



## WHAT IS A BLEEDING DISORDER?

Bleeding disorders are a collection of disorders that all include the inability to form a proper blood clot. Symptoms can include extended bleeding after injury, surgery, trauma, or menstruation. Sometimes bleeding can occur spontaneously, without a known or identifiable cause. Improper clotting can be caused by platelet issues or by missing proteins called clotting factors. Our bodies make 13 different clotting factors – if any of them are missing or defective, then the chain of clotting is broken, and a severe, moderate, or mild bleeding disorder can result.

Many of these disorders are inherited, but some, like hemophilia, can also be acquired. Others can occur from a variety of medical conditions or even medications.

Symptoms of bleeding disorders include:

- Bleeding into joints, muscles, and soft tissues
- Excessive bruising
- Prolonged, heavy menstrual periods
- Unexplained nosebleeds
- Extended bleeding after minor cuts, blood draws, vaccinations, surgery or dental procedures. Learn more and check your symptoms at: <https://betteryouknow.org/>

## TREATMENT OF BLEEDING DISORDERS

Treatment of bleeding disorders varies depending on the condition and its severity. For some bleeding disorders, there are clotting factor concentrates that can be infused prophylactically, or on-demand, at home to prevent bleeds. For other bleeding disorders there are topical products, nasal sprays, and fresh frozen plasma, which is administered in a hospital setting.

Clotting factor is a biologic drug derived from donated human plasma or manufactured in a laboratory through genetic recombination technology. There are no generic equivalents. Factor requires specialized storage and handling and is dispensed for home infusion through a Hemophilia Treatment Center 340B program or specialty pharmacies. It is essential that a patient receive the factor therapy that is prescribed by their hematologist; a patient's response and tolerance to a specific factor therapy is unique.

While available treatments have increased the life expectancy and greatly improved the quality of life of people with bleeding disorders, these medications do not come cheap. Clotting factor is prescribed according to body weight, i.e., the heavier or taller you are, the more factor you need. The average annual cost of medication for a person with severe hemophilia is approximately \$250,000 - \$300,000. A patient with an inhibitor has an immune response to the replacement factor. For those patients, the annual cost can be over \$1 million. Hence, health insurance for hemophilia patients is essential.



## HEMOPHILIA TREATMENT CENTERS (HTC)

Many hemophilia patients receive their care at an HTC. There are about 141 federally designated HTCs in the U.S. – with 10 of these centers in California. HTCs provide comprehensive, integrated, coordinated care via specially trained multi-disciplinary teams that include hematologists, pediatricians, nurses, social workers, physical therapists, orthopedists, and dentists, among others. Access to hemophilia treatment centers is critical for effective diagnosis and treatment of bleeding disorders. For more information about the treatment of bleeding disorders, see NHF's [Medical and Scientific Advisory Council \(MASAC\) Guideline 269](#).

## WOMEN WITH BLEEDING DISORDERS

While hemophilia is the most well-known bleeding disorder and is often thought of as a condition affecting men, women can also be affected by hemophilia and other bleeding disorders.

On average, it takes women 16 years to get a proper bleeding disorders diagnosis and therefore the Hemophilia Council of California, along with other national, state, local and international organizations, is seeking to raise more awareness about women and bleeding disorders.

## INSURANCE/HEALTH ACCESS WITH BLEEDING DISORDERS

About 50% of California Bleeding Disorders patients are on Medi-Cal, California Children's Services (CCS), the Genetically Handicapped Persons Program (GHPP), or some combination of those programs. Others are on private employer-funded plans or Covered California plans. People with bleeding disorders need health insurance to have access to providers and treatment.

Step therapy and copay accumulator adjusters are important insurance policy issues for the bleeding disorders community.



## CALIFORNIA STATUTE ON BLEEDING DISORDERS

125286.15. The Legislature hereby finds and declares all the following:

- **Hemophilia** is a rare, hereditary, bleeding disorder affecting at least **4,000** persons in California and is a chronic, lifelong, and incurable but treatable disease.
- **Von Willebrand disease** is a human bleeding disorder caused by a hereditary deficiency or abnormality of the von Willebrand factor in human blood, which is a protein that helps clot blood. Von Willebrand disease is a chronic, lifelong, incurable, but treatable, disease affecting at least **390,000** Californians.

## THE HEMOPHILIA COUNCIL OF CALIFORNIA

*The Hemophilia Council of California's mission is to improve access to care and treatment options to advance the quality of life for the 394,000 people living with bleeding disorders through advocacy, education, and outreach in collaboration with our founding member organizations – Central California Hemophilia Foundation, the Hemophilia Association of San Diego County, the Hemophilia Foundation of Northern California and the Hemophilia Foundation of Southern California.*