

Ohio Senate – Health Committee
Proponent Testimony HB 135
Kristen Catton, RN, BSN
Westerville, Ohio

Copay Accumulator: My story as an MS Patient

My name is Kristen Catton, I live with Multiple Sclerosis (MS) and reside in Westerville, Ohio. I started the medication Gilenya in February of 2015 after having been on two other MS disease modifying therapies that failed to control my MS or stop repeated flare-ups. Gilenya costs approximately \$9200.00 per month or approximately \$110,000./year. With my private employee health insurance, my copay for the medication would be \$3800.00/month. I was not able to afford the cost of this medication and was very lucky that Novartis (the manufacturer) had a program that would cover the cost of my out-of-pocket copay up to \$15,000/year.

At the time, my out-of-pocket pharmacy costs under my health insurance were ~\$9000.00/year, something that I would have had great difficulty paying. When I started Gilenya, Novartis provided me with a copay assistance card that I would provide to my insurance, which would pay my copay for the medication. The money that Novartis was paying for my copay was then being applied to insurance plan deductible and the insurance company received the payment. When my out-of-pocket deductible was paid (\$9000.00- which Novartis paid) I would no longer have a copay for the rest of the calendar year. This was tremendously helpful. I continued to proceed this way for 3 years. Every year I would apply for Novartis copay assistance, was approved, and would use my copay assistance card to pay my out-of-pocket cost for Gilenya until my deductible was met.

On 4th year on Gilenya, I was using my copay assistance as usual for the first 3 months of the calendar year. Then in April, while on the phone with the specialty pharmacy (which I was required to use under the regulations of my health insurance), I was informed that my copay would be \$3800.00. I proceeded to inform the rep on the line that I should have no copay and I should have already met my out-of-pocket maximum by now (Novartis was paying \$3800/month for the past 3 months which would total over \$11,400 and my deductible was ~\$9000.00). The rep then told me that my copay was coming up \$3800.00 and they could not give me the medication until I paid the total amount. She told me to call my insurance company to figure it out. Mind you, I was only issued a 30-day supply of Gilenya at a time. Every month I would call the specialty pharmacy when I had 10 days of the medication left. When this all happened and I was told I needed to pay \$3800 immediately, I only had 10 days of Gilenya on hand, so I needed to act quickly to get this straightened out. I could not just stop the med, as there are severe possible medical consequences of stopping any MS DMT cold turkey. Needless to say, I was terrified!

I proceeded to immediately call my employee sponsored health insurance plan, and after HOURS of being on the phone with various people who had no idea what was going on, I called my HR department to get some help. Come to find out, my employer at that time, had changed

my health plan that year and were now using something called “copay accumulator” which stated that I was no longer able to use my copay assistance to cover my copay. Of note, this was BURIED in the details of the 40 pages of explanation of my new insurance plan. I then inquired if I was no longer able to use my copay assistance through Novartis to help pay my copay, what had happened to the over \$9000.00 that Novartis had already paid my health insurance for the 1st three months of year?? I was then told the money covered my copay for 3 months, but the money did not go towards my deductible. I then asked, “what good is that, it just delayed me having to pay my deductible for 3 months!” I was flabbergasted!! How could they get away with this??? I immediately starting researching, making phone calls to my MS doctor, MS society reps and others to ask if they had heard about this. Most had never even heard of this at that time. I got busy then writing my senators and representatives asking HOW IN THE WORLD this was allowed! MS drugs, on average, cost in the hundreds of thousands of dollars per YEAR!! Who in the world could afford these meds or the high deductible??? No one!!

I was then told by a representative of my health insurance that me, or other patients, getting help by pharmaceutical companies to pay our deductibles “wasn't fair”. He had the nerve to tell me “When someone needs surgery no one pays their deductibles, so it’s not fair that you are getting help~ you need to pay your deductible”. First off, is someone going to be having surgery every month for the rest of their lives, like MS patients will need these meds for the rest of their lives??? No. It’s not about fairness, it’s about companies making more money off the backs of patients like me.

I ended up putting the cost of my copay on my credit card that month. I was in despair. I had no idea how I could keep paying for this medication every year for the rest of my life. Fortunately, I was able to work with Novartis and was able to get help paying for the medication on an emergency basis but going forward I knew it was going to be very challenging being able to afford this medication in the long term. This is the life of a person with a chronic, incurable disease. We require medications that keep us alive and functioning, but at every turn we are met with circumstances like these that put us in untenable situations where we must decide between paying the mortgage or getting the medications that keep us able to work and being functioning members of society. This is reality and its overwhelming, exhausting and dehumanizing.

Kristen Catton

4607 Pine Tree Court
Westerville, Ohio 43082