WPBDF
Western Pennsylvania Bleeding Disorders Foundation

HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

SPRING 2023

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WPBDF
Western Pennsylvania
Bleeding Disorders Foundation

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Staff office hours are Monday-Friday from 9 a.m. until 4 p.m. Every attempt will be made to return calls received during regular office hours on the same day.

MISSION STATEMENT

WPBDF strives to enrich the lives of those with bleeding disorders in Western Pennsylvania and respond to the needs of the community in a dynamic environment.

DESIGNATE UNITED WAY GIFTS TO THE CHAPTER

If your company is participating in the United Way campaign, you may designate all or a portion of your gift to the Foundation.

WPBDF Contributor Agency Code Number is: 83

EVENTS CALENDAR

May 2, 2023
Gene Therapy Research: Understanding the Science
Grand Concourse
Pittsburgh, PA

May 19-20, 2023
Parents & Tiny Tots
Wyndham University Center
Pittsburgh, PA

May 24, 2023
Hemgenix Program
Atria's Tavern
Murrysville, PA

June 11, 2023
Common Factors Program & Pittsburgh Pirates Baseball Game
Renaissance Pittsburgh Hotel

July 13, 2023
Hemgenix Program
Location TBA
Erie, PA

July 16, 2023
WPBDF Annual Meeting
Sheraton Station Square
Pittsburgh, PA

July 30 - August 4, 2023
Camp Hot-to-Clot
Camp Kon-O-Kwee
Fombell, PA

August 11, 2023
Back to School
Dave & Busters - North Hills
Pittsburgh, PA

August 17 - 19, 2023
NHF BDC
Gaylord National Resort & Convention Center
National Harbor, Maryland

August 26, 2023
Women's Wellness Day
Pittsburgh Botanic Garden
Pittsburgh, PA

September 9, 2023
Unite for Bleeding Disorders Walk & Run for Their Lives 5K
North Park Swimming Pool
Allison Park, PA

September 14, 2023
Hemgenix Program
Location TBA
Robinson Twp., PA

September 23, 2023
New Parent Network
Kennywood
West Mifflin, PA

October 14, 2023
Fall Program
Wexford, PA

October 24, 2023
Insurance Program
Location TBD

December 2, 2023
Take A Bough Fundraiser
Red Fox Winery
Hickory, PA

December 9, 2023
Winterfest
Shadow Lakes Country Club
Aliquippa, PA

VISIT WPBDF.ORG FOR MORE INFORMATION ON OUR UPCOMING EVENTS.

Do you have a great OBGYN?

Please share with us if you have an OBGYN who provides the comprehensive care and understanding which you require for your or your daughters' bleeding disorder! We would like to know the providers in PA who are taking great care of our community.

**Scan this QR code
OR
Follow this link to complete our form**

https://forms.gle/nhcvrQjrSWzzwdfX8

CONTACT US

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@WPABDF

LETTER FROM THE EXECUTIVE DIRECTOR AND BOARD PRESIDENT

Dear Chapter Members & Friends,

Spring is here! Even though the weather is still a bit chilly, we hope everyone takes time to enjoy the fresh air and sunshine. We have a lot of great events coming up and are so excited to see everyone.

March was Bleeding Disorders Awareness Month, and we started off the month advocating for the community by holding a state-wide Advocacy Ambassador Retreat. We had over 50 advocates in attendance! It was wonderful teaming up with the Eastern Pennsylvania Bleeding Disorders Foundation to hold this event, and we are looking forward to many more joint events in the future. We also participated in NHF's Washington Days and along with Foundation staff, were able to bring 10 advocates from Western PA. It was a great experience to see our advocates in action, and I am so thankful for all their hard work and dedication.

We received proclamations from all over Western Pennsylvania which worked to spread awareness and recognition of bleeding disorders. We are continuing to meet with local legislators to ensure funding to all seven Hemophilia Treatment Centers in Pennsylvania, and we would love your participation. Please email kara@wpbdf.org to receive more information on how to get involved in our Advocacy Ambassador Program.

We have increased our ability to provide emergency financial assistance and are continuing to make our Grocery Assistance Program permanent and ongoing. This year, and through this program alone, we have been able to grant 87 requests totaling nearly $30,000. If you need assistance, please do not hesitate to reach out. We are here to help.

Every day, through many different obstacles, your kindness makes our work possible. When you donate, volunteer, or advocate, your work makes a lasting impact for people right here in Pennsylvania. We simply cannot do it without you! Your support means the world to us.

Thank you for all you do on behalf of the bleeding disorders community.

Sincerely,

Kara Dornish, Executive Director

R. Scott Domowicz, Board President

ADVOCACY UPDATE

PENNSYLVANIA ADVOCACY AMBASSADOR RETREAT

On Saturday, March 4, 2023, the Western and Eastern Pennsylvania Bleeding Disorders Foundations came together to hold a Pennsylvania Bleeding Disorders Advocacy Ambassador Retreat at the Omni Bedford Springs Resort in Bedford, PA. This was the first time the Pennsylvania Chapters have come together in-person to hold a joint event. We were thrilled to have over 50 advocates from across Pennsylvania participate in this retreat.

Kerry Lange, of our lobbyist firm Milliron & Goodman, started the education portion of the event with a presentation on Pennsylvania Policy. She reviewed the Foundation priorities which includes the budget line-item three-part request, copay accumulator reform, and a proclamation from Governor Shapiro for World Hemophilia Day, as well as the Capitol Building to be lit red to spread awareness of bleeding disorders on April 17.

BUDGET LINE ITEM

As we begin the FY 2023-24 Pennsylvania budget process, we are requesting the following:

- Increase state support from $1,017,000 to $1,250,000;
- Include language in the fiscal code to maintain the existing distribution of funding to the 7 Hemophilia Treatment Centers; and
- Maintain the hemophilia line item as a separate line item in the budget bill.

It is important to note that 100% of the Hemophilia Program line item goes directly to patient care (i.e., mostly for non-billable nursing and social work services vital for patient care) and it is critical to preserve the existing Hemophilia Treatment Center (HTC) model for the comprehensive and coordinated care for patients. A portion is also used as an emergency fund to help patients in financial hardship due to their bleeding disorder. This year, there has been an unprecedented number of requests, and it is anticipated the emergency assistance funds will be used up by the end of the month.

There are approximately 33,000 patients with hemophilia and thousands more with other inherited bleeding disorders in the U.S. More than 3,000 reside and receive care in Pennsylvania at one of the seven-state supported hemophilia treatment centers, recognized as centers of excellence by the Commonwealth. The seven Pennsylvania HTCs are:

1. The Children's Hospital of Philadelphia
2. St. Christopher's Hospital for Children
3. Hospital of the University of Pennsylvania
4. Penn State Hershey Medical Center

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WPBDF ATTENDS NHF'S WASHINGTON DAYS!

It was exciting to be back in-person for the National Hemophilia Foundation's Washington Days this year! Advocates and Chapters from all over the nation joined this event to advocate for support for the federal bleeding disorders programs and access to care. This year, 52 chapters participated from 45 states + Puerto Rico. Nearly 400 advocates were present for over 250 visits on Capital Hill! We were thrilled to team up with the Eastern PA Bleeding Disorders Foundation with a combined PA Team of 26 advocates! The Western PA Bleeding Disorders Foundation staff attended along with 10 advocates from Western PA! These included David Hiller, Matthew Hiller, Delores Johnson, Ethan Webb, Kyrie Holliday, Cassie Miller, Samantha Short, Mindy Perry, Steve Stern, and Ryker Stern. We all headed down to Washington DC on Wednesday, March 8, for training and dinner with our state teams. On Thursday, March 9, the Pennsylvania Team headed to Capitol Hill and had meetings with the offices of Senator Fetterman, Representative Cartwright, Representative Fitzpatrick, Representative Meuser, Senator Casey, Representative Deluzio, Representative Scanlon, Representative Thompson, and Representative Houlahan.

OUR REQUESTS

Federal Bleeding Disorders Programs

There are federal programs that support our community. We ask Congress to support these programs:

- National Institutes of Health (NIH): Funds biomedical research on bleeding disorders. NIH is working to implement a national blueprint for research on inhibitor prevention and eradication.
- Centers for Disease Control and Prevention (CDC): Funds HTC surveillance and prevention activities, and supports outreach and education programs provided by national bleeding disorders patient organizations.
- Health Resources and Services Administration (HRSA): Provides funding for HTCs to provide multi-disciplinary services not typically covered by insurance, such as PT and social work services. Also, as HRSA grantees, most HTCs participate in the 340B Drug Discount Program, which supports comprehensive care offered to all their patients.

Ask: Support federal funding for these programs in the FY24 appropriations processes.

Affordability and Access to Care

What are Copay Accumulator Adjustor Programs (CAAPs) and how do they impact access?

- CAAPs say copay assistance does not count towards a patient's out of pocket (OOP) max. Only dollars paid directly by a person count.
- People with blood disorders who need copay assistance but can't use it may have to use less or stop taking their meds. This causes complications (increased ER visits, joint bleeds/damage, and missed days from work/school) that harm people and increase costs.
- This also affects people with other expensive conditions. NHF helps lead the All Copays

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ELOCTATE®
[Antihemophilic Factor
(Recombinant), Fc Fusion Protein]

JOIN THE CONVERSATION.

LEARN ABOUT ELOCTATE.

Sanofi Community Relations and Education Managers (CoRes) have years of experience working with patients on ELOCTATE and can provide you with helpful resources and support.

MEET YOUR CoRe, CARRIE KOENIG

Serving Western PA
"The resilience and tenacity of the hemophilia community are what inspire me most."

Carrie.Koenig@sanofi.com
(667) 500-4326

Contact your local CoRe

sanofi

NHF'S WASHINGTON DAYS RECAP

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Count Coalition, which includes 120+ organizations representing people with cancer, MS, HIV/AIDS, and other rare and chronic conditions.

- Private plans should be required to count all copays towards a person's OOP max - regardless of who pays.

The Help Ensure Lower Patient (HELP) Copays Act
The HELP Copays Act (HR 830) is a bipartisan bill introduced by Reps. Carter (R-GA) and Barragan (D-CA) that:

- Clarifies the Affordable Care Act's definition for cost sharing to ensure payments made "by or on behalf of" patients count.
- Closes an essential health benefit (EHB) loophole, making any covered item or service part of the EHB package, so that all cost sharing counts.

ASK: House; Ask Representatives to co-sponsor HR 830
Senate; Introduce a companion bill.

On Thursday night, a recognition dinner was held for all the advocates. Ryker and his mom, Mindy, were invited to share their favorite part of the day. Ryker was excited to let everyone know that Representative Deluzio's office supports and will be recommending his co-sponsorship of HR 830.

The next day, we came together for breakfast and state advocacy training. We are excited to take the things we learned in DC back home to Pennsylvania. We will continue to build the relationships we made with members of congress and meet with them in their home district offices. If you are interested in getting involved, please reach out to Kara Dornish at kara@wpbdf.org or 724-741-6160.

FIRST TIME AT WASHINGTON DAYS

SAMANTHA SHORT

I was honored to be chosen by WPBDF to go to Washington Days this year. Starting on Wednesday, March 8, almost 400 advocates from 45 states and Puerto Rico gathered in the ballroom of the Hyatt Capitol Hill to prepare for over 250 scheduled meetings on the hill. Even after a long travel day for most, the room was buzzing with energy.

As a constituent for the 17th district, I was scheduled to meet with Representative Chris Deluzio's staff to discuss overall awareness for bleeding disorders, funding for HTCs and ask for support of HR 830 (HELP Copays Act). I was joined in my meeting by Janet, Jessica and Kara from WPBDF and the Stern family. As we walked to the meeting, the sun was shining, the cherry blossom trees were just starting to bloom and the sheer magnitude of the Capitol building was breathtaking. The emotions of what we were about to advocate for were immense. I took my assignment seriously as I was representing all of you.

I'm happy to report that the meeting couldn't have went any better. Alex, a staffer from Rep. Deluzio's office, was kind and listened to all of our stories. He fully supported our efforts and will recommend the congressman’s full support of the bill. One of the best parts of the meeting was when he encouraged us to keep in contact with him to make sure he was on top of any needs we had.

I encourage anyone interested in advocacy to attend Washington Days. The experience was wonderful. Also, if you see me at a WPBDF event, please come up and introduce yourself, I would love to meet you!

PENNSYLVANIA ADVOCACY AMBASSADOR RETREAT

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5. Thomas Jefferson University Hospital
6. Lehigh Valley Hospital
7. The Hemophilia Center of Western Pennsylvania

The seven-state supported HTCs are critical to the 3,000 Pennsylvanians who receive care at these facilities. Without this support, Pennsylvania will incur approximately 5x more costs for these citizens, from emergency and inappropriate care via Medicaid and lost tax revenue from those who become unable to remain gainfully employed. The Hemophilia Program saves Pennsylvania lives and saves Pennsylvania money.

COPAY ACCUMULATOR REFORM

Drug manufacturers can offer copay assistance programs to assist patients with the purchase of their prescription medications. The goal is to alleviate a person’s out-of-pocket expenses and have the assistance dollars count toward the deductible. The purpose of the assistance programs is defeated if/when insurers implement copay accumulator programs, preventing the drug manufacturer’s assistance from counting towards the insurance deductible and out of pocket maximum.

Legislation

SB 372 (Ward, R-Blair): Amends the Insurance Company Law by requiring insurers to count the drug manufacturers assistance program towards the deductible and out-of-pocket costs. The bill was introduced and referred to the Senate Banking & Insurance Committee on February 21, 2023.

Capitol Discussions

The PA Department of Insurance was opposed to the copay accumulator bill last session and will likely oppose again. Several insurers offered compromise language: maximizers.

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Stakeholders, including the Western and Eastern PA Bleeding Disorders Foundations, oppose maximizers and will not accept this compromise. Maximizers are still not allowing assistance to be counted toward a patient's deductible or out of pocket maximum.

The Bleeding Disorders Foundations have circulated a letter of support for SB 372 this session and are involved in the Pennsylvania All Copays Count Coalition. We are in need of patient stories. If you are experiencing a copay accumulator or maximizer please reach out to Kara Dornish, WPBDF Executive Director, at kara@wpbdf.org or 724-741-6160.

Your stories are crucial as we work on getting this legislation passed. It is also important that you file a complaint with the insurance commissioner, if you are experiencing a copay accumulator or maximizer.

Next, Miriam Goldstein, Interim Vice President, Public Affairs at the Hemophilia Federation of America, presented Hot Topics in Policy. She discussed the two challenges and pressing issues: Protecting Medicaid enrollees against loss of coverage when Medicaid eligibility redeterminations resume and affordability of private insurance.

Medicaid Unwinding

At the start of the pandemic, HHS declared a public health emergency (PHE). In March 2020, responding to the COVID PHE, Congress passed a law boosting federal matching funds for all state Medicaid programs. In

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How to Identify Copay Accumulators

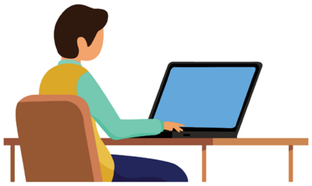
1 Open the Summary of Benefits page for your insurance and review the explanation for your deductible and out-of-pocket maximum.

2 Search the insurance plan's "Schedule of Benefits" for keywords: coupon, copay card, manufacturer coupons, and/or discount prescription card program.

3 Review the Pharmacy Limitations and Exclusions section for any of the above keywords.

4 Call the insurance company directly and ask them about their copay assistance policy.

While not all insurances are implementing copay accumulator programs, many insurance plans include language that allows them to implement these programs at any time. Please look out for these programs before enrolling in an insurance plan. If you experience your insurance policy not allowing copay assistance to be counted toward your deductible or out of pocket maximum, please contact us at 724-741-6160 or email info@wpbdf.org.



How to file a complaint with the Insurance Commissioner.

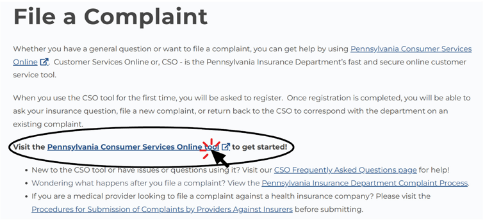
Step One:

Go to:

https://www.insurance.pa.gov/Consumers/insurance-complaint

Step Two:

Click on the Pennsylvania Consumer Service Online Tool (CSO) link.



File a Complaint

Whether you have a general question or want to file a complaint, you can get help by using Pennsylvania Consumer Services Online. Customer Services Online or, CSO - is the Pennsylvania Insurance Department's fast and secure online customer service tool.

When you use the CSO tool for the first time, you will be asked to register. Once registration is completed, you will be able to ask your insurance question, file a new complaint, or return back to the CSO to correspond with the department on an existing complaint.

Visit the Pennsylvania Consumer Services Online tool to get started!

- New to the CSO tool or have issues or questions using it? Visit our CSO Frequently Asked Questions page for help!
- Wondering what happens after you file a complaint? View the Pennsylvania Insurance Department Complaint Process.
- If you are a medical provider looking to file a complaint against a health insurance company? Please visit the Procedures for Submission of Complaints by Providers Against Insurers before submitting.

Step Three:

Login in or, if this is your first time visiting the website, make an account. The CSO Tool will guide you step by step in filing your complaint.

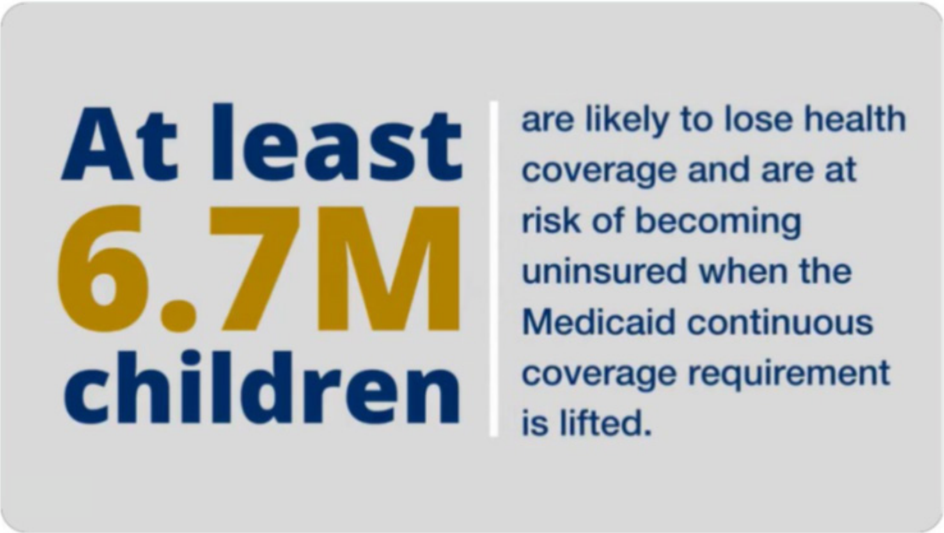
If you prefer not to use the CSO tool, you can choose to download a complaint form and submit it to us using:

Fax:
(717) 787-8585

Email:
ra-in-consumer@pa.gov

Mail:
Pennsylvania Insurance Department
1209 Strawberry Square
Harrisburg, PA 17120

If you have any questions please feel free to reach out to the Pennsylvania Insurance Department toll-free at 1-877-881-6388.


At least 6.7M children are likely to lose health coverage and are at risk of becoming uninsured when the Medicaid continuous coverage requirement is lifted.

exchange for the funding boost, state Medicaid programs had to commit to “maintenance of effort” (MOE) requirements for so long as the PHE declaration remained in effect. This meant that state Medicaid programs were barred from disenrolling existing Medicaid beneficiaries for the duration of the PHE. Since March 2020, the PHE declaration has been continuously renewed. Over this period, Medicaid/CHIP enrollment increased by more than 25%, up to nearly 95 million nationwide – much of this due to the freeze on disenrollments.

In late December 2022, Congress passed a law de-coupling the Medicaid continuous eligibility requirements from the PHE. The law allows states to re-start Medicaid eligibility reviews as early as February 1, 2023, and resume Medicaid disenrollments as early as April 1, 2023. The federal Medicaid regulator (CMS) subsequently released guidance laying out timelines for the Medicaid unwinding.

WHO’S AT RISK FOR LOSING COVERAGE DURING THE UNWINDING?

- Those no longer eligible for Medicaid, including people whose earnings now place them above income for Medicaid coverage. Some will be eligible for ACA Marketplace plans, and/or their kids may be eligible for CHIP – but they will need help navigating their options.
- Those impacted by administrative issues, including:
  - People who have moved and don’t have up-to-date contact information on file with Medicaid.
  - People who have problems getting through the red tape and bureaucratic processes in their state program.

PENNSYLVANIA’S APPROACH TO UNWINDING

- Process will begin in March; first terminations will occur in May. Note that not all renewals will go out in that period. Pennsylvania plans to take the full 12 months allowed by law to send out renewals.
- Pennsylvania Medicaid will send renewal packets via mail.
- Enrollees will receive information about their renewal about 90 days before due date.
- Enrollees can submit their renewals via mail, online portal, telephone, or in-person.
- Enrollees can opt-in to receive text messages from PA Dept of Human Services.
- Enrollees must complete the renewal forms even if they have no changes to report.
- If you or someone you know has Pennsylvania Medicaid:
  - Go to dhs.pa.gov/COMPASS
  - Make sure your contact information is up to date
  - Respond promptly to all communications from Pennsylvania Medicaid

COPAY ACCUMULATOR ADJUSTERS AND MAXIMIZERS

With copay accumulators, the insurer accepts the manufacturer assistance, but the insurer doesn’t credit amounts paid out of the manufacturer copay assistance toward the patient’s deductible or out-of-pocket (OOP) maximum obligations. The insurer draws down the full value of the copay assistance. Once those dollars are used up, the patient is billed for the copay/coinsurance associated with their next prescription fill.

HOW COPAY MAXIMIZERS WORK

Maximizers are typically found in large group/self-funded health plans. The health plan or pharmacy benefit manager (PBM) declares a prescribed drug a “non-essential health benefit” (“non-EHB”). This ploy allows the health plan to disregard Affordable Care Act limits on patient cost-sharing. The health plan or PBM sets the required copay or coinsurance

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for the drug at a level designed to deplete all available manufacturer copay assistance. The health plan or PBM tells the patient that the only way to avoid those excessive cost-sharing amounts is for the patient to sign up with a third-party maximizer program, which will in turn enroll the patient in the manufacturer copay assistance program. So long as the patient complies with these requirements, patient's cost-sharing for their drug will be reduced to $0 or de minimis amount. While the health plan or PBM accepts (in fact, drains) the full value of the manufacturer copay assistance program, none of those dollars count toward patient's total cost-sharing. The patient remains fully exposed to their deductible and OOP for all care other than the non-EHB drug.

FEDERAL-LEVEL EFFORTS TO REIN IN CAAPS AND MAXIMIZERS

- Patient advocates are advocating with the U.S. Congress. HR 830 would apply Copay Accumulator Adjuster Program (CAAP) protections across the board (all 50 states, self-funded employer health insurance as well as state regulated insurance).
- Patient advocates are asking federal agencies to adopt rules banning accumulators. The U.S. Centers for Medicare and Medicaid Services (CMS) issues an annual rule governing operations of health plans for the coming year. HFA and NHF asked CMS to include CAAP protections in that rule for 2024.
- Multiple lawsuits are challenging CAAPs and maximizers in the federal courts.

Next, Matt Delaney, Government Relations Specialist at the National Hemophilia Foundation, presented *How to Advocate*. Matt reviewed where we are in 2023 federally, in Pennsylvania, and on the local level.

FEDERAL

Introduction of the HELP Copays Act in 118th Congress; HR 830 sponsored by Rep. Buddy Carter (R-GA) and Rep. Nanette Barragan (D-CA).

- Bans co-pay accumulator adjuster programs on the federal level, MANY more plans impacted than state-based legislation.

CDC funding for HTC data collection and research, HRSA funding (340B), NIH (research agency), My Life Our Future, (Inhibitor Research).

- $5.1 million for HTC's (CDC, Division of Blood Disorders)
- $3.5 million for CDC Hemophilia Program
- $3.5 million for HRSA Hemophilia Program

IN PENNSYLVANIA

- Maintaining the PA Hemophilia Program in the state budget and keeping it as a separate line item.
- Increase the fiscal year amount in the PA budget from $1,017,000 to $1,250,000 to support all seven-state supported HTC's.
- SB 372 (co-pay accumulator adjuster legislation): Sponsored by Sen. Judy Ward (R-Blair).
- PA Medicaid advocacy, making connections with your state legislators, gene therapy considerations, and regulatory advocacy.

ON THE LOCAL LEVEL

- Bleeding Disorders Awareness Month Resolutions DO matter! It spreads awareness and creates understanding, both amongst lawmakers and the general public. We are the experts on bleeding disorders; the more recognition we receive in the state house, the

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more change can be affected. Lawmakers should go to the community for guidance before making any decision impacting our community. Resolutions can do exactly that!
- We have received resolutions proclaiming March as Bleeding Disorders Awareness Month from the following counties: Beaver, Allegheny, Butler, Fayette, Greene, Lawrence, Somerset, McKean, Venango, and Westmoreland; and the Cities of: Altoona, Canonsburg, Erie, and Johnstown.

Matt shared tips and information on how to be a successful advocate. He explained how advocacy comes in many forms including e-mail, social media, attending town halls and conference calls, letter writing, phone calls to offices, setting up meetings with officials and their staff, and community awareness.

Jessica Graham, Coalition Coordinator at the New York State Bleeding Disorders Coalition, shared tips and stories of success New York had in getting copay accumulator reform passed in New York state. Janet Barone, Program Director of WPBDF, explained how a photo book can be useful in legislative meetings. She shared her photo book and explained how powerful photos can be when telling your story and using it in a way to highlight the legislative issues.

Before dinner, WPBDF staff and members of the community ran through some legislative role plays to give an example of best practices when meeting with lawmakers and their staff. At the end of the night we came together to play PA Advocacy Kahoot! This was a great way to test everyone's knowledge and see how much they learned after a day of education. The competition was fierce, and it was a very close match! Congratulations to the winners, 1st Place: Dave Hiller (aka Jingles!), 2nd Place: Maria Shoemaker, and 3rd Place: Jessica Graham.

The next morning, we broke out into three groups to discuss the PH 95 Loophole, Women with Bleeding Disorders, and Medication Accessibility in Hospitals. Before departing, the groups came together to share their findings.

PH 95 LOOPHOLE

In Pennsylvania, Medicaid will cover children aged 18 and under who are living with a bleeding disorder.

- A child can qualify for Medical Assistance even if she or he has other health insurance.
- The assets of the parent(s), guardians, and the child (money in the bank, stocks bonds etc.) DO NOT count in determining eligibility for Medical Assistance.
- The income of caregivers and guardians other than the parents DO NOT count.
- The income of the parent(s) DO NOT count if the child's condition meets certain disability standards.

You can find more information about this program and all the documents needed to apply here: https://www.phlp.org/uploads/attachments/ck2xjueg002dg5qu8w454mpbf-ph-95-guide-update-april-2019.pdf

You can apply for Medical Assistance using any of the following methods:
1. Online at COMPASS: www.compass.state.pa.us
2. By phone: 866-550-4355 (TTY 800-451-5886)
3. By certified mail using the paper application (download it here: http://services.dpw.state.pa.us/oimpolicymanuals/ma/

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4. In person at your local County Assistance Office.
5. If you have any questions or would like assistance, the social workers at the HCWP are happy to help. Call the Hemophilia Center of Western PA at (412) 209-7280.

WOMEN, GIRLS, AND PEOPLE WITH THE POTENTIAL TO MENSTRUATE WHO HAVE BLEEDING DISORDERS

Unfortunately, in our community, many women, girls, and people with the potential to menstruate who have bleeding disorders share the same story: their doctors never took their symptoms seriously. They were told they couldn't have bleeding disorders, and it took a major and often life threatening event for them to get a proper bleeding disorder diagnosis. We discussed how important it is to share your story and spread awareness of bleeding disorders for the advancement of the current lack of proper diagnosis and treatment for all women, girls, and people with the potential to menstruate who have bleeding disorders. Too many are either going without diagnosis and treatment altogether or are turned away when seeking care. Many are questioned to prove symptoms when standard of care dictates to treat first, seek imaging second. NHF's MASAC has crafted guidelines for treatment of bleeding disorders yet these may not be reaching providers where and when it counts.

What you can do

1. Share Your Story

- If you are a women or person with the potential to menstruate and would like to share your story by writing an article for our newsletter or agreeing to be interviewed for a story, please contact Kara at kara@wpbdf.org.
- Share your story with the FAIR Time for Women Coalition: https://bit.ly/FAIRtimesurvey

Women and Girls
STORIES NEEDED!
Scan the QR code below to get started.

FAIR TIME FOR
WOMEN COALITION

ftfwcoalition@gmail.com

2. Videos

- Make Your Own Video - You can tell your story, list symptoms of bleeding disorders, and direct people to betteryouknow.org and Clinics and Services for Women and Girls with Bleeding Disorders and Sickle Cell Disease: https://www.fwgbd.org/clinics. If you make your own video, please be sure to let us know and tag both the Eastern and Western PA Bleeding Disorder Foundations so we can keep sharing it!
- Share a Video - If you don't want to make your own video, NHF made videos you can share: https://www.betteryouknow.org/spread-the-word/share-better-you-know-video

3. Share Resources

- Get resources out to the community to spread to school nurses, health teachers, college campuses, health clinics, OBGYNs, etc. WPBDF can provide you with literature and handouts to bring to these locations, please contact Kara at kara@wpbdf.org or 724-741-6160.
- The social workers are also great resources and can provide education to school nurses. Call the Hemophilia Center of Western PA at (412) 209-7280.

Medication Accessibility in Hospitals

Sadly, the stories are familiar – patients in Pennsylvania bring their bleeding disorder medication to an emergency department and the hospital refuses to allow them to bring the medication inside the building and/or refuses to administer the medication. Bleeding disorders are rare and factor concentrates are very expensive. Many hospitals do not stock the medication in their hospital pharmacies. Critical time passes by while the hospital is contacting pharmacies to obtain the same medication that the patient has on-hand. It's not unheard of for a patient to leave a hospital to infuse themselves in the parking lot or back at home or to receive care at another hospital. However, in extreme cases, a patient might not be in a condition where they can check themselves out of the hospital or it might be dangerous to their health for them to leave the hospital setting.

NHF's MASAC (Medical and

... CONTINUED ON THE NEXT PAGE

Scientific Advisory Council) Document #257, GUIDELINES FOR EMERGENCY DEPARTMENT MANAGEMENT OF INDIVIDUALS WITH HEMOPHILIA AND OTHER BLEEDING DISORDERS, states, "Patients with bleeding disorders who present to an emergency department for care should receive appropriate, expeditious management. To this end, MASAC has developed the following guidelines. Triage 1) Individuals with bleeding disorders should be triaged urgently as delays in administering appropriate therapy, such as infusion of factor concentrate, can significantly affect morbidity and mortality."

Patients are often advised by their healthcare team to bring their medication with them when they have an emergency, and they should continue to follow those instructions. But what are the rules for hospitals allowing patients to bring their own medication? See the following excerpts:

Federal rules, 45 CFR §482.23(c)(6)
The hospital may allow a patient (or his or her caregiver/support person where appropriate) to self -administer both hospital-issued medications and the patient's own medications brought into the hospital, as defined and specified in the hospital's policies and procedures.

Interpretative Guidelines §482.23(c)(6)(i)
Hospitals have the option of establishing a program for self-administration by patients, or, when applicable, patient caregivers or support persons, of hospital-issued medications. The existence of this regulatory option does not mean that a hospital must offer medication self-administration programs or that a patient has a right to self-administer their medications. Each hospital can establish their own rules.

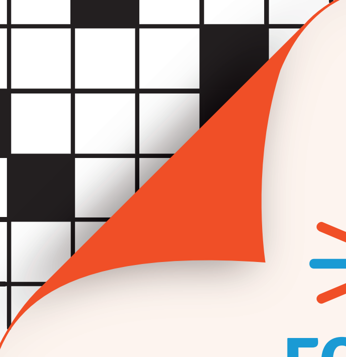
Is there something we can do to help reduce or eliminate delays in administering bleeding disorder medication in emergency settings? We want to better understand the scope of this problem and bring patient stories to the Department of Health to establish an awareness and initiate discussions. Do you have a story about you or a loved one being refused to bring your medication into a hospital or not being allowed to have hospital staff or you/your caregiver administer the bleeding disorder medication that you brought in? If you have experienced either of these or a similar situation, please share your story with us, by filling out this form: https://www.surveymonkey.com/r/NSM2XCK

Please note: It's important to continue to follow the instructions and guidelines your doctor has given you. In an emergency, contact your Hemophilia Treatment Center as soon as possible to let them know you are heading to an emergency department, so they can call the hospital/emergency department and begin coordinating care.

GETTING CHEESY WITH CHEF MIKE!

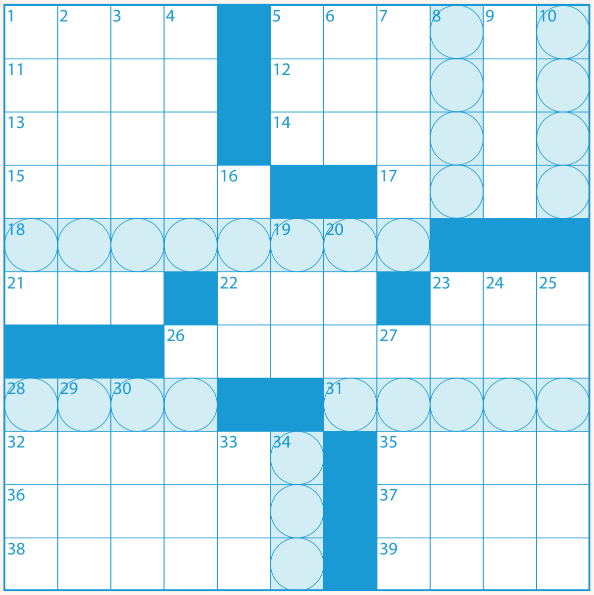
BIOMATRIX

On the evening of Sunday, January 29, our bleeding disorders community came together virtually over Zoom to cook Sunday night dinner together! All the families who registered received a gift card to purchase ingredients before the event and cook along. Chef Mike Hargett taught us how to make lightened up dreamy, creamy broccoli cheddar soup and provided us with some cooking tips to use in the future. Mike Hargett is a professional chef, double transplant recipient, and a person with hemophilia who lives by the mantra that his conditions don't define him; he defines them. Mike trained at Le Cordon Bleu College of Culinary Arts in Portland and completed an externship at the Ritz Carlton in Maui, which led to a variety of restaurant cooking opportunities. As the world's first person with hemophilia to receive a heart and a kidney transplant, Mike's positive attitude, good-humored personality, passion for cooking, and perseverance embody his spirit of "cooking with heart." Thank you to Chef Mike for cooking with us and answering our questions, and thank you to BioMatrix for sponsoring this event!



CAN YOU SOLVE FOR A DIFFERENT HEMOPHILIA A TREATMENT?

Test your HEMLIBRA knowledge



ACROSS

1. Wine barrel
5. Deep fissures
11. Mideast gulf port
12. District
13. Ripped
14. Familiar with
15. Mean
17. Roost
18. The #1 prescribed prophylaxis for people with hemophilia A without factor VIII inhibitors*

*According to IQVIA claims data from various insurance plan types from April 2020 - May 2021 and accounts for usage in prophylaxis settings in the US.

21. Calendar divs.
22. Regret
23. Banquet hosts (abbr.)
26. International travel necessity
28. Check out the _____ treated bleeds data with HEMLIBRA
31. Number of dosing options HEMLIBRA offers
32. Small hole in lace cloth
35. Central Plains tribe
36. Melodic
37. Towering
38. Reduce
39. Spanish cheers

DOWN

1. Memorable, as an earworm
2. Devotee
3. Medical fluids
4. Prepare to propose, perhaps
5. PC's "brain"
6. Owns
7. Concert venue
8. See Medication Guide or talk to your doctor about potential _____ effects
9. Winter hrs. in Denver and El Paso
10. HEMLIBRA is the only prophylactic treatment offered this way under the skin
16. Pre-Euro currency in Italy
19. Subway alternative
20. Relax
23. Human
24. New Orleans cuisine
25. Mentally prepares
26. Collared shirts
27. Instagram post
28. Ardent enthusiasm
29. Brontë heroine Jane
30. Old Portuguese coins
33. Opposite of WNW
34. More than_____ thousand patients have been treated with HEMLIBRA worldwide†

---

† Number of people with hemophilia A treated as of October 2021.

SOLUTIONS

Across: 1. cask, 5. chasms, 11. Aden, 12. parish, 13. tore, 14. used to, 15. cruel, 17. nest, 18. HEMLIBRA, 21. yrs, 22. rue, 23. MCs, 26. passport, 28. zero, 31. three, 32. eyelet, 35. Otoe, 36. ariose, 37. tall, 38. lessen, 39. oles
Down: 1. catchy, 2. adorer, 3. serums, 4. kneel, 5. CPU, 6. has, 7. arena, 8. side, 9. MSTs, 10. shot, 16. lira, 19. bus, 20. rest, 23. mortal, 24. Creole, 25. steels, 26. polos, 27. photo, 28. zeal, 29. Eyre, 30. Reis, 33. ESE, 34. ten

Discover more at HEMLIBRA.com/answers

INDICATION & IMPORTANT SAFETY INFORMATION

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.

These serious side effects include:

- **Thrombotic microangiopathy (TMA),** a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events),** which may form in blood vessels in your arm, leg, lung, or head

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects.**

HEMLIBRA®
emicizumab-kxwh
injection for subcutaneous use | 150 mg/mL

Medication Guide
HEMLIBRA® (hem-lee-bruh)
(emicizumab-kxwh)
injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

Your body may make antibodies against HEMLIBRA, which may stop HEMLIBRA from working properly. Contact your healthcare provider immediately if you notice that HEMLIBRA has stopped working for you (eg, increase in bleeds).

See "**What are the possible side effects of HEMLIBRA?**" for more information about side effects.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use HEMLIBRA?

See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

- See "**What is the most important information I should know about HEMLIBRA?**"

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

General information about the safe and effective use of HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048
HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan

For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 12/2021

HEMLIBRA®
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

Genentech
A Member of the Roche Group

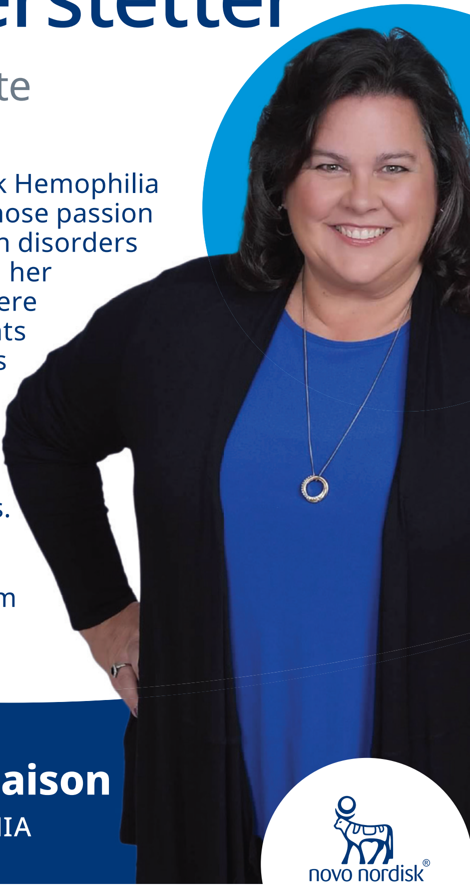
CONGRATULATIONS!

M&G

Congratulations to Kerry Lange, of our lobbyist firm, Milliron and Goodman, for being recognized as Pennsylvania City & State's Above & Beyond which recognizes remarkable women blazing new trails in the state of Pennsylvania. Thank you for everything you do for the bleeding disorders community in Pennsylvania.

Lorie Kerstetter

Patient advocate



About Lorie

Lorie is a Novo Nordisk Hemophilia Community Liaison whose passion for helping people with disorders began years ago when her son was born with severe hemophilia A. She wants to advocate for families in the hemophilia community and is excited to educate them about Novo Nordisk products.

Connect with Lorie

LOKS@novonordisk.com
(717)-368-2851

Hemophilia Community Liaison

NORTHERN APPALACHIA
(WV, Western NY, PA)

novo nordisk®

Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

GETTING TO KNOW HCWP STAFF

TATUM DONAHUE
CLINICAL NURSE

Birthplace: Pittsburgh, PA

First job: Cashier at Shop N' Save

Accomplishment you're proudest of: Raising two toddlers while in nursing school

What three words describe you best? Compassionate, funny, caring

Dream vacation: Greece

Things you can do without: Television, traffic, toxic energy

Person you'd most like to have dinner with: One of my great, great grandparents

Movie you could see anytime: Stand by Me

TV show you try not to miss: Whatever I'm binging on Sunday nights

Three things that can always be found in your refrigerator: Creamer, salsa, eggs

Secret vice: Tiramisu

Who would play you in the movies? Juliette Lewis

Your pet peeve about Pittsburgh: Potholes

People may be surprised to know that: I played basketball from grade school through high school.

IMPORTANT CHANGES COMING TO PA MEDICAID AND CHIP

This content was authored and reused with permission by the Centers for Medicare & Medicaid Services (CMS).

Do you or a family member currently have health coverage through Medicaid or the Children's Health Insurance Program (CHIP)? If so, you may soon need to take steps to find out if you can continue your coverage. Soon, states will resume Medicaid and CHIP eligibility reviews. It's important that you respond to any communications you receive from your CHIP or Medicaid program. This means some people with Medicaid or CHIP could be disenrolled from those programs. Here are some things you can do to prepare right now.

Make sure your address is up to date.
Make sure Pennsylvania has your current mailing address, phone number, email, or other contact information. This way, they'll be able to contact you about your Medicaid or CHIP coverage.

Check your mail.
Pennsylvania may mail, email you, or even text you about your Medicaid or CHIP coverage. This message will also let you know if you need to complete a renewal form to see if you still qualify for Medicaid or CHIP. If you get a renewal form, fill it out and return it to your state right away. This may help you avoid a gap in your coverage.

What if you don't qualify for Medicaid or CHIP?
If you or a family member no longer qualify for Medicaid or CHIP, you may be able to buy a health plan through the Health Insurance Marketplace or Pennie.com.

- 4 out of 5 enrollees can find plans that cost less than $10 a month after tax credits.
- Most plans cover prescription drugs and provider services such as, doctor visits, urgent care, hospital visits, and more.

Visit HealthCare.gov to find Marketplace plans and see if you might save on premiums. When you apply, don't forget to include current information about your household, income, and your state's recent decision about your Medicaid or CHIP coverage.

Get More Information

- Find contact information for your state Medicaid office at https://www.hemophiliafed.org/resource/state-medicaid-websites, and follow instructions for how to contact them.
- Or visit Medicaid.gov for more information about Medicaid or CHIP renewal.
- Call the Marketplace Call Center at 1-800-318-2596 to get details about Marketplace coverage.

PENNSYLVANIA

Copay Assistance Diversion Programs

D

For failing to protect vital patient assistance

Copay Accumulators 101

Millions of Americans endure long and expensive medical journeys to get the medications that best treat their needs. Copay accumulator adjustment policies and copay maximizer programs are schemes from insurers and pharmacy benefit managers (PBMs) that prevent patient assistance funds from counting toward a patient's out-of-pocket maximums, or deductibles. These policies undermine patient access to life-saving prescription drugs, making it more difficult for people living with serious, complex, chronic illnesses to adhere to a treatment plan.

Findings for Pennsylvania 2023 Marketplace Plans

A new report by The AIDS Institute shows that **7 out of 11** plans in Pennsylvania have copay accumulator adjustment policies that harm vulnerable patients.

- These plans have copay accumulators: Capital Advantage Assurance, Keystone Health Plan East (Independence Blue Cross HMO), QCC Insurance Company (Independence Blue Cross PPO), UPMC Health Options, UPMC Health Coverage, Oscar Health, Cigna+.

  +Plan utilizes a copay maximizer or variable copay program.
- These plans do not have copay accumulators: Geisinger Health Plan, Geisinger Quality Options, Highmark, Inc., PA Health and Wellness (Ambetter).

Pennsylvania has received a **D** for failing to protect patient assistance because **63.6%** of marketplace plans have copay accumulator adjustment policies.

Need for State Action

Pennsylvania can join 16 other states to protect residents from these harmful practices by insurance companies and PBMs.

- AR, AZ, CT, DE, GA, IL, KY, LA, ME, NC, NY, TN, VA, WA, WV, and Puerto Rico have enacted legislation that requires insurers to count third party payments, including copay assistance, toward patient cost-sharing limits.

The All Copays Count Coalition suggests the following bill language for Pennsylvania to combat this problem: "When calculating an enrollee's overall contribution to any out-of-pocket maximum or any cost sharing requirement under a health plan, an insurer or pharmacy benefit manager shall include any amounts paid by the enrollee or paid on behalf of the enrollee by another person."

THE AIDS INSTITUTE

Read the full report: theaidsinstitute.org/copays

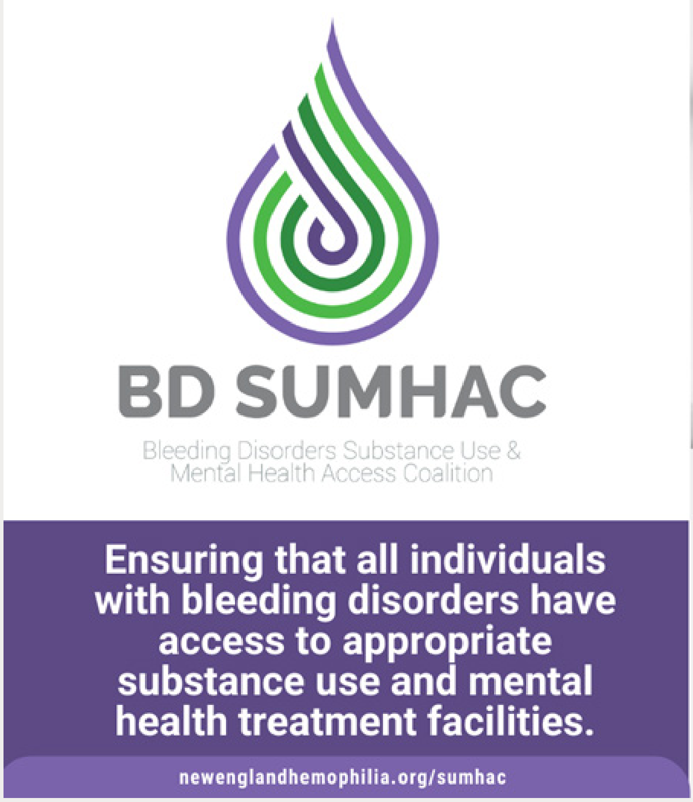
GET INVOLVED IN A NEW COALITION

Is equitable treatment for mental health or substance abuse crises important to you or your connections within the blood and bleeding disorders community? Then you may be interested in getting involved with Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC).

This coalition features members from across the country and a variety of bleeding disorder related groups and chapters, who all unite on one thing: Getting community members the mental health/substance use disorder treatment they so desperately need, when they need it most.

Learn more about the Coalition at https://newenglandhemophilia.org/sumhac.

Expand your advocacy and spread this important word today!

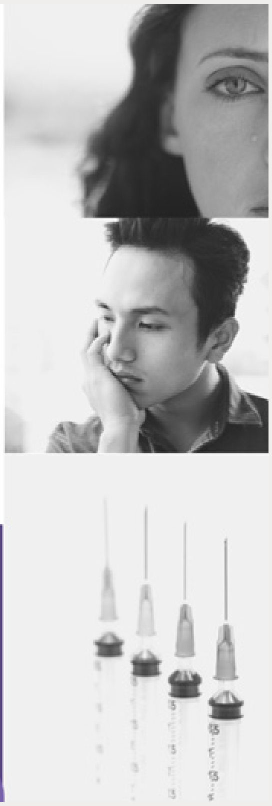


BD SUMHAC

Bleeding Disorders Substance Use & Mental Health Access Coalition

Ensuring that all individuals with bleeding disorders have access to appropriate substance use and mental health treatment facilities.

newenglandhemophilia.org/sumhac



BOWLING FOR BLEEDING DISORDERS BACK IN-PERSON!

The Eighth Annual Bowling for Bleeding Disorders fundraiser was held at Paradise Island Bowl in Neville Island, Pennsylvania on Sunday, February 12, 2023. The cost to attend was $25 per participant which included shoe rental, bowling, pizza, wings, and unlimited soft drinks.

Sixty-Four bowlers competed for the prize of highest score and best style. Congratulations to Todd Z., from Team Cassie, for winning the award for highest score and congratulations to Ryker S., from Team Rolling for Ryker, for winning the award for Best Style!

At this event, we also recognized two individuals for their generosity and support of the bleeding disorders community. Mindy Perry and Lindsay McNany received WPBDF's Community Spirit Award. WPBDF would like to extend a huge thank you to these wonderful ladies!

We are extremely grateful for everyone who participated in this event. We are excited to report that over $8,000 was raised! The money raised will provide emergency and medical patient assistance, educational programs, and support groups to benefit the bleeding disorders community in Western PA.

Thank you to our sponsors:

CSL Behring

Genentech
A Member of the Roche Group

Optum

MINDFULNESS

On Thursday, February 23, WPBDF partnered with Takeda to hold a virtual program on Mindfulness. The program was led by Jan Martin, a Community Education Specialist with Takeda and has been with the company since 2019. She brings 40 years of nursing experience to the table, 22 years in the ICU and 15 years as a nurse coordinator in the HTC at University Hospitals in Cleveland.

Mindfulness means being aware and being present in the moment. It is a skill that takes practice, but when implemented, has many benefits. Practicing mindfulness can lower stress, improve focus, and increase clarity. Jan led us through a series of breathing exercises and encouraged us to take the time to focus on our breath and how we are feeling. We discussed times when we were distracted or stressed and how practicing mindfulness would have been beneficial. Jan taught us ways we can practice mindfulness in everyday life. One of these techniques is R.A.I.N. This acronym tells us to recognize what's going on, allow the experience, investigate with kindness, and natural awareness, which can be used to separate ourselves from the experience and take time to see it for what it is.

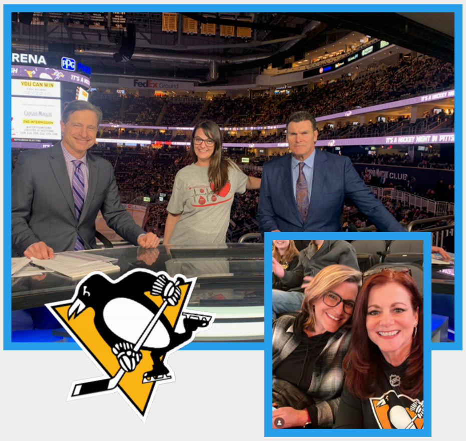
We discussed the importance of taking breaks throughout the day to breathe. Deep breathing sends a message to the brain to relax, which in turn tells the body to decrease the stress responses. Breathing retrains our nervous system's response to triggers and allows us to step back so we can proceed with positivity.

THE WESTERN PA BLEEDING DISORDERS FOUNDATION IS SEEKING NEW BOARD MEMBERS!

ARE YOU PASSIONATE ABOUT THE BLEEDING DISORDERS COMMUNITY? WOULD YOU LIKE TO USE YOUR TIME AND TALENTS TO MAKE A POSITIVE DIFFERENCE? HELP SUPPORT WPBDF'S MISSION BY JOINING OUR BOARD OF DIRECTORS.

Scan this QR code to apply or go to https://www.surveymonkey.com/r/QMM7TFW

PITTSBURGH PENGUINS



On Tuesday, January 24, nearly 70 people came out to not only cheer on the Pittsburgh Penguins as they took on the Florida Panthers, but also showed their support for the Western PA Bleeding Disorders Foundation! A portion of all tickets sold through WPBDF's unique ticket link was donated back to the Foundation. In total, we raised $680 that will provide education, support groups, and patient assistance to individuals and families affected by bleeding disorders in Western PA. The Penguins took home a win that night, beating the Panthers 7-6 in overtime! It was an exciting game, and we are so thankful for everyone's continued support of WPBDF!

THE WPBDF SCHOLARSHIP 2023-2024

The WPBDF
Scholarship

Any person or immediate family member of a person with hemophilia, von Willebrand Disease, or other inherited bleeding disorder is eligible to apply for this scholarship. One full award of $2,500 per degree program or course of study will be granted. Partial awards may be granted. The Foundation is delighted to be able to support our community in this way. We wish you the very best of luck as you pursue your education.

For more information:
https://bit.ly/wpbdfscholarship23

Scholarship Funds
One full award of $2,500 per degree program or course of study will be granted. Partial awards may be granted. Individuals who have received a partial award (less than $2,500) from WPBDF in the past are welcome to reapply. The Foundation is delighted to be able to support our community in this way. We wish you the very best of luck as you pursue your education.

The Process
The 2023-2024 process will be as follows:

Applications are being distributed by the Western Pennsylvania Bleeding Disorders Foundation. Applications must be received or postmarked by July 1, 2023. Criteria should include academic excellence (past or present), community service, and personal statements.

Winner(s) will be announced at the WPBDF Annual Meeting on Sunday, July 16, 2023.

Learn more: bit.ly/wpbdfscholarship23

THE HEMOPHILIA CENTER
of Western Pennsylvania

The Hemophilia Center of Western Pennsylvania clotting factor program was established in 2000 as a complement to the Center's other comprehensive care services. The clotting factor program allows the Center the opportunity to offer clotting factor to its patients, thereby supplementing its comprehensive treatment care model and providing the best possible care for its patients.

Factor Program Services

- All factor product brands available
- Online factor ordering available
- 24 – 48 hour delivery
- Same day courier service for emergent needs
- On-call services, 24/7
- Home treatment supplies
- Lot tracking for recall notification
- Online home treatment records
- Insurance benefit information assistance

Patient Benefits

- Direct communication and service from the Center's treatment team
- Support of the Center's operations
- Expansion of patient services

Please contact the Center at (412) 209-7280 for more information about how this program can benefit you and the entire bleeding disorder community.

The Hemophilia Center of Western Pennsylvania supports patient choice consistent with the Veterans Health Care Act of 1992 and maintains a freedom of choice policy where patients are informed of their choices regarding factor replacement products.

HCWP CORNER

KATHALEEN SCHNUR, LCSW

Dear HCWP community,

Happy spring (at least that's what the calendar tells us even if the weather seems confused)! I hope this finds you all well! We'd like to share some updates and reminders to our community. We encourage our patients to call back 24-48 business hours after placing a factor order if they have not received a call from their specialty pharmacy for delivery. This is a proactive measure our patients can take to ensure timely delivery. Additionally, please clear or set up your voicemail boxes; often we need to speak with our patients before we can fill an order, and not being able to leave a message or contact our patients will delay the order.

HCWP promotes optimal health and well-being for our patients and their families, and we must see our patients in the clinic to achieve this. We would like to remind you that patients should be seen by our team every 12 months (or as directed by your HCWP physician) to ensure that all aspects of patient care (including physical, emotional, psychological, educational, financial, and vocational needs) are covered appropriately. All patients and families are given a factor policy to sign during the registration process that highlights this. It is not best care to prescribe medication or make surgical or dental recommendations for patients we have not seen. Please outreach the clinic social worker if barriers exist to accessing care (i.e. lack of transportation, insurance). The social worker will assist you in resolving those challenges to ensure appropriate medical care; call 412-209-7280. If you are due for your appointment, please call and schedule now, we are booking up quickly.

Please note that we have our Amish Outreach events scheduled for the last 3 weeks in May, staff will be available; however, we will not have our usual clinics those weeks.

As we are moving toward warmer weather, people are planning getaways and vacations. Please check your factor to make sure it's not expired and make sure you have an updated travel letter. Call your local HTC for assistance. Also, to our almost-graduating high school seniors or others looking to pursue post-secondary education or training, please look at the available bleeding disorder scholarships: https://www.hemophilia.org/community-resources/financial-assistance/scholarships.

Finally, the Center is very excited to announce that we will be moving to a new facility. The Center has been busy planning a move this fall to its new location at the Sterling Building in the North Oakland section of Pittsburgh. The new facility is approximately 1 ½ miles from our current location at the Boulevard of the Allies. The new facility is larger and will provide more exam and consult rooms than we currently have which will allow us to expand patient offerings. We will provide updates as renovations progress.

We look forward to seeing you in the center and at community events!

Sincerely,
Kathaleen M Schnur, LCSW

BLEEDING DISORDERS AWARENESS MONTH

I WANT TO START A CONVERSATION ABOUT...

Make a donation today to provide families and patients in need with education, support groups, advocacy training, and patient assistance: https://give.classy.org/wpcnhfdonate

Scan to Donate!

WINTER TEEN RETREAT

I can still hear the sounds of the bells and the roaring laughter from a very competitive game of Bleeding Disorders Jeopardy—just one of the many memorable moments at the Winter Teen Retreat! An amazing group of teens joined us from Friday, January 13 to Sunday, January 15, at the Promise Camp & Retreat Center, in Clinton, PA, for a weekend of learning, friendship, and fun! From the moment everyone gathered in the dining hall, there was non-stop chatter. The games began early as counselors and teens implemented impromptu ice breakers. Shout out to counselors Ryan Balog, Nicolette Cloutier, Julia Shoemaker, John Yunghans and junior counselors Trent Clayton and Georgia Ebsworth for keeping the fun and energy flowing all weekend!

Life skills are always part of the theme at our teen retreats, as we aim to support teens in their journey toward independence with their healthcare and other skills required to live independently. Throughout the weekend, the group prepped for and cleaned up after every meal, and on Saturday night, they cooked a meal together. Nurse Kim (Kimberly Walsh, RN) led a session on first aid and each participant assembled a first-aid kit to keep. In addition, the teens learned the importance of saving and budgeting money and learned how to create a personal budget. The teens also heard from a panel of older teens about life experiences, such as applying for a job, safety tips when driving/riding in car with friends, and advice on sharing information with others about your bleeding disorder. The group also learned how to problem solve together, as they worked through a team challenge with knotted rope, played an escape room game, and more.

One of the highlights of the weekend was a lesson on planting and caring for plants, led by students from the Penn State Beaver campus' Student Farm Club and Biology Club. Each teen planted and decorated a terrarium with succulents. Each terrarium was unique and looked awesome!

Another highlight was Bleeding Disorder Jeopardy—who knew that testing your knowledge on bleeding disorders could be so much fun?!
Speaking of fun, there was also time to take a break from programming and enjoy time together, relaxing and playing games. The game room, which was complete with an air hockey table, foosball table, pool table, and

... CONTINUED ON THE NEXT PAGE

ping pong table, was a great space to gather for table games and board games alike.

Time spent together learning and sharing experiences isn't limited to teen retreats. The teens also have their own track at WPBDF's Education Weekend, and the teens typically gather once or twice a year outside of those events for other networking and learning opportunities.

Leadership is one of the key skills that we incorporate year-round in Teen Group programming. We currently have two teens who serve as volunteer Teen Group Co-Coordinators, Raina S. and Ethan W. They help plan retreats and other events, along with the guidance and support of Katherine Bush, Social Worker, from the Hemophilia Center of Western PA, and Janet Barone, Program Director, from the Western PA Bleeding Disorders Foundation.

Below, Raina and Ethan share their answers to questions about their experiences with the Teen Retreat.

1. In your opinion, what do you think is the most important part about bringing teens from the bleeding disorders community together for a retreat?

Raina: One of the important aspects of the teen retreat is everyone coming together to learn and have a good time. Within the short amount of time together, we learned about first aid, skills for living, and the importance of understanding your diagnosis and the responsibilities you have as an adult with a bleeding disorder.

Ethan: I think it's good to hang out with people who are going through close to the same thing you are and having people who can give you advice for the stuff you're about to go through, that they just recently went through.

2. What do you like about being involved in the retreat planning process?

Raina: The most enjoyable part of planning the retreat is brainstorming ideas that hopefully everyone will enjoy. The rewarding aspect of planning is seeing everything come together throughout the weekend as well as the other teens bonding with each other.

Ethan: I like being able to help with ideas and being able to let everyone have as much fun as possible.

3. What activity(ies) did you enjoy the most?

Raina: I really enjoyed the Bleeding Disorder Jeopardy game because everyone was screaming and laughing due to the questions being so competitive. I also liked the game room because everyone was together in one atmosphere having fun.

Ethan: I really like cooking, mostly because of a personal preference. It's something that you work a little hard for and are able to enjoy it afterwards. And being able to do it with friends makes it better!
4. What was something new you learned at the retreat?

Raina: Something I learned was the importance of understanding your bleeding disorder when finding a job. Coming from someone who doesn't have a bleeding disorder, it was eye opening to hear about the job employment process, as well as the importance of the information you decide to share in an interview.

Ethan: I wouldn't say I learned [how to drive] but I definitely got a better understanding of what it's like to drive.

The Teen Group is open to teenagers who are aged 13-18 (who have not yet graduated from high school) who have a bleeding disorder or are the sibling of someone with a bleeding disorder. For more information, contact Katherine Bush (kbush@vitalant.org / 412-209-7286) or Janet Barone (janet@wpbdf.org / 724-741-6160).

ADVOCACY AMBASSADOR RETREAT

CASSANDRA MILLER

On March 4, members of the Western Pennsylvania and Eastern Pennsylvania Bleeding Disorders Foundations met at the Omni Bedford Resort in Bedford, PA to learn about PA advocacy and the hot topics in policy. We started off the day learning about the various Pennsylvania policies that Kerry Lange, Senior Associate at Milliron & Goodman, and her team are working on this year. One of the big topics we covered was copay accumulators and copay maximizers. We also learned how to advocate and what things to expect during the meetings. Janet Barone, Program Director at WPBDF, shared her advocacy photo album with us, which she uses to share her story with legislators and or their staffers. These photo albums help us stay on track while in our legislative meetings and can include things like a quick overview of bleeding disorders and what they are, photos to help tell our story, and notes about the issues or our 'asks'. By working on our photo albums, we were also able to work on our stories. As a seasoned advocate, I really enjoyed being able to help the newer advocates write their stories and how to connect it to our ask. At the end of the day, we were able to see a few legislative meeting scenarios so we can be better prepared to know how a meeting will run when we get to D.C. We ended the night with an Advocacy Kahoot Game where we got to to review the things we learned during the day in a fun competitive game.

On Sunday, we broke out into three breakout groups after breakfast. In these groups, we talked about the PH-95 Loophole, Women with Bleeding Disorders, and Medication Accessibility in Hospitals. We talked about the issues that we thought were important to our advocacy efforts and thought of ways to better educate our communities and increase awareness. Overall, this experience, bringing both the Western and Eastern Foundations together, helped form a strong front for our whole state and the connections made were invaluable. The number of resources and information that we gathered was astounding and will in turn allow us to go out and share with our communities.

FACTOR FLUENCY

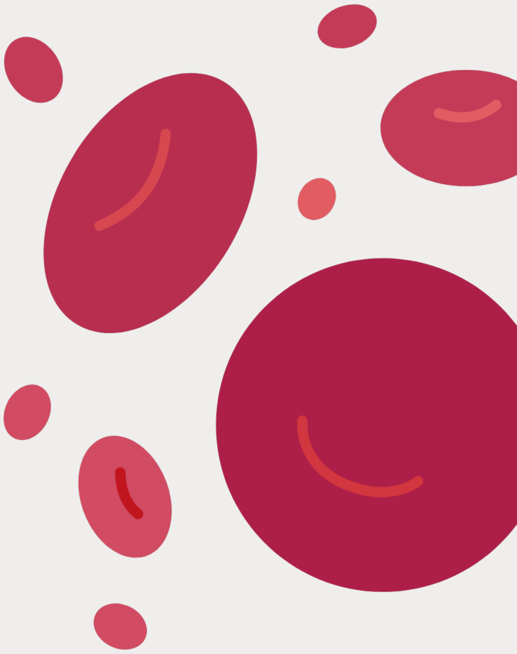
sanofi

Many of us might consider ourselves fluent when it comes to understanding clotting factor, but do we really understand how factor activity levels are measured?

On March 22, we gathered over dinner to learn more. Carrie Koenig, Community Relations and Education Manager with Sanofi, provided a detailed understanding about the importance of factor activity levels. She explained Pharmacokinetics and why factor levels are more than just peaks and troughs, during the program, *Factor Fluency: Higher Factor Activity Levels Matter.*

We were joined by a group of engaged community members who participated in the discussion and shared their personal experiences. We walked away with a better understanding of factor activity levels, as well as information to discuss with our medical providers at future clinic appointments at our hemophilia treatment center.

We thank Carrie Koenig and Sanofi for bringing this enlightening program to Western Pennsylvania.

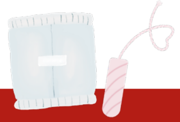


WPBDF
Patient Assistance Fund

The WPBDF Patient Assistance Fund is available to help families and individuals in the bleeding disorders community in unusual, emergency situations. It is supported by generous contributions from individuals, foundations, and corporations committed to supporting the bleeding disorders community.

Examples of appropriate grants are:

Utility Bills



Period Products

for women with bleeding disorders

Transportation

Transportation for bleeding disorder-related medical appointments

Medical ID Jewelry

Knee, elbow, and ankle braces

Medical supplies not covered by insurance

The WPBDF Patient Assistance Fund should be used as a payer of last resort and is not meant to be used to remedy chronic financial problems.

Process to Apply

To assist in the review and validation of applications for aid, we accept requests from the Hemophilia Center of Western Pennsylvania and its affiliated social workers. These individuals typically know the candidates, understand their current financial state, and are better suited to determine the severity of the need for emergency funds. They can also assist with creating a plan and connecting candidates to community resources. The social workers submit the individual's application for emergency aid supported by proper documentation.

If the person needing assistance is not a patient of the Hemophilia Center of Western Pennsylvania, the Foundation will handle the request directly with the third party or the referring physician's office. In this case, the patient must provide proof of medical condition or recommendation from his/her physician. They must also complete all paperwork to become a member of the Foundation if they have not already done so.

Follow-up calls may be necessary when information is missing or to discuss the specific case when the need is unclear. Whenever possible, the payment will be made directly to the provider.

If you have any questions contact Janet Barone, Program Director, at 724-741-6160 or janet@wpbdf.org.

Thank you to the Hemophilia Alliance Foundation and CVS for their support of this program!

WPBDF's Grocery Assistance Program

The Western Pennsylvania Bleeding Disorders Foundation realizes hardship can strike at any time. We will be continuing to offer a Grocery Assistance Program to anyone in the bleeding disorders community who is struggling with a financial hardship. This fund will provide gift cards for groceries, $100 per family member, up to $400 per family.

Learn more at:
wpbdf.org/programs/patient-assistance/

RUN FOR THEIR LIVES

Bleeding disorders can't stop us.

Scan the QR code to learn more or visit bit.ly/runfortheirlives2023

Join us for the 14th Annual Run for Their Lives 5K happening in-person on September 9, 2023! Your participation will help raise awareness of bleeding disorders and help raise needed funds for education and advocacy. Run through beautiful tree-lined streets in North Park, located in northern Allegheny County, just north of Pittsburgh, PA!

SATURDAY, SEPTEMBER 9, 2023

NORTH PARK SWIMMING POOL | S. RIDGE DRIVE, ALLISON PARK, PA 15101

Unite for Bleeding Disorders

WPBDF
Western Pennsylvania
Bleeding Disorders Foundation

HEMOPHILIA ALLIANCE

Takeda

Western Pennsylvania Bleeding Disorders Foundation's

15th Annual Unite for Bleeding Disorders Walk

Saturday, September 9, 2023

9:30 AM - 11:30 AM (Check-in begins at 9:00 AM)

North Park Swimming Pool
S. Ridge Drive, Allison Park, PA 15101

Questions? Contact Pittsburgh Walk Manager Jessica Lee
jessica@wpbdf.org or call 724-741-6160

Register online at:

https://uniteforbleedingdisorders.org/event/wpa

Scan the QR code to learn more!

CAMP HOT-TO-CLOT UPDATE

We are so excited to be able to announce…. Registration for Camp Hot-to-Clot 2023 is OPEN!!

For our newer families and community members, Camp Hot-to-Clot is an overnight summer camp in Western Pennsylvania for youth who have a bleeding disorder or who have a sibling with a bleeding disorder.

OUR MISSION is to enrich the lives of youth with bleeding disorders, ages 7-17, in Western Pennsylvania and surrounding areas through inclusion, empowerment, and the development of knowledge and life skills.

OUR GOALS are to provide an experience that:

- Ensures emotional and physical safety for everybody
- Provides a positive, supportive culture that inspires personal growth, confidence, and independence
- Promotes learning related to life skills and bleeding disorders
- Creates a sense of community and lasting friendships
- IS FUN!!!

Registration can be completed on the Camp Kon-o-Kwee website at the following link: https://konokweespencer.campbrainregistration.com/. Please begin applications for all campers you plan to send this year by the end of April, as we need to be very aware of our numbers as we transition to our new model. Please also be aware that we may have more limited space this year than in years past, so again, signing up sooner is the best way of helping your youth make it to camp.

After you complete the online portion of your registration, you will be sent medical forms to have completed for your campers. These forms can be uploaded to your YMCA registration after completion. If receiving and uploading forms electronically is a challenge, please let us know so that we can get you the forms another way. We ask that these forms be submitted by June 15th. If your camper is an HCWP patient who has been seen since August 5, 2022, they will not need a new appointment for us to complete the medical form.

If you run into challenges with registration (this is new for us too!) please reach out and let us know so that we can assist in resolving concerns. Please call our camp phone number at 412-209-7344 or feel free to send an email (kbush@vitalant.org).

We are so glad to be able to see an actual year of camp on the horizon. We are working hard to make sure that our youth get to learn and grow from the experience of camp once again, and that they have the chance to grow in the community with each other.

CONSUMER ADVOCACY COMMITTEE (CAC)

Would you be interested in applying to be a volunteer on the HCWP CONSUMER ADVOCACY COMMITTEE (CAC)?

Responsibilities include:
- Attend CAC meetings (three meetings per year).
- Advise HCWP staff of issues/concerns pertaining to treatment, care, and services.
- Help evaluate HCWP programs and services.
- Communicate the needs of the bleeding disorders community to HCWP.

Terms of Service:
Each member will serve on the committee no less than one year with annual renewal of term at each member's and HCWP facilitators' discretion.

Please note:
HCWP welcomes the input of CAC members as a way of looking at our services through new eyes from the unique patient/family member perspective. We hope that our CAC members will freely provide suggestions, spark creativity, and provide (gentle) criticism when needed. The role of the CAC is advisory only. Implementation of CAC recommendations is at the HCWP Director's and Board of Directors' discretion.

If you are interested or have further questions, please reach out to Kathaleen Schnur (412-209-7267) or Katherine Bush (412-209-7286).

HEMGENIX

Dinner and Educational Program

CSL Behring

HEMGENIX®
etranacogene dezaparvovec-drlb

The Western PA Bleeding Disorders Foundation invites you to dinner and an educational program on Hemgenix.

Wednesday, May 24, 2023 6:30 PM

Atria's Tavern
4869 William Penn Highway
Murrysville, PA 15668

This education program offers you the opportunity to:

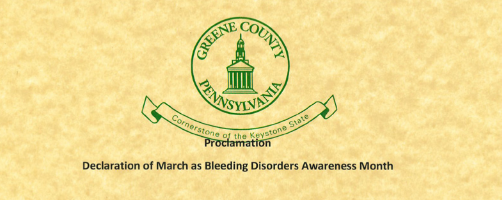
- Learn about Hemgenix, the first and only FDA approved gene therapy for Hemophilia B
- Gain valuable information and deepen your understanding of Hemgenix through a live Q&A session
- Ask questions and receive new resources on gene therapy

This program will be presented by Dr. Richard Lemons, the medical director, division chief, and professor of pediatrics in the Division of Pediatric Hematology/Oncology at the University of Utah in Salt Lake City. He is also director of the pediatric hematology/oncology fellowship program at the University of Utah.

To register, send an email to rsvp@wpbdf.org or call 724-741-6160. Please be sure to include the number of people you are registering for and any food restrictions we should be aware of.

WPBDF
Western Pennsylvania
Bleeding Disorders Foundation

WPBDF does not give medical advice or engage in the practice of medicine. WPBDF under no circumstances recommends treatment for specific individuals and in all cases recommends that you consult your physician or local hemophilia treatment center before pursuing any course of treatment.

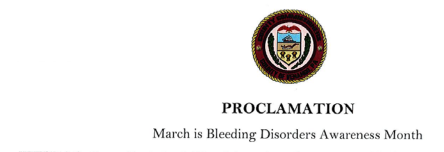


GREENE COUNTY PENNSYLVANIA

Cornerstone of the Keystone State

Proclamation

Declaration of March as Bleeding Disorders Awareness Month

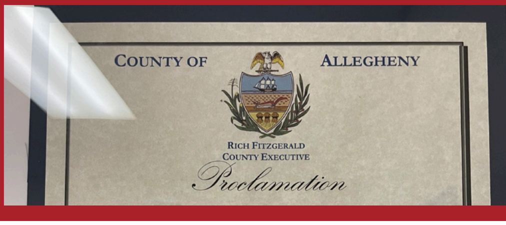


PROCLAMATION

March is Bleeding Disorders Awareness Month

WHEREAS, the Venango County Board of Commissioners, is proud to commemorate March 2023 as Bleeding Disorders Awareness Month in the County of Venango; and

WHEREAS, this designation will formalize and expand upon the designation over 35 years ago of March 1986 as "Hemophilia



COUNTY OF ALLEGHENY

RICH FITZGERALD
COUNTY EXECUTIVE

Proclamation

MARCH IS BLEEDING DISORDERS AWARENESS MONTH!

Each year, we celebrate March as Bleeding Disorders Awareness Month to bring much needed attention to inheritable blood and bleeding disorders. This month shines a light on patients and families with hemophilia, von Willebrand disease, rare factor disorders, and platelet disorders to share their lives, stories, struggles, and successes.

We received Bleeding Disorders Awareness Month proclamations from the following counties: Beaver, Allegheny, Butler, Fayette, Greene, Lawrence, Somerset, McKean, Venango, and Westmoreland; and the Cities of: Altoona, Canonsburg, Erie, and Johnstown.

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION
775 4th Street
First Floor
Beaver, PA 15009

WPBDF's

Annual Meeting

Save the Date!

Sunday, July 16, 2023

Sheraton Pittsburgh Hotel
300 W Station Square Dr,
Pittsburgh, PA 15219

HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION
775 4th Street, First Floor
Beaver, PA 15009
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