

Virginia Hemophilia Foundation | **SPEAC**ing for the Bleeding Disorders Community

Who We Are

The Virginia Hemophilia Foundation (VHF) is dedicated to serving and supporting the needs of those impacted by a bleeding disorder through education, advocacy, and community. Our vision is to become the recognized voice and go-to resource for those impacted by a bleeding disorder.

Who We Serve

VHF has served those affected by inherited bleeding disorders for the state of Virginia since 1975. We also help monitor blood product safety and advocate for adequate and affordable health insurance for the general public.

Why We Serve Them

There is currently no cure for inherited bleeding disorders. There are very effective treatments available in the US, but they may require lifelong infusion of expensive drugs that are manufactured from human plasma or through recombinant biotechnology.

A child with severe hemophilia can spend over \$200,000 per year to treat bleeding with intravenous doses of the missing clotting factor. Some children and adults build up inhibitors, or antibodies, to the treatment making it difficult to control bleeding. When this happens costs can exceed \$1,000,000 per year.

Hemophilia can result in: Bleeding within joints that can lead to chronic joint disease and pain. Bleeding in the head and sometimes in the brain which can cause long term problems, such as seizures and paralysis. Death can occur if the bleeding cannot be stopped or if it occurs in a vital organ such as the brain.

The entire family is affected by the bleeding disorder physically, emotionally, and financially. With over 40 years of experience, we provide programs and services to people affected by inherited bleeding disorders so that they can better cope and can become self-advocates for themselves and/or their family. We partner with Hemophilia Treatment Centers (HTC's), other agencies, and medical professionals to provide programs and services unique to those with bleeding disorders to best meet their needs.

How We Serve Them

VHF strives to meet the needs of those affected by an inherited bleeding disorder through several programs and services.

We **SPEAC** (Support, Prevent, Educate, Advocate, Cure) for the community we serve:

SUPPORT - Families affected by inherited bleeding disorders

- Determine what needs are unmet and develop programs to meet those needs
- Provide people with inherited bleeding disorders and their families with a forum for learning, sharing, and supporting one another
- Protect the patient choice of product

PREVENT - Complications such as joint limitations, chronic pain, and financial and emotional hardships

- Provide people with inherited bleeding disorders and their families with a safe environment for discussion regarding treatment, access to care, and quality of life
- Work in tandem with the HTC's to promote a healthy lifestyle and preventative care

EDUCATE - Families, health care providers, and the community on the unique needs of those with inherited bleeding disorders

- Deliver quality educational programs and resources that meet the needs of the community for all stages of life
- Inform the general public about inherited bleeding disorders and VHF
- Advise the community about all of the programs and services offered
- Teach community members how to become their own self-advocates

ADVOCATE - At local and national levels through improved communication with policy makers

- Develop a strong advocacy role for health-related issues regarding the inherited bleeding disorder community
- Build relationships with and provide education to legislators, insurance directors, and state health and Medicaid departments
- Monitor legislation that may have a direct impact on the community's concerns
- Provide information for issues and concerns related to health care programs, services, and access

CURE - By supporting groundbreaking research

- Keep abreast of innovations and developments with industry manufacturers
- Contribute to the Judith Graham Pool (JGP) Postdoctoral Research Fellowships that supports the science and pre-clinical research in bleeding disorders

Where We Are Going

We are on the road to a cure by reducing morbidity and improving the outcome and quality of life. The next step toward a cure is to provide treatment that requires fewer weekly infusions. Until that is possible, we are focused on treating the total person, with programs to provide emotional support, educational programs to provide more knowledge about insurance and treatment, and youth programs to promote healthy living, independence, and planning for the future. We are advocating to guarantee funding for federal hemophilia programs and research, to ensure blood and blood product safety, and to protect access to affordable, quality care and treatment. We are increasing awareness about bleeding disorders so that patients are diagnosed and treated sooner and become a part of our community sooner so that we can enhance their quality of life.

What We Need

With the programs and services, we have provided over the past 35 years, we have seen improved preventative treatment, a better understanding and importance of insurance, and continued access to treatment. We have helped children transition to adulthood; live a full, healthy, and productive life; and become a self-advocate for

their care. However, there are many others to help and many challenges to overcome.

In order to continue effectively serving those with inherited bleeding disorders, we need financial resources, board commitment and participation, volunteer recruitment and involvement, increased communication with health providers, increased public awareness, and a strong strategic direction and focus.

How You Can Help

We have the expertise and experience to provide the needed programs and services, but we are continually in need of financial support to make this happen. Without that support, individuals with inherited bleeding disorders may not get the treatment and support they need which can lead to greater risk of complications and permanent, debilitating injury. Please join us in helping make a difference in their lives so that they can lead a long, productive, and healthy life.

Your support will go a long way!

- \$2,000 pays for a Lyman Fisher College Scholarship
- \$1,000 supports Educational Scholarships for National Meetings
- \$500 helps to send a kid to a week of Camp Youngblood
- \$250 provides one family emergency assistance
- \$100 supports a family's attendance to our annual state education meeting
- \$50 pays for a lifesaving Medic Alert Tag
- \$25 ensures gas cards are available for transportation to medical appointments