

Development of an Artificial Pancreas:

**Will New Technologies Improve Care
For People with Diabetes and Reduce the Burden
On the Health Care System?**

Statement of Caroline Sweeney
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United States Senate
Committee on Homeland Security
and Governmental Affairs

Good morning, Senator Collins and members of the Committee. I am Caroline Sweeney from Gray, Maine, and I am here today with my 4 year old son Aidan. Before I tell about the worst day of my life and how my son's life was forever changed, I want to say a special thank you to you, Senator Collins, for all that you do to help find a cure for diabetes. You give my family so much hope that one day my son won't have to struggle with the daily burden of diabetes and we won't have to worry about what the disease is doing to his body as he grows older and faces the reality of significant complications. I am proud to live in Maine and to have you as my Senator. Thank you.

On February 10, 2004, my world fell apart. I had taken my son, Aidan, then 22 months old, to the pediatrician because he had been up all night drinking water and soaking diapers. 26 weeks pregnant with my second child, and tired of waiting for the doctor to return to the examining room with Aidan's blood sugar results, I opened the door and was quickly escorted back into the room by the nurse. I will never forget the look on her face as I asked, "Everything is alright, isn't it?" She looked at me with tears in her eyes and shook her head, "No." Covered in urine, I held my crying son tightly and gasped for breath as I fell against the examining table. My son, the child I had longed for my entire life, was sick - sick with a disease for which there is as yet no cure: Type I (Juvenile) Diabetes. Aidan was in diabetic ketoacidosis, a complication which threatened his life. My life, but more importantly, my son's, would never be the same. I went through every emotion - I wanted to scream; I wanted to hit; I wanted to run; I wanted to be numb. Most of all, I wanted it to go away.

But Diabetes never does go away. Aidan is now 4 years old. He receives insulin through a pump, which he wears on a belt around his waist, 24 hours a day. The pump is connected to an inch long catheter tunneled beneath the skin on his bottom. So far, we have changed his catheter over 500 times. Not surprisingly, he doesn't like the catheters. Most site changes become bargaining sessions, and despite the anesthetic cream, he feels every stick. His little bottom is studded with scars.

His fingertips are scarred from being tested up to 12 times a day -- that's more than 11,000 tests in 2 ½ years. Like the site changes, he doesn't like the testing. Sometimes, Aidan will run away when it is time to test his blood sugar or hide his hands behind his back, crying for me not to test him. At pre-school, he has asked his teacher to test his blood sugar in the bathroom so the other kids will not watch.

Despite his efforts, he can never escape his tests. He is forced to test his blood sugar everywhere -- at pre-school, at the grocery store, at restaurants, at the playground, at friends' homes, and even in his bed during sleep. The tests are constant, frustrating, and exhausting. Growth spurts and minor illnesses can cause his blood sugar levels to rise or fall unpredictably, and change his insulin demands as well. His emotions shift with every blood sugar fluctuation, making it impossible to distinguish between "typical 4 year old behavior" and "low" or "high blood sugar behavior." Often he has been unable to warn me even when his sugars are at life-threatening levels. 2 ½ years into his illness, he will still sleep through dangerously low blood sugars and be asymptomatic while awake. And so I test.

And I worry. I am always fearful - fearful that my son's blood sugar will rise so high that he will enter into a coma or drop so low that he will seize or even worse. Every night, I check his blood sugar before I go to bed and pray to God that he will wake up in the morning. I never sleep through the night. I keep a baby monitor on my pillow just so I can hear him breathe. I have found myself running into his bedroom in the middle of the night, carrying glucagon and a syringe, thinking that I have heard him seizing. I am always relieved when morning comes and I hear his little footsteps entering my bedroom.

I have become not only Aidan's mother, but his health care provider. With each good morning and goodnight kiss comes a finger stick. The responsibilities of his diabetes care are many – endless testing, counting and recording and interpreting everything that he eats, calculating insulin doses, giving insulin, changing catheter sites, keeping his supplies in stock, trying to explain to him just why it is that he cannot eat the chocolate cake that his friends are eating when his sugar is too high. The list goes on.

Still, despite diligent care and tight glucose control, I am aware my son is still more likely to suffer from heart disease, kidney failure, nerve damage, stroke, blindness, amputations, and an early death. This is most difficult to face as a parent. I try to live day by day with my son, but find myself wondering: will he one day lose a limb? Will he end up on dialysis? Will he go blind? Will he live to see the age of 50?

Aidan can only be left in the care of others whom are trained in diabetes, including babysitters and school. 14 weeks after Aidan was diagnosed with Diabetes, I gave birth to our second son, Michael, now 2, and just 3 months ago gave birth to our daughter, Caitlin. Both deliveries put us in a state of panic over who would take care of Aidan. Family on both sides were forced to pick up their busy lives and come to Maine in the weeks before both deliveries so they could be trained in Diabetes care. I can vividly remember my mother learning how to operate Aidan's insulin pump while timing my contractions. While my biggest concern should have been my unborn child, I could not seem to escape the worry about Aidan's care.

From the moment little Michael and Caitlin were born, they have never been able to have my complete attention because of Aidan's Diabetes. Aidan's illness comes first – before nursing, diaper changes, cries, baths - even hugs and kisses. I recently realized the impact of this when Michael, my 2 year old, insisted on having his blood sugar checked, claiming to have diabetes too. Much of his life is also dependent on Aidan's blood sugars. He knows that if Aidan's blood sugar is high at dinnertime that he has to wait with the rest of the family before he can eat. He knows that sometimes Aidan needs to drink juice really fast and sometimes only *he* can have juice and Aidan cannot. He knows that his Mommy and Daddy sometimes stick a needle into Aidan's bottom and that Aidan doesn't like that. I don't know what impact this will have on Michael in the years to come. I can only try to help him understand the severity of his brother's disease, while praying that he and his sister do not one day get diabetes.

As parents, we try from the moment our children are born to protect them from any harm. Two years ago, I never felt more helpless when all I could do was hold the tiny hand of my 22 month old son in the intensive care unit and pray he would not die. I vowed at that moment to do everything I could to find a cure for Diabetes. I stand before you today, with my son, my hero, asking for your support in saving his life. While the continued glucose monitor and artificial pancreas are not cures, they can offer Aidan and children like him a tremendous improvement in his quality of life, free from thousands of finger stick tests, and offer me the gift of peace -- peace in knowing that my son is safe and hopefully able to live a longer life with this terrible disease.

I encourage Congress to continue to show its support for these promising technologies and to help ensure that they are available and accessible to all who could benefit. Thank you.