

January 11, 2023

Madam Chair Lee and members of the committee, I am Danelle Johnson from Horace, ND. I am here representing myself. I support this bill because our daughter Danika (20), lives with auto-immune Type 1 Diabetes, as do many residents in our state. She is insulin dependent to sustain her life, for the duration of her life, or until a cure is found. I have advocated at local, state and federal levels for years and have yet to see progress for residents of North Dakota until the Federal Inflation Reduction Act capped the monthly cost of insulin for Medicare enrollees at \$35.

The inability to afford insulin is more daunting than having a family member diagnosed with Type 1 Diabetes. We were told if we\she takes care of herself, she can live a long, healthy life, free of complications. The medical care team can't prepare you for not being able to afford insulin and supplies necessary to dose and administer insulin therapy. This can be the start of losing hope. The burden can lead to anxiety\depression, addiction, suicide, poor performance at school or work, financial ruin, isolation, homelessness and a variety of issues, just to get their hands on this liquid gold.

Together, we have an opportunity to change this trajectory.

22 States and the District of Columbia enacted legislation for accessible and affordable insulin therapy. North Dakota is operating on You PAY or You DIE. This manipulated market is unsustainable and costs lives.

There is not a generic (biosimilar) option and in the US, we are charged 7 to 10 times more than other developed countries for insulin. There is a "fake" generic for example: insulin aspart, which is the same as brand name Novolog & Fiasp, is insulin made by the same company with a different label, and at a much lower price. The cost of insulin has risen over 1200% since 1990 with no substantial changes to the product. That would make your gallon of milk cost over \$3000, and you can live without milk, but 8.3 Million American's can't live without insulin. Insulin is the hormone that converts glucose to energy to survive.

Some comments that might deter legislators from supporting this bill.

1. "Cap or mandates don't work"
2. "It's a slippery slope"
3. "If we do it for insulin, we have to do it for other drugs and procedures"
4. "If we pay for your insulin, other insured's premiums will increase"
5. "If diabetics don't continue to pay this outrageous price, the manufacturers can't research and develop new drugs"
6. "If we cap prices, we may lose the rebates offered"
7. "I paid for my family's medical bills, you should pay for yours"
8. "We value life at all ages"

My responses:

1. "You are right, in a manipulated market nothing works. We need to instill reasonable controls to protect people from blackmail for their life.
2. It doesn't have to be a slippery slope. If a treatment for any disease has also been available for 100 years, and it has increased in price by 1200%, and it is 100% proven effective for millions of people, and allows people to reach a higher potential at work or school, and is proven to delay devastating and disabling complications by all means, YES IT SHOULD be accessible and affordable to everyone for the good of society.
3. No, you don't have to do this for everything, this is a tactic to pit one disease against another. Insulin dependent diabetes has proven it takes lives due to rationing because of cost barriers, over and over.
4. Show me the studies, show me the numbers, show me the reality if this is true. Or is it true because the insurer makes it seem so? There is more data supporting that fewer complications related to diabetes like heart disease, kidney failure, diabetic retinopathy, stroke, blindness and amputations actually lowers the costs overall.
5. Federally, it has been proven that Big Pharma spends MORE money on lobbying, than on research and development of new drugs or therapies. Are you REALLY saying that people with diabetes should continue to DIE even though there is a known, 100% proven therapy available because it is so expensive it can support research, so one of your loved ones can live because of a newly discovered drug or treatment?

6. I am aware of zero studies showing if we cap the price of insulin, the costs will rise for other members of the group. Please show them to me. However, if we lose the fake rebates that are being subsidized on the backs, or lives of diabetics, yes, your premiums CAN and in my opinion SHOULD go up. If I knew I was being subsidized a few dollars on my premium but causing someone's loss of life, I would personally be devastated. If we were transparent with this information, I know others would be too.
7. If you paid for all your family medical costs decades ago, know that it isn't an apples to apples comparison because high deductible health plans and runaway prescription drug costs didn't exist then. That doesn't mean I don't agree it was hard to do.
8. If you truly value LIFE, you will work to help us make progress for affordable and accessible insulin therapy.

I am also advocating at the Federal level for the bipartisan *Improving Needed Safeguards for Users of Lifesaving Insulin Now (INSULIN) Act*, however we need to act now in North Dakota. Diabetics have carried the burden far too long, especially with the popularity of employer sponsored high deductible health insurance plans being the only option for many families. Diabetes claimed 100,000 lives in 2021, making it one of the leading causes of death in the US.

Diabetes is the most expensive chronic disease in the US where \$1 of every \$4 spent on healthcare is for a diabetes related care or treatment. This is unsustainable for the healthcare system, as 64,000 people are diagnosed with insulin dependent Type 1 diabetes every year, and that doesn't take into account all the other types of diabetes that require insulin. In closing, I look forward to collaborating with you to make progress on this issue to create a bill we can agree on and

Lack of Insulin Stops a Beating Heart and it truly is that Black and White.

Respectfully,

Danelle R. Johnson