

Testimony to the Interim Banking and Insurance Committee August 21, 2019

Senator Carpenter, Representative Rowland, and Members of the Interim Banking and Insurance Committee, thank you for the opportunity to speak to you today on the rising cost of insulin. My name is Angela Lautner. I have lived with Type 1 diabetes (or T1D) for 19 years. I am founder of the Kentucky #insulin4all chapter, a grassroots group of volunteers raising awareness of the rising cost of insulin. We are supported by the global efforts of T1International.

No human survives without insulin. Insulin was first discovered in the 1920's and the first US patent was awarded in 1923. Dr. Banting was offered large sums of money but instead said that "Insulin does not belong to me, it belongs to the world". Today, the way that insulin is priced in America has caused people with T1D to again see that death is very much a reality as insulin prices continue to climb and are now priced out of reach.

This is a vial of insulin. Right now, I need just over 2 of these every month TO STAY ALIVE.

Since my diagnosis of T1D, I've watched the copays and price I pay for insulin climb without restriction or transparency. For many years, I just thought that it's the "way it is" and "there's nothing I can do about it".

I've lived through 4 layoffs as a professional in the airline industry. In every single layoff, my biggest concern was "How will I be able to pay for the insulin and care that I HAVE TO HAVE to live?". I have borrowed money from my family to help pay for my insulin and expensive COBRA insurance payments, and have even gone without insurance. I am here to tell you that patient assistance programs offered by insulin manufacturers do not help everyone.

What you need to understand is if I lose my job, lose my insurance, or lose access to the insulin I need on my insurance plan's formulary, death stares me in the face.

In 2017 under my current employer's old insurance plan, OptumRX sent me a letter stating that an insulin that worked best for my body was removed from my plan's formulary due to cost. I took the letter into my endocrinologist's office and could only ask "Now what?". I spent much of 2017 searching for discount cards that reduced the cost by varying amounts. What you need to know about discount cards is that they expire.

Last October, I purchased one of these vials of insulin over the counter at a Costco pharmacy in Winnipeg, Canada for just \$22USD. No insurance needed. No phone calls. No piles of paperwork. No begging for my life. On the same day that I purchased this vial of insulin, the same vial at the Costco pharmacy back home in Florence, Kentucky had an over-the-counter retail price of over \$300.

The insulin in this vial has NOT changed since 1996. What HAS changed is the PRICE. In 2018, a study by the British Medical Journal stated that the production costs for a vial of analog insulin, such as this Humalog, may only range between \$3.69 and \$6.16. The analysis considered expenses for production, ingredients, and delivery.

Recently, Sen. Chris McDaniel asked me what the insulin supply chain would say if he asked them why the price of insulin continues to climb. I have gathered their statements from recent Congressional testimony below.

Comments and Testimony April 10th, Energy and Commerce Cmte on “Priced out of a life-saving drug: Answers on the Rising Cost of Insulin”

Mike Mason of Eli Lilly points to insurance plans and pharmacy benefit managers- “Eli Lilly believes that insurance coverage gaps including those on high deductible healthcare plans, the Medicare Part D coverage gap, and those with no insurance are among those hit the hardest on the cost of insulin.” Mr. Mason also cites situations where the insulins that work for us as patients with T1D are removed from our plan formularies, also known as “non-medical switching”, a situation that happened to me in 2017.

Doug Langa of Novo Nordisk-

“Unfortunately, as a pharmaceutical company, we do not have the ability to control what an individual insured patient pays for his or her prescriptions; that is a function of the individual’s health plan benefit design. Similarly, we do not have control over whether the rebates we pay to ensure formulary access actually result in lower out-of-pocket costs for patients; that is the decision of the PBM, which determines how to apply the rebate.”

Amy Bricker of Express Scripts, points back to the increase of list prices-

“Express Scripts welcomes lower list prices, known as a manufacturer’s wholesale acquisition cost (“WAC”), and has gone on record favoring them. List prices are exclusively controlled by manufacturers. Over the last several years, the list prices for insulin products have steadily increased...We have not observed a manufacturer *decreasing* its list price for any insulins.”

Finally, remember what I said about the insulin that worked best for me being removed from coverage? Here is what Mr. Dutta of OptumRX told Congress-

“But the solution that will benefit everyone who uses insulin is true generic and biosimilar competition which will drive down list prices. Insulin costs too much already, yet manufacturers keep raising prices.” In the same testimony, OptumRX states that they “negotiate better prices with drug manufacturers for our customers and consumers”. My testimony is that they didn’t. As my plan’s pharmacy benefit manager in 2017, they removed ALL long-lasting insulins from my plan’s formulary except for the one that did not work my body. Not all insulins are interchangeable or work the same for everybody just because they are a ‘long-lasting’ insulin.

It took decades to get to this point. It may take years for action to occur on Capitol Hill, but people in Kentucky are suffering and dying NOW. Two co-workers of Seely Wetherell from

Newport, KY approached me and stated that Seely was rationing insulin in the days leading up to his death in 2018. In June of this year, Kayla Davis from Owensboro died as a direct result of the price of insulin and barriers to the insulin she needed to live. She was 28.

Here are considerations to address the cost of insulin that CAN happen at the state level.

1. The KY General Assembly can pass an insulin price transparency bill that seeks answers across the entire insulin supply chain to explain each entity's part in the rising price of insulin, starting with the 3 insulin makers who control the US supply of insulin. Everyone in the insulin supply chain continues to blame another entity for the rise in insulin prices. While on KY's Medicaid plan in 2015, insulin consumed 9.1% of Kentucky's entire non-hospital Medicaid drug expense. We can find out why.

2. Pass BR105 by Rep. Danny Bentley, An Act Relating to Prescription Insulin, which places a \$100 cap on copays for some Kentuckians who are covered under insurance plans purchased in the Marketplace and small/large group plans that are not multi-state insurance plans and not regulated by ERISA.

3. In addition to BR105, the General Assembly must seek a path to ensuring every T1D in the Commonwealth has access to affordable insulin--everyone on high deductible health plans, those who are uninsured, and those who are on multi-state insurance plans where the \$100 co-pay cap would not be applicable.

Together, we can make Kentucky a leader for others to follow to ensure every single person who requires insulin injections has it without restriction, without barriers, without begging. Imagine if Kentucky was the place where we KNOW we will never face death from the cost of insulin and protected from the actions of profits over our lives.

Truly affordable insulin is a "right to life" issue.

We are tired of inaction, tired of excuses, tired of suffering, tired of begging with hundreds of hours of phone calls and paperwork every year, tired of Kentuckians dying, and we are not going to stop talking about the cost of insulin until it is once again "available to everyone who needs it rather than a commodity for anyone's profit". This issue cannot wait through another year. Incrementalism is not the answer. Waiting only means that we will be back here again telling you that more Kentuckians have died when they should be alive & thriving.

You have the power to provide relief now. Fix this by doing everything in your power at the state level and including patients in all facets of discussion. Thank you for your time. We welcome further discussions leading up to the 2020 Session.