



Quarterly Newsletter

2024 Q1

In this newsletter you'll find:

- Upcoming Events
- Women's Retreat Recap
- Washington Days Inspires Advocates
- Spring Into Fundraising
- Spark STEM Corner: Natural Egg Dyes
- Meet Mary Lou

Upcoming Events

Annual Education Retreat | April 20-21, Sutton, WV

- 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. The Annual Education Retreat will be held at a new place this year at the Flatwoods Days Inn and Conference Center! Come join us as we continue to grow the bleeding community and show you are not alone in all of this!

Camp Winaca HemoVon | June 10-14, Marlinton, WV

- This is a 5-day residential camp for children and teens ages 7-17 who have either a bleeding disorder or a childhood cancer diagnosis. It offers a camp experience for youth to be independent from their family, in a medically safe and educationally supportive environment while promoting personal growth, self-worth, self-reliance and creativity.

Summer Catch Up | July 20, Grafton, WV

- Join us for the Tygart Lake Summer Fun Day! Fun Days include an educational lunch and a day at the Adventure Lake. This is a great opportunity to just hang out with other community members, explore exciting new things, and most importantly have fun!! The day will start with lunch at the lodge at 11am and then you can enjoy the lake and splash park until it closes at 6:00 PM.

Visit the [Events Calendar](#)

Recap

2024 Women's Retreat

The 2024 WV NBDF Women's Retreat was a resounding success! We had over 20 women and girls attend a full day of learning and connection. The day started with our community members meeting with our wonderful sponsors. Then we went into our program, with the theme of "self-care".

Our first speaker was Cathy Tiggs, LSW, from Cleveland HTC. She shared many mental health facts, as well as how our community can cope with bleeding disorders.



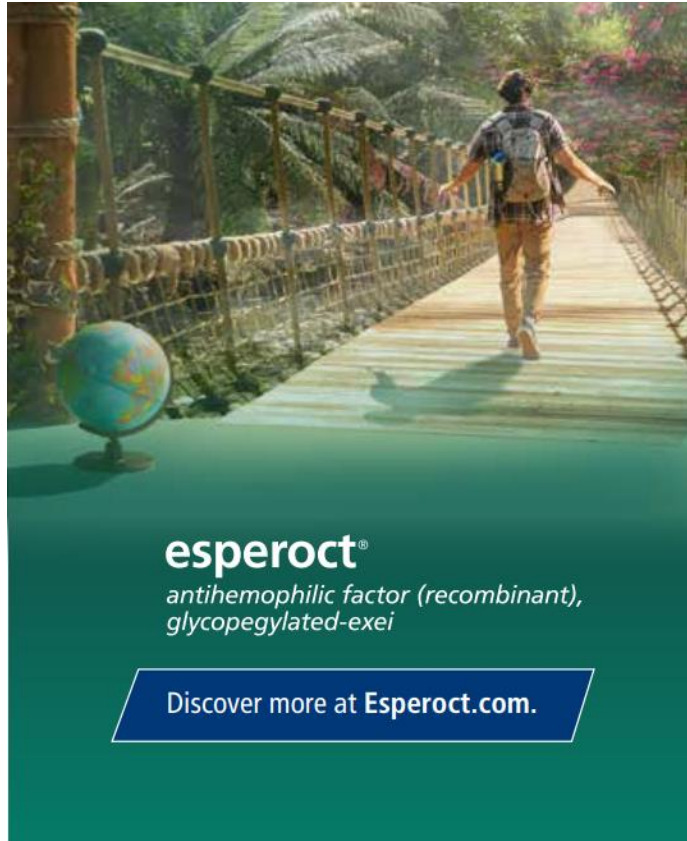
Next, Stormy Johnson spoke about how we perceive ourselves and how others perceive us. We participated in an activity called "Kintsugi" where we broke a small porcelain dish, then put it back together, symbolizing that sometimes we are broken, and we can find a way to be beautiful in our brokenness. Our last speaker of the day was Dr. Angie Forsyth, DPT. She shed light on the mechanics of a joint bleed and provided practical ideas for the participants to manage the bleeds and keep the health of the joint intact.

We ended the first day with a wonderful dinner and connection time. On Sunday, we met and discussed issues that our WV families face, connected with each other, and had lunch before we said our goodbyes. The retreat was much needed for many in attendance, and we look forward to the 2025 WV NBDF Women's Retreat!

Thanks to our Women's Retreat Sponsors!



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Advocacy in Action

Washington Days Inspires Advocates



Community members, Crystal Blackwell and Eric Pence, join NBDF staff at Senator Manchin's office for their first time advocating in Washington DC on behalf of West Virginians with bleeding disorders.

Each March, volunteers from around the country come together to learn more about advocacy and meet with their representatives to discuss the needs of the bleeding disorders community. Like last year, the big topics of discussion included continued funding for HTC's and the need for a federal ban on Copay Accumulator Adjuster Programs (CAAPs) through support of the *HELP Copays Act*.

Copay Accumulator Adjuster Programs create an issue because they say that copay assistance doesn't count towards a person's out of pocket maximum or deductible. This means that after assistance from the pharmaceutical manufacturer runs out, patients will still need to pay up to their out-of-pocket max before their insurance will kick in and cover the rest, leaving medications too costly for many people to afford.

West Virginia has a ban on CAAPs programs, but that doesn't cover all types of insurance. So, while many West Virginians are protected, there are still many people struggling to access their medication. Federal legislation through support of the *HELP Copays Act* would eliminate this issue for everyone. Learn more about the *HELP Copays Act* [HERE](#).

News

Spring Into Fundraising

Have you heard of **Unite Your Way**? It's a program that allows you to build your own fundraiser for the chapter. This could be anything from holding a bake sale in your neighborhood to getting family and friends to sponsor you for every mile you run. We wanted to highlight an upcoming fundraiser that you can be a part of. The Coen Family is planning a [Purse Bingo](#), with all proceeds going to the chapter. If you like bingo, purses, or just supporting the community, come check it out.

We also wanted to shout out the Unite Walk teams, Team "Poke"emon and Wybie's Warriors, for starting off early this year. Thank you so much! And if YOU want to get involved with the Unite Walk, [sign up here](#).

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Supporting our community
is the foundation of what we do



That's why Novo Nordisk goes beyond offering a broad range of treatments and is dedicated to providing educational resources and one-on-one support!

We have **resources** for people living with:

- Hemophilia A
- Hemophilia B
- Hemophilia A with inhibitors
- Hemophilia B with inhibitors
- Glanzmann's thrombasthenia when platelets don't work
- Factor VII deficiency
- Factor XIII A-subunit deficiency

Get connected locally with one of our Hemophilia Community Liaisons (HCL) to see how they can help you!



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Natural Egg Dyes

Did you know you can make your own dye for eggs from old vegetable scraps, berries, flowers, and even spices? Check out [this video](#) testing a variety of homemade dyes and learn more about the science behind egg dyeing [here](#).

News

Meet Mary Lou WV Chapter Interim Executive Director



Hello! I am Mary Lou Warner. I work for the National Bleeding Disorders Foundation (NBDF) as the Manager of National Chapter Operations, and I also work for you! I will be taking over the lead role at the chapter as we search for the next Executive Director. I live in Des Moines, Iowa and am married with two teenage boys and two dogs. I have been in the community since 2020, when I took on the role of Executive Director for Bleeding Disorders of the Heartland (formerly Hemophilia of Iowa). In 2022, I transitioned to NBDF to work exclusively with the National Chapters. I have learned so much from this community and am humbled to serve you. Please feel free to reach out to me at any time, as I would love to connect with you and hear about you!

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.