

# A Brief History of Bleeding Disorders

Bleeding disorders have been recognized for centuries, with early references appearing in ancient texts that noted inherited patterns of excessive bleeding within families.

In 1803, Dr. John Conrad Otto published the first scientific description of what is now known as hemophilia, identifying its hereditary nature and its tendency to affect males. By the early 20th century, additional bleeding disorders—such as von Willebrand disease—were identified, and researchers began to better understand how blood clotting works.

Until the mid-1900s, treatment options were extremely limited, often relying on whole blood transfusions. Life expectancy for individuals with severe bleeding disorders was significantly shortened. Major breakthroughs came in the 1960s and 1970s with the development of cryoprecipitate and clotting factor concentrates, allowing for more effective treatment and even at-home care.

However, the 1980s brought a devastating setback when contaminated blood products led to widespread transmission of HIV and hepatitis C within the bleeding disorders community.

Since the 1990s, advances in safety, including screened blood products and recombinant (synthetic) therapies, have dramatically improved outcomes. Preventive treatments are now standard, and ongoing innovations—such as extended half-life therapies and gene therapy—are transforming care.

**Today, bleeding disorders are considered manageable conditions, with individuals living longer, healthier, and more active lives than ever before.**

## Why We Advocate For Our Community

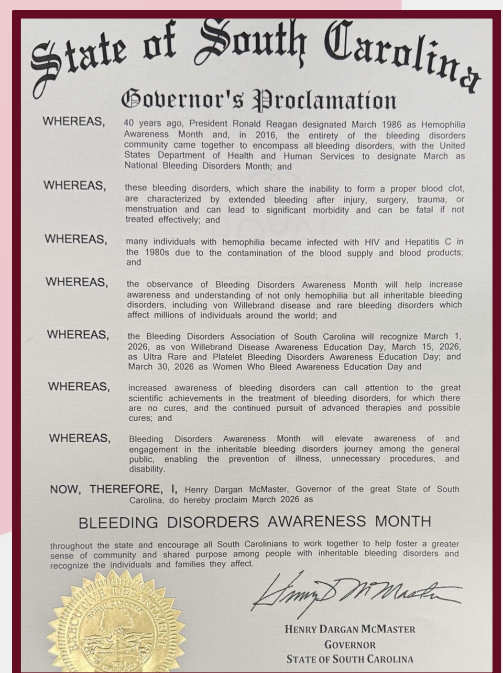


Advocacy is a key component of our mission at BDASC. It is also important to those affected by bleeding disorders in assuring health care needs are being met especially when living with a rare and chronic, lifelong disorder. Advocating for you and your family will be key in your quality of care.

Knowing how to advocate for yourself and your family takes practice and learning. The South Carolina Hemophilia and Bleeding Disorders Advocacy Coalition and

Ambassador program will help enhance your advocacy skills, answer your questions about advocacy, and arm you with the materials that you'll need when talking with policymakers and others about hemophilia and bleeding disorders.

**The strength and the voices of this community has driven the timeline on the following page.**



# Bleeding Disorders History

1973	<p><b>Hemophilia of South Carolina is established by a small group of families living with Hemophilia.</b> The Hemophilia Act of 1973 allows federally funded comprehensive hemophilia treatment centers to be established.</p>
1976	<p><b>The first camp for kids with Bleeding Disorders in South Carolina is hosted by HSC at the Clemson Outdoor Laboratory and was called, Camp Running Brave. It was the only camp for kids with bleeding disorders on the east coast and served S.C., N.C., G.A., F.L., V.A., El Salvador and K.Y.</b></p>
1977	<p>DDAVP is developed to help boost levels of both factor VIII and von Willebrand factor.</p>
1982	<p>The CDC reports the first cases of people with hemophilia through the use of tainted blood products to treat bleeding disorders.</p>
1983	<p>HIV is identified. Blood products are recalled after two identified blood donors die of AIDS. By October of 1983 manufacturers begin issuing clotting factor recalls.</p>
1984	<p>A research team has successfully cloned the human gene for the production of Factor VIII.</p>
1986	<p>President Ronald Reagan proclaims March "Hemophilia Awareness Month." The first product for the treatment of von Willebrand Disease is approved.</p>
1988	<p>The first World AIDS day is noted as a global health day.</p>
1989	<p>The structure of the VWF Gene is successfully cloned for the first time.</p>
1990	<p>Congress passes the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. Genome Mapping Begins.</p>
1992	<p>The first recombinant factor VIII product is approved by the FDA.</p>
1994	<p>MASAC issues recommendations for prophylaxis treatment for individuals with factor VIII or factor IX.</p>
1996	<p>The first Washington Days advocacy event is held by NHF.</p>
1999	<p>The first factor IX recombinant product is approved by the FDA.</p>
2003	<p>The CDC's Universal Data Collection system publishes a report demonstrating that since 1998, no new infections of hepatitis A, B and C or HIV have been linked to blood products used to treat hemophilia.</p>
2007	<p>Prophylactic treatment becomes standard of care in the United States for people living with hemophilia.</p>
2009	<p>The first Rare Disease Day is celebrated in the United States.</p>
2010	<p>The movie Bad Blood debuts, chronologizing the HIV crisis in the hemophilia community. <b>Hemophilia of South Carolina hosts its first Legislative Advocacy Days.</b></p>
2013	<p>Gene Therapy for Hemophilia begins.</p>
2015	<p>First recombinant therapy for von Willebrand Disease is FDA approved for adults.</p>
2016	<p>March officially becomes known as the national Bleeding Disorders Awareness Month.</p>
2017	<p>My Life, Our Future: Development of the World's Largest Genetic Research Repository for Hemophilia. Chris Bombardier is the first hemophiliac to summit Mount Everest. FDA approves the first subcutaneous treatment for hemophilia A.</p>
2018	<p>The FDA gives Priority Review to the first gene therapy for Hemophilia A.</p>
2021	<p><b>Hemophilia of South Carolina becomes <u>Bleeding Disorders Association of South Carolina</u> to reflect a more inclusive organizational name as serving all bleeding disorders.</b> NHF in collaboration with ASH, ISTH and WFH publishes guidelines on the diagnosis and treatment of von Willebrand Disease.</p>
2022	<p>The FDA approves the first Gene Therapy treatment for adults with Hemophilia B.</p>
2023	<p><b>BDASC, in partnership with other rare and chronic patient advocacy organizations, creates a statewide collaborative known as the <u>Palmetto Health Collective</u> to be a voice for the rare and chronic disease patients in South Carolina.</b> The first Research National Blueprint for Inherited Bleeding Disorders was published in the Expert Review of Hematology. <b>BDASC participated in its development.</b></p>
2024	<p><b>First patient in South Carolina receives Gene Therapy.</b> <b>BDASC introduces von Willebrand Awareness Day, Ultra Rare Awareness day and Women Who Bleed Awareness Day within South Carolina and Nationally.</b></p>
2025	<p><b>BDASC provides its first annual state-wide advocacy training program - FAMS.</b></p>
2025 - 2026	<p>New innovative re-balancing treatments become available for those living with hemophilia.</p>