

****EMBARGOED UNTIL TUESDAY, AUGUST 21, 2018, AT 3:00 p.m.****

**Written Testimony
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Richfield, MN
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Good Afternoon, Thank you for allowing me to join you today to talk about the current crisis our country is facing concerning prescription drug prices.

My name is Nicole Smith-Holt and I am the mother of Alec Smith, my son Alec was just about to turn 24 when he fell ill and was diagnosed with Type 1 Diabetes. Type 1 diabetes is an autoimmune disease, it affects more than 1.25 million Americans and it is estimated that 40,000 people are diagnosed in the USA each year. Type 1 does not discriminate- it knows no color, no gender, no age, no religion, no socio-economical class, it doesn't matter if you lead a healthy life style or not- no one is immune to the diagnosis and it cannot be prevented.

My son Alec was a healthy, active, hard-working young man, he tried to not allow diabetes to control his life, he took control of his diabetes. The one aspect that he had no control over - and neither do the other millions of diabetics - is the cost of their life sustaining insulin and diabetic supplies. It is reported that 1 in 4 diabetics have been forced into rationing their insulin at some point. Rationing is extremely dangerous because if a person with type 1 diabetes does not have enough insulin in their system, their body starts to shut down. Rationing insulin is what took my sons life on that horrible day of June 27th 2017.

I received a call that no parent ever wants to receive or expects to receive. I was told that my son was found dead in his apartment, on his bedroom floor all alone. My son aged off my health insurance on June 1st 2017 because he turned 26, he went to the pharmacy on or around the 22nd on June and was told his bill was \$1300 for his monthly supply of insulin. The bill included 5 pens and his diabetic supplies. Unfortunately, Alec was about a week from payday so he did what too many diabetics have done, he began to ration what insulin he left. Alec was found dead 3 days before payday.

My story is not so different from what I hear from other families. Far too many times I have heard of people resorting to buying insulin from the black market, swapping supplies from Facebook support groups, using expired insulin and test strips, trading sex for insulin, using pet insulin, starving themselves to reduce the number of units they need, not paying rent, and rationing or skipping dosage: allowing themselves only enough insulin to not die. Basically, millions of people with diabetes are playing Russian roulette. Parents are selling their homes, cashing in on retirement and college funds, working 2 and 3 jobs and selling their plasma. Young adults are dropping out of college, they are getting married just to have insurance or not getting married to the loves of their lives because they will lose their state funded insurance. I heard of people with diabetes traveling to other countries to get their insulin and some have even relocated to these countries. Many report stock piling supplies and insulin – even expired insulin just in case because no one knows what the price of insulin will be like next month.

Some are even basically planning their own funerals because they cannot continue to pay the price of insulin.

Insulin was created almost 100 years ago. Prior to that, the diagnosis for Type 1 Diabetes was a certain death sentence. The creation of insulin was amazing and saved so many lives but here we are in 2018 and facing a death sentence once again because the cost of this life saving medication is priced out of reach for far too many. Since 1996 there has been no real formulary improvements to insulin yet the price has increased approximately 1200% and we have had no justification presented to us to explain this increase. If we looked at the standard rate of inflation in 1996 a vial of insulin cost \$21, today with inflation that vial of insulin should cost no more than \$34. Without laws in place to prevent Pharma from yet more increases we will continue to hear of diabetics resorting to dangerous work a rounds to prolong their lives. These work a rounds are often deadly and Alec is not the only one who has paid the ultimate price. Antavia Lee Worsham, Shane Patrick Boyle, and Seely Whetherall also died because of the high price of insulin – just to name a few.

In the United States Health Care is looked at as a privilege instead of a right. The rest of the developed world believes that people have a right to affordable and accessible health care and we have a right to affordable and accessible insulin and medications. The WHO has deemed insulin as an essential medication and every other industrialized nation recognizes this except for the US. Why is it that we allow Pharma and health insurance companies and pharmacy benefit managers to run our health care system? Is it because of the many millions of dollars they spend each year lobbying and buying our politicians? Why are we allowing them to police themselves? Why are they given the freedom to decide who lives and who dies?

This happens because no one is forcing them to have transparency, no one is forcing them to have caps on list prices, no one is forcing them to allow for generic creations? They stand there untouched by laws and are making billions in profits while those who struggle to afford their medications suffer and die.

Many will say that these companies offer assistance programs. Let me tell you about these programs from my experience. There are very long waiting times, lots of paper work that needs to be completed by the patient, the doctor, the pharmacist, and very few actually qualify because of the income limits. These are nothing but hurdles and barriers for patients. A diabetic can only live 1-2 days without insulin, and these programs take weeks or months. My concern is that they are creating these barriers as PR stunts to show that they care, rather than simply lowering the price. Why should a person who requires a medication to live have to use a charity program or beg the manufacturer for help? Why not just make your medication affordable for all? In my eyes, if you have to offer these charity programs, help lines and patient assistance programs – your company is fully aware that your product is too expensive!! My response is that LIST PRICE MATTERS. Far too many Americans have high deductible plans or no coverage at all, so they are paying a very high price every single month to stay alive. Approximately 57% of people using insulin are subject to paying list price at some time or another.

Some will say that there is \$25 insulin at Wal-Mart. Yes Wal-Mart sells \$25 insulin. It is the older version. It is less effective, more difficult to manage and is bought without a prescription which means your physician is not assisting you with management. This insulin is linked to loss of vision, loss of limbs, kidney failure, coma and even death. The insulin reacts very differently then the insulin that most people are used to and causes more dangerous high and low blood sugars. Physicians have a very difficult time in trying to calculate the correct dosage for patients so it is a guessing game on how many units the patient should be using, and they will need to test their blood sugar more often. That means they will need to spend more money on test strips. Money they don't have. Telling people to take this older, less-expensive insulin is creating a 2 tier system that allows for those who have money to get the best product and those who have a lower income to be forced to use the harder to manage, less effective more dangerous product.

I am an advocate with T1INTERNATIONAL. We are advocating for accessible and affordable insulin for all diabetics. Our advocacy group is free from pharma funding and we need your support to stop the greed, to put a stop to price gouging. Big Pharma should not be allowed to put a price tag on our lives. We need for you to create and pass laws that protect us all from a certain death of corporate greed. We ask that you stand by advocacy groups who are not taking in funding from Pharma. There are many organizations out there who have their own agendas and say they are supporting diabetics when a major portion of their funding is coming directly from the ones who killed my son.

Our family and friends have paid the ultimate sacrifice in this health care crisis. We lost an amazing young man. He had so many hopes and dreams. He left behind a 5 year old daughter who now has to grow up without her father. His little brother lost his idol, his sisters lost a best friend and my husband and myself lost our child. I want this crisis to come to end, I want no other family to experience this great pain and loss, this should have never happened and I am counting on you all to help me make sure this does not happen to another family. Please remember Alec and remember that regular injections of insulin is used to keep a person with type 1 diabetes alive. It is truly like oxygen to them. Please don't let pharma companies continue to keep price-gouging oxygen for people with type 1.

Thank you

Nicole Smith-Holt

T1INTERNATIONAL ADVOCATE #INSULIN4ALL