

**Testimony to the Senate Committee on Health, Education,
Labor and Pensions
Subcommittee on Primary Health and Retirement Security
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My name is Elia Spates. I was diagnosed with type 1 diabetes 23 years ago and quickly my parents and I got a crash course in the world of insurance and the serious expense of diabetes.

The insulin that I take now costs over \$2000.00 out of pocket per month. The rise that I have seen in this price in the last 23 years is astronomical. In fact from 2002 to 2013 the cost of insulin tripled. When you pay over \$800 per month, for an individual, in insurance premiums and paying an additional \$2000 per month until your deductible is met your family starts to feel a financial pinch. The only way you see to cut back on the spending is to cut back on the insulin. Before you know it your diabetes is out of control, your blood sugars swing dramatically, seizures happen and you are even found unresponsive. It is time to treat the disease seriously. The financial side of diabetes is as much or more a burden as the disease itself.

I am certainly not the only diabetic out there who has rationed insulin to help fend off a steadily accumulating debt. In fact 45% of diabetics at one time or another will compromise their care to cut costs. However, what is happening is that those who are not as fortunate as I land themselves in the hospital, in traumatic circumstances, and maybe even die. 7.5 million Americans rely on insulin and 1.5 million of those are type 1 diabetics.

A few years ago my doctor suggested going to Canada. I live just 4 miles from the Canadian border so this was logical...until you give it just an ounce of thought. I pay over \$10,000 a year in insurance premiums, so that I can go buy my insulin in another country and it doesn't count toward my deductible?! It is completely asinine to think I would go to another country to buy inexpensive medication and yet pay for a health care plan in my own country that is only compounding my diabetic problems.

Twice I have arrived at the pharmacy to pick up medication that had been prescribed by my doctor and both times I was told that my insurance company was no longer going to cover 'that brand' without prior authorization, however they were happy to cover another suggested brand that was biosimilar NOT bioequivalent. With this first medication it had taken me over a year to get it

approved by the insurance company and I was finally having success using it and now it was being disallowed?

It is infuriating to know that in one fell swoop your perfect combination can be undone by the companies that produce the medication, and the pharmacy benefits managers who market it to the insurance companies who now give it preferred status on their health care formularies.

Just six months later an insulin I had been on for over 4 years became no longer an option. Once again it needed a prior authorization, BUT, there was a similar medication I could have. Now had this been the difference in brand name to generic I could perhaps have understood. HOWEVER, this was from one name brand insulin to another and in fact it was now \$5 more out of pocket for me. It doesn't take a genius to figure out that this was happening because of how the money passes between the hands of the producers of the insulin, the PBM's and the insurance companies.

I appreciate being a part of a good business deal when I see one and as a woman in business I fully understand supply and demand. I was raised in the humanitarian principles of achieving success. Doing things ethically and watching the bottom line to make a profit is essential. It is however unethical, unscrupulous and completely wrong to gouge people, particularly so at the expense of their health.

To think that we are outpricing our own citizens and virtually holding out of reach scientific marvels to those who need it is an embarrassment.

We have seen a 300% rise in our cost of insulin in just a matter of years yet in the same amount of time Canada has seen virtually no rise in cost at all. Three major producers of insulin have all had the same price hikes over that time. It is interesting that pharmaceutical companies provide amazing rebates on these products yet the bulk of the rebates are cashed in by the PBM's not the consumer. This practice provides preferred status on the insurance company formularies for the pharmaceutical companies, hardly an arms length transaction. Rebates alone have risen from 2% in 2013 to 56% in 2018.

100 Years after the invention of insulin there are of course generic insulins out there which have been formulated. My understanding is that they sit on a dark and dusty shelf in the back of the room titled 'pay for delay'. This is that devious little plan in which big pharma companies pay off the generic companies to delay the release of their product. Big pharma gets to keep the largest part of their sales, the generic company makes even more than if they put it out on the market, and I

continue to pay top dollar. Any middle school student working their vocabulary list can tell you that that is a perfect description for collusion.

There are days that it is almost impossible to contemplate the unethical, immoral American healthcare and pharmaceutical system that has been created out of greed. I have to believe that those who perpetuate it probably haven't been burned by it. It is more than likely that they don't feel the initial pressure of the extreme insurance premiums because they don't have to pay them. Those participating probably don't drop thousands in deductibles either. And I am certain that they aren't showing up to the pharmacy counter to find out that the medication that had finally put them in good health is now not allowed because their insurance company has a different option for them, one not discussed with them or their doctor. Those perpetuating this travesty are probably also benefiting from some of Big Pharma's slice of the financial pie.

So when we ask the question "Why Does the US Pay the Highest Prices in the World for Prescription Drugs?" the answer should really be given by our elementary school children because it is that simple. It is simply because of greed. We are fooling ourselves and the citizens of this country by behaving like we don't know why we pay more. We all know, the question just becomes who is going to fix it? Who is going to put themselves out there? Who is going to take the high road and not the handout? Who is going to say, "Lives are at stake here and for once put yourself in those shoes and do what you would want done for you, your parents, your wife, your brother, your son, your daughter.

This is a bipartisan issue. Make it one. Do what's right, do it quickly and then sleep well at night knowing you chose to help the people, who by voting, entrusted you with their well being.