



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders

FACT SHEET
ADDRESSING NEEDS OF WOMEN WITH BLEEDING DISORDERS

REQUEST: Support funding for the Centers for Disease Control and Prevention's (CDC) Division of Blood Disorders to enable hemophilia treatment centers (HTCs) to identify, evaluate and care for girls and women at risk for bleeding disorders.

CDC estimates that 2.5 million women in the US have a bleeding disorder. While the fastest growing population seen in HTCs is girls and women, the vast majority of women with bleeding disorders are undiagnosed and are not receiving needed treatment. With a small increase in funding, HTCs can target their outreach efforts on a regional basis to the communities they serve. Some may increase contacts with school nurses and pediatricians in an effort to identify young women affected by bleeding disorders as soon as symptoms are present. Others may use health information technology and telehealth to reach out to rural health clinics and community health centers to encourage referrals for comprehensive services.

Facts about Women and Bleeding Disorders

- The most common women's bleeding disorder is von Willebrand disease (VWD). VWD, like hemophilia, is typically an inherited disorder. Women with VWD experience heavy menstrual periods and prolonged bleeding following injury, surgery and childbirth. The CDC estimates up to 1%-2% of the population has VWD.
- Of the 30,000 women in the U.S. who have a hysterectomy due to heavy bleeding each year, many could have been treated medically.
- It takes an average of 16 years from the onset of symptoms until diagnosis for a woman with VWD.
- Women benefit from the HTC team-based approach to care, which provides comprehensive evaluations and genetic counseling, coordinates care with primary care and ob/gyn physicians, and manages surgeries and childbirth.

Facts about Hemophilia Treatment Centers

- The CDC's Division of Blood Disorders provides funding for a national network of 140 HTCs. These centers provide comprehensive services to patients with hemophilia and other bleeding and clotting disorders. Current CDC funding for the network of HTCs is \$6.8 million.
- Through outreach, public education and increased awareness of primary care and ob/gyn physicians, more women are being referred to HTCs for testing and comprehensive care. Today, the fastest growing population for HTCs is women with bleeding disorders.

Support Increased Funding for the CDC To Enable HTCs to Better Serve Women with Bleeding Disorders!