

MARYLAND LEGISLATION

February 28, 29 2024

Good afternoon, my name is Melissa Hurtt, and I am here today on behalf of the Bleeding Disorders community. My son, Jay, was born with severe hemophilia 29 years ago and I too, have moderate hemophilia. We live in Lothian; MD and I appreciate the opportunity to witness to you today on the urgency and impact of

- Maryland Senate Bill SB595 – I would especially like to thank Senator Hershey for your sponsorship of this bill.
 - Finance Committee
- House Bill HB 879 - I would especially like to thank Delegates S. Johnson and A. Johnson for your sponsorship of this bill.
 - Health & Government Operations

I AM HERE TODAY TO ASK YOU TO VOTE “YES” TO THESE POLICIES AND HERE’S WHY....

Hemophilia is a rare genetic disorder where the patient is missing a critical clotting protein necessary in the clotting cascade. Bleeding episodes can occur spontaneously in the brain and other organs, joints and muscles and are excruciatingly painful and can be life-threatening and at the minimum crippling and disabling. Bleeding episodes are managed by intravenous infusions of clotting factor replacement. The medication is extremely expensive and no “generics” are available.

In 2019, I suffered a spontaneous knee bleed that required 90 days of IV infusions totaling more than \$225,000, 6 months of physical therapy and I was on disability for more than 9 months. Unfortunately, I still walk with a limp at times.

As a result, of managing my and my son’s hemophilia; I am pretty savvy about health insurance and specifically shop to ensure manageable deductibles, affordable maximum out of pocket expenses and look for “co-pays” for our medication vs. “co-insurance” because clotting factor is so expensive. I also review formularies to ensure our products are available.

This past November, I retired and shopped “The Maryland Health Connection.” I worked with a broker, explained my unique needs and we found a manageable, affordable plan. We rely on co-pay assistance from the manufacturer to offset our out-of-pocket expenses, so I was quite shocked to learn last week, that the insurance carrier I selected on the Maryland Exchange will soon be coming after my co-pay assistance pocketing the \$10K provided by the manufacturer for my benefit. I read my 195-page policy and nowhere is this information disclosed. So, I would say that my insurer has done quite the “bait and switch” an unfair business practice in and of itself. The Maryland Health Exchange is a state program, and consumer needs to be protected.

My story is benign compared to my son’s story....

By the time Jay was 18 years old – he had received more than 4000 intravenous infusions in his elbows or antecubital veins and hands. Repeated sticking of these veins leaves a mark or “track mark” ... The cost of the *medication alone* by the tender age of 18 was more than \$16million dollars.... I never really thought much of his track marks because they represented successful infusions of a lifesaving medication to stop bleeding episodes. What I did not consider is how a stranger or future employer might see those track marks. Jay had gone for an interview to be a lifeguard and so wore lifeguard attire including a short-sleeved t-shirt. When Jay got home from the interview, I asked how it went? He said great – the guy loved me, but then I put my hands on the table, and I saw him look at my hands and arms and the interview just ended, and I think he thought I was a drug addict?”

Hemophilia stole his innocence and a normal childhood and now insurance companies are stealing money given for his care and life-saving medication. 3rd party co-pay assistance was meant for Jay’s care and NOT INTENDED for the profits of insurance companies...

Ladies and gentlemen – you alone TODAY have within your ability to course correct this unfair business practice and I am asking you to vote YES on this policy for 3 reasons:

1. This is a consumer protection bill, and it is in the best interest of Maryland residents/constituents to have affordable access to life-saving medications...
 - a. Healthy hemophiliacs are a lot less expensive than disabled ones.
 - b. The healthcare system is already overloaded why add to it by making life-saving medications unaffordable.
 - c. Disabled citizens become unemployed citizens increasing further the burdens on unemployment and Medicaid...
2. 19 Other states to date plus DC and PR are ahead of Maryland in recognizing the need to ban co-pay accumulators.
3. This is a Bi-partisan policy and in the states where the bans have been passed; the bills have passed unanimously.

Thank you for your time and attention and I look forward to seeing the outcome of our efforts today.