

Testimony to the Committee to Conduct an Interim Study Concerning the Costs of Prescription Drugs

February 28, 2020

Having nearly collapsed from internal bleeding, in late 2016 I was diagnosed with cirrhosis of the liver not caused by hepatitis or alcohol. A specialist informed me that a consequence of this condition was a serious buildup of ammonium gas in my blood that had serious consequences of its own. He prescribed a drug called Xifaxin and sent the prescription to my pharmacy. When I went to pick it up, I was informed that the insurance company had denied paying for it and the cash price would be about \$3,000 for a one-month supply. I asked if there was a generic version of the drug and the pharmacy said none was available.

Upon investigation, it turns out the insurance company was insisting I take a far less expensive liquid known to be less effective but with some significant side effects in some people. I was happy to do so but soon found out that I was among the group that quickly experienced those nasty side effects. The doctor's office contacted the insurance company and it insisted I stay on the cheaper treatment for, I believe, at least 30 days, at which time they would reconsider covering the more expensive drug. Due to the side effects I experienced, I was only able to take the liquid medicine intermittently and infrequently as I became homebound when experiencing the side effects.

At the end of the period of mandated abuse, the drug was cleared for me to order. The remaining issue was the price, as the insurance company benefit was less than half the price, even after my securing a coupon from the drug manufacturer. My personal finances at the time did not have room for this added expense so I set another doctor's appointment to discuss alternatives.

Out of curiosity, I researched if the drug might be available from a Canadian pharmacy and, hopefully, cheaper. What I learned made me very angry.

It turns out that the fancy, high-priced Xifaxin was and had been available in a generic form for a while – everywhere in the world but not in the United States. I found the \$3,000 expense for a 30-day supply of Xifaxin in the U.S. could be turned into a \$187 expense, including shipping, for a 100-day supply of the generic Rifaximin, with no insurance policy involvement – a reduction from \$100 a day to \$1.87 a day!

The three points I want to stress to you today are;

1. The cost of Xifaxin for a U.S. patient is exorbitant and prohibitively high for most Americans. By the way, this drug was actually developed to treat other medical conditions, so this burden is not restricted to those with liver disease.
2. The barriers to generic alternatives ARE a pricing issue. I personally would be curious to know why the market has not induced a U.S. supplier of a drug that is so expensive. Surely there would be willing customers, me included.
3. There are many who could benefit from this drug who do not have the skills or the time to research their alternatives. They are rightly classified as victims of the system.

Most of my career has been in high technology and consulting with high-tech start-up companies. I understand the value of patents and the desire to maximize return on investment for research, but the

markets for life-enhancing and life-saving drugs have too often proven to be predatory. Government's involvement in preserving people's quality of life and restraining the forces that would disregard that goal is a worthy and righteous endeavor. I encourage your continued work of behalf of all Nevadans.

Respectfully submitted,

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