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To:
Rep. Jene Vickery, Chairperson
Members of the Kansas House Insurance Committee

Good afternoon and thank you for the opportunity to testify before you on House Bill #2557, which would limit out-of-pocket, cost-share per month to \$100 for insulin. It is both a privilege and honor to sit before you today and share information on how the cost of insulin has affected my family and others.

I could begin by submitting information found on the Internet and filling my testimony with charts and graphs that reveal the rising cost of insulin over the past decades. It isn't difficult to Google those facts and figures and as members of this committee I am sure you have had - and will have - many research opportunities. What may not be as easy is to find someone willing to sit before you and share personal experiences and put a face to the story of the effect of Big Pharma, their insulin price gouging and the consequence of greed. I don't want to waste this moment by submitting numbers and outcomes of research, but rather tell you our story and the stories of others in my circle and what they are experiencing.

My husband, Michael Lucke, is an insulin dependent Type 2 diabetic, this being a chronic condition that affects the way the body processes blood sugar. Type 2 diabetes, the most common type of diabetes, is a disease that occurs when your blood sugar is too high. For the past 30 years he has relied on medication and diet restrictions to stay healthy. He checks his blood sugar several times a day and sees an endocrinologist every three months. His list of medications is long. When we leave the house he carries a bag of medications, protein bars and snacks to eat if his sugar level gets too low. Monitoring sugar levels and dealing with the highs and lows can be daunting, but it is our reality. Diabetes is not just a disease, it is a way of life and we've lived it for three decades. It never occurred to me that one day we might be struggling with our finances to purchase a drug that is inexpensive to manufacture, and a one that my husband needs to save his life.

Prior to turning 65 we attended a workshop at Stormont Vail Hospital that was facilitated by an insurance expert to help us navigate through the maze of Medicare and selection of supplement plans. We learned very quickly that his expertise would be very valuable in helping us select a plan that would work best for Michael's list of medications. He turned 65 in November 2019 and January 2020 was his first month on Medicare. Needless-to-say we were not prepared for the cost of his medications in January. With the deductible requirement, his insulin jumped from \$60 to \$400. That increase was in addition to the \$100 in other required diabetes-related medications and the \$99 monthly premium for his Medicare Plan D.

This past Monday we learned that the deductible has been met. The charge for his insulin in February was \$120. I know what you might be thinking, that's only \$20 above what House Bill #2557 is working towards, and you are right. But there is so much more to understand because what we paid on Monday isn't the end of our worry. With high insulin costs, Medicare Plan D patients end up in what some pharmacists call the "donut hole" by March or April, after that time they may be forced to pay full price. The coverage gap or "donut hole" is reached when with the insurance and the consumer have spent \$4,020. To put this in perspective, we picked up \$1,600 worth of insulin on Monday and, although only paid \$120, it won't take long before we are in the donut hole. Most plans will pay zero while you are in the donut hole. Some plans pay percentages, all plans are different so we will see what the next few months have in store for us.

Back in 1996, when Eli Lilly's Humalog first came out, the price for a 1-month supply of insulin was \$21. Today, vials of analog insulins, including Humalog, sell for about \$300. Patients with Type 1 diabetes typically require two or three vials of insulin per month, but patients who are more resistant to insulin, such as those with Type 2 diabetes, may require six or more. There are manufacturer coupon cards available to reduce copays, but I have been informed by a professional that anyone on Medicare is excluded and it is considered fraudulent to use them. With high insulin costs, most Medicare Plan D patients end up in that donut hole by April so many will begin to pay full price, ration their dosage, or do without.

I would like to share some first-hand information I've obtained from friends facing this same situation

Ms. A:

This family found out three years ago that their son is a Type 1 diabetic. Type 1, once known as juvenile diabetes, is a chronic condition which the pancreas produces little or no insulin. She shared with me their insurance premium is \$1,000 a month and her husband would be reluctant to ever consider a change in employment for fear of how it will change their insurance coverage. She told me that in 2019, "It cost me and insurance \$20,000 to keep my son alive."

Ms. B:

Ms. B is 67-years-old and has been a Type 1 insulin dependent diabetic since 1980. In November 2019 her out-of-pocket expense was \$588, which includes both her glucose testing strips and medications. In addition to that monthly expense, her Plan D supplement went from \$139 to \$155 in 2020. She told me, "It's hard, but still do feel thankful I can afford it." On Monday she shared with me while at the pharmacy recently she witnessed an elderly woman crying because her insulin was going to take the balance of her Social Security check, leaving nothing for food. Ms. B told me, "I will never forget it."

David:

David had a stroke in November brought on by a tick born illness. As a result he was put on steroids that accelerated the severity of his Type 2 diabetes which had been controlled with a low dose of Metformin, an oral medication. He now requires insulin. Last month, total out-of-pocket cost for his insulin was \$330. That expense, along with other diabetic related medications, brought his total out-of-pocket cost to \$515. David has yet to return to work and has no income. Fortunately he remains on his employer's health insurance, BlueCross/ BlueShield Gold level coverage.

The new diagnosis:

Then there is the 9-year-old that was recently diagnosed with Type 1 diabetes. He cannot feel or doesn't understand what low blood sugar feels like, so Children's Mercy prescribed a continuous glucose monitor. The start up supplies alone were over \$1,000. That doesn't include any insulin costs.

Those that just can't afford it:

A 67-year-old female caring for her husband who has cancer. She is also a cancer survivor. Her insulin copay in January was \$476 for a 20-day supply. She is going to stop taking it because she simply cannot afford it. And then there is the husband and wife in our community, both over 65 and diabetic. In 2019 they spent over \$5,000 on insulin.

All of these scenarios are true. All are Kansans. All desperately need legislation that places limits on out-of-pocket copay on insulin.

I am here today, not just for my family, but for all the others that have not been given this opportunity. It is heartbreaking to know that due to the bankrupting effects of insulin costs, many people feel forced to ration their monthly prescriptions or go without. There are too many that are making the decision between purchasing their life-saving insulin or putting food on the table, gas in their car, or paying their utilities.

Numerous stories have been published about people who do this and later suffer the ultimate sacrifice: death. It shouldn't be this difficult. Diabetics shouldn't have to make a choice that can have such dire consequences and crippling complications.

I want to thank you again for the opportunity to testify before this committee. I'm nobody special. I am not a medical professional or a scientist. I'm just a 65-year-old grandmother from Kansas that is fighting for her husband's survival and the survival of others, many whose faces I haven't seen and stories I haven't heard. I urge you to follow step with the states of Colorado and Illinois and legislate a limit on the amount of copay diabetics are facing every month at their pharmacy.

When working on this bill please remember how very important your decisions are to those needing insulin to survive. You, someone you know or, more importantly, someone you love is counting on you. Their life depends on it.

Thank you,

Jodi Lucke