STATEMENT OF MARY TYLER MOORE INTERNATIONAL CHAIRMAN, JDRF

Before the Senate Homeland Security and Governmental Affairs Committee

June 21, 2005 10:00 a.m. 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.