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TESTIMONY

Testimony

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Tarentum, PA On Behalf of

Juvenile Diabetes Research Foundation International Regarding Federal Support of Juvenile Diabetes Research Before the

Senate Permanent Subcommittee on Investigations

Good afternoon. My name is Michelle and this is my daughter Eliza. Thank you for allowing me to tell you a little bit about our lives.

When you plan to have children, you dream of whose eyes they will have; whose personality traits they will carry; or what they will do in their lifetime, such as becoming a doctor; or if they will have children of their own.

I was diagnosed with Juvenile Diabetes at the age of three. When I was young, I was told that I probably wouldn't be able to have children. Everything I read said that women who have diabetes shouldn't have children. It was common for diabetic mothers to experience severe complications after a pregnancy such as retinopathy and kidney disease. Let alone the fears of congenital birth defects in a baby, or worse yet, a miscarriage or a stillborn birth. It was just too risky for baby and mother.

As I got older, there were many advances. Glucose meters and insulin pumps improved our ability to monitor and control blood sugar levels. Things have changed. Yes, I could have children if I wanted, as long as I was careful and kept myself under tight control.

Well, I was thrilled. My entire life, I felt as though God put me here on earth to be a mother. To have children was my only wish.

Eliza was born in 1996. All the things I dreamed of, I noticed.

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She has my husband's eyes. She has my smile and my personality—as stubborn as a bull! But the one thing I never dreamed of giving her was diabetes. My doctor said the chances were slim to none, so not to worry. And I didn't.

Well, I'm here to tell you that the chances aren't slim enough. One night, Eliza got up at about 2:30 a.m. and asked me for water, which she had never done before. I had the strangest feeling when she asked, but I just let it pass. I was just being overly concerned, I thought. She was a child who wanted a glass of water . . . what could be more normal, right? The next morning, we went through four cups of fluid before I got up the nerve to test her. Those 15 seconds, while waiting for the meter to count down, were the longest of my lifetime. My worst nightmare was confirmed in a matter of a 15-second blood test. I diagnosed Eliza on July 11, 1999 at home with my glucose meter. My daughter Eliza has diabetes.

Talk about guilt. I hated myself for a long time. Sometimes I still do. I ask myself often, isn't my diabetes enough? I have sacrificed 26 years of my life to this disease. Why does she have to sacrifice hers? Sometimes I cry myself to sleep at night, fearing the next day's insulin pump catheter insertion. I pray that she won't hate me for giving her this disease. To make matters more strenuous, in May, my other daughter, Rebeka, turned three. The anxiety begins again.

I believe that we all have a purpose in life. Sometimes people go their entire lives without knowing their purpose. I often thought that mine was having diabetes so I could be a role model for Eliza.

But being here today has changed my beliefs. I see that Eliza and all these children have diabetes so that WE have role models. Eliza is a brave little girl, just as all the children here today. More brave than any of us could ever be, facing this disease HEAD ON.

Please promise to remember Eliza and all the children here today. Please help them fight for what they have earned. A cure for diabetes.

Please promise to remember me. Help me and my mom find a cure for diabetes.

Thank you.

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