Written Testimony of Kathy Sego

American Diabetes Association Volunteer

Drug Pricing in America: A Prescription for Change Part I

United States Senate Finance Committee

January 29, 2019

Washington, DC

Media Contact:
Michelle Kirkwood
Vice President
Science & Medicine Communications

American Diabetes Association
(703) 299-2053
mkirkwood@diabetes.org

For Further Information, Contact:
Meghan Riley
Vice President
Federal Government Affairs

American Diabetes Association
(703) 253-4818
mriley@diabetes.org

Statement to the U.S. Senate Finance Committee

Kathy Sego

January 29, 2019

Good morning. Thank you, Chairman Grassley, Ranking Member Wyden, and distinguished members of the Senate Finance Committee for the opportunity to testify before you today. My name is Kathy Sego. I am a choir teacher from Indiana. My husband and I have two children. Our son Hunter has type 1 diabetes.

More than 30 million Americans have diabetes and approximately 7.4 million of them rely on insulin. For millions of people with diabetes—including my son, and all individuals with type 1 diabetes—access to insulin is literally a matter of life and death. There is no medication that can be substituted for insulin and nobody should ever have to go without it due to prohibitive costs. An American Diabetes Association study estimates that diabetes costs a total of 327 billion dollars a year, but for my family, the true cost cannot be calculated.

My son, Hunter, thrives as a student and football player at DePauw University. On the surface, you would never know that he lives with a chronic disease. Hunter was diagnosed with type 1 diabetes on August 23, 2004, one month before his seventh birthday. On that date, our lives changed. Ever since, I have been an advocate and volunteer with the American Diabetes Association, fighting to make sure Hunter and all people with diabetes can stay healthy and have the same rights as people without diabetes.

Diabetes is a an every day struggle. Every meal, every snack, every workout must be calculated. Hunter checks his blood sugar 10 times a day and doses his insulin accordingly. Any misstep can cause dangerous health problems. For Hunter, and every person who relies on it, insulin is as important as water or oxygen. Imagine if the one thing you relied on to survive was nearly out of reach because it was too expensive. That, for us, is insulin.

Four years ago, when Hunter was starting college, he offered to go to the pharmacy to pick up his insulin. I thought, my son is growing up. I was proud. But for Hunter, growing up means understanding the cost of diabetes. The cost that day was $1,700 and Hunter called me in a panic. We have insurance, it simply could not be that expensive. The price tag was accurate. What made it worse was—it was just for one month.

What happens next brings me to tears. My energetic, athletic, and positive son was not himself. He seemed depressed. His grades dropped. He looked labored on the football field. His professors and coaches noticed the change, too.

I found out that Hunter had decided to purchase one vial of insulin instead of the four vials he needed for the month. Unbeknownst to me and my husband, Hunter was rationing his insulin.

Rationing meant he didn't eat in order to keep from having to give insulin that metabolizes food. So, armed with 25% of the amount of insulin, he averaged eating less than 1 time per day. Daily expenditure energy, for even a non-athlete, requires more fuel. But as Hunter was trying to give his all on the field, he essentially found himself starving and making himself sick. In response, he started eating, but not dosing with the necessary insulin to allow enough oxygen to feed his organs, muscles and brain cells. All the while, he began accumulating ketones (known as keto-acidosis), which left him 20 pounds lighter in the course of only two weeks. The combination of ketones and lack of oxygen could have ended with him in the morgue.

Thankfully for Hunter, we caught wind of this and he is okay today. But insulin rationing can lead to devastating—even deadly—complications, which I never want my son to experience. I'm heartbroken to know that my son felt he was a financial burden to us. Money over life is not the choice I want him to make, and I agonize over the idea that this could happen again.

In everything my family does we think first of the cost of Hunter's insulin. It is the root of every decision we make. We don't eat out. I don't turn on the heat in our home. I play a risky game with my utility bills—strategizing how long I can stretch them out before paying the past due fees. Our electricity was turned off because I needed to purchase the medicine that keeps my son alive. Almost every dollar I make goes towards health expenses, yet the increasing cost of medicine and care keep us in an endless cycle of trying to find innovative ways to generate other sources of money to pay for it all. Both my husband and I work 80 plus hours a week.

This doesn't have to be this way. It is not like this everywhere in the world. We hosted an exchange student from Hungary and her family flew us to their home for a visit. We went to the pharmacy for insulin; it cost ten dollars. The same vial of insulin that costs us $487 out of pocket in the U.S. cost ten dollars in Hungary. I wanted to stockpile it. I wanted to buy every vial, but they only allowed us to bring home a one-month supply.

My son is about to graduate college. When that happens, it will be one of the proudest moments of my life. However, unlike other parents, that moment also fills me with dread. Hunter’s life choices are contingent on his ability to pay for the medicine that keeps him alive.

Hunter has these worries too. He wonders—Can he pay for an apartment? Utility bills? His student loans? Will he be able to have a social life? Take a girl on a date? The thing is, it really comes down to this: Hunter needs insulin to live, but should that need for insulin keep him from living?

Our family is not alone in this struggle. More than 7 million Americans use insulin and more than 400,000 have signed the American Diabetes Association’s online petition calling for action to make insulin affordable for all who need it. I’m here today on behalf of every family that is impacted by this disease and by these costs to ask for your help in easing this burden. This is not a call for a handout or a way to allow those who live with diabetes to be given a free ride. We just want to keep those 7 million alive without having to do what my son thought was his only option to stay alive.

The scientists who discovered insulin sold the patent to the University of Toronto for one dollar each to ensure affordable insulin for all who needed it. Nearly one hundred years later it is my most desperate wish that we make their vision come true.

Again, thank you for the opportunity to testify before the Committee.