



NATIONAL HEMOPHILIA FOUNDATION

for all bleeding disorders

Hemophilia Programs – Ensuring Access to Care, Enhancing Prevention, and Outreach

Request: Maintain full funding for the federal hemophilia programs at the Maternal and Child Health Bureau (MCHB) and Centers for Disease Control and Prevention (CDC) to ensure access to hemophilia treatment centers (HTCs) and other critical education, research and surveillance activities.

About Bleeding Disorders and Hemophilia Treatment Centers (HTCs)

- Hemophilia is a rare, chronic bleeding disorder affecting about 20,000 people in the US. Von Willebrand Disease (VWD) is a related bleeding disorder that affects up to 1 million Americans.
- People with hemophilia require life-long infusions of expensive clotting factor therapies that replace missing or deficient blood clotting proteins, thus preventing debilitating and life-threatening internal bleeding.
- Since 1974, Congress has authorized and funded HTCs to ensure access to comprehensive, multidisciplinary, specialized care for people with bleeding disorders.
- CDC studies show that mortality and hospitalization rates are 40% lower in people who use HTCs compared with those who do not, even though more severely affected patients are more likely to be seen in HTCs.
- A patient needs assessment survey completed in 2013 found that 90% of the 4000 survey respondents felt it was important to receive care at a federally-funded HTC and that the four HTC core services (hematology, nursing, social work and physical therapy) met their needs.

Federal Hemophilia Programs

Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB)

- With \$4.9 million in funding from HRSA, HTCs provide critical, comprehensive multidisciplinary services not typically reimbursed by insurance, such as physical therapy assessments, social work and case management services.
- In keeping with HRSA's emphasis on patient-centered, integrated care, HTCs serve as "specialty medical homes" for people with bleeding disorders, from childhood through end of life. This system of care is widely recognized and serves as a model paradigm for other chronic diseases.

CDC Division of Blood Disorders

- The CDC Division of Blood Disorders program includes \$5 million for HTC research, surveillance, and prevention activities. This funding level must be maintained to monitor blood and blood product safety within the hemophilia population and to improve treatment and prevention strategies.
- Recent CDC research has resulted in a more effective test for inhibitors, which is a complication of hemophilia that prevents clotting factor treatments from working to stop bleeding, increasing co-morbidities and treatment related costs. The CDC has also increased surveillance for inhibitors, which culminated in an expert recommendation that people with hemophilia be tested annually for inhibitors.
- CDC also supports outreach and education programs provided by the national patient organizations in hemophilia and other bleeding and clotting disorders. Funding for these important programs should be maintained to improve access to needed interventions and further prevent complications.

Federal hemophilia programs must be adequately funded to ensure that people with bleeding disorders continue receiving high-quality care.