

**Ziva Mann**  
**28 Manemet Rd**  
**Newton, MA**  
[ziva.mann@gmail.com](mailto:ziva.mann@gmail.com)  
**617 905-5905**

To the Members of the Health Policy Commission,

On behalf of the Massachusetts bleeding disorder community and New England Bleeding Disorder Advocacy Coalition (NEBDAC), and for myself and my family, I want to thank you for the opportunity to share our perspective on the importance of co-pay assistance.

My name is Ziva Mann, and I live in Newton with my husband and two boys, aged 13 and 17. My 17 year old, Shai, has severe hemophilia A. And, as I learned after he was born, I have mild hemophilia A.

Hemophilia A is a genetic condition, and there is no cure. Shai was born with it, and he's severe - which means that his body is missing a protein in his blood so he doesn't clot normally. This means that he is at risk for spontaneous bleeding into his muscles, joints -and most terrifyingly, his head. This internal bleeding can lead to long term damage, disability and even death. In MA, there are 750 people like Shai - and 67,000 living with other kinds of bleeding disorders.

Before the clotting medication to treat hemophilia, called "factor" was invented in the 1960's, kids like Shai didn't live past age 11. Today, Shai has clotting medication that works for him and we expect him to have a normal lifespan. Every other day, Shai gets up, showers, brushes his teeth, eats breakfast, and gives himself an intravenous infusion of about 2000 units of clotting meds. Thanks to his factor, Shai played varsity soccer, was the lead in his high school plays, and is currently sweating his way through his AP tests and finals. If he skips a dose of factor, he pays for it, usually with painful internal bleeding.

But Shai's medication and all factor medication is very expensive. The average cost for an adult with severe hemophilia is \$350,000 per year. Shai's regular every other day dose costs approximately \$2,000, which adds up to about \$365,000 per year in medication alone.

Copay assistance allows families like mine to cover the high out-of-pocket costs associated with factor. Because of the high cost, many in our community will hit our out-of-pocket max on our insurance in our first shipment of factor. Without co-pay assistance, lots of families end up paying their entire out of pocket costs in January. For our family, that would be \$8,000. It's a lot of money.

This past January, I was grateful that I had co-pay assistance to cover the costs of Shai's factor, and my younger son's generic EpiPens (\$371). I did not have co-pay assistance to help cover the costs of the medication to treat my mild hemophilia and had to make a painful choice not to fill the prescription. We just didn't have an extra \$717.81 to spend on my medication, so as a person

with mild hemophilia, I rolled the dice. So far, I've gotten away with it. But please don't tell my hematologist.

In our community, our clotting factors are all name brand biological products - there are no generics, and people respond differently to different brands. This is why we work with our doctors, to understand how Shai's body responds to his clotting meds, how fast he metabolizes it and which brand of factor to use. Because all of the current manufacturers of factor products offer the same level of co-pay assistance to the bleeding disorder community, that discussion with his medical team is what decides what medication he uses - not co-pay assistance. Co-pay assistance helps us cover the costs, and enables consistent treatment.

When I've working in primary care, I've seen many other people doing what I'm doing now, trying to stretch their meds - so-called "rationing" - or do without, when they couldn't afford the cost. It's the kind of savings that tends to cost more, in the long run. In the bleeding disorder community, poor access to recommended treatment means that, before long we'll see the costs of trying to manage a bleed that wasn't treated right away, or deal with long-term damage to joints, pain management, lost work (or school) - everything our treatment plans are designed to avoid.

We know that the cost of healthcare is a problem, and that solutions need to be found. As individuals, as a community, we're doing everything we can to make the right choices, with our doctors, to balance cost and a healthy, full life. We learn how to stick needles into our babies' veins at our kitchen tables, and teach our kids how to use a needle when they're as young as 6 years old. We try to keep the costs low - and we keep our kids' care at home. We know our medication is expensive. But the consequences of not having access to the right medications, or being able to afford them are also enormous. It's literally life or death.

As you make your recommendations to the legislature, please keep in mind that, for my family - and our community - co-pay assistance programs give us access to the medications that helps kids like Shai lead full, active lives, as opposed to facing pain, disability and even death.

thank you.

A handwritten signature in black ink, consisting of a stylized 'Z' followed by a long, sweeping horizontal line that curves slightly upwards at the end.

Ziva Mann

New England Hemophilia Association member

New England Bleeding Disorder Advocacy Coalition (NEBDAC) representative