

**THE JUVENILE DIABETES RESEARCH FOUNDATION
AND THE FEDERAL GOVERNMENT: A MODEL
PUBLIC-PRIVATE PARTNERSHIP ACCELERATING
RESEARCH TOWARD A CURE**

HEARING

BEFORE THE

COMMITTEE ON
HOMELAND SECURITY AND
GOVERNMENTAL AFFAIRS
UNITED STATES SENATE
ONE HUNDRED TENTH CONGRESS

FIRST SESSION

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**THE JUVENILE DIABETES RESEARCH FOUNDATION AND THE FEDERAL GOVERNMENT:
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ACCELERATING RESEARCH TOWARD A CURE**

TUESDAY, JUNE 19, 2007

U.S. SENATE,
COMMITTEE ON HOMELAND SECURITY
AND GOVERNMENTAL AFFAIRS,
Washington, DC.

The Committee met, pursuant to notice, at 9:30 a.m., in room SD-106, Dirksen Senate Office Building, Hon. Joseph I. Lieberman, Chairman of the Committee, presiding.

Present: Senators Lieberman, Levin, Akaka, Tester, and Collins.
Chairman LIEBERMAN. Good morning.

Well, I must say, of all the hearings that I have had the honor to convene, this is the most beautiful group of people in front of me that I have ever seen. So welcome this morning.

I am Senator Joe Lieberman, and it is my honor to be the Chairman of this Committee this year. I want to welcome our witnesses to this hearing of the fifth Children's Congress organized by the Juvenile Diabetes Research Foundation.

Senator Susan Collins is the Ranking Member of this Committee. For years, she was the Chairman, and as we said, in the roll of the dice or the twist of fate or whatever it is, it turned out that I have the title of Chairman this year, but nothing has changed in our partnership in this Committee other than our titles. She is an extraordinary person, and I am really honored to work with her.

Senator Collins has taken a particular interest in juvenile diabetes and chaired four similar hearings that have focused on breakthroughs in research, the partnership between the JDRF and the National Institutes of Health, and the challenges in developing effective treatments and a cure for juvenile diabetes.

First off, I do want to say before I turn the gavel over to her that I am very sorry that she got the memo that we were supposed to wear yellow today. [Laughter.]

And I didn't get it, but there is a very little bit of yellow in my multi-colored tie.

Anyway, to recognize and really honor Senator Collins' superb and important leadership on this important public health challenge, I am going to turn the gavel over to her. I look forward to her opening statement. If she so chooses with the gavel in her hand, I will then make an opening statement. But then she will Chair the hearing. Senator Collins.

OPENING STATEMENT OF SENATOR COLLINS

Senator COLLINS. Thank you very much, Senator Lieberman. It is really nice to have the gavel back, even if it is just for this one hearing. But it is typically gracious of you that when I asked you if I could Chair today in view of my longstanding interest in this issue, you didn't hesitate. You immediately acceded to my request, and I am very grateful for that.

As you mentioned, this is the fourth Juvenile Diabetes Research Foundation Children's Congress that I have had the honor to Chair, and I am very grateful for your leadership, as well. I know that there is a delegate from Connecticut here today.

I also want to welcome all of our distinguished witnesses, but most of all, I want to welcome all the children who have joined us today.

It is just wonderful to have you here. Now, have any of you been to Washington before? A few of you have—quite a few of you have. Well, then you know it is very unusual for us to have children come to our hearings, much less testify. But it is important that children are here from all over the country and indeed around the world to tell Congress just what it is like to have diabetes, how serious it is, and how important it is that we fund the research necessary to find a cure.

I want to give a special welcome to the delegate from Maine, 13-year-old Caitlin Crawford, who will be testifying on the second panel today.

As the founder and the Co-Chair of the Senate Diabetes Caucus, I have learned a lot about the disease and the difficulties and the heartbreak that it causes for so many American families as you await a cure. Diabetes is a lifelong condition that affects people of every age, race, and nationality. It is the leading cause of kidney failure, blindness in adults, and amputations not related to injury. Moreover, it is estimated that diabetes accounts for more than \$132 billion of our Nation's annual health care costs and that health spending for people with diabetes is almost double what it would be if they did not have diabetes.

These statistics are truly overwhelming, but what really motivates me to devote so much energy to this issue is meeting more and more people like our delegates today and their families whose lives have been changed forever by diabetes, and that is why it so important that you have all traveled here to tell your stories. You put human faces on all of those statistics. You can teach us what Congress can do to help us better understand and ultimately conquer this terrible disease.

The burden of diabetes is particularly heavy for children and young adults with type 1, or juvenile diabetes. It is the second most common chronic disease affecting children. Moreover, it is one that you never outgrow.

People ask me all the time why I am so interested in juvenile diabetes. They ask, do I have a family member who is afflicted with it, and I do not. What got me interested was a meeting that I had when I became a new Senator back in 1997 with JDRF members in Maine. They came into my office, and I will never forget this 10-year-old boy who told me that all he wanted was to take one day off from his diabetes.

But I realize that even if it is your birthday, or Christmas, or another holiday, you can't take a day off from diabetes, and the average child with diabetes will have to take more than 50,000 insulin shots in a lifetime.

While the discovery of insulin was a landmark breakthrough in the treatment of diabetes, it is not a cure. Thankfully, there is much good news for us to report today. Since I founded the Senate Diabetes Caucus in 1997, funding for diabetes research has more than tripled, so it is now up to about \$1 billion. As a consequence, we have seen some encouraging breakthroughs, and we are on the threshold of a number of important new discoveries, as Mary Tyler Moore and I were discussing briefly this morning.

For example, a new drug that has been tested in clinical trials has been shown to have the possibility of stabilizing or even reversing the progression of type 1 diabetes, demonstrating for the first time that the clinical course of the disease can be altered.

Advances in technology, like continuous glucose sensors, are helping people better control their blood glucose levels, and that is key to preventing diabetes complications. These advances are also moving us closer to the long-term goal of an artificial pancreas, and drugs originally designed for cancer therapy are showing tremendous potential for treating diabetic eye disease.

Now, we are making progress, but now is no time to take our foot off the accelerator. We basically have two choices. We can sit back and continue to pay the bills and endure the suffering, or we can aggressively pursue a national strategy aimed at curing this terrible disease.

In August 2006, the National Institutes of Health released a report called "Advances and Emerging Opportunities in Type 1 Diabetes Research: A Strategic Plan." It charts a course that we must take. The Juvenile Diabetes Research Foundation has brought together leading researchers and economists who estimate just how much it would cost to fully fund the research opportunities identified in this landmark report. The estimate is that it would cost approximately \$557 million in 2009, rising to about \$1.2 billion in 2013. Clearly, we have our work cut out for us, but we can do it.

The good news is that there is strong support in Congress for increasing funding for diabetes research, including Senator Lieberman's strong support. Last month, 64 senators joined me in sending a letter to the Senate leadership urging increased funding for type 1 diabetes to accelerate our race to a cure.

And I am hopeful that this morning's hearing, plus all of the visits that you are doing with senators all over the Hill, will help to build on that support and give us the momentum we need for increased research funding to find better treatments, a means of prevention, and, yes, ultimately, a cure.

Thank you, Mr. Chairman. I am delighted to call on you for your statement.

OPENING STATEMENT OF CHAIRMAN LIEBERMAN

Chairman LIEBERMAN. Well, thank you, Madam Chairman, for that excellent statement.

Let me welcome everyone here and particularly give a special welcome to Caroline McEnery from my home State of Connecticut,

who is going to share her story with us today. Also, her fellow nutmeggers, which is what we call people from Connecticut—it is too long a story to tell. [Laughter.]

Or maybe the more familiar today—if you follow UConn men or women’s basketball—we say fellow Huskies Aiden Falla, Amanda Rossi, and Sedrick Trotman, with whom I look forward to meeting after this hearing.

And let me just add an exclamation point to what Senator Collins has said to thank you for coming and to tell each of you, particularly the children here, you will be amazed at how important it is that you and your families have taken the time to be here because in your meetings with individual senators and members of the House of Representatives, you will educate, you will motivate, and you will move us to getting the things done that we want to get done.

Probably you have all heard the story of the discovery of insulin, but there are parts of it that I love to tell, and I tell it because it is a hopeful story. Obviously, before that, diabetes really was a dreadful disease. In the winter of 1921—that is a long time ago in a child’s life, but in the span of history, when we think of how long people have had diabetes, it is fairly recent—1921, following months of experiments and tests, a doctor from Canada, right to the north of us, Frederick Banting, and a team of researchers announced that they had successfully lowered the blood sugar in dogs that had diabetes that they were experimenting with and that led to the new—that was their breakthrough of insulin therapy. The news flashed around the world, not as quickly as it does today through the Internet, but it went around the world, bringing hope to millions.

And it is a wonderful story that in an extraordinary display of compassion, the Banting research team walked away from the fortune, the monetary fortune their discovery would have earned them selling the production rights to insulin for a mere dollar.

The idea that led to the discovery of insulin—this will be an interesting little story for you and your parents, I hope—occurred to Dr. Banting as he was getting ready for bed one night following a long day’s work on unrelated research, unrelated to the problem of diabetes. Eventually, he won a Nobel Prize for his discovery because that night, he scribbled the idea that he had before he went to bed into his notebook which he kept by the side of his bed. So keep a notebook by the side of your bed, kids, for those big ideas. And later, he would say—this is particularly important for those of us who are senators to hear—no one has ever had a really great idea while wearing a suit. [Laughter.]

I don’t know, we may have to consider—all right.

So obviously, since the discovery of insulin, we have made extraordinary progress, as Senator Collins described, in managing diabetes. But when it comes to children’s diabetes, obviously, our understanding of the cause and the cure is not yet within our grasp, though I would say, based on the tremendous advance of medical science, that it is definitely within our reach, and Dr. Banting’s late-night revelation should really fill us with hope that there are researchers out there today, tonight, who are going to have similar discoveries that will advance the cause.

That is why it is so important to support the work of the Juvenile Diabetes Research Foundation. The numbers speak for themselves. I am just going to mention these numbers to talk about the societal significance here. Nearly 21 million Americans have diabetes, and about 1.5 million new cases are diagnosed each year. The remarkable story in response is that over the last three decades, JDRF has raised and provided more than \$1 billion for juvenile diabetes research, and there is a great partnership between JDRF and NIH in moving this research forward. The bottom line here is we have come a long way, but we have a long way to go, and that is why your presence here today is so important.

When I come to a subject like this and I think of Dr. Banting and all the advances in the treatment and managing of diabetes that Senator Collins referred to, I think of this. There are a lot of reasons, I suppose, people have in the world today for being upset or depressed, but a lot of those unfortunately are true, world events, I mean. But when you look at the incredible advances in technology and medical science and you think of the things that you are going to see during your lifetime, that I have seen in my lifetime that I never would have dreamed—I am still kind of amazed that I can pick up this little piece of plastic and send an e-mail to somebody halfway around the world and hear back in about four seconds, not to mention the extraordinary advances in treating and curing diseases that people never dreamed would be so well treated and cured.

So let us go forward, understanding that JDRF does tremendous work. NIH has done tremendous work. They have been flat-funded lately overall, and that is not good. So a lot of us, Senator Collins, Senator Akaka, and I are going to be working to increase funding, particularly for juvenile diabetes research.

I know you will inform us. I know you will leave us with hope, and I hope you leave here with even more hope than you came with.

Thank you very much, Senator Collins.

Senator COLLINS. Thank you, Senator.

I want to thank Senator Akaka and Senator Tester for joining us also today.

Leading off our first panel this morning, I am pleased to welcome once again Mary Tyler Moore to the Committee. She is very well known for her work in film and television, but she is well known to anyone whose life has been touched by diabetes for serving as the International Chairman of the Juvenile Diabetes Research Foundation. It has been my great pleasure to work very closely with her over the years. I admire her advocacy enormously, and we have a shared goal of finding a cure for this devastating disease. So Ms. Moore, it is a great honor to welcome you back today.

Next, we are going to hear from Adam Morrison, an all-American basketball player in college. Adam now plays for the Charlotte Bobcats and this past season finished second in scoring among all NBA rookies. He was diagnosed with type 1 diabetes when he was 14, and he is going to tell us about the special challenges he faces as he continues managing his diabetes while pursuing a successful professional basketball career. And I know that the children here

are going to be really interested because they are very active in sports, as well.

And last but certainly not least, we will hear from Dr. Griffin Rodgers, who is the Director of the National Institute of Diabetes and Digestive and Kidney Diseases at the NIH. Dr. Rodgers will highlight the advances and opportunities in research and will provide some examples of research that is supported by the Special Diabetes Program, and we are pleased to welcome you, as well.

It is my understanding that Senator Akaka has a brief opening statement that he wants to give, and I will call on Senator Tester, as well. Because the children are on a schedule, I will ask the statements to be brief. Senator Akaka.

OPENING STATEMENT OF SENATOR AKAKA

Senator AKAKA. Thank you very much, Madam Chairman, and I want to add my welcome to all of you, our witnesses, the parents who are here, and, of course, our distinguished young people who are here.

I really appreciate your coming here, and I also appreciate the leadership of Senator Collins, who for many years now has led this important effort here in the Senate.

Diabetes is a significant health problem in my home State of Hawaii. Many people like to think of Hawaii as a place where we don't have it, but we do. An estimated 100,000 people in Hawaii have diabetes. Diabetes is a disease that disproportionately affects Native Hawaiians, Pacific Islanders, and Asian Americans. Native Hawaiians, Japanese, and Filipino adults living in Hawaii are twice as likely to be diagnosed with diabetes as compared to Caucasian residents.

Diabetes is extremely difficult for patients to manage, as you well know. However, there are some promising research efforts underway, which we will learn more about today. We must continue to increase the funding for diabetes research to develop improved methods to treat, manage, and prevent diabetes. We must also enact meaningful stem cell legislation, as well, and we must allow researchers like Dr. Rodgers to be involved in ethical, federally funded research projects intended to help individuals suffering from a wide range of diseases, including diabetes.

I look forward to hearing the testimony from our witnesses today who will share their experiences of overcoming diabetes. I am pleased that one of my constituents is here with us today, and I would like to welcome her.

Natasha Garcia has been working with the Hawaii State Legislature on diabetes-related issues, and now she is here talking to the U.S. Senate about this disease. We are so happy to have you. Will you hold your hand up, Natasha? Thank you very much for being here.

And also, I want to say hello to your dad, Leo Garcia, who is in the audience. Leo, thank you very much for being here, and I was going to tell you, if you don't know who he is, look for the "aloha" shirt. [Laughter.]

The challenges faced by all of the children here remind us of the tremendous importance of our work here in Washington, DC.

I also want to thank our witnesses, Mary Tyler Moore, and the Juvenile Diabetes Research Foundation for all of their efforts to improve the lives of so many people.

In addition, I appreciate Adam Morrison for joining us today and serving as a role model for our children by overcoming the challenges presented by diabetes, as well as Dr. Rodgers. I want to wish you well in your efforts at NIH. As you know, we try very hard to make sure you are well funded. So thank you very much for being here.

Thank you, Madam Chairman. I ask that my full statement be included in the record.

[The prepared statement of Senator Akaka follows:]

OPENING STATEMENT OF SENATOR AKAKA

Mr. Chairman, thank you for conducting today's hearing on juvenile diabetes. I also appreciate the leadership that the Ranking Member, Senator Collins, has shown on this important issue.

Diabetes is a significant health problem in my home state of Hawaii. An estimated 100,000 people in Hawaii have diabetes. Diabetes is a disease that disproportionately affects Native Hawaiians, Pacific Islanders, and Asian Americans. Native Hawaiians, Japanese and Filipino adults living in Hawaii are twice as likely to be diagnosed with diabetes as compared to Caucasian residents.

Diabetes is extremely difficult for patients to manage. Taking insulin injections and carefully monitoring blood sugar levels are not easy tasks for both children and adults alike. Even with careful management, diabetes can contribute to significant health problems, such as heart disease, stroke, eye disease and blindness, kidney disease, and medical complications.

There are some promising research efforts underway, which we will learn more about today. We must continue to increase the funding for diabetes research to develop improved methods to treat, manage, and prevent diabetes. We must also enact meaningful stem cell legislation. We must allow researchers to be involved in ethical, federally funded research projects intended to help individuals suffering from a wide range of diseases, including diabetes.

Unfortunately, the President is expected to again veto the stem cell legislation. The President's restrictions on stem cell research prevent federal funds from being used for research on newer, more promising stem cell lines. This is critical because embryonic stem cell lines now eligible for federal funding are not genetically diverse enough to realize the full therapeutic potential of this research. The President's stem cell policy prevents researchers from moving ahead in an area of research that is very promising.

I look forward to hearing the testimony from witnesses today who will share their experiences of overcoming diabetes. I am pleased that one of my constituents is with us today. Natasha Garcia has been actively involved in advancing diabetes-related issues in the Hawaii State Legislature. I also am delighted that her father, Leonardo, is also here today. The challenges faced by all of the children here remind us of the tremendous importance of our work here in Washington.

I also want to thank Mary Tyler Moore and the Juvenile Diabetes Research Foundation for all of their efforts to improve the lives of so many people. In addition, I appreciate Adam Morrison for joining us today and serving as a role model for children by overcoming the challenges presented by diabetes.

Again, Mr. Chairman, thank you for conducting this important hearing. I look forward to continuing to work with all of you to improve the lives of individuals suffering from diabetes.

Senator COLLINS. Without objection. Senator Tester.

OPENING STATEMENT OF SENATOR TESTER

Senator TESTER. Thank you, Madam Chairman. I also would ask unanimous consent for my full statement to be put into the record.

Senator COLLINS. Without objection

Senator TESTER. I, too, want to thank all of you for being here today. Especially Dr. Rodgers for your work at the National Insti-

tutes of Health. It is critically important we give you the resources necessary so you can do the kind of research to help a lot of folks that are in this room here today.

Adam Morrison, the potential NBA star, if you are not already there, and a great player for Gonzaga, but few folks know that what really got him off on the right foot is he spent 6 years in Glendive, Montana. We really appreciate all you have done to set a role model example for everybody with diabetes.

And Mary Tyler Moore, somebody who I grew up watching on TV, I really appreciate all the work that you, too, have done for juvenile diabetes.

And for the young people who are here sitting in front and out in the audience, Allison Trent from Missoula, who is one of the folks here, I appreciate your coming today. I think it is incredibly important that we, as policy makers at the Federal level, do things to make sure that you have the best ability to achieve your hopes and dreams for the future.

Dealing with juvenile diabetes is something that a good, close personal friend of mine who I graduated from high school with was diagnosed with at the age of 12. When I talk to him, most of the time on a monthly basis, he is always asking me about how stem cell research is coming along, and I really think that drives it home for me that we need to take every avenue possible and fund every avenue possible so that our next generation, the reason I serve in the U.S. Senate, has the ability to succeed and make this country as great as it has been in the past.

With that, Madam Chairman, thank you very much.

[The prepared statement of Senator Tester follows:]

OPENING STATEMENT OF SENATOR TESTER

Mr. Chairman, this is a very important hearing. I am pleased that Adam Morrison is here today to talk about his own experience as a diabetic, NBA star and most importantly a native Montanan from Glendive!

As a rural state, Montana often finds itself on the fringes of access to information and support for numerous health care concerns, juvenile diabetes being one of them. I find it telling that while there are more than 53,000 people in Montana who have been diagnosed with diabetes and it is estimated that an equal number of folks across the state have undiagnosed diabetes, we have few statistics focused exclusively on juvenile diabetes. Even while we know that one out of every three children born since 2000 will develop diabetes during their lifetime, it is unclear how many of these will be diagnosed with juvenile diabetes.

Type 1 or juvenile diabetes is a chronic disease that poses challenges for every member of the family—the young person affected and his or her parents as well. Thanks to new and constantly improving treatment options, developed by some of the organizations here today, children can expect to lead a full and active life, despite needing to receive insulin injections multiple times a day in order to remain healthy.

When considering issues of access to health care in Montana, I always look to see how our Indian Health Service is able to serve the needs of the community, especially because the problem of diabetes is particularly acute among Native Americans.

Therefore I am sure you can understand why I was disappointed to learn that the president's budget for FY 2008 would have:

Maintained the same insufficient funding as FY 07 of \$150 million for the Indian Health Diabetes fund, down from the \$163 million granted in FY 06.

And barely increased the funding for the National Institute of Diabetes and Digestive and Kidney Diseases, from \$1.855 billion in FY 07 to \$1.858 billion for FY 08.

As of 2002, Montana has only 14 recognized diabetes education programs and 60 Certified Diabetes Educators spread across our great State. Access to treatment, education and resources is especially critical in rural areas where the number of

trained health professionals is significantly lower and spread-out than in most States.

I'm looking forward to hearing about what kinds of programs will be developed and offered to these families as a result of this partnership.

These kids and their families deserve to live full lives, so I'd like to know what you all are doing to follow up with folks after they hear about the kinds of support and treatment options that programs like yours open up.

Mr. Chairman, I've taken up far too much time. I yield back.

Senator COLLINS. Thank you.

Ms. Moore, if you would proceed with your statement.

**TESTIMONY OF MARY TYLER MOORE,¹ INTERNATIONAL
CHAIRMAN, JUVENILE DIABETES RESEARCH FOUNDATION**

Ms. MOORE. Senator Collins, Senator Lieberman, I want to say good morning and thank you for the opportunity to be here with you today, along with these wonderful children.

As I was preparing to come to Washington for Children's Congress and the hearing, I thought back to the very first Congress in 1999, and I will be honest with you—it was never my intention to appear before you 8 years later, still talking about the need to push forward aggressively on research toward a cure for type 1 diabetes.

The good news is that we are making real progress on the research front. Progress resulting from the strong public-private partnership between JDRF and the Federal Government. Progress that is impacting many people with diabetes in a positive way right now.

The bad news is that, for me and the children in this room, every day living with diabetes is a day closer to the serious complications from this disease. For me personally, diabetes has taken quite a toll. As you may know, I have been battling the disease for almost 40 years. That is, every minute of every day for 40 years. That is a long time to be constantly counting, measuring, calculating, and hoping that all I am doing to stay in good control actually works, because, you see, keeping your blood sugar in normal range when you have diabetes is difficult, even for those who are most diligent. I lost count long ago of the number of fingerpricks and shots that I have self-administered, as well as the hypoglycemia episodes that all who suffer from diabetes fear.

All of us know that our hope of a cure lies in medical research, and that is why we all work hard to raise the dollars to support the best science. Yet the pace of research can be frustrating. It takes a long time to build the knowledge base, test various theories in the lab, build the necessary infrastructure, before we even reach the point of beginning clinical research. But once we reach that point, testing new therapies in people, the research accelerates. That is when hope becomes tangible, not simply an idea to hold onto.

In type 1 diabetes research, this is happening. We have entered a time of opportunity, when the pace of translating knowledge into benefits to patients will be determined by the strength of our public-private partnership.

We are taking on this challenge, and we need the Federal Government to do the same. Next year, JDRF will fund approximately

¹The prepared statement of Ms. Moore appears in the appendix on page 32.

\$170 million of research, more in a single year than any time in our history and nearly three times as much as we were funding in 1999. But more exciting than the dollar amount is the type of research we are funding. In the last fiscal year, JDRF launched eight new clinical trials, bringing our total of active trials to 29, compared with five at the start of the year 2000.

And the Federal Government, through your leadership Senator Collins, has provided critical support as well through the Special Diabetes Program. This program was created in 1997 because Congress recognized that funding for type 1 diabetes needed to be increased significantly to capitalize on the opportunities that existed at that time. It reflects the decisions of policy makers to undertake a highly targeted, innovative, and clinically oriented approach to research on type 1 diabetes and its complications.

As a result, the funds provided through this program have been deployed in a different manner than usually is the case. By all measures, the program is working and has delivered real results. It is an example of how medical research should be funded at the Federal level.

That is why Congress has renewed the program twice, and the funding has risen to the current level of \$150 million per year. The program has become a key component in the Federal Government's focus on type 1 diabetes research, and it provides approximately 35 percent of all Federal support for type 1 research.

The Special Diabetes Program has primarily supported unique collaborative research consortia and clinical trial networks focused on type 1 diabetes and its complications. Without support by this program, these innovative and critically important efforts either could not have been undertaken at all or not funded at a significantly optimal scale of operation.

Think about what this means in human terms. Today, there are approximately 60,000 people participating in clinical research directly supported by this program. These are people whose lives are being impacted in a positive way. And because of this investment, the research is setting the stage for millions of others to benefit.

We finally reached the bedside in our push from the laboratory bench. We must sustain this forward momentum and not allow ourselves to slip back. But this critical cure-enabling program is now set to expire, so we are asking Congress to again recognize its effectiveness and importance. Extend it for an additional 5 years and increase the funding to \$200 million per year.

Let me give you some concrete examples of research progress made possible by this strong public-private partnership between JDRF and the Federal Government. A new drug has been shown in human clinical trials to stabilize or reverse the immune attack of type 1 diabetes and, for the first time, provides evidence that the clinical course of the disease can be altered long-term. These trials are underway involving newly diagnosed children.

Drugs originally designed for use in cancer therapy are being repositioned to treat people with both type 1 and type 2 diabetes who suffer from diabetic eye disease, the leading cause of blindness in working-age adults. Results have been very promising.

Advances in medical technology for continuous glucose monitoring have brought the field closer to realizing an artificial pan-

creas that could function much like a normal pancreas. A number of companies have continuous glucose sensors on the market, and people who are using them are able to achieve much tighter control of their blood glucose levels.

The day we were diagnosed, we made a promise along with our parents, brothers, sisters, spouses, and loved ones to do whatever we could to help accelerate a cure. We are here today to advocate for ourselves and to ask you to make a promise to each of us, a promise to prevent a reduction of 35 percent in Federal support for type 1 diabetes research and to work hard to increase funding.

Some of the young children I met during the first Children's Congress in 1999 have since gone on to college, away from their families and support systems, bringing their diabetes and the challenges that go along with it with them. They are actively living their lives, pursuing their dreams, and doing what they can every minute of every day to keep themselves healthy.

When you hear from some of the child delegates in a few minutes, you will see that they are very brave and are facing their diabetes with the knowledge that they need to do whatever is in their power to help, and they are. As many of you know, we are a very determined bunch! We don't ask others to do what we haven't already challenged ourselves to do. We are here to remind you of the urgency of your efforts to increase research dollars and to show that we will continue to do our part to remain your partner. I am here to ask you to look into the eyes of these beautiful kids and show them through your actions that you care about their future.

I thank you so much for this opportunity, but more importantly, I thank you for all that you have done and that you will continue to do to help those living with type 1 diabetes. Together, I know we will get to our shared goal of a cure.

Senator COLLINS. Thank you very much for your eloquent testimony.

[Applause.]

You can see why Mary Tyler Moore is such a powerful advocate, and I am so honored that once again she has started our hearing off. So thank you for being here.

Mr. Morrison.

TESTIMONY OF ADAM MORRISON,¹ NATIONAL BASKETBALL ASSOCIATION PLAYER, CHARLOTTE BOBCATS

Mr. MORRISON. Good morning. It is an honor to be here today to appear before this Committee to tell you about the ways juvenile diabetes has affected my life and the need to fund research so we can find a cure as soon as possible.

First, I want to thank you, Senator Collins, for chairing today's hearing and your ongoing leadership in the Senate Diabetes Caucus.

As you well know, my name is Adam Morrison. Basketball has always been a part of my life. I have been shooting hoops since I was 13 months old. My dad, John Morrison, coached college basketball in Wyoming, South Dakota, and Montana. Now I am a professional basketball player with the Charlotte Bobcats of the National

¹The prepared statement of Mr. Morrison appears in the Appendix on page 35.

Basketball Association. I was drafted in 2006 after playing 3 years at Gonzaga University in Spokane, Washington. I love playing basketball. The game takes determination, focus, and discipline. In fact, diabetes has just made me more determined to make it in the NBA.

I was diagnosed with type 1 diabetes when I was 14. My mom and dad knew that there was something wrong when I lost 30 pounds in one month, and let's just say I wasn't very big. When I was out at basketball camp at Gonzaga, I started noticing the symptoms. I felt very sick, dizzy, and tired. I scored four points in 3 days. I couldn't do anything. I was taken to the hospital, where I stayed for 3 days. It was hard at first to understand what was happening to my body, to know that I would be living with diabetes for the rest of my life. The first time the nurse came in to give me a shot of insulin, I told her that I wanted to do it myself because I felt like it was part of what I needed to do.

I was fortunate to be surrounded by people who gave me positive encouragement right from the first day of my diagnosis. My endocrinologist, Dr. Ken Cathcart, came into my room at the hospital and looked me right in the eye and told me that I was going to be OK and I could do anything with my life. Having diabetes was not going to stop me from dreaming big dreams. Then I just went back to being a normal kid and playing basketball. I didn't want to miss any time on the court.

In my senior year of high school in Spokane, I broke single-season and career scoring records in my high school conference and led my school to the finals of the State tournament.

Before I went on to the NBA, I was lucky to have the opportunity to reach out to other people with diabetes, like Chris Dudley, who played in the National Basketball Association for 14 years. Chris told me that, short of a cure, the one thing he wished for was to play one game where he didn't have to focus on his diabetes. That is true for me, too.

I test my blood glucose levels every day and several times during games. I wonder if it is too low. It is always on my mind. I have to stay really disciplined to keep it all together when I play basketball. For example, I wait exactly 2 hours and 15 minutes before tip-off and eat two five-ounce steaks, a vegetable, and a baked potato. It is the same meal before every game so that I can keep my glucose levels as balanced as possible.

When I am not playing basketball, I wear an insulin pump that attaches to a small catheter in my abdomen, and like all the kids in this room, I have to stick my finger to test my blood glucose level anywhere from 10 to 12 times every day. We all have to calculate the number of carbohydrates we eat, the amount of exercise we get, and the insulin we need to take to keep our blood sugar level in the normal range.

I look around this room and I see kids who are at the age that I was when I was diagnosed. It is when my life changed. It seemed like it just happened overnight, and then it changed forever. Our diabetes is with us every day of our lives. It never goes away, and we never get a time out.

I want to be a role model for people with diabetes and show the 150 kids that are sitting here today that you can still do what you

want to do. You can still be successful and have diabetes. It is a disease that you can't see, but you still have to be careful or you will have complications. You have to have determination. You have to continue to dream big dreams, but follow your doctor's advice and stay healthy.

To the Senators in this room, I want to ask you to do everything in your power to help us find a cure by funding the best research that we possibly can have in this country. The insulin we take is not a cure, but simply a life support. We must continue to strive for a cure.

Congress can and must reauthorize and fund the Special Diabetes Program that gives us all hope. We must allow scientists to take full advantage of the research opportunities that currently exist that may lead to new treatments and a cure. Have the determination, focus, and discipline for a win here today. Please fund diabetes research. It is life or death for many of us.

Thank you for the opportunity to speak today.

Senator COLLINS. Thank you very much, Mr. Morrison.

[Applause.]

Thank you for your testimony. Basketball happens to be my favorite sport, so I don't know whether that is why JDRF chose you to come here today, but they clearly chose very well, and I appreciate your being here.

I suspect that a lot of the children who are here today play sports. If you play a sport, put up your hand.

[Show of hands.]

Wow. That is great. That is terrific. Well, you have just heard that sports are good for you and it is something that you can do.

Dr. Rodgers, we are delighted to have you here today, as well. Please proceed.

TESTIMONY OF GRIFFIN P. RODGERS, M.D., M.A.C.P.,¹ DIRECTOR, NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES, NATIONAL INSTITUTES OF HEALTH, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Dr. RODGERS. Thank you, Senator Collins and Members of the Committee. Good morning. Thank you for the invitation to testify today about type 1 diabetes.

And as the newly appointed Director of the National Institute of Diabetes and Digestive and Kidney Diseases, I am pleased to provide you with some brief highlights of the formal testimony, which I have submitted for the record.

But before I begin, let me acknowledge your leadership, Senator Collins, in really focusing attention on type 1 diabetes research, which is benefiting every child here today.

Now, in response to the Committee's request, I am pleased to highlight some of the research advances and opportunities made possible by the Special Statutory Funding Program for Type 1 Diabetes Research.

This program is administered by our Institute on behalf of the Secretary of Health and Human Services. It involves numerous other components of the National Institutes of Health, as well as

¹The prepared statement of Dr. Rodgers appears in the Appendix on page 37.

the Centers for Disease Control and Prevention and patient advocacy groups. The Juvenile Diabetes Research Foundation International, in particular, is an important partner in our research efforts to prevent and to ultimately cure type 1 diabetes.

Type 1 diabetes is an autoimmune disease in which the body's own immune system attacks and destroys insulin-producing beta cells in the pancreas. I provided with my testimony two handouts. I have shown on the first handout that it is a slowly progressive disease.¹ In genetically susceptible individuals, an inciting event such as some as yet unknown environmental trigger, leads to the immune system's destruction of these insulin-producing beta cells. The beta cells may be destroyed over the course of months or perhaps years before patients lose their ability to make sufficient insulin to regulate blood sugar levels. This loss is depicted by diabetes onset on that figure. When diagnosed, patients require insulin administration to live, and over time, patients can go on to develop disease complications that affect their eyes, their hearts, their nerves, and other organs throughout the body.

The Special Diabetes Program supports a multi-pronged research effort to study every aspect and every step of type 1 diabetes progression that is depicted. For example, we are searching for genetic factors and environmental triggers of the disease, disease prevention strategies, new ways to slow or stop disease progression in newly diagnosed patients, innovative approaches to disease management, novel strategies to prevent and to treat complications, and ways to cure the disease by cell replacement therapy.

Our efforts are already paying off with improvements in the lives of type 1 diabetes patients. For example, recent data have demonstrated that patients are living longer, healthier lives than ever before. We have evidence that prevention efforts are reducing the rate of diabetic kidney disease. A long-term study has shown that intensive therapy to control blood sugar levels in patients not only dramatically reduces the risk of complications involving the kidneys, the nerves, and the eyes, but it also reduces the risk of heart disease. New continuous glucose monitoring technologies are making it easier for patients to control their blood sugar levels, which as I mentioned is key to preventing these disease complications.

Now, as shown in that second handout, there are three new minimally invasive continuous glucose monitoring devices that have recently been approved or are currently undergoing approval processes by the Food and Drug Administration.¹ One of these devices was recently approved for use in children.

The progress I have highlighted demonstrates how research is leading to tangible improvements in health and quality of life, but it really is imperative that we build upon these advances to further benefit the children here today and all the other people with type 1 diabetes.

I am pleased to report that we are poised for even more achievements with the launch of numerous long-term, high-impact, collaborative research efforts to combat type 1 diabetes and its complications. These efforts receive support from the Special Statutory Funding Program for Type 1 Diabetes Research.

¹The documents submitted by Dr. Rodgers appear in the Appendix on page 30.

For example, one long-term, large-scale, and bold undertaking is called The Environmental Determinants of Diabetes in the Young (TEDDY). This study is currently enrolling newborns and following them until the age of 15 years in order to identify environmental triggers of the disease. TEDDY is the only study in the world that has the significant statistical power to give us this information. If we determine, for example, that it is a virus, or a component of food, or some other environmental trigger of disease, this knowledge would be critically important and could revolutionize our ability to prevent type 1 diabetes. Just as past long-term NIH investments in research have improved patient care, we are extremely optimistic that the long-term investment in TEDDY could result in a major breakthrough in our understanding of how type 1 diabetes develops.

Through networks supported by the Special Diabetes Program, the NIH has also recently launched new clinical trials to test therapies to prevent type 1 diabetes or to stop the progression of the disease in patients who have been recently diagnosed. These networks are critically important for testing emerging therapies for disease prevention and early treatment. The program has also enabled the creation of a research pipeline that is propelling progress in drug development for diabetes complications. This pipeline includes basic research in the laboratory, pre-clinical research in animal models, and clinical trials in people.

Research is also ongoing to find ways to replace insulin-producing beta cells that have been destroyed by immune system attack—by transplantation or through other means, such as regeneration. Cell replacement therapy can potentially be a real cure for this disease.

Together, these and other efforts are attacking the disease at all stages to bring the maximum benefit to the people at risk or who already are diagnosed with type 1 diabetes.

Thank you for this opportunity to provide these highlights of the advances and opportunities supported by the Special Diabetes Program. The NIDDK looks forward to continuing to work with its collaborators and partners, such as the Juvenile Diabetes Research Foundation International, in order to achieve our common goal of preventing and curing type 1 diabetes. Improving the lives of all people with this disease, including the children here today, continues to be the motivation behind our efforts.

I am pleased to answer any questions that you may have, and thank you again for inviting me.

Senator COLLINS. Thank you very much, Doctor.

[Applause.]

Thank you. We appreciate your update on the research.

Senator Levin just came in. He is chairing a Committee hearing elsewhere. He has asked that I express his commitment to you and also I will put his statement in the hearing record.

[The prepared statement of Senator Levin follows:]

OPENING STATEMENT OF SENATOR LEVIN

Good Morning. It's wonderful to see so many of our nation's children here today to take part in the Children's Congress.

It's particularly inspiring to see the self-confidence and courage these children possess in coming here this week to speak to all of us as educators, advocates, and leaders.

My name is Senator Carl Levin of Michigan, and I serve as Chairman of the Armed Services Committee and a Member of the Homeland Security and Governmental Affairs Committee.

I understand that there is a remarkable young man here from my home state, Tré Hawkins, who is going to share his story with us today.

Tré is the only child at his school in Detroit with Juvenile Diabetes, and since his diagnosis, he has gained the support of his school community where three teachers have taken classes on diabetes in case of an emergency and his peers know to give him only sugar-free snacks.

Because of Tré, his teachers, peers, and family have all learned about this disease and are now also prepared to help others afflicted with Juvenile Diabetes. I thank them for their efforts and commend Tré for his continued courage and advocacy.

Thank you all for coming here today and sharing your stories with us and leading us through this campaign to fund research that will help find a cure for Juvenile Diabetes.

Senator COLLINS. Dr. Rodgers, let me start with you. The Special Diabetes Program is currently authorized at \$150 million a year. It expires next year, and this program currently provides about 35 percent of all federally supported type 1 research. How important is it for Congress to renew this funding and increase it to \$200 million, as Mary Tyler Moore has suggested?

What would be the impact on diabetes research if this program were allowed to expire?

Dr. RODGERS. Expiration of this Special Funding Program would have a significant impact on what we do. We would have to eliminate or certainly greatly curtail many of our research initiatives currently supported by the program. These include research consortia and networks where we are on the threshold of realizing research advances from previous investments in these opportunities.

Therefore, I would say the scope and the pace of the research will have to be reduced. There is also going to be a loss of momentum in bringing the benefits of this research to the patients if this special funding isn't extended.

NIDDK is currently engaged in a process, together with a number of outside special experts, to understand what we would have to do in terms of prioritization of existing projects. Clearly, we will have to either greatly reduce, curtail, or substantially cut back on programs that are currently ongoing.

Senator COLLINS. And is it important to the research underway that the program be extended before it expires? I mean, you don't want to have a situation where you have to stop important research and then try to pick it up. Is it important that Congress act this year to prevent the program from expiring next year?

Dr. RODGERS. Thank you, Senator. If the program is extended this year as opposed to next year, that would greatly assist our planning and management strategies. For example, we are quite reluctant to start long-term projects, particularly clinical trials, when there is uncertainty about out-year funding.

Second, the general process at the NIH is that there is some lead time associated with the development of special research funding opportunities or awards, making announcements for these awards, having the proposals come in from the investigators, having those proposals reviewed by our so-called study sections, and then ultimately awarding them. Now, because that process is associated

with a lead time, having a seamless transition would make this much more effective.

Senator COLLINS. Thank you. Mary, you mentioned in your testimony that you have been dealing with the complications and the course of the disease for nearly 40 years. When you look at all the research that is underway, is there a particular advance that excites you the most?

Ms. MOORE. Well, yes. The test that shows that, no matter how long people have had diabetes, there is now reason to believe that the beta cells are still alive, some of them, and they can be stimulated to regenerate, to grow and produce insulin just like a healthy person's pancreas will.

That is really good for me because throughout these years that I have had diabetes, many things have begun to fail me. I have something called claudication in the legs, which means that the arteries, the veins are clogged and the blood can't get to them. This results in my not being able to walk for more than a block and a half without having to stop and overcome the pain. I was a dancer, and it is heartbreaking to have to deal with that. My vision is at a very low state. I can still get by, but boy, you should see my shins. They are so black and blue from bumping into things.

Senator COLLINS. Adam, you are a great role model to the children who are here today. You show them that you can be a world-class athlete despite having diabetes. Do you have any particular advice that you would like to give these children today?

Mr. MORRISON. Yes. I had the chance to speak to these delegates yesterday, and I will say it again to all these kids that what you are doing here in Washington is very special for you young kids. And what Dr. Rodgers and Mary are doing is great. And understand that, if you take care of yourself, you are going to be fine. You can do whatever you want, whether that is athletics or whatever you want to pursue your dreams in. I was told that when I was diagnosed, and so that is the message I want to send to all these young kids. Hopefully, with your help in Congress, we can find a cure in their lifetime and we won't have to have these meetings anymore. So thank you.

Senator COLLINS. Thank you.

Mary, the last Children's Congress—or actually I think it was the 2003 Congress, focused on the Pancreatic Islet Cell Transplantation Act. I introduced that bill, and thanks to the great grassroots efforts of JDRF, it was signed into law. Do you know where that research stands and how it is going? I am going to ask Dr. Rodgers, as well, but I would like—

Ms. MOORE. I think you should ask Dr. Rodgers—

Senator COLLINS. OK. [Laughter.]

Ms. MOORE [continuing]. But I know in broad strokes, it is going very well.

Senator COLLINS. Thank you. Dr. Rodgers, could you give us an update on that bill, because without the work of all the families who are in this room, we would not have gotten that bill signed into law, and it is an example where the grassroots efforts of JDRF have made such a difference.

Dr. RODGERS. You are absolutely right, Senator. Having this move forward really has made a tremendous difference. This legis-

lation gave credit to organ procurement organizations for pancreata used to procure islets for basic and clinical research. This incentive made it easier for islet processing sites to obtain pancreata for isolating islets.

We think the major benefit of this legislation will be realized when our Clinical Islet Transplantation Consortium begins islet transplantation protocols, which will involve over 150 patients. A large number of pancreata will be needed for these trials. The law is really critically important because it is allowing this to occur in a seamless manner. It has had a major benefit, and I applaud the effort in moving that forward.

Senator COLLINS. Thank you.

I am going to thank this panel of witnesses. There are many more questions that I could ask you, but I am very cognizant of the young people that we have with us today. So thank you so much for your eloquent and encouraging testimony. It has been a great honor to work with you, and I very much appreciate your being here today. Thank you.

[Applause.]

I am now going to call forward our next panel of witnesses this morning. It consists of children who know first-hand the burdens of living with diabetes.

Our witnesses on this panel are Caroline McEnery of Fairfield, Connecticut; Caitlin Crawford of Yarmouth, Maine; Tré Hawkins of Detroit, Michigan; and Abraham and Curtis Strader of Lakeville, Minnesota, who are accompanied by their mother, Ann.

All of the members of this panel are delegates to the Juvenile Diabetes Research Foundation Children's Congress and other delegates have obviously joined us in the well, as well, today.

I also want to recognize the other delegate from Maine who is here today. That is the Chairman's prerogative, the home State prerogative, and that is Aiden Sweeney, and Aiden and his mother testified a year ago at a hearing that we held to look at the progress we were making in producing an artificial pancreas.

So I want to thank you all for being here, and we are going to start with Caroline. Thank you, Caroline.

**TESTIMONY OF CAROLINE McENERY,¹ DELEGATE, AGE 17,
JDRF CHILDREN'S CONGRESS, FAIRFIELD, CONNECTICUT**

Ms. McENERY. Good morning, Senator Collins, Senator Lieberman, and Members of this Committee.

I would like to thank Senator Lieberman for all that he does to help us come closer to a cure. I am so proud to be from Connecticut and appreciate his commitment to advancing diabetes research.

Thank you for inviting me and the other kids on this panel to speak to you today. It is exciting and a little scary to be part of a congressional hearing, but I know that it is important for Congress to hear from kids who are living with type 1 diabetes every day, and I am thankful for this opportunity.

My name is Caroline McEnery, and I am 17 years old. I was diagnosed with juvenile diabetes when I was 9. Unlike most children with diabetes, I wasn't diagnosed by a doctor. I was diagnosed by

¹The prepared statement of Ms. McEnery appears in the Appendix on page 51.

my mom and dad. This is because diabetes is not a rarity in my family. My older sister, Caitlin, now 22, was diagnosed with diabetes when she was 3. As soon as I began to display symptoms, my parents knew exactly what was wrong with me. Their worst nightmare had come true. They now had two children living with this disease.

Finding out that I had diabetes was especially hard for me. I had watched my sister struggle with the disease for 9 years before I was diagnosed, and what I was about to endure was no surprise. I knew how demanding diabetes was and that it would be with me every second of every day until a cure is found. I knew that with each meal came a needle, with each birthday party, a sugar-free cake, and with each good night to my parents, the worry about a low blood sugar episode during the night. More than anything, I knew that I would be different than all of my friends.

I am lucky to have a family that already knew so much about diabetes at the time of my diagnosis. However, despite their knowledge, diabetes still takes a toll on all of us. My mom and dad have to get up in the middle of the night to check my blood sugar at 2 a.m. to make sure that I am not too high or too low in order to prevent seizures. If my blood sugar is too high before a family mealtime, everyone must wait to eat so that my insulin has time to work.

My diabetes and the vigilant scheduling that it requires is a burden on my entire family. No matter how hard we try to work around it, we can never avoid it.

Not a minute goes by when I forget that I have diabetes. My insulin pump is attached to me 24 hours a day, and until a cure is found, I will never get a break from it. Whether I am at home, at school, or on the volleyball court, I am always worrying about what my blood sugar is. As much as I try to hide having diabetes, it is inescapable. When I go out for ice cream with friends, it is never just ice cream to me. It is 40 grams of carbohydrates and four units of insulin.

There are days where I just want to give up on my diabetes, but I keep going. My strength for handling this challenging disease comes from the hope that someday soon, I will no longer have to.

When we were small, my sister and I shared a bedroom. At night, we would talk about things like Disney princesses, Barbie dolls, and what we wanted to be when we grew up. As we grew older, the topics ranged from boys and makeup to clothes and nail polish. However, after diabetes shattered our family for a second time, our late-night talks became an opportunity for us to voice our fears to one another about the burden of managing diabetes every day and the threat of complications that we both face in the future.

No matter how many times a day I check my blood sugar, change my pump site, exercise, or closely count carbohydrates, I still face the impending risks of blindness, heart disease, kidney disease, and nerve damage. Every year, I have an annual eye doctor appointment, not because I am near- or far-sighted, but to screen for complications of diabetes in my eyes. I dread this appointment because despite of all the work I do day in and day out to manage my diabetes, I still fear that every year will be the year they tell me I am going to begin to lose my sight because of my diabetes.

Researchers all over the world are working to find a cure, and I know that the funding Congress provides for research is helping and is resulting in exciting advances. One advance that is very real to me is the development of continuous glucose sensors that track a person's blood sugar level in almost real time and help them to stay in better control to reduce their risk for developing complications later in life.

At the beginning of this year, I began participating in a continuous glucose monitoring clinical trial. The CGM is a system that is built into my insulin pump. I wear a transmitter, which is connected to a wire probe and inserted under my skin. I have to change the second site every 3 days, in addition to my pump site, which I change every other day. The CGM gives me freedom, which I did not have before. I no longer worry about having a seizure during the night because my sensor will alert me before this happens. I can participate in sports with ease because I can see what my blood sugar is throughout my games.

Although the CGM has made my diabetes care much more manageable, it is certainly not a cure. I still have to test my blood sugar twice a day and calculate my insulin doses, and this trial requires that I visit the doctor every 2 weeks rather than every 3 months.

Congress must do its part, too, by making funding for diabetes research a priority. I would have given anything to shop for a junior prom dress like all of my classmates without thinking about how to incorporate an insulin pump hidden underneath. I am fortunate enough to remember what it was like to live a life without diabetes, and I hope that someday I can experience that again. I want to be able to tell my children about the day I was cured of juvenile diabetes, and it can't be done without you. Please help me, my sister, and the 3 million other Americans with juvenile diabetes be able to say, I used to have diabetes.

Senator COLLINS. Thank you very much, Caroline.

[Applause.]

Thank you. You did a great job. Caitlin from Yarmouth, Maine.

**TESTIMONY OF CAITLIN CRAWFORD,¹ DELEGATE, AGE 13,
JDRF CHILDREN'S CONGRESS, YARMOUTH, MAINE**

Ms. CRAWFORD. Hello. My name is Caitlin Crawford, and I am 13 years old, and I live in Yarmouth, Maine. Maine is a great place to live, and I feel so lucky to have you, Senator Collins, as my Senator. You do so much for people with diabetes, and you give us all so much hope. Thank you for that.

I was diagnosed with type 1 diabetes 22 months ago on August 19, 2005. That was the day my life changed forever. Unlike some of the kids in this room, I remember what life used to be like before I had diabetes, and I would give anything to go back to being a normal kid. Every day for the past 22 months, I test my blood sugar 10 to 12 times, take five to seven insulin shots, and worry all the time, especially when I close my eyes at night to go to bed.

I am a skier on the middle school team in Yarmouth, and in a lot of ways, the way I think about each ski race is how I think

¹The prepared statement of Ms. Crawford appears in the Appendix on page 53.

about my diabetes. I have been trained to go down the mountain, looking at each gate, attacking the hill, and crossing the finish line. In ski racing, the first gate is the hardest. As you push out of the starting block, everything has to be perfect.

This is just like getting up in the morning when you have diabetes. I really have to think ahead. How do I feel? How much exercise will I be doing today? What am I going to eat? How much insulin am I going to have to take today? I have to make sure that my bag is always full of the supplies that I need to carry me through the day. I do sometimes forget and pay the consequence later.

When you are racing, you never really hear the fans as you are speeding down the mountain, but you know they are supporting you and cheering you on. With diabetes, I need to rely on their support every day. My fans are my family, friends, coaches, doctors, and nurses.

My No. 1 fan is my family, and they are amazing. I have realized what they have had to give up to help me, especially my mother, who left her job when I was diagnosed. My brother, Wes, gives up a lot because of me. If I am not feeling well or my numbers are off, everything has to stop, and that means sometimes something he really wants to do. My dad is the rock. He picks us up on all of those hard days. My friends are there, but I always feel that I am different and not like them. I wish that I could just be like them, to be so carefree. My school nurse is also the best. She is always looking out for me so I can think about my studies.

When I ski, sometimes I slip and catch an edge, but I get back up and continue on. This is how I feel about diabetes. I have had some really bad lows and some really bad highs. I have watched a taxi drive away in New York City and realized in that cab was my diabetes bag, and we were 300 miles away from home. We got it back after a few stressful hours. Another time, I got stuck on a chairlift, and as I sat up in the air looking down, I realized that I did not have my diabetes supplies with me. After 40 minutes, I was still stuck, thinking that this could turn into something really bad soon.

Unlike ski racing, where each race has a beginning and an end, diabetes is always with me. I can never take a break. It is hard, and sometimes I just want to stop and take a break—stop testing my blood sugar, stop having to take insulin shots, stop counting all the carbs in my food, and stop worrying about what might happen to me all the time. But I know this isn't an option.

When I think about my future, I think about being the best skier I can be. I also think about what diabetes is doing to my body and that unless a cure is found, I might be facing serious complications.

I know that my hope for a cure lies in medical research. I am doing my part to keep myself healthy, and I am asking Congress to help by providing more funding for research. Progress is being made, but there is still more work to do. I will continue to do my part, participating in walks, speaking to friends, or just being a friend to a new diabetic. But time is not on my side, and we cannot do it without your help.

When I race, I wear the number 19 on my back, and when people hear, "Go Number 19," it is just not for me to ski faster. It is also

the day that my life changed forever. Thank you for listening to my story.

Senator COLLINS. Thank you very much, Caitlin.

[Applause.]

Good job. I can see why you are a good skier, as well, and you can count me as part of your team of fans.

Tré, thank you for being here.

**TESTIMONY OF TRÉ HAWKINS,¹ DELEGATE, AGE 12, JDRF
CHILDREN'S CONGRESS, DETROIT, MICHIGAN**

Mr. HAWKINS. Good morning. My name is Tré Hawkins, and I live in Detroit, Michigan. I am 12 years old. To you, I may look like a regular kid, but I was diagnosed with type 1 diabetes when I was 7 years old, and I have spent every day since then wanting to be a regular kid, free from diabetes.

It was my grandmother who recognized the symptoms. She was worried about my weight, my constant hunger and thirst, and about my going to the bathroom every 10 to 15 minutes. She took me to see the doctor, and they did a urine test, and my sugar level was very high. The doctor had her take me directly to Beaumont Hospital, and I stayed there for 3 or 4 days until they got my glucose level under control. At that time, I knew I was sick, but I didn't know how much my life was going to change.

It was difficult at first at school because my classmates didn't understand diabetes. My teachers were concerned about what to do if I became sick while at school. Three of my teachers took a weekend class to learn about diabetes and what to do if I became sick. They then had me talk to my classmates about diabetes, and now I have some playground buddies that look out for me at recess and know what to do if I get sick.

I know that I am lucky to have such good support at school. It is a little better now, but I still have trouble keeping my sugar level in the normal range during school because I have to count the carbs I eat and there are no labels on the food to tell me how many carbs are in what I am eating. When my sugar level goes too high or too low, I have trouble concentrating in class and I don't feel well.

This disease has been a financial burden on my grandparents and my mom, but they try hard to make my life as normal as possible and they don't complain. When you have type 1 diabetes, you have to take insulin every day and there are a lot of supplies that go along with it.

I am glad that you invited kids to talk to you about what it is like to have diabetes and why a cure is important to us. For me, a cure means being able to be a kid, to play baseball and ride my bike without fear of my blood sugar dropping too low. It means no more pricking my fingers at least five times a day. It means no more getting sick at school because my sugar level has gone too high. It means no more scheduling my eating and counting carbs. For me and the kids just like me, it means freedom, freedom to be just a kid.

¹The prepared statement of Mr. Hawkins appears in the Appendix on page 55.

Thank you for this opportunity to speak to you today, and thank you for listening. I am just a kid, but I have big dreams. Right now, my biggest dream is to be cured from diabetes. Please remember me—Tré Hawkins from Detroit, Michigan—and work hard to provide more money for diabetes research so this dream can become a reality.

Senator COLLINS. Thank you, Tré. Great job.

[Applause.]

Thank you, Tré. You did a terrific job.

We are now going to hear from Ann, who is going to speak on behalf of her sons.

TESTIMONY OF ANN STRADER,¹ MOTHER OF ABRAHAM AND CURTIS STRADER, DELEGATES, AGE 6, JDRF CHILDREN'S CONGRESS, LAKEVILLE, MINNESOTA

Ms. STRADER. Senator Collins and Senator Lieberman, thank you for holding this hearing and giving us the opportunity to share our stories with you. I am speaking today on behalf of my 6-year-old identical twin boys, Abraham and Curtis Strader, who both live with type 1 diabetes.

Raising twin boys lends itself to a lot of energy, enthusiasm, wrestling, and noise. Raising twin boys with diabetes requires constant management, daily care, and thousands of finger pokes.

I remember after Abe and Curt were born, we brought them home from the hospital. I would often sit in the glider in their nursery and just watch them sleep. They were absolutely precious. I felt a sense of joy that was accompanied by the overwhelming feeling of being their protector. I knew that my boys would be well loved, cared for, and that my husband and I would always keep our boys protected and safe. Then, just 2 years later, diabetes struck.

In 2003, when Abe and Curt were just 2 years old, both were diagnosed with diabetes in a span of 2 weeks. In that 2-week period, half our family had become diabetic. Neither my husband, Neil, nor I have a single case of type 1 diabetes in our extended families. We quickly learned the seriousness of diabetes and the importance of managing the disease in order to keep our boys healthy.

Children with diabetes typically have a shortened life expectancy and a higher risk of stroke, blindness, and kidney failure. All of those devastating eventual effects seem far off, but the one that always scares me the most is the fact that no one knows how low blood sugars affect brain development in young children like Abe and Curt.

With the diagnosis came the loss of predictability and stability. I took a leave from my job as a teacher to stay home and provide full-time care for my boys. I no longer could leave them with just someone who would provide care for them. I could only leave them with someone who knew how to check blood sugars, give insulin shots, count carbohydrates, document with detail, and identify symptoms of hypoglycemia and hyperglycemia. Of course, they must be able to give a glucagon shot in case my child were to become unconscious.

¹The prepared statement of Ms. Strader appears in the Appendix on page 56.

I remember when we were in the hospital with Abraham, and he would cry and cry when the nurse would come in to give him shots. He would scream, "Make her stop, Mommy. Make her stop." My heart was crushed. I was Abe's protector, and now this disease had made me helpless. I realized that soon I would be the one giving him shots that were causing him fear, pain, and anger. I have no choice but to do this. It is a matter of fact that without proper management and care, our children would die.

As a family, my husband and I have made a commitment to manage the disease so that the disease doesn't manage us. But most days, this is easier said than done. Abe and Curt are not able to consistently tell us when they feel like their blood sugar is high or low. It is a matter of constant testing. As parents, we have to try to judge if their behavior is related to blood sugars or are they just acting like regular kids.

Their blood sugars are impacted by food, exercise, anxiety, and their own growing bodies. Sometimes exercise will impact Abe and Curt immediately, and other times it will drop them low up to 12 hours later. It is this sort of unpredictability that keeps us getting up every night at all hours to check their blood sugar. I can't even begin to describe to you the worry that we have as parents that we carry around with us every day and night. Worry that we are not managing their diabetes as well as we should, worry that one of my boys will experience a low blood sugar episode in the night and not wake up in the morning, worry that as much as we try to allow them to be regular kids, diabetes is robbing them of their childhood, and worry about what having diabetes will mean for them as they grow older.

But this worry is nothing compared to what Abe and Curt go through every day. Neil and I have administered approximately 5,500 shots and 23,360 finger pricks to our boys in the past 4 years. For the first 2 years living with diabetes, my children received three to four insulin shots a day and we checked their blood sugar with a finger poke six to ten times around the clock. My husband remembers having to ask a neighbor to come over to help hold one of the boys down so he could administer a shot.

When Abe and Curt were 4 years old, they started wearing insulin pumps. We have experienced great relief from shots, but finger pokes are still constant. We have experienced tighter management, but high and low blood sugars are still a battle. A pump is a great management tool, but it is not a cure.

After the boys were diagnosed, my husband and I knew we had to make a choice. We could sit around and feel victimized, or we could become proactive in finding a cure for this disease. Over the past 4 years, we have actively raised money for JDRF through our local Walk For a Cure. Our family team, Team Twin Power, has raised over \$45,000, and I do all I can for JDRF in its mission for a cure. However, I know that no matter how much money our family or families like mine across the country raise, we need increased Federal support for diabetes research to get to our goal of finding a cure.

I am asking Congress—on behalf of Abe and Curt and the millions of kids who are living with type 1 diabetes—to increase Federal funding for diabetes research. Be our partner. Give Abe and

Curt the hope that a cure will be found in their lifetime. I promised my boys that I will do all I can to get to a cure as soon as possible. I am asking you to make the same promise to them.

I would like to share a few statements that Abe and Curt have made about living with diabetes and what they would like our lawmakers to know about living with this disease.

Abe has said, "I want to tell lawmakers we have to get a cure for diabetes so I wouldn't have to wear a pump all the time. I want them to know it hurts when my mom has to change my site. I would like to tell them that sometimes my blood sugar is low, and it makes me feel really dizzy and sick. It is hard to do my best work at school when I feel dizzy and sick."

And Curt says, "I want to tell people in Washington I don't like having diabetes. I have to wear a pump all the time or I would get really sick. One day, I threw up at school because my blood sugar was really high. I didn't feel well at all."

Abe and Curt have just finished kindergarten. They enjoy playing soccer, T-ball, and going to water parks. They don't know what life is like without a blood sugar meter, shots, a pump, and counting carbohydrates. I would give anything for them to know a future without diabetes.

This past December, my son Abe woke up on Christmas morning, and just like thousands of other kids, he could hardly wait to open gifts. He quickly ripped into a colorful box from his grandma. Inside the box, she had put a small Star Wars toy and several dollar bills for him to pick out something at the store. Abe quickly grabbed the toy and turned to me and said, "Wow, Mom. Look at all this money we can use to find a cure for diabetes."

It is not every 6-year-old who thinks about giving money to research. We all look forward to a day without diabetes.

Senator COLLINS. Thank you very much.

[Applause.]

Thank you. Do either Curtis or Abe want to say anything to us?

Curtis STRADER. Please promise to remember me.

Abraham STRADER. Please promise to remember me.

Senator COLLINS. I promise.

[Applause.]

Good job, boys. Thank you very much for your testimony.

Ann, let me start with my first question for you. First of all, I so admire your devotion to your children, but also your advocacy work. It seems to me that another advantage when you get involved in a group like JDRF is you meet other families who are coping with the same kinds of challenges that you are having. Has that been helpful to you as well from that perspective?

Ms. STRADER. I think it helps you to keep from feeling isolated, and to come here and see all these kids, I know for Abe and Curt, we don't know very many other children in our area that they are friends with that have diabetes, and so for them to come here and see all the kids in yellow shirts is helpful for them. I remember them looking at me and saying, "All these kids have diabetes?" and they couldn't believe it. It was very evident when we were standing to sing on the Capitol lawn and Abe found two other kids that have matching purple pumps with his and just how affirming that was for him that other kids deal with this day in and day out. It is a

great thing for families like ours to get involved with JDRF, and it helps to create awareness for other people, as well.

Senator COLLINS. Thank you.

Tré, I understand that you are interested in being a professional football player when you grow up, is that right?

Mr. HAWKINS. Yes. I want to be a running back.

Senator COLLINS. All right. So did it help you today to hear Adam's testimony? He is a professional athlete. Does that help to inspire you to achieve your goal, too?

Mr. HAWKINS. Yes.

Senator COLLINS. Did you know any other children who had juvenile diabetes at your school in Michigan?

Mr. HAWKINS. Nobody. I am the only one who has diabetes in my school.

Senator COLLINS. Is that hard for you?

Mr. HAWKINS. Yes.

Senator COLLINS. I bet it is, but it sounds like you have got some good buddies that help you, is that right?

Mr. HAWKINS. Yes, I do.

Senator COLLINS. So that must be a help.

Caitlin, what about you? Was it hard to tell your friends about your diabetes?

Ms. CRAWFORD. It kind of was because no one really knows what it is. There are only five of us in our whole town, and four of them are all in the high school. I am the only one in the middle school. So no one really had any idea, but no one really treats me any differently.

Senator COLLINS. That is great. So your friends help you, also. And it sounds like you have a great school nurse who helps, as well. That must be a plus for you, too.

And Caroline, you told us about the clinical trial that you are part of, the continuous glucose monitor. How did you find out about this clinical trial?

Ms. MCENERY. Well, one of the doctors at the Yale Diabetes Program told me about it, and I was really interested in becoming a participant, so I called the woman who was running it and then I started.

Senator COLLINS. That is great. That is not only going to help you, but by your participating in this clinical trial, you will help all these other children who might benefit from that kind of monitor in the future. So I think you should feel really good about that.

Ms. MCENERY. Yes, I do.

Senator COLLINS. That is great.

Caitlin, when you found out that you had diabetes, were you worried that you might not be able to be on the ski team anymore?

Ms. CRAWFORD. Well, I knew my uncle had diabetes, but I didn't really know what it meant. I didn't really think much about skiing at the time. I was just thinking, am I going to be OK? I was kind of nervous at first starting again because I wasn't sure what was going to happen with sports now. But sports are a big part of my life. I do lacrosse in the spring, and I do soccer in the spring, and I do skiing, both Nordic and downhill, in the winter, and then I do soccer in the fall, so it helps maintain my blood level.

Senator COLLINS. That is wonderful. I think it is just great that you have kept all that up.

I do want to thank all of you for being here today. You remind of us how important the mission is for us to renew the Special Diabetes Program and increase the funding from \$150 million to \$200 million.

And I want to tell all of the children who are here today that you have a special assignment, OK. Here is your assignment. It is a little bit like homework, but it is more fun. Your assignment is to go see your Members of Congress or your Senators and tell them that we need more money for research. Will you do that for me?

CHORUS. Yes.

Senator COLLINS. Good because, you know, if you go and talk to them, I will tell you, we will get the job done.

All of you have asked that I remember you, and I just wanted to say to all the children who are here today that I promise to remember each and every one of you and to work for the funding that will produce better treatments, but most importantly, that will point the way to a cure.

So thank you so much for coming all the way from your home States to be with us today. You remind us of what this is all about, and you inspire us to continue to fight for the money for diabetes research. So thank you so much for being here today.

I want to thank JDRF for doing just a wonderful job and Mary Tyler Moore, who is such an inspiring international chairman and who has helped advance the public's understanding of this terrible disease. I want to thank all of you who have come from all around the country.

I want to thank Larry Soler, who we work so closely with and does such a fabulous job for JDRF.

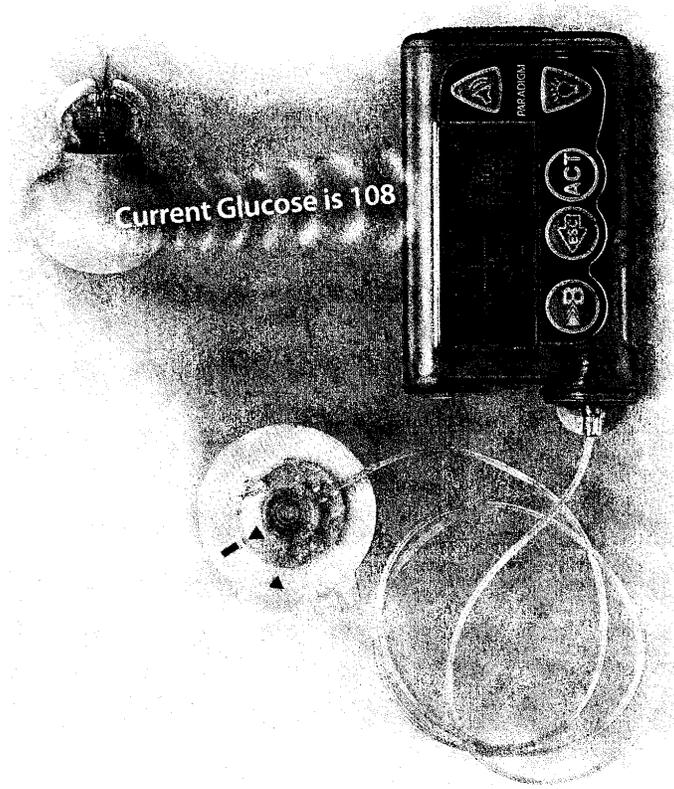
I also want to thank Priscilla Hanley on my staff. She has worked with me for years, and she has adopted this as her personal cause, as well as mine.

So thank you all for teaching us so much today, for putting a human face, such wonderful human faces, on this disease and for inspiring us to fight for a cure. Thank you.

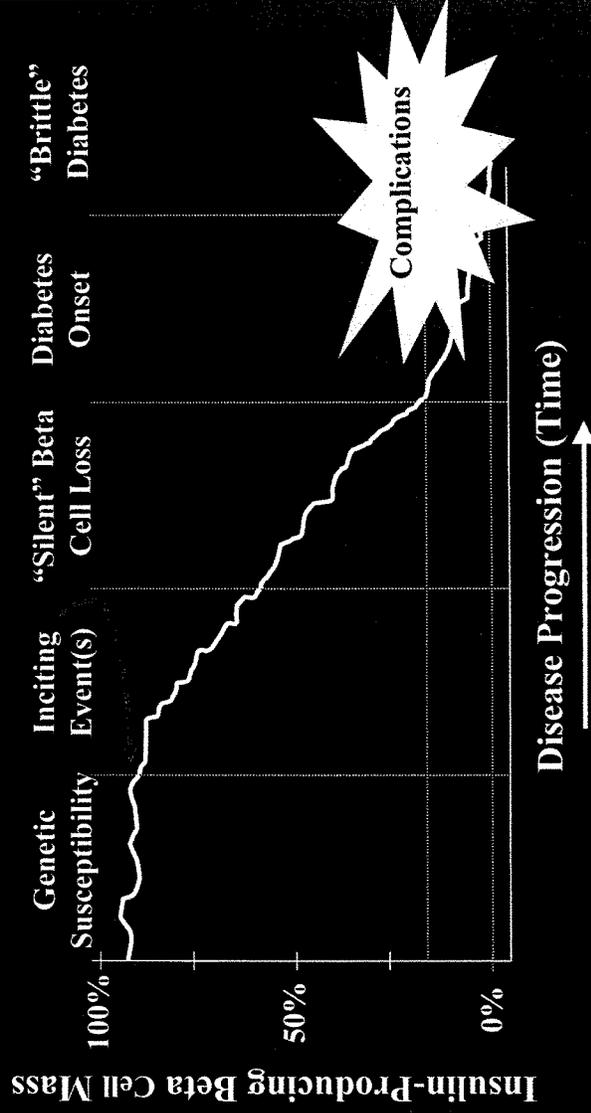
The hearing record will remain open for 15 days for additional materials, and this hearing is now adjourned. Thank you.

[Whereupon, at 11:07 a.m, the Committee was adjourned.]

APPENDIX



Type 1 Diabetes: A Slowly Progressive Autoimmune Illness

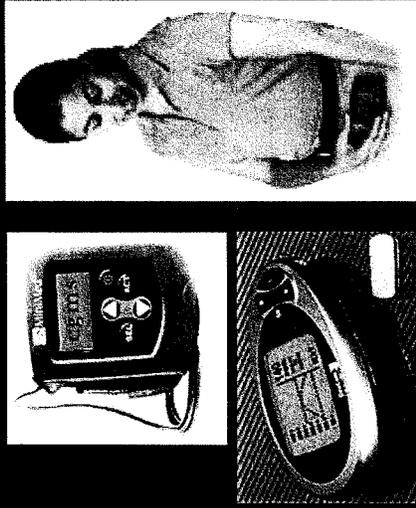


Continuous Glucose Monitoring

For every 1 percent fall in HbA1c—a measure reflecting a patient's blood glucose control for the preceding two to three months—there is a 37 percent reduction in eye, kidney, and nerve complications

Tight glucose control cuts heart disease in half in patients with type 1 diabetes

Only about 44 percent of people with diabetes achieve recommended glucose control with current technology and medications



Continuous glucose monitors facilitate tight control of blood glucose levels

**Testimony of Ms. Mary Tyler Moore
International Chairman, Juvenile Diabetes Research Foundation**

Good morning Senator Lieberman, Senator Collins and members of this Committee. Thank you for the opportunity to be here with you today along with all of these wonderful children.

As I was preparing to come to Washington for Children's Congress and this hearing, I thought back to the first Children's Congress in 1999. I will be honest with you, it was never my intention to appear before you eight years later-- still talking about the need to push forward aggressively on research towards a cure for type 1 diabetes. The good news is that we are making real progress on the research front. Progress resulting from the strong public-private partnership between JDRF and the federal government. Progress that is impacting many people with diabetes in a positive way right now. The bad news is that for me and the children in this room, every day living with diabetes is a day closer to the serious complications from this disease.

For me personally, diabetes has taken quite a toll. As you may know, I have been battling diabetes for almost 40 years – that is every minute of every day for 40 years. That is a long time to be constantly counting, measuring, calculating, and hoping that all I am doing to stay in good control actually works. Because you see, keeping your blood sugar in normal range when you have diabetes is difficult even for those who are most diligent. I lost count long ago of the number of finger pricks and shots that I have self administered, as well as the hypoglycemia episodes that all who suffer from diabetes fear.

All of us know that our hope of a cure lies in medical research, and that is why we all work hard to raise the dollars that support the best science. Yet the pace of research can be frustrating – it takes a long time to build the knowledge base, test various theories in the lab, build the necessary infrastructure before we even reach the point of beginning clinical research. But once we reach that point – testing new therapies in people – the research accelerates and that is when hope becomes tangible, not simply an idea to hold onto.

In type 1 diabetes research, this is happening. We have entered a time of opportunity when the pace of translating knowledge into benefits to patients will be determined by the strength of our public-private partnership. JDRF – our tens of thousands of volunteers around the country – are taking on this challenge and we need the federal government to do the same. Next year, JDRF will fund approximately \$170 million dollars of research – more in a single year than anytime in our history and nearly three times as much as we were funding in 1999. But more exciting than the dollar amount is the type of research these dollars are supporting. In the last fiscal year, JDRF launched eight new clinical trials, bringing our total of active trials to 29—compared with five at the start of 2000.

And the federal government – through your leadership, Senator Collins – has provided increased support as well through the Special Diabetes Program. This program was created in 1997 because Congress recognized that funding for type 1 diabetes needed to be increased significantly to capitalize on the opportunities that existed at that time. It reflects the decisions of public policy makers to undertake a highly targeted, innovative,

and clinically-oriented approach to research on type 1 diabetes and its complications. As a result, the funds provided through this program have been deployed in a different manner than regularly-appropriated NIH funds. And by all measures, the program has worked and has delivered real results. In many ways, it is an example of how medical research should be funded at the federal level. That is why Congress has renewed the program twice and the funding has risen to the current level of \$150 million per year. The program has become a key component in the federal government's focus on type 1 diabetes research, and it provides approximately 35% of all federal support for type 1 research.

The Special Diabetes Program has primarily supported unique, collaborative research consortia and clinical trials networks focused on type 1 diabetes and its complications. Without support by this program, these innovative and critically important efforts either could not have been undertaken at all, or not funded at a scientifically optimal scale of operation. Think about what this means, in human terms -- today there are approximately 60,000 people participating in clinical research directly supported by this program. These are people whose lives are being impacted in a positive way -- today -- because of this investment, and this research is setting the stage for millions of others to benefit. We have finally reached the bedside in our push from the laboratory bench. We must sustain this forward momentum and not allow ourselves to slip back.

But this critical, cure-enabling program is now set to expire. So we are asking Congress to, again: recognize its effectiveness and importance; extend it for an additional five years, and; increase the funding to \$200 million per year.

Let me give you some concrete examples of research progress made possible by this strong public-private partnership between JDRF and the federal government:

- A new drug has shown in human clinical trials to stabilize or reverse the immune attack of type 1 diabetes and -- for the first time -- provides evidence that the clinical course of the disease can be altered long-term. These trials are underway involving newly diagnosed children.
- Drugs originally designed for use in cancer therapy are being repositioned to treat both type 1 and type 2 diabetes patients with diabetic eye disease -- the leading cause of blindness in working age adults. Results have been very promising.
- Advances in mechanical technology for continuous glucose monitoring have brought the field closer to realizing an 'artificial pancreas' that could function much like a normal pancreas. A number of companies have continuous glucose sensors on the market and people who are using them are able to achieve much tighter control of their blood glucose levels.

We are not here to complain. The day we were diagnosed we made a promise -- along with our parents, brothers, sisters, spouses, and loved ones -- to do whatever we could to help accelerate our timeline to a cure. We are here today to advocate for ourselves and to ask you to make a promise to each of us. A promise to prevent a reduction of 35% in

federal support for type 1 diabetes research and to work hard to increase funding. Some of the young children I met during the first Children's Congress in 1999 have since gone off to college – away from their families and support systems, bringing their diabetes – and the challenges that go along with it -- with them. They are actively living their lives, pursuing their dreams, and doing what they can every minute of every day to keep themselves healthy.

When you hear from some of the child delegates in a few minutes, you will see that they are very brave and are facing their diabetes with the knowledge that they need to do whatever is in their power to help. And they are. As many of you know, we are a very determined bunch! We don't ask others to do what we haven't already challenged ourselves to do first.

We are here to remind you of the urgency of your efforts to increase research dollars and to show you that we will continue to do our part to remain your partner. I am here to ask you to look into the eyes of these beautiful, children and to show them – through your actions -- that you care about their future.

Thank you so much for this opportunity, but more importantly, thank you for all that you have done and all that you will continue to do for all of us living with type 1 diabetes. Together, I know that we will get to our shared goal of a cure.

**Testimony of Mr. Adam Morrison
NBA Player, Charlotte Bobcats**

Good morning. It's an honor to be here today to appear before this committee to tell you about the ways juvenile diabetes has affected my life and the need to fund research so that we can find a cure as soon as possible. First, I want to thank you, Senator Collins, for chairing today's hearing and for your ongoing leadership in the Senate Diabetes Caucus.

My name is Adam Morrison. Basketball has always been a part of my life. I've been "shooting hoops" since I was 13 months old.....it is in my blood. My Dad, John Morrison, coached college basketball in Wyoming, South Dakota, and Montana. Now I am a professional basketball player with the Charlotte Bobcats of the National Basketball Association. I was drafted in 2006 after playing for three years at Gonzaga University in Spokane, Washington.

I love being on the court. The game takes determination, focus, and discipline. In fact, having diabetes just made me more determined than ever to accomplish my dreams of playing in the NBA.

I was diagnosed with type 1 diabetes when I was 14 years old. My Mom and Dad knew that something was wrong when I lost 30 pounds in a month. When I was at a basketball camp at Gonzaga during this time, I felt sick, dizzy, and exhausted. I scored 4 points in three days, I couldn't do anything. I was taken to the hospital where I stayed for three days. It was hard at first to understand what was happening to my body, to know that I would be living with diabetes for the rest of my life. When the nurse came in to give me my first shot of insulin, I figured that I needed to step it up. I told the nurse that "Since I'm going to be doing this the rest of my life, you might as well show me how to do it." Diabetes is now simply just a part of who I am, plain and simple.

I was fortunate to be surrounded by people who gave me positive encouragement right from the first day of my diagnosis. My endocrinologist, Dr. Ken Cathcart, came into my room at the hospital and looked me right in the eye...and told me that I was going to be O.K., and that I could do anything I wanted to in life. Having diabetes was not going to stop me from dreaming big dreams.

Then I just went back to playing basketball. I didn't want to miss any time on the court. In my senior year of high school in Spokane, I broke single-season and career scoring records in my high school conference and led my school to the finals of the state tournament.

Before I went to the NBA, I was lucky to have the opportunity to reach out to other people with diabetes like Chris Dudley, who played for the Portland Trail Blazers. Chris told me that "short of a cure, the one thing that I could wish for was to play one game where I didn't have to focus on my diabetes." It's true.

I test my blood glucose levels everyday, and several times during games. I wonder if it's too low. It is always on my mind. I have to stay really disciplined to keep it all together

when I play basketball. For example, I wait exactly until two hours and 15 minutes before tip off and eat two five-ounce steaks, a vegetable, and a baked potato. It is the same meal before every game so that I can keep my glucose levels as balanced as possible.

When I am not playing basketball, I wear an insulin pump that attaches to a small catheter in my abdomen. And, like all the kids in this room, I have to stick my finger to test my blood glucose level anywhere from 10 to 12 times a day. We all have to calculate the number of carbohydrates we eat, the amount of exercise we get, and the insulin we need to take to keep our blood sugar in a normal range.

I look around this room and I see kids who are at the age that I was when I was diagnosed. It is when my life changed, it seemed like it just happened overnight, and then it changed forever. Our diabetes is with us everyday of our lives. It never goes away. We never get a time out.

I want to be a role model for people with diabetes, and show the 150 kids that are sitting here today, that you can still do what you want to do; you can still be successful and have diabetes. It is a disease that you can't see, but still you have to be so careful or you will have complications. You have to have determination. You have to continue to dream big dreams but follow your doctor's advice and stay healthy.

To the Senators in this room, I want to ask you to do everything in your power to help us find a cure by funding the best research that we possibly can have in this country. The insulin that we take is not a cure, but simply a life support. We must continue to strive for a cure. Congress can and must reauthorize and fund the Special Diabetes Program that gives us all hope. We must allow scientists to take full advantage of the research opportunities that currently exist that may lead to new treatments and a cure. Have the determination, focus, and discipline for a win here today. Please fund diabetes research...it is life or death for so many of us.

Thank you for this opportunity to appear before you today.



**Testimony
Before the Committee on Homeland Security
and Governmental Affairs
United States Senate**

**Progress and Plans in Type 1 Diabetes
Research**

Statement of

Griffin P. Rodgers, M.D., M.A.C.P.

Director

*National Institute of Diabetes and Digestive and
Kidney Diseases*

National Institutes of Health

U.S. Department of Health and Human Services



**For Release on Delivery
Expected at 9:30 a.m.
Tuesday, June 19, 2007**

Chairman Lieberman and Members of the Committee, as the recently appointed Director of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), I appreciate the invitation to testify at this hearing on type 1 diabetes, entitled “The Juvenile Diabetes Research Foundation (JDRF) and the Federal Government: A Model Public-Private Partnership Accelerating Research Toward a Cure.” On behalf of the NIDDK and the other Institutes and Centers of the National Institutes of Health (NIH) within the U.S. Department of Health and Human Services (HHS), I am pleased to report that we are vigorously pursuing research on type 1 diabetes and its complications—along with the JDRF and other research partners with whom we share important goals. Such partnerships have helped to synergize and propel research to combat this disease. Through collaborative and well-coordinated research, we are gaining insights into the molecular mechanisms underlying disease development, testing promising therapies to prevent and treat the disease and its complications in people, and striving for a cure. Today, as requested by the Committee, I will discuss recent advances and future opportunities in type 1 diabetes research, including research supported by the Special Statutory Funding Program for Type 1 Diabetes Research. I will also address the Committee’s interest in our plans if the Special Diabetes Program is not renewed.

Type 1 diabetes strikes mainly in childhood and adolescence. It is an “autoimmune” disease, in which the body’s own immune system attacks and destroys the insulin-producing beta cells found in clusters called “islets” within the pancreas. To survive, people with type 1 diabetes require daily administration of insulin in the form of injections or via an insulin pump. They must also monitor their food intake and physical activity in order to manage the disease. Even with continuous and vigilant management, patients are still susceptible to developing serious, long-term complications that can damage the eyes, kidneys, nerves, heart, and other organs.

Today, I will be describing some of the strides forward that we have made with respect to improving the lives of people with type 1 diabetes. For example, continuous improvements in therapy, as a result of research, have contributed to recent findings that people with type 1 diabetes are living longer, healthier lives than ever before. Prevention efforts are reducing rates of diabetic kidney disease in people with type 1 diabetes. New continuous glucose monitoring technologies are helping patients control their blood glucose levels, which is key for preventing disease complications. Blood tests can predict the risk of developing the disease in relatives of people with type 1 diabetes; this knowledge has enabled the launch of clinical trials testing new prevention strategies. It is imperative to build on these successes and continue basic and clinical research to further improve patients' quality-of-life and to seek ways to prevent and cure the disease.

The NIH is focused on six broad goals in type 1 diabetes research, which are to: (1) understand the genetic and environmental causes of type 1 diabetes; (2) prevent or reverse the disease; (3) to develop cell replacement therapy as a cure; (4) prevent or reduce hypoglycemia (low blood sugar), which limits tight control of blood glucose; (5) prevent or reduce complications; and (6) attract new talent and apply new technologies to research. Through this multifaceted approach, we can obtain a comprehensive understanding of the disease process—the foundation for future advances in treatment, prevention, and approaches to a cure.

Relative to each of the six research goals, I would now like to highlight recent research progress, as well as ongoing efforts in unique, innovative, and collaborative research consortia and clinical trials networks. These efforts have involved not only partnerships among scientists with complementary expertise from multiple academic institutions, but also partnerships among many of the Institutes and Centers of the NIH, HHS's Centers for Disease Control and

Prevention (CDC), and patient-advocacy groups. JDRF has played an instrumental role in facilitating and in contributing support to many of these collaborative research endeavors. Most of these efforts are being pursued with some contribution under the Special Diabetes Program, about which you asked me to testify today.

Understanding the Genetic and Environmental Causes of Type 1 Diabetes

Type 1 diabetes is caused by a combination of genetic and environmental factors. We already know some of the major genes that predispose people to develop type 1 diabetes, and additional key genes have recently been identified. Further discovery of the genes involved in type 1 diabetes will provide new targets for prevention and therapy, as well as help us predict more accurately who will develop the disease. To this end, we established the "Type 1 Diabetes Genetics Consortium" to collect genetic material from 2,800 families with two or more siblings having type 1 diabetes. The Consortium has already recruited over 2,400 families for this study, and recruitment is ongoing. It also conducted one of the largest linkage studies ever performed for a common disease and found several genetic regions associated with type 1 diabetes risk, which researchers are further exploring.

We know much less about the environmental factors that trigger onset of type 1 diabetes in genetically-susceptible individuals. To address this question, an international consortium is identifying infants at high-risk for developing type 1 diabetes and following them through adolescence to search for environmental factors that may trigger disease. This long-term, NIDDK-led study, called "The Environmental Determinants of Diabetes in the Young," or "TEDDY," has enrolled over 3,000 newborns, and recruitment is ongoing. This study is making significant progress toward amassing the largest data set and samples on newborns at-risk for autoimmunity

and type 1 diabetes anywhere in the world. To maximize the return on the investment in TEDDY, samples from the study will be made widely available to researchers worldwide. Importantly, TEDDY may also contribute to understanding the development of celiac disease, which is an autoimmune disease primarily affecting the gastrointestinal tract. Some genes confer susceptibility to both celiac disease and type 1 diabetes, and many people have both diseases. Thus, TEDDY may not only benefit people with, or at-risk for, type 1 diabetes, but it can also benefit people with celiac disease and other autoimmune diseases. NIH's National Institute of Child Health and Human Development (NICHD) leads another effort, called the "Trial to Reduce IDDM [insulin-dependent diabetes mellitus] in the Genetically At Risk," or "TRIGR," which is examining a specific environmental factor, cow's milk, in development of type 1 diabetes.

We are learning, for the first time, how many children in the U.S. have type 1 and type 2 diabetes. The Search for Diabetes in Youth Study, which is supported by CDC and NIDDK, has reported the first national data on the prevalence of diabetes in youth: one of every 523 youth had physician-diagnosed diabetes in 2001. Now that this baseline assessment of diabetes rates in children nationwide has been completed, the study is poised to evaluate trends in diabetes incidence and progression over time.

Preventing or Reversing Type 1 Diabetes

To spur the testing of promising new strategies to prevent, delay, or reverse progression of type 1 diabetes, the NIDDK leads a clinical trials network, the Type 1 Diabetes TrialNet. Several clinical trials are under way. For example, TrialNet recently launched a trial to test whether oral insulin administration can prevent type 1 diabetes in a subset of people who have high levels of a certain disease marker—anti-insulin antibodies. TrialNet also launched a trial to

determine if a drug, called rituximab, could prevent further insulin-producing beta cell destruction in people newly-diagnosed with type 1 diabetes. The TrialNet infrastructure is critically important for testing emerging therapies for disease prevention and early treatment.

The Immune Tolerance Network (ITN), led by NIH's National Institute of Allergy and Infectious Diseases (NIAID), is conducting several clinical trials to test therapies to reverse disease in newly-diagnosed patients with type 1 diabetes. For example, ITN is testing an agent, called anti-CD3, which has shown promising results with respect to halting disease progression.

Research is also ongoing to image pancreatic beta cells in order to monitor type 1 diabetes disease progression and response to therapy. Toward this goal, researchers recently used imaging technology to visualize both normal beta cells and transplanted islets *in vivo* in rat, mouse, pig, and baboon models of the disease. In one method, a compound that could be imaged was injected into the animal model, bound to a protein found in beta cells, and could be detected on an image of the pancreas. In another method, an iron compound was taken up into isolated islets prior to transplantation and was visible using magnetic resonance imaging (MRI) technology. The first approach permitted the researchers to noninvasively monitor beta cell destruction as the laboratory animal transitioned from a healthy to a disease state, and the second method showed where transplanted islets go and how long they live. Both approaches are being tried in type 1 diabetes patients. If successful, the approaches could be tremendously useful in monitoring disease progression and response to therapy. Finally, an MRI method has been developed that can visualize the inflammation associated with onset of type 1 diabetes. This approach is being investigated in animal models and newly-diagnosed patients.

Research is also ongoing to identify biomarkers of autoimmunity in type 1 diabetes. Biomarkers are measurable molecular, biological, or physical characteristics that indicate a

specific underlying physiologic state. Biomarkers are critically needed to predict disease risk, to monitor disease, and to monitor autoimmune responses during therapeutic intervention.

Developing Cell Replacement Therapy

Insulin therapy is a poor substitute for the body's exquisitely precise regulation of blood glucose by insulin-producing pancreatic beta cells. In contrast to insulin administration, a real cure could emerge from cell-based therapy, such as the transplantation of insulin-producing cells. Scientists participating in the Immune Tolerance Network successfully replicated the "Edmonton Protocol" for transplanting human pancreatic islets. The results showed that, a year after the final treatment, 44 percent of the transplant recipients no longer needed insulin injections. An additional 28 percent had partial islet function, which was associated with resolution of hypoglycemic unawareness (a condition in which people cannot recognize early symptoms of dangerously low blood glucose). Insulin independence did not persist indefinitely in most cases, and less than a third of the people who had been freed from insulin after one year remained so by two years. However, individuals with functioning islets had improved control of their type 1 diabetes, even though they still needed to take insulin injections. The results of this study extend the demonstration that islet transplantation may become an alternative to whole pancreas transplantation. They also highlight the continued need for safer, more tolerable anti-rejection therapies.

To further bolster research efforts on islet transplantation, the NIDDK and NIAID co-sponsor an ongoing Clinical Islet Transplantation Consortium. To expedite progress and promote safety in islet transplantation, an islet transplant registry publishes an annual report with comprehensive and current data on all islet transplants performed in North America.

A major barrier in the field of islet transplantation is an inadequate supply of islets. The NIDDK teamed with NIH's National Center for Research Resources (NCRR) and the JDRF to form Islet Cell Resource Centers, which provide human islets for both clinical transplantation and basic research studies. In addition, we are accelerating research on many aspects of beta cell development and function with the goal of increasing the supply of islets for transplantation. A key component of this effort is the NIDDK-sponsored Beta Cell Biology Consortium. Researchers in this Consortium have created numerous research tools, such as mouse models, antibodies, cell lines, and gene chips, that are not only propelling research progress within the Consortium, but are also accelerating research progress in the broad diabetes research community. For example, the Consortium developed "promoter" chips, which are available to the scientific community and contain over 35,000 regulatory regions on mouse DNA.

In addition, the NIAID leads a research consortium that is studying methods for transplanting islets from pigs to non-human primates. Xenotransplantation, which involves the transfer of cells, tissues, or organs from one species to another, may eventually help to alleviate the shortage of islets available for transplantation.

Another barrier that limits widespread use of islet transplantation is the lifelong immunosuppressive drug treatments that are required to prevent rejection of transplanted islets, as well as recurrence of the underlying autoimmunity that caused type 1 diabetes initially. Scientists are testing approaches to altering the immune system in human transplantation studies. These new approaches may be safer or have fewer side effects than the drugs currently used. Other efforts involve testing novel methods to induce immune tolerance after transplantation into non-human primates.

Researchers are also studying alternative strategies to restore beta cell mass and function. For example, research in beta cell regeneration is determining if adult beta cells could be coaxed to form more beta cells, or if other resident cell types could be directed toward a beta cell fate.

Preventing or Reducing Hypoglycemia in Type 1 Diabetes

Perhaps the most distressing, acute complication in people with type 1 diabetes is hypoglycemia. It is caused by excessive treatment with insulin relative to food intake and physical activity. The potential for hypoglycemic episodes has impeded the use of intensive insulin therapy even though major clinical trials have shown that such therapy can significantly reduce the risks of longer-term diabetic complications. A major goal of research is to “close the loop,” to link glucose monitoring and insulin delivery. Researchers are laying a foundation for an “artificial pancreas” that would mimic the body’s own insulin-sensing and insulin-delivery mechanisms. While not a cure, an artificial pancreas has the potential to significantly improve diabetes care and management and to alleviate a patient’s burden.

I am pleased to report that—with recent technological advances, many made possible by NIH-supported research in academia and industry—the first steps have been taken toward closing the loop. This progress has come in the form of new continuous glucose monitoring technologies. These devices have recently been approved for use in adults and children by the Food and Drug Administration (FDA) within HHS. They reveal the dynamic changes in blood glucose levels by assessing glucose levels hundreds of times per day and displaying trends so patients can see if their levels are rising or falling. Alarms warn the patient if blood glucose becomes too high or too low. This revolutionary technology can make it easier for patients to accurately determine how much insulin or food they need to keep blood glucose at healthy

levels, and it can enhance their ability to achieve the tight control necessary to prevent disease complications.

The NICHD leads a network, called "DirecNet," which has carried out several independent and scientifically rigorous studies to determine the benefit of new continuous glucose monitoring technologies. Using the new technologies, DirecNet researchers found, for example, that exercise much earlier in the day increases the risk of nocturnal drops in blood glucose. This finding resulted in the practical suggestion of increased bedtime snacks on days when children with type 1 diabetes are particularly physically active.

Preventing or Reducing the Complications of Type 1 Diabetes

The complications of diabetes affect virtually every system of the body; diabetes and its complications can shorten average life expectancy by up to 15 years. Recent studies have brought good news: people with type 1 diabetes are living longer and healthier lives than ever before. Data from Allegheny County, Pennsylvania, have shown that the long-term survival of children with type 1 diabetes has greatly improved over time. The prognosis continues to improve, with a reduced likelihood that kidney failure, diabetic nerve damage, and death will occur, as research has led to continuous improvements in therapy.

The NIH is fostering exciting new opportunities to intensify the study of diabetic complications. Because people with both type 1 and type 2 diabetes develop complications, research on the complications of type 1 diabetes can also benefit people with type 2 diabetes, and vice versa.

The landmark NIDDK-supported Diabetes Control and Complications Trial (DCCT) demonstrated that intensive control of blood glucose levels is extremely effective in preventing

complications affecting the eyes, kidneys, and nerves. Long-term results from the follow-on study to the DCCT now show that intensive therapy also dramatically reduces the risk of heart disease, which is the leading cause of death in people with diabetes. Results also showed that a finite period of good glucose control provides benefits years down the road. Thus, patients and physicians are advised to start intensive therapy as early as possible following diagnosis.

Recently-reported results have brought more good news for people with type 1 diabetes: recurrent episodes of severe hypoglycemia associated with intensive glucose control appear not to affect patients' long-term cognitive function. Even though the acute effects of hypoglycemia are very worrisome, this result is reassuring to patients and to parents of children with diabetes.

Prevention efforts are having dramatic and positive effects on rates of diabetic kidney disease in people with type 1 diabetes. The incidence rate of end-stage renal disease in Caucasians under 30 years of age with diabetes, most of whom have type 1 diabetes, is about half the rate seen in the late 1980s and early 1990s. Credit for recent gains likely goes to implementation of strategies to prevent kidney disease, including improved management of diabetes.

Type 1 and type 2 diabetes together are the leading cause of new blindness in people 20-74 years old. To combat this devastating complication, NIH's National Eye Institute supports the "Diabetic Retinopathy Clinical Research Network," which is conducting multiple protocols to identify new prevention and treatment strategies for diabetic eye disease.

In the area of diabetic foot ulcers, researchers found that a new technology, which measures the oxygenation of tissue surrounding the wound, could accurately predict whether a foot ulcer will heal. Based on these results, the FDA recently approved the new technology for use by healthcare providers. Because foot ulceration precedes the majority of lower-limb

amputations, finding new ways to predict healing could lead to personalized treatments to reduce the burden of this complication.

Development of animal models is key to preclinical drug development. Thus, another focus of research is a program to develop animal models that replicate development of diabetic complications in humans. This program has generated numerous promising models for studying complications involving the heart, kidneys, and nervous system.

In addition to clinical studies, basic research is under way to identify the genes that may increase a person's susceptibility to developing complications of diabetes. This knowledge can help predict which patients are prone to them, as well as illuminate new targets for prevention and therapy. It could also lead to personalized therapies for people who have a genetic susceptibility to developing certain complications. Researchers are also studying angiogenesis, or new blood vessel formation, as it relates to diabetic complications.

Attracting New Talent and Applying New Technologies to Research on Type 1 Diabetes

Type 1 diabetes research spans a broad range of scientific disciplines. For this reason, a cadre of exceptionally talented and dedicated researchers is needed to bring expertise to bear on scientific challenges. As research is being done in the laboratory, or at the "bench," there is a need to rapidly move those results to the clinic, or "bedside," to benefit patients directly. Thus, the NIH is sponsoring "bench-to-bedside" initiatives, in which teams of basic scientists and clinical researchers work together on translational research projects focused on type 1 diabetes. Researchers supported through this initiative have demonstrated in a mouse model of diabetes that the incidence of diabetes could be significantly delayed by using genetically-engineered cells expressing certain immunosuppressive molecules. Scientists have also demonstrated that

kidneys of diabetic mice have reduced levels of a protein that blocks blood vessel formation. These and other insights are increasing our understanding of type 1 diabetes and its complications, which is leading to new therapeutic targets and strategies.

Another important translational research effort is the Type 1 Diabetes-Rapid Access to Intervention Development (T1D-RAID) program. T1D-RAID has provided resources for preclinical development of several therapeutic agents that are being tested in clinical trials.

T1D-RAID and the other research consortia and networks that I have described feed into an integrated and comprehensive research pipeline. This pipeline facilitates research to: identify promising therapeutic targets and agents in the laboratory; generate animal models that mimic human type 1 diabetes and its complications; test promising agents in these animal models; and test promising therapies in people. An example of an agent that has moved through this research pipeline is called lisofylline. In a mouse model of type 1 diabetes, treatment with lisofylline after islet transplantation was shown to protect the animals from recurrence of the underlying autoimmunity that initially caused the disease. Because of these promising results, T1D-RAID manufactured lisofylline for testing in humans. The Clinical Islet Transplantation Consortium will soon be testing lisofylline in a human islet transplantation clinical trial. This is just one example of how the NIH not only supports the fundamental, basic research that leads to novel discoveries, but also supports a critically important research pipeline to translate promising results that could directly benefit patients.

Future Directions

Looking to the future, in order to inform the program-development process for NIH-supported type 1 diabetes research in the years ahead, the NIDDK spearheaded a strategic

planning effort under the aegis of the Diabetes Mellitus Interagency Coordinating Committee. This planning process culminated in the development of a Type 1 Diabetes Research Strategic Plan, which was released in August 2006. With extensive input from external scientific and lay experts, the Plan highlights recent advances in the field, and sets forth objectives for future research on type 1 diabetes and its complications.

The letter of invitation to this hearing asked me to address which programs and/or initiatives might be reduced or ended if the Special Diabetes Program is not renewed by Congress. Those decisions have not yet been made; however, we will continue to seek the advice of external scientific and lay experts in helping us to prioritize our efforts. One of our highest planning priorities is to maintain our commitment to clinical studies, which involve patient volunteers. Another priority is to maximize the Program's long-term investment in major research consortia and networks that are poised to make important research progress, or that are likely to produce discoveries that would be otherwise unattainable.

Conclusion

I am grateful for the opportunity to share with you these few examples of recent advances and ongoing research efforts. We continue to be inspired by the dedicated efforts of individuals affected by type 1 diabetes, and by organizations that represent them, such as the JDRF. We look forward to continuing to partner with the JDRF on research efforts to combat type 1 diabetes and its complications. We are grateful for the full range of support the NIH has received for type 1 diabetes research. We continue to be diligent in our fight against diabetes so that we can help all the children in this room and the many other Americans whom they represent here today. Improving their quality-of-life—with the ultimate goal of curing their disease—is the driving force behind our efforts.

I will be pleased to answer any questions you may have.

**Testimony of Ms. Caroline McEnergy
Fairfield, Connecticut**

Good morning Senator Collins and members of this Committee. Thank you for inviting me and the other kids on this panel to speak to you today. It is exciting – and a little scary – to be part of a Congressional hearing, but I know that it is important for Congress to hear from kids who are living with type 1 diabetes every day and I am thankful for this opportunity.

My name is Caroline McEnergy and I am 16 years old. I was diagnosed with juvenile diabetes when I was nine. Unlike most children with diabetes, I wasn't diagnosed by a doctor; I was diagnosed by my mom and dad. This is because diabetes is not a rarity in my family. My older sister, Caitlin, now 21, was diagnosed with diabetes when she was three. As soon as I began to display symptoms, my parents knew exactly what was wrong with me. Their worst nightmare had come true: they now had two children living with this disease.

Finding out that I had diabetes was especially hard for me. I had watched my sister struggle with the disease for nine years before I was diagnosed, and what I was about to endure was no surprise. I knew how demanding diabetes was, and that it would be with me every second of every day until a cure is found. I knew that with each meal came a needle, with each birthday party a sugar-free cake, and with each goodnight to my parents the worry about a low blood sugar episode during the night. More than anything, I knew I would be different than all my friends.

I am lucky to have a family that already knew so much about diabetes at the time of my diagnosis. However, despite their knowledge, diabetes still takes a toll on all of us. My mom and dad have to get up in the middle of the night to check my blood sugar at 2:00 a.m. to make sure that I am not too high or too low in order to prevent seizures. If my blood sugar is too high before a family meal time, everyone must wait to eat so that my insulin has time to work. My diabetes and the vigilant scheduling that it requires is a burden on my entire family. No matter how hard we try to work around it, we can never avoid it.

Not a minute goes by when I forget that I have diabetes. My insulin pump is attached to me 24 hours a day and until a cure is found I will never get a break from it. Whether I am at home, at school, or on the volleyball court I am always worrying about what my blood sugar is. As much as I try to hide having diabetes, it is inescapable. When I go out for ice cream with friends, it is never just ice cream to me; it's 40 grams of carbohydrates and 4 units of insulin. There are days where I just want to give up on my diabetes. But, I keep going. My strength for handling this challenging disease comes from the hope that someday soon I will no longer have to.

When we were small my sister and I shared a bedroom. At night, we would talk about things like Disney princesses, Barbie dolls, and what we wanted to be when we grew up. As we grew older, the topics ranged from boys and makeup to clothes and nail polish. However, after diabetes shattered our family for a second time our late night talks became an opportunity for us to voice our fears to one another about the burden of

managing diabetes every day and the threat of complications that we both face in the future. No matter how many times a day I check my blood sugar, change my pump site, exercise, or closely count carbohydrates, I still face the impending risks of blindness, heart disease, kidney disease, and nerve damage. Every year I have an annual eye doctor appointment; not because I am near or farsighted, but to screen for complications of diabetes in my eyes. I dread this appointment, because despite all of the work I do day in and day out to manage my diabetes, I still fear that every year will be the year they tell me I am going to begin to lose my sight because of my diabetes.

Researchers all over the world are working to find a cure, and I know that the funding Congress provides for research is helping and is resulting in exciting advances. One advance that is very real to me is the development of continuous glucose sensors that track a person's blood sugar level in almost real time and help them to stay in better control to reduce their risk for developing complications later in life. At the beginning of this year, I began participating in a Continuous Glucose Monitoring Sensor Clinical Trial. The CGM is a system that is built into my insulin pump. I wear a transmitter, which is connected to a wire probe and inserted under my skin. I have to change this second site every three days, in addition to my pump site which I change every other day. The CGM gives me freedom, which I did not have before. I no longer worry about having a seizure during the night, because my sensor will alert me before this happens. I can participate in sports with ease, because I can see what my blood sugar is throughout my games. Although the CGM has made my diabetes care much more manageable, it is certainly not a cure. I still have to test my blood sugar twice a day, and calculate my insulin doses. And this trial requires that I visit the doctor every two weeks, rather than every 3 months. Congress must do its part, too, by making funding for diabetes research a priority.

I would have given anything to shop for a junior prom dress like all my classmates, without thinking about how to incorporate an insulin pump hidden underneath. I am fortunate enough to remember what it was like to live a life without diabetes, and I hope that someday I can experience that again. I want to be able to tell my children about the day I was cured of juvenile diabetes, and it can't be done without you. Please help me, my sister, and the three million other Americans with juvenile diabetes be able to say "I used to have diabetes."

**Testimony of Ms. Caitlin Crawford
Yarmouth, Maine**

Hello! My name is Caitlin Crawford. I am 13 years old and I am from Yarmouth, Maine. Maine is a great place to live, and I feel so lucky to have you, Senator Collins, as my Senator. You do so much for people with diabetes and you give us all so much hope. Thank you for that.

I was diagnosed with type 1 diabetes 22 months ago on August 19th 2005. That was the day that my life changed forever. Unlike some of the kids in this room, I remember what life was like before diabetes, and I would give anything to go back to being a “normal” kid. Every day for the past 22 months I test my blood sugar 10 to 12 times, take 5 to 7 insulin shots and worry all the time, especially when I close my eyes at night to go to bed.

I am a skier on the Middle School Team in Yarmouth. And in a lot of ways, the way I think about each ski race is how I think about my diabetes. I have been trained to go down the mountain – looking at each gate – attacking the hill and crossing that finish line. In ski racing, the first gate is the hardest – as you push out of the starting block everything has to be perfect. This is just like getting up in the morning when you have diabetes – I really have to think ahead – how do I feel? How much exercise will I be doing today? What am I going to eat? How much insulin am I going to have to take today? I have to make sure that my bag is always full of the supplies that I need to carry me through the day. I do sometimes forget and pay the consequence later in the day.

When you are racing – you never really hear the fans as you are speeding down the mountain but you know they are supporting you and cheering you on. With diabetes, I need to rely on this support every day. My fans are my family, friends, coaches, doctors and nurses. My number one fan is my family and they are amazing. I have realized what they have had to give up to help me, especially my mother who left her job when I was diagnosed. My brother, Wes gives up a lot because of me. If I am not feeling well or my numbers are off – everything has to stop and that means sometimes something he really wants to do. My dad is the rock. He picks us all up on those hard days. My friends are there but I always feel that I am different and not like them – I wish that I could just be like them to be so carefree. My school nurse is the best also. She is always looking out for me so I can think about my studies.

When I ski, sometimes I slip and catch an edge, but I get back up and continue on. This is how I feel about diabetes. I have had some real bad lows and some real bad highs. I have watched a Taxi drive away in New York City and realized in that cab was my diabetes bag and we were 300 miles away from home. We got it back after a few stressful hours. Another time, I got stuck on a chair lift, and as I sat up in the air looking down I realized that I did not have my bag of diabetes supplies with me. After 40 minutes I was still stuck, thinking that this could turn into something really bad soon.

Unlike ski racing, where each race has a beginning and an end, diabetes is always with me. I can never take a break. It is hard and sometimes I just want to stop and take a break - stop testing my blood sugar, stop having to take insulin shots, stop counting all the carbs

in my food, and stop worrying about what might happen to me all the time. But I know this is not an option.

When I think about my future, I think about being the best skier I can be. I also think about what diabetes is doing to my body and that unless a cure is found I might be faced with serious complications. I know that my hope for a cure lies in medical research. I am doing my part to keep myself healthy, and I am asking Congress to help by providing more funding for research. Progress is being made, but there is more work to do. I will continue to do my part, participating in walks, speaking to friends or just being a friend to a new diabetic. But time is not on my side and we can't do it without your help.

When I race, I wear the number 19 on my back and when people hear "go #19!" – it is just not for me to ski faster – it's also the day my life changed forever.

Thank you for listening to my story.

**Testimony of Mr. Tre' Hawkins
Detroit, Michigan**

Good morning. My name is Tre' Hawkins and I live in Detroit, Michigan. I am 12 years old. To you, I many look like a regular kid. But I was diagnosed with type 1 diabetes when I was seven years old, and I have spent every day since then wanting to be a regular kid, free from diabetes.

It was my grandmother who recognized the symptoms. She was worried about my weight, my constant hunger and thirst, and about my going to the bathroom every 10 to 15 minutes. She took me to see the doctor and they did a urine test and my sugar level was very high. The doctor had her take me directly to Beaumont Hospital and I stayed there for three or four days until they got my glucose level under control. At that time I knew I was sick, but I didn't know how much my life was going to change.

It was difficult at first at school, because my classmates didn't understand diabetes. My teachers were concerned about what to do if I became sick while at school. Three of my teachers took a weekend class at the hospital to learn about diabetes and what to do if I became sick. They then had me talk to my classmates about diabetes and now I have some playground buddies that look out for me at recess and know what to do if I get sick. I know that I am lucky to have such good support at school.

It's a little better now, but I still have trouble keeping my sugar level in the normal range during school because I have to count the carbs I eat and there are no labels on the food to tell me how many carbs are in what I am eating. When my sugar level goes to high or too low I have trouble concentrating in class and I don't feel well.

This disease has been a financial burden on my grandparents and my mom, but they try hard to make my life as normal as possible and they don't complain. When you have type 1 diabetes, you have to take insulin every day and there are lots of supplies that go along with it.

I am glad that you invited kids to talk to you about what it's like to have diabetes and why a cure is important to us. For me, a cure means being able to be a kid – to play baseball and ride my bike without the fear of my blood sugar dropping too low. It means no more pricking my fingers at least five times a day. It means no more getting sick in school because my sugar level is too high. It means no more scheduling my eating and counting carbs. For me and the kids just like me, it means freedom. Freedom to just be a kid.

Thank you for this opportunity to speak to you today and thank you for listening. I am just a kid, but I have big dreams. Right now, my biggest dream is to be cured of diabetes. Please remember me – Tre' Hawkins from Detroit, Michigan – and work hard to provide more money for diabetes research so this dream can become a reality.

**Testimony of Mrs. Ann Strader
On behalf of Abraham and Curtis Strader
Lakeville, Minnesota**

Senator Collins and Senator Lieberman, thank you for holding this hearing and for giving us the opportunity to share our stories with you. I am speaking today on behalf of my six year old identical twin boys, Abraham and Curtis Strader, who both live with type 1 diabetes. Raising twin boys lends itself to a lot of energy, enthusiasm, wrestling, and noise. Raising twin boys with diabetes requires constant management, daily care, and thousands of finger pokes.

I remember after Abe and Curt were born, and we brought them home from the hospital, I would often sit in the glider in their nursery and just watch them sleep. They were absolutely precious. I felt a sense of joy that was accompanied by the overwhelming feeling of being their protector. I knew that my boys would be well loved, cared for, and that my husband and I would always keep our boys protected and safe. And then just two years later, diabetes struck.

In 2003, when Abe and Curt were just two years old, both were diagnosed with diabetes in a span of two weeks. In that two week period, half of our family had become diabetic. Neither my husband, Neil, nor I have a single case of type 1 diabetes in our extended families. We quickly learned the seriousness of diabetes and the importance of managing the disease in order to keep our kids healthy. Children with diabetes typically have a shortened life expectancy, a higher risk of stroke, blindness, and kidney failure. All of those devastating eventual effects seem far off, but the one that always scares me the most, is the fact that no one knows how low blood sugars effect brain development in young children like Abe and Curt.

With the diagnoses came the loss of predictability and stability. I took a leave from my job as a teacher to stay home and provide full time care for my boys. I no longer could leave them with just someone who would provide care for them. I could only leave them with someone who knew how to check blood sugars, give insulin shots, count carbohydrates, document with detail, and identify symptoms of hypoglycemia and hyperglycemia. Of course, they must be able to give a glucagon shot in case my child were to become unconscious.

I remember when we were in the hospital with Abraham, and he would cry and cry when the nurse came in to give him shots. He would scream, "Make her stop mommy, make her stop." My heart was crushed. I was Abe's protector and now this disease had made me helpless. I realized that soon it would be me giving him shots that were causing him fear, pain, and anger. I have no choice but to do this. It is a matter of fact that without proper management and care our children would die.

As a family, my husband and I have made the commitment to manage the disease so that the disease doesn't manage us. But most days this is easier said than done. Abe and Curt are not able to consistently tell us if they feel like their blood sugar is high or low. It is a matter of constant testing. As parents, we have to try and judge if their behavior is related to blood sugars or if they are just acting like a 'regular' kid. Their blood sugars are impacted by food, exercise, anxiety, and their growing bodies. Sometimes exercise

will impact Abe and Curt immediately and other times it will drop them low up to 12 hours later. It is this sort of unpredictability that keeps us getting up every night at all hours to check their blood sugars. I can't even begin to describe to you the worry that we – as parents – carry around with us every day and night. Worry that we are not managing their diabetes as well as we should. Worry that one of my boys will experience a low blood sugar episode in the night and not wake up in the morning. Worry that, as much as we try to allow them to be 'regular' kids, diabetes is robbing them of their childhood. And worry about what having diabetes will mean for them as they get older.

But this worry is nothing compared to what Abe and Curt go through every day. Neil and I have administered approximately 5,500 shots and 23,360 finger sticks to our two boys in the past four years. For the first two years living with diabetes my children each received 3 to 4 insulin shots a day and we checked their blood sugars with a finger poke 6 to 10 times a day around the clock. My husband remembers having to ask the neighbor to come over to help hold one of the boys while he would administer their shots. When Abe and Curt were four years old, they started wearing insulin pumps. We have experienced great relief from the shots, but the finger pokes are still a constant. We have experienced tighter management, but high and low blood sugars are still a battle. A pump is a great management tool, but it is not a cure.

After the boys were diagnosed, my husband and I knew we had a choice to make. We could sit around and feel victimized or we could become proactive in finding a cure for this disease. Over the past four years we have actively raised money for JDRF through our local Walk for a Cure. Our family team, "Twin Power" has raised over \$45,000 dollars. I do all I can for JDRF and its mission for a cure. However, I know that no matter how much money our family or families like mine across the country raise, we will need increased federal support for diabetes research to get to our goal of finding a cure. I am asking Congress – on behalf of Abe and Curt and the millions of kids who are living with type 1 diabetes – to increase federal funding for diabetes research. Be our partner. Give Abe and Curt the hope that a cure will be found in their lifetime. I promised my boys that I will do all I can to get to a cure as soon as possible. I am asking you to make the same promise to them.

I would like to share a few statements Abe and Curt have made about living with diabetes, and what they would like our lawmakers to know about this disease.

Says Abe, "I want to tell our lawmakers, we have to get a cure for diabetes, so I wouldn't have to wear a pump all the time. I want them to know it hurts when my mom has to change my site. I would tell them that sometimes my blood sugar is low and it makes me feel really dizzy and sick. It is really hard to do my best work at school when I feel dizzy and sick."

And says Curt, "I want to tell the people in Washington I don't like having diabetes. I have to wear a pump all the time or I would get really sick. One day I threw up at school because my blood sugar was really high. I didn't feel well at all."

Abe and Curt have just finished kindergarten. They enjoy playing soccer, T-ball, and going to water parks. They don't know what life is like without a blood sugar meter, shots, a pump, and counting carbohydrates. I would give anything for them to know a future without diabetes.

This past December, my son Abe woke up on Christmas morning, and just like thousands of other kids he could hardly wait to open gifts. He quickly ripped into a colorful box from his grandma. Inside the box, she had put a small Star Wars toy and several dollar bills for him to pick out something at the store. Abe quickly grabbed the toy and turned to me and said, "Wow mom, look at all this money we can use to find a cure for diabetes." It is not every six year old who thinks about giving money to research. We all look forward to a day without diabetes.

QUESTIONS SUBMITTED FOR THE RECORD
HEARING ON
"THE JUVENILE DIABETES RESEARCH FOUNDATION AND THE FEDERAL
GOVERNMENT: A MODEL PUBLIC-PRIVATE PARTNERSHIP ACCELERATING
RESEARCH TOWARD A CURE"
COMMITTEE ON HOMELAND SECURITY AND GOVERNMENTAL AFFAIRS
U.S. SENATE
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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Post-Hearing Questions for the Record
Submitted
From Senator Pete V. Domenici

Sen. Domenici: In the past 25 years, the number of people with diabetes has doubled, so that today approximately 21 million Americans have diabetes.

It has been nearly ten years since the research program was created. The prevention and treatment of diabetes has improved greatly over the past decade and I believe it is in large part due to the funding and research accomplished through the Special Type 1 Diabetes research program. Its reauthorization and continued funding is vital to the continuation of our fight against diabetes.

I believe that the Federal investment has produced tangible results in the research and treatment into diabetes. Can you comment on what the NIH has accomplished with this money that represents a strong return on the federal dollar?

Dr. Rodgers: The Special Funding Program has led to many scientific accomplishments and has contributed to improving the lives of type 1 diabetes patients. For example, because research has led to improvements in therapy, recent epidemiological data show that people with type 1 diabetes are living longer, healthier lives than ever before. Mortality at 20 years after diagnosis was reduced by 84 percent for those diagnosed in 1975–80, compared to those diagnosed in 1950–59. Data also suggest that prevention efforts are reducing rates of diabetic kidney disease in people with type 1 diabetes.

The Epidemiology of Diabetes Interventions and Complications (EDIC) Study, which was supported in part by the Special Diabetes Program, has shown that intensive blood glucose control reduces heart disease in people with type 1 diabetes. Heart disease is the leading cause of death in these patients. EDIC has also demonstrated long-term benefits of near-term blood glucose control with respect to preventing or delaying disease complications. This research has

transformed diabetes management, leading to the recommendation that type 1 diabetes patients begin intensive control as early and aggressively as possible.

Because tight glucose control is extremely important but difficult to achieve, the Special Diabetes Program also supports research to help patients manage their disease. The Special Diabetes Program helped the NIH to support the development of new continuous glucose monitoring technologies. These revolutionary technologies could help to improve patients' ability to control their blood glucose levels and to prevent devastating disease complications. Research is ongoing to "close the loop" to link glucose monitoring and insulin delivery. With support from the Special Diabetes Program, the Centers for Disease Control and Prevention's (CDC) Hemoglobin A1c Standardization Program is a key tool to enable translation of tight blood glucose control into common practice. The standardization effort has been a great success, and has facilitated vital, life-saving, and life-improving efforts for people with diabetes, such as the National Diabetes Education Program's campaign: "Control Your Diabetes for Life."

In addition to these and other scientific accomplishments, the Special Diabetes Program has enabled the creation of collaborative, large-scale research consortia and clinical trials networks that are working together to tackle high-risk, high-impact projects. These projects are focused on overcoming major barriers to research progress, as well as on developing key resources for use by the broad scientific community. For example, clinical trials networks have recently launched new trials to prevent the disease in at-risk individuals and to halt disease progression in newly-diagnosed patients. Research efforts to identify genetic causes and environmental factors of disease could illuminate new targets for prevention and therapy. Because many of these long-term efforts have only recently begun, their full impact will not be realized for many years. Thus, the scientific accomplishments to date are just the beginning of the gains that are expected in the future.

Sen. Domenici: Without renewal of the special funding, what types of projects are currently underway that would be ended or curtailed?

Dr. Rodgers: As we make contingency plans, we realize that adjustments to our programs will have to be made if the Special Diabetes Program is not renewed. Progression to full scale clinical trials from pilot studies currently under way in the Type 1 Diabetes TrialNet could be impacted. Another effort that may be scaled down is the Beta Cell Biology Consortium. This Consortium focuses on developing beta cell replacement therapy. It supports high impact research studies as well as generating numerous research resources, such as antibodies, mouse models, and microarray chips, that are being used by the broad scientific community and by scientists studying diabetes who use these key resources in their own research. Furthermore, the work by this group is important for both type 1 and type 2 diabetes, because understanding the beta cell is central to achieving progress in combating both forms of the disease. In addition, the activities of the Islet Cell Resource Centers that provide islets for use in both clinical islet transplantation and basic research studies could be adjusted. Hundreds of investigators have already received islets through this resource.

Another example of a program that could be modified is the Type 1 Diabetes-Rapid Access to Intervention Development (T1D-RAID) program. This program provides resources for pre-clinical development of agents to test in clinical trials, in order to promote bench-to-bedside

translation of promising agents. Some agents developed by T1D-RAID are moving into clinical trials.

These are just a few specific examples. In other areas, the scope and pace of research could be modified.

If the Special Diabetes Program is not extended, we will try our best to meet our commitments to the patients participating in clinical trials and clinical research studies, as well as to maximize our research investment to date. These types of long-term studies have yielded valuable knowledge that we want to maintain and build upon. We will continue to seek the advice of external scientific and lay experts to help us prioritize efforts and make alternative decisions. We are confident, however, that future NIH-supported investigator-initiated research will build upon the many scientific advances and resources that have been made possible by the Special Diabetes Program.

Sen. Domenici: If the program is reauthorized and the mandatory funding levels are increased from \$150 million per year to \$200 million per year, what will the NIH be able to accomplish with the additional funding?

Dr. Rodgers: With the current level of resources appropriated, NIH is supporting the highest priority research in this area. If the Special Diabetes Program were to be extended at \$200 million per year, the NIH could capitalize on scientific opportunities to launch new clinical trials to test novel strategies to prevent or treat type 1 diabetes. The NIH could also seize opportunities to bolster studies in the promising field of beta cell regeneration, which is relevant to both type 1 and type 2 diabetes. Furthermore, research could be intensified to understand the basis of autoimmunity, the destructive process that is central to type 1 diabetes. Such efforts would not only benefit people with type 1 diabetes, but also people with other autoimmune diseases. NIH could also continue to build upon recent progress with respect to imaging insulin-producing beta cells in the pancreatic islet. Currently, there is no way to detect the first signs of beta cell destruction or to monitor beta cell loss as the disease progresses. The ability to visualize beta cells could enable earlier intervention to stop or slow disease progression, as well as permit scientists to monitor response to therapy. In addition, new studies could be undertaken to address the burden of daily disease management that creates tremendous stresses for patients and their families. Opportunities exist to support research to study practical issues related to diabetes management, such as studies of how best to employ new monitoring technology to improve glucose control and behavioral research to improve patients' adherence to therapy.

The August 2006 Type 1 Diabetes Research Strategic Plan would serve as a scientific guide for future research efforts if the Special Diabetes Program were to be extended. The Plan was developed under the auspices of the statutory Diabetes Mellitus Interagency Coordinating Committee, with broad input from external scientific and lay experts. The NIH would continue to seek input from external experts to prioritize research efforts outlined in the Strategic Plan.