

**A WAY OUT OF THE DIABETES CRISIS IN INDIAN
COUNTRY AND BEYOND**

HEARING

BEFORE THE

COMMITTEE ON INDIAN AFFAIRS

UNITED STATES SENATE

ONE HUNDRED ELEVENTH CONGRESS

SECOND SESSION

—————
JUNE 30, 2010
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Printed for the use of the Committee on Indian Affairs



U.S. GOVERNMENT PRINTING OFFICE

62-518 PDF

WASHINGTON : 2010

For sale by the Superintendent of Documents, U.S. Government Printing Office
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A WAY OUT OF THE DIABETES CRISIS IN INDIAN COUNTRY AND BEYOND

WEDNESDAY, JUNE 30, 2010

U.S. SENATE,
COMMITTEE ON INDIAN AFFAIRS,
Washington, DC.

The Committee met, pursuant to notice, at 9:40 a.m. in room 628, Dirksen Senate Office Building, Hon. Byron L. Dorgan, Chairman of the Committee, presiding.

OPENING STATEMENT OF HON. BYRON L. DORGAN, U.S. SENATOR FROM NORTH DAKOTA

The CHAIRMAN. We are going to now turn to the Oversight Hearing on the issue of diabetes, which is a crisis in Indian Country.

I am going to ask the witnesses for the hearing to please take their position at the table.

I am going to ask, if I might, the permission of Dr. Judith Fradkin, M.D., the Director, Division of Diabetes, Endocrinology and Metabolic Diseases at the National Institutes of Diabetes and Digestive and Kidney Diseases, NIH, if you will take your seat at the table.

I would like to ask your permission if I might bring the other four witnesses to the table at the same time and we will hear from Dr. Fradkin first. Let me ask Mr. Wes Studi to come to the table, Mr. Gary Hall, Dr. Melvina McCabe and Ms. Caitlin Baker.

Let me thank all of you for taking the time to travel here and to come to a hearing on what I think is a very important subject. This is not the first time that we have had hearings on the subject of diabetes, particularly as it affects American Indians.

The high prevalence of diabetes among Native Americans and across the United States is not something we can ignore. But, if you take a look at the prevalence of diabetes on Indian reservations, it is extraordinary.

I recall, over two decades ago, flying one morning into the Three Affiliated Tribes, the Fort Berthold Indian Reservation, to hold a hearing with then Congressman Penny of Minnesota and the late Congressman from Texas Mickey Leland, and we held a hearing on the Indian Reservation at Fort Berthold on the subject of diabetes.

We had many people attend the hearing, who had lost arms and legs, who were on dialysis, who had chronic health problems, and they described a rate of diabetes that was ten times the national average. Not double, triple, quadruple, five times, but ten times the

national average. They said that adult Indians on that reservation over the age of 40, 50 percent of them had diabetes.

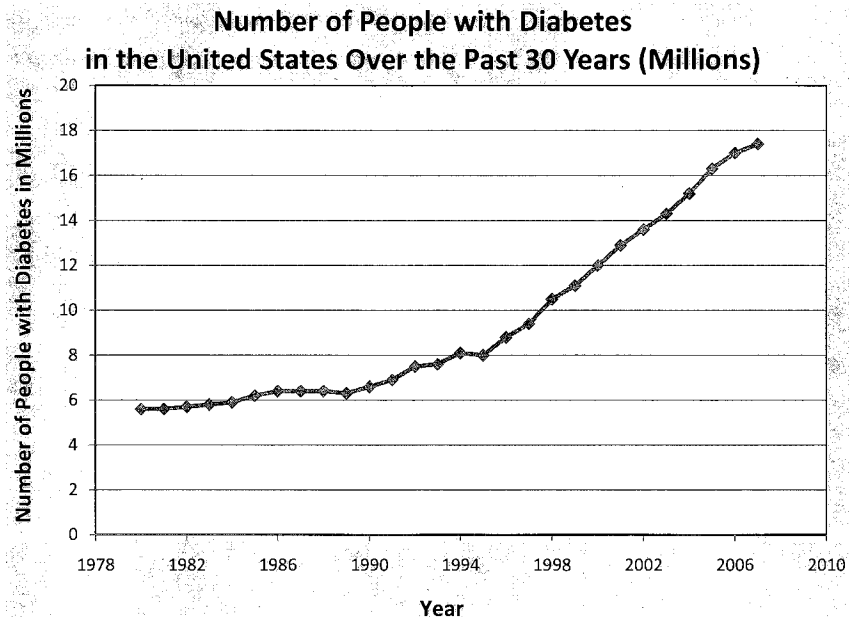
Ultimately, I was able to help create and get funding for a diabetes treatment center and now they have a dialysis unit there. But it was the first time that I had had my eyes opened about this unbelievable scourge called diabetes, particularly as it affects American Indians.

Diabetes is a disease that is on the rise all across our Country and it is a very serious issue. But a lot of people do not understand that it is a much more chronically prevalent issue on Indian reservations.

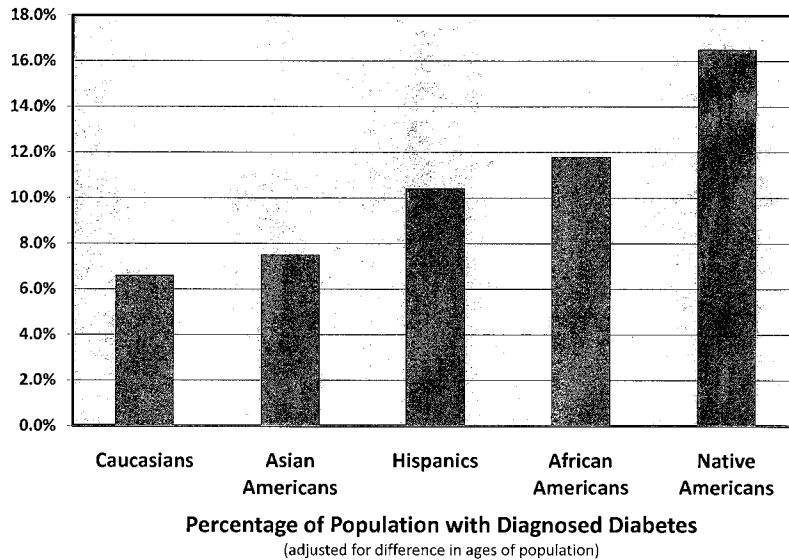
I want to have a chart put up that shows that over 24 million people in this Country now have diabetes, 6 million undiagnosed and close to 50 million who are borderline diabetic.

The CHAIRMAN. As you can see on this chart, the prevalence of diabetes in this Country has increased more than fourfold over 30 years. The burden of this disease is even much more substantial, if we can show the second chart, on Indian reservations, among Native Americans.

[The information referred to follows:]



Diabetes Prevalence in Indian Country



Reference: <http://www.cdc.gov/diabetes/pubs/estimates07.htm>

The CHAIRMAN. Native Americans suffer the highest prevalence for diabetes of any population in our Country. As the second chart shows, more than 16 percent of American Indians suffer from diabetes. That is an average of all Native Americans. In fact, in some tribal communities, such as one in Arizona, more than 70 percent of the population has been diagnosed with diabetes.

The outdated and the under-funded healthcare system on Indian lands also, I think, hinders the ability of Native Americans with diabetes from getting the kind of necessary treatment that is required. For the most part, this can be a treatable disease. But the lack of adequate treatment can lead to kidney failure, blindness, heart failure, stroke, amputation and more.

A prime example is kidney failure. Native Americans are more than three times as likely as the general population to suffer from kidney failure as a result of diabetes. Kidney failure almost always requires dialysis. But until the passage of the Indian Healthcare Improvement Act just several months ago, a piece of legislation that we wrote in this Committee, the Indian Health Service did not have the authority to provide dialysis services to Native Americans suffering kidney failure. We need to improve diabetes treatment in a very substantial way.

The Special Diabetes Program, first authorized in 1997, is a proven effort in combating diseases and diabetes. This program has led to clinical advancements in delaying the onset of diabetes and reducing the risk of serious complications, providing key programs to Native Americans.

The Special Diabetes Program funding is going to expire in 2011. I have introduced legislation to reauthorize the program and I am proud to say that that bill now has 60 U.S. Senators as co-spon-

sors. I am working hard for the passage of this bill so that program can continue. It is very important.

As I close, I want to share a story with you that I think highlights how important it is that we work for a cure for diabetes. I have a photograph here that I show you with the permission of the relatives. This is Isabel "Izzy" Burger. She is 11 years old and a member of the Little River Band of Ottawa Indians. Diagnosed with diabetes in 2007. She is a normal kid that likes to fish, hike, spend time with friends, but diabetes is always on her mind, always on her mind day and night.

Her parents are fortunate to have private insurance, but they still face thousands and thousands of dollars in medical bills each year so that she can get the care she needs. And perhaps even harder she, like other diabetics, has to monitor her blood sugar levels and stick herself multiple times a day for testing. And in order for her to play at a friend's house, to run outside, or even eat lunch at school, she has to prick her finger and check her blood sugar.

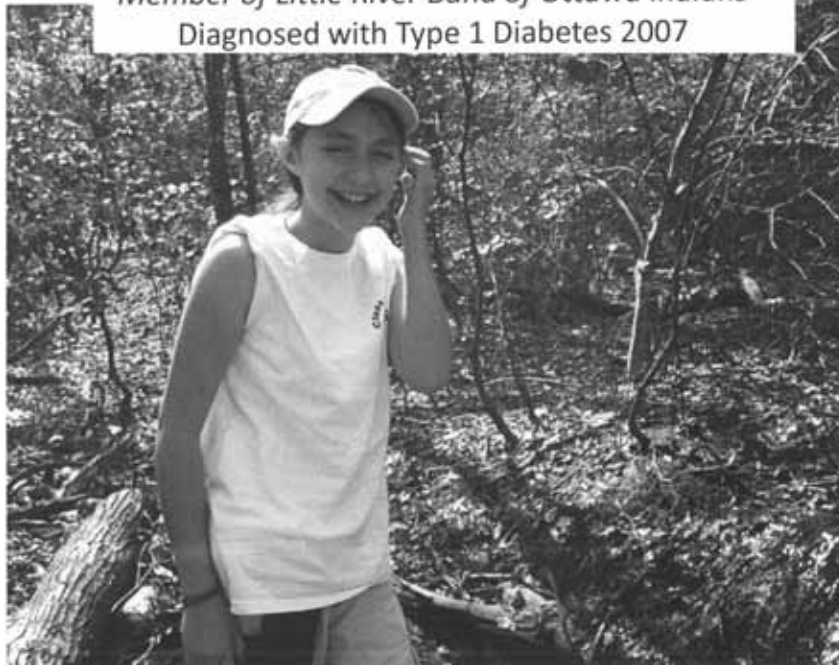
She once wrote a letter to the President of the United States to talk about the issues that impact the lives of diabetic kids every single day. I believe that Izzy is with us here today. Izzy are you here? Can you stand up?

We thank you very much for being with us today. We thank you for witnessing the kind of circumstances and the kind of treatment that is needed for diabetics of all ages, but especially diabetics who are young people who live on Indian reservations. Izzy, thank you for being with us. That is a pretty good picture of you, by the way.

[Laughter.]

Isabel "Izzy" Burger

Member of Little River Band of Ottawa Indians
Diagnosed with Type 1 Diabetes 2007



The CHAIRMAN. Let me, before I call on the witnesses, call on my colleagues for any comments. Again, as I said, we have held a number of hearings on diabetes because, if you go onto a reservation, you are not there very long without understanding that diabetes is a very special scourge to Native Americans. And it is something that we just have to continue to try to put all the spotlights together to find ways to address this.

The CHAIRMAN. Senator Johnson?

STATEMENT OF HON. TIM JOHNSON, U.S. SENATOR FROM SOUTH DAKOTA

Senator JOHNSON. Thank you, Mr. Chairman, for holding this critical, important hearing. Too many of our Native people are affected by or susceptible to this devastating disease. The rates throughout Indian Country only continue to grow. I am looking forward to this testimony this morning as we seek solutions to reverse this trend.

Thank you.

The CHAIRMAN. Senator Tester?

STATEMENT OF HON. JON TESTER, U.S. SENATOR FROM MONTANA

Senator TESTER. Yes, thank you, Mr. Chairman. And, as always, I appreciate you bringing forth an issue that is critically important to Indian Country, critically important to the Country as a whole.

As I go around the State of Montana and visit with my friends in Indian Country, almost without exception healthcare is the number one issue and diabetes is the number one issue when we talk about healthcare in Indian Country.

And we have got to have healthy adults to have good parents. And we have got to have healthy kids to be good students. And we need healthy elders for good roll models.

The statistics are plain, they are clear. We have got an incredible problem that we need to do our level best to address, 2.6 times more likely to be diagnosed with diabetes if you are Native American. The death rate is 3 times higher from diabetes than the rest of society.

There are opportunities out there. Education, of course, is one of the keys. Education on the traditional skills, fitness and recreation, foods and recipes, expertise consulting service and provisions of instructional material, all those things are critically important to utilize through travel colleges and high schools and elementary schools as we go forth.

There is one other thing that I think we should be doing. We should really be focusing on technology and stem cell research and those kinds of things to really get to the root of it with Indian Country a part of those research projects.

It is, we have had, or I have been a part of at least, several hearings on diabetes, both in this Committee and other Committees. It is, from my perspective, and I am not a diabetic, but I have got a close, close personal friend who is, it is a terrible disease to have to live with because, as Senator Dorgan pointed out as the picture of Izzy was up on the board, it is something that I think diabetics think about every day when they wake up and every night when they go to bed and the time that is in between. It has incredible challenges associated with it.

So, hopefully this hearing will step us on a path to really come forth with some solutions and ideas to address this problem in Indian Country and, quite honestly, throughout the Country. I think it behooves us all to address it here because it is such an epidemic, but also throughout the whole Country. So, hopefully in Indian Country we can lead the way on this.

Thank you, Mr. Chairman. I appreciate the opportunity.

The CHAIRMAN. Senator Tester, thank you very much. Senator Tester and I held a hearing on the Crow Nation Indian Reservation in Montana a while ago, and the discussion included the issue of diabetes. This is true of almost any hearing on any reservation.

I want to introduce all of the witnesses and then I will call on Dr. Judith Fradkin first.

Dr. Fradkin is a medical doctor with the National Institutes of Health conducting research on diabetes and she is going to tell us about diabetes and the progress made in that field in recent years. Dr. Fradkin, thank you very much for being with us.

Mr. Wes Studi is an actor and a Native American health advocate in Santa Fe, New Mexico. I know Mr. Studi, not personally, but I know him from the Last of the Mohicans and from Dances with Wolves, two movies that I enjoyed very much and enjoyed especially your performance, Mr. Studi.

He is an actor and Native American health advocate living in Santa Fe, New Mexico and he will highlight the prevalence of diabetes in the United States, including in tribal communities, and talk about what is being done to address the rate of diabetes and what more can and must be done to combat the disease.

Mr. Gary Hall is an Olympian swimmer and, like most swimmers, is a tall guy. I met him this morning. I had not met Mr. Hall before, but all very fast swimmers seem to me to be fairly tall. He is a three-time Olympian and a ten-time Olympic medalist in swimming. He will talk about his own experience living as a competitive athlete with Type I Diabetes.

He will also testify about recent advances in diabetes management and progress and trying to find a cure. He has his own foundation dedicated to raising awareness and funding diabetes research.

Dr. Melvina McCabe is a physician, the President of the Association of American Indian Physicians in Albuquerque, New Mexico. She will describe recent research conducted on the prevalence of diabetes among Native Americans including prevention, education and treatment. Also, her experience, she will discuss, as a physician working with tribal communities in trying to prevent treating diabetes.

And finally, Caitlin Baker is a 16-year-old Muscogee Creek Indian from Oklahoma, a Native American youth and competitive swimmer. She works with Native youth, educating them on the importance of a healthy lifestyle including the importance of diabetes prevention. She will discuss these efforts and her organization. Her organization is CAITLINB, which stands for Competitive American Indians Turning Lifestyles Into New Beginnings, a clever use of your name, I might say.

[Laughter.]

The CHAIRMAN. Let us begin with Dr. Fradkin. Thank you very much for being with us, and thanks for your work at the National Institutes of Health. You may proceed.

And I would say to all of the witnesses that your entire statement will be made a part of the permanent record of this Committee, so you are free to summarize.

**STATEMENT OF JUDITH E. FRADKIN, M.D., DIRECTOR,
DIVISION OF DIABETES, ENDOCRINOLOGY AND
METABOLIC DISEASES, NATIONAL INSTITUTE OF DIABETES
AND DIGESTIVE AND KIDNEY DISEASES, NATIONAL
INSTITUTES OF HEALTH, U.S. DEPARTMENT OF HEALTH AND
HUMAN SERVICES**

Dr. FRADKIN. Mr. Chairman and Members of the Committee, as Director of the Division of Diabetes, Endocrinology and Metabolic Diseases at the National Institute of Diabetes and Digestive and Kidney Diseases, thank you for the invitation to participate and testify at this hearing on diabetes.

On behalf of the NIDDK and the National Institutes of Health, I am pleased to report that we are vigorously pursuing research on diabetes and its complications. A high priority of NIH-supported research is to understand and to eliminate the disproportionate burden that diabetes places on minority groups including American In-

dians, the population, as you just noted, that has the highest rate of diabetes in the United States.

Today I would like to tell you about NIH-supported diabetes research, including research supported by the Special Statutory Funding Program for Type I Diabetes Research, which the NIDDK administers.

This program was established by Congress for research on the prevention and cure of Type I Diabetes and has resulted in many scientific advances that are improving the health and quality of life of people with diabetes.

A parallel funding stream, the Special Diabetes Program for Indians, is administered by the Indian Health Service and has led to substantial improvements in diabetes care in the American Indian population.

Mr. Chairman, the need to pursue research on the prevention, treatment and cure of diabetes is greater than ever because the rates of several types of diabetes are rising. The good news is that we have made tremendous progress in recent years which has led to improvements in survival and quality of life for people with diabetes.

Now, thanks to continuous glucose monitoring technology, some parents of young children with Type I Diabetes can sleep through the night without having to arise repeatedly to check the child's blood glucose levels. This device measures blood glucose levels every few minutes and sounds an alarm if levels are above or below target, a technological peace of mind allowing parents to sleep more soundly. The development of this technology was supported, in part, by the NIH's Special Diabetes Program.

Because genetic and antibody tests can now predict with great accuracy which children will develop Type I Diabetes, we can now test prevention strategies. To find new approaches to prevention, we launched the TEDDY study, which is supported by the Special Diabetes Program.

TEDDY researchers have screened over 400,000 newborns to determine if they have genes that put them at increased risk for Type I Diabetes. Over 8,000 of these newborns are enrolled in the study and are being followed until age 15, with a goal of identifying environmental triggers of Type I Diabetes.

To date, the number of children who have developed autoimmunity and Type I Diabetes is exactly as predicted, showcasing the tremendous power of these predictive tests.

The Special Diabetes Program's SEARCH for Diabetes in Youth study is, for the first time, telling us how many children in the U.S. have diabetes, and we will be able to see how these rates change over time.

We can prevent or delay the development of Type II Diabetes in people at high risk for this disease as demonstrated by the NIDDK-led Diabetes Prevention Program clinical trial. A modest amount of weight loss through diet changes and moderate exercise substantially reduced the occurrence of Type II Diabetes at 3, and now at 10 years, after enrollment in the trial.

This intervention worked in all ethnic and racial groups studied, including American Indian populations. The IHS has utilized fund-

ing from the Special Diabetes Program for Indians to launch prevention efforts based on these findings.

For people who already have diabetes, IHS efforts supported by the Special Diabetes Program for Indians have improved blood glucose control among American Indian populations as measured by the A1c test. This is important because NIH-sponsored trials found that good A1c control reduced rates of diabetes complications.

The Type I Diabetes Special Program has supported successful efforts to standardize A1c measurements in clinical laboratories across the Country so physicians can reliably monitor glucose control. This standardization has made possible improvements in A1c levels nationwide, including in vulnerable populations such as American Indians and Alaskan Natives.

Diabetes during pregnancy brings risk to mother and child. Because of the NIH-supported Hyperglycemia and Adverse Pregnancy Outcome Study, we now have precise information on what blood glucose levels should be during pregnancy to avoid complications near birth.

These are just a few examples of how far we have come in recent years through vigorous support of research toward increasing knowledge of diabetes and improving the health of people with the disease. However, much work needs to be done to curb the diabetes epidemic.

For example, it is critical to move beyond continuous glucose monitoring technology and link glucose monitoring to insulin delivery to create a so-called artificial pancreas. This technology could help patients achieve good blood glucose control that has been shown to reduce complications and alleviate the burden of self-care that you just spoke about so eloquently.

Now that we have thousands of samples collected through the TEDDY Study, it is vital to use new and emerging technologies to analyze those samples and identify environmental triggers of Type I Diabetes.

Building on the success of many new available medicines for Type II Diabetes, comparative effectiveness research can help inform doctors' decisions about what medications to prescribe for their patients and when.

Perhaps most important to combating the diabetes epidemic is reversing the trend of both Type I and Type II Diabetes occurring at younger ages because earlier onset of disease means earlier development of complications and premature mortality.

For women, earlier development of diabetes also endangers her offspring. The inter intrauterine environment plays an important role, not only in problems at the time of birth, but also in the future development of diabetes and obesity, a finding observed among the Pima Indians in Arizona. Thus, it is critical to pursue research to break the vicious cycle of ever-growing rates of diabetes by preventing or mitigating the effects of diabetes and obesity during childbearing years and pregnancy.

By building on recent advances in diabetes research, we are poised to realize even greater improvements in the health and quality of life of people with diabetes. We have come far, but we must come further.

Thank you, Mr. Chairman, for your leadership in calling this hearing to continue focusing attention on the importance of diabetes research and for your continued support of NIH research.

[The prepared statement of Dr. Fradkin follows:]

PREPARED STATEMENT OF JUDITH E. FRADKIN, M.D., DIRECTOR, DIVISION OF DIABETES, ENDOCRINOLOGY AND METABOLIC DISEASES, NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES, NATIONAL INSTITUTES OF HEALTH, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mr. Chairman and Members of the Committee: I am Judith Fradkin, Director of the Division of Diabetes, Endocrinology, and Metabolic Diseases of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). Our Institute has primary responsibility for diabetes research at the National Institutes of Health (NIH), an agency of the U.S. Department of Health and Human Services (HHS).

On behalf of the NIDDK and the other Institutes and Centers of the NIH, I am pleased to report that we are vigorously pursuing research on diabetes and its complications. Through collaborative and coordinated research, we are gaining important insights into the molecular mechanisms underlying disease, identifying and testing promising therapies to prevent and treat the disease and its complications, and striving for a cure.

Today I will provide an overview of NIH-supported diabetes research, including research supported by the Special Statutory Funding Program for Type 1 Diabetes Research (Special Diabetes Program), which is led by the NIDDK on behalf of the Secretary, HHS, and is conducted in collaboration with multiple other Institutes and Centers of the NIH and the Centers for Disease Control and Prevention (CDC). A parallel funding stream, the Special Diabetes Program for Indians, is administered by the Indian Health Service (IHS), to address through prevention and treatment the growing problem of diabetes in those communities.

ADVANCES FROM DIABETES RESEARCH

This year marks the NIDDK's 60th anniversary of conducting and supporting research to combat debilitating diseases within its mission, including diabetes. Diabetes is a devastating disease that affects approximately 23.6 million people in the U.S. and is the seventh leading cause of death.¹ Diabetes lowers average life expectancy by up to 15 years,² increases cardiovascular disease risk two- to four-fold, and is the leading cause of kidney failure, lower limb amputations, and vision loss in working age adults.³ In addition to the human costs, the estimated total financial cost for diabetes in the U.S. in 2007 was \$174 billion.⁴

¹ CDC. National diabetes fact sheet: general information and national estimates on diabetes in the United States, 2007. Atlanta, GA: U.S. Department of Health and Human Services, CDC, 2008.

² Portuese E and Orchard T: Mortality in Insulin-Dependent Diabetes. In *Diabetes in America* (pp. 221-232). Bethesda, MD: National Diabetes Data Group, NIH, 1995.

³ CDC. National diabetes fact sheet: general information and national estimates on diabetes in the United States, 2007. Atlanta, GA: U.S. Department of Health and Human Services, CDC, 2008.

⁴ *ibid*

Diabetes is characterized by the body's inability to produce and/or respond appropriately to insulin, a hormone that is necessary for the body to absorb and use glucose, or sugar, as a cellular fuel. The most common forms of the disease are type 1 diabetes, in which the body loses its ability to produce insulin, and type 2 diabetes, which is due to a combination of insulin resistance and insufficient insulin production. Women can also develop gestational diabetes, a risk factor for type 2 diabetes, during pregnancy. Rarer forms of diabetes also exist.

To appreciate the tremendous progress that has been achieved in recent decades, we can look back at how diabetes was treated in 1950, at the inception of the Institute. Sixty years ago, patients monitored their blood glucose levels with urine tests, which recognized high but not dangerously low glucose levels and reflected hours-old, not current, glucose levels. People with type 1 diabetes relied on painful injections of animal-derived insulin. People with type 2 diabetes had few treatment options: injections of insulin or drugs that stimulated insulin release from the beta cells of the pancreas. Both of these therapies had associated risks. No proven strategies existed to prevent disease complications, such as blindness, heart disease, kidney disease, and nerve damage.

Insights gained from NIDDK- and NIH-supported research over the past 60 years have contributed to a knowledge base leading to improvements in survival and quality of life for people with diabetes. Doctors now use simple blood tests to diagnose diabetes and to assess long-term blood glucose control. People at high risk for type 2 diabetes can prevent or delay disease onset by losing a modest amount of weight through dietary changes and moderate exercise. People with type 1 diabetes can reduce their risk for complications by intensively controlling blood glucose levels. Doctors can prescribe new classes of oral drugs and combinations of drugs to treat people with type 2 diabetes. Patients can use new technologies, such as insulin pumps and continuous glucose monitors, to manage their diabetes. As a result of these past accomplishments, people with diabetes are living longer and healthier lives than ever before. I am pleased to provide you with a few specific examples of how NIH-supported research has contributed to these tremendous improvements in the health and quality of life of people with diabetes.

RESULTS OF MAJOR CLINICAL TRIALS AND TRANSLATING THOSE RESULTS TO
IMPROVE PUBLIC HEALTH

One approach to combat the diabetes epidemic in the U.S. is to prevent the disease. A landmark clinical trial studying type 2 diabetes prevention was spearheaded by the NIDDK. The Diabetes Prevention Program (DPP) clinical trial showed that people with pre-diabetes—defined as having blood glucose levels that are higher than normal but not yet high enough to be diagnosed as diabetes—can dramatically reduce their risk of developing type 2 diabetes through lifestyle changes that achieve modest weight loss or through treatment with the drug metformin.⁵ The interventions worked in all ethnic and racial groups studied, including American Indian participants, in both men and women, and in women with a history of gestational diabetes. Research now shows that, after a 10-year period of following DPP participants, the interventions result in long-term benefits: people still had a lower risk of developing type 2 diabetes and those who made lifestyle changes also had reduced cardiovascular risk despite taking fewer drugs to control their heart disease risk factors.⁶ IHS diabetes programs were among the first to implement the DPP results into diabetes prevention programs for American Indians and Alaska Natives, with advice and guidance from NIDDK scientists. Results from IHS' ongoing evaluation are demonstrating the same outcomes that were achieved in the DPP study.

Building on these critically important results, the NIDDK supports research to translate DPP findings to improve public health and benefit the approximately 57 million Americans with pre-diabetes.⁷ One successful research effort utilizes local YMCAs for delivering a group-based DPP lifestyle intervention. A pilot study showed that this group-based approach reduces costs to deliver the intervention, while achieving similar levels of weight loss in participants,⁸ a larger trial is ongoing. Based on these impressive findings, earlier this year, United Health Group announced a partnership with YMCAs to offer a diabetes prevention program in six U.S. cities, with plans for a national roll out over the next couple of years.

⁵ Knowler WC, et al. Reduction in the incidence of type 2 diabetes with lifestyle intervention or metformin. *N Engl J Med* 346:393-403, 2002.

⁶ Diabetes Prevention Program Research Group, et al. 10-year follow-up of diabetes incidence and weight loss in the Diabetes Prevention Program Outcomes Study. *Lancet* 374:1677-86, 2009.

⁷ CDC. National diabetes fact sheet: general information and national estimates on diabetes in the United States, 2007. Atlanta, GA: U.S. Department of Health and Human Services, CDC, 2008.

⁸ Ackermann RT, et al. Translating the Diabetes Prevention Program into the community. The DEPLOY Pilot Study. *Am J Prev Med*. 35: 357-63, 2008.

Another way that the DPP results are being translated to the public and health care providers is through the National Diabetes Education Program (NDEP), which is a partnership between the NIDDK and the CDC. The NDEP developed the “Small Steps. Big Rewards. Prevent Type 2 Diabetes” education campaign to disseminate the DPP results. The IHS has been a critical NDEP partner, helping to create and disseminate culturally appropriate messages for American Indian and Alaska Native communities. The NIDDK and its collaborators remain dedicated to building on the tremendous successes to date in order to take advantage of new and emerging opportunities to expand type 2 diabetes prevention efforts, including to American Indian and Alaska Native populations.

Another NIDDK-led clinical trial has changed the face of type 1 diabetes management. The Diabetes Control and Complications Trial (DCCT), and its follow-on, the Epidemiology of Diabetes Interventions and Complications (EDIC) study, conclusively demonstrated that early and intensive blood glucose control prevented or delayed the debilitating complications of type 1 diabetes involving the heart, eyes, kidneys, and nerves.⁹ These impressive findings, which were supported in part by the Special Diabetes Program, have revolutionized the management of type 1 diabetes, as physicians now recommend that people control their disease as early and intensively as possible. Intensive treatment is being translated into improved health, as researchers recently reported that the outlook for people with longstanding type 1 diabetes has greatly improved in the past 20 years.¹⁰

The NIDDK-supported United Kingdom Prospective Diabetes Study showed that people with type 2 diabetes also benefit from improved glucose control early in the course of the disease with respect to reducing rates of disease complications.¹¹ However, in people with long-standing type 2 diabetes who also are at high risk for heart disease, more intensive blood glucose control than is currently recommended by treatment guidelines can be dangerous, as demonstrated in the ACCORD clinical trial, which is led by NIH’s National Heart, Lung, and Blood Institute.¹² The

⁹ The Diabetes Control and Complications Trial Research Group. The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *N Engl J Med* 329: 977-986, 1993; Nathan DM, Cleary PA, Backlund JY, et al. Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications (DCCT/EDIC) Study Research Group. Intensive diabetes treatment and cardiovascular disease in type 1 diabetes mellitus. *N Engl J Med* 353: 2643-2653, 2005.

¹⁰ DCCT/EDIC Research Group, et al. Modern-day clinical course of type 1 diabetes mellitus after 30 years' duration: the diabetes control and complications trial/epidemiology of diabetes interventions and complications and Pittsburgh epidemiology of diabetes complications experience (1983-2005). *Arch Intern Med* 169:1307-16, 2009.

¹¹ Holman RR, et al. 10-year follow-up of intensive glucose control in type 2 diabetes. *N Engl J Med* 359:1577-89, 2008.

¹² Action to Control Cardiovascular Risk in Diabetes Study Group, et al. Effects of intensive glucose lowering in type 2 diabetes. *N Engl J Med* 358: 2545-49, 2009; ACCORD Study Group, et al. Effects of intensive blood-pressure control in type 2 diabetes

trial found that lowering blood pressure to normal levels did not significantly reduce the risk of cardiovascular events overall, although it may reduce the risk of stroke. In the lipid trial, combination therapy of a statin and a fibrate appeared to be safe, but did not lower the risk of heart attack, stroke, or death from heart disease more than statins alone. The ACCORD findings indicate that people who have longstanding type 2 diabetes and are at high risk for a cardiovascular event and are well controlled as per current recommendations do not need to be treated more intensively to reduce heart attacks, strokes, and other cardiovascular events. Thus, such controlled patients can be spared from unnecessary additional medications. These key results from type 2 diabetes clinical trials suggest that, rather than a one-size-fits-all approach, recommendations for treating people with type 2 diabetes can be personalized. Again, with advice and guidance from NIDDK scientists, IHS has successfully translated these results into practice in American Indian and Alaska Native communities through an intensive case management approach called the Healthy Heart Project through the Special Diabetes Program for Indians.

Further insights into the management of type 2 diabetes are expected to emerge from the NIDDK-led Look AHEAD (Action for Health in Diabetes) clinical trial, which is examining the health effects of a lifestyle intervention designed to achieve and maintain weight loss over the long term in over 5,000 overweight and obese adults with type 2 diabetes. Encouraging results are already emerging. After following participants for 1 year, researchers found that people in the intensive lifestyle arm showed improved diabetes, blood pressure, and lipid control, with reduced medication use and costs.¹³ After 4 years, researchers observed a sustained effect of the lifestyle intervention on weight loss, as well as improved glucose control with reduced medication use.¹⁴ Participants continue to be followed to assess longer-term outcomes. The trial includes American Indian participants, and the IHS has been an important partner in conducting the trial. These are just a few examples of the NIH-supported clinical trials that have provided unprecedented insights into diabetes prevention and management.

mellitus. *N Engl J Med* 362:1575-85, 2010; ACCORD Study Group, et al. Effects of combination lipid therapy in type 2 diabetes mellitus. *N Engl J Med* 362: 1563-74, 2010.

¹³ Redmon JB, et al. Effect of the look AHEAD study intervention on medication use and related cost to treat cardiovascular disease risk factors in individuals with type 2 diabetes. *Diabetes Care* 33: 1153-8, 2010.

¹⁴ The Look AHEAD Study: Design of the Lifestyle Intervention and Four-Year Weight Losses. Presented at the American Diabetes Association 69th Scientific Sessions, June 2009. Publication in press, *Archives Int Medicine*.

DISPROPORTIONATE IMPACT ON MINORITY POPULATIONS

Type 2 diabetes occurs more frequently among racial and ethnic minority groups in the U.S., including American Indians, African Americans, Hispanic/Latino Americans, and Asians/Pacific Islanders.¹⁵ In fact, American Indians have the highest rates of type 2 diabetes in this country.¹⁶ Because of this disparity, the NIH has included large numbers of minority participants in its type 2 diabetes studies. For example, nearly half of the DPP participants were from minority groups, and the interventions worked in all groups. Those results are being translated in culturally appropriate ways through the NDEP and other translational research efforts.

Type 2 diabetes is an emerging health problem in youth, particularly minority youth, being driven by the obesity epidemic. The NIH and its partners are tackling this issue on many fronts. For example, just this week, researchers announced results from the NIDDK-led HEALTHY clinical trial, which examined whether a middle-school based intervention could lower risk factors for type 2 diabetes. The study was conducted in schools with a high enrollment of minority children and youth from low-income families. The intervention was found to lower the obesity rate in students at highest risk for type 2 diabetes—those who started out overweight or obese in sixth grade. However, schools that implemented the program did not differ from comparison schools in the study's primary outcome—the prevalence of overweight and obesity combined—which had declined by 4 percent in both the intervention and control schools by the end of the 3-year study.¹⁷ These results are important for informing future school-based efforts to reduce overweight and obesity in children, and the IHS can use and build upon these results as they consider approaches to improve health in their young populations.

Another school-based effort is the Diabetes Education in Tribal Schools (DETS) Project, on which NIDDK and IHS partner. The DETS Project is a K-12 curriculum focused on increasing American Indian/Alaska Native students' understanding of health, diabetes, and maintaining life in balance; understanding and application of scientific and community knowledge; and interest in science and health professions. DETS provides an opportunity to reach beyond supporting diabetes-related research to provide the resources to support the

¹⁵ CDC. National diabetes fact sheet: general information and national estimates on diabetes in the United States, 2007. Atlanta, GA: U.S. Department of Health and Human Services, CDC, 2008.

¹⁶ *ibid*

¹⁷ Presented at the American Diabetes Association 70th Annual Sessions, June 2010.

translation of science to the community to have a more long-term beneficial impact on the health of American Indians and Alaska Natives. IHS has played a critical role in the development and dissemination of the DETS curriculum throughout the Indian health system. The NIDDK is currently building on the success of the DETS Project to develop a K-12 curriculum for African American and Hispanic students.

For children who already have type 2 diabetes, the NIDDK supports the Treatment Options for Type 2 Diabetes in Adolescents and Youth (TODAY) clinical trial at centers around the country, to test three different treatment regimens for type 2 diabetes in children 10-17 years of age. A large percentage of children who are enrolled in this study are from minority groups disproportionately burdened with type 2 diabetes; the TODAY center at the University of Oklahoma is enrolling American Indian youth into the trial. Through TODAY and other studies, the NIDDK hopes to ameliorate type 2 diabetes and its complications in this most vulnerable population.

Gestational diabetes mellitus (GDM) also disproportionately affects minority groups. Although this form of diabetes generally goes away after the baby is born, it leaves both mother and child at increased risk for developing type 2 diabetes. Important insights about GDM have emerged from the Hyperglycemia and Adverse Pregnancy Outcome (HAPO) study, which is led by NIH's *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD). The HAPO study showed that the higher a pregnant woman's blood glucose is, the higher her risk of pregnancy complications—whether or not her blood glucose reached the level at which GDM was diagnosed at the time of the study.¹⁸ The effect is significant enough that a recent panel of experts has recommended changing the diagnostic criteria for GDM to be less stringent, such that under the proposed new guidelines, the prevalence of GDM will more than double.¹⁹ The good news is that the DPP showed that a healthy diet and exercise can help prevent later type 2 diabetes in women who have had GDM. For this reason, the NDEP, in collaboration with the NIH Office of Research on Women's Health, recently expanded its educational campaign for women with a history of GDM to raise awareness of the health risks for these women and their offspring.

¹⁸ HAPO Study Cooperative Research Group, et al. Hyperglycemia and adverse pregnancy outcomes. *N Engl J Med* 358: 1991-2002, 2008.

¹⁹ International Association of Diabetes and Pregnancy Study Groups Consensus Panel. International association of diabetes and pregnancy study groups recommendations on the diagnosis and classification of hyperglycemia in pregnancy. *Diabetes Care* 33: 676-82, 2010.

RESEARCH SUPPORTED BY THE SPECIAL DIABETES PROGRAM

Through support from the Special Diabetes Program, the NIH is supporting a wide range of diabetes research efforts that are having a far reaching impact. For example, the NIH supports research to improve diabetes treatment strategies, to help patients achieve blood glucose control associated with reduced rates of complications and to reduce the burden of diabetes self-care. Research supported by the Special Diabetes Program contributed to the development of continuous glucose monitoring technologies, which reveal dynamic changes in blood glucose levels by assessing glucose levels hundreds of times per day and displaying trends. The NIH is committed to capitalizing on this technology and supports research on “artificial pancreas” technology to “close the loop” and link insulin delivery to continuous glucose measurements. This technology has the potential to benefit people with both forms of diabetes.

The NIDDK also supports research on cell replacement therapy for people with diabetes, which could potentially restore the body’s ability to produce sufficient levels of insulin and properly control blood glucose levels. The NIDDK-led Beta Cell Biology Consortium is making significant progress in understanding beta cell biology and development toward the goal of generating unlimited supplies of beta cells in the laboratory for transplantation, or promoting growth of new beta cells in the pancreas. Because impaired function of the beta cell is central to both type 1 and type 2 diabetes, this research can inform treatment strategies for people with both forms of the disease.

Although the DPP identified effective strategies to prevent or delay type 2 diabetes, disease prevention remains a major goal of type 1 diabetes research. The NIDDK-led Type 1 Diabetes TrialNet is tackling this goal by conducting prevention trials, including a trial testing whether oral insulin could prevent the disease in people who have high levels of antibodies to insulin (a pre-clinical marker of disease). TrialNet plans to launch a second prevention trial with an agent proven to slow beta cell loss in new onset type 1 diabetes. An NICHD-led clinical trial, called TRIGR (Trial to Reduce the Incidence of Type 1 Diabetes in the Genetically at Risk), is determining whether weaning newborns at risk for type 1 diabetes to extensively-hydrolyzed formula, as compared to standard cow’s milk formula, will reduce the risk of developing type 1 diabetes.

Type 1 diabetes has a strong genetic basis that is modified by environmental factors. The last few years have seen unprecedented discoveries in type 1 diabetes genetics research. Recent research through the Type 1 Diabetes Genetics Consortium and their collaborators has identified over 40 genes or genetic regions associated with type 1 diabetes.²⁰ The NIDDK is now supporting research to pinpoint the exact genes involved and to understand their function in health and disease. New insights about the genetic underpinnings of type 1 diabetes can inform new strategies for prevention or treatment, and even on a personalized or customized basis.

With respect to environmental factors, The Environmental Determinants of Diabetes in the Young (TEDDY) study has recently completed recruitment of over 8,000 newborns at high genetic risk for type 1 diabetes and is now following them to age 15 to identify environmental triggers of disease. Identification of a dietary or infectious cause of type 1 diabetes could have an enormously positive impact on public health through a diet change or vaccine for disease prevention, for example. To maximize the return on the investment in TEDDY, samples from the study will be made widely available to researchers worldwide. Importantly, TEDDY may also contribute to understanding the development of celiac disease, which is an autoimmune disease primarily affecting the gastrointestinal tract. Some genes confer susceptibility to both celiac disease and type 1 diabetes, and many people have both diseases. Thus, TEDDY may benefit not only people with, or at-risk for, type 1 diabetes, but also people with celiac disease and other autoimmune diseases.

New insights about diabetes in youth are stemming from the CDC-led SEARCH for Diabetes in Youth study, which is a multicenter epidemiological study identifying cases of diabetes in children and youth less than 20 years of age in six geographically dispersed populations that encompass the ethnic diversity of the United States. SEARCH is defining the incidence and prevalence of diabetes in youth, including American Indian youth, which is important for informing public health efforts. Because of SEARCH, for the first time we know how many children in the U.S. have diabetes, and we will be able to see how the rates are changing over time. This knowledge could help to explain the findings from HEALTHY showing that overweight and obesity rates seemed to fall in both the intervention and control schools; SEARCH could help us determine if this trend is also being seen on a broader level. In

²⁰ Barrett JC, et al. Genome-wide association study and meta-analysis find that over 40 loci affect risk of type 1 diabetes. *Nature Genetics* 41: 703–707, 2009.

addition, SEARCH has found that, for Asian/Pacific Islander and American Indian youth aged 10–19 years, the rate of new cases of type 2 was greater than the rate for type 1 diabetes.²¹ IHS is currently working with the CDC to develop a national diabetes in youth registry, using SEARCH criteria, in order to track the rates amongst many tribes. With ongoing surveillance through SEARCH we may be able to see the effects of programs, such as the DETS curriculum, NDEP campaigns, and IHS efforts, on the health of American Indian/Alaska Native youth.

Although most children are accurately diagnosed with type 1 or type 2 diabetes, a subset of children may have clinical characteristics that overlap between the two major forms of diabetes, making it difficult for physicians to easily determine diabetes type. To address this issue, SEARCH is also leading an effort to classify diabetes type in youth by developing clinical definitions and epidemiologic definitions of diabetes type, which is important not only for SEARCH research, but also for clinical purposes to ensure that all children with diabetes are accurately diagnosed and given the proper treatment.

Contributing to these efforts is a research program to standardize the measurement of autoantibodies in blood that are predictive of type 1 diabetes. This standardization has enabled improved characterization of childhood diabetes through the SEARCH study and an appreciation of the existence of hybrid forms of diabetes having characteristics of both type 1 and type 2. Accurate antibody measurement has also benefited enrollment in the TODAY clinical trial, which, as I mentioned earlier, is testing different treatment options for type 2 diabetes in youth. More precise antibody measures have allowed more patients to enroll into the trial because eligibility excluded those with autoimmunity, and previous assays were non-specifically falsely identifying some potential participants as having autoimmunity.

Another program is improving standardization of hemoglobin A1c (HbA1c), which is a measurement that provides information on a person's average blood glucose levels for the past 2-3 months. This standardization program has been critical to IHS's efforts to improve type 2 diabetes control in the populations it serves. Standardization has permitted the IHS to compare people's HbA1c levels over time and across different sites, to evaluate the impact of their programs and demonstrate substantial improvements in diabetes care in American Indian/Alaska Native populations. In addition, building on the success of the standardization program, the

²¹ CDC. National diabetes fact sheet: general information and national estimates on diabetes in the United States, 2007. Atlanta, GA: U.S. Department of Health and Human Services, CDC, 2008.

American Diabetes Association recently recommended HbA1c as a more convenient approach to diagnose type 2 diabetes.²² Last month the IHS incorporated these new recommendations into its Standards of Care for Diabetes, used throughout the Indian health system to guide the diagnosis and treatment of diabetes. Thus, this standardization program, as well as numerous other research efforts supported by the Special Diabetes Program, are not only benefiting people with type 1 diabetes, but are having a far-reaching impact toward improving health.

DIABETES PROGRAMS IN INDIAN COUNTRY

Currently, the IHS Division of Diabetes Treatment and Prevention (DDTP) provides leadership and programmatic oversight to the diabetes teams and programs that exist in most communities served by the Indian health system. The mission of DDTP is to develop, document, and sustain a public health effort to prevent and control diabetes in American Indians/Alaska Natives. This mission is accomplished by promoting collaborative strategies for the prevention of diabetes and its complications to over 1.9 million American Indians and Alaska Natives through an extensive American Indian and Alaska Native diabetes network. The network consists of a national program office; Area Diabetes Consultants in each of the 12 IHS Areas; 19 Model Diabetes programs in 23 different IHS and Tribal sites, and over 500 diabetes teams and programs at local IHS, Tribal and Urban (ITU) Indian health settings, both Special Diabetes Program for Indians (SDPI) grant programs and non-SDPI programs. This extensive diabetes network supports these diabetes teams and programs by providing administrative and programmatic support, training and technical assistance, and the dissemination of the latest scientific findings and "best practices" to the programs. The IHS combines both clinical and public health approaches to address the problem of diabetes and its complications.

Congress created the IHS Diabetes Program in 1979 in response to the growing epidemic of diabetes. Much has been achieved since then. Over the years IHS, together with its Tribal and urban partners, has worked toward a common purpose, to prevent and control diabetes, sharing information and lessons learned along the way. The IHS has shown, through its public health evaluation activities, that the ITU programs that have evolved over the years have been very successful in improving diabetes care and outcomes, as well as in launching primary prevention

²² International Expert Committee. International Expert Committee report on the role of the A1C assay in the diagnosis of diabetes. *Diabetes Care* 32: 1327-34.

efforts, on reservations and in urban clinics. An evaluation of the SDPI and diabetes clinical measures suggests that population-level diabetes-related health is better among our American Indian/Alaska Native patients since the implementation of SDPI. The greatest benefit for American Indians and Alaska Natives with diabetes has likely been in the reduction in microvascular complications—eye, kidney and nerve diseases—due to improvement in long-term high blood sugar levels. Further reducing microvascular and macrovascular complications—atherosclerosis, coronary heart disease, stroke, and peripheral vascular disease—will require continued efforts to improve glucose, blood pressure and cholesterol values. However, the greatest long-term benefit will most likely be from the diabetes primary prevention activities now becoming commonplace in American Indian and Alaska Native communities. In its thirty one years, the IHS Diabetes Program has demonstrated the positive public health impact that is possible when Tribal and Congressional initiatives are focused on a common outcome. Here are some examples:

Key clinical outcome measures have significantly improved, such as:

- The mean long-term blood sugar control level (A1C) overall improved significantly from A1C=9.00 percent (1996) to A1C=8.02 percent (2009).
- The mean LDL cholesterol level decreased 24 percent from 118 mg/dl (1996) to 94.5 mg/dl (2009)

Since the start of SDPI, there are:

- 49% more weight management programs for adults
- 58% more nutrition education programs for adults
- 66% more physical activity programs for adults
- 34% more diabetes clinics
- 47% more diabetes registries
- 73% more primary prevention programs for children and youth
- 49% more weight management programs for children and youth
- 44% more school-based healthy eating programs for children and youth
- 45% more school-based physical activity programs for children and youth

In its SDPI Diabetes Prevention and Healthy Heart Demonstration Projects, IHS has demonstrated that:

- People are losing weight.
- Body mass index is going down
- Blood pressure is going down
- Blood sugars are going down
- Blood lipids are going down
- Smoking is decreasing
- Participation in physical activity is increasing.

The IHS has addressed a chronic disease in partnership with Tribes and other Indian organizations as well as collaborative involvement of other federal agencies and private organizations. Positive signs, such as a 33.4% decrease in the incidence of diabetes-related new dialysis cases among American Indians and Alaska Natives nationwide since 1999 as reported by the U.S. Renal Data Service, suggest the positive achievements developed under the program.

COORDINATING RESEARCH ACROSS THE GOVERNMENT

Diabetes research is effectively coordinated throughout the government toward a common goal of improving health. One important venue for coordination is the statutory Diabetes Mellitus Interagency Coordinating Committee (DMICC), which is chaired by the NIDDK and includes other components of NIH and other HHS and federal agencies that support diabetes-related activities, including the IHS.²³ The DMICC facilitates cooperation, communication, and collaboration on diabetes among these government entities. DMICC meetings help members identify emerging issues and opportunities and develop ways in which different government components can work together and build upon each other's expertise and resources. This approach helps ensure that federal diabetes activities are coordinated and not duplicated, and also stimulates collaborations.

The DMICC, with leadership by the NIDDK, has undertaken a diabetes research strategic planning process to help guide federal investment in diabetes research. The draft Plan is

²³ See <http://www2.niddk.nih.gov/AboutNIDDK/CommitteesAndWorkingGroups/DMICC/Default.htm> for list of DMICC members.

currently posted on the NIDDK website and is expected to be finalized later this summer. The Plan was developed as a collaborative effort across federal agencies and with input from the external research and patient advocacy communities. It includes a section on “Special Needs for Special Populations,” which specifically addresses issues related to combating diabetes in minority populations and other special populations including children and pregnant women. The Plan will guide the NIH, other federal agencies, and the investigative and lay communities in our pursuit of a common goal of conquering diabetes.

FUTURE DIRECTIONS FOR RESEARCH

As the NIDDK reflects on the past 60 years of supporting and conducting research on diabetes, it is clear that the scientific progress achieved during that time period has been remarkable. People with the disease are living longer and healthier lives than they did a few short decades ago. However, diabetes still places an enormous personal and economic toll on our country, so it is critically important to continue the pursuit of research to make further improvements in patients’ health and quality of life.

Looking to the future, the NIDDK will continue to build on the landmark scientific discoveries of the past to foster new research breakthroughs. Vital to this effort is the continued vigorous support of basic, pre-clinical, and clinical research, including research to address disparities in minority populations disproportionately burdened by diabetes. NIDDK enjoys a special relationship with IHS, providing ongoing scientific expertise and guidance in translating new research breakthroughs into the real world settings of American Indian and Alaska Native communities. We will continue to foster that relationship in order to ensure that this population has access to cutting-edge science in its fight to prevent and treat diabetes. We will also continue to develop educational materials to disseminate new research findings to patients, their families, and health care providers. Strategic planning and collaboration, including the new Diabetes Research Strategic Plan, will continue to guide future research directions. The NIH will remain steadfast in our goal to support and conduct research that can continue to improve the health of people with and at risk for diabetes.

In closing, thank you Mr. Chairman and members of the Committee for the opportunity to share with you a few highlights of NIH-supported diabetes research efforts. I am pleased to answer any questions you may have.

The CHAIRMAN. Dr. Fradkin, thank you very much for your testimony. There is some hopeful testimony in that statement. I appreciate that a lot.

Mr. Studi, I did not mention, I see from the biography that you also were involved in the film Avatar but, since I am one of the few Americans, based on gross receipts from the box office, that did not see Avatar, I forgot to mention—

Mr. STUDI. That is three people that I know now.

[Laughter.]

The CHAIRMAN. Yes, well, Senator Tester and I are two of the three.

[Laughter.]

Mr. STUDI. You were supposed to keep that to yourself.

[Laughter.]

Mr. STUDI. There is a rumor it may be re-released, this summer.

[Laughter.]

The CHAIRMAN. Thank you for being here, and why don't you proceed.

**STATEMENT OF WES STUDI, PROFESSIONAL ACTOR; MEMBER,
CHEROKEE NATION**

Mr. STUDI. Chairman Dorgan and other members of the Committee, I am honored to be here this morning. And thank you for the opportunity to participate in today's Oversight Hearing entitled A Way Out of the Diabetes Crisis in Indian Country.

My name is Wes Studi and I am a member of the Cherokee Nation of Oklahoma. And while I currently reside in Santa Fe, New Mexico, I was born in a place called Nofire Hollow between Tahlequah and Stillwell in Northeastern Oklahoma.

Now, as a son of a ranch worker, I attended a number of elementary schools throughout Northeastern Oklahoma and finally wound up at a Chilocco Indian agricultural school in Northern Oklahoma as a high schooler.

My first language is Cherokee and I strongly believe in the importance of handing down our language, customs and rich traditions from one generation to the next. I have written two children's books in Cherokee and English both for the Cherokee Bilingual Education Cross Cultural Center in Tahlequah, Oklahoma and I am proud also to have served our nation in combat during the Vietnam War.

And I am very fortunate to have a very, well, I say very, successful film career. I played roles in several, or many motion pictures actually, including Dances with Wolves, the Last of the Mohicans, Geronimo and, yes, as you mentioned, the recent Avatar.

Now, in my film career, I have often portrayed fearless leaders who have battled and fought against formidable challenges. I am also very proud to be here today to honor, actually more proud to be here to honor the leaders in American Indian and Alaska Native communities who have committed themselves to the fight against diabetes.

Now, I am not a scientist or a doctor. I am simply a tribal member who fully understands the toll diabetes has taken, and it reaches far beyond the tribal communities. And clearly, the United States has a diabetes epidemic on its hands.

While we are now beginning to see the costly and damaging effects of this disease in the rest of the nation, it is a problem that is all too familiar for those of us in the Indian Country. For years, Type II Diabetes has ravaged tribal communities and has had a devastating physical, emotional and spiritual impact on our people.

I have family members and friends living with diabetes and I know people in our community who have endured amputations and other devastating complications of diabetes as a result of not having access to quality diabetes care.

Our American Indian and Alaska Native communities have the highest rate of diabetes, as you mentioned, more than double the

prevalence of the general population. In some of our communities, more than half of all adults have been diagnosed with diabetes and diabetes in our youth is on the rise.

We suffer the highest rates of complications and mortality from diabetes, more than three times the national average. We are getting diabetes at earlier ages and are dying in greater numbers from the disease when compared with the rest of the Nation.

However, our story is not just one of suffering, misery and despair. It is also a story of great perseverance, determination and hope for the future. Tribal communities have come together to fight back against diabetes and the destruction it has wrought. Across Indian Country, there are inspiring stories of elders, community leaders, women, men and children who have been empowered with the knowledge, and tools, to effectively combat this disease.

This great work and progress is not accomplished by tribal communities alone. It takes a partnership with and resources from the Federal Government to support the continued research, education, outreach and range of services that have gone into this momentous effort. The success of the Special Diabetes Program, SDP, in particular demonstrates what can be accomplished when we work together.

Established more than a decade ago, the Special Diabetes Program, made up of the Special Diabetes Program for Indians and the Special Diabetes Program for Type I Diabetes, has made significant strides against this disease and has dramatically improved the lives of those with, and risk for, diabetes.

The SDPI now has a presence in 35 States and supports over 450 Indian Health Service tribal and urban Indian health programs. It has allowed tribal communities to implement a wide range of strategies to address the burden of diabetes in a manner that is most effective and culturally appropriate for our diverse and unique communities.

These efforts have shown great success in managing the disease by delaying or eliminating the development of complications and, in some people, preventing the onset of diabetes altogether.

The American Diabetes Association, the National Indian Health Board and the Juvenile Diabetes Research Foundation recently joined together to collect stories from many people whose lives have benefitted from the Special Diabetes Program. The strength, courage and resolve of these citizens rival any of the characters I have ever played on the big screen. I would like to highlight the story of one woman from North Carolina who has taken control of her diabetes and her life.

Ulela Harris of the Eastern Band of Cherokee Indians was diagnosed with diabetes in 1993. Now, although she had eight brothers and sisters with diabetes and lost both her father and sister to complications from the disease, she still did not understand what diabetes was and lacked the knowledge to manage it effectively. At the time of her diagnosis, there was limited clinical support for diabetes management and she was seen by a nutritionist and sent home with medications.

After many years of insulin injections and oral medications, her blood sugar levels were still dangerously high and, in 2007, Ulela joined the Cherokee Diabetes Prevention Program, which provided

her access to the critical case management and diabetes education she needed to manage her diabetes.

One year later, she was able to bring her diabetes under control and no longer required insulin or oral diabetes medication. Through this program, she also lost 35 pounds and has been motivated to take on new challenges such as the First Annual Cherokee Ironman-Ironwoman Triathlon.

It is through the power of story that our American Indian and Alaska Native culture and traditions are passed on from one generation to the next. And Ulela's story is one of the many being told throughout our communities that are gradually replacing stories of the fear and pain of diabetes with new stories of inspiration and hope for our future generations.

Native people have made significant contributions to the current understanding of effective diabetes treatment and prevention. The research conducted among the Pima Indians in the early 1960s alerted this nation to the epidemic of diabetes today.

Today, we are proving that given the appropriate resources and tools to address diabetes, we can make great progress in conquering the challenges of diabetes and saving lives.

While we have hope for the future, the journey is far from over. To continue on this path of hope and progress, we need more resources to conduct research, provide assistance, and purchase the medications necessary, the medications necessary to sustain and expand our SDPI diabetes treatment and prevention programs.

I would like to personally thank you, Chairman Dorgan, for your commitment to the health and well-being of Native people, especially for your leadership to reauthorize the Special Diabetes Program. With ongoing support from members of this Committee, the Congress, tribal communities and the Indian Health System, we can continue to work in partnership to change the landscape of diabetes and transform the overall health and wellness of American Indian and Alaska Native people.

Together, we can continue to fight diabetes, for our ancestors, our tribal communities and our future generations.

Thank you so much for the opportunity to be here today. Thank you so much.

[The prepared statement of Mr. Studi follows:]

PREPARED STATEMENT OF WES STUDI, PROFESSIONAL ACTOR; MEMBER, CHEROKEE NATION

Chairman Dorgan, Vice Chairman Barrasso, other members of the Committee, I am honored to be here this morning. Thank you for the opportunity to participate in today's oversight hearing entitled "A Way Out of the Diabetes Crisis in Indian Country and Beyond."

My name is Wes Studi and I am an enrolled member of the Cherokee Nation. While I currently reside in New Mexico, I was born in Nofire Hollow, Oklahoma (between Stillwell and Tahlequah). As the son of a ranch worker, I attended a number of elementary schools growing up but settled on the Chilocco Indian Boarding School in Northern Oklahoma as a teenager. My first language is Cherokee and I strongly believe in the importance of handing down our language, customs, and rich traditions from one generation to the next. I have written two children's books in Cherokee for the Cherokee Bilingual/Cross Cultural Education Center.

I am proud to have served our nation in combat during the Vietnam War, and I am very fortunate to have a successful film career. I have played roles in several major motion pictures including, "Dances with Wolves," "Last of the Mohicans," "Geronimo: An American Legend," and most recently "Avatar." In my film career I have

often portrayed fearless leaders who have battled and fought against formidable challenges.

I am also very proud to be here today to honor the leaders in American Indian and Alaska Native communities who have committed themselves to the fight against diabetes.

The Burden of Diabetes in American Indian/Alaska Native Populations

I'm not a scientist or a doctor; I am a tribal community member, who fully understands the toll diabetes has taken, reaching far beyond our tribal communities. Clearly, the United States has a diabetes epidemic on its hands. While we are now beginning to see the costly and damaging effects of this disease in rest of the nation, it is a problem that is all too familiar for those of us in Indian Country. For years, type 2 diabetes has ravaged tribal communities and has had a devastating physical, emotional, and spiritual impact on our people. I have family and friends living with diabetes and I know people in our community who have endured amputations and other devastating complications of diabetes as a result of not having access to quality diabetes care.

Our American Indian and Alaska Native communities have the highest rates of diabetes—more than double the prevalence of the general population. In some of our communities, more than half of all adults have been diagnosed with diabetes and diabetes in our youth is on the rise. We suffer the highest rates of complications and mortality from diabetes, *more than three times* the national average. We are getting diabetes at earlier ages and are dying in greater numbers from the disease when compared with the rest of the nation.

The Battle Against Diabetes

However, our story is not just one of suffering, misery and despair—it is also a story of great perseverance, determination and hope for the future. Tribal communities have come together to fight back against diabetes and the destruction it has wrought. Across Indian Country, there are inspiring stories of elders, community leaders, women, men, and even children, who have been empowered with the knowledge and tools to effectively combat this disease.

This great work and progress is not accomplished by tribal communities alone. It takes a partnership with, and resources from, the federal government to support the continued research, education, outreach, and range of services that have gone into this momentous effort. The successes of the Special Diabetes Program (SDP) in particular demonstrate what can be accomplished when we work together.

Established more than a decade ago, the Special Diabetes Program, made up of the Special Diabetes Program for Indians (SDPI) and the Special Diabetes Program for Type 1 Diabetes, has made significant strides against this disease and have dramatically improved the lives of those with, and at risk for, diabetes. The SDPI now has a presence in 35 states and supports over 450 Indian Health Service, Tribal and Urban Indian health programs. It has allowed tribal communities to implement a wide range of strategies to address the burden of diabetes in a manner that is most effective and culturally appropriate for our diverse and unique communities. These efforts have shown great success in managing the disease by delaying or eliminating the development of complications, and in some people, preventing the onset of diabetes all together.

Taking Control

The American Diabetes Association, the National Indian Health Board, and the Juvenile Diabetes Research Foundation recently joined together to collect stories from the many people whose lives have benefitted from the Special Diabetes Program. The strength, courage and resolve of these citizens rival any of the characters I have portrayed on the big screen. I would like to highlight the story of one woman from North Carolina who has taken control of her diabetes and her life. Ulela Harris of the Eastern Band of Cherokee Indians was diagnosed with diabetes in 1993. Although she had eight brothers and sisters with diabetes and lost both her father and sister to complications from the disease, she still didn't understand what diabetes was and lacked the knowledge to manage it effectively. At the time of her diagnosis, there was limited clinical support for diabetes management and she was seen by a nutritionist and sent home with medications. After many years of insulin injections and oral medications, her blood sugar levels were still dangerously high. In 2007, Ulela joined the Cherokee Diabetes Prevention Program, which provided her access to the critical case management and diabetes education she needed to self manage her diabetes. One year later, she was able to bring her diabetes under control and no longer required insulin or oral diabetes medications. Through this program, she lost 35 pounds and has been motivated to take on new challenges, such as the first annual Cherokee Ironman-Ironwoman Triathlon.

It is through the power of story that our American Indian and Alaska Native culture and traditions are passed on from one generation to the next. Ulela's story is one of the many being told throughout our communities that are gradually replacing stories of the fear and pain of diabetes with new stories of inspiration and hope for our future generations.

Hope for the Future

Native people have made significant contributions to the current understanding of effective diabetes treatment and prevention. The research conducted among the Pima Indians in the early 1960's alerted this nation to the epidemic of diabetes. Today, we are proving that, given the appropriate resources and tools to address diabetes, we can make great progress in conquering the challenges of diabetes and saving lives.

While we have hope for the future, the journey is far from over. To continue on this path of hope and progress, we need more resources to conduct research, provide assistance, and purchase the medications necessary to sustain and expand our SDPI diabetes treatment and prevention programs.

I would like to personally thank you Chairman Dorgan for your commitment to the health and well being of our Native people, especially for your leadership to reauthorize the Special Diabetes Program. With ongoing support from members of this committee, the Congress, tribal communities, and the Indian health system, we can continue to work in partnership to change the landscape of diabetes and transform the overall health and wellness of American Indian and Alaska Native people. Together, we can continue to fight diabetes, for our ancestors, our tribal communities and our future generations.

Thank you for the opportunity to be here before you today. I would be happy to answer any questions you may have for me.

The CHAIRMAN. Mr. Studi, thank you very much for your passion and your willingness to come to Washington, D.C. and provide that testimony.

And Mr. Gary Hall. Mr. Hall, thank you for traveling here as well. I believe you told me you are from Seattle, so that is some long distance. We appreciate your work and your willingness to testify. You may proceed.

**STATEMENT OF GARY HALL, JR., THREE-TIME OLYMPIAN
SWIMMER, TEN-TIME OLYMPIC MEDALIST**

Mr. HALL. Good morning. Thank you, Chairman Dorgan. And members of the Committee, thank you.

My name is Gary Hall, Jr. It is my honor to appear before you today to speak about the influence of Type I Diabetes on my life and the impact of research in managing and preventing and curing diabetes.

My family's ties to swimming run deep and I have been drawn to the water my entire life. I won my first national title when I was 18, and continued my success at the University of Texas, after which I won two gold and two silver medals at the 1996 Olympics. Things were going according to plan and I felt really good about my path in life.

In 1999, my world changed. Having no previous exposure to diabetes, I was caught off guard when I started experiencing symptoms of the disease. I was extremely tired, constantly dehydrated, and had blurred vision. Finally, I collapsed.

I was diagnosed with Type I Diabetes. My immune system was attacking the insulin-producing cells in my pancreas, and I would need to inject or pump insulin into my body several times a day, every day, for the rest of my life. My entire life had changed forever.

My previous focus on training shifted to learning of insulin shots, glucose tests and carbohydrate ratios. I took time off from swimming and, with the help of the Juvenile Diabetes Research Foundation, devoted myself to researching this disease.

It shocked me to learn about the complications associated with both Type I and Type II Diabetes. Blindness, amputations, kidney failure and stroke were now closer to becoming a reality for me than I ever thought.

Diabetes is a terrifying disease. But I resolved not to let it stop me or the pursuit of my dreams. I soon returned to swimming determined not only to win at the sport, but also to show the world I could do it with diabetes. And as I sit before you today, I am proud to say I accomplished just that. Since being diagnosed with Type I Diabetes, I won six medals at the 2000 and 2004 Olympic Games for the United States.

All of my accomplishments cannot change the severity of this disease and the heavy toll it is taking on my body. While I hope that my story is an inspiration for those living with diabetes, I must say that all of the children, adults and families impacted by this disease are truly the greatest inspiration to me. Knowing the reality of life with diabetes, I am constantly amazed at the stories of families and individuals who give back while persevering through this disease.

Take Anela from Hawaii, who was diagnosed with Type I Diabetes when she was 9 years old. She is so determined to be part of the cure that she enrolled in a research trial studying the environmental factors that may contribute to diabetes. Anela is actively helping researchers determine the cause of diabetes so they can find a cure for it.

Another example is Scott from Nevada, whose son was diagnosed with Type I Diabetes when he was 8 years old. With no family history of diabetes, Scott enrolled in a clinical research study that showed he was at high risk for developing diabetes.

Five years later, when he was eventually diagnosed, he immediately enrolled in another study to test a drug designed to halt the autoimmune attack involved in Type I Diabetes. Years later, Scott still produces some of his own insulin, and the drug appears to be slowing the progression of the disease and the development of complications.

By participating in research, Anela and Scott have contributed to the tremendous advancement in diabetes treatments and technologies that are improving the lives of people living with diabetes.

These advancements would not be possible without the Special Diabetes Program, which funds 35 percent of all diabetes research at the National Institutes of Health. This program supports the large-scale, multi-center research trials like the ones Anela and Scott participated in, and also funds critical diabetes education, treatment and prevention programs for Native Americans.

Thanks to the Special Diabetes Program, research has moved from the lab to human clinical trials that are identifying those at high risk for Type I Diabetes and testing therapies to prevent the onset of the disease and slow its progression. This program is funding groundbreaking research to help advance an artificial pancreas

that would help patients achieve better glucose control, reducing the risk of diabetes complications.

And on the complications front, a clinical trial funded by the Special Diabetes Program recently confirmed the ability to halt, and even reverse, diabetic eye disease, or retinopathy, which is the leading cause of adult onset blindness.

I would like to offer a special thanks to Chairman Dorgan for sponsoring legislation, along with Senator Susan Collins, to renew the Special Diabetes Program this year. Mr. Chairman, your extraordinary leadership and commitment to renew this program is deeply appreciated by me and all people living with diabetes.

I would also like to thank Vice Chairman Barrasso and the members of this Committee, a majority of which are co-sponsors of Senator Dorgan's legislation, S. 3058. This program is drastically changing, if not saving, the lives of countless Americans living with diabetes. Its renewal will bring us one step further along on our path to a cure for this devastating disease, and provides hope.

Thank you again for having me here today and for your commitment to diabetes research and the individuals across this Country living with diabetes.

Thank you.

[The prepared statement of Mr. Hall follows:]

PREPARED STATEMENT OF GARY HALL, JR., THREE-TIME OLYMPIAN SWIMMER,
TEN-TIME OLYMPIC MEDALIST

Good morning. Thank you Chairman Dorgan, Vice Chairman Barrasso, and members of the Committee. My name is Gary Hall, Jr., and it is my honor to appear before you today to speak about the influence of type 1 diabetes on my life and the impact of research in managing, preventing and curing diabetes.

My family's ties to swimming run deep, and I've been drawn to the water my entire life. I won my first national title when I was 18 and continued my success at the University of Texas, after which I won 2 gold and 2 silver medals in the 1996 Olympics. Things were going according to plan, and I was feeling really good about my path in life.

In 1999, my world changed. Having no previous exposure to diabetes, I was caught off guard when I started experiencing symptoms of the disease. I was extremely tired, constantly dehydrated, and had blurred vision. Finally, I collapsed.

Later in the hospital, I was diagnosed with type 1 diabetes. My immune system was attacking the insulin-producing cells in my pancreas, and I would need to inject or pump insulin into my body several times a day, every day, for the rest of my life. Within hours, my entire life had changed forever. My previous focus on training shifted to learning of insulin shots, glucose tests and carbohydrate ratios.

I took time off from swimming and, with the help of the Juvenile Diabetes Research Foundation, devoted myself to researching this disease. It shocked me to learn about the complications associated with both type 1 and type 2 diabetes. Blindness, amputations, kidney failure and stroke were now closer to becoming a reality for me than I had ever imagined. Diabetes is a terrifying disease, but at that moment, I resolved not to let it stop me or the pursuit of my dreams.

I soon returned to swimming, determined not only to win at the sport, but also to show the world I could do it with diabetes. And as I sit before you today, I am proud to say I accomplished just that. Since being diagnosed with type 1 diabetes, I have won 6 medals in the 2000 and 2004 Olympic games.

All of my accomplishments can't change the severity of this disease and the heavy toll it is taking on my body. While I hope that my story is an inspiration for those living with diabetes, I must say that all of the children, adults, and families impacted by this disease are truly the greatest inspiration to me. Knowing the reality of life with diabetes, I am continually amazed at the stories of families and individuals who give back while persevering through this disease.

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By participating in research, Anela and Scott have contributed to the tremendous advancements in diabetes treatments and technologies that are improving the lives of people living with diabetes. These advancements would not be possible without the Special Diabetes Program, which funds 35% of all diabetes research at the National Institutes of Health. This program supports the large scale, multi-center research trials like the ones Anela and Scott participated in and also funds critical diabetes education, treatment and prevention programs for Native Americans.

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I would like to offer a special thanks to Chairman Dorgan for sponsoring legislation along with Sen. Susan Collins to renew the Special Diabetes Program this year. Mr. Chairman, your extraordinary leadership and commitment to renew this program this year is deeply appreciated. I would also like to thank Vice Chairman Barasso and the members of this committee, a majority of which are co-sponsors of Sen. Dorgan's legislation, S. 3058. This program is drastically changing—if not saving—the lives of countless people with diabetes. Its renewal will bring us one step farther along on our path to a cure for this devastating disease.

Thank you again for having me here today and for your commitment to diabetes research and individuals across this country living with diabetes.

Thank you again for having me here today.

The CHAIRMAN. Mr. Hall, thank you very much. Your story is a very inspiring one to all of us, and we appreciate you being here.

Dr. Melvina McCabe, thank you for being here. President of the Association of American Indian Physicians in Albuquerque. You may proceed.

**STATEMENT OF MELVINA McCABE, M.D., PRESIDENT,
ASSOCIATION OF AMERICAN INDIAN PHYSICIANS**

Dr. McCABE. Chairman Dorgan, thank you very much. Other Committee members, I thank you very much for inviting me to testify. And it is an honor for me to testify on behalf of my people.

Diabetes is truly a crisis in Indian Country. The crisis is all-encompassing, affecting not only the physical health of our Indian Nations, but also affecting the mind and the spirit. As one of our own stated, when the spirit is in pain, what does it matter if you take your medication or take a walk?

I will present the data, some of the data, in Indian Country and some of the findings to date on activities that have been implemented in Indian Country.

Senator Dorgan, you presented many of the statistics already. The one thing I would like to add is that the Indian Health Service data on American Indians and Alaska Native children and young people, between 1990 and 2009, reveals a 161 percent increase in Type II Diabetes in those aged less than 15 years. Diabetes and the

co-existing morbidities continue to plague our Native peoples and, in particular, diabetes is now affecting those very dear to us, our children and our young people.

The lifestyle interventions of weight loss and exercise remain the mainstay in diabetes prevention and cardiovascular risk reduction. For every kilogram of weight loss, there is a 16 percent decrease in diabetes risk. The development of new diabetes medications is not to be minimized, but lifestyle interventions are key.

Other panel members have referenced the Diabetes Prevention Program. Some of the statistics that came out of that program are a 58 percent reduction in diabetes incidents with the intensive lifestyle intervention group, and a 31 percent reduction in the Metformin compared to placebo.

A promising trend in diabetes outcomes is noted with the implementation of the Indian Health Services Special Diabetes Programs for Indians. After 1998, community walking and running programs increased from 20 to 92 percent. Community exercise programs increased from 16 to 69 percent. School age physical activity programs increased from 9 to 69 percent. Tribally-defined interventions in reduction in TV watching increased from 25 to 35 percent. And weight management programs for children increased from 8 to 72 percent.

The improvement in clinical interventions was a reduction of the A1c from 11 to 7.9 percent, a reduction in the cholesterol levels by 20 percent, and a reduction in proteinuria by 32 percent.

The Journey to Native Youth Health Project is a collaborative, community-based participatory approach partnership between the Montana Rocky Boy and Crow Indian reservations and the University of Montana for preventing risk factors associated with diabetes in Native youth aged 10 to 14. The early findings from this study strongly suggests this intervention favorably impacts diabetes risk factors in Native youth by increasing moderate to vigorous activity and increasing caloric output.

They have submitted a full-scale trial for funding. They have not heard back yet. Senator Tester, this would be exciting news for your State if this grant was funded.

The Navajo Nation has adapted the Diabetes Prevention Program materials for youth and Navajo people in their efforts to reduce diabetes. In addition, they have chosen to share with anyone their materials and have conducted training around the U.S. to implement this effective intervention. Senator McCain, your State needs to be congratulated for producing leaders in diabetes reduction efforts and who are willing to share their experience.

The Pima Indians, since 1990, have experienced a decline, albeit small, in the overall incidence of end-stage renal disease. The authors of the study suggest that while it is not completely clear as to the reasons for this, it does appear that greater access to diabetes medications may have impacted this change.

The Cheyenne River Sioux used the Medicine Wheel nutrition intervention to demonstrate a positive trend in weight loss compared to the control group.

Diabetes is not a solo actor. In order for us to truly define effective interventions, we must address all other variables that affect the rates of diabetes in our communities.

Access is a big issue. Access issues in relation to diabetes include, but are not limited to, distances traveled to healthcare facilities, availability of medications, health literacy, storage of medications, cultural literacy of the healthcare providers, and language barriers.

My sister-in-law travels 1 hour and 15 minutes one-way, 5 days a week, for dialysis. My brother, who is a private contractor, takes her to her dialysis treatments. This impacts his ability to work and to provide for his family. One can understand the far reaching consequences that lack of access creates.

Socio-economic. We cannot forget the variables of poverty, Western educational level, and occupation that contribute to the high rates of diabetes or any chronic disease. I have to tell the story of a patient of mine with diabetes, and this is not an uncommon scenario. His A1c level was 13, his blood pressure was 150/90, he weighed 300 pounds and he had a family to support.

After several attempts at controlling his diabetes with our armamentarium, I asked him what was going on in his life. He stated, I have a family to feed. I fill my prescriptions, but instead of taking my medications as directed, I take them twice a week so that they will last longer. I cannot afford the healthy foods because they are more expensive. He recently suffered a stroke and is now in a nursing facility.

Culture. Understanding the cultural perspective of diabetes is critical for successful interventions in reducing diabetes risk. Some studies suggest that Indian people may have a fatalistic view of diabetes, young American Indians and Alaska Native diabetics may have a different body image than the white population. We must understand those cultural variables.

Public Health. The role of public health is critical and includes the development of tribal, state, national partnerships, partnered program planning, data collection and evaluation. All governmental agencies must include American Indian/Alaska Native data sets on diabetes.

And if we think a little bit outside of the box, identifying measures that would reduce the risk of diabetes other than the pre-diabetes state is very important in addressing reduction of risk. The metabolic syndrome which assesses cardiovascular risk might actually be a better measure of diabetes risk than the fasting blood sugar.

Overall planning for major changes in our society that impact physical activity is important. Examples that have impacted the physical activity, particularly in our youth, are the introduction of the television set. We did not plan for what outcome was going to be on that. We did not increase our physical activity recommendations. Taking physical activity out of our school curriculum, improved technology that results in a reduction in physical activity.

And finally, nutrition. Policy makers must be aware that while the majority of society may have access to electricity and running water, American Indians and Alaska Natives do not necessarily enjoy these privileges. Without electricity, how do we store our insulin appropriately, how do we store healthy foods such as fresh vegetables, fruits, milk? In Indian Country, canned foods can be a staple because of the lack of electricity.

In closing, the approach to diabetes risk reduction is multi-factorial, but the key components still appear to be weight loss and exercise. This is the first time that our communities have success stories in making effective lifestyle changes by implementing interventions that have been developed by and for the communities. And that is key, that these interventions are developed by and for the communities.

This is a new generation of health role models for our Indian children. Know that we can make the changes necessary in the battle against diabetes. In order for us to maintain and sustain this momentum that we are now seeing in our communities to address diabetes, we are confident that Congress will continue to support this effort.

Thank you very much.

[The prepared statement of Dr. McCabe follows:]

PREPARED STATEMENT OF MELVINA McCABE, M.D., PRESIDENT, ASSOCIATION OF AMERICAN INDIAN PHYSICIANS

Introduction

Chairman Dorgan, my name is Melvina McCabe, I am a Navajo physician working as an academician at the University of New Mexico School of Medicine Department of Family Medicine in Albuquerque, NM. I am also the current President of the Association of American Indian Physicians whose offices are based in Oklahoma City, Oklahoma. I am honored to testify today and grateful that you have invited me and grateful to the committee as a whole for considering the testimony.

Diabetes is truly a crisis in Indian Country. The crisis is all-encompassing, affecting not only the physical health of our Indian Nations, but also impacting the mind and the spirit. As one of our own stated: "when the spirit is in pain, what does it matter if you take your medication or take a walk?"(1). I will present the statistical data and research findings and community intervention activities on diabetes in Indian country.

Statistical Data

According to CDC data, in 2005, the age-adjusted prevalence rate of diabetes in American Indians/Alaska Natives (AI/AN) was 16.5 percent compared to the non-Hispanic white rate of 6.6 percent and was highest for all underrepresented populations. Of note is the considerable geographic variation: Alaska Native adults with a rate of 6 percent and southern Arizona adults with a rate of 29.3 percent. AI/AN's have the highest prevalence rate of diabetes in all age and gender categories compared to the white and other underrepresented populations. The IHS data on AI/AN children and young people, between 1990–2009, reveals a 161 percent increase in Type 2 DM in those age <15. A significant risk factor for diabetes is obesity. AI/AN youth, in particular, were more obese when compared to the U.S. general population (2). AI/AN with diabetes had higher rates of HTN, renal failure, lower-extremity amputations, and cardiovascular disease than the general U.S. population with diabetes (3). Diabetes and the coexisting morbidities continue to plague our AI/AN people and, in particular, diabetes is now affecting those very dear to us, our children and young people.

What Works

The lifestyle interventions of weight loss and exercise remain the mainstay in diabetes prevention and cardiovascular risk reduction. For every kg of weight lost, there is a 16 percent decrease in diabetes risk. The development of new diabetes medications is not to be minimized, but lifestyle interventions are key.

- The Diabetes Prevention Program bore out these key interventions (4). The study revealed a 58 percent reduction in diabetes incidence with the intensive lifestyle intervention group, a 31 percent reduction in the Metformin group compared to placebo. The interventions were exercise, weight loss, availability of a coach, and behavior modification.
- A promising trend in diabetes outcomes is noted with the implementation of the Indian Health Service Special Diabetes Program for Indians. After 1998, community walking and running programs increased from 20 percent to 92 percent;

community exercise programs increased from 16 percent to 69 percent; school age physical activity programs increased from 9 percent to 69 percent; tribally defined interventions in reduction in TV watching increased from 25 to 35 percent, and weight management programs for children increased from 8 percent to 72 percent (5). The improvement in clinical interventions were a reduction of the A1C from 11 percent to 7.9 percent between 1996–2009, reduction in mean LDL cholesterol by 20 percent, and reduction in proteinuria by 32 percent.

- The Journey to Native Youth Health project is a collaborative, community-based participatory approach partnership between the Montana Rocky Boy and Crow Indian reservations and the University of Montana for preventing risk factors associated with diabetes in Native youth, age 10–14 years old. The early findings from this study strongly suggests this intervention favorably impacts diabetes risk factors in Native youth by increasing moderate to vigorous activity and increasing caloric output compared to the control group (conversation with Blakely, PI; June 28, 2010). Based on these findings, a full-scale trial has been submitted for funding and will be the first trial utilizing the DPP intervention specifically for Native Youth. Senator Tester, this would be exciting news for your state.
- The Navajo Nation has adapted the DPP materials for use for Navajo people in their efforts to reduce diabetes. In addition, they have chosen to share with anyone their materials and have conducted training around the U.S. to implement this effective intervention. Senator McCain, your state needs to be congratulated for producing leaders in diabetes reduction efforts and who are willing to share their experience.
- A relatively new medication is the incretin mimetics. Incretins have been shown to increase insulin secretion, but also increase satiety and weight loss. Another addition to our effective medication armamentarium.
- The Pima Indians, since 1990, have experienced a decline in the overall incidence of end-stage renal disease. The authors of this study suggest that while it is not completely clear as to the reason(s) for this, it appears that greater access to diabetes medications may have impacted this change (6).
- The Cheyenne River Sioux used the Medicine Wheel nutrition intervention to demonstrate a positive trend in weight loss and BMI compared to the control group (7).

Other Considerations

Diabetes is not a solo actor. In order for us to truly define effective interventions, we must address all other variables that affect the rates of diabetes in our communities.

- *Access:* Decreased healthcare access has been identified as a factor contributing to the health disparities in our nation. Access issues in relation to diabetes include but are not limited to distance traveled to health care facilities, availability of medications, health literacy, storage of medications, cultural literacy of the healthcare providers, and language barriers. My sister-in-law travels one hour and 15 minutes, one-way, 5 days a week for dialysis; my brother, who is a private contractor, takes her to her dialysis treatments. This impacts his ability to work and to provide for his family. One can understand the far reaching consequences that lack of access creates.
- *Socio-economic:* We cannot forget the variables of poverty, Western educational level, and occupation that contribute to the high rates of diabetes or any chronic disease. I have to tell the story of a patient of mine with diabetes and this is not an uncommon scenario. His A1C level was 13, his B/P was 150/90, he weighed 300 lbs, and he had a family to support. After several attempts at controlling his diabetes with our armamentarium, I asked him what was going on in his life. He stated “I have a family to feed”. “I fill my prescriptions but instead of taking my medications as directed, I take them twice a week so that they will last longer”. “I cannot afford the healthy foods because they are more expensive”. He recently suffered a stroke and is now in a nursing facility.
- *Culture:* Understanding the cultural perspective of diabetes is critical for successful interventions in reducing diabetes risk. Some studies suggest that Indian people may have a fatalistic view of diabetes, young AI/AN diabetics may have a different body image view than the white population.
- *Public Health:* The role of public health is critical and includes the development of tribal/state/national partnerships, partnered program planning, data collec-

tion, and evaluation. All governmental agencies must include American Indian/Alaska Native data sets on diabetes.

- *Outside the Box*: Identifying measures that would reduce risk of diabetes other than the pre-diabetes state is very important in addressing reduction of risk. The metabolic syndrome which assesses cardiovascular risk might actually be a better measure of diabetes risk than the FBS. The measures are HDL, triglycerides, blood pressure, FBS, and waist circumference.

Overall planning for major changes in our society that impact physical activity is important. Examples are: the introduction of the television set, taking physical activity out of school curricula, improved technology that results in a reduction in physical activity.

- *Nutrition*: Policy makers must be aware that while the majority society may have access to electricity and running water, American Indians and Alaska Natives do not necessarily enjoy these privileges. Without electricity, how do we store our insulin appropriately, how do we store healthy foods such as fresh vegetables, fruits, eggs, milk. In Indian country, canned goods can be a staple because of the lack of electricity.

In closing, the approach to diabetes risk reduction is multifactorial, but the key components still appear to be weight loss and exercise. This is the first time that our communities have success stories in making effective life-style changes by implementing interventions that have been developed by and for the communities. This is a new generation of health role models for our Indian children. Know that we can make the changes necessary in the battle against diabetes. In order for us to maintain and sustain this momentum that we are seeing now in our communities to address diabetes, we are confident that the Congress will continue to support this effort.

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The CHAIRMAN. Dr. McCabe, thank you very much.

And finally we will hear from Caitlin Baker, a 16-year-old Muscogee Creek Indian from Oklahoma. My understanding, Caitlin, is that your mother, Edith Baker, has accompanied you and is sitting behind you today. Is that correct?

Ms. BAKER. Yes.

The CHAIRMAN. Welcome to you.

Ms. BAKER. Thank you.

The CHAIRMAN. Caitlin, you may proceed.

STATEMENT OF CAITLIN BAKER, MEMBER, MUSCOGEE CREEK NATION

Ms. BAKER. I am Caitlin Baker. I am from Norman, Oklahoma. I am 16 years old and I am a member of the Muscogee Creek Nation. I have run my own outreach program for the last four years that works with Native American communities spreading the message that Type II Diabetes can be prevented through physical activity and healthy lifestyle choices, of course.

I have traveled to communities across the Nation and my message is prevention. I feel that my generation has been raised with the continual message that diabetes is rampant in Native communities. My peers many times feel that Type II diabetes is inevitable. They tell me that they know they will get it eventually because their parents, grandparents and other family members may have diabetes already.

This feeling of inevitably can cause them to not take prevention seriously. This, in turn, affects the success of programs put in place to prevent diabetes. I feel that one major change that needs to be taken is the shift from inevitably to preventability. Stress to youth that diabetes is preventable. Inform them how to avoid diabetes. And then follow through by giving them the tools needed, like access to physical activity and healthier food options.

I also stress to youth how important it is to use your voice and speak to leaders of your community. This does not include just health professionals, but also tribal leaders. Youth should go to their tribal leaders with what they feel that they need to make the healthy choices in their lives. Their voice is a powerful weapon. And I also ask their leaders to listen. Youth want to be heard and respected.

I have been in communities where youth have asked for simple things like a say in their lunch menu, a soccer field, a pool, to have drinking and smoking banned in their public parks. This is what youth want. And involve your kids, and let them have ownership of the healthy changes being made in their communities.

I once visited a jogging trail in Davenport, Oklahoma, which was the vision of local school kids in Davenport. The students decided they wanted one, so they raised the money and got the grants and they built it. When I saw it a year later, there was no trash and no graffiti. The local kids were proud of it and respected it.

So, no offense to grownups, but I feel that if they had taken it over, they may still be figuring out how to build it and what to name it.

[Laughter.]

Ms. BAKER. So, I am not saying that grownups are not needed and they cannot get things done, but just that involving your youth is a positive thing. If you involve your youth, it makes them feel proud. Encourage them to be involved in planning and carrying out those plans. This will give them pride in themselves and in their communities.

I also stress partnerships. I would not be able to do the work that I do without my partners. I hope that more organizations, both tribal and non-tribal, will work together. Diabetes prevention goes hand-in-hand with heart disease and tobacco control. The organizations working in these areas should be open to working together.

Breathing problems and heart disease cause poor circulation, which in turn causes complications in diabetes patients. It seems that all of these areas should be working together to get the message across of prevention. And be aware of the work each other are doing. That way, nobody is duplicating the same programs so they share funding.

Also, know your community. I have spoken with kids in New York, South Dakota, Oklahoma, Nebraska, New Mexico and Arizona, to name a few. Everywhere I go there is a different issue with their youth. The diabetes programs that I work with ask me to address prevention and physical activity, but also to tailor my message to what their community is struggling with. Each community is different. Take time to ask and figure out what these issues are. Do not approach this with a one answer for everyone attitude.

I do not mean, through my testimony, to give the impression that programs are not working. I can only speak about programs that I have been a part of and all of them have been positive experiences. My thoughts and ideas come from seeing the way that these programs work.

So, in closing, many times people compliment me on the work that I do. I always appreciate words of encouragement, but I tell them that there are kids like me in every community. So, you should seek out those kids and encourage them.

The topic today is the way out of the diabetes crisis in Indian Country. So, in my opinion, it is to involve every person in your community. Involve your youth and listen to them. We are living the crisis of diabetes and we do not want to live with diabetes forever. Let us work with you and find a way out of the crisis.

Thank you, Chairman Dorgan, for letting me a part of your discussion and all of the Senate members who were not here.

[The prepared statement of Ms. Baker follows:]

PREPARED STATEMENT OF CAITLIN BAKER, MEMBER, MUSCOGEE CREEK NATION

Senate members my name is Caitlin Baker, I am 16 years old and live in Norman Oklahoma. I am a member of the Muscogee Creek nation. For the last 4 years I have run an outreach program that works with Native American communities spreading the message that diabetes can be prevented through physical activity and healthy lifestyle choices. I have traveled to communities across the nation. My message is prevention. I feel that my generation has been raised with the continual message that diabetes is rampant in Native communities. My peers many times feel that diabetes is inevitable. They tell me that they know they will get it eventually because their parents, grandparents and other family members have diabetes. This feeling of inevitability can cause them to not take prevention seriously. This in turn affects the success of programs put in place to prevent diabetes. I feel that one major change that needs to be made in the programs is a shift from inevitability to PREVENTABILITY. Stress to youth that diabetes is preventable. Inform them how to avoid diabetes and then follow through by giving them the tools needed like access to physical activity and healthier food options. Tell youth and communities what needs to be done to prevent diabetes and then work with them to provide what is needed.

I stress to youth how important it is to use their voice and speak to the leaders of their communities. Not just health professionals who are working in diabetes prevention but also tribal leaders. Go to them with what they feel they need to make good lifestyle choices. Their voice is a powerful weapon. I also ask their leaders to listen. Youth want to be heard and respected. I have been in communities where youth have asked for simple things like a say in their lunch menus, a soccer field, a pool, to have drinking and smoking banned in their public parks. These are what youth want. Involve your kids; let them have ownership of healthy changes being made in their community. I once visited a jogging trail that was the vision of the local school kids in the small town of Davenport, Oklahoma. The students decided they wanted one so they raised money, got grants and built it. When I visited it a year later there was no trash, no graffiti. The local kids were proud of it and respected it. No offense to any grownups but I felt like if the adults had been handling it, they might still be discussing how to get it built and arguing what to name it. My point is not that adults aren't needed or can't get things done; just that including the youth is a positive thing. Encourage them to be involved in planning and carrying out those plans. This will give them pride in themselves and their communities.

I also stress partnerships. I would not be able to do the work I do without my partners. I hope that more organizations, both tribal and non-tribal will work together. Diabetes prevention goes hand in hand with heart disease and tobacco control. The organizations working in these areas should be open to working together. Breathing problems and heart disease cause poor circulation, which in turn causes complications in diabetes patients. It seems that all these areas should be working together to get the message across of prevention and be aware of the work each other are doing. Share ideas and funding so that no one is duplicating programs.

Also, know your community. I have spoken with kids in New York, South Dakota, Oklahoma, Nebraska, New Mexico, and Arizona. Everywhere I go there is a different issue with their youth. The diabetes programs I work with ask me to address prevention and physical activity but also to tailor my message to what their community is struggling with. Each community is different, take time to ask and learn what issues there are. Don't approach this with a one answer for everyone attitude.

I don't mean through my testimony to give the impression that programs aren't working. I can only speak about programs I have been involved in and all have been positive experiences. My thoughts and ideas come from seeing the way those programs are working.

In closing, many times people compliment me on the work I do. I always appreciate words of encouragement, but I also tell them that every community has kids like me. Find and encourage them. The topic today is "the way out of the diabetes crisis in Indian country." In my opinion the best way out is to include all members of our communities. Ask and listen to your youth. We are living the crisis of diabetes. We don't want to live with diabetes. Let us work with you to find a way out of the crisis.

Thank you for inviting me today to join in your discussion.

Attachments

For the past four years I have run an outreach program, CAITLINB, that works with various partners to provide Diabetes Prevention programs to Native American communities.

The following written testimony provides a look at the different programs I have partnered with.

OKLAHOMA CITY INDIAN CLINIC

Established in 1974 the OKCIC services the greater Oklahoma City Native population. My involvement has been with their Diabetes prevention program TURTLE CAMP. This program works with children ages 7-12 teaching them healthy nutrition, physical activity and cultural awareness. Over 650 children have experienced Turtle Camp since 2007. My experience has been overwhelming positive.

I personally feel this is a program that should be duplicated in every Native community. Turtle Camp teaches children through fun activities and family involvement. Children attend the Turtle Camp and learn about making goals for themselves. One kid in particular camp to camp overweight and led a sedentary lifestyle. Now at 14 years old, he has qualified for US Nationals in Freestyle Wrestling. He learned the importance of setting goals and increasing physical activity to improve lifestyle. Attached are more statistics on the positive outcomes of Turtle Camp.


Turtle Camp is...

A Lifestyle Intervention Program

Geared toward

- ▶ decreasing the progression of overweight and obesity in AI youth
- ▶ providing them the necessary skills to make healthier lifestyle choices

Accomplishing these goals through nutrition, physical activity, and diabetes education.



Turtle Camp is included in several other programs at the Oklahoma City Indian Clinic. One program looked at physical activity for diabetes prevention among youth as a best practice.

B2: Best Practice: Physical Activity for Diabetes Prevention and Care

B2.1: Target Population: OKCIC patients with or at-risk for diabetes and their families.

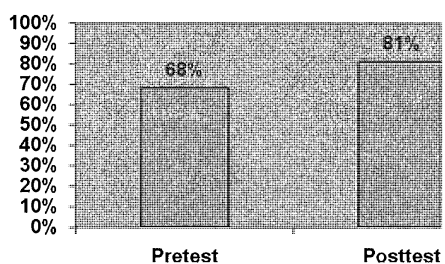
B2.2: Goal: Provide support for lifestyle changes in physical activity and nutrition.

B2.3: Objectives/Measures for Best Practice

Objective 1: To increase by 10% diabetes and diabetes prevention knowledge of American Indian children ages 7-12 years old who attend a youth wellness camp, Teaching Urbans Roads to Lifestyle and Exercise (TURTLE) Camp, by the end of third day camp.

Measure 1a: Evaluate pre- and post-test scores within one month of each event.

Pre and Post Test Scores



This graph above is one example of the significant improvement seen in knowledge at Turtle Camp. Every camp has similar results with significant improvement in knowledge.

Below are statistics for BMI from 2007 and 2008 for Turtle Camp.

Comparing BMIs of 2007-2008 TURTLE Camp and TURTLE Camp Reunion

Camp - Reunion	N	DF	t Value	Pr > t
Mar07 Camp - Sept07 Reunion	11	10	1.15	0.2655
Jun07 Camp - Jan08 Reunion	17	16	1.70	0.1070
Jul07 Camp - Jan08 Reunion	15	14	1.85	0.0802
Oct07 Camp - Apr08 Reunion	12	11	2.08	0.0572

Above shows a graph that represents 50% of the kids that participated reduced their BMI.

As part of the Turtle Camp program, several other programs have been developed and implemented.

Project POWER: Of the 34 kids that participated since the fall 2009 in the after school program, over 85% reduced their BMI % at the end of 8 and 12 weeks.

Youth Fitness Program: currently have 50 kids enrolled in the program. The kids, 8-17 participate in bi-monthly bike events. Each bike night, the kids ride 8-10 miles. The parents are also encouraged to attend. Several bike or walk during the evening bike program. We have also partnered with Chesapeake Energy and Rock town to host several kayaking and indoor climbing events. This program encourages physical activity.

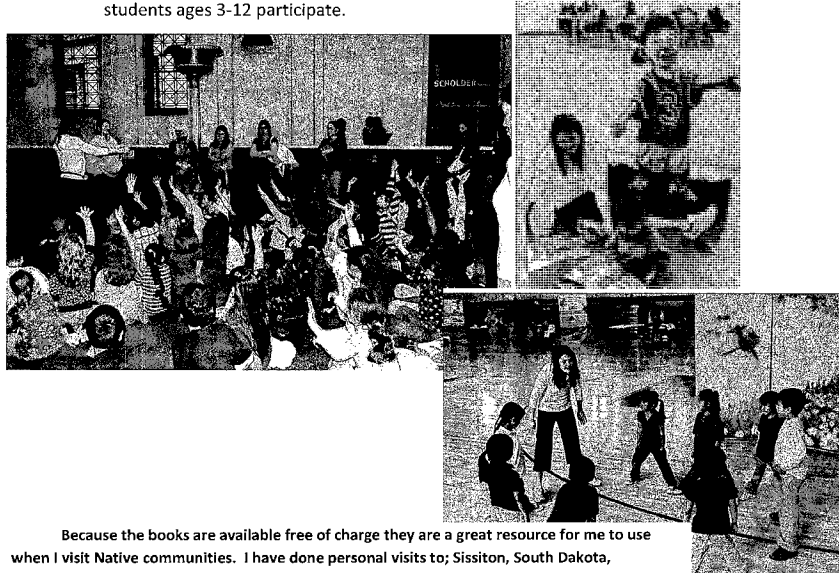
Turtle Camp was funded in previous years, but now Turtle Camp is NOT funded. Through partnerships and community support, we are able to provide the children with small programs. Funding is necessary to continue improving the lives of many more Native youth.

Centers for Disease Control and Prevention Eagle Series Books

The CDC provides a series of 4 books written on a 4th grade level. These "EAGLE SERIES" books deal with diabetes prevention, on a level children can understand. The books also encourage a return to traditional ways including physical activity and healthy eating. The books feature native children being taught by wise animal characters.

The CDC Native Diabetes Wellness Program has a travelling exhibit of the original artwork. I have participated in their Eagle Series events providing role modeling and physical activities.

The locations that I have traveled to with the CDC include; the Pueblos of New Mexico and New York City. In the Zuni Pueblo we had approximately 800 students ages 3-12 participate.



Because the books are available free of charge they are a great resource for me to use when I visit Native communities. I have done personal visits to; Sisseton, South Dakota, Tucson, Arizona and various locations in Oklahoma. While there I hand out the EAGLE BOOKS and talk to students about making healthy choices.

A great example of a program was held in Sisseton, South Dakota. The Indian Health Services invited me to come and visit their local schools. While there I met with students at the public school, the Tribal school, the tribal head start and a small rural school. Being able to meet with students face to face and engage them in conversation is very important.

The Eagle Books: Stories about Growing Strong and Preventing Diabetes

The Eagle Books are a series of four books which are brought to life by wise animal characters Mr. Eagle and Miss Rabbit and a clever trickster, Coyote, who engage Rain That Dances and his young friends in the joy of physical activity, eating healthy foods, and learning from their elders about health and type 2 diabetes prevention.

The Eagle Books were authored by Georgia Perez of Nambe Pueblo, and illustrated by Patrick Rolo, Bad River Band of Ojibwe, Wisconsin and Lisa A. Fifield, Oneida Tribe of Wisconsin, Black Bear Clan.

The first book, *Through The Eyes of The Eagle* introduces the characters of Mr. Eagle and Rain That Dances, the American Indian boy he befriends. Mr. Eagle reminds the young boy of the healthy ways of his ancestors.

In *Knees Lifted High*, the second book, Rain That Dances introduces Thunder Cloud, his best friend, to Mr. Eagle who encourages the boys to be physically active every day.

The third book, *Plate Full of Color*, introduces Miss Rabbit and the boys' friends, Little Hummingbird and Simon. Miss Rabbit teaches the value of eating a variety of colorful and healthy foods.

Tricky Treats, the final book in the series, introduces the character of Coyote, a trickster, and encourages children not to be tricked by coyote when choosing foods to eat.

The Eagle Books are available through:

CDC

Free single copies of the Eagle Books are available from CDC by calling 1-800-CDC-INFO (1-800-232-4636).

American Indian and Alaskan Native Programs

For programs serving Native American children, the Eagle Books are available through the Indian Health Service <http://www.ihs.gov/MedicalPrograms/Diabetes/RESOURCES/Catalog/rde/index.cfm>

Public Health Foundation

The books are available for a cost-recovery fee from the Public Health Foundation by calling 877-252-1200, or visit www.phf.org.



Diabetes Primary Prevention among American Indians and Alaska Natives

An Overview of CDC's Native Diabetes Wellness Programs' Projects

Eagle Books

☑ The Eagle Books are a series of four books brought to life by wise animal characters who engage a young boy and his friends in the joy of physical activity, healthy eating, learning about traditional ways from elders, and preventing type 2 diabetes in Indian Country.

☑ Several years ago tribal leaders guided CDC to focus on youth. Leaders recommended an emphasis on:

- Stories about diabetes—the disease was almost unknown among American Indians and Alaska Natives before the 1950s, so there were no stories about diabetes.
- Traditional culture as a source of health and reaching children with messages about the healthy foods and activities of their people, involving elders in the teaching and integrating the messages through schools.

☑ Following the guidance from tribal leaders, CDC's Native Diabetes Wellness Program collaborated with the Tribal Leaders Diabetes Committee and Indian Health Service to create the Eagle Books.

☑ The series was written by Georgia Perez who lives in Nambe Pueblo, NM and was a community health representative for 19 years. The artwork is the product of Native artists Patrick Rolo (Bad River Band of Ojibwe, Wisconsin) and Lisa A. Fifield (Oneida Tribe of Wisconsin, Black Bear Clan).

☑ Over 2 million books have been disseminated in Indian Country and the rest of the U.S.

- Bulk supplies of the books are free to American Indians and Alaska Natives through IHS
- Single copies of the books are free to everyone through the CDC Web site or 800 number
- The books have been translated into Native languages, including Chickasaw, Paiute, Shoshone, Spanish, and the Creek Council is currently translating the books into Creek.

☑ Original artwork from the books is currently traveling the country in an exhibition entitled: *Through the Eyes of the Eagle: Illustrating Healthy Living for Children.*

○ The tour kicked off at the Smithsonian's Nation Museum of the American Indian in Washington, DC and New York, NY.

○ I participated in outreach to school groups and families at two venues, including the Smithsonian and the Indian Pueblo Cultural Center in New Mexico.

☑ Eagle Books Community Campaign materials are available to interested tribes such as Keweenaw Bay Indian Community (Ojibwa) in Michigan and Indian Pueblo Cultural Center in New Mexico, who have already hosted community and school events.

☑ A K-12 school curriculum, *Health is Life in Balance Diabetes Education in Tribal Schools (DETS)* was released in 2008, and the Eagle Books are part of the K-4 curriculum. This project was led by the National Institutes of Health, supported also by CDC and Indian Health Service. Eight Tribal Colleges and Universities developed the curriculum which is being adopted by many schools across the country.

Traditional Foods Grants

☑ In 2008, The CDC's Native Diabetes Wellness Program awarded Traditional Foods grants to 17 tribes.

☑ The five-year grant is titled *Using Traditional Foods and Sustainable Ecological Approaches for Health Promotion and Type 2 Diabetes Prevention in American Indian and Alaska Native Communities Project*.

☑ The grants focus on issues tribal leaders identified as priority areas:

- Preventing type 2 diabetes in youth;
- Encouraging renewed interest in traditional ways, including stories about health; and
- Sharing stories about health.

☑ CDC is working with tribes to support their efforts to emphasize traditional foods and physical activity because traditional culture is a source of health.

- Foods such as berries, squash, beans, corn, and fish are healthy foods and the related physical activity in gathering, harvesting, and preparing these foods goes hand in hand.

Young boy learning to cut arrow shafts from rough leaf dogwood

☑ In many communities, elders are working with youth to teach gardening and other traditional activities, such as fishing, hunting, and gathering berries and wild plants.

☑ The tribes are growing and gathering foods using traditional ecological approaches with a long view towards sustainability.

JUNE 2008

Department of Health and Human Services Indian Health Service Division of Diabetes Treatment and Prevention
<http://www.ihs.gov/medicalprograms/diabetes/>

Diabetes in American Indians and Alaska Natives:

Facts At-a-Glance

U.S. AMERICAN INDIAN AND ALASKA NATIVE POPULATION

3.3 million

Number of American Indians and Alaska Natives in 2007 (according to the U.S. census)
 Number of federally recognized American Indian and Alaska Native Tribes

561

DIABETES IN AMERICAN INDIANS AND ALASKA NATIVES

16.3%

Percent of American Indian and Alaska Native **adults** who have diagnosed diabetes (compared with 8.7% of non-Hispanic whites)

1,758

Number of American Indian and Alaska Native **youth** under the age of 19 who have diagnosed diabetes (2005)

68%

Percent increase in diabetes from 1994 to 2004 in American Indian and Alaska Native youth **aged 15-19 years**

95%

Percent of American Indians and Alaska Natives with diabetes who have **type 2 diabetes** (as opposed to type 1 diabetes)

30%

Estimated percent of American Indians and Alaska Natives who have **pre-diabetes**

2.2 times higher

Likelihood of American Indians and Alaska Natives to have diabetes compared with non-Hispanic whites

58%

Increase in diabetes prevalence among American Indians and Alaska Natives aged 20–29 from 1990 to 1998, as compared with 9.1% in the U.S. general population

3 times higher

Death rate due to diabetes for American Indians and Alaska Natives compared with the general U.S. population (2004)

Make a Splash

As a competitive swimmer I saw the benefit that swimming can provide Native Americans. I believe swimming offers communities the opportunity to have fitness programs for all age groups. Also, the need for swim lessons is important due to Native Americans having the second highest drowning rates of any minority. I have numerous swim clinics that incorporate exercise, eating healthy and staying tobacco free.

USA swimming offers resources to communities that help them implement water safety programs.



Make a Splash is a national child-focused water safety initiative created by the USA Swimming Foundation to save lives.

The *Make a Splash* goal: for every child in the US to learn to swim.

This initiative exists because nine people drown each day in the U.S., and in ethnically-diverse communities the youth drowning rate is 2-3 times higher.

It works by aligning the nation's top learn-to-swim resources in an effort to save lives. *Make a Splash* educates parents through a national awareness campaign, saves lives by joining forces with grassroots learn-to-swim programs and reaches thousands of children each year.

In its first 3 years of partnering with local swim lessons providers, *Make a Splash* has created a network of 222 Local Partners in 42 states.

Those 222 partners have enrolled more than 350,000 children in their lessons in the first 3 years.

Make a Splash dollars have provided scholarships for over 16,100 children into those lessons.

Because the Native American population is one of the least represented by percentages in swimming, we have begun to network in the Native communities. USA Swimming Diversity Membership Specialist, Manny Banks, attended the National American Indian and Alaska Native Child Care Conference, Tribal Child Care: Recognizing Our History, Honoring Our Achievements, Preparing Our Future (May, 2010 in Anaheim), and the 2010 CAN-AM Native American Swimming Championships just this weekend (June 26-27, 2010 in Hardin, MT).

Swimming is a family sport that can be enjoyed by young and old alike and promotes a healthy lifestyle which can mean lower rates of diabetes, obesity and heart disease. And finally we realize there are few Native Americans involved in competitive swimming in the US and Canada.

Children who have a swimmer as a role model are twice as likely to become swimmers themselves. Olympic gold medalist Cullen Jones has made a huge impact in the African American community. We hope to identify and encourage promising Native American swimmers to become role models and go on to become future members of the US and Canadian Olympic swim teams. We want Native American swimmers on our Olympic swim teams."

While competitive swimming is a great sport, it is only one avenue for kids who learn to swim. Caitlin Baker is a phenomenal ambassador for youth fitness in the Native Community. She understands that learning to swim is not only a life-saving skill; it can lead to a lifetime of fitness. We applaud her efforts and look forward to partnering with every community she has the opportunity to reach, so that the Make a Splash water safety initiative can support all children in learning to swim.

By joining efforts and working together, we can make a difference in the drowning statistics and rates of diabetes and childhood obesity.

PATHSTAR

In 2009 I participated in PATHSTAR'S annual swim from Alcatraz Island to Shore. San Francisco Pediatrician, Nancy Iverson developed the PATHSTAR program to bring Native Americans from the Pine Ridge Reservation to San Francisco. While in the program participants are taught how to eat healthy and exercise. The week long program ends with the 2 mile swim from Alcatraz Island to shore. Below is more information on this wonderful program.



MISSION

PATHSTAR is committed to revitalizing physical, mental, emotional, and spiritual health among Native American individuals, families, and communities by inspiring practices that contribute to self reliance and well-being.

We do this through our intensive week-long educational and experiential San Francisco-based Alcatraz swim program, through support and advocacy in overcoming geographic, economic, and political obstacles for culturally relevant and sustainable community practices regarding diet and lifestyle choices on Pine Ridge Reservation in South Dakota, and through programs leading to mentoring and role modeling that reinforce the benefits of meeting challenges and inspiring healthy change.

VISION

Imagine Native Americans, both on and off reservations, living healthy lives of meaning and purpose, reclaiming the best of indigenous traditional practices, augmenting these with the cultivation of wholesome 'new traditions' and serving as a catalyst for inspiring self-reliance and optimism among families and communities. Imagine individuals and families demonstrating the resourcefulness that grows from the experience of having personally met challenges and accomplished goals while embracing their cultural values and wisdom and contributing to education and community development.

Imagine the incidence of diabetes and heart disease among Native populations being as low as it was when the Northern Plains Indians were regarded as the healthiest in the world. Imagine every child completing high school, whether in reservation or non reservation schools. Imagine support systems strong enough that individuals, families and communities meet adversity with dignity and self-reliance.

That is the PATHSTAR vision.

Native Nations Sports Association

The Native Nations Sports Association is a program that incorporates mentorship. I believe this program will continue to grow and be a positive influence in Indian Country.

Business Plan

Building a multi-generational legacy of change in a family and/or community structure starts with a strong foundation reinforced by the sustained hopes and dreams of the younger generation. The perception of hopelessness has hindered their ability to dream. Perceptions need to change. NNSA – Hero Development Organization (NNSA-HDO) is poised to change that dynamic.

We develop and manage programs that foster, encourage, develop, enable, promote and monitor Native American student athletes who have (and seek) the merit, passion and dream for a higher degree of learning; to compete and succeed at the collegiate level.

NNSA-HDO believes visible and interaction with local heroes is critical to sustained community development. Heroes inspire Hope; Hope fosters Dreams; Dreams motivate individuals; Individuals achieve success. NNSA-HDO is primarily a youth development organization, to provide the resources necessary for student athletes to pursue and achieve success at the college and professional level.

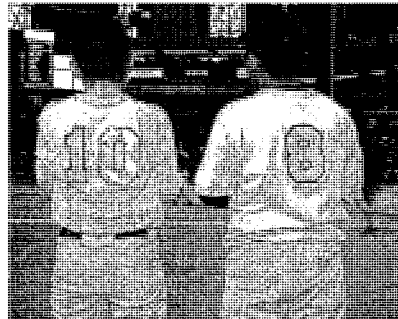
We lead an innovative alliance partnership of professionals and providers, accountable to: the advancement of student athletes' higher standards of self-worth; the development of a sustainable resource network to strengthen family unity; and building skilled leaders for a stronger community.

NNSA-HDO is developing a sustainable partnership network; to implement and manage integrated academic, athletic and social programs that focus on student athlete advancement as well as the external social issues impacting Native American communities. NNSA-HDO understands the importance of numerous experts working together and its initial role to orchestrate the alliance but we realize it is the family that makes a home and homes are the foundation of a strong community.

We support scholarship participants' continual development and assessment through a coordinated network of education, athletics, health & nutrition, vocational, life skill and career mentorship programs that stimulate multi-generational community involvement opportunities for sustainable economic development.

The community service and interaction of local NNSA-HDO heroes are the windows for others to see a positive view of the future. Participants in the programs shall incorporate the importance of maintaining culture and heritage on and off of tribal lands while pursuing dreams for success.

The concept of sustained Hero interaction in conjunction with a national alliance partnership network is the first of its kind for Native Americans youth, families and their communities.



TOBACCO CONTROL

I have worked closely with various tobacco control programs, such as; SWAT (students working against tobacco), Cleveland County Tobacco free Coalition and Tobacco Free Kids. I feel strongly that diabetes prevention and a tobacco free lifestyle need to be working hand in hand. I have included some basic statistics about the connection of diabetes and tobacco use.

- The evidence shows that people who smoke are more likely to get diabetes. According to a study published in the *American Journal of Epidemiology*, smoking 16 to 25 cigarettes a day significantly increases your risk for Type 2 diabetes.
- Smoking also causes other health problems that are known to cause diabetes, such as high cholesterol and high blood pressure.
- Nicotine consumption not only increases blood pressure, but it also increases the amount of bad fats circulating in the blood vessels and decreases the amount of good fat available – another factor that increases a person’s likelihood of getting type 2 diabetes.
- For those who already have diabetes, smoking greatly increases their risk of related health complications.
- For example, having diabetes or pre-diabetes puts you at increased risk for heart disease and stroke. And smoking further increases that risk. In fact, smoking 1-5 cigarettes per day presents a significant risk for a heart attack. Higher blood pressure—a result of smoking—requires that the heart pump harder in order to overcome the opposing pressure in the arteries. This increased work, much like that related to increased heart rate, can wear out a heart faster.
- Diabetes is the most common cause of kidney failure, accounting for nearly 44 percent of new cases. But smoking further increases a person’s risk of kidney damage because the higher blood pressure caused by smoking can also cause organ damage where blood is filtered, such as in the kidneys.

Sources:

- <http://www.diabetes.org/news-research/research/access-diabetes-research/quitting-smoking-may-raise.html>,
- <http://www.tobaccofreekids.org/research/factsheets/pdf/0264.pdf>,
- <http://diabetes.niddk.nih.gov/dm/pubs/stroke/index.htm>
- <http://aje.oxfordjournals.org/cgi/content/full/160/2/158>

The CHAIRMAN. Ms. Baker, thank you very much.

Let me mention the reason for me being the only Senator because I think it is important. And by the way, let me also point out, you said that you were not suggesting grownups were not necessary. Without grownups, there would be no children.

[Laughter.]

The CHAIRMAN. But having said that, let me explain to you that this week is a rather unusual week in that our beloved colleague, Senator Byrd, passed away. His body will lie in state tomorrow in the Senate Chamber and there will be a funeral on Friday in West Virginia that most of us will attend.

Because tomorrow Senator Byrd's body will lie in state in the Senate Chamber, there will be no Senate business. And so much of what was going to be done this week became truncated into today, Wednesday, virtually all of my colleagues are either chairing or participating in markups or hearings of Environment and Public Works and Energy and Judiciary and the Kagan hearings and so on. So, it created a difficult circumstance today. But your testimony is heard by all of the staff of the Committee Members who have participated today.

So, I thank you very much for coming. I wanted to explain to you the special circumstances today.

Let me ask some questions. Dr. Fradkin, what is the most positive thing you can tell me about work, at the NIH, in trying to cure diabetes? Because I hear, from time to time, or I see news reports that, this is the one disease that may be cured. We are so close here and there.

Give me the strongest nugget that you can of what research, and what makes you believe that finally, perhaps, at long last we might be able to cure this disease. Or, does such information exist?

Dr. FRADKIN. I was at the American Diabetes Association scientific sessions in Orlando and, just yesterday, the results of a very exciting trial were presented. This was a trial of sensor-augmented pump therapy for Type I Diabetes.

What they showed was when people wore the continuous glucose monitors and had some communication but the data from that monitor was not being used to control the rate of delivery of the pump—it was not yet automated, the patient still had to make the changes—they got dramatic improvements in their hemoglobin A1c. That is the test that measures how good your control of diabetes is and which is associated with fewer complications. The patients had markedly fewer episodes of low blood sugar than we saw in the previous Diabetes Control and Complications Trial that proved that good control reduced complications.

So, we are making huge progress toward this artificial pancreas that is one of the major goals of our special program funding. We still need to move further to actually link the two devices. When I told you that parents could sleep through the night, what I meant is that they do not have to set their alarms to wake up to test their children. But that does not mean they are still sleeping through the night because the sensors are going off and sounding alarms when the sugar is not normal.

What we want is for the sensor to be able to directly control the delivery of insulin, to take the burden off of these finger pricks that kids are doing every hour. We want kids to be able to forget for awhile that they have Type I Diabetes and live a normal, carefree childhood.

And I think if we can make progress in what we call closing that loop, that is tremendously encouraging. And I can give you some similar examples with regard to Type II Diabetes.

The CHAIRMAN. But you are talking about, particularly, advances in monitoring. Which is so very important, no question about that, because that deals with the health and mortality of the patient.

I am asking about things that you see that suggest, because of changes in research and capability. The first owner's manual for

the human body exists now with the genome projects and so on. Is there a body of research out there that gives you hope that perhaps 10 years from now you might testify somewhere and say well, in this area, we were able to actually cure or reverse? Tell me your assessment of that, as opposed to just monitoring.

Dr. FRADKIN. I told you about this TEDDY trial where we have just finished the recruitment. We have found 8,000 children who are at very high genetic risk for Type I Diabetes. We are monitoring them, looking at their diet, looking at blood samples which are going to be looked at with incredible new technologies that have come out of the genome project, and, for example, if we could find an infectious trigger through these samples, we are going to analyze the kids who are at high genetic risk who did and did not get Type I Diabetes.

If we could find an infectious trigger or some aspect of the diet, we know something is happening in the environment that is causing Type I Diabetes because rates are going up by several percent per year. If we could find an infectious cause and have a vaccine that could prevent Type I Diabetes, that is what we are aiming for.

So, at every step along the disease, we are trying to make improvements in the care for people who have diabetes, and we are trying to prevent diabetes.

The CHAIRMAN. Thank you.

Dr. McCabe, some in the audience may not know from the reference of a physician the difference between Type I and Type II Diabetes. Would you describe that?

Dr. MCCABE. Yes. Type I Diabetes is a state where there is a lack of insulin production. Type II Diabetes, there are a couple of things that are going on. One is, most likely, insulin resistance, and a decrease in the secretion in insulin production.

The CHAIRMAN. I am going to ask some additional questions with your practice.

Mr. Hall, when you were diagnosed with Type I Diabetes, you talked about being devastated, did not know what this means, and so on, and then decided to proceed, nonetheless, to resume swimming, continue training, and won. I think you said, six additional medals, after that diagnoses.

What impact did Type I Diabetes and the treatment and the lifestyle changes you had to make have on your ability to maintain that level as a world class swimmer?

Mr. HALL. Diabetes management is an additional step that none of the competitors that I raced against had to contend with. It is through that shared experience with the rest of the diabetes community that I am able to express my empathy with those that are diagnosed and living with this disease. It is sincere and appreciated.

The challenges of managing diabetes are extreme. When diabetes nurse educators are talking to a newly-diagnosed patient, they will show them a picture of me with a gold medal and say this is possible. But the picture that they do not share with those patients is me helpless with a hypoglycemic reaction calling out for help and some orange juice. And that happens a lot more frequently than winning a gold medal.

The challenges are real. In Imperial China, death by a thousand cuts was a form of torture and death. I sometimes feel that diabetes is death by thousands and thousands of injections and finger pricks. And I think that sums up some of the feelings that are shared by a lot of people that are required to live with this every day without any break from diabetes.

The CHAIRMAN. In some ways, the dilemma here is that you look like the picture of health, and yet, you have a very serious illness. And I have seen the other picture. I have gone to Indian reservations and I have seen people sitting in dialysis units. I have seen people walk on crutches because they had a leg amputated. And I understand almost instantly, even if I do not talk to the person, what the circumstances are of that amputation. The background is diabetes.

And so, you look like the picture of health, and yet you have Type I Diabetes. I suspect that the two physicians here kind of confront those realities in the practice. They can see an Olympic swimmer winning medals with Type I Diabetes and so it is not so bad, it is manageable. And yet you described that even now your management of your disease is a 24 hour a day management. Is that correct?

Mr. HALL. That is correct. That is correct. And I am example that diabetes is an epidemic, that diabetes knows no boundaries of race or border.

The CHAIRMAN. Dr. McCabe, tell me about your practice. What percent of your patients have diabetes?

Dr. MCCABE. By describing my practice, you will get an idea of what percent have diabetes. I was trained in family medicine. I did a two-year fellowship in geriatrics. So, my practice, mainly, is geriatrics. So, a high percentage of my patients have diabetes.

The CHAIRMAN. And what percentage of your patients have had access to adequate screenings so that they could detect this diabetes as early as is possible and begin to manage it?

Dr. MCCABE. I would like to say 100 percent, but I know that is not the case. I know that is not the case. In this Country, we do not do as well in screening as we really need to.

The CHAIRMAN. Especially on the Indian reservations, it seems to me.

Dr. MCCABE. Exactly.

The CHAIRMAN. One of the keys, as I have seen it is, in addition to treatment, on Indian reservations, front end screening to try to identify those that have this disease, and then move them into treatment. But the lack of screening, and the lack of understanding that if someone is not feeling well and they have certain symptoms and so on, they never get the diagnosis, look, here is the problem and here is the way to manage it. I think screening is critically important.

Dr. MCCABE. And I think the Indian Health Service is making great efforts and improving the quality of healthcare on the diabetes front and that includes identifying diabetes early. I alluded in my statement earlier that the fasting blood sugar may not be the only way now to really identify someone who is at high risk. I talk about the metabolic syndrome and if we can use some of those criteria, we may be able also to identify a little bit earlier.

The CHAIRMAN. Mr. Studi, my understanding is that you, earlier this year, were involved in efforts to encourage Native Americans to get the flu vaccine, encouraging those infected with the flu to take prescribed medicine and so on. Have you been involved in that kind of activity?

Mr. STUDI. Yes. Earlier this year, we made some PSAs for encouraging Native Americans to get their shots for what was called the Swine Flu and I think they were, to some extent, effective.

The CHAIRMAN. In many ways, that approach, in your case dealing with the flu and the encouragement to get the vaccine, it relates to the question of, how difficult is it to get Native Americans to be able to, number one, acquire the medicine necessary to manage a disease like diabetes, and then to make sure they take that medicine.

I think it was Dr. McCabe who described someone who said well, I buy the medicine but I take it only twice a week in order to afford it. And, of course, that has a very serious health consequence.

So, when I saw that you had done some PSAs on, get our vaccine, get vaccinated, take the medicine, that is also a part and I would guess that both doctors believe, that is a part of what we have to do with respect to treatment of this disease called diabetes.

Mr. STUDI. Oh, absolutely. Prevention is the whole thing that we going after. And I did it somewhat reluctantly because the vaccine was not being made as available as it possibly could be at that time. And so, while I was working with some people who were very enthusiastic about doing this, I was somewhat reluctant, and I had also heard that it was difficult to find the amount and the type of shots that were supposed to be made available. But, fortunately, I was wrong as time went on and this was, the shots were made available as time went on.

But you do have to take into consideration that areas are not, areas where you can get your shots and that kind of thing are not as easily accessible for all people. And I am talking about large reservations where people have to travel long distances to clinics and that kind of thing.

In the long run, yes. These things are definitely tied around prevention, and prevention has to do with lifestyle, and that is what I attempt to advocate.

The CHAIRMAN. Yes, I think it is the case on a broader point that those who were here first, the First Americans, really, are getting second class healthcare in this Country, in terms of what was promised to them. The delivery, by treaties that were signed saying we will provide you healthcare, that trust responsibility in which the Government promised, the Government simply has not met those obligations. This is why we have worked very hard to pass the Indian Health Care Improvement Act. I am proud to say that is now law of just a couple of months.

Caitlin Baker, you talk about outreach and the organization that you have created to do outreach with young people. I am assuming that you probably, talk about lifestyle and those things. I hope you are talking about teen suicide, broken families, and drug use, all of the things that confront young people.

I have gone to reservations and sat, just myself as the only adult with a roundtable of kids, just to talk to them about their lives. And they face plenty of challenges, as you know.

But this issue of diabetes I assume is on the minds of every young Native American because they see their aunt, their uncle, their mom, their dad, grandpa, grandma fighting this disease, perhaps going to the dialysis center, going through treatment.

Give me your assessment. What are young people thinking about with respect to diabetes and are they pretty acutely aware of the potential of diabetes in their lives?

Ms. BAKER. Well, most people my age are, and a lot of my peers that I work with, they all know diabetes because, you know, grandma has it, auntie has it, somebody in their family will have it. My grandmother has diabetes and she is 90. She is really old. But there are a lot of people who are much younger who have diabetes as well.

A good friend of mine, he would pour tons of sugar in his tea, and I would look at him and be like, what are you doing? I mean, he is Native as well. So, you know, try to encourage good lifestyle. But, you know, he is talking about, you know, I feel like I am going to get it anyway because my mother has it. Both of his parents have it.

So, I feel like sometimes doctors, not all doctors, but sometimes they will tell him, you know, you are more likely to get it because your parents have it or your grandparents have it. So, I feel that a lot of people my age, especially Native youth, feel that they may get it.

Younger kids, though, I think they are more educated in diabetes starting now. The CDC comes out with the Eagle books which are a series of children's books for second grade and below that introduce diabetes at a very young age at a level that they can understand it. And talking about healthy living. So, in that way, it is a good education to have for these kids.

The CHAIRMAN. You do not have diabetes as I understand it.

Ms. BAKER. No.

The CHAIRMAN. What made you decide to form the organization that you formed and to do the kind of outreach with young people about these issues?

Ms. BAKER. Well, when I was 12, I went to the North American Indigenous Games for swimming. I was the only swimmer from Oklahoma. And part of being on a swim team, you might know, is having members, a relay, you know, a support system there for you. And so, this whole program started with me recruiting more swimmers that were Native to go on the next games with me, which we ended up not going because, well, I do not know why.

So, that is kind of where this all started. The more I got involved with it, the more people that I met, I started seeing more issues, suicide, teen pregnancy was a big issue that I worked with, let's see, diabetes, of course, and of course, having access to pools.

I worked a lot with having pools accessible because I worked with the Olympic Committee and Native Americans are the second highest drowning rates in the nation. So, I worked a lot with getting pools built, starting clinics, doing some clinics. I did some clin-

ics with Josh Davis and Mark Spitz before, and they are two great swimmers that I got to work with.

But, you know, just programs like that kind of implicating healthy lifestyles which swimming, I feel, is a very family-oriented sport.

The CHAIRMAN. Are you a competitive swimmer now?

Ms. BAKER. Yes, I am.

The CHAIRMAN. Do you consider Gary Hall an old man?

[Laughter.]

The CHAIRMAN. The reason I ask the question, without trying to make fun here, is you described your grandma as real old at 90.

Ms. BAKER. She is 90.

[Laughter.]

Ms. BAKER. I do not think there is anybody who is 90 in here.

[Laughter.]

The CHAIRMAN. Let me also, I kind of grinned when you referred, obliquely, to the fact that I was the only Senator here. All of the adults recognized that but decided not to say anything about it.

[Laughter.]

The CHAIRMAN. But, at age 16, you have the license to do that.

[Laughter.]

The CHAIRMAN. I would warn you not to go over to the Floor of the Senate today because, if you get to the gallery and look down onto the Floor of the Senate, you will see a Senator perhaps speaking with great passion and no one else in the room. And you, probably will, want to observe that when you get back home as well.

[Laughter.]

The CHAIRMAN. Your work inspires me and I think you will make a difference in people's lives and I appreciate what you do.

Let me ask, if I might, Izzy, would you be willing, if we brought a chair next to Mr. Hall, to come forward just for a moment? Would you do that? We will just pull up a chair next to Mr. Hall there. And I want to ask Mr. Hall another question as well at some point.

Izzy, you are 16 years old, 16. Is that right?

Ms. BURGER. No.

The CHAIRMAN. Oh, that is Caitlin. You are how old?

Ms. BURGER. I am 11.

The CHAIRMAN. Eleven. I should have known that. You probably think Caitlin is real old.

[Laughter.]

Ms. BURGER. Not really. I have some sisters older than her.

The CHAIRMAN. You heard the testimony from Gary Hall, a remarkable athlete and swimmer and Olympic champion. You are a young woman, a young girl who has been diagnosed with diabetes. Tell me about what you do to manage this disease. How does the disease affect your life?

**STATEMENT OF ISABEL "IZZY" BURGER, MEMBER, LITTLE
RIVER BAND OF OTTAWA INDIANS**

Ms. BURGER. Well, I like to play a lot of sports like basketball and softball. And I like to go fishing. And sometimes if my blood sugar is too high, I am forced to do those things, which I am fine with. But if it is too low, I cannot do those things, like maybe at a time when I want to do those things with friends.

So, I have to kind of manage it well because, if I do not, sometimes I kind of do not have privileges of something that normal kids would be able to do whenever they want.

The CHAIRMAN. Do you have to be attentive every day, all day, to this disease?

Ms. BURGER. Pretty much, because if I start to feel not normal, like if I start to feel really thirsty or really tired, then I have to realize that and check my blood sugar and fix it if there is a problem.

The CHAIRMAN. How many children are in your class at school? The reason I am going to ask the question is, are there others who have diabetes? Do you have friends who have diabetes that have to manage their disease and so you talk together about it?

Ms. BURGER. Not really. I am the only one.

The CHAIRMAN. So, where did you get the information with which to manage your disease?

Ms. BURGER. When I was first diagnosed, my doctor was really good with it. I went to DeVos Children's Hospital in Grand Rapids. And she was very good at describing the disease at a level that I could understand.

The CHAIRMAN. Do you have relatives that have diabetes?

Ms. BURGER. Yes. My grandmother has Type II Diabetes and she kind of helped me with it, like described how to bring it down if it was too high and things like that.

The CHAIRMAN. Well, you are a very poised young woman. Do you want to introduce your mom?

Ms. BURGER. Yes, my mom is right there.

[Laughter.]

Ms. BURGER. Her name is Jessica Burger and she is really good with it. She helps me a lot.

The CHAIRMAN. We appreciate your being here and thanks for letting me ask you to come up and say a word. I appreciate that.

Ms. BURGER. Thank you for having me.

The CHAIRMAN. Gary, I am going to ask a couple of other questions of the witnesses.

As you know, we are trying to get the legislation on the Special Diabetes Program. We are also trying to pump more money into the National Institutes of Health. At one point we wanted a program to double the NIH funding, which we did. There were about 6 or 7 of us in the Senate particularly that took it under our wing and decided that we really ought to put a lot more money into research because it pays very big dividends.

Now we are trying to keep up with the rate of inflation because we have less money and we have fiscal policy problems.

But I remain convinced that the search needs to be number one, to better monitor, and that relates to some technology with monitoring devices and so on, but especially, most especially, to keep pursuing very aggressively to find a cure.

Dr. Fradkin, when we provide money to the NIH, to virtually any institute, that money goes out all across the Country in trials and various approaches. Tell me, what is happening to the money for diabetes at the NIH? Just give me a description, generally speaking, where does all that go, how is it invested, and for what purpose?

Dr. FRADKIN. One program that you might be very interested in because of your interest in a cure is our Beta Cell Biology Consortium. That is a group of scientists around the Country, and even internationally, that are trying to find ways to re-grow the beta cells, the insulin-producing beta cells, in people who have Type I Diabetes, either to convert other cells in the body to insulin-producing beta cells or to find a stem cell within the body that could be stimulated to grow into a beta cell, or to take stem cells from outside the body, convert them into beta cells, and then administer them.

That is an approach to the cure that is going on across the Country and even internationally with the support of the Type I money.

The CHAIRMAN. So, most of that is in the stem cell research area?

Dr. FRADKIN. It is stem cells, both taking stem cells that are being studied in the test tube to try to create beta cells, but also trying to figure out ways to find the stem cells within a person's own body that might be stimulated to re-grow in somebody who has lost their beta cells.

The CHAIRMAN. And is there any evidence, or any early evidence, whether embryonic stem cell research or some other research, is better suited to finding a cure?

Dr. FRADKIN. Sir, we have made tremendous progress in this area. We now are able to take embryonic stem cells and we have identified the various genes that need to be turned on to move one of those cells toward an insulin-producing cell and we can get all the way toward making one of those cells make insulin.

The next stage though, there are a couple of different problems that we need to overcome to make this a cure. One is to modulate the immune system so that even if we create a new beta cell and either give it to people or they grow their own beta cells, that it will not be destroyed by the immune system. And the other thing is that even though we have gotten to the point where those cells can make insulin, we need to get them to make insulin in the exquisitely-regulated way in which tiny changes in glucose modulate the production of insulin.

So, we have a number of next steps to take. But I think that is an example of the kind of consortia that we create.

Most of the funding, about two-thirds of the funding, is spent directly by NIDDK, which manages the funding, and most of that is going to large, multi-site consortia that involve sites across the Country. So, for example, our clinical trials network includes a whole network of hundreds of sites to enroll people all over the Country in efforts to prevent or to treat newly-diagnosed Type I Diabetes.

We also use the funds through other components of NIH. For example, the trial that showed these very promising effects on eye disease was conducted by the National Eye Institute. We provide money to the Centers for Disease Control to monitor the epidemic and to develop standardization of the A1c that I mentioned. So, the funds are very, very broadly distributed.

The CHAIRMAN. All right.

Mr. Studi, the issue of traditional culture and practice on Indian reservations. Have you observed how that might or might not play a role in both detection and treatment of diabetes?

Mr. STUDI. Well, as a matter of fact, I think the real disaster of the whole thing is that it is so accepted as a part of life. Diabetes is like, as the young lady mentioned, it is like everybody has it, somebody has it here or there, relatives and friends. It is practically accepted to the point of, well, there is really nothing we can do about it, you know? It is just a fact of life. It is something that we have to live with.

Well, I think that part of SDP's goal is in educating the public to the point, or the Indian public, to where I speak, you know, that there is cause to be glad that there is somebody working towards a cure for this, as well as the development of more treatments and research that is going on.

The educational arm of the whole thing is that we need to get the idea out that no, it is not an acceptable thing. It is just another epidemic that has scourged Indian Country since the beginning of our cultures coming together.

The CHAIRMAN. Mr. Hall, how old are you?

Mr. HALL. I am 35.

The CHAIRMAN. So, your Olympic competitive swimming career is likely over.

Mr. HALL. That is true.

[Laughter.]

The CHAIRMAN. Maybe I should not have declared that, I should have let you answer that.

[Laughter.]

The CHAIRMAN. But you will remain, I assume, someone who is fit and athletic and you will exercise so you will always probably have to manage this disease in the context of training and exercise. Tell me just a bit about the organization that you created. As I understand it, you created an organization with respect to outreach and information with respect to diabetes. Is that correct?

Mr. HALL. Well, I am involved with several nationwide programs, one through the United States Olympic Committee that is encouraging schools to measure the distance and encourage walking among students, where it is a measured every six weeks program, World Fit is the name of that program.

And also just in trying to create general diabetes awareness. I have been involved with makeover programs. Yes, happiness is not possible without health.

The CHAIRMAN. Have you had a chance to, an opportunity, to go to some Indian reservations to talk about diabetes?

Mr. HALL. I spent many years in Arizona and was familiar, early on, with the problems, even prior to my diagnosis with diabetes, with the Pima Indian population and their struggles with diabetes.

The CHAIRMAN. Well, thanks for your work. Some people would just get a bad diagnosis and do everything they could to address it themselves, overcome it themselves and that is it. But you have done much, much more than that and I appreciate very much your willingness.

Mr. HALL. Thank you for saying that. The inspiration that I have been honored to offer to people with diabetes is so small compared to the hope that the Special Diabetes Program research offers to the diabetes population. The research is promising and any lapse

in funding would disrupt that important research that provides hope to all of us.

The CHAIRMAN. Thank you very much.

Dr. McCabe, one of the things that has come up in a couple of pieces of testimony today is that television is a pretty awful competitor for exercise. And, you know the desire to get young people, particularly young people, off of the chair from watching television and out into the yard exercising is a critical part. Particularly for those who have the disease diabetes, it is a critical part in managing it. Is that correct?

Dr. MCCABE. Absolutely.

The CHAIRMAN. So, are you going to take care of the television problem?

Dr. MCCABE. Absolutely.

[Laughter.]

Dr. MCCABE. No, it truly is. And again, as I alluded to, I think when we have introductions of new technology that are introduced into this Country, concomitant with that we have to see what the impact is going to be. And for television itself, it has been on increased rates of, I think, diabetes, because there is decreased physical activity associated with that.

So, that is the future planning. That is the long-range planning that we must begin. And it is not only for American Indians and Alaska Natives. It is for the whole Country. Our rates of diabetes for this whole Country are high.

The CHAIRMAN. It is important to say again. We are holding this hearing in the Indian Affairs Committee, but this is a national epidemic. There is no question about that. And it is growing very rapidly and has to be addressed.

But, the epidemic is especially acute, much more so than the national statistics, on Indian reservations many of which are in remote areas, many, many, many miles from other healthcare facilities. And that makes it very difficult because we have had to try to see if we could put dialysis units and detection and treatment centers in very rural areas.

I cannot tell you the number of people I have talked to who had to go 80 miles one-way for a dialysis treatment on a remote Indian reservation, to be put on a bus and taken some place. And those are the lucky ones that get taken there. Others that do not get diagnosis quickly enough and lose limbs and lose their sight. It is such an awful disease. It ravages the body throughout the life of the patient.

Caitlin, let me again say that I think it is really inspiring and special in my life when I meet somebody who is really young, and by that I mean a teenager or less even, somebody who is really young who is doing interesting things in working outside of themselves and wanting to become a part of something bigger than themselves.

Ms. BAKER. Thank you.

The CHAIRMAN. You will make a difference and you will, I think, save lives and help other Indian children. So, I appreciate the work you do.

Ms. BAKER. Thank you.

The CHAIRMAN. Let me thank all of you. This Committee, as I indicated, we were able to get the Indian Healthcare Improvement Act passed after, I believe it was 18 years since when it was last addressed. We able to get that signed into law by the President this year.

We just in recent days, last week in fact, Thursday night, were able to get passed the Tribal Law and Order Act, which is unbelievably unimportant. We have rates of violent crimes on some Indian reservations that are 5 and 10 and 12 times the national average. It is very hard to live with any sort of confidence or hope for the future if you do not feel safe.

And so, we are going to get the Indian Health Care Improvement Act implemented. We are going to get the Tribal Law and Order Act done in this Congress. And we are going to push very hard to get the Special Diabetes Program reauthorized. That is a priority for this Committee.

And the willingness of the five of you to travel some distance to come and testify today is very much appreciated. We thank you very much.

This hearing is adjourned.

[Whereupon, at 11:12 a.m., the Committee was adjourned.]

A P P E N D I X

PREPARED STATEMENT OF THE NATIONAL INDIAN HEALTH BOARD

The National Indian Health Board appreciates the work of the Senate Committee of Indian Affairs to elevate the issue of diabetes in American Indians and Alaska Natives (AI/AN) by holding this oversight hearing. We would like to provide additional comments on diabetes and the Special Diabetes Program for Indians.

Established in 1972, the NIHB serves all 564 federally recognized AI/AN Tribal Governments by advocating for the improvement of health care delivery, as well as upholding the federal government's trust responsibility to AI/ANs. We strive to advance the level and quality of health care and the adequacy of funding for health services delivered directly by the Indian Health Service (IHS) or directly operated by Tribes and Tribal Organizations. Our Board Members represent each of the twelve IHS Areas and are generally elected at-large by their respective Tribal Governmental Officials within their regional area. The NIHB is the only national organization solely devoted to the improvement of Indian health care on the behalf of the Tribes.

Diabetes in Indian Country

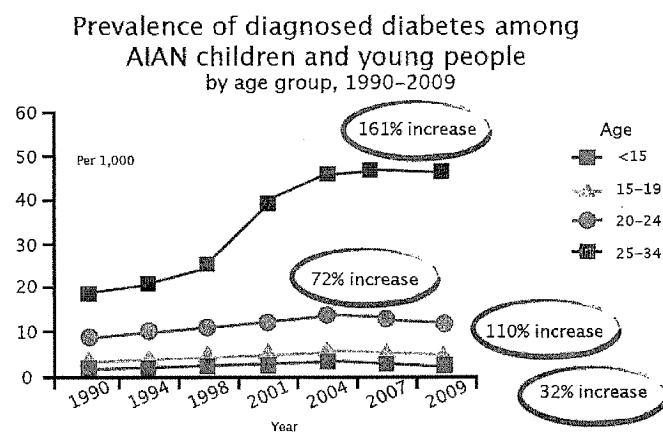
Less than 100 years ago, diabetes was virtually unknown in Native communities. Today, AI/AN communities suffer disproportionately high rates of type 2 diabetes. In many tribal communities, diabetes is three to five times the national average. AI/AN adults are 2.2 times more likely to have diabetes compared with non-Hispanic whites.¹ Furthermore, in comparison with 8.7% of non-Hispanic whites, 16.3% of AI/AN adults have been diagnosed with diabetes.² In some AI/AN communities, more than half of the adults aged 18 and older have been diagnosed with diabetes, with prevalence rates reaching as high as 60%.³ Adding to these troubling statistics is the rise of obesity and type 2 diabetes among our young people. The highest increase in type 2 diabetes has occurred among AI/AN young adults ages 25-34 years, with a 161% increase from

¹ Indian Health Service (June 2008). *Diabetes in American Indians and Alaska Natives: Facts at a Glance*. Retrieved from http://www.ihs.gov/MedicalPrograms/Diabetes/index.cfm?module=resourcesFactSheets_AIANs08.

² Id.

³ *Special Diabetes Program for Indians: Together We Fight Diabetes for our Ancestors, Our Communities and Future Generations* citing the Indian Health Service Report to Congress, 2007.

1990-2009. Alarming, diagnosis of diabetes has also risen 110% in AI/AN adolescents, 15-19 years old during the same period.



AI/AN people are also more likely to die from diabetes or diabetes related causes than other Americans. The diabetes mortality rate is nearly three times higher in the AI/AN population than the general U.S. population (2003-2005)⁴. The diagnosis of diabetes also leads to diagnosis of other diseases, which lead to further health complications. For example, AI/ANs have a 3.5 times higher rate of diabetes-related kidney failure compared to the general U.S. population in 2004.⁵

The Special Diabetes Program for Indians

Despite these alarming statistics, there is progress being made that, if continued, will help to stem the tide of diabetes in Native communities. It is difficult to highlight this progress without calling attention to the Special Diabetes Program for Indians (SDPI). That is because prior to the creation of SDPI, there was no focused federal effort to address diabetes in tribal communities. Moreover, in the twelve years since SDPI began providing support to communities for diabetes treatment, prevention and education, data has been collected that shows real progress.

Congress created the SDPI in 1997 in the wake of increasing public concern about the human and economic costs of diabetes in the U.S. and its growing prevalence among the AI/AN

⁴ Indian Health Service (January 2010). *Indian Health Service Factsheets: Indian Health Disparities*. Retrieved from <http://info.ihs.gov/Disparities.asp>.

⁵ See note 1.

population. The SDPI was implemented through consultation with Tribes to develop the methodology and the process for distribution of the funds. In 1998, the IHS formally established the Tribal Leaders Diabetes Committee (TLDC) to provide advice and recommendations on policy and issues concerning diabetes and related chronic diseases. The TLDC is comprised of an elected Tribal Leader from each of the 12 IHS Areas, one IHS representative and one representative from five national organizations, including the NIH. Currently, I have the honor to serve as the Co-Chair of the TLDC along with Dr. Kelly Acton with the IHS Division of Diabetes Treatment and Prevention.

The TLDC's collaborative effort with the IHS has been an important factor of the SDPI. The IHS recognized from the start of this program that it would have to make careful choices about where to invest these funds and knew these choices would best be made with input from Tribal leaders who serve on the TLDC. In addition, the TLDC plays a key role in ensuring that the IHS consults with Tribes before making decisions on diabetes treatment and prevention efforts.

Growth and Impact of SDPI

In the beginning, the SDPI funds provided funding to 333 non-competitive grant programs to IHS, Tribal, and urban Indian health programs in 35 states to begin or enhance diabetes treatment and prevention programs in Indian communities. The result has been the creation of innovative, culturally appropriate strategies that address diabetes. The Community-Directed Diabetes Programs continue today with 385 grant programs funded. The IHS encourages the use of the Indian Health Diabetes Best Practices and promotes the development of local programs based on local community needs and priorities. This focus on the local priorities and community centered has been the key to the success of the program as the local tribal community designs the program based on the needs of their community.

In 2004, at the direction of Congress, the SDPI expanded with the addition of two demonstration projects, which included 66 competitive grants. Thirty-six grantees participated in the Diabetes Prevention Demonstration Projects, which focused on preventing diabetes through lifestyle changes, such as exercise and weight loss. The remaining 30 grantees participated in the Healthy Heart Demonstration project that targets Indian people who have been diagnosed with diabetes by treating for related cardiovascular diseases.

Today, the IHS provides funding and support for diabetes prevention and treatment programs, services, and activities to over 450 IHS, Tribal and urban Indian SDPI programs, serving nearly all federally recognized tribes. The following is a sample of some of the prevention, screening, and treatment services provided by the IHS, Tribal, and urban diabetes programs:

- Clinical annual examinations of the eyes, teeth, and feet to prevent diabetes-related complications
- Laboratory tests to assess diabetes control and complications
- Nutrition education and counseling services by registered dietitians
- Culturally appropriate diabetes education and awareness activities
- Diabetes primary prevention programs for children and families
- Community-based healthy eating programs at area schools and nursing homes
- Community physical fitness activities

Since the inception of the SDPI, diabetes-related health outcomes have improved significantly in AI/AN communities. For example:

- One of the most important improvements is an 11 percent decrease in the mean blood sugar level (A1C) of AI/ANs with diagnosed diabetes, a major achievement over 12 years. Decreases of this magnitude translate to a 40% reduction in diabetes-related complications such as blindness, kidney failure, nerve disease and amputations.⁶
- The mean total cholesterol level has decreased by 16% from 1997-2009, and mean LDL cholesterol (“bad” cholesterol) has been reduced 20%. Research has shown that lowering cholesterol levels may help reduce the chance of developing cardiovascular complications associated with diabetes such as heart attacks, stroke or heart failure.
- The prevalence of protein in the urine (a sign of kidney dysfunction) was reduced by 32% during 1997-2009.⁷ New cases of diabetes-related dialysis in AI/ANs decreased 31% between 1999 and 2007, while remaining relatively unchanged in other races. Preventing kidney failure is critical to preventing people with diabetes from needing dialysis or kidney transplants.⁸

The SDPI has allowed many of the IHS, Tribal and urban programs to provide preventive and other basic elements of diabetes care that were not available to AI/ANs prior to the SDPI. In fact, it is proving to be both a successful effort and a good investment. The SDPI funding has enabled the IHS, Tribal, and urban Indian programs to provide expanded prevention, screening and treatment diabetes services. Through an increase in prevention and screening activities, the economic costs of treating diabetes and diabetes-related complications in Indian communities should be lessened. However, more importantly, the SDPI funds have significantly enhanced diabetes care and education in AI/AN communities, as well as built a desperately needed infrastructure for diabetes programs.

The outcomes of the SDPI have helped to advance other IHS diabetes programs such as the Model Diabetes Program, which was established under the Indian Health Care Improvement Act. The Model Diabetes Program also promotes collaborative strategies with Tribes for the prevention and treatment of diabetes. The 19 Model Diabetes Programs in the Indian health system have made significant contributions, including state-of-the-art comprehensive, clinical diabetes care through a multidisciplinary preventive and treatment approach, and education and nutritional counseling services. In addition, the recent passage of the reauthorization of the Indian Health Care Improvement Act provides IHS with the authority to provide dialysis. With funding to support this new provision, IHS will have program to help treat diabetes.

⁶ *Special Diabetes Program for Indians: Together We Fight Diabetes for our Ancestors, Our Communities and Future Generations* citing Indian Health Service Report to Congress, 2007.

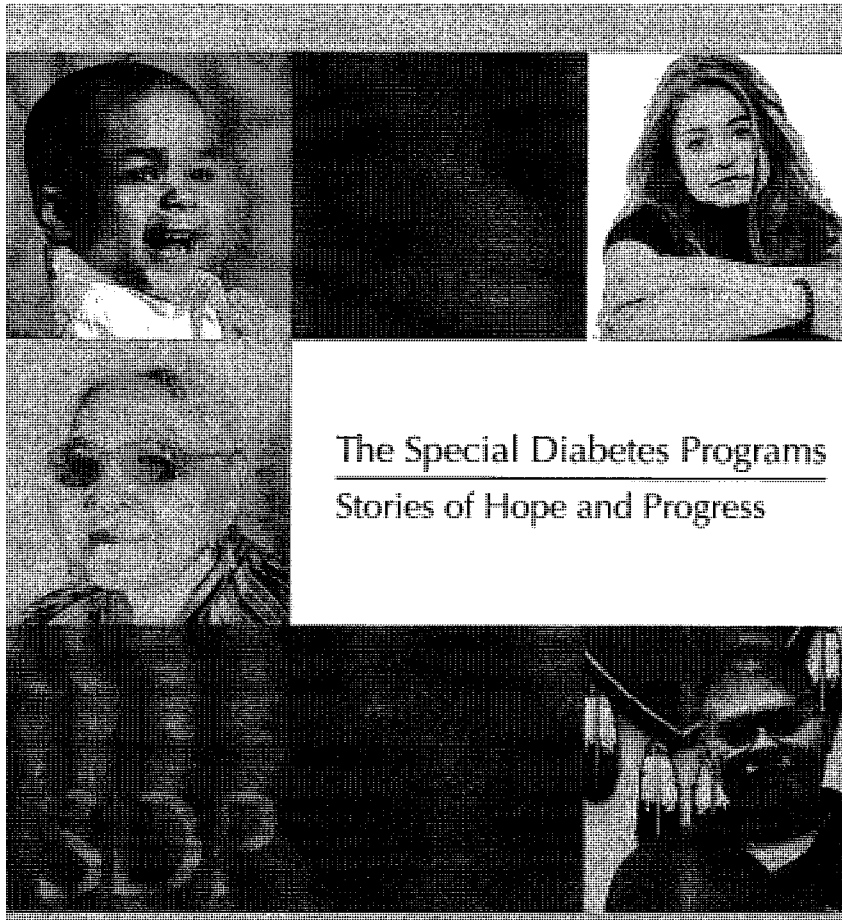
⁷ *Special Diabetes Program for Indians: Together We Fight Diabetes for our Ancestors, Our Communities and Future Generations* citing Indian Health Service, DDTP Fact Sheet.

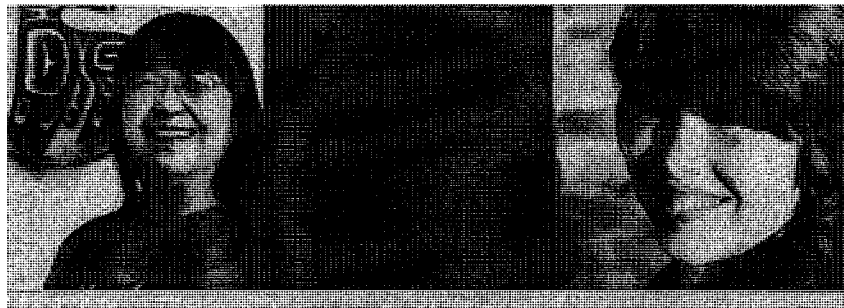
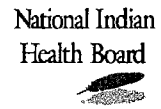
⁸ *Special Diabetes Program for Indians: Together We Fight Diabetes for our Ancestors, Our Communities and Future Generations* citing 2009 USRDS Atlas available at <http://www.usrds.org/atlas.htm>.

The Future

The vision of the TLDC is to empower AI/AN people to live free of diabetes through healthy lifestyles while preserving cultural traditions and values. The SDPI is a vital program that is fulfilling this mission of the TLDC. I am proud of what the SDPI has accomplished. This program has been life saving to people who have diabetes, life-changing to those who have avoided diabetes because of early detection and prevention efforts, and perhaps most importantly, it is helping to ensure a diabetes-free future for our children and future generations.

Diabetes is one of the greatest public health challenges facing Native communities as well as our country as a whole. Making real progress in this area and ensuring that future generations will be free of the burden of this disease will take the federal government and tribal governments working together. We have shown it can work. Now we need to recommit ourselves and this hearing is a good first step.







The Special Diabetes Program (SDP) is comprised of two parts -- the Special Diabetes Program for Type 1 Diabetes (Special Type 1 Program) and the Special Diabetes Program for Indians (SDPI). Congress created these programs in 1997 in response to the need for additional resources to take advantage of opportunities to advance type 1 diabetes research, as well as to address the disproportionate burden type 2 diabetes had on American Indian and Alaska Native (AIAN) populations. Together, these programs have become our nation's most strategic and effective federal initiative to combat diabetes and its complications.

These programs have been successful on many levels. The basic and clinical research supported by the Special Type 1 Program is delaying the full onset of type 1 diabetes in some participants, helping us to better understand the underlying genetic and environmental causes of diabetes, and preventing, treating and reversing some of the devastating complications associated with the disease. SDPI data demonstrates positive clinical outcomes for people participating in SDPI-supported programs. SDPI-supported programs not only reduce the risk for complications such as heart attack, blindness, amputations, and kidney failure in those participating they also prevent the full onset of type 2 diabetes in many individuals through the implementation of successful prevention programs based on scientific and community evidence-based care.

Success can be demonstrated in many ways, and while scientific outcomes prove the program's achievements, another important measure of success is the tremendous positive impact SDP has on people with diabetes. This book documents that success by enabling people to share their own stories of how their lives have been directly improved and enhanced by the SDP. In many cases, the program has saved their lives, or improved their future by preventing diabetes or reducing their risk of developing serious complications. While there is a story from every state, this is just a small sample of the many individuals, families and communities who have benefited from the program.

The Special Diabetes Program is set to expire in 2011 unless Congress acts to renew it. This program has been cited by many as a model of how a focused federal effort can produce a significant return on the federal investment. As you will see in the following pages, that return can be measured not only in data and dollars, but also in the direct impact on people. On behalf of the people benefitting from the Special Diabetes Program, we call on Congress to provide a multi-year renewal for this critical program to change the future of this deadly disease and help stop diabetes.

Sincerely,

Larry Hausner
Chief Executive Officer
American Diabetes Association

Alan J. Lewis, Ph.D.
President and Chief Executive Officer
Juvenile Diabetes Research Foundation

Stacy A. Bohlen
Executive Director
National Indian Health Board

INTRODUCTION

Special Diabetes Program for Type 1 Diabetes

Type 1 diabetes is a devastating disease for which there is no cure. Type 1 diabetes occurs when the body's immune system attacks and destroys insulin-producing beta cells in the pancreas, disrupting endocrine and metabolic functions. People with type 1 diabetes must take insulin in order to stay alive, which means multiple daily injections, or having insulin delivered through an insulin pump, and testing their blood sugar by pricking their fingers for blood six or more times a day. Insulin helps manage this disease, but it isn't a cure. In addition to insulin management, people with diabetes must also carefully balance their food intake and their exercise to regulate their blood sugar levels, in an attempt to avoid hypoglycemia (low blood sugar) and hyperglycemia (high blood sugar), which can be life threatening.

Congress and the National Institutes of Health (NIH) have recognized the need for a focused research agenda dedicated to type 1 diabetes and its complications. In 1997, the Congressionally mandated Diabetes Research Working Group report cited serious limitations in diabetes research, in general, and in type 1 diabetes in particular, and urged Congress to "increase significantly the nation's investment to conquer this disease." Congress responded by creating the Special Diabetes Program for Type 1 Diabetes, making mandatory funds available for type 1 diabetes research administered by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the NIH.

The Special Diabetes Program for Type 1 Diabetes has demonstrated tangible results and is a critical part of our nation's federal investment in diabetes research. The program supports a multi-disciplinary approach to type 1 diabetes research across multiple NIH institutes and centers, making it a model for trans-NIH research efforts. The Special Diabetes Program is currently supporting the following highly promising, major clinical trials:

- o **Type 1 Diabetes TrialNet:** This national network conducts clinical trials of therapies to prevent type 1 diabetes in people who are at risk for developing the disease, and to stop it from progressing in those who are newly diagnosed.
- o **Type 1 Diabetes Genetics Consortium and the Environmental Determinants of Diabetes in the Young Study:** These large, collaborative clinical studies are answering fundamental questions about what causes type 1 diabetes, and can lead to preventive or curative therapies.
- o **Clinical Islet Transplantation Consortium:** This consortium performs multi-center, Phase III trials that will lead to FDA approval of islet cell transplantation therapy.
- o **Diabetes Research in Children Network:** This clinical network fills a critical research gap by testing and validating new diabetes management technologies in children.
- o **Beta Cell Biology Consortium:** This international collaboration focuses on understanding the development and function of insulin-producing beta cells, with the goal of developing a cell-based therapy for people with diabetes.

The Special Diabetes Program represents 35% of federal funding for type 1 diabetes research. The program has created significant research opportunities that are helping to improve the lives of people living with diabetes, prevent the onset of the disease in others, and bring us closer to a cure for this costly and growing disease. A timely, multi-year renewal of the Special Diabetes Program will allow us to build on the program's advances in its initial years by accelerating the translation of the discoveries already made into treatments and cures for the benefit of all Americans living with diabetes.

Special Diabetes Program for Indians (SDPI)

Type 2 diabetes is a growing epidemic. Type 2 diabetes, the most common form of diabetes, occurs when the body fails to produce or properly use insulin, a hormone needed to convert sugar, starches and other food into energy. To manage their diabetes, people need to make lifestyle changes (such as regular exercise and healthy weight maintenance). Others must also use oral medications and/or insulin injections. Until recently, type 2 diabetes was primarily found in adults and was associated with obesity. However, the number of young adults and children with type 2 diabetes has dramatically increased in recent years. Type 2 diabetes can result in costly and devastating complications including amputations, kidney failure, heart attack and stroke and blindness.

Type 2 diabetes is a serious problem in American Indian and Alaska Native (AIAN) populations. AIANs have the highest age-adjusted prevalence of diabetes among all U.S. racial and ethnic groups – more than double the prevalence in the general population. In some AIAN communities, more than half of adults aged 18 and older have diagnosed diabetes, with prevalence rates reaching as high as 60 percent. The AIAN population suffers from higher rates of diabetes complications because they develop diabetes earlier in their lives compared to the general population, and their mortality rate is more than three times higher than the national average.

The Indian Health Service (IHS) has implemented innovative, effective and culturally relevant strategies to address this life-threatening disease. More than a decade ago, Congress responded through the establishment of the Special Diabetes Program for Indians (SDPI) under the Balanced Budget Act of 1997. Currently, the SDPI provides funding in 35 states for over 450 IHS, Tribal, and Urban Indian programs, serving nearly all federally recognized tribes. Using proven diabetes treatment and prevention strategies – such as patient education, quality diabetes care, physical activity, nutrition and weight management activities – the program has improved health outcomes among the AIAN population. SDPI funding has also supported the implementation of two large scale diabetes and cardiovascular disease prevention projects in which 66 programs are successfully translating the latest diabetes research into effective clinical and community-based strategies.

The SDPI has resulted in significant improvements in diabetes prevention, control and care in AIAN communities. SDPI funding has resulted in improvements in key diabetes care outcomes measures, including significant reduction in the average level of Hemoglobin A1c (indicating better diabetes control); improvements in cholesterol, blood pressure control, and kidney function; and reductions in amputation rates. The successes from SDPI could ultimately benefit all people with diabetes. At the same time, the program has allowed IHS to design and implement systems to improve data collection and analysis.

The SDPI will expire in 2011 unless Congress takes action to renew this critical program. The SDPI provides Indian health programs and tribal communities with essential resources and tools to combat the diabetes epidemic. A timely, multi-year renewal of the SDPI is critically needed to disseminate and implement the advances made in diabetes prevention and treatment thus far, across all AIAN communities. It must continue to meet the escalating demands of the disease.

The Special Diabetes Programs

Stories of Hope and Progress

Mary Belle's Story

"School, sports, sleepovers, and just going outside to play can be hard when you have diabetes. It is always with you."

- Mary Belle Johnson

Two years ago, when I was eight years old, my mom brought me to the doctor because I was drinking and going to the bathroom a lot, and I was very tired. My doctor told me that I had type 1 diabetes, and I was sent to the hospital where I stayed for three days. Diabetes changed my life and my parents' lives, too. They had to learn fast how to manage my diabetes. Life with diabetes is hard; you have to manage it all the time. We check my blood sugar up to ten times a day, and my mom and dad have set their alarm clock every night since I was diagnosed to check my blood sugar in the middle of the night so I don't have serious high and low blood sugars while I am sleeping.

Soon after I was diagnosed, my doctor told us about a clinical trial that was testing the effect of putting kids on an insulin pump right after they were diagnosed. I didn't know what a clinical

trial was, but I am happy that I participated. Being in the trial helped to keep my blood sugar in good control, and I decided to stay on the pump after the trial ended. And I know that what the scientists learned from kids like me in the trial will help other kids who have diabetes. No one else in my family has diabetes, but my sister, brother and mom all participate in a clinical trial as part of TrialNet that tests them for antibodies that put them at high risk of developing diabetes. So far, they have tested negative, but they will continue to get tested every year. My whole family is so thankful for the research that is helping scientists figure out what causes diabetes and how to better manage it until they can find a cure.

Diabetes in Alabama

According to 2008 CDC data, approximately 379,000 people in Alabama – 10.2% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications and conditions. **In addition to the human toll diabetes places on people in Alabama, the financial burden diabetes places on the health system in the state is staggering – in 2007, the direct and indirect costs of diabetes in Alabama was approximately \$2.5 billion.**



Mary Belle Johnson

ALABAMA

Charlotte's Story

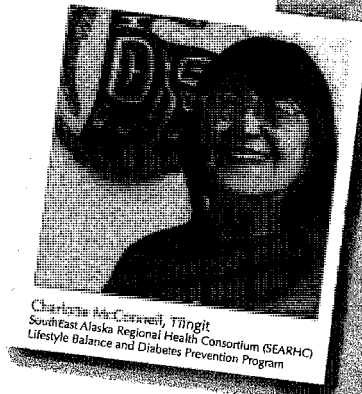
"We seriously need the Diabetes Prevention Program in our community. The longer it is here the more people it will help to prevent diabetes." - Charlotte McConnell

Through the Diabetes Prevention Program I found out I had pre-diabetes. I had also been told I had high cholesterol and blood pressure and they wanted to put me on pills but I didn't want to take their pills. I wanted to lower my blood sugar, blood pressure and cholesterol with food and exercise. The Diabetes Prevention Program was there to help me get my blood sugar back to normal and improve my health without having to take pills, so I joined the program and started going to classes. The classes have really helped keep me on track. I've learned ways to eat less fat, and how to cook and prepare my meals in a more healthy way. I really like the positive changes that are now evident in my overall health. When I completed the program I stopped going to classes and found my cholesterol and blood pressure were starting to go up again. So, I came back to the program and I'm doing better now and my blood sugar is back in the normal range.

It is so important to have the Diabetes Prevention Program available to us because we are seeing more people with diabetes in our community. The diabetes staff are very helpful and they bring in professionals to explain things (sometimes scary things) about our health and diabetes. We also have the support of all the other participants working to prevent diabetes and be healthier. The stories everyone shares give us the courage we need to keep on doing the right things to be healthy and prevent diabetes.

Diabetes in Alaska

According to 2008 CDC data, approximately 31,000 people in Alaska – 6.9% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Alaska, the financial burden diabetes places on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in Alaska was approximately \$419 million.**



Charlotte McConnell, Tiingit
Southeast Alaska Regional Health Consortium (SEARHC)
Lifestyle Balance and Diabetes Prevention Program



Rudy's Story

"Today, after 20 years of insulin injections, I am able to manage my diabetes without insulin."

- Rudy Clark



Rudy Clark, Hualapai
Hualapai Healthy Heart Project

Before I was diagnosed with type 2 diabetes in 1978, I really didn't know much about diabetes. My father, who died when I was young, had his leg amputated and I thought he just went into a coma. As I learned more about the full impact of diabetes, I realized it was probably a diabetes-related coma that caused his death. What my father went through with his health problems is one thing that motivates me to stay healthy and be available to my children and grandchildren.

I had made many healthy changes over the years but I woke up one day and decided to commit to learning all I could about diabetes and joined the Hualapai Healthy Heart Program. I took classes on heart health and managing diabetes, and learned about reading labels to pick which foods to eat. The most challenging part for me has been

trying to maintain a steady weight and keeping up with a vigorous schedule for exercise. I ride bikes, walk, jog, and use the Hualapai Fitness Center and always invite others in the community to join me.

I try to let everyone know that our tribe has programs like Healthy Heart that will show them how to commit to make small changes and start eating healthy and exercising, not just to help them control their diabetes but to hopefully one day prevent it. Diabetes is something that we should attack and pay attention to as a native nation. We need to fight diabetes, using our cultural and traditional methods because we now know that we can control our blood sugar.

Diabetes in Arizona

According to 2008 CDC data, approximately 376,000 people in Arizona – 7.9% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Arizona, the financial burden diabetes places on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in Arizona was approximately \$3.46 billion.**

ARIZONA

Angelina's Story

**"Participating in this research has changed my life. I want the world to know how important this research is."
- Angelina Mazzanti**

Before being diagnosed with type 1 diabetes, I was just like other teenagers, more or less. My days were filled with activities, dance lessons, soccer, spending time with friends and, due to my dyslexia, lots of time spent staying busy with school. Then, all of a sudden things started to change. First, it was my hip, then my stomach starting hurting. I started losing a lot of weight. I didn't know what was wrong with me until I went to Children's Hospital on April 25, 2006 and was told that I had type 1 diabetes.

Although I have a positive outlook on my future, I can honestly say that between being dyslexic and having diabetes, life sometimes seems really hard. But I am not one to complain, and since my diagnosis, I have been participating in research studies that will not only help me but others with diabetes.

After my diagnosis, I enrolled in TrialNet's Anti-CD20 study. The study is trying to see if it is possible to stop or slow down the immune system's attack in newly diagnosed type 1 diabetes patients so that the remaining insulin-producing cells can survive and keep making the insulin your body needs. The longer I produce my own insulin the less likely I am to develop diabetes complications that can lead to kidney failure or blindness. Having this disease is so very hard. But being a part of this research community really gives me hope that I am making a difference in ridding the world of diabetes. And a cure will make it all worth it.

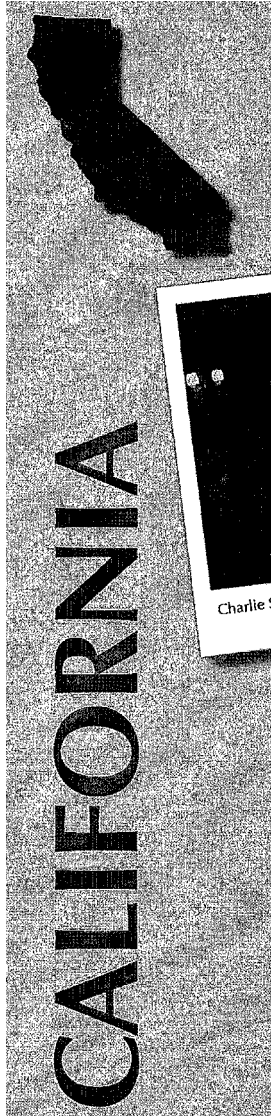
Diabetes in Arkansas

According to 2008 CDC data, approximately 201,000 people in Arkansas – 8.8% of the state's population – had diagnosed diabetes, and many of them suffer from serious complications or conditions. **In addition to the human toll diabetes places on people in Arkansas, the financial burden diabetes places on the health care system in the state is staggering -- in 2007, the approximate direct and indirect cost of diabetes in Arkansas was approximately \$1.43 billion.**



Angelina Mazzanti





Ann's Story

"I never thought diabetes would be one of the things I passed on to my son. My promise to Charlie is that I will do everything I can to help find a cure. Participating in research is how I am fulfilling my promise to him." - Ann Seidel Domergue

I was diagnosed with type 1 diabetes when I was six years old, and I've worked hard my whole life to manage my diabetes. Over all the years that I had diabetes, I took 255,000 units of insulin and pricked my fingers 56,210 times. But when my son Charlie was diagnosed at age 2, I was no longer just a woman with type 1 diabetes – I also became a mother fighting for my child's life.

Right around the time Charlie got diagnosed, my diabetes took a turn for the worse. I was no longer able to sense when my blood sugar was falling dangerously low. Low blood sugars could cause me to become disoriented, faint or even have a seizure, so I knew that I had to help myself if I was going to be able to care for my son. In 2003, I received an islet transplant that initially enabled me to stop taking insulin and

stopped many of my problems with low blood sugars. Unfortunately, due to difficulties with the immunosuppressive drugs, my transplanted islets eventually stopped working. However, in 2008 I was fortunate to receive a whole pancreas transplant.

While my journey has been difficult, I am now free from diabetes – yet I worry about Charlie every day. I am glad the Special Diabetes Program is conducting research to perfect islet transplantations, and to use less toxic immunosuppressive drugs, so that the procedure can one day be an option for Charlie and other children with type 1 diabetes.

Diabetes in California

According to 2008 CDC data, approximately 2,220,000 people in California – 8.3% of the state's population – had diagnosed diabetes, and many of them suffer from serious complications or conditions. **In addition to the human toll diabetes places on people in California, the financial burden diabetes places on the health care system in the state is staggering – in 2007, the approximate direct and indirect cost of diabetes in California was approximately \$24.42 billion.**

Sam's Story

"It's scary to think that the longer I have this disease the closer I may be to developing serious complications."
- Sam Garelick

I have two devices attached to me at all times – my insulin pump and my continuous glucose monitor. I got my first insulin pump when I was eight years old. I am grateful for these tools, but I know that they are not a cure for my type 1 diabetes. A couple of years ago, I was at the mall and I put my pump down in the bathroom to wash my hands, and someone stole it. They must have thought it was a cell phone or musical device. It was scary to think that I was without the technology that is helping to keep me alive.

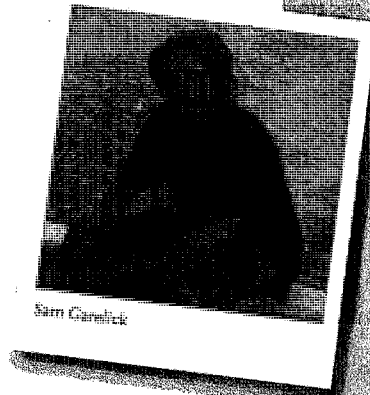
I have participated in a lot of research studies – trials involving continuous glucose monitors, a TrialNet study, and a study looking at the diabetes/celiac disease connection. I was also in a cholesterol study and a snack study. Through my participation in research studies, I have learned that I am at high risk of also developing other diseases like celiac. I am big on sports. I love playing hockey, baseball, soccer. Now I am focusing more on soccer.

I look forward to the day when I can just play without having to have all these tools attached to me, and always have to carry food in case my blood sugar drops too low. I hope research will get us to that day sooner.

I know this disease is hard on me, but I also know that it's hard on my entire family. When I go low, or get sick, it impacts everyone around me. This isn't a disease you can manage alone.

Diabetes in Colorado

According to 2008 CDC data, approximately 206,000 people in Colorado – 5.9% of the state's population – had diagnosed diabetes, and many of them suffer from serious complications or conditions. **In addition to the human toll diabetes places on people in Colorado, the financial burden diabetes places on the health care system in the state is staggering – in 2007, the approximate direct and indirect cost of diabetes in Colorado was approximately \$2.51 billion.**



COLORADO

David's Story

"Diabetes is probably harder on my wife than it is on me. When I recover from a low blood sugar episode which often makes me difficult, the first thing I do is tell my wife I love her." - David Ladd



David Ladd

I was diagnosed with type 1 diabetes when I was 23 years old, and I have been participating in diabetes research for over 26 years. I first got involved with research studies when my doctor told me about a study that was looking to gather information about diabetes, its complications and the impact of better glucose control.

I was, and continue to be, passionate about controlling my diabetes and learning as much as possible about it. I entered the Diabetes Control and Complications Trial (DCCT) in 1983, one day before my 40th birthday. This landmark study demonstrated that tight control of blood glucose levels beginning as soon as possible after diagnosis can greatly reduce a person's risk of developing diabetes-related complications in the future.

I am currently enrolled in the Epidemiology of Diabetes Interventions and Complications (EDIC) study which is an ongoing follow-up effort to the DCCT and is made possible by the Special Diabetes Program. Participating in these research studies has had a big impact on my life. I work hard at managing my diabetes and I have not experienced any major complications. But I know that until a cure is found, every day that I live with diabetes is a day closer to potentially developing serious complications.

Diabetes in Connecticut

According to 2008 CDC data, approximately 191,000 people in Connecticut – 6.6% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications and conditions. **In addition to the human toll diabetes places on people in Connecticut, the financial burden diabetes places on the health system in the state is staggering – in 2007, the direct and indirect cost of diabetes in Connecticut was approximately \$2.43 billion.**

Shannon's Story

"Having diabetes is all that I know. It's my entire way of life." - Shannon Behan

I was diagnosed with type 1 diabetes on September 9, 2003 when I was 7 years old. It's a day I will never forget. I remember that I was thirsty and tired all of the time. My parents took me to the emergency room where I was diagnosed and I had to stay there for five days. It was a scary time for me. Within a year of being diagnosed, I started wearing an insulin pump which made it easier to control my blood sugar levels. But even with the pump, my blood sugar dropped so low one time that I had a seizure.

After my seizure, I started wearing a continuous glucose monitor. In addition to my insulin pump, this technology continuously monitors my glucose levels and has an alarm that goes off when my levels go too high or too low and has been tested in kids through the Special Diabetes Program. And even with all of this technology, my mom still gets up every two hours during the night to check my blood glucose levels to make sure they don't drop too low. And when my parents are away, my sister Colleen, who is fourteen months younger than me, watches my blood sugar levels and she wakes up early to make sure I am okay.

Wearing all this technology isn't always easy as an active 14 year old. I play the saxophone, participate in the marching band and in color guard. I'm also in my 11th year of dance - I take ballet, point, tap and jazz. Even simple things like sleepovers are hard to do. In the summer I love to surf and hang out at the beach. I do all these activities with my pump on and CGM continually checking my glucose.

Diabetes in Delaware

According to 2008 CDC data, approximately 56,000 people in Delaware - 8.1% of the state's population - had diagnosed diabetes, and many of them suffer from serious diabetes related complications and conditions. **In addition to the human toll diabetes places on people in Delaware, the financial burden diabetes places on the health system in the state is staggering - in 2007, the direct and indirect cost of diabetes in Delaware was approximately \$492 million.**



Toni's Story

"I want people to understand what living with this disease requires. Everyone needs to know the importance this research has in managing and curing type 1 diabetes. No one should have to go through this, and hopefully we won't have too much longer." - Toni Bethea



Toni Bethea

I was diagnosed with type 1 diabetes when I was 5 1/2 years old. I don't remember being diagnosed, but now, after living with type 1 diabetes for 9 years, I can't imagine having to go through what my mom went through taking care of me at that age with all this disease requires. I know that since the time I was diagnosed, the progress in developing tools to help people with diabetes has been remarkable. I work hard at managing my diabetes, and even though it is getting easier with these new tools, it is still very difficult.

Being a teenager with diabetes requires a lot of additional responsibility, and some days you just want to take a break from it all, but you can't. Living in Washington, DC, I have had the opportunity to learn how Congress has supported the Special Diabetes Program and how these dollars are benefiting

people like me by moving the research out of the lab and into people's lives. For example, the DirectNet program that is supported by the Special Diabetes Program is using advanced glucose sensing technology to help control glucose levels. This research is making technologies such as the continuous glucose monitors a reality.

Living with this disease is hard, but I am thankful that I can manage it with these tools and I am hopeful because I know this research is getting us closer to a cure. And a cure is what I, and everyone with this disease, need.

Diabetes in Washington DC

According to 2008 CDC data, approximately 37,000 people in the District of Columbia – 8.4% of the District's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on the people in the District of Columbia, the financial burden diabetes places on the District's health system is staggering – in 2007, the direct and indirect cost of diabetes in the District of Columbia was approximately \$574 million.**

Casey's Story

"People get ready, because a cure is on its way!"
- Casey Burkhalter

My family doesn't have a history of diabetes, so when my older brother was diagnosed with type 1 diabetes we were all in shock. And then five years came a double shock to my family when I was diagnosed with the same disease. I was only ten years old. To be as active as I am means I have to really work to manage my diabetes so I don't have to give up doing anything I love.

I enrolled in a research study called the Diabetes Research in Children Network (DirecNet) which is using advanced technology to help control blood glucose levels. This research, made possible by the Special Diabetes Program, is making technologies such as the continuous glucose monitor a reality. These monitors test blood glucose levels almost constantly throughout the day and night, making it possible for people to have better control over their blood glucose levels, which minimizes severe hypo- and hyper-glycemic events.

Since I enrolled in this study, I have been reading a lot about the research being done on type 1 diabetes – it is an unofficial hobby of mine. I've learned that studies have shown that getting tight control of your blood glucose levels now offers life-changing benefits in the long term such as preventing the damages that this disease can have on a person's eyes, kidneys and nerves. Complications are something I think about a lot, and all of this research that is being done to prevent or delay the development of complications really gives me hope of a brighter future.

Diabetes in Florida

According to 2008 CDC data, approximately 1,306,000 people in Florida – 8.1% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Florida, the financial burden diabetes places on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in Florida was approximately \$12.24 billion.**

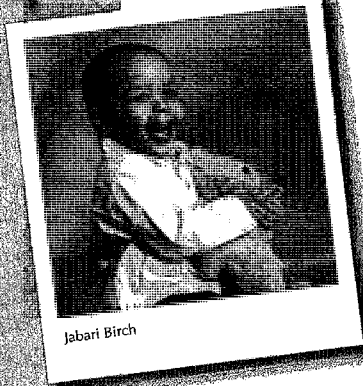


FLORIDA



Jabari's Story

"Having diabetes is hard, but I know that I need to take good care of myself until the researchers can find a cure. I know they are working hard for me every day." - Jabari Birch



Jabari Birch

According to his mother Monica, six year old Jabari doesn't remember what life was like without diabetes. Jabari was diagnosed with type 1 diabetes when he was just one year old, one of the growing number of children getting the disease at younger and younger ages.

Jabari was the first person in his family to be diagnosed with diabetes, and after his diagnosis, his entire family enrolled in the TrialNet Natural History Study to see if anyone else in the family was at risk of developing it. Fortunately, the results have been negative, but his family continues to get tested every year.

Jabari's family knows that their participation in TrialNet not only helps them but also helps researchers learn more about how type 1 diabetes develops.

"Jabari means courageous," his mother said. "He has lived up to his name." At such a young age, Jabari has already shown tremendous courage in the management of his type 1 diabetes, testing his own blood sugar and managing his insulin pump all on his own.

Diabetes in Georgia

According to 2008 CDC data, approximately 705,000 people in Georgia – 10.4% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Georgia, the financial burden diabetes places on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in Georgia was approximately \$5.1 billion.**

Anela's Story

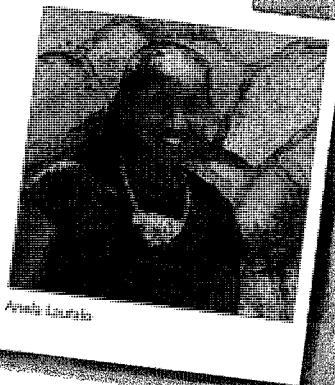
"If everyone with diabetes does their part to help researchers understand what causes diabetes and how to prevent it, then one day there may be a world without diabetes." - Anela Lautalo

I was diagnosed with type 1 diabetes when I was 9 years old. My life hasn't been the same since that day. There's never a vacation. It is like a bad dream that lasts all day, all year, for my entire life. You never get a break from diabetes, not even on your birthday.

I test my blood sugar six to eight times each day, every day, and have to give myself 6 to 8 shots each day to manage my blood sugar levels. And some days it is hard to keep your blood sugar in good control, even when you try really hard.

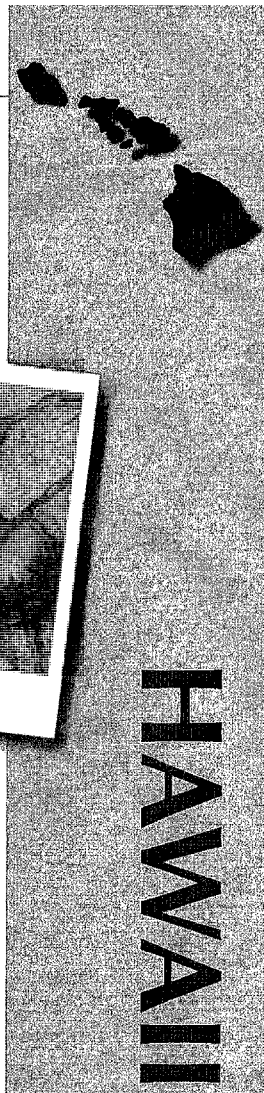
I am the only one in my family to be diagnosed with type 1 diabetes, and I want to do all I can to help researchers learn the cause of diabetes so that one day other kids won't have to live with this disease.

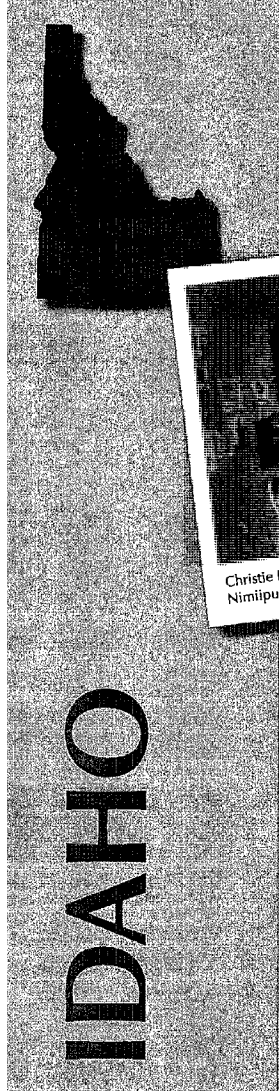
I am trying to do my part by participating in SEARCH, an important research project made possible by the Special Diabetes Program. There is so much that people don't know about diabetes and by participating in SEARCH, I am helping researchers learn more about what causes this disease and how to cure it. It gives me hope that we will have a cure soon!



Diabetes in Hawaii

According to 2008 CDC data, approximately 79,000 people in Hawaii – 7.4% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Hawaii, the financial burden diabetes places on the health system in the state is staggering – in 2007, the direct and indirect costs of diabetes in Hawaii was approximately \$1.04 billion.**





Christie's Story

"I am most proud of just being healthy today. Losing the weight is a bonus but I'm most thankful about reducing my chances of become diabetic." - Christie Lussoro

Diabetes and heart disease runs in my family on both sides, so I knew I was at high risk. I was getting nervous because I didn't ever want to be diagnosed with diabetes so I joined the Nimiipuu Diabetes Program. I was excited about getting started and couldn't wait to begin an exercise program.

The program staff was so supportive and helped me customize a plan to suit my needs. They gently pushed me to increase my physical activity intensity level even when I would get frustrated.

I have lost 31 pounds overall, have more energy, and my old back problems have begun to fade away. I have learned that working out can be fun, relaxing and a great stress reliever.

Now my kids enjoy going with me to the fitness center which is also helping reduce their chances of having heart disease and preventing diabetes.

The Diabetes Program has given me access to a fitness center and fitness coordinator, nutrition services and valuable diabetes education that will have a long lasting, healthy impact on my entire family.

Diabetes in Idaho

According to 2008 CDC data, approximately 81,000 people in Idaho – 7.4% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Idaho, the financial burden diabetes places on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in Idaho was approximately \$664 million.**

Brenda & Carson's Story

"Being diagnosed with diabetes a few years after my son was a hard reality to accept because I know what the future might hold for us both if a cure is not found." - Brenda Degner

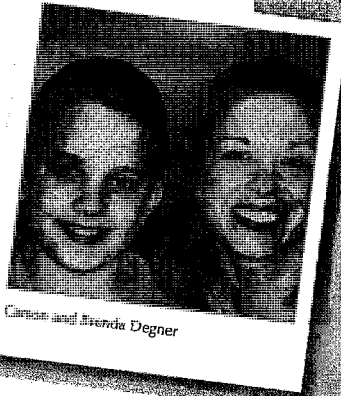
My mom was diagnosed with diabetes when she was 17. Even with a family history of diabetes it was still a tremendous shock when my son Carson was diagnosed when he was only nine months old. Now, Carson is an active 9 1/2 year old, but in order for him to enjoy all the things children his age should enjoy, we have to work around the clock to manage his diabetes.

He wears an insulin pump and a continuous glucose monitor. It's a lot of technology attached to a small child, but I am so grateful that the research has progressed to a point where these tools are available to him. But even with these technologies, we still have to work hard to balance his insulin, food, activity, school, exercise, and stress on an hourly basis.

Diabetes entered our lives again in 2007 when I developed the disease. I was diagnosed early thanks to my participation in the TrialNet Natural History Study that screens close relatives of people with type 1 diabetes to assess their risk of developing the disease. Thankfully, because we were able to identify my diabetes in the early stages, I was able to go on insulin very early and have a long honeymoon period where my body still produced some insulin. Knowing that I was at high risk helped me avoid a possible trip to the emergency room, and the severely high blood sugar levels that could have resulted in a diabetic coma or worse. We need this research to cure this disease, and I will do all that I can to help.

Diabetes in Illinois

According to 2008 CDC data, approximately 827,000 people in Illinois – 8.4% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Illinois, the financial burden diabetes places on the health care system in the state is staggering – in 2007, the direct and indirect costs of diabetes in Illinois was approximately \$7.26 billion.**



Carson and Brenda Degner



The Corn's Story

"After Tristan was diagnosed, diabetes became a family affair." - Becky Corn



Clorice, Ethan, and Tristan Corn

My oldest child Tristan is 7 years old and has lived with type 1 diabetes for over half his life. He was diagnosed in 2006 when he was only 3 years old. I am always wondering whether my other two children will be diagnosed. I am so grateful that research is underway to help doctors identify people at risk of developing type 1 diabetes so that they can benefit from early interventions. My 4 year old daughter, Clorice, participates in the TrialNet Natural History Study that is supported by the Special Diabetes Program. As part of this study, she has blood drawn once a year, and it is tested for antibodies that would indicate she is at high risk of developing type 1 diabetes. Luckily, so far she has only had negative results.

My youngest son, Ethan, is two and a half years old and participates in the Nutritional Intervention to Prevent Type 1 Diabetes Study that is also supported by the Special Diabetes Program. His

cord blood was collected at birth and genetic testing was done. Thanks to this research we now know that he is at high risk for developing diabetes, which is what qualified him to participate in this study. This research is helping scientists learn more about the effect of a dietary substance that, when given to pregnant women in their third trimester and infants less than 5 months of age, could possibly prevent type 1 diabetes. This research is showing us so much about type 1 diabetes, why people get it, how to detect it and hopefully stop it. As a parent, I need to know all I can about this disease and how it could impact mine and other families. That is why we participate and why this research must continue.

Diabetes in Indiana

According to 2008 CDC data, approximately 426,000 people in Indiana – 8.7% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes complications or conditions. **In addition to the human toll diabetes places on people in Indiana, the financial burden diabetes places on the health system in the state is staggering – in 2007, the direct and indirect costs of diabetes in Indiana was approximately \$3.09 billion.**

INDIANA

Becky's Story

"Being diagnosed with pre-diabetes was the wake up call I needed to focus on making healthy changes to prevent diabetes."

- Becky Youngbear-Alvarado

It's been almost 3 years since I was diagnosed with pre-diabetes by the Meskwaki Diabetes Prevention Program. I knew I was overweight but not aware that I was at high risk of getting diabetes if I didn't change my lifestyle. The program not only provided me with a wake up call to change what I was eating to prevent diabetes, they gave me the knowledge and skills I needed to lose weight and live a healthy lifestyle. As a result of my participation in the Diabetes Prevention Program, I have lost 23 pounds and my blood sugars are back in the normal range. The healthy changes I have made to prevent diabetes are also having a tremendous impact on the health of my family. Even beyond my family, people in the community will stop me and ask me how I've been able to lose weight. I always tell them that I found out I had pre-diabetes, joined the Diabetes Prevention Program, and slowly and in a healthy way, I lost the weight and have been able to prevent diabetes.



Becky Youngbear-Alvarado, Meskwaki
Meskwaki Diabetes Prevention Program

Almost 3 years later, the staff is still monitoring my health monthly. I know I'm fortunate to have been diagnosed with pre-diabetes because it made me eligible to join the Diabetes Prevention Program. What's difficult is that there are so many people in our community who do not have pre-diabetes and do not qualify for this special program. This a life saving program that should be open to anyone who wants to prevent diabetes, as well as for those who want to learn how to get better control of their diabetes.

Diabetes in Iowa

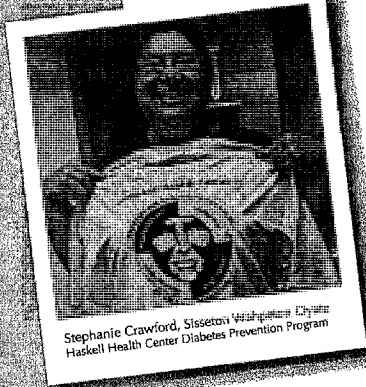
According to 2008 CDC data, approximately 160,000 people in Iowa – 6.3% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes complications or conditions. **In addition to the human toll diabetes places on people in Iowa, the financial burden diabetes places on the health system in the state is staggering – in 2007, the direct and indirect costs of diabetes in Iowa was approximately \$1.47 billion.**

IOWA

Stephanie's Story

"If it wasn't for this program I would very likely be a person with diabetes. I thank God for this program I really do."

- Stephanie Crawford



Stephanie Crawford, Sisseton, South Dakota
Haskell Health Center Diabetes Prevention Program

The Diabetes Prevention Program came along at the right time of my life. Being diagnosed with pre-diabetes scared me. I did not want to have diabetes and I especially didn't want to have to take insulin. So, in 2007, I joined the program with a group of others like me who had also been newly diagnosed with pre-diabetes.

While attending the program's 16 week course we met weekly and I learned more about diabetes than I had ever known before. My mother was able to attend the classes with me which gave me even more support as I set out to learn what I could do to prevent diabetes. Even though we went to the classes as a group, the staff took the time to work with us all individually to help us set achievable diet and exercise goals.

I can't say enough good things about this program and the staff. Over time, they helped me lose 20 pounds, get better control of my blood pressure, and most importantly enabled me to get my blood sugars down to a normal range.

I have a good friend who has just been diagnosed with pre-diabetes and has signed up with the program. She asked me to attend the classes along with her as she begins her own journey to prevent diabetes and I agreed to go with her for support. I am looking forward to my diabetes re-education because I know it will help me maintain the positive healthy lifestyle changes I have made.

Diabetes in Kansas

According to 2008 CDC data, approximately 161,000 people in Kansas – 7.3% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes complications or conditions. **In addition to the human toll diabetes places on people in Kansas, the financial burden diabetes places on the health system in the state is staggering – in 2007, the direct and indirect costs of diabetes in Kansas was approximately \$1.29 billion.**

KANSAS

Paula & Emilee's Story

"If researchers can better understand the genetic causes of type 1 diabetes by studying families like ours, then this will be our contribution to the cure." - Paula Fairchild

My sister was diagnosed in 1990, my uncle in 1995, and my grandmother had three sisters who all had type 1 diabetes. Nevertheless, it was still a shock when my daughter Emilee was diagnosed at the age of seven. Diabetes has forced Emilee to grow up faster than most kids, and she works hard at managing her blood sugar levels. But although we manage this disease, what we need is a cure. And thankfully research is getting us there. I know all too well that she faces a future filled with the possibility of serious complications – like eye disease, cardiovascular disease and kidney disease – and I'll do everything I can so she never has to suffer through them.

Researchers are working to understand why type 1 diabetes is so prevalent in families like ours. With this knowledge, they will be able to better identify people at risk of developing the disease and design prediction and prevention studies to attack this devastating disease before it begins.

This is why I am participating in a clinical trial supported by the Special Diabetes Program to identify people at risk of developing diabetes. The more researchers understand why people are diagnosed with type 1 diabetes, the closer they get to curing it.



Diabetes in Kentucky

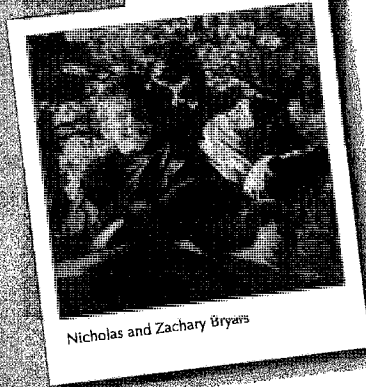
According to 2008 CDC data, approximately 320,000 people in Kentucky – 9.4% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes complications or conditions. **In addition to the human toll diabetes places on people in Kentucky, the financial burden diabetes places on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in Kentucky was approximately \$2.04 billion.**

KENTUCKY

Nicholas & Zachary's Story

"You have to watch what you eat, and you have to watch other people eat things that you can't have."

- Nicholas Bryars



Nicholas and Zachary Bryars

I am ten minutes younger than my twin brother Zack. He likes to remind me that he is the 'older' one and because of that he gets to do things first. But there is one thing that I did first, and that was learn how to live with type 1 diabetes. I was diagnosed three years ago when I was 9 years old. It happened on the first day of a July 4th family vacation at the beach and I spent most of the week in the ICU.

I went to Diabetes Camp the following summer, and my whole family got tested as part of the TrialNet Natural History study that looked into whether the rest of my family was at risk for type 1 diabetes. My brother Zack tested positive for insulin antibodies and was immediately enrolled in an oral insulin study. The goal of the trial was to prevent or delay the full development of type 1 diabetes in high risk people like Zack.

The following summer, Zack developed

diabetes. We all hope that he was receiving the placebo as part of the study.

Zack and I participate in research that studies the development of diabetes in twins. Our other two brothers, Chris and Matt, also get tested annually for markers of type 1 diabetes. Through this we learned that Matt, Zack and I were all positive for markers of celiac disease. Unfortunately, Matt and I both developed celiac disease, but thanks to what we learned from the study, my parents were able to get us treatment right away. My brothers and I like to read all sorts of books, play video games, and we love being outside. Zack and I try hard not to let diabetes define us.

Diabetes in Louisiana

According to 2008 CDC data, approximately 340,000 people in Louisiana – 10.1% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Louisiana, the financial burden diabetes places on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in Louisiana was approximately \$2.43 billion.**

Hannah's Story

"I try not to let diabetes slow me down, but it's hard because you never get a break. Diabetes is always with you. The research that is being done is what gives me hope of a cure." - Hannah Ryder

My life changed forever when I was diagnosed with type 1 diabetes when I was 9 years old. After being in the hospital for four days I hoped it was cured when I got to go home. I soon figured out that this wasn't going to go away when my parents kept checking my blood sugar and giving me shots and measuring all my food.

After my diagnosis, my mom enrolled our whole family in the TrialNet Natural History Study to see if anyone else in our family was at risk of developing diabetes. My mom was found to be at risk but so far she doesn't have diabetes.

After I got diabetes, I was also diagnosed with celiac disease. Managing both diseases is hard, but I try not to let it keep me from doing the things I love like color guard, figure skating, and softball.

My mom tells me about the amazing research that is being done to help find a cure for me and to prevent others from getting diabetes. I have learned a lot about the TEDDY trial which is researching environmental factors that trigger both type 1 diabetes and celiac disease. When I grow up I want to go to culinary school and open my own restaurant and not have diabetes.

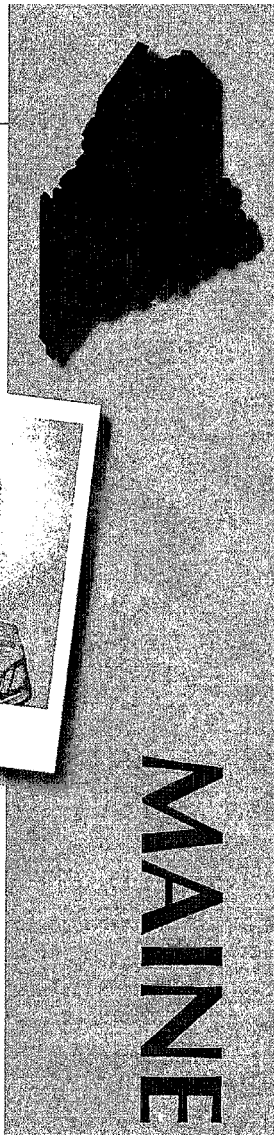


Hannah Ryder

Diabetes in Maine

According to 2008 CDC data, approximately 85,000 people in Maine – 7.3% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes complications or conditions.

In addition to the human toll diabetes places on people in Maine, the financial burden diabetes places on the health system in the state is staggering – in 2007, the direct and indirect cost of diabetes in Maine was approximately \$776 million.



MARYLAND

Sallie's Story

**"I was enrolled in a DRCR clinical trial and have been receiving study-related treatment to my eyes. Now I have 20/20 vision in both eyes – a spectacular improvement."
- Sallie Cartwright**



Sallie Cartwright

I was diagnosed with type 2 diabetes nearly four years ago at the age of 66. My husband and I had recently moved to Maryland, and I noted that I was unable to read road signs. I thought it was just a matter of getting driving glasses.

But when I saw an ophthalmologist, I was told that my right eye was worthless and my left eye was legally blind, and that I would no longer be able to drive.

The ophthalmologist immediately referred me to an investigator for the Diabetic Retinopathy Clinical Research (DRCR) Network, which is funded by the Special Diabetes Program. I enrolled in a DRCC clinical trial, and thanks to the treatment I received as part of the trial, now I have 20/20 vision in both eyes.

It would take five years to describe how I feel about the personalized and professional care I have received as part of this study. Everyone in my retinal specialist's office acknowledges me by name and takes interest in how I am doing.

My family has no history of diabetes. To date, I have been able to manage my diabetes through a strict diet, exercise and weight loss.

Diabetes in Maryland

According to 2008 CDC data, approximately 366,000 people in Maryland – 8.2% of the state's population – had diabetes, and many of them suffer from serious complications or conditions related to diabetes. **In addition to the human toll diabetes places on people in Maryland, the financial burden diabetes places on the health system in the state is staggering – in 2007, the direct and indirect cost of diabetes in Maryland was approximately \$3.78 billion.**

David's Story

"This research has saved my life."
- David Ford

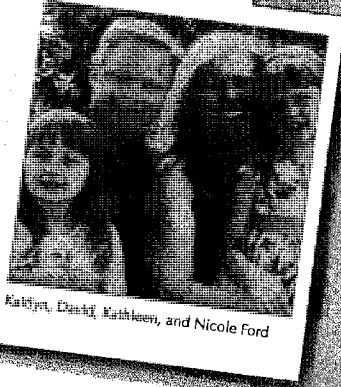
When people ask me how I feel about living most of my life with diabetes, I say that I am thankful – thankful that my mother read an article in our local paper about the Diabetes Complication and Control Trial (DCCT) and insisted that I participate. Thankful that my participation in the trial not only changed the clinical course of my disease for the better, but also that my participation has helped improve the management of diabetes for so many.

I enrolled in DCCT/EDIC in 1984, and I still go every year to be tested and for follow up. Before I enrolled in the DCCT trial, my A1C levels were commonly above 13, putting me at high risk for serious complications. I know that the DCCT has worked for me because I haven't had an A1c higher than 7 in years.

At this time, I am not experiencing any complications from my diabetes. My two daughters: Kaitlyn (7) and Nicole (9) participate in TrialNet's Natural History Study to determine if they are at high risk of developing type 1 diabetes. They have continued to test negative for all antibodies that would put them at risk. Participating in this research has changed my life. Management of diabetes has come so far, but we need to find a cure. Thankfully, this research is getting us closer.

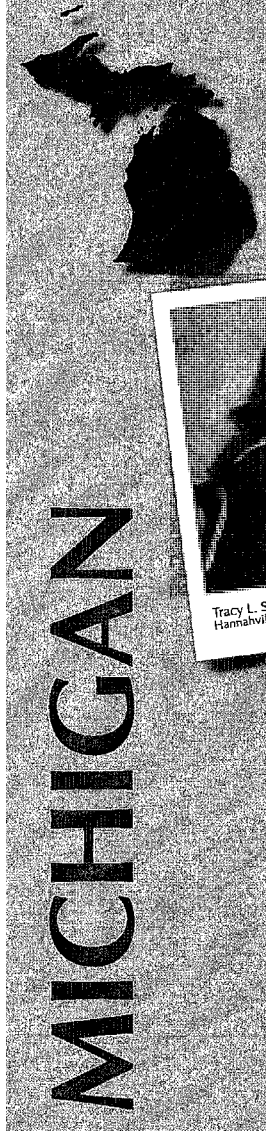
Diabetes in Massachusetts

According to 2008 CDC data, approximately 363,000 people in Massachusetts – 6.9% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people from Massachusetts, the financial burden that diabetes places on the health system in the state is staggering – in 2007, the direct and indirect cost of diabetes in Massachusetts was approximately \$4.32 billion.**



Kaitlyn, Emily, Kathleen, and Nicole Ford

MASSACHUSETTS



Tracy's Story

"I had been around diabetes all my life but it was only 2 years ago-through community diabetes education-that I began to fully understand the disease."

- Tracy L. Sagataw

Almost my entire family-my mother, brother, aunts, uncles, and grandparents are living with or have died from complications of diabetes. My earliest childhood memory of diabetes is seeing needles lying around the house and not knowing what they were for. Even though I have been around it all my life and have seen people in my community on dialysis or with amputations, it was only about two years ago that I actually began to fully understand the disease.

At that time, I had just started working as an Outreach Worker and began to get involved with many of the programs at the clinic, including the diabetes program. I learned about pre-diabetes and that there was scientific proof that type 2 diabetes could be prevented. Soon, I found myself on a different part of my wellness journey. Overall, with a combination of diet and exercise I

have lost 40 pounds. The weight management program and the Reach for Wellness Fitness Center contributed largely to that. I have seen my people suffer enough, that alone keeps me motivated to stay on this path.

Special diabetes funding is important in our community because we need the staff and tools to educate more people about diabetes prevention, diabetes itself, and to provide continued care for the people living with diabetes.

Diabetes in Michigan

According to 2008 CDC data, approximately 685,000 people in Michigan – 8.6% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes complications or conditions. **In addition to the human toll diabetes places on people in Michigan, the financial burden diabetes places on the health system in the state is staggering – in 2007, the direct and indirect costs of diabetes in Michigan was approximately \$5.43 billion.**

Tracy L. Sagataw, Hannahville Indian Community Diabetes Program

Arne's Story

"We have an Ojibwe saying, "We do these things to keep our traditions and language alive." The only way to do this is to keep our elders alive and the best way to do that is through our diabetes prevention efforts and everything that goes with it."

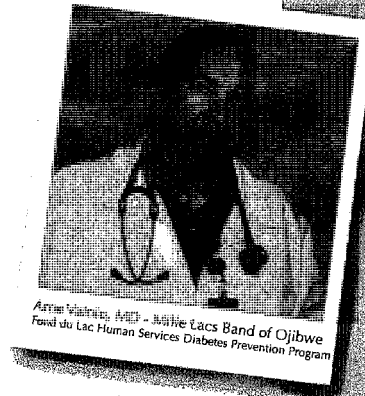
- Arne Vainio, MD

My mom endured multiple complications from diabetes including, amputations of both her legs and a kidney transplant. On the night of my graduation from residency she passed away from congestive heart failure. Then at age 46 my brother had a stroke which started me on my personal journey to look at my own health risks. That journey has evolved into writing health articles for a variety of Native publications and a video-documentary that has gone viral in Native communities.

Along the way, I was diagnosed with pre-diabetes, enrolled in the Fond du Lac Diabetes Prevention Program, lost 17 pounds and today my blood sugar is no longer in the pre-diabetic range. I think it was strange for others in the classes when I first started attending, but I learned a lot in the 16 week Lifestyle Balance curriculum and 3 year commitment. I felt it was extremely helpful that the program was a team effort with clinicians, diabetes educators, lifestyle coaches, dietitians, fitness coaches, and support staff. I especially appreciated the sharing and being at the table with the other participants who were also focused on diabetes prevention and improving their overall health. The education and support from both the staff and participants was invaluable. We are a sharing community. That is our heritage and that's how we learn our language and culture.

Diabetes in Minnesota

According to 2008 CDC data, approximately 229,000 people in Minnesota – 5.6% of the population – had diagnosed diabetes, and many suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Minnesota, the financial burden diabetes places on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in Minnesota was approximately \$2.68 billion.**



MINNESOTA

Pastor Thomas' Story

"The Diabetes Prevention Fitness Program has helped me to prevent diabetes and now, health and fitness are top priorities in my life." - Pastor Thomas Ben

Over the years, the Choctaw Diabetes Prevention Program has been very active in our community, promoting diabetes awareness by way of handouts, presentations and special events. I learned that diabetes was preventable, which got me to begin thinking about my own family history of diabetes. So, when I found out about the fitness program offered by the Diabetes Prevention Program, I decided to join and do what I could to get healthier and at the same time, reduce my risk of getting diabetes.

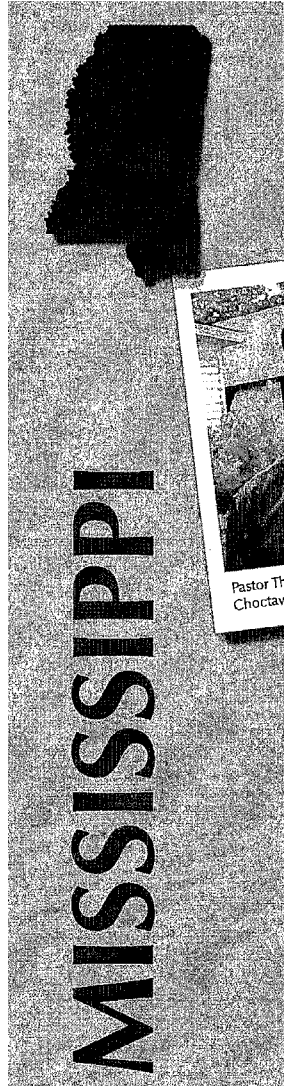
Before I joined the program exercise was not a priority in my life. However, the variety, intensity and structure of the fitness program has kept me actively involved and focused on my health for the past two years and I still participate 3 to 4 times a week. Since starting the program I've seen great results including

a 25-pound weight loss and now, exercise and health are top priorities in my life.

The Diabetes Prevention Program is very beneficial because it offers our community the chance to not have to wait for a diagnosis of pre-diabetes or diabetes and provides the resources, education and support to take control of our health now. The dedication and ongoing efforts of the program staff make it a successful community program.

Diabetes in Mississippi

According to 2008 CDC data, approximately 245,000 people in Mississippi – 10.9% of the states population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Mississippi, the financial burden diabetes places on the health system in the state is staggering – in 2007, the direct and indirect cost of diabetes in Mississippi was approximately \$1.77 billion.**



Michelle's Story

"I just want my boys to be able to play, and live without the daily burden of diabetes. I just want my boys to have a normal life." - Michelle Maloney

My son Patrick, now 7 1/2, was diagnosed with type 1 diabetes when he was only 21 months old. When his brother, William, was born a little over 3 years later we immediately enrolled him in a clinical trial called TRIGR. This trial, supported by the Special Diabetes Program, follows children who test positive for insulin antibodies to determine if the elimination of cow's milk formula can reduce development of type 1 diabetes. For two years, William was tested for antibodies on a regular basis. In January of 2010 he started to show signs of type 1 diabetes. We tested his blood sugar, and when the reading came back very high, we knew we needed to take him straight to the hospital, where he was diagnosed with type 1 diabetes.

Patrick and William are both active in sports, specifically soccer and baseball. Patrick is also taking up piano. We work to manage this devastating disease the best we can. Patrick uses both an insulin pump and a continuous glucose monitor. William, because of an early diagnosis, still remains in the 'honeymoon' phase of the disease, and because his body is still producing some insulin, he requires minimal insulin shots to keep his blood sugar levels normal. Our family has no history of diabetes. And although we have been forced to learn to manage it, we need to find a cure. We participate in the research because we need to find out what causes this disease and how to stop it. If we can help in this way, we will and we will do more. No family should have to do or go through this.

Diabetes in Missouri

According to 2008 CDC data, approximately 385,000 people in Missouri – 8.1% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Missouri, the financial burden on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in Missouri was approximately \$3.01 billion.**



The Maloney's: Patrick, Michelle, Brett, William, & Patrick Jr.

MISSOURI

Faye's Story

"We need the Diabetes Center here so hopefully one day we can prevent people from ever getting diabetes in the first place." - Faye Filesteel



Faye Filesteel, Assiniboine
Fort Belknap Healthy Heart Project

I was diagnosed with diabetes in 2005. My mother had diabetes and so does my son, but it wasn't until I joined the Healthy Heart Program that I began to really understand the disease. I learned all kinds of things I never knew before, but most importantly I learned that there were things I could do to control and even reverse my diabetes. So, with the education and support of the program staff and the support from other people with diabetes in the classes, I was determined to do all I could do to take better care of myself.

I'm so thankful for the Diabetes Center. The staff is very helpful and always stays on top of things and help keep me focused. I've made changes to my diet and I'm eating healthier. I begin walking outside when the weather is good and use the treadmill at the Diabetes Center when the weather is bad. I enjoy the

walking and I'm signed up to walk with our Healthy Heart group in the 2010 Icebreaker Marathon in Great Falls.

I've seen the damage that diabetes can do and I'm grateful that soon after I was diagnosed that the Diabetes Center and the Healthy Heart Program was here. I have seen such good results that my doctor told me that soon I would likely not need to take metformin anymore. I wish more people would get involved in the program before their diabetes gets out of hand.

Diabetes in Montana

According to 2008 CDC data, approximately 48,000 people in Montana – 6% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications and conditions. **In addition to the human toll diabetes places on people in Montana, the financial burden diabetes places on the health system in the state is staggering – in 2007, the direct and indirect cost of diabetes in Montana was approximately \$508 million.**

Clarissa's Story

"I've had 3 relatives lose limbs to diabetes. Diabetes needs to be taken seriously and wiped out - as we now know it can be."

- Clarissa Hoffman

I am a 34 year old Native American woman who comes from a long line of great people. We have had to endure and survive in spite of near extinction and yet there is still disease and sickness we must overcome. Diabetes is one of them that is passed down to us and we know it can be stopped.

I am very happy to be a part of the change that will help future generations put an end to diabetes. Ho-Chunk Hope is teaching that change and through this program I was diagnosed with pre-diabetes. I love Ho-Chunk Hope. It is a great, life changing and people saving program. The program has helped me learn and re-learn how to take care of myself and fight diabetes. I am exercising more and cooking in a healthier way that is better for my family and me.

I know I'm responsible for how my children eat and the habits they form, so I need to make sure I do what's best for them by first taking care of myself while at the same time making permanent healthier choices for the whole family. Ho-Chunk Hope has helped teach me those ways and has also shown me the way to a healthier lifestyle. I am "off the diabetes-charts" now - I'm no longer pre-diabetic!

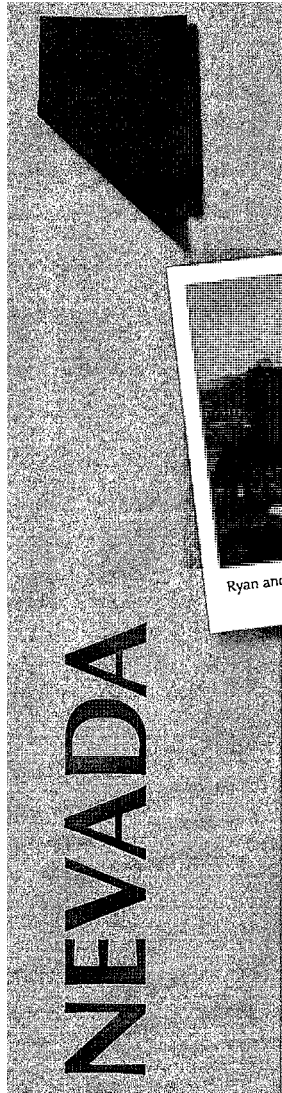


Clarissa Hoffman, Ho-Chunk Tribe of Nebraska
Ho-Chunk Hope Diabetes Prevention

Diabetes in Nebraska

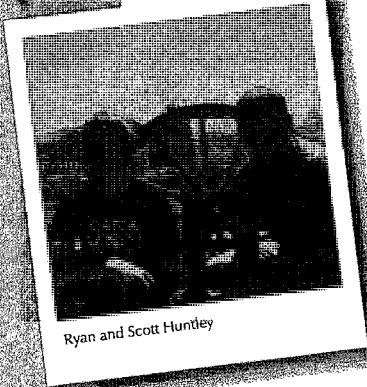
According to 2008 CDC data, approximately 99,000 people in Nebraska – 7% of the state's population – had diagnosed diabetes and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll that diabetes places on the people in Nebraska, the financial burden diabetes places on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in Nebraska was approximately \$809 million.**

NEBRASKA



Scott's Story

"I thought my participation would help researchers and others who would develop diabetes, but the study ended up helping me." - Scott Huntley



Ryan and Scott Huntley

My son Ryan was diagnosed with type 1 diabetes when he was eight years old. Our family did not have a history of diabetes, and his diagnosis came as quite a shock to us all.

I decided to enroll in a study called the TrialNet Natural History Study that identifies indicators for developing type 1 diabetes, so that I could do my part in helping the researchers in their effort to find a cure for people like my son. The study showed I was positive for insulin antibodies, and five years later I was diagnosed with type 1 diabetes.

Thanks to my participation in TrialNet, my doctors were able to identify the markers for diabetes early, which enabled me to enroll in a second clinical trial testing the drug rituximab that appears to be slowing the progression of my disease, which will delay the onset of serious complications.

The longer I benefit from this research, the farther away the complications from this disease are for me. This research benefits me, my son, and the millions of those with this disease. If I could do more I would.

Diabetes in Nevada

According to 2008 CDC data, approximately 160,000 people in Nevada – 8.3% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Nevada, the financial burden diabetes places on the health system in the state is staggering – in 2007, the direct and indirect cost of diabetes in Nevada was approximately \$1.52 billion.**

Patsy's Story

"I don't have diabetes, but diabetes is a part of who I am." - Patsy Krook

My family's journey with type 1 diabetes began with my mother who was diagnosed in 1961 at the age of 36. At the time, she had 10 children. Today, with an extended family of over 240 members living in the US, type 1 diabetes is in all four generations of the Ojala family.

As our family grows, so does the prevalence of diabetes. My sister Pam was diagnosed with type 1 diabetes when she was 15; my daughter was diagnosed when she was 19; I have 3 nephews, 1 niece and 1 great nephew who all have the disease.

Because type 1 diabetes is so prevalent in my extended family, I have been organizing annual family screenings through the TrialNet's Natural History Study, which is supported by the Special Diabetes Program. The screenings can identify the autoantibodies that signal an increased risk for type 1 diabetes up to 10 years before symptoms actually appear. Through this screening, I have learned that four of my children have these autoantibodies, including my daughter who has since developed type 1 diabetes.

The TrialNet program is so important because it can help lead to an early diagnosis of type 1 diabetes. And for those newly diagnosed with type 1 diabetes there are important intervention studies that are exploring ways to slow down the disease progression and preserve insulin production, which can help reduce the complications of this devastating disease.

Diabetes in New Hampshire

According to 2008 CDC data, approximately 74,000 people in New Hampshire – 6.7% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in New Hampshire, the financial burden of diabetes on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in New Hampshire was approximately \$876 million.**



Karen's Story

"Almost everyone in my husband's family has passed away from complications of diabetes." - Karen Bachmann



Karen, Tim, John, and William Bachmann

In December of 1998, my husband Tim lost a lot of weight and we feared that he had some form of cancer since his father passed away from cancer 8 years before. One day, he was watching a football game and his vision became blurry. His brother has type 1 diabetes, so while at his house we tested my husband's blood sugar level. When we saw how high the number was, Tim went straight to the hospital. Then, in the spring of 2001, my son William was also diagnosed with type 1 diabetes at the age of 2 1/2. Diabetes was not new to Tim's family. His mother, two brothers and two uncles all passed away from diabetes complications. We are all grateful for the research that hopefully will ensure that our family's future is different.

When my youngest son John was born, researchers tested his cord blood because of our family history with type 1 diabetes and discovered he has two genes that are linked to the development of diabetes. We then enrolled him in a clinical trial called TRIGR which is supported by the Special Diabetes Program. He had a special food intervention and has regular blood work. He will be 7 years old, still participates and has yet to develop the disease. Significant progress has been made related to genetic factors and environmental triggers of type 1 diabetes. This is setting the stage for future research and capitalizing on ongoing research. These ongoing trials, such as TRIGR, are testing approaches to overcome possible environmental triggers of disease in at-risk children. I have learned over the years about how management of this disease has improved. But insulin isn't a cure. And all those living with type 1 diabetes know that research is the way to a cure.

Diabetes in New Jersey

According to 2008 CDC data, approximately 585,000 people in New Jersey – 8.3% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in New Jersey, the financial burden of diabetes on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in New Jersey was approximately \$5.8 billion.**

Elsie's Story

"If it wasn't for the Heart Saver Project, we would be suffering."
 - Elsie R. Pino

NAVAJO "Ajéí baa há whéén
 dzin yíí nidaat nish
 yígí do hóółq̄h gó éh
 tí'da'hoo'nííh do nité."

"It was hard for me for the first few months but the program is helping me. I am herding sheep and eating more vegetables. Before, I had no energy, just laying here. I like the service. It helped me be more on my feet." (As told to an interpreter)

Elsie is 75 years old and was diagnosed with type 2 diabetes in 1987. She is a native Navajo speaker, lives alone in a one room house, and raises her own sheep, dyes the wool, and weaves beautiful rugs. Since joining the Heart Saver Project she has been able to lower her cholesterol and get better control of her blood sugar, which is helping reduce her risk for heart attack and stroke.

Through Heart Saver funding, we have the resources to go to Elsie's home, bring her to the clinic for diabetes case management, and provide her with a Navajo-speaking case manager who has been trained in Navajo interpretation of diabetes medical terminology. Without these valuable resources, Elsie is one of many of our Navajo elders living with diabetes who would not be able to receive the quality diabetes care they so deserve. Beyond improving the health of our Navajo elders who, like Elsie, are living with diabetes, SDPI resources are helping our community preserve valuable Navajo traditions and culture. (Submitted by Heart Saver Project Staff)



Elsie R. Pino, Navajo
 Ramah Navajo Heart Saver Project

Diabetes in New Mexico

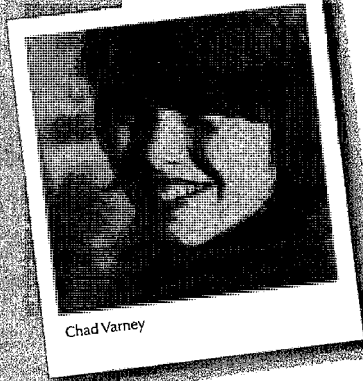
According to 2008 CDC data, approximately 115,000 people in New Mexico – 7.5% of the population – had diagnosed diabetes, and many suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on the people in New Mexico, the financial burden diabetes places on the health system in the state is staggering – in 2007, the direct and indirect cost of diabetes in New Mexico was approximately \$1.25 billion.**

NEW MEXICO

NEW YORK

Chad's Story

"It would be awesome if I could just go back to playing again, without thinking about counting my carbs, checking my blood sugar or giving myself shots." - Chad Varney



Chad Varney

Two years ago I was a normal, active, healthy kid. I play hockey, lacrosse, soccer and football. Then just after the end of my hockey season I was so thirsty all the time and just felt really awful. I knew that I had diabetes. My mom checked my blood sugar - my uncle also has diabetes so he brought the meter over - and it just said HIGH. When we got to the hospital my blood sugar was over 1000, a level that can be life-threatening.

I manage my diabetes by giving shots and I have to eat the right things too all the time, so I can keep playing the things I love. Right after I got diagnosed my mom put me on this study where I take a drug called Abatacept. The goal of the trial is to see if the drug slows down the progression of my diabetes. I still need to take insulin, but not so much as other people do. I hope it keeps working, and

I hope that other people who get diagnosed can use this in the future too.

My mom signs our whole family up for research trials. I don't want to have this disease any more. It's scary today and it's really scary to think about the future. I am glad we have all these tools to keep it in control. But it would be awesome if I could just go back to playing again without thinking or remembering or checking.

Diabetes in New York

According to 2008 CDC data, approximately 1,230,000 people in New York - 7.9% of the state's population - had diagnosed diabetes and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in New York, the financial burden diabetes places on the health system in the state is staggering - in 2007, the direct and indirect cost of diabetes in New York was approximately \$12.86 billion.**

Ulela's Story

"After 17 years, I no longer require insulin to manage my diabetes. Honestly, I love the Cherokee Diabetes Program!" - Ulela Harris

I lost my parents and a sister from complications of diabetes. I have 8 brothers and sisters living with diabetes and I was diagnosed in 1993 and immediately went on insulin. In those days, before the SDPI, we were diagnosed, sent to a nutritionist and sent home with medication. In spite of my family history of diabetes I really didn't understand the disease. My motivation to join the Cherokee Diabetes Prevention Program in 2007 came when I was at the clinic because my blood sugars were out of control, even though I was on the maximum dosage of insulin and oral medications.

I was shocked when the nurse suggested that my "central obesity" might be interfering with my medications. I left that clinic visit with an "I'll show you" attitude and began attending diabetes education classes, the fitness center and cooking classes. With the support of the program staff, I have lost 35 pounds and in 2008 I was in control of my diabetes and no longer required insulin or oral medications. Honestly, I love the program. It has challenged me in new ways and given me the opportunity to take control of my diabetes, my health, and my future. Taking control of my diabetes enabled me to complete the first annual Cherokee Ironman-Ironwoman Triathlon which included a 3.2 mile run, 8 mile bike, and half mile swim!



Ulela Harris, Treasurer, Board of Cherokee Indians
Cherokee Diabetes Program

Diabetes in North Carolina

According to 2008 CDC data, approximately 626,000 people in North Carolina – 9% of the state's population – had diagnosed diabetes and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on the people in North Carolina, the financial burden diabetes places on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in North Carolina was approximately \$5.31 billion.**

NORTH CAROLINA

Cheryl's Story

"Today, I feel like I'm letting myself, my kids, and my future grandchildren down if I don't take care of my health." - Cheryl Donovan



Cheryl Donovan, Turtle Mountain Chapter
On Eagles Wings Diabetes Prevention Program

Since my mom, my aunt and my grandmother all had diabetes I had become used to having my blood sugar checked over the years but I always ended up in the normal range. So when the Diabetes Prevention Program first started, the staff aggressively began to screen for pre-diabetes and recruit community members into the program. Because of my family history I agreed to be tested. When I got the results they said, "You're lucky. You have pre-diabetes, and we want you to enroll in the program because diabetes is preventable."

My first reaction was that I didn't have the time to attend the 24 week classes but it didn't matter to the staff. They were persistent and if I couldn't make the class they brought the class to me, even if it meant meeting with me after work. They gave me choices, showed me different exercises I could do, and taught me new grocery shopping and cooking habits.

Before the program I was under the impression that if your family had diabetes you were going to have it too. Now I know that is not true. With the education and support of the SDP supported prevention program, I was able to lose 70 pounds and my blood sugars are completely normal and I'm no longer pre-diabetic! The valuable skills I have learned and having access to the program give me the confidence to know I can continue on this healthy path.

Diabetes in North Dakota

According to 2008 CDC data, approximately 34,000 people in North Dakota – 6.4% of the state's population – had diagnosed diabetes, and many of them suffer from serious complications or conditions. **In addition to the human toll diabetes places on the people of North Dakota, the financial burden diabetes places on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in North Dakota was approximately \$309 million.**

Kathy's Story

**"After living with diabetes for so many years, I was beginning to question my future."
- Kathy White**

I was diagnosed with type 1 diabetes in my 20s, and shortly after being diagnosed I was pregnant with my first child, causing even more worry. I have lived with this disease over half of my life. Diabetes can make life difficult and frustrating. I did my best to keep my glucose under control, but I was never successful, even while using an insulin pump and continuous glucose monitor.

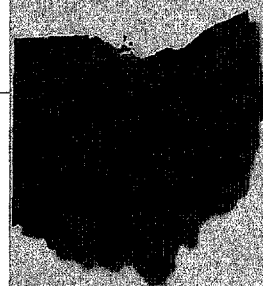
I was limited in what I could do physically and I had to worry about being able to concentrate at my job as a medical technologist. Sometimes after experiencing a low blood sugar, I would feel terrible for hours. After having diabetes for over 25 years, I began to develop complications such as retinopathy and was battling with severe lows that would occur without my having any awareness. I began to feel as if I was losing the battle with diabetes.

I learned about islet cell transplantation in a diabetes magazine and qualified for a transplant. I had an islet cell transplant in July 2008 and after two months of allowing the cells to slowly acclimate in my liver, I was able to discontinue insulin. I have to take immunosuppressive drugs, and they have some side effects, but for me they are not nearly as inhibiting as insulin was.

The islet transplant has worked well for me, but I know that the procedure needs to be improved so that it is appropriate for more people with type 1 diabetes such as children. The research supported by the Special Diabetes Program is moving us closer to that day.

Diabetes in Ohio

According to 2008 CDC data, approximately 847,000 people in Ohio – 9.1% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Ohio, the financial burden diabetes places on the health system is staggering – in 2007, the direct and indirect cost of diabetes in Ohio was approximately \$5.93 billion.**



Kathy White

OHIO

OKLAHOMA

Glendine's Story

"I want everyone to know that you don't have to wait until you have a stroke to take advantage of all the Healthy Heart Program has to offer. Get started early and learn how to manage your diabetes!"
- Glendine Blanchard



Glendine Blanchard, Absentee Shawnee Tribe
Absentee Shawnee Tribe Healthy Heart Program

I lost my mother to complications from diabetes in 2007 and the very same year I was also diagnosed with diabetes. I learned about the tribal Healthy Heart Program after I had a stroke in 2008 and it really opened my eyes. I found out that my stroke put me at greater risk for having another stroke and that I could participate in the Healthy Heart Program on a monthly basis to help me prevent it from happening again.

The program has given me the opportunity to get more involved in managing my diabetes and taught me the skills I need to take better care of myself and my family. With the support of the program staff and diabetes education classes, I have made changes in the foods I eat and I'm much more physically active than I used to be.

Last year the Healthy Heart program added diabetes education classes and a fitness program near my work, which really took away my excuses not to focus on my health. I also have 3 daughters, one son and 12 grandchildren and the lifestyle changes I've made as a result of what I've learned are having a positive impact on their health as well.

I'm really thankful for the Healthy Heart Program because it helps keeps me focused on managing my diabetes and helps me to maintain a normal life.

Diabetes in Oklahoma

According to 2008 CDC data, approximately 276,000 people in Oklahoma – 9.6% of the state's population – had diagnosed diabetes, and many of them suffer from serious complications or conditions. **In addition to the human toll diabetes places on people in Oklahoma, the financial burden diabetes places on the health system in the state is staggering – in 2007, the direct and indirect cost of diabetes in Oklahoma was approximately \$1.87 billion.**

Taylor's Story

" I truly believe this program can dramatically improve the health of the Klamath Tribes and bring us...Mo ben dic hosIntamblek! (Good Health in the Klamath language)" - Taylor David

As both a Klamath Tribal Member and tribal employee, it has been my extreme pleasure to both watch and participate in the Klamath Tribes Diabetes Prevention Program. I first became interested in joining when I saw how the program was helping my family members. Over the past year, as a participant of the Klamath Diabetes Prevention Program, I have come to view it as both a life-saver and life-extender not only for myself, but also for my fellow tribal members.

With the support of my Lifestyle Coach, I've lost 38 pounds and my blood sugars no longer fall in the pre-diabetic range. The weight loss has really helped me with my Indian dancing. I'm a jingle dancer and not only can I dance without pain in my ankles and knees, I can perform longer. It is power for me. The program and my Lifestyle Coach have always gone above and beyond the call to make sure I had everything I needed to be successful improving my overall health. Beyond diabetes prevention, this program has given me the motivation to push myself and once-again believe in myself. In the past three months I've conquered my fear of both heights and speed and ran my first 5k this past weekend in Portland with over 5,000 other participants and also learned how to snowboard! I would have never had the courage or been in the shape necessary to accomplish these things had it not been for the Diabetes Prevention Program. It is imperative that these types of programs are firmly in place to lead us to the next level of good health.



Taylor David, Klamath
Klamath Diabetes Prevention Program
Cow Creek Consortium

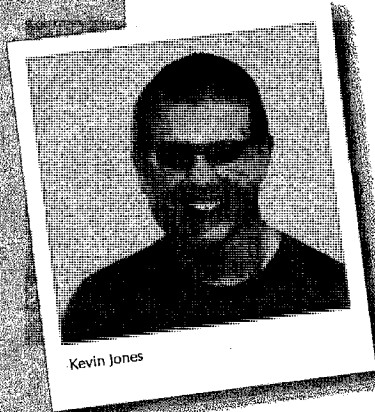
Diabetes in Oregon

According to 2008 CDC data, approximately 199,000 people in Oregon – 6.5% of the state's population – had diagnosed diabetes, and many suffer from serious diabetes related complications and conditions. **In addition to the human toll diabetes places on the people in Oregon, the financial burden diabetes places on the health system in the state is staggering – in 2007, the direct and indirect cost of diabetes in Oregon was approximately \$2.18 billion.**

OREGON

Kevin's Story

"I've learned to take everything in stride, but you can never forget you have diabetes. Every time I drive a car I have to check my blood sugar; every time I eat a meal I have to check and give insulin. It's always with you." - Kevin Jones



When I was 15, out of the blue I started to experience unbelievable thirst, and I was extremely tired. I wasn't feeling like myself at all. My mom took me to the doctor, where he checked my blood sugar level. My reading came back at 700 and I was sent immediately to the hospital. A year after I was diagnosed, I found out that I qualified to participate in a beta cell preservation study. The goal of the study is to preserve the cells that produce insulin and delay the full onset of diabetes. The more insulin your cells produce on your own, the fewer insulin shots you need to inject yourself, and your blood sugars are easier to control.

When I found out that I qualified for the research study, I was really excited and also scared. I was excited to think that if I was in the study group that received the medicine, then maybe I would be able to use less insulin. But I was scared because I didn't know what to expect. I decided to participate. I don't know if I received the study drug or not. But since the start of the study, I am still producing some of my own insulin, and I use less insulin than the amount used by most people my age and weight three years after diagnosis. In the span of two years I went from knowing almost nothing about type 1 diabetes to being an active part of the diabetes research community. I am really interested in biology, it's my major in college. I think my participation in this trial has helped to grow that interest and advance a cure for this disease.

Diabetes in Pennsylvania

According to 2008 CDC data, approximately 848,000 people in Pennsylvania – 7.9% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Pennsylvania, the financial burden diabetes places on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in Pennsylvania was approximately \$6.79 billion.**

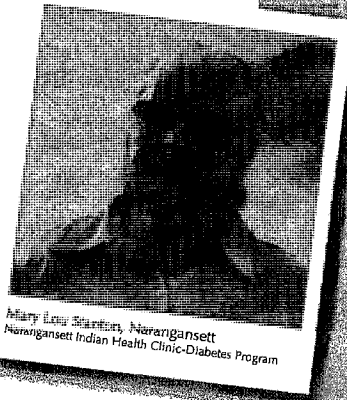
Mary Lou's Story

"I want to continue participating in the Diabetes Program so I can continue to control my diabetes, feel good and prevent the complications to my eyes, heart and kidneys."
- Mary Lou Stanton

Like many of our tribal members, I also have a family history of diabetes. I am 79 years old and I was diagnosed with type 2 diabetes in 1997. I am very pleased that we have such quality diabetes care here. The Diabetes Program allows myself and other community members access to important medical care for our diabetes. It provides us with medications and care by a physician and nurse practitioner as well as opportunities for educational programs which all help us to better care for our diabetes and prevent complications.

The diabetes education they offer has not only taught me how to manage my diabetes but I have also learned why it is so important to control my diabetes. This program has made it possible for me to participate in an exercise program which has had many benefits. In addition, the program provides fellowship and social support which is very important in dealing with diabetes.

Since participating in the program I have a better sense of well being, better mobility and I have lowered my blood sugars and my blood pressure. Being active in the program has helped me to manage my diabetes with pills instead of having to take insulin.



Mary Lou Stanton, Narragansett
Narragansett Indian Health Clinic-Diabetes Program

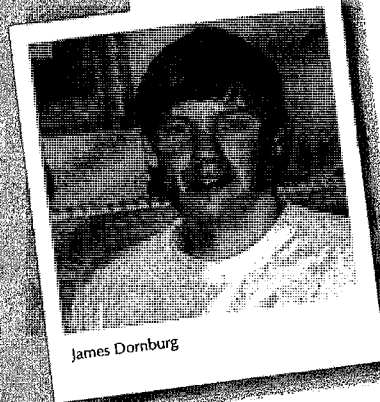
Diabetes in Rhode Island

According to 2008 CDC data, approximately 61,000 people in Rhode Island – 6.9% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Rhode Island, the financial burden diabetes places on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in Rhode Island was approximately \$714 million.**

RHODE ISLAND

James' Story

"When I was diagnosed I was in the pediatric ICU for over 5 days – no family should ever have to go through that." - James Dornburg



James Dornburg

I was diagnosed with type 1 diabetes in 1992 when I was 10 months old. At that time I was the youngest person in South Carolina to be diagnosed with the disease. A few months before being diagnosed I had the chicken pox. I've learned that research funded by the Special Diabetes Program is looking into environmental triggers – such as exposure to viruses like the chicken pox – that may lead to type 1 diabetes. Although there was no family history of type 1 diabetes, my mother enrolled herself and the rest of our family in TrialNet Natural History Study, which is made possible by funding from the Special Diabetes Program. Our family is tested annually, and to date no one has tested positive for antibodies that put them at high risk of developing the disease.

I manage my diabetes through multiple injections every day. I have to stay on top of my diabetes every minute of every day. When a person with diabetes goes through growth spurts or gets sick, it throws everything off, and it is common to have huge variations in blood sugar levels.

Although I manage my diabetes, what I really need is a cure. This research is getting us there.

Diabetes in South Carolina

According to 2008 CDC data, approximately 328,000 people in South Carolina – 9.4% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in South Carolina, the financial burden diabetes places on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in South Carolina was approximately \$2.64 billion.**

Pete's Story

"My blood sugars are now in normal range, my blood pressure is good and I feel good. It's been the high point in my life, being diabetes free." - Pete Fills the Pipe

I didn't know about pre-diabetes until this program. Our whole reservation is high risk for poverty, stress, suicide and diabetes. When I found out I was pre-diabetic, it was a trauma for me. I'm 58 years old and most of my friends and cousins are gone now from either diabetes or alcoholism. We've had to eat what was given to us since we've been on the reservation. You know, the food distribution programs weren't so good. It's changed now, this program teaches us how to eat and cook to be healthy and to exercise everyday. I walk 2.5 miles a day now.

My traditional belief is to respect life and that includes my body. You have to take care of your whole self, spiritually, emotionally and physically. Whatever is hard in your life you can pray and it will help you, but you have to meet the Creator half way. The program has helped me learn how to live a healthy lifestyle. I started by making small changes. It's been hard changing my habits and I've had to discipline myself but it's worth it. In our culture, in everything you do, you feed the people. It's part of our tradition, its how we honor each other. But you know what - it doesn't hurt to say "no" to unhealthy food or eat a smaller amount or feed the people something good for them. The program has helped me learn this. Our people go through this program and we learn and share this with our families. We become mentors. We're just now beginning to see the results of this program in our communities. I believe our diabetes rates are going down because of this program. It's become part of our healing, keeping ourselves in balance.

Diabetes in South Dakota

According to 2008 CDC data, approximately 39,000 people in South Dakota – 6.1% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in South Dakota, the financial burden diabetes places on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in South Dakota was approximately \$386 million.**

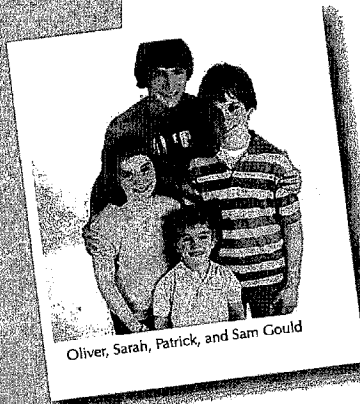


Pete Fills the Pipe, Oglala Lakota
Pine Ridge IHS Diabetes Prevention Program

SOUTH DAKOTA

The Gould's Story

"Surely researchers can learn from our family about the causes of this disease in order to help prevent it in others." - Ellen Gould



Oliver, Sarah, Patrick, and Sam Gould

Diabetes first entered our lives in July of 2004 when our oldest child, Patrick, was diagnosed at the age of 12. Less than two years later, Sarah, who was six at the time, began to show similar symptoms. Our family was devastated all over again. Shortly after her diagnosis, the rest of our family enrolled in the TrialNet Natural History study. Our hearts sank when the simple blood test they received showed that Oliver, age 3, and Sam, age 10, were at high risk for developing type 1 diabetes. Later tests indicated that Sam did have type 1, although he was not showing the classic symptoms at that time.

While our family was dealing with helping a third child manage diabetes, Oliver began taking a pill as part of the TrialNet study to see if full onset of type 1 could be delayed for months or years. We don't know if he received a placebo or oral insulin, but he was diagnosed in 2008 at the tender age of 4.

With four out of eight children with type 1 diabetes, a cure means everything to my family and we are willing to be part of the solution even with juggling our already busy life. Our hope is that by participating in TrialNet and other studies made possible by the Special Diabetes Program we are helping researchers find ways to prevent and delay type 1 diabetes in others.

Diabetes in Tennessee

According to 2008 CDC data, approximately 518,000 people in Tennessee – 10.7% of the states population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Tennessee, the financial burden diabetes places on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in Tennessee was approximately \$3.08 billion.**

Rick's Story

"This research might lead to insights on transplantation of other organs, which will help people who undergo kidney, heart, liver, and other types of organ transplantation." - Rick Haley

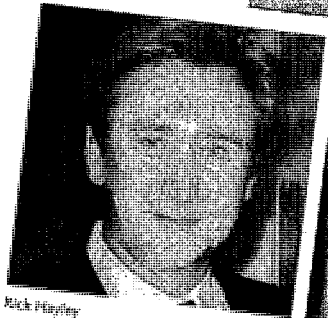
Two years after college graduation, I developed type 1 diabetes. In 2000, I participated in an islet cell clinical research trial. After the transplant, my daily intake of insulin was reduced from 80 units to 30 units and my blood sugar levels were in better control. However, eighteen months after the transplant, as I was gradually weaned of the immunosuppressive drugs, the islet infusion failed. Even though I have to give myself insulin, I still have benefited from the procedure. I now recognize when my blood sugar levels drop dangerously low, so my susceptibility to severe, life threatening hypoglycemic episodes has decreased.

The Clinical Islet Transplantation Consortium that is supported by the Special Diabetes Program is bringing hope of islet transplantation to more people and is conducting research to perfect the procedure. The Consortium is studying the use of less-toxic approaches to the procedure and is evaluating new, less invasive immunosuppressive strategies.

Despite my diabetes, I continue to live an active life. I compete on a national and international level in waveski surfing. And after serving eleven years as a Governor-appointed member of the Texas Diabetes Council, I now serve on the Texas Governor's Advisory Council on Physical Fitness. My participation in this trial is giving researchers the tools to get closer to a cure for type 1 diabetes and its complications. I will do all I can so all those living with this disease can live their lives to the fullest.

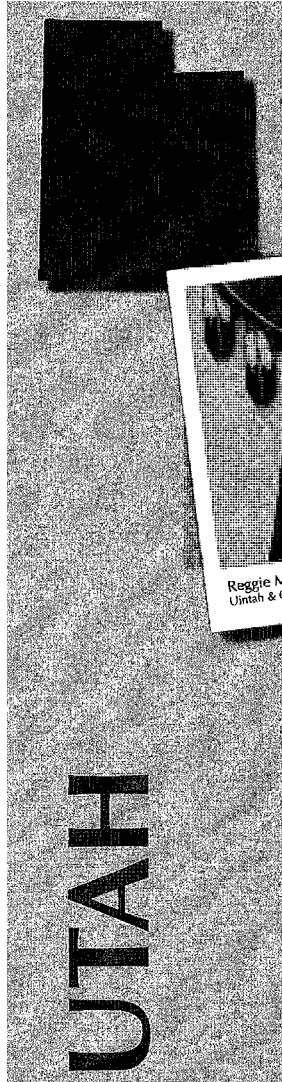
Diabetes in Texas

According to 2008 CDC data, approximately 1,727,000 people in Texas – 10.4% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Texas, the financial burden diabetes places on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in Texas was approximately \$12.46 billion.**



Rick Haley

TEXAS



Reggie's Story

"It's a good feeling to know that by staying on this healthy path, I may soon be able to control my diabetes without medication."
 - Reggie Martinez



Reggie Martinez, Navajo Nation, Utah
 Uintah & Ouray IHS Clinic - Healthy Heart Project

I was diagnosed with diabetes in 2001. When I first joined the Healthy Heart Program I weighed over 300 pounds and my A1c (average blood sugar test) was a very dangerous 12.4. I started going to classes, learning about getting healthy, and setting goals and slowly I began to get motivated to take better care of my health.

Before I went to these classes I ate a lot of processed and fried foods, didn't pay attention to portion sizes and didn't exercise. Now, all that and more has changed.

While in the program, I lost 70 pounds, my A1c dramatically decreased from 12.4 to 6.2, the metformin medication I was taking to control my diabetes was decreased from 1000 mg daily to 250mg daily, and I went from being a Healthy Heart participant to the Healthy Heart

gym operator. I'm happy I made the decision to join the program.

It's a good feeling to be able to set goals, achieve them and help others do the same. People now come up to me and ask me questions or for suggestions with their fitness and food plans. We may sit down and just talk or I may go to the gym with them. Either way, sharing what I've learned from my experiences in the Diabetes Prevention Program helps me stay fit and healthy.

Diabetes in Utah

According to 2008 CDC data, approximately 107,000 people in Utah – 6.8% of the state's population – had diagnosed diabetes, and many suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Utah, the financial burden diabetes places on the health system is staggering – in 2007, the direct and indirect cost of diabetes in Utah was approximately \$927 million.**

Hannah's Story

"When I get older I want to be an endocrinologist so I can help others who have diabetes."

- Hannah Pomerantz-Kasper

I was diagnosed with diabetes when I was 13. Not a day goes by that I don't think about what my life was like up until I was diagnosed, but I am determined not to let diabetes slow me down. I still go to birthday parties, sleepovers, perform in school plays, and run cross country, but now my insulin pump and my continuous glucose monitor go with me.

You have to manage this disease until there is a cure. I am thankful for diabetes research because I know that I am fortunate to have access to my insulin pump and continuous glucose monitor which make living with diabetes more manageable. I can't imagine having to manage this disease without them.

I know that federal research has made these tools possible. My whole family is involved in research. My brother and sister participate in the TrialNet Natural History Study on a regular basis to measure their risk for developing type 1 diabetes. So far they have tested negative for insulin antibodies that would put them at high risk for developing this disease.

The more we learn about diabetes – and the reasons why I have it – bring us closer to curing it. We have to find a cure.

Diabetes in Vermont

According to 2008 CDC data, approximately 33,000 people in Vermont – 6.2% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Vermont, the financial burden on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in Vermont was approximately \$347 million.**



Hannah, Alex and Shaina

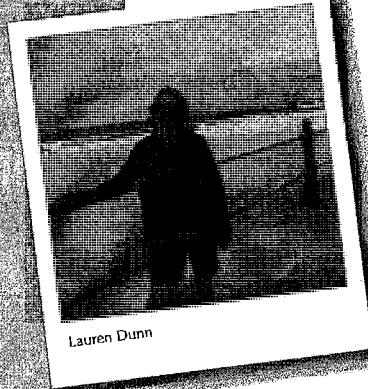


VERMONT

Lauren's Story

"My research team has been wonderful to work with. It's pretty humbling to have so many people so dedicated to help improve your health and quality of life."

- Lauren Dunn



Lauren Dunn

I try as much as possible not to let diabetes get in my way. After 27 years with diabetes, the day to day management becomes like wearing a watch – it's just part of the routine. I'm a medical social worker and stay pretty active outside of work. But I'm constantly thinking about my blood sugar levels, and I test my levels 6-8 times every day. I'm also very sensitive to stress – my blood sugars go really high when I'm stressed out. My job can be very emotionally stressful, and I always know when I need a break or need to get myself centered, as it shows in my glucose readings.

I love to be active, but when I exercise, I usually have to plan it out pretty well to make sure that exercise doesn't negatively impact my blood sugar.

One of my biggest frustrations is when diabetes slows me down or makes me have to stop what I'm doing. I currently

use an insulin pump and glucose meter to manage my diabetes. I have a continuous glucose monitor that I use to monitor trends. I count just about every carbohydrate that goes into my body and I use exercise as part of my management. I am highly motivated, and I work very hard to manage my diabetes; however I still struggle with roller coaster days of high and low blood sugars.

Although my diabetes is managed, I know we need a cure. I will do whatever it takes. I have participated in several research studies over the years. The most recent ones included the overnight closed and open loop artificial pancreas trials, and the exercise/overnight closed and open loop artificial pancreas trials.

Diabetes in Virginia

According to 2008 CDC data, approximately 469,000 people in Virginia – 7.8% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Virginia, the financial burden diabetes places on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in Virginia was approximately \$4.4 billion.**

VIRGINIA

Buddy & Les' Story

"The Healthy Heart Program has given us a new confidence in our overall health."

- Buddy and Les Hoptowit (Brothers)

I signed up for the Healthy Heart Program first and got my brother Les to join a month later. We both live with type 2 diabetes and being involved in the program is important to us because we have seen the devastation of diabetes in our community and have lost family members to diabetes complications-especially heart disease.

Before the Healthy Heart Program became available to us we had to have separate medical appointments for everything we needed to take care of our diabetes and then we would have to go back to have our prescriptions filled.

Now, we have direct access to our own pharmacist-case manager and we get excellent, personalized care. It is so much better because we get diabetes education, foot checks, and our medications refilled and adjusted, all in one visit.

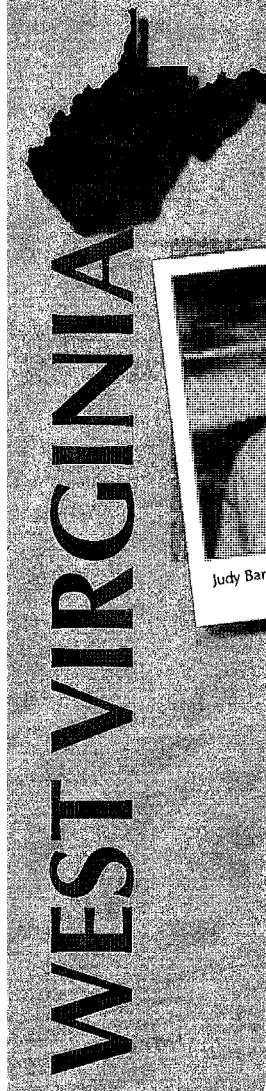
Although it hasn't always been easy, we are more physically active, and eat healthier. We have managed to make healthy changes and get better control of our diabetes and reduce our risk for heart disease.



WASHINGTON

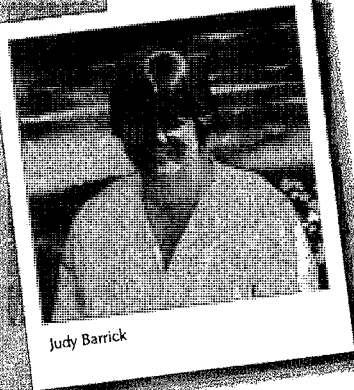
Diabetes in Washington

According to 2008 CDC data, approximately 345,000 people in Washington – 6.9% of the state's population – had diagnosed diabetes, and many of them suffer from diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Washington, the financial burden diabetes places on the state's health system is staggering – in 2007, the direct and indirect cost of diabetes in Washington was approximately \$3.97 billion.**



Judy's Story

"Participating in this trial has changed the course of my life." - Judy Barrick



Judy Barrick

I know that I am lucky. When I was 15 I suddenly lost a great deal of weight and then lapsed into a coma. Some days later I woke up to the news that I was diagnosed with type 1 diabetes. I enrolled in the Diabetes Complications and Control Trial (DCCT) when I was in college, and during the first few years of the trial I would have to stay in the hospital for many days. Later, I became pregnant with my daughter while participating in the DCCT trial, and I am convinced that the trial not only saved my life but changed the life of my daughter as well. I learned how important intensive management of my blood sugar was, not only at that point in time, but also in determining my future. Thankfully, I have yet to develop any complications associated with living with type 1 diabetes.

Participating in this research changed my life for the better. It is also giving researchers information to understand type 1 diabetes that is bringing us closer to a cure. We need to learn as much as we can about this disease so we can cure it.

I manage my diabetes through multiple insulin injections, and my diabetes never gives me a day off. I work hard to not let diabetes keep me from doing the things I love to do. I am an avid traveler and still have a taste for adventure. I am not going to let diabetes take that away from me.

Diabetes in West Virginia

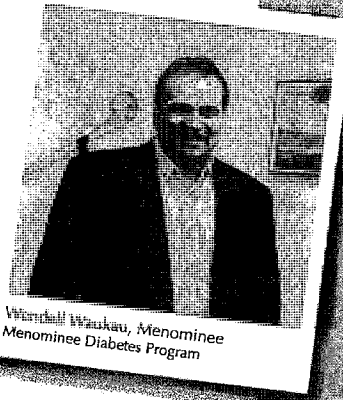
According to 2008 CDC data, approximately 164,000 people in West Virginia – 10.3% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in West Virginia, the financial burden diabetes places on the health system in the state is staggering – in 2007, the direct and indirect cost of diabetes in West Virginia was approximately \$999 million.**

Wendell's Story

"I joined the DP to avoid taking insulin for as long as possible. That was 3 years ago and I'm still controlling my diabetes without medication."

- Wendell Waukau

I was somewhat disappointed when I was diagnosed with type 2 diabetes in June 2007. Disappointed because I thought I knew enough about it, having watched family and others on the reservation deal with the challenges of living with diabetes. On the day I was diagnosed, there was one thing I new for certain. I knew I wanted to avoid taking insulin for as long as possible. It's been three years since that day, and with the support of the Menominee Tribal Clinic's Diabetes Program, I have been able to successfully manage my blood sugars without any diabetes medications. I've been successful so far, but I'm also very aware of the reality of this disease and know that I have to work to maintain the changes I've made with diet and exercise to remain free from diabetes medications. So, I have stayed in close contact with the diabetes educator, the dietitian and the fitness staff. Their positive messages, willingness to listen and nonjudgmental coaching have played a key role in my ability to successfully manage my diabetes.



Wendell Waukau, Menominee
Menominee Diabetes Program

I am a big believer that programs don't change people—relationships do. The Menominee Tribal Clinic's Diabetes staff have created an environment in our community and in our schools in which positive, healthy relationships are occurring. They have empowered me to take control of my diabetes and my overall health and they have also provided a strong foundation for many of the positive healthy changes being made in our people.

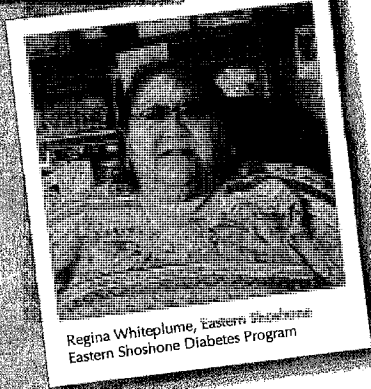
Diabetes in Wisconsin

According to 2008 CDC data, approximately 293,000 people in Wisconsin – 6.5% of the state's population – had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Wisconsin, the financial burden diabetes places on the health system in the state is staggering – in 2007, the direct and indirect cost of diabetes in Wisconsin was approximately \$2.99 billion.**



Regina's Story

"When I asked for help, the Diabetes Program was there. They gave me the support I needed to take control of my diabetes." - Regina Whiteplume



Regina Whiteplume, Eastern Shoshone
Eastern Shoshone Diabetes Program

I was diagnosed with type 2 diabetes in 1984. My father, my grandmother and my older brother all passed away from complications of diabetes. A few years ago when my blood sugars were out of control, I became concerned but I really didn't know what to do bring them down. After hearing about the Diabetes Program I decided to call them and ask for help so I could try learn more about diabetes and what I could do to motivate myself to get control.

In 2009 I started going to the diabetes education classes with my oldest son who had recently been diagnosed with diabetes. Over the years I had heard some basic things about the disease but it couldn't compare with the diabetes education I received in the program. The educators are very knowledgeable and know how to work with people to get the messages across and I didn't miss

a single class. Now I understand more about how diabetes affects my health. I've been able to make many healthy changes in the amounts and kinds of foods I eat and I exercise more. The small, slow changes I have made over time are working for me. I have lost almost 30 pounds and I can walk longer distances. I am now more in control of my blood sugars and lately, I've noticed that I feel stronger, have a lot more energy and find myself moving more. I think there are many people in our community that really don't know what they can do to control their diabetes and be healthier. I want everyone to know what I learned from the diabetes Program - that it's never too late to start taking care of yourself and learning what you can do to get control of diabetes and avoid dialysis and amputations.

Diabetes in Wyoming

According to 2008 CDC data, approximately 29,000 people in Wyoming - 6.8% of the state's population - had diagnosed diabetes, and many of them suffer from serious diabetes related complications or conditions. **In addition to the human toll diabetes places on people in Wyoming, the financial burden diabetes places on the health system in the state is staggering - in 2007, the direct and indirect cost of diabetes in Wyoming was approximately \$258 million.**

Glossary & Additional Information

TYPE 1 DIABETES - Type 1 diabetes is an autoimmune disease in which the body's immune system attacks and destroys the insulin-producing cells of the pancreas. While its causes are not yet entirely understood, scientists believe that both genetic factors and environmental triggers are involved.

TYPE 2 DIABETES - In type 2 diabetes, either the body does not produce enough insulin or the cells ignore the insulin. Insulin is necessary for the body to be able to use glucose for energy.

HEMOGLOBIN A1c - A blood test for people with diabetes that reveals the average blood sugar values over the past 3 months. This test is used to monitor patients with diabetes and assess their level of disease control. The goal for most people with diabetes is an A1c below 7%. The Diabetes Control and Complications Trial showed that people with diabetes who keep their hemoglobin A1c levels close to 7% have a much better chance of delaying or preventing diabetes complications that affect the eyes, kidneys, and nerves than people with levels 8% or higher. Lowering the level of hemoglobin A1c improves a person's chances of staying healthy.

INSULIN - When food is eaten, the body breaks down all of the sugars and starches into glucose, which is the basic fuel for the cells in the body. Insulin takes the sugar from the blood into the cells. When glucose builds up in the blood instead of going into cells, it can lead to diabetes complications.

NATIONAL INSTITUTES OF HEALTH - The NIH is part of the Department of Health and Human Services (HHS) and is the primary federal agency for conducting and supporting medical research. The National Institute for Diabetes and Digestive and Kidney Disorders (NIDDK) is the Institute within the NIH that administers the Special Type 1 Program.

INDIAN HEALTH SERVICE - The IHS is part of the Department of Health and Human Services (HHS) and it administers the federal health program for American Indians and Alaska Natives. The Division of Diabetes Treatment and Prevention (DDTP) within IHS administers the Special Diabetes Program for Indians.

CENTERS FOR DISEASE CONTROL AND PREVENTION - The CDC is part of the Department of Health and Human Services (HHS) and is the federal agency responsible for protecting the public's health through disease prevention and health preparedness. The Division of Diabetes Translation (DDT) at CDC partners with NIDDK on some of the clinical studies examining the environmental triggers for type 1 diabetes.

For additional resources, please visit:

American Diabetes Association www.diabetes.org
 Juvenile Diabetes Research Foundation www.jdrf.org
 National Indian Health Board www.nihb.org

National Institute of Diabetes and Digestive Diseases, National Institutes of Health:

Special Statutory Funding Program for Type 1 Diabetes Research: Progress Report 2010:
<http://www2.niddk.nih.gov/AboutNIDDK/ReportsAndStrategicPlanning/T1DStatutoryFundingProgress2010.htm>

Evaluation Report on the Special Statutory Funding Program for Type 1 Diabetes Research (August 2007):

<http://www2.niddk.nih.gov/AboutNIDDK/ReportsAndStrategicPlanning/EvaluationRptSpecialStatutoryFundingT1DResearch.htm>

Division of Diabetes Treatment and Prevention, Indian Health Service:

<http://www.ihs.gov/MedicalPrograms/Diabetes/index.cfm?module=programsSDPI>