



WEST VIRGINIA CHAPTER NATIONAL HEMOPHILIA FOUNDATION

SPRING E-NEWSLETTER 2023

In this newsletter you'll find:

- Save the Dates for upcoming programs
- Advocacy in Action
- Happy Bleeding Disorders Awareness Month
- Walking for Awareness
- Women's Retreat Recap
- Spring STEM Corner

*Happy Bleeding Disorders
Awareness Month*





Save the Date !

The following dates and events are subject to change

Now Conference: April 21, Phoenix, AZ

- The Now Conference is a national educational conference for individuals and families who are living with VWD. It is a forum to learn about new medical advances, to gain tools that can help you better manage your disorder, and to share with others facing the same or similar challenges. If you are accepted to this event they will cover most of the cost, and have daycare for children.

Harpers Ferry Aerial Adventures: April 22, Harpers Ferry, WV

- Join our friends at Medexus Pharma, DrugCo, & Octapharma for a day of outside adventure at the River Riders Family Adventure Resort in Harpers Ferry, WV. We will start out with an educational lunch in The Pavilion followed by zip lining and rope adventures on your own.

Annual Education Retreat: May 7, Roanoke, 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 Stonewall resort again this year! 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 5-9, 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 Fun Days: TBD

- This year we will be trying something new! instead of having Family camp we have decided to try Summer Fun Days! By doing it this way we can make sure everyone in the state gets the opportunity to attend with less distance to travel! Family fun days will give the opportunity for community members to connect, explore new exciting things, and most importantly have fun!! Stay tuned as we finalize dates for July!!

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. Apply for financial assistance to attend this event on the event calendar!

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

All About Advocacy



Advocacy is an essential part of WVNHF's missions. It's an opportunity for individuals like YOU to tell their stories, share any struggles, and talk to law makers about issues important to the bleeding disorders community. You may not realize it, but there are people advocating on behalf of the community all the time. Advocates work to lower drug costs, fund HTC's, and teach representatives what it's really like to be affected by a rare disorder. Read more to learn what the chapter is doing and how you can get involved with this important work.

WVNHF Advocacy

In February we visited Charleston to speak with state representatives about the West Virginia Rare Disease Advisory Council, why we were against co-pay maximizer legislation, and to educate legislators about bleeding disorders and Medicaid redeterminations.

Earlier this month we attended Washington Days, NHF's largest advocacy event of the year. During Washington Days, community members and staff are trained on federal issues like funding for HTC's and lowering out of pocket drug costs. Then we split up by state and visited the offices of WV's Congress including Senators Capito and Manchin, and Representative Mooney.

Get Involved

You can make a difference by becoming an advocate for the West Virginian bleeding disorders community. Later this year we're having advocacy workshops throughout the state that will teach the basics. You don't have to have any prior experience, just a willingness to learn. More advocates mean more stories, and a louder voice! Stay tuned for more info on the upcoming workshops.



Happy **BLEEDING DISORDERS AWARENESS MONTH**

Bleeding Disorders Awareness Month started in March 2016, after being designated as a national health observance by the U.S. Department of Health and Human Services. We are excited that we've received a proclamation from Governor Jim Justice, declaring March as Bleeding Disorders Awareness month in West Virginia. Visit [NHF's website](#) for more Bleeding Disorder Awareness Month info.



Register for the Unite Walk and make or receive a \$25 donation during Bleeding Disorders Awareness Month

Be entered to win one of FIVE \$250 Amazon gift cards provided by  **NATIONAL HEMOPHILIA FOUNDATION**
for all bleeding disorders

Receive the 2023 Unite Walk t-shirt

AND a WVNHF travel mug



The Unite for Bleeding Disorders Walk is the largest awareness campaign and fundraiser for West Virginia each year. Funds raised during the walk support events like the Annual Meeting, help cover hotel stays for people who need medical treatment, and just keep the lights on at the chapter. The Walk's success is based totally on the participation of the community.

[Register for the Walk](#)

Advertisement

FACTOR UP with ALTUVIIIIO™

Higher-for-longer Factor VIII levels in the near-normal to normal range (**over 40%**) for most of the week

ALTUVIIIIO™
Antihemophilic Factor (Recombinant),
Fc-VWF-XTEN Fusion Protein-ehtl



HIGHER FACTOR LEVELS FOR LONGER
Above 40% for most of the week (near-normal to normal range).^{*†}

48

HOUR HALF-LIFE IN ADULTS

In a Phase 3 study,[†] ALTUVIIIIO offered adults the longest half-life of any Factor VIII therapy.

0.7

BLEEDS PER YEAR[‡]

Mean annual bleed rate observed in 128 people previously treated with prophylaxis therapy.[‡]

In people taking ALTUVIIIIO in the XTEND-1 study, 21% of people had headache, 16% had joint pain, and 6% had back pain

^{*}Average trough levels were 18% for adults 18 years and older, 9% for adolescents aged 12 years to under 18 years, 10% for children aged 6 years to under 12 years, and 7% for children aged 1 year to under 6 years.

[†]159 adults and adolescents with severe hemophilia (aged 12 years and older) were enrolled in the XTEND-1 study; 133 people were in Group 1 and switched to ALTUVIIIIO prophylaxis from prior prophylaxis therapy. Efficacy of prophylaxis was evaluated in 128 of these patients.

[‡]Data based on treated bleeds.

CONNECT WITH YOUR CoRe TODAY

Learn more about ALTUVIIIIO, living with hemophilia, and treatment options from your local CoRe.



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Serving DC and the Virginias

INDICATION

ALTUVIIIIO™ [antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-ehtl] is an injectable medicine that is used to control and reduce the number of bleeding episodes in people with hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ALTUVIIIIO when you have surgery.

IMPORTANT SAFETY INFORMATION

What is the most important information I need to know about ALTUVIIIIO?

Do not attempt to give yourself an injection unless you have been taught how by your healthcare provider or hemophilia center. You must carefully follow your healthcare provider's instructions regarding the dose and schedule for injecting ALTUVIIIIO so that your treatment will work best for you.

Who should not use ALTUVIIIIO?

You should not use ALTUVIIIIO if you have had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ALTUVIIIIO?

Tell your healthcare provider if you have had any medical problems, take any medications, including prescription and non-prescription medicines, supplements, or herbal medicines, are breastfeeding, or are pregnant or planning to become pregnant.

What are the possible side effects of ALTUVIIIIO?

You can have an allergic reaction to ALTUVIIIIO. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called "inhibitors" against ALTUVIIIIO. This can stop ALTUVIIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

The common side effects of ALTUVIIIIO are headache, joint pain, and back pain.

These are not the only possible side effects of ALTUVIIIIO. Tell your healthcare provider about any side effect that bothers you or does not go away.

Please see full [Prescribing Information](#).

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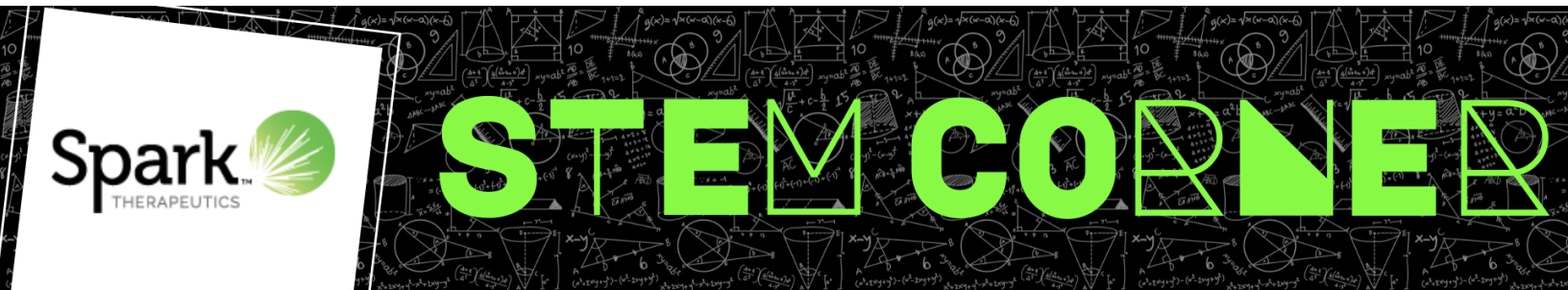
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Women's Retreat Recap



This month we had West Virginia's first Women's Retreat. Ladies came from every corner of the state and even Ohio to spend the weekend in Parkersburg. It was a fun weekend full of community and long needed education just for women. We are hoping to partner with other chapters to throw have an even bigger retreat next year.

Thank you to our sponsors: Medexus Pharma, Bayer, Takeda, InfuCareRX, HPC Specialty Infusion, Novo Nordisk, and NHF!



Did you know research shows that being in nature can have a beneficial effect on physical and mental health? Spending time in a natural environment has been linked to:

- Reduced stress
- Lower heart rate
- Increased rates of healing from injury
- Lower risk of depression
- Increased focus and attention

Check out a few STEM activities that will get you outside this Spring.

[25 Nature Crafts \(some are for adults, some for kids\)](#)

[Visit one of the nearly 50 WV State Parks](#)

[Plant a butterfly garden](#)