

Dear Chairman Lipps, Vice-Chair Holmes, ranking member Boyd and members of the House Health Committee

My name is Robbie Huston, I am from Cincinnati, Ohio and I have the rare disease Acromegaly. I am here as a proponent of House Bill 469, prohibiting certain health insurance cost-sharing practices. These practices also called copay accumulators or copay maximizers are strategies being used by insurance companies to keep copay assistance payments from applying towards an insured's deductible and out of pocket maximums.

I would like to share my story, so you can understand the devastating impact these practices will have on those with chronic illnesses.

In 2019, I was diagnosed with Acromegaly, a hormonal disorder caused by a tumor on the pituitary gland. Basically, a brain tumor that causes your body & your bones to keep growing. Besides being extremely painful, your organs & tissues, grow and swell, causing countless problems, cardiovascular complications being the most dangerous one. It took a long time to be diagnosed. Test after test showed nothing wrong. X-rays, specialists, a surgery and still no reason for my pain. I even had an MRI in 2018, that diagnosed me with a pituitary tumor, but for one reason or another, I was never given this information. It was getting hard for me to do my job, the pain was crippling, I wasn't sleeping and I'd started to faint on a regular basis. Six months after the previous MRI, I was officially diagnosed & three weeks after that I had brain surgery. The doctors were able to remove 95% of the tumor. But, the 5% left meant I would need to be put on medication, most likely for the rest of my life.

A few months after having surgery, I started getting a monthly shot called Somatuline Depot, this is to keep what is left of the tumor from growing back and stop it from producing too much Growth Hormone. Which in turn keeps my heart, organs & tissues from swelling, also it keeps my face, feet, hand & chest bones from growing, which causes debilitating pain. This is a very expensive medication, my dose costs about \$7,500 per shot. When I found out I would need a this expensive medication for the rest of my life, I was shocked & scared, I had no idea how I was going to be able to pay my large deductible upfront or pay the coinsurance that came after. This medication is considered a non-preferred medication. So, on top of reaching the extremely high deductible before my insurance will cover it, there is also a coinsurance applied of 35% even after I hit my deductible.

I was relieved when I found out the drug manufacturer had a copay assist program that would cover my portion up to \$20,000 a year. I would be able to get the medication I needed.

In my naivety, I even felt a little gratified that Big Pharma was going to have to foot some of the bill for their overpriced medications.

Then I received a letter from my insurance company, Cigna, last month, that they will no longer apply the MONEY they receive from the drug manufacturer towards my deductible or towards my out of pocket expense. That I can choose to keep using, what they call "drug manufacturers coupons" to help with the expenses, but it will NOT go towards my deductible or out of pocket maximums. If I choose not use the assistance, I will need to come up with \$6,000 to pay for my dose in January. \$3,500 deductible + 35%. I would hit my out of pocket expenses.

That amount of money is more than 2 months gross pay for me, if we talk net pay, it would be like 4 months of bring home pay and not paying for anything else. Food, housing, utilities. Here is the really scary fact that keeps me awake at night. I will have to use the copay assistance, because I will not be able to come up with \$6,000. That will only get me to April, when my copay assistance will run out of

funds. After my assistance runs out I will no longer be able to get my medication. Once my last dose wears off, the headaches will start, that will be the tumor becoming active again. My extremities will start to swell and this is when the pain kicks into high gear, along with the insomnia, sleep apnea, colon polyps and high blood pressure. Internally, my organs will begin to swell, my heart will become enlarged and cause cardiovascular problems.

Example of untreated Acromegaly:

Acromegaly



20-26

I understand why insurance companies want insureds to use generic less expensive drug options when they are available. But with a rare disease, you don't have many options. I only have ONE option to choose from, a somatostatin inhibitor. There are NO generics of this medication. There aren't any other treatments available. I wish there were more options for me to choose from, getting a shot with an 18 gauge needle every month is not fun. It makes me tired & gain weight.

I also understand that everyone in my company has to hit the deductible, before coverage begins and up until Acromegaly, I made it work. I could make my prescriptions last by cutting doses in half or just skip the absolutely non-life threatening medications altogether. You can also go to a doctor, get an x-ray or go to emergency room without cash up front & then you can make payments. You can't tell a pharmacy hey just bill me for it. "I'll gladly pay you Tuesday for a hamburger today" doesn't work for medication. It's a no pay no play system.

I am not disabled now, I can work, but if I can't get my medication, I will eventually become disabled, in a very slow and painful way. That is if the disease doesn't kill me first.

Sincerely,

Miss Robbie Huston
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