

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

My name is Robbie Huston, I am from Cincinnati, Ohio. I am here as a proponent of House Bill 135, 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 third party assistance payments from applying towards an insured's out of pocket expenses.

I would like to share my story, to help you understand the devastating impact these practices will have on those with rare or chronic illnesses. In 2019, I was diagnosed with the rare disease Acromegaly. A hormonal disorder caused by a tumor on the pituitary gland producing excess growth hormone. This causes deformative osteoarthritis, facial deformity, crippling arthritis, cardiovascular problems, joint & bone disorders. The list goes on and on, those are just a fraction. As an adult when your bones start growing again with no place to go it cause excruciating pain. It takes a long time to be diagnosed, on average, 10-12 years. Most of the damage is already done by then. You can't reverse bone growth. I was 45 when I was finally diagnosed. The large size of the tumor said I'd had this for at least 10 years. I first went to the doctor for the headaches & achy wrists in 2009. In 2017 I had carpal tunnel surgery, it did NOT work. Now my feet & back hurt constantly. I went from a 7.5 shoe size to a size 10. I could no longer wear rings, my fingers had become too big. I had high blood pressure, sleep apnea, insomnia, adult Acne, skin lesions & constant exhaustion. Test after test showed nothing wrong. X-rays, chiropractor, blood test, specialists and still no reason for my pain or problems. It was hard for me to do my job, the pain was crippling. I didn't know what I was going to do. I was afraid I was going to get fired. I knew I would have take a leave of absence, but I couldn't figure out how, since I didn't have a diagnosis. I thought I must be going crazy. I wasn't sleeping. I began fainting regularly. I was at my breaking point when I got lucky & did a search on Google with the right words and it suggested Acromegaly. I asked to have my Growth Hormone level tested. It was off the charts. I was sent for a MRI and was officially diagnosed within a week. Three weeks after that brain surgery. The doctors were able to remove 95% of the tumor. But, the 5% they couldn't get meant I would need to be put on medication, the rest of my life.

I started a monthly shot, Somatuline Depot, this medication keeps the remaining tumor from growing back and controls my Growth Hormone. In turn this keeps my heart, organs & tissues from swelling. It stops the bones in my face, feet, hand & chest from growing and on most days it keeps the worst of the pain at bay. The headaches are significantly decreased. My heart is no longer enlarged. My face has stopped growing & deforming before my eyes. I'm able to work and be a productive member of society because of it.

Its a very expensive medication, my dose costs around \$7,500 per shot. I was shocked when I heard the price. There is not a generic alternative. There is not any less expensive treatment options available. When you have a rare disease, you don't have many options. I couldn't afford the medication. I have a high deductible health plan and this medication is also considered a non-preferred tier 3 medication. So, I would be responsible for 35% coinsurance even after I hit my \$3,500 deductible. I was so relieved when I found out about the copay assistance program. It would cover my out of pocket expenses up to \$20,000 a year. Finally, a break! I already had so many medical bills piled up from the years of procedures and testing.

from the assistance will no longer
 Then i'm back in the same boat again needing
 in April either O when my assistance runs out I will no longer be able to my get my
 medication. The last dose will wear off, the headaches will start, the tumor bec 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 originally wrote this testimony in December, the story is still the same. I just need to update you on whats happened in the past 3 months. I put off getting my last shot of 2020 for 2 weeks, so my January dose could be put off longer. I didnt take my first shot of 2021 until February 28th. I did use the coinsurance assistance. I have break through symptoms, but in my mind its better to get some treatment than going without for the rest of the year. I understand that everyone in my company has to hit the high deductible, before coverage begins and up until Acromegaly, I made that work. I could make my oral 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" that 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. Then i will have to go on public assistance. I'll lose everything .

Sincerely,
 Miss Robbie Huston
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