

Testimony of

Ellen Gould

Mother of JDRF Children's Congress Delegates

Patrick, Samuel, Sarah and Oliver

Nashville, TN

At the Hearing entitled

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

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Before the

Senate Committee on Homeland Security and Governmental Affairs

Good morning and thank you for the opportunity to speak to you today about my family's story of living with type 1 diabetes and our hope for a cure. I am Ellen Gould from Nashville, Tennessee and joining me are my children, Patrick who is 17, Sam who is 12, Sarah who is 10 and Oliver my five-year old. Yes, all four of them have type 1 diabetes and helping them manage their disease can be quite a challenge.

Our journey with type 1 diabetes started in July of 2004 when Patrick was diagnosed. My husband and I had noticed that he was rapidly losing weight, constantly thirsty and unusually tired. A trip to the pediatrician turned into a hospital stay with the required boot camp of sorts where we received a crash course on diabetes management. Patrick quickly learned how to manage his blood sugars but for an active teenager going through growth spurts, controlling his blood sugars was often a challenge. Today Patrick uses shots because the years of having diabetes left scar tissue where he would insert his infusion sets, so a pump isn't his best option.

Type 1 diabetes hit home again in January of 2006. Sarah began to show similar symptoms as Patrick had just two years earlier. We were devastated all over again. Fortunately her brother was and still is an excellent role model and we had a lot of experience with highs/lowes and sick days under our belt so she was able to quickly adapt to the routine. Unlike her brother, she wears a pump which requires different prescriptions and management.

Shortly after Sarah's diagnosis, my husband and I learned about a clinical trial called TrialNet, which is funded by Special Diabetes Program. Researchers were looking for children whose siblings had type 1 to see if the children were at risk for developing type 1. We immediately enrolled our family. The initial screening required a blood test. My heart sank when Sam and Oliver's results came back positive for diabetes antibodies, meaning they were clearly at risk of developing full-blown type 1. Later tests indicated that Sam did have type 1, although he was not showing the classic symptoms at that time.

While we were dealing with helping a third child manage diabetes, at the age of 3, Oliver started taking a pill as part of the TrialNet study to see if the full onset of type 1 could be delayed by months or years. I don't know if he received a placebo or oral insulin, but last fall he too was diagnosed with type 1. He's a real trooper – he tests his own blood sugar and has learned to handle the injections.

So, as you can see, my husband and I have our hands full. While the kids are very responsible with their diabetes care, they still need oversight. We're constantly filling prescriptions, scheduling doctors' appointments, filling out forms for school and various activities, educating others and making sure our kids are safe. We have four other children at home so you can only imagine how busy our lives are.

Finding a cure means everything to my family and we are willing to be part of the solution even with juggling our already busy life. We are very active in our local JDRF chapter, and do all that we can to educate others and raise funds for a cure. We have participated in research studies and will continue to do so.

This isn't just about the Gould family. It is about the thousands of children who have to live with this terrible disease every day. It is about the thousands of children who are going to be diagnosed with the disease.

While insulin therapy helps us manage this disease, insulin is not a cure. On many occasions, we carefully measure blood sugars, count carbs and inject what we think is just the right amount of insulin. It is so discouraging when we measure just a few hours later and their blood sugar is way above normal range. How many high blood sugars are too many? When will long term complications with their eyes, kidneys or heart start to show? Sometimes we have to deal with the low blood sugars. Like the Saturday morning several months ago when we were awakened by Sam, collapsed in his room, incoherent, because of a dangerously low blood sugar. It took us 20 minutes to get him back to normal - but what happens the next time if we don't hear him? As their mother, I just want to reach out and make it better – but I can't. I can't cure this disease, I can't make it better for my kids. I need help.

We are so very grateful that so many Senators and Representatives have been doing their part by being strong and vocal supporters of the Special Diabetes Program. It is our hope that the Special Diabetes Program will continue well into the future so that clinical trials, such as TrialNet, can continue and lead to better treatments and eventually a cure for type 1 diabetes.

Thank you.