

My name is Brittany Selby, I reside in Summit County Ohio. Unfortunately, I am unable to join you in person today, but am writing to you as a proponent of House Bill 135 which would serve to restrict health insurance cost-sharing practices such as copay accumulators and copay optimizers.

My son was born in February 2020. Within days of his birth, it became apparent that something was not right - basic newborn tests were causing excessive, unstoppable bleeding. You can only imagine the emotional toll testing and waiting and meeting with teams of doctors had on our newly formed family- particularly during the initial phases of pandemic protocols being implemented. Just over a week after being discharged from labor and delivery, we received the diagnosis that my son had Severe Hemophilia A- meaning he is completely missing the factor 8 protein required to allow his blood to clot. Being completely unaware such a condition existed, this diagnosis was devastating to us. Working with our Hemophilia team at Akron Children's Hospital, we learned that treatments for his condition had come a long way over the years, and the future I was finding in my Google searches was not what my son's future would look like. At about 5 months old he was able to start a prophylactic medication that makes his body 'think' it has the factor 8 he needs to allow his body to form necessary clots to prevent excessive and unstoppable bleeding. I administer his medication weekly through an injection in his thigh- it's certainly not fun, but we comfort him after and tell him this shot is what keeps his body safe (he also gets a Kit Kat). I know in the future, when he can understand he will forgive me for all the pokes. I am thrilled to say that since starting medication, my son has not had any spontaneous bleeding events- saving us what could have been many trips to the emergency room for normal toddler bumps and bruises sustained as he learned to crawl, walk and play.

My son's medication is very expensive, costing over \$12,000 per month (just over \$3000 per shot which we administer 4 times per month) and there is no generic alternative available. I remember hearing this number for the first time and immediately starting to cry. With a high deductible insurance plan, meeting our deductible and out of pocket max was, in truth, not something we had in the plan. I think in my adult life I had only met my insurance deductible once prior to pregnancy! With this news, we knew we were looking at meeting our deductible and out of pocket max for the next 18-26 years, as long as my son remains on our insurance plan. Our social worker told us about patient copay assistance programs offered by third party administrators that would assist our family in offsetting these costs. We submitted our applications and for 2021 we were able to utilize the copy assistance program offered. In late December 2021, I received a letter from a third party representative advising that we would need to sign up through their program to administer any patient copay assistance. We had approximately 7 days to respond, before January 1, 2022. I immediately called to get details- the representative advised that they were notified my son received a medication that was eligible for a patient copay assistance program and that through their relationship with our insurer, the patient copay assistance would be collected directly instead of reimbursed to the patient on an as incurred basis. Since I already had everything set up, my initial inclination was to opt out. The representative advised I could opt out, but if I did the classification of the medication would be changed and I would be switched to co-insurance at a rate of 35% (approximately \$3400/month) and that any payments towards that medication would not be considered in our deductible or out of pocket maximum. \$3500 per month, was certainly not a number we could afford so I went ahead and provided them the necessary information.

As of this writing, our deductible and max out of pocket costs for 2022 have been met and paid, in addition to the \$15000 in patient copay assistance that was collected from the manufacturer in the first

quarter. To provide perspective, according to Heathcaretracker.org, out of pocket cost expenditures (which do not include premium costs) averaged \$1181 in 2020.

I understand that both insurance companies and drug manufacturers are for profit businesses. I also understand the sentiment from opponents that this is a bigger problem and that the cost of health care and medications need to be addressed at the root... but that is not a problem that is going to be solved in the immediate future. In the meantime, allowing use of insurance accumulators and optimizers has shifted the cost burden to patients and caregivers, essentially putting vulnerable people with chronic health conditions that require high cost medications into an impossible choice between their physical well being and their financial one.

Ohio House Bill 135 will direct insurers to apply all forms of payment received to count towards the patient's deductible and out of pocket maximum, regardless of their origin. On behalf of my family, my bleeding disorder community and all Ohioans impacted by the predatory nature of copay accumulators and optimizers, I respectfully request your support in passing HB135.

Thank you for your time and consideration,

Brittany Selby

www.healthsystemtracker.org/chart-collection/u-s-spending-healthcare-changed-time/