

Testimony of Quinn Ferguson

Age 14, JDRF Children's Congress Delegate

from Poland Spring, Maine

At the Hearing entitled:

"Diabetes Research: Reducing the Burden of Diabetes at All Ages and Stages"

Wednesday, July 10, 2013, 2:00 p.m.

Before the

Senate Special Committee on Aging

Dirksen Senate Office Building, Room G-50

Washington, D.C.

Thank you, Senator Collins, Senator Nelson, and Members of the Aging Committee for inviting me to testify. My name is Quinn Ferguson. I am 14 years old and I am from Poland Spring, Maine. I have been living with type 1 diabetes since I was diagnosed a week before my 9th birthday.

I will never forget the day I was diagnosed – actually, I was misdiagnosed. I was at my grandparents' house when I opened my eyes and I was on the ground -- I had passed out and had fallen. So my mom drove me immediately to the hospital. On the way, I started throwing up. But my doctor said it was a concussion and sent me home.

A week later, I was still not feeling better. After looking online to find out what was causing my symptoms, my nana brought over my grandpa's diabetes test kit – he has type 2 diabetes - and my blood sugar was 600 – more than four times the normal range. After that, I was diagnosed with type 1 diabetes or T1D.

Voices have been silenced and lives cut short because of this disease. I am here today to speak for them as well as speak for myself. And I am not alone in my story– people are misdiagnosed every day, or not diagnosed at all, suffering the consequences and sometimes paying the ultimate price. I am here today because they could not be, and because we need to do more about this disease.

Every day since I was diagnosed, I have had to check my blood sugar at least ten times a day -- even in the middle of the night. I measure *everything* I eat and drink, and I think about my blood sugar constantly when I am in school, on the football field, or in a chess match. If I don't, I could experience a seizure or a coma, or suffer from long-term complications like eye disease, kidney failure, and/or heart problems.

I am fully responsible for my diabetes – from caring for myself to taking charge of my attitude on T1D. While there are times that I get down, I know that I am not out. I am a stronger person living with this disease, but every day is a trial by fire. I never have a day off, and, even as a teenager, I will never outgrow T1D.

Thanks to medical research, life will get better- it has to (get better). I am not giving up on a cure, and hope Congress won't either and will continue to support the Special Diabetes Program -my hope for a cure.

While we wait for a cure, I am doing my part by educating others about T1D and enrolled in a TrialNet study that tested the drug abatacept to stop or slow down destruction of insulin-producing beta cells. Those newly diagnosed with T1D who got the drug produced insulin longer than people who did not for almost one year.

The study is now testing the drug in people at risk, but not yet diagnosed, to see if it can help delay or prevent T1D because having a relative greatly increases the chances of being diagnosed. Without the Special Diabetes Program, TrialNet studies of almost 20,000 patients will not see results.

The Special Diabetes Program investment also led us to the artificial pancreas technology now being tested in T1D patients. They are living my dream – they do not have to worry constantly about blood sugars and can sleep through the night because the artificial pancreas is managing the disease. It is automatically testing blood sugar and giving insulin as needed, and will help keep people with T1D safe and healthy until a cure is found.

My great grandfather, Alfred Clark Ferguson, came to the "new world" on an orphan ship when he was five years old. At that age, he could only dream of a future where "the sugars" would never take parents away from their children again. He lived to see science find a treatment for diabetes. Whether my generation lives to see a cure depends on research and funding. We need your help.

Today, I am surrounded by 160 delegates and their parents who represent the millions doing everything possible for a cure. I am grateful that Senator Collins and so many in Congress have been so supportive, and I urge you to keep it up. Our hope for a full life depends on it.

Thank you, Chairwoman Collins and Members of the Aging Committee, for holding this hearing and providing me the opportunity to represent those who could not be here today and give you a glimpse into life with T1D.

While the worry never goes away, we know that there are better days ahead. That is why we need your support for the Special Diabetes Program, so that perhaps one day we can say that the world is free from T1D!

I look forward to answering any questions you may have. Thank you.