

	<p><b>HEALTH COMMITTEE</b></p>
	<p>Witness Form</p>

Today's Date November 28, 2022

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Organization Representing: Parent - Advocate Ohio Bleeding Disorders Council

Testifying on Bill Number: HB135

Testimony:  Verbal  Written  Both Testifying As:

Proponent  Opponent  Interested Party

Are you a Registered Lobbyist?  Yes  No

Special Requests: N/A

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Chairman Huffman, Vice Chair Antani, Ranking Member Antonio and members of the Health Committee, Thank you for the opportunity to provide proponent testimony on House Bill 135. I'm Randi Clites. I wear lots of different hats in the healthcare advocacy space in Ohio, but today I am here to testify in my most important role, a Mom. First I want to very sincerely thank Reps West, Manchester and Chairman Lipps for their leadership on this issue. The work that they have done for the past 3 General Assembly's is way above the call of duty. Before I share my sons story, I am going to wear my hat as one of the lead patient advocates on this issue to address a few of the opponents' arguments against, and talking points, on this issue.

Copay Accumulators started in our state about 7 years ago. I received a call from a fellow mom in Northeast Ohio explaining the letter she received from the Health Insurance Plan stating her copay assistance she was receiving to access her sons clotting factor would no longer count towards her out of pocket maximum. This became the catalyst for me becoming a leading patient voice on this issue in Ohio and across the Country. Since then, this issue has become a huge part of my advocacy work.

You should know that Copay Accumulator Adjuster Programs do not apply to all drugs. The plan designs target certain specialty high-cost drugs. Most of these drugs are in a specialty tier where co-insurance is applied instead of a typical copay. The plan benefit summary we have access to as an enrollee just reads these adjuster programs MAY apply to your prescription drug coverage. It is very difficult for a consumer to figure out if their specialty drug will be impacted until they see the first Explanation of Benefit where it will show the amount collected doesn't count towards their deductible. If the patient isn't savvy enough to catch it, they will in a few months when they realize the increased out of pocket costs.

These programs DO NOT target drugs with a typical coupon in a way many of you would think of. The programs target drugs with third party patient assistance programs. **AGAIN, THIS IS NOT ABOUT A COUPON THAT WILL EXPIRE WITHIN A CERTAIN TIMEFRAME.** Patient assistance programs have an application process and only expire when your approved assistance amount is exhausted. It can even be as high as \$15,000 worth of assistance; which will cover the federal max out of pocket limit. That collected amount by a specialty pharmacy is 100% of the amount owed to meet the deductible and coinsurance. For bleeding disorders patients accessing clotting factor, that is always our annual max out-of-pocket, which for this year is \$8,700. This happens year after year.

Lastly, 99.6% of all medications that are eligible for patient assistance do not have generic equivalents. Again, most targeted prescription drugs that apply a copay accumulator are expensive specialty drugs that have very high out of pocket costs treating our most vulnerable patient populations.

Now to share how this issue has impacted my family directly. My son is now 20 years old. He was born with severe hemophilia. Although hemophilia is usually an inherited bleeding disorder, we had no family history. The average cost for treatment for hemophilia is easily \$400,000 per year.

Before coming to serve in the Ohio House in 2019, my family consisted of two the 1,554,113 Ohioans depending on the individual marketplace for our health insurance coverage. We found ourselves in this space when my husband's small group employer could no longer endure the burden of our son's high medical costs. With under 10 employees there was no way to spread that cost to make it affordable for his business, so he stopped providing his employees with family coverage. So, I did my homework since I had been educated on the plans available in Ohio and picked the one plan that did not use the copay accumulator in the plan design in the Marketplace. There were two plans that covered Akron Children's and the doctors that I needed. SummaCare was the cheaper option and had no copay accumulator in the plan design. The cost of his medicine did fall under our medical benefits, so to fill his first prescription we had to pay \$7,900 out of pocket to meet our deductible and co-insurance. That is when we had to start to depend on copay assistance. Before this we had been on the CMH program because before then our out of pocket costs were about \$3,000 a year. CMH gave us much needed assistance every other year, to meet that out of pocket maximum. THAT we could afford; but we could not afford the \$950 a month premium and the \$7,900 cost to access his clotting factor. We have met our max out of pocket for 20 years straight.

There is no generic drug available to treat his condition and costs between products are very comparable. When he was born, we were told he would likely be the first generation of severe bleeders to live a normal life span without extended hospital stays or major joint damage needing replacement before his 50's. We have managed to keep him privately insured his whole life and although we've had medical debt most of his life, we never had any major financial issues because of access to patient assistance and Ohio's Title V Program - CMH. He is exactly what we had hoped physically to achieve. He has had access to treatment his entire life. He is living his best young adult life working at a dealership working with cars as he has dreamt about since he was 3 years old.

However, his success hasn't come burden or stress free. I started a new insurance plan on March 1, 2021. I was reading through my benefit summary and I found that my new plan has an updated take on the co-pay accumulator, which is now called a maximizer or optimizer. Collecting more than what is limited by the ACA for Essential Health Benefits - which prescription drugs are typically found - is a loophole that many self-insured plans have implemented, which HB135 will not be able to impact. However, the programs are similar enough to share as a family impacted by copay assistance not counting towards the deductible or out of pocket maximum to show what will happen to their access to their entire healthcare journey.

For the first time in my sons' life, any assistance we received in 2021 to pay our co-pays or co-insurance would not count towards our out-of-pocket costs. When I testified in the House Health Committee in March of last year, we were just guessing on what our copay assistance would be paying, so I encourage to pull up my testimony from that hearing to read what I expected might happen. Now I'm here to share what exactly happened to my son.

At 20 years old, earning just under \$30,000, and after three months of the specialty pharmacy collecting copay assistance he received a bill for \$21,880 for his medication; which broke down to \$15,530.85 for the first month supplies and then \$6,350 for the second month. While the opponents may tell you that this program will not impact families, his medication delivery was delayed after this invoice was mailed to him. I put in multiple hours of calling the plan, specialty pharmacy and patient assistance to track down why he was charged this amount and why his shipment was being held. I was assured it was just a billing error. He should not have received that bill and it should not have impacted his monthly delivery of his life sustaining medicine. BUT IT DID. It was the first time in 19 years we ran out of his medicine. When I called to tell the specialty pharmacy if he did not get his shipment of medication within 48 hours he would need to go to the ER for treatment, it was delivered and we were assured once again the invoice was a billing error. That was August 2021. We have still not received a zero-balance bill. He worried for months this would negatively impact his credit and ability to ever qualify for a car or home loan.

In November of 2021, I received a phone call from the patient assistance program that his patient assistance had been exhausted. I asked if they would be able to share with me the amount that the specialty pharmacy had collected on our behalf and they were not able to provide that amount. Just that his benefits were maxed out. I called the specialty pharmacy to see if he would receive an invoice again for \$6,350 a month, but I was assured he would not. He has not received another invoice.

After our explanation of benefits showed the patient assistance program was billed \$6,350 monthly throughout 2021, our January of 2022 statement showed our balance due was \$16,949.53 with a note that "copay assistance was paid." In February of 2022, those same numbers were showed as our balance due by patient assistance. However, in March of 2022 that amount was no longer showing and there was zero balance due. My plan summary document clearly states my annual drug out of pocket limit is \$5,900, except for specialty drugs which is the max of any available manufacturer-funded copay assistance....which we are forced to sign up for through a third party vendor or we must pay that \$6,350 a month to access my sons medicine.

My son had a medical emergency in September of 2022. He is still receiving medical bills that he is worried he will not be able to pay. I wish I had the exact numbers to share but it is still being processed. At this point, I know it is more than \$2,000. I can't describe in words the amount of stress and helplessness I feel as his mom knowing that his assistance was maxed out at about \$15,000 yet he still needs to come up with a couple thousand dollars of his own money every year to access the care he needs. We should be able to do better for hardworking Ohioans.

Mr. Chairman and Committee Members, I realize the drug supply chain costs are rapidly rising. I understand employers are struggling to pay increasing premiums. But patients are struggling too. This program is predatory. Patients have no influence on the drug supply chain or benefit designs, yet we are being put in the middle. The amounts that are being charged to us just so patient assistance can be exhausted is putting a huge amount of financial stress on our already medically fragile families.

I beg you to get clarification from the plans and the specialty pharmacies, please ask;

What drugs they are targeting with copay accumulator programs?

What is the average amount that they are collecting from patient assistance programs?

How much do those patients targeted by the copay accumulators then must pay out of pocket for their other healthcare services?

Is this delaying care in other aspects of the patients' healthcare? And what impact is that having?

Have copay accumulators yielded them cost saving on premiums?

Do they have data showing this is having a positive impact in drug utilization?

I respectfully ask for your support in passing this much-needed consumer protection. Please join the 15 other states in protecting consumers from this practice. Ohioans need the playing field leveled by not allowing this discriminatory practice to continue. Mr. Chairman I'd be happy to answer any questions.