

Madam Chair and members of the committee, I am Danelle Johnson from Horace. I am here representing myself. I support this bill because I have a daughter living with Type 1 Diabetes. I have been advocating for years at State and Federal levels and have yet to see changes for the majority of North Dakotans that are insulin dependent to sustain life.



Madam Chair and members of the committee, I am Danika Johnson from Horace. I am here representing myself. I support this bill because it affects me personally. I too have been advocating up to the Federal level. I worry how I will pay for college student loans and health insurance premiums and diabetes supplies to help keep me alive and healthy as I become more financially independent.

Life or Death



it really IS that black & white

- If you have access to insulin as prescribed you have the ability to manage this disease.
- Inability to afford insulin as prescribed, rationing as they call it, is dangerous and deadly, and all too common.

Independent



Dependent

- We have given our daughter all the tools, support, opportunities and experiences to be a well-rounded independent adult.
- This disease has been draining our finances for 7 insurance calendar years, even though dx only 5.5 years ago. It feels hopeless, to think we won't be able to continue and that she will be forced to become dependent on Medicaid or similar program at a very young age.

Unafraid



Afraid

- I used to live unafraid. I am fortunate to have fantastic family, friends and co-workers. We have home insurance, car insurance, health insurance, life insurance, disability insurance. We have planned to be prepared.
- Despite all our best efforts, we now live afraid of the day our daughter is forced to suffer the awful complications of a disease that could be managed well, simply because we/she can no longer afford her life saving supplies.

Generic



No Generic

Do you know, there are only 3 insulin manufacturing companies in the world? Insulin was discovered and first used 100 years ago. The patent was sold for \$1 for each of the 3 scientists, because they felt it was unfair to profit from something that belonged to the world, not to them. They felt it was morally wrong to profit from something the world needed to sustain lives.

Manage diabetes



Survive diabetes

- People who have insulin dependent diabetes can absolutely effectively manage their disease when using the prescription as prescribed.
- Affordability issues all too often force people to try and just survive diabetes, by still being breathing, not by being able to feel well, healthy and live life like we all want too.

Infinite



Finite

- Genetically engineered synthetic insulin was first produced in 1978 at the City of Hope in Duarte, CA. Danika and I have toured the facility, been in a research lab for diabetes, saw a real human donated pancreas from someone who had Type 1 Diabetes, and saw the physical building where the discovery of the ability to make synthetic insulin occurred.
- This solved the supply chain problem where they used to have to harvest insulin from pork or bovine pancreases.

Insulin



No Insulin

- Insulin = Life and Health
- No Insulin = Devastation and Death

Healthcare



Disease care

- We often talk about healthcare and prevention.
- I can't tell you the number of times I have received information to change our lifestyle and diet to reverse her diabetes. Ughhh, I want to scream, you don't know what you are talking about!
- However, lack of proper insulin dosing to manage insulin therapy, causes health conditions that are much more costly such as kidney failure, blindness, heart disease, stroke, nerve damage and amputations. There is no prevention happening here, it is permission to give up trying to manage, and let the complications occur.

Easy



Complicated

- I wish the problem had an EASY button.
- I know it doesn't, I know it is complicated, I know there are many players in the supply chain, but that doesn't mean we should be complacent and allow this behavior to continue. I know you just keep working until you get it done!

Lifestyle



Autoimmune

- What people generally think of when talking about diabetes, is that it is caused by lifestyle and diet CHOICES.
- Type 1 Diabetes, is an autoimmune disease which is often accompanied by at least one secondary autoimmune disease. Danika has both Type 1 diabetes and Hashimoto's thyroid disease. She was an FM Acro gymnast from the age of 3, she was in track, volleyball, tennis. Waterskis, downhill skis, runs etc.

Co-pay



Co-insurance

- Many people have experienced the change from older types of insurance plans with set copay amounts per prescription.
- The more common type of plan now is the High Deductible Health Plans which require the patient to pay set copays and/or coinsurance which is a percentage of the retail price of a prescription **before** rebates are applied, to meet large deductible and out of pocket expenses before fully covering the insulin and supplies.

State



Federal

- I understood in 2019 when we had SCR4002 to study the issue, it was recommended that we work at the Federal Level. Danika and I did just that and continue to do so.
- We met with US Sen. Cramer, US Sen. Hoeven and US Representative Armstrong. We discussed the issue around access and affordability of insulin and diabetes supplies, and also for the Special Diabetes Program which provides funding for research, but also supports the states in their cost of diabetes programs.
- US Sen. Cramer took swift bipartisan action to cosponsor 3 bills related to these issues. I can provide more detail if you wish.

Action



Complacency

- North Dakota can be a leader along with 13 other states and the District of Columbia in passing regulation to help resolve this issue.
- 20 other states are also working on legislation to do the same.
- Or we can be complacent and hope it fixes itself, it hasn't for years, and only continues to get worse, because it can.
- I am a small town farm girl from Forman, ND, I went to NDSU, I started my career at Great Plains\Microsoft and then now work at NAU Country creating crop insurance software that implements the federal farm bill program. My husband is from Fargo. Our parents are here, 5 out of 6 siblings & families are here, friends are here, work is here, our communities are here. But no matter how much we would like to stay, saving our daughter's life by moving where her life is valued tops everything else. So we have considered moving away.

Choice



Lack of Choice

- The choice of which insulin is used needs to be determined by the provider and the patient based on the whole health picture of the individual.
- Lack of Choice can be detrimental to patient and increase already burdensome paperwork for provider.

Life Sustaining



Life Ending

- Insulin is as deadly as it is lifesaving. That is why the bill is including access to affordable insulin therapy supplies at the very basic, base level to meet today's standard of care.
- This bill currently doesn't address insulin pumps or continuous glucose monitors, which absolutely show they are very effective at helping manage the diabetes care, but we know we can't get too far ahead of ourselves. Right now, my goal is to allow North Dakotans the ability to live without fear of being able to afford the bare minimum supplies to sustain life.

Lack of Insulin



Stops a beating heart.

TRUTH

- With accessible and affordable insulin for all North Dakotans, I will gain the hope that insulin diabetics will no longer lose their lives for this reason.
- Having our state understand we have bore the burden for far too long and diligently work on finding some sort of relief or resolution to this problem is what I am working for.
- As advocates and Mothers, we were only asking for the emergency declaration so that all lives are equally valued, and we don't have to wait another 2 years to have the same access as state employees.

Life or Death



it really IS that black & white

SB 2183 – Access to Insulin

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