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Senators urged to expand funds for diabetes research

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WASHINGTON - Aidan Sweeney swiveled in a large leather chair at a conference table in the U.S. Senate committee hearing room. A small tube used to monitor the 4-year-old's blood sugar and inject him with insulin crept out from a belt that sat above his basketball boxer shorts. He colored while his mother gave gut-wrenching testimony that left tears in many eyes and the room silent.

"As parents we try from the moment our children are born to protect them from any harm," Caroline Sweeney testified. "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."

It was during that traumatic hospital stay that Aidan was diagnosed with type 1, or juvenile, diabetes.

The Sweeney family, residents of Gray, Maine, provided a compelling face for the many families with diabetic children as lawmakers heard Wednesday from doctors and researchers about the potential for improving care and the quality of life for people with the disease.

The Homeland Security and Governmental Affairs Committee hearing was chaired by Sen. Susan Collins, R-Maine, who founded and co-chairs the Senate Diabetes Caucus. The subject of the hearing was "The Potential of an Artificial Pancreas: Improving Care for People with Diabetes." An artificial pancreas would free children from finger-stick tests and insulin injections.

"Diabetes is a life-long condition that affects people of every age, race and nationality," Collins said in her opening statement.

The disease that affects 21 million Americans can lead to blindness, heart attacks, kidney failure, amputations and death. In juvenile diabetes, the body's immune system attacks the pancreas and destroys the islet cells that produce insulin. Insulin regulates the amount of sugar in the blood, and people with diabetes must closely monitor their blood sugar levels through testing several times a day.

"His fingertips are scarred from being tested up to 12 times a day: that's more than 11,000 tests in two and a half years," Caroline Sweeney said.

Aidan receives insulin 24 hours a day through a pump that he wears on a belt around his waist. The pump is connected to an inch-long catheter tunneled beneath the skin on his bottom, his mother said.

But the development of an artificial pancreas could change all that.

An artificial pancreas would link two existing technologies — the insulin pump that Aidan uses and a continuous glucose monitor that provides real-time data on glucose levels and sounds an alarm if levels are too high or too low. The key to developing the artificial pancreas is finding a way to link these two technologies together.

The Juvenile Diabetes Research Foundation International, the world's largest charitable contributor to Type 1 diabetes research, has given grants to Yale Medical School and five other top scientific facilities to find a way to "close the loop."

The National Institute of Diabetes and Digestive and Kidney Diseases, part of the National Institutes of Health, is researching mathematical ways of predicting what is happening in the body and how much insulin is needed. They also are exploring other ways to monitor glucose, such as in eye fluid using a contact lens as a sensor.

But there are more benefits to the creation of an artificial pancreas than just those that relate to people with diabetes, lawmakers were told.

"Fewer complications can, arguably, lead to one of the greatest health advances and financial savings in medical expenditures in U.S. history," said Arnold W. Donald, president and chief executive officer of the research foundation.

All types of diabetes cost the health care system more than \$130 billion a year, Donald said. That's because it is among the leading causes of heart disease, stroke, eye disease, kidney failure and amputation. "Decreasing the rate of diabetic complications in the U.S. can mean savings of literally billions of dollars in health care costs," he said.

The Sweeneys are fortunate. Aidan's father, Timothy Sweeney, is an emergency room physician, and his mother is a registered dietician. The two are familiar with medical procedures, needles and equipment. They live comfortably, and Aidan's insulin pump is not cost-prohibitive. But that's not the case for many other families in Maine whose insurance will not cover such devices, Timothy Sweeney said.

He said he hopes that Congress will increase spending for diabetes research.

"I stand before you today, with my son, my hero, asking for your support in saving his life," Caroline Sweeney said. "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."