



# HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

WINTER 2026



**EMERGENCY  
PREPAREDNESS TIPS**

**PAGE 9**

**CAMP 2026 INFORMATION**

**PAGE 19**

**PURSE BINGO**

**PAGE 16**

**WINTER PROGRAM**

**PAGE 20**



## BOARD OF DIRECTORS

- President** Samantha Short  
**Vice President** Victoria Baker  
**Secretary** Jason Miller  
**Treasurer** Christina Miller
- Board Members**  
 Cassandra Miller  
 Autumn Moore  
 Ashley Lynn Priore  
 Stephanie Shropshire  
 Kristen Spezialetti

## STAFF

- Executive Director** Kara Dornish  
**Program Director** Janet Barone  
**Development Director** Jessica Lee  
**Office Assistant** Laurie Sano

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

- |  |  |   |
|--|--|---|
| <p><b>January 22</b><br/>Hympavzi Dinner Program<br/>Grand Concourse<br/>Pittsburgh, PA</p> <p><b>February 2</b><br/>Pittsburgh Penguins Fundraiser<br/>PPG Paints Arena<br/>Pittsburgh, PA</p> <p><b>February 12</b><br/>Women's Group Galentine's Day<br/>Robin Hill Park<br/>Moon Township, PA</p> <p><b>February 21</b><br/>Shared Decision Making Lunch Program<br/>Bravo Robinson<br/>Pittsburgh, PA</p> <p><b>February 27</b><br/>Alhemo Dinner Program<br/>Juniper Grill<br/>Cranberry Township, PA</p> <p><b>March 4-6</b><br/>NBDF's Washington Days<br/>Washington D.C.</p> <p><b>March 22</b><br/>New Parent Network<br/>Virtual Program</p> <p><b>March 24</b><br/>Vonvendi Dinner Program<br/>Grand Concourse<br/>Pittsburgh, PA</p> | <p><b>March 28</b><br/>Youth Group<br/>Laser Storm Pittsburgh<br/>Pittsburgh, PA</p> <p><b>April 15</b><br/>World Hemophilia Day Program<br/>Location TBD<br/>Erie, PA</p> <p><b>April 16-19</b><br/>HFA Symposium<br/>New Orleans, LA</p> <p><b>April 17</b><br/>World Hemophilia Day Program<br/>Monterey Bay Fish Grotto<br/>Pittsburgh, PA</p> <p><b>May 4-5</b><br/>The Joey Smiles Advocacy Ambassador Education and Training<br/>Hilton Harrisburg<br/>Harrisburg, PA</p> <p><b>May 16</b><br/>New Parent Network<br/>Pittsburgh Zoo &amp; Aquarium<br/>Pittsburgh, PA</p> <p><b>May 21</b><br/>Hympavzi Dinner Program<br/>Il Pizzaiolo<br/>Warrendale, PA</p> | <p><b>May 30</b><br/>Backyard Brawl Cornhole Tournament WV vs WPA<br/>Cobblehaus Brewing Co.<br/>Coraopolis, PA</p> <p><b>June 12-14, 2026</b><br/>Stay In Motion Education Weekend<br/>Seven Springs Mountain Resort<br/>Champion, PA</p> <p><b>July 11, 2026</b><br/>Annual Meeting &amp; Education Day<br/>Bayfront Convention Center<br/>Erie, PA</p> <p><b>July 26-31</b><br/>Camp Hot-to-Clot<br/>Camp Kon-O-Kwee Spencer<br/>Fombell, PA</p> <p><b>August 13-15</b><br/>National Bleeding Disorders Conference<br/>Orlando, FL</p> <p><b>August 22</b><br/>Regional Education Day<br/>Oglebay<br/>Wheeling, WV</p> <p><b>September 19</b><br/>Unite for Bleeding Disorders Walk &amp; Run for Their Lives 9K<br/>North Park Swimming Pool<br/>Gibsonia, PA</p> |
|--|--|---|

VISIT [WPBDF.ORG](http://WPBDF.ORG) FOR MORE INFORMATION ON OUR UPCOMING EVENTS.

## Pittsburgh Penguins Fundraiser

**February 2**  
PPG Paints Arena  
1001 Fifth Ave,  
Pittsburgh, PA 15219

\$10 from each ticket purchased through the link below will be donated back!

**Game Time: 7:00 PM**

Get tickets at [bit.ly/wpbfd-penguins-2026](http://bit.ly/wpbfd-penguins-2026) or scan the QR code!



### CONTACT US

**Western Pennsylvania Bleeding Disorders Foundation**

775 4<sup>th</sup> Street  
First Floor  
Beaver, PA 15009

Phone: 724-741-6160  
Toll Free: 800-824-0016  
Fax: 724-741-6167

[www.wpbdf.org](http://www.wpbdf.org)  
[info@wpbfd.org](mailto:info@wpbfd.org)

@WPBDF

@WPBDF

@WPABDF

# LETTER FROM THE EXECUTIVE DIRECTOR

Dear Community Members & Friends,

Happy New Year! As we begin a new year together, I want to express my heartfelt gratitude to our members, volunteers, community partners, and supporters. I am incredibly thankful for our staff and board, whose leadership, dedication, and compassion guide our work every day. It is truly a privilege to serve alongside such a committed team, and together, we are all here to support you.

Together, this collective support allowed us to expand our patient assistance, education, advocacy, and community connection across western Pennsylvania. Because of your generosity, this holiday season we were able to grant over \$4,600 in holiday gifts to 106 children in our community. Since July, we have provided over \$8,000 in grocery assistance, supporting 20 families, and granted emergency assistance funds to 150 individuals, totaling over \$25,600 in support. We are truly grateful to be able to help community members during times of hardship.

The start of a new year is a meaningful time for reflection and renewal, and I want to encourage everyone to prioritize self-care in the months ahead. Managing a bleeding disorder or caring for a loved one can be physically and

emotionally demanding. Please remember that you do not have to navigate these challenges alone. Our staff is here to help and to connect you with resources whenever needed.

Advocacy remains at the heart of our mission. This year, we are proud to host the Joey Smiles PA Advocacy Ambassador Education and Training, a two-day program held in Harrisburg. Day one focuses on learning and preparation, and day two gives participants the opportunity to go to the Capitol to meet with legislators and make their voices heard. We encourage all members to join us and take part in this meaningful experience.

Our Advocacy Program is now named in honor of Joey Smiles, recognizing his deep passion for advocacy and dedication to helping others. Joey faced life with a positive spirit and a generous heart, always striving to make a difference in the bleeding disorders community. By naming this program after him, we honor his memory and ensure that his compassion, commitment, and inspiring example continue to guide and uplift all who participate.

Please never hesitate to reach out if you need support. We continue to offer assistance with period products, grocery gift cards, and emergency financial



assistance. If you or your family are experiencing hardship, we encourage you to contact us. We are all here to help.

I am deeply grateful to this community and for the trust you place in us. I look forward to a great year ahead, filled with continued support, advocacy, and hope.

Wishing you good health and happiness in the year ahead.

**Kara Dornish**  
Executive Director, WPBDF



# LETTER FROM THE BOARD PRESIDENT

'Tis the season! As temperatures drop and holiday stress seems to soar, it's important to focus on the good this season brings. Like many others, the holiday season always brings a variety of emotions for me—from the warmth of family gatherings and festive celebrations to the financial pressures and emotions that often surface in these cold, gray months.

A common issue I see in our community is loneliness and isolation. Before attending foundation events, I had never met another person with von Willebrand disease; in my world, I was one of one. It's all too common, especially during a health crisis, to feel profoundly isolated. How could anyone else possibly understand what I'm going through? WPBDF has created a safe space where we can connect with others who truly understand the trials and tribulations of living with a

bleeding disorder. Simply having someone listen to your story can be an incredible lifeline. This winter season, I urge you to reach out to your friends, family, and fellow community members. A simple "How are you?" might just change someone's entire season.

Our community is built not only on connections but on meaningful connections that go far beyond the surface. We form real friendships that stand the test of time. The best example of this is our current teen program. I couldn't be prouder of our teens and the relationships they have built with one another. I've even heard there's a lively group text keeping them all connected!

The new year brings fresh optimism and hope for the future. Recently, I've had the chance to attend a few volunteer events at the University of Pittsburgh. I've been particularly impressed by the young students and



how optimistic and full of hope they are. These students have completely won me over with their empathy for our cause and their thoughtful ideas about how their generation can create a brighter future.

No matter what 2026 holds for you, rest assured we are here supporting you through it all. Wishing everyone a happy, healthy, and prosperous new year!

**Samantha Short**  
Board President, WPBDF

## WPBDF IN THE COMMUNITY

This past fall, the Western Pennsylvania Bleeding Disorders Foundation (WPBDF) was busy spreading awareness about bleeding disorders across Western Pennsylvania! Over the past few months, staff and volunteers reached new communities, sharing education

and resources with government officials, community leaders, and individuals affected by bleeding disorders—many of whom were previously unaware of the support and services available to them. Keep reading below for a recap of the exciting events WPBDF attended across the region!

Do you have a connection with your local school district, college, library, or health fair? Do you know of another community location

where our period packs and nosebleed kits are needed? Reach out to Kara at [kara@wpbdf.org](mailto:kara@wpbdf.org) or give the Foundation office a call at 724-741-6160 to learn how you can get involved!

### ST. MARYS ROTARY CLUB

On Tuesday, September 30, Kara Dornish, Executive Director of the Western Pennsylvania Bleeding Disorders Foundation (WPBDF), had the special opportunity to return to her hometown of St.



*Kara Dornish, WPBDF Executive Director, and Josh Hanes, President of the Rotary Club, after learning about bleeding disorders!*

Marys, PA, to speak at the St. Marys Rotary Club. Josh Hanes, President of the Rotary Club, kindly invited Kara to share the important work WPBDF does to support individuals and families affected by bleeding disorders across the region and to provide resources to the members.

Kara was deeply touched by the warm welcome and genuine interest from the group. The members asked thoughtful questions and engaged in meaningful conversation about bleeding disorders, particularly the unique challenges faced by women living with these conditions. Returning home to raise awareness about WPBDF's mission and the resources available to those affected was a personal highlight. Kara left inspired by the connections made and encouraged by the support of her hometown community in spreading knowledge and understanding about bleeding disorders.

WPBDF sincerely thanks Josh Hanes and the St. Marys Rotary Club for their time, attention, and encouragement in helping raise awareness and strengthen our community.

## PENN STATE DUBOIS

On Wednesday, October 1, WPBDF was honored to participate in the Penn State DuBois Health and Wellness Fair. Our Executive Director, Kara Dornish, attended alongside her mom, who volunteered for the day and is already excited about joining us at future events. Together, they connected with students, shared educational resources, and raised awareness about the support available through the Foundation and Hemophilia Treatment Centers. The event also provided an excellent opportunity to connect with other community organizations in Jefferson County.

Each outreach opportunity reinforces our commitment to these efforts, as we continually meet individuals who can benefit from our resources and support. We are grateful to Penn State DuBois for hosting us and to everyone who visited our table. By raising awareness and sharing resources, we are helping to build a stronger, more informed, and supportive community for those affected by bleeding disorders across Western Pennsylvania.

## CRAWFORD COUNTY HEALTH FAIR

WPBDF Program Director, Janet Barone, and Development Director, Jessica Lee, attended the Crawford County Health Fair on Friday, October 10, at the Crawford County Courthouse in Meadville, PA. While the fair primarily served Crawford County employees, WPBDF staff had the opportunity to connect with department leaders from the County Commissioners' office and Health and Human Services, as well as other employees who are personally experiencing

symptoms or have a bleeding disorder and were previously unaware of the Foundation.

Thank you to Crawford County for this invitation and providing us the chance to share important information about the signs and symptoms of bleeding disorders with the community!



*Janet Barone, Program Director at WPBDF, attends the Coalition for Hemophilia B's Family Meeting on the Road event in Pittsburgh!*

## COALITION FOR HEMOPHILIA B

On October 25, the Coalition for Hemophilia B hosted one of its Family Meetings on the Road events in Pittsburgh. WPBDF's Program Director, Janet Barone, attended the gathering and staffed the Foundation's exhibit table, offering attendees information about our organization and the many services we provide. The event offered a wonderful opportunity to reconnect with long-time members of the bleeding disorders community and to welcome new friends as well.

The Coalition provided a full day of education and connection for adults, while children enjoyed childcare that included a trip to the Pittsburgh Zoo & Aquarium.

**CONTINUED ON PAGE 12...**

# ADVOCACY UPDATE



**KERRY LANGE, SENIOR ASSOCIATE**  
**MILLIRON GOODMAN**

## HARRISBURG OVERVIEW

2026 is an election year. All 203 members of the House of Representatives and 25 out of 50 Senators are up for re-election (only even-numbered district seats). In addition, Governor Josh Shapiro and Lt. Governor Austin Davis are also up for re-election.

A few members have already announced their plans to resign/retire at the end of session in November 2026 including:

1. Rep. Seth Grove (R-York) (State House of Representatives – D-196)
2. Rep. Mary Jo Daley (D-Montgomery) (State House of Representatives – D-148)
3. Rep. Anita Kulik (D-Allegheny) (State House of Representatives – D-45)

The primary is scheduled for Tuesday, May 19, 2026. Please note that May 12, 2026 is the last day to apply for a mail-in or civilian absentee ballot.

## PA GENERAL ASSEMBLY

The legislature continues to operate with slim margins between Democrats and Republicans in both chambers, making strong bipartisan support a necessity for every piece of legislation.

Here is the current breakdown:

- House: 102 D - 101 R (2/3 =

- 136)  
• Senate: 27 R – 23 D (2/3 = 34)

A handful of representatives will be resigning from the House in January (before the end of the current session):

1. State Rep. Torren Ecker (R-193): Elected to Adams County Court of Common Pleas
2. State Rep. Dan Miller (D-42): Elected to Allegheny County Court of Common Pleas
3. State Rep. Lou Schmitt (R-79): Elected to Blair County Court of Common Pleas
4. State Rep. Josh Siegel (D-22): Elected Lehigh County Executive

Special elections will be held in the coming months to fill these four seats. Those elections must be held at least 70 days after each resignation.

## REVENUE COLLECTIONS

The Independent Fiscal Office (IFO) recently released their Fiscal Outlook for FY 2025-26 through FY 2030-31. Here's a brief overview:

- General Fund surplus projected to be depleted in FY 26-27;
- Rainy Day Fund (currently \$4.7 B) projected to be depleted by FY 27-28;
- FY 25-26 deficit is currently projected at \$3.7 B and projected to grow to \$7.7 B by FY 30-31; and
- \$1.3 B temporary measures used in FY 25-26 must be

back-filled next year.

## 2025-2026 BUDGET

On November 12, 2025, 135 days past the June 30 deadline, the General Assembly passed a budget and the Governor signed it into law.

- The total spend is \$50.09 Billion, a 4.6% increase over last year.
- There are no new revenue sources (no new taxes, no increased tax rates, no removal of any tax exemptions) and they didn't utilize the Rainy Day Fund (\$4.7 B).

## HEMOPHILIA LINE ITEM

We are pleased to announce that we secured full funding for the hemophilia line item at \$1,017,000 and kept it separated from the other rare disease line items.

In addition, the Fiscal Code clarifies that funding for the hemophilia treatment centers (HTCs) shall be distributed in the same proportion as fiscal year 2019-2020, protecting the HTCs from potentially competing against each other for grant dollars.

## 2026-2027 BUDGET

Given the deficit projections, we expect a more austere budget proposal from Governor Shapiro on February 3, and another difficult budget cycle ahead.

After the Governor's Budget Address, the House and Senate Appropriations Committees will hold hearings with each state agency to discuss the details of the proposal. Those hearings are typically scheduled throughout February and March. And then the legislature has until June 30 to pass a budget.

In the meantime, our office will continue our engagement and educational outreach with legislators and staff and prepare for upcoming appropriations requests as well as a variety of insurance and healthcare related topics.

### 2026 SPRING SESSION SCHEDULE

We are halfway through the 2025-26 legislative session. All introduced bills have until November 30, 2026 to pass through the legislative process and get across the Governor's desk. If they don't make it through, they effectively die and must be reintroduced in the following session for future consideration.

The House and Senate released their spring session schedule as follows:

Senate	
January	6, 26, 27 & 28
February	2, 3 & 4
March	16, 17, 18, 23, 24 & 25
April	20, 21 & 22
May	4, 5 & 6

House	
January	6 (NV), 26, 27 & 28
February	2, 3 & 4
March	23, 24 & 25
April	13, 14, 14, 27, 28 & 29
May	4, 5 & 6

# 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!



## THE JOEY SMILES ADVOCACY AMBASSADOR EDUCATION AND TRAINING

**May 4-5, 2026**

Harrisburg Hilton  
One N 2nd St,  
Harrisburg, PA 17101

This is an overnight training and advocacy day. Training begins at 3 pm on Monday, May 4. On Tuesday, May 5, we will head to the PA state capitol where you will have the opportunity to meet with your local legislators.

**Learn more at <https://wpbdf.org/events>**

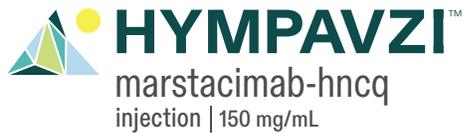
To register, email [rsvp@wpbdf.org](mailto:rsvp@wpbdf.org) to receive the registration form.





# Here For You For Over 25 Years

Pfizer continues to support the community, having helped develop innovative treatment options for over 2 decades.



**xyntha<sup>®</sup> solofuse<sup>®</sup>**  
Antihemophilic Factor (Recombinant)



For information on Pfizer's hemophilia products, programs, or services, Patient Navigators (PNs)\* are available to help you access the information you need.

**Visit [TogetherForRare.com](https://www.togetherforrare.com) to learn more.**

\*Pfizer PNs are not measured or awarded based on sales performance, nor will they ask you to switch products.



# FALL PROGRAM RECAP: "BEFORE THE FUR HITS THE FAN"

We're so grateful to our presenter, Jessica Graham, for sharing her session, "Before the Fur Hits the Fan: Emergency Preparedness." As an EMT, a mother of someone with a bleeding disorder, and someone living with one herself, Jessica offered practical and insightful tips to help our community stay safe and ready in any emergency.

After the program, attendees enjoyed a beautiful afternoon at Soergel's Orchards for their Fall Festival. Thank you to everyone who came out. We loved spending the day with you!

Thank you to our sponsors for making this program possible:



**COTTRILL'S**  
PHARMACY, INC.

**CSL Behring**

**CVS specialty**

**InfuCare Rx**



**sanofi**

**SOLEO HEALTH**  
Innovators in Specialty Infusion

**SPECIAL THANKS TO:**

*CK Colburn Keenan Foundation, Inc.*



## Before the Fur Hits the Fan: Emergency Preparedness

*Jessica Graham, EMT-B*

### General things to keep in mind

- Take advantage of opportunities to learn & don't be afraid to ask questions, even if you rarely have bleeding-related issue - important to be able to effectively communicate important information in case of emergency
- Most emergency medical personnel are not familiar with bleeding disorders - you may encounter confusion & delayed/inadequate care
- Better to address minor injuries before they become serious

### Being better prepared - things to know & do

- Know the 4 "D"s: disorder, drug, dose, doctor
- Teach children the name of their disorder & address so they can tell emergency personnel (or teach them to point out their medical ID)
- Have a "Go Bag" with a dose of factor and copy of treatment letter and/or first aid kit - make sure friends & family know where it's kept
- Make sure your house number is visible (if applicable)
- Have a family member or friend who can advocate for your care in case you can't (emergency contact) & know their phone number

### Being better prepared - HTC/hematologist

- Visit your HTC/hematologist regularly to ensure your treatment protocol is updated as needed
- Consult ASAP before scheduled medical/dental procedures - assess bleeding risk & determine appropriate treatment protocol
- Ask which ERs carry factor/which ER to go to in an emergency
- Order meds & supplies on time
- Ask for an emergency/travel letter
  - ER might need to use factor/medication brought in from home
  - Whether patient is authorized to mix own factor
  - Factor to be administered prior to any diagnostic testing, including treatment protocol regarding head injuries (treat with or without symptoms)
- If you don't treat with factor regularly, ask about keeping a dose at home

### Being better prepared - local emergency rooms

- Meet with local ERs to discuss bleeding disorder, treatment, & triage for bleeding-related emergency
- Ask about policy regarding bringing factor from home



**CHECK-OUT MORE EMERGENCY PREPAREDNESS TIPS ON THE NEXT PAGE!**

## Being better prepared - medical information

- Have a plain medical ID bracelet or necklace
- Wallet card/medical information mini-wallet
- Seat belt cover
- PA Yellow Dot Program & Emergency Contact Information System
- Add "ICE" in front of emergency contact names in phone
- Utilize lock screen medical information app on phone
- MedicAlert QR Code Products
- Keep multiple hard copies in central location at home & in car
- Keep digital copies on phone - share with close family & friends
- Update medical information regularly (put a reminder on your calendar at regular intervals) - weight affects dosing
- MedicAlert Advantage: add documentation - can fax to ER
- Get updated emergency/travel letter on regular basis

## Being better prepared - affected children

- Ask HTC about doing a school visit
- Meet with nurse & teachers to discuss your child's needs
  - Provide information about types of possible bleeds & explain that some are internal and may have no outwardly visible signs
  - Consider getting a 504 plan for special accommodations
  - Preferred ER for the child to go to in case of emergency (unless the situation is life-threatening or involves significant trauma)
  - Request a dose of medication be kept on hand in case of emergency

## Being better prepared - local fire/EMS agency

- Meet with local fire/EMS agency - especially helpful for affected children who may not be able to explain their condition
- Ask if they keep records on special needs patients in their district & provide copy of medical information if they do
- Ask if they can have local dispatch flag your address - include phone number of your HTC/hematologist

## Things to keep in mind about calling 911

- EMS likely unfamiliar with bleeding disorders, especially in rural areas with lower call volumes and volunteer EMS agencies, but all emergency medical personnel are trained in dealing with uncontrolled bleeding
- Different levels of EMS care
  - EMT-B (basic): check vitals and provide basic emergency care
  - EMT-A (advance): can typically give basic IV medications and intubate (depending on state & county protocols)
  - EMT-P (paramedic): highest level of pre-hospital care

## Things to keep in mind about calling 911, continued

- Depending on the type of call, details communicated, agency responding, personnel available, etc., the first EMS personnel to arrive may not be a paramedic
- Enroute treatments are generally limited & they probably won't be able to administer factor (have to follow state & county protocols)
- You can ask EMS to transport patient to closest hospital that carries factor, but patients with a life-threatening condition will likely be taken to closest ER & those with significant trauma will be taken to a trauma center

## When you have to call 911 - general tips

- Try to stay calm & make sure the scene is safe
- Unlock doors
- Turn on outside light (at night)
- Clear a path for EMS & put pets away
- Send someone to let EMS know patient location
- Grab anything that needs to go with the patient (cell phone & charger, insurance card, etc)

## When you have to call 911 - patient care

- Don't move patient if call is due to trauma (unless necessary due to safety/location)
- Help them stay calm & keep talking to them
- Have one person stay with the patient at all times (if possible)

## When you have to call 911 - dispatch

- Tell dispatch that the person has a bleeding disorder ("bleeder") & which local ER they need to be taken to if emergency is bleeding-related or could result in bleeding
- Calmly communicate all relevant information
- Answer all questions in a clear & concise manner

## When you have to call 911 - HTC/hematologist

- Notify HTC/hematologist ASAP & ask them to call ahead and prepare ER
- Make sure both you and HTC/hematologist are clear on which ER you are going to
- Let them know if planning on bringing factor from home

## When you have to call 911 - EMS on scene

- Inform EMS about bleeding disorder & make connection between injury/symptoms & bleeding disorder
- Ask about transporting patient to preferred ER if emergency is bleeding-related or could result in bleeding
- Provide dose of factor & treatment letter whenever possible
- Provide list of medical conditions, medications, allergies - write a quick list if you don't have one

# HCWP CORNER

KATHERINE BUSH, LCSW

Hello to all WPBDF Members and Your Families,

It seems that one way or another, we have made it through another year! We hope that 2025 was kind to you, and we hope that 2026 is even kinder (and we especially hope that if 2025 was not good to you!).

Here at HCWP we are looking forward to another year of doing the best that we can for you, and over the past year, we have grown our staff and added new services with that goal in mind. We are very excited to have a gynecologist on staff, in addition to a full-time advanced practice provider (PA). Please remember that our adult clinics continue to be on Monday and Thursday, our pediatric clinics on Wednesday, and some additional specialty providers (pediatric platelet disorders and clotting patients) on certain Tuesdays and Thursdays. We are busy, but we like it that way! It means we are providing the care that people need. Please remember we need a current appointment with you in order to provide things such as medication refills and orders for procedures. You can reach out to schedule (or see when you are due for an appointment) at 412-209-7280. In some instances, we may be able to offer a virtual appointment.

During the last year, we also continued to provide our Amish outreach clinics in the spring and Camp Hot-to-Clot in the summer.



Volunteers at Abiding Mission's Breakfast Fellowship, in partnership with the Hilltop Alliance, pack period packs and nosebleed kits!

## WPBDF IN THE COMMUNITY

CONTINUED FROM PAGE 5...

Families reunited in the evening for a shared dinner program, a fall craft activity, and meaningful conversations. The warm and engaging atmosphere helped strengthen community bonds.

### HILL TOP ALLIANCE

On November 12, WPBDF Executive Director Kara Dornish, Board President Samantha Short, and Jessica Lee partnered with the Hill Top Alliance and Abiding Missions to host a volunteer

program focused on education and assembling period packs. The team joined the Breakfast Fellowship, where they gave a brief presentation about bleeding disorders and the services WPBDF provides. Samantha also shared her personal story, offering insight into her symptoms and what life is like living with a bleeding disorder.

Together, this incredible group packed over 200 period packs and 100 nosebleed kits, which will be distributed to schools, libraries, and colleges across Western Pennsylvania. WPBDF is deeply grateful to the Hill Top Alliance for organizing this event and to all the volunteers who took extra kits to share in their own communities, helping to spread education, support, and awareness far and wide!

Both went very well, and we are excited that both programs will be occurring in 2026, with Amish outreach scheduled for the spring (specific dates to be determined) and camp to be held from July 26-July 31, 2026. We also consider ourselves very fortunate to continue our partnership with WPBDF in meeting the needs of our community, with activities such as retreats and education weekends. We continue to be very thankful for all that WPBDF does.

We anticipate that some of you may be a bit nervous about the year ahead and what it may bring, especially regarding insurance and healthcare system changes. Our goal is for you to continue to have access to the care that you need, in a way that will not cause financial hardship. Please reach out to us if

you are running into challenges.

While we can't control what happens outside our doors, we can work alongside you to make things as manageable as we can. Another one of our goals, of course, is for you to know that you aren't in it alone. We do have a wonderful way of looking out for each other in the bleeding disorder community, and help may be available if you reach out. We cannot stress enough how very thankful we are to have real, concrete, readily available support for our patients. We do want to be wise stewards of these resources, however, so please be mindful of our policies and limits. These policies are available upon request.

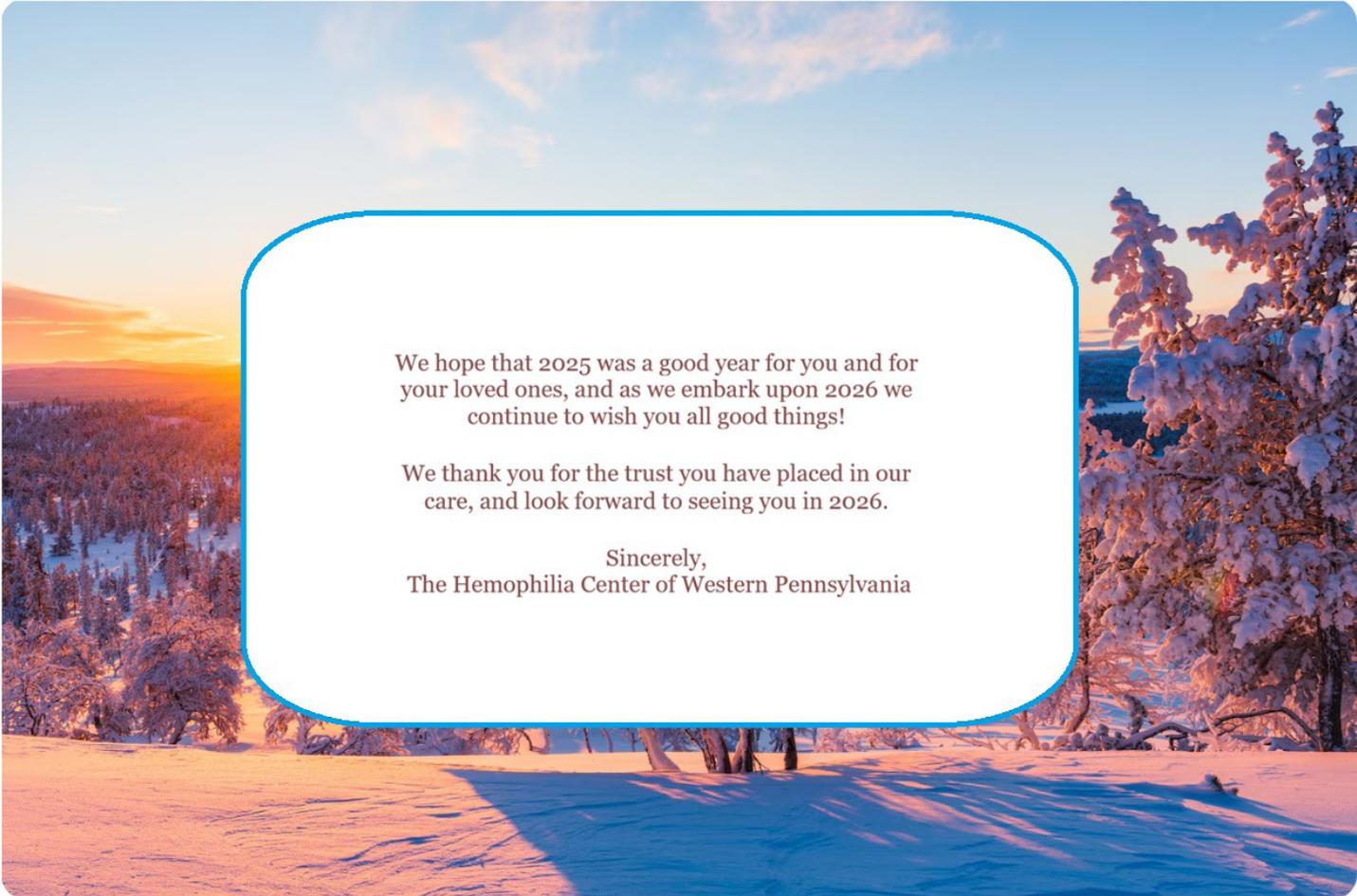
Please remember that we continue to be here to meet your care needs even when it's not your

appointment time. If you are traveling and need a letter, lose your medical ID, need a verification letter for a scholarship, or need something else entirely, please give us a call.

And as always, please continue to reach out to us with any questions or concerns that you may have about your care or barriers that may keep you from receiving care. Please let us know what would make us better and what has been going well with your care. The more we know, the better we can be.

Sending our best wishes for a healthy and happy year to all of you,

The HCWP Staff



We hope that 2025 was a good year for you and for your loved ones, and as we embark upon 2026 we continue to wish you all good things!

We thank you for the trust you have placed in our care, and look forward to seeing you in 2026.

Sincerely,  
The Hemophilia Center of Western Pennsylvania



## STATEWIDE STAKEHOLDER MEETING STRENGTHENS COLLABORATION ACROSS PENNSYLVANIA

On Tuesday, December 2, the Western and Eastern Pennsylvania Bleeding Disorders Foundations gathered with representatives from all 7 Hemophilia Treatment Centers (HTCs) in Pennsylvania, Foundation staff and board members, Matt Delaney from the National Bleeding Disorders Foundation, Karen Bowe from the Hemophilia Alliance, and Kerry Lange from Milliron Goodman

Government Relations for a statewide Stakeholder Meeting at the Hilton Harrisburg. The meeting brought together stakeholders from across Pennsylvania to exchange ideas, coordinate efforts, and explore ways to better support the bleeding disorders community statewide.

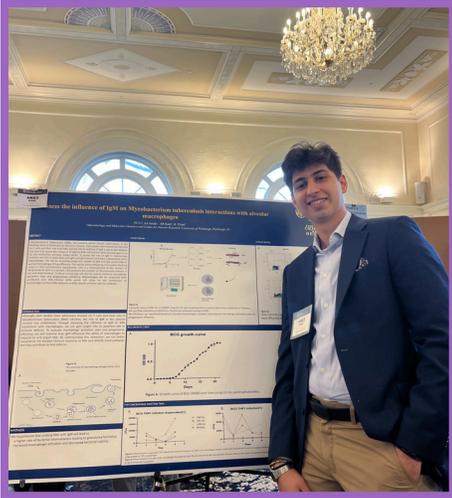
The meeting opened with Kara Dornish reviewing survey results, highlighting shared themes and exploring ways to collaborate on solutions. Kristine Tanase then presented on the Bleeding Disorders and Substance Use and Mental Health Access Coalition (BDSUMHAC), sharing the work the PA Coalition has accomplished and outlining goals for 2026. Matt Delaney provided updates on federal issues, Kerry Lange presented on key state-level issues, and the Pennsylvania Health Law Project joined virtually to educate attendees on HR1 and its implications for Pennsylvania.

The final hour featured a facilitated guided discussion, led by Sarah Pilacik, giving participants the opportunity to share insights, identify priorities, and strengthen cross-state collaboration.

The day highlighted an important theme: when we plan, learn, and share knowledge together, we can accomplish so much more. Collaboration like this reinforces the power of teamwork and the meaningful difference coordinated efforts can make for the bleeding disorders community.

The Foundations are grateful to everyone who participated and contributed to the discussion. Presentations from the meeting are available for review on our website: [wpbdf.org/advocacy](http://wpbdf.org/advocacy). By continuing to work together, the Foundations and HTCs are committed to strengthening support, education, and outreach for individuals and families across Pennsylvania.

# GETTING TO KNOW HCWP STAFF



**ANUJ KAUL**

**CLINICAL RESEARCH ASSOCIATE II**



**Birthplace:** Mars, Pennsylvania

**First job:** Busser/Host at an upscale restaurant

**Accomplishment you're proudest of:** I started a Science Club in high school with 100 members and created STEAM Day. Each year, high school students create science workshops like elephant toothpaste explosions, oobleck, and Van De Graaff machines and present them to students in grades K-8. In April of 2026, it will be the 5<sup>th</sup> annual Steam Day in my hometown. I am proud to have made an impact on the way young kids in my community make science exciting!

**What three words describe you best?** Curious, Passionate, Excited

**Dream vacation:** Hopping around Australia and Japan

**Things you can do without:** Coffee

**Person you'd most like to have dinner with:** My sisters

**Movie you could see anytime:** The Dark Knight

**TV show or podcast you try not to miss:** Steelers Games

**Three things that can always be found in your refrigerator:** Milk, Eggs, and Ranch

**Secret vice:** Taco Bell

**Who would play you in the movies?** Apparently I look like a young Ray Romano???

**Your pet peeve about Pittsburgh:** I cannot find parking anywhere

**People may be surprised to know that:** I started a volunteer program for people to run with dogs at the local animal shelter!

# EMOTIONS, SENSATIONS: YOURS OR MINE?

On Sunday, November 16, families came together for the last New Parent Network program of 2025, *Emotions, Sensations: Yours or Mine?* This program was designed to equip parents with practical tools to better understand their children's emotional and physical experiences, including fear of medical procedures and coping with pain.

Prior to the program, each family received a package with supplies to support hands-on learning at home. Each kit included a set of emotion flashcards, a feelings wheel, a stress ball, bubbles, helpful handouts, and a craft for families to complete together.

The program opened with fun family introductions, followed by interactive activities led by Kathaleen Schnur, LCSW, with the Hemophilia Center of Western PA. Kathaleen guided families through exercises focused on identifying and expressing emotions, including a fun and engaging game where participants guessed emotions based on facial expressions. She highlighted how adults can unintentionally misinterpret children's emotions and encouraged parents to reflect

on times when their own feelings may have been misunderstood. Families also learned how to use a feelings wheel for identifying emotions by starting with a basic feeling in the center and moving outward to more specific emotions to better understand and communicate what they are experiencing.

A key segment was on curiosity-based communication—listening closely to the body's messages and validating children's feelings, especially during injuries or medical procedures. Families participated in an activity called "Whose Story is it?" where they explored whether emotions in each scenario belonged to the parent, child, or both. This exercise

**CONTINUED ON PAGE 18...**



# WPBDF'S FIRST-EVER PURSE BINGO RAISES OVER \$10,000 FOR THE COMMUNITY!

On Saturday, November 8, the Western Pennsylvania Bleeding Disorders Foundation (WPBDF) hosted its first-ever Purse Bingo Fundraiser at the Vanport Firehall in Vanport, PA—and the event was a huge success! With more

than 100 enthusiastic attendees, the inaugural fundraiser brought in over \$10,000 to support individuals and families living with bleeding disorders across Western Pennsylvania.

Funds raised from the event directly support local programs that educate, connect, and empower the bleeding disorders community. Families throughout WPBDF's 26-county service area will have improved access to the educational resources and support they need to thrive!

The evening's excitement began at 5:00 PM as guests streamed in to claim their seats, stock up on snacks, and collect their bingo cards. Early bird bingo kicked off at 5:30 PM, awarding \$25 cash prizes to the first lucky winners. At 6:30 PM, the main event began—13 rounds of lively bingo featuring gorgeous designer purses from Kate Spade, Michael Kors, Coach, and more. All the handbags

were generously donated by the volunteer planning committee, local supporters, and community partners including Canine Kingdom and Vera Bradley North Hills. In addition to the bingo rounds, attendees had the chance to win nearly 30 beautifully crafted raffle baskets. WPBDF extends a special thank you to Lauren Temple, who gathered items and expertly assembled and wrapped each basket. Guests also enjoyed a 50/50 raffle, mystery tickets, and a lottery ticket raffle. The incredible crowd sold the Foundation out of both the 50/50 and mystery raffle tickets!



Special Thanks to our Event Sponsors:

**GOLD SPONSORS:**



**SILVER SPONSOR:**



**BINGO CARD SPONSOR:**



**WATER SPONSOR:**



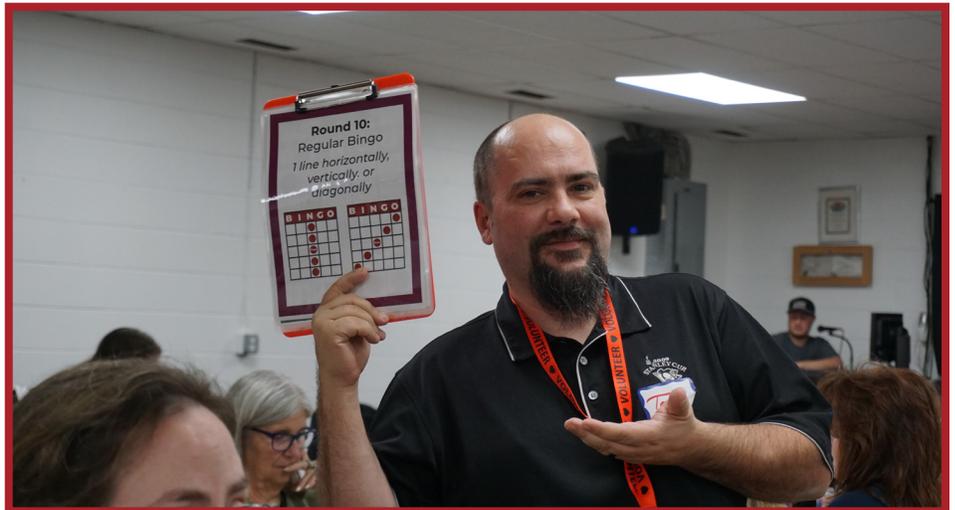
**MIXER BAR & CONCESSION SPONSORS:**



**DÉCOR SPONSOR:**



WPBDF also extends heartfelt appreciation to the dedicated volunteer planning committee: Emily Nikithser, Maria Shoemaker, Samantha Short, Kristen Spezialetti, Maria Steele Voms Stein, Lauren Temple, and Melinda Perry. Their creativity, energy, and countless hours of preparation brought this event to life.



WPBDF thanks everyone who attended, donated, and volunteered. Congratulations to all the winners! The support of the community helps raise awareness, strengthen connections, and change lives for those affected by bleeding disorders.

Missed your chance to join us for this spectacular evening? **Save the date for Saturday, October 24, 2026 at the Vanport Firehall!** We hope to see you at the next one! Stay up-to-date on our upcoming events at [www.wpbdf.org](http://www.wpbdf.org).

Ready for a new treatment option?  
Talk to your doctor to see if Alhemo®  
could be right for you.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

**Alhemo**®  
concizumab-mtci  
injection | 60 mg | 150 mg | 300 mg pens



Celebrating  
**35**<sup>+</sup>  
YEARS  
serving the community



Alhemo® is a prescription medication.

Learn more at  
**Alhemo.com**



Needles sold separately and may require a prescription in some states.

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

Alhemo® is a registered trademark of Novo Nordisk Health Care AG.

Novo Nordisk is a registered trademark of Novo Nordisk A/S.

© 2025 Novo Nordisk All rights reserved. US25AHM00008 January 2025

# EMOTIONS, SENSATIONS: YOURS OR MINE?

CONTINUED FROM PAGE 15...

helped parents reflect on their own emotional responses and how these may influence their children.

The program concluded with simple, effective calming techniques families can use at home, including blowing bubbles

for exhaling slowly, squeezing a stress ball, and giving themselves a “butterfly hug.”

This was the final New Parent Network event for 2025. These events are designed specifically for families who have a child aged 0-7, who has a bleeding disorder. If you have a young child with a bleeding disorder and would like more information about New Parent Network events or would like to be matched with mentor family, please contact either Janet Barone ([janet@wpbdf.org](mailto:janet@wpbdf.org)) or Kathaleen Schnur ([kschnur@vitalant.org](mailto:kschnur@vitalant.org)).



We sincerely thank the following for supporting the 2025 New Parent Network series of events, making this event possible:

**accredo**®  
Specialty Pharmacy

**CSL Behring**



**sanofi**



# Camp Hot-to-Clot 2026

**What is it?** Camp Hot-to-Clot is a free overnight summer camp in Western Pennsylvania for youth who have a bleeding disorder or a sibling with a bleeding disorder.

**When is it?** July 26-July 31, 2026

**Where is it?** Camp Hot-to-Clot is held at Camp Kon-o-Kwee (a YMCA facility) located at 126 Nagel Road Fombell, PA 16123.

**Who is it for?** Camp is for youth ages 7-17 years old with a bleeding disorder, as well as their camp-ready siblings in the same age range.

**What happens there?** We have a traditional summer camp experience, complete with archery, basketball, canoeing, creative arts, fishing, gaga, soccer, swimming, and more! We also focus on meeting peers also impacted by bleeding disorders, building relationships in the bleeding disorder community, learning more about bleeding disorders, and becoming more independent in managing medical needs and life in general. Also, and very importantly, we have FUN!!

**How do I sign up?** Please email Katherine Bush at [kbush@vitalant.org](mailto:kbush@vitalant.org) with the details on your interested campers (names, age, and date of birth). Once the registration link is available it will be distributed by email.

**What if I have questions?** Feel free to send an email or to call Katherine at 412-209-7286. All questions welcome!

If you are interested in volunteering or being a counselor, please reach out to the center at 412-209-7286 and let us know. We're already looking forward to it!



# CELEBRATING COMMUNITY AND GLOBAL IMPACT AT OUR 2025 WINTER PROGRAM

On Saturday, December 13, the Western Pennsylvania Bleeding Disorders Foundation (WPBDF) closed out 2025 with a joyful and inspiring Winter Program at Shadow Lakes Country Club. This festive gathering brought together our local community while highlighting our global connections through partnerships with the World Federation of Hemophilia (WFH) and Save One Life.

The afternoon was filled with holiday cheer, including a special visit from Santa, festive games, and meaningful opportunities to connect with friends, sponsors, and fellow community members. Over a delicious brunch, each table read stories about a child living with a bleeding disorder in another country. Guests discussed the challenges these children face, including limited family income and significant barriers to accessing essential care, and reflected on what touched them most about the stories. Participants later found out that each story was about a child still



waiting to be sponsored through Save One Life.

We were honored to welcome Dawn Rotellini, Chief Operating Officer of the National Bleeding Disorders Foundation. Dawn shared insights on the WFH's global impact, emphasizing the critical work being done to support people with bleeding disorders worldwide. She reminded us that approximately 75 percent of individuals with bleeding disorders have limited or no access to treatment, and for women, girls, and people with the potential to menstruate, this number is even higher. An estimated 95 percent of women with bleeding disorders worldwide do not have access to the medications they need, underscoring the urgent need for advocacy and support.

Our Program Director, Janet Barone, spoke about Save One Life, highlighting how the organization provides direct support to individuals and families in countries with limited access to care. Janet encouraged attendees



to sponsor a child or contribute to the Foundation's Save One Life fund, giving more children the opportunity to access life-changing care.



We are deeply grateful to our sponsors for making the Winter Program possible:

♥ **CVS specialty™**

**CSL Behring**

**THE HEMOPHILIA CENTER**  
of Western Pennsylvania

**InfuCare Rx**

  
**novo nordisk®**

**Pfizer**

**sanofi**

**About the Organizations:**



**World Federation of Hemophilia (WFH)** works globally to improve care for people with hemophilia and other inherited bleeding disorders through advocacy, education, research, and programs that increase access to treatment. Learn more at [wfh.org](http://wfh.org).



**Save One Life** provides direct support to individuals and families affected by bleeding disorders in countries with limited access to



care, ensuring access to education, resources, and life-changing opportunities. Learn more at [saveonelife.net](http://saveonelife.net).

After the presentations, attendees participated in a hands-on timeline activity. They placed key events in bleeding disorders history in order, from treating bleeds with leeches and bloodstones, to fresh frozen plasma, to the development of gene therapy. This interactive activity celebrated how far the community has come while keeping global access challenges in perspective.

Special thanks to the Colburn Keenan Foundation for supporting our holiday games, gifts, and prizes.

Thank you to everyone who joined us for the final program of 2025. Your support strengthens our community, honors our shared history, and connects us to a worldwide network of advocacy, care, and hope.



# 2025 TEEN RETREAT: LEARNING, LEADERSHIP, AND LIFE SKILLS

Another Teen Retreat is in the books! This event has become a favorite for those involved with planning and staffing it—there’s no place else we’d rather be! Once again, an amazing group of teens gathered for a weekend of fun, education, and camaraderie.

This year’s event included several favorites that teens have come to expect, such as participating in an escape room, cooking a meal together, learning life skills—including managing finances and responding to medical emergencies, learning about bleeding disorders through a fun and competitive game of Jeopardy, and enjoying time together in the game room and around the campfire.

New activities are introduced at each retreat to keep things fresh. This year’s activities included an outdoor scavenger hunt. Teams of teens used maps of the campground and the United States to answer trivia questions and find clues that would lead them to the next destination. During the scavenger hunt, the teams gathered envelopes containing



information that was later used in a group discussion and a first aid training session. In addition, to expand on lessons about finances and budgeting, we incorporated a blind taste test in which everyone had the opportunity to sample brand-name foods and beverages alongside their generic, less expensive counterparts. It was a fun activity with some surprising results!

Teen retreats are open to teenagers who have a bleeding disorder and their siblings aged 13-18, who are in middle school or high school. We were thrilled to welcome both returning teens and first-time attendees to the 2025 retreat!

Teen Group events are a collaborative effort between the Western Pennsylvania Bleeding Disorders Foundation and the Hemophilia Center of Western Pennsylvania. Janet Barone, Program Director, WPBDF and Katherine Bush, Social Worker, HCWP work closely together to plan and implement teen events, such as the Teen Retreat. In addition, two teenagers, Dexter S.

and Nya F., currently serve as Teen Group Coordinators and help plan and implement events like the Teen Retreat, while gaining valuable leadership skills.

The retreat weekend would not be possible without the support of all WPBDF staff and volunteers. Special thank you to Nurse Kimberly Walsh and to the cabin counselors—Tori Baker, Georgia Ebsworth, Maggie Egenlauf, Ryan Balog, Liam Egenlauf, and Ethan Webb—for their time and support.

## A TEEN'S PERSPECTIVE

BY DEXTER S., TEEN GROUP CO-COORDINATOR

From November 14 to 16, we held our annual Teen Retreat in Clinton, Pennsylvania at Promise Camp and Retreat center. During the weekend, we did budgeting activities like learning how to allocate a paycheck to cover our expenses and save money. We also learned how much food costs through activities based on *The Price is Right* gameshow. We completed our annual medical safety course. During this activity, we learned how to alert first responders about our medical



conditions by wearing medical ID jewelry and keeping medical information in a headrest cover. We also did bonding activities during the weekend, such as cooking a taco dinner and dessert, which helped teens learn how to cook using all kinds of kitchen appliances. We also did a scavenger hunt with facts about bleeding disorders—it was the highlight of the weekend for me. The weekend also gave us a lot of time to reconnect with our friends we don't get to see often through activities such as game time, icebreakers, and an escape room. The teen retreat is always so awesome and so thought out. I can speak for a lot of the teens when I say that being able to see so many of our friends for a weekend is so amazing, as well as a learning experience.



*Pictured above: Dexter S., Teen Group Co-Coordinator*





WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

775 4<sup>th</sup> Street  
First Floor  
Beaver, PA 15009

## WPBDF Winning Women

# Galentine's Event

Join us for a fun and uplifting evening of connection, creativity, and purpose! This special event celebrates the incredible women in our bleeding disorders community while giving back in a meaningful way.

Thursday, February 12

6:00 - 8:30 PM

Robin Hill Park - Carriage House, 949 Thorn Hill Run,  
Coraopolis, PA 15108

**Dinner will be provided. There's no cost to attend!**

This event is open to women of the Foundation who have a bleeding disorder, as well as spouses, partners, and parents or guardians of individuals with a bleeding disorder. Mature teenage girls with a bleeding disorder, or who are siblings of someone with a bleeding disorder, are also welcome to attend.

Register by February 6 by sending an email to [rsvp@wpbdf.org](mailto:rsvp@wpbdf.org) or calling the WPBDF office at 724-741-6160.

## Learn more at [wpbdf.org](http://wpbdf.org)

The Western Pennsylvania Bleeding Disorders Foundation is an organization of acceptance and tolerance for all of its members and the patients it serves, regardless of race, color, ethnicity, national origin, religion, sex, sexual orientation, gender identity or expression, age or disability.



# HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

775 4<sup>th</sup> Street, First Floor

Beaver, PA 15009

Phone: 724-741-6160 Toll Free: 800-824-0016 Fax: 724-741-6167

[info@wpbdf.org](mailto:info@wpbdf.org)