other cancer-related screening, prevention, and public health education efforts supported through the CDC to support and expand much-needed and proven effective cancer prevention, early detection, and risk reduction efforts. Specifically, ONS advocates:

—$250 million for the National Breast and Cervical Cancer Early Detection Program;
—$65 million for the National Cancer Registries Program:
—$25 million for the Colorectal Cancer Prevention and Control Initiative;
—$25 million for the Comprehensive Cancer Control Initiative;
—$20 million for the Prostate Cancer Control Initiative;
—$10 million for the National Skin Cancer Prevention Education Program;
—$9 million for the Ovarian Cancer Control Initiative;
—$5 million for the Geraldine Ferraro Blood Cancer Program;
—$130 million for the National Tobacco Control Program; and
—$70 million for the Nutrition, Physical Activity, and Obesity Program.

SUSTAIN AND SEIZE CANCER RESEARCH OPPORTUNITIES

Our nation has benefited immensely from our past federal investment in biomedical research at the National Institutes of Health (NIH). ONS has joined with the rest of the cancer community in advocating $30.19 billion for the NIH in fiscal year 2005. This increase of 8.5 percent over fiscal year 2004 funding will allow NIH to sustain and build on its research progress resulting from the recent NIH budget doubling effort while avoiding the severe disruption to that progress that would result from a minimal increase.

Cancer research is producing extraordinary breakthroughs—leading to new therapies that translate into longer survival and improved quality of life for cancer patients. We have seen extraordinary advances in cancer research resulting from our national investment that have produced effective prevention, early detection and treatment methods for many cancers. To that end, ONS calls upon Congress to allocate $6.2 billion to the National Cancer Institute (NCI) in fiscal year 2005 as recommended by the NCI Director in the Bypass Budget submitted to Congress annually under the requirements of the National Cancer Act of 1971. The NCI Bypass Budget represents the best estimation of the scientific community regarding the resources needed to continue our battle against cancer.

The National Institute of Nursing Research (NINR) supports basic and clinical research to establish a scientific basis for the care of individuals across the life span—from management of patients during illness and recovery to the reduction of risks for disease and disability and the promotion of healthy lifestyles. These efforts are crucial in translating scientific advances into cost-effective health care that does not compromise quality of care for patients. Additionally, NINR fosters collaborations with many other disciplines in areas of mutual interest such as long-term care for older people, the special needs of women across the life span, bioethical issues associated with genetic testing and counseling, and the impact of environmental influences on risk factors for chronic illnesses such as cancer. ONS joins with the nursing community in advocating an allocation of $160 million for NINR in fiscal year 2005.

CONCLUSION

ONS stands ready to work with policymakers to advance policies and support programs that will reduce and prevent suffering from cancer this year and sustain and strengthen our nation's nursing workforce. Moreover, ONS maintains a strong commitment to working with Members of Congress, other nursing societies, patient organizations, and other stakeholders to ensure that the oncology nurses of today con-

tinue to practice tomorrow and that we recruit and retain new oncology nurses to meet the unfortunate growing demand that we will face as the baby boom generation ages. We thank you for this opportunity to discuss the funding levels necessary to ensure that our nation has a sufficient nursing workforce to care for the patients of today and tomorrow and that our nation continues to make gains in our fight against cancer.

PREPARED STATEMENT OF THE ASSOCIATION OF WOMEN'S HEALTH, OBSTETRIC AND NEONATAL NURSES

The Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN) appreciates the opportunity to comment on the fiscal year 2005 appropriations for nursing education, research, and workforce programs, as well as programs designed to improve maternal and child health. AWHONN is a membership organization of 22,000 nurses whose mission is to promote the health of women and newborns. AWHONN members are registered nurses, nurse practitioners, certified nurse-midwives, and clinical nurse specialists who work in hospitals, physicians' offices, universities and community clinics across North America as well as in the Armed Forces around the world.

AWHONN appreciates the support that this Subcommittee has provided for nursing education, research and workforce programs, as well as maternal and child health programs in the past. We realize that there are many competing priorities for the Subcommittee members, and we admire your consistent support.

GROWING NURSING SHORTAGE

AWHONN supports the advancement of quality care through an adequate nurse workforce. Data from the Bureau of Health Professions, Division of Nursing's National Sample Survey of Registered Nurses—February 2002, confirm that of the approximate 2.7 million registered nurses in the nation, only about 82 percent of these nurses were working full-time or part-time in nursing. The increase in the number of licensed RNs that was reported from 1996–2000 was the lowest increase reported in previous national surveys. In addition to the shrinking pipeline of nurses coming into the program, the dominant factor in this shortage is the impending retirement of up to 40 percent of the workforce by 2010 or soon thereafter. This will occur at the same time that the needs of the aging baby boomer population will markedly increase demand for health care services and the services of registered nurses.

This critical demand is reinforced by the fact that in February 2004, the U.S. Bureau of Labor released statistics detailing how registered nurses have the largest projected 10-year job growth in the United States. Labor projects a need for 2.9 million nurses in 2012, up from 2.3 million actively working nurses that was projected in 2002. As a result, it will take long-term planning and innovative initiatives at the local, state and federal level to assure an adequate supply of a qualified nurse workforce for the nation.

Nurse Workforce Development Programs

AWHONN recommends a total of $205 million for fiscal year 2005 to fund the Nurse Workforce Development programs in Title VIII

The Nurse Education Act (Public Health Service Act, Title VIII), enacted in 1964, represents the only comprehensive federal legislation to provide funds for nursing education. The programs authorized in this portion of Public Law 105–392 help schools of nursing and nursing students prepare to meet patient needs in a changing health care delivery system, favoring programs in institutions that train nurses for practice in medically underserved communities and Health Professional Shortage Areas.

Reauthorized as the Nursing Workforce Development section in 1998, the new NEA gives the Department of Health and Human Services more discretion over the focus of federal spending, while keeping with previous goals. In 2002 Congress enacted the Nurse Reinvestment Act which provides funding for new and expanded programs. These programs include scholarships, career ladders, internships and residencies, retention programs and faculty loans designed to encourage students to consider nursing, keep nurses in nursing and ensure that nurse educators are plentiful enough to educate future nurses that we desperately need. The new programs received an initial appropriation of $20 million in fiscal year 2003. This appropriation was in addition to $93 million in funding provided for existing Title VIII programming. Unfortunately, due to limited funding in the first 2 years of the new authorization the loans and scholarships programs have not been successful in providing support to students in nursing schools. In the first year, only 574 loan repay-

ment contracts were made nationally, averaging roughly 11 loan repayment agreements per state and less than 2 percent of all scholarship applicants were funded.

The shortage of registered nurses and the effect of the shortage on nurse staffing and patient safety demand a significant increase in funding for these nurse education programs. Nursing is the largest health profession with over 2.7 million nurses, yet only one-tenth of 1 percent of the federal health funding of the nation is directed to nursing education. A significant increase in funding for these programs would lay the groundwork to expand the nursing workforce, through education, clinical training and retention programs, in order to address some of the serious nursing shortage issues. This investment in nursing education and retention will ultimately benefit us all through improved patient care and health outcomes.

The nursing shortage is not confined solely to care providers; there is also a growing, significant shortage of nurse faculty. The American Association of Colleges of Nursing (AACN) reports that the average age of nursing professors is 52, and for associate professors the average age is 49. The impending retirement of these seasoned educators will impact the ability of our schools and universities to meet the educational health care needs of the nation. In addition, each year nearly 1,800 full-time faculty members leave their positions while only 350 to 400 nursing students receive doctoral degrees. According to AACN, U.S. nursing schools turned away over 11,000 qualified applicants to baccalaureate nursing programs in 2003 due to insufficient faculty, clinical sites, classroom space, and budget constraints. While the capacity to implement faculty development is currently available through Section 811 and Section 831, adequate funding and direction is needed to ensure that these programs are fully operational. Options to provide support for full-time doctoral study are essential to rapidly prepare the nurse educators of the future. AWHONN suggests that a portion of the funds be allocated for faculty development and mentoring. Further, AWHONN recognizes the importance of appropriate investments in advanced practice nursing programs. As in other professions the advanced degree has become a necessary achievement for career advancement and registered nurses who pursue the MSN degree are a part of the cadre of nurses who go on to become faculty. Our nation does need more nurses with basic training to enter the field, but focusing only on these nurses only addresses half the problem. The nursing shortage encompasses nursing faculty—advanced practice nursing and basic nursing must both receive additional funding, but not one at the expense of the other.

Maternal and Child Health Bureau

AWHONN recommends $850 million in funding in fiscal year 2005 for the Maternal and Child Health Bureau

This program provides comprehensive, preventive care for mothers and young children, as well as an array of coordinated services for children with special needs. In fact, the Maternal Child Health Block Grant (MCH) serves over 80 percent of all infants in the United States, half of all pregnant women, and 20 percent of all children.

MCH programs are facing increased demands for services due to continued growth in the Children's Health Insurance Program, which in turn identifies more children who are eligible for other MCH Services. Title V complements Medicaid and the State Children's Health Insurance Program by providing "wrap-around" services and enhanced access to care in underserved areas. Additional funding would give states the resources they need to expand prenatal and infancy home visitation programs, an approach that has been shown, in NINR research, to improve the prenatal health-related behavior of women and reduce rates of child abuse and neglect as well as maternal welfare dependence.

Indian Health Service

AWHONN recommends an fiscal year 2005 appropriation of $5.54 billion for IHS.

The Indian Health Service (IHS) is the principal Federal health care provider and health advocate for Indian people with the goal of "ensur[ing] that comprehensive, culturally acceptable personal and public health services are available and accessible to all American Indian and Alaska Native people." IHS is tasked with an enormous responsibility in providing care to over half of the American Indian population.

The American Indian and Alaska Native people have long experienced lower health status when compared with other Americans. Lower life expectancy and the disproportionate disease burden exist perhaps because of inadequate education, disproportionate poverty, discrimination in the delivery of health services, and cultural

differences. These are broad quality of life issues rooted in economic adversity and poor social conditions.

A recent study of federal health care spending per capita found that the United States spends $3,803 per year per federal prisoner, while spending about half that amount per year, per Native American: $1,914. per capita health care spending for the U.S. general population is $5,065 per year. A significant increase in funding over fiscal year 2004 spending levels is necessary for the Federal government to fulfill its responsibility to Indian Country and achieve its stated goals.

While the nursing shortage continues nationwide, IHS has been disproportionately impacted by the lack of RNs. IHS nurses are older, with an average age of 48 and nearly 80 percent of RNs are over the age of 40, and the average vacancy rate for RNs is 14 percent. IHS administers three interrelated scholarship programs designed to meet the health professional staffing needs of IHS and other health programs serving Indian people. These programs are severely under-funded. Targeted resources need to be invested in the IHS health professions programs in order to recruit and retain registered nurses in Indian Country.

Additionally, Section 112 of the Indian Health Care Improvement Act, Public Law 94–437, authorizes grants to public or private schools of nursing, tribally-controlled community colleges and tribally-controlled post secondary vocational institutions for the purpose of recruiting, training and increasing the number of professional nurses who deliver health care services to Indian people. On average, Section 112 programs provide five undergraduate scholarships per year and two master's program scholarships. This important program should be expanded to provide many more scholarships, both at the undergraduate and graduate levels, in an effort to offer meaningful relief to the nursing shortage for IHS healthcare providers and the patients they serve.

National Institute of Nursing Research (NINR)

AWHONN recommends an increase of $25 million over fiscal year 2004 funding levels for the NINR, resulting in an fiscal year 2005 appropriation of $160 million

NINR engages in significant research affecting areas such as: health disparities in ethnic groups, training opportunities for management of patient care and recovery, and telehealth interventions in rural/underserved populations. These research programs directly help patients and families and contribute to decreased medical costs and increased quality of patient care. This research allows us to refine the practice and provide quality patient care in its current challenging environment.

NINR research improves health outcomes for women. Recent public awareness campaigns target differences in the manifestation of cardiovascular disease between men and women. The differing symptoms are the source of many missed diagnostic opportunities among women suffering from the disease, which is the primary killer of American women. In a study funded by NINR, researchers were able to qualitatively analyze the intensity of pain and limitation of activity experienced by women suffering from angina, both of which were found to be of greater intensity than that experienced by men. The study concluded that the gender variation could significantly impact diagnosis and treatment of female patients suffering from related cardiovascular problems.

Because of the emphasis on biomedical research in this country, there are few sources of funds for high-quality behavioral research for nursing other than NINR. It is critical that we increase funding in this area in an effort to improve the consumer's experience with the health care system, optimize patient outcomes and decrease the need for extended hospitalization.

National Institute of Child and Human Development (NICHD)

AWHONN supports a 10 percent increase in funding for NICHD for fiscal year 2005, bringing the appropriation to $1.315 billion

NICHD seeks to ensure that every baby is born healthy, that women suffer no adverse consequences from pregnancy, and that all children have the opportunity to fulfill their potential for a healthy and productive life unhampered by disease or disability. With increased funding NICHD could expand its use of the NICHD Maternal-Fetal Medicine Network to study ways to reduce the incidence of low birth weight. Prematurity/low birthweight is the second leading cause of infant mortality in the United States and the leading cause of death among African American infants. AWHONN, like many organizations directly involved in initiates to improve the health of women and newborns, looks to NICHD to provide national initiatives, such as the Maternal-Fetal Medicine Network to assist with the care of pregnant women and babies.

Recently NICHD announced the publication of research that led to the finding of predictors of preeclampsia, a life-threatening complication impacting 5 percent of all pregnancies. Abnormal levels of two molecules found in the blood, soluble fms-like tyrosine kinase 1 (sFlt–1) and placental growth factor (PlGF), seemed to predict the development of preeclampsia. This finding has been touted as the most promising lead yet discovered in the effort to prevent and cure preeclampsia.

National Institutes of Environmental Health Sciences (NIEHS)

AWHONN supports an 8 percent increase in funding for NIEHS for fiscal year 2005, bringing the appropriation to $680 million

Research conducted by the NIEHS plays a critical role in what we know about the relationship between our environmental exposures and disease onset. Through the research sponsored by this Institute, we know that Parkinson's disease, breast cancer, birth defects, miscarriage, delayed or diminished cognitive function, infertility, asthma and many other diseases and ailments have confirmed environmental triggers. Our expanded knowledge, as a result, allows both policy makers and the general public to make important decisions about how to reduce toxin exposure and reduce the risk of disease and other negative health outcomes.

One impressive collaborative research project spearheaded by the NIEHS is the recent development of Breast Cancer and the Environment Research Centers. These centers, co-funded by the National Cancer Institute, will study the prenatal-to-adult environmental exposures that may predispose a woman to breast cancer. Recognizing that one in eight women in the United States can expect to have breast cancer in her lifetime, and that the causes of most of these cases are not known; the centers will enroll different ethnic groups of young girls and study their life exposures to a wide variety of environmental, nutritional and social factors that impact puberty.

Centers for Disease Control and Prevention (CDC)

AWHONN recommends an fiscal year 2005 appropriation of $7.9 billion for the CDC

For nearly 60 years, the Centers for Disease Control and Prevention (CDC) has evolved to assume responsibility for programs in infectious disease surveillance, control and prevention, injury control, health in the workplace, prevention of heart disease, cancer, stroke, obesity and other chronic diseases, improvements in nutrition and immunization, environmental effects on health, prevention of birth defects, laboratory analyses, outbreak investigation and epidemiology training, and data collection and analysis on a host of vital statistics and other health indicators. Now more than ever, CDC's role in protecting the nation's health through prevention has become evident as we address issues of terrorism, emergency preparedness and health system capacity and infrastructure. Increased funding for CDC is critical.

For over 30 years, CDC has been deeply involved in the prevention of birth defects through programs like the Folic Acid Education Campaign and the new National Center on Birth Defects and Developmental Disabilities (NCBDDD). The public health impact of birth defects is tremendous. Of the 4 million babies born each year in the United States, approximately 150,000 are born with a serious birth defect. According to CDC, the lifetime costs of caring for infants born in 1992, with at least one birth defect [1] or cerebral palsy was about $8 billion. The emotional and financial burden for the families with affected children is devastating. CDC funds several programs critical to reducing the number of children born with birth defects.

Heart disease and stroke are the first and third leading causes of death in the United States, causing one death every 33 seconds and $298 billion a year in healthcare costs and lost productivity, according to CDC estimates. Women are most commonly misdiagnosed for cardiovascular disease and nearly 8 million women are currently living with cardiovascular disease. Cardiovascular disease kills nearly half of all American women. Additionally, 61 percent of American adults are overweight or obese and nearly 14 percent of children and adolescents are overweight. Obesity is considered a major public health problem because it serves as the gateway disease for many other illnesses including but not limited to: depression, type 2 diabetes, hypertension, congestive heart failure, stroke, poor female reproductive health and pregnancy complications. These are but two examples of illnesses with pro-

[1] These birth defects include: Spina bifida, truncus arteriosus, single ventricle, transposition/double outlet right ventricle, Tetralogy of Fallot, tracheo-esophageal fistula, colorectal atresia, cleft lip or palate, atresia/stenosis of small intestine, renal agenesis, urinary obstruction, lower-limb reduction, upper-limb reduction, omphalocele, gastroschisis, Down syndrome, and diaphragmatic hernia.

grammatic public health funding through CDC. Any cuts to these programs will potentially leave millions of Americans without primary prevention programs that ultimately save lives and money. We respectfully request that you provide CDC chronic disease prevention and health promotion programs with $1.1 billion to ensure that these programs have the resources necessary to translate preventive health research into practice. This investment will save lives and billions in health care costs and productivity.

Please find below a summary of AWHONN formal funding recommendations for these and other federal health programs.

Programmatic area	Final fiscal year 2004	President's budget fiscal year 2005	AWHONN's request
Nurse Workforce Development Programs	$142,763,000	$147,000,000	$205,000,000
Maternal & Child Health Block Grant	730,000,000	730,000,000	850,000,000
Indian Health Service	3,671,000,000	3,356,000,000	5,540,000,000
Title X—Family Planning	278,000,000	278,000,000	350,000,000
Newborn Hearing Screening	13,000,000	.....	13,000,000
AHRQ	305,000,000	305,000,000	443,000,000
NIH	28,041,000,000	28,805,000,000	31,685,500,000
NINR	135,000,000	139,000,000	160,000,000
NICHD	1,242,000,000	1,281,000,000	1,315,000,000
NIEHS	631,000,000	650,000,000	680,000,000
CDC	6,972,000,000	6,859,000,000	7,900,000,000

Thank you for the opportunity to submit testimony on these critical areas of funding.

Contact: Lisa M. Greenhill, MPA, Legislative Manager Department of Public Affairs Association of Women's Health, Obstetric and Neonatal Nurses 2000 L St. NW, Suite 740, Washington, DC 20036 (202) 261–2402 lisag@awhonn.org

---

PREPARED STATEMENT OF THE AMERICAN HEART ASSOCIATION

Heart disease, stroke and other cardiovascular diseases kill more Americans each year than the next 5 leading causes of death combined, putting people of all ages at risk. Cardiovascular diseases remain our nation's No. 1 killer and a major cause of disability. We are concerned that our government is still not devoting sufficient resources for research and prevention to America's No. 1 killer—heart disease—and to our country's No. 3 killer—stroke.

STILL NO. 1—AN UNHAPPY DISTINCTION

Cardiovascular diseases represent a continuing crisis of pandemic proportions. More than 64 million Americans suffer from these diseases, and risk factors are on the rise. While smoking is the top preventable cause of death, the obesity epidemic is catching up. Obesity rates are rising in adults and in children. Also, an estimated 50 million Americans have high blood pressure, 37 million adults have high cholesterol, and more than 11 million have diagnosed diabetes. Also, cardiovascular diseases cost Americans more than any other disease—an estimated $368 billion in medical expenses and lost productivity in 2004. Heart disease is the major cause of premature, permanent disability of American workers, accounting for about 20 percent of Social Security disability payments. Stroke is a main cause of disability. Heart defects are the most common birth defect and cause more infant deaths than any other birth defect.

YOU ARE PART OF THE SOLUTION

Now is the time to capitalize on progress in understanding heart disease, stroke and other cardiovascular diseases. Promising, cost-effective breakthroughs in treatment and prevention are on the horizon. A continued, sustained investment in the NIH and appropriate funding for NIH heart disease and stroke will support promising and critically needed new initiatives and the translation of that research into useful clinical and state programs. For fiscal year 2005, we urge you to:

Appropriate $30.6 billion for the National Institutes of Health (NIH)—to provide a continued, sustained investment in life-saving medical research

NIH research provides new treatment and prevention strategies, creates jobs, and maintains America's status as the world leader in the biotechnology and pharmaceutical industries.

Provide $2.5 billion for NIH heart research and $410 million for NIH stroke research

Researchers are on the brink of advances to enhance prevention and to provide new treatments so you and your loved ones can be spared the pain and suffering of heart disease and stroke.

Allot $80 million for Heart Disease and Stroke for the CDC to expand, intensify and coordinate prevention like expanding the State Heart Disease and Stroke Prevention Program and augmenting the Paul Coverdell National Acute Stroke Registry

Science must be translated into state programs that hearten Americans to make healthy lifestyle choices to avert and control heart disease and stroke and track and improve stroke care delivery.

Support $45 million to continue to help our communities treat cardiac arrest in time to save victims' lives by initiating automated external defibrillator (AEDs) programs

The Rural Access to Emergency Devices Act (part of Public Law 106–505) and the Community Access to Emergency Defibrillation Act (part of Public Law 107–188) help communities purchase AEDs and train emergency and lay responders in their use.

HEART AND STROKE RESEARCH BENEFITS ALL AMERICANS

The doubling of the NIH budget has led to new breakthroughs in treating heart disease and stroke patients and their risk factors for these diseases. Several examples follow.

High Blood Pressure.—A clinical trial concluded that customary diuretic drugs should be the first treatment for lowering blood pressure. The diuretic tested as well or better than some newer types of drugs in preventing high blood pressure complications, including fatal and non-fatal heart attacks, strokes and heart failure. The cost implications are significant because diuretics cost a fraction of the price of the newer drugs.

Hormone Replacement Therapy.—Researchers concluded that long-term estrogen plus progestin therapy risks outweigh its protective benefits. Women study participants taking estrogen plus progestin had increased risks of heart attack, stroke, breast cancer and blood clots.

Heart Attack.—More than 5 million patients with chest pain visit emergency departments each year, but only about 40 percent can be immediately diagnosed with heart attack using standard diagnostic tests. Results from a collaborative study using advanced, non-invasive magnetic resonance imaging showed that MRI can detect a heart attack in emergency room patients with chest pain more accurately and faster than standard diagnostic tests. Since patients can be scanned in under 40 minutes, MRI technology will save lives and reduce disability among survivors by allowing doctors to diagnose heart attacks and start treatment faster.

Recurrent Stroke Prevention.—Results of two clinical trials showed that aspirin was just as effective in preventing recurrent strokes as expensive drugs. Outcomes of the first trial indicated that aspirin appears to be as effective as warfarin in preventing a second stroke, when heart conditions such as atrial fibrillation, a common heart rhythm and rate problem, are not present. Results from the second study showed that aspirin is as effective as ticlopidine, a type of clot inhibitor, in preventing a second stroke in African-Americans who have twice the risk of suffering or dying from a stroke, compared to whites. These results will dramatically change physician care in preventing second strokes in the general public and in African-Americans. Given the lower cost, ease of administration and reduced side effects, compared to warfarin and ticlopidine, aspirin will be a cost-effective method in preventing subsequent strokes.

We join other members of the research community in advocating for an fiscal year 2005 appropriation of $30.6 billion for the NIH to provide a continued, sustained investment in life-saving medical research and support investigation into new therapies. The NIH budget for heart disease and stroke remains disproportionately under funded compared to the enormous burden of these diseases and the numerous promising scientific opportunities that could advance the fight against these disorders. Heart disease, stroke and other cardiovascular diseases meet the NIH's criteria for priority setting (public health needs, scientific quality research, scientific progress potential, portfolio diversification and adequate infrastructure support), but the NIH still invests only 7 percent of its budget on heart research and a mere 1 percent on stroke research. We have a particular interest in individual NIH components that relate directly to our mission. Our funding recommendations for these Institutes follow.

HEART RESEARCH CHALLENGES AND OPPORTUNITIES FOR NHLBI

Advances have been made by more than 50 years of American Heart Association-funded research and more than a half-century of investment by Congress in the National Heart, Lung, and Blood Institute. While more people are surviving heart disease and stroke, they can cause permanent disability, requiring costly medical care and loss of productivity and quality of life.

We urge this Committee to appropriate funding for the NHLBI and for its heart disease and stroke-related efforts to support and expand current activities and to invest in promising and critically needed new initiatives to aggressively advance the battle against heart disease and stroke. To accomplish this goal, we advocate an appropriation of $3.5 billion for the NHLBI, including $2.1 billion for heart disease and stroke. This added investment is needed to focus on heart disease and stroke challenges and opportunities. Several of these follow.

Heart Failure Management.—Heart failure is a major cause of hospitalization and readmission. Medicare recipients represent about 65 percent of repeat hospitalizations within 1 year. Yet, perhaps 50 percent of these hospitalizations are avoidable. Additional funding would allow the NHLBI to initiate a planned multi-center, randomized trial to evaluate management strategies for heart failure patients in terms of their ability to prevent death or hospital readmission. Costs, quality of life, physician compliance, and patient adherence to prescribed treatment will also be assessed. This clinical trial will identify and disseminate useful and effective tools for translation of proven therapies for heart failure into patient care.

Tissue Engineered Blood Vessel Replacement and Repair.—A need exists to develop alternatives to natural blood vessels for adults who endure heart artery bypass surgery and for children born with complex heart defects who need multiple blood vessel grafts. With increased funding, this planned initiative will complement exiting tissue engineered research programs to stimulate efforts to "grow" small-diameter, functional blood vessels.

Cardiovascular Health Study.—Initiated in 1987 to determine risk factors for development and progression of cardiovascular diseases in nearly 6,000 Americans age 65 and older, the Cardiovascular Health Study (CHS) is scheduled to end in 2005. The wide variety and complexity of data and samples collected in the CHS represent an unique national research resource. With increased funding, this planned proposal will stimulate innovative use of CHS data and material, provide opportunities for open and efficient use of the information for the entire scientific community; and continue follow-up of study participants.

Community-Responsive Interventions to Reduce Cardiovascular Risk in American Indians and Alaskan Natives.—American Indian and Alaska Native communities bear a disproportionate burden of heart disease, stroke and other cardiovascular diseases. But, few preventive interventions have been tested. Tribal leaders have urged that research in their communities focus on finding solutions for the most serious issues these populations face, including cardiovascular diseases. To address the concerns of the tribal leaders, with increased funding, researchers will evaluate approaches to reducing behavioral cardiovascular disease risk factors in American Indian and Alaskan Native populations. A central part of this planned initiative will be the development of interventions that can be incorporated into community patient care programs or delivered through other public health avenues in native communities.

STROKE RESEARCH CHALLENGES AND OPPORTUNITIES FOR NINDS

Stroke is the No. 3 killer of Americans and a major cause of permanent disability. Many of America's 4.8 million stroke survivors face debilitating physical and mental impairment, emotional distress and huge medical costs. About 1 in 4 stroke survivors is permanently disabled. An estimated 700,000 Americans will suffer a stroke this year, and nearly 164,000 will die. In addition to the elderly, stroke also strikes newborns, children and young adults.

We urge you to provide sufficient funding for the NINDS to support and expand current activities and to invest in promising and critically needed new initiatives to aggressively prevent stroke, protect the brain during stroke and enhance rehabilitation. To accomplish this goal, we advocate for an fiscal year 2005 appropriation of $1.8 billion for the NINDS, including $204 million for stroke. Some challenges and opportunities follow:

Strategic Stroke Research Plan.—As a result of congressional report language during the fiscal year 2001 appropriations process, the NINDS convened a Stroke Progress Review Group. Their report serves as a blueprint for a long-range strategic stroke research plan. They identified serious gaps in stroke knowledge and outlined

5 research priorities and 7 resource priorities that would spur stroke research. But, more funding is needed to continue to implement this plan.

Emerging Stroke Risk Factors.—Although more Americans are controlling major stroke risk factors, such as high blood pressure and smoking, the number of stroke victims continues to rise. Scientists are defining new risk factors, re-examining existing ones and reconsidering the long-held belief that no difference exists in risk between young and older patients with similar risk factors. Researchers are studying heart valve disease, irregular heartbeats, the role of inflammation in damaging arteries, and the long-term effects of high blood pressure. Increased funding to study these areas may lead to new ways to prevent stroke.

Therapeutic Strategies for Stroke.—Several major clinical trials have identified new methods for preventing and treating stroke in high-risk populations. But, with the increased number of strokes, and with the disparities in stroke treatment, new ways to prevent strokes, to raise awareness, and to better treat strokes need to be developed and evaluated. Funding for new clinical studies is vital for developing cutting-edge stroke treatment and prevention.

Stroke Education.—Less than 5 percent of patients eligible for tPA—the only FDA approved emergency treatment for clot-based stroke—receive it. As a member of the Brain Attack Coalition, a group of organizations devoted to fighting stroke, we work with the NINDS to increase public awareness of stroke symptoms and the need to call 9–1–1. Together, we launched a public education campaign, Know Stroke, Know the Signs. Act in Time, and we are striving to develop systems to make tPA available to appropriate patients. When these measures are implemented, stroke treatment will change from supportive care to early brain-saving intervention. More funding is needed to educate the public and health providers about stroke.

RESEARCH IN OTHER NIH INSTITUTES BENEFIT HEART DISEASE AND STROKE

Research seeking to prevent and find better treatments for heart disease, stroke and other cardiovascular diseases is supported by other NIH entities like the National Institute on Aging, the National Institute of Diabetes and Digestive and Kidney Diseases, the National Institute of Nursing Research and the National Center for Research Resources. It is important to provide sufficient additional resources for these entities to continue and expand their critical work.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

The AHRQ acts as a "science partner" with public and private health care sectors in improving health care quality, reducing health care costs and broadening access to essential services. They help develop evidence-based information needed by consumers, providers, health plans and policymakers to improve health care decision making. We join with the Friends of AHRQ in advocating for an appropriation of $443 million for the AHRQ to advance health care quality, cut medical errors and expand the availability of health outcomes information.

CENTERS FOR DISEASE CONTROL AND PREVENTION

Prevention is the best way to protect Americans' health and ease the financial burden of disease. Resources must be made available to bring research to places where heart disease and stroke strike—our towns and neighborhoods. Setting the pace on prevention, the CDC builds a bridge between what we learn in the lab and translates findings into programs in the communities where we live. We advocate an fiscal year 2005 appropriation of $8.1 billion for the CDC, with a $340.5 million increase for state-based chronic disease prevention and health promotion programs.

Within that figure, we support an appropriation of $80 million for the CDC's Heart Disease and Stroke line to better expand, intensify and coordinate prevention activities against these diseases such as enhancing the State Heart Disease and Stroke Prevention Program, and the Paul Coverdell National Acute Stroke Registry. It will also allow the CDC to start a heart attack and stroke signs health communications campaign, public and health care provider education, and invest in standardized methodology on lipid and other measurements. A Heart and Stroke Division, with ample resources and capacity, would heighten CDC's efforts on these diseases.

Thanks to this Committee's support since fiscal year 1998, the CDC's State Heart Disease and Stroke Prevention Program covers 33 states. But, only 11 states receive funding to actually implement programs to help prevent and control heart disease and stroke. The remaining 22 states have completed program planning and are prepared and waiting to implement a state-tailored program. This initiative allows states to design and/or implement programs to meet state specific needs to prevent heart disease, stroke and other cardiovascular diseases. Since cardiovascular diseases remain the No. 1 killer in every state, each state needs funding for basic im-

plementation of a State Heart Disease and Stroke Prevention Program. With fiscal year 2004 funding, the CDC can only elevate one state from planning to program implementation.

An appropriation of $80 million would allow the CDC to expand the number of states participating in this State Heart Disease and Stroke Prevention Program by 5 states to conduct a state-tailored heart disease and stroke prevention plan, and elevate 10 more states from the planning stage to program implementation and support the other currently funded states. Also, the CDC would enlarge the Paul Coverdell National Acute Stroke Registry. This registry tracks and improves delivery of acute stroke care—care that can mean the difference between a fairly normal life and long-term disability. The CDC developed and conducted registry prototypes from 2001–2003 and will begin to fund three state registries in fiscal year 2004.

We recommend the following fiscal year 2005 funding levels for the following CDC programs:

—$210 million for the Preventive Health and Health Services Block Grant;
—$70 million for the Nutrition, Physical Activity and Obesity Program;
—$125 million for the Youth Media Campaign;
—$82.4 million for the School Health Education Program; and
—$130 million for the Office of Smoking and Health.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

About 340,000 Americans die each year from sudden cardiac arrest. About 95 percent of the victims die before reaching a hospital. AEDs are small, easy-to-use devices that can shock a heart back into normal rhythm and restore life. The Rural Access to Emergency Devices Act and the Community Access to Emergency Defibrillation Act authorize funds for state and local governments to start AED programs. States, cities and towns nationwide eagerly await funds from these vital public health service grant awards, with available funds far below state requests. An appropriation of $45 million is required to support these authorized programs.

DEPARTMENT OF EDUCATION

Physical inactivity is a key risk factor for heart disease and stroke. Yet, our youth have fewer chances for physical education. Congress has been appropriating money for the Carol M. White Physical Education for Progress (PEP) Act to provide funding for school-based physical education programs, which teach life-long physical activity habits and thus prevents diseases, like heart disease and stroke. We advocate for an appropriation of $100 million for PEP.

ACTION NEEDED

Increasing funding for research, prevention and treatment programs will allow continued strides in the battle against heart disease, stroke and other cardiovascular diseases. Our government's response to this challenge will help define the health and well being of Americans for decades.

PREPARED STATEMENT OF LIVING CITIES: THE NATIONAL COMMUNITY DEVELOPMENT INITIATIVE

Thank you, Senator Specter and Subcommittee members, for the opportunity to share with you the views of Living Cities: The National Community Development Initiative on the administration's fiscal year 2005 budget request for the Office of Community Services within the U.S. Department of Health and Human Services (HHS.)

Living Cities is a nonprofit consortium of 15 major financial and philanthropic organizations working to increase the vitality of cities and improve the lives of people in distressed urban neighborhoods. These organizations are AXA Community Investment Program, Bank of America, the Annie E. Casey Foundation, J.P. Morgan Chase & Company, Deutsche Bank, Fannie Mae Foundation, Robert Wood Johnson Foundation, W.K. Kellogg Foundation, John S. and James L. Knight Foundation, John D. and Catherine T. MacArthur Foundation, the McKnight Foundation, Metropolitan Life Insurance Company, Prudential Financial, the Rockefeller Foundation, and Surdna Foundation.

In addition, HHS and the U.S. Department of Housing and Urban Development (HUD) are investment partners in Living Cities. HHS and HUD representatives attend Living Cities meetings, but are not voting members of the organization. Neither HUD nor HHS had any involvement in the preparation of this testimony, and the testimony does not represent either agency's views in any way. This testimony

also does not represent the views of individual member organizations in Living Cities. This testimony is entirely and exclusively on behalf of Living Cities, a stand-alone charitable organization.

Started as NCDI in 1991, Living Cities has worked with the Local Initiatives Support Corporation (LISC) and The Enterprise Foundation to make strategic investments in the work of nonprofit community development corporations (CDCs) in 23 cities—Atlanta, Baltimore, Boston, Chicago, Cleveland, Columbus, Dallas, Denver, Detroit, Indianapolis, Kansas City, Los Angeles, Miami, Minneapolis-St. Paul, Newark, New York City, Philadelphia, Phoenix, Portland, Oregon, San Antonio, San Francisco Bay Area, Seattle, and Washington, D.C.

The results are tangible. Improvements can be seen in transformed neighborhoods—new homes, places of employment, and the visible presence of stronger community organizations. The Living Cities investment of $254 million has directly supported the creation of almost 20,000 affordable housing units and 1.7 million square feet of commercial, industrial and community facilities developed by CDCs, and has leveraged $2.2 billion, a leverage ratio of nearly 9:1. The federal investment in the Living Cities initiative over the first decade was $36 million, achieving a leverage ratio of 61:1 for these federal dollars.

Based upon our experience, we find that urban neighborhoods have the workers, purchasing power, and physical assets ready to be tapped through a combination of public and private investments. That is why our collaborative is doubling our commitments in the current decade, increasing our investments by an additional half-billion dollars between 2001 and 2011.

IMPORTANCE OF ACCOUNTABILITY

We believe that lessons can be drawn from Living Cities' experience of investing in distressed urban neighborhoods, useful lessons for policy and funding decisions to strengthen distressed communities nationwide. Like this Subcommittee, we demand individual accountability and results from the entities that receive Living Cities resources. Since our inception, we have engaged outside experts to take a hard look at what CDCs are achieving. We are glad to share the results of these studies with the Subcommittee.

Beyond our own research, two federal agencies, the General Accounting Office and the Office of Management and Budget, this year applauded the successful use of federal NCDI/Section 4 funds to strengthen CDCs by improving their internal management, increasing their capacity, and widening their impact.

HHS/OCS: A VITAL PARTNER IN COMMUNITY REVITALIZATION

The history of CDCs is well known. CDCs began forming in the 1960s to address the failure of mainstream government and market structures to provide decent housing, safe neighborhoods, good jobs, and resident participation in planning for their own future. From the outset of the CDC movement, communities that were served ranged from a few square blocks in a single urban neighborhood to multi-county rural areas. Target populations have been equally diverse—including all races and ethnic groups, farmers, immigrants, welfare recipients, small business owners, juveniles, the homeless. What has been consistent among CDCs is that each one has come from and represents a community, and each one has harnessed resources from both the public and private sectors of the economy.

Different administrations have lent their support to CDCs over the decades. During the 1960s, CDCs were viewed as complementary to government. Their role was to encourage neighborhood development, promote anti-poverty strategies, and deliver social services—with generous federal support provided to fuel them. During the Reagan years, CDCs came to be seen by some as alternatives to government. CDCs developed stronger alliances with state and local governments and with private sector partners. These alliances expanded the impact of CDCs. By the 1990s, CDCs were viewed as playing a dual role—as complementary to government and as enhancements to markets.

As you know, the Department of Health and Human Services, Office of Community Services, Community Services Block Grant Act Secretary's Discretionary Fund for Community Economic Development is a significant program of federal assistance to CDCs. This program has been a resource that is critical to the success of community development, a resource that needs to continue.

We focus here on the Discretionary Grant Program of the Office of Community Services, because this program has stood the test of time and has proven to be very successful in using federal dollars to leverage private sector investments to create jobs through economic development projects sponsored by CDCs. This success is il-

lustrated by the following examples of economic development projects selected from some of the CDCs and cities in which Living Cities invests.

Asociacion de Puertorriquenos en Marcha, Inc. in Philadelphia

Received a $500,000 grant from the Office of Community Services that leveraged investment to support $5,100,000 in total development costs for the Gateway Plaza in Philadelphia.

The OCS grant created 125 jobs.

Abyssinian Development Corporation in New York City

Received a $500,000 grant from the Office of Community Services that leveraged investment to support $16,000,000 in total development costs for the Pathmark Supercenter.

The OCS grant created 275 jobs.

Northeast Neighborhood Development in Cleveland

Received a predevelopment grant of $75,000 to perform market and business studies on the potential for improving the retail climate of a key intersection in its community.

While the program is still underway, the OCS grant has already created 10–15 jobs.

Vermont Slauson Economic Development Corporation in Los Angeles

Received a $450,000 grant from the Office of Community Services that leveraged investment to support $1,200,000 in total development costs for the Ranch Markets project.

The OCS grant created 70 jobs.

Bethel New Life in Chicago

Received a $700,000 grant from the Office of Community Services that leveraged investment to support $3,225,000 in total development costs for the Material Recovery Facility project.

The OCS grant created 145 jobs.

Jane Addams Resource Corporation in Chicago

Received a $250,000 grant from the Office of Community Services that leveraged investment to support $1,100,000 in total development costs for the 4422–36 North Ravenswood project and a $300,000 OCS grant that leveraged investment to support $1,000,000 in total development costs for the 4410 North Ravenswood project.

These OCS grants together created 55 jobs.

In order to build on such successful public and private investments in distressed urban neighborhoods, Living Cities finds it to be critically important to continue investment in job creation for low-income people and to continue funding at the highest possible level for programs that have a long history of success. As we have committed to doubling our investment in the current decade, we urge the Subcommittee to support a commensurate increase in funding for the OCS Discretionary Grants Program. We also offer to work with the Subcommittee to explore ways in which the OCS grants can foster further public/private cooperation so as to leverage additional private investment by Living Cities.

The work that has been done over the past decade to strengthen CDCs has increased their capacity to participate in the OCS Discretionary Grants Program. CDCs are providing the infrastructure to achieve economic and social redevelopment of low-income neighborhoods. CDCs take the risks as early investors, providing seed money and working capital for community development projects that become catalysts for further private investment. They encourage the participation of residents in the redevelopment of their communities, prepare the workforce for employment, develop local businesses and provide capital and technical support to other businesses in their target areas. CDCs secure funding for these activities from government, financial institutions, corporations, foundations and other individual funders

Living Cities is supporting CDCs in these activities through our investments in their work and by supporting research on urban markets, including the collection of data on which business and investment decisions are based. Based upon our experience, we see that even very troubled neighborhoods can revive when community leaders, government, and the private sector work together.

We are optimistic about the future of America's cities, given the very real progress we see. In the past decade, the population of the nation's largest 50 cities grew by nearly 10 percent. This was accompanied by a rise in city incomes that outpaced the national average (7 percent versus 4 percent, respectively) and an increase in housing units, homeownership and mortgage lending. At the same time, in certain

urban areas concentrated poverty fell 24 percent in the last decade and urban crime decreased. Inner cities have become hubs of economic activity, with annual retail spending power of $85 billion or the equivalent of 7 percent of U.S. retail spending. Business investment has returned to some urban markets, bringing goods, services and job opportunities. This progress bodes well for the economic strength of cities, their regions, and the nation, economic strength that we believe depends upon strong economies in urban neighborhoods.

PILOT CITIES INITIATIVE

Now in the second decade, Living Cities funders have challenged themselves to do more. First, we have committed to investing an additional $500,000,000 in the current decade. We also are building on the successes of the first 10 years by creating a new investment model, the Pilot Cities Initiative in Baltimore, Chicago, Miami and the Twin Cities of Minneapolis and St. Paul. This initiative is creating new ways for Living Cities investment partners and other funders to align resources over a sustained period of time in order to have a greater positive impact in distressed communities.

Through this new, more powerful model, funders will engage in collaborative efforts to develop healthier neighborhoods by enhancing the linkages between inner city neighborhoods and their residents and the larger economies of their cities and their regions. This initiative also will encourage CDCs to develop new relationships with philanthropy and to expand the impact of economic development by working more closely with other institutions that are serving the same neighborhoods.

CONCLUSION

Despite the significant gains made in Living Cities communities during the first decade and our ambitious plans for the next, we have learned that future gains will be severely limited without additional federal investment. We respectfully request that the Subcommittee consider:

—Increasing the current funding level for the OCS Discretionary Grants Program by an amount that Living Cities will match;
—Encouraging the use of grants to attract further private investment and foster more public/private partnerships; and
—Allowing funding dollars to be used to collect data that document the opportunities in the workforce and the purchasing power of lower-income communities, with OCS serving as the lead federal agency in gathering and making information accessible to people who make business and investment decisions.

It will take a concentrated national effort, but we are determined to see cities across the country reach and sustain healthy status in our time, a level that is worthy of the richest society in the history of humankind. With the support of private and public resources, including the OCS Discretionary Grants Program, CDCs can continue their significant work towards the goal of economic well-being, a goal that includes job opportunities for low-income people.

Thank you for this opportunity to present our views regarding this important program to the Subcommittee.

PREPARED STATEMENT OF THE AMERICAN PUBLIC TRANSPORTATION ASSOCIATION

INTRODUCTION

Mr. Chairman, thank you for the opportunity to submit a statement for the record to the Subcommittee on Labor, Health and Human Services and Education regarding the fiscal year 2005 Labor, Health and Human Services and Education Appropriations Bill.

We submit our views to the Subcommittee to make the point that not only can public transportation make a critical difference in how people get to jobs, health care, training and other social services, but can also provide significant cost efficiencies in the process. It is our hope to work with committee staff in developing report language to highlight this important issue.

ABOUT APTA

The American Public Transportation Association (APTA) is a nonprofit international association of over 1,500 public and private member organizations including transit systems and commuter rail operators; planning, design construction and finance firms; product and service providers; academic institutions; transit associations and state departments of transportation. APTA members serve the public in-

terest by providing safe, efficient and economical transit services and products. Over 90 percent of persons using public transportation in the United States and Canada are served by APTA members.

THE EFFICIENCIES OF TRANSPORTATION COORDINATION ARE RECEIVING GREAT ATTENTION FROM CONGRESS AND THE ADMINISTRATION

Mr. Chairman, the current budgetary climate and the emphasis it has brought on doing more with limited resources provides a fitting context for our focus on of transportation coordination. We believe that relatively minor legislative changes based on simplicity and common sense can provide for necessary consistencies across programs to make transportation coordination work.

Recognizing the efficiencies and additional riders and resources that are possible through improved coordination, APTA has long believed in the potential of greater coordination between human service providers and transportation providers. We have long seen the potential for coordinated transportation to lower the costs of services to taxpayers, enhance the scope and quality of service to customers, and to avoid the duplicate purchase and use of equipment.

In May 2003, the House Committee on Transportation and Infrastructure and the House Committee on Education and the Workforce held a joint hearing to examine both the potential of and the obstacles to coordination. One Member at that hearing noted that enhancing the coordination of human services and transportation had been a topic of interest to Congress since the 1970s. But, when all was said and done, much more was said than done.

The joint House hearing heard from the General Accounting Office (GAO) that there are some 62 federal programs that spend money on transportation. The GAO also found that leadership on coordination was lacking in that coordination seemed to be on everyone's list of things to do but nowhere near the top of anyone's list. There was a Federal Coordinating Council but it rarely met. The situation at the federal level was replicated at the state level. Where states had leadership on coordination through coordinating councils often created by the governors, coordination was often impressive. Where that was not the case, coordination was simply not happening. Like the tango, it takes more than one state or federal agency to coordinate. Those who took coordination seriously often found they were "playing catch with themselves."

In our observation, Congress and the Administration are now taking coordination seriously. Department of Transportation Secretary Norman Mineta and Federal Transit Administrator Jennifer Dorn are reaching out with some success to get more federal agencies on the dance floor. With the launching of the Department of Transportation's "United We Ride" initiative, the Department of Health and Human Services, the Department of Labor, the Department of Education, and other federal agencies are beginning to recognize best practices at the state level and make resources available to enhance state performance. President Bush, to his great credit, has issued an Executive Order calling on federal agencies to assess their roles in coordination and report back to the White House in 1 year on progress they are making to enhance the coordination of transportation programs.

CONGRESS IS ADDRESSING TRANSPORTATION COORDINATION ON SEVERAL FRONTS

Several pending bills contain language that would bolster the coordination of federal transportation programs. APTA is supportive of these efforts.

Pending bills to reauthorize the Federal Transportation Equity Act for the 21st Century (TEA 21) contain numerous provisions that will enhance transportation coordination, including allowing funding from human service programs to be used as a match for FTA programs so long as programs are coordinated, broadening the eligibility guidelines for Job Access and Reverse Commute (JARC) funding, recognizing Mobility Management as an eligible program expense, and requiring local certification plans for the New Freedom, JARC, and Elderly and Disabled programs.

As part of the pending welfare reform legislation, the Senate Finance Committee has approved an amendment supported by APTA calling upon states that use Temporary Assistance for Needy Families (TANF) funds for transportation purposes to certify that they have consulted with transportation agencies in the provision of such services. It seems to be a simple common sense matter, but it often doesn't happen. Such certification will make a requirement of what is now often an afterthought. The House-passed welfare reform bill (H.R. 4) contains an important provision in its TANF program that would treat transportation subsidies as "nonassistance" for purposes of the Act and therefore need not be discontinued when a person exhausts their eligibility for public assistance. Like childcare support, transportation

aid is essential to those who not only want to get a job, but also those striving to retain their job.

Similarly, there are provisions in the Senate's version of the Workforce Investment Act that call on state and local workforce planners to account for how people are to get to training and available jobs. It makes as much sense to coordinate training with available transportation as it does to link training to available employment. Along with childcare, the ability to get to a job efficiently is often the factor that determines whether a person can get and retain employment.

It is APTA's hope that significant progress can be made in the next year as both Congress and the Executive Branch focus attention on replacing old habits with new habits.

PUBLIC TRANSPORTATION PROVIDES AFFORDABLE AND EFFICIENT ACCESS TO HEALTH CARE

Following the old adage, "follow the money," we note that the GAO identified a major source of transportation spending in the Medicaid program. Close to $1 billion is spent on transportation to assist Medicaid clients. APTA members in Connecticut and Florida have had some success offering mainline transit service to those for whom it is appropriate through a Medicaid Pass Program. Medicaid clients see their transportation options enhanced at the same time the Medicaid program sees its costs lowered. Transit operators experience an increase in ridership while being reimbursed by the Medicaid program. Such programs can be a win/win/win situation for those who need services, those who pay for them, and those who provide the service.

Public transportation has already demonstrated its ability to effectively provide non-emergency transportation to health care services when given a chance. In 1997, the Healthcare Financing Administration estimated it was losing $1.2 billion annually in non-emergency medical transportation subsequently states began to coordinate services with local transit systems and by 2000 20 percent of the nation's Medicaid rides were on public transit.

While lack of coordination between providers of transportation assistance programs for the elderly and disabled and public transportation systems is not a new problem, the need for these services will continue to grow. According to a recent FTA study, 32 million senior citizens rely on transit as their driving ability decreases; 27 million Americans with disabilities depend on transit to maintain their independence; and 37 million people who live below the poverty line and cannot afford to drive rely on transit to get to work. The population of elderly transit users is expected to rise, growing nearly four times faster than the general population between 2010 and 2030; yet according to the AARP, more elderly people now live in suburban settings that lack transit options than ever before.

Public transportation has worked hard to improve its service. Between 1990 and 1999, the percentage of wheelchair accessible buses has increased dramatically. Systems continue to update their vehicles, including trains and buses, to ensure that individuals with disabilities can use their service. With access available to populations served by HHS and other social programs across the country, public transportation is clearly in a position to help these people and save taxpayer dollars right now.

PUBLIC TRANSPORTATION DELIVERS PEOPLE FROM WELFARE TO WORK

Similar to its success in helping the elderly and disabled, public transportation is already at work helping the population of low-income workers and job seekers such as TANF clients by providing low-cost, efficient transportation services.

Many welfare recipients do not own cars and must rely on public transportation to get to work. And while most welfare recipients live in central cities, most newly created jobs are in the suburbs. Public transportation has been successful in many cases in providing transportation options to these job seekers, especially under the JARC program, but barriers remain. For instance, Fort Worth's transportation authority, The T, has noted that it has difficulty coordinating various sources of funding to provide transportation service that gets workers from the central city to the suburbs because local service providers are required to track separate data from both the Department of Labor and the Department of Housing and Urban Development.

CONCLUSION

Mr. Chairman, the public transportation community stands ready to provide a cost efficient, easy-to-use and effective solution to the increased demand for transportation options for communities served by federal programs such as TANF. The

U.S. Department of Transportation is already required to coordinate with HHS, but it needs to improve coordination with HHS as well as with other agencies at all levels of government. Many states and local governments are excelling at this process. Millions of additional federal dollars could be saved by requiring all states to follow their lead.

Enabling effective coordination between all federal agencies and the DOT requires statutory changes to provide the Coordinating Council with authority to require recipients of federal funds at all levels to work together. Taking advantage of the TEA 21 and TANF reauthorizations to require state and local governments that receive TANF and JARC funds to coordinate their services would be an excellent first step. This will put the experience and resources of transit to use to effectively serve our disadvantaged populations.

Mr. Chairman and Members of the Committees, we urge you to take public transportation service and the cost efficiencies it provides into consideration as you mark up your fiscal year 2005 appropriations bill. We would be pleased to work with your staff in developing report language in that regard.

In closing, APTA would like to urge this Subcommittee to remain vigilant as you monitor the progress of executive agencies and the Coordinating Council in the next year. Progress is being made but there is much more to do.

Thank you.

PREPARED STATEMENT OF THE COALITION OF NORTHEASTERN GOVERNORS

The Coalition of Northeastern Governors (CONEG) is pleased to provide this testimony for the record to the Senate Subcommittee on Labor, Health and Human Services, and Education regarding fiscal year 2005 appropriations for the Low Income Home Energy Assistance Program (LIHEAP). The Governors appreciate the Subcommittee's consistent support for the LIHEAP program, and we recognize the difficult decisions facing the Subcommittee in this time of severe fiscal constraints. However, in light of sharply higher home energy prices, we request the Subcommittee to provide $3 billion for LIHEAP in regular fiscal year 2005 funding and $3 billion in advance appropriations for fiscal year 2006.

LIHEAP is a vital tool in making home energy more affordable for almost 5 million of the nation's very low-income households—the elderly and disabled on fixed incomes and families with young children. Recent survey data compiled by the National Energy Assistance Directors' Association (NEADA) provide a glimpse of the difficult choices made by low-income households and the strong, ongoing need for LIHEAP assistance. The percentage of income spent on total home energy by these low-income households can be four times higher than average households. For many of these households, annual income is simply not sufficient to pay high winter heating bills, even in periods of economic growth. Even after taking constructive actions to reduce their home energy use, too many low-income residents are forced to make dangerous choices between heating their homes, paying the full rent or mortgage, seeking medical attention, or purchasing food or vital medications. The NEADA survey found that an estimated 38 percent of LIHEAP recipients went without medical or dental care; approximately 28 percent did not make a rent or mortgage obligation; 30 percent did not fill a prescription or take the full dosage; and 21 percent became sick because the home was too cold.

The rise in winter heating fuel prices hits these vulnerable citizens especially hard. The Northeast is heavily dependent on deliverable home heating fuels such as home heating oil, kerosene, and propane. Price volatility in these fuels adversely affects the low-income households who, without the disposable income to purchase fuels off-season, typically enter the market when both the demand for and price of fuels are high.

Rapidly rising energy prices, the very cold winter conditions in many parts of the country, and the continued high unemployment among low-wage workers continue to put heightened demand on the states' already stretched LIHEAP programs. In fiscal year 2004, states expect to serve an estimated 4.8 million low-income households with LIHEAP assistance, an increase of 6 percent over the 2002–2003 period. However, the number of low-income households eligible for LIHEAP assistance increased by a similar 6 percent—to approximately 34.6 million households. In short, in spite of the welcomed increase in LIHEAP funding, only a fraction—approximately 15 percent of eligible households—continue to be served at current LIHEAP funding.

An increase in the regular LIHEAP appropriation to $3 billion for fiscal years 2005 and 2006 will enable states across the nation to reach more of those vulnerable citizens in need of assistance and more fully implement cost-effective measures to

meet their continuing energy needs. Today, most winter heating programs have exhausted their program resources at the end of the heating season, leaving little or no resources for cooling programs this summer; or they have limited ability to assist families who, in arrears on heating bills, face the prospect of having their home heating source cut off. In addition, without funds to carryforward to the new heating season, state LIHEAP programs lack the capability to undertake the "pre-buy" programs that help stabilize heating fuel prices for low-income households and expand the reach of limited program funds. An increased federal appropriation, and advance funding, would allow states to manage the program resources in a manner to better take advantage of market opportunities.

Enactment of advance funding is vital to the states' program planning activities for the coming heating season. In the Northeast, where the heating season begins in early October, states generally spend up to 70 percent of the LIHEAP funds during the first two quarters of the fiscal year. Therefore, states must begin to plan and do program outreach in the spring and summer if they are to begin their LIHEAP program as soon as the new fiscal year starts. Advance funding helps ensure that states have the necessary funds to open their programs and provide timely assistance to low-income families who lack the financial resources to bear the initial costs of deliverable home heating fuels.

The current uncertainty of world energy markets underscores the importance of states being able to prepare for the potential of volatile energy prices. These preparedness activities, while critical, cannot fully shield our lowest-income citizens from the impacts of higher heating fuel prices. Your support for fiscal year 2005 LIHEAP appropriations at the $3 billion level and the enactment of advance fiscal year 2006 appropriations is urgently needed to enable our states to help mitigate the potential life-threatening emergencies and economic hardship that confront the region's most vulnerable citizens.

We thank the Subcommittee for this opportunity to share the views of the Coalition of Northeastern Governors, and we stand ready to provide you with any additional information on the importance of the Low Income Home Energy Assistance Program to the Northeast.

PREPARED STATEMENT OF THE AMERICAN PUBLIC POWER ASSOCIATION

The American Public Power Association (APPA) is the national service organization representing the interests of over 2,000 municipal and other state and locally owned utilities in 49 of the 50 states (all but Hawaii). Collectively, public power utilities deliver electricity to one of every seven electric consumers (approximately 40 million people), serving some of the nation's largest cities. However, the vast majority of APPA's members serve communities with populations of 10,000 people or less.

We appreciate the opportunity to submit this statement supporting funding for the Low-Income Home Energy Production Assistance Program (LIHEAP).

APPA has consistently supported an increase in the authorization level for LIHEAP to $3.4 billion annually—an increase that was embodied in the stalled Energy Policy Act and has also been advanced more recently in the Senate's version of the Poverty Prevention and Reduction Act, a bill that has not yet been considered in the House. In the absence of final action on an increased authorization level for the program, the Administration's request of $2 billion for fiscal year 2005 ($1.8 billion in state block grant funding and $200 million in emergency funding) is a good start. However, APPA believes that the Subcommittee should consider appropriating the $3.4 billion necessary in fiscal year 2005 to more fully meet the energy needs of low-income households.

APPA is proud of the commitment that its members have made to their low-income customers. Many public power systems have low-income energy assistance programs based on community resources and needs. Our members realize the importance of having in place a well-designed low-income customer assistance program combined with energy efficiency and weatherization programs in order to help consumers minimize their energy bills and lower their requirements for assistance. While highly successful, these local initiatives must be coupled with a strong LIHEAP program to meet the growing needs of low-income customers. In the last several years, volatile home-heating oil and natural gas prices, severe winters, high utility bills as a result of the western electricity crisis, and the effects of the economic downturn have all contributed to an increased reliance on LIHEAP funds.

Also when considering LIHEAP appropriations this year, we encourage the Subcommittee to provide advanced funding for the program so that shortfalls do not occur in the winter months during the transition from one fiscal year to another. LIHEAP is one of the outstanding examples of a state-operated program with mini-

mal requirements imposed by the federal government. Advanced funding for LIHEAP is critical to enabling states to optimally administer the program.

Thank you again for this opportunity to relay our support for increased LIHEAP funding for fiscal year 2005. We look forward to a favorable outcome.

PREPARED STATEMENT OF THE MEALS ON WHEELS ASSOCIATION OF AMERICA

Mr. Chairman and Members of the Subcommittee, we are Enid A. Borden and Margaret B. Ingraham, Chief Executive Officer and Director of Policy and Legislation, respectively, of The Meals On Wheels Association of America (MOWAA). The Association represents local community-based meal programs from every state that provide congregate and home-delivered meals and other nutrition services to older persons in need. It is on behalf of MOWAA, its member programs, and the literally hundreds of thousands of frail, elderly and at-risk individuals that they serve that we present this testimony.

As part of the appropriations process in which this subcommittee engages every year, you doubtless hear from hundreds, probably thousands of individuals and organizations representing programs funded through the enormous bill under your purview. Each comes to advocate for a specific project or program and to make the case as to why that program merits a particular level of federal financial support in the next fiscal year. In that regard, MOWAA is no different from the others from whom you have heard. But in other ways—significant ones that we will enumerate briefly—MOWAA, or rather the senior meal programs that are our members—are significantly different.

Please allow us the opportunity to put our request in an historical and human perspective. In 1972 when it reauthorized the Older Americans Act, Congress included senior nutrition programs among the services funded under the Act. Today, "Meals On Wheels," as those programs have come to be popularly called, are perhaps the most widely recognized and universally lauded of Older Americans Act programs. It should come as no surprise to you that we also believe they are the most important. Why? The answer is simple. Because food is fundamental to life and health and psychological and emotional well-being. There is no arguing that fact. All of us eat regularly, generally 21 meals per week and we even may sneak a snack here or there when we get hungry. But many of America's most vulnerable citizens, the frail and at-risk elderly, have no ability to shop for or to prepare meals for themselves. For them, home-delivered meal programs are a virtual lifeline. In some cases, they are the only source of nutritious food that a senior has; and even then, most programs have the resources to provide only five meals each week.

Last year, according to the Administration on Aging over 253 million meals were served with Older Americans Act funds. That is impressive indeed. But the sad reality on the underside of that success is that hundreds of thousands of equally needy seniors were not served. A conservative estimate is that 4 out of every 10 home-delivered meal programs have waiting lists. And currently, the old-old age group (defined as 85 and older) is the fastest growing cohort in the U.S. population. So, simply stated, if appropriations levels are not increased, and increased substantially, the unspeakable will occur. That is, even larger numbers or frailer individuals will be going hungry. Mr. Chairman and members of the subcommittee, we believe that is unacceptable in this the wealthiest nation on the planet.

Earlier we mentioned historical context. Let me return to that. In fiscal year 1992, 20 years after the establishment of OAA nutrition programs, the federal financial commitment was just over $607 million. (That figure represents the sum of Title III C–1, III C–2 and NSIP (then called USDA/NPE)). For fiscal year 2004, the President has requested $719 million. Yes, that is an increase; but it is a grossly inadequate one. For during the intervening years since 1992, other important factors have changed. First, there is inflation. Then there is the population shift, which has dramatically increased the number of individuals needing assistance with nutrition services. In 1992 there were 42.7 million individuals age 60 and older in the United States, and approximately 3.3 million of those were 85+. In this year (2004) the number of those 85+ is over 4.7 million. That, by any standard, is astounding growth. And it is growth that has gone largely uncompensated. Here is what we mean by that.

We asked one of this country's most distinguished actuaries to look at these numbers, to look at population growth and inflation (by applying the annual CPI-U) and then to produce an "equivalent" appropriation level. That is, we asked him to calculate what the federal commitment to each elder was in fiscal year 1992 and then to determine what funding levels these senior meal programs should have received in fiscal year 2004 to ensure parity with 1992. Why parity? Because we know that

you agree that today's elders are just as important a part of our society today as they were 12 years ago. Today's elders—your parents and grandparents and perhaps even siblings and neighbors, certainly your constituents—are as deserving as those who came before them of receiving senior nutrition program services when they can no longer provide meals for themselves. Had you provided parity in 2004 with 1992, based on the changes in the CPI-U and the 85+ population alone, the funding level would have been approximately $1.158 billion, an almost 61 percent increase over the $719 million being requested by the Administration for the next fiscal year. This year's request, in fact, is less than the 1992 enacted level for Nutrition Services Incentive Program (NSIP, formerly USDA); it is less than the 2002 enacted level for Title III C–1; and it is the same level as the fiscal year 2003 enacted level for Title III C–2. In other words, overall the request is much less than adequate for us to keep faith with the older population that depends on local community-based meal programs in every State in this great country. We are not so unrealistic as to believe that we can achieve parity in 1 year, although we do believe our case has merit. Mr. Chairman and members of the subcommittee, the Meals On Wheels Association of America does urgently and sincerely request that you increase funding for senior meal programs by no less than 10 percent for each line item over last year's levels, to approximately $786 million combined.

The year 2005 will mark the 40th Anniversary of the Older Americans Act, and we can think of no more fitting way to recognize the invaluable contribution that OAA programs have made in the lives of older Americans and to demonstrate Congress' continued commitment to elders than by adopting funding levels that will help local programs serve those in need.

Before we close we do want to make one more point, that is often overlooked when it comes to senior nutrition programs. These senior meal programs that receive funding through the Older Americans Act exemplify how effectively public-private partnerships can serve citizens in need. For that is what these programs are: public-private partnerships that reflect the unique needs and characteristics of the communities in which they operate and that rely on a number of funding sources. Federal dollars are only a portion of the funds on which these programs rely in order to operate. But they are a critical part, for they enable programs to leverage money from a variety of other sources, such as States and local governments, foundations, corporations and individuals. In the home-delivered program, for example, each $1 in federal funds leverages $3.35 from other sources. So even a modest increase in funding of 10 percent could assist in a major way in meeting unmet need.

As you consider our request, you may want to keep in mind in whose behalf MOWAA is making it. Each and every one of these "frail, homebound individuals" is unique, just as you and I, so it is impossible to give you a description that covers them all. But here is a simple profile: the average Meals On Wheels recipient is an elderly woman in her very late seventies or eighties; she is more than twice as likely as her contemporaries to live alone, apart from family and friends. She is likely to be functionally impaired (have trouble walking, for example) and have three or more diagnosed chronic health conditions. In addition, she probably has an income below 200 percent of poverty. Whatever the reason, she cannot shop, cook, or prepare meals for herself. In other words, she relies on Meals On Wheels programs to ensure she gets proper nutrition. And without that, she would probably be at risk of being forced to move out of her home prematurely into an institutional care facility. These folks reside in cities and suburbs and rural communities across America.

Thank you for the opportunity to bring these issues to your attention. Again, on behalf of MOWAA, local meal programs across America, and, most important, the at-risk and frail seniors that turn to them for meals and other nutrition services, we ask that you give serious consideration to renewing the commitment of your colleagues in previous Congresses and to increasing funding to a level that moves resolutely toward a level that is commensurate with that of a decade ago. A 10 percent increase for fiscal year 2005 is a good first step.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF NUTRITION AND AGING SERVICES PROGRAMS

Chairman Specter and Ranking Member Harkin: The National Association of Nutrition and Aging Services Programs (NANASP), a professional membership organization representing the interests of members at all levels of the aging network dedicated to providing quality nutrition and other direct services for older Americans, recommends an increase of 10 percent for the three Older Americans Act (OAA) nutrition programs as part of the fiscal year 2005 appropriations bill for the Department of Health and Human Services under your jurisdiction.

This position is taken in concert with the position of the 50-member Leadership Council of Aging Organizations (LCAO) of which NANASP is a member. LCAO supports a 10 percent across the board increase for all Older Americans Act programs.

NANASP's focus is the congregate and home delivered meals programs and the Nutrition Services Incentive Program, since our more than 800 members nationally work on the front lines every day providing seniors with nutrition and related services.

The President's budget called for a slight increase in funding of $4.35 million for the three OAA nutrition programs. However, the amount of the increase is only 0.6 percent of the total funding and does not even come close to inflation, estimated at 3 percent over the past fiscal year. In fact, the nutrition programs are entering a second decade of a funding deficit which is eroding the effectiveness of the programs for those being served. Whereas inflation has increased by 44.45 percent since 1990, funding for the OAA has only increased by 24.4 percent. Also since 1990, funding has only increased 9.8 percent for the congregate nutrition program.

Administration data for fiscal year 2002 indicates that while the OAA nutrition programs are serving more individuals, they are serving fewer meals to these individuals. This defeats a main benefit of the program which is to provide eligible seniors with a minimum of one-third of their required daily dietary allowance. The reduction in meals can present genuine hardships to the seniors who are served, especially those in the greatest economic need who are to be targeted for service under the Older Americans Act.

Furthermore, data provided by AARP forecasts that nearly 5 million meals will be cut from both the congregate and home delivered meals programs if no adjustments are made to the President's fiscal year 2005 budget. The question to ask is how do these meals get replaced?

A modest 10 percent increase in the nutrition programs constitutes about $71 million. This will help these programs to maintain services to their existing seniors thus avoiding the need for new or expanded waiting lists. Older adults waiting for basic services often wind up on nursing homes and are at risk for losing their homes and independence.

The Older Americans Act nutrition programs are a proven success story with more than 30 years of serving seniors in your state and throughout the country. Funds provided for these programs are investments in promoting and maintaining the independence of seniors. The Older Americans Act nutrition programs are more than just a meal. These are preventive programs: they help avert malnutrition and control chronic conditions such as diabetes, and through socialization and other individual contact help keep seniors from becoming isolated.

Programs with the longevity and proven track record of the elderly nutrition programs need to be supported with adequate, but fiscally reasonable funding levels. That is what we advocate today.

NANASP encourages you and all members of the Subcommittee to visit an elderly nutrition program in your state either during the upcoming spring recess or during May, which is Older Americans Month. NANASP is happy to provide you with the names and addresses of programs from your state. See firsthand how these programs are great value propositions. They provide value through their services to seniors and they provide value to the taxpayer dollar by delivering a core service and more in an efficient and localized manner in a home or community setting where older adults want to stay.

NATIONAL INSTITUTES OF HEALTH

PREPARED STATEMENT OF THE AMERICAN INSTITUTE FOR STUTTERING

Mr. Chairman and members of the Subcommittee, I am Catherine S. Montgomery, Executive Director of the American Institute for Stuttering (AIS). AIS was founded in 1997 in response to the need for a comprehensive treatment and training facility for stuttering in the United States. It is the only nonprofit facility in this country that offers both intensive and non-intensive treatment options for people of all ages while also providing clinical training to both new and established speech-language pathologists.

Stuttering is one of the few disorders that people still laugh at. The disorder wreaks havoc in one's life that few understand, and much of it is silent suffering, below the surface. Healthy intelligent children who stutter are placed in "special classes" and labeled eccentric, mentally ill and emotionally disturbed. In all honesty, many of these children have IQs 10 to 14 points higher than the general population. Public education is needed to rectify a long history of neglect and misunderstanding.

Developmental stuttering typically begins between the ages of 3 and 8 years of age. Some of the most important work now being done in stuttering is in early intervention treatment. It is very cost effective, yet many do not receive treatment due to a lack of clinicians trained specifically in speech-language pathology. There is also a dire lack of public awareness about the necessity for earlier diagnosis and treatment possibilities.

Despite the fact that stuttering affects approximately 3 million people in the United States, it remains almost imperceptible as a public health issue. It should be noted that suicide among teenagers who stutter is 3 to 4 times higher than the general population. AIS is launching "Let's Talk," a national public education and fundraising campaign to create a major cultural shift in public attitudes about stuttering.

"Let's Talk" targets six program objectives to better serve the stuttering community:

1. Public Education
2. Research
3. Clinical Treatment
4. Treatment Scholarships
5. Clinical Training
6. Advocacy

The American Institute for Stuttering has embarked upon a new professional relationship with New York Medical College and Ben Watson, Ph.D. Dr. Watson is among the few preeminent researchers in the United States whose focus is on learning more about the neurological roots of stuttering. He is now conducting two new exciting studies that will help move us along in our search for the cause of stuttering.

We know a great deal about the speech and language abilities and brain function of adults who stutter and we are learning a great deal about the speech and language abilities of young children at the onset of stuttering. Some people who stutter as children do not stutter as adults. The reason for that is not known but Dr. Watson is exploring this question through investigation of speech, language and brain function in young children who do and who do not stutter.

Previous studies show that brain activity in some people who stutter differs from that seen in nonstutterers. We now need to find out if, and how these differences in brain activity are related to stuttering. To answer these questions, scientists from New York Medical College and the Harlem Hospital Center are studying brain activity in persons who stutter during the production of both stuttered and fluent speech. This study may clarify the relationship between changes in brain activity and fluency breakdown.

The disorder of stuttering has been one of the most seriously misunderstood of human handicapping conditions. Approximately 1 percent of the population of the United States, some 3 million Americans, suffer this inability to speak freely and try to cope with the daily agonizing struggle and ridicule that accompanies it. The American Institute for Stuttering is dedicated to filling the serious void in the availability of quality treatment and training.

The American Institute for Stuttering asks that you support a 10 percent increase in the budget of the National Institutes of Health in order to maintain the momentum that has been built up over the past half-decade. Further, we would ask that additional funds be made available for the National Institute of Deafness and Other Communications Disorders (NIDCD) to support stuttering research. There is currently about $3 million of federal funding dedicated to stuttering research. This works out to about $1 per person afflicted with this disorder. Moreover, Mr. Chairman, we respectfully request that the committee provide NIDCD with resources to support a consensus conference on stuttering. Such a conference will bring together the leading scientists in the field to assess the current state of the science and will hopefully identify future research opportunities.

Thank you for this occasion to present this testimony.

PREPARED STATEMENT OF THE NATIONAL PRIMATE RESEARCH CENTERS

The Directors of the National Primate Research Centers (NPRCs) respectfully submit this written testimony for the record of the U.S. Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education. The NPRCs appreciate the commitment that the members of this Subcommittee have made to biomedical research through strong support for the National Institutes of Health (NIH). Given your leadership on this issue, the NPRCs urge Congress to direct resources to vital biomedical research infrastructure in order to ensure that the suc-

cess of the federal investment in NIH will not be compromised as a result of deficient research resources.

The NPRCs are a national network of eight primate research centers supported by the NIH National Center for Research Resources (NCRR). The centers comprise the National Primate Research Program (NPRP), which was developed in 1960 in response to recommendations provided to Congress by the National Heart Institute Advisory Council. This program seeks to address human health problems through scientific research using the animal models that most closely resemble humans in their genetics, physiology, and disease processes—primates. The NPRCs were developed specifically as resources to advance primate research by providing specialized research facilities and technologies as well as unique living environments for primates. NPRCs support research that is sponsored by nearly every institute of NIH. For example, NPRCs conduct research to help understand and treat diseases such as heart disease, cancer, diabetes, Alzheimer's, Parkinson's, and AIDS. They also conduct research on emerging infectious disease and on many aspects of biodefense. Each NPRC makes its facilities available to investigators from around the country. In fact, the NPRCs support more than 1,500 NIH funded investigators each year. This collaborative research environment allows scientists to combine their individual expertises beyond the scope of established disciplinary research projects.

Research involving animals is a vital element in achieving this goal of continued medical progress for human health. The specific availability of information in the primate genome, which is quite similar to the human genome, makes primates essential in studies that require an integrated understanding of a whole biological system. Primate studies allow scientists to answer fundamental questions regarding both specific diseases and normal physiological processes that cannot be addressed directly in humans or effectively in more evolutionarily distant species such as rodents. Recent reports suggest that extensive analysis of genome structure and function in nonhuman primates could make immediate and significant contributions to the overall mission of NIH by accelerating progress in understanding many human diseases.

In the 1950's, primate research produced the first vaccine for one of the world's worst childhood killers, the Polio virus, reducing the number of cases in the United States from 58,000 to one or two per year. Primates have also served as the best model for various types of HIV research, and their availability for use has resulted in at least 14 licensed anti-viral drugs for treatment of HIV infection. Primate models will continue to be necessary to defend the world against future and assuredly occurring scourges of which we have already had hints, like SARS and West Nile Virus. In addition to these deadly viral epidemics, primate research has enabled the discovery of better treatments and therapies for diseases such as diabetes, heart disease, high blood pressure, kidney disease, depression, and other psychiatric illnesses. Treatments for stroke and cataracts, and the advancement of prenatal and postnatal care have also resulted from primate research. Furthermore, in addition to the potential to provide answers for long-standing research questions, primate research provides an unparalleled opportunity to address more recently defined research priorities such as those relating to the threat of bioterrorism.

Mr. Chairman, as you and your Subcommittee work to define your priorities for the year and set goals for the future, NPRCs ask that you continue the commitment of support for NIH and its mission by providing the highest funding level possible in the NIH appropriations bill. An increase would enable researchers to continue vital merit based studies on devastating diseases and disabilities, as well as address new and emerging national health priorities. The NPRCs believe this increase is justified by both the health needs and research capabilities of the nation. The President's budget asks for a 2.6 percent NIH increase; however, NPRCs, the Ad Hoc Group for Medical Research Funding, and other leaders of the research community hope for more. Funding for NIH has helped to expand our nation's capabilities in biomedical research, and develop new treatments and cures for many diseases, but many unsolved human health mysteries still remain. Medical research is a long-term process and in order to continue to meet the evolving challenges of improving human health we must not let our commitment wane. It is therefore essential to sustain the momentum of NIH-funded research so that it continues to meet the goal of improving the health of all Americans.

NIH relies on the NPRCs to provide centralized, professional care, management, and research conducted with primates. Consequently, the NPRCs, which are funded by annual NIH P51 base grants, have become an indispensable national scientific resource. Increased base grant funds from NIH/NCRR to meet the current and projected NPRC operational and modernization costs are critical to the success of NPRCs and their programs. NPRCs directors ask that you direct NIH to adopt and fund the NPRP Five Year Federal Advancement Initiative, developed by the NPRCs

directors, for the NPRP, which addresses necessary upgrades and program capacity expansions. The total anticipated cost of the NPRP Federal Advancement Initiative would be $100 million over the current funding level for the NPRP P51 base grant during the 5 year period of fiscal years 2005–2009. Over 5 years, the NPRP Federal Advancement Initiative aims to increase the following by 20 percent : (1) the nationwide availability of primates; (2) the quality and capacity of primate housing and breeding facilities, as well as the availability of related state-of-the-art diagnostic and clinical support equipment at NPRCs; and (3) the number of personnel trained in primate care and management at the NPRCs. The NPRCs urge Congress to direct NIH to adopt and fund the Federal Advancement Initiative, beginning with a $36 million increase in funding for the P51 base grant in fiscal year 2005. The NPRCs also ask that Congress directs NIH to engage in a meaningful planning process to invest in the long-term needs of the NPRCs.

For 2 consecutive years, language strongly in support of NPRCs has appeared in the report accompanying the Labor/HHS/Education Appropriations bills. The reports recognize the importance of the NPRCs as well as centers' demanding resource requirements. The fiscal year 2004 House report directs NCRR to periodically assess NPRCs needs, and to increase the P51 base grant funds for the centers. The report also directs NCRR to submit the first of the periodic assessments along with the fiscal year 2005 budget request. As you know, the Senate issued report language stating that NCRR is expected to fully commit to the Five Year Federal Advancement Initiative. Thus far, while NPRCs have seen modest increases in base grant funds, the initiative has yet to be applied and funded by NCRR.

Biomedical researchers across the nation are experiencing shortages in the availability of primates for essential research. NPRCs, the federally funded primate resource, have found it increasingly difficult to provide sufficient numbers of primates for ambitious and high priority federal research projects on cancer, AIDS, and biodefense. In many cases, NIH funded scientists must wait a year or more to begin their research due to the limited availability of primates and/or space. These critical shortages can only be addressed by expanding existing breeding colonies and developing bridging programs to effectively use under-utilized species of primates in research. Ultimately, this would reduce the wait period for the use of primates, expediting the start of critical research projects. Presently, the budget of each NPRC falls below the amount required to maintain crucial services at existing levels. By adopting and funding the Federal Advancement Initiative, not only will the centers be able to sustain existing programs, but they will have the ability to build much needed programs that will better serve the nation's federally funded primate researchers.

Accommodating and properly caring for increasing numbers of primates also requires additional funding to modernize and expand primate housing and research facilities. As primate populations grow and primate resources increase, proper infrastructure will be necessary to house and care for these additional animals. Under the Federal Advancement Initiative, additional P51 base grant funds will also be invested in repairs, renovation, and construction of research facilities, as well as the purchase of modern laboratory equipment. These are essential upgrades needed to ensure that the federally funded research community can translate new discoveries into treatments and cures. Increased funding under the P51 will give the NPRCs the ability to develop the state-of-the-art capabilities and facilities necessary to keep pace with the expanded NIH research agenda.

Since nonhuman primates represent the most sophisticated and relevant animal models for many areas of biomedical research, there is a heightened need to use primate models prior to human clinical trials, as well as a heightened responsibility to properly care for and manage these animals. Thus, the Federal Advancement Initiative proposes to use increased P51 base grant funding to ensure that adequate numbers of experts are trained in laboratory animal medicine and research. Each NPRC requires a highly trained and experienced primate management team comprised of behavioral specialists, veterinarians, and primate research experts. As the number of primates at the NPRCs grows, proportional expansion of the primate management teams is essential to maintain primate health and research success.

The NPRCs provide scientists across the nation with unmatched access to these crucial research models in the process of making significant medical discoveries and translating these discoveries into effective therapies and treatments. This is an essential and valuable centralized service for researchers who cannot afford to use and maintain scarce and expensive primates solely for individual research projects. For every dollar provided to the NPRCs, more than $10 in NIH research is leveraged, which is equivalent to approximately $600 million in NIH research that could not otherwise be carried out.

With this in mind, the NPRCs express their sincere hope that the nation will continue to sustain the healthy development of its biomedical research program and that this Subcommittee will continue its support and leadership on behalf of NIH and its research partners across the nation.

Mr. Chairman, as you and your Subcommittee work to define your priorities for the year and set goals for the future, the NPRCs directors ask that you direct NIH to adopt and fund the NPRP Five Year Federal Advancement Initiative. Investing in and enriching the NPRCs will help to expand our nation's capabilities in biomedical research, and enable the development of new treatments and cures for many diseases. NIH adoption of the NPRP Federal Advancement Initiative will allow NPRCs, as well as NIH, to continue to meet and advance the goal of improving the health of all Americans.

Thank you for the opportunity to submit this written testimony and for your attention to the recommendations of the NPRCs concerning funding for NIH in fiscal year 2005 and implementation of the NPRCs Five Year Federal Advancement Initiative.

PREPARED STATEMENT OF THE FACIOSCAPULOHUMERAL MUSCULAR DYSTROPHY SOCIETY

Mr. Chairman, it is a great pleasure to submit this testimony to you today.

My name is Carol Anne Perez, of Lexington, Massachusetts, and I am testifying as Executive Director of the FacioScapuloHumeral Muscular Dystrophy Society (FSH Society, Inc.) and as an individual who has lived with the devastating facioscapulohumeral muscular dystrophy (FSHD) disorder for nearly 70 years.

Facioscapulohumeral muscular dystrophy (FSHD) is the third most prevalent form of muscle disease. FSHD is a neuromuscular disorder that is transmitted genetically to 120,000 people. Conservatively, it affects 14,000 persons in the United States. For men, women, and children the major consequence of inheriting FSHD is progressive and severe loss of all skeletal muscles gradually bringing weakness and reduced mobility. The usual pattern is of initial noticeable weakness of facial, scapular and upper arm muscles and subsequent weaknesses of other skeletal muscles. Retinal and cochlear disease, as well as mental retardation, can be associated with FSHD. Many with FSHD are severely physically disabled and spend the last 30 years of their lives in a wheelchair. The toll and cost of FSHD physically, emotionally and financially are enormous. FSHD is a life long disease that has an enormous cost-of-disease burden and is a life sentence for the innocent patient and involved persons and their children and grandchildren as well. As a human services professional, wife, mother, and grandmother I am now in wheelchair due to the effects of FSHD.

In accordance with its primary purpose of serving the FSHD community, both in the United States and abroad, the FSH Society, through outreach at home and international networking, has brought together more than 3,000 FSHD-affected families committed to working cooperatively. From the moment of their introduction into the FSH Society, these families, and, in many instances, their friends are bonded with their fellow members both by their common knowledge of what it is to live with FSHD and by the ardent desire they all feel to be part of a concerted effort to discover how to treat the disease and, ultimately, to cure it.

People who have FSHD must cope with continuing, unrelenting, unpredictable and never-ending losses. The most unlucky, those who are affected from birth, are deprived of virtually all the ordinary joys and pleasures of childhood and adolescence. But no matter at which stage of life the disease makes itself known, there is never after that any reprieve from continuing loss of physical ability, or ever for a moment relief from the physical and emotional pain that FSHD brings in its train. Every morning, FSHD sufferers wake up to face the reality that neither a cause for their disease nor any treatment for it has yet been found.

Insidiously and systematically, FSHD denies a person the full range of choices in life. FSHD affects the way you walk, the way you dress, the way you work, the way you wash, the way you sleep, the way you relate, the way you parent, the way you love, the way and where you live, and the way people perceive and treat you. You cannot smile, hold a baby in your arms, close your eyes to sleep, run, walk on the beach, or climb stairs. Each new day brings renewed awareness of the things you may not be able to do the next day. This is what life is for tens of thousands of people affected by FSHD worldwide.

Through the FSH Society, FSHD patients have found ways to be useful to medical and clinical researchers working on their disease. The FSH Society acts as a clearinghouse for information on the FSHD disorder and on potential drugs and devices

designed to alleviate its effects. It fosters communication among FSHD patients, their families and caregivers, charitable organizations, government agencies, industry, scientific researchers, and academic institutions. It solicits grants and contributions from members of the FSH Society, and from foundations, the pharmaceutical industry, and others to support scientific research and development. It makes grants and awards to qualified research applicants. In less than 5 years, the FSH Society has raised more than $1 million for research and has invested it in two dozen innovative research programs internationally. One of the FSH Society's key assets, its Scientific Advisory Board, is composed of international experts whose awareness of current FSHD research ensures both that new research is not duplicative but complementary and that it will fill gaps in existing knowledge. The FSH Society's work in education, advocacy, and training has led to increased funding in the United States and abroad. It was a key participant in drafting the Muscular Dystrophy Community Assistance Research and Education Act of 2001 (MD CARE Act) which in the United States mandates research and investigation into all forms of Muscular Dystrophy.

The Appropriations Committees in both the U.S. House and the U.S. Senate have repeatedly instructed the National Institutes of Health (NIH) to enhance and broaden the portfolio in FSHD and muscular dystrophy in general. The NIH accounting for the total overall NIH and the subset of muscular dystrophy appropriations in millions of dollars for the past 5 years follows:

NATIONAL INSTITUTES OF HEALTH (NIH) APPROPRIATIONS HISTORY SOURCE: NIH/OD BUDGET OFFICE & NIH CRISP DATABASE ON-LINE

[Dollars in millions]

Fiscal year	NIH overall dollars	MD research dollars	MD percent of NIH	FSH research dollars	FSHD percent of MD	FSHD percent of NIH
2000	$17,821	$12.6	0.071	$0.4	3.18	0.0022
2001	20,458	21.0	0.103	0.5	2.38	0.0024
2002	23,296	27.6	0.118	1.3	4.71	0.0056
2003	27,067	39.1	0.144	1.5	3.83	0.0055
2004E	27,887	40.2	0.144	2.7	6.71	0.0097

Due to major initiatives from the volunteer health agencies and the extramural community of researchers, FSHD research at the NIH and funding through the NIH is moving ahead at a steady pace though seemingly incredibly slow for those of us suffering from FSHD. Notwithstanding these positive changes at the NIH as well as major cooperative initiatives from the volunteer health agencies and the extramural community of researchers, we realize that major changes are slow but we are hopeful that this year the NIH will initiate new and increased funding for FSHD.

Funding increases for FSHD as related to the entire muscular dystrophy portfolio are not keeping pace with all muscular dystrophy. FSHD is the third most prevalent form of muscle disease and a common muscular dystrophy. Yet, in 2003 it received only 3.83 percent of the total NIH wide muscular dystrophy portfolio and that number has improved slightly to an estimated 6.71 percent for fiscal year 2004.

Mr. Chairman, as you know, the National Institute of Child Health and Human Development (NICHD), the National Institute of Arthritis and Musculoskeletal Disorders (NIAMS), and, the National Institute of Neurological Disorders and Stroke (NINDS) are three of the National Institutes of Health (NIH) institutes called upon by the Muscular Dystrophy Community Assistance Research and Education Act of 2001 (MD CARE Act) to develop a research plan for muscular dystrophy (MD) research and education conducted through the National Institutes of Health. Certainly, other NIH institutes will be called into action where appropriate such as NHLBI, NEI, NIA, NIMH, NHGRI, NCRR, FIC, and OD.

NATIONAL INSTITUTES OF HEALTH (NIH) MUSCULAR DYSTROPHY AND FSHD APPROPRIATIONS HISTORY SOURCE: NIH/OD BUDGET OFFICE & NIH CRISP DATABASE ON-LINE

[In millions of dollars]

Fiscal year	Total NIH dollars on MD	NIAMS dollars on MD	NINDS dollars on MD	NICHD dollars on MD	NIH wide dollars on FSHD
2000	12.6	4.8	4.9	1.2	0.4

NATIONAL INSTITUTES OF HEALTH (NIH) MUSCULAR DYSTROPHY AND FSHD APPROPRIATIONS HISTORY SOURCE: NIH/OD BUDGET OFFICE & NIH CRISP DATABASE ON-LINE—Continued

[In millions of dollars]

Fiscal year	Total NIH dollars on MD	NIAMS dollars on MD	NINDS dollars on MD	NICHD dollars on MD	NIH wide dollars on FSHD
2001	21.0	9.2	8.2	0.5	0.5
2002	27.6	11.1	9.8	0.6	1.3
2003	39.1	15.5	13.2	4.5	1.5
2004E	40.2	15.9	13.5	4.7	2.7
2005E	41.0	16.3	13.7	4.8	2.8

In fiscal year 2004 year-to-date, the National Institute of Child Health and Human Development (NICHD) does not have a single research grant or project directly focused or covering FSHD. NICHD is spending $0 out of an estimated $4.7M on directly titled FSHD projects. NICHD is spending 0 percent of its muscular dystrophy budget on FSHD.

In fiscal year 2004 year-to-date, the National Institute of Arthritis and Musculoskeletal Disorders (NIAMS) is funding two directly titled projects on FSHD and the NIH FSHD Research Patient Registry. The directly titled grants and contracts are 5–R21–AR–48318–03 at $198,000, 5–R21–AR–48327–03 at $125,000, and, 3–N01–AR–02250–004 $175,754. Directly focused and titled research grants on FSHD actually decreased in fiscal year 2004 due to the expiration of a third R21 and no new directly titled and relevant projects being funded. No new projects directly titled and focused on FSHD have been initiated in the past 3 years. Not a single one. The total direct expenditure from the lead institute on FSHD muscular dystrophy, the NIAMS, was $498,754. The NIAMS is spending 3.1 percent of its total muscular dystrophy budget on FSHD. Something is definitely and clearly wrong with this picture.

In fiscal year 2004 year-to-date, the National Institute of Neurological Disorders and Stroke (NINDS) is funding seven directly titled projects on FSHD and the NIH U54 Cooperative Research Center at the University of Rochester. The NINDS is currently funding four R21 style grants, two R01 style grants, the U54 MD CRC, and the NIH FSHD Research Patient Registry. NINDS has increased its portfolio by one R21 grant, two R01 grants and one U54 Cooperative Research Center in the last year. The NINDS is spending 16.3 percent of its total muscular dystrophy budget on FSHD. The NINDS has shown an uncanny ability to move the field of FSHD research ahead with many excellent research projects as well as sponsoring the unprecedented NIH Cooperative Research Center. The second request for applications for the next round of Wellstone Muscular Dystrophy Centers has just been announced. The late Senator Wellstone would have been proud of the achievements made to date in the area of muscular dystrophy and it is very befitting and appropriate that the muscular dystrophy research centers create a living memory for his substantial efforts.

While it is recognized that research grants, grant applications and interest of the researchers may ebb and flow, we are seriously concerned and perplexed with the total lack of presence by the NICHD in FSHD and weak showing of FSHD grants and the dip in direct FSHD support by the NIAMS, ostensibly the lead institute at the NIH, on muscular dystrophy. FSHD is the third most prevalent form of muscular dystrophy and the NIAMS has 3.1 percent of its dystrophy portfolio allocated to this disease. In the case made that the NIH is not receiving enough grants applications for FSHD, it can be said that the volunteer health agencies and extramural community of researchers have done everything in our power to grow the area of research and to promote new researchers and research projects. The NIH needs to recognize that there is a systemic problem as relates to FSHD and that the extramural research community needs to know that there are specific grant mechanisms and announcements with money associated.

The NINDS, NIAMS, NICHD and relevant NIH institutes understand that FSHD is a unique disease and that there are exciting breakthroughs around understanding the molecular basis of FSHD. Elucidation of the molecular pathogenic pathways of the FSHD disease is instrumental to improved patient diagnosis, counseling, management and treatment. It is now generally accepted that FSHD is caused by a deletion (contraction) of D4Z4 repeats on the chromosome 4q. New mutations are frequently encountered and approximately half of cases seem to be due to somatic rearrangements. An interesting gender difference in disease expression in mosaic patients—males are more susceptible to disease—suggest a hormonal modulation of

the phenotype. FSHD is associated with a genomic rearrangement and it is unlikely that the D4Z4 deletion structurally compromises a putative FSHD gene. Evidence strongly supports a model in which the D4Z4 contraction induces a change in the chromosomal environment, more specifically the chromatin structure, which in its turn modulates the gene expression of gene(s) in cis or in trans. This may occur by a spreading or looping mechanism, or more speculatively, by a mechanism similar to transvection as chromosome ends of 4q and 10q seem to exhibit a higher pairing frequency and other forms of cross talk. However, identification of the exact molecular mechanism and the crucial target gene(s) has still to be done. There is increasing evidence for FSHD-specific changes in the chromatin structure and the histone code. Most arguments suggest a unique (novel) pathogenic mechanism behind FSHD. Elucidation of this intricate molecular network is instrumental to the development of evidence-based treatment (and preventive) strategies.

The following is a non-exhaustive list of top priority research targets and areas for investigation that has been given by FSHD research experts to the NIH for consideration as the NIH research plan is developed. The order is not intended to indicate priority rating. (1.) Detailed characterization of individual candidate genes on chromosome 4q; (2.) Identification of the difference between 4qA and 4qB; only short 4qA is causing FSHD; (3.) The molecular causes and consequences of the exchange between 4q and 10q; (4.) Chromatin structure and nuclear organization—histone code; methylation, acetylation etc.; (5.) Establishment of the gene expression modulation on chromosome 4q and genome-wide; (6.) Development of functional models in vitro (cellular) and in vivo (transgenic); (7.) Implementation of systems biology (integrated –omics and bioinformatics) to reveal molecular and metabolic pathways involved; (8.) Harmonize and standardize molecular diagnostic procedures; (9.) Systematic ascertainment and characterization of (homogenous) patient populations for clinical trials; (10.) Generation of tools and reagents to monitor (pharmacological, training, or gene therapy) interventions; (11.) Identification of additional FSHD loci and genes.

Congress has been very generous with the NIH. Congress has repeatedly mandated more effort in muscular dystrophy research in general and FSHD research in particular. But this is not happening. We ask Congress to continue its support for the overall budget increases for the NIH as this will alleviate the serious budget constraints faced by this most remarkable federal agency. We also ask that Congress request an explanation from the program staff and Directors of the NIH NIAMS and NICHD for the inability to do better in the area of FSHD despite repeated Congressional requests. We implore Congress to request the NIH to specifically build the research portfolio on FSHD through all available means, including re-issuing specific calls for research on FSHD at an accelerated rate, to make up for historical and present neglect.

Mr. Chairman, we trust your judgment on the matter before us. We believe the Committee should explore why muscular dystrophy in general and FSHD in particular has been left behind in the great rise in research support at the NIH. Frankly, we are extremely frustrated that amid a huge increase in funding and strong unambiguous expressions of Congressional support, the NIH commitment in facioscapulohumeral muscular dystrophy (FSHD) is so feeble. Mr. Chairman thanks to your extraordinary efforts, consideration and work in this area I have hope that we will find solutions and that hope keeps me going.

Mr. Chairman, again, thank you for providing this opportunity to testify before your Subcommittee.

PREPARED STATEMENT OF THE AMERICAN PSYCHOLOGICAL SOCIETY

SUMMARY OF RECOMMENDATIONS

—As a member of the Ad Hoc Group for Medical Research Funding, APS recommends $30.78 billion for NIH in fiscal year 2005.

—APS requests Committee support for increased behavioral and social science research and training at NIH in order to: better meet the Nation's health needs, many of which are behavioral in nature; realize the exciting scientific opportunities in behavioral and social science research, and; accommodate the changing nature of science, in which new fields and new frontiers of inquiry are rapidly emerging.

—Committee support is requested for specific behavioral science activities at a number of individual institutes. This testimony provides examples to illustrate the exciting and important behavioral and social science work being supported at NIH.

Mr. Chairman, Members of the Committee: On behalf of our members, I want to thank the Committee for your leadership in the bipartisan effort to double NIH budget. As a member of the Ad Hoc Group for Medical Research Funding, the American Psychological Society recommends $30.78 billion for NIH in fiscal year 2005.

While the process of doubling the budget of NIH was completed on schedule, by no means is our work finished. We must think of that process not as a culmination, but as the beginning of something miraculous in the world of science and discovery. Within NIH budget, my testimony focuses on the behavioral and social science research activities of NIH.

OVERVIEW—BASIC AND APPLIED PSYCHOLOGICAL RESEARCH RELATED TO HEALTH

The effects of behavior on health are indisputable. Many serious health conditions—heart disease, lung disease, diabetes, schizophrenia, AIDS, and so many more—are behavioral in origin. Consider, for example, the devastating health consequences of smoking, drinking, taking drugs, engaging in risky sexual behaviors. None of these conditions can be fully understood without an awareness of the behavioral and psychological factors involved in causing, treating and preventing them.

APS members include thousands of scientists who, with NIH support, conduct basic, applied, and clinical research related to physical and mental health at our Nation's leading universities and colleges. Virtually every institute at NIH supports some amount of psychological science. 24 of the 27 institutes at NIH fund behavioral science research, and seven institutes commit over $100 million to this enterprise. Six institutes commit over 20 percent of their resources to behavioral science research. That places these pursuits squarely at the forefront of the most pressing health issues facing this nation. We ask that you continue to help make behavioral research more of a priority at NIH, both by providing maximum funding for those institutes where behavioral science is a core activity, and by encouraging NIH to advance a model of health that includes behavior in deciding its scientific priorities.

BEHAVIORAL SCIENCE RESEARCH TRAINING—A GUARANTEED INVESTMENT

The National Academy of Sciences is currently conducting its congressionally authorized study of research personnel needs with regard to the National Research Service Awards. In recent years, NIH has chosen to only implement the recommendations of NAS selectively, if at all. NAS produces unbiased, highly analytical reports, and they should receive more attention from all of the NIH institutes. This is a serious issue in behavioral science at NIH, where the demand for behavioral science investigators at NCI, NIMH, and other institutes outpaces the current supply of behavioral science researchers. In order to meet the future needs of research in health and behavior, NIH must have a comprehensive training strategy in place today, one that focuses on training young investigators in the core disciplines of behavioral and social science research as well as in multidisciplinary perspectives.

This Committee has expressed interest in this study in the past. Your colleagues in the House stated in their fiscal year 2004 appropriations report, "The Committee recognizes the continuing need for young investigators and clinical scientists, and encourages NIH to increase its support for research training and loan repayment programs. The Committee is aware that the National Academy of Sciences is currently conducting its congressionally authorized study of research personnel needs with regard to the National Research Training Awards. This Committee has expressed interest in this study in the past, and is looking forward to receiving NAS's recommendations with regard to health research training priorities."——(H. Rpt. 108–188 p. 97)

I would now like to turn my attention to the behavioral science research that is taking place at the individual institutes.

NATIONAL INSTITUTE OF MENTAL HEALTH (NIMH)

Strengthening Clinical Science and Evidence Based Treatment.—In January, the National Institute of Mental Health hosted a conference in cooperation with the Academy of Psychological Clinical Sciences. Its goal was to begin a dialogue on the growing gap between psychological clinical science training and clinical treatment. Building a solid footing for the training and development of future clinical researchers was the broad aim of the gathering. The meeting between the Academy and NIMH brought leaders of the two groups together to outline the challenges to clinical science training and develop a strategy for strengthening that training. Also discussed was the need to encourage more students to pursue research careers, and support the use of evidence-based treatments by practitioners. We believe this is the perfect illustration of what Congress had in mind when it chose to double the NIH

budget; applying advances in science and research to the treatment of those in need, and watching the two fields progress as one to the benefit of all. We ask the Committee to support the efforts of NIMH as the institutes takes this very complex first step in the on-going fight against mental illness.

Basic Behavioral Research at NIMH.—The behavioral science research branch at NIMH plays a pivotal role at the institute, funding research in cognitive science, personality and social cognition, and biobehavioral regulation. Knowledge derived from the investigation of basic behavioral processes is critical to the specification of behavioral abnormalities in mental disorders, as well as to the identification of risk and protective factors and the development of effective interventions. NIMH is to be commended for promoting the transfer of knowledge into application. At the same time, basic behavioral research at NIMH must continue to receive the same strong support it traditionally receives there. This is crucial, as NIMH is a de facto source of basic behavioral knowledge that is tapped by many other institutes. Until other institutes begin to support larger amounts of basic behavioral science research connected to their respective missions, it is essential that NIMH's programs of research into behavioral phenomena such as cognition, emotion, psychopathology, perception, development, and others continues to flourish. The National Mental Health Advisory Council has formed a task force that is currently examining the basic science portfolio of NIMH, including basic behavioral science. Their charge is to recommend the best course of research for the future, based on past successes and the current direction that research is headed in. Basic behavioral research is critical not only to the mission of NIMH, but also to the health of the nation. We ask the Committee to encourage NIMH's continued efforts to strengthen the ties between basic and clinical behavioral research, and to monitor NIMH's basic behavioral science portfolio in order to ensure continued progress in our understanding of the causes, treatment, and prevention of mental illness and the promotion of mental health.

NATIONAL INSTITUTE OF GENERAL MEDICAL SCIENCES (NIGMS)

NIGMS is the only National Institute specifically mandated to support research not targeted to specific diseases or disorders. That legislative mandate also extends to behavioral science research. The research mission of NIGMS encompasses "general or basic medical sciences *and related natural or behavioral sciences* [emphasis added] which have significance for two or more other national research institutes."——(TITLE 42, CHAPTER 6A, SUBCHAPTER III, Part C, subpart 11, Sec. 285k) Unfortunately, NIGMS does not now support behavioral science research or training. This is an enormous oversight, given the wide range of fundamental behavioral topics with relevance to a variety of diseases and health conditions. Congress addressed this issue for the past 5 years in the reports on the fiscal year 2000, fiscal year 2001, fiscal year 2002, fiscal year 2003, and fiscal year 2004 appropriations for NIH. Specifically, you said: "The Committee believes that NIGMS has a scientific mandate to support basic behavioral research because of the clear relevance of fundamental behavioral factors to a variety of diseases and health conditions. The Committee encourages the NIGMS to incorporate basic behavioral research as part of its portfolio, especially in the areas of cognition, behavioral neuroscience, behavioral genetics, psychophysiology, methodology and evaluation, and experimental psychology."

Last September, Senators Specter, Harkin, and Inouye engaged in a colloquy on this subject, which appeared in the Congressional Record. All three of these Senators agreed on the important role that basic behavioral science plays in our national research agenda. Pressing national health issues such as post-traumatic stress disorder, unintentional injuries, and tobacco, alcohol and drug addiction can all benefit from basic behavioral research. We ask the committee to please continue its efforts to have NIGMS include basic behavioral research and research training in its portfolio.

In response to these repeated requests from Congress, a working group has been established with the charge of examining the basic behavioral science research portfolio for the whole of NIH. Consisting of experts in basic behavioral sciences from both inside and outside NIH, this group was established to offer recommendations on the future of this research, in terms of both what should be studied and at which institutes. It will report its findings to the NIH Director's Advisory Council. In their fiscal year 2005 Congressional Justification document, NIGMS cited this working group and committed to working with it. We ask that the committee monitor the progress of this working group and carefully evaluate its findings.

Basic behavioral research in addiction (significance for NIDA, NIAAA, NCI and NHLBI), obesity (significance for NIDDK, NHLBI, and NICHD), behavioral genetics (significance for NIDA, NIAAA, NINDS, and NHGRI) and neuroscience (significance

for NIMH, NINDS, and NHGRI) just to name a few, are all within the NIGMS mission. We ask the Committee to direct NIGMS to develop a plan for establishing a basic behavioral science research program at NIGMS.

NATIONAL INSTITUTE ON DRUG ABUSE (NIDA)

NIDA is committed to bringing the Nation the best possible prevention and treatment interventions for drug abuse and addiction by harnessing the power of science. They accomplish this mission through a wide variety of research centers and projects, all of which are on the cutting edge of today's science and research methods.

National Drug Abuse Treatment Clinical Trials Network (CTN).—NIDA's National Drug Abuse Treatment Clinical Trials Network (CTN) is helping bring new medications and behavioral treatments for addiction to communities. Since its establishment in 1999, the CTN has expanded from 5 to 17 sites across the country. The mission of the CTN is to conduct studies of behavioral, pharmacological, and integrated behavioral and pharmacological treatment interventions of therapeutic effect in rigorous, multi-site clinical trials to determine effectiveness across a broad range of community-based treatment settings and diversified patient populations; and then transfer the research results to physicians, providers, and their patients to improve the quality of drug abuse treatment throughout the country using science as the vehicle.

Brain, Behavior, and Health: An Integrative Approach.—Scientific understanding has reached a stage where all the elements of the human brain can be mapped out. NIDA will take a leadership role in working with other NIH Institutes and Centers and with external groups, to better understand the interactions among brain, behavior, and health. Understanding these connections will help us NIDA in the development of new prevention strategies. Science will find ways to make us better able to modify behavior in ways that encourage people to take advantage of existing preventive strategies. All the research initiatives being put forward by NIDA for fiscal year 2005 will be undertaken within this integrated approach to brain, behavior, and health.

Comorbidity.—The mentally ill are at very high risk for substance abuse and addiction. Comorbidity between drug abuse and mental illness needs to be addressed in order to provide treatments and services that are truly effective. NIDA would like to expand research to better understand the comorbid nature of these disorders and to translate this knowledge into improved prevention and treatment strategies. We ask this Committee to increase NIDA's budget in proportion to the overall increase at NIH in order to reduce the health, social and economic burden resulting from drug abuse and addiction in this Nation.

NATIONAL INSTITUTE ON ALCOHOL ABUSE AND ALCOHOLISM (NIAAA)

NIAAA has broadened its behavioral science portfolio in order to understand the underlying psychological and cognitive processes that lead people to drink, and the impact of chronic alcohol abuse on those processes.

Advancing Behavioral Therapies for Alcoholism.—Behavioral, non-pharmacological therapies currently are the most widely used method of treating alcohol dependence and alcohol abuse. To advance the effectiveness of behavioral therapies, NIAAA is examining approaches to improving clinicians' abilities to engage and retain adults and adolescents in treatment. NIAAA plans to expand research on the mechanisms of action of successful behavioral therapies, behavioral therapies for alcohol-abusing patients who have psychiatric disorders, which significantly complicates therapeutic interventions, and combinations of new medications with behavioral therapies to sustain recovery.

Underage Drinking.—After the successful launch of NIAAA's initiative to reduce college drinking through education and intervention (the web site has received over 12 million hits in just under 2 years), the attention of the institute has gone one step further and is now more committed than ever to the eradication of underage drinking. Risk factors for alcoholism manifest largely in adolescence, and possibly in childhood. Underage drinking leads to problems for young people that will have long term effects on their lives. This is a public health risk that requires the best research, including behavioral and psychological science research that Congress can support. The development of better prevention strategies and learning more about the mind/body interaction, as well as environmental influences, are some of the steps that NIAAA has taken in this fight against a formidable and destructive opponent. We ask this Committee to increase NIAAA's budget in proportion to the overall increase at NIH in order to reduce the health, social and economic burden resulting from alcohol abuse and addiction.

Having already established itself as a leader among NIH Institutes in many fields of research, NCI has made enormous advances in the behavioral sciences.

NCI's Behavioral Research Program.—Scientists estimate that as many as 50 percent to 75 percent of cancer deaths in the United States are caused by human behaviors such as smoking, physical inactivity, and poor dietary choices. NCI's comprehensive behavioral science research program ranges from basic behavioral science to research on the development, testing and dissemination of disease prevention and health promotion interventions in areas such as tobacco use, diet, and even sun protection. Focusing on transdisciplinary and collaborative research, NCI's Behavioral Program has expanded to five branches, including a basic biobehavioral research branch, a health communication and informatics research branch, and the tobacco control research branch.

Health Communications.—Recognizing the central role of effective communication in addressing issues of health and behavior, NCI has also undertaken a major effort to develop science-based communications strategies for disseminating information and persuasive messages about cancer prevention and treatment to the public. Researchers are exploring innovative strategies for communicating cancer information to diverse populations, looking at various communication approaches such as message tailoring and framing with application in multiple communication channels. These messages draw from a foundation of basic behavioral and social science research into such issues as how people learn and remember health information, how they perceive health risks, and how they are persuaded to adopt healthy behaviors.

We ask Congress to support NCI's behavioral science research and training initiatives and to encourage other institutes to use these programs as models.

I would now like to turn to some crosscutting initiatives in which behavioral research plays a critical role.

NIH Roadmap.—There has been much attention paid in recent months to the cross NIH initiative known as the "Roadmap." This project will take NIH into the 21st century by revolutionizing the way the institutes think about research and its application into and impact on health services. Transdisciplinary teams of researchers, including behavioral scientists, will conduct high risk/high reward research that will put us on a path towards a healthier population. An excellent example of this transdisciplinary research and the importance of behavioral science is an RFA for health research training issued under the Roadmap program entitled: INTERDISCIPLINARY HEALTH RESEARCH TRAINING: BEHAVIOR, ENVIRONMENT AND BIOLOGY. Among the goals of the RFA is the study of mental disorders by approaches that integrate neuroscience, genetics, behavioral science, computational science/modeling, and clinical sciences, in an attempt to understand the confluence of genetic, biological, behavioral and environmental factors involved in the etiology, treatment and prevention of these disorders.

Obesity.—Obesity is a health problem all too often overlooked; yet, recently it has begun to receive the attention it is warranted. It is no longer a condition that can be overlooked, as it is the leading cause of health problems in America, even more so than smoking. Motivation, counseling, marketing and communication are all important tools if we are to create a healthier nation led by healthier children. If we are to see results, the message that we communicate must be rooted in science and research. Evidence based research, translated into practice, will ensure safe and effective messages. The use of science in promoting behavioral changes should not and cannot be ignored. It has shown us that obesity leads to increased risk of diabetes, heart disease, and even cancer. The behavioral and physiological changes that occur during high-risk periods for weight gain must be clarified. This information can then be used to design individualized interventions, in order to prevent future weight gains and obesity. Research in this field benefits several institutes, such as NHLBI, NICHD, NIDDK, NIA, and NCI.

Sexual Behavior Research and Peer Review.—Recently, much publicity has been given to research conducted at NIH that involves human sexuality and sexually transmitted disease. This research is critical to the health of all Americans, and must continue unimpeded. Recent attacks on NIH for supporting research in health and behavior are motivated by objections to particular behaviors or to the populations being studied. These attacks are intended to stop funding of research relating to such things as reproductive functioning, sexually transmitted diseases, substance abuse, and other public health problems. This research has enormous implications for understanding and preventing a range of health problems, including HIV and AIDS; problems of physical, mental and social development in children; violence; addiction; teen pregnancy; and numerous other conditions that stem from behavioral threats to health. These problems are not limited to particular segments

of our society; the health and economic consequences of these behaviors affect individuals, families and communities of all ethnic backgrounds, professions, and income levels. Our best and only hope for combating these issues is a robust health research agenda based on scientific priorities and methods. The American Psychological Society strongly supports the scientific peer review system of the National Institutes of Health and we encourage Congress and the public to reject efforts to undermine that system by attacking selected grants. NIH's system for evaluating research proposals ensures that the best science is brought to bear on our nation's most pressing public health problems. On this subject, NIH director Zerhouni wrote to Congress: "I fully support NIH's continued investment in research on human sexuality, and I believe that the peer review process has worked properly and provided a level of valuable and independent view in this important area of research." In the interest of public health, our Nation's leaders must take whatever steps are necessary to protect the scientific peer review system from the chilling effects of ideological influences.

It is not possible to highlight all of the worthy behavioral science research programs at NIH. In addition to those I've discussed here, many other institutes play a key role in NIH behavioral science research enterprise. These include the National Institute on Aging, the National Heart Lung and Blood Institute, the National Institute of Child Health and Human Development, the National Institute of Neurological Disorders and Stroke, and within NIH Director's office, the Office of Behavioral and Social Sciences Research. Behavioral science is a central part of the mission of each of these, and each deserves the Committee's support.

This concludes my testimony. Again, thank you for the opportunity to discuss NIH appropriations for fiscal year 2004 and specifically, the importance of behavioral science research in addressing the Nation's public health concerns. I would be pleased to answer any questions or provide additional information.

PREPARED STATEMENT OF THE AMERICAN THORACIC SOCIETY

SUMMARY—FUNDING RECOMMENDATIONS

[In millions of dollars]

Agency	Amount
National Institutes of Health	30,000.0
National Heart, Lung and Blood Institute	3,165.8
National Institute of Allergy and Infectious Disease	4,733.3
National Institute of Environmental Health Sciences	694.1
Fogarty International Center	71.5
National Institute of Nursing Research	148.5
Centers for Disease Control and Prevention	7,500.0
National Institute for Occupational Safety and Health	306.9
Office on Smoking and Health	130.0
Environmental Health: Asthma Activities	70.0
Tuberculosis Control Programs	528.0

The American Thoracic Society (ATS) is are pleased to submit our recommendations for programs in the Labor Health and Human Services and Education Appropriations Subcommittee purview.

The American Thoracic Society, founded in 1905, is an independently incorporated, international education and scientific society that focuses on respiratory and critical care medicine. The Society's members help prevent and fight respiratory disease around the globe through research, education, patient care and advocacy. The Society's long-range goal is to decrease morbidity and mortality from disorders and life-threatening acute illnesses.

MAGNITUDE OF LUNG DISEASE

Lung disease in America is a serious problem. Each year, an estimated 342,000 Americans die of lung disease. Lung disease is responsible for 1 in every 7 deaths, making it America's number three cause of death. More than 35 million Americans suffer from a chronic lung disease. In 2002, lung diseases cost the U.S. economy an estimated $141.8 billion in direct and indirect costs.

Lung diseases represent a spectrum of chronic and acute conditions that interfere with the lung's ability to extract oxygen from the atmosphere, protect against environmental or biological challenges and regulate a number of metabolic processes.

Lung diseases include chronic obstructive pulmonary diseases, lung cancer, tuberculosis, pneumonia, influenza, sleep disordered breathing, pediatric lung disorders, occupational lung disease, sarcoidosis, asthma and severe acute respiratory syndrome (SARS).

The ATS is pleased that the Subcommittee provided increases in the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) budget last fiscal year. The ATS is pleased that the Administration and Congress modestly increased the National Institute of Health (NIH) budget in fiscal year 2004. However, we are extremely concerned with the President's fiscal year 2005 budget that proposes a mere 2 percent increase for NIH and signficiant cuts for CDC. We ask that this Subcommittee recommend a 10 percent increase for NIH. In order to stem the devastating effects of lung disease, research funding must continue to grow to sustain the medical breakthroughs made in recent years. While our statement will focus on selected parts of the Public Health Service, we are firmly committed to appropriate funding for all sectors of our nation's public health infrastructure.

COPD

Chronic Obstructive Pulmonary Disease (COPD) is the fourth leading cause of death in the United States and the third leading cause of death worldwide. Yet, COPD remains relatively unknown to most Americans. COPD is the term used to describe the airflow obstruction associated mainly with emphysema and chronic bronchitis and is a growing health problem.

While the exact prevalence of COPD is not well defined, it affects tens of millions of Americans and can be an extremely debilitating condition. It has been estimated that 13.3 million patients have been diagnosed with some form of COPD and as many as 24 million more are undiagnosed.

In 2001, 13.3 million adults, aged 18 and older in the United States were estimated to have COPD. In addition, according to the new government data based on a 2001 prevalence survey, 3 million Americans have been diagnosed with emphysema and 11.2 million are diagnosed with chronic bronchitis. In 2001, 118,000 people in the United States died of COPD, with the death rate for women with COPD surpassing the death rate of men with COPD. COPD costs the U.S. economy an estimated $32.1 billion a year.

Medical treatments exist to address symptom relief and slow the progression of the disease. Today, COPD is treatable but not curable. Fortunately, promising research is on the horizon for COPD patients. Research in the genetic susceptibility underlying COPD is making progress. Also, there are promising research leads on medications to repair damage to lung tissue caused by COPD. Additional research is needed to pursue these leads.

Despite these promising leads, the ATS feels that research resources committed to COPD are not commensurate with the impact COPD has on the United States and the world. Clearly more needs to be done to make Americans aware of COPD, its causes and symptoms. We understand that the National Heart Lung and Blood Institute (NHLBI) is developing a public education program on COPD. The ATS supports this effort and encourages the NHLBI to partner with the patient and physician community in developing the COPD public education campaign. Additionally, we recommend the Subcommittee encourage NHLBI to devote additional resources to finding improved treatments and a cure for COPD. It affects tens of millions of Americans and can be an extremely debilitating condition. It has been estimated that 13.3 million patients have been diagnosed with some form of COPD and as many as 24 million more are undiagnosed.

The ATS is pleased to announce the formation of a new congressional caucus that will focus on COPD. On March 30, 2004, the Congressional COPD Caucus officially began its work and the ATS encourages members of this Subcommittee to join.

ASTHMA

Asthma is a chronic lung disease in which the bronchial tubes of the lungs become swollen and narrowed, preventing air from getting into or out of the lung. A broad range of environmental triggers that vary from one asthma-sufferer to another causes these obstructive spasms of the bronchi.

Last month, the CDC issued a new report indicating that asthma rates have risen for the past 10 years. It is estimated that close to 20.3 million people suffer from asthma, including an estimated 6.3 million children. While some children appear to out grow their asthma when they reach adulthood, 75 percent will require life-long treatment and monitoring of their condition.

Asthma is expensive. The growth in the prevalence of asthma will have a significant impact on our nation's health expenditures, especially Medicaid. The direct medical costs and indirect costs for asthma are estimated to exceed $14 billion annually. Asthma also represents the most common cause of school absenteeism due to chronic disease. In 2001, there were 2 million emergency room visits due to asthma.

Asthma also kills. In 2001, 4,200 people in the United States died as a result of an asthma attack. Approximately 65 percent of these deaths occurred in women. A disproportionate share of these deaths occurred in African American families.

As the prevalence of asthma has grown, so has asthma research. Researchers are developing better ways to treat and manage chronic asthma. Research supported by the National Heart, Lung and Blood Institute (NHLBI) has discovered genetic components as well as how infectious disease contributes to asthma. NHLBI researchers have also developed better animal models to allow expression of selected asthmatic genetic traits. This will allow researchers to develop a greater understanding of how genes and environmental triggers influence asthma's onset, severity and long-term consequences.

Progress is being made to fight the growing asthma epidemic. We are pleased to report that the fourth American Lung Association Asthma Clinical Research Centers (ACRC) Network study began in September 2003. That study hopes to determine if patient education and the ways of presenting asthma drugs can improve treatment. The first ACRC study concluded that a considerable reduction in the number of hospitalizations, resulting in lower health care costs, could be achieved if all people with asthma were vaccinated for influenza. The 19 ACRC centers around the United States evaluate treatment, education and other intervention strategies for asthma in adults and children. This network is one of the largest clinical research networks in the United States and will continue to develop innovations that will directly benefit patients.

The ATS also feels that the Centers for Disease Control and Prevention (CDC) must play a leadership role in the ways to assist those with asthma. National statistical estimates show that asthma is a growing problem in the United States. However, we do not have accurate data that provide regional and local information on the prevalence of asthma. To develop a targeted public health strategy to respond intelligently to asthma, we need locality-specific data. CDC should take the lead in collecting and analyzing this data.

Last year, Congress provided approximately $37 million for the CDC to conduct asthma programs. CDC will use these funds to conduct asthma outreach, education and tracking activities. We recommend that CDC be provided $70 million in fiscal year 2005 to expand programs and establish grants to community organizations for screening, treatment, education and prevention of childhood asthma.

In the past, Congress enacted legislation that directs the National Asthma Education and Prevention Program at NHBLI to develop a plan for the federal government to respond to the growing asthma epidemic in the United States. This plan should bring together key public and private organizations to develop a national asthma plan to coordinate the many elements of an effective public health response to asthma. Components of a national plan should include research, surveillance, patient and provider education, community awareness, indoor and outdoor air quality, and access to health care providers and medication.

TUBERCULOSIS

The first lung disease research began with the treatment of those who had tuberculosis (TB) (TB) or "consumption", as it was called at the turn of the 20th century. Tuberculosis is an airborne infection caused by a bacterium, *Mycobacterium tuberculosis.* Tuberculosis primarily affects the lungs but can also affect other parts of the body, such as the brain, kidneys or spine.

Tuberculosis is spread through coughs, sneezes and close proximity to someone with active tuberculosis. People with active tuberculosis are most likely to spread the disease to others they spend a lot of time with, such as family members or coworkers. It cannot be spread by touch or sharing utensils used by an infected person.

Tuberculosis takes a toll on the U.S. economy, with total direct and indirect costs of $1.1 billion. There are an estimated 10 million to 15 million Americans who carry latent tuberculosis infection. Each has the potential to develop active tuberculosis in the future. About 10 percent of these individuals will develop active disease at some point in their lives. In 2003, there were 14,871 cases of active tuberculosis reported in the United States. This is only a 1.4 percent decline in the number of cases reported in 2002 and is the smallest annual decrease reported since 1992, the

year the incidence of tuberculosis peaked during a period of resurgence from 1985–1992.

Upon review of this information, many have concluded that a cycle of neglect has begun, reminiscent of the previous resurgence. The ATS, in collaboration with the National Coalition for Elimination of Tuberculosis, recommends an increase of $105 million for TB control in fiscal year 2005 to allow the CDC undertake an unprecedented initiative, Intensified Support and Activities to Accelerate Control (ISAAC) to enhance, maximize and target resources to sustain the momentum of the past decade and accelerate the control and elimination of tuberculosis. ISAAC targets tuberculosis in African Americans, tuberculosis along the United States-Mexico border, allows for universal genotyping of all culture positive TB cases and expands clinical trials for new tools for the diagnosis and treatment of tuberculosis.

In the summer of 2000, the Institutes of Medicine (IOM) published a report, entitled: *Ending Neglect: The Elimination of Tuberculosis in the United States.* The report documents the cycles of attention and progress toward TB elimination, the periods of insufficient funding and the re-emergence of tuberculosis. The IOM report provides the United States with a road map of recommendations on how to eliminate tuberculosis in the United States. The IOM report identifies needed detection, treatment, prevention and research activities. The report concludes that with proper funding, organization of prevention and control activities and research for development of new tools, tuberculosis can be eliminated as a public health problem in the United States. We have endorsed the IOM report and its recommendations. The components of ISAAC begin to fully implement the recommendations of the IOM.

While declining overall TBB rates is good news, the slowing of the decline in rates and the emergence and spread of multi-drug resistant TtuberculosisB poses a significant threat to the public health of our nation. Increased support is needed if the United States is going to continue progress toward the elimination of tuberculosis.

The NIH also has a prominent role to play in the elimination of tuberculosis. Currently there is no highly effective vaccine to prevent TB transmission. However, the recent sequencing of the TB genome and other research advances has put the goal of an effective TB vaccine within reach. The National Institute of Allergy and Infectious Disease has developed a Blueprint for Tuberculosis Vaccine Development. We encourage the subcommittee to fully fund the TB vaccine blueprint.

Fogarty International Center TB Training Programs

The Fogarty International Center (FIC) at NIH provides training grants to U.S. universities to teach AIDS treatment and research techniques to international physicians and researchers. The goal is to develop a cadre of health professionals in the developing world who can begin controlling the global AIDS epidemic.

Because of the link between AIDS and TB infection, the FIC has created supplemental TB training grants for these institutions to train international health care professionals in the area of TB treatment and research. This supplemental program has been highly successful in beginning to create the human infrastructure to treat the nearly 2 billion people who have tuberculosis worldwide.

However, we believe TB training grants should not be offered exclusively to institutions that have received AIDS training grants. The TB grants program should be expanded and open to competition from all institutions. The ATS recommends that Congress provide an additional $3 million for the FIC to expand the TB training grant program from a supplemental grant to an open competition grant.

NIOSH—RESEARCHING AND PREVENTING OCCUPATIONAL LUNG DISEASE

The ATS is extremely concerned that the president's budget proposes to cut the National Institute of Occupational Safety and Health (NIOSH) extramural research program. We strongly encourage this subcommittee to reject the Administration's proposed cut to the NIOSH research program. Occupational safety and health research are valuable and deserve additional funding.

Protecting the health of our nation's workforce will require research, training, tracking and new technologies. We recommend that the Subcommittee provide a $30 million increase for the NIOSH budget. The $30 million increase will be used for the NIOSH Emergency Preparedness agenda, including activities at the National Personal Protective Technology Laboratory, improve workers' safety, and invest in protective technology that will help our nation respond to the growing threat of bioterrorism. In addition, increased NIOSH funding is needed for NIOSH-sponsored prevention, intervention and information programs. These programs respond to existing workplace health programs, conduct prevention education programs, and work with labor and industry groups to lower the risk of workplace injury and illness.

Finally, the overall funding increase for NIOSH will increase training of occupational health professionals in the United States. A recent IOM Report, *Safe Work in the 21st Century: Education and Training Needs for the Next Decades Occupational Safety and Health Personnel,* identified a growing shortage of trained occupational health professionals in the United States. Unlike the majority of medical subspecialties, occupational health professionals do not receive Medicare training support. One such program is the Capacity Building for Worker safety and health that includes training opportunities for occupational health professionals at NIOSH—sponsored Centers of Excellence. We believe more funds are needed in order to track the incidence of serious work-related illnesses and injury.

PHYSICIAN WORKFORCE SUPPLY

As the number of people diagnosed with lung diseases rises, we need to ask, who will be treating lung disease patients in the future? The ATS is also concerned about the supply of physicians in the United States. The ATS is concerned about the supply of physicians in the United States. A recent study published in the Journal of the American Medical Association predicts that there will be an acute shortage of physicians trained to treat patients with critical care illness and lung disease starting in 2007.[1] While the study focuses on supply of pulmonary/critical care physicians, what is driving the shortage is the predicated increase in demand for physician services caused by the aging of the U.S. population.

Policy makers have given much thought and attention to how the aging population will affect Social Security and other programs for the elderly. Significant attention has been given to the acute shortage of nurses. However, such forward thinking does not seem to be applied to our physician workforce.

We are pleased that Bureau of Workforce Analysis at the Health Resources and Services Administration (HRSA) will be conducting a study on physician workforce supply in the United States. We are hopeful that the HRSA study will confirm the looming shortage of physicians in the United States and make policy recommendations on how best to add physicians to the workforce before it becomes a serious crisis.

LUNG-DISEASE OPPORTUNITIES AND ADVANCES

Pulmonary researchers have made significant advances in lung disease research. NHBLI has identified areas of lung disease research that it will be exploring in the next year. One area of focus will be acute lung injury (ALI) and acute respiratory distress syndrome (ARDS). NHLBI created Specialized Centers of Clinically Oriented Research (SCCOR) in translational research in acute lung injury. Patients experiencing ALI and ARDS suddenly develop severe lung inflammation that results in hypoxemia, loss of lung compliance and possibly multi-organ system failure. The SCCOR program will foster multi-disciplinary basic and clinical research related to ALI and ARDS, which will eventually have a positive impact on their prevention, diagnosis and treatment.

Another area of focus is COPD and lung cancer research. Nearly a quarter of a million Americans die each year of either COPD or lung cancer. NHLBI hopes to address the gap in knowledge that a common pathogenetic mechanism may be involved as a risk factor for COPD and lung cancer. The research will focus on a search for the similarities of the cellular and molecular mechanisms that lead to COPD and lung cancer. This new research could have important implications for the prevention and management of both diseases.

One area of new and emerging research conducted by the NHBLI deals with Sleep-disordered breathing (SDB). SDB is a medical condition associated with upper airway obstruction and cessation of breathing that leads to repeated episodes of asphyxia during the night. SDB is very prevalent in the U.S. population with conservative estimates set at 2 percent to 3 percent of all children, 5 percent of middle age adults, and in excess of 15 percent of the aged population. The major health-related implications and morbid consequences of SDB include the neurocognitive and cardiovascular morbidities, depression, hypertension, increased frequency of myocardial infarction and stroke, and increased frequency of motor vehicle accidents due to the increased sleepiness induced by the disruption of sleep in SDB patients. Both the frequency of SDB and its consequences are anticipated to increase in the next decades due to the aging of the overall U.S. population and the ongoing epidemic of

[1] D. Angus, et al. Current and Project Workforce Requirements for Care of the Critically Ill and Patients with Pulmonary Disease: Can We Meet the Requirements of an Aging Population? JAMA 2000; 284:2762–2770.

obesity that afflicts our country. The ATS supports the need for more research into the causes, diagnosis and treatment of SDB.

In conclusion, lung disease is a growing problem in the United States. It is this country's third leading cause of death, responsible for 1 in 7 deaths. The lung disease death rate continues to climb. Overall, lung disease and breathing problems constitute the number one killer of babies under the age of 1 year. Worldwide, tuberculosis kills 3 million people each year, more people than any other single infectious agent. The level of support this Subcommittee approves for lung disease programs should reflect the urgency illustrated by these numbers.

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF CLINICAL ONCOLOGY

The American Society of Clinical Oncology (ASCO) is the world's leading professional society representing more than 20,000 physicians and health care providers engaged in cancer treatment and research. ASCO appreciates the opportunity to submit a statement for the Subcommittee record. This is a time when cancer clinical researchers faces tremendous challenges and also significant opportunities, and we recommend several actions that will ensure the efficient translation of basic research findings into new treatments.

ASCO members owe a tremendous debt to this Subcommittee and the Congress for your leadership over the past decade in boosting the funding for the National Institutes of Health (NIH). The doubling of the NIH budget between fiscal year 1999 and fiscal year 2003 is a particularly impressive accomplishment, but Congress acted as a steadfast friend to research for many years before the period by guaranteeing that NIH had the resources it needed to support basic, translational, and clinical research.

With the resources that have been provided to NIH and to biomedical researchers across the country, our knowledge of the genetic, molecular, and cellular basis of many diseases has increased dramatically. There has been a revolution in our understanding of cancer, and the traditional approach to cancer, which was based on the site of the cancer, is changing. Instead of seeking to develop treatments based on the location of the cancer, we are instead looking for treatments that correct the underlying genetic or molecular defect that causes the disease. The promise of cancer research has never been greater, although realizing that promise will be difficult and will require significant resources.

ASCO and others in the research community are aware of the current budget situation and the effect it will likely have on NIH appropriations. Nevertheless, we strongly urge that Congress make every effort to boost NIH funding, as continued funding increases will ensure that the basic research progress made in recent years will continue and that those basic research findings will be translated to new treatments. We endorse the recommendation of the Federation of American Societies for Experimental Biology and others in the research community that NIH funding be increased by 10 percent in fiscal year 2005, to a total of $30.6 billion.

THE NIH ROADMAP

The leaders of NIH have given serious consideration to reforms that will equip NIH to remain the world's leading biomedical research institute in the 21st century. ASCO believes that the three main areas of focus of the Roadmap—establishing new pathways to discovery, developing research teams of the future, and re-engineering the clinical research enterprise—are appropriate, and achieving these goals of the Roadmap would equip researchers for developing new treatments.

We are gratified that the NIH Roadmap emphasizes the need to re-engineer the clinical research enterprise. Although the cancer clinical trials system at the National Cancer Institute (NCI) is strong and has been a major factor in advances in cancer care, we welcome the NIH Roadmap's critical look at clinical trials systems as a means of improving those systems. Clinical researchers must be provided the tools, including informatics and tissue or specimen repositories, to conduct their work efficiently, and the Roadmap acknowledges the need for those investments.

In addition, the drafters of the NIH Roadmap properly identify a crisis in clinical research training and suggest steps to enhance training. ASCO has initiated programs to improve the training of cancer clinical researchers, and we welcome the special attention that NIH is directing to this issue.

Implementation of the NIH Roadmap initiatives cannot be accomplished at the expense of successful core programs at NCI and other institutes, but Congress should foster the important reforms outlined in the Roadmap.

THE CANCER CLINICAL TRIALS SYSTEM

NCI has supported the development of a sophisticated system for conducting clinical trials that depends heavily on the participation of community oncologists, along with oncologists at cancer centers around the nation. Patients who are treated in the community have the option of enrolling in clinical trials, as their oncologists are almost certainly part of the nation's clinical trials system. This system of treatment, where the majority of cancer patients receive their care in the community and have access to the full range of treatment options, including clinical trial enrollment, has evolved over the last 30 years.

The Medicare Modernization Act of 2003 (MMA) changes dramatically the method by which cancer chemotherapy services provided by oncologists in their offices are reimbursed by Medicare. The current system of payment for cancer chemotherapy drugs will be shifted from an average wholesale price methodology to an average sales price methodology, and accompanying reductions will be made in reimbursement for the services required to administer chemotherapy in the physician's office. The estimates are that, in the aggregate, reimbursement for cancer chemotherapy services will not decline from 2003 to 2004. However, ASCO's preliminary predictions suggest a dramatic reduction in payment for cancer care beginning in January 2005. One of the tasks facing ASCO is to monitor this situation carefully and report to Congress the effects of reimbursement changes.

We realize that this Subcommittee does not have jurisdiction over Medicare. We are raising this issue with the Subcommittee, however, because the potential effects of Medicare reimbursement changes include a serious threat to the clinical research enterprise. In surveys that ASCO has conducted among its members who are engaged in office-based practice, a significant number of those surveyed indicate that, in light of the potential Medicare reimbursement changes in 2005, they will be less inclined to participate in clinical research. Some members have already reported that they have stopped participating in clinical trials. ASCO members have for years reported that the per person payment they receive for NCI-funded clinical trials is inadequate to pay the costs associated with enrolling a patient on trial and collecting and reporting data from the trial. These physicians have subsidized NIH-funded trials with payments from industry-sponsored trials and from clinical income. According to reports from the field, oncologists will not be able to continue this cross-subsidization, because the funds simply will not be available to support this longstanding ad hoc practice.

The task ahead of us now is translating the significant advances in our fundamental knowledge of cancer into new treatments. In no area of research are the opportunities greater than in cancer, and those opportunities will be realized by the rapid completion of clinical trials testing new therapies. If the community physicians who enroll the majority of patients in clinical trials are no longer actively participating in clinical research, the clinical research enterprise will be slowed.

At the same time that ASCO monitors the effects of MMA cancer reimbursement changes and develops appropriate reform proposals, Congress should encourage NCI to undertake a review of the current system of paying for clinical trials. An immediate action that NCI can take is improving the payments to physicians for enrolling cancer patients in trials. Modest increases in payments have been approved by NCI in recent years, but they are inadequate. In addition, ASCO believes that more substantial changes—beyond a boost in the per-patient rate of payment—may be necessary to ensure that oncologists at cancer centers and in the community continue to participate in clinical research and that all other players in clinical research, including NCI and industry, remain committed to participation in cancer clinical research. This is an urgent matter, and we recommend action by NCI to address it.

MINORITY ENROLLMENT IN CLINICAL TRIALS

It is estimated that fewer than 5 percent of adults with cancer enroll in clinical trials. The rate of participation is even lower among minorities. ASCO commends NCI for its efforts to boost involvement of African American, Hispanic, Asian American, and American Indian patients in clinical trials, in part through the Minority-Based Community Clinical Oncology Program. This program includes 11 minority-based CCOPs and involves more than 40 hospitals and 100 minority investigators. We also support the Special Population Networks, which involve research institutions and community providers in investigations of the causes of cancer disparities. This knowledge is vital to our efforts to erase cancer disparities, and NCI is properly investing resources in this research initiative.

RESEARCH TO COMBAT BIOTERRORISM AND ENSURE HOMELAND SECURITY

ASCO is pleased that the biodefense request for fiscal year 2005 includes $47 million for the Public Health and Social Services Emergency Fund, which will support targeted research to develop medical countermeasures to treat nuclear or radiological injuries. Cancer researchers have expertise that will be critical to this effort, which includes: (1) developing drugs to prevent injury from radiological exposure; (2) improving methods for measuring radiological exposure, and (3) developing methods or drugs to restore injured tissues and eliminate materials from contaminated tissue. Cancer researchers are actively engaged in research to understand the late and long-term effects of cancer treatment, including chemotherapy and radiation therapy, and their expertise in these research areas equips them to be engaged in the targeted research that will likely be funded by the Public Health and Social Services Emergency Fund.

ASCO appreciates the opportunity to submit this statement. Congress, through its strong support of NIH, has facilitated an explosion of knowledge about cancer and other serious and life-threatening illnesses. Although we are poised to translate those basic research findings into new treatments, the clinical trials system for testing treatments is fragile. ASCO urges Congress to protect the clinical trials system, so that we can capitalize on the tremendous investment in basic research during the past decade.

PREPARED STATEMENT OF THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

Mr. Chairman and distinguished members of the Subcommittee, we appreciate the opportunity to submit written testimony on behalf of the National Multiple Sclerosis Society. The Society was founded in 1946. Since its inception, the Society's highest priority has been to support research aimed at finding the cause of MS, better treatments, and a cure. In 2004, the National MS Society will spend over $31 million on MS research supporting over 300 MS investigations. By the end of 2004, the Society cumulatively will have expended some $420 million since awarding its first three grants in 1947. This represents the largest privately funded program of basic, clinical, and applied research and training related to MS in the world.

Multiple sclerosis is a chronic, unpredictable and often disabling disease of the central nervous system. Symptoms range from numbness in the limbs, to loss of vision, and in some instances partial or total paralysis. The progress, severity and specific symptoms of MS in any one person can vary and cannot yet be predicted, but advances in research and treatment are giving hope to those affected by the disease.

The federal investment in the National Institutes of Health (NIH) plays a major role in MS research. There are two institutes that conduct or fund the majority of MS research: the National Institute of Neurological Disorders and Stroke (NINDS) which funds 75 percent, and the National Institute of Allergy and Infectious Diseases (NIAID) which funds about 20 percent.

For fiscal year 2004 and fiscal year 2005, it is estimated that NIH expenditures on MS research will be $101.3 million and $102.8 million, respectively. While this demonstrates a good NIH investment in MS, the amount seems low considering that the annual direct and indirect disease cost is approximately $20 billion for all people with MS in the United States.[1]

To ensure an adequate federal investment in MS research, the Society has a three-pronged strategy: (1) request funding for specific research priorities relevant to MS; (2) encourage collaboration across NIH institutes and between NIH and outside organizations; and (3) advocate for a 10 percent funding increase for NIH overall in fiscal year 2005. The National MS Society has had a long and productive relationship with NIH, particularly with NINDS. Our founder Sylvia Lawry helped spearhead the legislation that established NINDS in 1950. Intramural scientists from NINDS serve on our scientific advisory committees and help the Society make research project decisions. These outstanding scientists/physicians volunteer their time to ensure that the research supported by the Society and NIH are in concert, and not in opposition.

---

[1] Based on a 1994 Duke University study, indexed for 2002 by the National MS Society, the average annual cost of MS is estimated at $50,000 per person due to lost wages, increased medical care and other expenses. Nationwide, there are an estimated 400,000 people with MS.

FUNDING RESEARCH PRIORITIES RELEVANT TO MS

The National MS Society will continue to pursue research opportunities with NIH in priority areas that are key to furthering the understanding of MS. We also will closely monitor NIH's progress in expanding its commitment to MS research as suggested by Congress.

Last year, as part of our NIH advocacy efforts, the Society had the following congressional "report language" added by the House and Senate Appropriations Conference Committee as an instruction to NIH in the fiscal year 2004 omnibus appropriations package:

"The conferees urge NINDS to increase its overall investment in multiple sclerosis (MS) research. Special emphasis on imaging, biological markers and clinical trials for new therapeutics should be areas of high priority. The conferees are pleased to note the development of a joint symposium on MS genetics sponsored by NINDS and the National MS Society, and encourage the Institute to take a more active role at the NIH in furthering MS genetics research by developing collaborative strategies with the National Human Genome Research Institute and other relevant NIH institutes. The conferees request that NIH report back to Congress no later than September 30, 2004 with progress in its efforts to expand its commitment to multiple sclerosis. The conferees also are pleased to note a major success in past years in the creation of a joint collaborative research program in 'gender and immunity' between the National Institute on Allergy and Infectious Diseases (NIAID) and a major voluntary association for the disease, in which NINDS participates. The conferees encourage NINDS to seek similar collaborative activities related to MS."

The Society was pleased that late in 2003 NINDS funded a 5-year $30 million clinical trial that will test the effects of combining two of the MS injected therapies against the use of a single therapy. As part of this clinical trial, NINDS is including an additional $3–4 million to study the correlation between the clinical course of MS and data from biological markers (magnetic resonance imaging). The Society also was pleased that in 2003 NINDS and NMSS co-sponsored a scientific workshop on the role of genetics in MS. As an outcome of this workshop, the Society is looking to work closely with NINDS on genetics projects, such as the development of a collaborative and international MS genetics network. Such a network would facilitate the execution of small and large-scale studies utilizing both the latest technology to find genes that may confer susceptibility to MS.

We look forward to the year-end report from NINDS on its commitment to MS research.

In 2004, we will look to NINDS to establish a Working Group on MS (as has been done for Parkinson's Disease) to initiate planning to ensure that MS research is adequately supported throughout NIH and to collect information on research obstacles.

THE IMPORTANCE OF COLLABORATION

We cannot overemphasize the importance of collaboration. The National MS Society encourages NIH to increase collaboration across institutes and to pursue collaborative opportunities with other organizations.

—Collaboration fosters an interdisciplinary approach to the investigation of complex biomedical problems.

—Jointly funded research projects significantly leverage limited resources and advance the research agendas of all involved parties.

We are pleased to see that NIH Director Zerhouni made collaboration (both intramural and extramural) one of the pillars of his Roadmap Initiative—a 3-year plan addressing key research issues throughout NIH. As we see it, there is no other choice.

To date, the Society has been successful with NIH on jointly funding a major initiative on gender and immune function. In 2001, the Society entered into a $20 million collaborative project with NIAID and other NIH institutes to investigate gender effects on the immune function, including autoimmunity. This is important because most autoimmune diseases (including MS) are far more prevalent in women than men. The Society is co-funding six projects and will contribute up to $4 million to this project. We would like to engage in other collaborative projects, especially with NINDS.

The Society asks Congress to urge NIH to increase inter-institute collaboration as well as collaboration with external public, non-profit, educational and private sector organizations. Possible areas for collaborative research could include:

—*Neurological repair*.—How to effect recovery of tissue (and function) lost due to neurodegenerative diseases, including MS.

—*Neurological degeneration*.—Using MS as a model to study neurological degeneration in diseases such as Alzheimer's Disease, Parkinson's Disease and MS.
—*Genetics*.—The role of genetics in susceptibility to, and disease course of neurological and immunological disorders, including MS.
—*Imaging*.—Creation of Magnetic Resonance Imaging (MRI) centers to study repair, neuroprotection and other clinical issues that cut across a number of neurological disorders such as stroke, Alzheimer's Disease, Parkinson's Disease and MS. One possible eligibility requirement for these centers could be that a facility have expertise in at least two diseases.
—Pediatric research into diseases that rarely, but sometimes affect children.

We believe the NIH Director should establish inter-institute, cross-disease working groups in the above areas to examine and recommend worthy research topics that will set the stage for future collaborative projects.

Increased internal and external collaboration, which we hope will occur at NIH, points to the need for improved research tracking. The Society also asks that Congress recommend a standard project coding mechanism across all NIH institutes, so that the true research investment in various diseases is accurately represented to the public.

OVERALL NIH FUNDING INCREASE FOR FISCAL YEAR 2005

The Society is concerned that NIH may face a second year of overall low funding increases. Furthermore, in fiscal year 2003 and fiscal year 2004, only bioterrorism research received a healthy increase, with much smaller increases allocated for disease research. We fear the same may occur in fiscal year 2005. This is particularly disappointing after the fiscal years 1999–2003 funding campaign that doubled the NIH budget in the 5 year period.

—We urge Congress to appropriate a 10 percent fiscal year 2005 funding increase for NIH.
—While there is a need to increase our country's investment in bioterrorism research, we ask Congress to balance the fiscal year 2005 NIH appropriation to allow growth across all NIH institutes and all areas of disease research.

We thank the Subcommittee for this opportunity to comment and applaud your commitment to advancing the health and well-being of all Americans through investment in biomedical research.

PREPARED STATEMENT OF THE ASSOCIATION OF AMERICAN UNIVERSITIES

Mr. Chairman and members of the subcommittee: The Association of American Universities, representing 60 prominent research universities in the United States, appreciates this opportunity to submit testimony in support of the National Institutes of Health (NIH). Some 85 percent of the NIH budget is spent on research grants and contracts at higher education institutions across the United States. NIH research grants support nearly 40,000 graduate students and post-docs in universities and help develop a robust and diverse base of scientific talent critical to the future success of the nation's medical research efforts. AAU and its member research universities are very aware of the current restraints on domestic discretionary spending due to proposed funding increases for defense and homeland security programs, but have concerns about the long-term vitality of the biomedical research enterprise if the committee does not recognize that our nation's investment in NIH is also a top priority. AAU strongly urges the committee to provide a 10 percent increase in the fiscal year 2005 NIH budget because today's medical science translates into accelerated cures for tomorrow.

Past investment in NIH and our national biomedical research enterprise—the medical science performed by more than 217,000 scientists at more than 2,800 institutions around the country—has led to an exponential increase in the complexity of medical questions that can be asked and answered. NIH Director Elias Zerhouni has testified eloquently before your subcommittee about the health care revolution of a generation ago: medical research has transformed formerly lethal diseases into manageable afflictions and has given patients and their families more years of life. In the past 20 years, some of mankind's gravest scourges, such as childhood cancers, have been tamed. Deaths from heart attack and stroke have been cut by hundreds of thousands per year. HIV/AIDS, which was a death sentence 10 years ago, has become an onerous but survivable burden for those fortunate enough to live in the United States and receive triple-drug therapies. Today's biomedical research enterprise offers the hope of cures that add not just years to life, but quality of life to those years. AAU endorses the NIH "Roadmap for Research" developed by Dr. Zerhouni and his colleagues as an important framework for making the strategic in-

vestments that will fully capitalize on recent breakthroughs in genomics, bioinformatics, and molecular medicine. Cures—not just therapies—for juvenile diabetes, heart disease, osteoporosis, stroke and multiple cancers are within our grasp, if we can accelerate promising new research.

NIH-supported scientists have transformed the health and quality of life of all Americans. To take just one example, more than half of all cancers treated today will be cured. U.S. medical science is the envy of the world and the hope of mankind because science—not politics or ideology—has determined what research is supported. Recent investments in NIH funded research have:

—Yielded 100 new cancer drugs that are now in clinical trials. NIH-supported university research, for example, has produced therapies that target prostate cancer cells and the blood supply of other solid tumors, leaving healthy tissues untouched.

—Facilitated clinical trials to further develop at least 11 vaccines to address the HIV subtypes that together cause most of the HIV infections around the world. Since 1987, NIH's National Institute for Allergy and Infectious Diseases (NIAID) has enrolled more than 3,357 volunteers in 53 Phase I & Phase II preventive HIV vaccine trials of 28 candidate vaccines.

—Enabled scientists to identify the first drug to have an effect on both insulin production and insulin action as a potential therapeutic agent for type 2 diabetes. This example of an NIH investment in basic research could help the 17 million Americans who suffer from this disease.

—Revolutionized biomedical science through the sequencing of the human genome. Researchers now are able to locate, identify, and describe the function of many human genes. This new knowledge will lead to genetic tests to diagnose diseases and the development of drug therapies that are tailored to individual patients.

AAU urges the committee to provide appropriate funding for NIH or many promising opportunities will not be funded. If NIH receives inadequate funding in fiscal year 2005, we will lose significant opportunities to cure disease and comfort the afflicted. A 10 percent increase for NIH will:

—Enable faster and cheaper genomic sequencing. Currently it costs $2–3 billion to sequence an entire genome. An investment of $50 million today will enable the development of new technologies that will cut the cost of sequencing to $100,000 for a complex mammal within 5 years and drive the cost of an entire genome to $1,000 within 10 years.

—Support the new science of proteomics that has enabled physicians to distinguish among different types of ovarian or breast cancer tumors and reveal patterns that may have important clinical implications. Because of previous investments, doctors can now tailor therapies such as chemotherapy and radiation to patients based upon their tumor types, dramatically increasing cure rates and reducing the suffering of women who don't have to undergo painful therapies needlessly. Today's investment will drive the cost of diagnosis down to pennies per patient and further individualize cancer therapies.

—Fund the National Cancer Clinical Trial Database that allows patients to access information about NCI funded research by disease type; enables scientists to use recent technological innovations to produce vast amounts of information about the genes and proteins active within cancer cells; and allows cancer funding agencies to coordinate research efforts across agencies.

—Further reduce the time it takes to develop a vaccine, which has plummeted from 15 years to fewer than four. For example, two vaccine candidates for West Nile virus were in clinical trials within 3 years of West Nile's arrival in the continental United States. And biomedical researchers were able to take the knowledge and tools made possible by the NIH doubling to identify and sequence the SARS virus in a matter of weeks. As the nation braces for newly emerging infectious diseases such as bird flu or a bioterror attack, we must continue to develop new or improved vaccines.

CONCLUSION

As a nation, we enjoy the benefits of a system that recruits talented individuals and encourages them to compete for research funding. These individuals undergo a lengthy, rigorous and highly selective apprenticeship before they apply for their own research funds. The competition for research support is fierce, and at best only about 30 percent of the applicants for NIH funds are successful. When the success rate falls substantially below this level, important projects are disrupted and promising young people are dissuaded from research careers. Thus, in order to sustain

the high quality of the biomedical research system, we must continue to provide resources to encourage the research of our nation's best scientists.

It is imperative that this committee continue its legacy of bi-partisan support for NIH—the future health of the nation depends of it. In a year when defense and homeland security are top priorities, the committee must not allow investments for NIH to erode. The scientific community is tirelessly working to translate research into tangible benefits for all Americans. The health and quality of millions of lives depends on strong support from this committee for the fiscal year 2005 NIH budget.

Thank you for this opportunity to submit testimony and please let me know if you have questions.

PREPARED STATEMENT OF THE MARCH OF DIMES BIRTH DEFECTS FOUNDATION

The 3 million volunteers and 1,400 staff members of the March of Dimes appreciate the opportunity to submit the Foundation's federal funding recommendations for fiscal year 2005. The March of Dimes is a national voluntary health agency founded in 1938 by President Franklin D. Roosevelt to prevent polio. Today, the Foundation works to improve the health of mothers, infants and children by preventing birth defects and infant mortality through research, community services, education, and advocacy. The March of Dimes is a unique partnership of scientists, clinicians, parents, members of the business community, and other volunteers affiliated with 54 chapters in every state, the District of Columbia and Puerto Rico.

The volunteers and staff of the March of Dimes are deeply concerned that for the first time since 1958, the infant mortality rate increased in 2002. Increases in deaths due to premature birth, birth defects, and maternal complications during pregnancy are the top reasons for this increase. In our judgment, the modest funding increases recommended below would have an immediate and positive impact on this disturbing trend.

NATIONAL INSTITUTES OF HEALTH

The March of Dimes joins the larger research community in recommending a 10 percent increase in funding for the National Institutes of Health (NIH), bringing total federal support to just over $30 billion. A sustained investment in medical research is vital to discovering the interventions needed to prevent and treat diseases and conditions. Because of the profound impact on women and children of the work supported by the National Institute of Child Health and Human Development, funding for this Institute is of particular interest to the March of Dimes.

National Institute for Child Health and Human Development

The mission of the National Institute for Child Health and Human Development (NICHD) is closely aligned with that of the March of Dimes. The Foundation recommends an overall increase in funding of 10 percent for NICHD. With this increase in resources, NICHD could expand research in several areas that are crucial to improving the health of women and children. Additional funds would permit expansion of research into preterm labor and delivery and into the causes of birth defects, and would enable NICHD to begin implementing the National Children's Study of environmental and genetic influences on child health and development.

According to the National Center for Health Statistics, in 2002, more than 480,000 babies were born prematurely in the United States—1 in 8 births. Since 1981, the preterm birth rate has increased nearly 29 percent. Premature birth accounts for 23 percent of deaths in the first month of life. Those babies that survive are more likely than full-term infants to face serious multiple health problems including cerebral palsy, mental retardation, chronic lung disease, and vision and hearing loss. Preterm labor can happen to any pregnant woman and the causes of nearly half of all preterm births are unknown. An analysis of Agency for Healthcare Research and Quality data conducted by the March of Dimes Perinatal Data Center estimated that the total national hospital bill for premature babies was $13.6 billion in 2001. With overall hospital charges increasing rapidly—13 percent in 2001—the financial burden of prematurity is expected to worsen until we know how to prevent preterm births.

The March of Dimes recommends a 10 percent increase for NICHD in fiscal year 2005 and an increase of at least $50 million over the next 5 years to boost prematurity-related research. This increase should be devoted to a comprehensive biomedical research program to study preterm delivery etiology, prevention and treatment regimens.

Division of Reproductive Health

The National Center for Chronic Disease Prevention and Health Promotion, Division of Reproductive Health works to promote optimal reproductive and infant health, but does not have the resources it requires to study the growing problem of preterm birth. Therefore, the March of Dimes recommends a $20 million increase in fiscal year 2005 to expand research related to preterm birth. The growing problem of preterm birth requires an expanded, comprehensive prevention research agenda to identify the causes, risk factors and ways to prevent preterm birth. In particular, two specific programs should receive additional funding: (1) the Pregnancy Risk Assessment Monitoring System and (2) epidemiological research.

The Pregnancy Risk Assessment Monitoring System (PRAMS) is a state-specific, population based surveillance system designed to identify and monitor maternal behaviors and experiences before, during, and after pregnancy. Currently, CDC supports cooperative agreements with 31 states that allow PRAMS to cover about 60 percent of all U.S. births. Data collected through PRAMS is used by researchers and policy makers to increase understanding of adverse pregnancy outcomes, to develop and modify maternal and child health programs, and to incorporate the most up to date research findings into standards of practice. The March of Dimes recommends an increase of $5 million to expand PRAMS so that CDC can develop national estimates on behavioral as well as demographic risk factors for preterm birth.

Epidemiological research conducted at CDC is vital to reducing the incidence of preterm labor and delivery. The March of Dimes recommends an increase of $15 million to expand research on the prevention of preterm delivery for women at risk, focusing especially on factors contributing to higher rates of preterm delivery in African-American women. Increasing CDC's activities related to preterm birth will improve early detection of women at risk for preterm labor and lead to new interventions for those at greatest risk.

National Center on Birth Defects and Developmental Disabilities

According to CDC, birth defects are the leading cause of infant mortality accounting for more than 20 percent of all infant deaths and are responsible for about 30 percent of all pediatric hospital admissions. Of the 4 million babies born each year in the United States, approximately 150,000 are born with one or more serious birth defects. In addition, birth defects are the fifth-leading cause of years of potential life lost and contribute substantially to childhood morbidity and long-term disability. The causes of about 70 percent of all birth defects are still unknown.

The National Center on Birth Defects and Developmental Disabilities (NCBDDD) works to prevent birth defects for which causes have already been identified and conducts research on those defects for which causes have not yet been found. The March of Dimes urges members of the Subcommittee to increase funding for the Center to $160 million in fiscal year 2005 (includes the transfer of Hereditary Blood Disorders Division). This modest increase will provide the resources necessary to expand prevention activities where causes are known, and to accelerate the pace of research where causes have not as yet been identified. An increase of $15.9 million in funding for prevention, surveillance, and research activities is vital to making progress in the fight against birth defects.

Prevention: Folic Acid Education Campaign

The NCBDDD is conducting a national public and health professions education campaign designed to increase the number of women taking folic acid daily. According to CDC, each year, an estimated 2,500 babies are born with neural tube defects (NTDs), birth defects of the brain and spinal cord, including anencephaly and spina bifida. CDC estimates that up to 70 percent of NTDs could be prevented if all women of childbearing age consume 400 micrograms of folic acid daily, beginning before pregnancy. Fortification of the grain supply together with health provider and consumer education has resulted in a 32 percent decline in the rates of spina bifida. However, the growing popularity of low-carbohydrate diets has caused an increasing number of women to reduce or eliminate their daily intake of bread and other grains. A 2003 Gallup Organization survey conducted for the March of Dimes found that only 32 percent of women in the United States between the ages of 18 and 45 take a multivitamin containing folic acid on a daily basis, up only 4 percent since 1995. When asked what would make them more likely to take a multivitamin containing folic acid on a daily basis, 33 percent of women said they would be more likely to do so on the advice of their doctor or health care provider. Therefore, it is critical that CDC step up its campaign to educate every woman of childbearing age about the importance of taking a daily multivitamin containing folic acid.

To enable CDC to educate more women of child bearing age and their health providers about the importance of folic acid, the March of Dimes recommends an appropriation of at least $5 million in fiscal year 2005 for the Folic Acid Education Campaign.

Surveillance: State Cooperative Agreements to Improve Birth Defects Tracking

NCBDDD funds state initiatives to develop, implement, and/or expand community-based birth defects tracking systems, programs to prevent birth defects, and activities to improve access to health services for infants and children with birth defects. Surveillance forms the backbone of a vital public health network. CDC is currently supporting cooperative agreements with 28 states, each funded at an annual level of between $100,000 and $200,000 for each of 3 years. The March of Dimes encourages Subcommittee Members to add $3.4 million (a total of $7.5 million) to state-based birth defects surveillance activities. As you may know, resources have not been adequate to fund all states seeking assistance. Additional funding is needed to support creation of programs where none exist and improvement of programs already receiving support.

Research: Regional Centers for Birth Defects Research and Prevention

NCBDDD currently funds 10 regional Centers for Birth Defects Research and Prevention (each Center receives approximately $900,000 per year) to conduct epidemiological research on birth defects. The centers are located in Arkansas, California, Georgia, Iowa, Massachusetts, New Jersey, New York, North Carolina, Texas, and Utah. These centers obtain data and identify cases for inclusion in the National Birth Defects Prevention Study, the largest case-control study of birth defects ever conducted. The centers study the effectiveness of primary prevention of birth defects, the teratogenicity of various drugs, the environmental causes of birth defects and the genetic factors pertaining to susceptibility to environmental causes of birth defects. For example in response to a scientific study showing a possible association between the drug loratadine, also sold under the brand name Claritin®, and the occurrence of the birth defect hypospadias the National Birth Defects Prevention Study conducted a study that showed no association. This information will be useful to any woman who takes loratadine and becomes pregnant. The March of Dimes encourages the Subcommittee to add $10 million (for a total of $17.3 million in funding) to support the important and promising work of the regional centers.

ADDITIONAL CDC PROGRAMS

National Immunization Program

Immunizations are critical to the health and well-being of children. CDC's National Immunization Program provides grants to 64 state, local, and territorial public health agencies to reduce the incidence of disability and death resulting from vaccine preventable diseases. The March of Dimes urges the Subcommitttee to continue its longstanding policy of ensuring that federal vaccine programs are adequately funded to move the nation closer to the goal of vaccinating at least 90 percent of children and adults. To account for vaccine price increases, introduction of new vaccines, and to facilitate implementation of recent Institute of Medicine recommendations, the March of Dimes recommends an overall increase of $180 million in fiscal year 2005 for the National Immunization Program.

Polio Eradication

The March of Dimes was founded to find ways of preventing poliomyelitis. Although success in developing the Salk and Sabin vaccines enabled the Foundation to shift its focus to a new set of challenges, we continue to support completing the task of polio eradication worldwide. Global polio eradication will save lives and reduce unnecessary health-related costs. The March of Dimes supports a funding level of $106.4 million for CDC's fiscal year 2005 global polio eradication activities. With polio epidemics now confined to only 6 countries (Nigeria, India, Pakistan, Niger, Egypt and Afghanistan), it is important that the U.S. government maintain its commitment to completion of the worldwide eradication initiative.

National Center for Health Statistics

The Foundation also supports the vital work of the National Center for Health Statistics (NCHS) which provides information essential for research and programmatic initiatives. NCHS' surveys to assess the health status of American's care are critical to many programs and initiatives. For example, the National Vital Statistics System is a major source of information on utilization of health services, preterm births, low birthweight as well as outcomes including birth defects and infant mortality. Increased funding would allow CDC to modernize this system using

web-based technology that would facilitate rapid compilation of data and improvement in the accuracy and completeness of information obtained from health professionals and facilities. This information is needed to track trends in birth outcomes and to support birth defects registries. Additional resources would also enable CDC to continue the National Survey of Family Growth which provides essential information on factors affecting birth outcomes.

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

Newborn Screening

Newborn screening is a public health activity used to identify genetic, metabolic, hormonal and/or functional conditions in newborns. Many such disorders, if left untreated, can cause disability, mental retardation, and even death. Although nearly all babies born in the United States undergo newborn screening tests for some genetic birth defects, the number and quality of these tests varies from state to state. The March of Dimes recommends that every baby born in the United States receive, at a minimum, screening for a core set of nine metabolic disorders as well as hearing deficiencies.

In fiscal year 2004, the Congress provided first-time funding for implementation of Title XXVI of the Children's Health Act of 2000. This program is designed to strengthen state newborn screening programs; to improve states' ability to develop, evaluate, and acquire innovative testing technologies; and to establish and improve programs to provide screening, counseling, testing and special services for newborns and children at risk for heritable disorders. The March of Dimes proposes an appropriation of $25 million to support HRSA's work with states to expand the heritable disorders (newborn screening) program authorized through Title XXVI.

Maternal and Child Health Block Grant

Title V of the Social Security Act, the Maternal and Child Health (MCH) block grant, funds community-based services such as home visiting and respite care for children with special health care needs. MCH complements Medicaid and the State Children's Health Insurance Program by providing "wrap-around" services and other needed health services. The March of Dimes recommends fully funding the block grant at the authorized level of $850 million and notes that in order to hold states harmless an appropriation of $807 million is required. Additional funding would enable states to expand critical services such as prenatal and infancy home visitation programs, strategy that helps improve birth outcomes. According to the Maternal and Child Health Bureau, 900,000 children with special health care needs use MCH services. These children would also benefit as increased resources would enable states to raise spending limits for home visits respite care, physical and occupational therapy, durable medical equipment, and other support services.

Consolidated Health Centers

Consolidated (Community) Health Centers are an important source of obstetric and pediatric care for more than 13 million individuals, 40 percent of whom are uninsured. The Foundation recommends new funding sufficient to increase the number of centers and to improve the scope of perinatal services provided. Adding funds to this program would be consistent with the President's 5-year plan to create and expand health center sites in 1,200 communities and to increase the number of patients served annually to more than 16 million.

Thank you for the opportunity to testify on the federally supported programs of highest priority to the March of Dimes. The Foundation's staff and volunteers look forward to working with Members of the Subcommittee to improve the health of mothers, infants and children.

MARCH OF DIMES FISCAL YEAR 2005 FEDERAL FUNDING PRIORITIES

[In millions of dollars]

Program	Fiscal year	
	2004 funding	2005 March of Dimes recommendation
National Institutes of Health (Total)	27,878.0	30,666.0
National Institute of Child Health & Human Development	1,242.0	1,366.0
National Human Genome Research Institute	479.0	527.0
National Center on Minority Health and Disparities	192.0	211.0
Centers for Disease Control and Prevention (Total)	6,972.0	8,100.0

MARCH OF DIMES FISCAL YEAR 2005 FEDERAL FUNDING PRIORITIES—Continued

[In millions of dollars]

Program	Fiscal year	
	2004 funding	2005 March of Dimes recommendation
Center on Birth Defects and Developmental Disabilities	113.0	[1] 160.0
Regional Centers for Birth Defects Research & Prevention	7.3	17.3
State Cooperative Agreements to Improve Birth Defects Tracking	4.1	7.5
Folic Acid Education Campaign	2.5	5.0
Immunization	644.0	824.0
Polio Eradication	106.4	106.4
Safe Motherhood/Infant Health (NCCDPHP)	54.0	74.0
Pregnancy Risk Assessment Monitoring System	7.1	12.0
Prevention Research (Preterm Birth)	1.3	16.3
National Center for Health Statistics	128.0	181.0
Health Resources and Services Administration (Total)	6,600.0	8,000.0
Maternal and Child Health Block Grant	730.0	850.0
Newborn Screening	2.0	25.0
Newborn Hearing Screening	10.0	10.0
Consolidated (Community) Health Centers	1,617.0	1,867.0
Healthy Start	98.0	98.0
Agency for Healthcare Research and Quality	304.0	390.0

[1] Fiscal year 2005 funding recommendation includes $22 million transfer of the Hereditary Blood Disorders Division and $25 million in new funding.

PREPARED STATEMENT OF THE NEPHCURE FOUNDATION

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2005

—A 10 percent increase for the National Institutes of Health and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

—Continue to expand the NIDDK Nephrotic Syndrome (NS)/Focal Segmental Glomerulosclerosis (FSGS) research portfolio by aggressively supporting grant proposals in this area and encouraging the National Center for Minority Health and Health Disparities (NCMHD) to initiate studies into the incidence/cause of NS/FSGS in the African-American population.

—The NephCure Foundation enthusiastically supports the Scientific Conference/Workshop being sponsored by the National Institute of Diabetes & Digestive & Kidney Diseases (NIDDK). The workshop will take place early in 2005 and will examine areas of promise surrounding glomerular disease and will develop a future agenda for Focal Segmental Glomerulosclerosis (FSGS) research.

—The NephCure Foundation encourages follow up to the 2005 scientific workshop in hopes that it will initiate grant proposals focused on achieving the goals and opportunities developed by the workshop.

Mr. Chairman, and members of the subcommittee, I am pleased to present testimony on behalf of the NephCure Foundation (NCF), a non-profit organization driven by a blue-ribbon panel of respected medical experts and a dedicated band of patients and families working for a common goal—to save kidneys and lives.

I am Ed Hearn, former Major League Baseball Player for the Kansas City Royals. My career as a professional athlete came to an abrupt end in 1988, when I was diagnosed with Focal Segmental Glomerulosclerosis (FSGS), a debilitating and degenerative kidney disease. Today, after two life-changing kidney transplants, a successful bout against cancer, the aid of a breathing machine each night, a $3,000 IV once a month, and $40,000 of medication per year, I live to tell my story and to speak for those suffering from FSGS. My hope is that we can find the means to prevent this life-threatening disease from affecting our youth and from jeopardizing the normalcy of their lives as it has mine and many others. I remain hopeful that a cure for FSGS will be discovered, but until then, we must focus on prevention.

TREATMENT TRIALS BEGINNING, BUT NO CURE IN SIGHT

Mr. Chairman, FSGS is one of a cluster of glomerular diseases that attack the one million tiny filtering units contained in each human kidney. These filters are called nephrons and the diseases attack the portion of the nephron called the

glomerulus, scarring and often destroying the irreplaceable filters. Scientists do not know why glomerular injury occurs and they are not sure how to stop its inevitable destruction of the kidney.

When I was a teenager, doctors found protein in my urine and told me that some day I might have kidney trouble. I thought "Fine, maybe I'll have to deal with that when I'm an old man down the road." Some day happened much sooner than anyone expected. I believe that because I was a highly-conditioned athlete—and catchers are more conditioned than most—my body initially masked the symptoms of FSGS.

My first kidney transplant lasted more than 7 years until the FSGS returned. I received a second kidney from my aunt in 2000, but my body rejected it almost immediately, and I received a third transplant in May 2002. My story is not unique; there are thousands of other people in this country who have had their lives disrupted due to the sudden onset of FSGS.

We are extremely thankful that an NIDDK-funded clinical trial began this year to study the efficacy of the current treatments for FSGS, and that ancillary studies are underway to examine tissue samples of injured glomerulus. However, these clinical trials hold no particular hope for patients who suffer from FSGS.

As children are most often affected by this disease, there are thousands of young people who are in a race against time, hoping for a treatment that will save their lives. The NephCure Foundation today raises its voice to speak for them all, asking you to take specific actions that will aid our quest to find the cause and the cure of NS/FSGS.

First and foremost, we support a 10 percent increase for the National Institutes of Health and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

TOO LITTLE DATA ABOUT A GROWING PROBLEM

When glomerular disease strikes, the resulting Nephrotic Syndrome causes loss of protein in the urine and symptoms such as edema, a swelling that often appears first in the face. For example, many physicians mistake children's puffy eyelids as an allergy symptom. Stories of similar misdiagnoses are common at our Foundation. With experts projecting a substantial increase in Nephrotic Syndrome in the coming years, there is a clear need to educate pediatricians and family physicians about glomerular disease and its symptoms.

The NephCure Foundation has numerous education programs underway, including patient education seminars; the most recent of which took place in May 2003. News of our most recent activities can be found on our web site at www.nephcure.org. However, our efforts alone are not enough.

NIDDK launched a major federal outreach program early in 2002—the National Kidney Disease Education Program—we seek your support in urging NIDDK to assure that glomerular disease receives high visibility in this important program.

GLOMERULAR DISEASE STRIKES MINORITY POPULATIONS

Nephrologists tell us that glomerular diseases such as FSGS affect a disproportionate number of African-Americans and, according to NIDDK, "the worst prognosis is observed in African-American children." NephCure officials have described this situation in a meeting with Dr. John Ruffin, director of the National Center for Minority Health and Health Disparities (NCMHD).

As the NCMHD becomes fully operational and plans programs, our Foundation will continue to work with the Center to encourage the creation of programs to study the high incidence of glomerular disease within the African-American population.

We ask the Committee to join with us in expanding the NS/FSGS research portfolio by requesting that the National Center for Minority Health and Health Disparities seize the opportunity to establish research into the phenomenon of glomerular disease within the African American community.

MORE BASIC SCIENCE IS NEEDED

The current FSGS clinical trials which follow an estimated 400 patients over a 3-year period, are limited, according to the RFA, to examining the "impact of immunomodulatory therapy on proteinuria." While the trials may lead to safer or more efficient care for children with FSGS, no one is suggesting that they will bring us closer to finding the cause and cure. Science has yet to prove that FSGS is an immune-mediated disease.

Scientists tell us that much more needs to be done in the area of basic science, beginning with collection of tissue and fluid samples from a large number of pa-

tients on which years of important scientific research can be founded. NephCure is collaborating with the NIH in a major way to work for such progress.

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) has agreed to match, dollar-for-dollar, funds raised by NephCure that will allow researchers to obtain DNA samples from hundreds of FSGS patients in upcoming clinical trials. The NIDDK will match up to $300,000 raised by NephCure for a combined total of $600,000. These trials are an ancillary study in conjunction with the first-ever national medication trials of FSGS treatment that may possibly lead to better understanding of the more common Nephrotic Syndrome, which can be a precursor to FSGS.

We enthusiastically support NIDDK in sponsoring a scientific workshop/conference to take place early in 2005, with the intent to review the most promising existing science in glomerular disease, and focus on methods of translating this scientific information into improved patient care. This goal is consistent with the NIH Roadmap to Research initiative developed by NIH Director, Dr. Elias Zerhouni.

We sincerely believe that the workshop will expose opportunities and challenges in glomerular disease research, and evaluate the resources needed to carry out these opportunities and challenges. The workshop/conference will lend hope to the thousands of young people whose kidneys and lives are threatened by this terrible disease, and give meaning and honor to their heroic stories.

The NephCure Foundation encourages follow up to the scientific workshop/conference in hopes that it will generate grant proposals focused on achieving the research goals and opportunities developed by the workshop.

We anticipate the potential for a Program Announcement and the potential for a Special Emphasis Program Announcement resulting from the conference or some other traditional mechanism to generate grant proposals. These mechanisms to encourage investigator initiated grant proposals should help to continue to expand the NS/FSGS portfolio at NIH.

Mr. Chairman, as you know, patient support and advocacy groups such as the NephCure Foundation work closely with medical research organizations. They share a mutual understanding that unless major research efforts are undertaken, advances and improvements in the health of patients will not occur. Every year, the NephCure Foundation participates in advocating increased funding for the NIH and NIDDK. We want to reiterate how deeply grateful we are for your leadership and that of the subcommittee on medical research matters, which means so much for the health of the people in our nation.

I will be pleased to answer any questions you may have.

PREPARED STATEMENT OF THE DIGESTIVE DISEASE NATIONAL COALITION

SUMMARY OF FISCAL YEAR 2005 RECOMMENDATIONS

—Provide increased funding for the National Institutes of Health (NIH) at 10 percent for fiscal year 2005. Increase funding for the National Cancer Institute (NCI), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute of Allergy and Infectious Diseases by 10 percent for fiscal year 2005.

—Continue focus on digestive disease research and education at NIH, including the areas of Inflammatory Bowel Disease (IBD), Hepatitis and other liver diseases, Irritable Bowel Syndrome (IBS), Colorectal Cancer, Endoscopic Research, Pancreatic Cancer, Celiac Disease, and Hemochromatosis.

—$25 million for the Centers for Disease Control and Prevention's (CDC) Hepatitis Prevention and Control activities.

—$30 million for the Centers for Disease Control and Prevention's (CDC) National Viral Hepatitis Roundtable Program

Chairman Specter, thank you for the opportunity to again submit testimony to the Subcommittee. Founded in 1978, the Digestive Disease National Coalition (DDNC) is a voluntary health organization comprised of 25 professional societies and patient organizations concerned with the many diseases of the digestive tract. The Coalition has as its goal a desire to improve the health and the quality of life of the millions of Americans suffering from both acute and chronic digestive diseases.

The DDNC promotes a strong federal investment in digestive disease research, patient care, disease prevention, and public awareness. The DDNC is a broad coalition of groups representing disorders such as Inflammatory Bowel Disease (IBD), Hepatitis and other liver diseases, Irritable Bowel Syndrome (IBS), Pancreatic Cancer, Ulcers, Pediatric and Adult Gastroesophageal Reflux Disease, Colorectal Cancer, Celiac Disease, and Hemochromatosis.

Mr. Chairman, the social and economic impact of digestive disease is enormous and difficult to grasp. Digestive disorders afflict approximately 65 million Americans. This results in 50 million visits to physicians, over 10 million hospitalizations, collectively 230 million days of restricted activity. The total cost associated with digestive diseases has been conservatively estimated at $60 billion a year.

The DDNC would like to thank the subcommittee for its past support of digestive disease research and prevention programs at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). With respect to the coming fiscal year the DDNC is recommending an increase of 10 percent to $30 billion for the National Institutes of Health (NIH) and all of its Institutes. Specifically the DDNC recommends that the National Cancer Institute (NCI), the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK), and the National Institute of Allergy and Infectious Diseases (NIAID be given $5.25 billion, $2.01 billion, and $4.77 billion respectively. We at the DDNC respectfully request that any increase for NIH does not come at the expense of other Public Health Service agencies.

With the historic doubling of the budget for NIH completed and the challenging budgetary constraints the Subcommittee currently operates under, the DDNC would like to highlight the research being accomplished by NIDDK which warrants the increase for NIH.

INFLAMMATORY BOWEL DISEASE

In the United States today about 1 million people suffer from Crohn's disease and ulcerative colitis, collectively known as Inflammatory Bowel Disease (IBD). These are serious diseases that affect the gastrointestinal tract causing bleeding, diarrhea, abdominal pain, and fever. Complications arising from IBD can include anemia, ulcers of the skin, eye disease, colon cancer, liver disease, arthritis, and osteoporosis. Crohn's disease and ulcerative colitis are not usually fatal but can be devastating. The cause of IBD is still unknown, but research has led to great breakthroughs in therapy.

In recent years researchers have made significant progress in the fight against IBD. In 1998, the FDA approved the first drug ever specifically to fight Crohn's disease, a remarkable milestone. The DDNC encourages the subcommittee to continue its support of IBD research at NIDDK and NIAID at a level commensurate with the overall increase for each institute. The DDNC would like to applaud the NIDDK for its strong commitment to IBD research through the Inflammatory Bowel Disease Genetics Research Consortium. The DDNC urges the Consortium will continue its work in IBD research. The DDNC would also commend NIDDK for organizing and hosting the upcoming meeting entitled: "Research on Inflammatory Bowel Disease", later this month.

Given the recent advancements in treatment for these diseases and the increased risk that IBD patients have for developing colorectal cancer, the DDNC strongly believes that generating improved epidemiological information on the IBD population is essential if we are to provide patients with the best possible care. Therefore the DDNC and its member organization the Crohn's and Colitis Foundation of America encourage the CDC to initiate a nationwide IBD surveillance and epidemiological program in fiscal year 2005.

HEPATITIS C: A LOOMING THREAT TO HEALTH

It is estimated that there are over 4 million Americans who have been infected with Hepatitis C of which over 2.7 million remain chronically infected. About 10,000 die each year and the Centers for Disease Control and Prevention (CDC) estimates that the death rate will more than triple by 2010 unless there is additional research, education, and more effective treatments and public health interventions. Hepatitis C infection is the largest single cause for liver transplantation and one of the principal causes of liver cancer and cirrhosis. There is currently no vaccine for hepatitis C, and treatment has limited success, making the infection among the most costly diseases in terms of health care costs, lost wages, and reduced productivity. Patients who are older at the time of infection, those who continually ingest alcohol, and those co-infected with HIV demonstrate accelerated progression to more advanced liver disease.

The DDNC applauds all the work NIH and CDC have accomplished over the past year in the areas of hepatitis and liver disease. An example of this commitment has been the convening of the second National Institutes of Health Management of Hepatitis C Consensus Development Conference, which occurred in June 2002. The Conference made 17 specific and high priority research recommendations that need to be pursued to develop better treatments and a cure for hepatitis. The DDNC urges

that these recommendations be funded in fiscal year 2005. The DDNC also commends NIDDK for the establishment of the Biliary Atresia Research Consortium and the Adult-to-Adult Living Donor Liver Transplant Cohort Study. The convening of conferences on Hepatitis C and Renal Disease and Hepatitis C in Prisons, plus the New Direction for Therapy of Primary Biliary Cirrhosis are just some more positive examples of the work NIDDK has undertaken to combat hepatitis and liver disease. The DDNC urges NIDDK to continue support research in this area.

The DDNC supports $30 million for the CDC's Hepatitis Prevention and Control activities. The hepatitis division at CDC supports the hepatitis C prevention strategy and other cooperative nationwide activities aimed at prevention and awareness of hepatitis A, B, and C. The DDNC also urges the CDC's leadership and support for the National Viral Hepatitis Roundtable to establish a comprehensive approach among all stakeholders for viral hepatitis prevention, education, strategic coordination, and advocacy.

COLORECTAL CANCER PREVENTION

Colorectal cancer is the third most commonly diagnosed cancer for both men and woman in the United States and the second leading cause of cancer-related deaths. Colorectal cancer affects men and women equally. Although colorectal cancer is preventable and curable when polyps are detected early, a General Accounting Office report issued in March 2000 documented that less than 10 percent of Medicare beneficiaries have been screened for colorectal cancer. This report revealed a tremendous need to inform the public about the availability of screening and educate health care providers about colorectal cancer screening guidelines. In 2003, the New York City Department of Health has recommended colonoscopy for everyone over age 50 to prevent colorectal cancer.

The DDNC recommends a funding level of $25 million for the CDC's Colorectal Cancer Screening and Prevention Program. This important program supports enhanced colorectal screening and public awareness activities throughout the United States. The DDNC also supports the continued development of the CDC-supported National Colorectal Cancer Roundtable, which provides a forum among organizations concerned with colorectal cancer to develop and implement consistent prevention, screening, and awareness strategies.

PANCREATIC CANCER

In 2002, an estimated 28,300 people in the United States were found to have pancreatic cancer and approximately 28,200 died from the disease. Pancreatic cancer is the fifth leading cause of cancer death in men and women. Only 2 out of 10 patients will live 1 year after the cancer is found and only a very few will survive after 5 years. Although we do not know exactly what causes pancreatic cancer, several risk factors linked to the disease have been identified:

(1) *Age*.—Most people are over 60 years old when the cancer is found;

(2) *Sex*.—Men have pancreatic cancer more often than women;

(3) *Race*.—African Americans are more likely to develop pancreatic cancer than are white or Asian Americans;

(4) *Smoking*

(5) *Diet*.—Increased red meats and fats; and

(6) *Diabetes*

The National Cancer Institute (NCI) has established a Pancreatic Cancer Progress Review Group charged with developing a detailed research agenda for the disease. The DDNC commends NIDDK for the establishment in 2002 on an initiative entitled: *Liver, Pancreas, and Gastrointestinal Cell Genome Anatomy Project.* The DDNC hopes this new initiative will call more attention and greater resources to the diseases of the Pancreas. The DDNC encourages the Subcommittee to provide an increase for pancreatic cancer research at a level commensurate with the overall percentage increase for NCI and NIDDK.

IRRITABLE BOWEL SYNDROME (IBS)

IBS is a disorder that affects an estimated 35 million Americans. The medical community has been slow in recognizing IBS as a legitimate disease and the burden of illness associated with it. Patients often see several doctors before they are given an accurate diagnosis. Once a diagnosis of IBS is made, medical treatment is limited because the medical community still does not understand the pathophysiology of the underlying conditions.

Living with IBS is a challenge, patients face a life of learning to manage a chronic illness that is accompanied by pain and unrelenting gastrointestinal symptoms. Trying to learn how to manage the symptoms is not easy. There is a loss of spontaneity

when symptoms may intrude at any time. IBS is an unpredictable and fickle disease. A patient can wake up in the morning feeling fine and within a short time encounter abdominal cramping to the point of being doubled over in pain and unable to function.

The unpredictable bowel symptoms may make it next to impossible to leave your home. It is difficult to ease the pain than may repeatedly occur periodically throughout the day. A patient can become reluctant to eat for fear that just eating a meal will trigger symptoms all over again. IBS has a broad and significant impact on a person's quality of life. It strikes individuals from all walks of life and results in a significant toll of human suffering and disability.

While there is much we don't understand about the causes and treatment of IBS, we do know that IBS is a chronic complex of systems affecting as many as one in five adults. In addition:

—It is reported more by women than men;
—It is the most common gastrointestinal diagnosis among gastroenterology practices in the United States;
—It is a leading cause of worker absenteeism in the United States; and
—It costs the U.S. Health Care System an estimated $8 billion annually.

Mr. Chairman, much more can still be done to address the needs of the nearly 35 million Americans suffering from irritable bowel syndrome and other functional gastrointestinal disorders.

CELIAC DISEASE

Celiac Disease is a life-long condition in which the body develops an allergy to gluten, a protein found in wheat, barley, and rye, which can result in damage to the small intestine. Celiac disease affects as many as 2 million Americans. Onset of the disease can occur at any age. The common symptoms of Celiac Disease include fatigue, anemia, chronic diarrhea or constipation, weight loss, and bone pain. The only treatment for celiac disease is strict adherence to a gluten-free diet. Undiagnosed and untreated celiac disease can lead to other disorders such as osteoporosis, infertility, neurological conditions, and in rare cases cancer. Persons with Celiac Disease often have other associated autoimmune disorders as well.

The DDNC along with our Celiac Disease applauds the NIDDK for organizing and hosting the upcoming meeting entitled "Consensus Development Conference on Celiac Disease." The DDNC urges the Subcommittee to recommend more research, medical education, and public awareness around Celiac Disease.

The DDNC understand the challenging budgetary constraints and times we live in that is subcommittee is operating under, yet we hope you will carefully consider the tremendous benefits to be gained by supporting a strong research and education program at NIH and CDC. Millions of Americans are pinning their hopes for a better life, or even life itself, on digestive disease research conducted through the National Institutes of Health.

Mr. Chairman, on behalf of the millions of digestive disease sufferers, we appreciate your consideration of the views of the Digestive Disease National Coalition. We look forward to working with you and your staff.

Digestive Disease National Coalition

The Digestive Disease National Coalition was founded 25 years ago. Since its inception, the goals of the coalition have remained the same: to work cooperatively to improve access to and the quality of digestive disease health care in order to promote the best possible medical outcome and quality of life for current and future patients with digestive diseases.

PREPARED STATEMENT OF THE FIRST CANDLE/SUDDEN INFANT DEATH SYNDROME ALLIANCE

SUMMARY OF FISCAL YEAR 2005 RECOMMENDATIONS

—Provide a 10 percent increase for fiscal year 2005 to the National Institutes of Health (NIH) and a proportional increase of 10 percent to the individual institutes and centers, specifically, the National Institute of Child Health and Human Development (NICHD).
  —Transition from NICHD's successful SIDS 5-year research plan to a more comprehensive plan focusing on SIDS, stillbirth, and miscarriage.
—Continue to fund the SIDS and Other Infant Death Program Support Center at the Maternal and Child Health Bureau, within the Health Resources and Services Administration (HRSA).

—Fund 3 SIDS death scene protocol demonstration projects through the Centers for Disease Control and Prevention (CDC) in rural, urban, and suburban settings to provide a nation-wide protocol for dealing with SIDS death scenes.

Mr. Chairman and members of the Subcommittee, thank you for again allowing First Candle/SIDS Alliance the opportunity to submit testimony to this Subcommittee. First Candle is a national voluntary health organization uniting parents, caregivers, and researchers nationwide with government, business, and community service groups. Our mission is to promote infant health and survival during the prenatal period through 2 years of age through advocacy, education, and research, while at the same time providing compassionate grief support to those affected by an infant death.

Mr. Chairman, we still need your help, commitment, and support to help solve the mysteries of Sudden Infant Death Syndrome (SIDS) and stillbirth and ensure healthy pregnancies for all women.

Despite the fact that SIDS cases have been documented for years, organized scientific research into SIDS only began in the mid 1970's. In the three decades since, scientists are now beginning to make significant progress in unraveling this enigma of SIDS, which robs families of their infant children. As an example of this progress, we now know that in many SIDS related deaths there is an abnormality or underdevelopment in a region of the infant's brain, which is thought to control the heart and lung functions. In these cases, the irregularity may hamper normal respiratory activity. While this may not be the sole cause of SIDS, it could contribute to a larger respiratory problem leading to death when combined with other circumstances.

As a direct result of SIDS research and the "Back to Sleep" educational and awareness campaign on infant sleep positioning, SIDS deaths have been reduced by 50 percent since 1992, leading to the greatest decline in infant mortality rates in over 20 years.

Despite this exceptional news, our research and educational campaign is far from finished. There are still more than 2,500 SIDS deaths in the United States each year and SIDS continues to be the number one cause of death for children between 1 month and 1 year of age. SIDS is a major component of the United States infant mortality rate. In spite of these facts, we still do not yet understand the causes of SIDS nor do we possess any guaranteed method for its prevention.

Stillbirth is the death of an infant in-utero past 20 completed gestational weeks. The majority of these deaths occur at or near full-term; therefore, otherwise healthy babies die shortly before or during birth. There are more than 26,000 parents in the United States alone that experience a stillbirth annually, and it is estimated that nearly two-thirds of all stillbirth deaths remain unexplained. This translates to more than 70 stillborn babies delivered in the United States each day. More than half of these deaths are at 28 weeks or more gestation, and one in five full term babies are stillborn.

In spite of these statistics and the impact stillbirth has on families, little attention has been paid to the problem. There is a dire need for increased public awareness and federal funding to support stillbirth research and education programs. In 2003, NICHD committed $3 million to conduct five projects, which focus on central data collection and research protocols for stillbirth deaths. First Candle urges the Subcommittee to support continued funding for stillbirth research at NICHD.

First Candle is grateful for the Subcommittee's past support of SIDS activities, especially the support of NICHD. We urge you to again provide the additional funding necessary for the third Five-Year SIDS Research Plan to ensure that NICHD can continue to address critical SIDS research initiatives and expand on their recent funding for stillbirth research. Specifically, First Candle is supporting a funding increase of 10 percent for NIH overall, and a 10 percent increase for NICHD. We respectfully ask that the increases for NIH do not come at the expense of other Public Health Service agencies. Further research is essential to find the reasons for and means of preventing the tragedies of SIDS and stillbirth.

First Candle urges the Subcommittee to support infant death educational, awareness, and counseling activities that take place at the MCHB, and the death scene investigation protocol demonstration projects at the CDC. These programs are a vital companion to the research conducted at NICHD. Without prevention, awareness, counseling, and standardized investigation procedures, competent scientific research does not translate into meaningful advances for parents and families.

HIGHLIGHTS OF FEDERALLY FUNDED ACTIVITIES

National Institute of Child Health and Human Development (NICHD)

The mechanism of SIDS is still unknown; there are no clinical or biologic tests to identify a newborn at high risk of succumbing to SIDS; and more work is needed

to increase the implementation of "Back to Sleep" among all caregivers and in communities with high rates of infant death. To address and focus its efforts on these challenges, NICHD has developed and implemented three SIDS Five-Year Research Plans. Now that NICHD is focusing more globally on infant health, First Candle is encouraging the institute to transition from their successful SIDS 5-year research plan to a more comprehensive plan focusing on SIDS, stillbirth, and miscarriage.

Maternal and Child Health Bureau (MCHB)

First Candle has entered into a collaborative effort with MCHB to kickoff the "Healthy Child Care America Back to Sleep Campaign". This initiative builds on the success of the "Healthy Child Care America" and "Back to Sleep" campaigns to unite child care, health, and SIDS prevention partners across the country to reduce the number of SIDS-related deaths in child care settings.

The MCHB continues to support a number of SIDS and Other Infant Death related services and programs, including the following activities:

—National SIDS Resource Center, a major source of current information about SIDS.

—Maternal and Child Health Service Block Grant (MCH), which grants funds to states providing a range of services to SIDS families. Block grant funds support activities like: contact families immediately after death, discussion of autopsy results with the family, and support and counseling through the first year of bereavement. Unfortunately, in many jurisdictions across the country, funds for these services have been decreased or eliminated due to budgetary difficulties.

—Field training and curriculum to health care providers for case management of families who have experienced an infant death, and the development of model programs, particularly for the underserved and minorities. Demonstration grants have been established and are continuing in four states to target services for specific populations: California, Massachusetts, Missouri, and New York.

—National SIDS & Infant Death Program Support Center to address SIDS service issues at the federal level on an ongoing basis. First Candle runs this center, which opened in 1999, and has experienced notable success. The support center is working to expand bereavement services to family members of those who experience stillbirth and miscarriage.

Centers for Disease Control and Prevention (CDC)

To develop a better statistical figure on SIDS cases, Congress recommended in 1993 the establishment of a standard death scene protocol to offset discrepancies on unexplained infant deaths between states. It was hoped that this protocol would be adopted by states not only for statistical measure, but to help avoid what can become awkward and emotionally charged misunderstandings at the death scene. In 1996, CDC published the protocol, and since that time several states have adopted the standard. It is First Candle's long term goal to ensure that all states fully adopt and implement the protocol. To help realize this goal, First Candle would like Congress to appropriate funds for CDC to heed Congress' recommendations for the past several years and implement the demonstration projects that follow these guidelines in several community settings nationwide. We recommend a demonstration project in each of the following, a rural community setting, an urban community setting, and a suburban community setting. We would also encourage CDC to implement a nationwide survey to measure how many locales have already implemented the protocol independently and to analyze the results thus far.

In conclusion, we are all too painfully aware that SIDS has historically been a mystery, leaving in its wake devastated families and bewildered physicians. Not only have there been no answers on the cause of SIDS, but there have been no answers on how to effectively prevent its occurrence. Today we are beginning to find some of the answers on cause and prevention, and therefore reduce the risk of SIDS. Because of the "unknown", however, babies are still vulnerable even when parents and caregivers take the cautionary steps to prevent SIDS deaths. This tragedy will continue if research efforts are stalled or halted, especially when we are at the point where so much progress has been made. Now is the time for a re-energized effort against this tragic syndrome. Staggering statistics and the critical need for public awareness and research into the scope and causes of stillbirth has led to the joining together of parents and professionals to formally advocate for research into the causes and prevention of pre-term infant death. Now is the time for research into the horrible tragedy of stillbirth that too frequently becomes the outcome of a seemingly normal pregnancy.

On behalf of the thousands of families who have been devastated by the loss of a baby to SIDS, stillbirth, or miscarriage and the millions of concerned and fright-

ened parents, I ask for your support, and thank you again for allowing First Candle to submit this testimony.

First Candle/Sudden Infant Death Syndrome Alliance

First Candle/SIDS Alliance is an organization of parents and friends of SIDS, Stillbirth and Other Infant Death victims along with medical, business, and civic groups who are concerned about the health our nation's children. The Alliance is engaged in ongoing efforts to expand its scientific program, strengthen services for families, and provide public education and advocacy opportunities. An important goal is to improve community understanding and elevate SIDS, Stillbirth and Other Infant Death to the level of societal concern appropriate to one of our nation's major causes of infant mortality.

PREPARED STATEMENT OF THE NATIONAL SLEEP FOUNDATION

SUMMARY OF FISCAL YEAR 2005 RECOMMENDATIONS

—Provide a 10 percent increase for fiscal year 2005 to the National Institutes of Health (NIH) and a proportional increase of 10 percent to the individual institutes and centers, specifically, the National Heart, Lung, and Blood Institute (NHLBI).

—Urge the National Center on Sleep Disorders Research (NCSDR) to partner with other federal agencies, such as the Centers for Disease Control and Prevention (CDC), and voluntary health organizations, such as the National Sleep Foundation (NSF), to develop a collaborative sleep education and public awareness initiative.

Mr. Chairman and members of the Subcommittee, thank you for allowing me present testimony today on behalf of the National Sleep Foundation or NSF. I am Dr. James Walsh, Chairman of the Board of Directors of the National Sleep Foundation, Executive Director of the Sleep Medicine and Research Center affiliated with St. John's Mercy and St. Luke's Hospitals, and Clinical Professor of Psychiatry at St. Louis University. The National Sleep Foundation is an independent, non-profit organization whose mission is to enhance public awareness about the need for sufficient restorative sleep, to increase the detection and treatment of sleep disorders, to foster sleep-related programs and policy for the betterment of public health, and to promote sleep research. We work with thousands of sleep medicine and other health care professionals, researchers, patients, drowsy driving victims throughout the country, and collaborate with many government and private organizations with the goal of preventing health and safety problems related to sleep deprivation and untreated sleep disorders.

Sleep problems, whether in the form of medical disorders, or related to work schedules and a 24/7 lifestyle, are ubiquitous in our society. At least 40 million Americans suffer from sleep disorders; yet more than 60 percent of adults have never been asked about the quality of their sleep by a physician, and fewer than 20 percent have ever initiated such a discussion. Millions of individuals struggle to stay alert at school, on the job, and on the road. The latest estimates from the National Highway Transportation Safety Administration and the Federal Motor Carriers Safety Administration implicate fatigue and sleepiness in 1.1 million crashes annually. A recent study in Sweden showed that sleep disturbances are the second greatest risk factor for fatal accidents at work. Sleep apnea, a sleep-related breathing disorder which affects at least 5 percent of adult Americans, is closely related to some of America's most pressing health problems, such as obesity, hypertension, heart failure, and diabetes. Chronic insomnia, experienced by 10 percent of our population is a strong risk factor for depression and other widespread mental health conditions. Sleep disorders, sleep deprivation, and excessive daytime sleepiness add approximately $15 billion to our national health care bill each year. The National Center on Sleep Disorders Research estimates that by the year 2050, sleep problems will affect as many as 100 million Americans.

Sleep science has clearly demonstrated the importance of sleep to health and well being, yet research studies continue to show that millions of Americans are at risk for the serious health, safety consequences of sleep disorders and inadequate sleep. Moreover their quality of life suffers and the personal and national economic impact is staggering. NSF believes that every American needs to understand that good health includes healthy sleep, just as it includes regular exercise and balanced nutrition. We must elevate sleep to the top of the national health agenda. We need your help to make this happen.

Our biggest challenge is bridging the gap between the outstanding scientific advances we have seen in recent years and the level of knowledge about sleep held

by health care practitioners, educators, employers, and the general public. This gap in knowledge is being discussed as I present this testimony today, by hundreds of concerned professionals. Yesterday and today, the National Center on Sleep Disorders Research, the National Heart, Lung, and Blood Institute, and the Trans-NIH Sleep Research Coordinating Committee are sponsoring a translational conference entitled "Frontiers of Knowledge in Sleep and Sleep Disorders: Opportunities for Improving Health and Quality of Life." This two-day program has assembled health care providers, public health and education experts, policy makers, patient advocacy organizations, sleep medicine specialists, and other stakeholders. It is intended to address how information about sleep and sleep disorders can translate into improvements in public health and safety using cost-effective, comprehensive, and broadly-applied strategies for education, societal change, and improved sleep-related health care.

This conference is an important step in translating research into practice and into a broad-based public health message. The development of a sleep education and public awareness initiative would serve as a key legacy for the sleep translational conference and provide a forum for dissemination of the outcomes of the sleep translational conference. The National Sleep Foundation has been leading the way on public education regarding sleep and sleep disorders since it was founded in 1990. NSF and others have done a lot, but so much more needs to be done in order to educate the public and actually change behavior. Because resources are limited and the challenges great, we think creative and new partnerships need to be created to address the issues that are before us.

Therefore, we recommend that The National Center on Sleep Disorders Research be encouraged to partner with other federal agencies, such as the Centers for Disease Control and Prevention, and voluntary health organizations, such as NSF, to develop an ongoing, inclusive mechanism for public and professional awareness on sleep, sleep disorders, and the consequences of fatigue. Such a collaboration between federal agencies and voluntary health organizations would create an opportunity for dramatically improving public health and safety as well as the quality of life for millions, if not all, Americans.

Thank you again for the opportunity to present testimony before you today. I would be pleased to address any comments or questions.

PREPARED STATEMENT OF THE INTERNATIONAL FOUNDATION FOR FUNCTIONAL GASTROINTESTINAL DISORDERS

SUMMARY OF FISCAL YEAR 2005 RECOMMENDATIONS

—Provide a 10 percent increase, to $30.8 billion, for fiscal year 2005 to the National Institutes of Health (NIH) budget. Within NIH, provide proportional increases of 10 percent to the various institutes and centers, specifically, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). We request NIDDK's budget to be increased by 10 percent to $1.85 billion.
—Continue to accelerate funding for extramural clinical and basic functional gastrointestinal research at NIDDK.
—Continue to urge NIDDK to develop a strategic plan setting research goals on IBS and functional bowel diseases and disorders.
—Urge NIDDK to develop a standardization of scales to measure incontinence severity and quality of life and to develop strategies for primary prevention of fecal incontinence associated with childbirth.
—Provide funding to NIDDK and the National Cancer Institute (NCI) for more research on the causes of esophageal cancer.

Chairman Specter and members of the Subcommittee, thank you for the opportunity to present this written statement regarding the importance of functional gastrointestinal and motility research at the National Institutes of Health.

IFFGD, the International Foundation for Functional Gastrointestinal Disorders, has been serving the digestive disease community for 13 years. We work to broaden the understanding about functional gastrointestinal and motility disorders in adults and children.

Through publications, professional symposia, and other means IFFGD addresses issues and raises awareness about disorders and diseases that many people are uncomfortable and embarrassed to talk about. Bowel conditions are often hidden in our society. Not only are they misunderstood, but the burden of illness and human toll has not been fully recognized.

The majority of the diseases and disorders we address have no cure. We have yet to completely understand the pathophysiology of the underlying conditions. Many

patients face a life of learning to manage chronic illnesses that are often accompanied by pain and a variety of gastrointestinal symptoms. The costs associated with these diseases are great; conservative estimates range between $25–$30 billion annually. The human toll is not only on the individual but also on the family. Economic costs spill over into the workplace and every aspect of daily life. In essence these diseases reflect lost potential for the individual and society.

FECAL INCONTINENCE

At least 6.5 million Americans suffer from fecal incontinence. Incontinence is neither part of the aging process nor is it something that affects only the elderly. Incontinence crosses all age groups from children to older adults, but is more common among women and in the elderly of both sexes. Often it is a symptom associated with various neurological diseases and cancer treatments. Yet, as a society, we rarely hear or talk about the bowel disorders associated with multiple sclerosis, diabetes, colon cancer, uterine cancer, and a host of other diseases.

Causes of fecal incontinence are many and may include damage to the anal sphincter muscles, nerve damage, loss of storage capacity in the rectum, chronic diarrhea, or pelvic floor dysfunction. People who have fecal incontinence may feel ashamed, embarrassed, or humiliated. Society is not tolerant of loss of bowel control. Some individuals with incontinence don't want to leave the house out of fear they might have an episode of incontinence in public. Most try to hide the problem as long as possible and may not reveal it to their own doctor unless asked. Isolation adds to the burden of illness as these individuals withdraw from friends and family, and social support.

In November 2002, IFFGD sponsored, with NIH support, a multidisciplinary consensus conference—"Advancing the Treatment of Fecal and Urinary Incontinence Through Research: Trial Design, Outcome Measures, and Research Priorities." The proceedings were disseminated in the January 2004 Supplement of *Gastroenterology*, the journal of the American Gastroenterological Association. Among other outcomes, the conference resulted in six key research recommendations to address currently unmet needs:

1. More comprehensive identification of quality of life issues associated with fecal incontinence and improved assessment and communication of treatment outcomes related to quality of life.
2. Standardization of scales to measure incontinence severity and quality of life.
3. Assessment of the utility of diagnostic tests for affecting management strategies and treatment outcomes.
4. Development of new drug compounds offering new treatment approaches to fecal incontinence.
5. Development and testing of strategies for primary prevention of fecal incontinence associated with childbirth.
6. Further understanding of the process of stigmatization as it applies to the experience of individuals with fecal incontinence.

IRRITABLE BOWEL SYNDROME (IBS)

IBS affects between 25 and 45 million people of all ages in the United States (an estimated 10 to 15 percent of the population). The disorder affects people of all ages, even children. Approximately 60 to 65 percent of IBS sufferers in the United States are reportedly female and 35 to 40 percent are male. This chronic disease is characterized by a group of symptoms, which can include abdominal pain or discomfort associated with a change in bowel pattern, such as loose or frequent bowel movements, and/or hard or infrequent bowel movements. Although the cause of IBS is not understood, it is becoming clear that this disease needs a multidisciplinary approach in research.

Similar to other chronic illnesses and depending on severity, IBS can be emotionally and physically debilitating. Because of persistent, unpredictable, and often painful bowel symptoms, maintaining work or academic schedules becomes challenging. Individuals who suffer from this disorder may distance themselves from social activities and even may fear leaving their home.

In the House and Senate Fiscal Year 2004 Labor, Health and Human Services, and Education Appropriations bills, Congress recommended that the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) develop an IBS strategic plan. The development of a strategic plan on IBS would greatly increase the institute's progress toward the needed research on this functional gastrointestinal disorder.

GASTROESOPHAGEAL REFLUX DISEASE (GERD)

Gastroesophageal reflux disease, or GERD, is a very common disorder affecting both adults and children, which results from the back-flow of acidic stomach contents into the esophagus. GERD is often accompanied by persistent symptoms, such as chronic heartburn and regurgitation of acid. But sometimes there are no apparent symptoms, and the presence of GERD is revealed when complications become evident. Symptoms of GERD vary from person to person. The majority of people with GERD have mild symptoms, with no visible evidence of tissue damage and little risk of developing complications. However, periodic heartburn is a symptom so common that many people overlook its potential to cause tissue damage and disease. This is unfortunate because, through awareness and a diagnosis, individuals can receive one of several treatment options available for GERD. Untreated, GERD may lead to severe complications such as inflammation, stricture, or Barrett's esophagus, a potentially pre-cancerous condition.

Gastroesophageal reflux, involving regurgitation of gastric contents into the esophagus, affects as many as one-third or more of all full term infants born in America each year, but generally resolves by 6 to 12 months of age. Gastroesophageal reflux disease (GERD) results when symptoms persist or tissue damage occurs. Medical therapy may then be required in order to control the disease, which in infants commonly manifests as symptoms such as regurgitation with poor weight gain, esophagitis, respiratory symptoms, or irritability. In children and adolescents, the natural history of GERD is similar to that of adult patients, in whom GERD tends to be persistent and may require long-term treatment.

ESOPHAGEAL CANCER

Approximately 13,000 new cases of esophageal cancer are diagnosed every year in this country. Although the causes of this cancer are unknown, it is thought that it may be more prevalent in individuals who develop Barrett's esophagus. Diagnosis usually occurs when the disease is in an advanced stage; early effective screening tools are needed.

GASTROINTESTINAL MOTILITY DISORDERS

Gastrointestinal motility disorders can affect any part or parts of the gastrointestinal tract. Gastroparesis, chronic intestinal pseudo-obstruction (CIP), and Hirschsprung's disease, are just a few examples of gastrointestinal motility disorders.

Gastroparesis is a painful disorder where the nerves to the stomach are damaged or stop working, which leads to the stomach taking too long to empty its contents. Symptoms of gastroparesis can include: nausea, vomiting, early satiety or an early feeling of fullness when eating, weight loss, abdominal bloating, and abdominal discomfort. This disorder is often a complication of diabetes. An estimated 20 percent of people with type 1 diabetes develop gastroparesis. Individuals with type 2 diabetes can also develop gastroparesis.

Approximately, 200 new cases of Chronic Intestinal Pseudo-Obstruction or CIP are diagnosed in American children each year. This rare and serious disorder occurs when coordinated contractions, or peristalsis, in the intestinal tract become altered and inefficient. When this happens, nutritional requirements cannot be adequately met. CIP is often life threatening and treatment challenging. Continued clinical and basic research is needed before the disease is fully understood, and improved treatment or ultimately a cure found.

Hirschsprung's disease (HD) is a serious and sometimes life-threatening congenital disorder that is caused by absence of nerve cells in the rectum and/or colon, which can cause obstruction, inflammation, and severe constipation. It occurs in about one out of every 5,000 American children born each year. The treatment is primarily surgical to remove the abnormal bowel. Approximately 10–20 percent of children with HD will continue to have complications following surgery. These complications include infection, fecal incontinence, and persistent constipation.

FUNCTIONAL GASTROINTESTINAL AND MOTILITY DISORDERS AND THE NATIONAL INSTITUTES OF HEALTH

The International Foundation for Functional Gastrointestinal Disorders recommends an increase to $30.8 billion or 10 percent for NIH overall, and a 10 percent increase for NIDDK, or $1.85 billion. However, we request that this increase for NIH does not come at the expense of other Public Health Service agencies.

We urge the subcommittee to provide the necessary funding for the expansion of the NIDDK's research program on functional gastrointestinal (GI) and motility dis-

orders, this increased funding will allow for the growth of new research, a prevalence study and a strategic plan on IBS, and increased public and professional awareness of functional GI and motility disorders.

A primary goal of IFFGD's mission is to ensure that advancements concerning GI disorders result in improvements in care and the quality of life of those affected. As we all work together, it is hoped this goal will be realized and the suffering and pain millions of people face daily will end.

Mr. Chairman, on behalf of millions of patients and the families of those with functional GI or motility disorders thank you for your consideration.

The International Foundation for Functional Gastrointestinal Disorders

The International Foundation for Functional Gastrointestinal Disorders is a nonprofit education and research organization founded in 1991. IFFGD addresses the issues surrounding life with gastrointestinal (GI) functional and motility disorders and increases the awareness about these disorders among the general public, researchers, and the clinical care community.

PREPARED STATEMENT OF THE HEPATITIS FOUNDATION INTERNATIONAL

SUMMARY OF FISCAL YEAR 2005 RECOMMENDATIONS

—Continue the great strides in research and prevention at the National Institutes of Health (NIH) by providing a 10 percent budget increase for fiscal year 2005. Increase funding for the National Institute for Allergy and Infectious Diseases (NIAID) and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) by 10 percent.

—$41 million in fiscal year 2005 for a hepatitis B vaccination program for high risk adults at CDC as recommended by the National Hepatitis C Prevention Strategy.

—$40 million in fiscal year 2005 for CDC's Prevention Research Centers.

—Continued support of the National Viral Hepatitis Roundtable.

Mr. Chairman and members of the subcommittee thank you for your continued leadership in promoting better research, prevention, and control of diseases affecting the health of our nation. I am Thelma King Thiel, Chairman and Chief Executive Officer of the Hepatitis Foundation International (HFI), representing members of 425 patient support groups across the nation, the majority of whom suffer from chronic viral hepatitis.

Currently, five types of viral hepatitis have been identified, ranging from type A to type E. All of these viruses cause acute, or short-term, viral hepatitis. Hepatitis B, C, and D viruses can also cause chronic hepatitis, in which the infection is prolonged, sometimes lifelong. While treatment options are available for all types of hepatitis, individuals with chronic viral hepatitis (types B, C, and D) represent the majority of liver failure and transplant patients. Treatment options and immunizations are available for most types of hepatitis (see below). However, all types of viral hepatitis are preventable.

HEPATITIS A

The hepatitis A virus (HAV) is contracted through fecal/oral contact (i.e. fecal contamination of food, or diaper changing tables if not cleaned properly), and sexual contact. In addition, eating raw or partially cooked shellfish contaminated with HAV can spread the virus. Children with HAV usually have no symptoms; however, adults may become quite ill suddenly experiencing jaundice, fatigue, nausea, vomiting, abdominal pain, dark urine/light stool, and fever. There is no treatment for HAV; however, recovery occurs over a 3 to 6 month period. About 1 in 1,000 with HAV suffer from a sudden and severe infection that may require a liver transplant. Luckily, a highly effective vaccine can prevent HAV. This vaccination is recommended for individuals who have chronic liver disease (i.e. HCV or HBV) or clotting factor disorders, in addition to those who travel or work in developing countries.

HEPATITIS B

Hepatitis B (HBV) claims an estimated 5,000 lives every year in the United States, even though we have therapies to both prevent and treat this disease. This disease is spread through contact with the blood and body fluids of an infected individual. Unfortunately, due to both a lack in funding to vaccinate adults at high risk of being infected and the absence of an integrated preventive education strategy, transmission of hepatitis B continues to be problematic. Additionally, there are sig-

nificant disparities in the occurrence of chronic HBV-infections. Asian Americans represent four percent of the population; however, they account for over half of the 1.3 million chronic hepatitis B cases in the United States. Current treatments have limited success in treating the chronically infected and there is no treatment available for those who are considered "HBV carriers." Preventive education and vaccination are the best defense against hepatitis B.

HEPATITIS C

Infection rates for hepatitis C (HCV) are at epidemic proportions. Unfortunately, as many are not aware of their infection until several years after infection, we are dealing with an "epidemic of discovery." This creates a vicious cycle, as individuals who are infected continue to spread the disease, unknowingly. Hepatitis C is also spread through contact with an infected individual's blood. The CDC estimates that there are over 4 million Americans who have been infected with hepatitis C, of which over 2.7 million remain chronically infected, with 8,000–10,000 deaths each year. Additionally, the death rate is expected to triple by 2010 unless additional steps are taken to improve outreach and education on the prevention of hepatitis C, new research is undertaken, and case-finding is enhanced and more effective treatments are developed. As there is no vaccine for HCV, prevention education and treatment of those who are infected serve as the most effective approach in halting the spread of this disease.

PREVENTION IS THE KEY

Only a major investment in immunization and preventive education will bring these diseases under control. All newborns, young children, young adults, and especially those who participate in high-risk behaviors must be a priority for immunization, outreach initiatives and preventive education. We recommend that the following activities be undertaken to prevent the further spread of all types of hepatitis:

—Provide effective preventive education in our elementary and secondary schools helping children avoid the ravages of health problems resulting from viral hepatitis infection.
—Training educators, health care professionals, and substance abuse counselors in effective communication and counseling techniques.
—Public awareness campaigns to alert individuals to assess their own risk behaviors, motivate them to seek medical advice, encourage immunization against hepatitis A and B, and to stop the consumption of any alcohol if they have participated in risky behaviors that may have exposed them to hepatitis C.
—Expansion of screening, referral services, medical management, counseling, and prevention education for individuals who have HIV/AIDS, many of whom may be co-infected with hepatitis.

HFI recommends an increase of $41 million in fiscal year 2005 for further implementation of CDC's Hepatitis C Prevention Strategy. This increase will support and expand the development of state-based prevention programs by increasing the number of state health departments with CDC funded hepatitis coordinators. The Strategy will use the most cost-effective way to implement demonstration projects evaluating how to integrate hepatitis C and hepatitis B prevention efforts into existing public health programs. Additionally, HFI recommends that $10 million be used to train and maintain hepatitis coordinators in every state.

CDC's Prevention Research Centers, an extramural research program, plays a critical role in reducing the human and economic costs of disease. Currently, CDC funds 26 prevention research centers at schools of public health and schools of medicine across the country. HFI encourages the Subcommittee to increase core funding for these prevention centers, as it has been decreasing since this program was first funded in 1986. We recommend the Subcommittee provide $40 million for the Prevention Research Centers program in fiscal year 2005.

INVESTMENTS IN RESEARCH

Investment in the National Institutes of Health (NIH) has led to an explosion of knowledge that has advanced understanding of the biological basis of disease and development of strategies for disease prevention, diagnosis, treatment, and cures. Countless medical advances have directly benefited the lives of all Americans. NIH-supported scientists remain our best hope for sustaining momentum in pursuit of scientific opportunities and new health challenges. For example, research into why some HCV infected individuals resolve their infection spontaneously may prove to be life saving information for others currently infected. Other areas that need to be addressed are:

—Reasons why African Americans do not respond to antiviral agents in the treatment of chronic hepatitis C.
—Pediatric liver diseases, including viral hepatitis.
—The outcomes and treatment of renal dialysis patients who are infected with HCV.
—Co-infections of HIV/HCV and HIV/HBV positive patients.
—Hemophilia patients who are co-infected with HIV/HCV and HIV/HBV.
—The development of effective treatment programs to prevent recurrence of HCV infection following liver transplantation.
—The development of effective vaccines to prevent HCV infection.

The Hepatitis Foundation International supports a 10 percent increase for NIH in fiscal year 2005. HFI also recommends a comparable increase of 10 percent in hepatitis research funding at the National Institute of Diabetes and Digestive and Kidney Diseases and the National Institute of Allergy and Infectious Diseases.

NATIONAL VIRAL HEPATITIS ROUNDTABLE

Victims of hepatitis suffer emotionally as well as physically. They experience discrimination in employment, strained personal relationships and severe depression when treatments fail to control their illness as well as during their treatment. Traditionally, however, there has not been an organized effort to periodically convene all stakeholder organizations that play a role in hepatitis prevention, education, treatment and patient advocacy. Successfully addressing viral hepatitis will require a comprehensive and strategic approach developed by all key stakeholders.

In order to fill this void, HFI and CDC co-founded the "National Viral Hepatitis Roundtable." HFI believes that a National Viral Hepatitis Roundtable will enhance and assist CDC's viral hepatitis mission for the prevention, control, and elimination of hepatitis virus infections in the United States, as well as the international public health community. It will provide an infrastructure for the sharing of information and education of all stakeholders.

The "National Viral Hepatitis Roundtable" is a coalition of public, private, and voluntary organizations dedicated to reducing the incidence of infection, morbidity, and mortality from viral hepatitis in the United States through research, strategic planning, coordination, advocacy, and leadership.

HFI is dedicated to the eradication of viral hepatitis, which affects over 500 million people around the world. We seek to raise awareness of this enormous worldwide problem and to motivate people to support this important—and winnable—battle. Thank you for providing this opportunity to present our testimony.

The Hepatitis Foundation International

The Hepatitis Foundation International (HFI) is dedicated to the eradication of viral hepatitis, a disease affecting over 500 million people around the world. We seek to raise awareness of this enormous worldwide problem and to motivate people to support this important—and winnable—battle.

Our mission has four distinct parts:
—Teach the public and hepatitis patients how to prevent, diagnose, and treat viral hepatitis.
—Prevent viral hepatitis by promoting liver wellness and healthful lifestyles.
—Serve as advocates for hepatitis patients and the related medical community worldwide.
—Support research into prevention, treatment, and cures for viral hepatitis.

PREPARED STATEMENT OF THE CHARLES R. DREW UNIVERSITY OF MEDICINE AND SCIENCE

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2005

—A 10 percent increase for all institutes and centers at the National Institutes of Health (NIH), specifically the National Center for Research Resources (NCRR), the National Center for Minority Health and Health Disparities (NCMHD), and the National Cancer Institute (NCI).
—Urge NCI to continue to support the establishment of collaborative minority health comprehensive cancer centers at historically minority institutions in collaboration with existing NCI cancer centers. Continue to urge NCRR and NCMHD to collaborate on the establishment of a cancer center at a historically minority institution.

—Urge the Department of Health and Human Services, particularly the Office of Minority Health (OMH), to develop a focused effort on faculty support to address the residency training programs at minority medical institutions.

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present you with testimony. Charles R. Drew University is one of four predominantly minority medical schools in the country, and the only one located west of the Mississippi River.

Charles R. Drew University of Medicine and Science is located in the Watts-section of South Central Los Angeles, and has a mission of rendering quality medical education to underrepresented minority students, and, through its affiliation with the University of California Los Angeles (UCLA) at the co-located King-Drew Medical Center, Drew provides valuable health care services to the medically underserved community. Through innovative basic science, clinical, and health services research programs, Drew University works to address the health and social issues that strike hardest and deepest among inner city and minority populations.

The population of this medically underserved community is predominately African American and Hispanic. Many of these people would be without health care if not for the services provided by the King-Drew Medical Center and Charles R. Drew University of Medicine and Science. This record of service has led Charles R. Drew University (in partnership with UCLA School of Medicine) to be designated as a Health Resources and Services Administration Minority Center of Excellence.

A RESPONSE TO HEALTH DISPARITIES

Racial and ethnic disparities in health outcomes for a multitude of major diseases in minority and underserved communities continue to plague this nation that was built on a premise of equality. As articulated in the Institute of Medicine report entitled "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care", this problem is not getting better on its own. For example, African American males develop cancer 15 percent more frequently than white males. Similarly, African American women are not as likely as white women to develop breast cancer, but are much more likely to die from the disease once it is detected. In fact, according to the American Cancer Society, those who are poor, lack health insurance, or otherwise have inadequate access to high-quality cancer care, typically experience high cancer incidence and mortality rates. Despite these devastating statistics, we are still not doing enough to try to combat cancer in our communities.

In response to these findings and the high cancer rate in our own community, Charles R. Drew University of Medicine and Science proposes that a Minority Health Comprehensive Cancer Center be built on its campus.

The Center would specialize in providing not only medical treatment services for the community, but would also serve as a research facility, focusing on prevention and the development of new strategies in the fight against cancer.

Mr. Chairman, the support that this subcommittee has given to the National Institutes of Health (NIH) and its various institutes and centers has and continues to be invaluable to our University and our community. The dream of a state of the art facility to aid in the fight against cancer in our underserved community would be impossible without the resources of NIH.

To help facilitate the establishment of a Minority Health Comprehensive Cancer Center at Charles R. Drew University of Medicine and Science, the University is seeking support from the National Institutes of Health's National Center for Research Resources (NCRR), the National Center for Minority Health and Health Disparities (NCMHD), and the National Cancer Institute (NCI).

ACADEMIC RENEWAL AND CLINICAL FACULTY RECRUITMENT

Some of the major challenges faced in sustaining high quality graduate medical education programs in "safety-net" medical centers with missions focused on the medically underserved, are directly related to the lack of sufficient numbers of clinical faculty highly trained in academic medicine. To address these challenges, a plan for academic enrichment is proposed.

The plan is a strategic initiative to position Charles R. Drew University in the first decade of the 21st Century, as a leader in Urban Academic Health Sciences with an emphasis on training physicians and other health professionals to meet the needs of the medically underserved. The Plan for Academic Enrichment is an opportunity to enhance the impact of Charles R. Drew University as a national center of excellence in meeting the national, state, and local challenge of preparing a diverse complement of excellent physicians and other health professionals to close the health disparity gap by affording culturally sensitive quality care to the medically underserved and economically disadvantaged. A central component of the plan is the

enrichment of academic excellence through the recruitment of new, highly qualified clinical teaching faculty, with solid research skills, to be members of the Charles R. Drew College of Medicine faculty to strengthen both the graduate and undergraduate medical education programs.

CONCLUSION

Despite our knowledge about racial/ethnic, socio-cultural and gender-based disparities in health outcomes, the "gap" continues to widen in most instances. Not only are minority and underserved communities burdened by higher disease rates, they are less likely to have access to quality care upon diagnosis. As you are aware, in many minority and underserved communities preventive care and/or research is completely inaccessible either due to distance or lack of facilities and expertise. This is a critical loss of untapped potential in both physical and intellectual contributions to the entire society.

Even though institutions like Drew are ideally situated (by location, population, and institutional commitment) for the study of conditions in which health disparities have been well documented, research is limited by the paucity of appropriate research facilities. With your help, this cancer center will facilitate translation of insights gained through research into greater understanding of disparities in cancer incidence, morbidity and mortality and ultimately to improved outcomes.

We look forward to working with you to lessen the burden of cancer for all Americans through greater understanding of cancer, its causes, and its cures. We also look forward to working with the Department of Health and Human Services to address the residency training program issues at Charles R. Drew University.

Mr. Chairman, thank you for the opportunity to present on behalf of Charles R. Drew University of Medicine and Science.

PREPARED STATEMENT OF MENDED HEARTS, INC.

I am Robert H. Gelenter, the legal representative for the Mended Hearts, Inc, a national heart disease patient support group of more than 289 chapters across the country and in Canada. We visit patients in about 460 hospitals throughout the United States. I have been appointed by the group to assist in this lobbying effort—a volunteer position.

More than 28 years ago, I was diagnosed with a rare heart disease. After having severe chest pains and trouble breathing for more than 2 years, I was diagnosed with hypertrophic cardiomyopathy, a disease in which the heart enlarges. The heart muscle eventually thickens so much that it can't pump blood effectively and does not grow in the normal parallel patterns. An estimated 36 percent of young athletes who die suddenly die from this disease. But, it affects men and women of all ages. It is sudden and one of the things known about this disease is sudden cardiac death. There is no cure for this disease. Medication may work and there is surgery that may or may not alleviate the pain. If that doesn't work a patient may need a heart transplant, yet spare organs are scarce. The doctor who made my diagnosis was trained at the National Heart, Lung, and Blood Institute of the National Institutes of Health.

Initially, I received several medications which allowed me to engage in most activities. But, some activities, such as walking up hills, gave me problems like shortness of breath and severe chest pains. But, generally I could function normally. However, after about 11 years, the discomfort was increasing, and it became apparent that I was in serious trouble. I could not walk 60 feet without having to stop to catch my breath. Sometimes the pain was so great that I would almost double over in the middle of the street. My wife told me that my face would become gray. The perspiration would pour off by body. If I was lucky I could find a chair to sit on. The quality of my life had deteriorated so drastically that I knew I needed some treatment.

Finally in 1988, I went to Georgetown University Medical Center for an angiogram—the gold standard for diagnosing heart problems. The cardiologist who performed the angiogram told me that he had bad news and worse news. The bad news was that I had a 95 percent blockage in my left anterior descending heart artery—the so-called "widow makers spot." The worse news was that I had a major chance of having a major heart attack with a less than a 5 percent chance of surviving that heart attack because of the hypertrophic cardiomyopathy. At this point, my wife was quietly crying and I was perspiring profusely. Since Georgetown University Medical Center did not have the expertise to operate on me, they called the NIH to see if they would accept me as a patient. I was sent home pending notice from the NIH.

My parents begged me to go to New York or San Francisco for second opinions. But, I knew that I had run out of alternatives. No matter what the result, I needed treatment and I needed it immediately.

I was accepted by the NIH. After entering the National Heart, Lung, and Blood Institute on February 6, I was operated on February 11, 1988. No matter how trite the expression—that was the first day of the rest of my life. The surgery, considered drastic and rare, is still considered the gold standard throughout the world for the treatment of hypertrophic cardiomyopathy. The Murrow Procedure, in honor of the creator, was developed and improved at the NIH.

Although this surgery is no longer performed at the National Heart, Lung, and Blood Institute, there is another experimental ongoing protocol in which the same effect is being attempted by using alcohol to deaden the excessive heart tissue.

Now, I am on medication for the rest of my life. My condition is progressive. Eight years ago, I was fitted with a pacemaker to insure that my heart beats at the correct rate. I am 100 percent dependent on this pacemaker. Without the pacemaker, there are times when my normal heart beat is so slow that I would die.

I am eternally grateful to the physicians funded by the National Heart, Lung, and Blood Institute, particularly to Dr. MacIntosh and his staff, for the gift of life. Because of this marvelous research supported by the NHLBI, I have lived 15 years pain free. I have seen two children graduate from college and three grandchildren born, I have shared these years with a wonderful wife. I have been able to work at my profession—an attorney at law.

I have had the gift of life restored to me. So to express my gratitude for that gift, I visit patients recovering from heart episodes at two hospitals, Washington Hospital Center and Washington Adventist Hospital.

I ask for an fiscal year 2005 appropriation of $3.5 billion for the NHLBI, including $2.1 billion for its heart disease and stroke-related budget.

My experience is the proof that the research supported by the National Heart, Lung, and Blood Institute benefits not just the patients at the NIH Clinical Center, but throughout the United States. The benefits go worldwide as well.

Heart attack, stroke and other cardiovascular diseases remain the No. 1 killer and major cause of disability of men and women in the United States. Nearly 40 percent of people who die in the United States die from cardiovascular diseases. This year, more than 930,000 Americans will die from cardiovascular diseases, including almost 150,000 under the age of 65.

Thank you for your support of National Heart, Lung, and Blood Institute's heart research.

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF CARDIOLOGY

INTRODUCTION

The American College of Cardiology (ACC) is a 30,890 member non-profit professional medical society and teaching institution whose mission is to advocate for quality cardiovascular care—through education, research promotion, development and application of standards and guidelines—and to influence health care policy. The College represents more than 90 percent of the cardiovascular specialists practicing in the United States. The ACC submits for the record this statement of support for increased funding for heart-related research through the National Heart, Lung, and Blood Institute (NHLBI) in fiscal year 2005, as well as support for increased funding for the Agency for Health Care Research and Quality (AHRQ), education and awareness programs through the Centers for Disease Control and Prevention (CDC) State Heart Disease and Stroke Prevention Program, and state and local programs designed to increase public access to automated external defibrillators (AEDs).

The ACC expresses its appreciation to Congress for successfully completing the doubling of the NIH budget by fiscal year 2003. Although the increase in funding has greatly benefited cardiovascular-related research, the National Institutes of Health (NIH) still invests only 8 percent of its budget on heart research and a mere 1 percent on stroke research—a funding level that fails to reflect that 40 percent of all deaths in this country are attributable to cardiovascular disease. The ACC appreciates current budget constraints, but hopes this subcommittee will continue its commitment toward medical research funding and the improvement of public health in the fiscal year 2005 budget. According to a recent study conducted by MEDTAP International and co-sponsored by the ACC, national health advancements since 1980 are due primarily to investments in health care, and for each additional dollar

spent in the United States for health care services $2.40 to $3.00 in tangible gains have been made.

The ACC, however, is concerned that President Bush's proposed fiscal year 2005 budget calls for only a 2.6 percent increase above fiscal year 2004 levels for the NIH and only a 0.3 percent increase for the CDC's Heart Disease and Stroke Prevention Program. Low-level funding increases for NIH, in addition to inadequate funding levels proposed in the President's budget for enhanced public access to AEDs, and the flat-funding proposed for the AHRQ, is of great concern to the ACC and its members.

Cardiovascular disease continues to claim more lives each year than the next seven leading causes of death combined. Recent data shows that in 2001 more than 64 million Americans were shown to have suffered from at least one form of cardiovascular disease, of which nearly 1 million died as a direct result. The overall (indirect and direct) cost of cardiovascular disease for 2004 is estimated to be at least $368.4 billion. Heart disease is not only tragically rampant in the United States, but it is also financially burdensome. The ACC believes that further investment in life-saving research, as well as in education and awareness programs, is essential to combat the leading cause of death of men and women in this country.

The ACC Supports the Following fiscal year 2005 Appropriations Funding Levels:

—NIH (overall funding)—$30.6 billion

—NHLBI—$3.5 billion (includes $2.1 billion for heart- and stroke-related activities)

—AHRQ—$443 million

—CDC State Heart Disease and Stroke Prevention Program—$80 million

—Community and Rural AED Access—$45 million

MEDICAL RESEARCH

The ACC believes that the federal government must expand its financial commitment to medical research, most specifically at the NHLBI, through support for the NIH and its new "NIH Roadmap" initiative which was initiated at NIH to help identify major opportunities and gaps in biomedical research and allow for greater collaboration between all NIH institutes. Increased NHLBI funding over the years has allowed investigators to develop better diagnostic tools and surgical techniques, as well as study new methods of treatment for cardiac patients. We must aim for better patient prevention, early cardiovascular disease diagnoses, and improved treatment of our patients. As such, the ACC is particularly supportive of initiatives related to clinical cardiology and issues of clinical relevance to the practice of cardiology. The ACC also firmly believes in the value of promoting clinical investigative careers and of large-scale clinical trials which aid the discovery and application of therapeutic and/or medical treatments to cardiovascular disease. In addition, the ACC would like to stress the importance of funding the AHRQ at a level that allows for their continued application of research to cardiovascular care. AHRQ activities play a large role in ensuring that our members can provide patients with the most up-to-date and effective treatments available.

Research Success Due to Past Legislative Investment in NHLBI

Another major advancement during the NIH doubling was with the implementation of a major clinical trial testing approaches to lowering the risk of cardiovascular disease in adults with Type 2 diabetes. Seventy percent of Americans diagnosed with Type 2 diabetes ultimately die of cardiovascular disease. The ACC is quite concerned about the cardiovascular health impact of diabetes and obesity in Americans, particularly in children. This trial, referred to as Action to Control Cardiovascular Risk in Diabetes (ACCORD) evaluates the effects of intense blood sugar control along with very aggressive control of blood pressure and lipids. The overall goal of ACCORD is to discover a better treatment for those suffering from Type 2 diabetes than is presently available. The ACC is pleased to see research attention being paid to the correlation of diabetes and metabolic syndromes with cardiovascular disease, because this devotion of resources helps to gain a better understanding of and treatment methods for these debilitating diseases.

Research Success Due to Investments in Women and Heart Disease

This year, more women than men will die from cardiovascular disease, making the inclusion of women in more heart-related research studies absolutely integral. Since 1984, men have experienced a decline in deaths due to cardiovascular disease, yet despite a growing number of female-specific research initiatives, women have not yet experienced this decline.

To this end, the ACC is proud to be participating in several national campaigns this year that help raise awareness about the incidence and morbidity of heart dis-

ease and stroke in women, including the NHLBI's The Heart Truth, and the American Heart Association's "Go Red for Women." In addition, on February 20, 2004, the ACC teamed with the Sister to Sister Foundation for its National Woman's Heart Day to help provide free screenings, educational seminars, cardiovascular health information, and fitness and cooking demonstrations to women around the country. The ACC is pleased that new clinical studies are underway at NIH that will hopefully help clarify the gender differences that directly affect diagnosis and treatment of women with heart disease.

Women's Health Initiative

Thanks to Congress' financial commitment during the doubling of the NIH budget, the NHLBI was able to proceed with the Women's Health Initiative (WHI) which yielded the first conclusive evidence of risks associated with long-term estrogen plus progestin hormone replacement therapy (HRT). This groundbreaking discovery changed the delivery of care for millions of American women and raised the public's awareness regarding heightened risks for heart attack, stroke and/or blood clots during long-term HRT use. The ACC was pleased by the findings yielded through the WHI and would like to see continued research focused on the unique causes and outcomes of heart disease in women. The ACC also believes that only through randomized clinical trials can we fully understand how medicines and devices affect human health.

Women's Ischemia Syndrome Evaluation

The Women's Ischemia Syndrome Evaluation (WISE) Study is a four-center, NHLBI study evaluating approximately 1,000 women referred for elective diagnostic coronary angiography because of suspected ischemia, a shortage of oxygen and blood to the heart muscle. It is the largest NIH-funded study dedicated solely to women, with the goal of examining the nature and scope of gender differences in both chronic and acute cardiac ischemia.

Prior reports suggested that, compared with men, clinical manifestations of ischemic heart disease in women appear approximately 10 or more years later. Women demonstrate more symptoms suggesting ischemic heart disease, yet the symptoms in women, such as chest discomfort and dyspnea, are more difficult to interpret.

There is now a better snapshot of the extent of cardiovascular disease in women, thanks to WISE Study findings revealed at the ACC Annual Scientific Session in March 2004 (ACC 2004) by Barry L. Sharaf, M.D., F.A.C.C. Based on the 4-year, risk-adjusted outcomes by extent of coronary disease, there was a 9.4 percent death or myocardial infarction (MI) rate (or about 2.7 percent annually) in women with minimal or no symptoms of disease detected by angiography. This is an unacceptable event rate. In another presentation by Leslee J. Shaw, Ph.D., at ACC 2004 regarding the WISE Study, the estimated lifetime cost of care for cardiovascular disease detected by angiography was detailed. Dr. Shaw found that women with no disease detectable by angiography have in excess of three-quarters of a million dollars lifetime costs for care. In an era of shrinking health care resources, such a high cost is unsustainable. This high rate of death or myocardial infarction, combined with escalating health care costs, clearly demonstrates the need for improved detection of cardiovascular disease in women.

The ACC believes it is imperative to increase awareness among women about their risk of heart disease. Thanks to findings yielded from the WISE Study, cardiovascular specialists are gaining a better understanding that there is a "female-pattern" of ischemia-related symptoms that is distinct from that seen in men. Cardiologists have also come to understand that a "clean" angiogram in symptomatic women does not mean a benign outcome. The ACC believes that the WISE Study discoveries are a good start in unraveling the mystery of women and heart disease, but more research looking at issues like concealed plaque and inflammation in the vessel wall, the prognostic ability of blood markers, and the role of the microvasculature, needs to be conducted.

NHLBI Research Opportunities Threatened by President's Fiscal Year 2005 2.5 Percent Funding Increase

Much progress has been made in cardiovascular research and clinical trials to this date, but the ACC believes that if the numbers proposed in the President's fiscal year 2005 budget are instituted new and exciting opportunities could be postponed if not cancelled, and the continuation and/or expansion of current NHLBI cardiovascular research programs could also be threatened. The ACC encourages Congress to take necessary steps to avoid such a predicament through funding the NHLBI at $3.5 billion in fiscal year 2005, so that the following fundamentally important programs among others have a chance of development.

Enhancing the Use of Longitudinal Data on Cardiovascular Disease and its Risk Factors in Older Adults: The Cardiovascular Health Study (CHS)

This initiative would allow for continued utilization of the data and specimens collected during the CHS study which began in 1987 and is set to terminate in 2005. Specifically, the initiative would ensure access to CHS data and specimens to the entire scientific community and allow for continued follow-up of study participants. Investigators are particularly interested in the research and treatment of cardiovascular disease in elderly patients (age 75 and older), a focus area which could be enhanced through the use of longitudinal data obtained by the CHS.

Randomized Trial of Heart Failure (HF) Management

ACC believes that the incorporation of clinical practice methods and provider education into NHLBI trials benefits not only cardiovascular patients but also the cardiologists who translate new therapies into regular cardiovascular care techniques. This trial is a perfect example of a mutually beneficial initiative. The multi-center/randomized trial would assess costs, quality of life, physician compliance, and patient adherence to prescribed treatments in order to identify and disseminate clinically useful and effective tools for translation of proven therapies for HF into clinical practice.

Community-Responsive Interventions to Reduce Cardiovascular Risk in American Indians and Alaska Natives

Despite the fact that American Indians and Alaska Natives are disproportionately affected by cardiovascular diseases, the President's 2.5 percent budget increase for NHLBI in fiscal year 2005 is inadequate for fostering the development of preventative intervention into community health care systems or through other health care means within American Indian and Alaska Native communities. If instituted within the fiscal year 2005 budget cycle, this NHLBI program would work to find solutions to obesity, diabetes, and cardiovascular diseases within these minority communities.

Priority Research Programs at NHLBI for Fiscal Year 2005

The NHLBI finds new and innovative methods for yielding research and clinical trial results year after year. These results, when translated into practice, ensure that cardiovascular specialists and other health care providers are able to provide patients with the highest quality care possible. Due largely to the medical research and education programs supported by the NHLBI, many Americans who suffer from or are at risk for cardiovascular disease now have access to a greater variety of diagnostic tests, medical treatments, and information about prevention. The research priorities set forth by the NHLBI are a direct result of input from health care community, including that of ACC members. The ACC believes it is imperative to appropriately fund the NHBLI in fiscal year 2005 so that the NHLBI can continue to create and implement ground-breaking cardiovascular research.

Last year, the ACC recommended the implementation of an NHLBI program titled "Overweight and Obesity Prevention and Control at the Worksite," which would support the design and testing of innovative worksite intervention to prevent and control overweight and obesity in adults. Almost two-thirds (61 percent) of American adults are overweight or obese, and each year an estimated 300,000 American adults die of causes related to obesity. The ACC is pleased that this program has officially gained NHLBI recognition and is being considered for implementation in fiscal year 2005. Some of the strategies within the program include implementing environmental and policy changes to increase employees' physical activity, offering healthful food choices in cafeterias and vending machines, and enhancing social support from fellow workers to encourage improved diet and physical activity. The ACC encourages Congress to concur with this NHLBI-recommended program and allow for full funding of the "Overweight and Obesity Prevention and Control at the Worksite" in fiscal year 2005.

Currently there is a growing need to address cardiovascular infections caused by the bacterium *Staphylococcus aureus,* commonly referred to as Staph infections, following cardiac surgery. The ACC believes that there is great value in fully funding the NHLBI-proposed "Clinical Trials for the Prevention and Treatment of Infections after Cardiac Surgery" parallel randomized clinical trials. These trials would provide conclusive evidence of the need for improved control of Staph infections by assessing the costs and benefits of new antibacterial strategies. Due to the serious risk of infection following cardiac surgery, the ACC hopes that increased funding for the NHLBI will allow these important trials to be conducted.

Collaboration among federal agencies has proven an effective and efficient means for enhancing research, facilitating appropriate regulation, and providing accurate clinical outcomes data. An "Interagency Registry of Mechanical Circulatory Support

for Heart Failure" would create a registry of mechanical circulatory support for heart failure, as well as an associated tissue repository for shared use by all related federal agencies. Such a registry would help standardize reporting of patient characteristics, indications, implantation procedures, and adverse events. With increased funding for NHLBI in fiscal year 2005, such collaboration will be possible.

AHRQ—Moving Research into Practice

The research and education developments that the federal government has facilitated are remarkable and promising. However, the best research is of no value if it never reaches the patient. The AHRQ is charged with ensuring that advances in medicine become the baseline for medical care. By fulfilling the mission of placing today's breakthroughs in the hands of physicians tomorrow, AHRQ injects up-to-the-minute research into day-to-day medical decisions and treatments. The research facilitated by the AHRQ provides reliable information on health care outcomes, quality, cost, use, medical errors, and access, enabling the public to make better-informed decisions about health care. The ACC regularly works with AHRQ to create and disseminate cardiovascular clinical practice guidelines. Having the AHRQ address some of the evidence to practice issues remains a critical step in evaluating the utility of practice guidelines.

For example, in fiscal year 2000, AHRQ released the "Translating Research into Practice II (TRIP II)" request for applications (RFA). The response to this RFA was overwhelming, so much so that currently 13 studies are underway due to this initiative. TRIP II specifically focuses on increasing the frequency of partnerships between researchers and health care systems and organizations to heighten the effect of practice-based, patient outcome research in applied settings.

Although the AHRQ remains a vital partner to both the clinical research community and other private sector organizations, it has not received a funding increase in the past two budget cycles. This continuous flat-funding does not allow the AHRQ to adjust to annual inflationary costs, nor does it provide the opportunity for new development or growth. The ACC is extremely concerned by this funding plateau particularly because of the AHRQ's central role in reviewing current scientific evidence and providing practical clinical information to the public, such as its recent work on blood pressure monitoring. The ACC urges Congress to support increased funding of the AHRQ at $443 million in fiscal year 2005.

CARDIOVASCULAR DISEASE AWARENESS AND EDUCATION

CDC State Heart Disease and Stroke Prevention Program

Education and awareness campaigns that focus on for heart disease and stroke prevention are in underway at the CDC's State Heart Disease and Stroke Prevention Program, but progress has been stalled due to insufficient funding. Only 11 of the 33 designated CDC State Heart Disease and Stroke Prevention Programs are funded adequately enough to progress from the planning stage to the implementation stage. This program's inventive heart disease and stroke reduction/control programs, particularly among underprivileged Americans, would help to reduce the incidence and impact of cardiovascular disease as well as to raise awareness of secondary preventative measures.

The State Heart Disease and Stroke Prevention Program aims to prevent and control heart disease and stroke risk factors including high cholesterol and blood pressure. Yet, the program can not reach its full potential for saving lives and reducing the costs associated with the disease unless it becomes a fully functioning national program. The ACC encourages Congress to approve an fiscal year 2005 funding level of $80 million for the Heart Disease and Stroke Prevention Program at the CDC. Approving this funding level would guarantee elevation of additional states from the planning to the implementation stage of their prevention programs, to continue comprehensively fund those 11 states whose programs are underway in the "implementation stage," and to supply the states that have yet to begin the planning stage with the financial means for implementation and establishment of their own State Heart Disease and Stroke Prevention Programs.

Public Access to AEDs

Since its formal introduction in 1960, cardiopulmonary resuscitation (CPR) has been the mainstay in close-chest resuscitation of unresponsive cardiac attack victims. While this method is still an effective and recommended treatment for helping oxygenated blood reach the brain and organs, defibrillation through proper use of an AED is the only sure way to restore the heart's normal rhythm. For people experiencing sudden cardiac arrest, every minute counts. Unfortunately, for every minute that passes without defibrillation, a victim's chance of survival decreases by 7–10 percent. In only 8 or 10 minutes, death is nearly certain. The price of an AED

varies by make and model, but typically costs around $3,000—a small price when compared with needless loss of life.

AEDs accurately analyze cardiac rhythms and, if appropriate, deliver an electric lifesaving countershock. AEDs are widely used by trained emergency personnel and first responders such as firefighters and police personnel. Thanks to the growing body of evidence that "public access defibrillation," or PAD, can decrease the amount of time between cardiac arrest and defibrillation, there has been a concerted effort to expand public access to AEDs and to improve training and education on these lifesaving devices. AEDs can now be found in most high-traffic public areas including schools, shopping malls, airports and convention centers.

The ACC appreciates Congress' continued attention to the importance of public access to AEDs with the passage of several legislative initiatives over the past few years including the "Automatic Defibrillation in Adam's Memory Act" (Public Law 108–41), the "Rural AED Act," the "Cardiac Arrest Survival Act," and the "Community Access to Emergency Defibrillation Act." While the ACC appreciates the Congress' commitment to this important issue, the financial commitment to Community and Rural AED programs dwindled in the fiscal year 2004 budget despite the urging of the ACC and the AHA. Community and rural AED programs were grouped together and funded at less than $12 million, collectively in fiscal year 2004. The ACC is quite concerned that the benefits brought to communities around the country through increased access to AEDs could go unrealized if AED programs are not funded at a higher level in the fiscal year 2005 budget. The ACC, therefore, urges Congress to fund community and rural AED public access programs at $45 million in fiscal year 2005.

CONCLUSION

The ACC is optimistic about what the future holds for the treatment and prevention of cardiovascular disease. The potential for work completed through the NHLBI, the CDC State Heart Disease and Stroke Prevention Programs, and the AHRQ, is enormous with a strong financial commitment from this subcommittee. The ACC encourages the subcommittee to continue its investment in cardiovascular research and educational programs within the fiscal year 2005 budget and appreciates the opportunity to share its views on this important topic.

PREPARED STATEMENT OF THE NATIONAL COALITION FOR HEART AND STROKE RESEARCH

My name is Jack Owen Wood. I solicit your support for more aggressive federal funding for research into prevention and treatment of the sister diseases, stroke and heart disease. Strokes and heart attacks are occurring at an alarming rate.

I am representing the National Coalition for Heart and Stroke Research. The coalition consists of 18 national organizations representing more than 5 million volunteers and members united in support for increased funding for heart and stroke research. Members of the Coalition include: American Academy of Neurology; American Academy of Physical Medicine and Rehabilitation; American Association for Vascular Surgery; American Association of Neurological Surgeons; American College of Cardiology; American College of Chest Physicians; American Heart Association; American Neurological Association; American Stroke Association; Association of Black Cardiologists; Citizens for Public Action on Blood Pressure and Cholesterol, Inc.; Compliment; Congress of Neurological Surgeons; Mended Hearts, Inc.; National Stroke Association NASPE/Heart Rhythm Society; Society of Interventional Radiology; Society for Vascular Surgery; amd WomenHeart: the National Coalition for Women with Heart Disease.

I will deal primarily with one man's personal experience with stroke and its functional and financial costs—my own. I have only the use of my right arm.

I was born in 1937, raised in Vicksburg, Mississippi, earned an engineering degree at Mississippi State University and currently reside in Port Orchard, Washington.

I worked for the Boeing Company in Seattle, am a former Director of the Washington State Energy Office, served as Director of Cost and Revenue Analysis and as the Forcasting Manager for a major Northwest Area Natural Gas Utility until May 1, 1995.

On May 1, 1995, at the age of 57, I was stricken and severely disabled by my stroke. Two years later I experienced a triple bypass heart operation. You might say I've "been there and done that" for both major cardiovascular diseases. So you see, I am an expert.

Several years ago I was offered an exciting and rewarding volunteer opportunity. I was asked to lead the "JACK WOOD STROKE VICTOR TOUR" for the American Heart Association.

The JACK WOOD STROKE VICTOR TOUR was a 5-state lobbying tour. Through it I tried to meet personally with every Northwest Congressional representative on his or her home turf (in Alaska, Idaho, Montana, Oregon and Washington). In each meeting I was joined by local people, stroke survivors and their families and medical professionals. I told my story and asked them to join the Congressional Heart and Stroke Coalition and to support increased federal funding for heart and stroke research.

I am proud to say I traveled to 18 communities and met personally with 28 members of our delegation or their staff. Nearly half of our congressional delegation is now members of the Congressional Heart and Stroke Coalition.

One of the most powerful memories for me was the frequency in which Members of Congress or staff members related their personal experience with stroke. One member I spoke to lost both parents to stroke. I suspect many of you have stories too.

I realize your interest is greater than the physical impact of my stroke. Your concern must include the financial impact, not only to me, but also on our country from increased health care costs and lost productivity and its many implications.

I have confronted the difficult and painful task of calculating that cost to me. Besides being a man whose stroke took his ability to pick up and play with his grandchildren and his livelihood, I remain a statistician at heart. I couldn't resist calculating and telling that part of my story. But please remember my story is not dissimilar to that of many of the 4.8 million stroke survivors in the United States. Many of whom were stricken in their prime earning years. Who in a matter of moments, seemingly without warning, are transformed from a contributor and provider to a receiver and patient.

Allow me to highlight three figures that I feel sum up my data and should be important to you. I estimate that my stroke at age 57:

—Reduced my earnings before retirement age 65 by over $600,000.

—Subsequently, the cost to the federal government in lost income and other taxes, early Medicare payments and Social Security disability payments is over $320,000.

—My HMO spent approximately $150,000 to respond to and treat my stroke.

—One man, over $1 million.

About 700,000 Americans will suffer a stroke this year costing this nation an estimated $54 billion in medical expenses and lost productivity.

Earlier I described a stroke as occurring seemingly without warning. All too often as in my case, people either don't know or ignore the signs of a stroke, even one in progress. When my stroke hit I denied it. It took me two days after my stroke to acknowledge it and seek help. Because of research into new treatments, we now have tPA, a clot-busting drug, which if administered within 3 hours of the onset of stroke symptoms, can dramatically reduce the damage of clot-based strokes. Had I recognized and acknowledged my stroke, gone to a hospital with a neurologist on staff and had there been tPA, the impact of my stroke most certainly would have been lessened.

What is even more painful to me is that my impending stroke could have been detected. Unfortunately, we need to create easier and less expensive diagnostic techniques so that effective diagnostics can be given routinely as part of regular health exams. And they must be covered through insurance.

I am not asking for your sympathy. Instead, please think of me as two of the ghosts in the famous Dickens' story. Please don't misunderstand, I'm not casting you as Scrooge. See me as both the ghosts of things past and things yet to be. I too am here to tell you, the future, which I represent, needs not be. It is largely up to you.

I hope my story and estimate of the cost of my stroke convinces you that taking on stroke and heart disease through increased research, leading to better prevention, diagnosis and treatment is fiscally responsible. The human and financial costs are astronomical.

Thank you for your past support of research.

PREPARED STATEMENT OF THE COOLEY'S ANEMIA FOUNDATION

SUBJECT

Both Alicia and Michael are Cooley's anemia patients. In their testimony, they will point to the research successes and the need to continue the focus on the most

scientifically opportune fields of research. Alicia will describe the tragic impact of the inability of some patients to comply with the excruciating treatment regimen for the disease and Michael will request the subcommittee's help in supporting blood safety surveillance through the CDC and other important research at the NIH.

ALICIA SOMMA

Good morning, Mr. Chairman. My name is Alicia Somma. Michael Giammalvo and I both have Cooley's anemia, a fatal genetic blood disease for which there is currently no cure. Michael is going to describe to the subcommittee what treatment for Cooley's anemia, or thalassemia (which is the medical name) is like, and I am going to tell you the story of my friend Nick who simply could not stand to undergo the treatment.

MICHAEL GIAMMALVO

Good morning, Mr. Chairman. My name is Michael Giammalvo and I am 13 years old. I was born with Cooley's anemia, which is a fatal genetic blood disease. Because my body cannot produce red blood cells like most other people's do, I have to receive a blood transfusion every two weeks. Getting a blood transfusion that frequently is not fun, but I have to do it to stay alive.

The problem with this treatment is that it creates a very bad side effect. When people receive blood transfusions as much as Alicia and I do, the iron that is in the transfused blood goes into our bodies. The body does not know how to get rid of it, so it builds up in the heart and the liver.

To get rid of the iron, patients have to infuse a drug called Desferal. It is in a pump that we wear. The drug is pumped through a needle that we have to insert under our skin. Most Cooley's anemia patients have to infuse Desferal five days a week for 8–12 hours at a time. The needle hurts. I sometimes can't go to my friends' houses for sleepovers or do other things that other kids do.

There are times when I really don't want to take the Desferal and I make it hard on my parents. And, some patients, especially ones who are a little older than me—teenagers—just stop taking it. Alicia will tell you about somebody who did that.

ALICIA

Mr. Chairman, this is the first time I have spoken in public about what happened to my friend Nick Alessi—so please bear with me if this is a little hard for me.

As a child growing up with this fatal illness, it's difficult not to feel different. Being the only kid in your class making regular week-long trips to the hospital, you can't help but feel alone. Nick made that feeling go away for me. Going to get treated and seeing him there showed me that I wasn't the only person with Cooley's anemia. Sitting in that infusion room, he and I became friends, and he made my life normal.

Constantly updated on each other's health, when I heard Nick hadn't been compliant with our nightly treatment, I was crushed, almost as if it had happened to me. Over time, he grew very ill, the overloaded iron began attacking his heart, and we all knew he was in danger. I spoke with his father often, giving him advice on how to deal with this enormous obstacle.

We decided that I should talk to Nick myself, regardless of the awkwardness I'd feel, because his condition was getting worse everyday. We arranged to have dinner together and discuss his problems, but unfortunately, I never got that chance to have that dinner and I never got the chance to save my childhood friend. We had all tried our hardest to save Nicholas Alessi, and we all failed. It's just hard to convince someone that you have to do something so barbaric to yourself to save your own life. Dealing with this has been immensely difficult, knowing that it could all be prevented. As I said, Nick was my friend and now he is gone.

Mr. Chairman, NIH does research on using non-invasive methods of measuring iron in our livers and hearts and on addressing other related issues like osteoporosis (which I have even though I am only 18 years old), hepatitis C (which more than one third of our patients have), and more. CDC spends $2.2 million to monitor the safety of the blood we transfuse into our bodies. The FDA is currently reviewing a drug that might be taken orally to remove iron, rather than the long, painful infusion but it is still months or years away from being available to all patients.

Addressing these issues are all things that only the government can do. And, we would not ask this of our government if it were not so important. I know that you have a lot of people asking you for a lot of things today and that you can't do everything. But, Michael and I are here today to speak on behalf of Nick Alessi—because he can't be here to speak for himself. Thank you for all you have done and for all you will do in the future.

We would be pleased to answer any questions.

PREPARED STATEMENT OF THE DORIS DAY ANIMAL LEAGUE

Chairman Specter, Ranking Member Harkin and Members of the Subcommittee: The Doris Day Animal League represents 350,000 members and supporters nationwide who support a strong commitment by the federal government to research, development, standardization, validation and acceptance of non-animal and other alternative test methods. We are submitting our testimony on behalf of the Society for Animal Protective Legislation, too. Thank you for the opportunity to present testimony relevant to the fiscal year 2005 budget request for the National Institute of Environmental Health Sciences for the Center for the Evaluation of Alternative Toxicological Test Methods (NICEATM) for the Interagency Coordinating Committee for the Validation of Alternative Test Methods (ICCVAM) activities for fiscal year 2005.

In 2000, the passage of the ICCVAM Authorization Act into Public Law 106–545, created a new paradigm for the field of toxicology. It requires federal regulatory agencies to ensure that new and revised animal and alternative test methods be scientifically validated prior to recommending or requiring use by industry. An internationally agreed upon definition of validation is supported by the 15 federal regulatory and research agencies that compose the Interagency Coordinating Committee for the Validation of Alternative Methods (ICCVAM), including the EPA. The definition is: "the process by which the reliability and relevance of a procedure are established for a specific use."

FUNCTION OF THE ICCVAM

The ICCVAM performs an invaluable function for regulatory agencies, industry, public health and animal protection organizations by assessing the validation of new, revised and alternative toxicological test methods that have interagency application. After appropriate independent peer review of the test method, the ICCVAM recommends the test to the federal regulatory agencies that regulated the particular endpoint the test measures. In turn, the federal agencies maintain their authority to incorporate the validated test methods as appropriate for the agencies' regulatory mandates. This streamlined approach to assessment of validation of new, revised and alternative test methods has reduced the regulator burden of individual agencies, provided a "one-stop shop" for industry, animal protection, public health and environmental advocates for consideration of methods and set uniform criteria for what constitutes a validated test methods. In addition, from the perspective of animal protection advocates, ICCVAM can served to appropriately assess test methods that can refine, reduce and replace the use of animals in toxicological testing. This function will provide credibility to the argument that scientifically validated alternative test methods, which refine, reduce of replace animals, should be expeditiously integrated into federal toxicological regulations, requirements and recommendations.

HISTORY OF ICCVAM

The ICCVAM is currently composed of representatives from the relevant federal regulatory and research agencies. It was created from an initial mandate in the NIH Revitalization Act of 1993 for NIEHS to "(a) establish criteria for the validation and regulatory acceptance of alternative testing methods, and (b) recommend a process through which scientifically validated alternative methods can be accepted for regulatory use." In 1994, NIEHS established the ad hoc ICCVAM to write a report that would recommend criteria and processes for validation and regulatory acceptance of toxicological testing methods that would be useful to federal agencies and the scientific community. Through a series of public meetings, interested stakeholders and agency representatives from all 14 regulatory and research agencies, developed the NIH Publication No. 97–3981, "Validation and Regulatory Acceptance of Toxicological Test Methods." This report, and subsequent revisions, has become the sound science guide for consideration of new, revised and alternative test methods by the federal agencies and interested stakeholders.

After publication of the report, the ad hoc ICCVAM moved to standing status under the NIEHS' NICEATM. Representatives from federal regulatory and research agencies and their programs have continued to meet, with advice from the NICEATM's Advisory Committee and independent peer review committees, to assess the validation of new, revised and alternative toxicological methods. Since then, several methods have undergone rigorous assessment and are deemed scientifically valid and acceptable. In addition, the ICCVAM is working to streamline assessment

of methods from the European Union (EU) that have already been validated for use within the EU. The open public comment process, input by interested stakeholders and the continued commitment by the federal agencies has led to ICCVAM's success. It has resulted in a more coordinated review process for rigorous scientific assessment of the validation of new, revised and alternative test methods.

REQUEST FOR APPROPRIATIONS

On December 19, 2000, the "ICCVAM Authorization Act" which makes the entity a permanent standing committee, was signed into Public Law No. 106–545. For several years, the NIEHS has provided between $1 and $2.6 million per fiscal year to the NICEATM for ICCVAM's activities. In order to ensure that federal regulatory agencies and their stakeholders benefit from the work of the ICCVAM, it is important to fund it at an appropriate level. I respectfully urge the Subcommittee to support and appropriation for the NIEHS' NICEATM for ICCVAM's activities at $3.5 million for fiscal year 2005. This appropriation request includes all FTEs, funding for independent peer review assessment of test methods and meetings of the ICCVAM and other activities as deemed appropriate by the Director of the NIEHS.

REQUEST FOR COMMITTEE REPORT LANGUAGE

I also respectfully request the Subcommittee consider the following report language for the Senate Labor, Health and Human Services, Education and Related Agencies Appropriations bill:

"The Committee supports the assessment of scientific validation of new, revised and alternative toxicological test methods by the ICCVAM. The Committee urges the fifteen regulatory and research agencies composing the ICCVAM to use the expertise and credibility of the ICCVAM for assessments to obviate their individual consideration of new, revised and alternative test methods. The Committee also urges the regulatory and research agencies to incorporate scientifically validated new, revised and alternative test methods into their regulations, requirements and recommendations in an expeditious manner."

Thank you for the opportunity to submit this request on behalf of the Doris Day Animal League and the Society for Animal Protective Legislation.

PREPARED STATEMENT OF THE JEFFREY MODELL FOUNDATION

SUBJECT

Mrs. Modell will, first and foremost, thank the committee and its members for its past assistance and support. She will also testify in favor of increases in funding for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). Concerning CDC, she will request an increase in the current program that provides funding for a national education and awareness program related to primary immunodeficiency diseases to allow the Foundation to expand the program to reach underserved African-American and Hispanic communities. Within NIH, her testimony will focus specifically on NICHD, NIAID and NHLBI.

Mr. Chairman and Members of the Subcommittee: Thank you for the opportunity to testify before you today. I am Vicki Modell and, along with my husband Fred, we created the Jeffrey Modell Foundation in 1987 in memory of our son, who died at the age of 15 as a result of a life long battle against one of the 100-plus primary immunodeficiency diseases.

First and foremost, Mr. Chairman, I am here today to thank you and all the members of this committee on both a personal and a professional level. Personal because whenever Fred and I come to Washington, whether it is to testify here before the committee or to meet with the members of the subcommittee individually in their offices, every Member of Congress and every member of your staffs are unfailingly polite, courteous, interested and caring.

And, professional because over the last seven years that we have been coming to Washington, we have been given the opportunity to build a partnership with the Congress, the Centers for Disease Control and Prevention, the National Institutes of Health, as well as with our own supporters in the private sector, including industry and other concerned donors.

We believe that we have maximized the benefits for patients from the support that this subcommittee has afforded us. We are going to tell you a remarkable story of success, of hope, and of future challenges this morning.

This subcommittee is currently funding CDC with $2.2 million for physician education and public awareness of immune deficiencies. The Jeffrey Modell Foundation

operates the program under a contract with CDC. Although we only receive about $1.8 million of the money (CDC keeps the rest for its "administrative expenses"), we have leveraged that money into a $15 million national campaign.

The Foundation has raised more than $1.0 million, largely from our supporters in the pharmaceutical and blood-related industries. Working with the Ad Council and a major New York City ad firm, we put together a media campaign alerting families to the possibility that repetitive infections may indicate a deeper, underlying problem and explaining to parents how to get their children tested. That campaign has generated more than $12 million in donated media time on television and radio, as well as magazine ad space.

But, the campaign has been even more than the advertising.

—We have conducted physician symposia for CME credit all over the country.

—Working with NIH, we have produced educational materials for doctors and families. We have mailed 38,000 posters—one to every school nurse in the United States.

—NICHD has mailed information to every member of the American Academy of Pediatrics and the American Academy of Family Practice.

—We have developed and improved a terrific website.

All of these steps would not be possible without the support of this subcommittee, but there is so much more that we can do.

We fully recognize what a difficult appropriations year this is going to be. We know that, like every year, the demands on the subcommittee far exceed the allocation that you will likely have available. We also understand that our needs are small in the bigger picture of funding multi-billion programs like Pell Grants or the No Child Left Behind program. Yet, we have taken a small amount of money—for which we are eternally grateful—and generated $7 of private money for every $1 of government money.

Mr. Chairman, one of the great unmet needs in our education and awareness program is underserved African American and Hispanic populations. Any such program concerning an undiagnosed disease needs to make special provisions for reaching these groups. You need to seek time on different radio stations, different television networks, and space in different magazines.

Yet we know that this must be done. If you visit the Emergency Room at our home hospital in New York—Mount Sinai—then you visit the infusion room operated by the Department of Immunology, you see two very different populations. Yet the research tells us that there is not an ethnic component to this disease. That means that the visible differences relate to our medical system, not the incidence of disease.

We are prepared to take on this challenge, much as this Congress has been willing to address the problems of health disparities through the NIH and elsewhere. We believe that we can begin to make a dent in the problem by increasing the funding available for this program to $2.7 million from $2.2 million.

Mr. Chairman, as you know, we have other interests within the purview of this committee, as well. We have along history of collaboration with NICHD, which has been our strongest supporter under the able leadership of Dr. Duane Alexander. We have helped to fund research at NIAID. We have funded post-doctoral fellows at NHGRI. We are now jointly funding a conference with NHLBI.

Our interactions with these many NIH institutes has convinced us that further increases in their budget—to whatever level fits within your allocation—will be put to good use and will benefit chronically ill people like our patients.

Mr. Chairman, as I said in the beginning of my remarks, Fred and I are very grateful. We cannot begin to thank you and the subcommittee enough for all of the support and encouragement that we have received from you whenever we come to Washington. While we may never be able to repay all your kindnesses, you should know that the work that you do enables the work that we do. And, every young person who is diagnosed—early and properly—and then receives treatment is a young person who life is better for what you have done.

Thank you again. I would be pleased to answer any questions.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR DENTAL RESEARCH

SUMMARY

Dental research is concerned with the prevention, causes, diagnosis, and treatment of diseases and disorders that affect the teeth, mouth, jaws, and related systemic diseases. Dental health is an important, vital part of health throughout life.

INTRODUCTION

I am Dr. Michael Alfano, Dean of the New York University School of Dentistry. This testimony I am presenting is on behalf of the American Association of Dental Research (AADR). The AADR is a non-profit organization with over 5,000 individual members and 100 institutional members within the United States. AADR's mission is to enhance the quality and scope of oral health, advance research and increase knowledge for the improvement of oral health, and increase opportunities for scientific changes.

Mr. Chairman and members of the Committee, we want to thank you for this opportunity to testify about the exciting advances in oral health sciences. I would like to discuss our fiscal year 2005 budget recommendations for the National Institute of Dental and Craniofacial Research (NIDCR).

OVERVIEW

Oral health is an important component of health. Good teeth and healthy gums for chewing and appearance, as well as taste buds and saliva to enjoy food and facilitate speech, all make major contributions to quality of life. Over the years, discoveries stemming from dental research have reduced the burden of oral disease for many Americans—although much remains to be done to reduce further the prevalence of oral diseases and their impact on overall health and well-being, as identified in Surgeon General (SG) David Satcher's Report of 2002: *Oral Health in America* and reinforced by current SG Richard Carmona in his 2003 *National Call to Action to Promote Oral Health.*

Of even broader interest, however, the oral cavity also offers intriguing potential as a diagnostic window to the rest of the body—potential being pursued by the National Institute of Dental & Craniofacial Research (NIDCR). In fact, the Director of the National Institutes of Health, Dr. Elias Zerhouni, believed the potential for salivary diagnostics was so promising that he allocated some of his discretionary funds toward this research. Dr. Zerhouni has also complimented the NIDCR for its salivary research as exemplifying the type of interdisciplinary research that will be necessary to improve overall health outcomes for patients.

SALIVA AS A DIAGNOSTIC AND MONITORING TOOL

Saliva is the protective fluid of the oral cavity. With its vast supply of microbe killers, saliva combats invading pathogens such as HIV and a host of bacteria associated with oral and systemic diseases. Antibodies directed against pathogens, such as polio and cold viruses, are found in saliva. Large salivary glycoproteins, called mucins, appear to have antiviral properties as well.

Oral fluid is also a mirror of the body, containing many compounds indicating a person's health and disease status and, like blood and urine, its composition may be altered in the presence of disease. Saliva, however, may be collected in a much less invasive fashion than either blood or urine.

Technologies are being developed at the NIDCR and by multidisciplinary teams in universities supported by grants from the NIDCR. These technologies offer huge clinical and commercial opportunity and may one day catalyze a shift in our current health system of disease detection to real-time health surveillance. For example:

—Studies have uncovered in saliva the presence of a cancer-related protein whose concentration increases in the presence of breast cancer—a potential diagnostic marker for the early detection of breast cancer in women.

—Saliva is gaining value as a diagnostic aid and potential monitor of disease progression in systemic disorders, including Alzheimer's disease, Sjören's syndrome (an important autoimmune disease), cystic fibrosis, and diabetes.

—Saliva is also proving to be an effective tool to monitor levels of hormones and therapeutic medications.

—Research opportunities abound to develop more sensitive and specific assays to measure and understand changes in saliva beyond oral and systemic diseases in areas such as genetic defects, nutritional status, and age-specific changes.

GENE THERAPY USING SALIVARY GLANDS

Gene therapy, substituting effective genes for those that are missing or nonfunctional and not producing needed proteins, offers hope for many patients, especially those who have conditions caused by a deficiency in a single protein, such as Type I diabetes, growth hormone deficiency, and hypoparathyroidism. Many of the difficulties involved in the delivery of such genes to internal organs can be avoided by incorporating functioning genes into salivary glands, which can in turn make the deficient protein and provide therapeutic benefit. If resources become available, the

NIDCR is proposing an evaluation of gene transfer techniques in three clinical trials, involving patients with:

—adult growth hormone deficiency,
—chronic renal failure, and
—Sjören's syndrome and salivary gland damage.

BIOMIMETICS/TISSUE ENGINEERING

Advances in the design of materials and an increasing understanding of mechanisms by which tissues of the craniofacial complex develop have positioned scientists to replace tissues lost as a result of developmental defects, pathology, or trauma. Interdisciplinary teams of scientists supported by the NIDCR:

—continued to improve dental restorative and implant materials;
—identified mechanisms to address osteoporosis and other conditions by making one cell type become another, e.g., inducing more bone marrow cells to become bone cells rather than fat cells;
—discovered that the "baby teeth," which children begin to lose normally around age six, contain a rich supply of stem cells that may have more potential for differentiation into other cell types than do adult stem cells, and are identifying these other cell types as funding permits; and
—created a distinct portion of the lower jaw from rat adult stem cells that is the precise three-dimensional shape of the human mandibular joint.

Researchers have long dreamed of engineering new teeth, knees, hips, and other body parts from a person's own tissues. Research to date has provided a solid base for making this dream a reality. Noting the ease of access to the oral cavity, Dr. Bruce Baum, a scientist at the NIDCR, has noted that "the mouth is one of the best laboratories' in the body to study issues in human biology that go beyond dental research."

RESEARCH IN PATIENT CARE SETTINGS

In November 2003, the NIDCR announced support for Dental Practice-Based Research Networks (PBRNs) to provide an infrastructure for answering important clinical questions routinely faced by dental practitioners (http://grants.nih.gov/grants/guide/rfa-files/RFA-DE-05-006.html). Indeed, the 2002 American Dental Association Future of Dentistry report specifically recommends that national clinical research networks be established that link treatment approaches and outcomes in private practice settings.

By connecting community-based dental providers with experienced clinical investigators, PBRNs will enhance clinical research supported by the NIDCR and produce findings that are immediately relevant to practitioners and their patients. Because research is conducted in the real-world environment of dental practice, results may be more readily accepted by practitioners and rapidly integrated into dental practice. Importantly, PBRNs also provide a very cost-efficient mechanism for conducting clinical studies, because they use existing personnel and the infrastructure of established dental practices.

RECOMMENDATION

The National Institute of Dental and Craniofacial Research (NIDCR) is the leading agency supporting research in the oral and craniofacial area. NIDCR has already begun investing in all of the above areas, but the Institute needs additional funding if these initiatives are to become a reality. It is requested that an appropriation of $420,000,000 be provided for NIDCR in fiscal year 2005 to launch a major initiative to complete the development of the technology for using saliva as a low-cost, non-invasive, diagnostic instrument; to pursue gene therapy using the salivary glands; to accelerate efforts in biomaterials and tissue engineering (regeneration of teeth and other body parts); and to develop fully the recently announced Dental Practice-based Research Networks initiative.

In fiscal year 2005, the AADR also supports an appropriation of $30.6 billion for the NIH overall, $20,000,000 for CDC's Division of Oral Heath, $182,000,000 for the CDC's National Center for Health Statistics, and $443,000,000 for the Agency for Healthcare Research & Quality.

PREPARED STATEMENT OF THE SOCIETY FOR MATERNAL-FETAL MEDICINE

Mr. Chairman and Members of the Committee, I am James Ferguson, M.D., President of the Society for Maternal-Fetal Medicine. We appreciate the opportunity to testify before this Committee and are most appreciative of the support you have

provided over the years to the National Institutes of Health, in particular the National Institute of Child Health and Human Development.

The Society for Maternal-Fetal Medicine (SMFM), established in 1977, is a subspecialty organization, which was formed to promote research and education on issues that may confront a high-risk pregnant mother or unborn fetus. The SMFM has a very strong interest in improving pregnancy outcome through basic, translational and clinical research. Only through research can complications involving the mother or unborn fetus be understood, treated, prevented, and eventually solved.

Maternal-Fetal Medicine is a subspecialty within Obstetrics and Gynecology. Maternal-Fetal Medicine subspecialists pursue an additional 2 to 3 years of fellowship training following completion of their 4 year residency program in Obstetrics and Gynecology. Maternal-Fetal Medicine subspecialists provide consultative services to obstetricians, while in other cases they actually assume direct care responsibility for the special problems that high-risk mothers or high- risk fetuses face. The special problems faced by these mothers may lead to death, short-term or in some cases life-long problems for their babies. For example:

—*Preeclampsia*.—Preeclampsia is a dangerous condition characterized by high blood pressure and the presence of protein in the urine. It complicates 3 to 4 percent of pregnancies, strikes without warning and is a leading cause of maternal and fetal death. In some cases, the condition may progress to eclampsia, a series of potentially fatal seizures. Although the high blood pressure and seizures can be treated, the only cure for preeclampsia is delivery of the baby. Surviving infants are at increased risk for preterm birth, may be undergrown or have serious disorders requiring neonatal intensive care.

—*Preterm Birth*.—Preterm birth (Premature delivery) complicates approximately 10 percent of births and is a direct contributor to over 75 percent of the infant deaths and substantial newborn mortality and morbidity. Despite decades of committed research, the physiologic mechanisms underlying the onset of the process of giving birth, either preterm or term, have yet to be clearly identified.

—*Stillbirth*.—When fetal death occurs after 20 weeks or more gestation, it is referred to as stillbirth. For many parents who hear the heartbreaking news that their baby has died in the womb, the loss is completely unexpected. Half of all stillbirths occur in pregnancies that appear to be problem-free. While 14 percent of fetal deaths occur during labor and delivery, 86 percent of fetal deaths occur before labor begins. The only warning the pregnant woman may have that there is a problem is that the baby suddenly is no longer moving or kicking. The most common known causes of stillbirth include: placental problems, birth defects, growth restriction and infections. But for at least half of all stillbirths, the cause remains undetermined. Despite the significant and persistent burden of stillbirth, the phenomenon has remained largely unstudied.

—*Abnormal fetal growth*.—Abnormalities in the regulation of fetal growth may result in newborns that are significantly overgrown or undergrown and suffer complications related to the abnormal growth pattern. Inadequate fetal growth may occur in the absence of recognized causes e.g., maternal hypertension, smoking, or inadequate nutrition, and may be associated with intrauterine fetal demise or immediate neonatal and long-term consequences for the infant. Excess fetal growth may occur in pregnancies complicated by maternal obesity or diabetes, despite appropriate nutritional counseling and insulin therapy. Currently the management of under-and overgrown fetuses is empirical, aimed primarily at selection of safest time for delivery. There are no effective treatments to prevent or reverse either intrauterine growth restriction or fetal macrosomia.

—*Neonatal brain injury*.—The precise cause of the majority of cases of neonatal brain injury is unknown. In the past, much emphasis was placed on hypoxia and "asphyxia" as a cause. Recent studies suggest that maternal infection and subsequent fetal infection may play a major role in the causation of newborn brain abnormalities such as periventricular leukomalacia and white matter damage.

The National Institute of Child Health and Human Development (NIHCD) has been a leader in the field of maternal-fetal medicine research. Its commitment to basic, clinical and translational research has lead to new ways to treat and improve the health of pregnant women and infants. In the 1960's the birth weight at which infants had a 50-percent change for survival was approximately three (3) pounds; today it is 1½ pounds. Research conducted and supported by the NICHD, has given preterm infants and their families hope for the future.

RECENT ACCOMPLISHMENTS

NICHD supported research in maternal-fetal medicine has been dramatic. Great strides are being made in our understanding of pregnancy and its complications. Recent researching findings revealed that:

—abnormal levels of two molecules found in the blood appear to predict the development of preeclampsia. This observation is the most promising lead yet in the pursuit of this life-threatening disorder. If the development of preeclampsia can be reliably predicted, treatment strategies may be developed before more serious problems arise.

—women with heightened resistance to the hormone "insulin" in the early months of pregnancy are at risk to develop preeclampsia. This finding suggests that physicians may be able to initiate preventive measures early in a pregnancy for women with insulin resistance. The research also implicates insulin resistance as a causative factor in preeclampsia; thus, it may ultimately be possible to prevent preeclampsia by improving insulin sensitivity in at-risk women early in a pregnancy or even before conception.

—an anti-diabetes drug, metformin, lowered the risk of a miscarriage in the first trimester of pregnancy for women with polycystic ovary syndrome (PCOS). The investigators had already demonstrated that the drug increases blood flow in the uterus and brings about changes in the uterine lining.

MATERNAL FETAL MEDICINE UNITS NETWORK

The National Institute of Child Health and Human Development created the Maternal Fetal Medicine Units Network (MFMU) in 1986 to address major clinical questions in maternal fetal medicine and obstetrics, particularly with respect to the continuing problem of preterm birth. The Network supports 14 clinical academic institutions and one data center. Typically, the network has four to six studies and/or trials ongoing at any given time. This approach provides optimal efficiency and cost-effective research. Over the last year, two trials studying progesterone for the prevention of preterm birth in high-risk women and Factor V Leiden mutations have been completed. This research will benefit countless women at risk of preterm birth.Over the last year, a trial on the identification of a therapy, progesterone, that prevents recurrent preterm birth in high-risk women has been completed. This is one of the first advances in this area, despite extensive efforts over decades.

Areas of Need

NICHD is at the forefront of several novel and important research areas, but there are still many areas that we are not close to understanding about maternal health, pregnancy, fetal well-being, labor and delivery and the developing child.

—The next major advance in elucidating the etiology of preterm delivery involves understanding the mechanism through the evaluation of protein and gene expression. These techniques are widely used in other medical fields, and it is imperative that they are used to understand prematurity. Through these new technologies, wide scale, high output genomic and proteomic strategies should be used to identify mechanisms underlying premature birth.

—New tools are needed to assess fetal growth; and non-invasive methods to assess changes in the uterine cervix and muscle (myometrium), and placental changes over time.

—Research should focus on the pre-pregnancy and early pregnancy periods; the role of the cervix; the role of the placenta, including functional mechanisms related to pregnancy outcomes and fetal well-being, such as fetal growth and preterm delivery.

—Strategies for predicting preterm birth should include multivariate analysis, such as that used in neural network analysis, and should focus on identifying the potentially reversible changes that take place prior to and during the early phase of pregnancy.

—Research should focus on the cases with highest mortality and morbidity and should not be diluted by inclusion of less relevant cases of preterm birth that are close to term.

—Research is needed to:

  —develop clinical methods to identify pregnancies where delaying delivery is futile or in some cases detrimental.

  —determine the effects of intervention on outcome.

  —identify the risk factors for adverse outcomes arising as result of pre-eclampsia, (abruption, preterm birth) in hypertensive women.

  —Understand the pathophysiologic abnormalities that lead to adverse pregnancy outcome in hypertensive women.

—Research is needed to explain the exact mechanism of how infections lead to brain injury at various stages of pregnancy and brain development. In addition, delineation of the biochemical pathyway leading to injury may allow for interventions before irreversible injury occurs.

RECOMMENDATIONS

Without a sustained and continued investment in the areas of need, the health of pregnant women and their babies will continue to be at risk. The SMFM therefore recommends:

—An increase of 10 percent in fiscal year 2005 for the National Institutes of Health, bringing its total budget to $30.6 billion, as supported by the Ad Hoc Group for Medical Research Funding.

—An increase of 10 percent or $1.366 billion in fiscal year 2005 for the National Institute of Child Health and Human Development.

—NICHD fully support the MFMU Network so that it can continue to address important research questions, with an emphasis on issues pertaining to preterm births and low birth weight deliveries.

—That the NICHD have a major initiative to focus on genomics and proteomics to hasten a better understanding behind the pathophysiology of premature birth, discover novel diagnostic biomarkers, and ultimately aid in formulating more effective interventional strategies to prevent premature birth.

—That the NICHD fully fund the cooperative network of clinical centers and data center to study stillbirth.

Thank you Mr. Chairman and Members of the Committee for the opportunity to express our concerns and recommendations before this Committee.

PREPARED STATEMENT OF THE NATIONAL COALITION FOR OSTEOPOROSIS AND RELATED BONE DISEASES

Mr. Chairman and Members of the Committee: I am Joan Goldberg, Executive Director of the American Society for Bone and Mineral Research. I am here today on behalf of the National Coalition for Osteoporosis and Related Bone Diseases (the Coalition). We want to thank you for your continued support of the National Institutes of Health. Without your support the scientific achievements that have translated into direct benefits for millions of Americans afflicted with bone diseases such as Osteoporosis, Osteogenesis Imperfecta and Paget's disease of bone could not have been possible.

The participants of the Coalition are the National Osteoporosis Foundation, the American Society for Bone and Mineral Research, the Paget Foundation for Paget's Disease of Bone and Related Disorders and the Osteogenesis Imperfecta Foundation. The Coalition is committed to reducing the impact of bone diseases through expanded basic, clinical, epidemiological, and behavioral research and through education leading to improvements in patient care.

What do we know about bone? One misconception is that bone is a static tissue. Bone is a living tissue that makes up the body's skeleton. It is a truly remarkable structural material, which makes it ideal for its function of structural support. Bone provides mobility, protection of vital organs, and housing of the bone marrow. It is also a reservoir for calcium. This dynamic and highly tuned organ simultaneously balances growth to achieve strength and resilience, and repair without overgrowth. This balance is achieved by bone remodeling. An imbalance in remodeling, however, leads to the debilitating bone diseases such as osteoporosis, paget's disease of bone and osteogenesis imperfecta. These diseases are responsible for a large portion of healthcare expenditures in the United States. For example:

—OSTEOPOROSIS, or porous bone, is a disease characterized by low bone mass and structural deterioration of bone tissue, leading to bone fragility and an increased susceptibility to fractures of the hip, spine, and wrist. It is a major public health threat for 44 million Americans. Of the 10 million who have osteoporosis, 80 percent are women. Today, 2 million men have osteoporosis and almost 12 million more are at risk for the disease. Men with low levels of testosterone are especially at risk. This includes men being treated with certain medications for prostate cancer. Osteoporosis is responsible for more than 1.5 million fractures annually, including over 300,000 hip fractures; 700,000 vertebral fractures; 250,000 wrist fractures; and 300,000 fractures at other sites. The estimated national direct expenditures (hospital and nursing homes) for osteoporotic and associated fractures were $17 billion in 2001 ($47 million each day) and the cost is rising.

—PAGET'S DISEASE OF BONE, the second most prevalent bone disease after osteoporosis, is a chronic skeletal disorder that may result in enlarged or deformed bones in one or more regions of the skeleton. Excessive bone breakdown and formation can result in bone that is dense, but fragile. Complications may include arthritis, fractures, bowing of limbs, and hearing loss if the disease affects the skull. Prevalence in the population ranges from 1.5 percent to 8 percent depending on the person's age and geographical location. Paget's disease primarily affects people over 50.

—OSTEOGENESIS IMPERFECTA (OI) causes brittle bones that break easily due to a problem with collagen production. For example, a cough or sneeze can break a rib, rolling over can break a leg. There are four recognized types of OI, representing extreme variations in severity and affecting 20,000 to 50,000 people in the United States. In severe cases fractures occur before and during birth. Undiagnosed OI may result in accusations of child abuse. Besides fragile bones, people with OI may have hearing loss, brittle teeth, short stature, skeletal deformities, and respiratory difficulties.

—FIBROUS DYSPLASIA is a chronic disorder of the skeleton, which causes expansion of one or more bones due to abnormal development of fibrous tissue within the bone. Any bone can be affected, and involvement can be in one or several bones. Though many bones can be affected at once, fibrous dysplasia does not spread from one bone to another. At present there are no approved medical therapies. Surgery is sometimes recommended for severe complications.

Another bone-related complication of bone that must be called to your attention is bone metastasis (cancer spreading to bone). Bone metastasis is a frequent complication of cancer and occurs in up to 70 percent of patients with breast cancer and prostate cancer, and in approximately 15 to 30 percent of patients with lung, colon, stomach, bladder, uterine, rectal, and renal cancer. Bone metastases cause severe pain and fracture and once tumors spread to bone, they are incurable.

Federal funding appropriated by the Congress has allowed the National Institutes of Health to conduct and support research that has reduced the adverse impact of bone disease on quality of life. Research has—

—taught us how many Americans have low bone mass and therefore are at risk for osteoporosis. These individuals can now address their risk with exercise, diet, other behavioral and lifestyle changes, and medication, as appropriate.

—demonstrated that a variety of drugs currently available can reduce bone loss and fractures, and even build bone.

—led to a better understanding of calcium metabolism and, as a result, manufacturers of a variety of food products have fortified their products with this vital nutrient.

—identified the necessity of vitamin D, protein, iron, etc., in addition to calcium in building and maintaining strong bones, while also spotlighting the major public health problem of vitamin D deficiency.

—helped us to understand the need for weight-bearing exercise to build and maintain bone density and strength training to increase balance and flexibility to reduce falls.

—identified a genetic component in many bone diseases, paving the way for the development of genetic approaches to diagnosis and treatment.

—decreased fracture risk and extended the lifespan for children with OI.

It is apparent that the quality of life related to bone disease is improving for many Americans, but much still remains to be achieved in areas such as:

DIAGNOSTICS/IMAGING

—DXA is an imaging test that measures bone mineral density (BMD). It is the gold standard for predicting fracture risk, yet it may both under-diagnose and over-diagnose patients at risk. Moreover, DXA uses databases that are largely based on BMD scores of white women. Relating BMD scores to fracture risk for women of other racial groups and ethnicities—and doing the same for men—is even more imprecise.

—New diagnostic measures are required to predict fragility and fracture risk better through assessing skeletal strength three dimensionally, focusing on internal bone micro-architecture or structure.

TREATMENT/PHARMACOTHERAPY

—Much attention has been focused on the Women's Health Initiative study results and the risks involved in estrogen treatment. However, more information is needed about low-dose estrogen and its bone-protective benefits and risks.

—Most current drug treatments for osteoporosis work by slowing down the natural process of bone breakdown. PTH, a hormone, actually builds bone. However, we need more studies to learn how best to use the drugs currently available, for what populations, with or after what drug regimens, for how long, and how best to assess response and interaction with exercise and diet.
—The discovery of new molecules with unexpected roles in modulating bone mass points the way to development of other new therapies. One example is leptin, a molecule made by fat cells.
—A 5-year observational study suggested that regular intravenous doses of pamidronate (a bisphosphonate) helped increase bone mineral density, reduce fractures, increase mobility, and decrease bone pain in children with osteogenesis imperfecta. Controlled clinical drug therapy trials will enable assessment of the potential use of bisphosphonate drugs to improve quality of life for children and adults.
—The discovery that tumor cells increase the number of natural-occuring cells that destroy bone has improved treatment and quality of life for patients with bone metastases through the use of drugs called bisphosphonates. However, further research is needed to study the path of bone disease in breast cancer, prostate cancer, multiple myeloma, and other cancers that spread to bone.
—Research is needed to improve survival and quality of life and to prevent metastatic osteosarcoma for the approximately 600 children and teenagers in the United States who develop this cancer. Specifically, research is needed to:
  —Identify new intervention targets for therapy;
  —Develop better predictors of response to osteosarcoma treatment;
  —Develop in vivo and in vitro preclinical assays to improve treatment;
  —Study metastatic osteosarcoma biology compared to biology of normal bone cells and that of other cancer cells.

NOVEL APPROACHES

—Investigations into genetic approaches for bone disease are critical and stem from recent findings that bone doesn't form when one protein—Cbfa-1—is missing. Understanding how this protein is activated or turned on may lead to new therapies for bone disease.
—The identification and study of families with very high bone mass who never fracture have led to the discovery of the involvement of the "wnt pathway" in regulating bone mass. This pathway has not only become a potential therapeutic target for controlling skeletal mass, but has recently been implicated in the bone loss experienced in multiple myeloma (a bone- and blood-related cancer).
—Understanding the role of genes and the underlying abnormal functioning of cells involved in bone breakdown in patients with Paget's disease is critical to developing new treatments. We need additional investigation to understand the role the bone microenvironment plays in the development of Paget's disease and to identify the molecular processes involved.
—Bone marrow transplantation is being tested in the laboratory for the treatment of osteogenesis imperfecta. One technique requiring further development focuses on genetically engineering bone precursor cells, which reside in the bone marrow, so that the faulty osteogenesis imperfecta gene which causes frequent fractures would be blocked or turned off. Then these engineered cells could be transplanted back into the bone marrow to form healthy bone.
—The use of specific exercise regimes—such as jumping—in the growing child, and of vibrating devices, for adults, represent exciting avenues for continued exploration into low-cost approaches to strengthen bone.
—The potential for genetic therapy to cure osteogenesis imperfecta has been demonstrated in the test tube. Suppressing the gene that causes the mutant collagen must now be demonstrated in animal models.

Bone research must be considered a trans-NIH issue given that bone diseases can lead to or be linked to other diseases such as cancer. Studies are currently being supported and conducted by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (the lead institute for bone research), the National Institute on Aging, the National Institute of Diabetes and Digestive and Kidney Diseases, the National Institute of Child Health and Human Development, the National Institute of Dental and Craniofacial Research and the National Cancer Institute.

Mr. Chairman and members of the committee we are most appreciative of your past support for the programs of the National Institutes of Health. The momentum in research cannot stop. The American people are expecting and holding fast to the hope that one day cures will be found for the debilitating diseases of bone.

RECOMMENDATIONS

The National Coalition for Osteoporosis and Related Bone Diseases believe that improved treatments and a cures are in sight, but greater federal funding will be necessary if these advances are to be achieved. The Coalition, therefore:

—Joins the Ad Hoc Group for Medical Research Funding in urging the Committee to provide an appropriation of $30.6 billion in fiscal year 2005 for the National Institutes of Health—an increase of 10 percent.

—Supports the NIAMS Coalition recommendation of a 10 percent increase for the National Institute of Arthritis and Musculoskeletal and Skin Diseases, the lead bone research institute.

—Supports increased funding for NIA, NIDCR, NIDDK, NCI, and NICHD, other Institutes that also fund bone-related research, as well as seeks additional support for bone programs at NIBIB and NCAM.

—Requests more funding for training, transitional grants and debt repayment programs for young investigators and clinical scientists.

Mr. Chairman, thank you for the opportunity to testify before this Committee.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR CANCER RESEARCH

The American Association for Cancer Research (AACR) is the world's oldest, largest, and most prestigious professional society of cancer scientists and clinicians. The AACR embraces the mission of our 22,000 members to advance the prevention, detection, control and cures of cancer through research, education, and communication.

The AACR is the authoritative voice for those who constitute a continuum of cancer research. It is the work of those within this continuum that contributed to reduced death rates and stabilized incidence in lung, breast, prostate and colorectal cancers during the last decade. The effort to contain cancer is achievable, and the progress we have made is encouraging for the future.

Research by members of the AACR will lead to new ways of preventing, controlling and curing cancers in people of all ages. Scientists are mining information from the Human Genome Project to discover how cells use genetic information to become cancers. Researchers are identifying the genes that cause cancer and are designing targeted drugs that help regulate those genes. Other molecules target the proteins that are encoded by the cancer causing genes. Early detection technologies that use novel imaging methods to find the cancer causing genes and proteins in tumors are enabling clinicians to devise tailored treatment strategies with better odds of helping patients and with fewer side effects.

Discoveries within laboratories will aid in preventing, detecting, and controlling the disease of cancer, empowering cancer patients with a better quality lifestyle and a more productive, longer life. Some will be cured. Others, through novel means of early detection or powerful new therapeutics, will circumvent the arduous plight of cancer.

Opportunities in cancer research have never been so abundant. New challenges await us. Those challenges stem in part from the changing demographics within the United States and across the world. We are an aging population in the United States. As we age, our risk of cancer increases. Only 2.2 people in every 100,000 Americans under the age of 65 develop cancer. Once past that landmark age, 10 times that number of people develop cancer.

In the next 15 years, one-fifth of the American people will become 65 years or older. Already, 12 percent of the American population is 66 years or older. The risk of getting cancer is compounded by the large number of people entering this higher risk category. The number of people who develop cancer is expected to grow exponentially. As a society, we have the opportunity to avert this pending crisis.

Two recent actions have started us in the right direction to avoid a cancer crisis of epidemic proportions. The first was the recent completion of the 5-year doubling of the NIH budget. The second was the bold Challenge Goal pronounced in 2001 by the Director of the National Cancer Institute: To eliminate the suffering and death from cancer by 2015. The American Association for Cancer Research supports the Director's challenge goal and stands ready to assist and contribute in any way possible to meet this challenge.

The state of scientific knowledge and technology has never been greater. Continued strong investment now will allow us to accelerate the pace of discovery and optimize the use of existing and new knowledge for the development and delivery of effective new cancer treatments.

Many of these opportunities are cogently set forth in *A Plan and Budget Proposal for Fiscal Year 2005* prepared by the Director of the National Cancer Institute. In-

formally referred to as the "Bypass Budget," this document is mandated by Congress as part of the National Cancer Act of 1971. Its purpose is to set forth the National Cancer Institute's forward-looking strategic plan to build on its research successes, support the cancer research workforce with the technologies and resources it needs, and ensure that research discoveries are applied to improve human health. The Bypass Budget is provided directly to the President for formulating the budget request to Congress. It is developed in close consultation with all sectors of the cancer community, including scientists and cancer survivors, and represents the NCI Director's best professional judgment on the opportunities available and the resources needed to optimize progress in the fight against cancer in that fiscal year.

The American Association for Cancer Research strongly supports the concept of the Bypass Budget. It is a vital tool to generate further research advances. AACR has identified a series of priority areas for investment—within the scope of the National Cancer Institute's action plan—that will significantly contribute to the achievement of the Director's Challenge Goal.

In core scientific areas, AACR has identified the following priorities:

—*Enhancing Investigator-initiated Research*.—Individual investigators in their laboratories and clinics are the foundation stone for innovations and advances in biomedical science. Their discoveries lead to better science and its productive application to patient care. Yet fewer than one-quarter of peer reviewed and approved research grant requests from these scientists are funded by the NCI. Increased funding for competing research grants and resources for investigator-initiated research are vital to the success of the cancer research enterprise.

—*Molecular Targets of Prevention, Diagnosis, and Treatment*.—Some of the most promising recent advances in cancer research have come from our increased understanding of the molecular causes of cancer. Intensified research will increase the number of effective cancer interventions directed at validated targets.

—*Development of Cancer Imaging and Molecular Sensing Technologies*.—Imaging advances are increasingly important in cancer treatment and care to non-invasively assess cancer progression.

In the area of public health, AACR includes the following among its priorities:

—*Research on Tobacco and Tobacco-related Cancers*.—Tobacco use is the leading preventable cause of death in the United States and is linked to nearly one-third of all deaths from cancer. Significant research investments are essential to accelerate research to understand, prevent, and treat tobacco use and addiction and to develop effective public health strategies to combat it.

—*Research on Obesity, Physical Activity, Diet, and Nutrition*.—Obesity may soon exceed tobacco as the primary cause of cancer. Extensive further research is critical to develop effective preventive strategies and interventions to protect the majority of our population that is at risk.

—*Reducing Cancer-related Health Disparities*.—The burden of cancer falls unequally on our society, with the low-income, medically underserved, elderly, and minority populations affected disproportionately by the disease. Further research is urgently needed to discover the causes for these disparities and to develop and deliver effective interventions to eliminate them.

In addition to the recommendations above, AACR has identified five other priority areas that are of key importance to accelerating progress against cancer:

—*Cancer Prevention*.—Cancer prevention and behavioral modification must be fundamental components of any realistic attempt to meet the Director's 2015 Challenge Goal. Concentrated and accelerated research is essential to generate new knowledge and advances in this largely uncharted territory.

—*Aging and Cancer*.—Close to 60 percent of all new cancers are in persons older than 65. Further research is urgently needed to adequately prepare for the impact of our aging population on our nation's healthcare system.

—*Training Translational Researchers*.—The number of physician-scientists who take findings from the laboratory through the preclinical, clinical, and regulatory processes to the patient's bedside are dwindling. This kind of translational cancer research demands a high level of research skill. Managed care allows very little time for physicians to engage in such research, and there is minimal funding and no defined career path for translational and clinical cancer researchers. Increased federal funding for training is crucial to attract, educate, train, and retain these clinical personnel if we are to have the skilled workforce needed to defeat cancer in the near future.

—*Expanding Our National Clinical Trials Program*.—Patients in clinical trials receive the most advanced treatment and prevention approaches for their particular cancers. These trials are highly cost effective; however, fewer than 5 percent of adult cancer patients participate in clinical trials, as compared to nearly 80 percent of children with cancer. Augmented funding for the national clinical

trials program is necessary so that adult participation, especially by minority and underserved patients, is doubled to at least 10 percent.

—*Extending the Bioinformatics Infrastructure*.—The value of the vast expansion of biomedical knowledge generated by today's researchers will match its potential value and usefulness only when it is collected, organized, integrated, stored, and made readily and universally accessible to the entire research community. Funding is needed to develop the state-of-the-art bioinformatics infrastructure for data mining and integration that is vital to accelerate research progress.

To maintain this nation's leadership in advanced biomedical research, and to take advantage of the abundant opportunities for research progress, we ask that you provide the National Institutes of Health with a sufficient level of funding to sustain the research momentum generated by the completion of the 5-year doubling of the budget. NIH officials and outside experts have testified that annual increases of at least 10 percent are required to preserve the research energy that has been unleashed by the doubling.

The cancer community is grateful for the 3.1 percent increase in the budget that the NIH received in 2004, but is deeply concerned about its impact on future progress. This is particularly troubling in light of the President's fiscal year 2005 Budget Request that only seeks a 2.6 percent increase for the NIH for next year. AACR shares this concern and urges the Committee to move boldly to furnish the funding levels necessary to undertake promising new research initiatives and to extend ongoing cutting-edge research through 2005 and beyond.

Specifically we urge your support to increase the budget of the National Institutes of Health to at least $30.61 billion in 2005. This 10 percent increase will allow the NIH to sustain and build upon its research progress while avoiding the severe disruption caused by cuts or nearly flat funding that is less than the rate of inflation.

We also ask that you fully fund the fiscal year 2005 Bypass Budget of the National Cancer Institute. At that level of funding, the NCI will be able to realize many of the vitally important research priority areas identified above and make the boldest strides possible against this disease. Thus, the AACR requests that the Committee fund the fiscal year 2005 NCI Bypass Budget request of the Director in the amount of $6.2 billion.

We have made remarkable progress in cancer research since the passage of the National Cancer Act in 1971. Your unflagging support for biomedical research for more than three decades has saved millions of lives and nurtured the productive research careers of thousands of our brightest and most dedicated scientists. More than 9.6 million cancer survivors alive today attest to the successful achievement of many of the goals of the National Cancer Act. With your continued positive support and leadership, the cancer community will be able to capitalize on the research momentum to convert our discoveries and new knowledge into the strategies and therapies that will make the Director's 2015 Challenge Goal a reality for all Americans.

PREPARED STATEMENT OF THE LYMPHOMA RESEARCH FOUNDATION

I am Melanie Smith, Director of Public Policy and Advocacy for the Lymphoma Research Foundation (LRF). I would like to express our appreciation for the opportunity to submit this statement to the record of the Labor, Health and Human Services and Education Appropriations Subcommittee. The LRF is the nation's largest lymphoma voluntary health organization, devoted to funding lymphoma research and providing information about the diseases to individuals diagnosed with lymphoma and their families and friends.

Our ultimate goal is to find a cure for all forms of lymphoma. To that end, we fund some of the world's leading lymphoma researchers at outstanding academic institutions. These researchers are engaged in research aimed at understanding the basic mechanisms of lymphoma and improving the current treatments for the disease. LRF also aims to equip those who are diagnosed with lymphoma with up-to-date information about treatment options. The organization sponsors educational conferences at which the leaders in lymphoma research and treatment address patients and families regarding cutting-edge research and the most recent developments in therapies.

BACKGROUND ON LYMPHOMA

Lymphoma is a major health problem. This year, approximately 54,400 cases of non-Hodgkin's lymphoma (NHL) will be diagnosed in this country, and more than 19,400 Americans will die from NHL. Also this year, 7,880 cases of Hodgkin's lymphoma will be diagnosed, and more than 1,320 Americans will die from the dis-

ease. Lymphoma is the most common form of blood cancer and the third most common form of childhood cancer. Nearly 500,000 Americans are living with lymphoma.

In recent years, there have been exciting reports regarding the improvements in treatments for a number of forms of cancer, as well as reports that the incidence of cancer overall is declining. Regrettably, NHL stands in contrast to the general trends in cancer incidence, and the treatment options for NHL remain inadequate. Since the early 1970s, incidence rates for NHL have nearly doubled, although incidence rates have stabilized the last few years. And the 5-year survival rate for NHL stands at 57 percent. These are not satisfactory numbers, and they serve as measures of the work we still have to do.

RESEARCH ON LYMPHOMA

In recent years, we have learned a great deal about the genetic, molecular, and cellular basis of cancer. We do not know the cause of most lymphomas, but there is increasing information to suggest a link between environmental factors and infections and the development of many lymphomas. The environmental factors include chemicals, toxins, and ultraviolet light, and the infectious agents include simian virus-40, hepatitis C, and Epstein Barr virus. There is also evidence that in some individuals, immune dysfunction is a critical factor in the development of lymphoma.

Our knowledge of cancer has improved significantly in the last decade, in large part due to the strong commitment of Congress to the National Institutes of Health (NIH) and its willingness to boost NIH funding, year after year. These funds have supported strong basic and clinical researchers who are focused on unlocking the secrets to cancer. There is a need to sustain that commitment to NIH, in order to equip scientists engaged in basic research and facilitate the translation of basic research findings into new treatments. This is certainly true in the case of lymphoma. There is a need to clarify the interactions among the environmental, viral, and immunogenetic factors that contribute to development of lymphoma and to ensure the development of new treatments based on our enhanced understanding of lymphoma.

Over the last decade, several new lymphoma treatments have been developed, expanding the options for those who are diagnosed with the disease. Lymphoma patients and researchers have clearly benefited from the nation's significant investment in research, and Congress deserves the appreciation of the community of lymphoma patients and researchers. Among the lymphoma treatments approved in the last decade are a monoclonal antibody and two different radioimmunotherapies. While we applaud the new treatments of the last decade, they are not a magic bullet; for many, lymphoma continues to be a fatal disease.

New therapies that capitalize on different research approaches are currently under investigation. These include therapeutic vaccines, immunotherapies, and proteasome inhibitors. Other work is focused on refining the chemotherapy regimens and developing treatment regimens with lower toxicities. All of this work deserves the support of private and public research funders.

ROLE OF NIH IN LYMPHOMA RESEARCH

Although LRF plays a critical and creative role in funding lymphoma research, NIH is, and will remain, the key player in this field. NIH is the pivotal player not only because of the magnitude of its financial commitment to lymphoma research, but also because of the role it can play in bringing together all of the partners in the research community—NIH intramural researchers, academic researchers, private foundations, industry, and the Food and Drug Administration (FDA).

NIH is also in the best position to encourage, facilitate, and fund the translation of basic research findings into new treatments. It is absolutely critical that we not lose the research momentum that has been the result in significant part of the doubling of the NIH budget between 1999 and 2003. This will require much more attention to translational and clinical research.

LRF recommends that NIH strengthen its lymphoma research program by several actions:

—The National Cancer Institute (NCI) should boost its support for translational and clinical lymphoma research. NCI should evaluate its current investment in clinical research and expand or initiate programs to strengthen the clinical research effort.

—NCI should also enhance its support for correlative studies of tumor biology and treatment response, as well as its investment in research on the late and long-term effects of current lymphoma treatments.

—The rate of payment for enrolling patients in NCI-sponsored clinical trials must be increased, as the current rate is inadequate to meet the costs associated with enrolling a patient in a clinical trial and collecting and analyzing the data associated with trial participation.
—NCI should enhance its research effort focused on understanding the complex interaction among environmental, viral and immunogenetic factors that are involved in the initiation and promotion of lymphoma.
—Although NCI has historically been the lead institute in funding lymphoma research, other institutes—the National Heart, Lung and Blood Institute (NHLBI), the National Institute on Aging (NIA), and the National Institute of Environmental Health Sciences (NIEHS)—should also evaluate and improve their lymphoma research programs. NIEHS has recently launched a targeted program to investigate the environmental links to breast cancer, and a lymphoma-focused program would be a logical outgrowth of the breast cancer program.

A strong partnership among voluntary health agencies like LRF, academic researchers, industry, NIH, and FDA will be optimal for advancing lymphoma research and improving the outlook for those who are diagnosed with the disease. New strategies are necessary for the rapid translation of basic research findings into new treatments. These strategies may include systems for funding collaborative research projects that engage researchers in multiple institutions and multiple disciplines, including academic researchers and industry. Private foundations are looking at creative means to ensure that their research dollars are optimized, and we encourage NIH to employ the same creative and flexible approaches.

ROLE OF THE CENTERS FOR DISEASE CONTROL AND PREVENTION IN BLOOD CANCER EDUCATION

LRF is actively engaged in providing patients and their families and caregivers complete and up-to-date information about lymphoma, lymphoma research, and lymphoma treatment options. Because of our strong history in this area, we were gratified when Congress authorized and funded a program at the Centers for Disease Control and Prevention (CDC) for public and patient education on blood cancers. According to the authorizing statute and appropriations report language, the appropriated funds are intended to support private sector organizations that are engaged in blood cancer education. We believe these funds can be used effectively by organizations that have extensive experience in these educational efforts, and we encourage Congress to fund the program in fiscal year 2005, for a second year, to ensure that there is no sudden discontinuation of a worthy educational initiative.

LRF believes that strong partnerships will be a key feature of efforts to improve lymphoma treatments and provide lymphoma patients current information about their disease and treatment options. We encourage NCI to fund collaborative research ventures, and we urge CDC to support those private organizations that have years of experience in patient education. Those who receive a diagnosis of lymphoma face difficult choices, and we must work together to improve their options.

PREPARED STATEMENT OF WOMENHEART, THE NATIONAL COALITION FOR WOMEN WITH HEART DISEASE

Heart disease is the leading cause of death for American women, killing nearly 500,000 each year. Yet, according to a recent American Heart Association poll, less than half (46 percent) of women know this basic fact and, even more troubling, only 13 percent think that heart disease is their own most important health risk.

Ignorance often has fatal consequence. Women are not educated about their risk factors for heart disease so often do not take the necessary steps, such as cholesterol and blood pressure checks, to prevent or intervene in the earliest stages of the disease. They also are unaware of the signs and symptoms of heart attacks in women, which may differ than those in men. As a result, they do not get to the emergency room quickly enough to receive life-saving treatment. Many often die at home.

We ask the Subcommittee to increase funding for public education programs to increase women's knowledge of their heart disease risks and symptoms. Specifically, we urge a $10 million appropriation for NIH's National Heart, Lung and Blood Institute's existing "Heart Truth" campaign, which has been only modestly funded to-date. Through its adoption of the Red Dress as the national symbol for women and heart disease awareness, and the First Lady's participation in its public event, the campaign has put this long-ignored crucial women's health issue on the national agenda and is reaching thousands of women through its media relations and community outreach initiatives. However, a more significant campaign is needed to

reach the millions of American women who are at-risk for or undiagnosed with heart disease.

Thank you for your consideration.

The National Coalition for Women with Heart Disease is the nation's only patient advocacy organization representing the 8,000,000 that aims to increase their quality of life and quality of healthcare through support, information and advocacy. It is a non-profit public charity headquartered in Washington, DC.

PREPARED STATEMENT OF THE UPPER COUNTY BRANCH, MONTGOMERY COUNTY, MARYLAND STROKE CLUB

A STROKE SURVIVOR: A PERSONAL STORY

Hello. My name is Susan Emery. I am the presiding officer of the Upper County Branch of the Montgomery County Stroke Club and I'm a stroke survivor.

Our club conducts education and support activities for stroke survivors, their family members, and caregivers. We serve people in the Maryland suburbs of Washington, D.C., and are fortunate to be in the same county as the National Institutes of Health. We have benefited on many occasions by the participation of NIH staff members in our membership meetings. They have been generous in sharing information about their research into stroke prevention and treatment with us.

On December 26, 1965 at the age of 9, I was playing a new game with my brother and a few friends at the kitchen table. That's the last thing that I remember. I was unconscious for the next 2 days. My mother first learned, incorrectly, that I had spinal meningitis. I was transferred to another hospital where my mother was told that I had little chance of survival. Yet I'm here, more than 37 years later, and I've survived a stroke.

People seldom associate strokes with children. These strokes are rare, but they do happen. There are about three cases of stroke per year in every 100,000 children under age 14. One of the difficulties in dealing with strokes in children is getting the right diagnosis quickly. There are often delays in diagnosis of childhood stroke.

I spent 2 weeks in the hospital and the following 4 months in intensive physical therapy. My tenth birthday was spent in the hospital, and I have a picture in my photo album of myself with my mother and a new friend. My right eye is turned down, my mouth is turned down, but I'm still smiling. During the 4 months in therapy at Holy Cross in Detroit, I learned the basics: how to walk, how to talk, and how to move the fingers on my right hand. My mother followed the doctor's instructions and sent me back to school very quickly, where classmates helped me button and unbutton my coat and carry my books, and teachers taped papers to the desk so I could learn to write again. I survived that 4 months, and would never wish to repeat it.

I've been in therapy six times in my life. I need to tell you about the one time that was the most important to my family. I was 26 years old and had just had my first child. I kept her safe, for I knew my limitations. I always used my left hand to support her. But when she was 6 months old, she got to be a little heavy, and twice, as I was putting her on the floor to change her diaper, my right hand slipped from under her buttocks. She fell only inches in both cases and didn't even notice. But I noticed. I went in for 2 or 3 months of therapy close to Denver, Colorado, where I was living at the time. Here for the first time, they helped my right hand and arm dexterity through occupational therapy. I also learned that I had aphasia—the inability to speak, write or understand spoken or written language because of brain injury—because I called things like cornucopias, unicorns instead of fruit baskets. Instead of the word being the same, I picked a word that sounded the same. These therapists in Colorado worked with my mind and my body and I will forever be in their debt.

Close to 15 years ago, I made a new life for myself in Maryland. Here, I've been an outpatient at the National Rehabilitation Hospital three times: once for my right foot, once for my Achilles tendon and once for my right knee. I've seen numerous physiatrists, all of whom are excellent in their field. I've also seen my fair share of therapists. Since I've had therapy off and on for most of my life, I can honestly say that the first few times you go in to see a therapist, you'll come out hurting more than when you went in. But in the long run, they help tremendously.

On a work related note, I received a Bachelor of Science in 1978 from Michigan State University in Computer Science and worked for 12 years in the field. I started working in the telecommunications industry in 1990, and got a Master of Science from the University of Maryland, University College in Telecommunications Management. I now work for ITT Industries as a senior engineer on a contract sup-

porting the Federal Aviation Administration's leased telecommunications activities, and have worked there for more than 6 years. I've done more than survive. I've become a productive member of society.

Stroke research has changed my life. Without the research carried out 40 to 50 years ago, I would not have benefited from electric shock therapy that made me understand the muscles that moved my fingers. Without research done 30 years ago, I may not have been able to understand how to exercise my hand for dexterity. Without research performed 10 years ago, the people around me would not understand that they need to get me to the hospital quickly if ever I have another stroke. Without current support, researchers may never understand how to stop strokes before they happen or how to make current stroke survivors live healthier lives.

Stroke remains America's No. 3 killer and a major cause of permanent disability. An estimated 4.8 million Americans live with the consequences of stroke and about 1 in 4 is permanently disabled. Yet, stroke research receives a mere 1 percent of the National Institutes of Health budget. I strongly urge you to significantly increase funding for the National Institutes of Health-supported stroke research, particularly for National Institute of Neurological Disorders and Stroke-supported stroke research. NIH stroke research is essential to prevent strokes from happening to children and adults in the first place, and to advance recovery and rehabilitation of those who survive this potentially devastating illness.

PREPARED STATEMENT OF THE ILLINOIS NEUROFIBROMATOSIS, INC.

Thank you for the opportunity to present testimony to the Subcommittee on the importance of continued funding for Neurofibromatosis (NF), a terrible genetic disorder closely linked to cancer, learning disabilities, heart disease, brain tumors, and other disorders affecting up to 150 million Americans in this generation alone. Thanks in large measure to this Subcommittee's support; scientists have made enormous progress since the discovery of the NF1 gene in 1990. Major advances in just the past year have ushered in an exciting era of clinical and translational research in NF with broad implications for the general population.

I am David Evans, representing Illinois Neurofibromatosis, Inc., which is a participant in a national coalition of NF advocacy groups. I have lived with NF my entire life. Although I have not suffered any of NF's severe symptoms; I have experienced the social problems caused by being afflicted with NF. I have endured rude comments and harassment my entire life. On July 4, 1996 I was threatened with arrest if I would not leave a water park in Crestwood, Illinois. After other patrons complained to the owner, he informed me that I looked "terrible" and should wear a shirt or leave. I explained NF to him and assumed the matter was settled. Later however, he brought in the police and I was forced to leave. As a result of this experience I became active in Illinois NF, Inc. and have been on the board of directors since 1997.

WHAT IS NF?

NF is a genetic disorder involving the uncontrolled growth of tumors along the nervous system which can result in terrible disfigurement, deformity, deafness, blindness, brain tumors, cancer, and/or death. NF can also cause other abnormalities such as unsightly benign tumors across the entire body and bone deformities. In addition, approximately one-half of children with NF suffer from learning disabilities. It is the most common neurological disorder caused by a single gene. While not all NF patients suffer from the most severe symptoms, all NF patients and their families live their lives with the uncertainty of not knowing whether they will be seriously affected one day because NF is a highly variable and progressive disease.

Approximately 100,000 Americans have NF, and it appears in approximately 1 in every 3,500 births. It strikes worldwide, without regard to gender, race or ethnicity. Approximately 50 percent of new NF cases result from a spontaneous mutation in an individual's genes, and 50 percent are inherited. There are two types of NF: NF1, which is more common, and NF2, which primarily involves acoustic neuromas and other tumors, causing deafness and balance problems. Advances in NF research will benefit over 150 million Americans in this generation alone because NF is directly linked to many of the most common diseases affecting the general population.

LINK TO OTHER ILLNESSES

Researchers have determined that NF is closely linked to cancer, heart disease, learning disabilities, memory loss, brain tumors, and other disorders including deaf-

ness, blindness and orthopedic disorders. Research on NF therefore stands to benefit millions of Americans:

Cancer.—Research has demonstrated that NF's tumor suppressor protein, neurofibromin, inhibits RAS, one of the major malignancy causing growth proteins involved in 30 percent of all cancer. Accordingly, advances in NF research may well lead to treatments and cures not only for NF patients but for all those who suffer from cancer and tumor-related disorders. Similar studies have also linked epidermal growth factor receptor (EGF–R) to malignant peripheral nerve sheath tumors (MPNSTs), a form of cancer which disproportionately strikes NF patients.

Heart disease.—Researchers have demonstrated that mice completely lacking in NF1 have congenital heart disease that involves the endocardial cushions which form in the valves of the heart. This is because the same ras involved in cancer also causes heart valves to close. Neurofibromin, the protein produced by a normal NF1 gene, suppresses ras, thus opening up the heart valve. Promising new research has also connected NF1 to cells lining the blood vessels of the heart, with implications for other vascular disorders including hypertension, which affects 45 million Americans. Researchers believe that further understanding how an NF1 deficiency leads to heart disease may help to unravel molecular pathways affected in genetic and environmental causes of heart disease.

Learning disabilities.—Learning disabilities are the most common neurological complication in children with NF1. Research aimed at rescuing learning deficits in children with NF could open the door to treatments affecting 35 million Americans and 5 percent of the world's population. Indeed, leading researchers have already rescued learning deficits in both mice and fruit flies with NF1, which will benefit all people with learning disabilities, not just those with NF as well as save federal, state and local governments and school districts billions of dollars in special education costs.

Deafness.—NF2 accounts for approximately 5 percent of genetic forms of deafness. It is also related to other types of tumors, including schwannomas and meningiomas, as well as being a major cause of balance problems.

SCIENTIFIC ADVANCES

The progress that has been made in NF research has been nothing short of phenomenal. In just over a dozen years since the discovery of the NF1 gene, researchers are now on the threshold of developing a treatment and cure for this terrible disease. Scientists who previously had been pessimistic are now genuinely excited about engaging in therapeutic experimentation and the phase II clinical trials already being conducted by NIH. Because of NF's implication with so many other diseases, many NF researchers believe that NF should serve as a model to study all diseases. Indeed, one leading researcher has stated that more is known about NF genetically than any other disease.

In just the past few years, scientists have made major breakthroughs bringing NF fully into the translational era, with treatments close at hand. These recent advances have included:

—Phase II clinical trials on two drug therapies;
—Developing advanced mouse models showing human symptoms;
—Rescuing learning deficits in mice;
—Linking NF to hypertension, which affects 45 million Americans, as well as congenital heart disease; and
—Launching natural history studies to analyze the progression of the disease.

Other advances since 1990 include:

—*The discovery of the NF1 and NF2 genes and gene products*.—The NF1 gene was discovered in 1990 and the NF2 gene was discovered in 1993.
—Determination and understanding of the functions of the NF1 and NF2 genes and gene products, including the discovery of new pathways impacted by the NF genes and gene products. Most strikingly, researchers have discovered that NF regulates both the c-AMP pathway affecting learning and memory as well as the ras pathway affecting cancer. This discovery, which brought together cancer and neurology through NF's controlling both of these related pathways, holds monumental implications for finding the treatments and cures for many diseases which affect a vast segment of the population.
—*Development of advanced animal models*.—Researchers have developed advanced mouse models which exhibit human symptoms, such as malignant tumors, leukemia, and learning disabilities. Such animal models provide a unique method for addressing the fundamental aspects of disease development and for testing therapeutic strategies. NF researchers have also developed the fruit fly as a model animal organism to study not only NF but many other diseases.

—*Commencement of clinical trials at NCI*.—As a result of the enormous progress made in NF research, NCI has already commenced two clinical trials with pediatric NF1 patients, including phase II trials using of farnesyl transferase inhibitors and phase I trials using pirfenidone, and is developing a third clinical trial.
—*Development of drug and gene therapies*.—Leading NF researchers have been actively engaged in developing both drug and gene therapeutic experimentation in mice and fruit flies. In the case of NF1, these experiments have been directly related to tumor suppression and learning deficits. Researchers also believe that a gene therapy for NF2 can be developed; unlike other genetic forms of deafness, in which a mutation leads to a development or structural abnormality in the ear for which it would be difficult to envisage a treatment in the adult, NF2-associated deafness is potentially preventable or curable if tumor growth is halted before damage has been done to the adjacent nerve.
—*Rescuing learning deficits in animal models*.—A paper published in the January 30, 2002 edition of Nature demonstrated how researchers were able to rescue learning deficits in mice with the same mutation that causes NF1 in humans—disabilities once thought to be irreversible. This discovery has enormous implications for the 35 million Americans suffering from learning disabilities. Studies on fruit flies have also demonstrated that the neurofibromin protein regulates the c-AMP pathway which is known to control learning and memory.
—*Development of Infrastructure*.—Researchers, with the help of the government, have been building expanded national and international NF centers, consortia, and other infrastructure for clinical and translational research and treatment.

FUTURE DIRECTIONS

NF research has now advanced to the translational and clinical stages which hold incredible promise for NF patients, as well as for patients who suffer from many of the diseases linked to NF. This research is costly and will require an increased commitment on the federal level. Specifically, future investment in the following areas would continue to advance research on NF:
—Clinical trials;
—Development of a clinical trials network to connect patients with experimental therapies;
—Development of new drug and genetic therapies;
—Further development of advanced animal models;
—Expansion of biochemical research on the functions of the NF gene and discovery of new targets for drug therapy;
—Natural history studies and identification of modifier genes—studies are already underway to provide a baseline for testing potential therapies and differentiate among different phenotypes of NF; and
—Development of NF Centers, tissue banks, and patient registries.

CONGRESSIONAL SUPPORT FOR NF RESEARCH

The enormous promise of NF research—and its potential to benefit tens of millions of Americans in this generation alone—has gained increased recognition from Congress and the NIH. This is evidenced by the fact that seven Institutes at NIH are currently supporting NF research (NINDS, NCI, NICHD, NCRR, NEI, NIDCD, and NHLBI), and NIH's total research portfolio has increased from $3 million in 1990 to over $20 million in fiscal year 2004.

The enormous advances in NF research would not have been possible without Congress's continued support of the NIH, and I would like to personally thank the members of this Subcommittee for their leadership in doubling the budget of the NIH over 5 years.

At the same time, we are concerned that the NF research portfolio at both the National Cancer Institute and the National Institute of Neurological Disorders and Strokes has declined by several million dollars in recent years, despite appropriations report language recommending a greater investment. Given the potential offered by NF research for progress against a range of diseases, and the completion of the 5-year doubling of the NIH budget, we are hopeful that NCI and NINDS will substantially increase NF research funding. We appreciate the Subcommittee's strong support for NF research dating back to 1990, and will continue to work with you to ensure that opportunities for major advances in NF research are aggressively pursued.

This Subcommittee has long recognized that our goal should be to translate the promise of scientific discovery into an improved quality of life for all Americans. The example of the progress realized in NF research demonstrates the success of this vision and commitment.

Thank you again for the opportunity to tell you of the progress and potential of NF research.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR GERIATRIC PSYCHIATRY

The American Association for Geriatric Psychiatry (AAGP) appreciates this opportunity to present its recommendations on issues related to fiscal year 2005 appropriations for mental health research and services. AAGP is a professional membership organization dedicated to promoting the mental health and well being of older Americans and improving the care of those with late-life mental disorders. AAGP's membership consists of approximately 2,000 geriatric psychiatrists as well as other health professionals who focus on the mental health problems faced by senior citizens.

AAGP would like to thank the Subcommittee for its continued strong support for increased funding for the National Institutes of Health (NIH) over the last several years, particularly the additional funding you have provided for the National Institute of Mental Health (NIMH), the National Institute on Aging (NIA), the National Institute on Alcohol Abuse and Alcoholism (NIAAA), and the Center for Mental Health Services (CMHS) within the Substance Abuse and Mental Health Services Administration (SAMHSA). Although we generally agree with others in the mental health community about the importance of sustained and adequate Federal funding for mental health research and treatment, AAGP brings a unique perspective to these issues because of the elderly patient population served by our members.

There are serious concerns, shared by AAGP and researchers, clinicians, and consumers that there exists a critical disparity between appropriations for research, training, and health services and the projected mental health needs of older Americans. This disparity is evident in the convergence of several key factors:

—demographic projections inform us that, with the aging of the U.S. population, there will be an unprecedented increase in the burden of mental illness among aging persons, especially among the baby boom generation;

—this growth in the proportion of older adults and the prevalence of mental illness is expected to have a major direct and indirect impact on general health service use and costs;

—despite the fact that effective treatment exists, the current mental health needs of many older adults remain unmet;

—the number of physicians being trained in geriatric mental health research and clinical care is insufficient to meet current needs, and this workforce shortfall is projected to become a crisis as the U.S. population ages over the next decade;

—a major gap exists between research, mental health care policy, and service delivery; and

—despite recent significant increases in appropriations for support of research in mental health, the allocation of NIMH and CMHS funds for research that focuses specifically on aging and mental health is disproportionately low, and woefully inadequate to deal with the impending crisis of mental health in older Americans.

DEMOGRAPHIC PROJECTIONS AND THE MENTAL DISORDERS OF AGING

With the baby boom generation nearing retirement, the number of older Americans with mental disorders is certain to increase in the future. By the year 2010, there will be approximately 40 million people in the United States over the age of 65. Over 20 percent of those people will experience mental health problems. A national crisis in geriatric mental health care is emerging and has received recent attention in the medical literature. Action must be taken now to avert serious problems in the near future. While many different types of mental and behavioral disorders can occur late in life, they are not an inevitable part of the aging process, and continued research holds the promise of improving the mental health and quality of life for older Americans.

The current number of health care practitioners, including physicians, who have training in geriatrics is inadequate. As the population ages, the number of older Americans experiencing mental problems will almost certainly increase. Since geriatric specialists are already in short supply, these demographic trends portend an intensifying shortage in the future. There must be a substantial public and private sector investment in geriatric education and training, with attention given to the importance of geriatric mental health needs. We will never have, nor will we need, a geriatric specialist for every older adult. However, without mainstreaming geriatrics into every aspect of medical school education and residency training, broad-based competence in geriatrics will never be achieved. There must be adequate

funding to provide incentives to increase the number of academic geriatricians to train health professionals from a variety of disciplines, including geriatric medicine and geriatric psychiatry.

Current and projected economic costs of mental disorders alone are staggering. The direct medical expense to care for a patient with Alzheimer's disease ranges from $18,000 to $36,000 a year per patient, depending on the severity of the disease. In addition, there are substantial indirect costs associated with caring for an Alzheimer's disease patient including social support, care giving, and often nursing home care. It is estimated that total costs associated with the care of patients with Alzheimer's disease is over $100 billion per year in the United States. Psychiatric symptoms (including depression, agitation, and psychotic symptoms) affect 30 to 40 percent of people with Alzheimer's and are associated with increased hospitalization, nursing home placement, and family burden. These psychiatric symptoms, associated with Alzheimer's disease, can increase the cost of treating these patients by more than 20 percent. Although NIA has supported extensive research on the cause and treatment of Alzheimer's, treatment of these behavioral and psychiatric symptoms has been neglected and should be supported through NIMH.

Depression is another example of a common problem among older persons. Approximately 30 percent of older persons in primary care settings have significant symptoms of depression; and depression is associated with greater health care costs, poorer health outcomes, and increased mortality. Of the approximately 32 million Americans who have attained age 65, about 5 million suffer from depression, resulting in increased disability, general health care utilization, and increased risk of suicide. Older adults have the highest rate of suicide rate compared to any other age group. Comprising only 13 percent of the U.S. population, individuals age 65 and older account for 19 percent of all suicides. The suicide rate for those 85 and older is twice the national average. More than half of older persons who commit suicide visited their primary care physician in the prior month—a truly stunning statistic.

The enormous and widely underestimated costs of late-life mental disorders justify major new investments. The personal and societal costs of mental illness and addictive disorders are high, but advances in research and treatment will help save lives, strengthen families, and save taxpayer dollars.

THE BENEFITS OF RESEARCH ON PUBLIC HEALTH

The U.S. Surgeon General's Report on Mental Health (1999) and the Administration on Aging Report on Older Adults and Mental Health (2001) underscore the prevalence of mental disorders in older persons and provide evidence that research has lead to the development of effective treatments. These reports summarize research findings showing that treatments are effective in relieving symptoms, improving functioning, and enhancing quality of life. Preliminary findings suggest that these interventions reduce the need for expensive and intensive acute and long-term services. However, it is also well demonstrated that there is a pronounced gap between research findings on the most effective treatment interventions and implementation by health care providers. This gap can be as long as 15 to 20 years. These reports stress the need for translational and health services research focused on identifying the most cost-effective interventions, as well as creating effective methods for improving the quality of health care practice in usual care settings. A major priority (neglected to date) is the development of a health services research agenda that examines the effectiveness and costs of proven models of mental health service delivery for older persons.

Special attention also needs to be paid to inadequately or poorly studied, serious late-life mental disorders. Illnesses such as schizophrenia, anxiety disorders, alcohol dependence and personality disorders have been largely ignored by both the research community and the funding agencies, despite the fact that these conditions take a major toll on patients, their care givers, and society at large. Many of AAGP's members are at the forefront of groundbreaking research on Alzheimer's disease, depression, and psychosis among the elderly, and we strongly believe that more research funds must be focused in these areas. Improving the treatment of late-life mental health problems will benefit not only the elderly, but also their children, whose lives are often profoundly affected by their parents' illness.

While the funding increases supported by this Subcommittee in recent years have been essential first steps to a better future, a committed and sustained investment in research is necessary to allow continuous progress on the many research advances made to date.

NATIONAL INSTITUTE OF MENTAL HEALTH

In his fiscal year 2005 budget, the President proposed an increase of $729 million for the National Institutes of Health (NIH), which would bring the entire NIH budget to a level of $28.8 billion. However, this 2.6 percent increase over the fiscal year 2004 funding level pales in comparison with recent annual double-digit increases. A decline in adequate funding increases could have a devastating impact on the ability of NIH to sustain the ongoing, multi-year research grants that have been initiated in recent years.

For NIMH, the President is proposing $1.421 billion for scientific and clinical research, a 2.8 percent increase over the agency's fiscal year 2004 appropriation of $1.382 billion. It is important to note that from fiscal year 1999 through fiscal year 2004, NIMH received increases that lagged behind the increases received by many of the other NIH institutes. Furthermore, the increase proposed by the Administration for NIMH for fiscal year 2005 is lower than that proposed for most of the other institutes at NIH. As Congress moves forward with deliberations on the fiscal year 2005 budget, AAGP believes that NIMH should receive a percentage increase that, at the very minimum, is equal to the average percentage increase for the other NIH institutes.

Commendable as recent funding increases for NIH and NIMH have been, AAGP would like to call the Subcommittee's attention to the fact that these increases have not always translated into comparable increases in funding that specifically address problems of older adults. Data supplied to AAGP by NIMH indicates that while extramural research grants by NIMH increased 59 percent during the 5-year period from fiscal year 1995 through fiscal year 2000 (from $485,140,000 in fiscal year 1995 to $771,765,000 in fiscal year 2000), NIMH grants for aging research increased at less than half that rate: only 27.2 percent during the same period (from $46,989,000 to $59,771,000).

AAGP is pleased that NIMH has recently renewed its emphasis on mental disorders among the elderly, and commends the recent creation of a new Aging Treatment and Prevention Intervention Research Branch at NIMH as well as the establishment of an intra-NIMH consortium of scientists concerned with mental disorders in the aging population. However, funding for aging mental health research is still not keeping pace with that of other adult mental health research, and is actually decreasing proportionally when considered in the context of anticipated projections in growth of mental disorders in older persons. For example, the proportion of total NIMH newly funded extramural research grant funding devoted to aging research declined from an average of 8 percent from fiscal years 1995 to 1999 to a low of 6 percent in fiscal year 2000. To reverse this trend, it will also be important to constitute grant review committees with specialized expertise in geriatrics to ensure a fair review of research proposals. Review committees must take into account knowledge of the unique biological factors associated with the aging brain, the high prevalence of co-occurring medical illnesses, and the specific systems for financing and health services delivery for older Americans. In addition, AAGP would like the scope of this branch increased into a comprehensive aging branch that is responsible for all facets of clinical research, including translational, interventions, and disease-based psychopathology. Further, the branch should be given adequate resources to fulfill its primary mission within NIMH.

In addition to supporting research activities at NIMH, AAGP supports increased funding for research related to geriatric mental health at the other institutes of NIH that address issues relevant to mental health and aging, including the National Institute of Aging (NIA), the National Institute on Alcohol Abuse and Alcoholism (NIAAA), the National Institute on Drug Abuse (NIDA), and the National Institute of Neurological Disorders and Stroke.

CENTER FOR MENTAL HEALTH SERVICES

It is also critical that there be adequate funding increases for the mental health initiatives under the jurisdiction of the Center for Mental Health Services (CMHS) within the Substance Abuse and Mental Health Services Administration (SAMHSA). While research is of critical importance to a better future, the patients of today must also receive appropriate treatment for their mental health problems. SAMHSA provides funding to State and local mental health departments, which in turn provide community-based mental health services to Americans of all ages, without regard to the ability to pay. AAGP was pleased that the final budgets for fiscal years 2002, 2003 and 2004 included $5 million for evidence-based mental health outreach and treatment to the elderly. However, AAGP is extremely alarmed to see that this program was eliminated in President Bush's fiscal year 2005 budget proposal. Restoring and increasing this mental health outreach and treatment program must be

a top priority, as it is the only Federally funded services program dedicated specifically to the mental health care of older adults.

Originally funded in the Fiscal Year 2002 Labor-HHS-Education Appropriations (Public Law 107–116), AAGP worked with members of this Subcommittee and its House counterpart on this initiative, which was intended as a first step in the effort to curb the projected growth of older adults in America suffering from mental disorders. The House Appropriations Committee Report on Fiscal Year 2002 Labor-HHS-Education Appropriations states that $5 million should be appropriated for a senior mental health outreach and treatment program within CMHS and that the funds are "intended to begin to address" the predicted increase of older adults suffering from mental illness. Regarding the same program, the Senate Appropriations Committee Report states, "The Committee strongly encourages CMHS to devote additional resources in fiscal year 2002 and subsequent fiscal years to this issue." Unfortunately, this initiative has not seen the subsequent increases its creators intended when Congress created this program.

Funding for the dissemination and implementation of evidence-based practices in "real world" care settings must be a top priority for Congress. Despite significant advances in research on the causes and treatment of mental disorders in older persons, there is a major gap between these research advances and clinical practice in usual care settings. The greatest challenge for the future of mental health care for older Americans is to bridge this gap between scientific knowledge and clinical practice in the community, and to translate research into patient care. Adequate funding for this geriatric mental health services initiative is essential to disseminate and implement evidence-based practices in routine clinical settings across the states. Consequently, we would urge that the $5 million for mental health outreach and treatment for the elderly included in the CMHS budget for fiscal year 2004 not only be restored, but also be increased to $20 million for fiscal year 2005.

Of that $20 million appropriation, AAGP believes that $10 million should be allocated to a National Evidence-Based Practices Program, which will disseminate and implement evidence-based mental health practices for older persons in usual care settings in the community. This program will be a collaborative effort, actively involving family members, consumers, mental health practitioners, experts, professional organizations, academics, and mental health administrators. With $10 million dedicated to a program to disseminate and implement evidence-based practice in geriatric mental health, there will be an assured focus on facilitating accurate, broad-based sustainable implementation of proven effective treatments, with an emphasis on practice change and consumer outcomes. Such a program should include several development phases including identification of a core set of evidence-based practices, development of evidence-based implementation, and practice improvement toolkits and field-testing of evidence-based implementation. This program will provide the foundation for a longer-term national effort that will have a direct effect on the well-being and mental health of older Americans.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

One of the most valuable resources in our efforts to improve access to and the quality of geriatric mental health services is the Agency for Healthcare Research and Quality (AHRQ). In recent years the Agency has supported important research on mental health topics including studies on children's mental health issues, the impact of mental health parity on consumers' share of mental health costs, improving care for depression in primary care, and cultural issues in the treatment of mental illness in minority populations. This work has led to important contributions to the mental health literature, and the advancement of effective diagnosis and treatment of mental illness. We applaud these efforts and urge the Committee to increase support for the critical work of this Agency.

However, we are concerned that the research agenda of the Agency has not given more attention to geriatric mental health issues. The prevalence of undiagnosed and untreated mental illness among the elderly is alarming. Conditions such as depression, anxiety, dementia, and substance abuse in older adults are often misdiagnosed or not recognized at all by primary and specialty care physicians. There is accumulating evidence that depression can exacerbate the effects of cardiac disease, cancer, strokes, and diabetes. Research has also shown that treatment of mental illness can improve health outcomes for those with chronic diseases. Effective treatments for mental illnesses in the elderly are available, but without access to physicians and other health professionals with the training to identify and treat these conditions, far too many seniors fail to receive needed care.

AAGP believes there is an urgent need to translate findings from aging-related biomedical and behavioral research into geriatric mental health care. By utilizing

the resources of the evidence-based practice centers under contract to AHRQ, results from geriatric mental health research can be evaluated and translated into findings that will improve access, foster appropriate practices, and reduce unnecessary and wasteful health care expenditures. We urge the Committee to direct AHRQ to support additional research projects focused on the diagnosis and treatment of mental illnesses in the geriatric population. We also believe a high priority should be given to the dissemination of scientific findings about what works best, to encourage physicians and other health professionals to adopt "best practices" in geriatric mental health care.

CONCLUSION

Based on AAGP's assessment of the current need and future challenges of late life mental disorders, we submit the following fiscal year 2005 funding recommendations:

1. The current rate of funding for aging grants at NIMH and CMHS is inadequate. Funding for NIMH and CMHS aging-related health services grants should be increased to be commensurate with current need—at least three times their current funding levels. In addition, the substantial projected increase in mental disorders in our aging population should be reflected in the budget process in terms of dollar amount of grants and absolute number of new grants;
2. Previous years' funding of $5 million for evidence-based mental health outreach and treatment for the elderly within CMHS was eliminated in President Bush's fiscal year 2005 budget proposal. To help the country's elderly access necessary mental health care, this funding must be restored and increased to $20 million;
3. A fair grant review process will be enhanced by committees with specific expertise and dedication to mental health and aging;
4. Adequate infrastructure and funding within both NIMH and CMHS to support the development of initiatives in aging research, to monitor the number and quality of applicants for aging research grants, to promote funding of meritorious projects, and to manage those grant portfolios;
5. The scope of the recently formed Aging Treatment and Prevention Intervention Research Branch at NIMH should be increased to include all relevant clinical research, including translational, interventions, and disease-based psychopathology, and must receive NIMH's full support so it may fulfill its primary mission;
6. AHRQ should undertake additional research projects focused on the diagnosis and treatment of mental illnesses in the geriatric population, and dissemination of information on best practices; and
7. Funding for NIAAA must be increased by at least 20 percent to enable it to undertake more research and collect more data focused on issues such as the link between alcohol use and late-life suicide and the impact of alcohol use across the lifespan.

AAGP strongly believes that the present research infrastructure, professional workforce with appropriate geriatric training, health care financing mechanisms, and mental health delivery systems are grossly inadequate to meet the challenges posed by the expected increase in the number of older Americans with mental disorders. Congress must support funding for research that addresses the diagnosis and treatment of mental illnesses, as well as programs for delivery of geriatric mental health services that increase the quality of life for those with late-life mental illness.

AAGP looks forward to working with the members of this Subcommittee and others in Congress to establish geriatric mental health research and services as a priority at NIMH, CMHS, AHRQ and NIAAA.

PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

The American Society for Microbiology (ASM), the largest single life science society with 43,000 members, is pleased to provide testimony in support of the nation's investment in the extraordinary work of the National Institutes of Health (NIH). Advances in NIH research have markedly intensified over the past 5 years during which the NIH budget has grown thanks to the foresight of Congress and the Administration. Robust funding increases have resulted in rapid strides in cutting edge research and new research tools to facilitate the development of vaccines, therapies and interventions that save and improve the lives of millions of people.

To ensure that progress is sustained, the ASM recommends that Congress make research and public health a high national priority and provide an increase of 10 percent for the NIH for fiscal year 2005. Continued strong funding increases will enable NIH to accelerate and expand promising basic and clinical research that will

lead to new preventions and treatments for tragic and costly illnesses and disabilities that continue to afflict and claim the lives of many people. The ASM encourages Congress to provide higher funding levels for research and public health that will address the alarming burden of disease in the United States and abroad and help prepare the nation for novel health threats and the next disease emergency that will inevitably occur in the future.

The public health and security of the nation depend on the continuation of strong investments in research and public health. The severe acute respiratory syndrome (SARS) epidemic of 2003 highlights the continuing need for investment in a strong biomedical and public health system that is prepared to respond to emerging diseases, whether naturally occurring or intentionally introduced. Previous NIH investment in emerging diseases research has allowed expeditious studies of SARS to identify targets for antiviral drugs, diagnostics and vaccines. Not only are people at risk for chronic diseases such as cancer, heart disease, stroke, diabetes and Alzheimer's disease, but also from new and emerging infectious diseases, such as the HIV pandemic, highly virulent influenza viruses, West Nile Virus, hepatitis A and C, and the possibility of the deliberate release of disease by bioterrorists, which still remains a threat.

The accomplishments and investment in biodefense research, facilities and resources should also facilitate defenses against naturally occurring infectious diseases that pose a real and present danger to global public health. Infectious diseases account for 26 percent of total global mortality and are the third leading cause of death in the United States. Despite impressive advances in microbiology, old diseases remain entrenched and new ones can appear suddenly and spread quickly. Sufficient and sustained federal funding for research helps protect against these enemies to public health.

INVESTIGATOR INITIATED RESEARCH

Most of the budget appropriated to the NIH each year flows outside the agency to an estimated 212,000 research personnel affiliated with approximately 28,000 organizations across the United States and elsewhere. This extramural research community competes for NIH grants through a merit based peer-review process; of the growing number of applications each year, estimated to exceed 35,000, less than one-third are projected to receive NIH funding. The proposed fiscal year 2005 budget supports an increase in the number of new and competing grants from 10,135 to 10,393, an additional 258 grants. Investigator initiated research is the primary tool by which biomedical research is funded and conducted and requires increased funding to take advantage of scientific opportunities that lead to new knowledge and its applications to health care.

NIH ROADMAP FOR MEDICAL RESEARCH

Within the proposed fiscal year 2005 budget, the NIH Roadmap for Medical Research plan would receive $237 million, an increase of $109 million over fiscal year 2004. Announced in September 2003, this set of 27 initiatives actuates an agency wide commitment to maximize research investment through intensive, multi-disciplinary projects with high potential to solve serious health problems. The Roadmap realizes three 21st-century visions of a vigorous research enterprise: building new pathways to discovery through new technologies, databases, and other resources; creating multidisciplinary research teams better prepared to tackle the complexities of modern research; and re-engineering clinical research structures to expedite the rapid translation of discoveries from the lab to the clinic. This trans-NIH effort is an approach that promises to stimulate research advances and interventions for public benefit.

BIODEFENSE RESEARCH

After the anthrax mail attacks of 2001, biodefense research has emerged as a major feature of the NIAID's mission to understand the pathogenesis of disease-causing microorganisms and host responses to them. NIAID scientists now are pursuing numerous countermeasures as therapeutics, diagnostics, and vaccines. The agency mobilizes research capabilities and extramural partnerships to prepare against "deliberately emerging disease" outbreaks. The NIH and particularly the NIAID have become significant partners in the broad-based, multi-faceted U.S. homeland security program. The fiscal year 2005 budget highlights the significance of NIAID biodefense efforts, with nearly $1.7 billion for research and infrastructure, 4.5 percent above fiscal year 2004's $1.6 billion.

The biodefense agenda at the NIAID reflects a new focus on science based security. Basic research forms the backbone of the NIAID counterterrorism efforts and

includes microbial physiology and ecology, genomics, studies of pathogenesis and host defenses, and development of animal disease models. Strong funding appropriations by Congress and the Administration over the past 2 years have made possible significant progress, evidenced by the more than 50 major NIAID biodefense initiatives now in place. Most of these initiatives are new, with intramural, academic, and industrial partners investigating all aspects of bioagents and emerging diseases. Components include expansion of the nation's biodefense laboratory infrastructure, enhanced communication and data-collecting networks, interdisciplinary studies on potential bioweapons, and investigations into basic mechanisms of disease and disease pathogens.

In 2003 NIAID and its collaborators achieved significant successes in both basic and applied areas related to biodefense. A candidate vaccine against the Ebola virus was found to protect lab monkeys against the deadly disease. Other researchers discovered that the anthrax bacterium toxin affects host cells in a previously unknown manner, which will redirect some aspects of anthrax therapeutics. Genome sequencing projects are on going for at least one strain of every bacterium, virus or protozoan considered a of priority pathogen. This vast genomics effort includes mapping of agents for such diseases as anthrax, brucellosis, Q fever, plague, smallpox, and tuberculosis. Researchers recently developed a rapid test for measuring antibodies to vaccinia that is 5 to 10 times more sensitive than standard detection techniques. NIAID has screened more than 800 compounds for antiviral activity against poxviruses and two clinical trials of a new smallpox vaccine have been completed. The search continues for vaccines against a long list of pathogenic bacteria and viruses, including next generation vaccines against smallpox and new vaccines for plague, tularemia, and other viral hemorrhagic fevers.

Current NIAID biodefense programs build upon the NIH tradition of creating networks of institutions and scientists best qualified to solve complex problems. Last year the NIAID funded 8 of the 10 planned Regional Centers for Excellence for Biodefense and Emerging Infectious Diseases Research (RCEs), at a cost of about $350 million to be expended over 5 years. The RCEs will be responsible for a broad range of basic and applied research on disease biology, vaccines, and antibiotics, as well as development of novel computational and genomic approaches. As regional centers of excellence, they also will train new generations of science professionals in biodefense research, provide facilities for area researchers, and supply facilities and support to first-line responders in the event of a biodefense emergency. The NIH also is adding new biodefense-research facilities at its own Bethesda campus and at other NIH locations. Last fall, NIAID construction grants were awarded to leading universities for nine high-level biosafety laboratories. These state-of-the-art labs will contain special engineering and design features to prevent release into the environment of the most deadly microorganisms. The facilities also will be available to assist national, state and local public health officials when needed. Similar cooperative programs were established by the NIAID to encourage biodefense research within the pharmaceutical industry, human immunology research institutes, and computational science centers. The proposed fiscal year 2005 budget includes continued support of these efforts, as well as funding for the final two Centers for Excellence and $150 million for an additional 20 high-level biosafety laboratories.

INFECTIOUS DISEASE RESEARCH AND PUBLIC HEALTH

Centuries of triumph and defeat mark the human struggle against infectious disease. Many infectious diseases persist and continue to plague us. Each year populations are beset by one or more previously unknown diseases or pathogens. The World Health Organization estimates that more than 1,600 die each hour from an infectious disease, half under 5 years of age. Others suffer with debilitating infections. For instance, an estimated 40 million people worldwide are living with HIV/AIDS. Tuberculosis, malaria, and other familiar intractable diseases kill or sicken millions annually. New outbreaks surprise and alarm nations. Being prepared to detect, treat, and prevent any infectious disease is the central, science based mission of the NIAID, with well-funded medical research.

Newly emerging and re-emerging or resurging infectious diseases constantly change the landscape of microbiological research, creating moving targets for medical intervention and prevention. West Nile virus, monkeypox, dengue, multi-drug resistant tuberculosis and malaria are current examples of what faces NIAID-supported investigators. Last year's SARS outbreak illustrates the breadth and depth of NIAID research and response capabilities. It is a cautionary tale of how a previously unknown disease can quickly become a global news story of significant economic and public health importance. Within months the new respiratory illness had caused more than 8,000 cases and nearly 900 deaths in 30 countries, severely dis-

rupting international trade and travel—and yet it became a triumph for science and public health efforts, in large part due to effective, well-funded NIAID research. NIAID-supported scientists in Hong Kong were the first to show that SARS was caused by a virus; within days, they and CDC investigators identified the virus as a previously unknown type of coronavirus. An ongoing NIAID-funded program of influenza surveillance then found animal carriers of the virus in food markets in China. Related NIAID-supported work quickly followed, including several genetic analyses of the virus underway, an NIAID-developed mouse model of SARS, screening of up to 100,000 antiviral compounds for anti-SARS activity, several parallel approaches to vaccine development, as well as joint projects with private industry, researchers abroad, and China's Center for Disease Control. NIAID funding led to quick development of a rapid diagnostic test now being improved, and NIAID provides researchers with free SARS "gene chips" embedded with a reference strain of the virus for genetic screening of isolates. NIAID's extensive and multi-layered quick response to SARS was possible largely because of previous investments in virus and respiratory disease research.

Each year NIAID responsibilities for novel diseases grow greater, not less. Today a new threat of global potential, the so-called bird flu or H5N1 influenza, is emerging to join diseases like West Nile virus infection and bovine spongiform encephalopathy (BSE) as targets of NIAID initiatives. NIH supported laboratories are world leaders in research on transmissible spongiform encephalopathies that include BSE, Creutzfeldt-Jakob disease in humans, and chronic wasting disease in deer and elk. Last year there were more than 9,000 human cases of mosquito-borne West Nile virus infection in the United States. Since first detected in 1999, WNV has spread throughout North America and beyond. NIAID-supported scientists have developed an immunoassay to identify WNV and a new treatment already in early clinical trials.

A myriad of infectious diseases continue to take a toll on people worldwide. Infections of the respiratory tract continue to be the leading cause of acute illness worldwide. In the United States, diarrhea is the second most common infectious illness and diarrheal diseases account for 15 to 34 percent of deaths in some countries. NIAID funding supports a broad variety of basic and applied research to better understand food- and waterborne-illnesses. Sexually transmitted infections (STIs) affect over 15 million people in the United States each year. NIAID-supported researchers recently discovered an unusual bacterium that may be the cause of many reproductive tract infections in women. More than 25 STIs have now been identified, and NIAID is supporting multiple projects aimed at preventing and treating STIs. Currently a new vaccine for genital herpes is in advanced clinical trials.

Together, HIV/AIDS, malaria and tuberculosis account for more than 5 million deaths each year. One of the principal goals of 21st-century medical science is the development of safe and effective vaccines against these three global killers. In the United States, more than 500,000 have died from AIDS-related illness; the CDC estimates that 850,000 to 950,000 Americans are living with HIV infection. HIV/AIDS research continues to be a significant component of NIH research: The Administration's fiscal year 2005 budget requests $2.9 billion for HIV/AIDS research at NIH, a 2.8 percent increase over fiscal year 2004. NIAID investigators continue to develop new treatments, and the number of AIDS vaccines in development and testing increases steadily.

Malaria threatens more than one-third of the world's population and kills more than 1 million each year. Although United States cases of malaria are unusual, the NIAID has become a leader in the accelerated development of malaria vaccines. The agency has initiated its first trial of a candidate malaria vaccine in Africa. One-third of the world's population also fights tuberculosis, another major global focus of the NIAID. A new recombinant vaccine made with several proteins from the bacterium that cause TB will soon enter human trials. Scientists recently discovered genetic mutations in the tuberculosis bacterium that contribute to worrisome antibiotic resistance.

The increasing use of antimicrobials in humans, animals and agriculture has contributed to pathogen resistance to antibiotics and some diseases are becoming more difficult to treat because of the emergence of drug resistance. NIAID supports antimicrobial research and the goals of the Interagency Task Force for Antimicrobial Resistance.

In recognition of impressive NIAID contributions to public health and homeland security, the ASM emphasizes that only sustained financial investment will guarantee continued success against today's infectious diseases, tomorrow's unpredictable pathogens, and the growing threat of antimicrobial resistance.

PREPARED STATEMENT OF THE HUMANE SOCIETY OF THE UNITED STATES

On behalf of The Humane Society of the United States (HSUS) and our more than 8 million supporters nationwide, we appreciate the opportunity to provide testimony on our top funding priority for the Labor, Health and Human Services, and Education Subcommittee in fiscal year 2005.

PAIN AND DISTRESS RESEARCH

An estimated 40 percent of the National Institutes of Health (NIH) budget—or currently more than $11 billion—is devoted to some aspect of animal research. At this time, no funding is set aside specifically for research into alternatives that replace or reduce the use of vertebrate animals in research or that reduce the amount of pain and distress to which research animals are subjected. NIH may receive $28.8 billion in fiscal year 2005 if Congress fulfills the President's budget request. Out of this funding, we seek $2.5 million (0.009 percent) for research and development focused on identifying and alleviating animal pain and distress. We recommend that this R&D be conducted under the National Center for Research Resources (NCRR, responsible for NIH extramural funding). We also urge the Committee to specify in report language that NCRR should conduct this research in conjunction with, or "piggy-backed" onto, ongoing research that already causes pain and distress. No pain and distress should be inflicted solely for the purpose of this research, given the volume of existing research (we estimate a minimum of 20–25 percent of all animal research) that is believed to involve moderate to significant pain and/or distress.

In 1987, NIH announced a program to award grants for "research into methods of research that do not use vertebrate animals, use fewer vertebrate animals, or produce less pain and distress in vertebrate animals used in research." Many of the 17 program awards made from 1987 to 1989, totaling approximately $2.4 million, involved research on non-mammalian models, including projects on frogs, mollusks, and insects. Other awards included mathematical modeling and computer studies. This program, which was managed out of the Division for Research Resources (the precursor to NCRR), no longer exists at NIH, and it has not been replaced by any similar program.

A 2001 survey conducted by an independent polling firm indicates that concern about animal pain and distress strongly influences public opinion about animal research in general. Public support for animal research declines dramatically when pain and distress are involved: 62 percent support animal research when pain and distress are minimal, only 34 percent when moderate, and an even smaller 21 percent when animal suffering is severe. Despite this public concern, NIH has not continued to sponsor R&D exploring how to minimize animal suffering and distress in the laboratory.

During the past several years, our organization has been reviewing institutional policies and practices with respect to pain and distress in animal research. We have found that research institutions have inconsistent policies due to the lack of information on this subject, and that standards vary greatly from one institution to another. Painful techniques, such as the use of carbon dioxide to euthanize rats and mice, are widely practiced and approved even though studies indicate that carbon dioxide exposure for only a few seconds causes acute distress to humans. The federal standard for determining laboratory animal pain specifies that, if a procedure causes pain or distress to humans, it should be assumed to cause pain and distress to animals. Furthermore, while human experience can and should provide a useful guide in some cases, there are others in which humans are never subjected to the conditions facing laboratory animals. Information on pain and distress that animals themselves actually experience is important. For many accepted laboratory practices there is no scientific data regarding the painful or distressing effects on either people or animals.

A lack of data on the recognition, assessment, alleviation, and prevention of pain and distress in laboratory animals is commonly cited by scientists as a rationale for either not reporting pain and distress or not acting to mitigate it. This lack of data is obviously detrimental to the welfare of animals used in research, but it is also detrimental to the quality of science produced. Uncontrolled, undetected, and unalleviated pain, physical distress, or psychological distress result in alterations in physiologic and behavioral states, and confound the outcome of scientific research. Ultimately, the lack of information on pain and distress leads to misinterpretation of research results that could result in harmful effects in human beings when preclinical animal research results are applied to humans in clinical trials. It is worth noting that researchers themselves often comment publicly at scientific meetings

about the urgent need for funding in order to properly understand and mitigate pain and distress in research animals.

Our nation takes pride in leading the world in biomedical research, yet we lag behind many other countries in our efforts to minimize pain and distress in animal subjects. For example, the United Kingdom, Sweden, Switzerland, Germany, the Netherlands and the European Union all have committed funds specifically for the "three R's" (replacing the use of animals, reducing their use, and refining research techniques to minimize animal suffering).

We urge the Committee to make this small investment of $2.5 million to promote animal welfare and enhance the integrity of scientific research. We also respectfully request this accompanying committee report language:

"The Committee provides $2.5 million for the National Center for Research Resources to support research and development focused on improving methods for recognizing, assessing, and alleviating pain and distress in research animals. No pain and distress should be inflicted solely for the purpose of this initiative, since the investigations can and should be conducted in conjunction with ongoing research that is believed to involve pain and distress under Government Principle IV of Public Health Service Policy, which assumes that procedures that cause pain and distress in humans may cause pain and distress in animals."

Again, we appreciate the opportunity to share our views and top priority for the Labor, Health and Human Services, and Education Appropriation Act of fiscal year 2005. We hope the Committee will be able to accommodate this modest request that will benefit animals in research and the quality of the research. Thank you for your consideration.

PREPARED STATEMENT OF THE SOCIETY OF NUCLEAR MEDICINE

The Society of Nuclear Medicine (SNM) appreciates the opportunity to submit written comments for the record regarding funding for workforce education and training and biomedical research related programs in fiscal year 2005. SNM is an international scientific and professional organization founded in 1954 to promote the science, technology and practical application of nuclear medicine. Its 14,000+ members are physicians, technologists and scientists specializing in the research and practice of nuclear medicine.

To that end, SNM advocates ongoing and significant federal funding for programs to help ensure an adequate nuclear medicine workforce to care for the nation's citizens as well as increasing the our investment in biomedical research. The Society stands ready to work with policymakers at the local, state, and federal levels to advance policies and programs that will reduce and prevent suffering from disease.

WHAT IS NUCLEAR MEDICINE?

Nuclear medicine is a medical specialty that involves the use of small amounts of radioactive pharmaceuticals, called "Radiotracers" or "Tracers," to help diagnose and treat a variety of diseases. These tracers are detected by special types of cameras that work with computers to provide nuclear medicine physicians and the patient's doctor precise pictures of the area of the body being imaged. It is a way to gather medical information that may otherwise be unavailable, require exploratory surgery, or necessitate more expensive diagnostic tests.

Nuclear medicine procedures, such as PET (positron emission tomography) and SPECT (single-photon emission tomography), often identify abnormalities very early in the progression of a disease—long before some medical problems are apparent with other diagnostic tests. This early detection allows a disease to be treated early in its course when there may be a more successful prognosis.

An estimated 16 million nuclear medicine imaging and therapeutic procedures are performed each year in the United States. Nuclear medicine procedures are among the safest diagnostic imaging tests available. The amount of radiation from a nuclear medicine procedure is comparable to that received during a diagnostic x-ray.

Some of the more frequently performed nuclear medicine procedures include:

—Bone scans to examine orthopedic injuries, fractures, tumors or unexplained bone pain.

—Cardiac scans to identify normal or abnormal blood flow to the heart muscle, measure heart function or determine the existence or extent of damage to the heart muscle after a heart attack.

—Breast scans which are used in conjunction with mammograms to more accurately detect and locate cancerous tissue in the breasts.

—Liver and gallbladder scans to evaluate liver and gallbladder function.

—Cancer imaging to detect tumors and determine the severity (staging) of various types of cancer.
—Treatment of thyroid diseases and certain types of cancer.
—Brain imaging to investigate problems within the brain itself or in blood circulation to the brain.
—Renal imaging in children to examine kidney function.

SECURING AND MAINTAINING AN ADEQUATE NUCLEAR MEDICINE WORKFORCE

The field of nuclear medicine is not attracting enough incoming students to fill the current demand for nuclear medicine technologists (NMTs). Currently, there is approximately an 18 percent vacancy of NMTs as determined by the American Hospital Association (AHA). By 2010, the Bureau of Labor Statistics (BLS) projects that the United States will need an additional 8,000 NMTs to fill the projected demand created by the aging workforce and expanding senior population. Over the next 20 years, the BLS expects that there will be a 140 percent increase in the demand for imaging services. The use of diagnostic imaging services has been increasing by approximately 4 percent a year, even as the number of certified NMTs and registered radiologic technologists has remained stable. As a result, imaging technologists often work longer shifts and patients can face weeks of delay for routine exams.

A similar situation to the shortage of NMTs is developing for nuclear medicine physicians. According to the American Board of Medical Specialties (ABMS), there currently are 4,087 certified nuclear medicine physicians in the United States. At the same time, the number of physician training programs is also declining, exacerbating the future shortage.

Over the next 20 years, the number of people over the age of 65 with cancer is expected to double at the exact same time the nation will face shortages of medical personnel—including NMTs, physicians, nurses, laboratory personnel, and other specialists. New technology and an aging population have increased demand for NMTs, but personnel capacity is not keeping pace with the need. With an increasing number of people needing specialized care—such as nuclear medicine—coupled with an inadequate workforce, our nation faces a health care crisis of serious proportion with limited access to quality health care, particularly in traditionally underserved areas.

The workforce education and training programs at the Health Resources and Services Administration (HRSA) have created a network of initiatives across the country that supports the training of many disciplines of health providers. These are the only federal programs designed to create infrastructures at schools and in communities that facilitate customized training designed to bring the latest emerging national priorities to the populations at large and meet the health care needs of special, underserved populations.

These important workforce education and training programs are designed to increase access to health care in underserved areas by improving the quality, geographic distribution, and diversity of the health care workforce. To that end, SNM recommends funding of at least $550 million to fulfill this mission in the fiscal year 2005.

Additionally, the number of residency slots for training physicians in nuclear medicine is declining. The Society urges Congress to establish a nuclear medicine residency-training fund of $2 million per year for 5 years. This fund would provide 50 residency training positions each year to be used for an additional year of nuclear medicine training of radiology residents and additional 2-year nuclear medicine residencies. This addition of trained physicians will help ease the work force shortage and add to the number of available radiation protection experts in the event of a dirty bomb or other radiation incident.

SUSTAIN AND SEIZE RESEARCH OPPORTUNITIES

Our nation has profited immensely from our past federal investment in biomedical research at the National Institutes of Health (NIH). SNM is proud to join with the rest of the public health community in advocating $30.19 billion for the NIH in fiscal year 2005. This increase of 8.5 percent over fiscal year 2004 funding will allow NIH to sustain and build on its research progress resulting from the recent NIH budget doubling effort while avoiding the severe disruption to that progress that would result from a minimal increase.

The first successful nuclear magnetic resonance (NMR) experiments were performed in 1946 leading to the first nuclear magnetic resonance imaging (MRI) exam was performed on a human being in 1977. Critical advances in technology development now allow physicians to image in seconds what used to take hours. Research in biomedical imaging and bioengineering is progressing rapidly and recent techno-

logical advances have revolutionized the diagnosis and treatment of disease. Therefore, SNM requests $325 million for the National Institute of Biomedical Imaging and Bioengineering (NIBIB) to further the Institute's research in the development and application of emerging and breakthrough biomedical technologies that will facilitate improved disease detection, management, and prevention.

Cancer research is producing extraordinary breakthroughs—leading to new therapies that translate into longer survival and improved quality of life for cancer patients. We have seen extraordinary advances in cancer research resulting from our national investment that have produced effective prevention, early detection and treatment methods for many cancers. To that end, SNM asks the Committee to allocate $6.2 billion for the National Cancer Institute (NCI) in fiscal year 2005 as recommended by the NCI Director in the Bypass Budget submitted to Congress annually under the requirements of the National Cancer Act of 1971. The Bypass Budget represents the best estimation of the scientific community regarding the resources needed to continue our battle against cancer.

CONCLUSION

The Society of Nuclear Medicine once again stands ready to work with policymakers to advance policies that will reduce and prevent suffering from disease for all Americans, while ensuring an adequate nuclear medicine workforce. Again, we thank you for the opportunity to present our views on funding for nuclear medicine workforce and research related programs and stand ready to answer any questions you may have.

PREPARED STATEMENT OF THE NATIONAL PROSTATE CANCER COALITION

Mr. Chairman and members of the Committee, thank you for the opportunity to share my remarks. The National Prostate Cancer Coalition (NPCC) was founded in 1996 to combat a long overlooked killer of men. I came to NPCC in 2001, having just recently been impacted by the disease myself. In 2000, my grandfather was diagnosed with prostate cancer. Having served his country so valiantly in World War II, he was now facing a new battle. Luckily, because of early detection through the prostate specific antigen (PSA) test and the digital rectal exam (DRE), the disease was caught early and, following a radical prostatectomy, he is now cancer free. But there are many men who are not so lucky. That's why you must adequately fund prostate cancer research for veterans like my grandfather, families like mine, and men all over America.

Under the leadership of this committee we have seen prostate cancer research funding increase by nearly $300 million since in the last 6 years. While we have come a long way, there is still much work to be done. For the first year since the founding of NPCC, prostate cancer deaths will increase in 2004. Nearly 30,000 lives will be lost to the disease. Occurrences of prostate cancer are increasing as well, to over 230,000 men this year. While cases continue to grow, more men are catching the disease in its early stages, when the disease is most treatable, by early detection through screening.

NPCC would like to offer its gratitude on behalf of the 2 million American men with prostate cancer for the support this committee has offered in the past. The recent doubling of the National Institutes of Health's (NIH) budget has helped prostate cancer research funding to expand to record levels, but we must ensure this funding is used appropriately. To that end, your committee was instrumental in requiring NIH and the National Cancer Institute (NCI) to submit a professional judgment budget for fiscal year 2003-fiscal year 2008 to outline the agencies' plans for prostate cancer research. You have also been influential in requesting a fiscal budget for that document, which is expected to be submitted to the Committee by April 2004 (Senate Rpt. 108–081). While no one disputes the historic importance of doubling, we ask you to use your oversight capacity to ensure this funding is producing results for prostate cancer. Huge sums of taxpayers' money have been allocated to NIH over the years and it is now time to examine what this windfall has produced. Therefore, we request that you ask NIH to submit a yearly update on its prostate cancer research portfolio that reflects its progress according to the fiscal year 2003–fiscal year 2008 professional judgment budget.

We are entering an exciting time in biomedical research. The recent Food and Drug Administration's approval of Avastin has opened a new door for cancer research. Avastin targets cancerous cells by blocking their blood supply, an idea that had been previously dismissed by the medical community as "absurd." The drug not only signals a turning point in changing cancer into a manageable, chronic disease but also demonstrates the value of seeking out novel and innovative research. We

must encourage this kind of research at NIH, including assessing the value of stem cell research which has shown promise in research for neurological diseases, diabetes, and cancer.

Developing a new approach to research is a priority for NPCC. The Prostate Cancer Research Funders Conference, first convened in 2001 and then revitalized last fall, seeks to formulate a collaborative, public-private approach to seek out new ways of attacking the problem of prostate cancer. Originally co-convened by NPCC and NCI, participants now also include the Department of Defense, the Veterans Health Administration, the Centers for Disease Control and Prevention, the Food and Drug Administration, Canadian and British government agencies, private foundations/organizations and representatives from industry. Members of the Conference have come together to form a partnership that allows them to focus on key objectives and to address commonly recognized barriers in research. This could propel research forward significantly. As the Conference continues, we ask that the Committee make its functionality part of its oversight commitments to prostate cancer research. Currently, federal agencies participate voluntarily, but they can opt in or out based on the tenure of executive leadership and its time-limited decisions. For the conference to be successful federal agencies engaged in the prostate cancer research should, in our opinion, be required to participate, and we ask for your leadership to make that happen.

Recognizing the importance of cutting edge research initiatives and collaborative research efforts, NIH director Elias Zerhouni, M.D. recently unveiled the NIH Roadmap. The Roadmap's strategy mirrors that of the Funders Conference, specifically by seeking out new approaches and ideas and stimulating cross-institutional and cross-center research for all NIH driven biomedical research. Believing, we think correctly, that the synergies in the Roadmap can achieve outcomes that are greater than those any one Institute or Center can achieve, we support its efforts to advance key biomedical research initiatives at an exponential rate. NPCC applauds the Roadmap and pledges its support to take biomedical research in new directions.

As NIH and NCI look to redefine and increase the efficiencies of their research programs, Congress must equip them with the resources they need to implement new initiatives. Unprecedented increases in NIH and NCI's funding over the last 6 years have created opportunities never before available. We must take advantage of these achievements, to not do so will not only harm cancer patients everywhere but is, quite simply, poor business sense.

In his fiscal year 2005 budget, President Bush has requested a 2.6 percent increase ($28.8 billion) in NIH funding over the fiscal year 2004 level. Over the past 30 years, the agency has averaged an annual growth rate of 8 percent. Leading biomedical research groups like the Federation of American Societies for Experimental Biology (FASEB) have stated if increases are held to 2 percent-3 percent the grant funding rate at NIH will drop below 30 percent and approximately 500 fewer grants would be funded. To allow NIH and NCI to adequately continue to fund promising grants and research first realized during the budget doubling, Congress must appropriate at least an 8.5 percent increase ($30.25 billion) in funding for these agencies in fiscal year 2005. That may seem like a large number, but in reality, it is only a small fraction of the estimated $189 billion that cancer alone costs this nation yearly.

Increasing NIH's budget by 8.5 percent would also allow NCI to dedicate more than $400 million to prostate cancer research in fiscal year 2005. Last year, NCI received only a 3.3 percent increase in funding over the previous year's level. Yet, with previously committed grant awards and outlays to the NIH Roadmap, NCI is "effectively operating with a budget that is $2.7 million less than last year's operating budget (NCI Cancer Bulletin 2/3/04)." The President's fiscal year 2005 budget allocates $4.87 billion to NCI, slightly less than the fiscal year 2004 increase. This level will mean even tougher choices in awarding grants at NCI. We believe that Congress should fully fund the NCI Director's Bypass Budget at $6.2 billion, which would rapidly accelerate the nations' fight against all cancers.

As you know, education and early detection through screening are the catalyst to beating prostate cancer. Right now, the PSA blood test and DRE physical exam are the best measures for detecting prostate cancer early. We ask the Committee to allocate at least $20 million to the Center for Disease Control and Prevention's (CDC) prostate cancer awareness program. We also encourage the Committee to work with CDC to address our concern that the agency places insufficient value on these screening tools.

Thank you again for the leadership you have shown in advancing biomedical and, more specifically, prostate cancer research. Under your leadership, the nation's war on cancer has reached heights never before realized. We look forward to continuing to work with you and the members of the Committee until a cure is found.

DEPARTMENT OF EDUCATION

PREPARED STATEMENT OF THE SOUTHERN METHODIST UNIVERSITY SCHOOL OF ENGINEERING

Mr. Chairman and Members of the Subcommittee, I am very grateful to be able to offer testimony on the importance of maintaining our global economic leadership position through a wise and sustained investment in engineering education. And, I want to share with you the early success of a program called the Texas Engineering and Technical Consortium that has emerged as a national model for increasing the technical capabilities of our workforce.

As you know, engineering and technology is an important engine of our national economy. The innovations created by our working engineers have fueled the information revolution, increased our national security, brought more efficient health care, and created a larger food supply to the world.

Our remarkable engineering successes have been the product of our talented and highly skilled technical workforce. Unfortunately, recent national trends don't bode well for increasing the number of homegrown high-tech workers. A 2003 national survey [1] showed that the level of interest in engineering majors by college bound high school seniors has declined by 37 percent over the last 12 years. Sadly, this is a uniquely American phenomenon; much of the rest of world understands how important an engineering and technical workforce will be to their long-term economic health. Within the decade, some predict that India and China together could graduate nearly 1 million engineers per year, a number 20 times greater than the production of engineers here in the United States.

The recently released Hart-Rudman report for the U.S. Commission on the National Security/21st Century says:

"The harsh fact is that the United States need for the highest quality human capital in science, mathematics, and engineering is not being met." [2]

Why is This Important to Both Texas and the Nation?

Engineering and technology have been drivers of the Texas and national economy for nearly 100 years. With the discovery of oil at Spindletop by Austrian born engineer Francis Lucas to the kick-start of the high tech industry by Jack Kilby's invention of the integrated circuit in Dallas, Texas engineers have had a profound and historic impact for both our state's and nation's economy. And today, Texas is a major hub for engineering innovation—employing nearly half a million high tech and engineering workers, with annual wages of $36 billion, while exporting $29 billion in goods and services.

Yet today, this important and large industry is being replenished by only 4,500 new college graduates in engineering and computer scientists each year. This reality will impact all of us. For example, over the next decade, the Joint Strike Fighter program based at Lockheed Martin in Ft. Worth, expects to hire twice as many engineers each year than the entire state produces. This workforce imbalance is bad for Texas and bad for our nation. Our only hope for maintaining global leadership in engineering innovation is to invest today in the education of the best, most diverse, population of engineers in the world.

A CALL TO ACTION: CONTINUE INVESTING IN SUCCESSFUL PROGRAMS LIKE THE TEXAS ENGINEERING AND TECHNICAL CONSORTIUM

Fortunately, I am happy to report that the Texas Engineering and Technical Consortium, which you supported in last year's budget at $3 million, is beginning to pay real dividends. Texas Senators Kay Bailey Hutchison and John Cornyn led the way in supporting our request for federal resources to match state and corporate contributions.

This innovative effort, aimed at doubling the number of engineers and computer scientists graduating from our universities, is already having a significant impact. In fact, The Infinity Project, one program funded by TETC that I direct, is having a profound effect on national engineering education at the high school level—a key barrier to college success. This award winning engineering curricula has increased high school students' interest in engineering by 40-fold in schools that offer the program. And there are other great examples as well.

---

[1] "Maintaining a Strong Engineering Workforce," ACT Policy Report, authors R. Noeth, T. Cruce, and M. Harmston, 2003.

[2] Road Map for National Security: Imperative for Change, The Phase III Report of the U.S. Commission on the National Security/21st Century, pp. 30, February 15, 2001.

The wise investments of the state and federal government, along with high-technology companies of Advanced Micro Devices (AMD), Applied Materials, Hewlett-Packard, Intel, International SEMATECH, Lockheed Martin, Motorola, National Instruments, National Semiconductor, Sabre, and Texas Instruments is changing how Texas universities identify, recruit, educate, and mentor tomorrow's engineers. Through these efforts, TETC is establishing a national model for other states to follow as they address their own workforce needs.

But I am here to tell you that our work has really just begun. As a nation, we have struggled for decades to attract a diverse set of well-prepared students to the exciting world of engineering, math, and science. Permanent solutions to this problem have been elusive—and further still, programs that have shown promise often don't get the sustained funding necessary to have a real impact.

Therefore, on behalf of the 34 Texas universities and industry leaders participating in TETC, I ask that you continue investing in the Texas Engineering and Technical Consortium.

The program is sound and successful. I ask you to help make our progress sustainable.

CONCLUSION

I want to thank Chairman Arlen Specter, Ranking Member Tom Harkin, Members of the Subcommittee and, of course, Senators Hutchison and Cornyn once again for supporting TETC. On behalf of all of us across this nation who care deeply about the economic health of our country, I appreciate your interest in improving the quantity, quality, and diversity of America's technical workforce.

PREPARED STATEMENT OF THE K–12 SCIENCE, TECHNOLOGY, ENGINEERING & MATHEMATICS EDUCATION COALITION

We encourage you to continue the federal commitment to math and science education by maintaining the peer-reviewed Math and Science Partnerships (MSPs) at the National Science Foundation (NSF) and supporting robust funding for both the U.S. Department of Education (ED) and the NSF Math and Science Partnership programs.

We urge you to oppose the Administration's budget proposal that would phase-out the NSF MSP program and establish a new federal grant administered by the Secretary of Education that would, in effect, limit individual states' discretion to target much-needed funds for local science and mathematics education reforms.

We believe that the MSPs at both the Department of Education and at NSF are necessary and complementary. Without one, the other is significantly weakened.

The competitive, peer-reviewed, NSF MSPs seek to develop scientifically sound, model, reform initiatives that will improve teacher quality, develop challenging curricula, and increase student achievement in mathematics and science. The funds appropriated under NCLB for the ED MSPs go directly to the states as formula grants, providing funds to all states to replicate and implement these initiatives throughout the country.

While we support the Administration's proposal to increase funding for the ED MSPs, we oppose the creation of a new $120 million ED grant program that runs counter to congressional intent by focusing only on math and reducing state flexibility to target funds to areas of greatest need. We encourage you to oppose new restrictions on the additional funding slotted for the state-based ED MSPs.

In summary, we strongly urge Congress to:

—reject the Administration's proposed phase-out of the NSF MSP program;

—oppose additional restrictions to the ED MSP program; and,

—provide robust funding for both MSP programs.

If you have any questions, please contact Patti Curtis at 202–785–7385.

PREPARED STATEMENT OF AMERICANS FOR THE ARTS

REQUEST

Americans for the Arts is pleased to submit testimony supporting fiscal year 2005 appropriations of $53 million for the Arts in Education program of the U.S. Department of Education (USDE).

Americans for the Arts is one of the leading national nonprofit organizations for advancing the arts and arts education in America. With a 40-plus year record of objective arts industry research, we are dedicated to representing and serving local

communities and creating opportunities for every American to participate in and appreciate all forms of the arts. Our belief in the importance of practical research causes us to take special pleasure in supporting USDE's Arts in Education program, which is generating impressive evidence on the best ways to improve overall academic achievement by integrating the arts into the school curriculum. The evidence of improved academic achievement is itself impressive. For example:

—Mississippi's Whole School Initiative found that schools with a high degree of implementation far surpassed other schools in their ability to meet No Child Left Behind (NCLB) reading targets.

—In Houston, analysis showed that students in participating elementary schools out-performed their demographic peers on the Iowa Test of Basic Skills, and that the benefits lasted beyond graduation and on into middle school.

We have provided more detailed information on the Mississippi example below.

As members of the Subcommittee know, the Elementary and Secondary Education Act provides that funding up to $15 million be directed to the John F. Kennedy Center for the Performing Arts and VSA arts. Prior to fiscal year 2001, funding never exceeded that level. Since fiscal year 2001, however, Congress has appropriated funding sufficient to support a broader array of arts education programs. For fiscal year 2004, Congress appropriated $35.1 million. In addition to the Kennedy Center and VSA arts, USDE now supports grants competitions to:

—further develop established arts education models;

—support professional development for arts educators in four arts disciplines; and

—establish partnerships between schools and community cultural organizations to serve at-risk children and youth.

We ask the Subcommittee to appropriate $53 million for fiscal year 2005, with the bulk of the increase to be allocated to the Arts in Education Model Development and Dissemination Program, Professional Development training in music, theater, dance and the visual arts, as well as Cultural Partnerships for At-risk Children and Youth.

FOUR REASONS TO INCREASE ARTS EDUCATION FUNDING

The most important reason to support arts education is simply stated: arts education works for children. Research increasingly confirms its beneficial effects in several areas, including but not limited to academic achievement. We refer the Subcommittee to a research compendium *Critical Links: Learning in the Arts and Student Academic and Social Development*,[1] released by the Arts Education Partnership in 2002, which includes 62 separate studies pointing to "critical links" between arts education and reading, writing, mathematics, cognitive skills, motivation, social behavior, and the school environment. The studies suggest that arts education may be especially useful for students who are economically disadvantaged and/or in need of remedial instruction.

The second reason to increase funding is that schools desperately want it. Even now, when the accountability and testing regimens of NCLB have focused schools' attention on what some call "the basics," many schools understand that the arts are a core academic subject, as NCLB indeed stipulates, that they are essential, and that they work. The Department of Education's first model grant competition generated a flood of applications despite the tiny number of awards. A larger amount of funding, coupled with a smaller grant size, will at least begin to address the demand. Unfortunately, without an increase in funding, USDE will be unable to hold a new grant competition for 2 years.

The third reason is that while there is tremendous interest in arts education, substantial improvements need to be made to delivery systems. USDE's model grants program aims to further develop established programs that improve arts education, to evaluate these programs, and to disseminate the results. Thus, it is in accord with a central principle of the federal role in education: to find out what works and to disseminate this information to states and local school districts so that they may select and tailor programs to fit their own needs and circumstances. This is the reason that we urge the Subcommittee to recommend that funding include at least $1 million for evaluation and dissemination. We note that each of the projects funded under this program include a substantial research component. It is particularly important to add this modest amount of funding because the USDE's existing and planned research efforts, including the What Works Clearinghouse, do not include substantial work on arts education.

Finally, despite increases in overall federal spending for K–12 education, and despite the substantial flexibility given to states, evidence is beginning to accumulate

[1] http://www.aep-arts.org/CLTemphome.html

that schools are neglecting those areas of the curriculum that are not subject to the mandatory testing requirements of NCLB. The National Association of State Boards of Education (NASBE) identified the threat in its 2003 report *The Lost Curriculum*;[2] in response, NASBE's current quarterly policy journal, the *State Education Standard*,[3] is devoted entirely to "ensuring a place for the arts in America's schools." Earlier this month, the Council for Basic Education released a survey[4] of school principals in four states: fully one quarter of them report that they have decreased instructional time in the arts. Unfortunately—and perhaps even tragically—the shift away from the arts appears most concentrated in elementary schools and schools with large minority populations. We have supported NCLB, especially its inclusion of the arts as a core academic subject, and we believe that the problems facing arts education are a consequence that is very much unintended. Nevertheless, the problems are real and must be addressed. USDE's model development program—if there is sufficient funding for national dissemination—provides principals with desperately needed information on how to integrate the arts into the curriculum in a way that improves academic achievement.

CASE EXAMPLE: MISSISSIPPI'S WHOLE SCHOOLS INITIATIVE

In our testimony for fiscal year 2004 funding, we provided extensive information on structure and philosophy of the Whole School Initiative in Mississippi. This year, we can provide a preliminary analysis for the project's final evaluation report, which is due in June.

Recap of the Whole Schools Initiative

In 2001, the Whole Schools Initiative was 1 of 11 successful applicants for a grant from USDE's Arts in Education Model Development and Dissemination Program. The program's roots go back to 1991, when as a response to "back to basics" school reform and the lack of arts instruction in Mississippi, the Mississippi Arts Commission (MAC) commissioned a study of the Mississippi environment, appropriate national arts education models and relevant research. A pilot program began in 1992.

The Whole Schools Initiative was launched in 1998 with a core belief that art is essential to every child's education. It is the first comprehensive statewide arts education program in Mississippi. Its goals are to improve student academic achievement by infusing arts into the basic curriculum, to assist the professional and personal growth of teachers and administrators through arts experiences, to use the arts to increase parental and community involvement in schools and to assist schools in building a sustainable system for supporting arts infusion. Partnerships include local arts councils, Institutions of Higher Learning, the Mississippi Alliance for Arts Education, professional artists, local school districts and art museums.

Not only does the program improve the quality of arts education being offered in participating schools, it is often the only chance that Mississippi children, in poorly funded schools and from families living below the poverty level, will ever have to receive any formalized arts instruction. Nineteen of the initiative's 26 schools serve student populations where 35 percent or more of the students qualify to receive free/reduced lunches, fourteen schools have at least 70 percent and seven have at least 90 percent. Eleven schools involved in the initiative are located in rural communities and others serve them. Six of these schools have the lowest per pupil expenditure in the state.

This $1 million grant has allowed MAC to expand its role with universities, encouraging the development of pre-service courses that to strengthen arts infused instruction and aid arts majors in becoming effective instructional leaders. The grant has also enabled MAC to expand and refine its evaluation model. A final component of the USDE funding is allowing MAC to develop training materials and procedures that can be used to replicate the program in other settings. At the end of the 3-year grant period, the project will "blueprint" a model built on a research base, field-tested in a diverse set of schools, evaluated internally and externally, and which has already produced substantive results.

This funding has made possible extensive professional development opportunities for teachers and administrators. More than 15,000 students and 800 educators benefit annually from activities at a weeklong summer institute, two retreats, and field advisor visits. Other ways in which it is strengthening the program include a course for education majors that is being developed at the Delta State University, a "teacher friendly" and "teacher useful" interactive web site, and the designation of model

[2] http://www.nasbe.org/Research__Projects/Lost__Curriculum.html
[3] http://www.nasbe.org/Standard/index.html
[4] http://www.c-b-e.org/PDF/cbe__principal__Report.pdf

schools in the north, central, and southern regions of Mississippi where the initiative's work may be observed.

Other states will benefit from the documentation and dissemination of the initiative. Many states have a strong interest in implementing this model but lack the resources, knowledge, and experience to do so. States that have approached MAC and participated in the institute include New Mexico, Illinois, Kentucky, Florida, and Louisiana.

Preliminary Results of the Whole Schools Initiative

The preliminary analysis looks closely at WSI participating schools' NCLB performance in literacy, which was reported for the first time in the fall of 2003. Literacy was chosen as the analytic focus because most of the examined schools were elementary school buildings and learning to read was the foremost concern at that level. The first part of the analysis examines the performance of the 25 participating schools in the spring of 2003 and compares their results to the state average and to a matched set of comparison schools. The second examines a subset of 18 sites that: (1) completed a teacher survey concerning the implementation and impact of the initiative and (2) had grade levels that were included in the reporting requirements of NCLB.

The analysis suggests that two conclusions are warranted. First, schools attempting to create an arts-rich environment for their students performed as well as—if not slightly better than—both the state average for all Mississippi schools and a comparison group of schools demographically and geographically similar to themselves. Second, schools whose teachers reported higher implementation of WSI objectives far surpassed lower implementation schools in enabling their students to meet the all-important growth targets of NCLB. The implication of the analysis is that rather than stripping the curriculum of all but basic direct instruction in literacy and math under the spotlight of making adequate yearly progress, schools might consider enriching the learning environment with multiple opportunities to learn in the arts.

CONCLUSION

As the example of the Whole Schools Initiative demonstrates, federal funds boost the quality and quantity of support for arts education as well as the knowledge that can be gained and disseminated across the education establishment. Increased funding means more help for state departments of education, educators in schools, and local education agencies and cultural organizations. Most important, it means a better education for our children. We urge the Senate Subcommittee on Labor, Health and Human Services, and Education to recommend $53 million in funding for the USDE's Arts in Education programs in order to allow more programs like Mississippi's Whole Schools Initiative to flourish.

PREPARED STATEMENT OF THE CLOSE UP FOUNDATION

Mr. Chairman and distinguished members of the Subcommittee, my name is Stephen A. Janger, and I am president and founder of the Close Up Foundation. I am grateful for the opportunity to submit testimony in support of the Close Up Fellowships, previously known as the Allen J. Ellender Fellowships, which help low-income students and their participating teachers take part in our Close Up Washington civic education programs. On behalf of my colleagues at the Foundation and hundreds of thousands of young people and educators who have participated in Close Up through the years from school systems across the country, I want to express my appreciation for this Subcommittee's longstanding encouragement and support.

As you may recall, in my testimony last year, I described the impact of world events on Close Up's work—specifically, September 11 and the more recent hostilities in Iraq. We saw a decline in our program enrollments because of fear of travel to Washington, D.C., and subsequent travel bans. I am pleased to let you know that program enrollments appear to be improving and we are seeing a modest increase in participation over last year. I want to let you know also that we are doing all we can to broaden efforts to encourage participation in our civic education programs, knowing that our mission is more important and vital than it has been since our inception in 1971. We have reason to believe, based on our conversations with teachers and school districts, that next year will see an even more significant enrollment expansion because of the continued easing of travel anxieties and the relaxation of school travel bans.

The heart of our mission is the conduct of Close Up's weeklong program in Washington, D.C. During this program, students receive 12 to 14 hours of civic instruc-

tion and educational activities each day. Led by our trained Program Instructors, young people learn in a "living classroom" environment through study visits to Capitol Hill, embassies, and many of the country's most historic and symbolic sites. Policy specialists, journalists, lobbyists, and other insiders help show students how government works. Close Up's instructors add to these seminars by teaching the basics of government and citizenship through highly engaging role-playing, workshops, discussion groups, and simulations.

The centerpiece of the program is typically a face-to-face meeting with Members of Congress or your staffs. They are able to engage in a dialogue with an elected official or staff member "close up." In addition, students often see floor debates and committee hearings. They come to understand the process of government, may feel a bit less intimidated about how it works, and can begin to see that they have a role in the future of our democracy.

The difficult reality is that it has become more expensive to make this unique opportunity available for students from every background because the costs from even the most competitive vendors continue to increase. To pay for these experiences, our young participants, who come from very varied backgrounds and represent a wide range of academic performance, often start fundraising during their freshman and sophomore years to attend the program in their senior year. They generate funds from community contributions, fundraising activities, and old fashioned work to support the costs of travel and program tuition.

Not every Close Up participant is fortunate to come from an affluent background. Our work with Native Americans, Alaska Natives, Hispanics, African Americans, migrant students, the physically challenged, and students who are long-term cancer survivors takes us each year into populations with need for special help to make possible their participation. During my 34 years at Close Up, I have seen tens of thousands of these student-participants who have been able to participate in our Close Up Washington program only because of the Close Up Fellowships. The support of this Subcommittee not only covers up to half of a needy student's program, it serves as a meaningful "jump start" for the student who seeks additional support from local businesses, parents, schools and community organizations. In this way, the Fellowships have a significant multiplier effect at the community level.

The Carnegie Foundation published last year a highly collaborative report called "The Civic Mission of Schools." It may be the most significant statement in the civic education field in the last decade. It makes a strong case for making civic education much more of a priority in our elementary and secondary system of education. It also singles out practices, such as the experiential methodology of Close Up, as having the most effect. It also suggests that schools themselves cannot do it all by themselves. Partnerships, collaborations, use of external resources all can help schools better achieve their civic mission.

Beyond the funding support we work to generate each year from the corporate and philanthropic sectors, we could not be more proud of the partnerships we have been able to forge with states, districts, and individual schools. These partnerships not only provide a number of individual students and teachers with the opportunity to take part in Close Up's Washington program, but also to use this experience as a means of strengthening the entire curriculum and extracurricular activities as well in the area of civic education. This is another strong example of the multiplier effect.

I believe strongly that schools are still the best tool for instilling civic virtue and that community service, service learning, and participation in the development of public policy are essential training tools for good citizenship. With that in mind, I want to take this opportunity to briefly describe one of our programs that holds tremendous potential for growth.

Several years ago, we decided that our work with inner city schools needed greater focus and intensity. To that end we developed strong working relationships and raised significant extra financial support to dramatically increase the amount of fellowship resources for the major urban public school districts in Washington, D.C., Houston, and Tulsa. Within this current year, we have added Atlanta and Miami to this new series of program activities we call the Great American Cities Program.

Students receive a great deal of financial assistance from community support, and much is expected of them both before and after their Washington program experience. Students develop and implement community projects that contain in some form a public policy dimension. Teachers receive in-service training, led by our own staff and other experts, on how to foster and develop these programs. This is another example of the multiplier effect where Close Up Fellowships have provided through the years a partnership with school districts that enabled the launch of an innovative and effective program.

As you will read in a few testimonials following this statement—selected from the thousands we receive each year—Close Up's work with young people and educators provides inspiration, reduces cynicism and enhances understanding about the democratic process. Students see firsthand how individuals make a difference and that they themselves can leave things a little better than they found them.

Close Up was started more than three decades ago in another era of conflict to help address the disillusionment expressed by many young Americans during the Vietnam War. Our work has remained both relevant and effective, and is needed now more than ever. America today is faced with many policy choices, both international and domestic, that threaten to divide us. A greater dialogue among a thoughtful and patriotic citizenry is needed to help pull our country together. This has been our goal since our inception: to create a public of engaged, informed, and responsible citizens that Jefferson believed was the most important outcome of our nation's schools.

In closing, Mr. Chairman, I want to thank this Subcommittee for its strong support through the years. The nation's civic education efforts cannot afford to take a back seat to other curricula objectives. These efforts should underlie our important focus on literacy and science testing. It should be second nature to our young people that the blessings of this great country, and the responsibilities to sustain those blessings through active involvement in the democratic process, are the bedrock values and principles from which the liberties of personal and academic freedom are derived. These values and these principles are what set us apart as a nation.

The Close Up Foundation takes great pride in its national leadership in these values and principles from which we have never deviated since we began in 1971. The vital funding that we have received from this Subcommittee through the years, combined with our own efforts in the private sector to multiply that funding, has made it possible for hundreds of thousands of young people and their teachers representing every kind of background to understand and appreciate these core values and principles. Your continued support at an increased level for the Close Up Fellowships will help us do more—where it is most needed.

We respectfully request that this Subcommittee increase the Close Up Fellowships to a level of $4 million. This will enable us to multiply our efforts even further, so that those who are most often neglected or turned away from the civic involvement mainstream are brought into the democratic process. This is fundamental to our mission.

Thank you, Mr. Chairman, for your consideration of this request.

TESTIMONIALS OF CLOSE UP PARTICIPANTS

"I truly believe that your program is the most educational governmental program available to students in the United States. With the additions of teacher fellowships as well as student fellowships we are able to encourage and in fact provide for opportunities to all our students regardless of economic status or academic levels."——Todd Lee, Teacher, 2004 Tioga High School, Tioga, North Dakota.

"Many members of my staff have had an opportunity to met with a number of these students and their participating teachers directly. The feedback has been overwhelmingly positive. We are all pleased with the excitement for learning expressed about the program. We have also met regular with the leaders of the Close Up Foundation and their gifted young educators who are charged with conducting the program. To a person we are impressed by the integrity, commitment, and the passion they bring to their work."——Dr. David E. Sawyer, Superintendent, 2003 Tulsa Public Schools, Tulsa, Oklahoma.

"Close Up gave me the insider's view of Washington and our government. I now have a greater understanding of the political process. I learned that I can make a difference, and I now have a greater desire to participate in the political system. . . . Close Up gave me a passion and interest in the United States government."——Katherine McDermott, Student, 2004 Doniphan-Trumbull High School, Doniphan, Nebraska.

"Close Up is a huge part of my life. I met amazing people from all over the country and each one of those people helped me to fully establish and solidify my political views. Because of my involvement in Close Up I have been able to help educate my peers about how our government works as well as work for educating people about voting."——Andrea Nowak, Student 2004 Bishop Foley High School, Madison Heights, Michigan.

"I always had strong political views, but being surrounded by kids who 'didn't care' about current events, I never had to prove my ideas to anyone. Going on Close

Up, I realized that not everyone shared my views, in fact, some even said I was wrong! . . . While I didn't back down, I at least began to understand the other side's argument, something I would never have been able to do before. . . . Close Up opened me up to a whole new world of ideas, thought, and way of life. And while I may not agree, at least I can agree to disagree."——Emily Wolfe, Student, 2004 Newton South High School, Newton Centre, Massachusetts.

"The Close Up Program, in particular our time on Capital Hill, affords students the opportunity to experience democracy in a hands-on fashion, thus making it real to them. In addition, it validates the necessity of their role in a democratic society."——Lori Merkel, Teacher, 2003 East Valley High School, Spokane, Washington.

"This organization provides a unique experience for both students and teachers. I am a history teacher at Senn High School in Chicago. Like many Chicago Public Schools, we battle the effects of poverty every day in our classrooms. The opportunity the Close Up Foundation gives to these students is tremendous. This may be the only time in the lives of my students where they will have this type of access to Washington, DC and the officials who make decisions affecting their lives."——Johanna Klinsky, Teacher, 2004 Nicholas Senn High School, Chicago, Illinois.

". . . You . . . may not hear about the lives that are changed through your work each day, but please know that your support and leadership make dreams come true for students and create life-changing experiences. It may sound cliché, but it is so very true: Only in America can children who are born in the most humble of circumstances have real opportunities to make all of their dreams come true. Truly, the broad scope of American education positively impacts every student and extends to each student a special invitation to excellence."——Dr. Beverly Boone, Principal, 2003 The Anchor School, Biscoe, North Carolina.

PREPARED STATEMENT OF ZERO TO THREE

Chairman and Members of the Subcommittee: I am pleased to submit the following testimony on the Labor/Health and Human Services/Education and Related Agencies fiscal year 2005 Appropriations on behalf of ZERO TO THREE. My name is Matthew Melmed. For the last 9 years I have been the Executive Director of ZERO TO THREE. ZERO TO THREE is a national non-profit organization that has worked to advance the healthy development of America's babies and toddlers for over 25 years. I would like to start by thanking the Subcommittee for all of their work to ensure that our nation's at-risk infants and toddlers have access to early intervention and positive early learning experiences.

We know from the science of early childhood development that infancy and toddlerhood are times of intense intellectual engagement.[1] During this time—a remarkable 36 months—the brain undergoes its most dramatic development, and children acquire the ability to think, speak, learn, and reason. All babies and toddlers need positive early learning experiences to foster their intellectual, social, and emotional development and to lay the foundation for later school success. Babies and toddlers living in high-risk environments need additional supports to promote their healthy growth and development. Disparities in children's cognitive and social abilities become evident well before they enter Head Start or Pre-Kindergarten programs at age 4. I am here to talk to you today about why it is important to increase funding for three programs focused on the unique needs of low-income infants and toddlers—Early Head Start, the Child Care and Development Fund (CCDF) and Part C of the Individuals with Disabilities Education Act (IDEA).

EARLY HEAD START

What is Early Head Start?

Congress created Early Head Start in 1995 with strong bipartisan support. It is the only federal program specifically designed to improve the early education experiences of low-income babies and toddlers. The mission of Early Head Start is clear: to support healthy prenatal outcomes and enhance intellectual, social and emotional development of infants and toddlers to promote later success in school and life. Research demonstrates that Early Head Start is effective. The Congressionally mandated National Evaluation of Early Head Start—a rigorous, large-scale, random-assignment evaluation—concluded that Early Head Start is making a positive dif-

[1] Shonkoff J., and Phillips, D. (Eds.) (2000). National Research Council and Institute of Medicine. *From Neurons to Neighborhoods: The Science of Early Childhood Development.* Washington, DC: National Academy Press.

ference in areas associated with children's success in school, family self-sufficiency, and parental support of child development. Early Head Start serves over 63,000 low-income families with infants and toddlers through 708 community-based programs.[2] Unfortunately, only 3 percent of all eligible children and families are served.[3]

Is Early Head Start Effective?

Key to Early Head Start's success is its emphasis on the implementation of the Head Start Program Performance Standards, which ensure the highest quality care for babies and families and its comprehensive approach to serving children and families. What is most compelling about the Early Head Start data is that they reflect a broad set of indicators, all of which show positive impact—patterns of impacts varied in meaningful ways for different subgroups of families. For example, the National Evaluation found that Early Head Start produced statistically significant, positive impacts on standardized measures of children's cognitive and language development;[4] The Evaluation also found that Early Head Start parents were more involved and provided more support for learning; and that the program helped parents move toward self-sufficiency.

Funding

Currently, 10 percent of the overall Head Start budget is used to serve 63,000 low-income families with infants and toddlers through Early Head Start—only 3 percent of all eligible children. An increase in the overall Head Start appropriation is needed and will enable more eligible infants and toddlers to be served through the 10 percent Early Head Start set-aside. Congressional authorizers are currently considering an increase in the Early Head Start funding allocation—potentially doubling the allocation of funds for infants and toddlers enrolled in the program. Given the uncertainty of action on that legislation, we encourage the Subcommittee to increase the Early Head Start portion of the program to 12 percent of the total appropriation for Head Start in fiscal year 2005. Additional funds will enable us to protect and continue to build on the firm foundation that currently exists and to ensure that more eligible babies and families are able to benefit from the services of Early Head Start.

THE CHILD CARE AND DEVELOPMENT FUND (CCDF)

What is CCDF?

The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 revamped the structure of federal funding for child care and created the Child Care and Development Fund (CCDF). This streamlined block grant attempts to maximize states' flexibility in administering child care programs and establishes a single set of rules and regulations that apply to all components of the fund. CCDF funding is divided into three streams of federal funds: federal mandatory funds that do not require a state match; federal mandatory funds that do require a state match; and federal discretionary funds that do not require a state match. States are required to spend a minimum of 4 percent of CCDF funds on activities designed to improve the quality of child care. Today Congress earmarks $100 million of the CCDF funds for strategies to increase the supply and improve the quality of child care for infants and toddlers.

Is CCDF Effective?

CCDF provides funds to help improve the quality and supply of child care for low-income children and families. For example, the infant-toddler set-aside of CCDF, currently earmarked through the appropriations process, has helped states focus on the unique needs of infants and toddlers by investing in specialized infant-toddler provider training, providing technical assistance to programs and practitioners, and linking compensation with training and demonstrated competence. Another example is the quality set-aside of CCDF. The quality set-aside, currently 4 percent, provides funds to states in order to support and develop innovative strategies for improving the quality of child care. Strategies may include: training grants and loans to pro-

---

[2] U.S. Department of Health and Human Services, Administration for Children and Families (2002). *Early Head Start Information Folder,* www.headstartinfo.org/infocenter/ehs_tkit3.htm. 2002 EHS Fact Sheet www.acf.hhs.gov/programs/hsb/research/factsheets/02/hsfs.htm.

[3] 2002 EHS Fact Sheet www.acf.hhs.gov/programs/hsb/research/factsheets/02/hsfs.htm. CPS Annual Demographic Survey, March Supplement 2001 Table 23 "Single Years of Age—Poverty Status of People in 2001" http://ferret.bls.census.gov/macro/032002/pov/new23_004.html.

[4] U.S. Department of Health and Human Services, Administration for Children and Families (2002). *Making a Difference in the Lives of Infants and Toddlers and Their Families: The Impacts of Early Head Start.* Washington, DC.

viders; improved monitoring; resource and referral counseling for parents to find child care; and other services related to improving the quality of child care.

Funding

Despite modest increases in federal child care funding, CCDF funds are insufficient to serve all eligible children. In fact, the Center for Law and Social Policy (CLASP) estimates that states served only about 14 percent of federally-eligible children (approximately 1 out of 7) in fiscal year 2000. Connecticut has an estimated 17,000 children on its waiting list for child care assistance and has not served any new low-income working families not receiving welfare since August 2002. A substantial increase is needed to ensure that all states are able to serve more eligible children and families. Although states have made great progress in improving the quality of child care for low-income children, additional resources are necessary to ensure that more low-income children have access to quality child care. We must significantly increase the percentage of the quality set-aside (from 4 to 10 percent) to improve the quality of child care. Finally, because the infant-toddler set-aside is earmarked through the appropriations process, we must ensure that the set-aside continues to grow as the overall funding for CCDF continues to grow.

PART C OF IDEA

What is Part C of IDEA?

Part C of the Individuals with Disabilities Education Act (IDEA) authorizes the federal support for early intervention programs for babies and toddlers with disabilities, and provides federal assistance for states to maintain and implement statewide systems of services for eligible children, age birth through 2 years, and their families. Under Part C, all participating states and jurisdictions must provide early intervention services to any child below age 3 who is experiencing developmental delays or has a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay. In addition, states may choose to provide services for babies and toddlers who are "at-risk" for serious developmental problems, defined as circumstances (including biological or environmental conditions or both) that will seriously affect the child's development unless interventions are provided. The Part C system offers the opportunity to maximize the impact of Part B dollars (which provides for the education of children with disabilities ages 3–21). Early intervention services under Part C may prevent or minimize the need for more costly services under Part B later in a child's life. Research shows that intervention is more effective if begun before age 3.

Is Part C Effective?

The Office of Special Education Programs (OSEP) has commissioned the National Early Intervention Longitudinal Study (NEILS) to examine what happens to infants and toddlers with special needs and their families during and after Part C early intervention. NEILS is following a nationally representative sample of 3,338 infants and toddlers who received early intervention services. The sample consists of children from four age groups—the oldest children in the study exited early intervention in 1998, the youngest children in the study exited early intervention in 2001. For all age groups, the children were found to be advancing developmentally and showing greater mastery of milestones than they had when they entered early intervention.[5] For the children who entered early intervention between 6 and 12 months and between 12 and 18 months of age, a significant percentage had mastered many of the motor and self-help milestones by 1 year.[6] Children in these two age groups also showed progress with communication and cognition milestones.[7]

Funding

In spite of reports from states that referrals to Part C continue to increase, Part C has received only very small increases over the past few years. The fiscal year 2003 Part C appropriation was $434,159,000 while the current fiscal year 2004 appropriation for Part C is $444,363,000.[8] Although estimates of children with disabilities under age 3 range from 3 percent to 5.2 percent,[9] as of December 1, 2002, only

[5] U.S. Department of Education. (2002). Twenty-Fourth Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act, Washington, DC: U.S. Department of Education.

[6] Ibid.

[7] Ibid.

[8] Council for Exceptional Children, "Full Funding for IDEA: It's a Guarantee, Not Just a Promise." February, 2004. Arlington, VA: Council for Exceptional Children.

[9] Oser, C., & Cohen, J. (2003). America's babies: *The ZERO TO THREE Policy Center data book.* Washington, DC. ZERO TO THREE Press.

2.24 percent of all infants and toddlers (267,923) were served under Part C. Because the federal government is not paying its fair share to support the provisions of IDEA, the burden is placed on states and on families. And there is wide variation in the percentage of infants and toddlers enrolled in Part C across states. For example, Massachusetts serves 5.8 percent of infants and toddlers while Nevada serves less than 1 percent.[10] Substantial increases in the Part C appropriation are needed to ensure that all eligible infants and toddlers are served without having the burden placed on states and families.

CONCLUSION

During the first 3 years of life, children rapidly develop foundational capabilities—cognitive, social and emotional—on which subsequent development builds. These years are even more important for at-risk infants and toddlers. Early Head Start, the Child Care and Development Fund, and Part C of IDEA can serve as protective buffers against the multiple adverse influences that may hinder their development in all domains.

With the Subcommittee's help, we have made some gains over the past few years in increasing funding for early intervention and positive early learning experiences for at-risk infants and toddlers. The fact remains, however, that our overall policy and funding emphasis is still to wait until children are already behind developmentally before significant investments are made to address their needs. I urge the Subcommittee to change this pattern and invest in infants and toddlers early on, when that investment can have the biggest payoff—preventing problems or delays that become more costly to address as the children grow older. We do not need to accept that vulnerable children will inevitably have already fallen behind at age four and then provide special education and intensive prekindergarten services to help them play catch up. We know how to provide early intervention and positive early learning experiences to infants and toddlers that works. I hope the Subcommittee will make that initial investment to prevent very young children from falling behind.

Thank you for your time and for your commitment to our nation's infants, toddlers and families.

PREPARED STATEMENT OF THE UNITED TRIBES TECHNICAL COLLEGE

SUMMARY OF REQUEST

For 35 years United Tribes Technical College (UTTC) has been providing postsecondary vocational education, job training and family services to Indian students from throughout the nation. Our request for fiscal year 2005 funding for tribally controlled postsecondary vocational institutions as authorized under Section 117 of the Carl Perkins Vocational and Applied Technology Act is:

—$8 million under Section 117 of the Perkins Act, which is $800,000 over the fiscal year 2004 enacted level. This funding is essential to our survival, as we receive no state-appropriated vocational education monies.

—Ensure that the provision that has been included since fiscal year 2002 in the Labor-HHS Education Appropriations Acts that waived the regulatory requirement that we utilize a restricted indirect cost rate is continued.

—Funding for renovation of our facilities, many of which are original to the Fort Abraham Lincoln army installation. A recent study commissioned by the Department of Education shows a facility need for UTTC of $49 million.

Restricted Indirect Cost Issue.—Beginning in fiscal year 2002 the Labor-HHS-Education Appropriations Act provided that notwithstanding any law or regulation, that Section 117 Perkins grantees are not required to utilize a restricted indirect cost rate. We thank you for taking this action, and ask that it be continued in the fiscal year 2005 Act.

In 2001, the Department of Education, for the first time, directed Indian grantees (both Section 116 and 117 grantees) to apply a "restricted indirect cost rate" to their grants. This means each tribal grantee must obtain another indirect cost rate—exclusively for its Perkins Act grant—from its cognizant federal agency (which in most cases is the Inspector General for the Department of the Interior.)

The Department gave two reasons for applying a restricted rate to these Perkins Act Indian programs: (1) The 1998 Amendments to the Perkins Act (Sec. 311(a))

[10] IDEAdata.com (2004). "Number and Percentage (Based on 2002 population estimates) of Infants and Toddlers Receiving Early Intervention Services." Retrieved April 22, 2004, from www.IDEAdata.org

prohibits the use of Perkins Act grant funds to supplant non-federal funds expended for vocational/technical programs. This "supplement, not supplant" limitation previously applied to State grants, only; and (2) A long-standing Department of Education regulation (promulgated years before the 1998 Perkins Amendments) automatically applies the restricted indirect cost rate requirement to any Department of Education grant program with a "supplement, not supplant" provision.

UTTC has no quarrel with the bases and objectives of the "supplement, not supplant" rule and seeks no change to this statutory provision. The primary targets of this rule are States and possibly local government entities that run vocational education programs with State or local funds.

By contrast, however, UTTC has little or no ability to violate this rule, as we have no source of non-federal funds to operate vocational education programs. Unlike States, we have no tax base and no source of non-federal funds to maintain a vocational education program. We depend on federal funding for our vocational/technical education program operations. Despite our inability to violate the supplanting prohibition, we are, nonetheless, being disadvantaged by a Department of Education regulation intended to enforce the prohibition against States who do have the ability to supplant.

—*Impact of new requirement on grantees*.—Under DoEd regulations, a "restricted indirect cost rate" makes unallowable certain indirect costs that are considered allowable by other federal programs. Primarily, these are costs that DoEd believes the grantee would otherwise incur if it did not receive a Perkins grant, such as the cost of the grantee's chief officer and heads of departments who report to the CEO, as well as the costs of maintaining offices for these personnel.

Prohibiting the Perkins grant from contributing its appropriate share to the grantee's indirect cost pool will most likely mean that other federal programs operated by the grantee would be expected to pick up a great share of the indirect cost pool. This outcome may well result in objections from the other program agencies that do not want to bear costs properly attributable to the Perkins grant.

We are caught between conflicting federal agency requirements and will find ourselves unable to recover the necessary share of indirect costs attributable to each of the federal programs we operate.

UTTC Excels.—We bring to your attention the following facts about UTTC, an institution with:

—An 89 percent retention rate

—A placement rate of 90 percent (job placement and going on to 4-year intuitions)

—A projected return on federal investment of 11 to 1 (2003 study comparing the projected earnings generated over a 29-year period of UTTC Associate of Applied Science graduates with the cost of educating them.)

—The highest level of accreditation. The North Central Association of Colleges and Schools has accredited UTTC again in 2001 for the longest period of time allowable—10 years or until 2011—and with no stipulations. We are also the only tribal college accredited to offer on-line associate degrees.

The demand for our services is growing and we are serving more students.—For the Spring Semester 2004, we enrolled 661 students from more than 45 tribes and 17 states. The majority of our students are from the Great Plains states, an area that, according to the 2001 BIA Labor Force Report, has an Indian reservation jobless rate of 75 percent. UTTC is proud that we have an annual placement rate of 90 percent. We hope to enroll 2000 adult students by 2008.

In addition, as of the Spring Semester 2004, we serve 185 children in our Theodore Jamerson Elementary school, and 133 children in our infant-toddler and preschool programs, bringing the population for whom we provide direct services to 979.

UTTC course offerings and partnerships with other educational institutions.—UTTC offers 14 vocational/technical programs and awards a total of 24 2-year degree and 1-year certificates. We are accredited by the North Central Association of Colleges and Schools.

We are very excited about the recent additions to our course offerings, and the particular relevance they hold for Indian communities. These programs are: (1) Injury Prevention, (2) On-Line Education, (3) Nutrition and Food Services, (4) Tribal Government Management, and (5) Tourism.

—*Injury Prevention*.—Through our Injury Prevention Program we are addressing the injury death rate among Indians, which is 2.8 times that of the U.S. population We received assistance through Indian Health Service to establish the only degree granting Injury Prevention program in the nation. Injuries are the number one cause of mortality among Native people for ages 1–44 and the third for overall death rates. IHS spends more than $150 million annually for the

treatment of non-fatal injuries, and treatment of injuries is the largest expenditure of IHS contract health funds. (IHS fiscal year 2004 Budget Book).

—*On-Line Education*.—We are working to bridge the "digital divide" by providing web-based education and Interactive Video Network courses from our North Dakota campus to American Indians residing at other remote sites and as well as to students on our campus. We currently have 47 students (15.5 FTE) taking on-line courses. We are accredited by the North Central Association of Colleges and Schools to provide on-line associate degrees. We were invited by North Central to share our experiences in gaining on-line accreditation at their March, 2004 meeting in Chicago and did make that presentation. We have also been invited by New Mexico State University to do the same.

At this point, nearly half of the students taking on-line courses are campus-based students. On-line courses provide the scheduling flexibility students need, especially those students with young children. Our on-line education is currently provided in the areas of Early Childhood Education and Injury Prevention We will be asking approval this year from the North Central Association to offer full degree on-line programs in the following areas: Health Information Technology, Nutrition and Food Science, Elementary Education, and also possibly Criminal Justice. This approval is required in order for us to offer federal financial aid to the students enrolled in these on-line courses.

—*High Demand exists for computer technicians*.—In the first year of implementation, the Computer Support Technician program is at maximum student capacity. In order to keep up with student demand, we will need more classrooms, equipment and instructors. Our program includes all of the Microsoft Systems certifications that translate into higher income earning potential for graduates.

—*Nutrition and Food Services*.—UTTC will meet the challenge of fighting diabetes in Indian Country through education. As this Subcommittee knows, the rate of diabetes is very high in Indian Country, with some tribal areas experiencing the highest incidence of diabetes in the world. About half of Indian adults have diabetes (Diabetes in American Indians and Alaska Natives, NIH Publication 99–4567, October 1999)

We offer a Nutrition and Food Services Associate of Applied Science degree in an effort to increase the number of Indians with expertise in nutrition and dietetics. Currently, there are only a handful of Indian professionals in the country with training in these areas. Future improvement plans include offering a Nutrition and Food Services degree with a strong emphasis on diabetes education and traditional food preparation.

We also established the United Tribes Diabetes Education Center to assist local tribal communities and our students and staff in decreasing the prevalence of diabetes by providing diabetes educational programs, materials and training. We published and made available tribal food guides to our on-campus community and to tribes.

—*Tribal Government Management/Tourism*.—Another of our new programs is tribal government management designed to help tribal leaders be more effective administrators. We continue to refine our curricula for this program.

A newly established education program is tribal tourism management. UTTC has researched and developed core curricula for the tourism program and are partnering with three other tribal colleges (Sitting Bull, Fort Berthold, and Turtle Mountain) in this offering. The development of the tribal tourism program was well timed to coincide with the planned activities of the national Lewis and Clark Bicentennial last year. As you may know, Lewis and Clark and their party spent one quarter of their journey in North Dakota. UTTC art students were commissioned by the Thomas Jefferson Foundation to create historically accurate reproductions of Lewis and Clark-era Indian objects using traditional methods and natural materials. Our students had partners in this project including the National Park Services and the Peabody Museum at Harvard University. The objects made by our students are now part of a major exhibition in the Great Hall at Monticello about the Lewis and Clark expedition.

—*Job Training and Economic Development*.—UTTC is a designated Minority Business Center serving Montana, South Dakota and North Dakota. We also administer a Workforce Investment Act program and an internship program with private employers.

Economic Development Administration funding was made available to open a "University Center." The Center is used to help create economic development opportunities in tribal communities. While most states have such centers, this center is the first-ever tribal center.

Department of Education Study Documents our Facility/Housing Needs.—The 1998 Vocational Education and Applied Technology Act required the Department of

Education to study the facilities, housing and training needs of our institution. That report was published in November 2000 ("Assessment of Training and Housing Needs within Tribally Controlled Postsecondary Vocational Institutions, November 2000, American Institute of Research"). The report identified the need for $17 million for the renovation of existing housing and instructional buildings and $30 million for the construction of housing and instructional facilities.

We continue to identify housing as our greatest need. We have a waiting list of students some who wait from 1 to 3 years for admittance. For the first time in its history, in the 2002–2003 year, we were forced to find housing off campus for our students. Enrollment for the 2002–2003 year increased by 31 percent; and in 2003–2004 our enrollment increased another 20 percent. In order to accommodate the enrollment increase, UTTC partnered with local renters and the Burleigh County Housing Authority. Approximately 40 students and their dependents were housed off campus. The demand for additional housing also presents challenges for transportation, cafeteria, maintenance, and other services.

UTTC has now completed a new 86-bed single-student dormitory on campus. This dormitory is already completely full as are all of our other dormitories and student housing. To build the dormitory, we formed an alliance with the U.S. Department of Education, the U.S. Department of Agriculture, the American Indian College Fund, the Shakopee-Mdewakanton Sioux Tribe and other sources for funding. Our new dormitory has at the same time created new challenges such as shortages in classroom, office and other support facility space. However, more housing must be built to accommodate those on the waiting list and to meet expected increased enrollment.

Some of our housing must be renovated to meet local, state, and federal safety codes. In addition some homes may be condemned which will mean lower enrollments and fewer opportunities for those seeking a quality education.

Thank you for your consideration of our request. We cannot survive without the basic vocational education funds that come through the Department of Education's Perkins funds. They are essential to the operation of our campus and essential to the welfare of Indian people throughout the Great Plains region and beyond.

PREPARED STATEMENT OF THE AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM

Mr. Chairman and Members of the Subcommittee, on behalf of this nation's 34 Tribal Colleges and Universities (TCUs), which compose the American Indian Higher Education Consortium (AIHEC), thank you for the opportunity to share our fiscal year 2005 funding requests for programs within the U.S. Department of Education, and the U.S. Department of Health and Human Services—Head Start program.

This statement will cover two areas: (a) background on the tribal colleges, and (b) justifications for our funding requests.

BACKGROUND ON TRIBAL COLLEGES

The Tribal College Movement began in 1968 with the establishment of Navajo Community College, now Diné College, in Tsaile, Arizona. Rapid growth of tribal colleges soon followed, primarily in the Northern Plains region. In 1972, the first six tribally controlled colleges established AIHEC to provide a support network for member institutions. Today, AIHEC represents 34 Tribal Colleges and Universities located in 12 states, which were begun specifically to serve the higher education needs of American Indian. Annually, these institutions serve approximately 30,000 full-and part-time students from over 250 federally recognized tribes.

The vast majority of TCUs is accredited by independent, regional accreditation agencies and like all institutions of higher education, must undergo stringent performance reviews on a periodic basis to retain their accreditation status. In addition to college level programming, TCUs provide much needed high school completion (GED), basic remediation, job training, college preparatory courses, and adult education. Tribal colleges fulfill additional roles within their respective reservation communities functioning as community centers, libraries, tribal archives, career and business centers, economic development centers, public-meeting places, and child care centers. Each TCU is committed to improving the lives of its students through higher education and to moving American Indians toward self-sufficiency.

Tribal colleges provide access to higher education for American Indians and others living in some of this nation's most rural and economically depressed areas. These institutions, chartered by their respective tribal governments, were established in response to the recognition by tribal leaders that local, culturally based institutions are best suited to help American Indians succeed in higher education. TCUs combine traditional teachings with conventional postsecondary courses and curricula.

They have developed innovative means to address the needs of tribal populations and are successful in overcoming longstanding barriers to higher education for American Indians. Since the first tribal college was established on the Navajo reservation, these vital institutions have come to represent the most significant development in the history of American Indian higher education, providing access to and promoting achievement among students who may otherwise never have known postsecondary education success.

Despite their remarkable accomplishments, tribal colleges remain the most poorly funded institutions of higher education in the country. Persistently inadequate funding remains the most significant barrier to their success. Funding for basic institutional operations of 26 reservation based colleges is provided through Title I of the Tribally Controlled College or University Assistance Act (Public Law 95–471). Funding under the Act was first appropriated in 1981. Over 20 years later, the funding level has reached just 70 percent of the authorized level of $6,000 per full-time Indian student. In fiscal year 2004, these colleges are receiving $4,230 per full-time equivalent Indian student toward their institutions operating budgets. While mainstream institutions have had a foundation of stable state tax-based support, TCUs must rely on year-to-year federal appropriations for their basic institutional operating funds. Because TCUs are located on Federal trust territories, states have no obligation to fund them even for the non-Indian state-resident students who account for approximately 20 percent of TCU enrollments. Yet, if these same students attended any other public institution in the state, the state would provide basic operating funds to the institution.

Inadequate funding has left many of our colleges with no choice but to operate under severely distressed conditions. Although facilities initiatives of the last few years have resulted in widespread construction at TCUs, many colleges began in surplus trailers; cast-off buildings; and facilities with crumbling foundations, faulty wiring, and leaking roofs and have a long way to go. Sustaining quality academic programs is a challenge without a reliable source of facilities maintenance and construction funding.

As a result of more than 200 years of Federal Indian policy—including policies of termination, assimilation and relocation—many reservation residents live in abject poverty comparable to that found in Third World nations. Through the efforts of tribal colleges, American Indian communities receive services they need to reestablish themselves as responsible, productive, and self reliant.

JUSTIFICATIONS

Higher Education Act

The Higher Education Act Amendments of 1998 created a separate section within Title III, Part A, specifically for the nation's Tribal Colleges and Universities (Section 316). Titles III and V programs support institutions that enroll large proportions of financially disadvantaged students and have low per-student expenditures. TCUs clearly fit this definition as they are among the most poorly funded institutions in America, yet they serve some of the most impoverished areas of the country. TCUs are victims of their own success. This year two new tribal colleges are eligible to compete for funding under Title III. Despite the increase in the size of the pool of eligible institutions, the President's fiscal year 2005 Budget recommends an increase of $500,000 to this vital program. We urge the Subcommittee fund section 316 at $26 million, an increase of $2.7 million over fiscal year 2004 and $2.2 over the President's request, and we ask that report language included in since fiscal year 2003 be restated clarifying that funds not needed to support continuation grants or new planning or implementation grants be available for facilities renovation and construction grants.

The importance of Pell grants to our students cannot be overstated. Department of Education figures show that at the majority of all tribal college students receive Pell grants, primarily because student income levels are so low and our students have far less access to other sources of aid than students at mainstream institutions. Within the Tribal College system, Pell grants are doing exactly what they were intended to do—they are serving the needs of the lowest income students by helping people gain access to higher education and become active, productive members of the workforce. We urge Congress to fund this critical program at the highest possible level.

Carl D. Perkins Vocational & Applied Technology Education Act

Tribally-Controlled Postsecondary Vocational Institutions.—Section 117 of the Perkins Act provides basic operating funds for two of our member institutions: United Tribes Technical College in Bismarck, North Dakota, and Crownpoint Institute of

Technology in Crownpoint, New Mexico. We urge Congress fund this program at $8 million and reiterate language included since fiscal year 2002 stating that Section 117 Perkins grantees need not utilize restricted indirect cost rate.

The President's fiscal year 2005 budget proposes the elimination of the Native American Program Section 116, which reserves 1.25 percent of appropriated funding to support Indian vocational programs. We strongly urge Congress to continue this program, which is vital to the survival of vocational education programs being offered at TCUs.

Greater Support of Indian Education Programs Under ESEA

American Indian Adult and Basic Education.—This section supports adult education programs for American Indians offered by TCUs, state and local education agencies, Indian tribes, institutions, and agencies. Despite a lack of funding, TCUs must find a way to continue to provide basic adult education classes for those Indians that the present K–12 Indian education system has failed. Before many individuals can even begin the course work needed to learn a productive skill, they first must earn a GED or, in some cases, learn to read. According to a 1995 survey conducted by the Carnegie Foundation for the Advancement of Teaching, 20 percent of the participating students had completed a tribal college GED program before beginning higher education classes at the tribal college. At some schools, the percentage is even higher. Clearly, the need for basic educational programs is tremendous, and TCUs need funding to support these crucial activities. Tribal colleges respectfully request that Congress appropriate $5 million to meet the ever-increasing demand for basic adult education services.

American Indian Teacher Corps.—American Indians are severely under-represented in the teaching and school administrator ranks nationally. These competitive programs, aimed at producing new American Indian teachers and school administrators for schools serving American Indian students, support the recruitment, training, and in-service professional development programs for Indians to become effective teachers and school administrators, and in doing so excellent role models for Indian children. We believe that the TCUs are the ideal catalysts for these initiatives because of our current work in this area and the existing articulation agreements TCUs hold with 4-year degree awarding institutions. We request Congress support these programs at $10 million and $5 million, respectively, to increase the number of qualified American Indian teachers and school administrators in Indian Country.

Department of Health and Human Services/Administration for Child, Youth and Families/Head Start

Tribal Colleges and Universities (TCU) Head Start Partnership Program.—The TCU/Head Start partnership has made a lasting investment in our Indian communities by creating and enhancing associate degree programs in Early Childhood Development and related fields. New graduates of these programs can help meet the mandate that 50 percent of all program teachers earn an associate degree in Early Childhood Development or a related discipline by 2003. One clear impediment to the ongoing success of this partnership program is the erratic availability of discretionary funding made available for the TCU/Head Start partnership. In fiscal year 1999, the first year of the program, six TCUs received 3-year awards; in fiscal year 2000, seven additional colleges received 3-year grant awards; in fiscal year 2001, duration of grants was extended from 3-years to 5-years but only three additional TCUs received grants; in fiscal year 2002 no new grants were awarded; and in fiscal year 2003, eight new grants were awarded. The President's fiscal year 2005 budget includes a request of $6.9 billion for Head Start Programs. We request Congress direct the Head Start Bureau to designate a minimum of $5 million for the TCU/Head Start Partnership program, to allow current grantees ensure that this critical program can be continued and be expanded so that all TCUs might participate in the TCU/Head Start Partnership program.

CONCLUSION

Tribal colleges are bringing education to thousands of American Indians. The modest Federal investment in the tribal colleges has paid great dividends in terms of employment, education, and economic development, and continuation of this investment makes sound moral and fiscal sense. We very much need help to sustain and grow our programs and achieve our missions.

Thank you again for this opportunity to present our funding requests. We respectfully ask the Members of this Subcommittee for their continued support of TCUs and full consideration of our fiscal year 2005 appropriations request.

PREPARED STATEMENT OF FLORIDA STATE UNIVERSITY

Mr. Chairman, I would like to thank you and the Members of the Subcommittee for this opportunity to present testimony before this Committee. I would like to take a moment to briefly acquaint you with Florida State University.

Located in Tallahassee, Florida's capitol, FSU is a comprehensive Research I university with a rapidly growing research base. The University serves as a center for advanced graduate and professional studies, exemplary research, and top quality undergraduate programs. Faculty members at FSU maintain a strong commitment to quality in teaching, to performance of research and creative activities and have a strong commitment to public service. Among the current or former faculty are numerous recipients of national and international honors including Nobel laureates, Pulitzer Prize winners, and several members of the National Academy of Sciences. Our scientists and engineers do excellent research, have strong interdisciplinary interests, and often work closely with industrial partners in the commercialization of the results of their research. Florida State University had over $162 million this past year in research awards.

FSU recently initiated a new medical school, the first in the United States in over two decades. Our emphasis is on training students to become primary care physicians, with a particular focus on geriatric medicine—consistent with the demographics of our state.

Florida State University attracts students from every county in Florida, every state in the nation, and more than 100 foreign countries. The University is committed to high admission standards that ensure quality in its student body, which currently includes some 345 National Merit and National Achievement Scholars, as well as students with superior creative talent. We consistently rank in the top 25 among U.S. colleges and universities in attracting National Merit Scholars to our campus.

At Florida State University, we are very proud of our successes as well as our emerging reputation as one of the nation's top public research universities.

Mr. Chairman, let me tell you about a project we are pursuing this year through the U.S. Department of Education.

Florida State University (FSU), with support from the State of Florida and Governor Jeb Bush, initiated a state-wide partnership among the state's universities, local schools, teachers, principals, and other educational leaders to address the highest priority issues in K–12 education. The partnership, entitled the Multi-University Reading, Mathematics and Science Initiative (MURMSI), is designed to measurably improve teaching and learning in Reading, Mathematics and Science in Florida's K–20 schools with a special emphasis on students considered "at risk" due to economic or other conditions. It seeks to develop a deeper understanding of ways to improve Reading, Mathematics, and Science education through a strategically planned research agenda and action plans for change.

Randomized experiments that are highly valued in other fields, such as health, medicine, economics, psychology, political science—and more recently Pre-K education—are rare in K–12 education. As a result, existing research provides little knowledge about the cause and the effect of interventions and programs. The Education Sciences Reform Act of 2002 (H.R. 3801) passed by Congress includes language aimed to strengthen research design and methodology in education, including use of random assignment, when feasible, particularly in cases where researchers expect to make claims about causal relationships.

The connection between research and practice is also a weak link in K–12 education. A number of recent publications have substantiated a lack of connection between the results of systematic study and application in the field. Given the current budget outlook for Florida and the nation as a whole, it is critical that the dollars spent on education produce improved learning outcomes for students.

Well-designed research and development on priority educational issues can produce measurable gains in student performance. Critical knowledge related to improved learning must be produced and, in turn, applied throughout the state. To be effective, these R&D efforts must directly connect research, teacher preparation, professional development, practice and evaluation. To avoid duplication of effort, they must also be carefully coordinated across various stakeholder groups, including other universities, policy makers, K–12 leaders and teachers. By coordinating priorities, each entity can focus on its areas of expertise to accomplish the research, development, evaluation and dissemination functions essential to support Florida's K–20 system.

The work of this R&D collaboration—over a period of 5 years—involves the following:

—Assist Florida leaders and decision makers in developing a strategically planned research agenda targeting high priority statewide problems in K–20 Reading, Mathematics and Science education.
—Initiate, conduct and complete priority research projects (within each university) clearly responsive to critical statewide and national education needs using a data based, systems oriented model.
—Provide decision-makers timely technical advisories and summaries of findings on issues related to education policy and practice.
—Evaluate the impact of state K–20 initiatives designed to improve K–12 student performance in Reading, Mathematics and Science and disseminate the results.
—Design and recommend specific applications of the research findings and support implementation programs in school districts.
—Provide teacher professional development, especially in Reading, Mathematics and Science content areas, as teachers need to broaden and deepen their knowledge in response to changing educational and/or technological needs.

The first year of this initiative (fiscal year 2003) has been funded through a $1.5 million grant awarded to the FSU Learning Systems Institute by the U.S. Department of Education. Those resources were used to develop the research agenda described above and to initiate pilot research projects at universities across the state. During 2004, those pilot projects will continue and others will be added. In 2005, MURMSI will focus primarily on full implementation of the high priority research agenda in K–12 Reading, Mathematics and Science education. All aspects of this work will be done through the collaborative partnership and consensus-building process with other universities and stakeholders. Results of the research projects will be systematically shared with policy makers and educators throughout the state.

We are seeking $3 million in fiscal year 2005 to continue the work on this important state-wide project.

Mr. Chairman, this is just one of the many exciting activities going on at Florida State University that will make important contributions to solving some key concerns our nation faces today. Your support would be appreciated, and, again, thank you for an opportunity to present these views for your consideration.

PREPARED STATEMENT OF THE NCB DEVELOPMENT CORPORATION

On behalf of NCB Development Corporation, I am pleased to once again submit written testimony to the U.S. Senate's Committee on Appropriations Subcommittee on Labor, Health and Human Services, and Education on the subject of charter school facility finance. I am Terry D. Simonette, president and chief executive officer of NCB Development Corporation located in the District of Columbia and I would like to thank Chairman Specter and Ranking Member Harkin for the opportunity to submit this written testimony today on fiscal year 2005 funding for charter school facility finance which addresses the needs of the underserved and displaced communities under the jurisdiction of the Subcommittee. At the outset, let me share with you some background information on the NCB Development Corporation and our approach to address the charter school facility finance problem. Then I would like to share our thoughts on why charter schools should be looked at in a community development strategy.

NCB Development Corporation (NCBDC), an affiliate of National Cooperative Bank pursuant to the National Consumer Cooperative Bank Act (Public Law 95–351) is a national nonprofit organization that for 25 years has provided innovative financial and development services to improve the lives of low-income individuals, families, and communities. By creatively investing in our neighborhoods, advocating elected officials around public policy, and collaborating with other national and local community-based organizations, NCBDC helps charter schools finance and develop facilities; creates a policy environment that supports strong, self-sustaining communities; enables community health centers to expand to serve more patients; preserves and creates affordable housing; and helps socially responsible businesses thrive.

As you may already know, according to the Center for Education Reform, there are currently nearly 3,000 charter schools in 42 states and the District of Columbia giving nearly 750,000 students an opportunity to receive a quality education. Unlike traditional public schools, charter schools are not given a public building in which to operate. Instead, it is up to the charter school to find and fund an appropriate location. Operators, who are often concerned parents, teachers, or nonprofit organizations, typically have little experience with planning, zoning, and building code

regulations, let alone finding affordable space and adequate financing. And very few financing organizations are willing to lend to charter schools.

Since the mid-1990's, NCBDC has been considered an expert in the small community of organizations in the forefront of designing and implementing innovative financing strategies to meet a charter school's demand for capital. To date, between our lending and technical assistance programs, NCBDC has assisted 210 charter schools in 19 states obtain the facilities they require to accomplish their missions impacting 38,106 students, provided more than $66 million in facilities financing sustaining no monetary defaults and 0 percent loss rates on charter school lending, and helped leverage more than $100 million in additional funds. Major partners in these initiatives have included the U.S. Department of Education, Charter Friends National Network, the Florida Consortium of Charter Schools and the Midwest Charter Facilities Coalition.

As a 2001 recipient of a U.S. Department of Education National Activities Grant in and in partnership with the Charter Friends National Network established the Technical Assistance Project for Charter School Facilities to help charter schools develop and finance suitable buildings by providing on-the-ground technical assistance and workshops in facility development and financing. In the initial round of the highly competitive U.S. Department of Education's Charter School Facilities Financing Demonstration Grant Program, NCBDC partnered with The Reinvestment Fund, a leading community development financial institution based in Philadelphia, and Foundations, Inc., a leading technical assistance provider. In 2002, we were successful in receiving a $6.4 million grant to create the Charter School Capital Access Program (CCAP). CCAP successfully met the goal of raising $45 million from investors including PNC Bank of Pennsylvania to create a capital pool to help charter schools in the Mid-Atlantic States of New York, New Jersey, Pennsylvania, Delaware, and Virginia, and in the District of Columbia acquire, renovate, or construct facilities. This is a leverage ratio of nearly seven private dollars for every one public dollar.

In 2003, the U.S. Department of Education again recognized NCBDC's innovative work in charter school facility finance and awarded NCBDC a $6 million grant under the Credit Enhancement Program for Charter School Facilities, which is a valuable tool for motivating the private sector to get involved in charter school capital development. This grant will enable NCBDC to enhance facilities loans and educational opportunities for children in Florida, Georgia, Minnesota, and Wisconsin. NCBDC was one of four and the only repeat grantee having been awarded $6.4 million through the Department's initial Charter Schools Facilities Financing Demonstration Program as previously referenced.

Because we have seen firsthand the dire need for charter school facility finance, NCBDC supports the continuation and expansion of the Credit Enhancement for Charter School Facilities Program by increasing appropriations levels as authorized by the United States Congress in No Child Left Behind (NCLB or Public Law 107–110) signed into law on January 8, 2002.

According to a U.S. General Accounting Office (GAO) report commissioned by Congressional Requesters (GAO–03–899, September 2003) states: "The three greatest challenges facing new charter schools were securing a facility, obtaining start-up funding and acquiring the expertise necessary to run a charter school." The 2000 National Study of Charter Schools funded by the Office of Educational Research and Improvement within the U.S. Department of Education identified two of the same obstacles as lack of management expertise and inadequate facilities financing, which pose a formidable obstacle for the vast majority of start-up and established charter schools. Each of the three major financing approaches—municipal bonds, per pupil allocations, and conventional financing—offer only limited opportunities for charter schools that seek funds to lease, acquire, construct, or renovate a facility. There is a no more serious challenge facing charter schools nationally than obtaining upfront and ongoing financing for facilities. Despite the difficulty in securing credit, charter schools are remarkably resourceful in addressing their facilities needs, yet are generally unable to take advantage of the financing that is available to school districts and typically pay for facilities out of their regular operating funds. As a result, finding and funding a building impacts limited operating funds which in turn impacts teachers, administrative personnel and the purchase of everyday supplies.

Not finding a suitable home has delayed school openings, and forced schools to scale back their programs or shut down altogether, due to the inability to find adequate facilities. Charter schools are usually distinguished by their relatively small size; perceived instability of revenue streams, short operating track records, and political uncertainty. These characteristics pose formidable obstacles for the private sector, which has a low-risk tolerance and is often reluctant to lend in an "emerg-

ing" market. Consequently, charter schools also require new, creative financial models to address their growing demand for capital.

NCBDC applauds the President and the United States Congress in their commitment to charter school facility finance including the more than $37 million proved in the omnibus appropriations bill signed into law on January 23, 2004 (Public Law 108–199) for the continuation of the Credit Enhancement for Charter School Facilities Program and the President's $100 million request in his fiscal year 2005 budget released in February 2004. The Program will continue to assist charter schools in acquiring, leasing, and renovating school facilities. This is done through a competitive grant process to public and non-profit entities for loan guarantees, debt insurance, and other activities that facilitate private lending. While the demand for charter school facility finance is estimated nationally at more than $2 billion, $37 million falls far short of the $200 million in grants authorized yearly until 2007 in the NCLB, as outlined in the bipartisan Carper-Gregg Amendment in the act.

With our long history of a strong commitment to community development, particularly as it relates to underserved urban populations, NCBDC believes that strong schools are a cornerstone of any thriving community. Good schools keep families involved in neighborhoods, and this involvement is essential to community revitalization. Public charter schools encourage stability by offering parents a tuition-free choice outside the traditional public school; charter schools can keep families in communities with under-performing public schools. In addition, NCBDC has found that in the process of developing a facility, charter schools can be an effective tool for urban renewal and neighborhood revitalization. Finally, NCBDC believes that strong school-community partnerships, which are encouraged by charter schools, help build neighborhoods.

During this time of rising budget deficits and the rise in the cost of the war on terrorism, fiscal constraints make efforts to fulfill Congress' commitment to education, especially charter school facility finance, far more difficult then it has been in years past. Charter advocates, including NCBDC, have long been supportive of the efforts by the Administration and Congress to provide adequate appropriations for the charter school facilities initiatives set forth in the landmark bipartisan NCLB. We are hopeful that this Subcommittee, and ultimately this Congress, will provide appropriate charter school funding at the authorized levels, as charter schools are continuously faced with the lack of funding or expertise to purchase, build, or renovate a building and other physical plant requirements.

NCBDC appreciates this opportunity to reinforce the critical need served by supporting expanded funding for charter school facility finance. With your assistance, the charter school community can continue to make a difference in the lives of this nation's most vulnerable children, families, and communities. In summary, NCBDC requests a NCLB authorized fiscal year 2005 appropriation level of $200 million to help charters leverage private financing for facilities and start-up costs—an increase of $100 million over the President's fiscal year 2005 budget request and $163 million over the fiscal year 2004 appropriated level. In addition, NCBDC supports the continued expansion of the Public Charter Schools Program by supporting the President's fiscal year 2005 request of $219 million to provide grants to states to support 1,200 new and existing charter schools including $19 million for the new Charter Schools Per-Pupil Facilities Aid program.

Thank you again for allowing NCBDC to present its concerns regarding fiscal year 2005 appropriations provision of charter school facilities financing in written testimony before the Subcommittee.

RELATED AGENCIES

PREPARED STATEMENT OF THE NATIONAL FEDERATION OF COMMUNITY BROADCASTERS

Thank you for the opportunity to submit testimony to this Subcommittee regarding the appropriation for the Corporation for Public Broadcasting (CPB). As the President and CEO of the National Federation of Community Broadcasters, I speak on behalf of nearly 250 community radio stations and related organizations across the country. Nearly half our members are rural stations and half are minority controlled stations. In addition, our members include many of the new Low Power FM stations that are putting new local voice on the airwaves. NFCB is the sole national organization representing this group of stations which provide service in the smallest communities of this country as well as the largest metropolitan areas.

In summary, the points we wish to make to this Subcommittee are that NFCB:

—Requests $410 million CPB for fiscal year 2007, a $10 million increase over the fiscal year 2006 advance appropriation;

—Requests $60 million in fiscal year 2005 for conversion of public radio and television to digital broadcasting. Also supports funding for the Public TV interconnection system;
—Requests that advance funding for CPB is maintained to preserve journalistic integrity and facilitate planning and local fund raising by public broadcasters;
—Requests report language to ensure that CPB utilizes digital funds it receives for radio as well as television needs;
—Supports CPB activities in facilitating programming services to Latino and Native American radio stations;
—Supports CPB's efforts to help public radio stations utilize new distribution technologies and requests that the Subcommittee ensure that these technologies are available to all public radio services and not just the ones with the greatest resources.

Community radio fully supports $410 million for the Corporation for Public Broadcasting in fiscal year 2007.—Federal support distributed through the CPB is an essential resource for rural stations and for those stations serving minority communities. These stations provide critical, life-saving information to their listeners. Yet they are often in communities with very small populations and limited economic bases so that the community is unable to financially support the station without federal funds.

In larger towns and cities, sustaining grants from CPB enable community radio stations to provide a reliable source of noncommercial programming about the communities themselves. Local programming is an increasingly rare commodity in a nation that is dominated by national program services and concentrated ownership of the media.

For the past 28 years, CPB appropriations have been enacted 2 years in advance. This insulation has allowed pubic broadcasting to grow into a respected, independent, national resource that leverages its federal support with significant local funds. Knowing what funding will be available in advance has allowed local stations to plan for programming and community service and to explore additional non-governmental support to augment the federal funds. Most importantly, the insulation that forward-funding provides "go[es] a long way toward eliminating both the risk of and the appearance of undue interference with and control of public broadcasting."——House Report 94–245.

For the last few years, CPB has increased support to rural stations and committed resources to help public radio take advantage of new technologies such as the Internet, satellite radio and digital broadcasting. We commend these activities which we feel provide better service to the American people, but want to be sure that the smaller stations with more limited resources are not left out of this technological transition. We ask that the Subcommittee include language in the appropriation that will ensure that funds are available to help the entire public radio system utilize the new technologies, particularly rural and minority stations.

NFCB commends CPB for the leadership it has shown in supporting and fostering the programming services to Latino stations and to Native American stations. Satélite Radio Bilingüe provides 24 hours of programming to stations across the United States and Puerto Rico addressing issues of particular interest to the Latino population in Spanish. At the same time, American Indian Radio on Satellite (AIROS) is distributing programming for the Native American stations, arguably the fastest growing group of stations. There are now over 30 stations controlled by and serving Native Americans, primarily on Indian reservations.

This last year CPB undertook a comprehensive assessment of the Native American Radio system. It recognized the importance of these stations in serving local isolated communities (all but one are on Indian Reservations) and in preserving cultures that are in danger of being lost. The report recognized that ". . . very difficult environments." CPB funding is critical to these rural, minority stations. CPB's funding of the Intertribal Native Radio Summit in 2001 helped to pull these isolated stations together into a system of stations that can support each other. The report goes on to say "Nevertheless, the Native Radio system is relatively new, fragile and still needs help building its capacity at this time in its development."

CPB also funded a Summit for Latino Public Radio which took place this in September 2002 in Rohnert Park, California, home of the first Latino Public Radio station. These Summits have expanded the circle of support for Native and Latino Public Radio and identified projects that will improve efficiency among the stations through collaborations, and explore new ways of reaching the target audiences.

CPB plays a very important role for the public and community radio system. They are the convener of discussions on critical issues facing us as a system. They support research so that we have a better understanding of how we are serving listeners. And they provide funding to programming, new ventures, expansion to new

listeners, and projects that improve the efficiency of the system. This is particularly important at a time when there are so many changes in the radio and media environment with new distribution technologies and media consolidation. An example of this support is the grant that NFCB received to update and publish our Public Radio Legal Handbook online. This provides easy to read information to stations about complying with governmental regulations so that stations can function legally and use their precious resources for programming instead of legal fees.

Finally, community radio supports $50 million in fiscal year 2005 for conversion to digital broadcasting by public radio and television.—It is critical that this digital funding be in addition to the on-going operational support that CPB provides. The Administration's proposal that digital money should be taken from the fiscal year 2005 CPB appropriation would effectively cut stations' grants by more than 25 percent. This would have a devastating impact during these hard economic times when stations are facing major cuts from state and institutional funds. And it would come at a time when the local voices of community and public radio are especially important to notify and support people during emergency situations and to help communities deal with the loss of loved ones—things that commercial radio is no longer able to do because of media consolidation.

While public television's digital conversion needs are mandated by the FCC, public radio is converting to digital to provide more public service and to keep up with what commercial radio is doing. The Federal Communications Commission has approved a standard for digital radio transmission. The initial conversion of radio stations is being concentrated in 13 seed markets. CPB has provided funding for 42 stations in these markets to convert to digital, is supporting additional research on AM radio conversion, and is working with radio transmitter and receiver manufacturers to build in the capacity to provide a second channel of programming. Most exciting to public radio is the encouraging results of tests that National Public Radio has conducted that indicate that stations can broadcast two high quality signals, even while they continue to provide the analog signal. The development of 2nd audio channels will potentially double the public service that public radio can provide, particularly in service to unserved and underserved communities. This initial funding will only help a small number of the stations that will ultimately need to convert to digital or be left behind.

Community Radio also supports funding for the public television interconnection system.

Federal funds distributed by the CPB should be available to all public radio stations eligible for Federal equipment support through the Public Telecommunications Facilities Program (PTFP) of the National Telecommunications and Information Agency of the Department of Commerce. In previous years, Federal support for public radio has been distributed through the PTFP grant program. The PTFP criteria for funding are exacting, but allow for wider participation among public stations. Stations eligible for PTFP funding and not for CPB funding include small-budget, rural and minority controlled stations and the new Low Power FM service.

We appreciate Congress' direction to CPB that it utilize its digital conversion fund for both radio and television and ask that you ensure that the funds are used for both media. Congress stated, with regard to fiscal year 2000 digital conversion funds:

"The required (digital) conversion will impose enormous costs on both individual stations and the public broadcasting system as a whole. Because television and radio infrastructures are closely linked, the conversion of television to digital will create immediate costs not only for television, *but also for public radio stations* (emphasis added). Therefore, the Committee has included $15,000,000 to assist radio stations and television stations in the conversion to digitalization . . ."——(S. Rpt. 105–300)

This is a period of tremendous change. Digital is transforming the way we do things; new distribution avenues like digital satellite broadcasting and the Internet are changing how we define the business we are in; the concentration of ownership in commercial radio makes public radio in general and community radio in particular, more important as a local voice than we have ever been. New Low Power FM stations are providing new local voices in their communities. Community radio is providing essential local emergency information, programming about the local impact of the major global events taking place, culturally appropriate information and entertainment in the language of the native culture, as well as helping to preserve cultures that are dying out.

During this time, the role of CPB as a convener of the system becomes even more important. The funding that it provides will allow the smaller stations to participate

along with the larger stations which have more resources, as we move into a new era of communications.

Thank you for your consideration of our testimony.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF MUSEUMS

Chairman Specter, Senator Harkin and distinguished members of the Subcommittee, the American Association of Museums (AAM) appreciates the opportunity to testify on the fiscal year 2005 budget for the museum program at the Institute of Museum and Library Services (IMLS). The museum program at IMLS is the primary federal entity devoted to assisting museums in fulfilling their role as centers for lifelong learning for all Americans. We respectfully request your approval of the Administration's budget request of $41.4 million for the Office of Museum Services, which reflects a strong endorsement of the vital public service role museums play in their communities.

The American Association of Museums, headquartered in Washington D.C., is the national service organization that represents and addresses the needs of museums and to enhance their ability to serve the public. AAM disseminates information on current standards and best practices and provides professional development for museum professionals to ensure that museums have the capacity to contribute to lifelong education in its broadest sense and to protect and preserve our shared cultural heritage. Since its founding in 1906, AAM has grown to more than 16,000 members across the United States—nearly 10,500 individual museum professionals and volunteers, more than 3,000 museums, and 2,500 corporate members.

In its reauthorization of IMLS last year, Congress reaffirmed its commitment to the public to ensure that museums will continue to be centers of lifelong learning and to protect and preserve our nation's heritage. By appropriating federal dollars for these purposes, you ensure that society will have museums that are relevant, inspiring and accessible.

Through its grant awards, IMLS has supported museums that are responding to the needs of their communities. We are especially excited about the new Museums for America program, which provides a critical source of funding that supports museums and their roles in public service, education and stewardship. With a focus on strategic planning and institutional mission, it addresses the specific needs of the museum and its community while helping accomplish IMLS's broader national goal of creating and sustaining a nation of learners.

We have already seen the results of IMLS investments in our field. Through the 2003 Learning Opportunities Grants, more than $15 million was awarded to 169 museums. This included a grant to the State Museum of Pennsylvania to create a distance learning program that provides professional development to science teachers in Central Pennsylvania. As school districts meet the challenges put forward in the No Child Left Behind Act, museums are stepping forward with their vast collections, research, and staff expertise to strengthen teachers' current knowledge and classroom instruction in the method of scientific inquiry as well as the other disciplines of arts and humanities.

A project in Iowa is another example of museum-school collaborations. With support from IMLS, the Grout Museum District provided a weeklong Museum School to 1,000 third grade students from the Waterloo and Cedar Falls public schools district. Children, their families and teachers experienced local history. Students applied their lessons in math, science, and language to real-world situations while gaining a greater understanding and appreciation for how their community fits into the larger world.

With grants from IMLS, these museums developed programs that addressed the specific needs of their communities. These examples, however, also represent a much larger commitment museums are making to public education. A recent IMLS survey also shows that museum expenditures in support of K–12 education now exceed $1 billion annually. In fact, the percentage of museums' median annual operating budgets spent on educational programming has increased four-fold just since 1996. With more than 18 million instructional hours in 2000–01, museums are offering a broad range of services to schools. They are key partners in developing curriculum, providing professional development for teachers, and offering direct services to students through visits to museums, classroom visits by museum educators, and Web based educational materials and programs. In some communities, students attend schools that are actually housed in museums and run by museum staff.

The commitment of museums to education does not end with their ties to formal education. Museums are also places of lifelong learning. They provide an environment rich with opportunity for intergenerational learning and sharing where chil-

dren, their parents, and their grandparents can work together to connect ideas and experiences in direct, vivid and meaningful ways. Museum visitors can come to know the struggles and accomplishments of different cultures and unfamiliar people and achieve a deeper understanding of their own families, neighborhoods, the country in which they live, and the world.

Museums do not undertake this educational responsibility without an equal commitment to the care, protection and preservation of our nation's heritage found in their collections. There are more than 750 million objects and living specimens being held in the public trust by American museums. This number grows as museums continue to acquire the material patrimony of our civilization to assure that they remain publicly available for generations to come. A rough estimate places the annual expenditure for the care of those public collections at $1.1 billion. The need for conservation is ongoing and these costs will continue to grow with time as collections expand and age.

IMLS makes significant investments in both direct support for conservation and assistance to museums with identifying and prioritizing their conservation needs. In 2003, Conservation Support grants were awarded to 86 institutions. This program requires a 1:1 match and allows institutions such as the Wentworth-Coolidge Mansion in Portsmouth, New Hampshire to make much needed repairs to its gutters, improve drainage on the site, and make other improvements that will prevent further moisture damage to this national historic landmark and its unique contents.

Through the Conservation Assessment Program, Idaho's Twin Falls County Historical Museum, Texas' Sam Houston Memorial Museum, and Alabama's Magnolia Grove-Hobson Memorial Shrine were able to have a general conservation survey of their collections, environmental conditions and sites. Conservation priorities are identified by professional conservators who spend 2 days on-site and provide a written report to help museums develop strategies for improved collections care. Many institutions use the report for long-term planning and for attracting financial support to meet the conservation needs identified in the report.

America's museums, by their missions and tax exempt status, exist for the benefit of the public. The museums in your states and across the country are responsible for preserving the past, defining the present and educating for our future. The leadership and support of the federal government is critical to each of our nation's museums. The United States has a strong tradition of financial support for the public service mission of museums through public-private partnerships. Museums have three major income sources—private charity and foundation grants, earned and investment income, and government funding. Private charity represents 36 percent of museums' budgets, earned and investment income represents 33 percent and 11 percent respectively, and government funding—local, state, and federal—is 25 percent of museums' budgets. The largest portion of government funding is from the local and state level, with only 2.5 percent coming from the federal government. But it is a critical 2.5 percent.

This diversity of funding sources for museums is critical to their long term financial stability, but the recent economic uncertainty has strained all sources of funding for museums. The good news is that museums are remarkably resilient institutions and are determined to continue with their full array of public programs. This commitment is due in part to IMLS awards made through the Museum Assessment Program.

More commonly known as MAP, participating museums can select from a menu of four assessments and receive a professional review of their operations in that area. Following the review, museums are given recommendations and technical assistance which help them identify how they measure up to best practices in the field and where they might need improvement. This independent report informs an institution as it sets priorities and plans to become a better museum. In 2003, 170 grants were awarded to institutions in 42 states, including the East Ely Railroad Depot Museum in Nevada, Kent Plantation House in Alexandria, LA, and the Fort Worth Botanic Garden in Texas.

Museums must remain responsive to the needs of their communities. The public is concerned about education and our economy. Our institutions are seeking additional new ways to collaborate with the schools and teachers to instill in every child a passion for learning. We are working with local officials to make our communities vibrant and attractive to businesses and tourists. Our nation's museum directors and staff are deeply committed to their work and to serving the public. Every day in our nation's museums, thousands of museum educators greet school buses of children, historians and scientists research our past, and registrars catalog and track millions of objects. And museum directors across the country are always seeking the resources to sustain their institutions so they can fulfill their educational and stewardship responsibilities.

I particularly applaud IMLS and the Administration for recognizing that the needs of our museums are not just for the collections or the public programs, but also for the ongoing professional development of the leaders and staff within our museums—directors, curators, registrars, educators, conservators, and many others. In the fiscal year 2005 budget, the Administration has requested $1 million for the professional development of museum personnel. We will need to invest more, but I believe this to be a good start.

A commitment from the federal government is needed to help museums and their staff fulfill their public obligations. In partnership with IMLS we believe we can do just that, and I stress the word partnership. We fully support the strong U.S. tradition of public-private partnerships supporting museums' public service mission. We believe that IMLS is in a unique position with its expertise and flexibility to help us address these current challenges and to help our museums plan for the future. What the agency lacks is the financial resources.

IMLS needs sufficient funding to help our museums ensure that current and future generations have the fullest access to, and understanding of, our national heritage through the highest quality exhibitions, education programs and digitized materials for the Web. Innovation in museums allows them to better serve the public. As I noted before, we believe the administration's fiscal year 2005 request for the museum programs at IMLS is an important step towards further realizing the potential of museum education and community involvement.

We recognize, Mr. Chairman, that you and your colleagues are under intense pressure to balance the funding needs of the many worthy programs under your jurisdiction. As you consider that balance, I am sure you will recall that last fall you and your colleagues strongly endorsed the mission of IMLS by reauthorizing the agency for another 5 years. That is why we believe $41.4 million for fiscal year 2005 is a reasonable and fiscally responsible budget that will serve the public's demand for museums that are relevant, inspiring and accessible.

We appreciate the opportunity to testify before the committee today and thank you all for your support of our nation's museums and the museum program at IMLS.

PREPARED STATEMENT OF THE RAILROAD RETIREMENT BOARD

Mr. Chairman and Members of the Committee: We are pleased to present the following information to support the Railroad Retirement Board's (RRB) fiscal year 2005 budget request.

The RRB administers comprehensive retirement/survivor and unemployment/sickness insurance benefit programs for railroad workers and their families under the Railroad Retirement and Railroad Unemployment Insurance Acts. The RRB also has administrative responsibilities under the Social Security Act for certain benefit payments and Medicare coverage for railroad workers. During fiscal year 2003, the RRB paid $8.9 billion in retirement/survivor benefits to about 666,000 beneficiaries, and $94.1 million in unemployment/sickness insurance benefits to about 37,000 claimants.

As we explain in greater detail below, the RRB's budget request for fiscal year 2005 is comprised of two parts, $110.66 million for day-to-day administrative expenses, plus $4,947,800 for information technology infrastructure improvements. This request is intended to meet immediate and significant needs of the agency in two principal areas: (1) additional staffing, not only to manage current workloads, but even more importantly, to begin the process of recruiting and training to meet the RRB's staffing needs going forward; and, (2) modernization and improvement of our information technology infrastructure to ensure that the RRB's automated systems will continue to function effectively and efficiently in the future. These are pressing needs that must be addressed. However, at the President's proposed budget level of $102.6 million, not only would these critical, longer-term needs not be funded, but the RRB's ability to continue to deliver quality and timely service in the short term would also be severely jeopardized.

REQUEST FOR ADMINISTRATIVE FUNDING IN FISCAL YEAR 2005

The RRB has demonstrated fiscal responsibility over the years by requesting only what was needed to administer the programs under the Railroad Retirement and Railroad Unemployment Insurance Acts for which we are responsible. Even though our request is $13 million over the President's proposed budget, it represents our considered opinion which will enable us to continue our successful stewardship of the entitlement programs for our constituents. In considering this additional funding, we believe it is appropriate to look at the financial position of the benefit pro-

grams we administer in their entirety. Specifically, we would like to point to the successful implementation of the Railroad Retirement and Survivors' Improvement Act of 2001. Under that Act, we transferred a net $20.39 billion to the National Railroad Retirement Investment Trust (NRRIT) from its inception in February 2002 through September 30, 2003. The funds held by the NRRIT grew to $23 billion during that period, reflecting a 19.9 percent return on investments in fiscal year 2003, a market value gain of $2.7 billion. By comparison, our requested increase in administrative funding represents less than one-half of 1 percent of that increase.

A funding level of $110.66 million for ongoing operations would allow the RRB to maintain our current high levels of timeliness and accuracy in claims processing operations and to provide the quality service our customers expect. Our requested appropriation would provide sufficient funding for 1,046 FTE's—the same number we plan to use in fiscal year 2004. The additional funding would prevent a costly and disruptive reduction-in-force and allow us to hire some new employees for essential positions.

The efficient and timely administration of our Acts requires well-trained and experienced staff. Although the RRB has already suffered significant workforce reductions over the last few years, we have been able to maintain and even improve customer service. This has been accomplished using a core of experienced staff and productivity gains through technology. Our immediate concern today is the aging of our workforce. The bulk of the additional funding in fiscal year 2005, is to mitigate the expected loss of experienced staff by hiring and training new employees and to increase available resources for advances in information technology.

This funding level would also allow us to provide resources for important administrative needs, including travel, training and overtime to support our service to the public. We would also be able to reinstate employee benefit programs, including transit benefit subsidies, which have been suspended due to insufficient funding. At our request level, an additional $300,000 would also be available for information technology. We would use this money to replace aging desktop computing equipment and software.

ENTERPRISE ARCHITECTURE CAPITAL ASSET PLAN

Our budget request includes funding the first year of our Enterprise Architecture Capital Asset Plan for fiscal years 2005–2007, which addresses the major initiatives needed to implement our target enterprise architecture. This request is highlighted separately because of its significance to the long-term continued viability of agency programs, and the realization that movement toward the desired target architecture will be a multi-year effort. We are requesting an additional $4,947,800 to begin these initiatives in fiscal year 2005.

Gartner Consulting has recommended that we investigate alternatives for our Computer Associates' Integrated Database Management System (IDMS) and be prepared to actively retire the platform beyond 2006. The Enterprise Architecture Capital Asset Plan includes funding for contractual assistance, tools and training to begin this transition as well as related initiatives. Funding has been requested in four key areas:

—*Infrastructure modernization initiative ($1,445,000)*.—A variety of improvements to the agency's infrastructure are required to support our target enterprise architecture. This initiative provides agency-wide support at the desktop, systems and network levels. Components include improvements to our data center infrastructure, client/server software and information security.

—*Modernization blueprint initiative ($1,992,800)*.—The primary feature of this initiative is the conversion of the RRB's database from IDMS to a relational database management system. The agency's day-to-day operations are heavily dependent on application systems that are based on IDMS technology. Delaying this transition in fiscal year 2005 would create a high risk that the loss of these systems could compromise the RRB's ability to pay benefits and fulfill its mission in the future.

—*Metadata repository initiative ($555,000)*.—This project funds the development of a preliminary metadata repository, which is a critical success factor for implementation of inter-governmental and internal data sharing services. The metadata repository will enable us to integrate data from various sources and mediums, including railroad employers and employees, annuitants and beneficiaries, State agencies, and other Federal government agencies.

—*E-Government service delivery initiative ($955,000)*.—This project funds our initiative to expand electronic services to the public via the RRB Internet website. In addition, this initiative funds the continued expansion of a system being developed to meet the requirements of the Government Paperwork Elimination

Act, which will permit private employers to store and file electronically, with executive agencies, forms containing information pertaining to employees. We will expand services to railroad employers by providing for on-line completion or transmission of all employer paper forms.

PRESIDENT'S PROPOSED FISCAL YEAR 2005 BUDGET

The President's proposed budget includes $102.6 million for RRB administrative expenses in fiscal year 2005. This total includes $100.5 million for the ongoing costs of current agency operations. In addition, the President's proposed budget includes $2.1 million to contract with a non-governmental disbursement agent for payment of railroad retirement and survivor benefits in accordance with provisions of the Railroad Retirement and Survivors' Improvement Act of 2001 (Public Law 107–90).

We believe that an appropriation at this level would seriously undermine the quality and timeliness of services to our customers in fiscal year 2005. The negative impact would also carry forward to subsequent years due to staff reductions, administrative cutbacks, and further postponement of important automation initiatives.

The reductions at the President's proposed level of funding for fiscal year 2005, would undermine the RRB's ability to process claims in a timely manner, including those for retirement, survivor and disability annuities. Delays would also occur in processing subsequent annuity adjustments, requests for reconsideration and employer reports. Customer outreach services would be reduced, creating delays in responding to inquiries and taking applications for benefits.

Customer service would also be affected if we are required to contract for the use of a non-governmental disbursement agent in fiscal year 2005. Not only would this action increase the RRB's operating costs, but our Inspector General and others have questioned whether certain services provided by the Department of the Treasury, such as reclamations, would be provided as effectively by a non-governmental disbursement agent. On March 20, 2003, we submitted a legislative proposal to permit the Department of the Treasury to continue to make payments of railroad retirement benefits.

We would need to make extremely deep cuts in funding for administrative needs throughout the RRB to operate at the President's proposed level in fiscal year 2005. Because 80 percent of our budget is used for employees' salaries and benefits, a major staff reduction would be unavoidable. We estimate that the President's proposed funding would support only 969 full-time equivalent staff years (FTE's), which is 77 FTE's less than we now plan to use in fiscal year 2004. To reduce agency staffing, we would need to impose a year-long hiring freeze, leaving positions unfilled as vacancies occur through attrition. We would also need to conduct a reduction-in-force of 39 employees at the beginning of fiscal year 2005. The RIF would cost an estimated $473,000.

Information technology (IT) funding would also be severely limited. At the President's proposed level of funding, the RRB would have only $1,325,000 for investments under our ongoing IT Capital Plan. Although e-Government initiatives are essential to maintaining a high level of public service and improving productivity in coming years, we would need to severely curtail purchases of desktop computing equipment and software needed by the agency's staff. In addition, we would have no funding available for the major projects in our Enterprise Architecture Capital Asset Plan. This plan includes funding to begin migration of agency systems from the Integrated Database Management System, which is nearing obsolescence. Not funding this initiative creates a high risk that the loss of these systems could compromise the RRB's ability to pay claims and fulfill our mission in the future.

The proposed budget would also provide insufficient funding for other administrative needs, many of which have been sharply reduced in recent years. We have already suspended several of our employee benefit programs, including transit benefit subsidies and certain award programs, which had contributed considerably to employee morale in the past. These programs would continue to be suspended in fiscal year 2005. We would also continue to severely limit funds allocated for variable expenses, such as overtime, travel, training, supplies and equipment.

In addition to the requests for administrative expenses, the Administration's budget includes $108 million to fund the continuing phase-out of vested dual benefits, and $150,000 for interest related to uncashed railroad retirement checks.

FINANCIAL STATUS OF THE TRUST FUNDS

Railroad Retirement Accounts.—As a result of $18.9 billion in net transfers to the National Railroad Retirement Investment Trust, the net position of the railroad retirement accounts decreased by $18.1 billion in fiscal year 2003, to $551.1 million.

In June 2003, we released the 22nd Actuarial Valuation, including the annual report on the railroad retirement system required by Section 22 of the Railroad Retirement Act of 1974, and Section 502 of the Railroad Retirement Solvency Act of 1983. The actuarial valuation contains generally favorable information concerning railroad retirement financing. However, the long-term stability of the system, under its current financing structure, is still dependent on future employment levels and investment returns. The valuation included projections of the status of the retirement trust funds under three employment assumptions. These indicated cash flow problems only under a pessimistic employment assumption, and then not until calendar year 2022.

Railroad Unemployment Insurance Accounts.—The equity balance of the railroad unemployment insurance accounts at the end of fiscal year 2003 was $51.5 million, an increase of $35.8 million from the previous year. The RRB's latest annual report on the financial status of the railroad unemployment insurance system, issued in June 2003, was generally favorable. The report indicated that even as maximum daily benefit rates rise 44 percent (from $52 to $75) from 2002 to 2013, experience-based contribution rates are expected to keep the unemployment insurance system solvent. The small loan made in fiscal year 2002 was repaid in May 2003, and no new loans are anticipated even under our most pessimistic assumption. The average employer contribution rate remains well below the maximum throughout the projection period, but a 1.5 percent surcharge is now in effect and is expected for calendar year 2005 and probably 2006. We did not recommend any financing changes based on this report.

In conclusion, we want to stress the RRB's continuing commitment to improving our operations and providing quality service to our beneficiaries. Thank you for your consideration of our administrative budget request. We will be happy to provide further information in response to any questions you may have.