March 23rd, 2022

Chairman Zach Stephenson

Commerce Committee

Minnesota House of Representatives

509 State Office Building

St. Paul, MN 55155

**RE: HF 3611**

Dear Representative Stephenson,

I first want to say the Hemophilia Foundation of Minnesota/Dakotas (HFMD) appreciates your ongoing efforts to see that all Minnesotans get the health care they need. We are very grateful that you put HF 3611 on the agenda for a committee hearing on March 25th.

HFMD is a non-profit organization who represents families and individuals with bleeding disorders in Minnesota & South Dakota. Rare diseases like hemophilia are very expensive to treat. Many affected families and individuals count on 3rd party assistance to help offset their high out-of-pocket costs which is often the annual maximum.

Now, some health insurance companies are denying families from receiving this out-of-pocket assistance by adopting a practice known as the accumulator adjustor. These companies should not be able to use patients and families as pawns in attempt to steer patients toward using generic equivalents; especially when there are no generic equivalent options for many rare disease medications like those needed to treat hemophilia.

**About Bleeding Disorders**

Hemophilia is a rare, genetic bleeding disorder affecting about 20,000 Americans that impairs the ability of blood to clot properly. Without treatment, people with hemophilia bleed internally, sometimes due to trauma, but other times simply as a result of everyday activities. This bleeding can lead to severe joint damage and permanent disability, or even – with respect to bleeds in the head, throat, or abdomen – death.

Patients with bleeding disorders have complex, lifelong medical needs. They depend on prescription medications (clotting factor or other new treatments) to treat and avoid painful bleeding episodes that can lead to advanced medical problems. Current treatment and care are highly effective and allow individuals to lead healthy and productive lives. However, this treatment is also extremely expensive, costing anywhere from $250,000 to $1 million or more annually, depending on the severity of the disorder and whether complications such as an inhibitor are present.

**Importance of Copay Assistance to Rare Disease Patients**

Because patients with bleeding disorders require ongoing medication therapy for the course of their lifetimes, many such patients face the prospect of hitting their out-of-pocket maximum each and every year. Copay assistance programs play an essential role in mitigating this weighty financial burden – and allow patients to remain adherent to their prescribed treatment regimen, preserving their long-term health and thereby avoiding medical complications, and trips to the emergency room that will increase the overall cost of their care. **Patients with bleeding disorders cannot select alternative treatments: no generic drugs exist for hemophilia or related conditions.**

Please see the attached support letter from a coalition of advocacy groups who would be grateful to have you co-author and support HF 3611. If you have any questions, or need any additional information, please contact me. Thank you for hearing this bill and considering this request. We look forward to hearing back.

Sincerely,



James Paist

Executive Director