Testimony of Mrs. Ann Strader On behalf of Abraham and Curtis Strader Lakeville, Minnesota

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

Senator Collins and Senator Lieberman, thank you for holding this hearing and for giving us the opportunity to share our stories with you. I am speaking today on behalf of my six year old identical twin boys, Abraham and Curtis Strader, who both live with type 1 diabetes. Raising twin boys lends itself to a lot of energy, enthusiasm, wrestling, and noise. Raising twin boys with diabetes requires constant management, daily care, and thousands of finger pokes.

I remember after Abe and Curt were born, and we brought them home from the hospital, I would often sit in the glider in their nursery and just watch them sleep. They were absolutely precious. I felt a sense of joy that was accompanied by the overwhelming feeling of being their protector. I knew that my boys would be well loved, cared for, and that my husband and I would always keep our boys protected and safe. And then just two years later, diabetes struck.

In 2003, when Abe and Curt were just two years old, both were diagnosed with diabetes in a span of two weeks. In that two week period, half of our family had become diabetic. Neither my husband, Neil, nor I have a single case of type 1 diabetes in our extended families. We quickly learned the seriousness of diabetes and the importance of managing the disease in order to keep our kids healthy. Children with diabetes typically have a shortened life expectancy, a higher risk of stroke, blindness, and kidney failure. All of those devastating eventual effects seem far off, but the one that always scares me the most, is the fact that no one knows how low blood sugars effect brain development in young children like Abe and Curt.

With the diagnoses came the loss of predictability and stability. I took a leave from my job as a teacher to stay home and provide full time care for my boys. I no longer could leave them with just someone who would provide care for them. I could only leave them with someone who knew how to check blood sugars, give insulin shots, count carbohydrates, document with detail, and identify symptoms of hypoglycemia and hyperglycemia. Of course, they must be able to give a glucagon shot in case my child were to become unconscious.

I remember when we were in the hospital with Abraham, and he would cry and cry when the nurse came in to give him shots. He would scream, "Make her stop mommy, make her stop." My heart was crushed. I was Abe's protector and now this disease had made me helpless. I realized that soon it would be me giving him shots that were causing him fear, pain, and anger. I have no choice but to do this. It is a matter of fact that without proper management and care our children would die.

As a family, my husband and I have made the commitment to manage the disease so that the disease doesn't manage us. But most days this is easier said than done. Abe and Curt are not able to consistently tell us if they feel like their blood sugar is high or low. It is a matter of constant testing. As parents, we have to try and judge if their behavior is related to blood sugars or if they are just acting like a 'regular' kid. Their blood sugars are impacted by food, exercise, anxiety, and their growing bodies. Sometimes exercise

will impact Abe and Curt immediately and other times it will drop them low up to 12 hours later. It is this sort of unpredictability that keeps us getting up every night at all hours to check their blood sugars. I can't even begin to describe to you the worry that we – as parents – carry around with us every day and night. Worry that we are not managing their diabetes as well as we should. Worry that one of my boys will experience a low blood sugar episode in the night and not wake up in the morning. Worry that, as much as we try to allow them to be 'regular' kids, diabetes is robbing them of their childhood. And worry about what having diabetes will mean for them as they get older.

But this worry is nothing compared to what Abe and Curt go through every day. Neil and I have administered approximately 5,500 shots and 23,360 finger sticks to our two boys in the past four years. For the first two years living with diabetes my children each received 3 to 4 insulin shots a day and we checked their blood sugars with a finger poke 6 to 10 times a day around the clock. My husband remembers having to ask the neighbor to come over to help hold one of the boys while he would administer their shots. When Abe and Curt were four years old, they started wearing insulin pumps. We have experienced great relief from the shots, but the finger pokes are still a constant. We have experienced tighter management, but high and low blood sugars are still a battle. A pump is a great management tool, but it is not a cure.

After the boys were diagnosed, my husband and I knew we had a choice to make. We could sit around and feel victimized or we could become proactive in finding a cure for this disease. Over the past four years we have actively raised money for JDRF through our local Walk for a Cure. Our family team, "Twin Power" has raised over \$45,000 dollars. I do all I can for JDRF and its mission for a cure. However, I know that no matter how much money our family or families like mine across the country raise, we will need increased federal support for diabetes research to get to our goal of finding a cure. I am asking Congress – on behalf of Abe and Curt and the millions of kids who are living with type 1 diabetes – to increase federal funding for diabetes research. Be our partner. Give Abe and Curt the hope that a cure will be found in their lifetime. I promised my boys that I will do all I can to get to a cure as soon as possible. I am asking you to make the same promise to them.

I would like to share a few statements Abe and Curt have made about living with diabetes, and what they would like our lawmakers to know about this disease.

Says Abe, "I want to tell our lawmakers, we have to get a cure for diabetes, so I wouldn't have to wear a pump all the time. I want them to know it hurts when my mom has to change my site. I would tell them that sometimes my blood sugar is low and it makes me feel really dizzy and sick. It is really hard to do my best work at school when I feel dizzy and sick."

And says Curt, "I want to tell the people in Washington I don't like having diabetes. I have to wear a pump all the time or I would get really sick. One day I threw up at school because my blood sugar was really high. I didn't feel well at all."

Abe and Curt have just finished kindergarten. They enjoy playing soccer, T-ball, and going to water parks. They don't know what life is like without a blood sugar meter, shots, a pump, and counting carbohydrates. I would give anything for them to know a future without diabetes.

This past December, my son Abe woke up on Christmas morning, and just like thousands of other kids he could hardly wait to open gifts. He quickly ripped into a colorful box from his grandma. Inside the box, she had put a small Star Wars toy and several dollar bills for him to pick out something at the store. Abe quickly grabbed the toy and turned to me and said, "Wow mom, look at all this money we can use to find a cure for diabetes." It is not every six year old who thinks about giving money to research. We all look forward to a day without diabetes.