WPBDF
Western Pennsylvania Bleeding Disorders Foundation

HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

FALL 2025

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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

October 25
Coalition of Hemophilia B
Sheraton Pittsburgh Airport Hotel
Coraopolis, PA

November 8
Purse Bingo Fundraiser
Vanport Fire Hall
Vanport, PA

November 14-16
Teen Retreat
Promise Camp
Clinton, PA

November 16
New Parent Network
Virtual

December 2
Advocacy Stakeholder Meeting
Harrisburg, PA

December 13
Winter Program
Shadow Lakes Country Club
Aliquippa, PA

February 2, 2026
Pittsburgh Penguins Fundraiser
PPG Paints Arena
Pittsburgh, PA

March 4-6, 2026
NBDF's Washington Days
Washington D.C.

April 16-19, 2026
HFA Symposium
New Orleans, LA

April 15, 2026
World Hemophilia Day Program
Location TBD
Erie, PA

April 17, 2026
World Hemophilia Day Program
Monterey Bay Fish Grotto
Pittsburgh, PA

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

July 11, 2026
Annual Meeting & Education Day
Bayfront Convention Center
Erie, PA

August 13-15, 2026
National Bleeding Disorders Conference
Orlando, FL

August 22, 2026
Regional Education Day
Oglebay Resort
Wheeling, WV

September 19, 2026
Unite for Bleeding Disorders Walk & Run for Their Lives 5k
North Park Swimming Pool
Gibsonia, PA

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

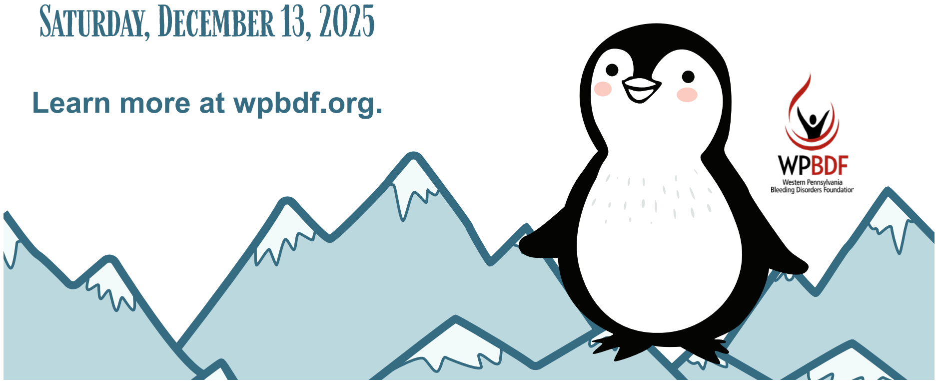
WPBDF'S

Winterfest

SAVE THE DATE!
SATURDAY, DECEMBER 13, 2025

Shadow Lakes Country Club
2000 Beaver Lakes Blvd,
Aliquippa, PA 15001

Learn more at wpbdf.org.



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LETTER FROM THE EXECUTIVE DIRECTOR

Dear Foundation Members and Friends,

Happy Fall! The crisp air, fall festivals, pumpkin spice everything, and fun Halloween costumes make this one of my favorite times of year. I hope you are enjoying the season and taking full advantage of the programs and resources WPBDF offers.

It was wonderful to see so many of you at the Unite for Bleeding Disorders Walk. This was my 13th Walk, and I am always inspired by the way our community comes together to support one another. The day was filled with energy and connection, and it was a beautiful reminder of the strength and generosity of our members. We are continuing to fundraise for the Walk through December, and we deeply appreciate your support. Your contributions allow us to continue offering education, awareness programs, and patient assistance to the community.

This fall has been full of exciting programs, from cheering on the Pirates at PNC Park to working side by side with Pitt volunteers to stuff over 1,000 period packs for school nurses across Western PA. Our Women, Girls, and People with the Potential to Menstruate Initiative continues to grow stronger, and thanks to your participation, we are not slowing down anytime soon.

Looking ahead, we know the upcoming year will bring changes that affect our community. We are here to help you prepare. Please read the advocacy update in this issue and check our advocacy page regularly at wpbdf.org/advocacy.

One of the most important things to keep on your radar is health coverage. To have your coverage begin on January 1, open enrollment in Pennsylvania runs November 1 to December 15, 2025, at pennie.com. Enrolling early helps avoid surprises and gives you time to confirm your doctors and medications are covered. If you are staying with the same plan, make an active choice to renew it and double check the details. The incredible social workers at the Hemophilia Center of Western PA are available to help if you have questions or need assistance.

We also know that big changes are coming to Medicaid. While the new rules do not take effect immediately, it is important to start preparing now. Make sure your contact information is up to date, respond promptly to all mail from Medicaid or your insurer, and keep records of work or qualifying activities. These small steps will help protect your coverage as the new requirements roll out.

Awareness and community outreach have been a top priority for us this year. We are proud to partner with local libraries, school districts, and community foundations to spread awareness of bleeding disorders and make resources accessible to more families. We are always looking for ways to get involved, whether through attending health fairs, participating in community events, or providing period packs, nosebleed kits, and other resources to schools, libraries, foundations, and more.

If you would like to be part of this important work, I would love to hear from you. Please reach out to me anytime at kara@wpbdf.org. Together, we are making a lasting impact. Thank you for being part of our community and for all the ways you continue to support WPBDF.

With deep gratitude and appreciation,

Kara Dornish
Executive Director, WPBDF

LETTER FROM THE BOARD PRESIDENT

It is my pleasure to officially introduce myself as the new president of the WBPDF Board of Directors in my first *Letter from The President*. I am honored to serve this wonderful community as your new President! My commitment to this Foundation and community remain the same – to put the well-being of the bleeding disorder community above all else. I couldn't have accepted this position without the wonderful support you as a community have provided me with. From the bottom of my heart thank you all for what you have contributed to our Foundation.

Serving alongside me is a wonderful board of directors, including our newly elected executive board; Victoria Baker will now serve as our new Vice President and Jason Miller as Secretary.

The past few months have been a whirlwind of activity. It was amazing to see so many familiar faces at the 2025 Unite for Bleeding Disorder Walk and 5k. It never fails to impress me – the number of supporters we have, especially during the pinwheel ceremony. Those of us affected by a bleeding disorder often feel alone in our journey, but events like these remind us of how strong we are when we unite together.

I also want to especially thank our staff for all the hard work they've put in this past year, including new major milestone events such as PABDC and the Pennsylvania/ West Virginia education day. These educational events are so important with the ever-changing medical landscape, including advances in technology and research. It is pivotal to keep informed not only as a patient, but as a bleeding disorder consumer. Today's education class may be tomorrow's real life emergency. That's why education (free and accessible) will always be a top priority for WPBDF.

Wishing all of you a wonderful fall and winter season! Until next time!

Samantha Short
Board President, WPBDF

ADVOCACY UPDATE

KERRY LANGE, SENIOR ASSOCIATE
MILLIRON GOODMAN

HARRISBURG OVERVIEW

The Pennsylvania General Assembly is in 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.

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

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

The Democratic caucus maintains a slim majority in the House and the Republican caucus maintains a narrowing majority in the Senate, which all underscores the need for strong bipartisan support to achieve legislative success. As you know, the caucus with the most members controls the chamber's legislative agenda and determines whether or not a bill receives consideration in committee and on the respective chamber floor.

All 203 state House members are

up for reelection next November, as are 25 of the 50 Senate seats (even-numbered districts).

BUDGET

As of September 20, (82 days passed the June 30 deadline), Pennsylvania does not have an agreed-to budget plan.

The budget process began in February with Governor Shapiro's 2025-26 budget address and corresponding proposal. It was a $51.3 billion spending plan, a 7.5% increase over last year's budget. Similar to his previous proposals, 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%. Even if passed, projected revenue from both recreational marijuana and skill games in the first fiscal year would be just shy of $1 billion. In addition, the Independent Fiscal Office projects the state's operating deficit to increase from $3.4 billion to $6 billion by next year.

After receiving the Governor's proposal, the House and Senate held Appropriations Committee hearings with each state agency to discuss the details and potential implications. Then internal negotiations began.

What's the cause of the delayed budget this year? A large focus of negotiations was on mass transit. Senate Republicans argued that SEPTA should utilize a portion of their own $2.4 billion trust fund to keep their services running, as well as increase security measures and ticket rates. But, state Transportation Secretary, Mike Carroll, argued that those capital dollars have already been allocated to transit improvement projects, and they need a more reliable, recurring revenue source.

In mid-July, the House passed a $50 billion spending plan (HB 1330) and sent it to the Senate. Two days later, the Senate stripped the bill of nearly all funding and staged it to become a vehicle, should an agreement be reached between the House and Senate.

A month later, the Senate reconvened and passed a separate $47.6 billion plan (SB 160) and sent to it to the House, where it was killed the next day.

Just a couple weeks ago, Governor Shapiro attempted to bridge the gap between the two parties by floating a $49.9 billion plan, which included the utilization of the $2.4 billion transit trust fund to temporarily fund SEPTA. However, he noted that his proposed two new revenue sources (recreational marijuana and skill games) must be included in the final package.

This nearly three-month delay leaves several education programs, county safety-net programs, and essential service providers with an unknown fiscal future. No one has received anticipated state funding, nor will they receive funding until the budget package is passed.

And the spending number is just the starting point. Once agreed to, they need to complete many other components of the budget package, including the education, fiscal, and tax codes. There is much work that remains to be done.

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

These budget requests continue to be our priority for WPBDF this session, as they are most critical for the patients and treatment centers. We have been advocating for an increase from $1,017,000 to $1,250,000.

As part of that advocacy, we were able to have several legislators representing HTCs across the state, including Representative Tom Mehaffie (R-Dauphin), Senator Tina Tartaglione (D-Philadelphia) and Senator Nikil Saval (D-Philadelphia), send supplemental letters of support for our budget request to their leadership teams in the House and Senate. Your grassroots advocacy also helped reinforce all these requests.

... CONTINUED ON PAGE 6

ADVOCACY UPDATE

CONTINUED FROM PAGE 5...

Both potential budget vehicles this session (HB 1330 and SB 160) protected the hemophilia line item at $1,017,000. However, the House and Senate have not reached a budget deal, so neither vehicle has made it across the finish line yet.

GRASSROOTS ADVOCACY

We encourage year-round advocacy with your personal legislators (Representative and Senator), especially to help advocate for the budget line-item requests.

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.

Legislators need the details on how each line item (including hemophilia) is spent. We shared the below HTCs responses with legislative offices, but it's helpful for you to share with your legislators as well.

The hemophilia line item is specifically 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 introduced bills and determine levels of engagement (support/oppose/amend/neutral).

So far this session (since January 1), nearly 3,000 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 receptables, 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 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 (R-Blair) reintroduced the co-pay accumulator bill as SB 268. It was referred to the Senate Banking & Insurance Committee.

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. Over the past year, 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 2025-26 legislative session.

SIGN UP TO RECEIVE ACTION ALERTS!

By signing up for action alerts, the Western and Eastern Pennsylvania Bleeding Disorders Foundations will notify you when issues arise that impact the bleeding disorders community. We will notify you with ways you can take action and easily contact your legislators on important legislation impacting the bleeding disorders community.

SCAN ME!

PREPARING FOR MEDICAID CHANGES

INFORMATION COURTESY OF THE NATIONAL BLEEDING DISORDERS FOUNDATION

On July 4, 2025, President Trump signed into law a bill that cuts $1 trillion from the Medicaid program and makes sweeping changes to eligibility, enrollment processes, and more. The new requirements don't go into effect immediately – but we know they are coming. Here are some steps you can take to protect your Medicaid coverage now and in the future as the new requirements go into effect.

⊕	**Know the name of your Medicaid program** (some go by names like HuskyHealth, BadgerCare, Apple Health; some programs are managed by insurers like Aetna or Centene).
🖥	Make sure that your **contact information is updated** with your Medicaid program, and make a practice of **logging into your Medicaid account** every few months to check for updates.
✉	Be sure to **open all mail and emails** from Medicaid and/or your state's health department and your insurer. If you receive any communication, **respond within the deadline** (typically 10-30 days).
✒	Begin keeping detailed **records of your monthly work or qualifying activities** (e.g., caregiving, school, community service). These can include pay stubs, schedules, attendance sheets, etc.

Preparing for Marketplace Open Enrollment (Fall 2025)

Big changes are coming this Fall to the ACA health insurance Marketplaces. Many insurance purchasers will face higher costs and more paperwork. Here are some tips to help guide you through the process.

Stay up to date with premium payments for the remainder of 2025 to avoid unexpected offsets or obstacles in 2026.

Read all notices from the Marketplace and your insurer and submit any responses by the deadline indicated.

Don't wait until the last minute to enroll for 2026 – you may have to complete more paperwork and income verification than in prior years.

Anticipate higher premiums for 2026 and, if needed, explore whether financial assistance is available.

Update your financial information with the Marketplace. Make sure you have **filed your taxes and reconciled credits** from the previous year.

Make an active choice for 2026, even if you are choosing to keep the same plan for next year.

Select a plan that covers your provider(s) and medication(s). Your HTC social worker may be able to help confirm that your plan covers what you need.

PROTECT YOURSELF AGAINST JUNK INSURANCE – start your search at healthcare.gov!

(Some states run their own Marketplaces with unique names but healthcare.gov will automatically redirect you to the right site.)

NATIONAL
BLEEDING DISORDERS
FOUNDATION


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

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 | 150 mg/mL
injection for subcutaneous use

Genentech
A Member of the Roche Group

2025 BLEEDING DISORDERS CONFERENCE

JASON MILLER

For the first time, I had the privilege of representing WPBDF at the Bleeding Disorders Conference in Aurora, Colorado this year, along with my son Spencer, who is affected by Factor VII Deficiency and a Platelet Function Disorder. It was a tremendous experience, with the opportunity to connect with members of our community from across the country. I would have loved the opportunity to attend with my whole family, as there were so many options for programming that overlapped, including an entire track for teens.

At the Opening Session, we connected with Kara, Janet, and Jess. This presentation was an amazing showcase of the NBDF's focus on diagnosis and treatment across all populations, including those where there have been historical gaps in care. This was a powerful reminder of where bleeding disorders care has come from, and how much further we have to go.

Spencer attended the child care program, where he made some great connections with other kids his age. This interaction with peers in the community is something that we value for all our kids, as it helps them to develop friendships and build connections with others who understand bleeding disorders. This community is so important to their future, and he was very excited to see some of his friends at the exhibition hall and pool in the evening after the sessions.

The exhibition hall was massive, and gave the opportunity to connect with many familiar faces and organizations, as well as some that we do not connect with often. One thing that was very evident in both the exhibitors and the sessions that they offered was a conscious choice to double down on content for the rare and ultra rare disorders. In talking to attendees who were there in the past, this was something that was lacking, and there were plenty of options and experts to talk to regarding the rare and ultra-rare factor disorders and the platelet disorders that do not always get the same airtime. In addition, there was plenty of programming for women, girls, and those who menstruate to help guide them toward diagnosis and treatment.

I spent a good chunk of my time in sessions related to ultra-rare factor disorders, advocacy, and research. There were many sessions across all these topics, but the advocacy and research sessions were the ones that really tied everything together.

In the current political climate, advocacy is so much more important. If we are not sharing our stories with our representatives at the local, state, and national levels, they are not going to understand the impact of their actions. It is tremendously important to share real life experiences that put a face to the condition. This helps them understand the impact on real people and families in their districts. Take the time to connect with the Foundation to get the information on current issues, and how you can help.

In our community, participation in research is tremendously important. The bleeding disorders community as a whole is not a huge group, and we are impacted by things that just do not affect those outside our community. This makes it essential that we participate in research studies to support new and improved treatments.

Overall attending BDC was a tremendous experience, and one that I hope to have again.

WPBDF IN THE COMMUNITY

Thoughout the summer, WPBDF continued to spread awareness for bleeding disorders by getting involved in various opportunities throughout Western Pennsylvania. Keep reading to hear from different advocates and volunteers who attended these events to share our mission and their story. Thank you to everyone who helped WPBDF make an impact!

WASHINGTON COUNTY

WPBDF Attends “Back to School Blast” to Raise Awareness About Bleeding Disorders

Tori Baker & Samantha Short

WPBDF Program Director, Janet Barone (left) and Executive Director, Kara Dornish (right) attend the Westmont School District’s Back to School Community Health Fair on September 4, 2025, in Johnstown, PA.

On August 23, the Western Pennsylvania Bleeding Disorders Foundation (WPBDF) was honored to participate in the “Back to School Blast” event, hosted by the Washington County Behavioral Health & Developmental Services in collaboration with Tanger Outlets and the South Strabane Police Department. Held at the Tanger Outlets in Washington County, the event brought together local families and community organizations to share resources, promote education, and celebrate the start of a new school year. Attendees were treated to complimentary face painting, balloon art, and a DJ, all provided by the event sponsors. Families were also given the chance to tour several Washington County emergency vehicles and meet the first responders responsible with keeping our community safe.

WPBDF Board President Samantha Short and Vice President Tori Baker represented the organization at the event, offering valuable educational materials and engaging in conversations to raise awareness about bleeding disorders. They connected with families across the community—some already familiar with bleeding disorders, and others eager to learn more. Some current community members also stopped by the table for a friendly hello! This event provided us an opportunity to further foster meaningful connections within our local communities, in line with WPBDF's mission.

Attendees were excited to explore WPBDF’s wide array of resources, including targeted educational packets for women and individuals with the potential to menstruate, as well as *Bleeding Disorders 101* bookmarks. We were also able to connect several attendees with our HTC, ensuring they receive the expert care they need.

Children especially enjoyed trying their luck at the PLINKO game, walking away with fun fidget toy prizes. The event proved to be a wonderful opportunity to share important information about bleeding disorders and ensure that Washington County residents know about the support

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HCWP CORNER

KATHAELEEN SCHNUR, LCSW

Dear HCWP Patients, Families, and the Bleeding Disorder Community,

Fall is in the Air and So Is Change
As the mornings grow crisper and the leaves begin to turn, the season reminds us that change is a natural and inevitable part of life. Healthcare is no different. Just like autumn transforms the landscape, recent legislation is bringing shifts that will impact our bleeding disorders community. While we don't yet know how all these changes will unfold, now is the time to stay informed, prepared, and proactive.

That's why being a savvy healthcare consumer is more important than ever. This means understanding key timelines, knowing your coverage, asking the right questions about costs, and being aware of plan limitations. With open enrollment for both Pennie (ACA Marketplace plans) and Medicare fast approaching, it's the perfect opportunity to review your options and ensure they align with your needs.

Just as vital, your story matters, not only for your personal care, but for our entire community. Staying connected with WPBDF helps you stay informed and get involved in advocacy efforts at both the state and federal levels. By sharing your experiences and raising our collective voice, we can shape the policies and protections that affect everyone with bleeding disorders.

Take Control of Your Care
Regular clinic visits are essential to your health and safety. Medications and treatment orders cannot be issued without an up-to-date appointment. As our clinic continues to grow, appointments are booking further in advance, so please plan ahead and schedule early.

The same is true for paperwork: letters, forms, and documents may take up to two weeks to complete. Planning ensures you get what you need, when you need it.

We're also excited to announce a new offering at our center: a monthly heavy menstrual bleeding clinic, launched in partnership with Mildred Duvet, MD. If you think this might benefit you, please don't hesitate to reach out for more information and to schedule.

Meanwhile, navigating insurance is becoming increasingly complex. Delays happen, coverage options can be limited, and persistence is key. Don't wait until the last minute to order your factor. Being proactive, asking questions, following up, and tracking important dates can make all the difference.

Evolving Tools, Evolving Responsibilities
Living with a bleeding disorder can be confusing, especially when symptoms are not always visible. Many in our community were raised in a time when any sign of discomfort was treated as a potential bleed, often without access to objective testing or specialized providers. Thankfully, that landscape is changing. Today, we have better diagnostic tools, improved understanding of the body, and powerful new treatments. With progress comes the responsibility to use these tools wisely and to treat when necessary. Overtreatment can pose serious risks, such as blood clots or complications from medication overuse.

This is especially true with the emergence of new rebalancing therapies for hemophilia. If you're considering or transitioning to one of these treatments, know that our team is committed to your safety and empowerment. Our care model is built on shared decision-making, where patients, providers, and the care team work together to ensure no one feels alone or unprepared. Your voice matters at every stage of your journey.

Broadening the Conversation
Historically, education and support around bleeding disorders have focused heavily on hemophilia. This is due in part to its well-documented history and the significant impact it has had on families. But the landscape is expanding.

Thanks to better diagnostic tools and growing awareness, more people are now being accurately identified with a range of bleeding disorders beyond hemophilia, such as the different types of von Willebrand disease, other factor deficiencies, platelet function disorders, and how bleeding disorders affect women.

This progress is exciting, but it can also be confusing, especially for those who don't see their experiences reflected in hemophilia-centered resources. That's why it's so important to recognize that while bleeding disorders connect us, no two experiences are exactly the same. Symptoms vary. Some are frequent and visible; others are rare or

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Connect with an ALTUVIIIO® Peer Mentor

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You'll have the opportunity to:

- Ask questions
- Hear firsthand experiences
- Learn helpful tips
- Get to know others in the community

> Maybe it's because I've always had such great support, but **engaging with others** is the best way for me to stay happy.
>
> —AJ

AJ | ALTUVIIIO patient

AJ is a promotional speaker compensated by Sanofi.

Sign up today to meet a Peer!

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A FUN WEEK AT HOT-TO-CLOT!

KATHALEEN SCHNUR, LCSW

This summer marked Camp Hot-to-Clot's third year back at camp since COVID. Nestled within the larger Camp Kon-O-Kwee YMCA Camp, our program brought together about 60 campers (patients and their siblings) for a week filled with adventure, connection, and growth.

The camp was large, the weather was hot, and the energy was next level! Our group gathered for a special Camp Hot-to-Clot Kick-Off campfire, where former campers shared their stories about how camp has shaped their lives. Later in the week, we participated in an activity focused on bleeding disorders, which involved creating a timeline that reflected the history of hemophilia treatments and the progress made in access to care over time. This exercise reminded us of how far our community has come. Hemophilia was the primary focus due to its well-documented history. Additionally, we read stories about kids in other countries dealing with hemophilia, which gave us a glimpse into their limited access to medicine and healthcare, as well as their daily lives, families, favorite foods, and how they play and learn. We appreciated the strength of kiddos around the world through those stories. They also showed us the importance of understanding and respecting different cultures and experiences.

Learning and fun went hand in hand throughout the week. A highlight was our creative approach to education: cookie decorating stations that illustrated the clotting cascade. This activity helped campers and the wider camp community gain a better understanding of the science behind bleeding disorders, all leading up to a camp-wide party.

Beyond the laughter, songs, and adventures, camp provided something deeper. Our campers developed essential skills in flexible thinking, adaptability, and independence. They explored not only the joys of camp life but also

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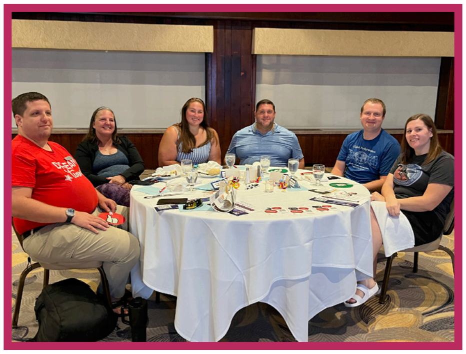
A NIGHT OF SUPPORT, LEARNING, AND CONNECTION

On Friday, August 8, families came together for an uplifting and informative New Parent Network event designed specifically for parents raising young children with bleeding disorders. The event, which focused on connection, education, and support, created a welcoming space for parents to share their experiences, build community, and leave with practical tools to support their family's journey.

The evening featured a variety of guided activities, led by Kathaleen Schnur, LCSW, from the Hemophilia Center of Western PA. Topics included expectations vs. reality, fear management, and myth-busting. This program allowed attendees to explore their concerns and ask clarifying questions in a safe and supportive environment. Group discussions fostered open conversation and mutual support, as parents connected over shared challenges and successes.

Throughout the program, participants gained valuable insights into bleeding disorders and learned strategies for normalizing bleeding in everyday family life. The session concluded with empowering affirmations to leave everyone feeling supported and inspired.



The event reflected the power of community, reminding everyone that while the journey may be challenging, no one needs to navigate it alone. One parent shared that talking with other parents of children with bleeding disorders really eased their mind. Another parent commented that they feel more confident with their child's diagnosis after attending events like this.

Dinner and childcare were provided and helpful resources were available for the families.

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:

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THE HEMOPHILIA CENTER of Western Pennsylvania

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Takeda

GETTING TO KNOW HCWP STAFF

ASHLEY LONG
PHYSICIAN ASSISTANT

Birthplace: Pittsburgh, Pennsylvania

First job: Fitness Attendant at the Upper St. Clair Rec Center

Accomplishment you're proudest of: Graduating PA school, planning a wedding, and starting my first PA job all within a couple of months!

What three words describe you best? Motivated, balanced, easygoing

Dream vacation: I would love to do a several week trip to Europe. Mainly, I would love to visit Italy & Greece!

Things you can do without: Mushrooms, the winter, negativity in general

Person you'd most like to have dinner with: Adele. I love her music and her personality!

Movie you could see anytime: Stepbrothers

TV show or podcast you try not to miss: Next Level Chef

Three things that can always be found in your refrigerator: Pickles, Celsius, any and all vegetables

Secret vice: Excessive caffeine and social media

Who would play you in the movies? Maybe Ashley Tisdale? Maybe it's just the name that's making me think that…

Your pet peeve about Pittsburgh: Infrastructure!!! Traffic & interchanges are the worst

People may be surprised to know that: I love hot yoga! Being able to move my body in any way makes me so much more mentally and physically strong.

ANNUAL MEETING CELEBRATES COMMUNITY, LEADERSHIP, AND ADVOCACY

Over 120 members of the bleeding disorders community gathered at the Sheraton at Station Square for the Western Pennsylvania Bleeding Disorders Foundation's 2025 Annual Meeting. The day included the Walk Kick Off, a delicious meal, and a Gateway Clipper sightseeing tour. It was also a time to recognize the incredible contributions of community leaders, advocates, and volunteers who make the Foundation's work possible. The morning began with rain, but the skies cleared just in time for the boat tour, providing a beautiful backdrop for connection, celebration, and acknowledgment of those who have made a lasting impact.

Celebrating a Year of Impact

Executive Director, Kara Dornish, welcomed attendees alongside Foundation staff Janet Barone, Jessica Lee, and Laurie Sano, as well as dedicated Board members. Kara highlighted the Foundation's accomplishments in 2025, including welcoming 71 new families, hosting 20 educational programs, and coordinating the Pennsylvania Bleeding Disorders Conference. This landmark event brought together 400 attendees and featured 40 educational sessions for adults and children, emphasizing learning, connection, and community-building across the state.

The Foundation provided over $50,000 in direct patient assistance to more than 300

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A FUN WEEK AT HOT-TO-CLOT!

CONTINUED FROM PAGE 15...

the importance of understanding their own diagnoses, treatments, and responsibilities as they grow. With the guidance and encouragement of the staff, campers practiced taking ownership of their care in age-appropriate ways, which helped build their confidence for the future.

Most importantly, camp gave the gift of community. Whether through shared challenges during a new activity, late-night laughter in cabins, or the comfort of knowing they're not alone, our campers experienced the power of belonging.

We are grateful for another incredible summer, one filled with independence, friendship, and tons of fun. As campers head home, we hope families will keep the conversations going about their bleeding disorder journeys, like their diagnosis, treatment, and what it means for them. Let's work together to help the next generation be strong, confident, and ready to take control of their health!

HCWP CORNER

CONTINUED FROM PAGE 13...

subtle. Even among individuals with the same diagnosis, the daily impact can look very different.

You Belong Here
Here's the truth: whether your symptoms are mild or severe, visible or invisible, you belong in this community. This is not a space for comparison or judgment. It's a place where we show up for one another, learn together, and make room for every unique journey. Together, we move forward with knowledge, with compassion, and with the strength of a community that understands.

~Kathaleen Schnur, MSW, LCSW
Clinical Social Worker/Mental Health Professional

A NEW APPROACH TO VWD TREATMENT

On September 17, individuals and families affected by von Willebrand Disease (VWD) came together to learn about a promising new treatment currently in clinical trials. The investigational therapy, VGA039, is now in Phase 3 and represents a potential breakthrough in VWD care.

VGA039 is designed to be used as a subcutaneous (under the skin) injection for prophylaxis. Because the treatment acts on Protein S to restore balance and form a stable clot, rather than acting on von Willebrand Factor, it is being tested in people with any type of VWD. The trial is enrolling people aged 12 – 75 who meet specific eligibility criteria.

To learn more about clinical studies, visit the FDA's website: https//www.fda.gov/drugs/development-approval-process-drugs/conducting-clinical-trials.

We thank Star Therapeutics for this learning opportunity.

STAR
THERAPEUTICS

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.

PATIENT ART CONTEST

The Hemophilia Center of Western Pennsylvania is excited to announce a patient art contest that will highlight and celebrate the strength, creativity, and resilience of individuals living with bleeding disorders.

Theme: "What It Means to Live Fully with a Bleeding Disorder"

We invite patients and their family members to share their experiences of living with a bleeding disorder through a lens of positivity, personal growth, and empowerment. Whether it's a moment of triumph, a supportive relationship, or a symbol of your journey, we want to showcase your unique perspective.

Selected artwork will be proudly displayed in the waiting areas of our treatment center to inspire and connect with others in the bleeding disorders community.

Contest Details:

Who Can Enter:
Individuals of all ages who are living with a bleeding disorder or are closely connected to someone who is (e.g., parent, sibling, caregiver).

Mediums Accepted:
Drawings, paintings, digital art, mixed media (flat only, no 3D). Artwork should be no larger than 11"x14".

Optional Statement:
A brief artist statement (2–3 sentences) describing the meaning behind your piece is encouraged but not required.

Age Group Categories:
Depending on the number of entries, we may categorize submissions by age group to ensure all voices are fairly represented (e.g., children, teens, adults).

Submission Deadline:
December 15, 2025

How to Submit:
Please send a picture of your artwork to kschnur@vitalant.org with your name, age, and contact information.

Why Participate?

- Have your art displayed in a professional healthcare setting
- Help create a welcoming, relatable space for patients and families
- Share your story and inspire others in the community

We can't wait to see how you express the vibrant, courageous life you live with a bleeding disorder!

Questions? Contact Kathaleen Schnur 412-209-7267 for more information.

REGIONAL SUMMER EDUCATION DAY AT OGLEBAY

Thank you to everyone who joined us for the Regional Summer Education Day at Oglebay Resort in Wheeling, WV. We welcomed 85 participants for a day filled with learning, connection, and community. We were especially proud to partner with the West Virginia Bleeding Disorders Foundation to bring our chapters together for this special event.

The day began with a light breakfast and exhibits from our sponsors, giving attendees the chance to connect, learn about new resources, and mingle before the educational programming.

The first session, *Advocating for Your Care in the Emergency Room*, was led by Dawn Rotellini from the National Bleeding Disorders Foundation. Dawn shared many of her own experiences, which made the session especially relatable and helpful. The program was highly interactive, with participants contributing their ER challenges and tips. Key takeaways included planning ahead by wearing medical ID jewelry (which the Foundation can provide at no cost), keeping medical information accessible, and talking with providers about when to go to the ER, proper dosages, and medications to avoid. Dawn also emphasized requesting an emergency and travel letter, remembering that the HTC is just a call away, and reaching out to them with any issues. Most importantly, she encouraged everyone to advocate for themselves and never downplay their symptoms.

Attendees then chose between two breakout sessions:

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WPBDF IN THE COMMUNITY

CONTINUED FROM PAGE 12...

and resources available to them. WPBDF was proud to be part of such a meaningful day of outreach, connection, and education.

If you'd like WPBDF to attend your local health fair or community event please reach out to us!

WESTMORELAND COUNTY

WPBDF Brings Bleeding Disorder Awareness to Johnstown

As part of our ongoing commitment to raising awareness about bleeding disorders, the Western Pennsylvania Bleeding Disorders Foundation was proud to participate in the Westmont School District's Back to School Community Health Fair on September 4, 2025, in Johnstown, PA.

WPBDF staff members Janet Barone and Kara Dornish represented the Foundation at the event, engaging with numerous families and providing valuable educational resources about the signs and symptoms of bleeding disorders. While parents and caregivers learned about the Foundation and our resources, their children had fun playing Plinko for a chance to win prizes—making the experience both informative and enjoyable for all ages.

Visitors with questions or concerns about bleeding symptoms for themselves or a loved one were encouraged to visit www.betteryouknow.org, where they could take a free risk assessment and access additional information and resources.

WPBDF is always looking for new opportunities to spread awareness. If you know of a local health or community fair with booth or exhibit space available, or if you'd like to volunteer to help staff an exhibit table, we would love to hear from you! Please contact the Foundation office at 724-741-6160 or email info@wpbdf.org.

BEAVER COUNTY

Discussing Bleeding Disorders with the Beaver Rotary Club

On Wednesday, August 13, the Western Pennsylvania Bleeding Disorders Foundation (WPBDF) had the pleasure of joining the Rotary Club of Beaver Pennsylvania for lunch to share information about bleeding disorders and the support our Foundation provides.

WPBDF Executive Director, Kara Dornish, opened the presentation by highlighting the Foundation's service area, explaining the signs and symptoms of bleeding disorders, and showcasing our awareness initiatives such as the Period Pack and Nosebleed Kit Initiatives. Development Director, Jessica Lee, followed with details about upcoming fundraisers and ways Rotary members could get involved.

The session wrapped up with a lively Q&A, with members showing great interest in the Foundation's work.

We are grateful to the Beaver Rotary Club for their warm welcome and engaging discussion! If you're part of a Rotary Club or other community organization, WPBDF would love the opportunity to speak with your group. To schedule a presentation, please contact our office at 724-741-6160 or email info@wpbdf.org.

WPBDF Partners with Beaver County Libraries to Raise Awareness

WPBDF Executive Director, Kara Dornish, was honored to attend the Beaver County Library System's monthly meeting on Wednesday, September 24. She shared the Foundation's mission and highlighted the support we provide to individuals and families affected by bleeding disorders.

Kara brought period packs, nosebleed kits, educational brochures, informative packets, and bookmarks for each of the 13 libraries. Through this partnership with the Beaver County Library System, these resources will now be available at all the libraries in Beaver County, helping to educate the public, raise awareness, and provide tangible support to those in need.

This collaboration is a meaningful step in expanding the reach of WPBDF's programs and ensuring that critical information and resources are accessible to everyone in the community.
Kara left the meeting inspired by the libraries' commitment to supporting health education and the difference this initiative will make.

The University of Pittsburgh Partners with WPBDF

From September 15 to September 20, The University of Pittsburgh hosted their Civic Action Week. This is a campus-wide event for students, faculty, staff, alumni, and the broader community to learn, engage, and encourage collective responses to pressing social issues. This year's Civic Action Week theme was Enriching Our Community Together.

On Monday, September 15, WPBDF Board President, Samantha Short, and Development Director, Jessica Lee, helped Pitt kick off the week with their Volunteer Fair. Students had the chance to learn about our service project and other volunteer opportunities available with the Foundation!

On Saturday, September 20, WPBDF partnered with Pitt to host a volunteer service project on campus. Students assembled over 1,000 period packs for school nurses across Western PA, promoting awareness about bleeding disorders in women and girls! Thank you to all the student volunteers who joined us and thank you to the Foundation volunteers, Victoria Baker, Lenore H., Justin Najimian, and Samantha Short for volunteering your time to help with this project!

Justin shares his experience at Pitt's Day of Service below:

On September 20, WPBDF partnered with Pitt Serves as a part of their Civic Action Week to assemble period packs to be distributed to school nurses across Western Pennsylvania. Pitt Serves is an organization that provides students at the University of Pittsburgh with service opportunities that allow them to directly engage and support their local community. Through the assistance of students throughout different universities in Pittsburgh, we were able to stuff over 1,000 period packs for distribution.

This service project is part of WPBDF's Women, Girls, and People with the Potential to Menstruate initiative which aims to improve the quality of life for women, girls, and individuals with the potential to menstruate and improve diagnosis of bleeding disorders among them. The period packs consist of a feminine wipe, a stain remover wipe, disposable underwear, tampons and pads of multiple sizes, and a menstrual disc. So far in 2025, this initiative has reached 258 school districts throughout Western Pennsylvania. Through placement of these packs throughout different high schools, individuals not only receive essential products for menstrual care, but also information that can be pivotal for diagnosis of a bleeding disorder for those who may be at risk. These packs have led to referrals to a hematologist and resulted in diagnoses of bleeding disorders that will prove essential to one's future care and management of their health.

As the students were hard at work stuffing period packs, volunteers shared their personal stories about living with a bleeding disorder, including their journey to diagnosis, current management of their care and struggles they currently face. The students present were eager to listen to our stories and the volunteers were appreciative of their genuine curiosity and desire to learn more about how to better improve care for women, girls and individuals with the potential to menstruate with bleeding disorders. A few even shared their own personal connection to the bleeding disorders community, highlighting how bleeding disorders are more commonly found than one may think.

Once the day wrapped up and we loaded all the stuffed period packs off for distribution, we thanked the students for their time, effort, and impact they had made. If you are interested in contributing to the Women, Girls, and People with the Potential to Menstruate initiative, there are several ways in which members of the foundation can do so. We are always looking for community events with booth or exhibit activities to promote the initiative. Additionally, any member with connections with local school nurses, high schools, universities, health clinics, OB/GYNs can help us further expand distribution of the period packs.

Lastly, volunteers from the Foundation are always welcome at events just like these!

UNIVERSITY OF PITTSBURGH | DIVISION OF STUDENT AFFAIRS
PITT SERVES

ANNUAL MEETING CELEBRATES COMMUNITY, LEADERSHIP, AND ADVOCACY

CONTINUED FROM PAGE 17...


WPBDF Board President, Samantha Short (left), poses with Volunteer of the Year, Cassie Miller (middle), and Executive Director, Kara Dornish.

individuals, helping cover essentials such as rent, utilities, transportation to medical appointments, and medical ID jewelry. Nearly $15,000 in grocery support was provided to 36 families facing food insecurity. The community generosity helped raise nearly $100,000 through eight successful fundraising events, ensuring continued support for programs and services that make a meaningful difference.

Leadership Transitions and Recognition
The meeting marked an important leadership transition. Vice President John Yunghans, who served on the Board for six years, passed the torch to newly elected President Samantha Short and Vice President Tori Baker. Samantha introduced new Board member Ashley Lynn Priore and conducted the Annual Meeting, thanking departing Board members for their service and presenting plaques and gifts to Scott Domowicz, John Yunghans, and Melinda Perry.

Scholarships were also celebrated, with Tori Baker, Scholarship Committee Chair, announcing awards to ten outstanding students. Winners included Justin Najimian and Billie Rolle ($2,250), Mary Laughlin ($2,000), Maggie Egenlauf, Jason Miller, and Ryan Palmer ($1,000), Ava Bush ($750), and Whes Ebsworth and Robert Weaver ($500).

Program Director, Janet Barone, recognized past Teen Group Coordinators, Maggie Egenlauf and Ethan Webb, and introduced the new coordinators, Nya Johnson and Dexter Shoemaker.

Top Volunteers and Advocates Recognized
Top volunteers for 2024-2025 were honored, including:

- Adam Boyle
- Joseph Ebersohl
- Melissa Kendrick
- Eileen Nikithser
- Michael Perry
- Michelle Perry
- Dexter Shoemaker
- Larry Short
- Maria Shoemaker
- Samantha Short
- Melinda Perry
- Stephanie Shropshire
- Jerrad Zonna

We are proud to honor Cassie Miller as the 2025 Volunteer of the Year. As Advocacy Chair for the Foundation, Cassie recruits and mentors others, meets with legislators, and represents the community at key events. She raises awareness for women with bleeding disorders, distributes educational materials, and donates proceeds from her handmade crafts to support programs and services. Cassie's leadership, commitment, and generosity make a lasting impact, and we are thrilled to recognize her as Volunteer of the Year.

Advocacy and Awareness
Dexter Shoemaker, a teen leader in the Foundation, was also highlighted for his dedication to advocacy. Even as a teenager, Dexter actively participates in legislative efforts and community initiatives. He speaks with

WPBDF's 2025 Top Volunteers (from left to right): Joseph Ebersohl, Larry Short, Samantha Short, Cassandra Miller, Maria Shoemaker, Jarred Zonna, Dexter Shoemaker, and Melissa Kendrick. Missing from the photo are Stephanie Shropshire, Melinda Perry, Michelle Perry, Michael Perry, Eileen Nikithser, and Adam Boyle.

admiration about his mother, Maria, whose example inspires him to use his voice for the community. Dexter's energy, leadership, and commitment demonstrate the power of the next generation to create meaningful change. Dexter and Maria Shoemaker highlighted the importance of advocacy, including copay accumulator legislation and the "One Big Beautiful Bill," emphasizing the need for state-level advocacy to protect access to care.

Cassie Miller, Advocacy Chair, shared updates on the Women, Girls, and People with the Potential to Menstruate Initiative, noting that distribution of period packs and nosebleed kits to 258 school districts has already made a real difference. Thanks to this outreach, four individuals have been diagnosed with a bleeding disorder, demonstrating the life-changing impact of raising awareness in underdiagnosed populations. Cassie encouraged attendees to volunteer, help assemble care kits, and support community outreach efforts.

Walk Kick Off and Community Celebration

The Walk Kick Off featured co-chairs Melinda Perry and Morgan Woods, who shared personal stories about why the Walk is so meaningful to them. Mindy walks for her son Ryker, who was diagnosed with hemophilia A at seven weeks old and described the Walk as one of their favorite events of the year, a chance to gather with the community and raise money for a wonderful cause. Morgan walks for her son Tristen, diagnosed with severe hemophilia A at six days old, and shared how the Walk connects families, provides support, and reminds everyone that no one in the community is alone.

The Walk video premiered, showcasing the importance of fundraising and community connection. The day concluded with the Gateway Clipper sightseeing tour, enjoyed by all as the sun emerged, celebrating the resilience, generosity, and dedication of the bleeding disorders community.

REGIONAL SUMMER EDUCATION DAY AT OGLEBAY

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Clayton Kubrick, PT, DPT, RMSK, from the Hemophilia Center of Western PA, presented the session, *Beyond Bleeds: Optimizing Joint Health in Adults with Bleeding Disorders*. Clayton discussed the critical role of physical therapy in preserving joint health among adults with bleeding disorders. He highlighted how recurrent bleeds can lead to hemophilic arthropathy and emphasized that early intervention is key to preventing irreversible joint damage. Special focus was given to the use of musculoskeletal ultrasound, a painless, non-invasive tool that can detect early signs of joint damage.

Maria Rohan, Community Education Specialist at Takeda, led *Navigating School with a Bleeding Disorder*. Audience members shared their experiences with IEPs, 504 plans, and communicating with teachers and school administration. Maria provided each participant with a School Guide folder containing valuable resources, including a template for a Personal Care Plan, a Bleeding Disorders 101 booklet, a physical activity guide, and more. The program offered practical strategies to help students and families advocate for themselves and ensure a smooth back-to-school transition. Attendees left feeling informed, empowered, and supported by both the resources and the community, with a clear reminder that help is always available.

In addition to the educational programming, families enjoyed a delicious buffet lunch and, on a beautiful day, were able to take full advantage of Oglebay Resort's outdoor pool, zoo, mini golf, and other activities. To our attendees, speakers, and sponsors, thank you for making this event possible. We are grateful for your support and look forward to continuing to build education and community together.

Western Pennsylvania Bleeding Disorders Foundation
WPBDF EDUCATION | ADVOCACY | SUPPORT

West Virginia Chapter
NATIONAL BLEEDING DISORDERS FOUNDATION

Thank You to Our Sponsors!

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GETTING TO KNOW WPBDF'S BOARD OF DIRECTORS

On July 13, Samantha Short and Victoria Baker were voted in as the new President and Vice President of WPBDF's Board of Directors. While they are not new to the Board, they are new to these positions. They are excited to share their vision for the future of the Foundation with you!

How are you connected to the bleeding disorders community of Western Pennsylvania? Why is WPBDF's mission important to you?

Samantha: I have VWD Type I and have personally faced extreme medical challenges due to it. That's why the mission of the Foundation is so important to me. I've been that patient sitting in the doctor's office, terrified. The education the Foundation provides free of charge, is one of the most vital resources we have as a community. It empowers us to make the best healthcare decisions. I also know about the financial impact bleeding disorders can have on a family, and no one should ever have to choose between food on the table or paying for their factor. At WPBDF, we not only provide financial assistance, but also work tirelessly to ensure our elected officials are aware of the challenges affecting our community.

Tori: I have VWD Type I mild and my mom, dad, and sister also have VWD Type I. I believe in the mission of WPBDF because they do a great job to provide services and support to families and individuals with bleeding disorders. From community events, advocacy training, and educational programming, WPBDF provides excellent programming to improve the quality of life to those with bleeding disorders and their family and caregivers.

How long have you been involved with WPBDF?

Samantha: I first got connected before I even had a Hematologist! While looking for resources, I stumbled upon the Foundation and have been a member ever since. It wasn't until the last few years that I became more involved with the foundation and found my passion for the bleeding disorder community!

Tori: I have been involved with WPBDF since I was a pre-teen. I first came to events with my family. The first event I can remember going to is the Gateway Clipper and the Family Weekend (when it was held near the Pittsburgh Airport).

What is a memorable moment you've had being a part of this organization?

Samantha: Just one of my favorite moments happened just a few months ago at PABDC. As a volunteer I knew the weekend would be a busy one. The weekend was off to a great start when a group message went out to all volunteers from our Executive Director, Kara. One of our vendors for the children's program had shown up with dozens and dozens of giant fitness balls that needed to be carried from the parking lot to the ballroom for an upcoming activity. Tori, Kara and myself showed up to several moving trucks full of these balls! While we originally started carrying them in one by one, we knew we would never finish in time for the activity. That's when the chaos and laughter began. We started bouncing and throwing the balls down the hallways of the Hershey Lodge, like a bunch of kindergartners at recess! I couldn't contain my laughter. It was a memory I will never forget!

WPBDF's Board of Directors Vice President, Tori Baker (left), with Board President, Samantha Short (right), at the Pennsylvania Bleeding Disorders Conference.

Tori: I have a few. Some of my fondest memories are my summers spent at Camp Hot to Clot. I recently found pictures from my first years at camp: making coke & mentos geysers and making our signature "tree" name tags. Another more recent memory was helping to organize

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and facilitate the women's retreat a few years ago. I enjoyed working with the WPBDF staff to plan the event and meet new members of the chapter. Women's health is so important - especially women with bleeding disorders.

What are your goals during your time as leaders of the WPBDF Board of Directors? What is your vision for the organization moving forward?

Samantha: One of my primary goals as president is to lead with transparency, collaboration, and respect for not only my fellow board members and staff but our community as a whole. Tori and myself have both approached this new term with these goals in mind. I am very lucky as president to have such a strong team behind me, I couldn't have asked for a better vice president and board.

One of the main goals for the foundation moving forward is to diversify our funding, seeking more unique and innovative funding sources to better support our initiates long term. Another goal is to invest in our community where it's most needed. We seek to do so by strategically planning and placing priority on programs/initiatives that you as a community thrive from while moving away from those that aren't serving the community.

Tori: Like Samantha, I think it's extremely important that we diversify our funding sources and branch out into the communities for support. Along these lines, I think it's so important to continue efforts to educate the general public on bleeding disorders. This can be through partnering with other organizations for volunteer days or participating in local health fairs. The vision is to continue to support our community members and continue to focus on board development and identify members who can enhance our current board and continue to build the leadership abilities of our current board members.

What skills or experiences do you bring to this leadership role?

Samantha: Small business is literally in my blood with a family full of entrepreneurs and small business owners. To keep the Foundation running smoothly, it takes a leader with experience in multiple areas, which with my history in a small business I've become accustomed to. My volunteer experience also lends nicely to the role as I'm familiar with most of our community and in turn their needs.

Tori: I have been volunteering with the WPBDF for the past 15 years in many capacities from camp counselor to serving on several planning committees for various Foundation events. In my professional life, I've worked various roles in a variety of industries from health insurance, nonprofit, and most recently public health. I also have experience in project management, policy analysis, health education, and strategic planning.

Outside of your duties as board members, what hobbies or activities do you enjoy?

Samantha: I love spending time with my family, including nostalgic car racing with my dad, Larry. I also love to travel and will never turn down a good road trip or a warm sunny beach. Recently I started learning to sew and have been enjoying it!

Tori: I enjoy spending time with loved ones and my 2 bernedoodles (Bernie & Ellie). I spend a lot of time reading, this year I made it a goal to read 100 books. I also have started crocheting this year, mainly blankets, but I hope to branch out and start a cardigan soon for the cooler weather.

Are you passionate about the bleeding disorders community?

Do you want to use your professional skills to make a meaningful impact?

Join the WPBDF Board of Directors!

We are currently seeking individuals with expertise in:

- Finance & accounting
- Investment management
- Corporate giving & fundraising
- Law & compliance

As a board member, you will have the opportunity to:

- Influence the strategic direction of our organization.
- Strengthen our community connections and fundraising efforts.
- Collaborate with a committed group of peers to drive meaningful change.

Interested in learning more? Reach out to Kara Dornish at kara@wpbdf.org!

WPBDF GAME DAY AT PNC PARK

On Sunday, September 21, WPBDF members came together in the World Series Suite at PNC Park for a special program and an afternoon of baseball. It was a hot day at the ballpark, but spirits were high as the Pirates brought home a win in a fantastic game. Before the first pitch, Ivan Sada shared his inspiring story about playing minor league baseball and how he never let his bleeding disorder hold him back. His message of resilience and determination resonated deeply with everyone in attendance. Guests enjoyed a buffet of classic ballpark favorites, including popcorn, cookies, chicken fingers, and hot dogs. Most importantly, it was a wonderful opportunity for our community to connect, relax, and enjoy a memorable day together.

A very special thank you to Octapharma and InfuCare for sponsoring this event and helping make it possible.

octapharma

InfuCare Rx

REMEMBERING JACKIE LUCAS

LAUREEN TEMPLE

Warrior, Free Spirited Flower Child, Heart of a Lion, Healer, Compassionate and Empathetic Leader, Quiet laughter, Humble and Gracious, Artistic, Teacher, Holder of Hands, Soft Spoken Empath.

As I gathered thoughts from so many that have been fortunate to know Jackie, these are the words that ring true for us all. Many met Jackie years ago as bleeding disorders that affected our lives brought us into her circle. For many in this community, Jackie is the first person that stepped forward to ask what you needed. Generally quiet and often more comfortable in the shadows, Jackie was a fierce advocate when she saw inequities, a need for a voice, a disparity in education and opportunities or just someone who was scared.

"I first met Jackie at a hemophilia support group meeting in the late 1990s. I was there as a friend of the community and as a home infusion nurse for my friend whose son has hemophilia A. I was struck at that meeting by Jackie being so prepared to answer questions and offer solutions to this group of young parents trying to regain their footing after having been knocked off balance by the overwhelming diagnosis and circumstances life had just thrown at them. This lady knew her business, her audience and how to light the path in the darkness.

It was one of our luckiest days as a bleeding disorders community that Jackie and Don Paul Lucas had heard about us and invited us to attend a meeting."

- Denise

When I first met Jackie, she and Don Paul were traveling the country, helping to provide necessary education and advocacy for patients with bleeding disorders and HIV/AIDS. This passionate crusade of support showed me their heart and soul. Living a meaningful life of service, Jackie went on to start HAVEN (Hemophilia and Von Willebrand Education Network) in the Erie area. Continuing on her mission, Jackie saw the need for a children's summer camp and opened Camp Hot-to-Clot. This camp was the first of its kind to welcome kids with bleeding disorders, as well as their siblings. She believed that siblings were an important support network,

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and their understanding of bleeding disorders was integral to the health of the whole family. For many of us in the extended community, camp became the most fulfilling week of the year. From crafts to running for snacks, camp counselors, camp nurses, carnival workers and myriad other ways to support this cause, everyone was welcome. This legacy lives on today in the hundreds of campers who are Hot-to-Clot alumni as well as the next generation of campers.

“Jackie’s vision for children living with a bleeding disorder was to have one week of the year to live with a disorder free mind. She wanted to find safe ways for them to participate in any activity-archery, rock wall climbing, creek stomping, and the ever famous Capture The Flag. Around the meaningful camp experience, she introduced important education around self infusion and independence. It wasn’t just the kids that learned. Jackie taught me to go with the flow as I followed her as camp Director. Things happen, even with all of the planning, some times its OK if there is a change in plans and that often makes the campers experience even better.”

- Dawn

“As a nurse at camp, I watched Jackie with the children, teens and even the parents. She cared deeply and listened intently ,especially with the children. She made sure every camper had what they needed (whether they brought it to camp or she figured out a way to get it). She loved camp traditions such as silly games for mail call and campfire songs. Camp Hot-to-Clot was her baby and her legacy.”

- Nora

Jackie was the Director of HAVEN for many years and was supportive of all the activities of HAVEN as well as the Western PA Bleeding Disorders Foundation. She attended every event for many years, driving in from Erie or across the country. She spoke up about women’s bleeding issues and helped to start a women’s retreat to raise awareness of the much overlooked symptoms that many women had. She knew the need to advocate for healthcare and shared that passion through education, awareness and advocacy. Jackie didn’t do these things alone but knew how to ask for assistance. There was no way to say no to her–definitely a super power.

“When I think of Jackie, I am struck by her essence. I remember a soft spoken, empath with a gentle soul and a fierce spirit. She was a master crafter and a think tank behind the scenes. We are lucky to have Jackie as part of our history of strong women in the Western Pennsylvania bleeding disorders community.”

- Melissa

Jackie’s passion also challenged others to step up into leadership roles in our community.
Many campers went on to be counselors. Many others went on to occupy Regional, National and International positions sharing her passion to serve this community and advocate for healthcare access and education.

"Jackie shaped both of my children into compassionate empathetic and socially conscious adults with her mentorship. I was so blessed to have her as part of the village that shaped both of my children. She set the example of community service and knowing how to advocate for yourself and those in need, to know how to access support systems and how to ask for help without feeling helpless.”

- Denise

“Jackie was a beacon. She showed us all how to shine. She saw everyone’s energy and shared her favorite color green as her healing energy. She taught the kids how to be seen and strong like a lighthouse standing tall through their storms. We will carry and remember her light.”

- Sue

No matter when and for how long you crossed Jackie’s path, you will forever be changed. Till we meet again dear friend.

JACQUELINE "JACKIE" LUCAS

FEBRUARY 19, 1953 – OCTOBER 25, 2024

WPBDF'S 2025 UNITE FOR BLEEDING DISORDERS WALK AND RUN FOR THEIR LIVES 5K

This year, our 17th Annual Unite for Bleeding Disorders Walk and 16th Annual Run for their Lives 5k was held in-person at the North Park Swimming Pool! These events brought friends and families together to raise nearly $60,000 to support the bleeding disorders community in Western Pennsylvania.

Everyone had a blast getting their faces painted, snapping photos at the photo booth, and enjoying a delicious snack! Thank you to First Class Entertainment for the DJ and photo booth services and Face Paint Pittsburgh! We also had special visits from AMO, the mascot for the Pittsburgh Riverhounds, and Princess Aurora. Thank you to both the Riverhounds and Enchanted Experiences for donating your time to bring these special visitors to the Walk this year. Team Rolling for Ryker held their first-ever Unite Carnival! Attendees had the opportunity to play carnival style games and win a prize. Finally, we'd like to give a big thank you to Cottrill's Pharmacy, Culligan Water, Eat' n Park, McDonald's (Allison Park), and Soleo Health for providing so many amazing snacks.

This day would not be possible without the support of our many team captains who rallied their runners and walkers and went above and beyond in all that they did. Thank you to all 27 of our Walk Teams! A special shout out to the teams who really went above and beyond and raised $1,000 or more:

- Conor's Clan - $7,085
- Rolling for Ryker - $3,452
- Red N' Plenty - $2,132

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- Cameron's Walking Sticks - $2,082
- Kara's Walkers - $1,912
- Maxwell House - $1,800
- TJ's Team - $1,777
- Clotting Cavaliers - $1,590
- Factor 9 Knight Crew - $1,550
- Blake's Bloodline - $1,550
- Team Jaxson - $1,042

Our top fundraisers were recognized and honored at the Walk. Congratulations to Conor's Clan who raised an incredible $7,085! Thank you to the Team Captain of Conor's Clan, Emily Nikithser. Conor is 9 years old, and Conor's Clan has been participating in the Unite for Bleeding Disorders Walk ever since he was born. This year, Emily tapped into her personal connections to find local and family businesses to sponsor the team, as well as utilizing social media to share Conor's story and help raise additional funds. She also hosted the team's annual car wash, which raised $1,175! We are so thankful for Emily, Conor's Clan, and all of the people who rally to support Conor each year. Thank you for all you do!

This year's Top Individual Fundraiser was Tracy Sethman, who raised over $2,000! Tracy leads Team Red N' Plenty. This year marked Tracy's 13th Walk, and she participates in honor of herself and her family, who are affected by von Willebrand Disease. We're so grateful for Tracy's hard work, dedication, and passion for the Unite Walk!

Finally, a big congratulations to the winner of the Awesome John Eyrolles Top Youth Fundraiser Award, Blake R. of Team Blake's Bloodline. Blake raised an incredible $1,550! After an injury in 2020, that resulted in continuous bleeding for several days, multiple emergency room visits and hospital visits, and a flight to the Children's Hosptial, Blake and his family received his bleeding disorders diagnosis. Surrounded by his loved ones, Blake walks for himself and to ensure families have access to quality healthcare and the best educational resources available. Thank you for all you do for the community, Blake!

Team Conor's Clan raised over $7,000 for the Unite for Bleeding Disorders Walk and received the award for Top Fundraising Team!

Tracy Sethman of team Red N' Plenty received the award for Top Individual Fundraiser, raising over $2,000!

Blake R. of Blakes Bloodline received the Awesome John Eyrolles Top Youth Fundraiser Award!

Thank you to all of our Factor Club Members who have raised $500 or more for the Unite for Bleeding Disorders Walk! Medals were awarded to the following Factor Club Members:

Mandy Aberegg
Gwen A.
Analise B.
Kelly Baker
Janet Barone

Adam Boyle
August B.
Cameron Cedeno
Lisa Data
Kara Dornish
Lynda Maxwell
Conor N.
Eileen Nikithser
Emily Nikithser
Patrick Nikithser
Melinda Perry
Michelle Perry
Michael Perry
Maurice Prendergast
Blake R.
Lauren Rhodes
Gabbie R.
Dawn Rotellini
Tracy Sethman
Samantha Short
Micah S.
Samantha S.
Stephanie Shropshire
Ryker S.
Ronald Weisser
Jen Werme
Russell Werme
Morgan Woods
Tristen W.

This year, eight walk teams designed their own team t-shirt to celebrate a year of hard work and effort fundraising for the Unite for Bleeding Disorders Walk. Thank you to Jamie and Darin from Printeesweet for the printing of them, UPMC for sponsoring the shirts, and for the many families that took the time to vote for their favorite. This year, team t-shirt voting opened online the week leading up to the in-person walk and allowed teams to share their designs with loved ones who may not have made it on Walk Day. Congratulations to Team Jaxson as the official Team T-shirt Winner, raising $172! Team Jaxson is the undefeated Team T-Shirt champion since 2022.


Team Jaxson wins the Team T-Shirt Contest for the third year in a row!

Thank you to Miles of Smiles Timing for the great job they did managing the Run for Their Lives 5k and to everyone who participated in the run. We are excited to announce that over $4,000 was raised! All the money raised will stay local to support the members of WPBDF.

Congratulations to the winners of the Run for Their Lives 5k!

Our Top Male Finishers:


First Place: Quintin Sano


Second Place: Matthew Rose


Third Place: Douglas Basinski

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Unite for Bleeding Disorders

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Thank You to Our Local Sponsors!

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Cottrill's Pharmacy, Inc.
Bell Supply Company
pa health & wellness
Soleo Health
Bridges
Culligan Water
Eat'n Park

Our Top Female Finishers:

First Place: Emily Thornton

Second Place: Nicki Benvenuti

Third Place: Sheryl Brenner

And our Top Youth (17 and under) Finishers:

First Place: Enzo U.

Second Place: Gabbie R.

Third Place: Noelle B.

Thank you to the sponsors of the Run for Their Lives 5k:

Gold Sponsors:

Bayer

CSL Behring

Silver Sponsors:

trainwell

Lastly, and most importantly, thank you to each and every one of you who came together with us to Unite for Bleeding Disorders. 100% of the money raised from the Walk and Run, will stay local to promote patient advocacy, support families in need by offering assistance with medical bills, travel, knee/elbow braces and other medical devices, provide medical ID jewelry to our members at no cost to them, provide local educational programming throughout the year, provide a support network to all our community members, and create and increase awareness about bleeding disorders.

Save the Date!

Unite for Bleeding Disorders Walk

Saturday, September 19, 2026

North Park Swimming Pool

9:00 AM

Learn more at: wpbdf.org

BINGO FOR BUGGY!

Lindsay McNany hosted her annual Bingo for Buggy fundraiser to support the Western PA Bleeding Disorders Foundation! We'd like to recognize her dedication to the Foundation and thank the generosity of everyone involved. Bingo for Buggy raised an amazing $1,200! These funds will support individuals living with bleeding disorders right here in Western PA. Thank you, Lindsay, for your passion and commitment to our cause! Together, we're making a positive impact in our community.

Are you interested in hosting your own fundraiser to support WPBDF? Reach out to Jessica at jessica@wpbdf.org or call the Foundation at 724-741-6160 to learn more!

WPBDF's Purse BINGO

Saturday, November 8, 2025

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

Doors open at 5:00 PM
Early Bird Bingo starts at 5:30 PM
Purse Bingo starts at 6:30 PM

Tickets include admission to the event, a bingo booklet (includes 6 cards per round, for 13 rounds) and access to the event mixer bar (guests 21+)! Seating is first come, first serve.

Cost per person is $25 if purchased in advance. Tickets will be available for $30 at the door.

All attendees must be 16 years or older to play bingo and win prizes. Attendees younger than 18 must be accompanied by a legal parent or guardian in order to play bingo and win prizes.

PURCHASE TICKETS AT: BIT.LY/WPBDFPURSEBINGO

The money raised at this event will stay 100% local to support the Western Pennsylvania Bleeding Disorders Foundation!

RICHLAND RESIDENT IN 'DISMISSED,' A DOC ABOUT THE CHALLENGES WOMEN FACE IN GETTING HEMOPHILIA DIAGNOSES

LILY STERN
PITTSBURGH POST GAZETTE

As many as one in four women has experienced unexplained heavy menstrual bleeding. As many as one in four women could have an underlying, undiagnosed health issue. And in the United States, the Centers for Disease Control and Prevention research reveals that it takes an average of 16 years for women to get diagnosed with a bleeding disorder.

Dawn Rotellini, of Richland Township, is an advocate and the COO of the National Bleeding Disorders Foundation (NBDF). She went 59 years of her life undiagnosed with hemophilia, despite knowing she was at risk for decades.

Rotellini discovered she was a carrier in high school, when she completed a biology paper on X-linked diseases, or those potentially carried via the X chromosome. Her father, a hemophilia patient, grew up in an era and area where he wasn't given sufficient educational resources on his condition.

"I didn't grow up knowing how to take care of hemophilia, because my dad just wasn't seen in that environment," she said. "His outcomes were pretty rough — poor joints and hepatitis from contaminated blood in his treatment back in the 1970s."

While pregnant with her second child, Rotellini knew the odds: She had a 50% chance of having another daughter who was a carrier, or a 50% chance of having a son with hemophilia. The latter became her reality, and she has been an avid advocate ever since. A just-released documentary, "Dismissed," from production company Believe Limited tells the stories of five women, including Rotellini, at different stages of their hemophilia journeys.

What is hemophilia?

Everyone has genes that make coagulation factors in their blood, which are necessary for blood to clot. Hemophilia is caused by a mutation in Factor 8 (Hemophilia A, more common) or Factor 9 (Hemophilia B) genes. It can cause excess bleeding or an inability to form blood clots.

These conditions are "X-linked" because they are passed down through the X chromosome, and they primarily affect people assigned male at birth. Since they only inherit one X chromosome, they will automatically have the disorder if their mother is a carrier.

Hemophilia was first identified in the 1800s, and women's hemophilia has often been overlooked due to male cases being more severe. Women with the condition inherit one normal and one abnormal X chromosome and typically only face mild symptoms, so it was historically assumed they could only be carriers of the disorder, not patients.

"In old textbooks, they say that, 'Women were the carriers of this disease, and their sons were the victims of it,' putting the shame and blame on mothers," Rotellini said. "I had a lifetime of bleeding symptoms, but never knew that I actually could have hemophilia until much later."

Hemophilia treatment center data, published in a 2021 article in the journal Haemophilia, indicated that nearly one in five patients with mild hemophilia is female, meaning specialized care is warranted and needed.

According to Craig Seaman, clinical director of the Hemophilia Center of Western Pennsylvania, the medical community is now in tune with the needs of a population that was ignored until 20-30 years ago.

"We now reach out to women we know from our male patients, whether it's their moms, sisters, daughters, and [let them] know to come in and check them out," he said.

Symptoms of hemophilia can include heavy bruising, uncontrolled bleeding after surgical procedures and frequent nosebleeds. Common symptoms specific to women are extensive menstrual bleeding and prolonged bleeding after childbirth.

Another bleeding disorder with similar symptoms is von Willebrand disease, caused by a deficiency in the von Willebrand factor, another clotting protein.

The documentary

While Bella Hunter, the director of "Dismissed," does not have a bleeding disorder, she has experienced feeling unheard due to a medical issue.

"I have chronic back pain, and it took me about seven years for doctors to finally give me an MRI," she said. She realized the discrepancy in her own medical care when a male friend walked into a hospital, declared he was having pain, and was given an MRI at his first appointment.

"Dismissed" is supported in part by Beyond the Bleed, a global initiative from French biopharmaceutical company Sanofi to raise awareness for hemophilia. Shooting for the documentary began in December.

The film follows a 15-year-old diagnosed with hemophilia, a pregnant woman seeking care, a woman left partially paralyzed after medical neglect, another seeking diagnosis after decades of overlooking symptoms, and long-time advocate Rotellini.

It was crucial for Hunter to find subjects at different stages of their diagnostic process, so the film could examine how such factors impact access to care. She also ensured the core crew and cast were predominantly female, to make the set more comfortable for participants.

"It's important to continue not only having women's stories be told, but also having women's stories be told by women," Hunter said. Hunter hopes for people watching to resonate with these stories, whether they are familiar with bleeding disorders or seeing their symptoms represented for the first time.

"The women in this film have been dismissed time and time again, and their stories demand attention," she said. "This film is not just about hemophilia; it's about the systemic silencing of women and the urgent need to change the narrative."

"Dismissed" premiered Aug. 22 at the NBDF's Bleeding Disorder Conference in Colorado, with plans for screenings by bleeding disorder organizations nationwide in the coming months. It's also available to watch on YouTube. Rotellini considers the film a call to action for doctors and researchers.

"The community is ready," Rotellini said. "I hope physicians hear this, and they hear it in the way of, 'If we can get [a woman] diagnosed and get treatment for her, then her quality of life is going to improve tremendously.'"

Women's health and diagnosis bias

One-third of women carrying the hemophilia gene experience symptoms, but many go more than 20 years before a diagnosis. Rotellini has been attending hemophilia clinics with her son since he was a child, but only had her own first comprehensive clinic visit earlier this year, at the age of 62.

"I've been there all these years while he was being taken care of, and never thought to raise my voice and say, 'I'm having these symptoms, and maybe this isn't normal,'" she said.

While some women are diagnosed with hemophilia after family experiences with the disorder, others learned their new families were at risk when they were diagnosed too late.

Marisa Ferger, board president at the Eastern Pennsylvania Bleeding Disorders Foundation, was diagnosed with mild hemophilia A at 31, after experiencing years of dismissal by OBGYNs.

“Getting diagnosed sent me on an emotional roller coaster,” Ferger, now 50, said via email. “I finally knew I wasn't crazy.”

For her family, the word “hemophilia” was a wake-up call, as her son was 16 months old at the time. Soon after, he was diagnosed with hemophilia as well.

“For years, I thought it was a burden to be female,” Ferger said. “If I had a diagnosis before I started a family, things would have played out very differently. Knowledge is power when it comes to health care.”

Since her diagnosis in 2006, Ferger has also learned about other facets of her health, such as the fact that women with hemophilia have a greater chance of developing osteoporosis. Knowing that, she emphasized the importance of joint and bone health.

“Each year, I meet women in their 60s and 70s who have only recently been diagnosed,” Ferger said. “Today, young women experiencing bleeding issues need to know they can be tested for possible disorders and that there is support for them.”

Ashley Lynn Priore, founder and CEO of the Queen’s Gambit Chess Institute in Shadyside, was diagnosed with von Willebrand disease at 22.

“I had always been tired,” she said. “I had always felt run down, had heavy periods, bad cramps, all of it. But it wasn't until my results came back that I was able to get some relief.”

Priore considers herself lucky to have found out about her disease earlier in life, especially before deciding to start a family.

“[Having] somebody to help me know I'm not alone in this is so helpful,” she said. “It's very, very common. People just don't have the resources to understand what it's all about.”

Part of the bias around identifying and sharing bleeding disorders is the taboo around publicly discussing menstruation.

“We are in a society that makes us want to be quiet about this,” Rotellini said. “This is documented, and yet we're still struggling to get the word out that we are under-diagnosed, under-recognized, under-treated and under-cared for.”

Resources in Pittsburgh

The Hemophilia Center of Western Pennsylvania in North Oakland serves and diagnoses children and adults with congenital bleeding disorders. Staffed by hematologists, nurses, social workers, physical therapists and genetic counselors, it’s one of 141 hemophilia centers nationwide.

Beyond inpatient treatment, the center teaches how to self-infuse intravenous medicine and provides genetic testing for families. It also partners with the Western Pennsylvania Bleeding Disorders Foundation (WPBDF), in Beaver, to share local resources.

“You come out [of the center] with tons of information,” Priore said. “You leave with a period pack, magazines, all of these resources.” She is now a board member at the WPBDF.

Once patients are connected with the foundation, they receive benefits such as a comprehensive patient assistance program.

“Anybody who has a diagnosed bleeding disorder can come to us and we’ll help with anything, including transportation, other medical bills, utility bills and car repairs,” said Kara Dornish, the foundation’s executive director.

WPBDF and HCWP programming includes Camp Hot to Clot, a children’s camp near Zelienople that supports youth with bleeding disorders and their siblings, and September’s UNITE walk in North Park.

Two years ago, the foundation launched an initiative to provide education in schools.

“We partnered with 258 school nurses throughout Pennsylvania,” Dornish said. “[They now] have packages on hand for any girls who are having heavy menstrual bleeding. Inside the period packs are symptoms of bleeding disorders and where they can go if they suspect they have one.”

Per an internal survey conducted earlier this year, the initiative has successfully identified bleeding disorders in numerous young women. Out of 88 responses, eight people sought a diagnosis and three received one.

Note: Males have a 50% chance of inheriting the disorder if their mother is a carrier.

TAKE CARE

“Take Care” is a phrase commonly used by connected people. It is usually intended to convey that the person cares for you and wants you to be okay. Given the additional stress resulting from recent events, it is time to revisit that simple phrase. What does it mean to take care of yourself? The following is an abbreviated list of some common strategies to help you cope with personal adversity.

- Get a good night sleep, eat right, and exercise regularly
- Be intentional about creating a balance between work, rest, and play
- Create realistic expectations of yourself and others
- Focus on what you can control
- Practice deep breathing coupled with soothing mantras

While all the aforementioned concepts make sense intellectually, it is quiet another thing to put them into practice.

Have you ever wondered why it is so hard to do things that are good for you? The answers to that question are sometimes very apparent. We feel we don’t have personal time, or we feel depleted and the idea of adding one more thing to our plate seems daunting and impossible.

There are also some answers that are not so obvious. In fact, they are locked away from our conscious mind and take the form of lessons learned a long time ago. Here are some possible culprits keeping you from acting in your own best interest:

- You were raised to put yourself last
- You were told that “self care” is selfish and/or unnecessary
- Your sense of self and your self-esteem is invested in being seen as productive or heroic by others
- You were raised in a family where your needs were not met or seen as important, so you internalized that sentiment and eventually became unaware of your own needs

If some of these statements resonate with you, we would like to offer a bit hope. There is widely accepted term called, “neuroplasticity.” In the simplest terms, it means that our brains can form new connections which, in turn, help us to form new thoughts about ourselves and the world we live in. So, what does this mean for you?

Like any personal changes, it takes deliberate attention; a commitment to look inside and evaluate where these messages came from and what you would like to do about the “truths” that are guiding your life. Here are a couple of questions which can help you get started:

- What did I learn about my self-worth, personal needs, and taking care of myself?
- Is that the narrative working for me in my adult life?
- Can I make a new decision on who I am and how I take care of myself?
- What can I do today that can lead to a positive personal change?

The recipe for personal change can be summed up as follows:

Awareness of what is not working for you and taking small, intentional steps that lead you in a self-loving, self-accepting direction.

Take care, friends!

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WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION
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WPBDF'S
TEEN RETREAT

November 14 - November 16, 2025

PROMISE CAMP & RETREAT CENTER
227 LANCE RD, CLINTON, PA 15026

Drop Off: 6:00-7:00 PM - Friday, Nov 14
Pick Up: 11:00 AM - Sunday, Nov 16

Learn more about this event at: www.wpbdf.org

HEMOGRAM

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