HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

SUMMER 2025

WPBDF
Western Pennsylvania
Bleeding Disorders Foundation

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Staff office hours are Monday-Friday from 9 AM until 4 PM. 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.

Hemogram is published quarterly by the Western Pennsylvania Bleeding Disorders Foundation. The material in this newsletter is provided for your general information only. WPBDF does not give medical advice or engage in the practice of medicine. WPBDF under no circumstances recommends particular treatments, and always recommends that you consult your physician or treatment center before pursuing any course of treatment.

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

July 27 - August 1, 2025
Camp Hot-to-Clot
Camp Kon-O-Kwee Spencer
Fombell, PA

August 8, 2025
New Parent Network
Oglebay Resort
Wheeling, WV

August 9, 2025
Regional Summer
Education Day
Oglebay Resort
Wheeling, WV

August 21-23, 2025
National Bleeding Disorders
Conference
Denver, CO

September 6, 2025
Unite for Bleeding Disorders
Walk and Run for Their Lives 5K
North Park Swimming Pool
Gibsonia, PA

September 21, 2025
Game Day Education
PNC Park
Pittsburgh, PA

October 4, 2025
Fall Program
Trinity Church
Wexford, PA

November 8, 2025
Purse Bingo Fundraiser
Vanport Volunteer Fire
Department
Vanport, PA

November 16, 2025
New Parent Network
Virtual Program

December 13, 2025
Winter Program
Shadow Lakes
Aliquippa, PA

March 4-6, 2026
National Bleeding
Disorders Foundation's
Washington Days
Washington D.C.

June 12-14, 2026
Stay In Motion Education
Weekend
Seven Springs Mountain
Resort
Champion, PA

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

COMMUNITY ANNOUNCEMENTS

The WPBDF
Scholarship

CONGRATULATIONS TO THE RECIPIENTS OF WPBDF'S 2025 ACADEMIC SCHOLARSHIP!

Read more about our scholarship winners on page 29!

Ava Bush
Mackenzie Cloutier
Whes Ebsworth
Maggie Eganlauf
Mary Laughlin
Jason Miller
Justin Najimian
Ryan Palmer
Billie Rolle
Robert Weaver

BECOME A MONTHLY DONOR!

FOR JUST $25 A MONTH, YOU CAN PROVIDE A LIFESAVING MEDICAL ID TO SOMEONE AFFECTED BY BLEEDING DISORDERS.

WPBDF
Western Pennsylvania
Bleeding Disorders Foundation

DONATE NOW AT WPBDF.ORG

CONTACT US

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LETTER FROM THE EXECUTIVE DIRECTOR AND BOARD PRESIDENT

Summer has finally arrived! It has been a whirlwind year, and we hope you are finding moments to unwind, focus on self-care, and enjoy the company of loved ones.

Here at the Western Pennsylvania Bleeding Disorders Foundation, we've been hard at work, and we're so proud of what has been accomplished so far in 2025.

One of the most impactful efforts this year has been our Women's Initiative, a collaboration between the Eastern and Western Pennsylvania Bleeding Disorders Foundations. Through this initiative, we've reached 258 school districts across Western Pennsylvania to raise awareness of bleeding disorders in women, girls, and people with the potential to menstruate and promote early diagnosis. By educating school nurses and providing resources like our period packs, nosebleed kits, and awareness materials, we're helping to ensure that more young people are identified earlier and connected with the care they need. It has been incredibly rewarding to see this work spark conversations and action in schools throughout our region.

We are also so grateful for all of our incredible volunteers who have joined us at community events and health fairs across Pennsylvania. Thanks to their time, energy, and dedication, we've been able to spread awareness of bleeding disorders to new audiences.

This spring, we also celebrated a major milestone: the first-ever Pennsylvania Bleeding Disorders Conference (PABDC), held May 16 to 18 in Hershey. This unforgettable weekend brought together nearly 400 attendees from across the state. What began as a shared vision between the leadership of both chapters became a reality through hard work, passion, and teamwork. PABDC was more than a conference, it was a celebration of our community, full of education, empowerment, and connection.

And the collaboration doesn't stop there. We're excited to announce that on August 9, we'll be partnering with the West Virginia Bleeding Disorders Foundation for a Summer Regional Education Day at Oglebay Resort in Wheeling, West Virginia. We hope you'll join us for a day of learning, connection, and fun with families from both states.

Thank you for being a vital part of our community. Whether you have attended a program, volunteered, or shared your experiences, your involvement helps us grow stronger together. We are so grateful for your support and look forward to seeing you soon.

Wishing you a joyful and healthy summer,

Kara Dornish
Executive Director, WPBDF

Scott Domowicz
Board President, WPBDF

A HISTORIC FIRST: THE 2025 PENNSYLVANIA BLEEDING DISORDERS CONFERENCE

PABDC
Pennsylvania Bleeding Disorders Conference

From May 16 to 18, nearly 400 attendees representing 120 families gathered in Hershey, Pennsylvania for the first-ever Pennsylvania Bleeding Disorders Conference (PABDC). This groundbreaking event brought together individuals and families from across the state for a weekend of education, connection, and inspiration.

The idea for a statewide conference was first envisioned years ago by Sarah Pilacik and Kara Dornish, Executive Directors of the Eastern and Western Pennsylvania Bleeding Disorders Foundations. Over the past two years, a dedicated planning team worked tirelessly to bring this vision to life. With the invaluable expertise of three Hemophilia Treatment Center social workers and the committed staff of both foundations, the event became something truly extraordinary. The weekend was filled with meaningful moments. Stories were shared. Friendships were formed. A community became a family. More than just educational sessions, the conference created a deep sense of belonging.

Highlights from the Weekend

The conference began on Friday evening with a lively Exhibit Hall and a welcome dinner. Phil Gattone, President and CEO of the National Bleeding Disorders Foundation, opened the weekend with a powerful message about the strength and unity of our community.

The evening concluded with the Dinner Symposium, *Gratitude Nation*, presented by Carrie Koenig, CoRE Manager at Sanofi. Her presentation highlighted the role of gratitude in building resilience and fostering strong communities. We are deeply grateful to Sanofi for sponsoring this impactful session.

Saturday morning opened with the Breakfast Symposium, *Personalizing Your Treatment Plan*, presented by Margarita Llibre Rogers and sponsored by Bayer. The session underscored the importance of tailoring treatment to fit each individual's lifestyle and medical needs.

Throughout the day, attendees participated in 24 engaging breakout sessions for adults, while children and teens enjoyed dynamic age-appropriate programming. During lunch, Tony Paciucci of Genentech led the Lunch Symposium, *Better Together: Integrating Mind, Body, and Joint Health in Bleeding Disorders*, exploring the progress made in holistic care and the importance of physical and emotional well-being.

One of Saturday's highlights was hands-on infusion training, where 76 participants including adults, teens, and children took part in experiential learning to build confidence in managing treatment.

The day concluded with an evening reception in the Exhibit Hall, offering time for networking, connection, and fun in the heart of Hershey.

Sunday began with the Breakfast Symposium, *How to Be a Savvy Consume*r, presented by Heather Hicks from NBDF. This informative session provided tools to help individuals make confident healthcare decisions and better navigate the complexities of the system.

The weekend closed with one final round of breakout sessions, including a moving patient panel. Seven individuals from Hemophilia Treatment Centers across the state courageously shared their personal stories, leaving a lasting impact on all in attendance.

With Gratitude

This historic event would not have been possible without the dedication, passion, and support of so many.

To the Conference Planning Committee — Janet Barone, Kara Dornish, Meredith Getz, Jessica Lee, Keyai Lee, Lisa Lee, Sarah Pilacik, Kathaleen Schnur, and Jess Selingo — thank you for your creativity, hard work, and thoughtful leadership.

To our incredible volunteers, speakers, and facilitators, your time and energy helped create an unforgettable experience for every attendee.

To our generous sponsors:

Diamond Sponsor: Genentech
Gold Sponsor: Ethical Factor Rx
Silver Sponsors: Bayer, BDRN, Cottrill's Pharmacy, CSL Behring, InfuCare Rx, Novo Nordisk, and Sanofi
Bronze Sponsors: Accredo, BioMatrix, CVS Specialty, HemaBiologics, Medexus, Optum, Promptcare, Pfizer, Soleo Health, Star Therapeutics, and Takeda

We also extend a heartfelt thank-you to the Hemophilia Center of Western Pennsylvania, the Hemophilia Alliance, and the Colburn Keenan Foundation for their generous contributions.

To the Boards of Directors of both foundations, thank you for your guidance, support, and belief in this vision.

And finally, to every attendee — thank you for being part of this special moment. Your presence, your stories, and your spirit are what made this conference so meaningful.

This inaugural Pennsylvania Bleeding Disorders Conference was a celebration of everything that makes our community strong. It was a weekend of connection, resilience, compassion, and hope.

TEENS CONNECT AT PABDC

ETHAN W.

PABDC was an exciting event, and I actually ended up learning a couple new things about bleeding disorders and chocolate. On Friday, my family and I arrived late because I had to work, and then it took us a good hour to figure out where our room was. After we finished our little tour around the amazing lodge (which if you asked me was just as cool as Seven Springs), and unpacked all our clothes, we headed down for dinner where we met new people and old friends. Dinner was pretty good after that 4-hour car ride, and once everyone on the stage started talking, I realized I was a bed away from going to sleep. I eventually took my little brother up to the room and we went to sleep.

Saturday was the most eventful day and really felt like a week. We started with an amazing breakfast, and if you ever want an amazing sweet and savory breakfast, Hershey is the place to get it. My family split up into different groups where I met up with Kit, Charlie, and Caleb who led and supervised the teen group. I was tasked with being the DJ and I played music during our sessions. Once everyone arrived, we started with icebreaker questions that split us up into groups to play a trivia game. Charlie hosted the game, and we started to warm up to each other and learn some fun facts about chocolate. After each session, we would have 10–15 minute breaks. We took some time to figure out who everyone was, including what type of bleeding disorders they had or if they were a relative or friend to someone who had one. In the next session, we had three young adults come in and explain some of the struggles they had transitioning into adulthood with a bleeding disorder. One story that I found really cool was Shanthi's. She told us how she was diagnosed only a few years ago despite having a history of bad bleeds, but when she did get diagnosed, she was able to start a club at her college where everyone, including her, could learn more about bleeding disorders.

After that session, we had a scavenger hunt at the Science Fair where we got to learn more about factor and other things that are in your blood. Then, we all hung out while we ate lunch. Not too long after lunch, Shanthi came back to brainstorm ideas on more events that we would all be interested in. Once we were done brainstorming, Sanofi came in and explained to us how factor helps restore the missing factors that a person with a bleeding disorder does not supply on their own. We had a snack break and started watching Bombardier Blood, which is a documentary about Chris Bombardier climbing the seven summits with severe hemophilia. After the movie, our parents came to pick us up. The rest of the day, my family and I walked through the exhibit hall and then went and had Mexican food for dinner.

Sunday, after breakfast, we did a timeline activity about the evolution of bleeding disorders that I actually did on my trip to Oregon, but I was way too tired to remember any of the answers. Then, we were supposed to fill in a bingo card of things we learned over the weekend, and we were rewarded with a gift card to the gift shop at the lodge. We helped clean the room as our parents came and picked us up. I don't know about anyone else, but I made sure I left Hershey with a Stuff your Cup Reese Cup. It is a Reese Cup as big as a toddler sized basketball and can last up to a month in a freezer. I really enjoyed this event because it was a good mix of hands-on activities and education. It was also pretty eye-opening to see how even though we are only a couple of hours away from each other, our Foundations are still very different. I'm very grateful to be able to attend things like this, especially now since I'm transitioning into adulthood with more than the information needed to know about my bleeding disorder.

ADVOCACY UPDATE

KERRY LANGE, SENIOR ASSOCIATE
MILLIRON GOODMAN

HARRISBURG OVERVIEW

The Pennsylvania General Assembly is approaching the second quarter of the two-year legislative cycle. All bills have until the end of the session, November 30, 2026, to get through the legislative process and across the Governor's desk.

Two special elections were held at the end of March:

House: Representative Matt Gergely (D-Allegheny) passed away in January and left a vacancy in the 35th House district seat. Dan Goughnour, a Democrat from McKeesport, won the special election.

Senate: Senator Ryan Aument (R-Lancaster) resigned to work for U.S. Senator Dave McCormick, leaving a vacancy in the 26th Senate district seat. In a major unexpected shake-up, Democrat James Malone won the special election. ***He is the first Democratic State Senator from Lancaster since 1889.***

The new ratios in the House and Senate are as follows:

- House: 102 Democrats; 101 Republicans
- Senate: 27 Republicans; 23 Democrats.

Democrats maintain a slim majority in the House and Republicans maintain a slightly less comfortable majority in the Senate.

Below are some committee chairs of interest to the Westen PA Bleeding Disorders Foundation (WPBDF):

Senate Health & Human Services Committee:

- Majority Chair Michele Brooks (R-Mercer)
- Minority Chair Art Haywood (D-Montgomery)

Senate Banking & Insurance Committee:

- Majority Chair Chris Gebhard (R-Lebanon)
- Minority Chair Sharif Street (D-Philadelphia)

House Health Committee:

- Majority Chair Dan Frankel (D-Allegheny)
- Minority Chair Kathy Rapp (R-Crawford)

House Insurance Committee:
- Majority Chair Perry Warren (D-Bucks)
- Minority Chair Tina Pickett (R-Bradford)

BUDGET

In February, Governor Josh Shapiro provided his 2025-2026 budget address and corresponding proposal.

It was a $51.3 billion spending plan, a 7.5% increase over last year's budget. Once again, it did not include any increases to the personal income tax (PIT) rates or sales & use (S&U) tax rates.

However, to help offset the state's current $3.4 billion operating deficit, the Governor proposed the legalization and taxation of recreational marijuana, taxed at 20%, and skill games, taxed at 52%. The projected revenue from both recreational marijuana and skill games in the first fiscal year (if passed) would be just shy of $1 billion.

The Independent Fiscal Office (IFO) projects the state's operating deficit to increase from $3.4 billion to $6 billion by next year.

The legislature has a constitutional deadline for passing a balanced budget by June 30.

BUDGET LINE ITEM

Each year, our priority for WPBDF is a three-part budget request:

- Protect/increase the hemophilia line item in the state budget;
- Separate it out from the other rare disease line items; and
- Ensure that the funding distribution formula remains as is.

Last year, we successfully secured $1,017,000 in the General Appropriations bill (SB 1001), kept

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ADVOCACY UPDATE

CONTINUED FROM PAGE 7...

it separated from other line items, and protected the distribution formula with language in the fiscal code (HB 2310).

These budget requests will continue to be our priority for WPBDF this session, as they are most critical for the patients and treatment centers. Ideally, we are advocating for an increase from $1,017,000 to $1,250,000. **We emphasize that we are preparing for a difficult budget season.** With these IFO predictions, the state budget process will likely become a much more heated and competitive process.

We note that several legislators representing HTCs across the state, including Representative Tom Mehaffie (R-Dauphin), Senator Tina Tartaglione (D-Philadelphia) and Senator Nikil Saval (D-Philadelphia), have authored supplemental letters of support for our requests and shared with their leadership teams in the House and Senate.

But your legislators need to hear from you as well! Legislators need to know their constituents to make this three-part budget request a top priority.

GRASS ROOTS ADVOCACY

Now is the time to start meeting with your personal legislators (Representative and Senator) to help advocate for the budget line-item requests. Please reach out to the district offices to schedule an in-person meeting.

We need to ensure that your legislators:

- Know you are a constituent;
- Are familiar or become more educated on hemophilia and other bleeding disorders; and *hopefully*
- Are supportive of the hemophilia line item and are willing to make it a budget request with their leadership in the House and Senate.

Because the budget process will likely be more competitive this year, legislators are asking for more details on how each line item (including hemophilia) is spent. We shared the below HTCs responses with legislative offices, but it might be helpful for you to share with your legislators as well.

Funding is applied to:

- Unified Care Protocol, which helps eliminate barriers to care;
- Consumer Advocacy Council, which provides a platform for patients to voice concerns and suggestions;
- Mental health support, including routine screenings; and
- Initiatives for job readiness and vocational training.

LEGISLATION

We continue to monitor for any bills that could potentially harm the community, as well as for bills that could support the community. Our firm coordinates directly with Kara and Sarah (and team!) to review the bills introduced and determine levels of engagement (support/oppose/amend/neutral). So far this session (since January 1), over 2,000 bills have been introduced!

Access to Menstrual Hygiene Products

Representative Roni Green (D-Philadelphia) introduced HB 337, which requires the Department of General Services to provide menstrual hygiene products, with a dispensing machine and disposal receptacles, in at least 50% of bathrooms in all state buildings.

We all know that these products are especially critical for women who have bleeding disorders. Women with bleeding disorders often have prolonged periods, heavy bleeding, and disruptions to everyday activities. These challenges are further exacerbated for those who struggle to afford or simply forget to bring feminine hygiene products with them to work. By providing more access to these products, Pennsylvania can truly help make a difference for women with bleeding disorders and improve overall office work productivity.

WPBDF sent a letter of support for HB 337 to the House State Government Committee, where it recently passed with a party-line vote (14-12). It will now go to the full House for a floor vote before going to the Senate for its consideration.

Co-Pay Accumulator

Senator Judy Ward reintroduced the co-pay accumulator bill as SB 268. It was referred to the Senate Banking & Insurance Committee.

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TAMAR
HEMLIBRA PATIENT SINCE 2019


DEVON
HEMLIBRA PATIENT SINCE 2020


MIRANDA
HEMLIBRA CAREGIVER TO TWIN SONS
TRISTAN & TALAN (AGE 11) SINCE 2018


VERONICA
HEMLIBRA CAREGIVER TO SON
IAN (AGE 7) SINCE 2020

HEMLIBRA: TRUSTED BY THE COMMUNITY FOR 7 YEARS AND COUNTING


SOREN
HEMLIBRA PATIENT SINCE 2022


HARVEY
HEMLIBRA PATIENT SINCE 2016


MARIA
HEMLIBRA CAREGIVER TO SON
CARLOS (AGE 16) SINCE 2019


OLIVIA
HEMLIBRA CAREGIVER TO SON
ARLO (AGE 6) SINCE 2018

First approved in 2017.* Over 8,100 patients in the US treated with HEMLIBRA.†

SCAN TO HEAR STORIES FROM THE COMMUNITY

*November 2017: FDA approval for adults and children with hemophilia A with factor VIII inhibitors.

†Number of patients with hemophilia A treated with HEMLIBRA in the US as of March 2024.

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

Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. 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).

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 (e.g. 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: 03/2023

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

Genentech
A Member of the Roche Group

ADVOCACY UPDATE

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Again, the bill amends the Insurance Company Law of 1921 by requiring insurers or pharmacy benefit managers to count any amounts paid, by the enrollee or paid on behalf of the enrollee by another party, towards the deductible or out-of-pocket limit.

The Milliron Goodman team is continuing to stay engaged on this issue. In fact, over the past six months, we've been able to establish an on-going dialogue directly with Insurance Commissioner Michael Humphreys and his leadership team.

Please continue to share your personal experiences regarding co-pay accumulators and any other insurance related concerns with the WPBDF team.

OTHER

WPBDF is partnering with the Bleeding Disorders Substance Use & Mental Health Access Coalition (BDSUMHAC) to focus on the intersection of bleeding disorders, substance use and mental health. At the state level, we are meeting with the Shapiro Administration, including leadership within the Department of Human Services and the Department of Drug & Alcohol, to advocate for improved access to services, increase overall awareness, etc.

THANK YOU!

As always, please feel free to contact our office with any questions or concerns. We look forward to continuing to represent you in the 2025-2026 legislative session.

ADVOCACY PRE-CON

CASSANDRA MILLER AND SAMANTHA SHORT

We officially kicked off the Pennsylvania Bleeding Disorders Conference with our Advocacy Pre-Con! The event was years in the making, from site visits to conference calls; our PABDC team pulled off this fantastic educational event. Staff from EPBDF and WPBDF, along with board members Marisa Ferger (Eastern), Cassie Miller (Western) and Samantha Short (Western) all pulled together to create this memorable event.

We were lucky enough to be joined by 30 advocates to hear about state issues from Kerry Lange, Milliron Goodman, and federal issues from Matt Delaney, National Bleeding Disorders Foundation. The first state ask Kerry spoke about was the state budget line item. We are requesting to increase the line item from the current $1,017,000 to $1,250,000 and to keep it separate from the other rare diseases. She also noted the need to clarify in the fiscal code that funding should be distributed to each of the seven Hemophilia Treatment Centers in Pennsylvania using the same formula as

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FAMILY CONNECTION

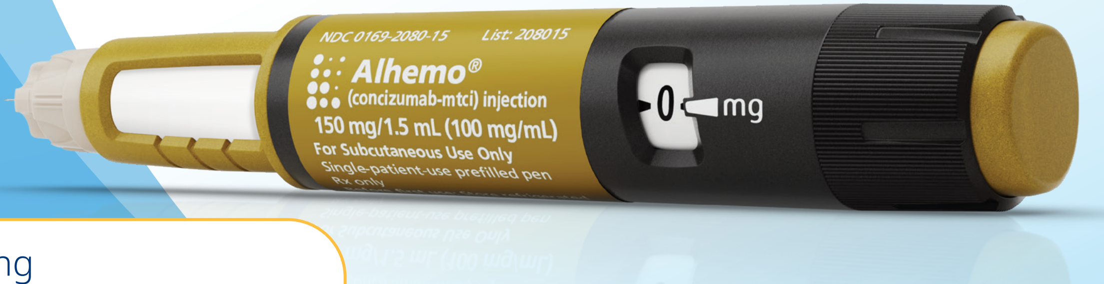
Living with a bleeding disorder can affect many aspects of daily life, including how individuals and families communicate about the condition. We've heard from community members who want to share information about their or their child's bleeding disorder—with friends, extended family, or select colleagues—and find that these conversations can range from open and supportive to challenging and frustrating.

While some people are comfortable discussing their experiences openly, including on social media, others are more reserved, preferring to protect their privacy and consider the long-term impact of what they share.

To help address these diverse communication needs, we hosted a special program, *Family Connection*, sponsored by Pfizer. The session was led by Kurt Feldmann, Community Engagement Leader at Pfizer, and covered key topics such as communicating outside the immediate family, navigating social media, and disclosure in work and school settings.

The program also included time for conversation, allowing participants to share personal experiences and learn from one another. We extend our sincere thanks to Pfizer for sponsoring this event, which took place on April 10 at the Grand Concourse in Pittsburgh.

Pfizer



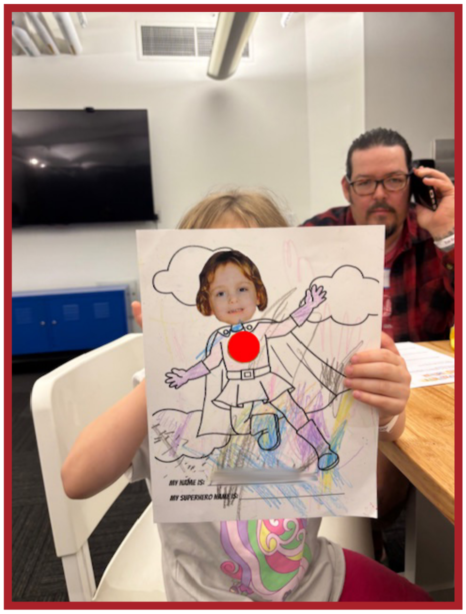
SUPER SUNDAY WITH THE NEW PARENT NETWORK

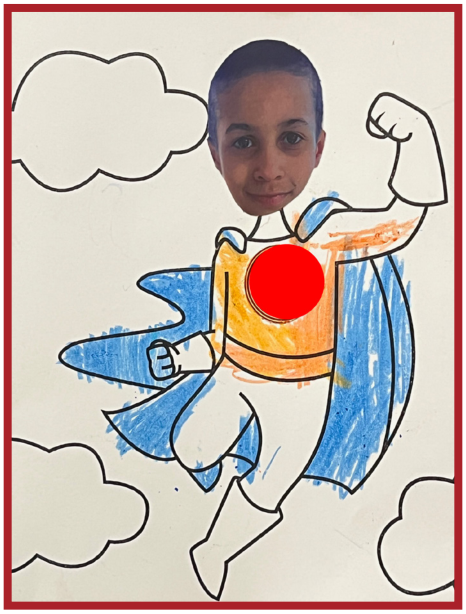
On Sunday, June 8, our New Parent Network families gathered for a fun-filled day at the Children's Museum of Pittsburgh! We were so excited to welcome both familiar faces and brand-new families.

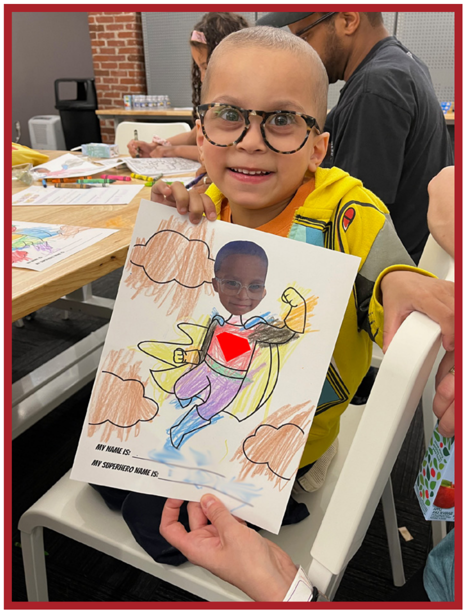
New Parent Network events are specifically designed for families raising little ones (from newborn to age 7) with bleeding disorders. Our goal is to provide a warm, supportive community where parents and kids can connect, share, learn, and grow together.

Families had the opportunity to meet one another, and children created their own superhero characters—complete with names and superpowers! If the world ever needs saving, we know exactly who to call! Lunch was served and the families had an opportunity to explore the museum before heading home.

If you have a child with a bleeding disorder in this age range and would like to find out more about the programs or be connected with a mentor parent, please reach out to either Kathaleen Schnur (kschnur@vitalant.org / 412-209-7267) or Janet Barone (janet@wpbdf.org / 724-741-6160).

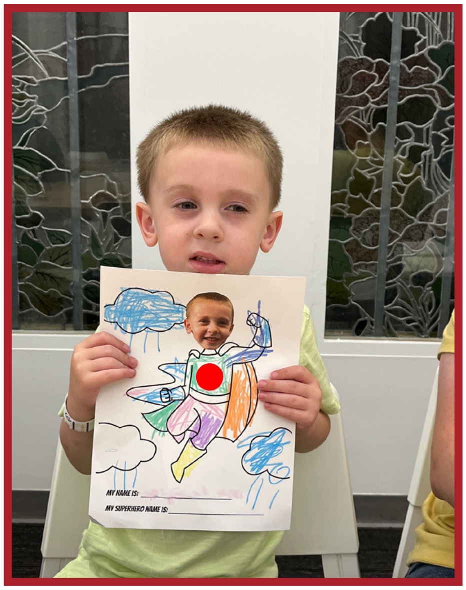






We are grateful to the following organizations for their generous support of the 2025 New Parent Network series of events:

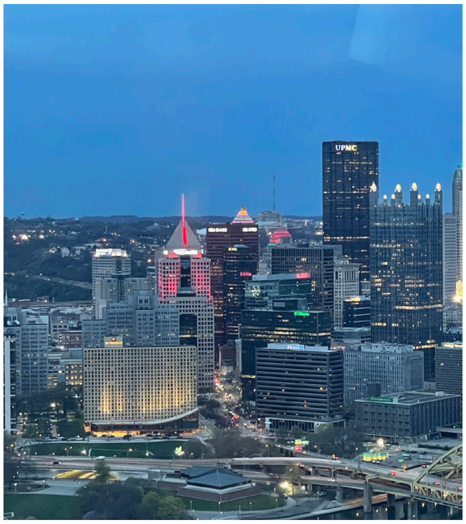
accredo
CSL Behring
novo nordisk
THE HEMOPHILIA CENTER of Western Pennsylvania
sanofi
Takeda



PENNSYLVANIA LIGHTS UP RED FOR WORLD HEMOPHILIA DAY!

Each year, landmarks all across the globe recognize World Hemophilia Day by lighting up red on April 17. This bridges the global community and raises awareness for bleeding disorders. Buildings in Pittsburgh lit red included the David L. Lawrence Convention Center Riverfront Plaza, Allegheny County Courthouse, Homestead Grays Bridge, the City-County Building , Heinz Hall Garden Plaza Waterfall, Gulf Tower, Kopper Tower, Fifth Avenue Place Spire, One Oxford Center, and Phipps Conservatory and Botanical Gardens.

In Philadelphia, Eagles Stadium, Benjamin Franklin Bridge, Philadelphia College of Osteopathic Medicine, One Liberty Place, Symphony House Condos, PECO Crown Lights, and TRIAD1828 were also lit red for this occasion. Thank you to all the organizations that joined us in lighting Pennsylvania Red this year!



WESTERN PA AND WEST VIRGINIA
BLEEDING DISORDERS FOUNDATIONS
PRESENT

Regional SUMMER EDUCATION DAY

WPBDF Western Pennsylvania Bleeding Disorders Foundation

West Virginia Chapter
NATIONAL BLEEDING DISORDERS FOUNDATION

SAT AUG 9

OGLEBAY RESORT
465 Lodge Dr, Wheeling, WV 26003

10AM-2PM

SESSIONS:

- ADVOCATING IN THE ER

CHOICE OF BREAK OUT:

- PHYSICAL THERAPY FOR ADULTS
- NAVIGATING SCHOOL WITH A BLEEDING DISORDER

This day will include exhibit displays, choice of educational breakout session, and lunch. Childcare will be provided! Passes to enjoy the many activities at the resort will be given out after the program!

TO REGISTER, SEND AN EMAIL TO RSVP@WPBDF.ORG OR CALL THE FOUNDATION OFFICE AT 724-741-6160. BE SURE TO INCLUDE THE TOTAL NUMBER OF PEOPLE YOU ARE REGISTERING FOR AND IF THERE ARE ANY FOOD ALLERGIES. IF CHILDREN ARE ATTENDING, PLEASE BE SURE TO INCLUDE THEIR AGES.

TRANSPORTATION ASSISTANCE IS AVAILABLE BY REQUEST. OVERNIGHT ACCOMODATIONS ON FRIDAY AVAILABLE FOR THOSE TRAVELING 150 MILES OR MORE. THIS PROGRAM IS OPEN TO WPBDF AND WVBDF MEMBERS WITH BLEEDING DISORDERS AND THEIR IMMEDIATE HOUSEHOLD FAMILY MEMBERS.

WPBDF'S TEEN GROUP UPDATES

We're thrilled to announce that Dexter S. and Nya J. have been selected as our new Teen Group Coordinators! After successfully completing the application and interview process, they are stepping into this important volunteer role to help lead and inspire their peers.

As Teen Group Coordinators, Dexter and Nya will assist in planning and organizing events for teens who either have a bleeding disorder or are siblings of someone with a bleeding disorder. The Teen Group is designed to support teenagers as they transition into young adulthood. It provides a safe, supportive space where teens can:

- Explore the unique challenges they face
- Build skills for medical independence
- Learn essential life skills for independent living
- Gain leadership experience
- Have fun and connect with others who understand their journey

For more information about the Teen Group or how to get involved, please contact Janet Barone (janet@wpbdf.org) or Katherine Bush (kbush@vitalant.org).

Nya J.

Hi! My name is Nya. I am so excited to have the position of teen coordinator! Going forward as a teen coordinator, I plan to focus on trying to get teens to come to more events, advocating for teens, and helping to plan different events for them!

Dexter S.

Hello, my name is Dexter and I am a teen coordinator. I am currently 15 years old. A couple things I would like to focus on while I'm a coordinator are Teen advocacy– it's a necessity for teenagers to help support their future–and helping to plan events. I cannot wait to provide input for what we should do at the future events.

We'd like to extend our deepest thanks to our incredible Teen Group Coordinators, Ethan W. and Maggie E., for their dedication and leadership. We are grateful for the time and energy they put into this role!

We look forward to their continued involvement as they serve as mentors and volunteers in the bleeding disorders community. We wish them the best in their next adventures!

ADVOCACY PRE-CON

CONTINUED FROM PAGE 11...

previous years.

The second state ask is for support for Copay Accumulator Legislation, SB268, which was reintroduced by Senators Judy Ward and Maria Collett, to ensure that all copays count.

Kerry was gracious enough to extend an invitation to Pennsylvania Congressman Tom Mehaffie, who spoke on his personal connection to our cause and how to best advocate in future meetings. Congressman Mehaffie serves the Hershey area with offices on Chocolate Avenue and is a small business owner turned politician. It's not often politicians are willing to devote time out of their personal schedules to meet with advocacy groups, and we thank Congressman Mehaffie greatly for his time.

Cassie Miller ran a mock meeting in which we learned the do's and don't of navigating advocacy. Teams slammed their buzzers when our mock "Advocates" made a mistake and the room quickly erupted into solutions of better ways to handle the mock scenarios. It was a great collaborative effort by all the advocacy ambassadors.

"Now more than ever, we need as many Advocacy Ambassadors as we can get so we can continue to fight for the rights for those in our bleeding disorders community. It was so great to see so many advocates come together from all over Pennsylvania to learn about the issues our community is facing and how to effectively use our voices to make change happen," said Cassie.

To conclude our Pre-Con, Board members congratulated all those in attendance on becoming official Advocacy Ambassadors for the Eastern and Western Bleeding Disorders Foundations, and certificates and pins were handed out as celebratory photos were taken of the new ambassadors.

"I can personally attest to the power of advocacy, there is no greater feeling than advocating for our community. Whether it be on a national level on Capitol Hill or a local meeting with your congressman/senator, every voice matters in our fight. I feel honored to be an advocacy ambassador for the WPBDF," Samantha said.

WPBDF'S

FALL

PROGRAM

Saturday, October 4, 2025

Trinity Evangelical Lutheran Church
2500 Brandt School Rd, Wexford, PA 15090

Stay up-to-date on WPBDF's upcoming events at: https://wpbdf.org/events.

GETTING TO KNOW HCWP STAFF

JODI SCHOONOVER

We are happy to introduce another behind the scenes hero from our center, Jodi Schoonover, who works in the pharmacy to make sure our patients' medication needs are met! Here are some fun things to know about Jodi:

Birthplace: Born in Elkins, WV. Grew up in Buckhannon, WV.

First job: Serving ice cream at Brake's Dairy King

Accomplishment you're proudest of: Either purchasing my first home or graduating college.

What three words describe you best? Honest, Empathetic, Caring

Dream vacation: Iceland

Things you can do without: Drama & Traffic

Person you'd most like to have dinner with: That's a hard question... Probably Dolly Parton

Movie you could see anytime: Hmm depends on my mood... Bridesmaids or Almost Famous

TV show you could happily binge: Sopranos or Shameless

Three things that can always be found in your refrigerator: Ranch, Cheese & Strawberry Preserves

Secret vice: It's not a secret if I tell you

Who would play you in the movies?: Gwyneth Paltrow in The Royal Tenenbaums

Your pet peeve about Pittsburgh: Road infrastructure

People may be surprised to know: I went to college for Physical Therapy Assistant.

HCWP CORNER

KATHERINE BUSH, LCSW

Hello to all WPBDF Members and Your Families,

Summer weather is FINALLY here! We're hoping that you and your families get the chance to get out and enjoy it, but don't forget that allergy medicine if you need it! And your sunscreen! And stay hydrated! As you make your summer plans, please remember to make sure that you are current with your clinic appointment. We continue to offer pediatric appointments on Wednesdays and adult appointments on Mondays and Thursdays. Virtual appointments may be possible if necessary. Please call the clinic to discuss this option. Appointments have been filling fast, so please reach out promptly to schedule.

Current appointments will help us know the info we need to help keep you safe on your travels and adventures. We can also provide you with documentation to take on your trips that can make it easier to travel with medications and (although we hope this isn't necessary!) facilitate any needed care while you are away. Please remember to give us advance notice if possible so that we can get any medications and documents that you may need out to you in a timely manner.

Factor refills are still available by phone or through our website (https://hcwp.vitalant.org/Home.aspx). We continue to have our on-call number (888-990-4297) available when the center is not open. Whenever possible, please call us before you arrive to the emergency room. Also, if you have a planned procedure, please reach out to us at least 10 days in advance so that we can arrange a plan to help keep you safe during your procedure.

Camp is scheduled for July 27-August 1, 2025 for affected youth aged 7-17 and their siblings within the same age group, and we are so excited to continue to offer this program. We have about 48 campers registered, and we are sure that Hot-to-Clot will be an amazing time. We are also very pleased that we were once again able to hold outreach clinics to

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WPBDF IN THE COMMUNITY

From appearing on Talk Pittsburgh, to working closely with local colleges, and even attending community events, WPBDF volunteers and staff have been busy raising awareness for bleeding disorders in our Western Pennsylvania community!

On March 13, WPBDF Executive Director, Kara Dornish, and Board Members, Samantha Short and Ashley Lynn Priore, appeared on Talk Pittsburgh to discuss the signs and symptoms of bleeding disorders, specifically in women, girls, and persons with the potential to menstruate. Kara discussed the Foundation and the resources available while Samantha and Ashley shared a bit of their personal stories. You can watch their segment on Talk Pittsburgh at: www.cbsnews.com/pittsburgh/video/raising-awareness-on-bleeding-disorders-and-how-a-local-group-is-helping-those-in-need/

WPBDF attended the Kane Health Expo in April, Representative Dan Miller's Disability & Mental Health Summit in May, and the Wellnes 4 Schools Summer Symposium, Beaver's Garrison Days, and Bridgeville's Day on the Avenue Festival in June. WPBDF staff and volunteers passed out information about the Foundation, explained what bleeding disorders are, and directed men and women who may be experiencing bleeding disorders symptoms to betteryouknow.org. We can't express enough gratitude to the volunteers who helped staff these booths, share their stories, and get us registered to attend some of these incredible events!

WPBDF continued to build relationships with local colleges and universities by attending Chatham University's Public Health Week on April 10. We quizzed students on their bleeding disorders knowledge, handed out resources to spread the word about the signs and symptoms of bleeding disorders, and directed people to visit betteryouknow.org to take a free risk assessment! A huge thank you to Hayden Barns of Chatham Student Health Services for inviting us and to all the students who stopped by to visit! We can't wait to come back next semester!

How Can I Help?

If you know of a community or health fair event with booth or exhibit opportunities, please let us know! Better yet, if you would be willing to display at the booth or donate a few hours of your time to help us staff the booth, your generosity would be much appreciated. WPBDF can provide all the materials you need. You will be tasked with sharing the symptoms of a bleeding disorder with individuals who stop by the booths, and if you're comfortable, sharing your story and experience with a bleeding disorder.

BLEEDING DISORDERS AWARENESS MONTH

NICOLE R.

Nicole R. (left) poses with her son, Elijah (middle) and fellow community member, Kingsley R. (right) after receiving a proclamation for Bleeding Disorders Awareness Month from the McKean County Board of Commissioners.

Did you know that our special month for raising awareness about bleeding disorders has been around for almost 40 years? It all started back in 1986 when President Reagan set aside March as National Hemophilia Awareness Month. For about 30 years, the focus was mainly on hemophilia. But in 2016, the month was officially renamed, "Bleeding Disorders Awareness Month." This new name recognized that our community includes people with many different conditions, not just hemophilia, but also von Willebrand disease, rare factor deficiencies, and platelet disorders.

This change was a big deal because it helped everyone feel included, no matter what bleeding disorder they have, their gender, age, or background. Throughout the years, this special month has helped teach others about our conditions, helped people get diagnosed earlier, brought our community closer together, pushed for better research and treatments, and celebrated the amazing strength of everyone living with bleeding disorders.

Counties throughout Western Pennsylvania recognized Bleeding Disorders Awareness Month by issuing proclamations and inviting WPBDF to attend their local Board of Commissioners meetings. This included: Butler County, Cambria County, Beaver County, Crawford County, Elk County, Fayette County, Greene County, Westmoreland County, McKean County, Venango County, Washington County, and the City of Erie, Pennsylvania.

Nicole R. and her son, Elijah, attended a meeting on WPBDF's behalf to accept a proclamation from McKean County. She shares her experience below:

We were honored to accept the McKean County Bleeding Disorders Awareness Month Proclamation on behalf of the Western Pennsylvania Bleeding Disorder Foundation in March. Elijah is the first in our family to be diagnosed with Hemophilia A since he has a new mutation. He is one of the many individuals with a lifelong bleeding disorder that slipped through the cracks due to limited knowledge and understanding. Our family has no history of Hemophilia and Elijah did not have all the textbook Hemophilia traits. This prolonged his diagnosis, due to limited knowledge of bleeding disorders, until we traveled to a specialized hospital that is associated with the Hemophilia Treatment Center. He was then quickly diagnosed and treated for a bleed that was ongoing.

The Western Pennsylvania Bleeding Disorders Foundation continually opens doors for families like ours to recognize possible abnormal bleeding tendencies while enabling them to advocate better for themselves. As well as providing continuing education and treatment options for families who have been part of the bleeding disorders community for years. In unspecialized areas that may not have bleeding disorder specialists, this is life changing.

This proclamation brings awareness and a spotlight within our community and surrounding regions for the need for continued support of the bleeding disorders community on a more substantial level while giving families like ours a platform to share our experiences. Involving Elijah and the next generation of individuals with bleeding disorders is critical to continue support and growth for years to come. We were privileged to be part of it.

HCWP CORNER

CONTINUED FROM PAGE 18...

serve our Amish community.

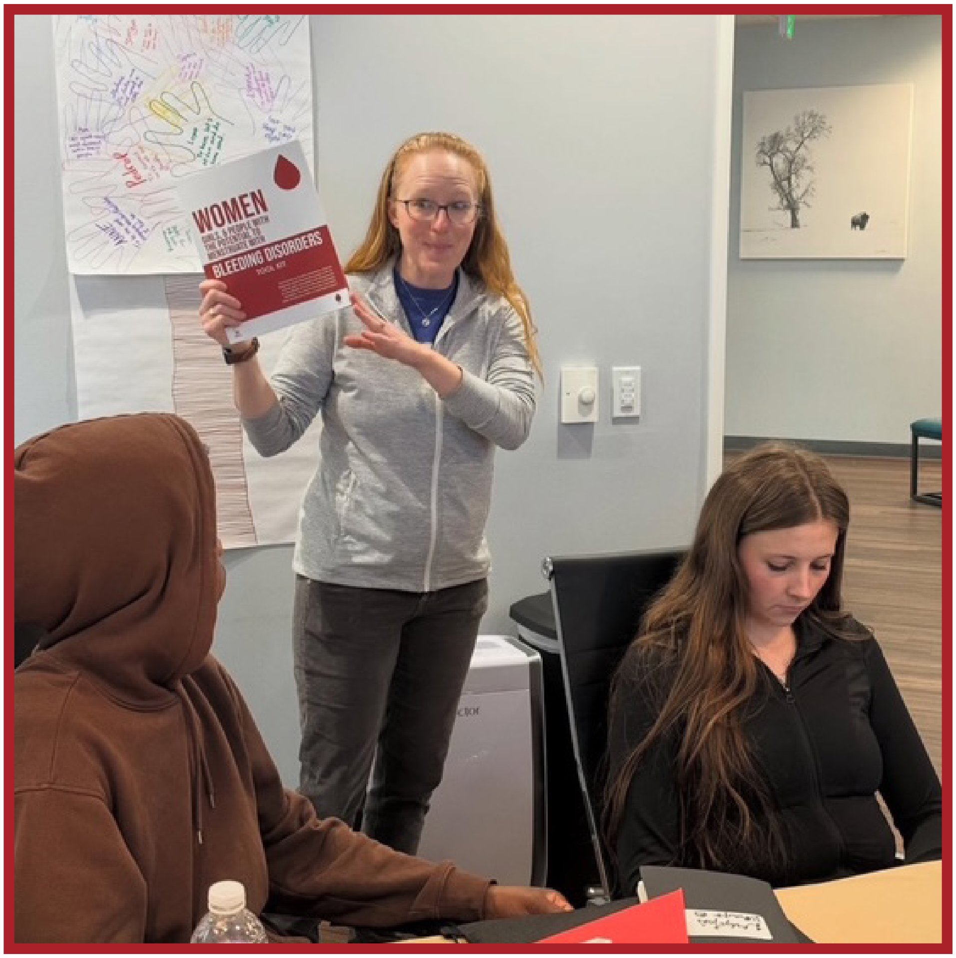
Please continue to make sure that you are completing our Patient Satisfaction Survey that you receive at your appointments. This is an important way for us to know how we are doing and to make changes as needed.

We are happy to introduce Ashley Long, a new physician assistant working at the center, as well as Anuj Kaul, the new research coordinator who is replacing Brandon Lawryk (who we are very sad to lose, but we wish him well on his school journey!).

Wishing you a wonderful summer full of laughter and relaxation,

The HCWP Staff

COAST-TO-COAST COLLABORATION: FUTURE LEADERS UNITE FOR BLEEDING DISORDERS AWARENESS



We were thrilled to be part of an inspiring collaboration with the Bleeding Disorders Council of California's Future Leaders, who took on a meaningful service project to raise awareness about bleeding disorders through the creation of period packs.

This incredible initiative began when Anne Henningfeld of Beyond Recreation reached out to us about a potential partnership—and we were all in! What started as an idea quickly turned into a nationwide effort, stretching from California to Pennsylvania.

All materials for the period packs were shipped from Pennsylvania to North Carolina, where Anne collected them and brought them to California. There, during a Future Leaders event, the youth participants were challenged to work together to assemble the packs. Anne explained the purpose and importance of the project, and in less than an hour, the group enthusiastically assembled more than 300 period packs. The teens were energized, with lots of conversation about how to bring this project to their own local organizations.

Afterward, the completed packs traveled back to North Carolina with Anne. In a wonderful twist of fate, her parents, Diane and Ken, happened to be driving from North Carolina to Michigan and passed through Pennsylvania, allowing Kara to meet them and collect the finished packs.

These packs truly took an

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COAST-TO-COAST COLLABORATION: FUTURE LEADERS UNITE FOR BLEEDING DISORDERS AWARENESS

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incredible journey, filled with heart, collaboration, and a shared commitment to supporting women with bleeding disorders.

Next, the period packs will continue their mission, making their way into school districts throughout Pennsylvania to help raise awareness and provide support to students in need.

A heartfelt thank you to Anne Henningfeld, her parents Diane and Ken, Lynne Kinst, and the Bleeding Disorders Council of California (BDCC) for their support. We are especially grateful to BDCC for sponsoring this initiative and generously covering the cost of shipping the products from PA to NC. Your dedication helped make this cross-country collaboration a reality.

We're so grateful to everyone involved for bringing such energy, creativity, and compassion to this project!

Saturday, November 8, 2025

Vanport Volunteer Fire Department
435 Jefferson St, Beaver, PA 15009

LEARN MORE & PURCHASE TICKETS AT: BIT.LY/WPBDFPURSEBINGO

GETTING TO KNOW WPBDF BOARD OF DIRECTORS

ASHLEY LYNN PRIORE

What influenced you to get involved with the Chapter and join our board of directors?

As someone with a bleeding disorder, I've always understood how important community, advocacy, and access to resources are—especially for young people navigating life with a chronic condition. WPBDF has played a pivotal role in supporting families like mine, and joining the board felt like a natural way to give back. I'm passionate about using my voice to ensure that every person with a bleeding disorder feels seen, supported, and empowered.

What is your background or current occupation?

I'm a strategist, entrepreneur, nonprofit leader, and lifelong chess player. I serve as the Founder & CEO of Queens Gambit, a national nonprofit using chess as a tool to build leadership skills in youth. I'm also the Founder & CEO of Queenside Ventures, a consulting firm working at the intersection of strategy, public relations, and leadership development—advising leaders across sectors, including sports, media, and politics. At the core of my work is a commitment to access, inclusion, and systems change.

What are you looking forward to as a new board member?

I'm excited to support WPBDF's strategic vision and bring a fresh perspective on community engagement, storytelling, and advocacy. I'm especially looking forward to collaborating with other board members and amplifying the voices of young people and underrepresented members of our community.

What do you like to do for fun?

When I'm not working or playing chess, you can usually find me reading, writing, or exploring local coffee shops.

QUIZ FOR A CAUSE!

KRISTEN SPEZIALETTI

Do you know the name of Wonder Woman's alter ego? On Monday, April 7, 6 teams tested their knowledge on topics ranging from comic books to Mambo No. 5 lyrics to raise money to support the Western Pennsylvania bleeding disorders community!

Kristen Spezialetti, WPBDF Board Member, organized the 2nd annual trivia night fundraiser at Sheffield Lanes in Aliquippa, PA, who generously donated their space for the evening.

Twenty-seven participants competed in a lively battle of wits for the title of Ultimate Trivia Champions. The night featured four exciting rounds—pop culture, sports, famous people, and geography—plus a fast-paced lightning round to keep everyone on their toes. The evening's winners, the Sheffield Terrors, took home the crown with an impressive 33 points!

"Combining my love of trivia and my passion for supporting our local bleeding disorders community was a no-brainer. Not only were we able to have a fun night, but we were able to be a small part of something greater," Spezialetti said. "I am proud to support the work of the WPBDF, and I would like to sincerely thank the attendees and local businesses who supported this event."

Thanks to the incredible generosity of all attendees and sponsors, the event raised over $500 to fund vital education, advocacy, and support programs for the bleeding disorders community in Western Pennsylvania.

GIRL TALK X WPBDF

SAMANTHA SHORT

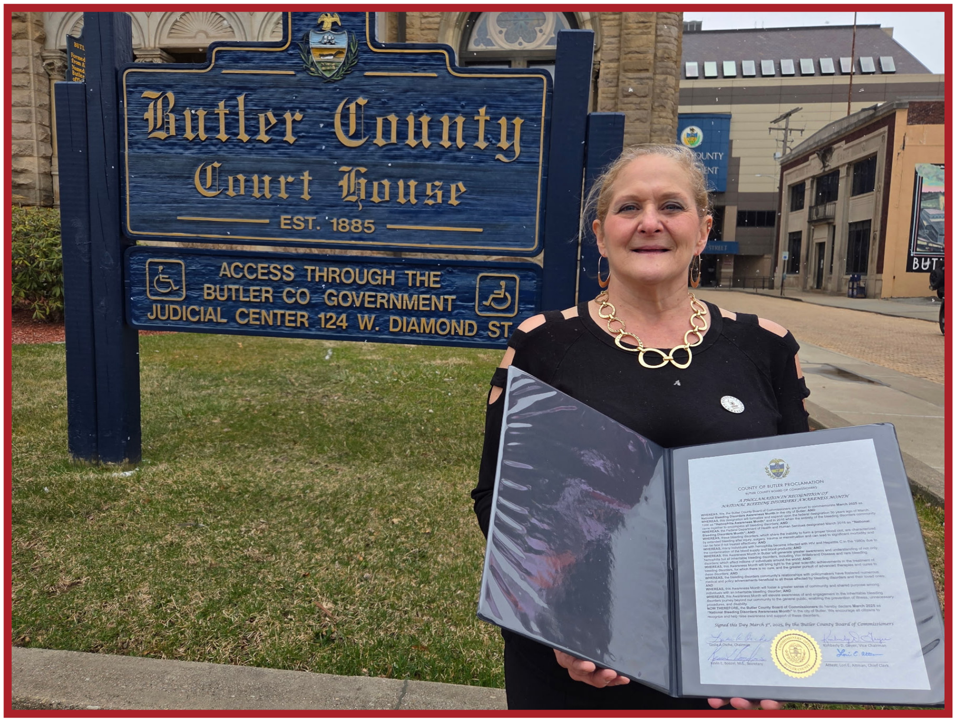
I was honored to be invited back to speak with the Girl Talk chapter at The Best of the Batch Foundation and share important information about bleeding disorders. Since 1999, former Steelers quarterback and local hero, Charlie Batch, along with his lovely family, have been enriching the lives of those in his hometown of Homestead, PA. Best of the Batch's mission is to unlock potential in communities to build the best future for kids and families by providing choices, motivation, and education.

This year, I presented our newly named collaboration, "Girl Talk X WPBDF." Girl Talk, led by Taylor Mitchell, is a program which aims to connect middle school and high school girls with mentors to provide guidance and advice for navigating life's challenges.

During my presentation, I discussed what my life was like as a young woman navigating a bleeding disorder and answered some real life question the girls had. I was so impressed by the young women's willingness to openly discuss menstrual health during the presentation. I was also pleased to learn from Taylor that Best of the Batch provides free menstrual supplies at their facilities. We finished up the afternoon by assembling period packs to be distributed to local rural health clinics and schools.

Thank you to the Best of the Batch Foundation for your continued support and partnership!

SPREADING THE WORD



On Wednesday, March 26, Advocacy Ambassador Jessamyn Butler attended the Butler County Commissioners' Meeting to accept a proclamation recognizing March as Bleeding Disorders Awareness Month. Her story was shared in the Butler Eagle!

You can read her story online at: https://www.butlereagle.com/20250331/bleeding-disorders-highlighted-by-foundation-at-county-commissioners

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.

CELEBRATING WORLD HEMOPHILIA DAY

The Western Pennsylvania bleeding disorders community celebrated World Hemophilia Day together at the Monterey Bay Fish Grotto on Thursday, April 17. Over 70 people enjoyed a delicious dinner and dessert while overlooking the beautiful city of Pittsburgh.

To kick-off this celebration, Carrie Koenig, Community Relations and Education Manager at Sanofi, began with a presentation highlighting the unbreakable bond that ties this global community together. Videos detailing the stories of patient advocates from across the world discussed important topics including the history and legacy of the bleeding disorders community as well as women, girls, and persons with the potential to menstruate and bleeding disorders. Attendees were then invited to share their own stories of navigating life with a bleeding disorder.

At the conclusion of the presentation, each person received a pipe cleaner. They were encouraged to shape their pipe cleaner into something that represented them, including a heart or a butterfly, and then link it with their family members. The chain grew longer and longer as each half of the room linked with one another, emphasizing the theme of the program – our unbreakable bonds. During the event, Sanofi also set up a variety of activity stations, including a selfie station, DIY photo frames, and beaded bracelet making.

As the sun began to set, Monterey Bay offered the perfect view to see Pittsburgh's skyline light up red! Thank you to everyone who joined us in this celebration and thank you to Sanofi for supporting this event!

sanofi

NO CUTS TO MEDICAID!

Medicaid provides quality and affordable health care coverage for about 1 in 4 Americans, and 3 in 10 people with bleeding disorders. Without Medicaid, many lower-income people living with bleeding disorders could not regularly access the medication, treatment, and care coordination they need to live healthy and productive lives.

Congress is looking to cut federal spending on Medicaid in order to achieve budget savings to spend on other priorities. The cuts up for debate will likely include policies such as:

- **Reducing how much the federal government pays toward the costs of running the Medicaid program**. Lower federal funding would leave the states with higher costs – triggering program rollbacks and ultimately forcing an end to Medicaid expansion coverage for non-disabled adults.
- **Imposing "work reporting requirements" as a condition for adults to keep their Medicaid coverage.** Medicaid work reporting requirements create red tape that people have to navigate to get and keep their health coverage. But evidence shows that the vast majority of Medicaid enrollees already work or qualify for an exemption, and cutting off health coverage does not encourage people to stay employed.

These policies would cause coverage losses and would threaten access to care for people with high-cost conditions such as bleeding disorders. Community members would be at risk of preventable complications, permanent disability, or worse.

HERE'S WHAT YOU CAN DO:

1. **EMAIL and CALL Your Members of Congress**
2. **DROP BY** your U.S. Senator's local in-district office!

EMAIL AND CALL YOUR MEMBERS OF CONGRESS

Right now, US Senators are debating a bill that would make deep cuts and harmful policy changes to Medicaid and to Marketplace insurance. This legislation (the so-called "One Big Beautiful Bill") has already passed the House, but it can't become law without Senate approval. We need to raise our voices to stop the bill in the Senate!

The stakes could not be higher. More than one-third of people in the bleeding disorders community get health insurance via either Medicaid or the Marketplace – insurance that covers essential treatment and medicines. The bill now, under consideration in the Senate, threatens access to coverage and care for us, and for up to 16 million other people from across all walks of life.

Medicaid

- The Senate should **REJECT** work reporting and paperwork requirements that make it harder for individuals to get or keep Medicaid coverage. People with bleeding disorders cannot afford to lose coverage due to paperwork!
- The Senate should **REJECT** new cost-sharing for adults covered under the Medicaid expansion pathway. Research shows that even modest cost-sharing causes low-income people to forego medically-necessary care, with dangerous consequences to their health.
- The Senate should **REJECT** policies that limit funding mechanisms that 49 states currently use to finance some of the states' share of Medicaid costs. Those limits would cause states to change coverage and reimbursement levels, harming everyone with Medicaid coverage.

ACA/Marketplace

- The Senate should **REJECT** policies that would increase premiums for Marketplace insurance. Instead, the Senate should act to extend enhanced tax credits that will otherwise expire this year – and prevent a spike in premiums.
- The Senate should **REJECT** policies that would make it harder for people to get and keep Marketplace insurance. It should scrap provisions in the House-passed bill that would shorten enrollment periods, increase paperwork, and make re-enrollment harder.

The National Bleeding Disorders Foundation has created an action alert to easily send a message and make a call to your member of Congress. We encourage you to utilize the message template and script from the National Bleeding Disorders Foundation to Fight Cuts to Medicaid and Marketplace Insurance! Thank you for defending the programs that provide essential health insurance for so many in our bleeding disorders community!

DROP BY YOUR U.S. SENATOR'S LOCAL IN-DISTRICT OFFICE!

Deliver one clear message:

"We ask you to stand with the bleeding disorders community members who rely on Medicaid for access to comprehensive healthcare and reject cuts and administrative requirements that force eligible constituents to prove they deserve coverage."

Thanks to HFA, we have a No Healthcare Cuts Playbook to guide you through your visit, it includes:

- Exactly what to say
- What to bring
- Tips to make your visit count
- A one-page leave-behind for staff

What is a Drop-By Visit?

A drop-by visit is an unannounced stop at your Senator's local office. While you may not meet with the Senator, the visit shows your concern and delivers a message directly to their staff.

Step-by-Step: How to Conduct a Drop-By Visit

1. Find Your Senator's Local Office

Senator Dave McCormick has two offices in Western Pennsylvania:

Pittsburgh, PA

310 Grant Street
Suite 2415
Pittsburgh, PA, 15219

Phone: 412-803-7370

Erie, PA

17 South Park Row
Suite B-150
Erie, PA, 16501

Phone: 814-240-5213

Senator John Fetterman has two offices in Western Pennsylvania:

Pittsburgh, PA

1000 Liberty Avenue
Suite 1811
Pittsburgh, PA, 15219

Phone: (412) 803-3501

Erie, PA

17 South Park Row
Suite B-120
Erie, PA, 16501

Phone: (814) 453-3010

2. Prepare Your Message

Your key ask:

"We ask you to stand with the bleeding disorders community members who rely on Medicaid for access to comprehensive healthcare and reject cuts and administrative requirements that force eligible constituents to prove they deserve coverage."

You can also share:

- How Medicaid impacts you or how you would afford to pay out of pocket for marketplace coverage if you did not have access to the insurance you have today
- That Medicaid is a lifeline for people with chronic and complex health needs, including those with bleeding disorders.

3. Bring or email the Leave-Behind

Include:

- Print out and deliver the Healthcare is Critical for People with Bleeding Disorders one-page fact sheet.
- Your name and contact info.

4. Your Message

- Be polite and respectful to front desk staff.
- Say why you're there: "I'm a constituent, and I want to deliver a message to the Senator. Please ask them to protect Medicaid and avoid creating new barriers to access."
- Ask to speak with a staff member, if available.
- Leave your materials and thank the staff.
- Take a photo

AFTER YOUR VISIT:

Fill out the Report-Back Form — it's how we track your impact and follow up with lawmakers. Reach out to Kara at kara@wpbdf.org after your visit as well to let us know how it went!

And post a photo with #NoHealthcareCuts and tag @hemophiliafed and @WPBDF to let everyone know we are watching—and we are not backing down.

All the handouts, forms, and links can be found at WPBDF's website at: https://wpbdf.org/fight-medicaid-cuts/

Thank you for your advocacy!

CLARIFYING THE 340B PROGRAM AND HOW IT SUPPORTS OUR BLEEDING DISORDERS COMMUNITY

KATHALEEN SCHNUR

At HCWP, we are committed to transparency, collaboration, and providing accurate information. This update is intended to clarify how the 340B Drug Pricing Program operates, explain how it supports patient care, and reaffirm that patients always have the right to choose their pharmacy within the limits of their health insurance coverage.

Let's Start with the Facts

- The 340B program is a federal initiative that allows Hemophilia Treatment Centers to purchase medications at discounted prices. The funds generated from these purchases do not go into individual pockets; they go directly back into the HTC to support services for people with bleeding and clotting disorders.
- HTCs are not-for-profit medical centers that are federally funded to provide comprehensive, team-based care.
- The 340B program was established to help fill the funding gaps that federal support alone can't cover.
- Every dollar earned through 340B is governed by strict federal guidelines, reviewed by regional leadership, and reported to the government annually.
- These funds must be used to benefit you, the patient, and support services that directly impact your care and quality of life.

How 340B Funds Help Patients

Using the 340B pharmacy does more than deliver your medications; it strengthens the entire care system. Here's how:

- Supports services like nursing, social work, physical therapy, and genetic counseling.
- Funds care coordination and patient education.
- Helps your HTC purchase critical equipment (such as ultrasound machines).
- Supports outreach to underserved communities and health equity efforts.
- Enables HTCs to conduct research and pilot innovative programs to improve care.
- In other words, your participation in the 340B program helps ensure that comprehensive, high-quality care remains available not just for you, but for everyone in the bleeding disorders community.

You Always Have a Choice

- You are ***never*** required to use your HTC's 340B pharmacy.
- Your insurance determines your pharmacy options. If your HTC 340B program is an option, and you choose not to participate, you will still receive the full range of services available through your HTC. We remain your partner in care, regardless of who provides your medication.
- We recognize that each family must make the decision that's best for them. Whether or not you participate in the 340B program, our team is here to support you.

Addressing the Misconceptions

We have received feedback suggesting that others believe 340B pharmacies are driven by profit or greed. We understand how confusing this can be and how harmful misinformation may cause worry or distrust. We want to be very clear:

- HTCs do not profit from patients.
- HTCs reinvest 340B income into patient-centered services that are otherwise underfunded or unavailable. These services are not luxuries; they are essential components of the care model that improve outcomes and save lives.
- Since 1973, HTCs have proven that comprehensive, team-based care improves health and quality of life. But as more people need care and costs continue to rise, federal funding has not kept pace. The 340B program helps close that gap—ethically, legally, and transparently.

FAQs

- *Will I have to change my product if I use the 340B pharmacy?*

No. You should be able to continue using the same factor replacement product you're using now.

- *Will I pay more by using the 340B pharmacy?*

Not necessarily. In fact, since HTCs buy at discounted rates, your costs may be lower.

- *If I don't use the 340B pharmacy, will I lose HTC services?*

Absolutely not. All patients are entitled to the full spectrum of care, regardless of their pharmacy choice.

We're Here to Talk

Your care, trust, and well-being are what matter most. We encourage you to reach out to your HTC team with any questions about your pharmacy options, the 340B program, or how our services are funded. We welcome open, honest conversations and value your input.

This article is part of our ongoing effort to provide clarity, based on feedback from our community. Thank you for your thoughtful questions, your advocacy, and your partnership in care.

Learn more in this short video: What is the 340B Program? (https://youtu.be/vDairD7bePs)

Together, we can keep our community strong, informed, and supported.

*Adjusted and elaborated from the MidAtlantic Region 340B Brochure.

2025 SCHOLARSHIP WINNERS

CONGRATULATIONS TO THE RECIPIENTS OF WPBDF'S 2025 ACADEMIC SCHOLARSHIP!

$2,250 SCHOLARSHIP WINNERS

Justin Najimian
Billie Rolle

$2,000 SCHOLARSHIP WINNERS

Mary Laughlin

$1,000 SCHOLARSHIP WINNERS

Maggie Egenlauf
Jason Miller
Ryan Palmer

$750 SCHOLARSHIP WINNERS

Ava Bush
Mackenzie Cloutier

$500 SCHOLARSHIP WINNERS

Whes Ebsworth
Robert Weaver

JUSTIN NAJIMIAN

As a genetic counseling student at the University of Pittsburgh, I am excited to enter the workforce as a genetic counselor. I look forward to being able to serve those with genetic conditions on a daily basis and assist them in becoming their own best advocates.

BILLIE ROLLE

I'm a licensed Cosmetology Instructor and am passionate about education, community service, and mentorship. I aim to open a diverse full-service salon that doubles as a training center. My vision is to empower future professionals, offering free services to those in need, while using beauty to uplift individuals and strengthen my community.

MARY LAUGHLIN

I'm close to earning my Bachelor's Degree in Art Education at Indiana University of Pennsylvania. I'll be certified to teach Kindergarten through twelfth grade. I've enjoyed exploring many different art mediums and am excited to offer my future students a wide range of techniques to learn. Thank you so much to the WPBDF for this scholarship, it's going to be a big help in reaching my educational goal!

... CONTINUED ON PAGE 30

MAGGIE EGENLAUF

My career goals will begin at Indiana University of Pennsylvania this fall majoring in Family Consumer Science Education. I plan to complete my education there, and become a high school FCS teacher. Along my way, I plan to keep close to the bleeding disorder community and hold my values.

JASON MILLER

I'm currently earning my MBA in IT Management as I prepare to shift from day-to-day development work into a future role in software architecture, combining my technical background with a broader strategic perspective to support innovation and growth.

RYAN PALMER

Thank you for providing me with this scholarship! I plan to attend Slippery Rock University in the fall and major in Computer Science. I am excited for this opportunity because it will give me the chance to really feel like an adult living independently, despite my Autism diagnosis.

AVA BUSH

Hello, my name is Ava Bush. I am a fourth generation Dairy Farmer who is currently enrolled in Gannon Universities 5-year Physician Assistant program. I hope to enter the Emergency Department or NICU after graduation, unless I find a field during clinical rotations that I love.

MACKENZIE CLOUTIER

In the future, I plan to pursue a Master's degree in both Cello Performance and Orchestral Conducting, with the goal of utilizing music as a tool for social growth and community building. I also plan on bringing music education–especially string education–to communities typically underrepresented and underfunded in music and arts opportunities.

ROBERT WEAVER

Robert will be pursuing his dream of studying science and technology, data analytics, and agricultural science. He hopes that through technology, agricultural, and industrial integration we can have a more sustainable and fruitful future, not only here on Earth but as we look out to the stars.

RUN FOR THEIR LIVES

Bleeding disorders can't stop us.

Check in begins at 7:30 A.M.
Race begins at 8:30 A.M.
Distance: 5K (3.1 miles)

Join us for the 16th Annual Run for Their Lives 5K happening in-person on September 6, 2025! 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!

"Our timing will keep you smiling"
Miles of Smiles® TIMING SERVICES

Thank you to our race timers, Miles of Smiles!

REGISTRATION FEE:
$30
Race Day fee:
$35

SATURDAY
SEPT 6
2025

NORTH PARK SWIMMING POOL

9901 S RIDGE DRIVE
GIBSONIA, PA 15044

Registration includes a race bib, finishers medal, technical t-shirt, goody bag, and access to virtual race results!

REGISTER AT: BIT.LY/RUNFORTHEIRLIVES2025

WPBDF
Western Pennsylvania Bleeding Disorders Foundation

A portion of proceeds will support the Western Pennsylvania Bleeding Disorders Foundation!

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

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION'S

17TH ANNUAL UNITE FOR BLEEDING DISORDERS WALK

9:00 to 11:00 AM
(CHECK-IN: 8:30 to 9:30 AM)

September 6
Saturday

North Park Swimming Pool
9901 S Ridge Dr,
Gibsonia, PA 1504

CONTACT US Jessica Lee | jessica@wpbdf.org| 724.741.6160

REGISTER TODAY! www.uniteforbleedingdisorders.org/event/wpa

Hemophilia Alliance · Takeda · National Bleeding Disorders Foundation

HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION
775 4th Street, First Floor
Beaver, PA 15009
Phone: 724-741-6160 Toll Free: 800-824-0016 Fax: 724-741-6167
info@wpbdf.org

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