



WEST VIRGINIA CHAPTER NATIONAL HEMOPHILIA FOUNDATION

SPRING E-NEWSLETTER 2022

In this newsletter you'll find:

- Save the Dates for upcoming programs
- A summary of our Virtual Washington Day
- Information on our new online forum
- From HemAware: What's the Latest on the Stimate Nasal Spray Recall?
- Updates on the Dental Program
- Claim your free iPad

*Happy Bleeding Disorders
Awareness Month*



Save the Date !

The following dates and events are subject to change

Camp Winaca HemoVon: June 6-10, 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.

Family Camp: June 10-12, Marlinton, WV

- Our weekend long sleep-away camp provides time for affected families throughout the state to come together, share experiences, and bond. Our new camp location has a pool and lake to fish or kayak on, tennis and basketball courts, archery and crafts. And obviously there will always be time for a campfire and s'mores.

Camp BleedSTEM: July 10-17, Morgantown, WV

- This is the camp for those teens who ask the big questions, who want to know how things work, and if they can be improved. Teens affected by a bleeding disorder entering 9th -12th grade will spend the days working to solve engineering challenges and spend the nights staying in WVU's dorms.

Chapter Meet & Greet Potluck: August 6, Location TBD

- Join us for games, field events, and fun. We'll play cornhole, eat delicious food, and hang out. 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 it's kind in the US, with high-caliber educational programs for key members of the bleeding disorders community: consumers, chapter leaders, healthcare professionals, and industry.

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

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

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A **ONCE-WEEKLY**
TREATMENT OPTION
FOR HEMOPHILIA B.

HOW DOES
THIS FACTOR IN?

To find out about a prescription
option, talk to your doctor or visit
[OnceWeeklyForHemophiliaB.com](https://www.OnceWeeklyForHemophiliaB.com)

NHF Washington Days



Although it was virtual, we were still able to host our annual Washington Days advocacy event where community members reach out to their state representatives on topics that are important to the Bleeding Disorders Community. We had a meeting with the offices of both Senator Manchin and Senator Capito to talk about two main issues.

1. To request funding for HTC's and national programs that research bleeding disorders and their treatments.
2. To push for the HELP Copays Act which allows financial assistance programs to count towards a person's copay costs.

It was great to meet with the staff and talk about the issues.

Join Our Online Forum: WVNHF Stronger Together

We've created a Facebook group for members of the West Virginia Bleeding Disorders Community to talk openly with each other, share resources, lend a hand, and connect.

It's open to anyone affected by a bleeding disorder and their family members. If you have a question, are struggling with an issue, or are good at giving advice, please consider joining the group.

[Join the Page Here](#)

Ask a Social Worker: What's the Latest on the Stimate Nasal Spray Recall?



This article is from NHF's Bleeding Disorders Magazine

Posted & Updated
February 14, 2022

Ask a Social Worker is a monthly column featuring questions from the community and answers from members of NHF's Social Work Working Group. If you have questions for our social workers, send them to askasocialworker@hemophilia.org.

Dear Lucy:

Are there any updates on the recall status of Stimate Nasal Spray?

In the hemophilia treatment center (HTC), social workers wear many different hats. One of the roles we are commonly asked to fulfill is to be a bridge to the rest of the HTC team and to the wider bleeding disorders community. Though we may not always have the answer, we are always willing to help find the answer or point patients and their families in the right direction. While the recall status of Stimate does not fall within our scope, I was happy to connect with members of my multidisciplinary HTC team to find an update for you.

The short answer is that Stimate Nasal Spray is not a commercially available treatment option at this time, and it probably won't be until the second half of 2023. Medical providers and patient advocacy groups are well aware of the hardship that the Stimate recall created for many people living with mild bleeding disorders who cannot easily access home infusion treatments. The National Hemophilia Foundation, the Hemophilia Federation of America and other patient advocacy groups have expended a great deal of effort through petitions to the Food and Drug Administration and pharmaceutical manufacturers to work on solutions that will address the needs of these patients.

Meanwhile, HTC physicians and pharmacists are always available to discuss treatment options with our patients and their family members. If your current treatment plan is not working for you, I strongly suggest that you ask your medical providers for assistance.

Medications often come in a variety of formulations, so trying a different form of a medication or adjusting the treatment schedule may be the key to successfully managing symptoms. The purpose of the multidisciplinary HTC team is to help our patients manage their bleeding disorders in a way that works for them and allows them to lead active, healthy lifestyles.

We understand that the adjustments required to live with a bleeding disorder are not always easy, so we welcome feedback from our patients on how we can better serve their needs.

—Lucy Ramirez, MSW, LCSW

Ramirez is a social worker at Rush Hemophilia and Thrombophilia Center in Chicago and a member of the Social Work Working Group.

[More HemAware Here](#)



Dental Program

With help from the CAMC HTC, our Dental Program is moving forward with folks from the southern part of WV starting to see providers who have been specifically trained to work with people with bleeding disorders.

The WVU HTC has also made some progress and will now be providing financial assistance to people who get treated through the WVU School of Dentistry.

We've applied for 4 grants so far this year to help train providers and provide financial assistance to community members who need dental work. Fingers crossed that we'll be able to provide this service statewide.

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.

WVNHF Financial Assistance Program

The Financial Assistance program is part of the West Virginia Chapter of the National Hemophilia Foundation's continuing effort to improve the quality of life of individuals and families affected by bleeding disorders by providing financial support. The Financial Assistance program is supported by generous contributions from individuals, foundations, and corporations committed to the bleeding disorders community.

[Financial Assistance Here](#)

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Dedication and Personal Support

Your Pfizer Patient Affairs Liaison is a professional dedicated to serving you and the hemophilia community by connecting patients and caregivers with Pfizer Hemophilia tools and resources. These Pfizer colleagues are committed to continuing Pfizer's more-than-20-year history of listening to the hemophilia community and working to meet its needs.



Linda Pollhammer

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"I've had experience with the rare disease community for over 35 years. Working with the community and helping them with their challenges is where I'm in my element."

My work is guided by:

Compassion

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Educating you about Pfizer's tools and resources, including the Pfizer Community Connections Program, the HemMobile® app for logging bleeds and infusions, B2B materials, and more

Connection

Connecting you with hemophilia advocacy groups and programs like Leading Edge, the National Hemophilia Foundation, The Coalition for Hemophilia B, and others

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