

TO: The Oregon House Committee on Health Care
FR: Marci Slater, Prescription drug patient, Welches
DA: Feb. 5, 2018
RE: Testimony in support of House Bill 4005

I am submitting this testimony in favor of HB 4005, and join lawmakers on both sides of the aisle and a large coalition in support of this measure.

I was diagnosed with multiple sclerosis in 1994 and I have been taking the injectable medication Copaxone since 2000. My quality of life depends on this drug so that I am able to walk without a cane and have the energy to live my life or have the cognitive abilities needed to manage my own life. I am completely dependent on it, which, given its high cost, is frankly frightening to me especially now that we are retired.

When I first started taking Copaxone in 2000 it cost \$700 a month. Today it costs close to \$9,000 a month. That is a nearly 1200 percent increase. Even more shocking to me, is that since I testified before you on this issue last year - when the price was \$7,000 - it has increased more than 28 percent; in less than a year.

This is not a new drug. It has been on the market for decades and nothing has changed about the drug in all that time to answer for such a catastrophic increase. Other MS medications like mine from several manufacturers have increased in price in tandem, which means that even if another medication would work for me, it wouldn't be more affordable. As this committee heard during a recent informational hearing, over the past 10 years, prices for MS medications have more than tripled to say the least!

Today we have insurance through AARP Medicare Advantage to cover most of the cost of the drug. My co pay alone is about \$9000 per year with insurance. Fortunately, I have been selected for a grant to help with that co pay. And we know what it's like to be able to pay for this expensive medication out of pocket. In 2001 my husband was laid off and we had to go on COBRA. It was expensive coverage but still cheaper than buying the medicine outright. Unfortunately, there is no grace period for Cobra, and when I was ten days late in paying our premium for the benefit they dropped me. I assume it was because of the cost of the medicine. We were left paying out-of-pocket for almost four years after that, which very nearly bankrupted us.

For too long, patients like me have been paying the price for drug manufacturer's price gouging. And now that there is a generic to replace Copaxone, the drug company has a new medication that is a different dose. It's an injection you do every three days instead of every day. I think they are doing that because of the competition on the daily dose from the new generic. My doctor recommended the new Copaxone product, but it didn't work for me. Then I tried the generic and it didn't work for me, either. Both caused me to go into a flair up of my MS symptoms because they were not being absorbed by my body as effectively as the daily dosing Copaxone.

What happens to me when I don't get the medicine? The answer is pretty clear; I'd end up in a nursing home with someone else taking care of me as my disease slowly deteriorates my ability to function independently.

There is no justification for a 1200 % price increase for this drug over the past 17 years. There is no justification for a 28 percent increase over one year.

I support HB 4005 because for the first time drug companies will be required to justify double-digit price increases. We will start to have some explanation for why competition from other similar medications increases my costs instead of lowering them.

Please vote yes on HB 4005.