S. HRG. 108–130

ALZHEIMER'S DISEASE, 2003

HEARING

BEFORE A

SUBCOMMITTEE OF THE

COMMITTEE ON APPROPRIATIONS

UNITED STATES SENATE

ONE HUNDRED EIGHTH CONGRESS

FIRST SESSION

SPECIAL HEARING

APRIL 1, 2003—WASHINGTON, DC

Printed for the use of the Committee on Appropriations

Available via the World Wide Web: http://www.access.gpo.gov/congress/senate

U.S. GOVERNMENT PRINTING OFFICE

89–018 PDF WASHINGTON : 2003

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ALZHEIMER'S DISEASE, 2003

TUESDAY, APRIL 1, 2003

U.S. SENATE,
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES,
COMMITTEE ON APPROPRIATIONS,
Washington, DC.

The subcommittee met at 9:35 a.m., in room SH–216, Hart Senate Office Building, Hon. Arlen Specter (chairman) presiding.

Present: Senators Specter, Craig, Harkin, and Murray.

OPENING STATEMENT OF SENATOR ARLEN SPECTER

Senator SPECTER. Good morning, ladies and gentlemen. The Appropriations Subcommittee on Labor, Health and Human Services, and Education will now proceed. This hearing coincides with the 15th Alzheimer's Association Public Policy Forum, and we will kick off the organization's Capitol Hill day today. An estimated 400 family caregivers and volunteers will attend.

The subcommittee began hearings on Alzheimer's back in 1980, and it has been virtually an annual affair since 1998. There are approximately 4 million Americans with Alzheimer's disease, costing the economy over $100 billion annually. As the baby boom generation ages, scientists predict the number of individuals with Alzheimer's will jump to 6 million by the end of this decade and as high as 14 million by mid-century, when the annual cost will be some $375 million a year.

The ravages of Alzheimer's are known only too well by the families of those who suffer from Alzheimer's. The illness came into sharp national focus when President Reagan was diagnosed with Alzheimer's and then made a public disclosure, and we have all watched what has happened with President Reagan since he left the White House in 1989, and we have seen the loving care from Mrs. Reagan, and that has brought a national awareness as to the enormous problems with Alzheimer's.

The funding for Alzheimer's has increased very, very materially from $308 million in fiscal year 1996 to $663 million, which is our request for this year. This increase in funding has been facilitated by an enormous increase in the funding for the National Institutes of Health generally. Senator Tom Harkin, Democrat of Iowa, and I have chaired this committee alternatively. You might not have noticed this, but we change parties every now and then in Washington.

We have passed the gavel in what we call a seamless exchange. Our view is that there is too much partisan politics in Washington

generally. People are sick and tired in America of political bickering, and it absolutely has no place when you are dealing with the funding of health care, so that in the recent years the funding for the National Institutes of Health has been increased from $12 billion to more than $27 billion. We have more than doubled the NIH funding, and that has had the effect of providing tremendous research assistance for ravaging diseases like Parkinson's and heart disease and cancer, Alzheimer's, and many, many others.

We are facing certain controversies on the issue of stem cells, for example, which burst upon the scene in late 1998. Stem cells come from embryos, and have proved to have enormous potential to combat ailments like Alzheimer's. Recently, there has been a charge of cloning, so-called therapeutic cloning, or what is really nuclear transplantation.

Without getting too deeply involved in that subject, suffice it to say today that it is very important for the 128 million people who are afflicted with ailments either themselves or by their families should be aware of the need for public support for funding for the National Institutes of Health, and for public support for research on stem cells and nuclear transplantation.

The House of Representatives has passed legislation which criminalizes medical research in what I consider to be very ill-advised legislation. More than 40 Nobel laureates have come forward asking that there be freedom for medical research, and it is important for you, ladies and gentlemen—you have first-hand knowledge of this debilitating disease—to be aware of this so that you can be activists in your communities, and you can advise your Members of the Senate and House of Representatives on a national basis what you would like to see done. That is the essence of representative democracy.

We have been joined by our distinguished colleague, Senator Larry Craig from Idaho. Senator Craig, would you care to make an opening comment?

OPENING STATEMENT OF SENATOR LARRY E. CRAIG

Senator CRAIG. Mr. Chairman, I will be brief. You have an outstanding group of panelists this morning, and let me thank you for holding the hearing and your advocacy for some of these issues that are so critically important.

I am here today as a member of the subcommittee. I am also here as chairman of the Special Committee on Aging in the Senate, and I am the adult child of aging parents, and I feel very fortunate that I have not had to face Alzheimer's directly, but indirectly, certainly with other members of my family, with friends and associates. It is very real, and all that you said, Mr. Chairman, is certainly true.

Alzheimer's disease can exhaust the human resources, cause physical and emotional hardships for caregivers and is a tremendous financial burden on families, and the tragic story goes on and on. That is why we are here today, to take the testimony of these experts and to see what we can do to continue to add to the research that is going on.

Funding for biomedical research for all diseases is a high priority, and this chairman has made it his priority, and Mr. Chair-

man, I thank you for doing so, because it is making a difference, and all of these advocates who are here today are making a difference, along with that research.

New discoveries obviously return values to the patient and their families, and the story goes on and on. This is a challenge that we are facing. It is a challenge that we will meet. It is a crisis in our community that we hope to solve with the necessary research and work, so thank you very much this morning, Mr. Chairman. I look forward to the testimony of these experts.

Senator SPECTER. Thank you very much, Senator Craig.

STATEMENT OF RICHARD J. HODES, M.D., DIRECTOR, NATIONAL INSTITUTE ON AGING, NATIONAL INSTITUTES OF HEALTH, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Senator SPECTER. Our first witness is Dr. Richard J. Hodes, who has served as the Director of the National Institute on Aging since 1993. He has held several other key posts at NIH, including clinical investigator at the National Cancer Institute, program coordinator for the U.S.-Japan cooperative cancer research program, and deputy chief of the Cancer Institute's Immunology Branch, a graduate of Yale, M.D. from Harvard Medical School.

Thank you for joining us, Dr. Hodes, and we look forward to your testimony. Our practice is to limit the testimony of each witness to 5 minutes. I think it is worth noting that there was a memorial service for Ambassador Annenberg recently, and our speakers included former President Gerald Ford and Secretary of State Colin Powell. Every speaker was limited to 3 minutes, including myself.

So I want you to know at the outset how generous 5 minutes is.

Dr. Hodes, we look forward to your testimony.

Dr. HODES. Thank you, Senator Specter, members of the committee, and thank you for this opportunity to share with you some of the progress being made to understand, diagnose, and treat Alzheimer's disease.

As noted, Alzheimer's disease is a tragic condition that affects those with the disease as well as family members, loved ones, the health care system, and in fact, the entire society. It is a burden that threatens to increase as the American population ages over the coming decades. Although this remains a critical public health issue, it does so in the context of dramatic improvements in our understanding of the disease, some of which I would like to share with you today.

Remarkably, as recently as 15 years ago, we knew nothing about the genes that can predispose to Alzheimer's disease, and very little about the underlying mechanisms. As recently as 10 years ago, we had no animal models in which to study the disease, 5 years ago there were no ongoing prevention studies and very little ability to identify individuals at high risk for the disease. As recently as 2 years ago there was no effective way in which to study the interactions of the plaques and tangles, the brain lesions that are characteristic of the disease.

All of these advances have occurred. We now, over the past year alone, have seen dramatic new progress. One of the basic underpinnings in our understanding of the disease is our ability to understand risk factors, both environmental and genetic. It is notable that we have now identified three genes which can cause Alz-

heimer's in early onset familial disease, as well as identifying, ApoE, an important risk factor gene for the more common late onset disease.

Notably, investigators are now closing in on identification of several additional genes, including those which appear on chromosomes 9, 10, and 12. To accelerate progress in this area we are now initiating an Alzheimer's disease genetics initiative collaboratively among institutes at NIH which will accumulate the contributions of genetic materials and contributions from centers across the country and around the world from population-based studies, and family studies, as well as case control studies. We will accumulate these in a database which importantly will be available to all investigators so that the power of studies to identify genes and targets for intervention will be increased dramatically.

In addition, new refinements and advances in neuroimaging have been extraordinary of late. There have been studies with techniques such as magnetic resonance imaging (MRI), which have now shown the ability to detect defects in the brains before the lesions of plaques and tangles can be seen. This is important because now we have the ability to detect changes before symptoms occur, at a time when intervention may be most effective.

New techniques, which not only can study structure but also function of areas of the brain, such as positron emission tomography (PET), show promise not only for early diagnosis, but being able to track the cause and progression of disease and most importantly, perhaps, to be able to track the effectiveness of interventions by neuroimaging methodologies, and to facilitate and accelerate developments in this area. We are currently coordinating the development of a neuroimaging initiative which notably will involve collaboration not only with NIA and multiple NIH institutes, but with the FDA, with the Alzheimer's Association, and with pharmaceutical as well as imaging industries to try to develop those techniques which can best monitor disease and our future assessment of therapies for prevention as well as treatment.

From imaging and laboratory studies, we are rapidly accumulating new strategies, new strategies for attacking the underlying processes that are responsible for Alzheimer's disease. These include immune approaches. These include the identification of new molecules that bind specifically to the lesions of Alzheimer's disease and can help to eradicate them. As noted, they involve the promise of stem cell research, which does have the capability and concept of providing neurons to replace those damaged or destroyed during the disease.

PREPARED STATEMENT

We are currently supporting 18 clinical trials of Alzheimer's disease, seven of which are large scale prevention studies. The unprecedented advances that we have had in understanding the underlying mechanism of the disease will in the next generation create new opportunities, new targets, and new strategies for interventions.

I thank you for the opportunity to share this progress with you. I will be happy to address any questions that you may have.

[The statement follows:]

PREPARED STATEMENT OF DR. RICHARD J. HODES

Senator Specter and Members of the Committee: Thank you for inviting me to appear before you today to discuss Alzheimer's disease (AD), an issue of interest and concern to us all. I am Dr. Richard Hodes, Director of the National Institute on Aging (NIA), the lead federal agency for Alzheimer's disease research. I am delighted to be here this morning to tell you about the progress we are making toward understanding, treating, and preventing AD.

As you know, AD is a devastating condition with a profound impact on individuals, families, the health care system, and society as a whole. According to data from the Alzheimer's Association, approximately 4 million Americans are currently battling AD, with annual costs estimated to exceed $100 billion. Moreover, the rapid aging of the American population threatens to increase this burden significantly in the coming decades: Demographic studies suggest that if current trends hold, the annual number of incident cases of AD will begin a sharp increase around the year 2030, when all the baby boomers (born between 1946 and 1964) will be over age 65. By the year 2050, the number of Americans with AD could double.[1]

But these numbers, however stark, do not tell the whole story. Although AD remains a major public health issue for the United States, we have made, and are continuing to make, dramatic gains in our ability to understand and diagnose AD that offer us the hope of preventing and treating the disease, reversing the current trends.

Fifteen years ago, we did not know any of the genes that cause AD, and we had only a limited understanding of the biological pathways that are involved in the development of brain pathology. Ten years ago, we could not model the disease in animals. Five years ago, we were not funding any prevention trials and had no way of identifying persons at high risk for the disease. And as recently as two years ago, we did not understand anything about how AD's characteristic amyloid plaques and neurofibrillary tangles in the brain relate to each other.

Today, we have accomplished all of these things through a far-ranging and innovative program of scientific endeavor. And in the past year alone, we have made a number of important discoveries.

A crucial underpinning of our efforts to develop interventions that delay or even prevent clinical manifestation of AD is the understanding of the events leading up to the disease's appearance, including risk factors. Through laboratory and population-based research, we have identified a number of risk factors for AD, including genetic and lifestyle factors. We already know three major genes for early-onset disease and have identified a major risk factor gene for late onset disease, ApoE4. Recent findings are enabling us to close in on several others, thought to be on chromosomes 9, 10, and 12.

In order to move the field of Alzheimer's disease genetics forward more rapidly, the NIA has developed an Alzheimer's Disease Genetics Initiative. A major component of this initiative is the collection of family-based, population-based, and case-control sample sets. To facilitate collection of the family-based sample set, administrative supplements were awarded last year to ten Alzheimer's Centers to identify families with two or more affected members and to collect blood and information from them for archiving in the National Cell Repository for Alzheimer's Disease (NCRAD). DNA and information on these individuals will be made available, with appropriate controls to ensure participant confidentiality, to the research community. The information gained through this initiative will be invaluable to the discovery of AD-related genes, which will in turn help us identify pathways affecting AD development or progression.

In addition to genetic and molecular risk factors, studies funded by a number of NIH Institutes are revealing the possible impact of diseases such as cardiovascular disease and diabetes on AD-related dementia in later life. Researchers in one study found that persons in a Latino population had a 7–8 fold increased risk of dementia if they had both type 2 diabetes and stroke compared to persons who had neither, suggesting that improved interventions to prevent diabetes and stroke may prevent dementia in substantial numbers of people. Results from the ongoing Cardiovascular Health Cognition Study demonstrated that measures of cognition, ApoE4 status, and certain results on magnetic resonance imaging (MRI) of the brain are together strongly predictive of both dementia and AD.

In fact, the development and refinement of powerful imaging techniques that target anatomical, molecular, and functional processes in the brain is giving us an im-

[1] Hebert LE, Beckett LA, Scherr PA, and Evans DA. Annual Incidence of Alzheimer Disease in the United States Projected to the Years 2000 Through 2050. Alzheimer Dis. Assoc. Disord. 15: 169–173, 2001.

proved ability to identify people who are at very high risk for AD, as well as a greater understanding of the disease's pathology. For example, in a recent mouse study, researchers found that changes in brain structure can be detected by magnetic resonance microscopy before amyloid plaques appear in the brain, suggesting that subtle pathologic changes are occurring long before signs and symptoms of the disease appear. Other investigators have found that metabolic changes in certain parts of the brain, as detected through positron emission tomography, show potential for predicting future decline in cognitively normal adults. Researchers are also working to improve our ability to image plaques and tangles in vivo, which will allow us to diagnose the disease with greater accuracy and more closely follow its progression and response to therapies.

These techniques, along with improved neuropsychological tests, are enabling us to diagnose AD early, while the patient can still take an active role in decision-making. This knowledge, in turn, may allow early intervention long before the disease affects the patient's level of functioning.

An Alzheimer's Disease (AD) Neuroimaging Initiative is under development as a study of normal aging, mild cognitive impairment (frequently a precursor of AD), and early AD, using serial magnetic resonance imaging and positron emission tomography scans, clinical and neuropsychological data, and collections of biological fluids and cells for other potential biomarkers. The Initiative is being planned with participation by NIA/NIH, the Food and Drug Administration, academic investigators, the pharmaceutical industry, the imaging equipment industry, the Alzheimer's Association, and the Institute for the Study of Aging. It is anticipated that information gained from this initiative will help us identify potential uses of imaging and other surrogate markers for following progression of cognitive decline and dementia, and for assessing the effectiveness of interventions to prevent or treat AD.

As we learn more about AD's pathology through imaging and laboratory studies, we are identifying a number of novel molecular characteristics that may prove to be targets for treating the disease or preventing it altogether. In this endeavor, animal models—particularly transgenic mice, but also worms, dogs, and even nonhuman primates—are invaluable research resources for studying age-related and disease-related changes in the brain and for testing promising interventions.

Two new research findings suggest that boosting normal, protective processes in the brain might help degrade or prevent the development of amyloid plaques. In one study, researchers found that gene transfer into mice of the enzyme neprilysin may help clear the protein that forms amyloid plaques in humans. In the other, researchers found that brain cells called astrocytes can degrade the beta amyloid peptide in cell cultures, suggesting that harnessing the protective function of these cells may be a strategy for AD prevention and treatment.

Another potential preventive strategy involves enhancing the function of chaperone proteins, which aid in proper protein folding. In various cellular models, researchers have noted an inverse relationship between levels of a heat shock protein (a chaperone) and neurofibrillary tangles in the brain, suggesting that up-regulation of molecular chaperones may suppress formation of neurofibrillary tangles. More research is needed to assess the clinical significance of these findings.

Researchers are also exploring immune approaches that target AD. In collaboration with the National Institute of Neurological Disorders and Stroke, NIA has issued a Request for Applications (RFA) and funded a number of studies to better understand the science underlying immunologic approaches. An encouraging outcome of this research is the observation that antibodies in the blood may draw soluble amyloid out of the brain, perhaps even reducing the size of plaques as well. The newest results suggest that other compounds that bind to amyloid may have the same effect. Whether these results in animal studies can be successfully applied to humans has not yet been evaluated.

Human stem cells, with their unique capacity to regenerate and give rise to many tissue types, are of particular interest in AD research because of their potential ability to generate new cells that could renew damaged brain tissue, replace dying neurons, or enhance the ability of the brain to respond to age-related impairments. Recent findings suggest that both human embryonic stem cells (hES), which can give rise to many cell types, and "adult" stem cells, which develop into specific cell types, show promise for the eventual treatment of AD and other neurodegenerative conditions. Researchers have recently developed a method for inducing hES cells to differentiate into neurons. These newly-derived cells exhibit the properties of cells ordinarily found in the brain and central nervous system, suggesting that hES cells could provide a source for neural progenitor cells and mature neurons for therapeutic use. Investigators have also found that in the adult hippocampus, neural stem cells can give rise to functional neurons that can integrate effectively into existing neural circuits.

In addition to interventions at the molecular level, scientists are increasingly enthusiastic about the role of behavioral variables, such as mentally stimulating activities throughout life, as a factor capable of maintaining cognitive health or even reducing the risk of cognitive decline or AD. Through its Advanced Cognitive Training for Independent and Vital Elderly (ACTIVE) study, NIA explored whether three specific interventions (on memory, reasoning, and speed of processing) could maintain or improve functioning in unimpaired, community-dwelling older adults. The investigators found that the interventions helped the participants to perform better on multiple measures of the specific cognitive ability for which they were trained, and that these improvements persisted for two years after training. Additional follow-up of participants is planned.

Research has also suggested that the use of several common, over-the-counter compounds may be associated with reduced risk of AD and dementia. For example, epidemiologic studies show a correlation between long-term use of non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen and a reduced risk of developing AD, and recent findings in animal models suggest the possibility that some newer anti-inflammatories may reduce inflammation as well as directly reduce the formation of amyloid. Likewise, researchers are developing and testing new antioxidant drugs that ameliorate or prevent brain cell damage or death caused by oxidative stress, a form of cell damage caused by molecules generated during normal energy metabolism. Chronic oxidative stress may be a contributing factor in neurodegenerative disorders, including AD. In studies of dogs and rats, diets rich in antioxidants resulted in a significant improvement in the ability of older animals to acquire progressively more difficult learning tasks. These results suggest that oxidative damage impairs cognitive function and that antioxidant treatment can result in significant improvements.

NIA is currently supporting 18 AD clinical trials, seven of which are large-scale prevention trials. These trials are testing agents such as estrogen, anti-inflammatory drugs, and anti-oxidants for their effects on slowing progress of the disease, delaying AD's onset, or preventing the disease altogether. Other intervention trials are assessing the effects of various compounds on the behavioral symptoms (agitation, aggression, and sleep disorders) of people with AD. The design and implementation of all of these clinical trials will be carried out in the context of the NIH Roadmap initiative to enhance clinical research infrastructure and methodology.

Another very important area of research involves easing the burden on caregivers of AD patients. Most Americans with AD are cared for at home by an adult child or in-law, a spouse, another relative, or a friend. For this reason, the AD "patient" is, in a sense, not only the person with the disease, but the entire family unit. The NIA's REACH Project (Resources for Enhancing Alzheimer's Caregiver Health), a large, multi-site intervention study aimed at family caregivers of AD patients, was designed to characterize and test promising interventions for enhancing family caregiving. Nine different social and behavioral interventions were tested, and investigators found that the combined effect of interventions alleviated caregiver burden, and that interventions that enhanced caregiver behavioral skills reduced depression. The second phase of the study, REACH II, combines elements of the diverse interventions tested in REACH into a single multi-component psychosocial behavioral intervention and is ongoing.

The goal of AD research is ultimately to identify the most effective strategies for preventing and treating AD in diverse populations. Recent research findings have provided an unprecedented base of knowledge upon which to design these strategies. Research on AD genetics, on the basic cellular biology of AD-related pathways, the changes taking place in the brains of persons with mild cognitive impairment and early AD, animal models, and hints of possible risk and protective factors from epidemiology studies, have all contributed to identification of new clinical opportunities. These diverse and productive research approaches will continue to drive the design of innovative pilot studies and full scale clinical trials that are most likely to yield effective strategies for preventing and treating AD.

It is difficult to predict the pace of science or to know with certainty what the future will bring. However, the progress we have already made will help us speed the pace of discovery, unravel the mysteries of AD's pathology, and develop safe, effective preventions and treatments, to the benefit of older Americans.

Thank you for giving me this opportunity to share with you our progress on Alzheimer's disease. I would be happy to answer any questions you may have.

Senator SPECTER. Thank you very much, Dr. Hodes. Before proceeding to the first round of questions, I would like to call two

members of the second panel. Mr. Sheldon Goldberg, if you will step forward, and also Dr. Marilyn Albert.

STATEMENT OF MARILYN A. ALBERT, Ph.D., DIRECTOR, DIVISION OF COGNITIVE NEUROSCIENCE, DEPARTMENT OF NEUROLOGY; CO-DIRECTOR OF THE ALZHEIMER'S DISEASE CENTER, JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE; AND CHAIR, MEDICAL AND SCIENTIFIC ADVISORY COMMITTEE, ALZHEIMER'S ASSOCIATION

Senator SPECTER. Dr. Albert is the director of the Division of Cognitive Neuroscience at the Department of Neurology, and co-director of the Alzheimer's Disease Center at the Johns Hopkins School of Medicine, and also the chair of the Medical and Scientific Advisory Committee of the Alzheimer's Association, receiving her doctorate from McGill University.

Thank you for joining us, Dr. Albert, and we look forward to your testimony.

Dr. ALBERT. It is a great pleasure to be here today, and thank you for inviting me back to talk to you about the progress and the promise of Alzheimer's disease research.

I've submitted in writing a document outlining five points related to strategy that we think will enable us to achieve effective treatments and prevention of Alzheimer's disease in the future, but in the short time that I have this morning I wanted to emphasize just a few points.

First, I wanted to say that I believe my colleagues and I in the scientific community in the United States and around the world really believe that we are at a crossroads with respect to the treatment of Alzheimer's disease. Because of previous investment in Alzheimer's disease research there is now a consensus about the mechanism of the underlying causes of the disease. Because of previous investment in research there is now the technological capability to attack the problem with a wide range of tools, and because of previous investment there is a cadre of clinical and basic scientists around the world who are willing to devote their careers to solving the problem.

If funding remains stable, which seems a real possibility, we believe that this will limit our ability to solve the problems that we see before us. As it now turns out, Alzheimer's disease is a much more complex problem than any of us ever anticipated, requiring novel approaches, and in particular what now seems to be clear is that there is a need for interdisciplinary, collaborative, large-scale efforts in solving several areas of problems, in addition to the funding that already exists, for providing funding to individual scientists and individual laboratories, and I would like to just give you a few brief examples.

The first has to do with the animal models that Dr. Hodes just referred to. As you know, we need good animal models to understand the disease better and to test prospective treatments, and it is clear that the animal models we have are not sufficient. We need to have better animal models. They need to be more widely available, because many are now protected by patents, and so limited in their distribution.

There has already been a consortium that has been developed with the Alzheimer's Association, several foundations and, in fact,

pharmaceutical companies in an effort to develop better animal models, to raise them, to distribute them, but it is clear that we need more funding for this effort.

With respect to the genetic studies that Dr. Hodes just mentioned, it is now clear that Alzheimer's disease is genetically very complex. As you heard, there are now four genes that have been identified with respect to Alzheimer's disease. We believe that there are at least an additional four to seven more to be found.

Years ago, when it was clear that this was a complex disease genetically, there was a consortium established of three medical centers. They created a database that was nationally available. There were 500 subjects in the database with clinical information and DNA, and it is now clear that that is not enough, so we need considerable more funding in this area.

With respect to clinical trials, as Dr. Hodes just mentioned, there are many promising agents available. The pharmaceutical companies, of course, are testing the drugs that they developed, but we need more testing of drugs that are under patent protection, and particularly with regard to prevention of Alzheimer's disease.

Finally, with respect to disease markers that Dr. Hodes just mentioned, it seems very clear that in order to be better in conducting the clinical trials that we need to conduct, we need better markers of disease and of disease progression.

The real fear right now among the scientists is that when we have effective treatments it might, in fact, take too long to find out that they are in our possession, that the standard methods that we have now for identifying improvement are not going to show us that there are changes that are really taking place, and that is why we need these new imaging methods and other biomarkers to better identify that we have effective treatments, and to monitor those treatments over time, and the imaging initiative that Dr. Hodes referred to is the method that we think will help the effort along, but of course it is very costly.

So from just these four examples, I think that you can see why so many of us believe that a collaborative, integrated, large-scale model of science is needed now, in addition to the usual effort that we are accustomed to of funding individual scientists and individual laboratories. I am sure you know that scientists tend to be individualists, so many of them have taken a long time to recognize that this is, in fact, what is needed, but recognize it they do, and as I have just mentioned, we are talking about a lot of money, $25 million for each clinical trial, $60 million for the imaging initiative.

PREPARED STATEMENT

I know, however, that this pales in comparison to the $60 billion that we spend on Medicare and Medicaid each year in taking care of Alzheimer patients, and I also know that if we have that money we could use it wisely, so we are asking you to increase the funding for Alzheimer's disease research. We are promising you that if you give it to us we will get the job done.

Thank you very much.

[The statement follows:]

PREPARED STATEMENT OF DR. MARILYN A. ALBERT

Thank you Senators Spector and Harkin for inviting me back to talk with you about the excitement and the promise of Alzheimer's research. Your consistent support of funding for Alzheimer research, and your endorsement of the $1 billion goal, is an indication of your own confidence in the Alzheimer research community. I am pleased to appear before you to report that your confidence is well placed.

Those of us in the scientific community who have been working on the problem of Alzheimer's disease for a long time are astounded at the extraordinary progress that has been made in the past two decades, and especially the tremendous leaps forward in just these past few years. That is the result of the investment you have already made and we thank you for your leadership and your persistence.

We know that you are under enormous budget pressures—with the economic slowdown, rising budget deficits, and the costs associated with the conflict in Iraq. We understand that Congress will have to make very hard choices among compelling needs and competing priorities. And, we understand that with the completion of the effort to double funding for the National Institutes of Health, requests for additional support for medical research will receive extra scrutiny.

Other witnesses this morning are providing compelling personal and economic evidence of the urgent need to find answers to Alzheimer's disease. I can tell you that the scientific reasons for investing more in Alzheimer research now are equally compelling. And I can assure you that every additional dollar you can direct to that research will be well spent as part of a carefully constructed strategy designed to get us to the answers faster, better, and in the long run, cheaper.

Our strategy for conquering Alzheimer's has shifted over the years and has become more ambitious, as we have learned more about the basic mechanisms of the disease and as new scientific tools like imaging and genetics have become available to us. We now think about Alzheimer's disease in three distinct stages.

When I started my work on Alzheimer's disease more than 20 years ago, and until fairly recently, we were focused on what we now consider to be the third stage—actual clinical dementia. At this point, the symptoms of Alzheimer's disease are clear and the disease is already taking its toll on the person's ability to function independently. Our goal at this stage is to treat those symptoms and slow decline, to help people live and function well in the community as long as possible. That is still part of our strategy. But it is probably not the way we are going to get the disease under control and avoid the huge costs to Medicare and Medicaid.

We now recognize that we need to attack Alzheimer's disease at much earlier stages, and we are pushing the science back to these stages now. There is middle prodromal stage, what some refer to as mild cognitive impairment, or "MCI." At this stage, there are early signs that the disease is evolving, but the patient does not meet clinical critieria for dementia. Our goal here is to slow the progression of the disease process—to postpone and hopefully to prevent full-blown Alzheimer's disease.

Ultimately, our goal is to reach back to an even earlier point—normal aging—to prevent the disease process from ever starting.

There are five critical components to this Alzheimer prevention strategy, all of which will require your additional financial support.

First, we have to maintain the pipeline of basic scientific discovery to develop the potential targets for treatment and prevention. At current funding levels, the NIH can support only about one in four qualified proposals that have been successfully peer-reviewed. It would take an additional $29 million for the National Institute on Aging to fund another 10 percent of the most promising proposals it receives.

Second, we need to develop better animal models of Alzheimer's that will more closely parallel the disease in humans. Right now, basic science is developing targets for potential treatment and prevention faster than we can possibly test them in full-scale clinical trials. Animal models allow us to screen for the most promising targets. It is expensive to develop and maintain these animal models and to put them in the hands of the general scientific community—it could take as much as $50 million to do that. But once the models are available, we will be able to test a potential new treatment at a fraction of the cost of human trials—a faster, cheaper way to narrow the targets for prevention and to speed effective drugs to market.

Third, we must test the most promising potential targets for prevention in large-scale clinical trials, in persons who are cognitively normal and in those in the prodromal stage. That is the only way to figure out whether early use of any of these compounds can have a protective effect. In the absence of a way to detect disease and follow its progress at these early stages, the only way to determine whether a compound works is to enroll large numbers of people in these trials and to follow them for a long enough period of time, three to five years, to see what happens.

Each of these prevention trials will cost $25 to $30 million, and we need to start them as rapidly as targets are identified.

The National Institute on Aging is leading efforts to try to find a way to do these prevention trials faster and at less cost. Which brings me to the fourth part of the strategy—the search for biomarkers that may allow us to see evidence of disease and to monitor its progress without having to wait for evidence from cognitive testing. That is the goal of NIA's proposed imaging initiative. It would serve two purposes: first, to find better treatments faster and second, to provide accurate earlier diagnosis. It is the first of these that holds the most immediate and exciting promise. In current prevention trials, we have to follow people for years until cognitive testing can demonstrate whether the compound being tested is actually having any preventive effect. If we can use imaging techniques to monitor changes in the brain that indicate progression of disease, then we will be able to determine whether a compound is having a preventive effect within a matter of months. This will substantially reduce the size, the length and the cost of prevention trials. And it will make an enormous difference in the speed with which companies can bring effective treatments to the market place—which is why they are so interested in partnering with NIA on this initiative. A second potential outcome of this imaging initiative will be development of effective techniques that will allow accurate early diagnosis of Alzheimer's so that, once we have effective preventions, they can be started in patients who need them soon enough to make a difference. The imaging initiative will cost an estimated $60 million. While NIA is working hard to enlist industry as investors in this initiative, it will take additional funds from Congress to implement it fully.

Fifth, we need to identify additional risk factors for Alzheimer's so that once we find the compounds that will work to prevent disease, we can target them to those who need and will benefit from them. We are now quite certain that Alzheimer's disease is caused by some combination of genetic and environmental risk factors. We have discovered some of those genetic risk factors, but there are undoubtedly more. NIA has developed a ground-breaking genetics initiative that is designed to speed the search for the remaining genes by creating a central pool of data and tissue that would be widely available to investigators in both academic and industry settings. The infrastructure for that initiative is in place and the Alzheimer's Association is working closely with NIA both to recruit families to participate in the initiative and to assure that issues of privacy and informed consent are fully met. The full cost of that initiative is estimated at $60 million.

This genetics initiative is just the latest chapter in the unique story of collaboration and cooperation that NIA has written.

—Through the Alzheimer's Disease Centers, NIA has brought researchers together across disciplines to bring their multiple lines of scientific inquiry together to tackle Alzheimer's disease.

—Through mechanisms like the Alzheimer's Disease Cooperative Study and the Alzheimer's Research Coordinating Center, NIA has encouraged, prodded, and occasionally compelled scientists to collaborate among laboratories and academic institutions—so that today, sharing of data and information and collaboration have become the standard way of doing business in the Alzheimer research community.

—Under Dr. Hodes' leadership, NIA has fostered cooperation and collaboration on Alzheimer research across institutes at NIH.

—And for more than 20 years, the Alzheimer's Association and the NIA have collaborated to maximize our public and private resources to attract new scientists to the field of Alzheimer research, to encourage novel lines of inquiry, and to bring researchers from academic institutions and industry together to develop strategies to move the entire field forward.

This unprecedented collaboration is the unsung story of Alzheimer research—and it should be a model for the future of all scientific research. You can be assured that any money you appropriate for Alzheimer research will be spent wisely, efficiently, and effectively.

$25 million, $29 million, $50 million, $60 million. Senators, these are big numbers and they come on top of the estimated $650 million that NIH is already spending on Alzheimer research. But they pale in comparison with the $50 billion that Medicare and Medicaid are already spending on this disease. With an additional $200 million this year, and a total $1 billion commitment as soon as possible, we have a very good shot at reversing the course of Alzheimer's disease before it is too late to save Medicare and Medicaid and the 14 million baby boomers who are at risk.

Senator SPECTER. Thank you very much, Dr. Albert. I think Senator Harkin may have heard the complimentary comments I was

making about him and rushed down so that I would not change any of my statements, but I said before you arrived, Senator Harkin, about our collaboration over the years, the seamless change of the gavel, knowing that if you want to get something done in Washington you have to cross party lines, and I now yield to you.

OPENING STATEMENT OF SENATOR TOM HARKIN

Senator HARKIN. Senator Specter, thank you very much, and I return the compliments. This is the fourth year in a row that we have had a specific hearing on Alzheimer's. I have chaired it, and Senator Specter has chaired it, which again is illustrative of what Senator Specter said. When it comes to these issues, health issues, and when it comes to Alzheimer's research in particular, there are no party lines around here. We are all in this together, and I just want to thank my chairman and my good friend Arlen Specter for all of his diligent work and his leadership in leading this subcommittee on appropriations and leading the obligations we have across a broad spectrum of health research in this country. But I can tell you from my own personal conversations with Senator Specter to all of you in this room, there is nothing that concerns him more, and to which he has dedicated more time and effort, than his focus on getting at the root causes of Alzheimer's, to making sure we fund this program, and to make sure we move ahead very aggressively in finding those early markers that you were talking about and those early stages so that we can have early interventions, and hopefully at some point reach some form of a preventive measure to cover everyone in this country.

The clock is ticking right now. Maybe someone mentioned this. There may be 4 million people now with Alzheimer's, costing our economy $100 billion a year. By 2050 they tell me there could be as many as 14 million Americans with Alzheimer's, costing us over $375 billion a year. If we could just delay the onset of Alzheimer's by 5 years we would save over $50 billion a year.

So again, that argues for us to really make sure that we fund this larger clinical trials and get on with it. Again, I talk about the money, but that does not begin to describe the emotional and physical toll that this disease takes on families and loved ones all over the country.

So I want to thank all of you who are here with the Alzheimer's Association, your Capitol Hill Day, please do your best in getting to the offices here in the Senate and in the House of Representatives to make sure that your story gets out, and to make sure that we get the kind of support that we are going to need later on, because we are just two, three, four, five on this committee. We need broad help from the House and the Senate in order to get through our funding, to make sure we get the amount of money we need to really tackle this job.

So again, Mr. Chairman, I thank you for your leadership. I thank you for being here. Dr. Hodes, thank you for your great leadership at the Institute of Aging, and thank you all for being here. I do not want to go on too long. I have got people standing there. We want to get you out of here and get you to the offices so you can do your job today convincing Senators and Congressmen to support our budget.

Senator SPECTER. Thank you very much, Senator Harkin. We do have quite a few people standing. There are some seats on the front row, and you are welcome to come and sit with the Senators. You will not get to question, though.

But there are empty seats, and you are welcome to take them.

Senator HARKIN. Mr. Chairman, I am sorry. I was remiss, I wanted to recognize Dwayne and Mary Jean Uptegraph from Dubuque, who took the time to travel, and they are testifying here later on, and I wanted to just recognize and thank them and other Iowans who are here today.

Senator SPECTER. Thank you, Senator Harkin.

STATEMENT OF SHELDON GOLDBERG, PRESIDENT AND CEO, ALZHEIMER'S ASSOCIATION

Senator SPECTER. We now turn to Mr. Sheldon Goldberg, who joined the Alzheimer's Association as president and chief executive officer on December 1 of last year. Previously, he was president and CEO of the Jewish Home and Hospital in New York. He holds a bachelor of science degree in educational psychology from the University of Wisconsin. Thank you for joining us, Mr. Goldberg, and the floor is yours.

Mr. GOLDBERG. Thank you very much, Senator. I am honored and it's a delight for me to appear before this committee and to join both you, Senator Specter and Senator Harkin in the long fight that you have had with this horrible disease, and to express our appreciation, and it is my honor to join you in that fight.

I have spent most of my career involved with long-term care, providing health care for people who suffer from this disease, and it is an honor to get on the other side of this issue to advocate for its eradication, to do the research and advocate for the services that are so critically needed. You have provided this leadership, and we have brought a number of our people from around the country to participate in this hearing and we thank you for that, as well as to persuade the Congress, to persuade the President, and persuade the American people that this is a fight and it is an issue that needs to be conquered, and that it is an urgent national priority.

Many are here to join me, and many will go about the business of helping to convey and convey a very compelling story about the need for research and eradication of this disease, and many will share their stories with you today, but there are millions of people across this country who have stories to tell that are heartfelt stories, who suffer from this disease.

Their stories are compelling in themselves in terms of going after this disease, of trying to aggressively cure, or treat, or finally eradicate this disease, but my approach is slightly different. I want to speak to you about the economic, the practical, the political reasons why we need to attack this disease, and why we need to eradicate this disease now.

Congress is confronted with budget deficits, and I do not envy you all the tough decisions you have to make, but one of the major areas you have to confront is the areas of Medicare and Medicaid, and very simply you will not be able to solve the issues surrounding Medicare and Medicaid unless we resolve the issues and

the uncertainty around Alzheimer's disease. That is the essence of my presentation and my point.

We will not solve the problem with Medicare and Medicaid until we solve and eradicate this disease. We will not be able to balance the Federal budget, especially when it comes to health care, especially in the future until we come to the conclusion that we need to eradicate and do something about this horrible disease.

Now, it is interesting, I want to just provide a few bits of information if I can. Literally, I believe Alzheimer's disease is driving the Medicare cost. For an individual who suffers from Alzheimer's disease, it costs three times as much money to provide Medicare services for that individual, and simply looking at the cost that will increase over the next 10 years, we are looking at at least a 55 percent increase just for those individuals who suffer from Alzheimer's disease.

I would note that us baby boomers have not arrived at the age to get Medicare benefits at that point, and at that moment it begins to take off. It does not take much to imagine, when the baby boomers arrive and suffer from this disease, if it is not eradicated, there are supposed to be 14 million baby boomers who suffer from this disease. It is almost a four times, 400 percent increase in the level of needs and the level of cost to meet their needs.

Medicaid is just as grim. At both the Federal and the State level, and I know you receive tremendous pressure. My background is representing the nursing home industry and long term care in this country. Prior to coming to this position I ran the largest and the oldest long term care system in this country serving literally tens of thousands in New York City, and I have to tell you our institutions and our services were filled. At least 60 percent of the people were there suffering from Alzheimer's disease, and it is literally the issues that are driving the system.

I cannot tell you how it bankrupts families. Everyone strives to keep their loved ones at home. They try to do the best they can and get the best resources they can, and literally families do go bankrupt from this disease, but I also have to tell you that they are bankrupting the Medicaid system, and if you simply look over the next 10 years, the numbers, we will be looking at an 80-percent increase just for Alzheimer's disease, for people who suffer from this disease in the Medicaid program.

If I were a Governor and I was appearing before this committee, I would be demanding funds for research to have launched an assault on this disease, because Medicaid programs are driving the State budgets across this country. We need to find the cure and eradicate this disease.

If I was a corporate CEO coming from one of our Fortune 500 companies in this country, I would be asking for research dollars, because simply it is one of the largest areas of productivity decreases because of individuals who have to meet family members' needs across this country. It is estimated it costs corporations $61 billion a year in just lost productivity because of the needs for Alzheimer's patients.

So there is much to be done. Now, there is a game plan, and they are able to present the game plan to the committee. Some of it goes in terms of how we modify the Medicare program to focus more on

a chronic care benefit. That will help somewhat, but it is not going to solve the problem. The problem will not go away. It may provide some minimal or modest relief.

Research we believe is the only answer, and is the only way of getting control of Medicare and Medicaid costs, and this is why we are calling on the Congress and asking for your assistance for approximately $200 million additional research dollars to continue the research that started and take on additionally critical cases and critical issues of research that have to go on. Now, I am not a scientist, but I understand the only solution to finding a solution to Alzheimer's disease is going to come through science.

Now, let me end, if I can, we know some things about Alzheimer's, and I am learning much more, that if you are going to get, you or I, Alzheimer's disease, the disease starts long before the manifestation of symptoms. It starts 10 years, maybe 20 years beforehand, and if you as Senators or I as an individual is destined to get Alzheimer's disease, it is vitally important that these changes that are going on in our brains at this time before we see the symptoms, it is vitally important we initiate the research to find the solutions to these problems.

PREPARED STATEMENT

I cannot tell you how honored I am to come before you. I cannot express the deepest appreciation we hold for you for your commitment to helping us eradicate this disease, and I can only speak for the people who across this country suffer from the disease and the many who fear it, and thank you very much for your support and your responsiveness.

[The statement follows:]

PREPARED STATEMENT OF SHELDON GOLDBERG

I am delighted to be back before Congress this morning in my new role as CEO and President of the Alzheimer's Association. My entire career has been in long term health care, but this is the most important job I have ever held. Senator Spector and Senator Harkin, you have been leaders for many years in the fight against Alzheimer's disease—it is an honor for me to join you.

Two years ago, you put the Senate on record in support of $1 billion for Alzheimer research, and thanks to your leadership, we are almost two-thirds of the way to that goal. The Alzheimer's Association is committed to helping you get the rest of the way—to reach that goal as rapidly as possible. Today's hearing is just the beginning of our redoubled effort to persuade Congress, the President, and the American people that the fight to conquer Alzheimer's disease must be an urgent national priority.

Sitting behind me in this room today are hundreds of women and men with heart wrenching stories of the devastating personal impact of Alzheimer's disease. They are people who have Alzheimer's, their families, and their care partners. You will hear from some of them this morning. The rest will leave here to go tell their stories to your colleagues, their own representatives in Congress. There are tens of thousands more like them, across the country, who will be following up with Congress in the weeks and months ahead.

These personal stories are compelling and should be sufficient cause for Congress to act, immediately and aggressively. But there are also very practical political and budgetary reasons for an all out assault on Alzheimer's now—and that is what I want to discuss with you.

This is a Congress that must confront growing budget deficits and a looming crisis in Medicare and Medicaid. My message is simple. You will not—you cannot—save Medicare and Medicaid unless you get Alzheimer's disease under control. You will not—you cannot—balance federal and state budgets if you let Alzheimer's disease continue on its present course.

Let me paint the picture for you.

THE COST OF ALZHEIMER'S DISEASE IS UNSUSTAINABLE

Alzheimer's disease is already driving up Medicare costs. The program pays 3 times more for basic health care for persons with dementia than it pays for other beneficiaries. That holds true across age groups and medical conditions. Within 10 years, annual Medicare costs for beneficiaries with Alzheimer's will increase by 55 percent—from $32 billion to almost $50 billion. And that is before the baby boomers enter the age of risk. Imagine what will happen to Medicare when 14 million baby boomers have Alzheimer's disease.

The outlook for Medicaid is just as grim. For 16 years, I represented long term care providers here in Washington. More recently, I ran one of the oldest and largest long term health care systems in the country. I can tell you that these systems are already full of people with Alzheimer's disease. Nearly 60 percent of residents of our nursing homes—and perhaps as many in assisted living—have dementia. They are already straining capacity to the breaking point.

We need to work as hard as we can to provide more options for people to stay at home with their families as long as they can. But eventually most people with Alzheimer's disease will need full time care that is beyond the ability of families to manage on their own. If we let 14 million babyboomers get to that point in Alzheimer's disease, we will be building nursing homes on virtually every street corner in America.

The cost of that long term will bankrupt families first. And then it will bankrupt Medicaid. Within 10 years, Medicaid's share of the annual nursing home bill for people with Alzheimer's will increase by 80 percent—from $18 billion to $33 billion. If I were a Governor, I would be beating down the doors of Congress demanding the funds for an all-out assault on Alzheimer's disease.

If I were a corporate CEO, I would be here urging you to act, because Alzheimer's disease is extracting heavy costs from American business as well. In 2002, that cost was $61 billion—the majority of it the result of lost productivity of workers caring for people with the disease. That was the equivalent of the profits in 2002 of the top 10 Fortune 500 companies. And it was almost twice as much as the 1998 estimate of a $33 billion cost to business.

THERE IS A CLEAR GAME PLAN TO CONQUER ALZHEIMER'S DISEASE

We still have time to mount a successful offensive against Alzheimer's disease. The Alzheimer's Association has laid out a clear game plan in this National Program to Conquer Alzheimer's Disease, which I would like to offer for the record.

Part of that game plan calls for changes in Medicare to focus a chronic care benefit that will keep people out of hospitals, emergency rooms, and nursing homes. This will help hold down increases in Medicare and Medicaid costs somewhat, and we are discussing this with the appropriate Committees of jurisdiction. But the only real way to save Medicare and Medicaid, and to get health care spending under control, is by reducing the numbers of people who need expensive care—and that will come only through research.

That is why we are calling on Congress to provide an immediate increase in appropriations for Alzheimer research of at least $200 million. With such an increase, Dr. Hodes and his colleagues at the National Institutes of Health will have the resources they need to maintain the momentum of Alzheimer research—to find effective ways to prevent and treat Alzheimer's disease while there is still time to make a difference. That level of funding will keep research flowing rapidly through the pipeline from basic science through clinical trials. It will also provide funds for the imaging and genetics initiatives that will get us to prevention and treatments faster, better, and in the long run, cheaper.

Dr. Hodes and Dr. Albert are here to explain the science to you. I want to underscore the cost. Each new clinical trial of a potential prevention will cost at least $25 million—but those trials are the only way to get discoveries out of the lab and into the practice of medicine. The imaging and genetics initiatives will each cost an estimated $60 million. It will take another $29 million to fund just 10 percent more of the most promising peer reviewed investigator initiated projects. The National Institute on Aging is aggressively recruiting private industry as full collaborators, and the Alzheimer's Association will commit all of the funds we can. But there is no way to solve the puzzle of Alzheimer's disease without the leadership, the influence, and the resources of the federal government, through the National Institutes of Health.

THIS IS A RACE AGAINST TIME

Budget procedures and politics encourage Congress to think one or two years at a time. So why the rush about Alzheimer's, some might ask? If the real explosion of people with the disease is still at least 10 years away, can't we put this off for a while and focus on other urgent priorities now?

Wrong! We know now that the damage to the brain that causes Alzheimer's starts 10, maybe 20, years before clinical symptoms appear. That means, Senators, that if you or I or any of your colleagues is destined to get Alzheimer's, something is already going on in our brains. The disease is already at work. That means we have to find the answers now. Ten years from now, it may be too late to save another generation. Ten years from now, it may be too late to save our health care system.

Our nation is facing huge challenges today—rising budget deficits, the war in Iraq, continued threats to our homeland security. We understand that this is a time when Congress has to make tough choices and set clear priorities. It is a time that demands personal sacrifice and postponed agendas.

It is also a time that requires leadership—leadership to make sure that we confront our most urgent domestic problems. In his State of the Union message, President Bush issued a challenge to Congress and the nation:

"We will not deny, we will not ignore, we will not pass along our problems to other congresses, to other presidents and to other generations . . ." he said.

Yet that is exactly what we will do if we do not find a way to stop Alzheimer's disease now. If we fail, then our health care system will implode, and Alzheimer's will be the detonator. We pay now, or we leave other congresses, other presidents, other generations to pay much more later.

Senator SPECTER. We will now begin the rounds of Senators' questioning, 5 minutes.

Dr. Hodes, you have emphasized in both your written and oral testimony the impact of stem cell research. Focusing for just a minute on nuclear transplantation, which is the effort to be sure that the donor receives stem cells which are consistent with his own DNA, to what extent is that experimentation important on conquering Alzheimer's?

Dr. HODES. Well, I think at this point, until experiments are done in additional related areas we do not know the final answer. The point you make is an important one, that it may be critical to derive a source of stem cells that are genetically identical to the individual being treated and, as we know, there are a number of potential sources for that.

One of them is adult stem cells which show certain potential for differentiation. We do not know, as yet, whether this will completely satisfy all the requirements, ultimately, for optimal intervention or not. An alternative is to use a technique such as nuclear transplantation to generate such cells from each individual, and until we have experimented with the alternative approaches, we do not know which will be successful, we do not know which will be preferable.

Senator SPECTER. But you want to maintain the open door for experimentation with all the available alternatives.

Dr. HODES. I think that the more alternatives we are able to pursue, the greater the probability of our finding a successful strategy.

Senator SPECTER. Dr. Albert, you make a comment about patents impeding research. Protection of patents is obviously important for those who invest substantial money, but I am concerned about patents impeding research, and the thought goes through my mind that it is contrary to public policy to have property interests which are impeding research where people with those patents are not cooperative, especially with NIH, or really with others, on a research

line in some way where profits could be protected, investment property interests could be protected.

Do you have any suggestion as to what might be done to facilitate research and still respect patent interests?

Dr. ALBERT. The animal model consortium that I mentioned is one way in which we can go about this. This represents a group of individuals from foundations, from the Alzheimer's Association, from the pharmaceutical companies who have formed a company, and the company is the one that is going to underwrite the development of these animal models.

Senator SPECTER. Are there some patent holders who are recalcitrant and unwilling to enter into cooperative ventures to promote research?

Dr. ALBERT. I think it is more related to the institutions that they are at. In some ways, these were problems that we did not foresee a few years ago, and when some of the animal models were developed the patents were obtained by their institutions and they feel very strongly about not releasing them.

Senator SPECTER. I would appreciate—and I do not mean to interrupt you, but I want to cover some questions, and each of us is limited to 5 minutes, including the chairman, and I intend to observe the rules meticulously. I would appreciate it if you would supplement your oral testimony by particularizing what is happening in the patent field and where we ought to look further. Congress can legislate on this subject, and we want to respect property interests, but we also do not want research to be impeded, so if you would supplement your oral testimony, we would appreciate that, because we would like to clear the way for this important research.

Dr. ALBERT. I would be happy to do that, Senator.

[The information follows:]

Question. How do patents get in the way of research on Alzheimer's disease?

Answer. The patent process is an important motivator for the development of new products and treatments for Alzheimer's disease. That is not what we are talking about here. The real issue is whether patents or other mechanisms prevent access by researchers to the fundamental knowledge necessary to advance our understanding of Alzheimer's disease. For example, when animal models or tissue samples containing genetic information are protected by intellectual property rights or subject to complicated material transfer agreements, the material may be available to other researchers only at prohibitive cost that drives up the cost of research and delays discovery.

Progress in Alzheimer's disease demands the rapid and unimpeded transfer of information and research tools among investigators and institutions. The National Institute on Aging has led efforts to stimulate and encourage cooperation, collaboration, and sharing among researchers and academic centers that has become the standard for Alzheimer research and a model for the larger scientific community. Here are two examples of efforts now in the early stages of implementation that are designed to assure that key information and research tools are broadly available to the Alzheimer research community without patents, claims of intellectual property rights or other mechanisms that would restrict or delay access.

The first is the Genetics Initiative now underway under the leadership of NIA. We are quite certain that there are a number of genes implicated in Alzheimer's disease that have yet to be identified. The goal of this initiative is to identify the remaining risk factor genes, associated environmental factors, and the interactions of genes and the environment. Finding those genes requires large numbers of samples for genetic analysis, more than can be collected at any one research site. The NIA has established and is funding a National Cell Repository for Alzheimer's Disease and has awarded grants to at least seven academic centers to recruit families, collect clinical data and blood samples, and provide DNA and cell lines along with phenotypic data to the Cell Repository. No intellectual property rights will attach to any of the data and tissue collected. These sample sets will be freely available

to qualified researchers and will serve as the "gold standard" against which researchers could test their findings. The full cost of this Genetics Initiative is estimated at $60 million and will require additional support from Congress.

A second area of interest is the development of animal models—key to speeding the search for effective clinical treatments. Basic science and results from epidemiological studies are identifying many candidates for potential treatments—more than we can afford to study in large scale human trials. A single prevention trial in humans takes at least 3 to 5 years and easily costs $25 to $30 million. By developing more effective animal models of Alzheimer's disease, it will be possible to test potential treatments faster and to identify the most promising candidates for human trials. All of that will get us to treatments faster, better, and cheaper. This strategy involves more, though, than just the development of animal models. It requires that the models, once developed, be broadly available to the Alzheimer research community. In the past, Material Transfer Agreements established by academic institutions where animal models originated have created administrative and financial barriers to broad utilization. The Alzheimer's Association is embarked on a very significant effort, with other private non-profit and industry interests, to establish a non-profit organization that is serving as a catalyst to bring together investigators working on animal models and to stimulate and support development of new models that would be freely available to the research community. This effort is undertaken in close coordination with the NIA. While the partners in this new organization will commit their own resources to support animal model research, it will take additional resources from Congress to the NIH to realize fully and rapidly the potential of this critical area of research.

Senator SPECTER. Mr. Goldberg, you make a comment about Medicare and Medicaid being key expenditures, which I agree with you about. What I would like you to do—you have asked for $200 million more in research. I would like you to supplement your oral testimony by giving us a projection as to what $200 million more would do by way of solving the Alzheimer's problem and how that would impact on Medicare and Medicaid expenditures. Now, that is very frequently an incentive for Congress to do things if you can save money at the end of the rainbow, and there is certainly a bigger avenue for saving.

[The information follows:]

Question. How soon will we have a cure for Alzheimer's Disease?

Answer. The target of Alzheimer research is not so much a "cure" but rather effective prevention and treatments that can delay onset and progression of the disease. Those are targets that most scientists believe are well within reach within the next 10 years if we maintain the current momentum of Alzheimer research. Of particular note is the very exciting work now underway to test, in clinical trials, the amyloid hypothesis of Alzheimer's disease. This includes the well publicized trial of a potential vaccine against the production of amyloid—a trial that is still underway as investigators are working to modulate the adverse effects of the first configuration of the vaccine. The trials are already showing promising signs of the production of antibodies to amyloid and of the actual reduction in the formation of amyloid plaques. Another important trial is underway, testing inhibitors of the enzymes that make amyloid—the toxin in the brain that causes cell death.

Other promising work continues on a wide range of compounds testing theories of inflammation, hormones, and cardiovascular risk factors as factors in the development and progression of Alzheimer's disease. All of this work is made possible by the continued advance in basic science funded by NIH.

Scientists have modeled the impact of the two most likely products of this current research—the first, a compound that would delay onset of Alzheimer's for an average of 6.7 years; the second, a compound that would delay progression from mild to moderate/severe disease. (Right now, progression occurs at a rate of 28 percent annually; this model would slow progression to an annual rate of 10 percent.)

If we can accomplish these dual objectives, then under this model, by 2050 we would see a nearly 36 percent reduction in the total number of cases of Alzheimer's disease. But of even greater significance—both for quality of life and cost to the health care system—the majority of cases—56 percent—would be mild Alzheimer's disease. This compares with current projections that, without such treatments, 63 percent of cases would be moderate to severe and require full time care.

Question. If we provide an additional $200 million for Alzheimer research, how much can we save Medicare?

Answer. The real cost of Alzheimer's disease to Medicare comes when dementia is overlaid on other common comorbid conditions among the elderly. For Medicare beneficiaries at any age, costs are three times higher among those who have cognitive impairments. But the difference in cost is most dramatic among those in the younger (65–74) age group—4.2 times higher. As shown in the answer to the previous question, development of effective treatments to prevent onset and delay progression of Alzheimer's disease will significantly reduce the numbers with the disease and, of those who have the disease, the percentage with moderate to severe dementia. If we can accomplish this, then we may be able to reduce the adverse impact of dementia on the cost of treatment of other medical conditions.

Senator SPECTER. A final question for you, Dr. Hodes. To the extent that you can specify, how close are we to a cure for Alzheimer's?

For $663 million, ladies and gentlemen. I think that is a fair question.

Dr. HODES. And the fairest answer I can give, Senator, is that we are a good bit closer than we were only a short time ago. I do not mean to be difficult in not responding, but the ability to answer with precision just when we will arrive at a final solution is elusive. The course of science and the complexity of the disease makes it impossible to know, but as Dr. Albert has expressed, the overwhelming consensus in the field, in the research field, which I certainly share, is that the pace of progress over these past years has been dramatic. It is bringing us closer than any of us dared hope we would be only a few years ago.

Senator SPECTER. My red light is on, so I will not ask any further questions, but to the extent the three of you could give us a projection on when we might cure Alzheimer's—and I know you cannot give us an absolute date, subject to increases in funding, that could motivate additional funding from the Congress.

Senator Harkin.

Senator HARKIN. Thank you, Mr. Chairman.

Dr. Albert, you spoke about the, now we know there is three different stages. At least you have broken it down into basically three different stages, and Dr. Hodes, you said that NIH is now supporting 18 clinical trials on Alzheimer's, seven of which are large-scale prevention trials. How long have these large-scale prevention trials been going on, and do you have any preliminary data from those that you might at least tell people they might do to prevent it now?

Now, for example, a lot of people are doing things like, they are taking statins, ibuprofen, ginko biloba, vitamin E, doing daily crossword puzzles, all kinds of things that people are doing now to try to ward off dementia. Have you gotten anything from these trials yet that you could tell what people might want to think about doing that at least would not be harmful to them and might be helpful?

Dr. HODES. As I mentioned, Senator, the prevention trials really began less than 5 years ago, and by their nature will take in general 5 to 7 years to complete, so we do not have results from any of them as yet. There is as yet no positive result demonstrating conclusively the ability of any of the interventions which you mentioned which are under study to delay or prevent the development of disease.

The very important question that you bring up concerning things which people ought to do because they help but cannot do any harm is a very important and reasonable question but a very difficult one to answer until research is completed. As long as we do not know the outcome of these trials, not only do we not know whether they will be successful, we also cannot be certain that they will not actually have adverse effects, and I think we have learned some disappointing lessons in that regard. For example, from the very widely publicized results of the women's health initiative, researchers are looking at the complexity of hormone replacement.

So we would project by the nature and timing of the studies that over the next 3 to 4 years we will begin to see results from some of these prevention trials and whether they are effective or not. From that point, we will be able to plan subsequent studies in that direction.

Senator HARKIN. Have you done any kind of investigations into families where maybe one person had come down with Alzheimer's but a sibling had not, or a couple of siblings had not, and looked at variations in diet, how they lived, what they did, that type of thing? Have you looked at anything like that?

Dr. HODES. Yes. That is a very important kind of study to be done, to try to dissect both the genetic and the environmental risk factors for Alzheimer's disease, and family studies of this kind have been carried out. Some have led to the identification of genetic risk factors, others have shown environmental correlates or risk factors based on epidemiologic studies, and you have alluded to some of them. We do know that in general individuals who have more education are less likely to have disease and that individuals who have a history of certain drug exposures are less likely to have disease. We know that individuals with a history of head trauma are more likely to have disease. These are providing, then, clues as to the kinds of clinical trials and studies that can be done to see whether any of these correlations actually translate into true cause-and-effect relationships, and that can be done most conclusively only by clinical trials.

Senator HARKIN. I want to join with the chairman and just say that if you could give us a better idea of what that extra $200 million you are asking for will specifically go for, and how it might help shorten the time frame to find some of these answers, that would be very helpful.

Dr. HODES. Absolutely. Just to elaborate briefly on some of the questions and agents you have mentioned, in terms of diet, we know recently that risk factors for Alzheimer's disease include such things as high levels of homocysteine, untreated high levels of cholesterol. We know that there are drugs such as the statins, or folic acid and B-vitamins, that can correct these abnormal blood values.

We know they have been studied rather extensively, for example, for the cardiovascular risk factors which they present, and studies which are now being initiated will similarly ask whether those very same interventions can delay onset and/or treat people already with symptoms.

Senator HARKIN. Thank you, Dr. Hodes. Thank you, Mr. Chairman.

Senator SPECTER. Thank you very much, Senator Harkin. Senator Craig.

Senator CRAIG. Well, to all of you, thank you very much. You bring us valuable information, and you make the case so dramatically well, and that is important for all of us to understand.

Dr. Albert, talk to me about the kind of teaming you see that needs to come about that does not necessarily come about in an individualized community of interest. How do you accomplish that, and what do you expect it to yield?

Dr. ALBERT. I think we already have examples of how to accomplish it, because in some respects the National Institute on Aging has established the infrastructure for this, so for example, for clinical trials there is a large infrastructure that involves 20 to 30 centers around the country that are collaborating on an individual clinical trial. It involves neurologists, psychiatrists, statisticians, neuropsychologists, and what makes it so costly is that it is very difficult to work across disciplines. You have to learn the language of the other person and, of course, just meeting and coordinating everything is very time-consuming and costly.

It is clear that it is paying off, because the little that we do know about how to more effectively treat Alzheimer's disease comes from such clinical trials where there is this kind of integration, and that is the model that we are hoping for for the imaging initiative that both Dr. Hodes and I mentioned whereby radiologists and neurologists and statisticians and experts in just image acquisition would all work together and would share a common database, collect information collaboratively and then analyze it collaboratively.

The unique aspect to that is that the plan is to have it be funded both jointly by industry and government, and so the pharmaceutical companies are also involved in helping to plan it so that they can get the kind of data that they think they most dearly need in order to evaluate drugs.

Senator CRAIG. That only comes with increased dollars, or can you now and are you now doing that?

Dr. ALBERT. It absolutely requires increased dollars. The estimated cost for the imaging initiative alone is $60 million, and my guess is that that is an underestimate, because we are talking about 20 to 30 centers around the country. We are talking about acquiring sophisticated imaging data on a large number of people, figuring out how to do it in a standardized way, evaluating it collaboratively across sites, so it is going to be very costly.

Senator CRAIG. Thank you.

Mr. Goldberg, your dramatic analysis of the impact on Medicare and, of course, Medicaid and States is real in all regards. I am spending a good deal of time looking at Medicaid now and prescription drugs, and how we adjust it to a dynamic health care system of the kind that we are obviously into, and one that is demonstrated by what you are here doing, and asking for today and doing.

We are driving health care costs dramatically because we now can approach so many other things that we were unable to do. I had Alan Greenspan recently before the Committee on Aging simply because he looks at global aging as an impact on our culture, and cultures around the country, and he said, Social Security is

easy to fix. It is relatively static and adjustable. Medicare is impossible for you to fix because you are trying to deal with a very dynamic industry.

Now, having said that, your appeal is important, and obviously to arrive at a cure or a managed environment to disallow the impact of Alzheimer's on our more senior community would help a great deal, but I am also struck with the reality of trying to deal with other dynamics in that.

If we only took those who are currently in Medicare and could discipline them to manage their health in a way, and I am talking about those with chronic illnesses, managed chronic illnesses, or those that can be managed and sustained and project life, we would reduce the cost of Medicare today by nearly 50 percent, and we could give them all of their health care free if they would comply simply with the protocol. We cannot do that. People won't do that. It is part of Senator Harkin's and my frustration about nutrition and health care and all of those kinds of things.

I mean, there are some very interesting dynamics out there, but you do put your finger on an important one, and we are driving toward that. You are competing with a lot of other interests. We will do the best we can, but the reality of trying to adjust this payment system, if you will, to this very dynamic health care economy is one that I do not think we are up to the task as of yet because we cannot shape it in a way that we can control the cost, and that is something that Congress asked us to do.

Thank you. Thank you, Mr. Chairman.

Senator SPECTER. Thank you very much, Senator Craig.

Senator Murray.

OPENING STATEMENT OF SENATOR PATTY MURRAY

Senator MURRAY. Thank you, Mr. Chairman, and thank you to you and Senator Harkin for your tremendous bipartisan work on funding research at NIH. It has made a tremendous difference, and I really appreciate your having this hearing and your continued advocacy for that.

I would like to thank everyone who is here today to remind all of us with all of what is going on in the world today there are people who are dealing with this serious illness in their families every single day, and how important it is for us to continue to fund the research.

I did want to ask the panelists, because all of you have mentioned genetic work on this, and one of the most promising breakthroughs in understanding the disease and seeking treatment options has been the discovery of a possible genetic link that could lead to early diagnosis and treatment, but I am concerned that the development of genetic testing could be hindered by a lack of protection against discrimination in employment and insurance.

If an employer knows that a worker could be predisposed to Alzheimer's disease they could use that information to deny future employment or advances or exclude them for insurance coverage, and we are going to be marking up a tough bill on genetic discrimination in the Health, Education and Labor Committee sometime here in the near future, and I wondered if any of you wanted to com-

ment on how important genetic nondiscrimination legislation is for your research.

Dr. ALBERT. Well, there is no question that everybody who is involved with genetic research is very concerned about confidentiality. At all the medical centers that I know there are special consent forms that need to be signed if anyone is in a genetic study that is separate from the consent form for the rest of the study.

We lay out for individuals how concerned we are about confidentiality, and how careful we are, but we also point out to them that right now there are concerns that there would be discrimination in the workplace, and we are very grateful for the legislation that you are proposing.

Senator MURRAY. Dr. Hodes.

Dr. HODES. I would certainly reinforce what Dr. Albert has said. In particular with genetic disease, the issues of even informed consent take on a special meaning in that a given individual may consent to studies regarding his or her own genetics, but family members who may not be giving their own consent, are in the end unavoidably affected by the informed consent of any other family member. So in the end, I think it is only the kind of legal protection that you are working so hard to develop that really can be functional and will go beyond the ability of any single individual to make a decision about his or her own confidentiality.

Senator MURRAY. Well, I hope we get your help and support in getting that through. It has been a long road, but I think it needs to be done, so I appreciate that. We have had a lot of conversation today about the amount of money needed for research, and Mr. Goldberg was very clear that we need to find an answer to this disease because of the cost on Medicare and Medicaid, but at the same time there are thousands if not millions of families who are dealing with it every single day.

Alzheimer's is not a disease that just affects one person. It affects everyone around them and their ability to be able to be productive in their own lives, and Senator Mikulski, who is the ranking member on the Aging Subcommittee of the HELP Committee, has been really working hard to expand efforts on family caregiver support as part of the Older Americans Act, and I wanted to, just because I think it is so important, if you would comment on how important these kinds of services are to patients and families, and is there anything else we should be doing to help support families?

Mr. GOLDBERG. Maybe I could comment. I think there is a tremendous amount of things that could help support families. We have a plan, obviously, to look at the Medicare program and to provide as much support to provide services in the community and in the home. Much of our programs of funding are really much more geared towards hospitals and nursing homes and other types of institutional environments. We need to structure everything possible to keep people as independent in their own homes as long as possible. The act of providing care on the caregiver is an exhausting task, so anything that can be created to provide relief, some respite care, fund day care programs, alternative types of services to people is vitally, vitally important, and so we would urge you, everything you can possibly do to do this.

My issue with the issues of Medicare and Medicaid is that I believe, I as a provider, that it is Alzheimer's which is driving the cost, especially for long term care. Our institutions are filled with people who suffer from Alzheimer's. Many people with multiple chronic disabilities remain in their own home much easier, but once the Alzheimer's really reaches a severe stage, they really lose that opportunity. That is why I would argue so strongly for the need for research to eradicate this disease, but I would argue also that we need to find every possible way to support people in their own homes.

Senator MURRAY. Not at the expense of helping the families who deal with this——

Dr. HODES. That is correct. I would only add that as much as we emphasize the research, epidemiologic, biologic, molecular, that's important to understand and approach the causes of Alzheimer's disease, so just as you note, research must be directed at present to identifying the stress upon caregivers. It is important to look at ways to reduce that stress and so to increase the quality of life for those afflicted and their families. Indeed, there are clinical trials ongoing to look particularly at novel and innovative mechanisms for reducing caregiver stress and providing environments that enable people to live the life——

Senator MURRAY. Such as? Can you give us an example?

Dr. HODES. Well, the first phase of a study called REACH, which was a multicenter study designed to look at nine different intervention components for reduction of stress has now been completed, and on the basis of that first study has led to a second generation, if you will, REACH II, which has taken the most promising components of these several studies into a clinical trial. It includes such things as providing respite care and looking at the new communications modalities such as the World Wide Web to provide resources, information and support for individuals.

Senator SPECTER. Dr. Hodes, would you complete your answer in writing? We have six more witnesses, and we are going to have to conclude this hearing by 11.

Senator MURRAY. Thank you, Mr. Chairman. I know my time is out, and I would love to hear more, because I think we have to pay attention to the families who are taking care of these people as well. Thank you.

Senator SPECTER. I quite agree, Senator Murray. If you would supplement your oral answers in writing, we would appreciate that.

[The information follows:]

The multi-site Resources for Enhancing Alzheimer's Caregiver Health program (REACH II) was funded in September 2001. It is designed to test a single multicomponent intervention to enable care-givers to learn and use cognitive and behavioral strategies, to impact both care recipient behaviors (e.g. wandering) and their own behaviors (e.g., managing stress). It will (1) identify and reduce modifiable risk factors among caregivers, (2) enhance the quality of care, and (3) enhance the well-being of caregivers. This 3-year renewal builds on the results of REACH I, a multi-site feasibility study. The ultimate objective is to translate findings into materials and programs that are readily useable in the community of caregivers. The study will also evaluate the cost effectiveness and public health significance of the intervention.

Senator SPECTER. I would like to call our next panel now, Mr. Dwayne and Ms. Mary Jean Uptegraph, Mr. Donald Kurtz, Mr. Mike Martz, and Mr. Terrell Owens.

STATEMENT OF MARY JEAN AND DWAYNE UPTEGRAPH, DUBUQUE, IA

Senator SPECTER. We begin with Mr. Dwayne Uptegraph, who was diagnosed with Alzheimer's disease in December 1999, 1 week before his 53rd birthday. Prior to that diagnosis, he was an art teacher for 31 years and coached football and basketball at Jefferson Junior High School in Dubuque, Iowa, a graduate of Upper Iowa University.

Mrs. Uptegraph recently retired from her job at a radiologist's office to spend more time with her husband. They have been married for 35 years and have three children and four grandchildren. Thank you for joining us, Mr. and Mrs. Uptegraph, and Mrs. Uptegraph, the floor is yours, and we look forward to your testimony.

Ms. UPTEGRAPH. Thank you very much, Senator Harkin, Senator Specter, for giving us the opportunity to testify this morning. We are truly honored to be here this morning representing the Greater Iowa Chapter of the Alzheimer's Association.

As you stated, my name is Mary Jean Uptegraph, and I am here today with my husband, Dwayne, our daughter, and our 5-year-old granddaughter. The four of us have traveled to Washington from Dubuque to ask you to please do everything you can to increase the funding for Alzheimer's research so that a cure or prevention can be found as soon as possible.

Our plea for increased research funding comes from the heart. Dwayne has Alzheimer's disease. He was diagnosed in December of 1999, 1 week before his 53rd birthday.

Dwayne graduated from Upper Iowa University in 1969 and we moved to Dubuque shortly after that so he could start his teaching career. He taught art at Jefferson Junior High for 31 years, and for 26 of those years he coached football, basketball, and track. Together, we raised three wonderful children, Todd, Kristine, who is here with us today, and Gretchen. Our children have blessed us with four amazing grandchildren who range in age from 6 months to 6 years, and we are looking forward to the arrival of our fifth grandchild in May.

Our story starts like many others have. Dwayne started to misplace things around the house, and one day he got lost while driving the 5 miles between our house and the school he taught at, the same route he had driven for 30 years. He also started misplacing things such as the art supplies and student assignments in his classroom.

After talking with the principal at the school, we went to the local internist, who performed several tests. Dwayne was then sent to a neurologist, where he underwent an MRI, a spinal tap, which there confirmed the presence of the ApoE gene that has been linked to Alzheimer's. He also went through a full battery of verbal and psychological testing.

Dwayne's neurologist immediately started him on the medication for his anxiety and large doses of vitamin E, in addition to one of the four available Alzheimer drugs. He has since added B6, B12,

folic acid, and aspirin to see if this does help. We informed Dwayne's principal, and the decision was made to let him finish out the remainder of the school year. The principal and Dwayne's coworkers were very supportive and understanding. He retired from teaching in June 2000 after 31 years.

I continued to work in the local radiology office, and we did a lot of planning for the future. We wrote our wills, signed a power of attorney, and we attended a few of the Alzheimer Association conferences and educational programs. We participated in the Memory Walk to help raise money for local programs and services.

Dwayne began volunteering in the art department at our neighborhood elementary school. It helps keep him both mentally and physically active. While he really enjoys his time in the classroom, there are moments that are frustrating for him. Dwayne spent his entire career as an educator. Today, he cannot provide the right answer when a fourth grader asks him to help with the spelling of a common word.

We have made additional changes in the last few months to spend more time together as a family and to accommodate Dwayne's needs. In December, I retired after 19 years of work. It had just become too difficult for me to hold down a full-time job and give Dwayne the support he needed. Dwayne sees his neurologist every 6 months, and he also visits a memory therapist once a month who helps him with his recall and thought process.

Senator Harkin, we are here today to ask you and Senator Specter for your understanding leadership in the fight against Alzheimer's disease, and to support your efforts to increase the funding. We need to stop this disease while we still have the chance. Dwayne's father died with Alzheimer's. Dwayne and I are worried that we have passed this disease on to our children and grandchildren.

We know that the scientists are on the verge of finding ways to prevent and treat Alzheimer's, and the actions Congress takes today may save future generations from this terrible thief that steals memories, disrupts careers, and affects millions of families. We are scared for the future, but grateful for our supportive family and the good life we have had so far. We want to do everything we can to raise the awareness about the disease and the need for research funding. On behalf of our entire family, we thank you for giving us the opportunity to share how Alzheimer's disease has affected our lives.

In closing, we would like to read a short letter that our grandson, Noah, has written to Senator Harkin. We brought this letter with us today and ask that it be entered into the congressional record as a part of the testimony:

Dear Senator Harkin, I hope my grandpa can get better. He is an artist and we draw pictures together. I hope you can help him. Love, Noah Goebel.

Dwayne has just a short couple of phrases he would like to express today.

PREPARED STATEMENT

Mr. UPTEGRAPH. I have a hard time expressing myself, but I am here today to ask you for your help. I pray that a drug will soon

be found to help me and everybody else who has this disease. Thank you.

[The statement follows:]

PREPARED STATEMENT OF MARY JEAN AND DWAYNE UPTEGRAPH

Thank you very much Senator Harkin and Senator Specter for giving us the opportunity to testify this morning. We are truly honored to be here, representing the Greater Iowa Chapter of the Alzheimer's Association.

My name is Mary Jean Uptegraph and I am here today with my husband of 35 years, Dwayne, our daughter and five-year old granddaughter. The four of us have traveled to Washington from Dubuque to ask you to please do everything you can to increase funding for Alzheimer research so that a cure or prevention can be found as soon as possible. Our plea for increased research funding comes from the heart—Dwayne has Alzheimer's disease. He was diagnosed in December 1999, one week before his 53rd birthday.

Dwayne graduated from Upper Iowa University in 1969 and we moved to Dubuque shortly after that so he could start his teaching career. He taught art at Jefferson Junior High for 31 years. For 26 of those years he coached football, basketball and track. Together we raised three wonderful children, Todd, Kristine (who is here with us today) and Gretchen. Our children have blessed us with four amazing grandchildren who range in age from 6 months to 6 years. We're looking forward to the arrival of our 5th grandchild in May.

Our story starts like many others. There were signs and symptoms that I overlooked for about 18 months before we finally sought help from a doctor. Dwayne started misplacing things around the house and a few times he got lost driving to familiar places in Dubuque. One day he got lost while driving the five miles between our house and his school—the same route he had driven for 30 years. During that episode, he pulled over to call me for directions but couldn't remember how to dial the phone. He had also started misplacing things, such as art supplies and student's assignments, in his classroom. His principal called me because Dwayne was starting to have anxiety attacks at school. He would get very upset and agitated every time he misplaced something in his classroom. The principal also told me that Dwayne was having a lot of trouble learning the school's new computerized grading system. Around the same time, we went on a family vacation to France. Dwayne became very anxious and confused when we visited some of the main attractions that were crowded with large groups of tourists.

After returning to Iowa, we went to a local internist who performed a lot of tests. Dwayne went through a full battery of verbal and psychological testing. He saw a neurologist and underwent an MRI and a spinal tap which confirmed the presence of the ApoE gene that has been linked to Alzheimer's. He underwent more tests . . . I honestly think he went through every medical test in the book! About six weeks after we started all of the tests he received the diagnosis of Alzheimer's. We were in total shock. Dwayne's neurologist immediately started him on medications for his anxiety and large dose of Vitamin E and Vitamin B6, in addition to one of the four available Alzheimer drugs.

We told Dwayne's principal and the decision was made to let Dwayne finish the remainder of the school year. The principal and Dwayne's coworkers were very supportive and understanding. At the time, Dwayne had a student teacher who provided day-to-day help. Dwayne retired from teaching that June after 31 years in the classroom, several years earlier than he had originally planned.

We slowly began to adjust to our changed lives. I continued to work as a billing specialist in a local radiologists office. We did a lot of planning for the future. We wrote our wills and signed a Power of Attorney so that I can make health care and legal decisions for Dwayne as the disease progresses. We saw an advertisement for the Alzheimer's Association in the local newspaper and went to a few of their conferences and educational programs. We participated in the Alzheimer's Memory Walk to help raise money for local programs and services. Dwayne began volunteering in the Art Department at the local elementary school. He still volunteers every day from 8:00 a.m. to 3:00 p.m. It helps keep him both mentally and physically active. While he really enjoys his time in the classroom there are moments that are frustrating for him. Dwayne spent his entire career as an educator. Today he can't provide the right answer when a fourth-grader asks for help spelling a common word.

We've made additional changes in the last few months to spend more time together as a family and to accommodate Dwayne's needs. In December, I retired after 19 years at my job in the radiologist's office. The decision to retire was tough but

it had become too difficult for me to hold down a full time job and give Dwayne the support he needed. Dwayne sees his neurologist every six months. During these visits, Dwayne undergoes verbal and mental testing to track how quickly his Alzheimer's is progressing. He also visits a memory therapist once a month who helps him with his recall and thought processes. Dwayne needed to be driven to all of his appointments because he had given up his car keys about 18 months after being diagnosed. In addition, I had begun to worry about Dwayne's safety. He was still able to use the stove but no longer mowed the lawn. And I was very concerned about what Dwayne would do once the school year, and his volunteer commitment, ended. He would be home alone while I was at work all day. Retirement seemed to be the best option for both of us.

Senator Harkin, we're here today to thank you and Senator Specter for your outstanding leadership in the fight against Alzheimer's disease and to support your efforts to increase research funding. We need to stop this disease while we still have the chance. Dwayne's father died of Alzheimer's. My grandmother and an aunt both suffered from dementia. Dwayne and I worry that we have passed this disease on to our children and grandchildren.

We know that scientists are on the verge of finding ways to prevent and treat Alzheimer's and that the actions Congress takes today may save future generations from this terrible thief that steals memories, disrupts careers and affects millions of families. We're scared for the future but grateful for our supportive family and the good life we've had so far. We want to do everything we can to raise awareness about the disease and the need for research funding. We've asked about getting Dwayne into several research trials but he has a kidney disease and the doctors say he's not a good candidate for most of the studies.

On behalf of our entire family, we thank you for giving us the opportunity to share how Alzheimer's disease has affected our lives.

Senator SPECTER. Thank you very much, Mr. and Mrs. Uptegraph. Thank you, Mr. Uptegraph for sharing those thoughts with us. We know it is not easy for you in any respect, and thank you, Mrs. Uptegraph for your testimony and for your care for your husband, and for the model which you are setting for so many million Americans. Thank you.

STATEMENT OF DONALD KURTZ, BLUE BELL, PA

Senator SPECTER. We now turn to Mr. Donald Kurtz, who was diagnosed with early onset Alzheimer's disease in August 2001 at the age of 57. He had spent over 30 years in the financial services industry, currently volunteers at a local rehabilitation center, and is active at the local Alzheimer's chapter early onset support group, graduate of West Point, served as an air observer in the Vietnam War, four children, two of whom are still in college. He resides in Blue Bell, Pennsylvania. Thank you for joining us, Mr. Kurtz, and we look forward to your testimony.

Mr. KURTZ. Thank you, Senator Specter. Good morning, Senator Specter and Senator Harkin. I am honored to be here today representing the great State of Pennsylvania and the Delaware Valley Chapter of the Alzheimer's Association. My name is Donald Kurtz. I sit before you as a devoted father of four children, a proud graduate of West Point, and as a 59-year-old man with Alzheimer's disease.

I am aware that on the outside it does not appear that there is anything wrong with me. Maybe I remind you of someone, a friend, a neighbor, perhaps even a colleague. Twenty months ago I was a lot like you and your colleagues. I was at the top of my professional career at a leading financial services firm, supporting my family and awaiting hefty tuition bills for talented children who were about to attend two of this country's top universities.

Then a neurologist delivered the news that changed my life—Alzheimer's disease. It was August 2001. I was 57 years old. While the diagnosis itself was a shock, it did provide an explanation for the memory problems I had been experiencing for approximately 2 years. When I was in my midfifties I started losing my keys and then my glasses on a regular basis. I came home from work one night, pulled my car into the garage, and left the engine running. I was constantly leaving my keys in our front door or in the mailbox.

My family started to notice my behavioral changes, and my daughter suggested seeing a neurologist. The neurologist examined me and we discussed the possibility of Alzheimer's disease, but the neurologist concluded that I was not in the right age group for my symptoms to be explained by Alzheimer's. However, after a battery of tests, an interview with the psychiatrist, and an MRI, the neurologist concluded that I did have Alzheimer's disease.

The economic devastation, especially at this young age, is one for which I was unprepared. My family needed my financial stream to pay for university tuition and expenses. My eventual in-home care and final institutionalization was never planned for, nor in my budget. As our Alzheimer's population continues to grow, we will not be able to support the residential needs of this growing population. Today, 10 percent of 65-year-olds have Alzheimer's disease, and if we live to the age of 85, 50 percent of us will have Alzheimer's disease. How will we accommodate the needs of this population?

Despite being knocked down in the prime of my life I never adopted a negative attitude or asked, why me? Instead, I thought back to my West Point training and decided that I would fight back. I made the decision to speak out, to be up front with people, and to do whatever I could do to educate people about Alzheimer's disease and the impact it has on individuals and families when it strikes so young.

I contacted my local chapter of the Alzheimer's Association and joined an early onset support group. I met peers who were experiencing the same problems I was, the lack of services and systems to support younger people with Alzheimer's. One of the men in my support group who could no longer drive had to drop out of a local art therapy program because he did not meet the age requirements of the available transportation assistance programs.

Today, I am under the care of two excellent neurologists at the University of Pennsylvania Medical Center and the Ralston House Memory Disorders Clinic. I am active in my Alzheimer's support group and I volunteer 2 days a week at the Chestnut Hill Rehabilitation Center. I tell the patients I have Alzheimer's disease, which brings them very close to me. I know how fortunate I am. I have a loving family, I have Roz, my care partner and the woman who has been by my side throughout this entire journey. She is here with me today.

Senator Specter, I served as an air observer in Vietnam from 1967 to 1968. I know what war in Iraq will mean for the women and men who have responded to their Nation's call, and for their families at home. I participated in 51 missions in Vietnam. Today,

I am on one single mission to urge Congress to increase the Federal Government's investment in research.

PREPARED STATEMENT

Some may say that in a time of war we have to put off other things we would like to do, but I am here in Washington to send the message that we cannot abandon our most urgent priorities at home. One of these is the fight against Alzheimer's disease. We must win this fight, not just for me and the more than 20 other individuals in this room, but for my children, grandchildren and for yours.

I thank you for your steadfast leadership on behalf of the Alzheimer's cause, and for the honor of appearing here today.

[The statement follows:]

PREPARED STATEMENT OF DONALD KURTZ

Good morning Senator Specter and Senator Harkin. I am honored to be here today representing the great state of Pennsylvania and the Delaware Valley Chapter of the Alzheimer's Association.

My name is Donald Kurtz. I sit before you as a devoted father of four wonderful children, as a proud graduate of West Point Military Academy and as a 59-year old man with Alzheimer's disease.

I am aware that on the outside, it does not appear that there is anything wrong with me. Maybe I remind you of someone—a friend, a neighbor, perhaps even a colleague. Twenty months ago I was a lot like you and your colleagues. I was at the top of my professional career, in a senior leadership position at a leading financial services firm, supporting my family and awaiting hefty tuition bills for talented children who were about to attend two of this country's top universities. Then a neurologist delivered the news that changed my life—Alzheimer's disease. It was August 2001 and I was 57 years old. I still remember what I did after I left the doctors office that terrible day. I went to the gym and got on the treadmill thinking that if I got the blood rushing to my brain, I could start to slow down the progress of the disease.

While the diagnosis itself was a shock, it did provide an explanation for the memory problems I had been experiencing for approximately two years. When I was in my mid-50's, I started losing my keys and then my glasses on a regular basis. One day I drove into Center City Philadelphia and left my car in a public parking garage with the engine running all day. Not long after that, I came home from work one night, pulled my car into our garage and again, left the engine running. I was constantly leaving my keys in our front door or in the mailbox. My neighbor would return them to me and say "looks like you've done it again, Don."

My family noticed the strange behavior too. When my kids were growing up we always played games together. One day I sat down to play Backgammon with my daughter, like I had done hundreds of times before. Only this time I couldn't remember how to set up the board. Not wanting to worry my daughter, I brushed off the lapse by explaining that I was just tired. Another time I was playing Scrabble with my other daughter and I couldn't add up the points for the simple four or five letter word that I had spelled. My daughter immediately knew that something was wrong and made an appointment for me to see a neurologist.

The neurologist examined me and we discussed the possibility of Alzheimer's disease. But the neurologist concluded that I wasn't in the right age group for my symptoms to be explained by Alzheimer's. However, after a battery of tests, an interview with a psychiatrist and an MRI, the neurologist concluded that I did have Alzheimer's disease.

The news was devastating to my family and friends. I chose to write a letter to my supervisor at work, explaining that I had early-stage Alzheimer's disease. My supervisor was shocked but supportive. At the time, I was a first vice president in the local office of one of the best-known global financial services firms. I had spent over thirty years within this industry only to have my dreams of continuing the work I loved come to a drastic halt.

The economic devastation especially at this young age is one for which I was unprepared. My family needed my financial stream to pay for university tuition and expenses. My eventual in-home care and final institutionalization was never

planned for and not in my budget. As our Alzheimer's population continues to grow we will not be able to support the residential needs of this growing population. Today, 10 percent of 65 year olds have Alzheimer disease and if we live to the age of 85, 50 percent of us will have Alzheimer's. How will we accommodate the needs of this population?

Despite being knocked down in the prime of my life, I never adopted a negative attitude or asked, "Why me?" Instead, I thought back to my West Point training and decided that I would fight back. I made the decision to speak out, to be upfront with people and to do whatever I could to educate people about Alzheimer's disease and the impact it has on individuals and families when it strikes so young. I contacted my local chapter of the Alzheimer's Association and joined an early onset support group. I met other men with early onset Alzheimer's who were in deep denial about their diagnosis. I also met peers who were experiencing the same problems I was—the lack of services and systems to support younger people with Alzheimer's. One of the men in my support group who could no longer drive had to drop out of a local art therapy program because he didn't meet the age requirements of the available transportation assistance programs.

I began to look for a way to stay active and give back to those who were worse off than I was. I started volunteering at Central Montgomery Medical Center, visiting sick patients, keeping them company and helping out at meal times. I also volunteered in a children's day care program at Montgomery County Community College.

Today I am under the care of two excellent neurologists at the University of Pennsylvania Medical Center and at the Ralston House Memory Disorders Clinic. I see my doctors every six months. I'm active in my Alzheimer's support group and I volunteer two days a week at the Chestnut Hill Rehabilitation Center. I visit with the patients and comfort them when they are feeling bad. I tell them I have Alzheimer's disease. I love my volunteer work and am lucky that I get to spend time with such wonderful people. I am still driving but only in areas that I know very well. I gave my word to my doctors and family that I would not drive in unfamiliar cities or towns. However, I dread the day that I have to give up the car keys because among other things, it will mean that I can no longer do the volunteer work.

I know how fortunate I am. I have a loving, supportive family. I have Roz, my care partner and the woman who has been by my side throughout this entire journey. She's here with me today. I enjoy spending time with my three grandchildren and like Dwayne and Mary Jean sitting next to me, am eagerly awaiting the birth of another grandchild in May.

Senator Specter, I served as an Air Observer in Vietnam from 1967–1968. I know what war in Iraq will mean, for the women and men who have responded to their nation's call and for their families at home. I participated in 51 missions in Vietnam. Today I am on a single mission—to urge Congress to increase the federal government's investment in Alzheimer research. Some may say that in a time of war we have to put off other things we'd like to do. But I'm here in Washington to send the message that we cannot abandon our most urgent priorities at home. One of these is the fight against Alzheimer's disease. We must win this fight not just for me and the more than 20 other individuals with Alzheimer's in this room but also for my children and grandchildren and for yours. I thank you for your steadfast leadership on behalf of the Alzheimer's cause and for the honor of appearing here today.

Senator SPECTER. Thank you very much, Mr. Kurtz. We know it is not easy to provide that testimony, but I think it is very important for people to hear real life experience, and we thank you, Mrs. Kurtz, for being at your husband's side.

STATEMENT OF MIKE MARTZ, COACH, ST. LOUIS RAMS

Senator SPECTER. We now turn to Mr. Mike Martz, head coach of the St. Louis Rams. He has held that position since February 2, 2000, before he was the team's offensive coordinator receiver's coach, designed the offensive strategy for the Rams' 1999 Super Bowl win, and we all know what a dynamic offensive strategy that was, summa cum laude graduate from Fresno State, where he played tight end.

Mr. Martz has become familiar to television viewers everywhere because the TV cameras always scan the coach on the sidelines to

see the emotional reaction after a good play or a bad play. I have never understood why there was so much scanning. I can understand in your case, Mr. Martz, because you are so photogenic, but otherwise it is hard for me to understand why we see so much of the coaches and so little of the spectacular receivers like Terrell Owens.

They never scan Mr. Owens because they make them keep their helmets on under the league rules. I can't understand that either.

Well, onto the serious business at hand, Mr. Martz. We appreciate you joining us and look forward to your testimony.

Mr. MARTZ. Thank you, Chairman Specter, and good morning Senator Harkin and Members of Congress here today. It is a real privilege for me to be here to offer this testimony. Like so many others in this room, I experienced the devastating effects of Alzheimer's. My mother had Alzheimer's the last 4 or 5 years of her life, and it slowly robs you of your mind, your dignity, and eventually your life, and we have to do whatever we can to stop this, and I am here today to ask you to provide whatever efforts that you can to help us stop this dreaded disease.

Just a few moments, if I can, and I know that I am only allowed 3 minutes or so. I could talk to you all day about the effects of this and what it did to this family and to my mother, but my mother's name was Betty Martz. She raised four boys. Originally we had five in the family. The oldest one was killed in a car accident.

My father left, and she was there with young boys that she had to raise on her own. She did not have a penny. She went to work. She is a professional lady. She became a coordinator of volunteers at Mesa Vista Psychiatric Hospital in San Diego, and she worked there for well over 20 years and did a terrific job. She was a very intelligent, very loving, and very caring person. She did not remarry. She elected to raise her four boys, and she spent the weekends, her free time back at the hospital providing care for the people at the hospital. We shared holidays with her patients that she cared for as well at home with the rest of the family.

As she retired, she moved out next to my older brother a few miles away, Fritz, and she started to settle in at about age 70, 72 into retirement and enjoy her grandchildren and some of the success that we were beginning to have.

Then, as usual, as you have heard so many times, things began to slip for her. She started to lose her memory. She lost her way out of the neighborhood. She had a hard time. She would turn the stove on to light a cigarette, would leave the stove on. We became very concerned. She was originally diagnosed with dementia. They said that the very best thing we could do for her was keep her in that environment. Well, my oldest brother then would have to be her caregiver. He was there every morning and every night after work, and it took a toll on him, as I know so many people in this room are aware of, and eventually this thing slid downhill.

She had two dogs with her. She would have 20 or 30 cups of food out for these animals. Every salesman that came by the door she bought from, a new roof, it did not make any difference, whether it was encyclopedias, she bought, and my brother would have to go back and get the money back from all these things, and eventually—my brother ran a crew for the power company in San Diego.

She would call him out in the field 20 or 30 times a day. She would call him at night. She was scared to death that somebody was breaking into the house.

This thing slid down so far that we just had to put her into some sort of a part-time care unit, and the only way she would go, because she refused to leave her home, is we took her living room and put it exactly in the room, just like it was at her house. My brother took her home while we did this, and then he brought her, and it worked. She did not realize that this was not her home.

Well, she was there very briefly, probably 2 to 3 months. The doors were open. She would wander into other patients' rooms, and for whatever reason she would end up with some of their articles from that room in her room and they just could not have her there any more. She went downhill within 2 months. She went into a full-care unit.

The last time that I saw her alive was in 1996. I was with the Redskins. It was right before the season started, and I went to visit her in the full-time care. It is a lockdown unit, and as I saw Mom and took her through the rose garden—she was an avid gardener. She loved to garden—she got down on her hands and knees and started to pull weeds out of the rose garden there. She was convinced that that was what she needed to do. She would pick up the twigs, and I would have to take them from her and explain to her each time who I was. She had no idea who I was.

Finally, as I took her back to her room she stood at the door in her gown and she started to sob because she just knew that she needed to know me, she should know me, but she kept asking who I was, and I said, I am your son, Mike, and then as I told her I was going to leave, obviously she started to cry and said, Mike, can't you please take me with you. I could not take her with me. That was the last time I saw her alive.

Fortunately, 6 months later, lung cancer did take her life so that she did not have to continue to suffer with Alzheimer's, and I saw her in a coma and she passed quickly, and I believe that that was a blessing.

There are many things that she missed out on, that we missed out on as a family. She never saw my oldest son graduate from college whom she was so close to. She never got to experience my success as an NFL coach, or becoming a head coach, or the Super Bowls, or any of those things that were so important to her, and she was such a terrific football fan. She missed all of those things, and that is my biggest regret.

The most devastating effect of this in my mind is to see someone so vibrant, so full of life slowly diminish, but there is one other aspect to this that has been touched on here today, and I would like to bring this up. My brother, if there is somebody in a family that has Alzheimer's, there is always somebody that is responsible for that individual, and that care goes on.

My oldest brother was responsible. He was there day and night for her, provided constant care for her. Two years after she died, the stress of the 4 years, eventually he suffered a heart attack, and it is just absolutely brutal.

I know that this is such a tragic disease that whatever we can do to stop this disease—I know that we talked about, listening in

here today, how long will it take to cure it. I do not know how long it is going to take to cure it. All I do know, we have to do whatever it takes, and that is a term that we use with our players, and Terrell will know this.

PREPARED STATEMENT

We have to do whatever it takes to stop this disease, because it will become, as these baby boomers approach that age it will become and is on its way to being a national tragedy. I would ask you to please not drop the ball on this thing. We can beat this disease. There is a tremendous game plan there in front of you. All we have to do is get your support and your commitment for this game plan and we can whip this disease, I know we can.

The clock is running, ladies and gentlemen, and it is not going to stop until we cure it.

[The statement follows:]

PREPARED STATEMENT OF MIKE MARTZ

Good Morning Chairman Specter, Senator Harkin and distinguished members of Congress. I consider it a privilege to be here today. I am Mike Martz, beginning my fourth season as head coach of the St. Louis Rams. I share a common experience with others attending this hearing. I, too, have experienced first-hand the devastating affects of Alzheimer's. I watched my mother suffer from the disease for many years.

As a coach, I firmly believe that an aggressive offense wins football games. As a son who watched his mother suffer, I strongly believe a strong offense by Congress is the only way we are going to beat Alzheimer's, the toughest opponent I have faced. Although life is far more precious than any football game ever played, I am here to give you the same message I give my players—take the ball and run. Together, as a team, we can beat this thing.

Today I would like to take a moment to tell you about my wonderful mother, Betty Martz. She raised my four brothers and me mostly on her own. Ironically, she worked incredibly long hours in healthcare—as the volunteer coordinator at Mesa Vista Hospital in San Diego. She was a terrific woman, very energetic and someone everyone enjoyed meeting. She was incredibly strong, a trait you would expect ANY mother of FIVE boys to possess.

We so looked forward to the day she retired as she would have time to finally relax and enjoy life. She elected to remain in her small, but comfortable home in San Diego with her two little dogs. Two of my brothers lived close and visited her often.

Mom was just 68 years old, and really beginning to enjoy her retirement, when we noticed that she had become forgetful—unusually forgetful. I will always remember that day when her doctor diagnosed her with Alzheimer's. My first thoughts were that this only happens to someone else's mother, not my strong mom who had always been so healthy. After her diagnosis, Mom, the always independent woman, insisted that she stay in her home. She managed for a short time with visits from my brothers, however, she slid downhill quite fast.

Though she had always kept a clean house, now somehow she forgot to do it. She stopped cleaning, and her home was in total disarray. She was still driving, but could not find her way out of the neighborhood. We had to disconnect her car battery to keep her home. She began having difficulty with her medications. She had one of those pill boxes labeled with the days of the week, but at times she would take 3 days worth of pills in one morning.

Eventually, due to Alzheimer's, she was unable to care for her two small dogs. At one point, she had 20 bowls of food set out for them. Those tiny dogs blew up like balloons, but Mom did not notice. Mom, who was as brilliant a person as I have ever known, even began making absurd purchases from door-to-door salesmen.

My brother Fritz was a superstar caregiver to our mother. Often, Mom would call him up to 20 times a day—so many calls for a man running a field crew for the power company. Sometimes she would call him at 3:00 in the morning to tell him about imaginary things that were happening to her. She would ask him to come over to protect her against imaginary demons.

The years of caregiving were a huge drain on my brother—it took him two years to recover from the incredible the stress and strain of being her primary caregiver. Fritz was constantly there for her, but this disease nearly killed him—he suffered a heart attack as a result.

After Mom could no longer manage on her own, we had to move her to a long-term care facility. By that point, she was running through all of her savings, and certainly would have gone through everything if cancer had not taken her life. As tragic as this may sound, the cancer seemed so much less harsh for Mom after having watched her fight the hopeless battle with Alzheimer's for so many years. You see, this disease robbed her of her life and her family.

The difficult thing with Alzheimer's is dealing with something over which you have absolutely no control. With many other diseases, there is a glimmer of hope and you maintain the ability to communicate and cope as a family. With Mom, we lost that ability to communicate even on the most simple level. We lost the opportunities to laugh and share memories. We were lucky if she could even put names and faces together. It was almost as if she had returned to being an infant—at a point in her life when she should have been enjoying retirement and grandchildren she had so looked forward to spoiling. She missed many life events that would have meant the world to her—seeing her first grandson graduate from college or witnessing the successes of her sons that she worked so hard to raise. My biggest regret is that my mother did not get to see me become a head coach in the NFL or to sit in the stands and cheer when I finally fulfilled a lifelong dream of coaching in the Super Bowl. It would have meant so much to her and to me knowing that her hard work paid off.

Now, I fear for my family and future generations. Imagine being hit with Alzheimer's in the prime of your life. I do not want Alzheimer's disease to cause my family the grief and pain that my brothers and I suffered. One of my biggest fears, though, is not being there for my children and grandchildren. After the experience with my mother's battle with Alzheimer's disease, I cannot imagine how I could handle anyone else in my family being diagnosed with this dreadful disease.

Before my mother was affected, I did not understand this disease. I am here to tell you that both the financial impact and the emotional impact are devastating for the patients and their families. I surely was not prepared for the emotional impact—watching my own mother lose her mind and her dignity. As of now, there is no hope for patients or their families. Ladies and gentlemen, it is so important; we MUST find a way to stop Alzheimer's. My understanding is that researchers are close to the answers. Additionally, we must discover a way to help the people who have this disease now and cannot afford the care and treatment they need.

In St. Louis, we have found that a high powered offense wins football games. Now is the time for Congress to line up on the offensive against Alzheimer's disease. As you know, successful strategy for winning games is in a playbook. The Alzheimer's Association has provided you a real life playbook, "A Race Against Time: A National Program to Conquer Alzheimer's Disease." You have heard today what needs to be done and how quickly it needs to happen. I am here to ask you to execute the game plan that will defeat Alzheimer's. It is time for Congress to take the offense against Alzheimer's disease.

Thank you for your time and support.

Senator SPECTER. Thank you, Mr. Martz, for sharing with us your experience, the tragedy with your mother. We like your football metaphors—whatever it takes, the clock is running, don't drop the ball. We are dedicated to it and the Congress and the administration have put money where their mouths are in more than doubling NIH funding, and we are determined to find the answer, and that is why we have asked for more specifics.

STATEMENT OF TERRELL OWENS, WIDE RECEIVER, SAN FRANCISCO 49ERS

ACCOMPANIED BY MARILYN HEARD

Senator SPECTER. We turn now to Mr. Terrell Owens, well known wide receiver for the San Francisco 49ers, drafted in 1996 out of the University of Tennessee, Chattanooga. In seven seasons with the 49ers, Mr. Owens has made two Pro Bowl appearances, broken 49ers' and league records and is one of the premier offensive play-

ers in the NFL. In the year 2001, he earned first team All Pro honors from the Associated Press, and a career high in league-leading 16 touchdown receptions. His grandmother, Alice Black, has Alzheimer's disease and resides in a nursing home in Alabama. Mr. Owens is accompanied by his mother, Ms. Marilyn Heard.

This is a challenge for you, Mr. Owens, to appear on NFL highlights. The NFL film crew is here today as is ESPN and Senator Harkin and Senator Murray and I are sure you will rise to the occasion.

The floor is yours. It is nice to see you without your helmet on.

Mr. OWENS. Good morning, Senator Specter and Senator Harkin. I am definitely grateful to be here this morning, and to all the Members of Congress, thank you for having me here today, and while I am here in Washington my grandmother, Alice Black, is in a nursing home in Talladega, Alabama, and at this point she only remembers me, her late husband, and the woman beside me, Marilyn Heard, which is her daughter and my mother.

Professionally I have been able to provide for her financially. My mom has been her caregiver, and it came to my attention around 1999, when I was attending a charity event in San Diego for a league mate of mine, and my mom called me, and I was about to go to the function and I noticed a change in her voice and she said my grandmother had been doing some things as far as forgetting stuff, and just wandering off, and she said she wanted her to talk to me.

I know the regular tone in my grandmother's voice, so once she got on the phone she sounded like, just a slowed down tape recorder, as if her batteries were running dead, and my mom got on the phone, and she was crying, and I tried to hold her up as best I could, and as soon as I hung up the phone I just burst into tears, because this is a lady that has raised me to be the person I am and molded me into the person I am.

I have always had the work ethic. She taught me to work hard, speak my mind, and speak strongminded. My grandmother is definitely the reason I am here today, other than her illness, and I think despite all the success that I have had on the football field I feel basically powerless as far as helping her and doing all the necessary things that I can to do for her, and I think along with many people here in the audience and Coach Martz and myself, I am definitely hoping and praying for the increase in funding for Alzheimer's research.

PREPARED STATEMENT

During last year I served as a celebrity team chair member of the Alzheimer's Association of Northern California and the Northern Nevada Memory Walk, and I definitely plan to serve again. Along with myself, Coach Martz and everyone here today that has been affected by the disease, we ask that you increase the funding to keep our loved ones around mentally as well as physically.

Thank you.

[The statement follows:]

PREPARED STATEMENT OF TERRELL OWENS

Good morning Senator Specter and Senator Harkin. I am honored to be here.

My name is Terrell Owens. I am here to talk to you about an incredible woman named Alice Black. Alice is my grandmother and she has Alzheimer's disease. While I'm here in Washington, she is in a nursing home in Talladega, Alabama. At this point, she remembers mainly me, her late husband and the woman who is here with me today, Marilyn Heard, her daughter and my mother.

Professionally, I have achieved one of my dreams—I play football in the National Football League. I am a wide receiver for the San Francisco 49ers. In my seven seasons in the NFL, I have caught hundreds of passes, scored many touchdowns, set numerous 49er and NFL records, and been to the Pro Bowl three times. Despite this success, I am basically powerless to help a woman that I love very dearly.

Football has provided me with a certain amount of fame and privilege; however, no amount of fame or privilege can heal my grandmother. While I gladly pay her medical and health care expenses, I cannot change the fact that she has Alzheimer's and continues to suffer.

My grandmother helped mold me into the person I am today. She helped raise me, my brother, and my sisters while my mother worked numerous jobs and sewed clothes on the side. Through the way she lived her life, my grandmother passed many special gifts to me. She was strict when necessary, but always caring and often playful. She taught me to work hard, to be proud of who I am, and to never back down or take a back seat to anyone. Many of her so-called old-fashioned beliefs became the bedrock for my success-self discipline, work ethic, and focus. Moreover, because of my grandmother's and my mother's steadfast convictions, I am never afraid to honestly speak my mind about matters that are important to me. Finally, my grandmother's indomitable spirit (she would often cite Scripture, sing hymns, and make sure that I attended church) created a similar spirit within me that gives me the strength to carry on as she continues to suffer.

One of the real tragedies of Alzheimer's is the isolation it produces. The woman who helped raise me is barely aware of my accomplishments or my position in life. I am proud to Alice Black's grandson and I simply wish that she was able to celebrate what we have become, where we are going, all the while remembering where we have been.

During 2002, I had the honor of serving as the celebrity team chair for the Alzheimer's Association Northern California & Northern Nevada Memory Walk. I plan to serve again this year as the celebrity chair for the 2003 Memory Walk. Through that experience, I filmed a public service announcement for the Alzheimer's Association and was able to make other contributions to the local Alzheimer's chapter. I know there are millions of others who have suffered with a loved one stricken with Alzheimer's just as my family and I have suffered. I am truly humbled to have been chosen to represent many of those persons here today. I believe I speak for all of us when I ask this Committee to help us help those who cannot help themselves.

I know what it takes to be successful in sports. My success is a direct result of the hard work that I put in during the off-season and off the field during the NFL season. When a game is on the line, I want to be the player my teammates look to make a big play or to score a touchdown for my team.

Unfortunately, I cannot go out and make a big play or score a touchdown that will cure my grandmother and the millions of others who suffer from Alzheimer's. However, I am here today as part of a team that can work together to defeat Alzheimer's. I am asking the Senators on this Committee and President Bush to help me, Coach Martz, and the millions of persons we represent to team with us to defeat Alzheimer's. Together, we can make a difference and defeat this horrible disease once and for all.

There is really only one thing I care about in this world—my family. It has been devastating for me and my family to watch my grandmother slip into the ravages of Alzheimer's. I know that you have many difficult decisions to make and that you must always balance many competing priorities and interests. Part of the reason I decided to appear today in front of this Committee is because of the enormous respect I have for it and the work it does. Thus, I urge you for my grandmother and for all of the other families that have been affected by this terrible disease, to increase funding for Alzheimer's research by $200 million this year and to keep Congress on track toward the goal of $1 billion for research.

Senator SPECTER. Thank you very much, Mr. Owens, for sharing with us your views. People know you and people listen, and I think it will be very, very helpful.

Because of the limited time I am going to waive my round of questions and turn directly to Senator Harkin.

Senator HARKIN. Thank you very much, Mr. Chairman. I just want to join with you and thank all of our witnesses who are here on this panel for your personal stories. We need to hear these, and the public at-large needs to hear this, because you know, we talk about dollars and budgets and all that kind of stuff, but what it comes down to is human beings and families, and what it does to families.

We all have our own personal stories of people we know and love that have had Alzheimer's or have Alzheimer's. I just went to dinner a week ago Sunday with a boyhood friend of mine who I grew up with, and he is now in a nursing home, and I took him out to dinner and several times during the evening he kept asking me about where we had met, and who was I, and it is just a terrible thing to see happen to someone.

But I thank you all for your personal stories, and I thank the Uptegraphs. Thank you, Dwayne, for being here and sharing with us, and Mr. Kurtz, and Terrell Owens. My gosh, I hope I can at least get to shake your hand on the way out. I have got to tell my staff I shook your hand anyway, because we have watched you play many, many times, and you are a great inspiration, and it does mean something to have someone of your stature here today and championing a cause like this because people do look up to you.

A lot of young people look up to you, and if you are espousing this cause and leading this, believe me, it just has great reverberations all over the United States, so I thank you for that.

Coach Martz, thank you very much again for being here and sharing with us also, and again we are a sports-minded Nation. We all love sports, and I know sports figures endorse different products and things like this, and I understand, that is fine, that is good, but we need you on this, too, and I cannot tell you how proud I am of both you and Terrell Owens for being here, because you can just have a great, great effect on the people that we have to go to then to get the support to get the kind of things we need through here, so thank you for taking the time and effort to be here. Thank you for your stories, and keep on leading the cause on this.

Thank you all very much.

Senator SPECTER. Thank you, Senator Harkin.

I just want to tell you, Mr. Owens, Senator Harkin appears more on C–SPAN than you do. They have a spot reserved for me on C–SPAN. It is 3 a.m.

They have reruns. Senator Harkin and I have a great following among America's insomniacs.

People can see you and Coach Martz and you on prime time.

Well, we thank you very much for coming, Mr. and Mrs. Uptegraph, Mr. and Mrs. Kurtz, Mr. Owens, Mr. Martz, for talking about your own personal experiences. It tells something to America when we hear it from the people who suffer from Alzheimer's, from Mr. Uptegraph and Mr. Kurtz, to see the loyalty and bravery and steadfastness of their wives, and when Mr. Martz talks about his mother in such emotional, direct terms and what it meant to her never having seen his great accomplishments, and Mr. Owens talks about his grandmother lovingly, and here with his mother, and we are committed to funding for Alzheimer's and these other terrible

maladies, and the Congress and the President have supported it, and we will continue the fight.

We have a large group from Pennsylvania. I would like to note the presence of Ms. Orion Reed, noted journalist and television star from Pennsylvania, who has been a witness here, an official Alzheimer, having suffered with the ailment in her family as well, and the folks from Pennsylvania in the first four rows have requested a photograph, and we will be coming down to do that right now.

PREPARED STATEMENT

We have received a statement from the Center for Senior Health, Jefferson College of Health Professions, Thomas Jefferson University that will be made part of the hearing record.

[The statement follows:]

PREPARED STATEMENT OF THE CENTER FOR SENIOR HEALTH, JEFFERSON COLLEGE OF HEALTH PROFESSIONS, THOMAS JEFFERSON UNIVERSITY

Mr. Chairman and Members of the Committee, thank you for the opportunity to submit testimony for this most important hearing on Alzheimer's Disease and Related Disorders (ADRD) as you begin to consider funding priorities for fiscal year 2004.

My name is Laura N. Gitlin, Ph.D., and I am the director of the Center for Senior Health (CSH), Jefferson College of Health Professions of Thomas Jefferson University, Philadelphia, Pennsylvania. I direct an applied research center with over 15 years of continuous funded research on the devastating effects of Alzheimer's disease and related disorders on family caregivers. The Center's nationally and internationally recognized program of research is dedicated to developing and testing the most innovative and promising interventions to help families provide quality care to persons with dementia, alleviate the stressors of caregiving, and support the daily function of persons with dementia to enable them to remain at home with life quality. Through NIH funded clinical trial research, my Center has successfully identified and tested specific strategies to help families manage the day-to-day challenges of assisting persons with progressive memory loss.

Despite increasing national research and policy attention on caregivers, family caregiving remains a significant public health concern. Most importantly, there remains a gap between what we have learned from research and what is currently practiced by health and human service professionals. There is a tremendous need to support projects that translate the most promising tested programs for family caregivers into effective clinical practices and training of direct service providers. In order to provide state-of-the-art services in home and community settings, translational research demonstration projects are a critical next step in our efforts to support persons with this disease and their family members in the home, the least costly setting of care.

NUMBER OF PERSONS WITH ADRD AND FAMILY CAREGIVERS

Mr. Chairman, over 4.5 million Americans are currently afflicted with ADRD. This number is expected to increase exponentially with the aging of our population, and particularly as the baby boom generation enters retirement. After the age of 65, the number of persons with dementia doubles each decade such that by the age of 85, 50 percent of persons have this disease. Persons with ADRD live an average of 4 to 20 years from the time of diagnosis. The vast majority of persons with ADRD live at home and are cared for by family members for the duration of the disease. That is, the home, a private residence, is the primary setting in which persons with ADRD live and in which the disease process must be managed.

Pennsylvania has one of the fastest growing elderly populations and serves as a microcosm of national trends. The fastest growing population in Pennsylvania are older adults 65 years of age and older. This group represents close to 15.6 percent of the population, significantly higher than the national average (12 percent). The Alzheimer's population represents 16 percent of the elderly in Pennsylvania, thus presenting a significant public health concern and rising health care costs in this state alone.

Millions of American families provide help to older people with dementia. It is estimated that in the near future, one out of four people will be a family caregiver.

For some family members, the caregiving role lasts for many years and even decades. Moreover, caregivers are increasingly asked to perform complex tasks similar to those carried out by paid health or social service providers. As the disease progresses, families find themselves socially isolated and unable to access needed resources including education, respite and assistance from trained health professionals.

THE PERSONAL AND ECONOMIC COSTS OF FAMILY REGIVING

Family regiving often occurs at great personal cost and involves the provision of extraordinary care, exceeding the bounds of normal family relationships. Research has consistently shown that key outcomes of the caregiving experience include psychological distress and burden, and psychiatric morbidity such as depression. Caregiving may also compromise physiological functioning and increase caregiver risk for physical health problems. Studies show for example that caregivers are less likely to engage in preventive health behaviors, show evidence of decrements in immunity measures, exhibit greater cardiovascular reactivity and slowing of wound healing, and are at increased risk for serious illness. Most significantly, family caregivers who are stressed by daily caregiving are at risk for mortality. Consequently, family members themselves often become the "hidden patients" who experience a range of negative outcomes such as emotional distress, clinical depression, poor health, fatigue, financial burden and a higher rate of mortality compared to non-caregivers.

The economic value of family caregiver services and the costs of caregiving to U.S. business in terms of decreased productivity by employees burdened with caregiving is substantial. The value of caregiver services has been estimated to be $197 billion per year (1997 dollars). The aggregate costs of caregiving in lost productivity to U.S. business is conservatively estimated as $11.4 billion (1997 dollars).

THE ROLE OF FAMILY CAREGIVERS

Individuals with ADD, particularly at the moderate to severe stages of the disease, typically require hands-on assistance with daily care such as grooming, bathing, eating, dressing, preparing meals, and transferring from bed to chair. Moreover, dementia patients usually require constant oversight to assure their own safety and well-being. Additionally, families must contend with many troublesome behaviors that can be difficult to manage such as agitation, repetitive vocalizations, resistance to care, wandering and trying to leave the home, awakening at night, and combativeness. These behaviors pose the most significant burden to family caregivers. Research has shown that families need access to and can benefit from education, social support and most importantly, in-home training in particular strategies which help to minimize the occurrence of these troublesome behaviors.

STRATEGIES FOR HELPING FAMILIES

The accumulating evidence of the negative effects of caregiving has stimulated the development and testing of numerous intervention programs. The first wave of intervention studies was primarily psychosocial, examining the impact of support groups, individual counseling, and education. Evidence was mixed with some studies showing only modest therapeutic benefits. A key finding was that programs designed for individual caregivers were more effective than group programs suggesting that providing hands-on assistance to families, particularly in the home, and customizing strategies to their needs may be necessary in order to effectively support their efforts. Recent research using rigorous randomized controlled trial designs have evaluated a broader range of intervention programs involving individual or family counseling, case management, skills training, home environmental modification, behavior management and combinations thereof. The evidence from these studies is very promising.

Our research has shown in particular that an occupational therapy in-home intervention involving education, skills training, and home environmental modifications effectively reduces caregiver burden, time spent in daily oversight, the occurrence of problem behaviors, and can delay functional decline in persons with dementia. Strategies such as modifying the home environment to assure safety, teaching effective communication approaches with the dementia patient, training caregivers in setting up daily routines and simplifying tasks such as dressing to facilitate involvement of the dementia patient, as well as instruction in techniques to manage their own distress, can make a significant and positive difference in the quality of lives for both the caregiver and dementia patient.

NEXT STEPS TO HELP FAMILY CAREGIVERS

A recent survey of 10 States, one of which was Pennsylvania, identified a key issue to be the shortage of direct care workers to provide needed education and skills training to family caregivers. Another key issue that was identified is that States should be given more opportunities to learn about promising practices and that services for persons with disability, including dementia, should target the family caregiver as well. Thus, the next critical step in helping families cope is to increase the training of direct service providers and translate clinical trial intervention research into public health programs. The development of best practice guidelines and training of health professionals based on proven protocols covering areas such as home modifications and environmental simplification, caregiver skills training in communication, task simplification and activity engagement and proven caregiver stress reduction and problem-solving techniques are essential. Our research shows that one health professional group who can truly help both the family caregiver and dementia patient are occupational therapists. Yet, this group needs training in best practices and occupational therapists are not integrated in existing family caregiving programs.

CONCLUSION

Mr. Chairman, I wish to thank you and the committee again for its leadership and vision in this area. Significant progress has been made in understanding ADRD, identifying potential pharmacological treatments to control aspects of the disease process and developing important approaches for early diagnosis. However, much remains to be done. There is no cure for the disease and families continue to bear the extraordinary burden of providing hands-on daily care throughout the course of the disease. Families provide this care at great personal sacrifice that often results in their own morbidity and in some cases mortality. Significant progress has been made in identifying intervention strategies that help families cope with their responsibilities and enable them to keep their loved one at home, the least costly setting of care. Yet, these strategies have not been translated into clinical practice and are not well represented in service programs. Addressing the challenges of caregiving in American society will require innovative basic research as well as translational demonstration projects that involve the development of best practices and training of health professionals, key among them being occupational therapists.

CONCLUSION OF HEARING

Senator SPECTER. Thank you all very much for being here, that concludes our hearing.

[Whereupon, at 11 a.m., Tuesday, April 1, the hearing was concluded, and the subcommittee was recessed, to reconvene subject to the call of the Chair.]

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