

Quarterly Newsletter

2025 Q1

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Upcoming Events

Annual Education Retreat | April 26-27, Roanoke, WV

WE ARE BACK at Stonewall Resort! The Annual Education Retreat brings together families from all over West Virginia for a weekend of education, bonding, and networking. It includes excellent education sessions, and opportunities for community members to connect. Looking forward to seeing all of you in April!

Camp Winaca HemoVon | June 9-13, Marlinton, WV

Camp Winaca HemoVon is a 5-day residential camp for children ages 7-17 who have either a bleeding disorder or a childhood cancer diagnosis. Mission: To positively impact and enrich the lives of children diagnosed with cancer or bleeding disorders by offering a camp experience, independent from their family, in a medically safe and educationally supportive environment while promoting personal growth, self-worth, self-reliance and creativity through activities and the development of personal relationships that will carry over to their daily lives and throughout their lifetime.

Summer Catch Up | August 9, Oglebay Resort, Wheeling, WV

This year's Summer Catch Up will be an exciting collaboration with the Western PA Bleeding Disorders Foundation. We will host a joint event at beautiful Oglebay Resort in Wheeling WV. You and your family will have the opportunity to learn and connect with families in the morning and enjoy all that Oglebay Resort has to offer in the afternoon. Registration is not open to join us for a day of education and fun!

WV Unite for Bleeding Disorders Walk | September 7, Morgantown, WV

The Walk is about YOU! It's an awareness event- to teach people about bleeding disorders that affect YOUR loved ones. It's a community gathering – to have fun with other people in YOUR community. It's a fundraiser- to provide programs and services that YOU take part in. With a CARNIVAL atmosphere and FOOD to enjoy, this is sure to be a great way to share in family fun for a good cause!

Visit the [Events Calendar](#) to learn more or register for any of these great events.

News

Important Treatment Updates

Read more about updates regarding treatments that may affect you.

[Medical Advisory #430: Regarding Recall of Lot \(# EY0330\) of ALTUVIIIO](#)

[Takeda Announces Discontinuation of Two Hemophilia Treatments](#)

Recap



2025 Women's Retreat Recap

The 2025 WV Chapter Women's Retreat was a SMASHING success. Thirty women from across 3 states joined together to learn more about women with bleeding disorders.

Some of the highlights included creating ways to track bleeds, learning to self-advocate with doctors, and doing Yoga in ways not thought possible. Women were able to connect and share stories, learn from each other, and create lasting friendships.

Mark your calendar for the next Women's Retreat occurring March 28-29, 2026, in Parkersburg, WV. We will also be adding a few sessions for MEN during the retreat, so keep on the lookout for more information in the coming months!!!

Thank you to our sponsors!

Thank you to our Presenting Sponsors: Takeda, Infucare RX, Novo Nordisk. Thank you to our exhibit sponsors: CSL Behring, Next Step SP, and Hemophilia Alliance.

News

March is Bleeding Disorders Awareness Month

Did you know that our special month for raising awareness about bleeding disorders has been around for almost 40 years? It all started back in 1986 when President Reagan set aside March as National Hemophilia Awareness Month. This happened during a really tough time when many in our hemophilia family were affected by contaminated blood products.

For about 30 years, the focus was mainly on hemophilia. But in 2016, something important changed - the month was officially renamed to "Bleeding Disorders Awareness Month." This new name recognized that our community includes people with many different conditions - not just hemophilia, but also von Willebrand disease, rare factor deficiencies, and platelet disorders.

[Explore the BDAM Toolkit](#)



Bean in a Jar

Spring is the time for growth and renewal. Watch and learn as a bean sprouts and grows, or use this experiment to start plants for in your spring garden. Learn more here.

News

Win Big When You Give

Bleeding Disorders Awareness Month is in full swing, and there's still time to make a difference by participating in our Unite for Bleeding Disorders Walk Recruitment Campaign in partnership with CVS Specialty Pharmacy!

By taking part, you'll be entered for a chance to win a \$100 Amazon gift card, provided by NBDF. Even better, TEN lucky participants will win!

Here's how you can enter in just three simple steps:

1. Register for your local Unite for Bleeding Disorders Walk.
2. Receive a \$25+ donation by March 31st.
3. That's it—you're automatically entered to win!

News

First VWD Patient Dosed with Investigational Sub-Q Therapy

Hemab Therapeutics recently announced that the first patient has been dosed in their phase 1/2 clinical trial of HMB-002, an investigational subcutaneous therapy for patients with von Willebrand disease (VWD). It is developed with a monovalent antibody to increase levels of both von Willebrand factor and factor VIII. HMB-002 is a prophylactic therapy to prevent bleeding in people with all types of VWD.

The trial, known as Velora Pioneer, is designed to evaluate the safety, tolerability, pharmacokinetics, pharmacodynamics, and efficacy of HMB-002 in individuals with VWD. According to a Hemab press release, this first patient was administered HMB-002 at Richmond Pharmacology in London under the supervision of Principal Investigator, Dr. Ulrike Lorch. The study is currently enrolling additional participants. The company also presented preclinical data on HMB-002 at the recent 18th Annual Congress of the European Association for Haemophilia and Allied Disorders (EAHAD).

“Von Willebrand Disease is characterized by a deficiency in VWF activity and sometimes associated with lowered levels of FVIII – both essential to control severe bleeding,” said Dr. Priyanka Raheja, the Royal London Hospital, Barts Health NHS Trust. “HMB-002 functions by increasing VWF and FVIII and could offer a complete disease correction for some and substantial modification for bleeding tendency for others. I am excited to be a contributing investigator on the Phase 1/2 trial.”

Source: Hemab Therapeutics press release dated February 27, 2025

Resources

- [Financial Assistance](#): If you are struggling to pay bills, need transportation or a hotel room for treatment, or aren't receiving the medical supplies you need- we have assistance to help with that.
- [Dental Program](#): We have funding to pay for dental care throughout the state and may be able to help you find a dentist if you need one.
- [Community Resources](#): Here are a few other resources for community members.

If there is anything you need that we can assist you with, please reach out! We're here for you.