

# Hemophilia

- Hemophilia is a rare genetic bleeding disorder that prevents blood from clotting properly, affecting between **30,000 and 33,000** people living in the United States and approximately more than **500 people in South Carolina**.
- The most common symptoms of hemophilia include: bleeding into joints; prolonged bleeding from cuts or injuries; nosebleeds; and bruising. However, symptoms vary depending on the severity of the disease.
- Those affected require life-long treatments of clotting factors and other therapies that can replace missing or deficient blood proteins to prevent debilitating and life-threatening internal bleeding. Costs for clotting factor therapies can **average more than \$300,000 per year**. However, the development of an inhibitor (which makes clotting factor ineffective), bleeding from trauma or surgery, and other complications, can easily elevate the annual cost to more than **\$1 million**.

# Von Willebrand Disease

- Von Willebrand disease (VWD), another inherited bleeding disorder that prevents the blood from clotting properly, affects approximately 1 percent of the population, or about **3.2 million people in the United States**, and is severely underdiagnosed. Based on this incidence, **South Carolina may have more than 50,000** individuals affected by this disease.

# Rare Bleeding Disorders

- There are several other very rare bleeding disorders, such as deficiencies involving clotting factor I, II, V, VII, X, XI, and XIII. There are additional rare platelet disorders that cause prolonged bleeding.

# BDASC Mission

Our mission is to raise awareness for and advocate on behalf of persons with bleeding disorders and their families; provide education and supportive services; and promote ongoing research to improve the quality of life for those affected.

**Hemophilia Treatment Centers**

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**National Hemophilia Foundation**  
<https://www.hemophilia.org>

**Hemophilia Federation of America**  
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# What are Bleeding Disorders?



**BDASC**

Bleeding Disorders Association of South Carolina

Insurance coverage is essential for individuals with hemophilia and other bleeding disorders. The medicines used to treat these disorders are essential for affected persons to live healthy and productive lives. But the cost of the medication puts treatment out of reach for any affected individual who lacks insurance coverage.

- ▶ Our community needs access to insurance that: protects people with pre-existing conditions; eliminates annual and lifetime caps on benefits; limits out-of-pocket costs imposed on patients; counts copay assistance towards deductibles and out-of-pocket maximums; and covers the full range of medically necessary services and products.
- ▶ Bleeding disorders treatments are complex biological products. **No generic products exist**, and the different medications that do exist are not therapeutically interchangeable. There is no one-size-fits-all approach that works in hemophilia care. Therefore, preferred drug lists (PDLs) and formularies for hemophilia treatments pose grave concerns for persons with bleeding disorders.

Since 1974, Congress authorized and funded hemophilia treatment centers (HTCs) to ensure access to comprehensive, specialized treatment care for people with bleeding disorders. Funding for federal programs assists HTCs, impacts bleeding disorders research, and in turn improves the lives of people living with bleeding disorders.



This educational brochure was created by the Health Equity, Diversity, and Inclusion Working Group and endorsed by the South Carolina Hemophilia Treatment Centers

- ▶ Health Resources and Services Administration (HRSA) Provides grants to programs that improve healthcare for people who are geographically isolated or economically or medically vulnerable. Also administers the 350B Drug Discount Program that helps stretch scarce federal resources so that HTCs can support multi-disciplinary, comprehensive care.
- ▶ Centers for Disease Control and Prevention (CDC) Provides funding for HTC data collection and research (e.g., Community Counts project). Also funds patient education and outreach programs, as well as laboratory research at the CDC.
- ▶ National Institutes of Health The nation's preeminence medical research agency, that is regularly making important healthcare discoveries and improving the lives of patients.
- ▶ Maternal and Child Health Bureau (MCHB) Assures access to high-quality and equitable health services to optimize health and well-being for all Maternal and Child Health (MCH) populations.