

Mister Chairman Holmberg and members of the committee, my name is Danelle Johnson from Horace. I am here representing myself. I support this bill because our daughter, Danika (19), is living with Type 1 Diabetes. We have been advocates for 5 years at local, State and Federal levels and have yet to see changes for the majority of insulin dependent North Dakotans to sustain life.

Life or Death, it really IS that black and white. I have chosen to illustrate in the context of real vs. researched costs. People equate cost with a dollar figure, but there are intangible costs and a return-on-investment calculation that guide our choices.

Do you **read** the headline “\$470 million direct medical costs for diabetes in ND” or do you **research** that in 2017 there was “\$190 million in indirect lost productivity costs because of diabetes in ND”.

Do you **read** the headline “access to insulin and diabetes supplies provides an individual with 100% proven ability to live a long healthy life”, or do you **research** “1 in 4 people in the US ration insulin and supplies because they cannot afford them”. Rationing has proven dangerous and deadly time and time again.

Do you **read** “patients demand the latest drugs” or do you **research** “Insulin manufacturers have a monopoly on a 100 yr. old drug, and there are no biosimilars (generics). The market will NOT correct a monopoly, I learned that at NDSU.

Do you **read** “about healthcare and prevention” or do you **research** “why in the US are we preventing people from sustaining their right to life by limiting access to insulin and basic supplies”. This has been proven repeatedly to cause long term health complications and death.

Do you **read** “the supply chain is the problem”, or do you **research**, in 1978 at the City of Hope in Duarte, CA, they discovered the ability to make synthetic insulin and therefore the supply chain problem of harvesting insulin from pork or bovine pancreases was solved. Danika and I toured this facility and saw the building this was discovered in, along with a human donated pancreas from a T1D individual in a

current research lab. Powerful, the supply is not the problem, but the supply chain process is part of the complex problem.

Do you **read** “the copay is \$25” or do you **research** that may be true, but individuals may also have a coinsurance percentage on top of that. In Danika’s case, the retail price of her 30-day supply of insulin is \$3,946.99, so our 20% coinsurance would be \$789.40. This is only 1 of her 11 prescriptions to manage diabetes.

Do you **read** “advocates are emotional and need to use facts and ask why insulin is so expensive instead of asking for others to pay for it”, or do you **research** that for many years, advocates from North Dakota and across the US have been asking this question of the supply chain. Danika as the JDRF Children’s Congress Delegate for ND and I travelled to Washington, DC and have worked with US Sen. Cramer for 2 years now on 3 bipartisan bills at the federal level to try to resolve some of the issues diabetics face.

Do you **read** “insulin is expensive” and think it cannot be that bad, or do you **research** that since 1991 the price of insulin has risen by 1200%, with no fundamental difference in the product. Example: \$3 gallon of milk in 1991 that still comes from cows, would suddenly cost you \$3,600. Outrageous - when you pick up your next milk, think of me!

Do you **read** “insulin saves lives” or do you **research** that “insulin is also deadly”. The amount of insulin it takes to cross that line is extremely small. We aren’t going to use more insulin than we need.

Do you **read** “68,097 residents in North Dakota have diabetes”, or do you **research** that 20,429 of those people are dependent on insulin to survive. When I listened to a federal hearing, representatives from all areas of the supply chain (except patients) said repeatedly “Sir, Even ONE death is too many”. I vividly hear that comment and it rattles me to my core. However, here we are almost two years past that April 2019 hearing on Capitol Hill and people are still dying, right here in our communities and our state and our country. It goes undetected because if you **read** an obituary you will not see the word “diabetes”, you need to **research and understand** that the heart

attack, stroke, kidney failure etc. happened because of complications from uncontrolled diabetes. People in the diabetes community know, they are heartbroken for families of the people we lose, we are terrified for our own loved ones, and we most certainly are NOT going to hear, "Did you hear the Johnson Family couldn't afford their insulin so their loved one died?"

I am willing to have conversations with anyone, I am not blaming any group, I know it is complex and complicated. I love my daughter more than anything (except her sister of course - - that must be equal!) and I would do anything I can for her. I choose to advocate in a positive, persistent, and determined manner to raise awareness, increase education, expose the true costs, and ask for your help in finding a solution.

Patients have borne the burden too long. Bringing everyone to the table to solve the issue so that all lives are equally valued, we are giving people the ability to manage their health and sustain their lives, instead of surviving death for another day while causing irreparable harm to their internal organs is what I am striving for.

The price of insulin even with insurance has become prohibitive and out of reach for too many people. Our daughter, Danika has a RIGHT TO HER LIFE that can be managed by insulin and basic supplies. Because it truly is black and white for us.

LACK OF INSULIN STOPS A BEATING HEART.

Respectfully,

Danelle Johnson