

February 13, 2019

TO: Rep. Moore
Rep. Brink
Rep. Derry

FROM: Brandon Schneider

RE: House File 204: Continuity of Care

Good Morning. I write to you to share my recent troubling experience regarding access to healthcare and to my medication.

First, I would like to share a little about me and my condition. I was born with a severe case of AVM (Arteriovenous Malformation). This is a condition that happens during fetal development. It's as simple as that. Either you're born with it or not. It's rare, but it happens. I'll skip the science of it, but what this means is **I am fully epileptic** and have been trying to manage my condition for years. I've been insured by Medica for the past 2 years and working with my medical team to manage my condition.

Neurologists classify the severity of AVM cases by using a ranking system: 1-5. If it's a 1, then it's treatable via surgery and there's a light at the end of the tunnel. The closer you get to 5, the worse the situation. I am a hard 5. It's not treatable, no surgery/embolization/etc. It's the entire right side of my brain. I am left with one option: to learn how to manage it. This involves loads of health protocols outside of the hospital including managing my diet, exercising, and managing my stress.

After 9 years in the making working with my medical team at Mayo Clinic of Rochester, we finally found the "cocktail" of medicine and the proper dosage for my seizure management. Let me tell you, this was not an easy undertaking. It has been difficult on my physical and mental health as well as my financial stability. My daily cocktail for being seizure free consists of Keppra – 1,875mg BID; Trileptal – 300mg BID and Vimpat – 250mg BID. I as well as my medical team and my family were thrilled to have found a solution to stabilize my condition.

This all changed in January 2019. I went to the pharmacy to get my Vimpat expecting to pay \$50 like I have every month in the past, but when my pharmacist rang up my medicine she told me I owed \$1,441.67. Needless to say, I was shocked. I didn't know what to do because I didn't have that kind of money to pay for my medicine, but I knew I needed to have it or I would be back in the hospital with uncontrolled seizures. Because I'm not made of money, I've been buying a week's supply at a time to stay alive and buy a little time, so I can figure this out. To date, I've spent \$498 on one weeks supply of medicine that used to cost me \$50 for a 30 day supply. I had to pay that \$498 or I could die.

The next day, I was forced to become an expert on the healthcare industry and this is what I learned. Vimpat is a "non-preferred brand" which is on the top shelf of Medica's formulary. Fun

fact, “non-preferred brand” is French for expensive as hell. There was a change in policy by Medica that I was not aware of. They are no longer offering co-payment coverage for medications, only co-insurance. My insurance plan through Medica last year covered costs at the pharmacy but apparently, they don’t offer that plan any longer.

So much to my surprise, here is my new plan:

*No co-payment coverage. My deductible is \$750. This new plan will kick in co-insurance after meeting the deductible. Co-insurance will cover 50% of each of prescription. The \$1,441.67 for a 30 day supply of Vimpat will turn into \$720.84. My max out of pocket is \$6,500. Once I hit that, Medica will pay the rest of my prescriptions in the year. But please know that won’t happen until **November of 2019.***

Again, my last name isn’t Gates, Buffet, or Kardashian so this plan isn’t a realistic option for me. I simply don’t have the means to pay for the same medicine I was stable on just the month before, paying a \$50 co-pay with the same insurance company. I really just don’t understand WHY an insurance company would want to take me off of this medication my doctors worked so hard to stabilize me on. It doesn’t make sense to me – financially or otherwise as this is a matter of life and death for me.

After learning of this I reached out for help. I was advised by Medica representatives is that I should find an alternative, a more affordable medicine. Please let me remind you that, I’ve been working to manage my seizures for over 9 years. So what else could I do? I called my neurologist and he explained there is NO alternative. Vimpat is one of a kind and it’s the kind that keeps me seizure free.

I have been left with no choice...Nine years in and finally a 6-month seizure-free milestone with the addition of Vimpat and the very insurance company that paid for my medication 30 days prior has decided to take that all away, for no reason other than the cost of the medication. I’m finally at a point where I’m able to get my driver’s license back and now this.

I spent the last several weeks calling every stakeholder involved no matter how far down the road. The insurance company representatives all say the same thing. “I’m sorry I wish I could be of more help there’s really not much I can do on my end.” The pharma manufacturer says the same thing. The pharmacy the same as well. Are you seeing a trend? There’re **good people out there** who want to help but they can’t because **the system is broken**. I understand you have the opportunity to help me. And I know I’m not the first person presenting this problem and I won’t be the last. It is crazy to think that insurance companies can set and break the rules without any ramifications. In addition, why should they be put in a position to make decisions about my medications, forcing me to a cheaper alternative. I thought only doctors were licensed to provide medical treatment and care in this state, I guess I was wrong.

After calling 15+ representatives I was offered an opportunity to appeal this decision. So I filled out an appeal form with the insurance company which involved rigorous correspondence with my neurology team. I also fill out a patient financial aid application with the drug manufacturer

in hopes of getting any assistance with the cost of my medication. I'm so grateful to my neurology team for all of their assistance in helping me with this rigorous paperwork. All to get the medication I received on the same plan 30 days earlier with a \$50 co-pay.

Now keep in mind that I have to convince these people that I **need** this medicine. So I again went to the experts on my medical team for their help. They provided me with a letter to submit with my appeal to an insurance company and application to a pharmaceutical company. The letter from my doctor, clearly explains that if I were to stop taking this medicine "cold-turkey" I would run risk of status epilepticus and intercranial hemorrhage, which can cause death. As I write this letter to you from Dubuque, Iowa today, I'm in a fight for my life as I race against the clock because I'm almost out of my week supply.

It's at this time thoughts start creeping into my head "maybe I'm not supposed to live, if it's this difficult for me to just stay alive then maybe I'm not supposed to."

Think about it, everyday I take nearly 5,000 mg of medicine and if I don't take the yellow ones I can DIE. It And those are the hardest to get.

And I can tell you there is no fear similar to when you're at the pharmacy, looking at the drug you need and knowing you might not get it, and you only have enough for the evening.

Thankfully, as I've gone along I have encountered great and decent people who have joined my corner because of the weight this burden carries. However, notice how it takes a village, I have been in correspondence with every stakeholder possible, all of them vouching for me and it's still an uphill battle.