



WEST VIRGINIA CHAPTER NATIONAL HEMOPHILIA FOUNDATION

SUMMER E-NEWSLETTER 2022

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Save the Date !

The following dates and events are subject to change

Black Bears Baseball: June 25, Morgantown, WV

- Come join us for a Black Bear Game sponsored by BAYER and SOLEO HEALTH. Snacks will be provided. Tickets are limited to 20 people. So make sure you register before we run out! It will be at the Monongalia County Ballpark. **Tickets are limited, so get them now!**

Chapter Meet & Greet Potluck: August 6, Nicholas County Veterans Memorial Park

- Join us for games, field events, and fun. We'll play cornhole, eat delicious food, and hang out. The park has a playground, pool, and skate park! It's also National Root Beer Float Day, so I think we'll have to make a variety of floats as a way to wrap up the day.

Bleeding Disorders Conference: August 25-27, Virtual or Live in Houston, TX

- This is the largest conference of its kind in the US, with high-caliber educational programs for key members of the bleeding disorders community: consumers, chapter leaders, healthcare professionals, and industry.

Unite for Bleeding Disorders Walk: September 17, Live in Charleston, WV

- This year's walk will be held in Charleston for the first time, with a PARK TAKEOVER at Glendale Park. Although this is our biggest fundraiser of the year, it's also a day to come together and celebrate. The bleeding disorders community is not just the people who are affected, but the friends, family, caretakers, and health care providers who support them. This is a day for all of us!

Check out our Events Calendar or Facebook for up to date info and registrations for events.

[View the Events
Calendar](#)

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to help you

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Annual Meeting Recap

Our first back-in-person Annual Meeting was a huge success. We had over 70 community members, medical professionals, industry partners, and staff participate in the event which was held at Stonewall Resort.

Educational topics included talks about mental health, physical therapy, joint protection, insurance options, and self-advocacy. We also had a talk about home infusion followed by an infusion workshop thanks to staff from the WVU HTC and Camp Winaca Hemovon.

After the talks community members spent time together enjoying the pool and rec area. Thank you to everyone who attended the annual meeting this year! We hope to see you at more events!



Annual Meeting Financials

We want to be transparent about the cost of our programs, so here is a breakdown of the financials from the Annual Meeting:

COSTS: 30,800

Costs include meals and rooms for participants, supplies, and staff travel and work time.

INCOME: 34,500

Income comes from sponsors of the program.

*****Nearly \$2000 of our costs were spent on food and rooms for people who registered and didn't alert us that they would not be attending.**

That's enough to help four people with financial assistance requests.***

Please if you are not able to attend an event that you have registered for, let us know so that we can cancel it appropriately.

Thanks again to our Annual Meeting Sponsors and Partners

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There's an easy new way for you to support our education, advocacy, and financial assistance programs. Just shop and Kroger will donate up to \$10,000 a month!

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STEP 3: Search for WV National Hemophilia Foundation and enroll.

That's it! That's all you have to do to make a difference in our community! The more people we enroll, the more money we will raise, so make sure to tell your friends and family that shop at Kroger.

[Enroll Today!](#)

Bayer Announces Discontinuation of Kogenate® FS

From the NHF Website:

Bayer has announced that they are discontinuing the recombinant factor VIII product Kogenate® FS. First approved by the U.S. Food and Drug Administration in 1993, the therapy has carried multiple indications for children and adults with hemophilia A. The company cited the increasing shift in patient usage towards newer extended half-life products as a primary consideration in the decision. The emergence of novel non-factor hemophilia therapies in recent years may also be contributing to this trend away from standard half-life therapies.

The company anticipates a potential depletion of the larger vial sizes of Kogenate® FS during the fall of 2022, with supplies of the smaller vial sizes likely to be available into 2023. Bayer has set up a hotline (1.833.40.BAYER) to field questions specific to the discontinuation. The line will be available Monday through Friday from 8:30am-8:00pm ET. More information can also be found on a [company webpage](#).

More information about various medications used to treat hemophilia A is [available here](#). If you are affected by this change, speak to your doctors to come up with a new treatment plan.

NHF does not give medical advice nor engage in the practice of medicine. NHF under no circumstances recommends a particular treatment for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.



UNITE FOR BLEEDING DISORDERS



The Unite for Bleeding Disorders Walk is quickly approaching. We've decided to change it up a bit, so this year's walk will be at Glendale Park in Charleston, on September 17th. The walk is designed to provide hope for the thousands of families forced to face the challenges caused by bleeding disorders. We are proud to be one of the many locations participating in the NHF Unite for Bleeding Disorder Walk Program.

The walk is our biggest fundraiser, and it is vital to have our community help in making this successful. All funds raised will go directly back into the community to help to continue supporting awareness, education, advocacy, research, and financial assistance programs for our bleeders.

If you can't make it that is ok! You can still make a difference by donating, sharing, and/or going on your own walk to support the cause. Make sure to send us your photos and videos so we can share them with the community and honor you support.

[Learn More Here](#)

We Still Have iPads!

We still have iPads available through our Virtual Connectivity Program. If you live in one of the following counties, you may be eligible for a FREE iPad.

Boone, Cabell, Kanawha, Lincoln, Logan, Mason, Mingo, Wayne, Western Putnam

Contact me (Chelsea) at chilty@hemophilia.org or 304-261-9622 for more info.

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Winaca Hemovon Camp Recap



Camp Winacca HemoVon was a big success this year. Camp is for kids and teens aged 7-17 who have a bleeding disorder or cancer diagnosis and is put on by the HTC's in West Virginia. Campers spent a week walking through the creek, roasting marshmallows, and playing games. They were troopers in the rain and had a cabin lip sync off.

The camp has tons of fun stuff to do, including riding horses, ziplining, swimming, and lots of sports. Staff also work with campers who need help learning how to self-infuse, and have a nightly talk session with the teens where they can talk through problems and feelings they are having.

If you have a 7-17 year-old next summer, we highly recommend signing up for this camp.



Dental Program

We now have funding to provide financial assistance for dental work throughout the state. If you haven't been to the dentist for awhile, need a cleaning, or need major work done, please contact the chapter, or ask your HTC staff about the program.

[Find Out
More Here](#)