



Virginia Hemophilia Foundation (VHF)

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804-740-8643 | info@vahemophilia.org | www.vahemophilia.org

VIRGINIA HEMOPHILIA FOUNDATION (VHF)

Lifelong Support for Virginians Impacted by an Inherited Bleeding Disorder

MISSION “Dedicated to serving and supporting the needs of those impacted by a bleeding disorder through **education, advocacy and community.**”

VISION “Become the recognized voice and go-to resource for those impacted by a bleeding disorder.”

HISTORY Formed in 1975, VHF is a 501(c)(3) nonprofit serving approximately 350 individuals with inherited bleeding disorders and their immediate families. VHF collaborates closely with the 3 federally funded Hemophilia Treatment Centers (HTCs) in Virginia and serves the following regions - Southwest Virginia, Roanoke, Blue Ridge, Central Virginia, and Hampton Roads.

What is an Inherited Bleeding Disorder?

Bleeding disorders are a group of lifelong inherited conditions, which result in problems with the body's blood clotting process. Currently, **there is no cure for these inherited bleeding disorders.** These disorders typically cause prolonged bleeding after an injury or surgery. In severe cases, spontaneous bleeding can occur for no discernable reason. Left untreated, excessive, and repeated bleeds result in painful, disabling joint and muscle damage that can lead to long-term mobility problems.

At VHF, we do whatever we can to support community members along their journeys.

Bleeding disorders include Hemophilia A (Factor 8 deficiency), Hemophilia B (Factor 9 deficiency), von Willebrand disease (VWD), platelet disorders, and rare factor deficiencies (Factor 7, 10 and others). Each of these conditions interrupt the body's clotting process, causing prolonged bleeding.

About 20,000-30,000 individuals of all races and ethnic groups in the United States live with hemophilia. Von Willebrand disease (VWD) is the most common inherited bleeding disorder, affecting up to 1% of the US population, and occurs equally among men and women.

Effective treatments are available to treat and prevent bleeds, but they may require lifelong infusions of expensive drugs. Even routine medical procedures can put patients with a bleeding disorder at higher risk of complications. Some patients and families have difficulty gaining access to treatments.

Living with an Inherited Bleeding Disorder

Costs for an individual with severe hemophilia can be over \$300,000 per year or more to treat bleeding with intravenous doses of the missing clotting factor or one of the newer alternative treatments. **Some patients build up inhibitors to treatment and costs may exceed \$1,000,000 per year.**



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Beyond the financial costs, living with a rare bleeding disorder can be isolating, debilitating, and lead to chronic health problems. VHF offers support and services to help Virginians living with inherited bleeding disorders learn to lead long, healthy, and productive lives.

How VHF Supports the Inherited Bleeding Disorders Community

VHF EDUCATES individuals, families, and the bleeding disorders community on the unique needs of those with inherited bleeding disorders in order to prevent complications and to enhance quality of life. We deliver tailored education and provide resources for all stages of life through programs such as:

- A Statewide Annual Education Meeting and a Medical Symposium
- Regular education sessions on topics such as mental health, school resources, emerging therapies, and aging
- A monthly electronic newsletter and a comprehensive website with resources for community stakeholders

VHF ADVOCATES to guarantee funding for local, state, and federal bleeding disorder programs and research, to ensure blood and blood product safety, and to protect access to affordable, quality care and treatment.

- We educate legislators, insurance directors, and state health and Medicaid departments on health-related issues regarding the inherited bleeding disorders community.
- Through trainings and regular meetings, we encourage community members to self-advocate and tell their stories to policymakers to affect change.
- Examples of our advocacy efforts include expanding Medicaid, eliminating accumulator adjustors, and having March declared Bleeding Disorders Awareness Month in Virginia.

VHF BRINGS TOGETHER Virginians with inherited bleeding disorders and their families for learning, sharing, and support. We provide a safe environment for discussion regarding treatment, access to care, and quality of life through programs like:

- Overnight retreats annually for men, women, teens, and the entire community
- Camp Youngblood, a week-long statewide overnight camp in partnership with the Hemophilia Association of the Capital Area (HACA) at Camp Holiday Trails for children ages 7-17
- Family Camp, a weekend of education, support, and traditional camp activities

VHF EMPOWERS and improves quality of life for individuals and/or families with inherited bleeding disorders through direct services. Examples include:

- Financial Assistance Program - Financial support to help pay for expenses incurred in the care, treatment, or prevention of an inherited bleeding disorder



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- Lyman Fisher Scholarship – A one-year award in the amount of \$2,000 for a full academic year
- Travel Scholarships for National Meetings - Enables our community to come together and exchange information on a wide variety of topics, from the basics of diagnosis to the most relevant developments in treatment and technology
- Terry Lamb Enrichment Scholarship - Used for any program that enhances one's self-esteem, confidence, health, leadership skills, and volunteerism
- New Family Education and Support in partnership with our Hemophilia Treatment Centers (HTCs)- Help newly diagnosed families find resources and a true community

How YOU Can Help the Inherited Bleeding Disorders Community

You can help VHF educate, advocate, build community, and empower those impacted by an inherited bleeding disorder by making a financial contribution, by volunteering your time and talents, and by raising awareness.

Join us in helping make a real impact so that our community members can lead long, productive, and healthy lives.

YOUR DONATION MAKES AN IMPACT

- **\$2,000** funds a Lyman Fisher Scholarship, allowing a student with a bleeding disorder or from a family impacted by a bleeding disorder to pursue higher education.
- **\$1,000** supports a Travel Scholarship, enabling a patient or family member to attend a national education and/or a federal advocacy meeting.
- **\$500** helps to send a child or teen to Camp Youngblood where they gain an increased sense of independence in managing their bleeding disorder.
- **\$250** provides a patient and/or their family emergency financial assistance.
- **\$100** supports a patient and/or their family's attendance to VHF's Annual Education Meeting and/or state Advocacy Training.
- **\$50** pays for a lifesaving Medic Alert Tag.
- **\$25** pays for direct patient support (in partnership with HTCs) by providing resources such as new family welcome kits and ensuring gas cards are available for transportation to medical appointments.