# BDSSC

#### About Us

**Bleeding Disorders of South Carolina** (BDASC) is a 501 (C) 3 Non-Profit organization and is a Chapter of the National Hemophilia Foundation (NHF) and a Chapter Member of Hemophilia Federation of America (HFA). BDASC was founded in 1973 by a group of parents interested in promoting awareness, providing group support, and assisting other national hemophilia organizations. The organization for 42 years existed as all-volunteer; providing programs and education, support and advocacy for access to care at the states capitol. Today, BDASC serves all 46 counties in the state, currently providing education and support services to over 1700 members and their families in 42 counties. BDASC provides the most current information and education in topics related to bleeding disorders, treatment therapies, insurance and advocacy. Today, BDASC has one full time Executive Director, a full time Engagement & Development Manager, and an advocacy consultant but relies on a strong volunteer base of its board of directors and members. Without our volunteers, we could not serve our mission.

## What Are Bleeding Disorders?

Approximately 3.2 million Americans live with Hemophilia, von Willebrand's disease, and other rare factor deficiencies that prevent their blood from clotting normally. This can lead to extended bleeding from injuries, traumas, and even surgery, all of which can be fatal if not treated effectively.

#### **Our History**

- 1720 A woman in Plymouth, New Hampshire, is identified as one of the first people in America to be a carrier of hemophilia.
- 1803 First recognized that hemorrhagic bleeding disorder primarily affected men, and ran in certain families.
- 1948 The National Hemophilia Foundation is formed.
- 1965 Dr. Judith Graham Pool discovers thawing plasma was rich in factor VIII. Freeze-dried powdered concentrates containing factor VIII and IX soon became available for home infusions.

1973 Hemophilia of South Carolina is established.

- Late 1970s to Mid-1980s Nearly half of all people with hemophilia became infected with HIV after using contaminated blood products.
- 1986 President Ronald Reagan proclaims March as "National Hemophilia Month."
- 1992 First recombinant factor VIII product approved by the Food and Drug Administration. The first factor IX would be approved five years later.
- 2010 Hemophilia of South Carolina holds its first legislative days and Gov. Mark Sanford proclaims March as Hemophilia Awareness Month.
- 2016 NHF and the U.S. Department of Health and Human Services worked together to designate March as an official U.S. health observance month Bleeding Disorders Awareness Month.
- 2018 The first subcutaneous treatment for hemophilia introduced to the market.
- 2020 HSC secures 30 proclamations throughout South Carolina commemorating March as Bleeding Disorders Awareness Month and the FDA gives Priority Review to the first gene therapy for Hemophilia A.
- 2021 Hemophilia of South Carolina becomes Bleeding Disorders Association of South Carolina to reflect all the Bleeding Disorders the organization serves.
- 2024 Bleeding Disorders Association of South Carolina creates the first nationally recognized von Willebrand's Disease Awareness Day.
- 2025 Bleeding Disorders Association of South Carolina creates the first nationally recognized Ultra Rare Bleeding Disorders Awareness Day.
- 2025 Bleeding Disorders Association of South Carolina creates the first nationally recognized Women Who Bleed Awareness Day.

### 9 cents **OF EVERY DOLLAR DONATED** HELPED TO BUILD...

#### resilience

Supporting kids, teens and family members engaged in virtual and in-person camps state-wide.

#### support

Helping over 88 families with our emergency & compassionate care financial assistance program.

#### community

Bringing 150+ community members together who walking over 400 miles, and 144 individuals who hit 1,022,976 yards of golf to raise awareness and funds to support the Chapter.

#### independence

Hosting over 60-75 virtual and in-person outreach programs on various topics, educating members and guests from across the state, country, and globe yearly.

#### \$25

Provides a gas card to help those in need attend educational meetings.

#### \$100

Helps provide financial assistance to attend educational and supportive meeting events.

#### \$250

Helps provide financial assistance for individuals with bleeding disorders attend clinic days at their Hemophilia Treatment Center.

#### \$350

pay an electric or other utility bill when times are tough.

Helps an individual Helps support (1) individual with our researchers asking Academic Scholarship Awards Program or cure. We provide can support WFH USA's Chapter Challenge providing Factor access to the developing world.

voice

advocates from 42 counties

federal legislators to protect access to health care and affordable treatment.

\$500

to meet with 33 state and

Organizing patient

#### \$1000

Helps support the questions and searching for a direct financial support through the National Hemophilia Foundation's Judith Graham Pool Postdoctoral Research Program.

Every dollar counts and we appreciate your support! Visit BDA-SC.org for additional information and donate today. Thank you!