

Testimony of Paul Sparks

Actor

From New York, New York

At the Hearing entitled:

“Progress Toward a Cure for Type 1 Diabetes: Research and the Artificial Pancreas”

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Dirksen Senate Office Building, Room 106

Washington, D.C.

Thank you, Chairman Collins, thank you, Ranking Member Casey, and the members of the Committee for inviting me to testify today. It's an honor for me to be here.

I'll start by saying, I know how important the research supported by the Special Diabetes Program is because in my own lifetime as a person with type 1 diabetes, I have seen – and benefited – from the advances discovered in our labs, tested in our clinical trials, and brought to market.

I was diagnosed with T1D when I was 27, living in New York, working as an actor – which also meant that I was working as a construction worker in order to pay my bills.

Over the course of about seven or eight months, I lost about 45 pounds. I noticed that I was going to the bathroom a lot. I was having muscle cramps all the time. I started not being able to see clearly. I was very thirsty – and constantly starving.

Basically, my body was falling apart. Thankfully, I went home to Oklahoma to see my parents for Thanksgiving. I looked so grim, so thin and so unhealthy, that my mother almost had a heart attack when she saw me.

Luckily, my brother was a medical resident at the time. Via a phone call, he recommended that I see a doctor soon, because it sounded like I had diabetes.

Well, I did see a doctor the next day, and my brother was right.

I spent the next few months trying to learn about T1D and figure out how to get the care I needed.

As the kids and parents here know, this is an anxiety-producing disease. You are the patient but you are also, in many ways, the care giver. You are responsible for keeping yourself healthy. And you have to stay on top of it; because if you don't, you will get very sick – or worse.

That's why the research and advances in care are so important.

Today, nearly 20 years after my diagnosis, I use inhaled insulin that quickly and safely brings my blood glucose back in range. And I wear a continuous glucose monitor, or CGM, that allows me to know at all times whether my glucose is going too high or too low so I can take action.

These advances have transformed the quality of my life.

I used to have to stash sugar on the set of plays I was in, in case I needed to stabilize my blood glucose. And I can tell you it's kind of strange when a character in a 18th century period drama pulls a bottle of orange juice out of a sofa cushion and starts chugging mid-dialogue!

Probably the most demonstrative example of how important these advances are: Three years ago, I turned off my GCM so that my very pregnant wife, Annie, could sleep peacefully through the night without any beeping, which occurs when my glucose level goes low. Because I'd switched

it off, it did not alert me, I suffered a severe low blood sugar while asleep, and woke up to a frightened pregnant wife, a crying four-year old, and seven New York City EMTs standing over me.

These new technologies, when they are turned on, and other research advances literally save my life every day and they save the lives of every one of these delegates. And we are at the cusp of a whole new generation of therapies, devices, and dare I say, a cure.

That's why we can't let up on research. We need more advances – so we can cure and prevent T1D – so all of us, like Charlie, Lorynn and Jonathan who are here on the panel with me, can live life without thinking about this disease at all.

We need to keep the momentum going by renewing the Special Diabetes Program before it expires at the end of September.

I'll let others today go on about the science and the policies that support it. But let me just say this: this research has made a difference in my life – it has made a difference in the lives of everyone in this room – and millions more.

So thank you, Chairman Collins, for your outstanding leadership, and thank you Ranking member Casey for your strong support of T1D research and coverage for technologies like the Continuous Glucose Monitor. It's great that people on Medicare now have access to CGMs just like the rest of us.

And thank you and your colleagues for the bipartisan support of the Special Diabetes Program. It's doing great work for the millions of Americans living with this disease – like me.

Thank you.