2021 SENATE HUMAN SERVICES

SB 2183

2021 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Sakakawea Room, State Capitol

SB 2183
1/19/2021

A BILL for an Act to create and enact section 26.1-36-09.16 of the North Dakota Century Code, relating to accident and health insurance coverage of diabetes drugs and supplies; to amend and reenact section 26.1-36.6-03 of the North Dakota Century Code, relating to public employees self-insurance health plans; to provide for application; to provide an effective date; and to declare an emergency

Madam Chair Lee opened the hearing on SB 2183 at 9:00 a.m. All members present: Senator Lee, Senator K. Roers, Senator Clemens, Senator Hogan, Senator Anderson, Senator O. Larsen.

Discussion Topics:

- Insulin pump and monitor market price fluctuation
- Cost benefit analysis
- PERS plan out of pocket expenses
- ERISA plan coverage
- Increase in health insurance premiums
- Rebates based on formulary list and rebate incentives
- Federal law mandate
- Blue Cross Blue Shield co-insurance on preventive drugs
- Changing effective date to upon renewal

[9:03] Senator Dever, District 32. Introduced SB 2183 and provided testimony #1481 in favor.

[9:26] Danelle Johnson and Danika Johnson, ND native. Provided testimony #2106 and #3881 in favor.

[9:51] Christine Fallabel, Director, State Government Affairs and Advocacy, American Diabetes Association. Provided testimony #1184 in favor.

[9:55] Janelle Moos, Advocacy Director, AARP North Dakota. Provided testimony #1344, #1345, and #1346 in favor.

[10:05] Scott Miller, Executive Director, North Dakota Public Employees Retirement System (NDPERS). Provided neutral testimony #1247.

[10:13] Daniel Weiss, Senior Executive Director, Pharmacy for Sanford Health Plan. Provided clarification to the committee on rebate incentives and provided neutral testimony #1299.

[10:21] Angela Kritzberger, Hillsboro, North Dakota. Provided testimony #1207 in favor.

[10:28] Chrystal Bartuska, Medicare Division Director, North Dakota Insurance Department. Provided oral neutral testimony

[10:32] Jack McDonald, on behalf of Americas Health Insurance Plans (AHIP). Provided testimony #1414 in opposition.

[10:35] Matt Gardner, Greater North Dakota Chamber. Provided oral testimony in opposition.

[10:37] Megan Houn, Director of Government Relations, Blue Cross Blue Shield. Provided testimony #3112 in opposition.

Additional written testimony: (7)

Donene Feist, Director, Family Voices of North Dakota. Provided written testimony #1180 in support.

Carlys Gast, Fargo, Citizen. Provided written testimony #1227 in favor.

Jim Nelson, North Dakota Veterans Legislative Council. Provided written testimony #1347 in favor.

Christina Dahl, Nurse Practitioner. Provided written testimony #1423 in favor.

Kasey Carlin, West Fargo, Citizen. Provided written testimony #1496, #1497, and #1498 in favor.

Rebecca Fricke, Chief Benefits Officer, North Dakota Public Employees Retirement System (NDPERS). Provided written neutral testimony #1314.

Derrick Hohbein, Chief Operating/Financial Officer, North Dakota Public Employees Retirement System (NDPERS). Provided written neutral testimony #1317.

Madam Chair Lee closed the hearing on SB 2183 at 10:42 a.m.

Justin Velez, Committee Clerk

Testimony on SB 2183

Senate Human Services Committee

Senator Dick Dever

January 19, 2021

Madam Chair, members of the committee, I am Dick Dever, Senator from District 32 here in Bismarck. We bring to you this morning a bill with passion – passion because of the tremendous impact it has on those who are affected by it.

SB 2183, in its simplest terms, places a cap on the monthly co-pay for insulin and "medical supplies for insulin dosing and administration". It also provides that coverage may not be changed by formulary. I'll speak to that again.

This bill does not come to us from a national organization. It does not come to us from a lobbyist. This bill comes to us from mothers of children with Type 1 Diabetes. They are passionate. They are well informed. They are driven by their love and concern for their children. Their testimony is far more important than anything I can say.

I don't like insurance mandates. This one is different. The cost of insulin is far higher than is justified. I feel like large pharmacy manufacturers are taking advantage of the fact that their consumers have no choice. This issue for many people is literally a matter of life and death.

As the bill was in the Employee Benefits Committee, Senator Anderson made the point that when the consumer is no longer the payer, they are more likely to demand the higher, more expensive product. He makes a valid point, but the flip side of that argument is that when the insurance company becomes the payer, they are similarly inclined to restrict the product to the lowest price. The goal should be the most effective medication as determined by the health care provider and the patient.

I have a daughter-in-law who is a school nurse in an elementary school here in Bismarck. I understand that the Bismarck School District provides a nurse in each elementary school and one for the three middle schools and one for the three high schools. She tells me that the average elementary school has one or two students with Type 1 diabetes, that they need assistance in managing their disease, and that high schoolers are better able to manage their own disease. She is very good at what she does.

The fiscal note shows a significant cost to the PERS Health plan. Several sessions ago, we considered another program that had a significant cost. We adopted a program patterned after what was known then as the Asheville Project. It provides a payment to pharmacists to who counsel and help patients manage their diabetes. In the reports that I have seen, that cost if far outweighed by the saving that have generated by the positive outcomes since.

I am happy to respond to any questions, but the greater testimony on this bill will come from those who follow.

#2106

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 hom 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

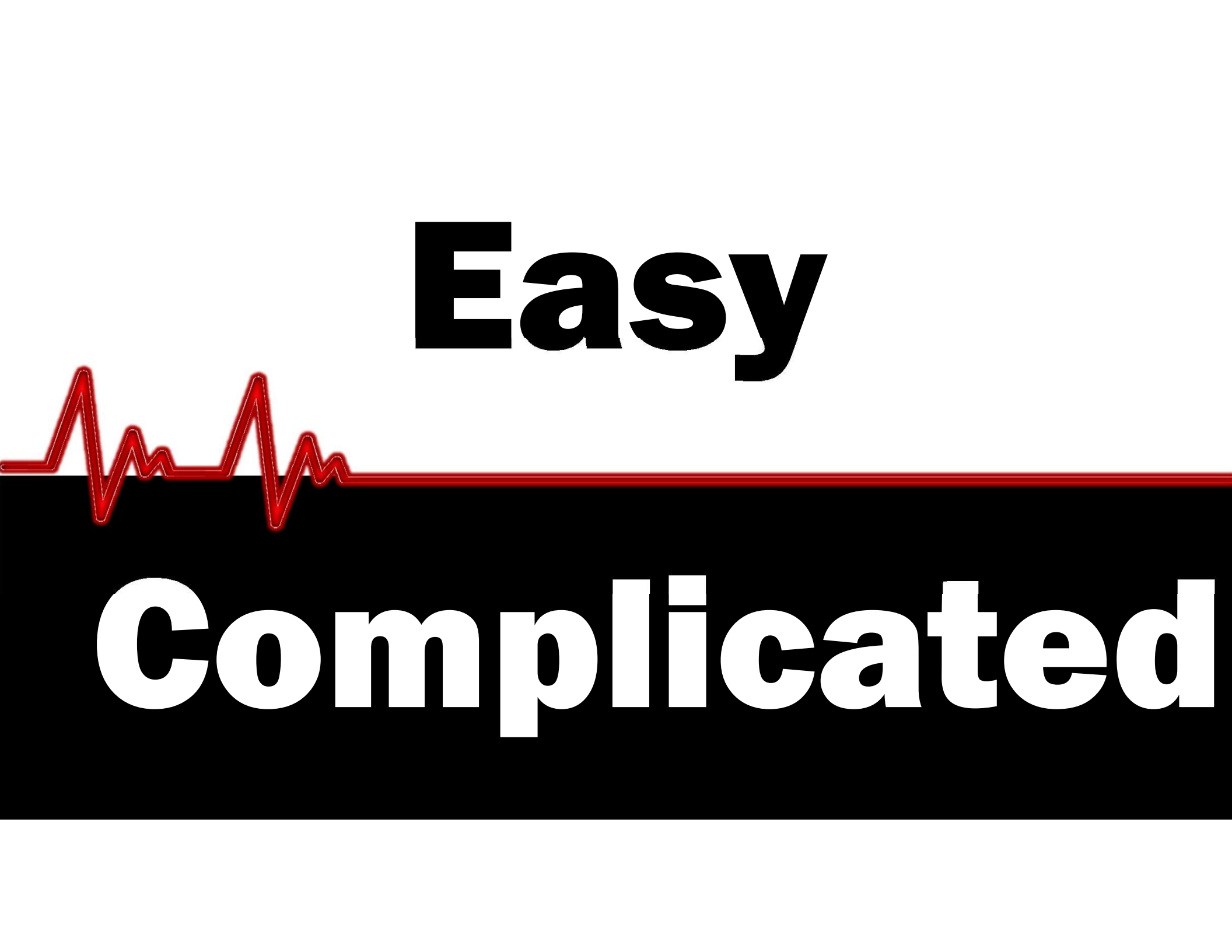
No Insulin

- 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

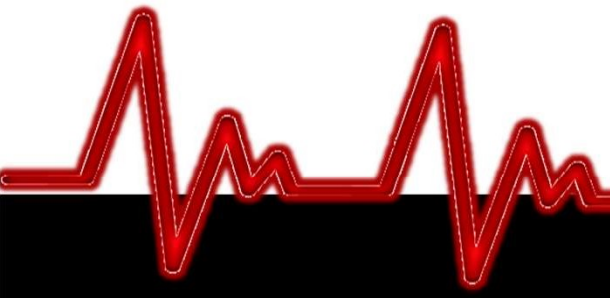
- What people generally think of when talking about diabetes, is that it is caused by lifestyle and diet CHOICES.
- Type 1 Diabetes, is an autoimmune disease which is often accompanied by at least one secondary autoimmune disease. Danika has both Type 1 diabetes and Hashimoto's thyroid disease. She was 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 applies, 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 if 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

Danelle Johnson 701-261-1687
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POINT PAPER

Problem: Medical Treatment for insulin dependent diabetics has become unaffordable and inaccessible for a growing number of patients to effectively sustain life with 100% success and manage their chronic illness so as to prevent further complications of stroke, kidney disease, blindness and heart disease.

Issues:

1. 68,097 North Dakotans are diabetic. 6,800 are Type 1 Diabetics who are 100% dependent upon insulin to survive. A subset of all other diabetics also rely on insulin.
2. Insulin and diabetes supplies supply chains offer no transparency to costs.
3. No Generic Option (Biosimilar as it is called in the case of insulin.)
4. Free Market does NOT bear the cost of insulin. Type 1 Diabetic's choice is: Pay or Die
5. Diabetes is the most expensive chronic disease in the United States. $1 out of every $4 health care dollars is spent on diabetes and related care. Individuals with diabetes have medical expenses approximately 2.3 times higher than those without.
6. Insulin Out of Pocket (OOP) costs are increasingly calculated as a percentage of the cost (co-insurance), rather than a fixed dollar amount (co-payment) and are typically based on the list price rather than the net price.
7. In North Dakota, a manufacturer's rebate for insulin can and is used to lower premiums for the employer and insureds, but the patient is charged co-insurance from the list price.
8. Insulin is deadly. Insulin therapy requires diabetic supplies such as test strips, meters, lancing devices, syringes, and lancets to make proper dosing decisions. All need to be accessible and affordable to do so.
9. The cost of insulin has risen 1200% since 1990 with no substantial changes to the product.
10. 8.3 Million Americans use insulin to control their diabetes. Three-fifths are insured under Medicare, Medicaid, or Children's Health Insurance Program (CHIP). Taxpayers are already footing the health care bill for over 50% of the people with diabetes.
11. Estimated cost savings when all persons have proper diabetes management care is $_____ (How to qualify savings?? North Dakota spent $470 million in direct expenses for diabetes care in 2017 and another $190 million spend on indirect costs from lost productivity.)

Solution: The North Dakota Legislature to approve a monthly co-payment cap of $25 for insulin and an additional $25 co-payment cap for diabetes supplies for the patient until further action is taken federally or by the supply chain itself to ensure affordability and accessibility for all North Dakotans to this life sustaining medication that has 100% ability to manage the disease when used properly.

Recommended Action: The committee approves the current Bill 21.0183.01000 and forwards it on through the process of being heard in front of the full legislature to assist all individuals in this crisis until a federal solution for all insulin dependent people can be approved.

1.19.2021

Good morning, Chairman and members of the committee. Thank you for hearing such an important bill today. My name is Christine Fallabel, and I am the Director of State Government Affairs and Advocacy for the Americans Diabetes Association. We support SB2183 and urge you to as well.

As we've heard today, people with diabetes are facing a crisis. A vial of insulin in 1996 had a list price of $21. Today, that same bottle of insulin has a list price of over $300. Advances in research and development and technology have been life-changing, but the chemical formulary for insulin has not changed in over two decades. People with diabetes are sometimes forced to choose between insulin and rent or insulin and food to survive. For a chronic, autoimmune disease that is not preventable and has no cure, that seems unnecessarily excessive and dangerous.

Health insurance plans, and specifically, high deductible health plans (which is the most common type of health insurance plan) offer people a way to have coverage that costs less per month in their premiums, but have a higher bar to reach before full coverage for medicine, like insulin, kick in. Insulin is a chronic disease management medicine. Without it, people with diabetes die, and very quickly. People with diabetes also require a lot of it: averaging 2-4 vials per month. So when deductibles are high, people, even with insurance, end up paying upwards of $1200 per month simply to live, or they're rationing their meds, which leads to deadly complications and high costs to the state.

This bill would alleviate a lot of strain for people by capping the co-pay of insulin, ensuring access to their life-sustaining medicine while longer-term policy solutions are investigated at both the state and federal level. The first state to cap the co-pay for insulin was Colorado in 2019, and since then 13 more states (plus DC) have passed similar caps, without increasing the cost of health insurance for residents. Additionally, there is pending legislation in over 20 more states. We need to join this movement.

We believe that no individual in need of life-sustaining insulin should ever go without due to prohibitive costs. We support SB 2183 and urge you to vote yes. Thank you for your time today.

Christine Fallabel, MPH

Director, State Government Affairs
The American Diabetes Association

American Diabetes Association®

Senate Human Services Committee
SB 2183
January 19, 2021
Janelle Moos, AARP North Dakota
jmoos@aarp.org – (701) 355-3641

Chair Lee and Members of the Senate Human Services Committee-

My name is Janelle Moos, Advocacy Director with AARP North Dakota. The high cost of insulin and other prescription drugs is putting life-saving medications out of reach for many North Dakotans. No one should have to choose between their prescription drug costs and groceries or rent.

Before I get into the reasons we are working so hard to fight the high cost of prescription drug prices I'd like to spend just a moment reminding you who we are and why we are here. AARP is a nonpartisan, nonprofit, nationwide organization with nearly 38 million members. 84,000 of those members live in North Dakota – a staggering number when you consider the overall population of our state.

The high cost of prescription drugs hits our members, and frankly all North Dakotans. In AARP's 2020 survey of North Dakota adults, in the past two years, one-quarter reported not filling a prescription that was provided by their doctor- 44 percent of those adults- decided not to fill a prescription that their doctor had given them because of the **cost** of the drug.

As you can see in one of my attachments, between 2012 and 2017, the average annual cost of prescription drug treatment increased 57.8 percent, while the annual income for North Dakotans only increased 6.7 percent.

On that same handout you can get a good feel for why they have to make that crushing choice. Near the top of the page are three common illnesses in North Dakota – cancer, diabetes and heart disease – with the number of residents of our state who have been diagnosed. More than 60,000 with cancer and nearly as many with diabetes. Below those numbers are common drugs used to treat them and their costs from 2017. Please, take note that we've included what those same drugs cost just five years earlier. **One nearly doubled, another jumped $100,000!**

On our Facebook page you can see some videos of North Dakotans facing these costs. There is one from Dennis, a diabetic, who told us about his concerns he may have to go back to work

after retiring to pay for his insulin- his co-pay is about $100/month- with insurance- without insurance, his co-pay would be about $400/month.
Even though insulin has been around for almost a century, the cost of the diabetes drug has skyrocketed in recent years, nearly tripling between 2002 and 2013. And Medicare Part D spending on insulin jumped 840 percent between 2007 and 2017, from $1.4 billion to $13.3 billion, far outpacing growth in the number of beneficiaries using insulin therapy, according to a Kaiser Family Foundation analysis.

All totaled, Americans with diabetes, the majority of whom are older adults, face insulin prices that average more than $5,000 per year, some reports show. And these high prices have led a growing number of patients who rely on the lifesaving drug to resort to rationing or skipping doses because they can't afford the medication.

Placing a cap on consumer's out-of-pocket prescription drug expenses is one approach that some states are considering to relieve consumer's financial burdens. States have designed out-of-pocket caps in a number of ways, including applying spending limits to certain drugs only, or applying the cap to either a consumers' monthly or annual prescription drug expenditures. AARP believes that such efforts should be implemented in conjunction with other policy changes that will help reduce prescription drug prices. We encourage the legislature to consider this bill along with other broader reforms such as prescription drug cost transparency and wholesale prescription drug importation in part of the conversation to help lower the cost of prescription drugs for North Dakotans.

Thank you again for your thoughtful work on this issue. We wholeheartedly appreciate any effort to make medicine more affordable.

#1345

How North Dakota Residents Are Impacted By High Rx Costs

60,228
North Dakota Residents
have been diagnosed with cancer.[1]

58,718
North Dakota Residents
have pre-diabetes or diabetes.[1]

22,311
North Dakota Residents
have heart disease.[1]

Between 2012 and 2017, the price of these name brand drugs increased:

Revlimid
treats forms of cancer

from $147,413/yr

to $247,496/yr[2]

Lantus
treats diabetes

from $2,907/yr

to $4,702/yr[2]

Aggrenox
treats heart disease

from $3,030/yr

to $5,930/yr[2]

Rx 31%

In 2017, 31% of North Dakota Residents stopped taking medication as prescribed due to cost.[3]

Sources:

[1] Total does not include skin cancer. Source: AARP Public Policy Institute analysis using 2017 data from the Behavioral Risk Factor Surveillance System.
[2] Stephen W. Schondelmeyer and Leigh Purvis. Rx Price Watch Reports. Washington, DC: AARP Public Policy Institute, June 2019, https://doi.org/10.26419/ppi.00073.000.
[3] Among 19-64 year old population. State Health Access Data Assistance Center (SHADAC) analysis of National Health Interview Survey data, State Health Compare, SHADAC, University of Minnesota, statehealthcompare.shadac.org, Accessed September 5, 2019

STOP GREED CUT DRUG PRICES NOW™ AARP Real Possibilities

#1346

Rx PRICE GOUGING vs. 50+ INCOME

Americans pay among the highest drug prices in the world and many are having to choose between buying the medications they need and other essentials. Meanwhile, brand name drug prices continue to increase at rates that far exceed general inflation. These relentless price increases could force many Americans to pay drug prices that exceed their entire income for a year.

AVG. ANNUAL COST

The average annual cost for one brand name drug, used on a chronic basis, was around $6,800 in 2017, almost $1,000 more than in 2015.[1]

PhRMA SPENDS BILLIONS

Big Pharma spent nearly $169 million for lobbying and more than $6 billion for advertising in 2018. [5]

IN OUR STATE

The average annual cost of prescription drug treatment increased 57.8% between 2012 and 2017, while the annual income for North Dakotans only increased 6.7%.[6]

NUMBER OF PRESCRIPTIONS

The average older American takes 4.5 prescription drugs, typically on a chronic basis.[2]

AMERICANS PAY MORE

Americans can pay double what similar countries pay for the same name brand drugs.[4]

RESEARCH & DEVELOPMENT?

Nearly 80% of every Big Pharma dollar goes to something other than research and development.[3]

STOP Rx GREED
CUT DRUG PRICES NOW℠

AARP® Real Possibilities

[1,2] Stephen W. Schondelmeyer and Leigh Purvis, "Rx Price Watch Report: Trends in Retail Prices of Brand Name Prescription Drugs Widely Used by Older Americans, 2017 Year-End Update," AARP Public Policy Institute, Washington, DC, September 2018.
[3] https://www.csrxp.org/wp-content/uploads/2019/05/CSRxP_One_pager_III_FINAL-SITERELEASE.pdf
[4] https://aspe.hhs.gov/system/files/pdf/259996/ComparisonUSInternationalPricesTopSpendingPartBDrugs.pdf
[5] https://www.opensecrets.org/lobby/induscode.php?id=H4300&year=2018 and https://jamanetwork.com/journals/jama/fullarticle/2720029
[6] Based on the price associated with taking 4 widely used brand name prescription drugs. Income is based on median person-level income.

TESTIMONY OF SCOTT MILLER

Senate Bill 2183 – Diabetes Drug and Equipment Mandate

Good Morning, my name is Scott Miller. I am the Executive Director of the North Dakota Public Employees Retirement System, or NDPERS. I am here to testify in a neutral position regarding Senate Bill 2183.

This bill creates a mandate regarding health insurance plan coverage of diabetes drugs and supplies. This bill does not comply with the statutory requirement that health insurance plan mandates first apply to NDPERS.

The primary components of the proposed bill that will have actuarial impacts on the PERS program are the $25 limit on member cost-sharing for insulin and insulin supplies and the restriction from use of a drug formulary to determine what types of insulin and supplies are covered under the plan.

The PERS plan requires members to pay a copay and coinsurance for insulin. Depending on the cost of the insulin prescribed and/or the cost of the supplies purchased, the member cost-share can exceed the proposed $25 limit. Therefore, imposing this limit will shift cost from members to the plan.

Drug formularies help to manage cost by allowing insurers and prescription benefit managers to negotiate favorable pricing and rebates from drug manufacturers. While formularies limit the drugs available, they include effective medications in all diagnostic classes. Restricting the use of a formulary for insulin coverage will result in the loss of rebates for the PERS program which will increase program cost. Below is the estimate of those increased costs.

Estimated Cost Impact on PERS 2020 Claims

Lost Member Cost Share	Lost Rebates	Total Dollar Impact	Percent Increase to PERS Premium
$977,394	$2,730,992	$3,708,386	1.2%

Mr. Chairman, this concludes my testimony.

SANFORD HEALTH PLAN

January 18, 2021

The purposes of this registration is to permit Daniel Weiss, Senior Executive Director – Pharmacy for Sanford Health Plan, to be available to assist the committee with questions and support NDPERS as the plan adminstrator for that program.

Madam Chairperson and members of the committee, my name is Angela Kritzberger and I am from Hillsboro. I am here today with our daughter Nina to ask for your support of SB2183 which provides a cap of $25 for insulin and basic diabetes supplies.

Nearly five years ago at the young age of 7, Nina was diagnosed with Type 1 Diabetes. There is nothing that Nina could have done to change this outcome because Type 1 Diabetes is an auto immune disease which attacks the insulin producing cells of the pancreas. We are forever grateful for the discovery of insulin in 1922, but dependent on the manufacturers who produce and sell it. Unlike other medications, there are no biosimilar or generic versions of insulin which have made the cost of insulin extremely high, increasing some 1,200% since 1990. In order for our daughter to live a long and healthy life, we must pay the price, or she will die.

We are a farm family who, because we are self-employed, must provide for ourselves an individual health insurance plan. In the past two years, we have paid close to $40,000 annually in premiums, deductible and co-insurance. Additional basic diabetes supplies that all diabetics must have on hand can cost up to an additional $500 as needed for test strips, ketone strips, syringes, rescue pens for hypoglycemic events as well as other supportive supplies reaching close to $1,000 a year and are not covered by insurance.

Type 1 Diabetes is a complex disease. I am proud of the hard work that Nina does to maintain healthy blood sugars. It is not an easy task for anyone let alone a young child who makes life and death decisions each and every day based on their physical activity, their food intake and their insulin needs. She is young and growing so her insulin needs are quite high. An average meal which might consist of a bun, protein, fruit or vegetable of 50 grams of carbs would cost an average of $10 just to cover her insulin needs for that one meal.

I stand before you today not only as a concerned parent who's child will one day age off of her parents health insurance plan and will have to ask herself if she can afford her life-saving insulin and diabetes supplies, but for the many who are living with this costly life-long disease which can lead to complications of the eye, kidney and heart potentially leading to amputation; or worse, those who have already died because they could not afford to live. It is a strain on our healthcare system, and it is an emotional and physical strain on diabetics and their caregivers. Affordable access to necessary life-saving medicines and supplies that prevent these costly life-long complications should be the standard of care.

I also stand before you today as an active member of my community who wishes for nothing more than to work hard so that I can continue supporting my community and its many nonprofit organizations. I understand the supportive and vital services that these organizations provide to members of our communities all across North Dakota, with many of them financially depending on each and every one of us to sustain their work.

The year 2020 will long be known for the global pandemic of COVID-19. It will also be remembered for the remarkable introduction of a successful vaccine that is expected to cure it. Diabetics have been praying, hoping, begging for a cure for nearly 100 years since the discovery of insulin and yet are they

are still dying every single day because they cannot afford to pay for it. They are dying because they cannot afford the insulin that the supply chain has put on the price of their life as a diabetic and depleting all hope of saving for a future and supporting their communities.

As parents, caregivers and advocates for someone living with diabetes, we may grow weary from telling our story, but we will never give up the fight. I hope North Dakota is willing to come to the table as other states have for meaningful discussions and answer this single question. I am asking you today – what is it that you choose for my daughter and for the thousands of North Dakotans who have been forced to pay the price of a disease they did not choose? I hope it is life.

Thank you for your time.

Wednesday, January 19, 2021

Senate Human Services Committee
SB 2183

SENATOR LEE AND COMMITTEE MEMBERS:

My name is Jack McDonald. I'm appearing on behalf of America's Health Insurance Plans or, as it is commonly known, AHIP. AHIP opposes this bill.

For many diabetes patients, the rising cost of insulin products has created an affordability crisis that threatens their health and well-being. Out-of-control prices for insulin products – and other prescription drugs – are a direct consequence of drug makers taking advantage of a broken market for their own financial gain at the expense of patients.

The lack of competition, transparency, and accountability in the prescription drug market has created extended, price-dictating monopolies with economic power that exists nowhere else in the U.S. economy. The result is that everyone pays more – from patients, businesses and taxpayers to hospitals, doctors, and pharmacists.

Capping the cost of insulin allows drug manufacturers to hide the real prices of their drugs from consumers while raising costs for everyone.

Our members support market-based solutions that hold drug makers accountable for high list prices and put downward pressure on prescription drug prices through competition, consumer choice, and open and honest drug pricing. Placing arbitrary caps on consumer cost sharing is not the right way to achieve lower costs. In fact, this bill may actually exacerbate cost issues because a blanket cost for all insulin products reduces health plans' and insurers' ability to negotiate with drug manufacturers to develop innovative benefit designs to lower out of pocket costs for insulin.

Thank you for your time and consideration. I'd be happy to answer any questions.

Madame Chair and Members of the Senate Human Services Committee,

BCBSND respectfully requests a Do Not Pass out of committee on 2183 for all of the reasons we testified to during the hearing. If that is not possible, we respectfully ask that the following amendments be considered:

1. Reinstate the PERS trial
2. Eliminate the emergency clause and make the effective date "upon plan renewal"
3. Reinstate formulary management so that rebates may be continue to be used to bring down premiums or offset some administrative costs, and
4. Add a study on the cost of insulin and efforts to contain the costs of insulin (to address the root cause of skyrocketing life saving drug costs in recent years.)

Please don't hesitate to reach out if you have any questions or concerns.
Kind regards,
Megan

Megan Houn
Director, Government Relations
BLUE CROSS BLUE SHIELD OF NORTH DAKOTA
701-255-5548 (work)
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SB2183
Senate Human Services Committee
Senator Lee Chair

Senator Lee and Members of the Committee,

My name is Donene Feist and I am the Director for Family Voices of North Dakota. Our work as you know, includes working with families who have children and youth with disabilities and chronic health conditions.

We stand today in support of SB2183. We hear from families on a regular basis, medical treatment for insulin dependent diabetics skyrocketing in price making it most difficult and often inaccessible with the best of health insurance for many across North Dakota and the country.

It is the one medication with a 100% success rate in managing their chronic illness. Families have little to no choice. For some it may mean putting milk on the table to feed the family or pay for medication. Their children and youth simply cannot go without.

Since 1990 the cost of insulin has risen 1200%. This is not a choice for families. Many families have more than one child/youth who have a diabetes diagnosis. Children with diabetes visited the emergency room 2.5 times more often than children without it. Acute inpatient services were used nearly five times more often.

We support this legislation by making a monthly co-payment cap of $25 for insulin and an additional $25 co-payment cap for diabetes supplies for the patients who utilize insulin for their diabetes management.

Our hope also for families is that the federal government will soon pass legislation addressing this immediate need or the supply chain itself will address to ensure affordability and accessibility for all North Dakotans. My fear for families is what happens, if they become unable to pay for this life sustaining medication. I cannot bear the thought.

Please pass SB2183, let's protect our children and youth with diabetes

Donene Feist
Family Voices of ND
701-493-2634
fvnd@drtel.net

My name is Carlye Gast. I'm a Fargo resident, an attorney, and a mom of five. My middle son, Harry, is an 11-year-old Type 1 diabetic. Today I am asking you to give a "do pass" recommendation to SB 2183.

Insulin is a blessing and a curse. On the one hand, it is a miracle drug and keeps my son alive. We saw that when he was initially diagnosed: he went from a very sick, barely conscious boy to almost feeling "normal" after just a day of insulin treatment. On the other hand, insulin is a costly, constantly-needed treatment for an incurable disease. The body's need for it is relentless, and just a day or two without it could result in severe illness or death.

When Harry was first diagnosed with Type 1 diabetes nearly two years ago, we felt crippled by the expense. We paid upwards of $1000 monthly for his insulin and supplies, and we questioned how it was sustainable. Fortunately, I was in a position to change my employer-sponsored insurance plan at the end of the year, and this relieved the burden. However, most North Dakotans do not have that luxury.

I'm not asking you to pass this bill to help me. I'm okay. I am asking you to pass it to help my son -- my hilarious, smart, soft-hearted, future engineer. It is heartbreaking when he asks me, "When I grow up, will you help me pay for my insulin if I can't afford it?" "Hey Mom, if they ever make an artificial pancreas, can I get one?" These are not the questions an 11-year-old should have.

I am also asking you to pass SB 2183 to help others. I have reached out to the North Dakota diabetic community, and I am horrified and frankly outraged by the sacrifices people have to make due to the cost of insulin: rationing and seeking insulin from others; moving to a cheaper home; traveling to Canada to purchase insulin; staying in an undesirable job just to keep a particular insurance policy; and being unable to afford other bills and necessities.

As a final note, I'd point out that within our state and country, we've recognized that early screening and preventative medicine are valuable tools that ultimately save lives and can stop conditions from developing, before they start. Mammograms, colonoscopies, and vaccines are generally covered by insurance without out-of-pocket expense. Insulin is the ultimate preventative treatment. With it, used properly, a full and productive life. Without it, death. It is that simple.

Thank you for your support.

The North Dakota Veterans Legislative Council is in support of this legislation and urges your yes vote Thank you

Written Testimony of Christina Dahl, NP-C, BC-ADM
Parent of a child with Type 1 Diabetes and Nurse Practitioner for Persons with Diabetes
In support of Bill SB 2183
January 18, 2021

Chair Judy Lee and members of the Senate Human Services Committee, thank you for the opportunity to discuss issues related to pricing, affordability, and patient access to insulin and supplies in the state of North Dakota.

My name is Christina Dahl, I am a parent of a child with Type 1 diabetes and a Nurse Practitioner, Board Certified in Advanced Diabetes Management providing medical care and education to patients living with diabetes in Fargo, ND. I am writing to ask for your support of SB 2183, which will cap out-of-pocket costs for insulin and necessary diabetes supplies.

My child Sarah, being diagnosed with Type 1 Diabetes, is dependent on insulin to survive. Sarah was diagnosed with Type 1 diabetes when she was 18 months old and is now 20 years old. Together, we have been able to successfully manage her diabetes and avoid complications to this point. We are very fortunate that her medications and supplies are affordable with insurance. However, I have serious concerns about Sarah no longer being covered by our current insurance carrier once she reaches the age of 23 and potentially not being able to afford life sustaining insulin or supplies.

Personally, we are not insured with a North Dakota based insurance company, so we will not experience immediate relief if SB 2183 passes. Even so, I am asking you to pass the legislation for other reasons, including helping advance the movement toward affordable insulin across the nation and helping others in the diabetic community including those I serve as patients in my medical practice.

The out-of-pocket cost of insulin and supplies needed to successfully manage diabetes is a significant problem nationwide and in North Dakota, and it must be addressed. In my medical practice I see first-hand the hardships and difficult decisions that patients are forced to make regarding cost of mediations and supplies needed to successfully manage their disease. It is truly heartbreaking and frustrating because I am aware of the potential outcomes of poorly managed blood glucose levels, the significant impact on quality of life these complications can have, and the associated healthcare costs.

In an attempt to illustrate the enormity of this problem, I have outlined some important statistics that include estimates of diabetes and its burden in the United states. The information to follow was obtained from The National Diabetes Statistics Report 2020, Diabetes in North Dakota 2018, and Beyond Type 1: Type 1 Diabetes Statistics.

- There are an estimated 34.2 million people of all ages or 10.5% of the US population with diabetes.

    - Approximately 1.6 million people are diagnosed with Type 1 diabetes requiring insulin.
    - Roughly 21% (6.9 million) of people with Type 2 diabetes require insulin.

- The incidence of Type 1 diabetes has increased significantly from 2001-2015 by 21% with an estimated 40,000 new diagnoses per year.

- Total direct and indirect estimated costs of diagnosed diabetes in the United States in 2017 was $327 billion. Estimated direct cost was $237 billion and indirect cost was $90 billion.

    - Medical care for people with diabetes accounts for one in four health care dollars spent in the U.S., and more than half of that expenditure is directly attributable to diabetes.
    - Individual medical expenses for persons with diabetes are approximately 2.3 times higher than those without.
    - Medications constitute the largest portion (43%) of excess cost associated the total direct medical burden:
        - $15 billion for insulin (**The average price of insulin nearly tripled between 2002 and 2013 with no substantial changes to the product)

- Persons with diagnosed diabetes are at a significantly elevated risk of complications and death compared with those without diabetes.
    - Proper management of blood glucose levels reduces the risk of complications. Each 1 percent reduction in hemoglobin A1c (improved glucose control) was associated with:
        - a 37 percent decrease in the risk for microvascular complications and
        - a 21 percent decrease in the risk of any end point or death related to diabetes.

    - Diabetes is a leading cause of blindness, kidney failure, heart attacks, stroke, and lower limb amputation.

    - Diabetes was the seventh leading cause of death in the United States in 2017 based on the 83,564 death certificates in which diabetes was listed as the underlying cause of death and was mentioned as a cause of death in a total of 270,702 certificates.

- In 2016 alone there were an estimated 448,000 emergency department visits related to hyperglycemic crisis (high blood sugar). Of these visits 85.6% of patients were hospitalized with the average cost of admission being $26,500.

- Preliminary data from T1International access and supply survey showed that 1 in 4 US respondents have rationed insulin due to cost.

The bottom line is, when necessary insulin and diabetes related supplies are readily accessible, affordable, and used properly; costly complications that drive these figures can be prevented.

The out-of-pocket cost of insulin and supplies needed to manage diabetes is a significant problem in North Dakota. Approval and implementation of this bill will have a direct impact on quality of life for those living with diabetes and significantly reduce overall healthcare costs for years to come. Many other states have passed regulation that increases insulin availability or decreased its cost. It is time for North Dakota to do the same.

Thank you kindly for the opportunity to share testimony regarding this issue. Your time and attention to this matter is greatly appreciated.

Dear Senator Lee, Representative Koppelman and Representative Schauer,

My name is Kasey Carlin and I am a mother of a child with Type 1 diabetes that resides in your district. I am writing to ask you to support Senate Bill 2183, which is the insulin drug and supply cost sharing limitation and formulary limitations bill, which I've linked below in this email.

My daughter was diagnosed with type 1 diabetes over seven years ago when she was three years old. We've been through many changes and challenges to do our best to maintain near normal blood sugars and provide her with the best opportunity to grow and be a healthy child and adult. However, this disease is at 24/7 disease that demands constant attention. We sacrifice sleep and work and money to manage this disease every day.

One thing that became very clear within days of her diagnosis was that this disease was going to be expensive to manage, and in the seven years we've been living with it, the expenses continue to rise. For a period of time, I never knew what our insulin costs were going to be from month to month. All I knew was to expect our copay to cost more than it did the month before, and that total cost was always in the hundreds of dollars. As my daughter has grown, her insulin needs continue to increase as well, which is also adding to increased costs.

Diabetes isn't just managed with insulin, it also requires many different supplies that include insulin pumps, pump cartridges, infusion sets, glucose monitors and strips, as well as supplies for a continuous glucose monitor system. We are currently only halfway through the first month of the year, and we've already reached our insurance deductible and have paid hundreds of dollars in co-insurance to afford just three month's worth of these supplies. The financial burden is tremendous. Additionally, I've often had to leave work to go to my daughter's school to help with some aspect of her diabetes management. Because of these work disruptions, I've had to pass on many opportunities which affected my trajectory towards promotion, thereby losing out on potential merit pay increases. This is a financial double whammy to our family. However, we are blessed to have good employment with good insurance benefits. I cannot imagine how families without the same benefits can manage the costs of this disease.

Diabetes treatment shouldn't just be for those who can afford it. It needs to be attainable for everyone. The passage of this bill would provide much needed assistance to the North Dakotans who need to access insulin and diabetes supplies. Eventually, my daughter will be an adult living with type 1 diabetes. She is going to need to use insulin for the rest of her life. Unless something changes, the financial burden to her will restrict her opportunities and dictate what type of employment she needs to obtain to have the financial means just to stay alive. Until drug prices are regulated on the federal level, North Dakota has the opportunity to help out its citizens with these costs, thus allowing them to live less financially stressful, healthy lives.

I've attached information that provides more information for the need of passage of this bill. I've also cc'd Danelle Johnson and Angela Kritzberger on this email as they are also Mother's of children with type 1 diabetes and are leading the support for this bill.

Thank you for your consideration,

Sincerely,

Kasey Carlin

834 12th Ave W

West Fargo, ND 58078

(701) 361-2807

https://www.legis.nd.gov/assembly/67-2021/bill-index/bi2183.html

POINT PAPER

Problem: Medical Treatment for insulin dependent diabetics has become unaffordable and inaccessible for a growing number of patients to effectively sustain life with 100% success and manage their chronic illness so as to prevent further complications of stroke, kidney disease, blindness and heart disease.

Issues:

1. 68,097 North Dakotans are diabetic. 6,800 are Type 1 Diabetics who are 100% dependent upon insulin to survive. A subset of all other diabetics also rely on insulin.
2. Insulin and diabetes supplies supply chains offer no transparency to costs.
3. No Generic Option (Biosimilar as it is called in the case of insulin.)
4. Free Market does NOT bear the cost of insulin. Type 1 Diabetic's choice is: Pay or Die
5. Diabetes is the most expensive chronic disease in the United States. $1 out of every $4 health care dollars is spent on diabetes and related care. Individuals with diabetes have medical expenses approximately 2.3 times higher than those without.
6. Insulin Out of Pocket (OOP) costs are increasingly calculated as a percentage of the cost (co-insurance), rather than a fixed dollar amount (co-payment) and are typically based on the list price rather than the net price.
7. In North Dakota, a manufacturer's rebate for insulin can and is used to lower premiums for the employer and insureds, but the patient is charged co-insurance from the list price.
8. Insulin is deadly. Insulin therapy requires diabetic supplies such as test strips, meters, lancing devices, syringes, and lancets to make proper dosing decisions. All need to be accessible and affordable to do so.
9. The cost of insulin has risen 1200% since 1990 with no substantial changes to the product.
10. 8.3 Million Americans use insulin to control their diabetes. Three-fifths are insured under Medicare, Medicaid, or Children's Health Insurance Program (CHIP). Taxpayers are already footing the health care bill for over 50% of the people with diabetes.
11. Estimated cost savings when all persons have proper diabetes management care is $_____ (How to qualify savings?? North Dakota spent $470 million in direct expenses for diabetes care in 2017 and another $190 million spend on indirect costs from lost productivity.)

Solution: The North Dakota Legislature to approve a monthly co-payment cap of $25 for insulin and an additional $25 co-payment cap for diabetes supplies for the patient until further action is taken federally or by the supply chain itself to ensure affordability and accessibility for all North Dakotans to this life sustaining medication that has 100% ability to manage the disease when used properly.

Recommended Action: The committee approves the current Bill 21.0183.01000 and forwards it on through the process of being heard in front of the full legislature to assist all individuals in this crisis until a federal solution for all insulin dependent people can be approved.

FEBRUARY 2020

SPECIAL DIABETES PROGRAM

North Dakota

PROGRAM BACKGROUND

The Special Diabetes Program (SDP) consists of two components: *The Special Statutory Funding Program for Type 1 Diabetes Research* that supports research on the prevention, treatment and cures of type 1 diabetes (T1D) and its complications, and *The Special Diabetes Program for Indians (SDPI)* that supports type 2 diabetes treatment and prevention strategies for American Indian and Alaska Native (AI/AN) populations. This program has demonstrated tangible results and has become a critical part of our nation's federal investment in diabetes. Currently, each part of the program is funded annually at $150 million.

NATIONAL BURDEN OF DIABETES

Diabetes affects over 26.9 million adults and children in the U.S., or roughly 8.2 percent of the population. Statistics from peer-reviewed journals and the Centers for Disease Control (CDC) show that the population diagnosed with diabetes grew by approximately 700,000 people annually between 2012 and 2015. Among people 20 years and younger, data has shown that between 2002-2015, overall incidence of type 1 diabetes significantly increased. It is projected that in the overall population, prevalence will continue to rise over time. One in four health care dollars and one in three Medicare dollars are spent on people with diabetes and estimates show that diabetes costs the U.S. economy $327 billion annually, a 26 percent increase from 2012.

MOVING THERAPIES FROM BENCH TO BEDSIDE

Promising ideas for novel therapeutic interventions for T1D can encounter roadblocks in movement from bench to bedside testing. Many investigators who have discovered a promising therapeutic agent in the laboratory may not have the resources to conduct multiple studies and bring their product to market. The NIDDK Central Repositories store data and biological samples, including samples available for genetic analysis, from significant, NIDDK-funded clinical studies to provide access to a wider research community. For example, nearly 300 studies have used the dataset from the landmark Diabetes Control and Complications Trial (DCCT) study.

BURDEN OF DIABETES IN NORTH DAKOTA

Diabetes is a common and growing disease in North Dakota. Approximately 68,097 people—or 11.2 percent of the state's population—have diabetes. People with diabetes suffer from many related complications or conditions. In North Dakota, there were 101 new cases of end-stage renal disease (ESRD) related to diabetes in 2015 alone. In addition to the human toll, the financial burden the disease places on North Dakota's health system is staggering— diabetes and prediabetes cost an estimated $596 million in North Dakota each year.

TESTING NEW THERAPIES IN PATIENTS

TrialNet and the Immune Tolerance Network (ITN) are providing the key infrastructure for testing promising therapies in people with T1D. TrialNet consists of over 200 clinical sites, including one in Fargo, that support the development and implementation of clinical trials using drugs aimed at preventing the disease in at-risk individuals and slowing the progression of T1D in newly diagnosed patients. For example, a recent TrialNet study showed that teplizumab, a form of immunotherapy, can delay the onset of T1D by nearly 2 years in people who present with islet cell autoantibodies but are not yet clinically symptomatic.

ITN is an international clinical network that develops and tests innovative strategies for immune tolerance to "re-educate" the immune system to prevent negative immune responses, such as the destruction of insulin-producing islets. ITN conducted the first multicenter clinical trial to replicate the Edmonton Protocol for islet transplantation that resulted in some patients achieving insulin independence for a year or longer after transplantation. ITN centers are also currently conducting a trial to test whether a rheumatoid arthritis drug

Continued on next page

SPECIAL DIABETES PROGRAM

North Dakota

THE SPECIAL DIABETES PROGRAM HAS PROVIDED APPROXIMATELY **$32.07 MILLION** TO TRIBAL COMMUNITIES IN NORTH DAKOTA

NORTH DAKOTA TRIBAL COMMUNITIES RECEIVING SUPPORT FROM THE SDPI

Fort Yates IHS
Spirit Lake Tribe
Three Affiliated Tribes
Trenton Indian Service Area
Turtle Mountain Band of Chippewa Indians

can halt the body's improper immune response to beta cells and extend the ability to naturally produce insulin in newly diagnosed people with T1D.

Currently, the SDPI provides grants for diabetes treatment and prevention services to 301 Indian Health Service (IHS), tribal, and urban Indian health programs in 35 states.

- **Between 1996 and 2013, the incident rates of ESRD in AI/AN people with diabetes decreased 54 percent**—that decrease is more than for any other racial group in the U.S. Given that the Medicare cost per year for one patient on hemodialysis was $90,000 in 2016, this reduction in new cases of ESRD means a significant decrease in the number of patients requiring dialysis, translating into an estimated $435.9 million in savings from 2006-2015 for Medicare alone.

- The average blood sugar level (A1c) decreased from 9.0 percent in 1996 to 7 percent in 2018. Scientific studies have shown that every percentage point drop in A1c translates into a 40 percent reduction in the risk of developing diabetes-related complications such as blindness, kidney failure, nerve disease, and amputations.

- The average LDL ("bad" cholesterol) declined from 118 mg/dL in 1998 to 70 mg/dL in 2018. Research has shown that lowering cholesterol levels may help reduce by 20-50 percent the chance of developing cardiovascular complications associated with diabetes such as heart attack, stroke, or heart failure.

- Blood pressure has been well-controlled throughout the SDPI era. Controlling blood pressure reduces the risk of cardiovascular disease by 33-50 percent and reduces the risk of complications by 33 percent.

TESTIMONY OF REBECCA FRICKE

Senate Bill 2183 – Diabetes Drug and Equipment Mandate

Good morning, my name is Rebecca Fricke. I am the Chief Benefits Officer of the North Dakota Public Employees Retirement System, or NDPERS. I appear before you today in a neutral position on Senate Bill 2183. I am available should there be any questions related to the impact of the bill on any of the NDPERS benefits.

TESTIMONY OF DERRICK HOHBEIN

Senate Bill 2183 – Diabetes Drug and Equipment Mandate

Good morning, my name is Derrick Hohbein. I am the Chief Operating/Financial Officer of the North Dakota Public Employees Retirement System, or NDPERS. I appear before you today in a neutral position on Senate Bill 2183. I am available should there be any questions related to the impact of the bill on any of the NDPERS benefits.

2021 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Sakakawea Room, State Capitol

SB 2183
2/2/2021

A BILL for an Act to create and enact section 54-52.1-04.20 of the North Dakota Century Code, relating to public employee insulin drug benefits; to amend and reenact subsection 2 of section 26.1-36.6-03 of the North Dakota Century Code, relating to self-insurance health plans; to provide for a report; to provide for application; to provide an expiration date; and to declare an emergency.

Madam Chair Lee opened committee discussion on SB 2183 at 2:56 p.m. Senators present: Lee, K. Roers, Hogan, Anderson, Clemens, O. Larsen

Discussion Topics:

- Prohibition on using formulary drug
- Revised fiscal note
- Insulin supplies
- Co-insurance cap

[2:56] Senator Howard Anderson. Provided the committee with proposed amendment 21.0798.01001. (testimony #5023)

Senator Anderson moves to **ADOPT AMENDMENT** 21.0798.01001
Senator Hogan seconded

Voice vote – motion passed

Senator K. Roers moves to **FURTHER AMEND** to include NDPERS 2 year inclusion, supplies coverage, and delete page 2, lines 1-14 and 27-30.
Senator Clemens seconded

Voice vote – motion passed 5-1-0.

Additional written testimony: N/A

Madam Chair Lee closed committee discussion on 3:39 p.m.

Justin Velez, Committee Clerk

21.0798.01001
Title.

Prepared by the Legislative Council staff for
Senator Anderson
February 2, 2021

PROPOSED AMENDMENTS TO SENATE BILL NO. 2183

Page 1, line 9, remove "**and formulary**"

Page 1, line 10, remove "**limitations**"

Page 1, line 12, after "a." insert ""Cost-sharing" includes copayments and coinsurance.

b."

Page 2, line 1, replace "b." with "c."

Page 2, line 15, replace "c." with "d."

Page 2, line 18, replace "d." with "e."

Page 3, line 7, remove "A policy may not allow for the use of a formulary to determine coverage of an insulin"

Page 3, remove line 8

Page 3, line 9, remove "6."

Renumber accordingly

moved by Anderson
Hogan 2nd

CS 2/3 1 of 2

21.0798.01002
Title.02000

Prepared by the Legislative Council staff for
Senate Human Services Committee
February 2, 2021

PROPOSED AMENDMENTS TO SENATE BILL NO. 2183

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to create and enact section 54-52.1-04.20 of the North Dakota Century Code, relating to public employee insulin drug benefits; to amend and reenact subsection 2 of section 26.1-36.6-03 of the North Dakota Century Code, relating to self-insurance health plans; to provide for a report; to provide for application; to provide an expiration date; and to declare an emergency.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. AMENDMENT. Subsection 2 of section 26.1-36.6-03 of the North Dakota Century Code is amended and reenacted as follows:

2. The following health benefit provisions applicable to a group accident and health insurance policy under chapter 26.1-36 apply to a self-insurance health plan and are subject to the jurisdiction of the commissioner: 26.1-36-06, 26.1-36-06.1, 26.1-36-07, 26.1-36-08, 26.1-36-08.1, 26.1-36-09, 26.1-36-09.1, 26.1-36-09.2, 26.1-36-09.3, 26.1-36-09.5, 26.1-36-09.6, 26.1-36-09.7, 26.1-36-09.8, 26.1-36-09.9, 26.1-36-09.10, 26.1-36-09.11, 26.1-36-09.12, 26.1-36-09.13, 26.1-36-09.14, 26.1-36-09.15, 26.1-36-11, 26.1-36-12.2, 26.1-36-20, 26.1-36-21, 26.1-36-22, 26.1-36-23.1, and 26.1-36-43. Section 54-52.1-04.20 applies to a self-insurance health plan and is subject to the jurisdiction of the commissioner.

SECTION 2. Section 54-52.1-04.20 of the North Dakota Century Code is created and enacted as follows:

54-52.1-04.20. Health insurance benefits coverage - Insulin drug benefits.

1. As used in this section:

   a. "Cost-sharing" includes copayments and coinsurance.

   b. "Insulin drug" means a prescription drug that contains insulin and is used to treat a form of diabetes mellitus. The term does not include an insulin pump, an electronic insulin-administering smart pen, or a continuous glucose monitor, or supplies needed specifically for the use of such electronic devices. The term includes insulin in the following categories:

      (1) Rapid-acting insulin;

      (2) Short-acting insulin;

      (3) Intermediate-acting insulin;

      (4) Long-acting insulin;

(5) Premixed insulin product;

(6) Premixed insulin/GLP-1 RA product; and

(7) Concentrated human regular insulin.

c. "Pharmacy or distributor" means a pharmacy or medical supply company, or other medication or medical supply distributor filling a covered individual's prescriptions.

2. The board shall provide health insurance benefits coverage that provides cost-sharing for a thirty-day supply of prescribed insulin drugs which does not exceed twenty-five dollars per pharmacy or distributor, regardless of the quantity or type of insulin drug used to fill the covered individual's prescription needs.

3. The coverage may not allow a pharmacy benefits manager or the pharmacy or distributor to charge, require the pharmacy or distributor to collect, or require a covered individual to make, a cost-sharing payment for a covered insulin drug in an amount that exceeds the amount of the cost-sharing payment for the prescribed insulin drugs under subsection 2.

4. Subsection 2 does not require the coverage to include cost-sharing and does not prevent the implementation of cost-sharing in an amount less than the amount specified under subsection 2. Subsection 2 does not limit cost-sharing on an insulin pump, an electronic insulin-administering smart pen, or a continuous glucose monitor. This section does not limit whether coverage classifies an insulin pump, an electronic insulin-administering smart pen, or a continuous glucose monitor as a drug or as a medical device or supply.

SECTION 3. APPLICATION. This Act applies to health benefits coverage that begins after June 30, 2021, and which does not extend past June 30, 2023.

SECTION 4. PUBLIC EMPLOYEES RETIREMENT SYSTEM - INSULIN DRUG BENEFITS. Pursuant to section 54-03-28, the public employees retirement system shall prepare and submit for introduction a bill to the sixty-eighth legislative assembly to repeal the expiration date for this Act and to extend the coverage of insulin drug benefits to all group and individual health insurance policies. The public employees retirement system shall append a report to the bill regarding the effect of the insulin drug benefits requirement on the system's health insurance programs, information on the utilization and costs relating to the coverage, and a recommendation regarding whether the coverage should be continued.

SECTION 5. EXPIRATION DATE. This Act is effective through July 31, 2023, and after that date is ineffective.

SECTION 6. EMERGENCY. This Act is declared to be an emergency measure."

Renumber accordingly

21.0798.01001

Sixty-seventh
Legislative Assembly
of North Dakota

SENATE BILL NO. 2183

Introduced by

Senators Dever, Mathern

Representatives Hanson, Keiser, Pyle, Schauer

A BILL for an Act to create and enact section 26.1-36-09.16 of the North Dakota Century Code, relating to accident and health insurance coverage of diabetes drugs and supplies; to amend and reenact section 26.1-36.6-03 of the North Dakota Century Code, relating to public employees self-insurance health plans; to provide for application; to provide an effective date; and to declare an emergency.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. Section 26.1-36-09.16 of the North Dakota Century Code is created and enacted as follows:

26.1-36-09.16. Insulin drug and supply cost-sharing limitations ~~and formulary limitations.~~

1. As used in this section:
   a. "Cost-sharing" includes copayments and coinsurance.
   b. "Insulin drug" means a prescription drug that contains insulin and is used to treat a form of diabetes mellitus. The term does not include an insulin pump, an electronic insulin-administering smart pen, or a continuous glucose monitor, or supplies needed specifically for the use of such electronic devices. The term includes insulin in the following categories:
      (1) Rapid-acting insulin;
      (2) Short-acting insulin;
      (3) Intermediate-acting insulin;
      (4) Long-acting insulin;
      (5) Premixed insulin product;
      (6) Premixed insulin/GLP-1 RA product; and
      (7) Concentrated human regular insulin.

~~b.~~c. "Medical supplies for insulin dosing and administration" means supplies needed for proper insulin dosing, as well as supplies needed to detect or address medical emergencies in an individual using insulin to manage diabetes mellitus. The term does not include an insulin pump, an electronic insulin-administering smart pen, or a continuous glucose monitor, or supplies needed specifically for the use of such electronic devices. The term includes:

(1) Blood glucose meters;

(2) Blood glucose test strips;

(3) Lancing devices and lancets;

(4) Ketone testing supplies, such as urine strips, blood ketone meters, and blood ketone strips;

(5) Glucagon, injectable or nasal forms;

(6) Insulin pen needles; and

(7) Insulin syringes.

~~c.~~d. "Pharmacy or distributor" means a pharmacy or medical supply company, or other medication or medical supply distributor filling a covered individual's prescriptions.

~~d.~~e. "Policy" means an accident and health insurance policy, contract, or evidence of coverage on a group, individual, blanket, franchise, or association basis.

2. An insurer may not deliver, issue, execute, or renew a policy that provides coverage for an insulin drug or medical supplies for insulin dosing and administration unless the policy complies with this section.

3. The policy must provide cost-sharing for a thirty-day supply of:

a. Prescribed insulin drugs which may not exceed twenty-five dollars per pharmacy or distributor, regardless of the quantity or type of insulin drug used to fill the covered individual's prescription needs.

b. Prescribed medical supplies for insulin dosing and administration, the total of which may not exceed twenty-five dollars per pharmacy or distributor, regardless of the quantity or manufacturer of supplies used to fill the covered individual's prescription needs.

4. A policy may not allow a pharmacy benefits manager or the pharmacy or distributor to charge, require the pharmacy or distributor to collect, or require a covered individual to make, a cost-sharing payment for a covered insulin drug or medical supplies for insulin dosing and administration in an amount that exceeds the amount of the cost-sharing payment for the prescribed insulin drugs or prescribed medical supplies for insulin dosing and administration under subsection 3.

5. ~~A policy may not allow for the use of a formulary to determine coverage of an insulin drug or medical supplies for insulin dosing and administration.~~

~~6.~~ Subsection 3 does not require a policy to implement cost-sharing and does not prevent the implementation of cost-sharing in an amount less than the amount specified under subsection 3. Subsection 3 does not limit cost-sharing on an insulin pump, an electronic insulin-administering smart pen, or a continuous glucose monitor. This section does not limit whether a policy classifies an insulin pump, an electronic insulin-administering smart pen, or a continuous glucose monitor as a drug or as a medical device or supply.

SECTION 2. AMENDMENT. Section 26.1-36.6-03 of the North Dakota Century Code is amended and reenacted as follows:

26.1-36.6-03. Self-insurance health plans - Requirements.

1. The following policy provisions apply to a self-insurance health plan or to the administrative services only or third-party administrator, and are subject to the jurisdiction of the commissioner: 26.1-36-03, 26.1-36-03.1, 26.1-36-05, 26.1-36-10, 26.1-36-12, 26.1-36-12.4, 26.1-36-12.6, 26.1-36-13, 26.1-36-14, 26.1-36-17, 26.1-36-18, 26.1-36-19, 26.1-36-23, 26.1-36-29, 26.1-36-37.1, 26.1-36-38, 26.1-36-39, 26.1-36-41, 26.1-36-44, and 26.1-36-46.
2. The following health benefit provisions applicable to a group accident and health insurance policy under chapter 26.1-36 apply to a self-insurance health plan and are subject to the jurisdiction of the commissioner: 26.1-36-06, 26.1-36-06.1, 26.1-36-07, 26.1-36-08, 26.1-36-08.1, 26.1-36-09, 26.1-36-09.1, 26.1-36-09.2, 26.1-36-09.3, 26.1-36-09.5, 26.1-36-09.6, 26.1-36-09.7, 26.1-36-09.8, 26.1-36-09.9, 26.1-36-09.10, 26.1-36-09.11, 26.1-36-09.12, 26.1-36-09.13, 26.1-36-09.14, 26.1-36-09.15,

26.1-36-09.16, 26.1-36-11, 26.1-36-12.2, 26.1-36-20, 26.1-36-21, 26.1-36-22, 26.1-36-23.1, and 26.1-36-43.

SECTION 3. APPLICATION. This Act applies to a policy delivered, issued, executed, or renewed after June 30, 2021.

SECTION 4. EFFECTIVE DATE. This Act becomes effective July 1, 2021.

SECTION 5. EMERGENCY. This Act is declared to be an emergency measure.

21.0798.01001
Title.

Prepared by the Legislative Council staff for
Senator Anderson
February 2, 2021

PROPOSED AMENDMENTS TO SENATE BILL NO. 2183

Page 1, line 9, remove "**and formulary**"

Page 1, line 10, remove "**limitations**"

Page 1, line 12, after "a." insert ""Cost-sharing" includes copayments and coinsurance.

b."

Page 2, line 1, replace "b." with "c."

Page 2, line 15, replace "c." with "d."

Page 2, line 18, replace "d." with "e."

Page 3, line 7, remove "A policy may not allow for the use of a formulary to determine coverage of an insulin"

Page 3, remove line 8

Page 3, line 9, remove "6."

Renumber accordingly

moved by Anderson
Hogan 2nd

2021 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Sakakawea Room, State Capitol

SB 2183
2/3/2021

A BILL for an Act to create and enact section 54-52.1-04.20 of the North Dakota Century Code, relating to public employee insulin drug benefits; to amend and reenact subsection 2 of section 26.1-36.6-03 of the North Dakota Century Code, relating to self-insurance health plans; to provide for a report; to provide for application; to provide an expiration date; and to declare an emergency

Madam Chair Lee opens the committee discussion on SB 2183 at 11:00 a.m. Senators present: Lee, K. Roers, Hogan, Anderson, Clemens, O. Larsen.

Discussion Topics:

- Cost benefit analysis
- Revised fiscal note

Senator Anderson moves **DO PASS, AS AMENDED, AND RE-REFER TO APPROPRIATIONS.**

Senator Hogan seconded

Senators	Vote
Senator Judy Lee	Y
Senator Kristin Roers	N
Senator Howard C. Anderson, Jr.	Y
Senator David A. Clemens	Y
Senator Kathy Hogan	Y
Senator Oley Larsen	N

The motion passed 4-2-0

Senator Anderson will carry SB 2183.

Madam Chair Lee closed the discussion on SB 2183 at 11:28 a.m.

Justin Velez, Committee Clerk

REPORT OF STANDING COMMITTEE

SB 2183: Human Services Committee (Sen. Lee, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** and **BE REREFERRED** to the **Appropriations Committee** (4 YEAS, 2 NAYS, 0 ABSENT AND NOT VOTING). SB 2183 was placed on the Sixth order on the calendar.

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to create and enact section 54-52.1-04.20 of the North Dakota Century Code, relating to public employee insulin drug benefits; to amend and reenact subsection 2 of section 26.1-36.6-03 of the North Dakota Century Code, relating to self-insurance health plans; to provide for a report; to provide for application; to provide an expiration date; and to declare an emergency.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. AMENDMENT. Subsection 2 of section 26.1-36.6-03 of the North Dakota Century Code is amended and reenacted as follows:

2. The following health benefit provisions applicable to a group accident and health insurance policy under chapter 26.1-36 apply to a self-insurance health plan and are subject to the jurisdiction of the commissioner: 26.1-36-06, 26.1-36-06.1, 26.1-36-07, 26.1-36-08, 26.1-36-08.1, 26.1-36-09, 26.1-36-09.1, 26.1-36-09.2, 26.1-36-09.3, 26.1-36-09.5, 26.1-36-09.6, 26.1-36-09.7, 26.1-36-09.8, 26.1-36-09.9, 26.1-36-09.10, 26.1-36-09.11, 26.1-36-09.12, 26.1-36-09.13, 26.1-36-09.14, 26.1-36-09.15, 26.1-36-11, 26.1-36-12.2, 26.1-36-20, 26.1-36-21, 26.1-36-22, 26.1-36-23.1, and 26.1-36-43. Section 54-52.1-04.20 applies to a self-insurance health plan and is subject to the jurisdiction of the commissioner.

SECTION 2. Section 54-52.1-04.20 of the North Dakota Century Code is created and enacted as follows:

54-52.1-04.20. Health insurance benefits coverage - Insulin drug benefits.

1. As used in this section:

   a. "Cost-sharing" includes copayments and coinsurance.

   b. "Insulin drug" means a prescription drug that contains insulin and is used to treat a form of diabetes mellitus. The term does not include an insulin pump, an electronic insulin-administering smart pen, or a continuous glucose monitor, or supplies needed specifically for the use of such electronic devices. The term includes insulin in the following categories:

      (1) Rapid-acting insulin;

      (2) Short-acting insulin;

      (3) Intermediate-acting insulin;

      (4) Long-acting insulin;

      (5) Premixed insulin product;

      (6) Premixed insulin/GLP-1 RA product; and

      (7) Concentrated human regular insulin.

c. "Pharmacy or distributor" means a pharmacy or medical supply company, or other medication or medical supply distributor filling a covered individual's prescriptions.

2. The board shall provide health insurance benefits coverage that provides cost-sharing for a thirty-day supply of prescribed insulin drugs which does not exceed twenty-five dollars per pharmacy or distributor, regardless of the quantity or type of insulin drug used to fill the covered individual's prescription needs.

3. The coverage may not allow a pharmacy benefits manager or the pharmacy or distributor to charge, require the pharmacy or distributor to collect, or require a covered individual to make, a cost-sharing payment for a covered insulin drug in an amount that exceeds the amount of the cost-sharing payment for the prescribed insulin drugs under subsection 2.

4. Subsection 2 does not require the coverage to include cost-sharing and does not prevent the implementation of cost-sharing in an amount less than the amount specified under subsection 2. Subsection 2 does not limit cost-sharing on an insulin pump, an electronic insulin-administering smart pen, or a continuous glucose monitor. This section does not limit whether coverage classifies an insulin pump, an electronic insulin-administering smart pen, or a continuous glucose monitor as a drug or as a medical device or supply.

SECTION 3. APPLICATION. This Act applies to health benefits coverage that begins after June 30, 2021, and which does not extend past June 30, 2023.

SECTION 4. PUBLIC EMPLOYEES RETIREMENT SYSTEM - INSULIN DRUG BENEFITS. Pursuant to section 54-03-28, the public employees retirement system shall prepare and submit for introduction a bill to the sixty-eighth legislative assembly to repeal the expiration date for this Act and to extend the coverage of insulin drug benefits to all group and individual health insurance policies. The public employees retirement system shall append a report to the bill regarding the effect of the insulin drug benefits requirement on the system's health insurance programs, information on the utilization and costs relating to the coverage, and a recommendation regarding whether the coverage should be continued.

SECTION 5. EXPIRATION DATE. This Act is effective through July 31, 2023, and after that date is ineffective.

SECTION 6. EMERGENCY. This Act is declared to be an emergency measure."

Renumber accordingly

2021 SENATE APPROPRIATIONS

SB 2183

2021 SENATE STANDING COMMITTEE MINUTES

Appropriations Committee
Roughrider Room, State Capitol

SB 2183
2/16/2021
Senate Appropriations Committee

Relating to public employee insulin drug benefits; Relating to self-insurance health plans,.

Senator Holmberg opened the hearing at 9:37 a.m.

Senators present: **Holmberg, Krebsbach, Wanzek, Bekkedahl, Poolman, Erbele, Dever, Oehlke, Rust, Davison, Hogue, Sorvaag, Mathern,** and **Heckaman.**

Discussion Topics:

- Co-Pay
- Impacts on Lives

Senator Dever, District 32, introduced the bill.

Danelle Johnson, testified in favor and submitted testimony #6644 and #6645.

Angela Kritzberge, testified in favor and submitted testimony #6587

Scott Miller, Executive Director, NDPERS, provided neutral testimony #6647

Daniel Weiss, Senior Executive Director, Sanford Health Plan, answered questions from the committee and submitted testimony #6634.

Carlye Gast, T1D Mother/Advocate, testified in favor and submitted testimony #6570.

Additional written testimony: #6505, #6617

Senator Holmberg closed the hearing at 10:30 a.m.

Skyler Strand, Committee Clerk

6644

POINT PAPER

Problem: Medical Treatment for insulin dependent diabetics has become unaffordable and inaccessible for a growing number of patients to effectively sustain life with 100% success and manage their chronic illness so as to prevent further complications of stroke, kidney disease, blindness and heart disease.

Issues:

1. 68,097 North Dakotans are diabetic. 6,800 are Type 1 Diabetics who are 100% dependent upon insulin to survive. A subset of all other diabetics also rely on insulin.
2. Insulin and diabetes supplies supply chains offer no transparency to costs.
3. No Generic Option (Biosimilar as it is called in the case of insulin.)
4. Free Market does NOT bear the cost of insulin. Type 1 Diabetic's choice is: Pay or Die
5. Diabetes is the most expensive chronic disease in the United States. $1 out of every $4 health care dollars is spent on diabetes and related care. Individuals with diabetes have medical expenses approximately 2.3 times higher than those without.
6. Insulin Out of Pocket (OOP) costs are increasingly calculated as a percentage of the cost (co-insurance), rather than a fixed dollar amount (co-payment) and are typically based on the list price rather than the net price.
7. In North Dakota, a manufacturer's rebate for insulin can and is used to lower premiums for the employer and insureds, but the patient is charged co-insurance from the list price.
8. Insulin is deadly. Insulin therapy requires diabetic supplies such as test strips, meters, lancing devices, syringes, and lancets to make proper dosing decisions. All need to be accessible and affordable to do so.
9. The cost of insulin has risen 1200% since 1990 with no substantial changes to the product.
10. 8.3 Million Americans use insulin to control their diabetes. Three-fifths are insured under Medicare, Medicaid, or Children's Health Insurance Program (CHIP). Taxpayers are already footing the health care bill for over 50% of the people with diabetes.
11. Estimated cost savings when all persons have proper diabetes management care is $_____ (How to qualify savings?? North Dakota spent $470 million in direct expenses for diabetes care in 2017 and another $190 million spend on indirect costs from lost productivity.)

Solution: The North Dakota Legislature to approve a monthly co-payment cap of $25 for insulin and an additional $25 co-payment cap for diabetes supplies for the patient until further action is taken federally or by the supply chain itself to ensure affordability and accessibility for all North Dakotans to this life sustaining medication that has 100% ability to manage the disease when used properly.

Recommended Action: The committee approves the current SB 2183 and forwards it on through the process of being heard in front of the full legislature to assist all individuals in this crisis until a federal solution for all insulin dependent people can be approved.

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

Mister Chairperson and members of the Appropriations committee, my name is Angela Kritzberger and I am from Hillsboro. I am a mother to Nina, who, at the age of 7, was diagnosed with Type 1 Diabetes. I have been working closely and tirelessly with Danelle Johnson and Carlye Gast of Fargo to address the issue of insulin affordability in North Dakota since our childrens' diagnoses. As parents, caregivers and advocates for someone living with a chronic life-threatening disease, we may grow weary from telling our story, but we will never give up the fight and always welcome honest conversations to shed light on this complex disease and its cost to thousands in North Dakota. We are also here to continue the fight for those who no longer have a voice to the issue.

When it comes to Type 1 Diabetes, it seems that we are continually faced with educating the people we meet as to what caring for a person who is insulin dependent is like. Why? It is simply a matter of life or death. We educate our families, friends, neighbors, teachers, caregivers, you as legislators and often times even our local medical support team. It is our responsibility as their caregivers to take the same oath as a physician: to do no harm.

I would like to take a moment of your time to illustrate what our physician has recommended for a care plan for our daughter, which includes rapid acting insulin with the use of a continuous glucose monitor and insulin pump.

A typical blood glucose for a person without diabetes and a working pancreas is under 100. At diagnosis, our daughter's was 598. It is our goal to keep our daughter within a range of 80-150. For her current insulin needs, she requires a slow drip of 3 units of insulin each hour over a 24-hour period. Within that 24-hour period, if she eats 3 grams of carbs, her ratio to carbs is 1 unit of insulin to treat her food. An average meal that might consists of 30 grams would require 10 units of insulin administered 15 minutes prior to eating. The duration of the insulin working in her body is factored for 3 hours but the net effect of the food on her blood glucose peaks around 1 – 1 ½ hours depending on the protein to fat ratio. Another calculation we have set is her sensitivity to insulin based on her current blood glucose called a correction factor or insulin sensitivity. She has five different settings that are programmed over a 24-hour period. The data that I can produce from her continuous glucose monitor helps me to closely monitor and readjust her multiple settings on a bi-monthly to monthly basis as needed so she can maintain a healthy blood glucose. An A1C is a measurement that providers use to determine the long-term effect of controlled or uncontrolled blood glucose. At diagnosis, our daughter's was 12; a non-diabetic would be under 5.7. Our providers goal is 7.5 and most recently I am extremely proud of the work we have done to shift her A1C to 6.3 in the last year. While a blood glucose gives you a snapshot of the current picture at any given second, the A1C provides a truer picture of the overall management of blood glucose levels.

Why do we use this approach? The answer is quite simple – while we want her to live a long and healthy life free from complications, we also hope to lessen the burden on the healthcare system as well as the continued financial burden that life with diabetes can bring. A hypoglycemic event, or low blood sugar, can cost over $2,000 for an emergency room visit; while a 3-day event for Diabetic Ketoacidosis, or high blood sugar, can cost over $20,000. Both of these events are serious and life threatening. With the aid of this technology and our continued focus on our daughter's health I am happy to say we have not yet had an ER visit or

hospital stay. Unfortunately, this could quickly take a turn for the worse even with near perfect control if she were to become sick from the flu or other illness because it puts added stress on the body which can affect blood glucose levels and raise the chance of serious health complications for people living with diabetes.

We are a farm family who, because we are self-employed, must provide for ourselves an individual health insurance plan. It is a high deductible plan with a maximum out of pocket at $7,000 and co-insurance of 10% Our monthly premium this year is $2,600. I would like to give a breakdown of our year thus far:

- **$3,000** = cash price before $7,000 out of pocket family maximum is met for insulin pump supplies and continuous glucose monitor supplies which last up to 3 months. It also includes $500 for basic supplies of glucagon pen, test strips, ketone strips, lancets, needles and syringes which are used as needed.
- **$150 =** for purchasing snacks to treat hypoglycemic events, low or no carb snacks, glucose tabs, auxiliary skin prep wipes, allergy sprays, and bandages.
- **$100** = No vision insurance from being self-employed. Health insurance plan will not cover even though she's diabetic.
- **$25** = co-pay for insulin. My carrier implemented a cap starting in 2021 that was not communicated during plan renewal and was previously $1,200 with a rebate that was set to expire at the end of the year.
- **Cost unknown.** Quarterly diabetic health exam with pediatric endocrinologist to review bloodwork, health trends and address any changes to care plan.

$3,275.00 TOTAL spent on supplies from 6 different vendors on 6 different days to date. [What you see in this suitcase shows on top the very basic supplies-the bottom is what we use in one month's time. The life of a diabetic is tethered to this.]

Managing this chronic life-threatening disease is like no other. Decisions are made independently and with little hesitation because treating this disease comes every second of every minute of every hour of every day of every week of every month of every year until a cure is found. It is not done with medical staff at our side. Too much or too little insulin can cause death. Without insulin death is imminent in days. The emotional and physical burden is heavy. We need to lift the financial burden for North Dakotans because it has been placed on them without their doing. If we cannot be the ones to find a cure, then we must be the ones to seek the funding from those who profit from their lives. Insulin has been around for over 100 years. Modern insulin has been around for close to 40 years and there still is not a generic option on the market.

Our SB 2183 was created and drafted with bipartisan support to help address the grave differences that we continue to hear on insulin and diabetes supplies affordability. We have worked not only on this current piece of legislation, but also introduced Senate Concurrent Resolution 4002 in the 66th ND legislative session and have met with Sen. Kevin Cramer to address these issues while being engaged in and supporting the work that is being done on the

federal level. While some may feel that this issue cannot be addressed through a state mandate, this often seems to be a knee-jerk response when we see other states that are passing similar legislation, and advocates that support us in the medical field that see these devastating issues firsthand. We strongly feel it starts right here.

What we have learned in our work is this: 1) If a person has access to health insurance, they offer significantly different levels of coverage for insulin, making it often times unaffordable. We also continue to hear discrepancies amongst carriers and plans. 2) Basic diabetes supplies are often not qualified to be processed through insurance plans but are easily accessible through a local pharmacy. 3) There are many other supportive supplies and costs associated with this disease that are not taken into account. This bill was created to cast a conservative net around the most basic needs of a person who is insulin dependent and basic supplies.

In conclusion, we feel there is no better time than now to come back to the table for meaningful discussion and to make the lives of North Dakotans and SB2183 whole again.

Thank you for your time.

TESTIMONY OF SCOTT MILLER

Senate Bill 2183 – Diabetes Drug and Equipment Mandate

Good Morning, my name is Scott Miller. I am the Executive Director of the North Dakota Public Employees Retirement System, or NDPERS. I am here to testify in a neutral position regarding Senate Bill 2183.

This bill creates a mandate regarding health insurance plan coverage of diabetes drugs. This bill does comply with the statutory requirement that health insurance plan mandates first apply to NDPERS.

The primary components of the proposed bill that will have actuarial impacts on the PERS program are the $25 limit on member cost-sharing for insulin and insulin supplies. The PERS plan requires members to pay a copay and coinsurance for insulin. Depending on the cost of the insulin prescribed and/or the cost of the supplies purchased, the member cost-share can exceed the proposed $25 limit. Therefore, imposing this limit will shift cost from members to the plan.

SB 2183 is one of several bills that would impose mandates on the NDPERS health plan, as you can see in the below table:

New Mandate	Dollar Increase	Premium % Increase
HB 1147 – Fertility Benefit Increase*	~$1,000,000/year	~0.3%
HB 1155 – VSIP Retiree Premium Subsidy*	$791,294/biennium	0.145%
HB 1233 – PBM Audit Requirement	$1,125,000/3 audits	Reserves
HB 1328 – Vitamin D Requirement	-	-
HB 1435 – Line of Duty Death*	Minimal	Minimal
HB 1465 – Any Willing Provider	Unknown, but large	Unknown, but large
SB 2170 – Canadian Reference Drug Pricing	Unknown effect	Unknown effect
SB 2179 – Telehealth Coverage (amended)	-	-
SB 2183 – Insulin Drugs	$624,329/year	0.22%

*Would potentially add non-governmental participants to our governmental plan

Note that the fiscal note for SB 2183 and the projected costs in the above table only reflect cost increases to the State for coverage by the NDPERS health plan. Any

increased cost to the state as a result of later imposing these mandates on non-NDPERS health plans is unknown.

For cost comparison purposes, below is a table of benefits we do not currently provide that are required for non-grandfathered plans (the NDPERS PPO health plan is a grandfathered plan). We routinely receive requests to cover these benefits.

NDPERS 2021 - 2023 Biennium Cost of Added Benefit Options		
Requested Options	Cost as a %	Estimated Cost over Binnium
Colonoscopies with no member cost share	0.30%	$1,913,267
Contraceptives with no member cost share	0.50%	$3,188,778
Breast Pumps with no member cost share	0.06%	$382,653

Mr. Chairman, this concludes my testimony.

6634

February 15, 2021

My name is Daniel Weiss, Senior Executive Director, Pharmacy at Sanford Health. I will be available to answer any questions concerning this legislative proposal and/or in support of NDPERS

My name is Carlye Gast. I am an attorney from Fargo, and I am an advocate for insulin affordability. I am testifying on behalf of myself as the mother of an 11-year-old boy with Type 1 diabetes.

Insulin is expensive. My son needs about 65 units of it a day. That's a tiny amount - a little over a tenth of a teaspoon. But it carries a sticker price of nearly $30 for that day's coverage. $30 for a *day*. He has two insulin prescriptions - a long-acting and a short-acting. He also has ten other prescriptions running, to cover all of the supplies so that he can safely use insulin: test strips, lancets, meters, glucagon should he go very low, ketone strips in case he is high. It's expensive.

The actuarial study provided for this bill does not really look at any one person's expense, or the expenses of all insulin diabetics in North Dakota collectively. It does not look at the impact of a 1200% increase in insulin cost over the past 20 or so years. It does not look at my son or others like him and consider them as having any value. It just looks at cost.

So let's talk about cost. Do you know what else costs a lot? No insulin. Or not enough insulin. Or improperly used insulin. The actuarial study does not appear to account for any cost savings that could come with our bill, but in fact, diabetes - thanks largely to poor control in many people - is the most expensive chronic illness in the United States. It is also the seventh leading cause of death in the United States.

Diabetes is a leading cause of a number of significant and severe diseases, including heart attack, stroke, and kidney disease. In fact, it is the leading cause of end stage kidney disease, causing nearly 40% of all cases. Dialysis has an *annual* cost of approximately $90,000 per patient, and a transplant can cost $400,000, plus a lifetime of anti-rejection drug costs.

Diabetes is also the leading cause of blindness. Direct and indirect costs of blindness total $60,000 per individual.

Significantly, diabetes is also the leading cause of lower extremity amputations in North Dakota. Per the CDC, in 2014, 87% of all lower extremity amputations that occurred in our state were due to diabetes. The two-year cost of a single below knee amputation is estimated to be $91,000, with a lifetime cost of more than a half million dollars.

The magic bullet for all of these horrible figures? Insulin! Basic supplies for the safe use of insulin! In the end, providing affordable insulin and supplies to patients could save employers, insurers, and the government a tremendous amount of money by avoiding complications, lost productivity, disability payments, and the like. This bill could be a win-win.

But also, it's just the right thing to do. At the Human Services Committee meeting, several of those testifying as either "opposed" or "neutral" to this bill said something along the lines of "We are sorry your children have this disease, but we don't think everyone else should have to pay for it." But what we are asking is not a novel concept. The government ensures that people are

able to get many preventative treatments through their insurance free of charge: vaccines, mammograms, screening colonoscopies, even HIV preventative medications and birth control. Insulin is similar to these, because it is the ultimate preventative medication, warding off all the complications I just discussed.

We are also comfortable as a society with having government and private businesses pay for things like wheelchair ramps, automatic doors, elevators, braille signs, audible crosswalk signals, and special hearing-impaired telephone services. We *should* be providing these accommodations. These are appropriate and allow people with disabilities to live *better* lives.

Today, I am asking for affordable insulin and basic supplies through SB 2183 so that insulin-dependent people can *live* lives. Period. The struggle is real, and it is ongoing. Sleepless nights, unpredictable impacts of activity, emotions, weather, and illness, are all part of this disease. Insulin and supplies should not be a burden to obtain. This population is burdened enough.

6505

TESTIMONY OF DERRICK HOHBEIN

Senate Bill 2183 – Diabetes Drug and Equipment Mandate

Good morning, my name is Derrick Hohbein. I am the Chief Operating/Financial Officer of the North Dakota Public Employees Retirement System, or NDPERS. I appear before you today in a neutral position on Senate Bill 2183. I am available should there be any questions related to the impact of the bill on any of the NDPERS benefits.

TESTIMONY OF REBECCA FRICKE

Senate Bill 2183 – Diabetes Drug and Equipment Mandate

Good morning, my name is Rebecca Fricke. I am the Chief Benefits Officer of the North Dakota Public Employees Retirement System, or NDPERS. I appear before you today in a neutral position on Senate Bill 2183. I am available should there be any questions related to the impact of the bill on any of the NDPERS benefits.

2021 SENATE STANDING COMMITTEE MINUTES

Appropriations Committee
Roughrider Room, State Capitol

SB 2183
2/18/2021
Senate Appropriations Committee

A BILL for an Act to create and enact section 54-52.1-04.20 of the North Dakota Century Code, relating to public employee insulin drug benefits; to amend and reenact subsection 2 of section 26.1-36.6-03 of the North Dakota Century Code, relating to self-insurance health plans; to provide for a report; to provide for application; to provide an expiration date; and to declare an emergency.

Chairman Holmberg opened the hearing at 10:35 a.m.

Senators present: Holmberg, Krebsbach, Wanzek, Bekkedahl, Poolman, Erbele, Dever, Oehlke, Rust, Davison, Hogue, Sorvaag, Mathern, and Heckaman.

Discussion Topics:

- **Vote**

Senator Dever presented amendment LC 21.0798.02001; testimony #6951

Senator Dever moved to adopt the amendment LC 21.0798.02001
Senator Bekkedahl seconded the amendment

Senators			***Senators***	
Senator Holmberg	Y		*Senator Hogue*	Y
Senator Krebsbach	Y		*Senator Oehlke*	Y
Senator Wanzek	Y		*Senator Poolman*	Y
Senator Bekkedahl	Y		*Senator Rust*	Y
Senator Davison	Y		*Senator Sorvaag*	Y
Senator Dever	Y		*Senator Heckaman*	Y
Senator Erbele	Y		*Senator Mathern*	Y

Motion Passes 14-0-0.

Senator Dever moved DO PASS AS AMENDED
Senator Erbele seconded the amendment

Senators			***Senators***	
Senator Holmberg	Y		*Senator Hogue*	N
Senator Krebsbach	N		*Senator Oehlke*	N
Senator Wanzek	Y		*Senator Poolman*	N
Senator Bekkedahl	Y		*Senator Rust*	N
Senator Davison	Y		*Senator Sorvaag*	Y
Senator Dever	Y		*Senator Heckaman*	Y
Senator Erbele	Y		*Senator Mathern*	Y

Motion Passes 9-5-0.

Senator Anderson will carry the bill.

Chairman Holmberg closed the hearing at 10:45 a.m.

Rose Laning, Committee Clerk

21.0798.02001
Title.03000

Prepared by the Legislative Council staff for
Senator Dever
February 18, 2021

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2183

Page 2, line 15, after "for" insert "up to"

Page 2, line 15, after "of" insert "a"

Page 2, line 15, replace "drugs" with "drug"

Renumber accordingly

REPORT OF STANDING COMMITTEE

SB 2183, as engrossed: Appropriations Committee (Sen. Holmberg, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (9 YEAS, 5 NAYS, 0 ABSENT AND NOT VOTING). Engrossed SB 2183 was placed on the Sixth order on the calendar.

Page 2, line 15, after "for" insert "up to"

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Renumber accordingly

Prepared by the Legislative Council staff for
Senator Dever
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