

Chair Delores G. Kelley  
Senate Finance Committee  
Miller Senate Office Building, 3 East Wing 11 Bladen St.,  
Annapolis, MD 21401

**RE: Support for SB 290**

Dear Chair Kelley and Finance Committee Members,

My name is Carrie Koenig. I live in Odenton with my two children, including my oldest, Nicholas, who was diagnosed with hemophilia when he was 2 days old. I am also an employee of the Hemophilia Federation of America, but today I am writing to you in my personal capacity in support of support of SB 290 – Out-of-Pocket Maximums and Cost-Sharing Requirements – Calculation.

Hemophilia is a rare genetic bleeding disorder. Without treatment, people with hemophilia bleed internally and into joint areas, sometimes due to trauma, but other times simply as a result of everyday activities. Because my father has hemophilia, I've always known I'm a carrier. While I was familiar with the disease, hearing that your own child has been diagnosed with a life-long, very serious chronic condition is not something that is taken easily. It didn't help that 2 days postpartum, you aren't exactly hormonally sound.

When Nicholas was an itty-bitty baby, he was prescribed what is called an "on demand" treatment plan, as he wasn't mobile. He would receive clotting factor, through IV infusions, before receiving immunizations and if he had an injury or bleeding episode. Any mother would feel helpless watching their 8-week-old child cry out while their physician attempted to access a vein in their scalp.

I knew that despite this diagnosis, Nicholas would be able to live a somewhat normal life thanks to treatment advancements. There's no cure for hemophilia, but there are now medications that can stop or prevent bleeding. When my father was a child, he had no treatment options available and was told he would not live past the age of 20. He was one of the lucky ones, he lived, but not without complications. Due to lack of treatment early on, he has two artificial knees and his ankles have self-fused together.

When Nicholas was 11 months old he had his first true bleed. He was at daycare and was crawling when he was injured. We ended up in the ER for infusions and imaging. Nicholas's first true bleed was heart wrenching to watch. Bleeds are excruciatingly painful and come with long term consequences emotionally; however, the financial costs were also great. As an infant, Nicholas' infusions ran about \$2500-\$5000 per dose.

After that, we knew it was time to start prophylaxis – a regimen of regular, ongoing infusions with clotting factor, intended to prevent and not merely treat bleeding. It is critically important to prevent bleeds while children are still young, as not doing so can lead to irreversible lifelong damage including the inability to walk as an adult.

Nicholas began prophylaxis at 15 months old, the first of many regular doses he would need for the rest of his life. There are no generic treatments for hemophilia, and no low cost options. The total cost for Nicholas' treatment is about \$300,000 per year. Copay assistance is truly the only way we are able afford this life-saving treatment that has protected Nicholas from joint damage and other complications. Due to the cost and complexity of the treatment regimen, selecting insurance is a balancing act for our

family. We have to make sure everything will be covered and that the premiums and out-of-pocket costs add up to something we can afford. Currently, we have a gold plan that we bought through the state exchange. Every year, we hit our deductible with our first prescription fill. Without copay assistance, our family could not afford our share of that cost despite the fact that both I and my husband work.

I worry about what would happen to Nicholas and our family if our plan were to begin a copay accumulator adjustment program, where the copay assistance was excluded from our deductible and out-of-pocket maximum. In other states, I know people with hemophilia whose plans have these restrictions. Some have lost their financial independence and because they can no longer afford their regular treatment; others have ended up in the ER for treatment of acute bleeding. This is bad for their health, bad for their ability to maintain employment or schooling, and expensive for the health system as a whole.

Without copay assistance, Nicholas's health and my family's financial security would be at great risk. Not being able to afford his prophylactic treatment would likely push us out of home treatment to being treated in the ER on a regular basis. That would force us into incredible, irreversible debt. I respectfully ask for your support of SB 290 so that my family and others like us can continue accessing life-saving treatment without jeopardizing our well-being and our financial stability.

Thank you,

A handwritten signature in cursive script that reads "Carrie M. Koenig".

Carrie Koenig  
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