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THE EFFECTS OF THE HIGH COST OF INSULIN

Senator Carpenter, Representative Rowland and Members of the Banking and Insurance Committee, thank you for your invitation to speak today on the rising costs of insulin and its effect on the health and future of myself and countless others who live with diabetes in Kentucky.

My name is Angela Summers. I am 48 years old. I was diagnosed with type 2 diabetes when I was 23 years old. I began using insulin when I was 28. The insurance that I had at the time was through New York State and the cost of my insulin was not an issue. Not until I changed jobs and moved back home to Kentucky in 2009. I was newly divorced. I worked both a full time and a part time job in social services. I had insurance through my full time employer. I PAID for my insurance. The cost of my insulin went from \$35 a month to over \$400 a month. I could have a roof over my head or I could pay for my insulin. I could keep my lights on or I could pay for my insulin. The stigma that goes along with being a type 2 diabetic makes even talking about it difficult. It makes reaching out for help paying for insulin nearly impossible. And so I bargained with myself. "I'll make one month's worth of insulin last 3 months... or I'll just get it next month." which turns into 6 months. There were years of that. Years of going to my endocrinologist and telling him I wasn't taking my insulin because I couldn't afford it. He would give me samples. I would be good for a month or two and then back without insulin. I couldn't depend on my doctors supplying my insulin. I wasn't the only patient they had that needed help. I was one of many that came to them with deteriorating health because of my high blood sugars. One of many that they warned.

Because of years of going without adequate insulin, I developed neuropathy. Neuropathy is a nasty disease that attacks your hands and feet first. But it does its damage because of the sugar in your bloodstream so it attacks EVERYTHING eventually. First it felt like my hands and feet were falling asleep; that feeling of pins and needles. Then after a while it turned into thousands of continuous bee stings, over and over. That will come and go. It comes back with no warning. If I managed not to shout some inappropriate expletive I had done well. Then it stops. I could only pray that there would be time in between the "attacks".

Six months later... I'm at work. I'm fine. Things seem fine. I'm in front of a group of families listening to their fears about their child's next step after aging out of Special Education classes in high school. They were terrified and looking to me for help. Then out of nowhere my foot feels like a hot poker has been stabbed through it. No warning; just the feeling of hot metal ripping through my flesh. I had no idea how long that pain would last. This happened to me time and time again. Eventually I took the medication that was prescribed to me to soothe that pain. I could afford that medication. It dulled the pain and made the episodes farther apart. But you see, the neuropathy continued. It didn't address the problem like insulin would have. It dulled the pain but that was it. Currently, much like diabetes, neuropathy has no cure.

I continued my doctor appointments. I knew how important they were. I knew how important my blood sugar was. But I had been an “out-of-control” diabetic. That’s what they call it you know; “an out-of-control diabetic.” Not a struggling diabetic. Not a diabetic in need of assistance, but out of control. More shame. This shame made it even more difficult to reach out. That shame and embarrassment works well for the pharmaceutical companies. After all they didn’t cause this. And if I won’t make a noise, why should it matter? My shame. My guilt. It works in their favor. Well, I won’t be silent anymore. Because other people need to know that they don’t have to be silent either. Diabetes, whether type 1 or type 2, SHOULD NOT be a death sentence.

The continuing inability to purchase insulin caused the progression of my neuropathy. That led to the development of Charcot in my feet. Charcot is a condition that causes the weakening of the bones in the foot. The bones become weaker and with weight bearing and walking the Charcot causes deformity of the foot. For me Charcot caused tiny fractures throughout my foot. These tiny fractures became a larger break where the toes in my right foot all broke and were shoved over. My big toe relocated to my second toe and so on. This break was not treatable as the Charcot was active and made my foot inoperable. This happened because I stubbed my toe in the middle of the night. The next morning I was in the ER. Charcot, like neuropathy AND diabetes is currently incurable. Because of the Charcot, in December of 2013 my right leg was amputated below the knee. The hospital surgeons knew me. I had wonderful doctors. And we all knew it was necessary. What I didn’t know was that I had a 30% chance of surviving more than 5 years. And with Charcot in the left foot as well that percentage is reduced. This past December was my 5 year mark. I was so happy that I made it past that number. I celebrated. I cried. I wondered if I would make it another 5 years.

I have had so many people approach me because of my prosthetic. Most are diabetic. And they approach me because they are scared. And they are ashamed. And they are begging for hope. And right now what I can tell them is that they can purchase insulin from Wal-Mart. It runs \$25 per vial. Its 70/30 insulin which prevents you from being able to treat your short range and long range levels accurately. It’s outdated. It’s not what most doctors want their patients to take. It’s not what MY doctor wants me to take. But my insurance covers it. And so I take it. Yes I have insurance. I have GOOD insurance. Except... it doesn’t cover the insulin I need to take. It covers inferior insulin. And so with my prosthetic, Neuropathy, Charcot and now a diagnosis of Gastro paresis, (that’s a disease where Neuropathy kills your stomach’s ability to process and move your food through your system), and most importantly to treat MY DIABETES... I use inferior insulin; because my insurance covers it, because I can afford it and because I’m not ready to die.

This is my story. I’m one person. But we are on the verge of an epidemic. Our children are being diagnosed with type 2 diabetes at an alarmingly young age. And we are not prepared. Insulin has been made nearly impossible for a vast number of people to afford. We can try the inferior insulin. We will get inferior results. I’m proof. And I’m one of the lucky ones. I only lost my leg. People are losing their lives in this battle. More than 100 million people are living with diabetes in the United States alone. You know someone who is diabetic. And right now you should be praying they can afford their insulin, because most likely they won’t reach out for help if they can’t. They don’t want to be a burden. They don’t want to ask for help this month

when they know that next month is an issue too. Every month is an issue. Pricing insulin at such astronomical amounts is nothing short of premeditated murder. No longer can it be said that the effects of inferior insulin or even worse the inability to get insulin at all. The effects are death.