



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders

Fast Facts

The National Hemophilia Foundation is dedicated to finding better treatments and cures for bleeding and clotting disorders and to preventing the complications of these disorders through education, advocacy and research. Established in 1948, the National Hemophilia Foundation has chapters throughout the country. Its programs and initiatives are made possible through the generosity of individuals, corporations and foundations as well as through a cooperative agreement with the Centers for Disease Control and Prevention (CDC).

About Bleeding Disorders

Hemophilia is a genetic bleeding disorder that prevents the blood from clotting normally. The main symptom is uncontrolled, often spontaneous bleeding. Internal bleeding into the joints can result in pain, swelling and, if left untreated, can cause permanent damage.

Hemophilia results from a deficient protein known as a blood clotting factor. The two main forms are hemophilia A (factor VIII deficiency) and hemophilia B (factor IX deficiency). Hemophilia A, the more prevalent of the two, occurs in 1 in 5,000 live male births. Hemophilia B represents about 20% of cases. The worldwide incidence of hemophilia is estimated at more than 400,000 people. Approximately 70% of people around the world do not have access to treatment.

- Currently, there is no cure for hemophilia. While treatment exists, it is costly and may require lifelong infusion of replacement clotting factor that is manufactured either from human plasma or using recombinant technology. Hemophilia occurs predominately in males. Women are carriers of the defective gene and may experience mild symptoms. In about one-third of cases there is no known family history of hemophilia. Instead the disorder results from a spontaneous genetic mutation.
- Nearly 90% of Americans with severe hemophilia became infected with AIDS in the '80s when the nation's blood supply was contaminated. More than 50% of those infected with HIV have died. Since 1986, there have been no reported cases of HIV transmission through factor concentrates in the U.S. Current donor screening measures and improved viral inactivation methods have been integrated into the manufacturing process to dramatically improve the safety profile of these plasma-derived products.

von Willebrand disease is a genetic bleeding disorder that prevents the blood from clotting normally. It is caused by a deficient or defective blood protein known as von Willebrand factor. It is estimated to affect over two million people in the U.S. Of the three main types, type I (the mildest form of the disease) accounts for 70% of cases. Symptoms include frequent nosebleeds, a tendency to bruise easily, and excessive bleeding following surgery. In women, the disease may also cause heavy, prolonged bleeding during menstruation and excessive bleeding following childbirth. It is often undiagnosed or incorrectly attributed to a gynecologic condition.

About Clotting Disorders

Clotting disorders are conditions in which the blood clots excessively. More than 600,000 Americans are affected by abnormal blood clots. People with these conditions also have the potential to develop dangerous clots, known as **deep vein thrombosis or DVT**. If left undiagnosed or untreated, life-threatening complications can occur. Approximately 146,000 people are affected by DVTs each year.

Conservatively, over 11 million people in the U.S. have one of several inherited clotting disorders, collectively known as **thrombophilia**. Factor V Leiden is the most common inherited form of thrombophilia.

Not everyone who has thrombophilia will experience a blood clot. The development of a blood clot is called thrombosis, which is a very common medical problem. Some people just need treatment when recovering from

surgery, during pregnancy or when immobile for long periods in a car or airplane. Others need to take anti-clotting medications for their entire lives.

About the National Hemophilia Foundation Advancing Medical Knowledge and Scientific Research

NHF awards grants to fund innovative research aimed at finding better treatments and cures for bleeding and clotting disorders. This research has led to vital insights into improved factor replacement therapies, more accurate hemophilia diagnostic methods, and a greater understanding of the genetic basis of hemophilia.

Our Medical and Scientific Advisory Council (MASAC), an internationally-respected group of scientists, physicians and other treatment specialists, issues quality of care and treatment recommendations for bleeding and other related disorders.

Public Policy Initiatives

The National Hemophilia Foundation supports increased federal funding for research. In addition, our public policy agenda includes working for improved access to high quality medical care, a safe blood supply, access to the full range of safe and effective treatments, adequate reimbursement at the public and private levels, and expanded federal funding for hemophilia treatment centers.

“Washington Days” – NHF’s annual national advocacy conference brings together people from across the country to make their voices heard and impact the legislative process.

Educational Programs and Initiatives

Our broad range of programs and services include:

- National Prevention Program (NPP)—Aimed at preventing or reducing the complications of bleeding disorders, key components of this education program are:
 - *Do the 5* – five key strategies for living a longer and healthier life.
 - *First Step* – information and support for families of infants and young children newly diagnosed with bleeding disorders. The *Train-the-Trainer* component brings together parents, Hemophilia Treatment Center staff and chapter representatives with practical strategies and support.
 - National Youth Leadership Institute (NYLI) – training to help young adults enhance their leadership capabilities and become future leaders in the bleeding disorders community.
 - “On the Road” – annual regional training conferences bring together individuals, families, healthcare professionals and staff from NHF chapters, associations and HTCs to network and to learn from one another.
- Project Red Flag – national public awareness campaign to educate women and healthcare providers about bleeding disorders in women.

For more information go to www.hemophilia.org or contact HANDI.

HANDI – NHF’s free, confidential information resource center answers questions, makes referrals, provides literature and maintains an extensive library collection on bleeding and clotting disorders. Phone 800.424.2634.

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