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JUVENILE DIABETES: EXAMINING THE PERSONAL TOLL ON FAMILIES, FINANCIAL COSTS TO THE FEDERAL HEALTH CARE SYSTEM, AND RESEARCH PROGRESS TOWARD A CURE

HEARING

BEFORE THE

COMMITTEE ON HOMELAND SECURITY AND GOVERNMENTAL AFFAIRS UNITED STATES SENATE

ONE HUNDRED NINTH CONGRESS

FIRST SESSION

JUNE 21, 2005

Printed for the use of the
Committee on Homeland Security and Governmental Affairs

U.S. GOVERNMENT PRINTING OFFICE

22–196 PDF WASHINGTON : 2006

For sale by the Superintendent of Documents, U.S. Government Printing Office
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JUVENILE DIABETES: EXAMINING THE PERSONAL TOLL ON FAMILIES, FINANCIAL COSTS TO THE FEDERAL HEALTH CARE SYSTEM, AND RESEARCH PROGRESS TOWARD A CURE

TUESDAY, JUNE 21, 2005

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

The Committee met, pursuant to notice, at 9:16 a.m., in room 216, Hart Senate Office Building, Hon. Susan M. Collins, Chairman of the Committee, presiding.

Present: Senators Collins, Lieberman, Akaka, Lautenberg, and Chafee.

OPENING STATEMENT OF CHAIRMAN COLLINS

Chairman COLLINS. Good morning, everyone, and a special good morning to all of the children who have joined us from all over the country who are here today. The hearing will now come to order.

As one of the Co-Chairs of the Juvenile Diabetes Research Foundation's 2005 Children's Congress, I am pleased and proud to hold this hearing to examine the devastating impact that juvenile diabetes has had on American children and their families. In addition to hearing this morning about the personal experiences of these young people, we also look forward to hearing about the research developments and breakthroughs in juvenile diabetes research that hold such a hope for better treatments and ultimately a cure.

This is the third Children's Congress hearing that I have had the honor to Chair. It has been a great privilege to work with Mary Tyler Moore, who has been the International Chairman of the Juvenile Diabetes Research Foundation (JDRF). The commitment of the JDRF to finding a cure is so inspiring.

I also want to welcome all of our distinguished witnesses, especially the 150 delegates to the Children's Congress who have traveled to Washington from every State in the country to tell Congress what it is like to have diabetes, just how serious it is, and how important it is for Congress to fund the research necessary to find a cure.

And I am particularly pleased to welcome the delegate from the great State of Maine. She is 11-year-old Stephanie Rothweiler of Falmouth. I met with her yesterday, and she is just terrific. You are all going to enjoy her testimony.

As the founder and the Co-Chair of the Senate Diabetes Caucus, I have learned a great deal during the past few years about this disease and the difficulties and heartbreak that it causes for so many American families as they 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. Health spending for people with diabetes is almost double what it would be if they did not suffer from the disease.

These statistics are truly overwhelming, but what really motivated me to devote so much energy to this cause was meeting more and more people like our delegates today and their families, whose lives have been forever changed by diabetes. In fact, it was a meeting that the JDRF set up for me in my very first year in the Senate that motivated me to found the Senate Diabetes Caucus.

I will never forget meeting in my Portland, Maine, office with a family who had a 10-year-old girl who had diabetes. She looked up at me and said that she wished she could just take one day off from having diabetes—her birthday or Christmas, just one day. And, of course, she can't. That made me feel that I had a special obligation to be her champion in Congress and to work for the research that one day will allow her to take days off from having diabetes.

The young people who are here today are so important. I want to tell all of you that, when you tell your stories to Members of Congress, we listen because you put the human face on this disease. You put the human face on all of those statistics. And you will help us focus on what Congress can do to better understand and to fund the research that will ultimately conquer juvenile diabetes.

In individuals with juvenile diabetes, the body's immune system attacks the pancreas and destroys the islet cells that produce insulin. An average child with Type 1 diabetes will have to take more than 50,000 insulin shots in a lifetime. Juvenile diabetes is the second most common chronic disease affecting children, and it is one that they never outgrow.

While discovery of insulin was a landmark breakthrough in the treatment of people with diabetes, it is not a cure. But there is good news on the horizon. Since I founded the Senate Diabetes Caucus in 1997, funding for diabetes research at the National Institutes of Health has more than tripled so that we are now spending more than $1 billion a year on this important research. And as a consequence, as a direct result of that investment, we have seen some encouraging breakthroughs, and we are on the threshold of a number of important new discoveries.

But now is not the time to take our foot off the accelerator. We must maintain our commitment to increasing funding for diabetes research so that we can take full advantage of these opportunities.

I am particularly excited about the promise that embryonic stem cell research holds for a cure for juvenile diabetes. Early research has shown that stem cells have the potential to develop into insulin-producing cells to replace those that have been destroyed in people with Type 1 diabetes. We simply cannot ignore the potential

that this research holds for the young people who are here with us today.

A major focus of the 2003 Children's Congress was the Pancreatic Islet Cell Transplantation Act, which I introduced to advance this important research. Thanks to the lobbying efforts of the JDRF children and their families, 52 Senators cosponsored that bill. And as further testimony to your powers of persuasion, it was passed unanimously by both the House and the Senate and signed into law by the President late last year. So just see what we can do when we all work together.

You are the very best advocates, and I am so pleased to have all of the children joining us today.

Senator Lieberman.

OPENING STATEMENT OF SENATOR LIEBERMAN

Senator LIEBERMAN. Thank you very much, Madam Chairman. Thanks for your leadership, which has really been life-enhancing and life-saving in this area.

Good morning, kids. How are you? It is not exactly summer camp here, is it? [Laughter.]

It is great to have you here. I thought when I walked in, if you would allow me to paraphrase Paul Revere, the red shirts are here and the gray shirts are here. [Laughter.]

But it is not the British that are coming, but this disease that has come and attacked us. You are here to make sure that we attack back and stop its movement forward. Plus, you are the best looking group of lobbyists that I have seen around Washington in a long time. [Laughter.]

Just by being here and telling your story, you are going to have an effect. I particularly thank all the witnesses for being here. I am proud that on the second panel, one of the witnesses is Ethan Falla of New Britain, Connecticut, 13. He is a member of his school Honor Society and is very active in sports. Senator Collins and I occasionally trade ethnic references, so I would like her to know that Ethan is an accomplished Irish dancer.

Chairman COLLINS. Great.

Senator LIEBERMAN. He thinks it would be cool, however, to be a mounted police officer, and I am sure he will do that and much more.

I just want to say a few words to add on to what Senator Collins said. The fact is that we live at an extraordinary time in human history. As a doctor said to me a while ago, we have learned more about the human body in the last 25 years than in all of history before that. It is amazing. And that knowledge that we have is already allowing us to treat—and if we work together will allow us to cure—diseases like diabetes and juvenile diabetes, that affect millions of people here in America and around the world. It began with DNA and the Human Genome Project and, of course, the extraordinary work that Senator Collins referred to that would hopefully go forward with embryonic stem cell research.

This is a disease that affects many people, but I want all of you to be optimistic that you are lucky enough to be alive at a time when we are going to be able to treat, and I want to stress again, cure these diseases if we just work together and put enough money

into the research to make it happen more quickly. It is within our reach.

I have been working on a proposal, which as soon as I get ready I am going to share with Senator Collins, because she and I have had a pretty good track record in getting things done around here—along with my colleagues on the Committee, Senator Akaka, Senator Lautenberg—a proposal that I am tentatively calling the National Center for Cures, which would be either alongside of or an independent part of the NIH. And the focus here is to make sure that we are not only investing, more money in basic research, as we are thanks to Senator Collins and others, but that we are also investing in a term I have learned—"transformational research."

Now, what does that mean? It is the research that is done to take the basic research that brilliant people are working on and to bring it to the medicine chest, to the bedside, to everybody's home. So it is not just fascinating research, but it is actually treatments and cures. That is the kind of coordinated effort I think we need, and it takes money to do it.

I close with a quote from Jonas Salk, developer of the polio vaccine. When I was a kid growing up, and that was so long ago that dinosaurs roamed the earth. [Laughter.]

Or at least it feels like that. But anyway, Salk was the developer of the polio vaccine, which affected so many people of my generation. Kids and parents lived in fear of the disease. Salk developed the vaccine and he said, "Our greatest responsibility is to be good ancestors." We don't think of ourselves that way. Those are words to live by, words to work by, and words to guide us as we move toward our goal of better treatments and, yes, cures for diabetes. We must be good ancestors, those of us up here, and those of you who will follow us. In the words of the Juvenile Diabetes Research Foundation International, "Let us be dedicated to finding a cure."

Thank you, Madam Chairman.

Chairman COLLINS. Thank you.

[Applause.]

Chairman COLLINS. Senator Akaka.

OPENING STATEMENT OF SENATOR AKAKA

Senator AKAKA. Thank you very much, Madam Chairman. Thank you for conducting today's hearing on juvenile diabetes.

I want to begin by using a word that is so well known in Hawaii, across the country, and around the world. I would like to hear a response from all of you young people and the audience, as well, and I want to begin by saying aloha.

Audience Response. Aloha.

Senator AKAKA. Thank you so much. In Hawaiian, "aloha" means love. And when I said aloha, I was telling you I love you. And when you said aloha, I know you didn't know—— [Laughter.]

But you are telling me that you love me, too. In this room, we are trying to see what we can do together.

So I am going to take the time to tell you how Hawaii has been affected by diabetes, as well as what we are doing here in Congress to help you.

Diabetes is a significant health problem in my home State of Hawaii. Do you know that an estimated 100,000 people in Hawaii have diabetes, according to the State Department of Health? And, the Hawaii Medical Service Association notes that approximately 2,300 people on the Island of Oahu alone have Type 1 diabetes. More than 900 people in Hawaii die every year of diabetes-related causes in Hawaii.

Diabetes is a disease that disproportionately affects Native Hawaiians and other Pacific Islanders. In fact, Native Hawaiians, Japanese, and Filipino adults living in Hawaii, are twice as likely to be diagnosed with diabetes as compared to other residents.

Diabetes is a disease that is extremely difficult for patients to manage, as you know very well. Taking insulin injections and carefully monitoring blood sugar levels are not easy tasks for 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 pregnancy complications. We must do more to increase funding for diabetes research and enact meaningful stem cell legislation to advance treatments and to make it easier to manage, treat, and prevent diabetes.

Though today's hearings focuses on juvenile diabetes, we are demonstrating our support for research to improve the treatment options available to all individuals suffering from both types of diabetes. Overall, we must continue to increase the funding for the National Institutes of Health.

I have been frustrated by the substantial slowing of the growth of the NIH budget over the past few years. I understand the tremendous importance of medical research to help alleviate suffering and improve the quality of life, and I will continue to support efforts to increase research funding substantially for NIH, especially for diabetes-related research.

Madam Chairman, like you, I am a cosponsor of S. 471, introduced by Senators Specter and Harkin, which would authorize Federal funding for research on stem cells derived from embryos donated from——

[Applause.]

Senator AKAKA [continuing]. Embryos donated from in vitro fertilization. I remain opposed to the President's stem cell policy, which prevents researchers from working on an area of research that is very promising and that could alleviate the pain and suffering of individuals.

I look forward to hearing the testimony of our witnesses today who will share their experiences of living with diabetes. I am especially pleased that one of my constituents, 13-year-old Dana Akiu, is visiting Capitol Hill today. She is sitting right in front of me here. Dana, despite having diabetes, plays soccer for Kamehameha Schools and the Real Hawaii Futbol Club. I welcome Dana, all of our young people, and the Juvenile Diabetes Research Foundation advocates who are in Washington today.

Again, Madam Chairman, thank you so much for conducting this important hearing, and I look forward to continuing to work with you and all of our colleagues to improve the lives of individuals who have diabetes. Thank you very much.

Chairman COLLINS. Thank you.

[Applause.]

Chairman COLLINS. I am going to ask, if you can, to refrain from clapping until we hear from the children's witnesses because we have a very short time this morning. The vote has been scheduled for 11 o'clock, so if I could ask that of you.

Senator Lautenberg.

OPENING STATEMENT OF SENATOR LAUTENBERG

Senator LAUTENBERG. Thank you, Madam Chairman. I don't take it as a direct response to the fact that I am about to speak, that the Chairman said don't clap. I might not have gotten any applause anyway. [Laughter.]

But I am so glad to see all of you here. I want to pay a compliment to Senator Collins because her early involvement in this fight against juvenile diabetes is well known. She sort of got the ball rolling here. All of us feel deeply about wanting to do something here, but Senator Collins really activated the activity of the response that you are seeing today.

And I want to thank Mary Tyler Moore and the rest of you on the witness stand for bringing this subject so much to the forefront. That is the only way we are going to get enough attention to this to move this process along.

Now, Senator Lieberman talked about things that might have happened when dinosaurs roamed the earth. Do you know what dinosaurs are? [Laughter.]

I grew up so long ago.

I want to congratulate Chairman Collins for the passage of pancreatic islet cell transplantation, which I was proud to cosponsor. The bill will make it easier for diabetes patients to receive this treatment, which has been described as the greatest advance in treating the disease since the discovery of insulin—a major step forward.

And I especially want to recognize those young people who come from New Jersey. Jimmy Babcock from Ringwood, Gabrielle Barton from West Windsor, Katrina Cruise from Clifton, Aaron and Shaynah Jones from Piscataway, and Sammy Rovins from Vorhee Estate are all here, and I am pleased to be in the same room with them. They are part of the courageous group that we see here today.

Now, I am a father of ten grandchildren. The oldest is 11, the youngest is a year and 3 months. Nothing concerns me more than the health of those children. I try to focus my activities here on things that are good for children's health and protection and better environment and protection against violence and protection against drunk drivers on the road. Anything that can protect young people, I support. And it is our job as Senators to give every child in America the best opportunity to realize their dreams.

When I look at these faces, it is an inspirational day, as opposed to looking at grumpy Senators that I see almost every morning. [Laughter.]

But we are pleased that you are all here. You look wonderful. We want you to feel as good as you look.

I don't know how anyone can look into the eyes of a child who has a disease like diabetes and say to them that we aren't doing everything in our power to find a cure. I am ashamed of that, and I wish that we could change things around. But that is exactly what some people are telling these young people and the half-a-million other Americans who live with juvenile diabetes.

Stem cell research can help us gain a better understanding of diabetes and other diseases that affect more than 100 million Americans—cancer, heart disease, Parkinson's, Alzheimer's—the diseases that afflict the young and the old. We can do something about these if we use the tools that we have at hand.

The time has come to expand the current policy on human embryonic stem cells so scientists and doctors in America can continue to make strides toward cures and treatments. That is what we want to do. Two years after the President announced his policy on stem cell research, only 19—and I don't want to confuse this with little details—stem cell lines, very few are available to be used by federally funded scientists, and all of these lines have already been contaminated and will never meet the standards required for human treatment. But they are there for experimentation and research.

The House of Representatives has voted to expand Federal funding for stem cell research. The Senate would support that, as well, but as you adults in the room, older people, have heard, we have had long debates about judges here and about what kind of a process we should use to move things along or not move them along.

Here, we have this program in front of us, and all it needs, very simply, is a vote in the U.S. Senate. There are 40 cosponsors of a bill that came from the House of Representatives that wants to make available stem cells to be used for research and funding to take care of the program. It is not a partisan issue, and I don't want to speak for any other Senator, but Republicans and Democrats are in favor of expanding stem cell research.

I asked our Majority Leader, who is a physician and a kind-hearted physician, someone who has flown to Africa to do heart work on people who normally wouldn't even have a doctor available, but he and we disagree on the process. I would urge him, and I would wish that he could walk in this room and look at your faces, and I guarantee you one thing. He would never say no in front of this audience, I promise you that. So I urge him, let the Senate vote on this issue.

I can't think of anything more important to these families, these children, or to the families of the millions of other Americans who are living with diseases that can be cured by stem cell research. I once again commend the Chairman for making that point in her opening remarks. How can we look into your eyes and deny you that hope and that opportunity? It is a question I can't answer, but I wish they were here to answer it in front of you.

Thank you very much, Madam Chairman.

[Applause.]

Chairman COLLINS. Thank you. Senator Chafee, we are delighted to have you here.

OPENING STATEMENT OF SENATOR CHAFEE

Senator CHAFEE. Thank you, Madam Chairman. I look forward to this hearing very much and welcome all the many citizens who are here to testify on this issue.

We are going to focus this morning on the impact of juvenile diabetes on children and their families and the enormous economic cost to our health care system of caring for diabetics, and also about the recent breakthroughs in juvenile diabetes research and the need for increased research funding and the potential for embryonic stem cell research, as Senator Lautenberg just talked about, to provide for new therapies and possible cures.

Thank you, Madam Chairman.

Chairman COLLINS. Thank you.

I am delighted to welcome our first panel this morning. Once again, our lead-off witness is Mary Tyler Moore. She is no stranger to this cause nor to this Committee. She is probably better known to most Americans for her work in film and television, but we know her for her remarkably effective advocacy on behalf of those with juvenile diabetes. She is, as I mentioned, the International Chairman of the Juvenile Diabetes Research Foundation, and we are just delighted to welcome her back again.

Our second witness is also no stranger to Hollywood. Douglas Wick is an Academy Award winning film producer and co-head with his wife, Lucy Fisher, of Red Wagon Entertainment, which has produced a number of major motion pictures, including the soon-to-be-released "Bewitched," which I just happen to have seen last night at a premiere. It is terrific, so I congratulate you for that. Mr. Wick's daughter, Tessa, was diagnosed with Type 1 diabetes when she was 8 years old, and she testified before us at a previous Children's Congress, so we are delighted to have her back here today, as well.

Next, we will hear from Gary Hall, Jr., a three-time Olympian and ten-time Olympic medalist. Mr. Hall holds the title of the "World's Fastest Man in the Water." That is quite a great title. He was diagnosed with Type 1 diabetes at the age of 25, at the height of his swimming career. He is a real inspiration to all the children who are here today. Look how much he has done despite having diabetes. Here he is, the fastest man in the world in the water.

And last, but certainly not least, we will hear from Dr. Allen Spiegel, the Director of the National Institute of Diabetes and Digestive and Kidney Diseases at the NIH. He also has testified before us previously, and we are delighted to have him here. He will highlight the opportunities in the area of juvenile diabetes research and provide us with some examples of the research that has been funded by the appropriations that we have discussed.

So thank you all, and Ms. Moore, we will start with you.

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

Ms. MOORE. Chairman Collins and Committee Members, good morning. It is a real pleasure to see you again and to thank you from the bottom of my heart for everything you have done to help

[1] The prepared statement of Ms. Moore appears in the Appendix on page 31.

us find a cure for diabetes in your role as Chairman of the Senate's Diabetes Caucus, including securing additional research funds, passing legislation, promoting islet cell transplantation, and standing up for stem cell research. You are a true partner in this cause and I am grateful for the invitation to speak this morning.

We are here once again, in fact, to be honest with you, for more years than I ever hoped would be necessary, to talk about the advances that have been achieved and the challenges of finding a cure for all people with diabetes.

In 2003, JDRF's Children's Congress was a catalyst for passage of the pancreatic islet cell transplantation legislation that you championed, Senator Collins. That bill goes a long way to advance a promising new therapy that has already enabled hundreds of seriously ill patients with Type 1 diabetes to experience dramatic improvements in their quality of life.

With JDRF and NIH support, researchers are now aggressively working on new transplant protocols that avoid the need for lifelong toxic drugs to prevent rejection. If successful, this research will make islet transplantation more suitable for a broader group of patients, possibly even including children. I am hopeful that this Children's Congress will serve as a catalyst for advancing other promising avenues of research, including, importantly, stem cell research and regenerative medicine.

I think most of you, or at least some of you, may know that I was diagnosed with Type 1, or juvenile diabetes, almost 40 years ago. And like every one of these children, I have struggled with my disease and confronted its tyranny every day of my life. Now that means that I have struggled every day of every one of those years to achieve metabolic balance between what I eat, what I do, and the insulin that I inject.

It means I have been forced to test my blood sugar several times a day and give myself multiple injections of insulin just to stay alive, day after day after day. It means I have been ripped awake more times than I care to recall in a state of extreme distress caused by life-threatening low blood sugars. Ask my husband, Robert, who wakes up with me in the middle of the night to help me fight our 24-hour-a-day battle.

It means I am not being spared the complications of diabetes. In fact, had it not been for several laser treatments on both of my eyes, cataract surgery, and a vitrectomy, I would be blind now. I have suffered painful nerve spasms and the threat of losing my limbs from poorly healing foot wounds. I have battled with peripheral vascular disease, which limits my ability to walk or dance. But I have fought back fiercely because to maintain my sense of self, I must, just as these children here today have waged their individual battles to deal with the burdens of Type 1 diabetes and do whatever it takes because they must.

I share this with you today not to complain, but because so much of what diabetes does to us is hidden from view, and I just believe the truth must be told, the reality shared. The difficulties that I have experienced are reflected in each of these children who have had their childhood stolen from them and who have been forced to contemplate a difficult and uncertain future that may all too soon include similar complications. For these reasons and so many more,

I have committed myself to JDRF and to doing all that I can to finding a cure for Type 1 diabetes and its complications.

When I became JDRF's International Chairman 20 years ago, I found an organization that truly fulfills the motto "of the people, by the people, and for the people," because we were founded by parents of children with Type 1 diabetes and everything we do is for the benefit of people personally affected by diabetes.

It has been 2 years since our JDRF Children's Congress delegation last appeared before you. Each time, you have listened and responded to our singular and collective requests for increased Type 1 diabetes research funding, and I know it is important for you to be assured that the research done with JDRF and the Federal Government's support over these years has resulted in a strong return on our mutual investment. Well, the answer emphatically is it has.

Because of your support and our close collaboration and alignment of goals, we have been able to move promising experimental findings into human clinical trials. Right now, I am thrilled to report there are literally dozens of them underway, human trials that have already begun to introduce new treatments addressing diabetes at all stages, from reversing long-term heart, kidney, eye, and vascular damage all the way to true disease prevention. I am talking about real treatments delivering better lives for people with diabetes. Now let me highlight just a few.

Doctors are testing new therapies to halt the autoimmune attack that causes Type 1 diabetes, and they see tremendously encouraging results. In fact, we are eagerly awaiting results this month from a Phase II trial on newly diagnosed Type 1 patients. Based on preliminary data, we expect this study will show that a synthetically engineered antibody designed using a naturally occurring human protein can stop the progression of Type 1 diabetes by preserving the function of the body's insulin-producing beta cells.

In the area of complications, new therapies to treat the disabling eye, nerve, kidney, and vascular disorders caused by diabetes are also working their way through clinical trials. In the rapidly growing field of regenerative medicine, we have increasing evidence that there are ways to grow insulin-producing cells in the laboratory to regenerate them in people with Type 1 diabetes. As a result, in human trials that will begin this year, researchers will start treating diabetes patients with experimental growth factors with the goal of triggering regeneration of insulin-producing cells, essentially helping people heal themselves.

And, of course, scientists tell us that we should be much more aggressively pursuing all forms of stem cell research, in particular embryonic stem cells, to help accelerate the delivery of new regenerative therapies like the one I have just mentioned, as well as numerous potential cell replacement treatments relevant to diabetes and so many other debilitating diseases.

We will only be able to do this if the Senate joins the House and votes to loosen the restrictions on Federal funding of embryonic stem cell research. I would ask that each and every one of you understand the importance of the related legislation that will soon come before you. The House of Representatives' historic passage of the Castle-Doggett Stem Cell Research Enhancement Act of 2005 just a few weeks ago was a milestone for medical research.

Not long ago, former NIH Director Dr. Harold Varmus stated, "It is not unrealistic to say that stem cell research has the potential to revolutionize the practice of medicine and improve the quality and length of life. We must provide our scientists with adequate tools to explore the potential and work toward better treatment and cures for people with diabetes, neurodegenerative disorders, spinal injuries, heart disease, cancer, and more."

As the Senate debates and votes on this stem cell bill, I ask you to remember us. Remember the stories we tell about injections, blood tests, about seizures, blindness, kidney failure, heart attack, amputations and strokes, about tearful nights and worrying parents, about lives altered wholly and completely, about what a cure really means to me and these courageous delegates and the millions just like us.

Much of the progress we have made in research thus far has been the result of strong public-private partnership between the Federal Government and JDRF. While we are here today asking the Federal Government to do its part in helping to fund research to give us a cure, thousands of passionate JDRF volunteers around the country raise private dollars toward the same effort.

Since our founding in 1970, JDRF has given nearly $1 billion to diabetes research, and we have just launched a campaign to raise $1 billion more in the next 5 years to accelerate the delivery of therapies in all the areas that I have just mentioned.

As before, however, we need the Federal Government as our partner. We are falling short of what the experts say is needed to get us to a cure as quickly as possible. The congressionally mandated Diabetes Research Working Group recommended a $1.6 billion budget at NIH to fund its share of all the extraordinary opportunities in this area. However, actual NIH funding today is only at approximately 65 percent of this goal. We must do better. We can, and with your confirmed support, I know we will. We deeply appreciate the commitment and the hope you have provided us in the past.

Madam Chairman and Committee Members, I cannot say often enough, diabetes is an all too personal time bomb which can go off today, tomorrow, next year, or 10 years from now. That is why we are working and doing everything in our power and then some to accelerate the cure. To achieve our goal of a world without diabetes, we must continue to work together as a Nation to fund the research, craft policies, and take bold actions that enable progress not merely in small steps, but in big leaps and bounds.

On behalf of myself and my 150 other fellow delegates, I thank you, Senator Collins, and your Committee for your unrelenting perseverance and leadership in the effort to make a cure for diabetes a national priority. I know that with all of us working together, we will fund it. Thank you.

Chairman COLLINS. Thank you for your eloquent testimony.

Mr. Wick.

TESTIMONY OF DOUGLAS WICK,[1] FILM PRODUCER AND CO-HEAD, RED WAGON ENTERTAINMENT

Mr. WICK. Thank you, Senator Collins, for your tireless efforts. Thank you, other Committee Members. Thank you, kids and your families, and particularly the other dads.

A few years ago when my family first came to the Children's Congress, it was like looking in a strange mirror. Everywhere, we saw other families with diabetes. All around us, children were pricking their finger, filling syringes, injecting themselves, and in every father, I saw myself. I realized I was part of a new tribe that was more defining than my race, my religion, or my economic status. I was a father of a child with an incurable disease.

In the weeks before our daughter, Tessa, was diagnosed, I was a guy with a great sense of possibility. I was about to make a movie about Second Century Rome, and I was searching the world to find the right place to build the ancient Coliseum for the movie "Gladiator." Our family had just returned from Christmas in Hawaii, and while we were there, our youngest daughter, Tessa, seemed unable to quench her thirst. She was gulping whole bottles of Evian, and we thought something was wrong.

When we went home, we went to see our doctor, and he said, "Your child has diabetes." It was that fast. But it wasn't until the afternoon that the reality came crashing onto me. I had gone to Tessa's school to pick her up to take her to the hospital. We loved that school. It was a place where the three sisters had been young, where I had learned about being a parent. It was a place of safety and protection. I went to Tessa's class to pick her up and I took her to the office to sign her out and there was a form, a place where you had to fill in the reason for having her leave early. I didn't know what to put, and I finally wrote "medical." It was the first time that I cried.

That night, I sat on Tessa's bed and tried to explain her new life to her. We used to call her "Frat Girl" because she was always in a good mood, but that night, she wasn't. She had had five shots that day, and she said, "Will I have to have any more shots?" "Yes," I answered. "How many?" "Two a day or more." "For how long?" "I am not sure." "But for how long?" "Well, as of right now, forever."

As I sat on Tessa's bed, she told me that she no longer believed in God because if there was a God, he wouldn't do this to kids. I have never felt more like a failure as I sat beside her. I was her dad. I was supposed to make things OK. I was supposed to keep her safe. I promised her somehow, some way, we would find a cure. That was 6 years ago.

My wife and I felt alone and afraid. Tessa was shy and self-conscious and didn't want the other kids at school to know. She didn't want to be different. But the word got out, and the word got out that Tessa was in trouble. The next day we went to school, and as she went to test her finger, prick her finger, there was a protective circle of children around her, and they never left.

These kids have walked mile after mile for diabetes, with Tessa's two sisters leading the way. They have sold hundreds of glasses of lemonade, squeezed money from their parents, and pounded on

[1] The prepared statement of Mr. Wick appears in the Appendix on page 34.

every neighbor's door with a simple plea, "Our friend has diabetes, and we are going to get a cure." Tessa found her proof of God all around her on the shining faces of these friends.

When she was 10, Tessa testified before this Committee. She was feeling very hopeful. But as she waited for her turn, like all of you, she heard details about her disease that we had tried to minimize—kidney failure, amputation, and blindness. Once again, I asked myself, what future could I offer my child?

I reached out to my friend, Nancy Reagan. My father, Charles Wick, had served in the Reagan Administration for 8 years. When the Reagans came home to Los Angeles, I had watched Mrs. Reagan robbed of her golden years where she intended to sit on the porch of the ranch, reminisce about Washington and the likes of all of you. But Mrs. Reagan was determined to spare other families her fate.

Together, we sought out the most respected scientists and researchers, and we were amazed at the consensus. The best brains in medicine and science, including the vast majority of Nobel Prize winners, were convinced about the promise of embryonic stem cells.

The day President Bush was to announce his position on Federal funding for stem cell research, our whole family sat around the TV waiting. As the President announced his new policy, my wife, who always kept her chin up for the children, started to cry.

The dreadful complications of diabetes, as you all know, can start after 5 years. Last year, we passed our 5-year mark. Now every time we go to the doctor, Tessa has a kidney test and an eye test, and after the visit, as we wait for the results, we are scared.

I am here today to beg you for my daughter's future and the future of these other children. Please let me tell my daughter that the Congress of the United States will use its might and heart to pursue every avenue of the science that can restore her health.

We can make movies about ancient Rome, where men like Maximus can rise up, sword in hand, to fight for good. But even Maximus can't save Tessa or any of these children. These children need a different kind of hero, one wearing not a toga but a suit or a dress, and one who will fight not in the arena but on the floor of the Senate for their health and their futures. Thank you.

Chairman COLLINS. Thank you for your very moving testimony.

Mr. Hall. Thank you.

TESTIMONY OF GARY HALL, JR.,[1] OLYMPIC GOLD MEDAL SWIMMER

Mr. HALL. Good morning. It is an honor and a pleasure to appear before this Committee today to speak about the way juvenile diabetes has impacted my life and the need to find a cure as soon as possible. I want to first thank you, Senator Collins, for all you do as Co-Chair of the Senate Diabetes Caucus and for holding today's hearing.

My name is Gary Hall. Most people know me from my swimming achievements in the Olympic games. I am a three-time Olympian, a ten-time Olympic medalist, and hold the record as the fastest swimmer in U.S. history and in organized competition worldwide.

[1] The prepared statement of Mr. Hall appears in the Appendix on page 38.

Swimming is in my genes to some extent. My father, Gary Hall, Sr., was also a three-time Olympian for the United States. I started swimming seriously when I was 14, and won my first national title at the Junior National Championships. I continued my success at the University of Texas in the mid-1990's and swam at the 1996 Olympic Games in Atlanta, where I won four medals. I was feeling very good about my life and where it was going.

But in 1999, I noticed an unsettling change coming over me. I was feeling tired all the time. I had a constant thirst I could not quench. My vision became blurry, and finally, I collapsed. This is when I was diagnosed with Type 1 diabetes.

The news was a shock, and I was incredibly upset and discouraged. Since there was no history of the disease in my family, you can imagine my disbelief. At the time, I really didn't have a good understanding of what diabetes was. Like a lot of people, I thought it happened to those people who were older and who had neglected their health for many years and didn't get enough exercise. I just didn't understand how this could have happened because I, on the other hand, had spent my entire life eating right, exercising, and minding my health.

After the diagnosis, the first thing I did was go home to my computer and look up as much on the disease as I could find. I learned that my pancreas had been attacked by my own immune system, preventing me from converting food into energy. I also learned that I would have to take insulin shots for the rest of my life just to stay alive.

As far as competitive swimming went, I had no idea if I would be able to continue. It was an earth shattering moment for me because I had gone through so much and felt that I was at the peak of my physical condition.

My diagnosis came one week before I was to compete in that season's biggest meet, the Spring National Championships, and all I could do was go away and clear my head. I ended up going to the mountains of Costa Rica with my wife, Elizabeth. She was incredibly supportive in helping me get through this life-altering week. In Costa Rica, I did a lot more reading about diabetes to gain an even deeper understanding of the disease. It was frightening. I read about people going blind, losing their legs and their kidneys to diabetes. For me, it was just a matter of when.

Sometimes, the burden of knowing what the disease could do made me feel destructive. At times like this, I would swim offshore into shark-infested waters until land was out of sight. I would turn around and swim back. But as time passed, I came to terms with my disease and knew I needed to accept the circumstances, and I decided that I had the opportunity to do something to educate people about the horrible effects of diabetes and the desperate need for a cure.

When I returned to the United States, I got in touch with Anne Peters, a Los Angeles endocrinologist, who assured me there was no reason to quit competitive swimming. I decided to go back into serious training, but with a new attitude toward everything. If there is a bright side to this, it is that I no longer take anything for granted, in swimming or in life in general. I live every day as if it is going to be the last.

I am happy to say that since my diagnosis, I have continued my swimming success, winning four more medals at the 2000 Olympic Games in Sydney and another two in 2004 in Athens. But I have also realized I can make an even bigger impact for people with diabetes. I have had a chance to encourage millions of people living and suffering with this disease. If I could talk about what I went through and what I have still been able to achieve, I might somehow alleviate the feeling of helplessness and defeat that can overcome a person, more often than not a child, when diabetes is first diagnosed.

Soon after my diagnosis, I became active with the Juvenile Diabetes Research Foundation and have been a staunch advocate for their research efforts. I am proud to be here today with these 150 amazing children you see sitting before you, telling you why you must do everything in your power to help find a cure through the best science available to America.

Diabetes is always with us. It is not something you can take a vacation from, even for a day. We have to test our blood sugar as often as 10 to 12 times every day, and we rely on insulin as life support. It is a delicate balancing act. We have to constantly calculate the number of carbohydrates we eat, the amount we exercise, and the number of insulin injections we need to take to keep our blood sugar levels in normal range. And still, we lead a life in which we are never more than a few minutes away from a dangerous change in blood sugar levels or the longer-term risks of life-threatening complications.

You all have the power that many of us envy, the ability to control public funds and public policy. We need more funding from Congress for diabetes research so that researchers can take full advantage of all the scientific opportunities that currently exist that may lead to a cure.

In addition, it is extremely important that you help expand the current policy on Federal funding for embryonic stem cell research. Embryonic stem cells represent one of our best hopes for curing Type 1 diabetes, and it is disheartening for those of us with the disease to see progress delayed by limiting what research can be done with Federal funding. When I swam in the Olympics, I always tried to be the best in the field, not for myself, but because I was representing my country. The United States has historically been the best and a world leader in scientific discovery. It is incredibly frustrating to see the United States falling behind other countries in this promising area of science.

I know first-hand that it is possible to achieve your dreams, even in the face of adversity. I ask that you look around this room at these brave children who struggle to overcome the adversity of diabetes every hour of every day. These kids represent future teachers and doctors, businessmen and businesswomen, mothers and fathers, maybe even a future Olympic athlete or U.S. Senator. In short, they represent our future.

Please help us to ensure that our collective future is bright by doing all you can to remove the cloud of diabetes that hangs over these children. Join us in educating Members of Congress about the incredible research opportunities that exist to develop therapies

and a cure for juvenile diabetes, including the potential of stem cell research.

Thank you for the opportunity to appear before you today. Thank you.

Chairman COLLINS. Thank you very much for your inspiring testimony.

Dr. Spiegel, welcome.

TESTIMONY OF ALLEN M. SPIEGEL, M.D.,[1] DIRECTOR, NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES, NATIONAL INSTITUTES OF HEALTH, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Dr. SPIEGEL. Thank you. Chairman Collins, Senators Lieberman, Chafee, and Lautenberg, I appreciate the opportunity to testify before you on the research efforts of the National Institutes of Health (NIH), directed toward improving the lives of people with Type 1 diabetes with the ultimate goals of curing the disease and preventing it in those at risk.

On behalf of my colleagues at NIH, I wish to express my appreciation to Congress for the support you have provided in funding NIH, and in particular for the Special Type 1 Diabetes Research Funding Program. I acknowledge our accountability to you for how we have used these funds and our accountability to the children and families here whose hopes for a better future depend on what we accomplish with these funds.

I have submitted for the record a detailed written statement, but here I will summarize some of the research accomplishments, challenges, opportunities, and our plans to address them.

I thought I could most readily convey the challenges of Type 1 diabetes using the image of life as an ocean voyage on a large ship. Every parent's wish for his or her child is a comfortable, productive, and long passage. Unfortunately, serious diseases can prematurely terminate that passage, and that is exactly what Type 1 diabetes did before the discovery of insulin in the 1920's. Striking children and teens, it in essence caused them to fall overboard without a life preserver because there was no effective treatment. Even someone with the swimming ability of a Gary Hall, Jr., would not have survived then.

Insulin provided a life-saving treatment, but it did not represent a true cure. With insulin treatment, one had to worry every moment of one's life about blood sugars being too high, leading to complications such as blindness and kidney failure, or blood sugar being too low, causing coma and even death. In essence, on insulin treatment, people with Type 1 diabetes were safe from drowning, but they were consigned to make the ocean voyage on a small lifeboat, laboriously trying to avoid ocean hazards doing the routine things in life most of us take for granted.

Over the years, research has led to steady improvement in the length and quality of life of people with Type 1 diabetes. Newer forms of insulin developed using biotechnology, more accurate glucose monitoring developed by bioengineers, all help achieve better blood sugar control. That is key, because NIH research showed

[1] The prepared statement of Dr. Spiegel appears in the Appendix on page 41.

clearly that tight control of blood sugar could significantly reduce the development of small blood vessel damage, leading to blindness and kidney failure.

Just 2 weeks ago, investigators from our EDOIC study of nearly 1,400 people with Type 1 diabetes reported that tight blood sugar control cut in half the occurrence of serious heart disease, the leading cause of death in Type 1 diabetes. All of this progress, though, still leaves people with Type 1 diabetes in that lifeboat. It is a better equipped lifeboat, able to travel much longer and avoid many hazards, but it is still not where we want to be.

We need to get children with Type 1 diabetes back on that large ship, no longer worrying around the clock about eating, exercising, and blood sugar. We need a cure.

The opportunities have never been greater. One line of research seeks to develop a closed-loop system, an artificial pancreas. Early NIH investments in glucose-sensing technology have spurred industry efforts to develop continuous glucose monitoring and to connect this with automated insulin delivery. DirecNet, a clinical network supported by the Type 1 funds, studies the latest continuous glucose monitoring technology in kids just like these to improve their treatment and help speed development of an artificial pancreas.

It is unlikely, though, that any mechanical system will ever attain the performance of the pancreatic islets whose beta cells normally sense a rise in blood glucose and release insulin in response. Proof of that came from the pioneering Edmonton protocol which showed that islet transplantation could lead to sustained independence from insulin treatment in adults with Type 1 diabetes. This left us, though, with two major hurdles to overcome, achieving transplant tolerance without the need for life-long immunosuppressive drugs, and finding an inexhaustible supply of insulin-secreting beta cells.

To overcome the first hurdle, NIH's Immune Tolerance Network and the newly formed Collaborative Islet Transplant Consortium seek to develop better ways to achieve transplant tolerance and long-term insulin independence.

For the second hurdle, our Beta Cell Biology Consortium brings together the best researchers in the country to study both adult and federally approved embryonic stem cells with the goal of developing a source for cell replacement therapy.

To truly achieve success, though, we need to be able not only to cure, but also prevent Type 1 diabetes. In essence, we need to prevent kids at risk of the disease from ever falling off that large ship. To do that, we need to know the genetic and environmental determinants of the disease, and the Special Type 1 Diabetes Funding Program has enabled us to form consortia to achieve these goals. We need to understand in detail why the immune system attacks its own pancreatic islets and to harness that information to develop safe and effective prevention methods.

Our research now allows us to identify those at high risk before they actually develop Type 1 diabetes. Recent results show that insulin itself is a key trigger of the autoimmune process, not just in mice, but in people. Though experiments in animals show that insulin given at just the right time could prevent the disease, our

DPT–1 trial, unfortunately, failed to show a benefit of injected insulin in people. A possible beneficial effect seen with oral insulin, though, will be carefully reexamined in our TrialNet Consortium, which is also doing other pilot prevention studies.

An antibody against immune cells has shown promise in preserving beta cell function in adolescents with recent onset Type 1 diabetes, and a controlled study to be published later this week reinforces that promise. We must be clear, though, that any cure or prevention method will have to be not only effective, but safe in both the short and long-term. While we don't want to leave kids with Type 1 diabetes stuck in that lifeboat forever, it is certainly preferable to ending up overboard because of unsafe interventions.

Developing safe and effective cure and prevention methods involves making tough decisions. To be certain we make the right ones, this January, I launched a new strategic planning process with extensive input from external scientific experts and patient advocacy groups such as the JDRF. We expect this plan to serve as a guide, allowing us to use our resources most effectively in addressing the challenges before us.

Chairman Collins, Senators Lieberman, Chafee, and Lautenberg, Children's Congress delegates and your families, distinguished guests, I hope you can appreciate that my colleagues I and at NIH and the researchers we represent are fully committed to this cause. You deserve nothing less. Thank you for your support and your attention.

Chairman COLLINS. Thank you, Doctor, for that encouraging data.

We have a bit of a time problem this morning because there is an unexpected vote that has been scheduled for 11 o'clock, and I want to make sure that we get to hear from all of our witnesses on the next panel. I am therefore going to ask my colleagues to only ask one question so that we can make sure we can get through the next panel. That is very hard for Senators, to only ask one question, especially when we have such an extraordinary panel before us.

Mr. Wick, I am going to direct my one question to you. You mentioned in your testimony the work that you are doing with Nancy Reagan and the promise that embryonic stem cell research holds for diseases like Alzheimer's, Parkinson's, spinal cord injuries. Could you elaborate for us on the promise of stem cell research for providing treatments or a cure for juvenile diabetes, because we do expect within the next month to have that important debate on the Senate floor.

Mr. WICK. Yes. As we started our exploration, obviously, I was searching as a father with a diabetic child and she was searching as a wife who had just lost her husband to Alzheimer's and suffered through his decline, but she is also, as you know, the daughter of a doctor and very interested in medicine.

So we met with several different scientists and also met with people independently, and we would compare notes, and what we got, and we were surprised, was how much consensus we heard really from, as you know, the vast majority of Nobel Prize winners and a huge majority of the most gifted medical people in the country, and they all said embryonic stem cell was certainly the best

shot for diabetes, would have some major impact on Alzheimer's, at worst, at least understanding the disease. And then my friend, Michael J. Fox, who I did "Stuart Little" with, has Parkinson's. And everywhere I turn, other families with diseases were finding embryonic stem cell was their hope. Of course, they need more stem cell lines.

Chairman COLLINS. Thank you. Senator Lieberman.

Senator LIEBERMAN. Thanks, Madam Chairman. Now that you and I have worked together to protect the right of filibuster on the Senate floor—— [Laughter.]

We can limit ourselves to one question here.

First, to all the witnesses, thank you for very compelling and effective testimony.

I am going to ask a quick question of Dr. Spiegel. In your written testimony, you cite six research goals for NIH. I want to ask you if you would identify what the most significant challenge is now that you are facing to the kind of progress that we want to see.

Dr. SPIEGEL. Thank you, Senator Lieberman. Indeed, the two major hurdles I described are the significant challenges. One is to understand the basis for the immune system attack on these pancreatic islets. Understanding that will not only potentially allow us to cure the disease in those who have it, reverse it in those with recent onset, but also prevent it in those at risk.

At the same time, for the cure of Type 1 diabetes, cell replacement therapy is challenging. This is, of course, where the stem cells come in. This is potentially extremely important. In this regard, we need to be able to learn how to grow many of these insulin-secreting beta cells in a dish, and this can be done. Scientists are working on it. Doing that kind of work will also allow us, as Mary Tyler Moore so eloquently said, to learn how to help regenerate the beta cells that are in the body and still functioning, even in some people with longstanding Type 1 diabetes, to a limited degree.

Senator LIEBERMAN. Thank you.

Chairman COLLINS. Thank you. Senator Chafee.

Senator CHAFEE. I thank the Chairman. I am sure the many people standing in back, the families standing in back, are grateful for short questions and answers also.

Dr. Spiegel also—and I thank the entire panel for your moving testimony—what kind of experience do you have on the private funding for embryonic stem cell research versus the public funding and the Federal funding? Is the private funding significant?

Dr. SPIEGEL. Certainly there is private funding for embryonic stem cell research. We work very closely in conjunction with the private sector, and this relates to Senator Lieberman's comments. The only way that we can make progress is for the federally supported researchers and for the NIH to work together with the private sector.

In this instance, while there are private efforts, we are somewhat shielded from those and so I can't really give you my experience. I meet with CEOs on an even, level playing field, working on areas like trying to prevent Type 1 diabetes with promising treatments. But in the arena of human embryonic stem cell research, there is a wall.

Chairman COLLINS. Thank you. Senator Lautenberg.

Senator LAUTENBERG. Thank you again, Madam Chairman, for bringing this panel in front of us. Before I ask my question, I just say thank you to each one of you, particularly the three who have been personally touched by juvenile diabetes, for your moving testimony.

As such, my question is for our distinguished Chairperson, and that is I don't know whether there is a video of the testimony that we heard this morning, but I would be willing to get together and try to devise an opportunity or develop an opportunity for all the Senators to see and hear the testimony as presented. It is an eloquent statement, and I say shame on us if we don't do something about this.

Look at these children, the most beautiful group of children that I have ever seen. Here they are, as Mr. Hall said, they have to learn that there is hope and there is opportunity for the future. Your example is one of the finest things that we could imagine, and that is get through it. Get on to a normal life and let these kids know there is that.

Dr. Spiegel, and I am cheating on the one question thing because questions to the Chairman don't count, but—— [Laughter.]

Dr. Spiegel, how do you respond to claims that adult stem cells are a sufficient or an appropriate replacement for embryonic stem cells in treating diseases such as those that have been discussed here this morning, particularly diabetes?

Dr. SPIEGEL. My response unequivocally is that we need both. And as you have heard, not only most scientists, Nobel Laureates, and others agree we need both. We need to pursue both avenues because that is our best hope of being able to learn how to cure this disease. We need to be able to do embryonic stem cell research—first, because it can give us a better understanding of what causes Type 1 diabetes; second, because it will actually inform our ability to work with adult stem cells as well as to stimulate endogenous regeneration; and finally, because, and one cannot guarantee or promise this, the embryonic stem cells themselves, if successfully turned into insulin-secreting beta cells, could be the source of cell therapy. So there are at least three reasons.

Senator LAUTENBERG. Thank you very much. Thank you, Madam Chairman.

Chairman COLLINS. Thank you, and thank you, Dr. Spiegel, for putting that on the record.

I want to thank this panel for your excellent testimony. Senator Lautenberg is right. I think it would benefit all of our colleagues to hear it. I know that many are watching from their offices, but his idea of sending around a tape is an excellent one, and we will follow up on that. But thank you so much for being here and for your eloquent testimony. Thank you.

[Applause.]

Our next panel of witnesses this morning consists of children who know firsthand the burden of living with diabetes. Our witnesses on this panel are Stephanie Rothweiler of Falmouth, Maine; Ethan Falla of New Britain, Connecticut; Aaron and Shaynah Jones of Piscataway, New Jersey; Ellie Clark of Grandville, Michigan, accompanied by her mother, Katie; and Lauren Stanford of

Plymouth, Massachusetts, who is the Co-Chair for the children at this year's Congress.

All of the members of this panel are delegates to the Juvenile Diabetes Research Foundation's Children's Congress. Other delegates, I want to point out, are seated right before us and also are throughout the room. We welcome all of them here today.

Now, two of my colleagues have very important constituents who are testifying before us on this panel, so first, I want to turn to the distinguished Ranking Member, Senator Lieberman, so that he can welcome our witness from Connecticut.

Senator LIEBERMAN. Thanks, Madam Chairman. I will be brief since I welcomed him in my opening statement. Ethan Falla is just an adorable red-headed kid from New Britain, Connecticut. He is a member of the school Honor Society, very active in sports, and as I mentioned, an accomplished Irish dancer.

Ethan, thanks so much for coming today, and I hope during your testimony you will share with everyone here today your poem about diabetes. That would be very important for everyone to hear. God bless you. You look great and you have a great future ahead of you.

Chairman COLLINS. Thank you very much, Senator Lieberman.

And now, I would like to turn to Senator Lautenberg so he can have the privilege of introducing his constituent, as well.

Senator LAUTENBERG. It is a privilege, indeed. I would say that, in response, Senator Lieberman always says the right thing, and he talks about how terrific Ethan is. But I want you to look at Shaynah and Aaron, and I will tell you that you would not see a more handsome, full of life pair of young people. I can't help but look at all of the young people out there, including little Ellie, and all of the children. They stimulate something in our souls and our hearts that tells us we have to do something about this.

And I am particularly grateful to Shaynah, who is 13 years old, diagnosed with juvenile diabetes 2 years ago, and Aaron, 10, diagnosed 5 years ago. It is a burden on their families, a burden on themselves, but they are two happy children with interests like any other child—sports, school band, video games—but their lives, as we have heard from so many, are affected every day by diabetes. But I hope you heard Gary Hall's message, too, and that is he went on to become this great swimmer after he was diagnosed with diabetes. So whatever your plans are, keep going, Shaynah and Aaron. I look forward to hearing your stories. Thanks for sharing them with us, and thank you, Madam Chairman.

Chairman COLLINS. Thank you, Senator.

Steffi, as I told you yesterday in my office, you get to go first. That is not only because I was so impressed with you yesterday when we met, but it is because I am the Chairman. [Laughter.]

And thus, I get to pick the person, and I am picking my constituent. So Steffi, take it away.

TESTIMONY OF STEPHANIE ROTHWEILER,[1] DELEGATE (AGE 11), JDRF CHILDREN'S CONGRESS, FALMOUTH, MAINE

Ms. ROTHWEILER. Good morning, Senator Collins and Members of the Committee. My name is Stephanie Rothweiler. I am 11 years old and live in Falmouth, Maine.

These days, all I hear is, "Steffi, what is your blood sugar?" or "Steffi, how much insulin are you going to give yourself?" Well, I wasn't always this way. I got diabetes when I was 5½. It was a week before Christmas in 1999. Thankfully, my family and I caught it early. Once you saw me, it wasn't hard to see that I was really sick. I had dark circles around my eyes, I had lost a lot of weight, and I looked like a twig. I was also always really tired, thirsty, and I couldn't stop going to the bathroom.

Let me tell you about my typical day living with diabetes. When I wake up, the first thing I do is check my blood. If it is out of range, that determines what I can eat for breakfast. When I am at school, I call the nurse three times a day—at snack, lunch, and before I go home—to report my blood sugar numbers. I also have to carry a blood testing meter with me at all times. On school trips, one of my parents has to come with me and if that is not possible, one of the school nurses has to go. My friends have learned what to do if I should become unconscious and how to help me.

Eating is a big problem. If my blood sugars are too high, I can't eat with my family and have to wait 20 to 30 minutes for the insulin to work. I am very active with tennis, Irish dancing, and softball. My whole family has learned how to count carbohydrates, know their glycemic index, and evaluate the impact of my exercise on my blood sugar levels. Every day, at every meal, activity, and during the night, my parents are calculating and projecting my blood sugar levels to keep me in good control.

At first, I thought diabetes was like a cold and that it would be gone in a week or so. Little did I know I would have it the rest of my life. I actually can't remember having a normal life without diabetes.

I have learned a lot about life that I may not have learned if I did not have this disease. One thing I have learned is how fortunate I was to have caught the diabetes early. I also know how lucky I am to have parents who give up their nights, weekends, and every hour of every day to take care of me and to make sure I stay in tight control of my blood sugar levels so I can stay as healthy as possible. I am also very lucky to have access to the best technologies. I wear an insulin pump, which makes it easier to stay in good control.

I know it is possible to find a cure. I think about all of the miraculous advances that have occurred in our time, and I know that a cure will only come from research. So I ask each Member of this Committee and every Member of Congress to do all they can do—to do all they can to support this promising research that will one day bring us a cure as quickly as possible.

Senator Collins, I owe you a special thanks for all you have done to support the research and policies to bring us closer to finding a cure for diabetes. I am also very lucky you are my Senator.

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[1] The prepared statement of Ms. Rothweiler appears in the Appendix on page 58.

I can't remember my life without diabetes, but I can certainly imagine how wonderful it would be to live without it.

Chairman COLLINS. Thank you so much, Steffi. That was just great. Let us give a round of applause for Steffi.

[Applause.]

Ethan, you are next.

TESTIMONY OF ETHAN FALLA,[1] DELEGATE (AGE 13), JDRF CHILDREN'S CONGRESS, NEW BRITAIN, CONNECTICUT

Mr. FALLA. Hi. My name is Ethan Falla. I live in New Britain, Connecticut. I am 13 years old, and I am like most other boys my age. I love to play sports, ride my bike, play video games, and I Irish dance. The difference between me and all my friends is that I have juvenile diabetes.

I have a really good memory and I can remember things most people forget. I can remember when I was 3—like it was yesterday. Sometimes I wish I could forget certain times in my life, like the day that I was diagnosed with diabetes. I was really afraid of the shots and the way that everyone acted. My mom couldn't stop crying and my dad looked really worried. I remember running behind the couch to hide from my mom and dad when they had to check my blood sugar or give me insulin. Those days were the hardest. One night when I was 4, I told my dad that by the time I was 16, there would be a cure for diabetes. Well, that only leaves 3 years for us to find a cure.

The reality of diabetes really hit home for me 2 years ago when my little brother, Aiden, was diagnosed with diabetes. I felt really bad because I thought it was all my fault. I cried the whole time he was in the hospital. I just couldn't imagine him having to go through all the finger sticks and shots, too. He was only 10 months old and it wasn't fair. Although I worry about myself, I worry more about my little brother, Aiden, because he is so little and so many things can go wrong.

The dream I have for me, my brother, all the kids in this room, and all the other children around the world who have diabetes is simple. At night, I dream of a world where we don't have to count carbohydrates or we don't have to prick our fingers and give ourselves insulin shots, or we don't have to worry every day about the complications of diabetes, a world where we could just be kids, free from diabetes.

Research foundations like JDRF are working hard to make that dream become a reality with support from Congress. If we all work together to find a cure, it will happen. Together, we will be known as the people who cured diabetes.

Chairman COLLINS. Thank you, Ethan.

[Applause.]

Aaron, we are delighted to have you and your sister here, too.

[1] The prepared statement of Mr. Falla appears in the Appendix on page 60.

TESTIMONY OF AARON JONES,[1] DELEGATE (AGE 10), JDRF CHILDREN'S CONGRESS, PISCATAWAY, NEW JERSEY

Mr. JONES. Good morning. My name is Aaron Jones, and I am 10 years old. I was diagnosed with juvenile diabetes when I was four. I have been living with this disease for 6 years. My older sister, Shaynah, has just been diagnosed, too.

My mom doesn't know how or why we both got juvenile diabetes because we are the only ones in our family who have it. Even though I am younger than Shaynah, sometimes I feel like her big brother because every time she needs help understanding her diabetes, I tell her what I know. Shaynah gets nervous because she knows that I sometimes have seizures because of my diabetes and she doesn't want to get them, too. We also both worry about our older brother, Justin, and our younger sister, Kara, worry that they may get this disease, too.

Living with diabetes is the pits. I live with it because I have to. The part I really don't like is taking insulin shots and always checking my blood sugar. It can be painful sometimes. I just don't feel like doing it. I also feel awful and tired when my blood sugars get too high or very low. I just want to feel like a normal kid without pricking my fingers 2,000 times each year or injecting myself with insulin 1,100 times a year.

Finding a cure is what keeps me smiling every day. Please help us find a cure in time to help me and my sister, Shaynah, and all the other kids who never get a day off from diabetes.

Chairman COLLINS. Thank you very much. Good job.

[Applause.]

Shaynah, we are delighted to have you here, too.

TESTIMONY OF SHAYNAH JONES,[2] DELEGATE (AGE 13), JDRF CHILDREN'S CONGRESS, PISCATAWAY, NEW JERSEY

Ms. JONES. I am Shaynah Jones, Aaron's older sister. I am 13 years old, and I have had diabetes for 2 years now. Having two kids with diabetes in one family really takes a toll on everyone.

For Aaron and me, managing our diabetes takes a lot of time away from our family. If we are with our family at a function, we have to stop what we are doing to check blood sugars or go somewhere to inject insulin. If there is a high or low blood sugar with one of us, then sometimes we have to cancel what we are doing so our parents can take care of us, especially for Aaron. If he goes too low, he can have a seizure, and that can be a real emergency.

The emotional stress of this disease is horrible for our entire family. If one of our blood sugars is out of control, it seems like the whole family is holding their breath until we get it back in line. If we misplace one of our meters, my mom gets upset because the numbers might not be right for the doctor. It can become difficult because we are stressed out all the time, worrying about whether we have everything relating to our diabetes in order, not to mention that we are worrying about just being kids.

Diabetes is so rough on my whole family. It is a heartache and heartbreak every day. Still and all, we wake up every morning

[1] The prepared statement of Mr. Jones appears in the Appendix on page 62.
[2] The prepared statement of Ms. Jones appears in the Appendix on page 63.

grateful for a new day and with a positive outlook on life. We are not giving up.

Chairman COLLINS. Thank you. Very good job.

[Applause.]

Katie, it is my understanding that you are going to speak for Ellie, so thank you.

TESTIMONY OF KATIE CLARK,[1] MOTHER, ON BEHALF OF ELLIE CLARK, DELEGATE (AGE 4), JDRF CHILDREN'S CONGRESS, GRANDVILLE, MICHIGAN

Ms. KATIE CLARK. My name is Katie Clark. Most people know me as Ellie Clark's mom. Ellie will be 5 next month. She is a sweet little girl who has been barraged since birth with complete strangers touching her blonde curly hair. We thought that was going to be her burden to bear. We were wrong.

Ellie was diagnosed with juvenile diabetes last year. To be exact, we found out at 4:45 p.m. on August 30. We had spent weeks denying the symptoms, and with those words every parent here will tell you devastated them, "There is glucose in her urine," our lives were turned upside down. She was diagnosed on what was supposed to be her first day at a new preschool. We spent my 30th birthday at the hospital and got through the denial in a few hours, which most say is really fast. I spent a better part of the next 2 weeks in a depression. I was also very angry. Anger is not the most common emotion at the very beginning. However, we are not new to this disease. I have had juvenile diabetes for 28 years.

It has only been 10 months. Ellie has callouses on her fingers. Her bottom has scar tissue from her insulin pump site changes. She has had 1,494 finger pokes. Her blood has been drawn five times, with two nurses holding her down and one drawing the blood. She has had 98 pump site changes. It has only been 10 months.

All I want is to give her back the life she was living before August 30 and a future brighter than one clouded by diabetes. I would give everything I have, even my own life, for Ellie not to have to endure another day of this dreadful disease.

One of the hardest things for me is knowing firsthand the challenges that Ellie is going to face as she grows up. Fifteen years—that is how much less of a life span Ellie and I have been dealt. And disease is something that affects every detail of every day of your life. It is not only about the finger pokes or the worry about whether you have enough supplies or when our next meal will be. The happiest days of my life have been clouded by diabetes, details the average person wouldn't ever think about.

I had an insulin reaction on my wedding day. And not only did my hair get messed up, but I ended up with orange juice on my wedding veil. For each of my pregnancies, I saw a high-risk OB once a week. In the 4 months leading up to their births, I saw them twice a week. In labor, I was forced to check my blood sugar every hour, and after birth, the nurses whisked my newborns away to check their blood sugar and force a tube down their throat to force glucose into their stomachs because their bodies were used to pro-

[1] The prepared statement of Ms. Clark appears in the Appendix on page 64.

ducing too much insulin. This is not the life I have dreamed of for Ellie.

The worst part of diabetes and the biggest impact it has had on my life is when Ellie is getting tucked into bed at night. That is when she asks the questions that are unanswerable, like, "Mommy, why do some people get diabetes and some people don't?" Or she says things like, "Daddy, I don't want diabetes anymore." This is when I realize we must do everything we can to find a cure for this disease. My sweet little girl with the blonde curls deserves it.

Chairman COLLINS. Thank you.

[Applause.]

Lauren, we are pleased to have you here today.

TESTIMONY OF LAUREN STANFORD,[1] DELEGATE (AGE 13), JDRF CHILDREN'S CONGRESS, PLYMOUTH, MASSACHUSETTS

Ms. STANFORD. Good morning. My name is Lauren Stanford. I am 13 years old, and I live in Plymouth, Massachusetts. I have had diabetes for 8 years now.

Before I tell you about my story, I want you to think about something. In this room right now, you see 150 kids with juvenile diabetes. That is 150 pairs of hands. Consider that, on average, each of these kids needs to prick their finger and draw blood for a glucose test six times a day. Add to that the fact that we have each had juvenile diabetes for an average of 5 years. If you do the math, you will see that this means that there are 150 pairs of hands that prick their fingers more than 1.5 million times and have spent over $2 million on just their test strips. If you look out into this hearing room, you will see the evidence of the 1.5 million times that diabetes has invaded a life. And we are just a snapshot of the millions of kids who suffer with diabetes. So take my story that I am about to share with you and multiply it just like we did those finger pricks and you will begin to understand the toll this disease takes on our world.

My story is about always working to win and finding out that with diabetes, in the end, you can almost never beat it. I am an "A" student. I compete on a swim and tennis team, and I am an expert skier. That is because I expect the best from myself. For 7 years, it was the same with my diabetes. I was a model patient.

But last fall, something happened. I got incredibly sick of it. I wanted so bad to be like my other teenage friends, who were free to worry about nothing more than boys, movies, and fun. I wanted to buy a Slushie without having to do algebra. So I started to lie to my parents, skipping blood checks and making up numbers. It got worse, and pretty soon, I was skipping insulin doses, too. I knew I was in trouble, but I couldn't stop. I would go to bed at night and say, tomorrow will be a new day. I will try hard and everything will be fine. But the next morning, I just couldn't get back to my life with diabetes. I was sick, but in a strange way, I felt free. So I kept lying and not taking care of myself. On October 30, a day before Halloween, I collapsed and was rushed to Children's Hospital in Boston where I was put in the intensive care unit. I almost died. Diabetes almost got me.

[1] The prepared statement of Ms. Stanford appears in the Appendix on page 66.

You might ask what would make a smart girl do such a stupid thing. I was completely burned out on diabetes. I felt like I had been through a medical appointment every few hours for the past 7 years and I just couldn't stand the endlessness of it anymore. It seems like as hard as I tried, there were always days where I was high or low. I couldn't be perfect.

I know now that this is not the way to win this battle. I have made myself a vow to be brave and not to give into this unforgiving disease, and I ask you Members of Congress to do the same. When it is tough to make a decision about supporting additional funding for diabetes research or expanding the current stem cell policy, think of me and all the kids in this room today. Don't give in because it is hard. Rather, like I had to do, face the hard work and difficult decisions that will lead me, the kids in this room, and all the millions of people around the world to a cure for diabetes. That is the only way we will win this battle, with your help. We kids cannot beat it on our own. We need you and your support.

Chairman COLLINS. Thank you.

[Applause.]

I have to tell all of you who have just testified that all of us hear a lot of witnesses, hundreds and thousands of witnesses over the years that we have been Senators, but I don't think we have ever had a more compelling, persuasive group of witnesses than the panel we have just heard. So I want to thank each of you for telling your story. Thank you.

[Applause.]

It is so touching and moving, and I think if all of you go and meet with your Senators, meet with your Members of Congress, and tell them your eloquent personal stories just as we have heard today, you will make such a difference. You will help all of us make the case for more research and for passing the stem cell bill because more research, including stem cell research, is the answer. It is the answer to this awful disease. And hearing your stories just makes me want to work all the harder to bring that about. I am going to redouble my personal commitment just because of what I have heard today.

And Steffi, I know that you have worked hard in Maine to help people be more aware of juvenile diabetes and the need for support. Could you tell us a little bit about Steffi's Stompers and the money that you have raised?

Ms. ROTHWEILER. Sure. Every year, we do a walk around Back Bay, and I have a team called Steffi's Stompers. I get a bunch of my friends and tell them that it is to raise money to help find a cure for diabetes. And my friends are more like my family to me, so they gladly give up part of their allowance or part of their savings, and they give it to me to give to the research foundations. Over the past 4 years, my team has raised over $75,000 to go to stem cell research.

Chairman COLLINS. Wow. That is fabulous.

[Applause.]

That is great. Senator Lieberman.

Senator LIEBERMAN. Thanks so much, Madam Chairman. I agree with what you said about the extraordinary testimony of these witnesses.

Shaynah, I don't know if anybody has ever told you, but your first name means something in another language, Yiddish. Shaynah means beautiful. You and all the other witnesses before us are beautiful, not just in your physical appearance, but in your inner strength and your soul. You have been given a problem and you are dealing with it and to the best extent possible, you are living lives as normal as you possibly can. I find your testimony to be occasionally heartbreaking, but in the end, inspirational.

Somebody said to me once in my life when I had had a real disappointment, a real problem, they said to me that everybody in the course of a life gets knocked down at some time or other, maybe more than once. The question is do you get back up? It seems to me that you are doing as much as you possibly can, and your testimony challenges those of us who are privileged to have the positions we have with the opportunity to bring about change that we have, to do more than we are doing to fund the kind of research that will give you not only better treatments, but cures. And to me, that begins with support of embryonic stem cell research. We can do that soon, and I hope we will.

Ethan, you have had diabetes now for 10 years. I wonder, over that 10 years, has the way in which you have been treated or treated yourself changed? Have there been new systems or things that you have been told to use or been able to use?

Mr. FALLA. Yes. When I first started with diabetes, my parents were giving me my shots. And then when I went to diabetes camp, I found out about the pumps and Lantis, and so I got on Lantis, and after I did Lantis for a couple months, we signed up for a pump, and now I am using the pump.

Senator LIEBERMAN. And that is really working well? It is much better for you. That is good. Thank you. That is the kind of progress we have made, but there is a lot more we can and will do together.

Thanks, Madam Chairman.

Chairman COLLINS. Thank you. Senator Lautenberg.

Senator LAUTENBERG. Thank you, Madam Chairman, and I thank each one of you for the message that you bring us today. It causes us to look inside a little more deeply and to say, what is our responsibility here?

Very seldom do we have hearings with witnesses, often business executives or scientists, and the tears that flow from those hearings are tears of boredom. [Laughter.]

And here, we have tears of affection for all of you. Katie, when we look at you and Ellie and hear your story, because my first temptation was to put my hand through her curly hair. [Laughter.]

I have six little granddaughters, four grandsons, but the granddaughters know how to get to me. The fact is that we want to help, and I make a pledge to you here today that we will fight as hard as we can to see that there is more given to research in this field and to stem cell research and to ask our colleagues and ask, why can't we get a vote? If you could only hear these children, it would tell you enough to say, hey, listen, we find money to fight wars. We find money to defend ourselves against terror. There can be no greater terror in my mind than to find out that you have a child

who has diabetes and what it entails in your life. So thank you. I love you all. Kisses.

[Applause.]

Chairman COLLINS. There certainly is no more caring, committed, and compassionate organization than the Juvenile Diabetes Research Foundation. It has been my great pleasure to work hand-in-hand with you during the last 8 years, and today's hearing reminds us that we can't rest. We cannot lift our foot from the accelerator. We must keep moving forward. I think that each person who was here today is committed to that cause.

So I want to thank all of you for being here today, the parents, the advocates, the Juvenile Diabetes Research Foundation staff. I see so many of you that I have worked with throughout the past 8 years. This collaboration isn't going to end. We are not going to rest until we have a cure.

My special thanks to all of the children who are here today. You are the best advocates possible.

[Applause.]

This hearing is now adjourned.

[Whereupon, at 11:05 a.m., the Committee was adjourned.]

APPENDIX

STATEMENT OF MARY TYLER MOORE INTERNATIONAL CHAIRMAN, JDRF

Chairman Collins, committee members. Good morning. It's a pleasure to see you again, Chairman Collins, and let me thank you, from the bottom of my heart, for everything you have done to help us find a cure for diabetes in your role as Chair of the Diabetes Caucus—including securing additional research funds, passing legislation promoting islet cell transplantation, and standing up for stem cell research. You are a true champion for our cause.

I am most grateful for the invitation to speak here this morning. We are here together once again--in fact, to be honest with you, more years than we had ever hoped would be necessary--to talk about the advances that have been achieved and the challenges of finding a cure for all people with diabetes.

In 2003, the Children's Congress was a catalyst for passage of the pancreatic islet cell transplant legislation that you championed, Senator Collins. This bill will go a long way towards advancing a new therapy that has enabled hundreds of patients to live without daily insulin injections and to experience dramatic gains in their quality of life. Researchers are now working on improvements and new protocols that won't require lifelong toxic drugs to prevent rejection, which would make transplantation suitable for children. I am hopeful that this Children's Congress will serve as a catalyst for advancing other promising avenues of research, such as embryonic stem cell research, that I will highlight in my testimony.

Many of you know that I was diagnosed with type 1, or juvenile, diabetes almost 40 years ago, and like every one of these children, I have struggled with my disease and confronted its tyranny every day of my life. That means that I have struggled every day of every one of those years to achieve metabolic balance between what I eat, what I do, and how I feel.

It means I have tested my blood sugar several times a day and given myself multiple daily shots of insulin every single day just to stay alive.

It means I have been ripped awake more times than I care to recall in a state of physical and emotional distress caused by life-threatening low blood sugars. Ask my husband, Robert, who wakes up with me, in the middle of the night, to help me fight our 24-hour-per-day battle.

It means that even with day-in, day-out, round-the-clock vigilance, I have often been unable to achieve good metabolic balance, my blood sugar levels going dangerously high or low.

And it means I have not been spared from the complications diabetes can bring. In fact, had it not been for several laser treatments on both of my eyes, I would be blind now. I

have suffered painful neuropathy, the threat of losing my limbs from poorly healing foot wounds, and I have battled with peripheral vascular disease. And I do mean battle. But I have fought back fiercely, just as these children here today have waged their individual battles to deal with the burdens of this disease and do whatever it takes to manage it.

I share this with you today, not to complain, but because so much of what this disease does to us is hidden from view and I believe the truth must be told, the reality shared. The difficulties I have experienced are reflected in each of these children who have had their childhood robbed from them and who have been forced to contemplate a difficult and uncertain future that may all too soon include similar complications.

For these reasons and so many more, I have committed myself to JDRF and to doing all that I can to find a cure for juvenile diabetes and its complications. When I became JDRF's International Chairman 20 years ago, I found an organization that truly fulfills the motto, "of the people," "by the people," and "for the people," because we were founded by parents of children with juvenile diabetes, and everything we do is for the benefit of people personally affected by diabetes.

It has been two years since our JDRF Children's Congress delegation last appeared before you. Each time we've appeared before you, you've listened and responded to our singular and collective requests for increased type 1 diabetes research, and I know it's important for you to be assured that the research we've done with the federal government over these years has represented a strong return on our mutual investment. Well, the answer is, emphatically, it has.

Because of federal support and our close collaboration and alignment of goals, together we've been able to move promising experimental findings into human clinical trials. Right now, I'm thrilled to report, there are literally dozens of them underway—that have already begun to produce treatments addressing diabetes at all stages, from reversing long-term damage all the way to true disease prevention—I'm talking about real treatments delivering better lives for all people with diabetes. In the interest of time, let me highlight a few:

We are exploring new therapies to halt the autoimmune attack that causes type 1 diabetes and see tremendously encouraging results as they move through human trials. We're eagerly awaiting results this month from a Phase II trial on newly diagnosed type 1 patients demonstrating that an antibody drug—taken from a normally occurring protein in the body—can stop the progression of type 1 diabetes by preserving the function of the body's insulin-producing beta cells.

In the area of complications, new therapies to treat the eye, nerve, kidney and vascular disorders of juvenile diabetes are working their way through clinical trials.

In the rapidly growing field of regenerative medicine, we have increasing evidence that there may be ways to grow insulin-producing cells in the laboratory or regenerate cells that have been destroyed in individuals with type 1 diabetes. In clinical trials that will

begin this year, researchers will use growth factors in patients with diabetes with the goal of triggering regeneration of insulin-producing cells. And, of course, scientists tell us that we should be much more aggressively pursuing all forms of stem cell research—in particular embryonic stem cells—to maximize their ability to help produce insulin cells.

We will only be able to do this if the Senate joins the House and loosens the restrictions on this research. I would ask that each and every one of you understand the importance of legislation that will soon come before you to expand the current restrictions on federal funding for embryonic stem cell research. The historic passage of the House embryonic stem cell bill just a few weeks ago was a milestone for medical research. Not long ago, former NIH Director, Dr. Harold Varmus stated: "It is not unrealistic to say that stem cell research has the potential to revolutionize the practice of medicine and improve the quality and length of life." We must provide our scientists with adequate tools to explore this potential and work toward better treatments and cures for people with diabetes, neurodegenerative disorders, spinal injuries, heart disease, and more.

As the Senate debates and votes on its own legislation, I ask you to remember us. Remember the stories we tell about injections and blood tests. About seizures and complications. About tearful nights and worrying parents. About lives altered wholly, completely, devastatingly. About what a cure really means to these courageous delegates.

The progress we have made in research thus far is the result of the strong public-private partnership between the federal government and JDRF. While we are here today asking the federal government to do its part in helping to fund research to get us to a cure, thousands of passionate JDRF volunteers around the country are raising private dollars towards the same effort. In addition, we at JDRF have launched a campaign to raise $1 billion in the next five years to achieve therapies in all of the areas I have just mentioned, and we need the Federal Government as our partner. We are falling short of what the experts say is needed to get us to a cure as quickly as possible. The Congressionally mandated Diabetes Research Working Group recommended a $1.6 billion budget at NIH to fund all of the extraordinary opportunities in this area. However, actual funding today is only at approximately 65% of this goal. We must do better. We can. And we will.

We deeply appreciate the commitment and the hope you have provided us in the past. Madame Chairman and committee members, as I cannot say often enough, diabetes is an all-too-personal time bomb, which can go off today, tomorrow, next year, or ten years from now. That is why we are doing everything in our power—and then some—to accelerate the cure. To achieve our goal of a world without diabetes, we must continue to work together as a nation to fund research, craft policies, and take bold actions that enable progress not merely in small steps, but in great leaps and bounds. On behalf of myself, and of my 150 fellow advocates here today, I thank you, Senator Collins, and your committee, for your unrelenting perseverance and leadership in the effort to make diabetes a national priority. I know that, with all of us working together, we will succeed.

Thank you.

Testimony By
Douglas Wick
Before the Senate Homeland Security
and Government Affairs Committee
June 21, 2005

Thank you, Senator Collins, for your tireless efforts to bring health to the children in this room, and to so many more across the country. When we came to the Children's Congress four years ago, and entered the lobby of the Marriott hotel, we saw a strange but familiar sight. It was all families with diabetes. Every kid or parent held some kind of bag with a blood tester and a few boxes of juice. There weren't so many pumps back then. People were sitting on the chairs in the lobby—pricking fingers, filling syringes, giving injections, and trying to take care of the siblings who never get enough attention. Everywhere I looked, it was like a strange mirror. I saw myself in every father. I was part of a new tribe, a new identity, and it was more defining than my race, religion, or economic status. I was a father of a child with an incurable disease… But let me go back to the beginning.

Six years ago, in the weeks before our daughter, Tessa, was diagnosed, I was a guy with a great sense of possibility. I was preparing a movie about 2nd Century Rome, and I was traveling around the world trying to figure out where we could recreate the ancient Coliseum. We chose the island of Malta and began construction. We brought in an army of artisans from around Europe to start building weapons and wardrobe. We hired animal trainers to train lions and tigers, and a rhinoceros that never made it into the movie.

We had just returned home from Christmas in Hawaii, where the kids loved playing in the warm ocean and sipping those fruit drinks that come in a pineapple. But Tessa, our youngest, had been gulping down whole bottles of Evian in one swoop—and my wife thought something was wrong. "I think she has diabetes," she said.

I thought my wife was insane, but we went to the doctor nevertheless. Tessa took a urine test and the nurse came into the waiting room a few minutes later and gave us our sentence. "You know what you were looking for," she said. "Well…you got it." But that wasn't yet the moment when it really sunk in. That came later that afternoon, when I went to pick up Tessa at school to take her to UCLA hospital.

We loved her elementary school… It was an oasis. It was where we started off as a young, innocent family with our three girls. It was a place where I had learned about being a father; where every teacher was loving; and together, we had watched our children bloom. I had to go to the office to sign Tessa out. And on the form, it asked for the reason for leaving early. I hesitated, and then wrote "medical".

It was the first time I cried.

That night, I sat on Tessa's bed and tried to answer questions about her future. She was eight years old. We used to call her "frat girl" because she was always in a good mood. But not that night.

She asked if she would have to have any more shots.
"Yes," I answered.
"How many?"
"A few a day."
She asked for how long.
"For a while," I said.
"But how long?" she asked again.
And I had to answer, "As of right now, forever."

She asked about pricking her finger. (That hurt more than the shots.)
"How many more times?"
What could I say? "5, 6, 8 times a day…for the rest of your life."
She said she hated God, because he was mean, and she hated her life.

I have never felt like more of a failure. I was her Dad, I was supposed to make things ok. I was supposed to keep her safe. But now, all I could offer her was to live needle to needle. Can you imagine as a father telling your child that her life as they know it is over, and that that the best future you can offer is one of pain and uncertainty? That wasn't going to be her life, and I promised her that somehow, some way…we would find a way to make it better.

That was 6 years ago.

The next week, I had to go back to Malta. My wife was overwhelmed with the new burden of being the doctor, nurse, mother, and father to a sick child. She was terrified that if she made the tiniest mistake in filling the syringe, she might put Tessa into a coma. She got up frequently every night to check her little girl and make sure she was still breathing. Then she got up first thing in the morning to act like everything was normal for Tessa and her two sisters, get them off to school, and then race off to her own job of running a studio.

Our family was at a crossroads. My wife and I felt alone and afraid. Tessa was shy and self-conscious about her disease. She did not want to be different, and made us promise to keep her diabetes a secret. But a few days later, Tessa's 9-year-old sister, in a noble attempt to cheer things up, got her entire class to sign a giant get-well card for Tessa. One girl even wrote, "Tessa, I will never forget you…!" So much for keeping it a secret. But "coming out" turned out to be a blessing in disguise.

The next day at school, Tessa's friends surrounded her as she pricked her finger and tested her blood sugar at lunch—and from then on, they never left her side.

They have walked mile after mile for diabetes, with her two sisters leading the way, they have sold hundreds of glasses of lemonade, squeezed money from their parents, squeezed more money from their parents' friends, their parents' workplaces, and pounded on every neighbor's door with the simple plea, "Our friend has diabetes and we want to cure her." The parents of those friends have not just opened their purses, opened their hearts, but they studied diabetes. They learned more about carbohydrates and dosing, so Tessa would feel safe and always welcome in their homes. And if Tessa ever needed proof of God, she saw it in the shining faces of these fine people.

So our family was managing. We became active in JDRF, and when Tessa was 10, she testified before this committee as a delegate to the Children's Congress. She was feeling very hopeful. Her walk team, Tessa's Troopers, had raised hundreds of thousands of dollars, and she felt proud she could be part of the cure. But as she waited for her turn to testify, she heard details about her disease that we had never mentioned.

She heard about horrible complications that could start to occur to her body after five years with the disease. She heard about kidney failure, amputation...blindness. I sat beside her as she listened. Once again, I could only wonder... What future was I offering my child?

I was still commuting to Malta when a human tragedy occurred on the movie. A great English actor, Oliver Reed, who played a character named "Proximo" who owned and trained the gladiators had dropped dead in the middle of the shoot. He was a great man and it was a terrible loss. And we had a practical problem. We had spent almost $100 million shooting the movie all over the world and now we couldn't finish the movie without him. He couldn't just disappear from the story.

But Hollywood has a history of making the impossible possible—and with the magic of modern technology, we were able to take close-ups from other parts of the movie, bring Oliver back to life, and complete his performance. I was working in a field where, if you can imagine it, you can make it happen. Surely, with that spirit, there was something more we could do for Tessa.

I spoke to the scientists at JDRF, and I spoke to friends who were struggling with other diseases. And they all talked about embryonic stem cell. We started to meet with scientists, and I was amazed at the consensus. I learned that the vast majority of Nobel Prize-winners believed that we were at the dawn of a new age of medicine.

I reached out to my friend Nancy Reagan. My father, Charles Wick, served in the Reagan administration for 8 years. When the Reagans came home to Los Angeles, I had watched as Mrs. Reagan suffered through her husband's decline. I watched her robbed of her Golden Years—the years when she had planned to sit on her California ranch and reminisce with her husband about the likes of all of you.

Mrs. Reagan and I both listened to more scientists who told us about a new kind of Morning in America. It might not happen today or tomorrow, but it was going to come—

a new era of medicine where mankind would shine its light on the shadows that surrounded so many families in the darkened rooms of sick loved ones. And like so many other families, we turned to Washington D.C.

Surely, if the might of the federal government, the power of the NIH (the greatest funder of medical research in the history of the world) put their minds on making embryonic stem cell a reality, the same spirit that put a man on the moon could cure our children's diabetes, and rid the world of so many other dreadful diseases. And we were so grateful as Senators started to speak out about his new science…

Senators Hatch and Specter, Kennedy and Feinstein, Harkin and Smith, and you, Chairman Collins, had done their own interviews with the best scientists in our country, and saw the same opportunity for 120 million Americans with diseases that might someday be cured by this research. We were optimistic.

The night President Bush was to announce his compromise on federal funding for stem cell research our whole family sat around the TV and watched. And as the President announced his new policy and his words sunk in, my wife, who always kept her chin up, started to cry.

We had a sick kid. What could we do?

We co founded Cures Now, and tried desperately to get the message of scientists out to the people. And when we failed in Washington, we co-chaired Proposition 71 in California. And the people spoke, and California will move forward with embryonic stem cell. But no one can make a real dent without the full might of the federal government.

Our five year mark, which once seemed so far away, has come and gone… and Tessa knows enough to be afraid. Now, every time she goes to the doctor, she has to have an eye test and a kidney test. And when she has a stomachache, or tired eyes—every time she goes in for her checkup—she fears there might be scary news.

That is her life.

I am here today to beg you for my daughter's future, and for the future of so many brave children like her. On behalf of all the fathers who have had to watch their children suffer, helpless to protect them, I ask for your help.

Please let me tell my daughter that the Congress of the United States will use its might and heart to pursue the science that can restore her health.

Please let me tell my child that the Congress of this great country will allow the stem cell lines to move the research forward—that you will explore any and all avenues.

We can make movies about men like Maximus who rise up, sword in hand, to fight for good. But Maximus, as good as he is at fighting tigers and emperors, can't do a thing for Tessa's future. She needs a different kind of hero, one wearing not a toga, but a suit or dress. And one who will fight—not in the coliseum—but on the floor of the Senate…for her health and her future.

Gary Hall Testimony

Good morning. It's an honor and a pleasure to appear before this committee today to speak about the ways juvenile diabetes has impacted my life and the need to find a cure as soon as possible. I want to first thank you, Senator Collins, for all you do as Co-Chair of the Senate Diabetes Caucus and for holding today's hearing.

My name is Gary Hall. Most people know me from my swimming achievements. I am a three-time Olympian, 10-time Olympic medallist, and hold the record as the fastest swimmer in United States history and in organized competition worldwide. Admittedly, though, there are probably people who remember me mainly for smashing a guitar on "The Tonight Show" with Jay Leno.

Swimming is in my genes to some extent—my father, Gary Hall Senior, was also a three-time Olympian. I started swimming really seriously when I was 16, and won my first national title two years later at Junior National Championships. I continued my success at the University of Texas in the mid-1990s and swam at the 1996 Olympic Games in Atlanta, where I won four medals. I was feeling really good about my life and where it was going.

But in 1999 I noticed an unsettling change coming over me. I was feeling tired all the time. I had a constant thirst I could not quench. My vision became blurry. Finally, I collapsed one night at a party. That's when I was diagnosed with type 1 diabetes.

The news was a shock, and I was incredibly upset and discouraged. Since there was no history of the disease in my family, you can imagine my disbelief. At the time, I really didn't have a good understanding of diabetes. Like a lot of people, I thought it happened to those who were older, overweight, and didn't get enough exercise. I just didn't understand how this could have happened because I, on the other hand, had spent my entire life eating right, exercising, and minding my health,. I was an Olympic athlete.

After getting out of the hospital, the first thing I did was go home to my computer and look up as much on the disease as I could find. I learned that my pancreas had been attacked by my own immune system, preventing me from converting food into energy. I also learned that I would have to take insulin shots constantly just to stay alive.

As far as competitive swimming went, I had no idea if I would be able to continue. It was an earth-shattering moment for me, because I had gone through so much and felt that I was at my peak physically. I had overcome so much opposition and had put in a long and tough season after the Atlanta Olympics, battling a shoulder injury. My diagnosis came one week before I was to compete in the season's biggest meet—the Spring Nationals—and all I could do was go away to clear my head.

I ended up going to the mountains of Costa Rica with my wife Elizabeth Peterson. She was incredibly supportive in helping me get through that life-altering week. In Costa Rica, I did a lot more reading about diabetes to gain an even deeper understanding of the disease. It was frightening: I read about people going blind, losing their legs and their kidneys to diabetes.

Sometimes the burden of knowing what the disease could do made me feel destructive. At times like this I would swim offshore into shark-infested waters, figuring the sharks would get me. When nothing happened, I would turn around and swim back. But as time passed, I came to terms with my disease. I knew I needed to accept the circumstances, and I decided I had the opportunity to do something to educate people about the horrible effects of diabetes and the desperate need for a cure.

When I returned to the U.S., I got in touch with Anne Peters, a Los Angeles Endocrinologist, who assured me there was no reason to quit competitive swimming. I decided to go back into serious training, but with a new attitude toward everything. If there's a bright side to this, it's that I no longer take anything for granted, in swimming, or in life in general. I live every day as if it's going to be my last.

I'm happy to say that since my diagnosis, I've continued my swimming success, winning four more medals at the 2000 Olympic Games in Sydney, and another two in 2004 at Athens. But I've also realized I can make an even bigger impact for people with diabetes. I had a chance to encourage millions of people living and suffering with the disease. If I could talk about what I went through and what I have still been able to achieve, I might somehow alleviate the feeling of helplessness and defeat that can overcome a person—more often than not a child—when diabetes is first diagnosed.

Soon after my diagnosis, I became active with the Juvenile Diabetes Research Foundation, and have been a staunch advocate for their research efforts. I'm proud to be here today with these 150 amazing children you see sitting before you, telling you why you must do everything in your power to help find a cure through the best science available to America.

Diabetes is always with us—it's not something you can take a vacation from, even for a day. We have to test our blood sugar 10 to 12 times per day and we rely on insulin as life support. It's a delicate balancing act. We have to constantly calculate the number of carbohydrates we eat, the amount of exercise we get, and the number of insulin injections we need to take to keep our blood sugar in normal range. And still, we lead a life in which we are never more than a few minutes away from dangerous changes in blood sugar levels, or the longer term risks of life-threatening complications.

You all have a power that many of us envy—the ability to control public funds and public policy. We need more funding from Congress for diabetes research so that researchers can take full advantage of all the scientific opportunities that currently exist that may lead to a cure. In addition, it is extremely important that you help expand the current policy on federal funding for embryonic stem cell research. Embryonic stem cells represent one of our best hopes for curing type 1 diabetes, and it is disheartening for those of us with disease to see progress delayed by limiting what research can be done with federal funding. When I swam in the Olympics, I was proud to be the best in the field, not for myself, but because I was representing my country. The U.S. has historically been the best and a world leader in scientific discovery. It is incredibly frustrating to see the U.S. falling behind other countries in this promising area of science.

I know first-hand that it is possible to achieve your dreams, even in the face of adversity. I ask you to look around this room at these brave children who struggle to overcome the adversity of diabetes every hour of every day. These kids represent future teachers and doctors, businessmen and businesswomen, mothers and fathers, maybe even a future Olympic athlete or U.S. senator – in short, they represent our future. Please help us to ensure that our collective future is bright by doing all you can to remove the cloud of diabetes that hangs over these children. Join with us in educating Members of Congress about the incredible research opportunities that exist to develop therapies and a cure for juvenile diabetes, including the potential of stem cell research.

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

Recent Developments in Research on Type 1 Diabetes

Statement of
Allen M. Spiegel, M.D.
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 10:00 a.m.
Tuesday, June 21, 2005

Chairman Collins and Members of the Committee, as 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, held in conjunction with the "Children's Congress" of the Juvenile Diabetes Research Foundation International (JDRF). 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, I am pleased to report that we are vigorously pursuing research on type 1 diabetes and its complications. We are gaining insights into the molecular mechanisms underlying disease development, working diligently toward more effective treatment and prevention strategies, and striving for a cure.

Type 1 diabetes – which affects approximately one million Americans – strikes mainly in childhood and adolescence. An "autoimmune" disease, it mistakenly attacks the body's own immune system and destroys the insulin-producing beta cells found in clusters called "islets" within the pancreas. Thus, patients require daily administration of life-sustaining insulin in the form of injections or via an insulin pump. They must also carefully monitor their food intake and physical activity in order to manage the disease. Even with continuous and vigilant disease management, patients are still susceptible to developing serious, long-term complications. It is crucial to continue basic and clinical research to identify new ways to improve the quality of life of type 1 diabetes patients, whether through advances in islet transplantation, insulin delivery, or other avenues. Research is the key to a cure.

The NIH is focused on six broad goals in type 1 diabetes research, developed through a strategic planning process initiated in 2000: (1) to understand the genetic and environmental causes of type 1 diabetes so that we can identify who is at-risk for developing the disease; (2) to prevent or reverse the disease; (3) to develop cell replacement therapy as a cure for diabetes; (4) to prevent or reduce hypoglycemia (low blood sugar) which limits tight control of blood sugar; (5) to prevent or reduce complications; and (6) to attract new talent and apply new technologies to research on type 1 diabetes. The research that we undertake to achieve these goals is supported by our regular appropriation and by the Special Statutory Funding Program for Type 1 Diabetes Research. Earlier this year, the NIDDK convened a panel of external scientific and lay experts in type 1 diabetes and its complications to perform a mid-course assessment of research consortia and networks supported by the Special Program. The panel endorsed all of the ongoing research programs. The panel also made recommendations for future research opportunities that could be pursued with the Special Funds, as well as suggestions for enhancing ongoing efforts to maximize knowledge gained from these important studies. Recommendations from this meeting are valuable to both the NIH and the investigative research community in future priority setting.

Today, research teams are vigorously studying different aspects of the disease, such as understanding associated genetic and environmental factors; the molecular steps that lead to the development of insulin-producing beta cells; how the misdirection of the body's immune system can be corrected to spare the beta cells from immune attack; and how persistent elevation of blood sugar levels leads to the devastating disease complications that damage the eyes, kidneys, nerves, heart, and other parts of the body.

The complexity of the disease requires that researchers from diverse fields attack it from many directions. Through this multifaceted approach, we can attain a comprehensive understanding of the disease process--the foundation for future advances in treatment, prevention, and approaches to a cure.

Relative to each of our six research goals, I would now like to highlight some of the specific advances and initiatives, and also the unique, innovative, and collaborative research consortia and clinical trials networks made possible by the Special Funding Program. 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, the Centers for Disease Control and Prevention (CDC), the JDRF, and the American Diabetes Association (ADA). I will highlight selected examples of our major efforts.

Understanding the Genetic and Environmental Causes of Type 1 Diabetes

Type 1 diabetes is caused by a combination of genetic and environmental factors. Identifying these factors is key to both prevention and cure. Already we know some of the major genes that predispose patients to develop type 1 diabetes, but identification of other key genes will provide new targets for therapy. To this end, we have formed a collaboration to collect genetic material from 2,800 families with two or more siblings having type 1 diabetes. I am pleased to report that we have already recruited over 400 families for this study, and recruitment is ongoing. This collection will be an invaluable resource to investigators in their search for culprit genes.

We know much less about the environmental factors that trigger onset of type 1 diabetes in a genetically susceptible individual. To address this question, an international consortium is using our knowledge of key susceptibility genes to identify infants at high-risk for developing the disease and follow them through adolescence in the search for environmental factors that may trigger disease onset. We call this study "The Environmental Determinants of Diabetes in the Young," or "TEDDY." This long-term study has recently begun recruiting patients. The Special Funding Program has also permitted us to address the important issue of whether rates of development of type 1 diabetes in America are changing over time. There are no comprehensive population-based estimates of diabetes burden among American youth. The CDC and NIDDK are supporting a population-based registry to define the prevalence and incidence of diabetes in children of diverse racial and ethnic backgrounds by diabetes type. This project, entitled "SEARCH," is identifying and following children with diabetes in six regions of the country, to help us understand how the disease strikes and unfolds.

Reversing or Preventing Type 1 Diabetes

To spur the testing of promising new strategies to prevent, delay, or reverse progression of type 1 diabetes, the NIDDK has established a clinical trial network, the Type 1 Diabetes TrialNet, in conjunction with the National Institute of Allergy and Infectious Diseases (NIAID), the National Institute of Child Health and Human Development (NICHD), the ADA, and the JDRF. TrialNet is an international network of investigators, clinical centers, and core facilities that support the development and implementation of clinical trials of agents to slow the progression of type 1 diabetes in

new-onset patients and to prevent the disease in at-risk patients. TrialNet is currently supporting several different protocols, including a study that is testing whether two different immunosuppressive medicines are able to stop the immune system from destroying beta cells in new onset type 1 diabetes.

The NIAID-led Immune Tolerance Network (ITN) is an international consortium of scientists and physicians evaluating novel clinical approaches to achieve a state of immune tolerance for the treatment of autoimmune diseases, asthma, and allergic diseases and the prevention of graft rejection. ITN is currently conducting and developing several clinical trials related to type 1 diabetes and islet transplantation. In addition, ITN and TrialNet actively collaborate to test promising interventions and strategies to prevent or reverse type 1 diabetes.

In another effort, an international NICHD-led trial addresses the role of a specific environmental factor, cow's milk, in the development of type 1 diabetes. This trial, called the "Trial to Reduce the Incidence of Type 1 Diabetes in the Genetically-At-Risk," or "TRIGR," is comparing the development of type 1 diabetes in infants who are weaned onto a hydrolysate of cow's milk formula, in which many of the cow proteins have been broken down, *versus* standard cow's milk formula. TRIGR, which is currently in the patient recruitment phase, was undertaken to confirm data derived from a human pilot study in Finland that was based on evidence from rodent models implicating cow's milk proteins in the pathogenesis of type 1 diabetes.

Preclinical work to explore new approaches to prevent type 1 diabetes is being pursued in the Cooperative Study Group for Autoimmune Disease Prevention, supported by NIAID and NIDDK. This multidisciplinary consortium conducts basic and clinical

research in type 1 diabetes and other autoimmune diseases. Researchers in the Cooperative Study Group have developed molecules that can be used to identify the cells of the immune system that are involved in the development of diabetes. The Cooperative Study Group is spearheading the "NOD mouse Roadmap," a comprehensive analysis of gene and protein expression and immune function during the development of type 1 diabetes in a mouse model of human disease. These studies may potentially define and provide markers to detect early disease onset.

Currently, there is no way to measure ongoing beta cell destruction to quantitatively monitor type 1 diabetes disease progression. In research toward overcoming this major research and clinical barrier, NIH-supported scientists discovered a new, non-invasive imaging technology that enabled them to monitor disease progression due to inflammation in a mouse model. The technology uses a vascular probe containing magnetic nanoparticles that can be detected by magnetic resonance imaging (MRI). Vascular probes have already been successfully used in humans to detect prostate cancer metastases; therefore, this technology has high potential of being translated to the clinic for type 1 diabetes to detect the inflammation caused when the immune system attacks the islet cells. Importantly, if successfully applied to type 1 diabetes, this technology can facilitate clinical trials of new therapeutic agents.

Recent exciting reports have suggested that the naturally produced hormone insulin is itself the critical initiator of the autoimmune destruction of pancreatic beta cells leading to type 1 diabetes. Although patients with the disease are known to have antibodies directed against insulin, and these antibodies are used to identify individuals at risk for the disorder, it was unclear whether insulin itself was the "key" autoantigen that

triggers the autoimmune attack. Two new lines of evidence, one in a genetically engineered mouse model of diabetes and the other using isolated T-cells (a type of cell in the immune system) from pancreatic lymph nodes of people with and without type 1 diabetes, strongly suggest that insulin is the key protein required for initiating the development of type 1 diabetes. This finding has important implications for development of new therapies. The NIH recently completed a clinical trial in which individuals at risk for type 1 diabetes were given insulin orally in an attempt to desensitize them to this potential trigger of autoimmunity. Although there was no benefit in the entire group of people studied, additional analyses have suggested that a subset of the study population--the group with the highest titers of antibodies directed against insulin--may have benefited from the therapy. We will soon begin a clinical trial to test whether insulin administered orally in this population can delay or prevent onset of type 1 diabetes.

Developing Cell Replacement Therapy

Insulin therapy, via daily injections or a pump, 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. A breakthrough protocol pioneered in Edmonton, Canada, yielded short-term insulin independence in up to 90% of patients with type 1 diabetes who received islet transplantation. This protocol was subsequently replicated in the NIDDK intramural research program and then in a multi-center international trial conducted by the ITN at nine sites in the United States, Canada, and Europe. Although the success rate varied among the centers, this study showed that the

new procedure can relieve some patients of the burden of daily insulin injections. However, the immunosuppressive drugs of the new protocol do carry significant side effects, and the long-term results have yet to be established. The NIDDK-supported Collaborative Islet Transplant Registry (CITR) published its first annual report last year. The report included data from 12 medical centers in the U.S. and Canada that performed islet transplants on 86 patients. The report showed that, at one year after the last islet infusion, 58 percent of recipients no longer had to inject insulin but were relying on the transplanted cells to meet their bodies' needs for the hormone. To further bolster research efforts on islet transplantation, the NIDDK and NIAID co-sponsor a major new Clinical Islet Transplantation (CIT) consortium. The group consists of five clinical centers in the U.S., Canada, and Sweden. The CIT will also conduct a clinical trial on islet transplantation in Medicare recipients as mandated in the Medicare Prescription Drug, Improvement, and Modernization Act of 2003.

A major barrier in the field of islet transplantation that limits its widespread use in clinical application is an inadequate supply of islets. NIDDK has teamed with the National Center for Research Resources (NCRR) and the JDRF to form the Islet Cell Resource Center consortium to provide human islets for both clinical transplantation protocols and basic research studies and to optimize the production methodologies. 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. This collaboration is providing scientists with access to information, resources, technologies, expertise, and reagents that are beyond the means of a single research effort. It represents

an unprecedented initiative to delineate each step in the pathway that leads to formation of beta cells that have the unique capacity for appropriately regulated insulin secretion and to develop methods to create ample supplies of these vital cells. Researchers in this consortium have generated a research tool, called Human PancChip 1.0, which contains over 12,000 human genes that are expressed in human pancreatic islets. They have also developed a Mouse PancChip 6.0, which contains over 13,000 mouse genes expressed in the pancreatic islets, and a tool called PromoterChip BCBC 3.0, containing regions controlling expression of 3,500 mouse genes involved in beta cell development and function.

The NIDDK is also supporting a new initiative to build on recent research demonstrating that beta cells can divide to produce more beta cells (or "regenerate"). If beta cells can be "coaxed" to form more sister cells, then this could be a potential therapy to reverse new onset type 1 diabetes or lessen the number of donor pancreata required for transplantation. In addition, the NIAID and NIDDK are sponsoring a new initiative to support studies of methods for transplanting islets from pigs to non-human primates. This is one aspect of xenotransplantation research, which involves the transfer of cells, tissues, or organs from one species to another.

A very exciting result was recently reported by scientists in the NIDDK Intramural Research Program. These scientists have induced human cadaveric insulin-producing cells to revert to islet precursor cells, proliferate, and then differentiate into islet-like cells again in which insulin production is regulated by glucose levels. With additional research, this work may help to clarify the natural lifecycle of the beta cell and may eventually have implications for cell replacement therapy.

Another barrier that limits widespread use of islet transplantation is the lifelong immunosuppressive drug treatments that are currently required to prevent rejection of transplanted islets, as well as recurrence of the underlying autoimmunity that caused type 1 diabetes initially. Both the Immune Tolerance Network and the Clinical Islet Transplantation Consortium are testing approaches to altering the immune system in human transplantation studies that may be safer or have fewer side effects than the drugs currently used. Another research consortium jointly led by NIAID and NIDDK, the Non-human Primate Transplantation Tolerance Cooperative Study Group, is evaluating the safety and efficacy of novel methods to induce immune tolerance to transplanted kidneys and islets in non-human primates to achieve long-term graft survival. This tolerance induction approach would avoid lifelong immunosuppressive therapies that can have deleterious and often life-threatening side effects.

Through this multifaceted bench-to-bedside approach, combining shared resources, collaborative fundamental basic research, preclinical development in animal models, and multicenter clinical trials, the NIH is pursuing every avenue toward progress in islet transplantation that can directly translate into potential therapies for type 1 diabetes patients.

Reducing or Preventing Hypoglycemia in Type 1 Diabetes

Perhaps the most distressing, acute complication in patients with type 1 diabetes is hypoglycemia, or low blood sugar. 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. Hypoglycemia is a particular problem in young children, who may not be able to realize and communicate their symptoms to parents. For these reasons, a key goal of ours is to attain greater understanding of hypoglycemia and develop new approaches to mitigate this problem. We have established research programs to address these important issues.

We have established a network, called "DirecNet," which is led by NICHD, to investigate the use of technological advances in the management of type 1 diabetes in children and to develop a better understanding of hypoglycemia. DirecNet has recently completed a study examining the impact of exercise on the incidence of nocturnal hypoglycemia in children with type 1 diabetes. The data, which are still being analyzed, indicate that exercise affects glucose levels in children over a longer period than previously appreciated; there is a strong association between exercise and delayed overnight hypoglycemia.

Because of the importance of the brain in sensing blood sugar levels, the NIDDK, in collaboration with National Institute of Neurological Disorders and Stroke (NINDS), is supporting an initiative to promote research on how the brain and other critical tissues sense and respond to hypoglycemia; understand the effects of hypoglycemia on brain function; and develop more effective methodologies to prevent hypoglycemia. These approaches are all directed toward improved management of the disease.

Preventing or Reducing the Complications of Type 1 Diabetes

The complications of diabetes affect virtually every system of the body. Diabetes increases the risk of blindness, kidney failure, chronic wounds and skin ulcers, nerve pain

and other neurological problems, lower limb amputation, heart disease and heart attacks, stroke, high blood pressure, gum disease, and pregnancy-related problems. Diabetes and its complications can shorten average life expectancy by up to 15 years. However, the good news is that patients with type 1 diabetes are living longer than ever before. Data from Allegheny County, Pennsylvania, have shown that the long-term survival of children with type 1 diabetes has improved over time, most likely representing better glycemic and blood pressure control since the early 1980's. In addition, clinical trials, including the Diabetes Control and Complications Trial (DCCT), have demonstrated that intensive control of glucose is extremely effective in preventing complications. Long-term results from the follow-on study to the DCCT, the Epidemiology of Diabetes Interventions and Complications (EDIC), now show that a finite period of good glucose control provides benefits that endure more than a decade after the trial ended. Therefore, further reductions in mortality can be expected as the findings of this landmark study are incorporated into practice.

The NIDDK continues to foster exciting new opportunities for the research community to intensify the study of diabetic complications. Support of these efforts comes from both our regularly appropriated funds and the Special Statutory Funding Program for Type 1 Diabetes Research.

Patients with type 1 diabetes have a four- to nine-fold increased risk of developing cardiovascular disease (CVD), and 75 percent will die from CVD, the leading cause of mortality in these patients. The National Heart, Lung, and Blood Institute (NHLBI) and the NIDDK have spearheaded a new initiative that supports basic and clinical studies to increase understanding of the effects of type 1 diabetes and its

metabolic complications on the early development and accelerated progression of CVD in these patients. New studies will also evaluate imaging techniques that might be used as endpoints in future clinical trials, reducing the time needed to see an effect of therapy.

The NIDDK, in collaboration with the NINDS, NHLBI, and the National Eye Institute (NEI), has sponsored a new initiative to stimulate research on the abnormal formation of new blood vessels observed in the development of complications of type 1 diabetes. Research on blood vessel formation (angiogenesis) has already yielded new therapies for cancer, and we are conducting basic and clinical research on angiogenesis in order to develop therapies, biomarkers, and imaging tools to improve the diagnosis and treatment of diabetic complications.

Another focus of research has been the development of animal models that faithfully replicate development of complications of diabetes in humans. This type of work is being done through the Animal Models of Diabetic Complications Consortium, which is supported by the NIDDK and the NHLBI. The Consortium has already developed a number of promising models for complications involving the heart, kidney, and nervous system. Development of animal models is essential for preclinical drug development.

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. For example, DNA collected from patients in the DCCT/EDIC study and their family members is being analyzed in order to find genes associated with the development of diabetic complications. The CDC and JDRF-led Genetics of Kidneys and Diabetes Study (GoKinD) has accrued the largest single collection of biosamples and data for research on

the genetic causes of kidney disease in type 1 diabetes. Researchers from this consortium recently announced the availability of these biosamples and data to the broad research community so that investigators could conduct studies to identify genetic risk factors for diabetic kidney disease. In addition, the Special Funding Program has allowed the Family Investigation of Nephropathy and Diabetes (FIND) study to expand its focus to include the genetic determinants of diabetic retinopathy. Identifying the genetic basis of disease complications will reveal new targets for therapy.

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

Type 1 diabetes research spans an extraordinarily broad range of scientific disciplines. For this reason, a cadre of exceptionally talented and dedicated researchers is needed to bring expertise to bear on understanding, treating, preventing, and curing type 1 diabetes. As more research is being done in the laboratory, or at the "bench," there is a need to rapidly move those results into the clinic, or "bedside," to benefit patients directly. For this reason, the NIH is sponsoring "bench-to-bedside" initiatives, in which teams of basic scientists and clinical researchers are successfully working together on translational research projects focused on type 1 diabetes. The funded research projects represent a broad spectrum of science related to the disease and its complications. Another important translational research effort that is supported by the NIDDK and the National Cancer Institute (NCI) is the Type 1 Diabetes-Rapid Access to Intervention Development (T1D-RAID) program. T1D-RAID provides resources for pre-clinical development of drugs, natural products, and biologics that will be tested in type 1

diabetes clinical trials. The goal of T1D-RAID is to facilitate translation from the lab to the clinic of novel, scientifically meritorious therapeutic interventions for type 1 diabetes and its complications.

In addition, we are supporting the research training and career development of pediatric endocrinologists. Due to heavy clinical demands, it is especially challenging for pediatric endocrinologists involved in diabetes care to also pursue research careers, yet their clinical expertise is invaluable to type 1 diabetes research. The NIDDK, in collaboration with the ADA and the JDRF, is therefore supporting research training and career development programs in pediatric endocrinology to increase the number of independent investigators who can contribute to research in this area. This program has already seen success: seven of the trainees have successfully competed for an individual NIH career development award, and two of the trainees have attained tenure-track faculty positions at other universities.

New and innovative technologies are continually being developed. Examples include technologies to describe the dynamics of protein interactions ("proteomics") and technologies to study cellular metabolites, such as lipids, amino acids, and carbohydrates ("metabolomics"). In order to capitalize on these new and emerging technologies, the NIDDK has developed an initiative to support studies on proteomics and metabolomics technologies to enhance understanding of type 1 diabetes and its complications. These types of studies, which can be performed at different times during disease development, could lead to invaluable insights into the etiology and development of type 1 diabetes and its complications.

Conclusion

I am grateful for the opportunity to share with you these few highlights of ongoing research efforts. In order to inform the priority-setting process for NIH-supported type 1 diabetes research in the years ahead, the NIDDK is spearheading a new strategic planning effort under the aegis of the statutory Diabetes Mellitus Interagency Coordinating Committee (DMICC). With extensive input from external scientific and lay experts, the Plan will summarize recent advances in the field, and set forth short-, intermediate-, and long-range objectives for research on type 1 diabetes and its complications. The Strategic Plan is expected to be released next summer.

Diabetes is a devastating illness for patients and their families. We continue to be inspired by the dedicated efforts of individuals affected by the disease, and by organizations that represent them, such as the Juvenile Diabetes Research Foundation International. We are grateful for the full range of appropriations 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 type 1 diabetes patients throughout America 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 am pleased to answer any questions you may have.

Good morning Senator Collins and members of the Committee.

My name is Stephanie Rothweiller. I am 11 years old and live in Falmouth, ME. These days, all I hear is "Steffi, what's your blood sugar?" or "Steffi, how much insulin are you going to give yourself?" Well, I was not always this way. I got juvenile diabetes when I was five and a half. It was the week before Christmas 1999. Thankfully my family and I caught it early. Once you saw me it wasn't hard to see that I was really sick. I had dark circles under my eyes, I had lost a lot of weight, and I looked like a twig. I was also always really tired, thirsty and I couldn't stop going to the bathroom.

Let me tell you about my typical day living with diabetes. When I wake up, the first thing I do is check my blood. If it's out of range, that determines what I can eat for breakfast. When I'm at school, I call the nurse three times a day – at snack, lunch, and before I go home to report my blood sugar numbers. I also have to carry a blood testing meter with me at all times. On school trips, one of my parents has to come with me and if that's not possible, one of the school nurses has to go. My friends have learned what to do if I become unconscious and how to help me.

Eating is a big problem. If my blood sugars are too high, I can't eat with my family and have to wait 20-30 minutes for the insulin to work. I am very active with tennis, Irish Dancing, and softball. My whole family has learned how to count carbohydrates, know their glycemic index and evaluate the impact of my exercise on my blood sugar levels. Every day at every meal, activity, and during the night, my parents are calculating and projecting my blood sugar levels to keep me in good control.

At first, I thought diabetes was like a cold, and that it would be gone in a week or so. Little did I know that I would have it the rest of my life. I actually can't remember having a normal life without diabetes.

I have learned a lot about life that I might not have if I didn't have diabetes. One thing I have learned is how fortunate I was to have caught the diabetes early. I also know how lucky I am to have parents who give up their nights, weekends, and every hour of every day to take care of me and make sure I stay in tight control of my blood sugar levels so I stay as healthy as possible. I am also lucky to have access to the best technologies – I wear an insulin pump which makes it easier to stay in good control.

I know that it's possible to find a cure for diabetes – think about all of the miraculous advances that have occurred in our time. And I know that a cure will only come from research. So I ask each member of this Committee and every Member of Congress to do all they can to support promising research that will bring us to a cure as quickly as possible. Senator Collins, I owe you a special thanks for all you have done to support research and policies to bring us closer to a cure for diabetes. I am so lucky that you are my Senator.

I can't remember what my life was like before diabetes, but I certainly can imagine how wonderful it would be without it!

My name is Ethan Falla. I live in New Britain, Connecticut, and I am like most boys my age. I love to play sports, ride my bike, play video games, and Irish dance. The difference between me and all of my friends is that I have juvenile diabetes.

I have a really good memory and can remember things most people forget. I can remember when I was three like it was yesterday. I sometimes wish that I could forget certain times in my life, like the day that I was diagnosed with diabetes. I was really afraid of the shots and the way that everyone acted. My mom couldn't stop crying and my dad looked really worried. I remember running behind the couch to hide from my mom and dad when they had to check my blood sugar level and give me my insulin. Those days were the hardest. One night when I was four, I told my dad that by the time I was sixteen, there would be a cure for diabetes. Well, that only leaves three years for a cure to be found.

The reality of diabetes really hit home for me two years ago when my younger brother Aiden was also diagnosed with diabetes. I felt really bad because I thought it was my fault. I cried the whole time he was in the hospital. I just couldn't imagine him having to go through all the finger sticks and shots, too. He was only 10 months old and it wasn't fair.

Although I worry about myself, I worry more about my little brother because he is so little and so many things can go wrong.

The dream I have for me, my brother, all the kids in this room and around the world who have diabetes is simple. At night, I dream of a world where we don't have to count our carbohydrates; where we don't have to prick our fingers and give ourselves insulin shots; where we don't have to worry every day about all of the complications of diabetes. A world where we can all just be kids, free of diabetes.

Research foundations like the JDRF are working to make that dream a reality with support from Congress. If we all work together to find a cure, it will happen. Together, we will be known as the people who cured diabetes.

Good morning. My name is Aaron Jones and I am 10 years old. I was diagnosed with juvenile diabetes when I was 4 years old and I have been living with this disease for 6 years. My older sister Shaynah has just been diagnosed, too.

My mom doesn't know why or how we both got juvenile diabetes, because we are the only people in our family who have it. Even though I am younger than Shaynah sometimes I feel like her big brother because every time she needs help understanding her diabetes I tell her what I know. Shaynah gets nervous because she knows that I sometimes have seizures because of my diabetes and she doesn't want to get them, too. We also both worry about our older brother Justin and our younger sister Kara. We worry that they may get diabetes.

Living with diabetes is the pits. I live with it because I have to. The part I really don't like is taking insulin shots and always checking my blood sugar. It can be painful and sometimes I just don't feel like doing it. I also feel awful and tired when my blood sugars get too high or very low. I just want to feel like a normal kid without pricking my finger two thousand times each year or injecting myself with insulin eleven hundred times a year.

Finding a cure is what keeps me smiling every day. Please help us find a cure in time to help me and my sister and all the kids who never get a day off from diabetes.

I am Shaynah Jones, Aaron's older sister. I am 13 years old and have had juvenile diabetes for two years. Having two kids with diabetes in one family really takes it toll on everyone.

For Aaron and me, managing our diabetes takes a lot of time away from our family. If we are with our family at a function, we have to stop what we are doing and check blood sugars or go to the bathroom to inject insulin. If there is a high or low blood sugar with one of us, then sometimes we have to cancel what we are doing so our parents can take care of us. Especially Aaron – if he gets too low he has seizures and that can be a real emergency.

The emotional stress of this disease is horrible on our entire family. If one of our blood sugars is out of control it seems like the whole family holds their breath until we get it back in line. If we misplace one of our meters, my mom gets upset because our numbers won't be right for the doctor. It can become difficult because we are stressed out all of the time worrying about whether we have everything relating to our diabetes in order, not to mention what we worry about just being kids.

Diabetes is so rough on my whole family. It is heartache and heartbreak every day! Still, we all wake up every morning grateful for a new day and with a positive outlook on life. We are not giving up!

My name is Katie Clark – most people know me as Ellie Clark's mom. Ellie will be five next month. She is a sweet little girl, who has been barraged since birth with complete strangers touching her blond curly hair. We thought that was going to be her burden to bear. We were wrong.

Ellie was diagnosed with juvenile diabetes last year. To be exact, we found out at 4:45 p.m. on August 30th. We had spent weeks denying the symptoms. And with those words every parent here today will tell you devastated them, "there is glucose in her urine", our lives were turned upside down. She was diagnosed on what was supposed to be her first day at a new preschool. We spent my 30th birthday at the hospital and got through the denial in a few hours which most would say is really fast. I spent a better part of the next two weeks in a depression. I was also so very angry. Anger is not the most common emotion at the beginning; however, we are not new to the disease. I have had juvenile diabetes for 28 years.

It's only been 10 months. Ellie has calluses on her fingers. Her bottom has scar tissue from her insulin pump sites. She's had 1494 finger pricks. Her blood has been drawn five times with two nurses holding her down and one drawing the blood. She's had 98 pump site changes. It's only been 10 months. All I want is to give her back the life she was living before August 30th and a future brighter than one clouded by diabetes. I would give everything I have, even my own life, for Ellie not to have to endure another day of this dreadful disease.

One of the hardest things for me is knowing first hand of the challenges that Ellie will face as she grows up. 15 years. That is how much less of an average life span Ellie and I have been dealt. And diabetes is something that affects every detail of every day of your life. It's not only about the finger pokes or the worry about whether you have enough supplies or when my next meal will be. The happiest days of my life have been affected – details the average person wouldn't think about. I had an insulin reaction on my wedding day and not only did my hair that I had just gotten styled get messed up, but I ended up with orange juice on my veil. For each of my pregnancies, I saw my high-risk pregnancy OB once a week and in the months leading up the their births, I saw the doctors twice a week. In labor I was forced to check blood sugars every hours, and after birth the nurses whisked my newborns away to check their blood sugars and force a tube down their throat to get glucose into their stomach because their little bodies

were used to producing too much insulin. This is not the life I dream of for my precious daughter.

The worst part of diabetes and the biggest impact it has had on my life is when Ellie is getting tucked into bed at night. That is when she asks the questions that are unanswerable like "Mommy, why do some people get diabetes and some people don't?" Or she says things like "Daddy, I don't want diabetes anymore". This is when I realize that we must do everything we can to find a cure for this disease. My sweet little girl with the blond curls deserves it.

My name is Lauren Stanford. I'm 13 years old and live in Plymouth, Massachusetts. I've had diabetes for eight years.

Before I tell you about my story, I want you to think about something. In this room right now, you see 150 kids with juvenile diabetes – that's 150 pairs of hands. Consider that, on average, each of these kids needs to prick their finger and draw blood for a glucose test six times a day. Add to that the fact that we've each had juvenile diabetes for an average of five years. If you do the math, you will see that means that these 150 pairs of hands have pricked their fingers more than 1.5 million times and have spent over $2 million on just their test strips. If you look out into this hearing room, you will see the evidence of 1.5 million times that diabetes has invaded a life. And we are just a snapshot of the millions of kids who suffer with diabetes. So take my story that I am about to share with you and multiply it, just like we did those finger pricks, and you will begin to understand the toll this disease takes on our world.

My story is about always working to win and finding out that with diabetes, in the end, you can almost never beat it. I am an A student. I compete on swim and tennis teams and am an expert skier. That's because I expect the best from myself. For seven years, it was the same with my diabetes. I was the 'model patient'.

But last fall something happened; I got sick of it. I wanted so bad to be like my other teenage friends who were free to worry about nothing more than boys and movies and fun. I wanted to buy a slushie without having to do algebra. So I started to lie to my mom, skipping blood checks and making up numbers. It got worse, and pretty soon I was skipping insulin doses, too. I knew I was in trouble, but I couldn't stop. I'd go to bed at night and say "tomorrow will be a new day. I'll try hard and it will be fine". But the next morning, I just couldn't go back to my life with diabetes. I was sick, but in a strange way I felt free. So I kept lying and not taking care of myself. On October 30th I collapsed and was rushed to Children's Hospital in Boston where I was put in the ICU. I could have died. Diabetes almost got me.

You might ask what would make a smart girl do such a stupid thing? I was completely burned out on diabetes. I felt like I had been through a medical test every few hours for the past seven years, and I just couldn't stand the endlessness of it anymore. It seemed like as hard as I tried, there were always days I was high or low. I couldn't be perfect.

I now know that this is not the way to win this battle. I have made myself a vow to be brave and to not give in to this unforgiving disease. And I ask you, Members of Congress, to do the same. When it is tough to make a decision about supporting additional funding for diabetes research or expanding the current stem cell research policy, think of me and all of the kids in this room today. Don't give in because it's hard; rather, like I had to do, face the hard work and difficult decisions that will lead me, the kids in this room, and the million of people around the world to a cure for diabetes. That's the only way we will win this battle – with your help. We kids cannot beat it on our own. We need you and your support.

Testimony of
James Schlicht
Chief Government Affairs & Advocacy Officer
American Diabetes Association

To the United States Senate Committee on Homeland Security and Governmental Affairs

Juvenile Diabetes: Examining the Personal Toll on Families, Financial Costs to the Federal Health Care System, and Research Progress Toward a Cure

June 21, 2005

Contact:
Megan Gordon
National Director, Federal Government Affairs
American Diabetes Association
703-299-2060
mgordon@diabetes.org

On behalf of the American Diabetes Association, I would like to thank the Chairwoman, Senator Susan Collins, for her leadership on diabetes issues as Co-chair of the Senate Diabetes Caucus. I would also like to thank both the Chairwoman and the Ranking Member, Sen. Joe Lieberman, for allowing the Association the opportunity to provide written testimony today on the impact type I diabetes is having on our nation.

I would also like to commend our partner, the Juvenile Diabetes Research Foundation, for testifying today on the importance of these issues. As the nation's leading nonprofit health organization providing diabetes research, information and advocacy for all people with diabetes, the American Diabetes Association has a significant interest in issues related to type 1 diabetes, formerly known as "juvenile diabetes," as well as the other two main types of this disease.

> Type 1 is most often diagnosed in children and young adults and may account for 5 percent to 10 percent of all diagnosed cases. Type 1 is a disease in which the pancreas no longer produces insulin because the body's own immune system has destroyed insulin-producing cells called islets. People with type 1 need regular blood-sugar testing and daily insulin shots to help their bodies break down and utilize food properly. The scientific nomenclature of this disease changed about a decade ago when researchers determined that type 1 was not limited to children. Indeed, while the majority of diagnoses are made in children, the diagnosis is also made in a significant number of adults. Part of the reason that the name was changed was because calling the disease "juvenile diabetes" was leading to improper diagnosis in adults.
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> In type 2 diabetes, which accounts for 90 to 95 percent of diabetes cases, the body fails to properly manufacture or use insulin. Until recently, type 2 was primarily seen in people over 50 years of age. This has changed as younger and younger Americans –now including children– are now being diagnosed with this type of diabetes.
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> Finally, approximately 4 percent of all pregnant women are diagnosed with gestational diabetes. Gestational diabetes usually goes away after pregnancy, but gestational diabetes puts these women at significantly increased risk of type 2 diabetes later in life. Additionally, children whose mothers have gestational diabetes are also at much higher risk of developing type 2 diabetes later in life.

Current data collection efforts rarely distinguish between the different types of diabetes, so the remainder of my testimony talks about diabetes as a whole. For example, when you look at all forms of diabetes, there are approximately 42,000 people suffering from diabetes in each congressional district; alarmingly, the number of people living with diabetes in this country is growing at a shocking rate. Between 1990 and 2001, diabetes prevalence in the United States has increased by more than 60%. *The number of Americans with diabetes is now growing at a rate of 8% per year and is the single most prevalent chronic illness among children.* Because the systemic damage that diabetes imposes throughout the body, it is no surprise that the life expectancy of a person with the disease is 10-15 years less than that of a person without diabetes.

Diabetes is also very costly to this country. In fact, one out of every 10 health care dollars is spent on diabetes and its complications. In addition to the $132 billion (2002 dollars) attributable directly to diabetes each year, this disease is a significant cause of heart disease

($183.1 billion each year), a significant cause of stroke ($43.3 billion each year), and the leading cause of kidney disease ($40.3 billion). Diabetes is also the leading cause of adult-onset blindness and non-traumatic lower limb amputations.

Finding a cure for diabetes would undoubtedly reduce the cost to our nation as well as improve the lives of millions of Americans. The American Diabetes Association funds several different research studies that are evaluating potential cures for people with type 1, advocates for a significant increase in federal funding for diabetes research at the National Institutes of Health, and strongly supports the "Stem Cell Research Enhancement Act" (S.471) which would expand the number of stem cell lines that are eligible for federally-funded research while also implementing strong ethical guidelines to improve federal oversight. This legislation would not only provide hope to patients with type 1 diabetes but also for all 18.2 million people with diabetes in need of significantly improved treatment options. We are very pleased that the U.S. House of Representatives has passed this legislation and are working with the bill sponsors in the Senate.

While the Association is committed to finding a cure and better treatment options, we also recognize that many of the current costs could be reduced by increasing awareness about the disease and improving prevention. By prevention, we mean not only preventing or delaying the onset of type 2, but also prevention complications among all people with diabetes. For example, simple preventive care such as routine eye and foot exams, self-monitoring of blood glucose, and improved glycemic control would reduce complications –and their costs– significantly. Specifically, eye disease, kidney disease and amputations could be reduced between 50 and 90 percent, thereby saving federal critical-care funding.

In addition to the more than 200,000 Americans who die from diabetes and related conditions each year, countless others take sick days from work and/or become unemployed because of the complications from diabetes. Much of this is preventable. Most of these individuals can re-join the workforce as productive employees if given access to awareness programs and adequate care.

The American Diabetes Association strongly supports increasing funding for the Centers for Disease Control & Prevention's (CDC) Division of Diabetes Translation (DDT) because this federal program is currently our front-line defense against increase rates of diabetes and its complications. DDT currently provides outreach and education efforts aimed at reducing diabetes and related complications in 26 states. While the Association strongly believes that significant funding is needed to fully fund programs in all 50 states, we are advocating an increase of $10 million for Fiscal Year 2006 in recognition of the current budget realities. An increase at this level will allow DDT to start programs in another 7 states.

There is no doubt that DDT can be successful in reducing the complications associated with diabetes when given the appropriate tools. For example, Minnesota is one of the funded 26 states and has been successful in developing a unified, statewide strategic plan that resulted in more than 800,000 Minnesotans receiving educational messages about controlling and preventing diabetes. **As a result of these programs, it is estimated that Minnesotans have seen a 40 percent reduction in complications leading to blindness, kidney failure and amputation, and a reduction in heart-related complications of as much as 50 percent.** Our goal is to give more states the opportunity to have similar successes.

In closing, the Association commends Senators Collins and Lieberman for their foresight in holding today's hearing to hear more about the impact diabetes has had on our country and ways in which we can decrease the significant costs. The Association strongly believes that our country must continue on the path to finding a cure, but must also take the necessary steps to put in place what we have already learned about prevention.

On behalf of the 18.2 million Americans with diabetes – a disease that crosses gender, race, ethnicity and political party; a disease that is among the most costly, debilitating, deadly and prevalent in our nation; and a disease that is exploding throughout our nation – thank you for the opportunity to submit this testimony. The American Diabetes Association is prepared to answer any questions you might have on these important issues.