



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders

**Hemophilia and Thrombophilia Treatment Centers
Comprehensive Care for People with Bleeding and Clotting Disorders**

Request: Maintain federal funding for the national network of specialized treatment centers providing comprehensive care for people with bleeding and clotting disorders.

In 1974, Congress established a national network of hemophilia treatment centers (HTCs) to ensure access to comprehensive, specialized care for people with bleeding disorders. Today, the approximately 140 primarily hospital-based HTCs receive federal support from the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC). These programs support nursing, rehabilitative and social services, as well as prevention, disease management and blood safety surveillance activities. The HTC role has expanded dramatically over the last three decades, evolving with the needs of patients with both bleeding and clotting disorders. The population served at many centers has doubled in the last 10 years, while funding has remained static. Current government funding for HTCs is approximately \$11 million.

Facts about Hemophilia and Thrombophilia Treatment Centers

- HTCs provide a comprehensive, team-based approach to care for people with bleeding and clotting disorders. Members of the care team at HTCs include: hematologists, pediatricians, nurses, social workers, physical therapists, orthopedists and dentists, all with specialized training.
- The CDC reports that the care provided at HTCs significantly improves prevention of complications for people with bleeding disorders. Mortality rates are 40% lower in people who use HTCs than in those who do not, despite the fact that more severely affected patients are more likely to be seen in HTCs.
- HTCs are now treating significantly larger patient populations including women with bleeding disorders such as von Willebrand disease (VWD) and people with clotting disorders such as thrombophilia. These patients are increasingly referred to HTCs for diagnosis and specialized treatment.
- Government funding has remained static; in some cases, it has been cut. Some centers have reported a shortage of nurses, cuts to social worker hours, and insufficient staff time to educate patients. Funding cuts would likely result in staff cuts and a reduction in quality of care.

Facts about the Patients Seen in Hemophilia and Thrombophilia Treatment Centers

- Hemophilia is a rare chronic bleeding disorder affecting about 20,000 people in the United States, most of whom are male. People with hemophilia require life-long treatment with high-cost clotting factor medications and other forms of specialized care.
- In the 1980s, nearly 90% of Americans with severe hemophilia became infected with AIDS from contaminated blood and blood products. More than 50% of those individuals have died. In addition, roughly 44% of all people with hemophilia were infected by the hepatitis C virus during that time.
- Women and men with von Willebrand disease (VWD), another genetic bleeding disorder, are the largest growing population of patients seen in HTCs. Although many individuals with VWD remain undiagnosed, it may affect as many as two million people in the U.S.

Clotting disorders, caused by excessive blood clotting, can result from inherited disorders or develop as a complication of other conditions. More than 600,000 Americans are affected by abnormal blood clots, and have the potential to develop dangerous clots, known as deep vein thromboses (DVTs). If left undiagnosed or untreated, these events can be life-threatening.