



March 15, 2011

The Honorable Ophelia Ford  
301 6th Avenue North  
Suite 318 War Memorial Bldg.  
Nashville, TN 37243

**Subject: SB 1536/Norris**

Dear Senator Ford:

The National Hemophilia Foundation (NHF) is the leading organization that advocates for the highly specialized needs of persons affected by hemophilia and other bleeding disorders throughout the United States. We are writing to urge you to reject SB 1536, which was introduced by Senator Norris and is presently before General Welfare, Health and Human Resources Committee. If adopted into law, this proposal would eliminate \$586,000 in funding for the State Hemophilia Program (SHP).

Hemophilia and other bleeding disorders are complex conditions for which there is no known cure. Patients often require life-long infusions of clotting factor therapies that replace missing or deficient blood proteins, thus preventing debilitating and life-threatening internal bleeding. While therapies are safe and more effective than ever, they are also more costly than other types of medication. For example, cost of treatment for a person with severe hemophilia can be \$250,000 a year or more. Developing an inhibitor (an immune response to treatment), complications such as HIV/AIDS, hepatitis and joint diseases, or bleeding as a result of trauma or surgery can increase those costs to \$1 million or more.

Diagnosis and treatment of these rare disorders are largely unknown to most physicians, and thus requires the expertise of a team of professionals at hemophilia treatment centers (HTC) who specializes in managing the unique health care needs of people with bleeding disorders. The HTC team typically includes hematologists, pediatricians, nurses, social workers, physical therapists, orthopedists and dentists among others. Numerous CDC studies have found lower rates of "mortality" and "hospitalizations" among patients who use HTCs.<sup>[1][2]</sup>

The SHP funding allows the state's HTCs to provide critical care to individuals in addition to educating patients and family members on managing conditions at home. In fact when bleeding disorders are properly managed, individuals are less likely to experience the debilitating pain and suffering associated with prolonged bleeding into joints and muscles, increasing quality of life and reducing total lifetime health care costs. Eliminating this vital source of funding will severely diminish the HTC's capacity to provide care, restricting patient access to vital resources.

Additionally, the SHP funding pays for: lifesaving clotting factor for uninsured individuals, COBRA premiums to help certain individuals maintain group coverage, and Medicare Supplement Insurance (i.e., Medigap policies) to help fill some of the gaps in coverage for

---

<sup>1</sup> Soucie JM et al. Mortality among males with hemophilia: relations with source of medical care. Blood 2000; 96:437-442.

<sup>2</sup> Soucie JM et al. Home-based factor infusion therapy and hospitalization for bleeding complications among males with hemophilia. Haemophilia 2001; 7:198-206.

Medicare recipients. Such measures are cost-effective; assuring individuals will have access to uninterrupted, quality care by alleviating the financial burdens that often cripples individuals and families. Moreover, having continuous access to clotting factor products limit complications and death from bleeding.

NHF understands that some budget cuts are necessary. However, complete elimination of the hemophilia program is highly unfair and it stands to endanger the lives of too many people with bleeding disorders. Therefore, we respectfully ask that you and the other members of the General Welfare, Health and Human Resources Committee vote “**no**” on SB 1536, ensuring that individuals with bleeding disorders will continue to have access to the care and treatment they need to maintain their quality of life.

Thank you for allowing us to convey our concerns and for giving them your careful consideration. If you have questions or concerns, please feel free to contact Ruthlyn Noel, Manager of Public Policy, at (212) 328-3730 or [rnobel@hemophilia.org](mailto:rnobel@hemophilia.org).

Sincerely,



Val Bias  
Chief Executive Officer