

**Testimony of Ms. Mary Tyler Moore
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At the Hearing entitled

**“The Juvenile Diabetes Research Foundation and the Federal
Government: A Model Public-Private Partnership Accelerating
Research Toward a Cure”**

Tuesday, June 19, 2007, 9:30 a.m.

Before the

Senate Committee on Homeland Security and Governmental Affairs

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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