New England Hemophilia Association

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May 21, 2019

MA Health Policy Commission
50 Milk Street, 8th Floor
Boston, MA 02109

Hand-Delivered & Emailed to:
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In Re: Study Required by Chapter 363 of the Acts of 2018

Tuesday, May 21, 2019, 10:00 AM

To the Members of the Massachusetts Health Policy Commission:

The New England Bleeding Disorder Advocacy Coalition (NEBDAC) and the Massachusetts bleeding disorder community greatly appreciate the opportunity to offer testimony about the importance of co-pay assistance. Since 1957, NEHA has served individuals and families with inherited bleeding disorders, who need information, education and support for their condition. NEBDAC was formed in 2016, as a volunteer advocacy coalition under NEHA. Both NEBDAC and NEHA provide advocacy and education about bleeding disorders in all 6 New England States.

In Massachusetts, 750 people live with hemophilia A, and 67,000 live with other kinds of bleeding disorders. Many of these depend on co-pay assistance programs to afford their necessary medications and therapies. Bleeding disorders cannot be cured, but they can be controlled thanks to a biological product known as "factor," that patients take through intravenous infusions. Before factor was available, the average life expectancy of a person with hemophilia A was only 11 years. Now, with access to factor and proper medical treatment, people with bleeding disorders can expect to lead full, productive lives.

But without the right treatment, members of our community are at risk for spontaneous bleeds, pain, suffering, lost wages, time out of school, long-term joint damage, disability, and even death. For our community, access to these products is literally a life or death issue.

The bleeding disorders community is grateful to have options with regard to factor products. However, all of the products are extremely expensive, brand name products; there are no generics. A single treatment of factor typically costs thousands of dollars, and individuals often require multiple treatments each week, if not daily, and we work closely with our doctors to make sure we're using the right medication, in the right amounts, and the right frequency. Even so, the average annual cost of treatment for a person with hemophilia is $350,000. However, approximately 30% of the time people will develop a complication called "an inhibitor" in which the patients' bodies mount an immune response to the factor. And it's expensive: one of our families whose three-year-old son had an inhibitor, had treatment costs of 1.6 million dollars in 2018. A significant percentage of that cost was due to factor.

We recognize that these costs are enormous. But the consequences to our community if we cannot access or afford the right factor products are also enormous.

Most of the community will reach their out-of-pocket max upon receipt of their first shipment of factor for the year and many families rely on co-pay assistance to help cover those costs. If co-pay assistance is eliminated, our families will be required to pay the max out-of-pocket on their insurance plan (likely in January) every year. Losing co-pay assistance would place a significant financial hardship on many of our families, who would struggle to find an additional $7,900-$15,800 in their budget to cover these costs.

Co-pay assistance helps our community ensure consistent treatment. If co-pay assistance is eliminated, there might be some short-term savings associated with reduced utilization of factor products. Most likely, this would be from patients are trying to ration their medications, stretching it out against doctors' orders to save money. With patients unable to follow the treatment plan from their doctor, we are likely to see increased costs to the system as these patients suffer the consequences of their decision in the form of pain, injury, disability, and death.

All the current manufacturers of factor products offer the same level of co-pay assistance to the bleeding disorder community. Therefore, co-pay assistance programs do not encourage patients to select more expensive factor products. Selecting the right product for treatment is an extremely important process that is done in close consultation with the patient's hematologist. Because patients' bodies respond differently to the different factor products, often patients must try several different products before landing on the product that manages their condition the best. In our community, factor product selection is clearly not influenced by the co-pay assistance program.

While we recognize the importance of trying to control health care spending, elimination of co-pay assistance for our community will not help further that goal. It will just hurt our families who need this critical financial support to access these life-saving factor products today.

Thank you for your consideration,

Richard Pezzillo

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