SPEACing for the Bleeding Disorder Community

Who We Are

The Bleeding Disorders Association of Northeastern New York (BDANENY) 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

BDANENY has served those affected by bleeding disorders for northeastern New York since 1968. We also help monitor blood product safety and advocate for adequate and affordable health insurance for the public.

Why We Serve

Bleeding disorders are life threatening, debilitating, and expensive to treat. A child with severe hemophilia will spend over $200,000 annually to prevent bleeding. Some children and adults build up inhibitors to the treatment and the costs can exceed $1,000,000 per year. Failure to treat the disorder can result in prolonged painful bleeds that cause permanent and severe damage. Access to affordable and adequate health care is critical to being a self-sufficient, contributing member of society.

When a person has a bleeding disorder, the entire family is affected—physically, emotionally, and financially.

With over 45 years of experience, the BDANENY provides programs and services to people affected by bleeding disorders so they can better cope and can become self-advocates for themselves and/or their family. We collaborate with Hemophilia Treatment Centers, other agencies, and medical professionals to provide programs and services unique to those with bleeding disorders to best meet their needs.

Support Prevent Educate Advocate Cure

333 Broadway Suite 320 Troy, NY 12180 (518) 729-3577
How We Serve

The Bleeding Disorders Association of Northeastern New York strives to meet the needs of those affected by a bleeding disorder through several programs and services. We SPEAC for the community we serve:

SUPPORT – Families affected by bleeding disorders
- Determine what needs are unmet and develop programs to meet those needs
- Provide people with 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 bleeding disorders and their families with a safe environment for discussion regarding treatment, access to care, and quality of life

EDUCATE – Families, health care providers, and the community on the unique needs of those with 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 bleeding disorders and BDANENY
- Advise the community about all of the programs/services offered
- Teach community members 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 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
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 for health care access, product choice and blood safety so that all those we serve receive the best care based on their needs. 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 45 years, we have seen improved preventative treatment, a better understanding of the 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 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.

CURE – By supporting groundbreaking research
- Keep abreast of innovations and developments with industry manufacturers
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 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.

$2,000 pays for college scholarships for individuals affected with a bleeding disorder

$1,000 will send an individual to an NHF/HFA Annual Meeting

$750 provides one family emergency assistance

$500 sends a child to a week of camp at Camp High Hopes, Camp Little Oaks or the Double H Camp.

Yes! I can help children and families living with bleeding disorders!

$100 supports a family’s attendance to our annual meeting

$50 pays for a family of five to attend our Snowflake Fest

$25 helps assure that patients attend their annual visit at the HTC through our Clinical Travel Assistance Program (CTAP)

Board of Directors
David Huskie– President
Bruce Weiner-Vice President
Cindi Keeler-Treasurer
Jeff Bostwick
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