

**Testimony in Support of House Bill 1127
Health Insurance - Coverage for the Treatment of Bleeding Disorders**

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Good Afternoon Chairman Middleton and Members of the Committee:

My name is Kisa Carter and I am the Public Policy Director for the Hemophilia Federation of America (HFA). Based in Washington DC, the HFA is a national non-profit organization that assists and advocates for the bleeding disorders community. We represent over 30 state-based organizations throughout the country including the Hemophilia Foundation of Maryland (HFM). As part of its mission, the HFA strives to ensure the availability of medically necessary treatment and access to the full range of clotting factor therapies. I am here to express the HFA's support for passage and implementation of House Bill (HB) 1127.

Hemophilia is a rare, chronic bleeding disorder that affects 1 in 10,000 Marylanders with many more (approximately 1-2% of the U.S. population) living with bleeding disorders such as von Willebrands Disease.

The state of Maryland needs best practices in place to preserve quality care.

At present, there are no legal standards addressing best practices with respect to the care of people with bleeding disorders. In lieu of a legal mandate, a series of recommendations provide the framework of controlling best practices for medical providers and vendors servicing individuals with a bleeding disorder. House Bill 1127 would create a legally binding standard set of practices so that people in the Maryland bleeding disorders community can expect a similar level of care regardless of where they go to access services and support. The treatment standards proposed in this measure, should they be enacted; would represent an important advance for Marylanders that ensures quality comprehensive care is provided in a systemic and routine way.

The elements of a minimum standard of service addressed in this measure would:

- Ensure clotting factor concentrates are processed and dispensed in a timely manner
- Ensure timely delivery of clotting factor concentrates
- Reduce unnecessary medical costs
- Preserve quality service and care
- Eliminate unnecessary emergency room visits

Studies show better health outcomes when care is received at specialized health care centers.

According to a study conducted and reported in the American Society of Hematology's (ASH) Blood Journal, "survival is significantly greater among hemophiliacs who receive medical care in a Hemophilia Treatment Center (HTC)".¹ Likewise, the Centers for Disease Control and Prevention (CDC) emphasizes the importance of care in a comprehensive hemophilia treatment center to aid in reducing or eliminating complications with bleeding disorders.

Less than optimal service leads to adverse health outcomes and increased costs.

You have heard from several individuals and family members today who support passage of HB 1127. Their personal stories highlight instances that impede access to quality care at specialized health care centers, emergency room visits with less than knowledgeable staff and unnecessary tragedies that have occurred. A standard set of practices that preserves quality care and promotes unrestricted access to quality care and medically necessary products can aid in preventing detrimental health outcomes. Furthermore, families can avoid costly complications, lost time from work and school, and unnecessary emergency room visits.

Access to comprehensive quality care, products and services is essential to controlling cost. A number of journal articles written by medical doctors and experts familiar with hemophilia and other bleeding disorders (see attached), indicate the costs savings associated with comprehensive, quality care. Through surveys, many of these articles report that utilization of a comprehensive treatment center and effective management of bleeding disorders by specialist, results in cost savings.

The HFA supports *Coverage for the Treatment of Bleeding Disorders*

The current economic climate has placed many industries in a position to search for creative ways to reduce costs, often to the detriment of people with rare, costly conditions such as hemophilia. The bleeding disorders community recognizes the pressure many industries are faced with, however in the long term, substandard care for people bleeding disorders will be more costly.

The HFA ask that you consider the unique needs of the bleeding disorders community through support for House Bill 1127. We urge you to protect and preserve the care that families with bleeding disorders deserve.

Thank you for your time and consideration.

¹ Soucie JM, Nuss R, Evatt, B, Abdelhak A, Cowan L, Hill H, Kolakoski M, Wilber N, and the Hemophilia Surveillance System Project Investigators. Mortality among males with hemophilia: relations with source of medical care. Blood 2000; 96:437-442.