

Mr. David Seltz
Executive Director
Massachusetts Health Policy Commission
50 Milk Street, 8th Floor
Boston, MA 02143

Re: Coupons, discounts, and other product vouchers for prescription drugs – notice of public listening session

Dear Mr. Seltz,

In light of the upcoming Health Policy Commission meeting in July, the undersigned patient, provider, and consumer organizations request that co-pay assistance remain allowable **permanently** under Massachusetts state law.

Co-pay assistance helps to offset the cost sharing imposed by insurers, and allows patients to adhere to their medically needed treatments. They are often the only way patients can access critical medications for a wide array of disease states including, but not limited to hemophilia, diabetes, cancer, rheumatoid arthritis, epilepsy, and mental health conditions. Copay coupons and similar programs provide a valuable source of assistance for many commercially-insured patients, especially those who are struggling to afford the increasing out-of-pocket costs associated with insurance coverage for their medications. This need has only been exacerbated during the COVID-19 crisis, when many families have lost a substantial portion of their income and are struggling to pay for basic necessities, including medications.

As you weigh the impact of co-pay assistance, please remember the stories and struggles of patients and their families throughout Massachusetts, such as the Mann family from Newton.

Ziva Mann lives in Newton with her husband and two boys. Her son, Shai, has severe hemophilia A. And, as she learned after he was born, she has mild hemophilia A.

Hemophilia A is a genetic condition, and there is no cure. Shai was born with it, and his body is missing a protein in his blood so he doesn't clot normally. This means he's 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 - as well as 67,000 people 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.

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

Clotting factors are all name brand biological products - there are no generics, and people respond differently to different brands. The Mann family works with Shai's doctors to understand how his 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 cover the costs, and enables consistent treatment.

Many in the hemophilia community will hit their out-of-pocket insurance max in their first shipment of the medication. Without co-pay assistance, lots of families end up paying their entire out of pocket costs in January. For the Mann family that would be \$8,000. It's a lot of money.

This past January, Ziva was grateful that she had co-pay assistance to cover the costs of Shai's factor, and her younger son's generic EpiPens (\$371). She did not have co-pay assistance to help cover the costs of the medication to treat her own mild hemophilia and made the painful choice not to fill the prescription. They just didn't have an extra \$717.81 to spend on her medication, so she rolled the dice.

No one should have to do that. But many people do what Ziva did, stretching their meds - so-called "rationing" - or do without, when they can't afford the cost. It's the kind of savings that tends to cost more in the long run, because it inevitably leads to more doctors' visits and sometimes trips to the emergency room.

We understand the cost of healthcare is a problem, that medication can be expensive, and that solutions need to be found. But it can't be found on the backs of patients.

As you make your recommendations to the legislature, please keep in mind that, for the Mann family and the families of thousands of other patients with different diseases, co-pay assistance programs are a lifeline, providing access to the medications that allow kids like Shai to live meaningful, productive lives. We simply can't afford to wait any longer.

Respectfully Submitted,

Arthritis Foundation
American Diabetes Association
Coalition of State Rheumatology Organizations
Crohn's & Colitis Foundation
Epilepsy Foundation New England
Greater Boston Sickle Cell Disease Association
Global Healthy Living Foundation
Hemophilia Federation of America
Massachusetts Association for Mental Health

Massachusetts Society of Clinical Oncologists
National Eczema Association
National Infusion Center Association
New England Hemophilia Association
New England Bleeding Disorders Advocacy Coalition
National Hemophilia Foundation
National Organization for Rare Disorders
Patients Rising Now
Rare New England