Chairman Lipps, Vice Chair Holmes, Ranking Member Russo and members of the Health Committee,

Thank you for the opportunity to provide proponent testimony on House Bill 135. First, to my past colleagues I miss you but man am I glad to be back in my old role as a parent and patient advocate. To the new members, I'm Randi Clites. I wear lots of different hats in the healthcare advocacy space, but today I am here as both a mom and policy director for the Ohio Bleeding Disorders Council.

First let me start with my patient advocate hat on. About five years ago, I got a frantic call from a fellow mother who had received a letter from United Healthcare telling her that her son's co-pay assistance could no longer count towards her deductible or maximum out of pocket amount. She was stunned and terrified, to say the least. I started making national calls to see if this was happening in other states. It seemed we were one of the first states to start the practice of co-pay accumulators. Very quickly, the trend started to grow around the country; but not all patients understood what was happening. Some got letters that were very direct while others didn't know until they got a huge bill. This seemed to be very discriminatory against those of us using specialty pharmacies. Patients were being put in the middle of the battles between pharmaceutical companies, insurance plans, and pharmacy benefit managers. Patient and family lives, both physically and financially, were being negatively impacted. I was especially fearful for what was going to happen to the treatment protocols that had allowed the new generation of bleeding disorders patients to thrive; they are the first generation to have access to safe treatment for their entire lifetime.

Let me explain what I started to see on a regular basis over the next few years as more plans started to include this program to their benefit designs. Accumulator rules changed to include organizations and individuals, so that patients were not able to get reprieve from the high costs even by turning to churches or family members. Although, this started with self-funded plans, commercial plans started to include it in their benefit designs.

We as parents and caregivers had to become fluent on benefit plan designs, explanation of benefits, provider bills, and claims appeals. Specialty Pharmacy Coverage moves from medical coverage to pharmacy benefits. And Back. Coverage tiers change. Increasing deductibles for both pharmacy and medical benefits started to be a regular plan design change. According to the Kaiser Family Foundation, the typical spend for out-of-pocket costs (this doesn't include premiums) is $800 per year. Patients with a bleeding disorder, or any high-cost medical need, is reaching the max out of pocket each year, usually within the first quarter. For 2021, the ACA capped this limit at $8,550. Think about this. We have heard multiple times during the pandemic households struggle to come up with $400 for an emergency expense. Families like mine have to come up with thousands of dollars just for out of pocket costs year after year. It is not sustainable. That is why we are forced to depend on assistance from programs. In 2021, nine out of ten health insurers in Ohio now have some form of co-pay accumulator program that prevented copay assistance from counting towards deductibles and out-of-pocket costs.

Now let me put on my mom hat. My son Colton is now 19. 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 a year. There is no generic for his treatment and costs between similar products are comparable. We have managed to keep Colton privately insured his whole life and although we've had medical debt most of his life, we never had any major financial issues. But his condition has impacted just about every part of our life, I had planned to be a stay-at-home Mom to 3 children when my husband and I got married two years after high school. We saved and purchased land to build before we had Colton at 27 years old. However, because of all his medical issues in his first three years of life our savings was gone. We would have never made it without assistance programs over the years. We have used Ohio's Title V program to meet our out-of-pocket costs, our community held fundraisers for us, our church provided us assistance, and we've depended on drug manufacturer co-pay assistance programs. I never thought that we wouldn't be able to provide for our child on our own.

I started a new insurance plan on March 1. I was reading through my certificate / benefit book. Not sure how many of you have done this, but if you have not, I challenge you to do so. I found that my new plan has a new take on the co-pay accumulator, which is called a maximizer. Ohio leading the way again. For the first time, any assistance we receive to pay our co-pays will not count towards our out-of-pocket costs. While everyone else working for my employer is paying $75 a month for a specialty drug, my sons specialty pharmacy can apply to get the co-pay assistance maximum from his drug manufacturer of $12,000 ($1,000 a month) and none of that amount goes towards my deductible or max out of pocket. Therefore, while the plan was designed to have a max out of pocket of $5,900 for each enrollee, they will get $12,000 from the drug manufacturer and if we use another drug in that class possibly another $5,900 from our personal funds.

Below is the language in my plan.

SPECIALTY DRUG PHARMACY BENEFIT - UP TO A 30 DAY SUPPLY

TYPE OF SERVICE	For Covered Services received from a CONTRACTING Specialty Drug Pharmacy, you pay the following portion, based on the Allowed Amount
Generic Prescription Drugs	$75 Copayment, or the maximum of any available manufacturer-funded Copay assistance (2)
Brand Name Prescription Drugs for which a Generic Prescription Drug is not available or manufactured	$75 Copayment, or the maximum of any available manufacturer-funded Copay assistance (2)

Coverage is provided for Contracting Home Delivery Pharmacies only. Services received from any Non-Contracting Home Delivery Pharmacy are excluded.

Prescription Drug Notes

1. Over-the-counter supplies/drugs require a Prescription Drug Order.
2.

This Plan includes a Specialty Prescription Drug Copay offset program ("Program"). By participating in the Program, the Covered Person's Prescription Drug Copays for Specialty Prescription Drugs may be set to the maximum of the current Plan design, or to the amount of any available manufacturer-funded Copay assistance, but the drug manufacturer will absorb most, or all, of this amount. As with other patient assistance programs, any financial assistance the Covered Person receives toward his or her cost of the drug does not apply toward the Covered Person's Out-of-pocket Maximum. **If the Covered Person chooses not to participate in the Program, he or she will be responsible for paying a significantly higher Prescription Drug Copay for that particular drug.**

Please contact Customer Care to find out what Specialty Prescription Drugs are part of this Program. The list is also available on 'My Health Plan,' Medical Mutual's secure member website.

Let me finish with my advocacy hat back on and quickly explain how a traditional co-pay accumulator could triple or quadruple dip on out-of-pocket costs. Let me use an example where the monthly cost of medicine is $30,000. Co-pay is a fixed amount usually between $75 - $250, but then there may also be a co-insurance amount to reach until the max out of pocket is met. In this example, let's say it's $2,500.

So, to get January's medication delivered to the patient, the Co-Pay Assistance program from the drug manufacturer pays the PBM $2,500 (the max of the co-insurance because 10% of $30,000 is $3,000, but max is $2,500.) Same thing happens again in February, because the assistance program has a max of $10k they have now collected ($5,000) half. March and April same thing happens; until they reach the max of the assistance program of $10k. Then in May the patient now must pay $2,500 to get the medicine. Huge surprise if they didn't read their benefit book or understand it when they read it. The plan was designed to only collect $2,500 and has now collected $12,500 before taking on the full cost of the drug. This is five times the amount they would if the patient paid cash in January.

Month	Cost	Co-Ins	Assistance	Patient	Insurance	Accumulation
Jan	$ 30,000	$ 2,500	$ 2,500	$ -	$ 27,500	Set to 0
Feb	$ 30,000	$ 2,500	$ 2,500	$ -	$ 27,500	Set to 0
Mar	$ 30,000	$ 2,500	$ 2,500	$ -	$ 27,500	Set to 0
Apr	$ 30,000	$ 2,500	$ 2,500	$ -	$ 27,500	Set to 0
May	$ 30,000	$ 2,500		$ 2,500	$ 27,500	$ 2,500
Jun	$ 30,000			$ -	$ 30,000	$ 2,500
Jul	$ 30,000			$ -	$ 30,000	$ 2,500
Aug	$ 30,000			$ -	$ 30,000	$ 2,500
Sep	$ 30,000			$ -	$ 30,000	$ 2,500
Oct	$ 30,000			$ -	$ 30,000	$ 2,500
Nov	$ 30,000			$ -	$ 30,000	$ 2,500
Dec	$ 30,000			$ -	$ 30,000	$ 2,500
		$12,500	$10,000	$2,500		

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