The Special Diabetes Programs
Stories of Hope and Progress
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:

- **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.
- **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.
- **Clinical Islet Transplantation Consortium**: This consortium performs multi-center, Phase III trials that will lead to FDA approval of islet cell transplantation therapy.
- **Diabetes Research in Children Network**: This clinical network fills a critical research gap by testing and validating new diabetes management technologies in children.
- **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.
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.
Rudy's Story

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

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.
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.
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.
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

I was diagnosed with type 1 diabetes when I was 23 years old, and 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

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 later 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 hyperglycemic 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.
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

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 becoming 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 Nimipuu 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.
The Corn's Story

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

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.
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

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 exercises 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.
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.
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

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.

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.
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

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 DRCR 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.
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.
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.
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.
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 has 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
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 7½, 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.
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

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!

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.
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

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

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

"Ajéí baa há whéén dzin yít nidaał nísh yigí do hóólíń gó éh ti’da’hoo’nilh 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)

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.
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

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!

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.
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 Donoven

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.
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

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.

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.
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.

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.
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

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.
"Surely researchers can learn from our family about the causes of this disease in order to help prevent it in others." - Ellen 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 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 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.
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

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.
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

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 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.
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.

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

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 knew 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.

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

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](http://www.ihs.gov/MedicalPrograms/Diabetes/index.cfm?module=programsSDPI)