

This document contains my original testimony from several different hearings for SB 2140 as it worked its way through the 2023 Legislative Session. It passed, and that started the required two year study period using the NDPERS plan. This has now become HB1114 for the 2025 Legislative session. I was the original author of this bill back in 2021.

Danelle Johnson, Type 1 Diabetes Advocate & Mom to Danika Johnson, a fellow advocate that is living with Type 1 Diabetes. Contact Info: 701-261-1687, daryldanelle@msn.com

TESTIMONY #1

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, and 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 Americans 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

TESTIMONY #2

Chairman Weisz and committee members. I appreciate the opportunity to testify remotely due to surgery. My name is Danelle Johnson from Horace, ND and I am here representing myself. Our daughter, Danika was dx with T1D in 2015 and is now 21. Every day, she moves closer to the reality of inconsistent access to insulin therapy in America, and every day we worry about the loss of our current coverage that provides access now.

OUR REALITY

When you know someone forced to PAY or DIE, and they can't PAY, and so they DIE you will understand why my advocacy efforts are passionate and critical. SB2140 would impose a price cap on insulin and basic supplies. It is similar to legislation passed by 22 states to delay onset of imminent complications from this terminal illness and avoid death by allowing people to be compliant with instructed care.

This is my third session attempt to initiate discussions, collaborate and raise awareness. Danika and I have also been federal advocates since 2019. There has not been any federal legislation that has

lowered out of pocket costs, that has made it to implementation, covering all ages regardless of their insurance situation.

You may hear and possibly believe these statements:

1) The bill won't help that many people

a. Approximately 64,000 people are diagnosed each year with Type 1 diabetes in the US. The ND Department of Health doesn't track specific types of diabetes. Saying we aren't going to help many people is an opinion until backed by factual data. The T1D community is growing every week in ND.

2) The bill will pass costs on to others

a. The enormous rebates from insulin used to subsidize health plan premiums and administration costs for all plan members would be lost if we didn't allow the use of formularies, which we have amended the bill to do. Costs passed on to other members has been proven by other states with insulin capping bills to be negligible at best.

3) Mandates don't work, we must allow free market

a. Insulin is not a free market, the "Big 3" insulin manufacturers have created an oligopoly – a market with little to no competition. With their actions absent competition, they have triggered an ongoing class action lawsuit for price fixing that was initiated in 2017.

4) Insurance companies are already doing this. When asked for details, the ND Insurance Commissioner's Office found it to be very complex to discern which plans were offering a copay cap. They couldn't provide documentation of exactly which plans from which ND insurers were doing so. This is not a factual statement until proven with data, it is a claim.

5) Dangerous precedent to declare this an emergency

a. Our legislature can and does make exceptions to laws, when deemed to be in the best interest of the people. As policymakers, you have that power. There are ample resources to draw cost studies from states that have already done this. And from the ND insurance providers that claim they have already been doing this. No need to study potential impact if it is already being done.

6) Businesses don't want higher health insurance costs

a. No one does. We all have a responsibility to educate business owners and business chambers, on tangible and non-tangible costs truthfully. Insulin therapy is 100% proven effective to sustain life and slow progression of this terminal illness. I consider this preventative with a positive ROI. Especially when the benefit is the person LIVES. Access to insulin allows for patient compliance and is more humane than inflicting intentional suffering and hardship for the benefit of others.

7) A copay cap isn't necessary because Insulin Manufacturers are slashing prices.

a. Eli Lilly themselves stated, the insulin they slashed the price on this week is only used by 3 out of 10 people. All people can't take all brands of insulin. Eli Lilly gained publicity after advocate pressure in 2019 and announced a half price version of Humalog, called Lispro. They received positive press and then do you know what happened? Pharmacies couldn't get supplies of it, so it "existed" in

theory, but people couldn't access it in reality. I believe it is our collective duty and responsibility as leaders and advocates to find a way to effect change that will preserve health and sustain lives, even if the margin is slim as some opponents claim.

I challenge you to CARE enough about your COMMUNITY, to make a COMMITMENT to have the COURAGE to discuss these statements in the context of insulin therapy in a manipulated market, with no biosimilar option available. I encourage and welcome further discussion or you can check out a website I co-author: www.insulinrequired.life I ask for a "DO PASS" recommendation on this bill. After all: Lack of Insulin Stops a Beating Heart and it truly is that Black and White.

Respectfully, Danelle R. Johnson, T1D Patient Advocate & T1D Mom

daryldanelle@msn.com 701-261-1687

TESTIMONY #3

POINT PAPER – Cost of Insulin products

Problem: The cost of insulin is presently unaffordable for a significant number of North Dakota residents who rely on it to survive. Nearly a quarter of insulin-dependent Diabetics ration insulin due to insulin's high monthly cost. Rationing insulin leads to serious complications including stroke, kidney disease, blindness, heart disease, and death.

Issues:

- 1) Patients. Type 1 Diabetes afflicts patients of all ages and is incurable, but easily treatable with insulin. Type 1 Diabetes is not caused by lifestyle choice, poor diet, or lack of exercise. Without insulin, Type 1 Diabetes is 100% fatal.
- 2) Cheap to Manufacture. Cost to manufacture insulin is low – only about \$5-6 for a monthly supply, yet there are no generic options on the market.
- 3) Expensive to Buy. Type 1 Diabetes is the most expensive chronic illness in the United States. The average Type 1 Diabetic spends approximately \$17,000 a year on out-of-pocket costs (OOP) for health care, not including their cost of insurance.
- 4) High Profit Incentive. The profit incentive for profit is high – approximately \$1,127 per month per patient or a profit margin of approximately 7000%.
- 5) Exponential increases. The cost of insulin has exponentially increased in the last thirty (30) years with no substantial changes or improvements to the product.
- 6) Rebates Come at a High Cost. Approximately twenty-five percent (25%) of the profit is redistributed to pharmacy benefit managers, insurance companies, and large subscribers as

rebates. The genesis of the rebates is the high cost of insulin, paid for by Type 1 Diabetics overpaying for their medication.

7) Myth of Free Market. The insulin market is not a free market. Insulin manufacturers, pharmacy benefit managers, and insurance providers work in tandem to extend patents, introduce barriers for generics and inflate prices.

8) Insulin is deadly. Insulin is both deadly and lifesaving. It requires various supplies to be effective and to reduce long term health consequences.

9) Legislation is necessary. Legislative pressure on insulin manufacturers is working. Insulin price capping bills in twenty-two (22) states have resulted in downward compression on pricing in the last two (2) years.

10) Price Reduction Programs are Ineffective. Price reductions, manufacturer programs, coupon offerings, and supplier programs are ineffective, narrowly focused, and largely motivated by publicity.

Solution: The North Dakota Legislature approve a monthly co-payment cap of \$25 for insulin and \$25 co-payment cap for supplies.

Recommended Action: The committee approves the current bill.