NATIONAL HEMOPHILIA FOUNDATION
www.hemophilia.org

FREQUENTLY ASKED QUESTIONS ABOUT HEMOPHILIA

1. **How many people have hemophilia in the United States?**

   As of this writing, approximately **20,000 people** are living with hemophilia in the United States.

2. **Are there different types of hemophilia?**

   Yes.

   Hemophilia A, also known as factor VIII deficiency, is the most common type of hemophilia. About 80% of people with hemophilia have hemophilia A. However, about 20% of people have hemophilia B (factor IX deficiency).

3. **Can women have bleeding disorders?**

   Yes.

   One of the most common bleeding disorders affecting women is von Willebrand Disease. Although the disease occurs in men and women, many researchers agree that vWD can be more complicated for women due to gynecological or obstetric complications. Women can also have hemophilia. It is very rare, but one way a woman might inherit hemophilia is if her father has it and her mother carries the gene for hemophilia as well.

4. **TRUE/ FALSE: Hemophilia only occurs when there is a history of a bleeding disorder in the family.**

   FALSE.

   One-third of all cases of hemophilia A and one-fifth of all cases of hemophilia B occur when there is no family history of the disorder. In these cases, hemophilia can develop as the result of a new or spontaneous gene mutation.

5. **If a man has hemophilia, will any of his children have hemophilia?**

   No.

   Men cannot pass the gene for hemophilia to their sons. However, all his daughters will be "carriers" of the gene for hemophilia. Every carrier has a one in four chance of having a child with hemophilia.

6. **TRUE/FALSE: People with bleeding disorders bleed faster than other people.**

   FALSE.

   The blood of every person flows at the same rate. In people with bleeding disorders, the mechanism that controls clotting does not work properly, making any bleed last longer in duration. If the cut is not very deep, such as a paper cut or scrape, the bleeding can stop by itself. More extensive injuries or internal bleeds, require treatment.

7. **Can some people with hemophilia bleed more often that others?**

   Yes.

FREQUENTLY ASKED QUESTIONS ABOUT HEMOPHILIA

Each person with hemophilia is unique. Some people have bleeds every week, some every month, and others maybe only once a year. How often a person bleeds is dependent upon the level of "working factor" in the blood. People with severe hemophilia have factor levels that are so low that everyday activities can cause spontaneous bleeds. Those with mild hemophilia may only experience bleeding after an injury or during surgery.

8. **TRUE/FALSE: Hemophilia is an expensive disease.**

   TRUE.

   Many of the technological advances in hemophilia treatment have come with high financial price tags. The life-long management of hemophilia places a large financial burden upon individuals and families. In fact, the average annual cost of clotting factor products can range from $60,000 to $300,000 dollars. Complications such as inhibitors, orthopedic surgery, hepatitis, and HIV disease can cause the costs to be over a million dollars each year. Having adequate health insurance coverage can profoundly impact an individual's access and quality of care.

9. **Does everyone with hemophilia have HIV/AIDS?**

   No.

   People with hemophilia are treated with clotting factor, a product developed from the blood donations of thousands of people. In the early 1980s, when HIV first began to spread in the United States, some individuals infected with HIV donated their blood. These donations were then used to make blood products, like clotting factor. As a result, about 8,000 individuals with hemophilia were exposed to contaminated product. Many but not all of these individuals have since died or contracted AIDS. In 1985, when the United States government began requiring that all blood donations be tested for HIV, all blood testing positive for HIV was subsequently destroyed. The technology for cleansing and purifying clotting factor has vastly improved in the last decade. Today, many people with bleeding disorders utilize "recombinant" or manufactured clotting factor created with little to no use of human blood. There have been no known cases of HIV from the use of clotting factor products in the United States since 1986.

10. **Will people with hemophilia have it all their lives?**

    Yes.

    Hemophilia is a life-long condition. Currently there is no cure, but scientists are actively engaged in finding the cure through gene therapy. One hope is that by inserting a healthy version of the defective blood factor gene, a person with hemophilia will be able to produce normal amounts of factor on their own. The National Hemophilia Foundation raises money for novel technologies and gene transfer research to find better treatments and an eventual cure for hemophilia.