

Chairman Lipps, Vice Chair Stewart, Ranking Member Liston and Members of the Public Health Policy Committee. Thank you for the opportunity to provide testimony on HB177.

I am Randi Clites. I wear a lot of different hats in the rare disease community, so my testimony today is based off my direct experience as a mom, caregiver, patient advocate from my 20 years as a mentor and friend to families that have a bleeding disorder, and a member of a few coalitions dealing with different types of copay diversion programs in my professional capacity. My full-time employment is with Little Hercules Foundation where I spend most of my time addressing federal legislation impacting the rare disease community and advising rare disease patient advocates on how to engage on state level policy issues. I still work on a part time consulting basis for the bleeding disorders community 5-10 hours a week managing a statewide dental program and serving as a statewide policy director for a coalition of providers and patient organizations. Both Little Hercules Foundation and Ohio Bleeding Disorders Council have weighed in on this bill with written testimony from the CEO of Little Hercules and Chair of the Ohio Bleeding Disorders Council.

I am here today to share how a patient family is impacted by a copay accumulator program and address some of the concerns the committee had during the last hearing. First, it is extremely important to understand that a copay accumulator program DOES NOT impact all drugs in the retail market and rarely does it impact a drug that has a cheaper alternative for the patient. It is not about coupon use driving a patient to a higher cost treatment option. And lastly, I will explain how these programs do not change consumer behavior in the way the opponents want you to believe that they do. They are hurting the most vulnerable patient populations in Ohio. Ohio has been utilizing these cost diversion programs since 2017-18 and healthcare and premiums costs do not show a benefit for the use of these programs in our state, but vulnerable patients are being negatively impacted.

In 2017, I got a call from a family I had been mentoring that they had received a letter from their employer stating that the next plan year their health benefits would no longer count any assistance they received towards their out-of-pocket costs. This was the first experience I had with helping a family understand their plan summary or benefit design. Let me explain why this was financially devastating for a family like ours. Most people know their deductible amount on their health plan, but do you know what your maximum out of pocket amount is? Have you ever reached that amount? If so, ever more than once or twice? For families like ours, we meet that amount year after year.

While the accusation made in the last hearing that patients would use more healthcare services after their deductible was met by assistance programs because we depended on the copay assistance to pay that amount, that is not the case for me or families like mine that use a lot of healthcare. The last thing our families need is more tests, appointments, surgeries, or treatments. Remember copay accumulator programs do not impact the typical coupon use prescription drug; they target specialty drugs used by the most chronically ill patients. They are only going to access the healthcare they need to stay as healthy as they possibly can.

My son's medicine is considered a specialty drug. We have to get it delivered to our home once a month from a Specialty Pharmacy; that Specialty Pharmacy is a required pharmacy from our plan. Unlike what the opponents had said, most patients targeted by a copay accumulator have no choice outside of the accumulator program or using the preferred specialty pharmacy. Before the ACA, drugs to treat hemophilia were generally accessed under the Medical Benefit. So we would have to meet the deductible in the first month of the year to get the medicine delivered. That amount ranged from \$500 -

\$2,500 (with max out of pocket from \$5,000 - \$8,750 from 2003-2019). Then the next month we would owe that same amount, until our max out-of-pocket was reached. That is why you will hear patients reference double dipping, while others in the same plan only pay their deductible one time, patients impacted by a copay accumulator could face a deductible being collected by them or on their behalf multiple times.

After the ACA, the rare disease community saw a shift in how expensive drugs were classified as Specialty Drugs. I was seeing plan designs that kept Specialty Drugs in the medical benefit and some switching them to prescription drug coverage. Most families preferred the prescription drug coverage, because the copay amount was a monthly amount that they could depend on paying that same amount monthly. And then a couple years later, the copays for specialty drugs began to be based off the price of the drug, which made it unaffordable for most patients. The amount most of us saw for specialty drugs in our plans was 30-50% of the cost of the drug, so we met our max out-of-pocket within the first quarter of the year. That is when almost all patients needed some type of assistance. Some got assistance from the specialty pharmacy directly, some from the State's Title V program, and some from the drug manufacturer copay assistance programs. It is extremely important that you understand these programs target drugs that have no cheaper alternative. The copays we are facing are hundreds to thousands of dollars a month. We fear the copay accumulator programs will eventually drive-up drug costs in specialty drugs. Because of the evolution of these programs, we are already seeing copay assistance programs go away. When patients know to look for a copay accumulator program in their benefit summary it is usually hidden in one or two sentences in a huge document. These programs have made it extremely difficult for consumers to track their out-of-pocket costs and plan for additional medical costs.

Per the 2023 Health Policy Institute of Ohio (HPIO) Health Value Dashboard, Ohio is ranked 40th in healthcare spending and 43rd in population health.¹ I hope you agree if copay accumulators were helping Ohio drive consumer behavior to cheaper alternatives, we would have better outcomes and lower health spending. Copay Accumulator Programs target very specific drugs that have copay assistance for the patient to access the drug that treats their condition, most of the time it is the only drug that treats their condition. Ohio has a D ranking from The AIDS Institute study on copay accumulator programs around the country. For the 2023 Marketplace Plans, 8 out of 11 plans have a copay accumulator program.²

In regard to the claim that banning copay accumulators will impact the premiums in Ohio, there are two studies that contradict that. The AIDS Institute in May of 2023 published a comparison of Marketplace average benchmark premiums between states with (at the time there were 16 states that had banned CAAPs between 2019 and 2022,) and without copay accumulator adjustment bans. It found no evidence that enacting a copay accumulator ban has a meaningful impact on average premiums.³ In June of 2022 (updated in June of 23,) an interactive tool was released on the Global Healthy Living Foundation website that compared all 19 states that have passed laws to ban copay accumulators. The finding is that "passing laws that protect patient assistance by banning accumulators and maximizers still has not led to increased insurance costs."⁴

I'll conclude by sharing, my son's condition is a rare condition that actually has 11 treatment options on the market. Most rare conditions do not have a treatment option but those that do only have one or two treatments. When a plan implements a copay accumulator program, ALL 11 HEMOPHILIA DRUGS

ARE TARGETED BY A COPAY ACCUMULATOR. Also, in the HPIO Dashboard it ranks Ohio 47th in total out-of-pocket spending because on average we pay \$799.68 out-of-pocket, but because of these programs our families in the rare and chronic condition space are paying more than that year after year for their entire lifespan. When they are fortunate enough to get assistance, it can bring their total out-of-pocket spend closer to that yearly average. We should be doing better in Ohio to protect our workforce and small employer groups. It is up to the employers and consumers to push back on these discriminatory programs that do nothing but drive up the out-of-pocket costs for our most vulnerable patients. I'd be happy to answer any questions you have.

¹ [Facts & Figures: Health Value Dashboard - Health Policy Institute of Ohio \(healthpolicyohio.org\)](#)

² [The AIDS Institute](#)

³ <https://aidsinstitute.net/documents/Copay-Assistance-Does-Not-Increase-Premiums-Final.pdf>

⁴ https://ghlf.org/copay-assistance-protection/#1658713434132_8026b016-ce47

Value factors

- 43 Population health
- 40 Healthcare spending

Health value rank

44



Source: Health Policy Institute of Ohio, 2023 Health Value Dashboard

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