



NATIONAL HEMOPHILIA FOUNDATION

www.hemophilia.org

## Fast Facts

The National Hemophilia Foundation is dedicated to finding better treatments and cures for inheritable bleeding 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 primary symptom involves uncontrolled, often spontaneous bleeding in areas of the body. The amount of bleeding depends on the severity of hemophilia. Internal bleeding, which commonly occurs in the spaces around joints, frequently results in pain, swelling and if left untreated, can cause permanent damage.

- *Hemophilia results from a missing or deficient protein needed for blood clotting. The two main forms are **hemophilia A** (factor VIII deficiency) and **hemophilia B** (factor IX deficiency).*
- *Hemophilia A occurs in 1 in 5,000 live male births. **Hemophilia A** is about four times as common as **hemophilia B**. The number of people with hemophilia in the United States is estimated to be about 20,000 individuals.*
- *The worldwide incidence of hemophilia is not well known, but estimated at more than **400,000 people**. Approximately 75% of people with hemophilia around the world still receive inadequate treatment or have no access to treatment.*
- *There is currently no cure for hemophilia. While there are very effective treatments available in the U.S., it may require lifelong infusion of “high-cost” drug products that are manufactured from human plasma or through recombinant biotechnology.*
- *Nearly 90% of Americans with severe hemophilia became infected with AIDS in the 1980s when blood and plasma donations in the U.S. were not properly screened for the HIV virus.*
- *Due to improvements in donor screening and current viral inactivation measures in the commercial manufacturing process, clotting factor products are now very safe. CDC’s blood safety surveillance system, in place since 1998, has found no reported cases of HIV or hepatitis infections associated with clotting factor products among hemophilia patients.*

**von Willebrand disease** is a genetic disorder in which the blood does not clot properly. It is caused by a deficient or defective blood protein known as von Willebrand factor. While often undiagnosed, VWD is believed to be the most common bleeding disorder and estimated to affect up to 1% of the U.S. population. Of the main subtypes, type I (the mildest form) is most common, accounting for 70% of all cases. Symptoms include frequent nosebleeds, easy bruising and excessive bleeding following surgery or dental work. Although VWD occurs in men and women equally, women are more likely to experience additional complications as a result of heavy or abnormal bleeding during their menstrual periods and excessive bleeding after childbirth.



**NATIONAL HEMOPHILIA FOUNDATION**

www.hemophilia.org

## **Fast Facts**

### **About the National Hemophilia Foundation**

#### **Advancing Medical Knowledge and Scientific Research**

Since 1972, NHF has been awarding grants and fellowships to support innovative research aimed at finding better treatments and cures for bleeding 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.

Through the efforts and guidance of NHF's Medical and Scientific Advisory Council (MASAC), an internationally-renowned group of expert scientists, physicians and other treatment specialists, NHF has long been engaged in advancing the standard of clinical care and issuing treatment recommendations for all bleeding 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:

- NHF Steps for Living Program, an on-line, life-stages education curriculum to assist those affected by bleeding disorders. *Steps for Living* is made up of four modules:
  - *First Step* for newly diagnosed ages 0-8
  - *Next Step*, for families of children 9-15
  - *Step Up* for young adults and their families ages 16-25
  - *Step Out for Adults 26 and older*

Modeled on NHF's current First Step program, the *Steps for Living* curricula contain information and resources for families and patients directly affected, as well as activities and resources for chapters and HTC staff to provide education and support to families throughout these different life stages. The *Steps for Living* curricula can be found on the NHF website.

- Mentor Connect Program: NHF new Mentoring program to decrease social isolation of parents of children with bleeding disorders.
- National Youth Leadership Institute (NYLI) – training to help young adults enhance their leadership capabilities and become future leaders in the bleeding disorders community.
- Victory for Women – national public awareness campaign to educate women and healthcare providers about bleeding disorders in women.



**NATIONAL HEMOPHILIA FOUNDATION**

www.hemophilia.org

## **Fast Facts**

### **Chapter Services**

NHF's 51 affiliated chapters agree to meet Chapter Standards in the areas of research, advocacy, program service, fund raising, and organizational development/infrastructure. Chapters receive hands-on support from NHF Chapter Services staff to help them achieve un-met Standards, in order that they can better serve their local communities. This also includes coordinating requests for assistance; acting as a liaison to build relationships between chapters and HTCs; supporting chapter efforts to promote research; and helping to devise tools and resources to meet chapter needs. Training opportunities are provided at the NHF Annual Meeting, Regional Leadership Seminars, and at other times during the year. These programs bring chapter staff and volunteers together to learn from each other, as well as from outside speakers.

Our goal is to strengthen and empower chapters through the following:

- Management and organizational training
- Advocacy partnership at the local, state and national levels
- Educational programs and initiatives
- National, regional and local training opportunities throughout the year
- Staffing assistance grants
- Educational program grants
- Grant writing support

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.

Revised 10-2-12