

**Testimony of**

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

**At the Hearing Entitled**

**“Type 1 Diabetes Research:  
Real Progress and Real Hope for a Cure”**

**Wednesday, June 24, 2009  
9:00 a.m.**

**Before the**

**Senate Committee on Homeland Security and Governmental Affairs**

Good morning Senator Collins, Senator Lieberman, and members of this committee.

As International Chairman of the Juvenile Diabetes Research Foundation, I want to thank you for your leadership and commitment to sustaining robust federal funding for diabetes research. Your efforts are resulting in real progress and real hope for millions of Americans personally affected by type 1 diabetes.

I am honored to be accompanied today by all of the terrific young delegates and special guests who surround us in this chamber and join me on this panel. We sincerely thank you for providing us the opportunity to testify about an issue that we know all too well – life with type 1 diabetes and our hope for a cure.

Ten years ago, Tommy Solo -- an 8 year old JDRF volunteer from Boston -- had a big idea. Tommy was frustrated with his Type 1 diabetes and was looking for something he could do to move us closer to a cure. He thought, “Why not have kids with diabetes, like me, go to Washington, D.C. and tell Congress we need their help?”

Even at age 8, Tommy understood, intuitively, what JDRF’s Moms and Dads and people personally affected by Type 1 had always known: When confronted by challenges to our personal well-being, the solution starts with our willingness to share our stories, make our case, and ask others to join us as partners in our cause.

Senators, we are grateful to you for welcoming our Children’s Congress delegates to these rooms over the years since, for listening to us, and for remembering us and our partnership for a cure with your legislative leadership and support.

But because our work, together, will not be done until we have found a cure, here we are again today. More than 150 child delegates from across the United States and several countries join me to participate in the 10<sup>th</sup> anniversary Children’s Congress, acknowledge the remarkable progress we’ve made, and reflect on the challenges which remain.

As many of you know, I have endured the ups and downs of type 1 diabetes for almost 40 years. And as all of these children and their families can attest, every single day with type 1 diabetes tests our will and determination to live a normal life. Each day I check my blood sugar several times, count carbohydrates in what I am going to eat, take multiple insulin injections, and exercise.

Even with this structured regimen, terrific doctors, and the loving support of my husband Robert, my blood sugars can still fluctuate tremendously. If I don’t take enough insulin, my sugars can go dangerously high – which, over time, can lead to long-term complications such as blindness, nerve damage, kidney failure and a host of other serious ailments. If I take too much insulin, my sugars can drop frighteningly low, which can acutely lead to feeling really sick and cold and anxious and lost and, in turn, lead to unconsciousness, seizures or worse.

I actually had my first hint of impending long-term complications of diabetes in 1981 – after only about 11 years of having the disease. I truly wish the technology that is available today and the understanding that we now have about how to manage diabetes was available when I was first diagnosed. Back then, to get an idea of what your blood sugar was, we relied on urine tests. They were not all that accurate, timely or helpful. I did the best that I could to control my blood sugars, but it was really difficult. And my doctors, even if they wanted to, couldn't really push me to do what was --as a practical matter -- not really doable. As a result, by 1981, I was well on my way to having vision-threatening diabetic retinopathy.

I wasn't alone. Diabetic Retinopathy is the leading cause of adult blindness.

I was terrified. How was I to continue doing the things I loved most – dancing, horse back riding, window shopping on Madison Avenue – if I went blind?

At the time I was diagnosed with Type 1, there was no simple treatment to prevent diabetic retinopathy. But when my retinas started to show evidence of damage due to diabetes, there was, thankfully, a new procedure available called “laser photocoagulation” that was able to keep me from going blind.

But not without costs. Because, in order to halt the progression of diabetic retinopathy and save your “central vision,” the laser must literally burn holes in your peripheral retina.

So the combination of the disease itself and its vision preserving treatment has resulted in my having a difficult time seeing when it is dark or when I'm in a room that isn't well lit. My peripheral vision, and vision below my waist, is also very limited. Simple things like navigating curbs on a street or changes in levels between rooms in an unfamiliar home, or seeing one of my precious pups taking a nap in an unusual place, or recognizing a welcoming hand that's been patiently waiting for me to shake it, are challenges of the first order!

For years, I kept the full impact of my diabetes under wraps. While people knew I had type 1 and that I was a long-time, outspoken advocate for a cure and International Chairman of JDRF, the general public didn't know the extent to which diabetes affected my day-to-day life.

But recently, at the prompting of a lovely young woman named Diane Revzin, and her father, Phil, I wrote a book about living with diabetes. Diane is a 19-year-old fellow diabetic; Phil is a book publisher.

My book is entitled “Growing Up Again – Life, Loves, and Oh Yeah, Diabetes.” It chronicles my battles with type 1 in the context of my broader life experience and career, and I hope it informs and even inspires people facing similar challenges. Though I am not here to promote my book, I'm happy to note that all my proceeds from its sale will be donated to JDRF to advance research for a cure.

As JDRF's International Chairman, I am, actually, just one volunteer in an army of determined moms, dads, children, loved ones and friends personally affected by diabetes. We are not sitting back waiting for the cure. These children before you have built lemonade stands, created walk teams, held bake sales, and organized car washes. Most importantly, they have spoken out about their lives with diabetes and shown, by their courage and hard work, that they can accomplish anything-- including being an important part of finding their own cures. Overall, JDRF's efforts have enabled us to contribute over \$1.3 billion to diabetes research since our founding in 1970, and over \$150 million last year alone. But curing diabetes is an enormous task. We can't do it alone. And that's why we're here.

We are so very grateful that this committee and Congress as a whole, have been our true partners in the fight to cure type 1 diabetes and its complications. The Special Diabetes Program -- which has been renewed by Congress four times since it was enacted in 1997 -- currently provides \$150 million per year for type 1 diabetes research. This critical funding has led to some remarkable advances...including real progress in developing new therapies that are potentially life-changing for all of us sitting before you, today.

I will ask our friend, Dr. Griffin Rodgers the Director of the NIDDK, to elaborate more on the scientific progress we've seen, thanks to the Special Diabetes Program funding. But there are a few areas of research that I would like to touch upon today, myself -- areas that affect me, personally.

Researchers are using the Special Diabetes Program funds to find a way to prevent and reverse diabetic retinopathy. This is very exciting work and it gives me great hope, especially for children and young adults with Type 1. As a result of these advances, people with diabetes may be able to live with far less fear of visual loss and have an alternative to laser therapies' "burn the village to save the village" approach.

Major advances are also being made in the development of new devices, called Continuous Glucose Monitors or CGMs. By measuring blood sugars, automatically, every few minutes, and graphically showing the results and the up and down trends, CGMs help people to better understand their diabetes, and avoid extreme highs or lows.

Teams of researchers are now working hard to connect CGMs with insulin pumps via a control algorithm --- thereby creating a fully automated system that can closely mimic the blood sugar control workings of a human pancreas. This intelligent pump would automatically administer insulin based on a person's blood sugar level and whether it was rising or falling. Human clinical trials are already underway, and the early results are very encouraging.

In short, with your help, we are making real progress towards discovery, development and delivery of cures and significantly improving the health outcomes of people with type 1 diabetes and its complications. To keep up this progress, however,

Congress must renew the Special Diabetes Program in 2010. Without your help, we face a 35% cut in federal funding for type 1 research – a cut that could turn hope into despair. With your help, new life-changing therapies and cures will, finally, be within our reach.

When a child is diagnosed with diabetes, it is a hectic, crazy time. There are ambulances or emergency rooms. You hear medical terms you never knew existed. Days blur into nights. But one thing is common at every diagnosis. Every parent of these delegates here today, every parent of every child ever diagnosed with type 1 diabetes makes a promise to them. We'll do everything thing we can to find a cure for you. We promise.

As their Chairman and “oldest delegate” – by just a year or two – I'm proud to be leading our 2009 Children's Congress Delegates in their efforts in DC this week. As we have started to do in this special hearing, today our goal is to persuade our Senators and Representatives to also make a promise. We hope you will “promise to remember us” when you vote on the Special Diabetes Program and other important issues that affect all of us with diabetes.

The energy and commitment of families affected by type 1 and the strong support of champions like you on Capitol Hill make me certain that we will, soon, be able to turn the promising research made possible by JDRF and the Special Diabetes Program into our “promises kept for a cure.”

Thank you from the bottom of my heart for all that you do for these children, for me, and for all others who are touched by type 1 diabetes. I look forward to continuing to work with you as we pursue our mutual goal of a cure. I promise.