



NATIONAL HEMOPHILIA FOUNDATION

for all bleeding and clotting disorders

Hemophilia Treatment Centers Comprehensive Care for People with Bleeding Disorders

Request: Reinstate funding for the hemophilia program at the CDC to support the national network of specialized hemophilia treatment centers providing comprehensive care for people with bleeding disorders.

President Obama's FY 2011 proposed budget for the Centers for Disease Control and Prevention (CDC) zeroes out the hemophilia program. Instead, the budget reallocates the money for a "public health approach to blood disorders." It is unclear what the CDC intends to do with this new approach and there is no guarantee that existing hemophilia program activities will be adequately supported under the proposed budget. CDC's hemophilia program provides funding for research, outreach and education activities, and blood safety surveillance. A key component of CDC's hemophilia program provides critical support for hemophilia treatment centers (HTCs).

Facts about Hemophilia Treatment Centers

- Congress authorized the national network of HTCs in 1974 to ensure access to comprehensive, specialized care for people with bleeding disorders. Today, there are approximately 140 federally-funded HTCs throughout the country.
- HTCs provide a comprehensive, team-based approach to care for people with bleeding disorders. Members of the HTC care team may 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.
- Elimination of the CDC's hemophilia program would likely result in staffing cuts at HTCs and would jeopardize quality of care for people with bleeding disorders.

Facts about the Patients Seen in Hemophilia 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 contracted HIV from contaminated blood and blood products. More than 50% of those individuals have since died. In addition, roughly 80% of all people with hemophilia were infected by the hepatitis C virus during that time, also as a result of contaminated blood products.
- 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 1% to 2% of the American population.