



Quarterly Newsletter

2024 Q3

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Upcoming Events

Spokes Men for Bleeders | October 5, Inwood, WV

- This 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. All proceeds from his ride benefit WVNBD. In turn, Steve & Lisa partner with WVNBD and sponsors to throw a finish line party for the riders and community members. This year, Spokes Men for Bleeders raised just over \$20,000 for the chapter, which is an all-time high for the event! All of the money raised will stay at the local chapter and be directed towards programs and events that benefit the West Virginia Bleeding Disorders community. WVNBD would like to thank Lisa and Steve for all of their hard work over the last 10 years, as they have raised a total of \$104,000 for the chapter!

Unite for Bleeding Disorders Walk | October 27, Morgantown, WV

- Join WVNBD for Halloween fun at the Unite for Bleeding Disorders Walk which will be held at Marilla Park in Morgantown. We plan to make this event extra special with costume contests, games, activities, and trick-or-treat along the walk route. Please consider participating, forming a team, or simply donating to the Unite Walk. We would love to see you at this family friendly event! Funds raised support families affected with bleeding disorders living in West Virginia. Click [HERE](#) to learn more about how to participate in the Unite Walk.

Virtual Holiday Party | December 5, 2024

- Let's wrap up the year by coming together and spreading some holiday cheer! Come join us for an evening of fun crafts and snacks, while we compete to win prizes. It's a great way to wrap up the year while bonding and is the last chance to see our WVNBDP chapter family before the holidays!

Visit the [Events Calendar](#)

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Are You Covered? It's Not Too Late for Medical Insurance.

As part of the COVID-19 public health emergency (PHE), state Medicaid programs were not allowed to conduct the typical annual re-determination process for beneficiaries. Stated simply, state Medicaid programs could not remove anyone from their rolls. This policy ended, however, and between February 1, 2023, and May 31, 2024, every single person enrolled in Medicaid – approximately 90 million people – had to have their eligibility redetermined (this is known as the Medicaid Unwinding). As of late summer 2024, all but five states have completed their initial redeterminations. Coverage losses have been large: according to KFF, almost 25 million Americans were disenrolled nationally, with wide variation in disenrollment rates across the states.

If you have lost your Medicare/Medicaid coverage, it's not too late to apply through the [Marketplace](#).

The Centers for Medicare and Medicaid Services (CMS) created a temporary special enrollment period (SEP) to help people who are no longer eligible for Medicaid or CHIP transition to Marketplace coverage in states using [HealthCare.gov](#). The SEP will run through November 30, 2024, which will overlap with the November 1 start of marketplace open enrollment.

RECAP 2024 Bleeding Disorders Conference

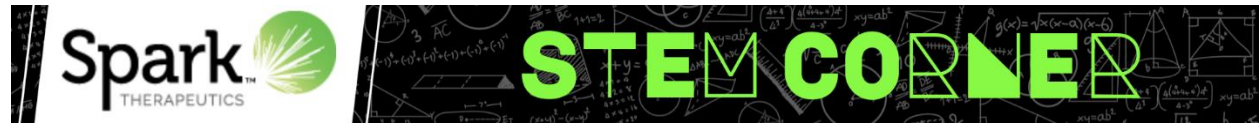


The 76th annual Bleeding Disorders Conference was held September 12-14 in beautiful Midtown Atlanta, GA. The WV chapter was able to send 2 community members to learn, grow and connect with others across the country, thanks to a travel grant provided by our friends at the Hemophilia Alliance.

The community members experienced three incredible days of educational sessions, networking, and exhibits. At the opening session, Phil Gattone, NBDF CEO, laid the foundation for his vision of “one voice” as NBDF continues to support and enhance the communities we live in and the chapters that serve these communities.

Closing ceremonies included many individuals recognized for their work within the bleeding disorders community, as well as a relaxing final night of connection at the Finale Party.

We look forward to offering a travel grant in 2025 to attend the 77th Bleeding Disorders Conference in Denver, Colorado, on August 21-23, 2025. See you all there!!!



Invisible Ink

Ghosts aren't the only ones invisible this fall. Check out this easy [invisible ink recipe](#) for a fun fall project.

News

From Patients to Pioneers: How Lived Experience Experts are Revolutionizing Bleeding Disorders Research

In a session that felt more like a heartfelt conversation among friends than a formal presentation, the National Bleeding Disorders Foundation (NBDF) research team opened our eyes to a powerful truth: the most valuable experts in bleeding disorders research are often the patients themselves.

Naomi Miller, Research Programs and Partnership Specialist with NBDF and Eliza VanZweden a member of the National Youth Leadership Institute (NYLI), passionately conveyed how "Lived Experience Experts" (LEEs) – individuals living with bleeding disorders – are not just subjects of research, but vital collaborators in pushing the boundaries of treatment and care.

"Every experience, every challenge, every triumph you've had is a piece of the puzzle we're trying to solve," Naomi emphasized, her eyes sparkling with conviction. The room nodded in collective understanding – who better to guide research than those navigating the daily realities of these conditions?

But it wasn't all rose-colored glasses. The team candidly addressed the elephants in the room – the fears, the time constraints, the mistrust that often keep patients from participating in research. As Eliza put it, "We get it. It's scary to step into the unknown. But that's where the magic happens."

The real magic, however, came when Nandini Pethe, Lived Experience Expert and Eliza shared their personal journeys. Their stories of transitioning from patients to advocates left many of us misty-eyed. "There were days I felt overwhelmed," Nandini admitted, "but then I'd remember – my voice could be the one that makes a difference."

As the session wound down, there was a palpable shift in the room. Eyes that had entered with uncertainty now gleamed with possibility. It was clear – in the world of bleeding disorders, every voice counts, every experience matters.

For those ready to take the leap, the [Community Voices in Research \(CVR\) registry](#) awaits. It's more than a database – it's a platform for change, a megaphone for the unheard, a bridge between lab coats and lived realities.

As we filed out, the chatter was electric. "Maybe my story could help," I overheard someone say. And isn't that the heart of it all? In this community, we're not just patients. We're pioneers, trailblazers, the experts of our own experiences. And together, we're writing the future of bleeding disorders care, one shared story at a time. For more information about Community Voices in Research, visit bleeding.org/CVR.

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.