

Chairman Weisz and committee members. I appreciate the opportunity to testify remotely due to surgery. My name is Danelle Johnson from Horace 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 a 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.

Respectfully,

Danelle R. Johnson

T1D Patient Advocate & T1D Mom

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