TESTIMONY

PROPONENT FOR SB 220

MINDY HEDGES
OHIO CITIZEN

Chair Bob Hackett, Vice Chair Mark Romanchuk, Ranking Member Hearchel Craig and Insurance Committee members Senator Andrew Brenner, Matt Dolan, Jay Hottinger, Stephen Huffman, Stephanie Kunze, George Lang, Tina Maharath, Tim Schaffer, Cecil Thomas and Steve Wilson. My name is Mindy Hedges, and I have been a Type 1, insulin dependent Diabetic for over 60 years. You see, I first was diagnosed at age 5, and was immediately put on daily, then twice a day, then four times a day insulin injections. That's the way insulin worked over that extended period of time. But now, thankfully, we have the wonderful insulin pump. It doesn't reduce the amount of medication, but it helps us to regulate it better, as it gives us a more continuous flow like a pancreas outside of our bodies. It is not easy to work, and the cost for the equipment to keep it regulated, clean, continually pumping, and blood checking equipment, as well as my insulin, cost me in out-of-pocket expenditures, over $7,000 per year.

Just to give you an idea of how many people this bill has the potential to help:

> Diabetes is one of the most prevalent and serious chronic diseases in the United States. More than 30 million (9.4%) people in the United States have diabetes, and 1 in 4 of them don't know they have it (Source: CDC National Diabetes Statistics Report, 2017). In 2015, approximately 1.5 million new cases of diabetes were diagnosed in adults ages 18 years and older, and that number is anticipated to grow as the U.S. population continues to age and become more overweight and obese (Source: CDC National Diabetes Statistics Report, 2017).
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> Diabetes is the 7th leading cause of death in Ohio and the United States (Source: 2018 Ohio Chronic Disease Burden Report). In 2016, diabetes was the primary cause of death for 3,500 Ohioans and was a contributing cause of many more deaths (Source: 2018 Ohio Chronic Disease Burden Report).
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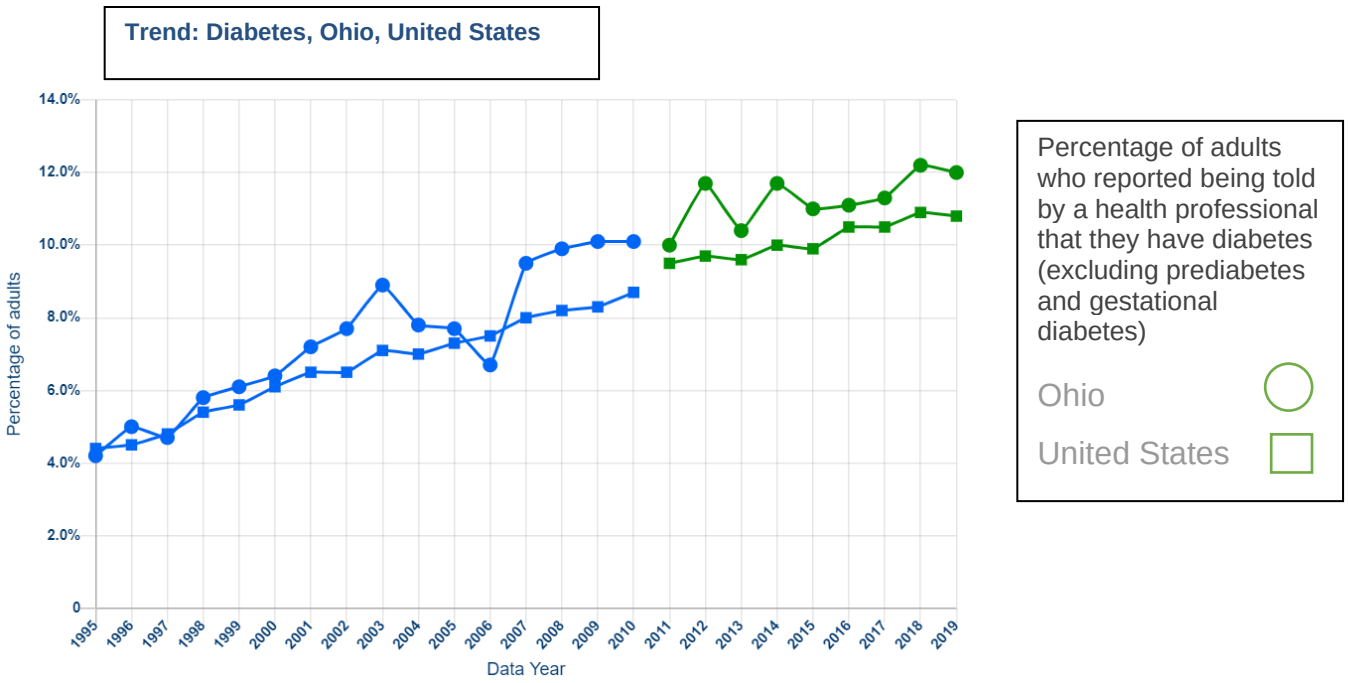
> In 2016, nearly 1 million (11.1%) Ohio adults had been diagnosed with diabetes (Source: 2018 Ohio Chronic Disease Burden Report). In addition, nearly 800,000 adults in Ohio had been diagnosed with prediabetes, and it is estimated that more than 1 million Ohio adults have prediabetes but have not been diagnosed, increasing their risk of progressing to type 2 diabetes later in life (Source: 2018 Ohio Chronic Disease Burden Report).



- CDC, Behavioral Risk Factor Surveillance System
- Note: Green begins new decade in 2011

As you can see, we have a major problem in Ohio.

Let me tell you a story that will help you understand how serious the cost of insulin is, particularly for those who don't have insurance, or, as we all know, have minimal insurance coverage or coverage that does not cover pharmaceuticals like they should. You also need to know the difficulty in getting it without a doctor's prescription.

I was visiting my daughter in Birmingham, Alabama, and it happened to have been the eve of Easter, and the 2nd night of Passover. We got back to her home and I realized I needed to change my pump to put a new pod on, which requires, over 3 days, 150 units of insulin. I didn't realize that the bottle inside my kit was almost out of insulin. It was 11:30 at night before a holiday.

We panicked. We ran to the pharmacy, who said that a bottle of insulin would be $550, but they wouldn't even sell it to me as I didn't have a prescription and my pharmacy was closed so they couldn't check. We then had to go to a hospital ER, who had to write me a prescription, then back to the pharmacy with the prescription. My insurance would not cover this insulin because it wasn't one that was on their "approved" insulin list. There are 3 fast-acting insulins - Lispro and Humalog, manufactured by Lilly ($24.540 billion in profit in 2020) and Novolog, manufactured by Novo Nordisk ($19.448B in profit in 2020), that are fast-acting. Most type 1 diabetics use this type of insulin in their pumps. The ER, however, had written a prescription for the "wrong" brand. So, after $90 for my ER co-pay, and then $550 for the insulin, I was $640 in the hole. And that was after paying way too much for the insulin I already had in my refrigerator at home.

Several months after this incident, my husband and I took a long-awaited trip to Toronto. When passing by a pharmacy there, just for kicks and giggles, I went in and asked for 2 bottles of the same insulin (same amount and same brand). They were $25 per bottle! So how can this be? Why are Americans paying $525 more for the same drug than our neighbors to the North? Although I realize they are a socialized government, the cost of pharmaceuticals cannot be that different! So, my husband and I decided that we would go to Canada to buy my diabetic supplies until I was of Medicare age.

Senator Chuck Grassley has been researching this issue for several years. His conclusions about why the pharmaceuticals price insulin so high needs to be changed. It is:

> Between 2012 and 2016, the drug's cost nearly doubled. A Humalog 50/50 vial costs an average of $390.23. It is considerably higher now, as I have shown in my example.
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> Grassley claims that the increase is tied to the business practices of manufacturers, health plans and PBMs, or pharmacy business managers. A 2019 House Committee on Energy and Commerce hearing featured testimony from CVS Health, Express Scripts, OptumRx, Eli Lilly, Novo Nordisk, and Sanofi. They couldn't lower the prices of insulin, the companies claimed, because of how PBMs and health insurance companies operate.
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> PBMs serve as a liaison between drug companies and health insurance companies, negotiating what insurance companies, pharmacies and patients pay for a drug. They can negotiate rebates, discounts, and other services. These rebates and other benefits are passed on to the health plans. Medicare is barred from participating in these negotiations.
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> A study published by the American Diabetes Association in 2018 showed that these negotiations encourage high list prices. As these list prices increase, "profits of the intermediaries in the insulin supply chain, such as wholesalers, PBMs and pharmacies, increase because each may receive a rebate, discount or fee calculated as a percentage of the list price." It is a **Catch 22**!
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> The study also reported that, because transparency is lacking within the insulin supply chain, "it is unclear precisely how the dollars flow and how much each intermediary profits."
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> Some insulin producers blame insulin's prices on the cost of innovation. However, Mayo Clinic hematologist S. Vincent Rajkumar dismissed this claim in a 2020 paper. Rajkumar wrote that limited innovation exists when it comes to insulin, and that what matters more is affordability.
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> A U.S. Senate Finance Committee staff report released this year stated, "Eli Lilly reported spending $395 million on (research and development) costs for Humalog, Humulin, and Basaglar between 2014 and 2018, during which time the company spent nearly $1.5 billion on sales and marketing expenses for its insulins."
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> The report also cited instances of 100-year-old drugs still going up in price. Every time a pharmacy dispenses therapeutic insulin, manufacturers pay PBMs administrative fees as high as 5 percent of the drug's wholesale acquisition cost, the Senate staff report states. "These fees are a significant revenue stream for PBMs and likely act as a countervailing force against lower list prices—PBMs may be reluctant to push for lower WAC prices since it would reduce their administrative fee-based revenue," the report stated.

My experience with Medicare, however, is no better. My pharmaceuticals are not less expensive, as our federal government does not yet negotiate pharmaceutical prices with these companies.

I had a very difficult conversation with my Medicare insurance provider last week, on this specific subject. They consider all of the fast-acting insulin (again, a majority of type 1 diabetics take this type of insulin), to be a tier 3, which I pay additional money for. The insulin I have recently changed to is a new generic brand, which one of the two fast acting insulin companies just came out with. They were not kind when they did this, by the way. Their patent was up, so they came out with the same insulin they had, called it generic and have acted faster than their major competitor.

This company advertises this brand as a generic, and all generic brands are classified as tier 1. The difference in cost is considerable, but dependent on the policy someone can afford on Medicare.

But again, please remember that the original cost for this bottle is $250!!! I can't imagine the out-of-pocket cost for this tiny bottle of insulin that is made with virtually no secret ingredient, just a lifesaving serum for over 1 million Ohioans.

A bottle lasts me slightly less than 2 weeks. That's almost $100 a month for insulin, plus $30 for every pod I use, which is changed out every 3 days. That's $300 per month for the pods and a total of $400 per month for my insulin and supplies. And that doesn't include my glucose monitor, insulin pump ($8,000+) or doctors visits.

I would be happy to meet with any of you at any time to discuss this personally. I can discuss the history and evolution of this terrible disease, who it effects, and how difficult it is to manage and why.

Any help you can give us would be amazing!

Thank you for reading and considering my testimony to pass SB 220.

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