

Dear Senator,

The Hemophilia Foundation of Michigan is a nonprofit serving Michiganders affected by bleeding disorders such as hemophilia, von Willebrand Disease, and related complications including HIV/AIDS and hepatitis. We have had the pleasure of meeting with you and your staff on many occasions and appreciate your support to families impacted by bleeding disorders.

We are writing on behalf of our 4,000 Michigan community members, to express our concern regarding the passage of the American Health Care Act in the House and our request that you will oppose the health care repeal bill in the Senate.

Bleeding disorders occur genetically, or through spontaneous mutations, and impair the body's ability to clot properly. The diverse group of individuals and families impacted depends on quality and affordable access to health insurance to maintain healthy, productive lives. Individuals with bleeding disorders can manage their disorder with intravenous infusions of clotting factor, a protein needed for their blood to clot. However, this medication can be extremely expensive, even with primary insurance.

Prior to the Affordable Care Act, individuals with bleeding disorders often faced exorbitant premiums due to their disorders classification as a preexisting condition, high out-of-pocket costs, and coverage denials. Many individuals would hit their lifetime cap on benefits in just a few years, rather than their lifetime.

It is crucial that the essential health benefits provision, as defined in the Affordable Care Act, remain mandatory for all states so protections such as the ban on lifetime and annual limits and the cap on out-of-pocket expenses remain meaningful.

Additionally, we ask that you keep in mind that 30 percent of our community now receives coverage through Medicaid, allowing them to lead full, productive lives. Low-income individuals affected by bleeding disorders are at great risk if they cannot afford insurance and lack access to their medication.

We hope that you continue to keep our Michigan families in mind as the health care debate continues in the Senate. If you have any questions regarding bleeding disorders, please feel free to contact, Sarah Procario, at sprocario@hfmich.org. We are happy to serve as a resource to your office and appreciate your continued support of our community.

Warm Regards,

Susan Lerch, Executive Director

Sarah Procario, Advocacy Manager



Gwyn Hulswit, Philanthropy Director

Sharon Ceci, Director of Finance and Operations

Patrice Thomas, Program Services Director

Lisa Clothier, Outreach and Community Education Manager

Laura Olson, Business Manager

Torey Allen, Educational Services Manager

Ashley Fritsch, Office Manager