

To Whom It May Concern,

My name is Madonna McGuire Smith and I am a person who lives with hypothyroidism. I was diagnosed nearly 23 years ago. Over the years, I have had major challenges with my thyroid, including cancer. Eventually, after finding cancer and at the advice of my doctors, I underwent a thyroidectomy.

Hypothyroidism, or underactive thyroid, makes it challenging to manage metabolism in the body. I have to take a pill each morning to mimic the function of the thyroid and to keep me alive. Without the medication, I would die within weeks. When my thyroid was removed in 2010, the doctor did a mini study on me to see what medication was best for keeping my TSH in the lower end of the normal range. We discovered that I was much better maintained when using the generic levothyroxine medication than I was when using the name brand Synthroid.

We moved to Oregon ten years ago and my endocrinologist repeated the same mini study with the same result – my TSH level was much better maintained on levothyroxine than it was on Synthroid. The doctor requested that I only get the generic when my medications were dispensed. Every doctor has indicated that (at least that is what they have told me) on my prescription when submitting it to my pharmacy.

Four years ago, our insurance changed and we were forced to use a mail-in pharmacy that acts as the Pharmacy Benefit Manager (PBM) for our insurance company. The PBM decided to start dispensing Synthroid instead of the generic. When I contacted the PBM, they told me that it was courtesy to me, an added bonus, that they were keeping me on name brand. I explained that I could not be on the name brand they told me that it was better for me and that it was a service they were providing to all of their patients on thyroid medication. I explained that I could not be on Synthroid, that I was much better managed on the generic, they sent me the generic the next time the drug was dispensed but then went back to sending Synthroid after that. I worked through my doctor's office to pressure them and I called repeatedly to pressure them and finally spoke to a pharmacist (not a customer service person, pharm tech or admin person) who told me that it is their practice to put everyone on Synthroid as a benefit to their patients. When I asked why? The person would not answer directly. I asked if they received some sort of kick-back or incentive to keep people on name brand, they would not answer directly but only told me that there had to be a very good reason entered into my record in order for me to not receive Synthroid. Because of my position in a health advocacy organization, I understand about the benefits for PBMs to keep people on name brand drugs – that financial benefit was not passed on to me or my husband's employer in the form of reduced cost for the name brand drug, as far as I know. Instead, it caused me to have miserable side effects for a couple of years as the doctor's office and myself fought with the PBM to dispense the drug I needed and not the drug that paid them a kick-back.

This is just one story in a long line of stories that my family has encountered with PBMs. Our family also has severe bleeding disorders and we have been manipulated and harassed by a specialty pharmacy PBM for years. We have real horror stories of having our child's life-saving medication withheld because the PBM didn't have access to the drug manufacturers copay assistance program. The story goes on and on.

I strongly urge you to pass HB 3013 imposing more controls on PBMs and more oversight. These practices need to be stopped and patient care needs to be the focus of pharmacies – the focus should not be about making money.

Thank you,
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