

Dear Honorable Committee Chair and Committee Members,

Good afternoon. I am Megan Waranch, and I reside in Owings Mills, MD, just outside of Baltimore, with my husband and two children. My youngest child, Cassius, was diagnosed with severe hemophilia at the tender age of 20 months. Today, I stand before you as an advocate for the hemophilia community, voicing my support for SB 595 – Out of Pocket Maximums and Cost-Sharing Requirements – Calculation.

Hemophilia is a rare genetic bleeding disorder that can cause internal and joint bleeding, sometimes due to trauma, but often from everyday activities. We have no family history of hemophilia, so Cassius's diagnosis of a lifelong, severe chronic condition was both surprising and traumatic. I recall being pregnant with Cassius and expressing to my mother that "something just didn't feel right". Today, I sit before you with a similar feeling regarding our current situation.

Fortunately, advancements in treatment have enabled Cassius to lead a somewhat normal life. While there is no cure for hemophilia, medications now exist that can prevent or stop bleeding. Following Cassius's diagnosis, his hematologists recommended a treatment called Emicuzimab, also known as Hemlibra in the marketplace. Hemlibra, a prescription medicine administered as a subcutaneous shot, is used for routine prophylaxis. It helps to prevent or reduce the frequency of bleeding episodes in those living with hemophilia A. However, Cassius also requires a backup prophylaxis, a treatment containing clotting factor that would prevent ongoing bleeds should he experience a bleed on Hemlibra. The annual costs for his treatments are around \$x, excluding any ER or hospital visits.

There are no generic or low-cost options for hemophilia treatment. Copay assistance has been our only means of affording these life-saving treatments for Cassius, which have protected him from joint damage and other complications. Since his diagnosis, I have become well-versed in the intricacies of insurance. I had to be, as insurance companies make it extremely difficult to understand what treatments are covered and whether your insurance plan has a copay accumulator. In fact, when Cassius was diagnosed, I was employed by CareFirst BlueCross BlueShield. I assumed we would be in the best of hands, but I quickly discovered that even benefits specialists working at insurance companies often lack knowledge of the coverage details for people with hemophilia, including the issue of copay accumulators.

When I left CareFirst and joined my new employer in the summer of 2022, I encountered the same experience. I asked questions about coverage for Hemlibra and backup prophylaxis to ensure they would be covered. I was assured by the corporate benefits team that the insurance accepted copay assistance and that Cassius's medications were fully covered. Due to the high costs of Cassius's treatment regimen, both our deductible and out-of-pocket maximum are reached during his first prescription fill of the year.

Regrettably, on February 1, 2024, we were notified by our specialty pharmacy, CVS Specialty Pharmacy, where we receive Cassius's monthly Hemlibra shipment, that we had a balance on

our account. After numerous exhausting conversations with our specialty pharmacy, our PBM, and our insurance carrier, we learned the insurance company, United Healthcare, had implemented an accumulator adjustment policy and accepted the assistance money, but did not apply it to our deductible and out-of-pocket maximum. We were advised we would be required to pay the entire deductible and out-of-pocket maximum before the next shipment could be released. There was no option for making payments. In this matter, our health plan now receives twice or more, the maximum out of pocket written for the policy, once by the assistance program, and once by me, the patient's mother.

Another analogy would be if a student received a college tuition scholarship from our organization, and the college accepted the scholarship but billed the student in full, stating they still owed the full amount because they did not pay it themselves. This would be hard to understand how the university could do that.

Please understand how frustrating it is when treatments are available, yet unattainable. Treatments are only as effective as they are accessible. I am deeply concerned about our current situation and how we will afford our deductible of \$6,000 and our out-of-pocket max of an additional \$9,000.

I was never notified by my employer or insurance company of a change to our plan regarding how copay assistance is managed and applied. We had no time to plan how we would come up with or save the \$15,000 or any additional ongoing costs related to Cassius's medications. It is also extremely troubling to know that our copay assistance is being held by our insurance company without being applied to our costs. Even more troubling is how our PBM and United Health Care are able to "double dip" by accepting copay assistance of \$15,000 and then billing me an additional \$15,000 on top of what they have accepted.

My husband and I both work, and we are faced with a current financial situation that we are unable to afford, while the insurance company has only increased their profit by an extra \$15,000. This is a significant amount of money to us, while it is a drop in the bucket for insurance companies.

You may have heard that premiums will go up if this practice is banned in Maryland. Several recent studies have been conducted that indicate little impact on insurance costs and show that allowing copay assistance to count towards a patient's deductible does not increase premiums, but in many cases, it lowers the costs as patients remain compliant and prevent disease progression and other complications. Without assistance, patients have no choice but to go to the ER for their treatment care which is expensive for our health care system.

Ensuring all copays count is about fair business practices. SB 595 will address these unfair practices, protecting patients by ensuring any payments made on their behalf count towards their out-of-pocket costs. I ask you to be a hero to my son, your constituents, and the rare and chronic disease community of Maryland. Nineteen other states, the territory of Puerto Rico, and the District of Columbia have passed similar legislation including our neighboring states,

Tennessee, Kentucky, Georgia, North Carolina, West Virginia, and Virginia. Please support SB 595 and pass it out of committee today!

Thank you.

Sincerely,  
Megan Waranch