

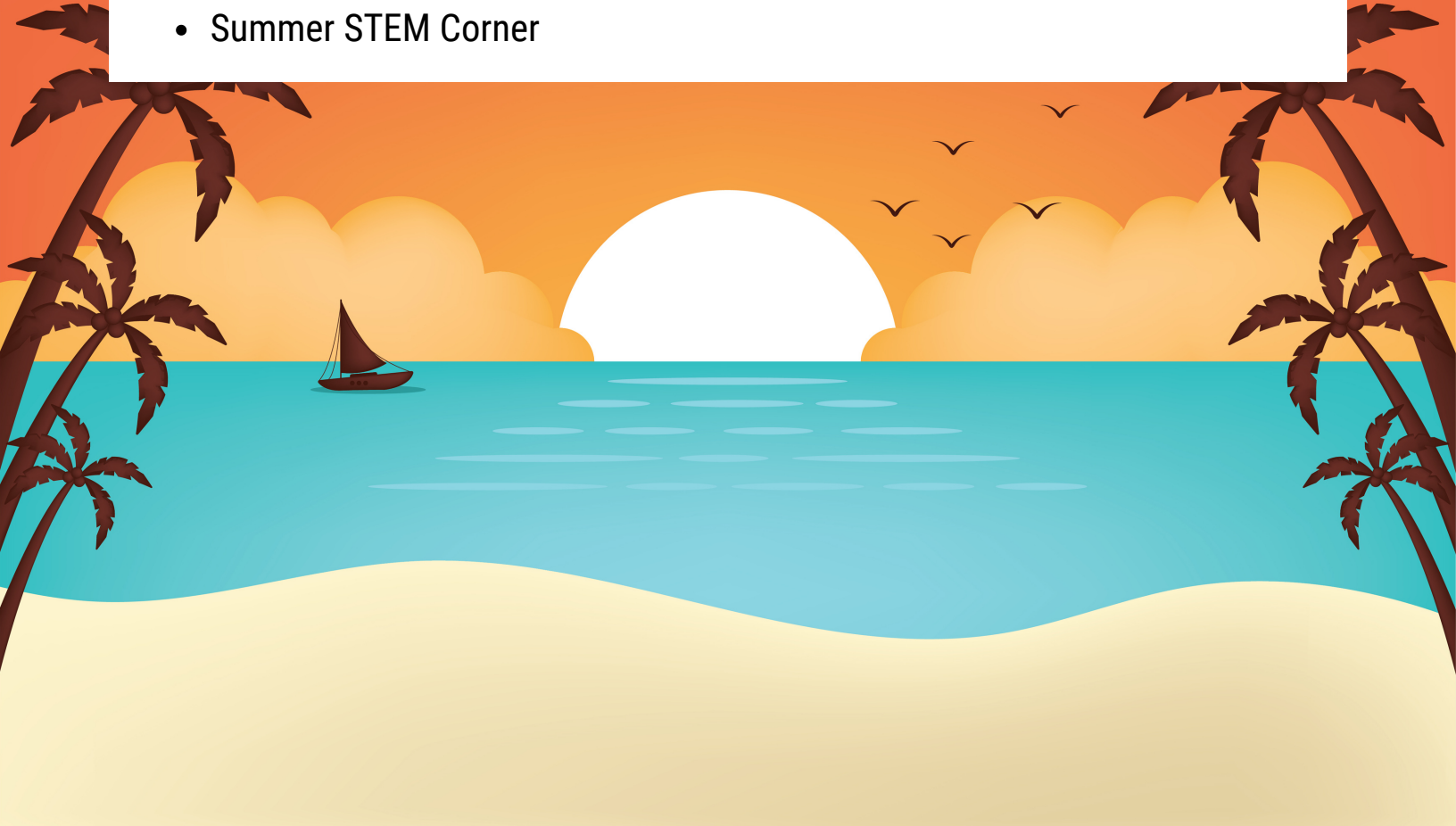


WEST VIRGINIA CHAPTER NATIONAL HEMOPHILIA FOUNDATION

SUMMER E-NEWSLETTER 2023

In this newsletter you'll find:

- Save the Dates for upcoming programs
- Advocacy in Action
- Bleeding Disorder Substance Use and Mental Health Access Coalition (BD SUMHAC)
- Junior National Championship
- Get Ready to Unite
- Annual Education Retreat Recap
- Summer STEM Corner





Save the Date !

The following dates and events are subject to change

Tygart Lake Summer Fun Days: July 29, 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 until it closes at 6:00 PM.

NHF's Bleeding Disorders Conference: August 17-19, National Harbor, MD

- NHF is thrilled to announce the 75th Annual Bleeding Disorders Conference (BDC)! Join us for three full days of educational sessions, networking opportunities, and access to our exhibit hall. Your registration includes entrance to our Opening Session, Awards Luncheon, and our exciting Final Night Event. We also have an Educational Kids Program available for children 12 years old and younger.

CSL Behring Junior National Championship: October 6-8, Henderson Nevada

- Developed by CSL Behring, the Gettin' in the Game Junior National Championship (JNC) was the first and currently the only national sports competition designed specifically for the bleeding disorders community. We have spots for 2 children/teens aged 7-18. You must apply and be chosen for this event.

Spokes Men for Bleeders: October 7, Harpers Ferry, WV

- Spokes Men for Bleeders is a grass roots awareness and fundraising effort started by West Virginia parents, Steve & Lisa Nick. Steve & Lisa have two sons with severe hemophilia. Years ago, Steve decided to begin a one-day, one-hundred-mile bike ride to bring awareness to West Virginians who live each day with bleeding disorders. In turn, Steve & Lisa partner with WVNHF and sponsors to throw a finish line party for the riders and community members. All proceeds from his ride benefit WVNHF.

Unite For Bleeding Disorders Walk: October 29, Morgantown, WV

- The Unite for Bleeding Disorders Walk this year will be a bit spooky. We plan to make this event extra fun with costume contests, games, activities, and trick-or-treat along the walk route. This is our biggest fundraiser of the year! It will be great! Funds raised support families affected with bleeding disorders living in West Virginia.

Check out our [Events Calendar](#) or [Facebook](#) for up to date info and registrations for events.

Advocacy in Action



Medicaid Cuts

There are concerns that Congress may cut funding for and create new barriers to coverage and care under Medicaid. Medicaid is critical to the community, with about 30% of people with a bleeding disorder using it for coverage.

We need to act NOW to let our Senators and Representatives know that we oppose any provision that creates barriers to access to the Medicaid program.

[Sign the Petition](#)

Advocacy Trainings

Be on the look for our regional advocacy trainings coming this fall! We'll have one in each of the panhandles, one in Morgantown, and one in Charleston.

Advertisement

There are ways
to help you

**AFFORD YOUR
HEMOPHILIA A
MEDICINE.**

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Bleeding Disorders Substance Use & Mental Health Coalition

In late 2021, a 20-year-old individual with a bleeding disorder asked their HTC for help in finding a residential treatment facility for his substance use disorder. He was denied access due to his need for IV medications. Without the proper treatment he overdosed and died.

BD SUMHAC was formed to address the issue of people with bleeding disorders being denied residential treatment for mental health and substance use. In surveying HTCs across the country, they found that multiple people with bleeding disorders had been denied access to these facilities.

BD SUMHAC has an advocacy plan in place to fight against this practice and has created a toolkit to help HTC staff who are trying to help their patients into residential treatment centers. [Learn more about the coalition here.](#)

Support BD SUMHAC

WVNHF is matching up to \$200 of donations to support this work. [Check out the fundraiser here.](#)

Looking for mental health or substance use resources?

Call 988 for the Nation Suicide and Crisis Hotline or text HOME to 741741 for the Crisis Text Line.

For local help visit the [WV Bureau for Behavioral Health.](#)



Developed by CSL Behring, the Gettin' in the Game Junior National Championship (JNC) was the first and is currently the only national sports competition designed specifically for the bleeding disorders community.

Kids aged 7-18 will learn about the importance of physical fitness in managing a bleeding disorder, build relationships with fellow members of the bleeding disorders, and participate in baseball, basketball, golf, or swimming activities to learn the fundamentals and enhance their skills in that sport. [Learn more about the JNC.](#)

Important Notes:

- This program is for kids and teens aged 7-18. One parent or guardian will accompany the participant.
- CSL Behring covers all travel costs and meals during the event.
- There are only 2 spots available. Applications are due August 1st and will be chosen via a lottery. [Apply Here](#)



Get Ready to Unite!

Formerly the National Hemophilia Walk, Unite for Bleeding Disorders is a nationwide event that raises funds and awareness for all bleeding disorders. Participants raise money for crucial research, advocacy and education by joining together in a fun and festive event.

This year's Unite walk is in Morgantown on October 29th. We're going to dress up, decorate pumpkins, and trick-or-treat.

How to Get Involved:

- **Become a Team Captain:** You can make the most impact by starting your own Walk team. By becoming a team captain, you can share your personal story by letting people know why supporting the bleeding disorders community is so important to you. The more people who join and fundraise for your team, the more impact you can make!
- **Make a Donation:** Maybe you aren't in a place to be on a Walk team this year. You can donate to the Walk or select a team and help them reach their goal.
- **Volunteer:** This year's Walk will include a costume contest, a pumpkin patch, and trick or treating. You can volunteer to help with one of these fun activities, registration, or set up.

[Support the Walk](#)

[Fundraising Guide](#)



Wybie's Warriors

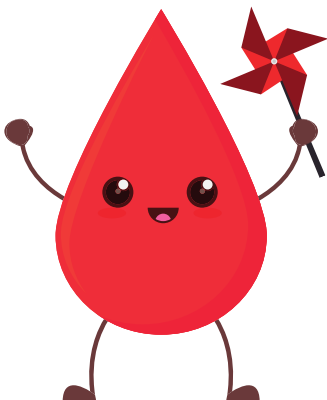
📍 2023 UNITE WALK (Morgantown, WV)

JOIN OUR TEAM

SUPPORT US

Shout out to our TOP TEAM!

Keep up the good work everyone!



ANNUAL MEETING RECAP



We had a great time this May at the Annual Education Retreat at Stonewall Resort. We had over 20 families and 15 industry partners in attendance. We were lucky enough to have GutMonkey join us again for the teen program. This year we tried to focus more on community, with more talks specific to the chapter and its members. We had a great fireside talk at the end of program led by WV community member Eddie Harbert where we talked about HTC's, treatment in the past vs today, and how to advocate for yourself and your family. Look for the save-the-date for next year's meeting, coming soon!

THANK YOU TO OUR SPONSORS!

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Solar S'mores!

Take advantage of the summer sun by building an oven out of an old pizza box and a few items you probably have laying around the house. Eating s'mores in the pursuit of science sounds like a win-win. [You can find the instructions here.](#)