

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

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

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

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

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

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

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

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

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