WPBDF
Western Pennsylvania
Bleeding Disorders Foundation

HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

SPRING 2025

WPBDF
Western Pennsylvania
Bleeding Disorders Foundation

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

MISSION STATEMENT

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

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

DESIGNATE UNITED WAY GIFTS TO THE CHAPTER

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

WPBDF Contributor Agency Code Number is: 83

EVENTS CALENDAR

April 7, 2025
Trivia Night Fundriaser
Sheffield Lanes
Aliquippa, PA

April 10, 2025
Family Connection
Grand Concourse
Pittsburgh, PA

April 17, 2025
World Hemophilia Day Program
Monterey Bay Fish Grotto
Pittsburgh, PA

May 16-18, 2025
Pennsylvania Bleeding Disorders Conference
Hershey Lodge
Hershey, PA

June 8, 2025
New Parent Network
Children's Museum of Pittsburgh
Pittsburgh, PA

July 13, 2025
Annual Meeting
Sheraton - Station Square
Pittsburgh, PA

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

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

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

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

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

October 4, 2025
Fall Program
Trinity Church
Wexford, PA

November 8, 2025
Designer Purse Bingo
Vanport Fire Hall
Vanport, PA

November 16, 2025
New Parent Network
Virtual

December 13, 2025
Winter Program
Shadow Lakes
Aliquippa, PA

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

COMMUNITY ANNOUNCEMENTS

Have something to share with the WPBDF community? Submit a community announcement to jessica@wpbdf.org to be included in the next Hemogram!

BLEEDING DISORDERS CONFERENCE
Aurora, Colorado • August 21-23, 2025

NBDF'S 2025 BLEEDING DISORDERS CONFERENCE EDUCATIONAL GRANT APPLICATION OPEN!

Scan the QR code or visit bit.ly/wpbdfgrant2025 to learn more and submit your application!

If you would prefer a paper application, please contact the Foundation office at 724-741-6160.

CONTACT US

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LETTER FROM THE EXECUTIVE DIRECTOR AND BOARD PRESIDENT

Dear Community Members and Friends,

March gave us the unique opportunity to celebrate both Bleeding Disorders Awareness Month and Women's History Month — two powerful observances that allowed us to elevate the voices of those living with bleeding disorders and spread awareness about these often misunderstood conditions. It was a month marked by connection, advocacy, and empowerment.

We are incredibly grateful for the dedication and courage shown by our community members who shared their stories, triumphs, and challenges. Your openness has been pivotal in raising awareness and fostering a deeper understanding of the hurdles faced by individuals and families impacted by bleeding disorders. Whether attending legislative meetings, spearheading volunteer projects, sharing personal experiences, or advocating at local commissioner meetings to declare March as Bleeding Disorders Awareness Month, your efforts have made a lasting impact. Thank you for shining a light on our community.

This March, we were honored to be invited as guests on Talk Pittsburgh, where we highlighted the often-overlooked issue of bleeding disorders in women. Many women with bleeding disorders endure long delays in diagnosis and inadequate treatment due to persistent misconceptions. The average delay in diagnosis is a staggering 16 years — far too long. We are committed to continuing our efforts to raise awareness and advocate for earlier diagnoses and better care for women in our community.

Looking ahead, we're excited about the upcoming Pennsylvania Bleeding Disorders Conference, taking place May 16-18. We're thrilled to collaborate with the Eastern Pennsylvania Foundation and hemophilia treatment centers across the state to bring this essential event to life. The conference will offer valuable education, connection, and support for individuals and families navigating life with a bleeding disorder.

Advocacy remains at the core of our mission, and it's more crucial now than ever. With the ongoing uncertainties surrounding Medicaid and an upcoming budget season filled with challenges, it's vital that we continue working together to ensure individuals with bleeding disorders have access to the care and resources they need.

Grassroots advocacy plays a key role in amplifying our community's voice and driving meaningful change. Meeting with local legislators in their districts is essential to making sure the needs of those affected by bleeding disorders are heard and addressed. If you would like to get involved in our advocacy efforts, please reach out to me (Kara) at kara@wpbdf.org.

Thank you for your continued support and dedication to our community. Together, we're making a significant difference in the lives of those living with bleeding disorders.

With heartfelt gratitude,

Kara Dornish
Executive Director, WPBDF

Scott Domowicz
Board President, WPBDF

GALENTINE'S DAY WITH WPBDF'S WINNING WOMEN'S GROUP

SAMANTHA SHORT, WINNING WOMEN'S GROUP CO-COORDINATOR

We all come from different backgrounds, but are united in so many ways besides just our bleeding disorders. Our group includes unique women with inspiring stories to share, and I always leave our winning women's group feeling inspired and having learned something new.

So what is Galentine's Day anyways?

Galentine's Day is a day to celebrate strength, values and bonds of friendship amongst women. Our members have evolved and created long lasting and powerful friendships within the group, and so many of my favorite people gathered with us to celebrate!

We spent the evening at AR workshop in Gibsonia, each of us creating our own masterpiece. With choices ranging from wooden trays to hand painted signs, the staff at AR guided us through our projects with ease. Melissa Kendrick, from Cottrill's Pharmacy, sponsored the event and supplied us with a delicious dinner, catered by Olive Garden. She also provided an additional craft of "intention hearts". Each glass heart shaped ornament could be filled with different gems, dried herbs and flowers to set our intentions for the next year. The project was a great finale to a superb evening. Another fantastic event for the Winning Women's Group!

COTTRILL'S
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ADVOCACY UPDATE

KERRY LANGE, SENIOR ASSOCIATE
MILLIRON GOODMAN

HARRISBURG OVERVIEW

The 2025-2026 session began on January 7 with a swearing-in ceremony for all Representatives and Senators.

Due to the recent passing of Representative Matthew Gergely, a special election was held in the 35th Legislative district (Allegheny County) on March 25. A special election was also held in the 36th Senatorial District (Lancaster County) to replace former Senator Ryan Aument, who resigned to work for U.S. Senator Dave McCormick. Democrat Dan Goughnour won the 35th House District seat and Democratic East Petersburg Mayor James Malone won the 36th Senate District seat. The House will now operate with a one-seat majority (102D; 101R). The Senate will continue with a Republican majority (27R; 23D).

All four legislative caucuses have elected their leadership teams for the new session, as follows:

Senate Republican Leadership:
- President Pro Tempore: Kim Ward (R-Westmoreland)
- Leader: Joe Pittman (R-Indiana)
- Whip: Wayne Langerholc (R-Cambria)
- Appropriations Chair: Scott Martin (R-Lancaster)
- Caucus Chair: Kristin Phillips-Hill (R-York)
- Caucus Secretary: Camera Bartolotta (R- Washington)
- Policy Chair: Dave Argall (R-Schuylkill)
- Caucus Administrator: Lisa Baker (R-Luzerne)

Senate Democratic Leadership:
- Leader: Jay Costa (D-Allegheny)
- Appropriations Chair: Vincent Hughes (D-Philadelphia)
- Whip: Tina Tartaglione (D-Philadelphia)
- Caucus Chair: Maria Collett (D-Montgomery)
- Caucus Secretary: Steve Santarsiero (D-Bucks)
- Policy Chair: Nick Miller (D-Lehigh/Northampton)
- Caucus Administrator: Judy Schwank (D-Berks)

House Republican Leadership:
- Leader: Jesse Topper (R-Bedford/Fulton)
- Whip: Tim O'Neal (R-Washington)
- Appropriations Chair: Jim Struzzi (R-Indiana)
- Caucus Chair: Martina White (R-Philadelphia)
- Caucus Secretary: Clint Owlett (R-Bradford/Tioga)
- Policy Chair: David Rowe (R-Juniata/Mifflin/Snyder/Union)
- Caucus Administrator: Sheryl Delozier (R-Cumberland)

House Democratic Leadership:
- Speaker: Joanna McClinton (D-Philadelphia)
- Leader: Matt Bradford (D-Montgomery)
- Appropriations Chairman: Jordan Harris (D-Philadelphia)
- Whip: Mike Schlossberg (D-Lehigh)
- Caucus Chair: Rob Matzie (D-Beaver)
- Caucus Secretary: Tina Davis (D-Bucks)
- Policy Chair: Ryan Bizzarro (D-Erie)
- Caucus Administrator: Leanne Krueger (D-Delaware)

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

Senate Health & Human Services Committee:
- Majority Chair Michele Brooks (R-Mercer)
- Minority Chair Art Haywood (D-Montgomery)

Senate Banking & Insurance Committee:
- Majority Chair Chris Gebhard (R-Lebanon)
- Minority Chair Sharif Street (D-Philadelphia)

House Health Committee:
- Majority Chair Dan Frankel (D-Allegheny)
- Minority Chair Kathy Rapp (R-Crawford)

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

In February, Governor Josh Shapiro provided his 2025-

... CONTINUED ON PAGE 6

ADVOCACY UPDATE

CONTINUED FROM PAGE 5...

26 budget address and corresponding proposal. It is a $51.3 billion spending plan, a 7.5% increase over last year's budget. Once again, he did not propose 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 a rate of 20%, and skill games, taxed at a rate of 52%. In addition, he again called for an increase in minimum wage from $7.25/hour to $15/hour by January 1, 2026.

Following the release of the budget proposal, the House and Senate Appropriations Committees held budget hearings with all state agencies to discuss the details and how it aligns or doesn't align with their initiatives for the upcoming year.

Internal negotiations will now begin. The legislature has a constitutional deadline of June 30 for passing a balanced budget.

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 were able to secure $1,017,000 in the General Appropriations bill (SB 1001), keep it separated from other line items, and protect the distribution formula with language in the fiscal code (HB 2310).

These budget requests will continue to be our priority for WPBDF this session, as it is critical for the patients and treatment centers. Ideally, we are advocating for an increase from $1,017,000 to $1,250,000.

We continue to note that we are preparing for a difficult budget season. The Independent Fiscal Office (IFO) is projecting a deficit of $3.4 billion this year and projecting that number to increase to $6 billion next year. With these deficit predictions, the state budget process will likely become a much more heated and competitive process.

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

Your legislators need to hear from you as well! Grassroots advocacy will become more critical with these IFO predictions. Legislators will need to know their constituents to make this three-part budget request a top priority.

LEGISLATION

Access to Menstrual Hygiene Products

There are several co-sponsorship memos addressing the issue of increased access to menstrual hygiene products in both the House and Senate. As one example, Representative Darisha Parker (D-Philadelphia) is planning to reintroduce a package of bills that would allow the PA Departments of Human Services and Health to apply for a waiver, if the U.S. Dept of Agriculture creates a waiver, allowing those who receive SNAP/WIC dollars to utilize the dollars to purchase menstrual hygiene products. Her bill package also establishes a grant program to provide public schools with funding to purchase the products at no expense to students. The package hasn't been introduced yet, but could become a budget-time discussion again.

Once introduced, WPBDF will likely reengage with letters of support and other advocacy initiatives.

Co-Pay Accumulator

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

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

So far, there is no proposed companion in the House.

The Milliron Goodman team is continuing to stay engaged on this issue. Please continue to share your personal experiences regarding co-pay accumulators with the WPBDF team.

GRASSROOTS ADVOCACY

Now is the time to start reaching out to your personal legislators (Representative and Senator) to 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.

Here are some tips:

- Do some homework. Research your legislators, committee assignments, co-sponsorship memos and sponsored legislation. This offers insight into their legislative interests.
- Always identify yourself as a constituent.
- Remember, you are the expert on bleeding disorders and know what the community needs. You do not have to be an expert in the legislative process!
- Be clear, brief and accurate! Sharing your story and experiences is very persuasive!
- Be persistent, but not argumentative if your legislator doesn't seem supportive. Provide points to support the request, such as the value of the HTCs in day-to-day care for patients and your personal experience with your HTC.
- Get to know legislative staff! They play a critical role in the legislative offices and can often help legislators remember the issues and next steps.
- Express appreciation.
- Continue to build the relationship!

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.

David Macharola (middle) and his wife, Sandra (right), meet with Congressman John Joyce, M.D. (left) during NBDF's Washington Days.

ADVOCATES AT WASHINGTON DAYS 2025

DAVID MACHAROLA

Early Wednesday morning, we prepared to leave for Washington Days. The day began like many other winter days in my home area of Central Pennsylvania: cloudy gray, rainy, and cold, with a line of severe thunderstorms and high winds from New York to Florida. People traveling to Washington from parts of the West, who we met at the conference, told us it was a bumpy ride with some delays. To the Hyatt Regency in Washington on Capitol Hill, we traveled with short right and left turns, hoping the GPS would announce directions faster; one missed turn may not be corrected by simply going around the block. The first evening conference event was exciting. It was great to meet old acquaintances from years ago, and new colleagues, and we were elated to see 500 people in attendance. The conference room looked like a national convention. Even Hawaii was there! It was fabulous that they traveled from Hawaii to Capitol Hill to see their representatives and protect the three issues critical to bleeding disorders.

I was amazed to see all the kids in attendance. They sat through the speeches and discussions, appeared content, and had a good time. The lectures and discussions were boring for kids, and they may not have been paying attention, but what matters is that they are here as future advocates, and they represented the future of bleeding disorders very well. Their attendance is a great beginning.

We finally have a more significant identity than when I was much younger, and the moms of hemophiliacs were our loudest and fieriest advocates, which continues today. Never underestimate the power of Mothers. Unaware that those moms, as carriers of Hemophilia, probably suffered from reduced clotting factors and were truly unrecognized members of the bleeding disorders community. Having representatives from Hemophilia, Von Willebrand Disease, Rare Factor deficiencies, Platelet Disorders, and Bleeding of an Unknown Cause present at this meeting solidifies my interpretation of the new identity of bleeding disorders with over three million people. Not to forget, March is Bleeding Disorders Awareness Month.

I listened to the stories of sufferers of Hemophilia and Von Willebrand disease who described the issues and effects of critical bleeding episodes, emergency room visits, treatments, and diagnosis, and the most challenging part was the pain associated with these events. I'll never tire of hearing these stories, and I cheer for them and their bravery and resilience. My heart breaks for everyone who is in pain and disappointment for those who don't recognize the danger of bleeding and potential death.

All of our congressional pleadings include how dangerous bleeding and debilitating the disease is and how it can prevent people from working, playing, and having a happy, productive life. When government program budgets are reviewed, we must ask our congressional leaders not to cut critical programs that help with bleeding disorders; we always fear that a stroke of a red line item could indicate our end of care. We must continue to develop strategies and advocacy programs to target the issues every budget session with a greater fervor than the previous year. Ultimately, we need politically active members from the bleeding disorders community in Senatorial and Congressional seats nationwide.

Thursday morning started early with a good breakfast and a brisk cold walk to Capitol Hill. We thought we could enter the capital complex and then tunnel over to the adjacent office buildings without having to go outside and back through security screening. However, many entrances were closed, and some areas around the buildings were stationed off, so we had to go around the capital. I could boast a four-mile hike that more than satisfied my exercise requirements.

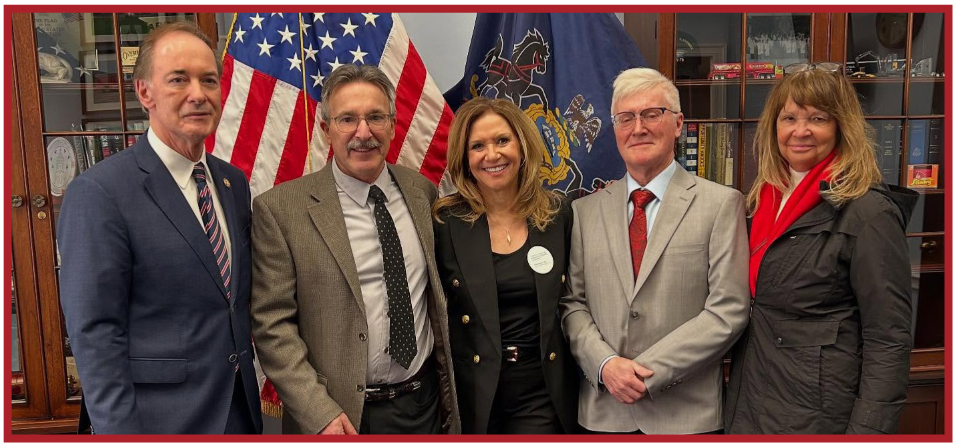
My congressional meeting was with my district Congressman, Dr. John Joyce, who we were not sure we would get to meet with. While we were gathering in the hall before our appointment, we saw John come out of the office with one of his staff members, and they briskly paced down the hall and turned a corner. A short time later, John returned to the office and apologized for having to leave for a congressional vote. He didn't want to miss it. Congressman Joyce was very polite, accommodating, and interested in what we had to say. I spoke to John about my history of living with hemophilia, recognizing that he is a physician and medically knows about bleeding disorders. We shared a common theme about my marching in the Altoona Area High School Marching Band under the direction of Darwin Bistline in the 1970 Cherry Blossom Festival Parade. I marched in that parade with two full-length leg braces under my uniform pants, without factor treatment, military-style marching, close to five miles, and the band took first place. Congressman Joyce's sister is married to a member of the Bistline family, and he spoke about how great the band director and the Bistline family name are. I agree with him entirely. Mr. Bistline taught me to play the clarinet and all the band members to be kind and respectful and to show pride in our community. We presented the three issues concerning the funding of programs with Congressman Joyce and left articles on the issues for his use.

Our next visit was to meet with Senator Dave McCormick; we met with his staff standing in his office lobby. Senator McCormick did not have a health representative in the office at that time. McCormick's staff were hopeful that they would have one soon. A few colleagues from our group made their plea to the staff about their story and bleeding disorders, and they did come away with the opportunity to meet with Sen. McCormick soon.

We stopped by Senator Fetterman's office, who was unavailable to meet with us, but a delegation member delivered the handouts to the office.

Later in the evening after dinner, I was amazed and cheered the speech by Phillip M. Gattone, President of the National Bleeding Disorders Foundation. We are grateful to have a president working hard for our lives. His heart-touching talk about bleeding disorders and our coalition of becoming a community is what we are — "a community"

My experience at the Washington Days event at Hyatt Regency did provide us with clean rooms, good food, and camaraderie. I hope we were successful and our message stays in their minds when you say bleeding disorders. However, there's a bit of discourse based on Washington's current volatile political atmosphere. Some representatives no longer hold town halls in their districts, and that withdrawal makes it difficult, if not impossible, to hear from advocates about bipartisan common ground issues.



Left to right: Congressman John Joyce, M.D., David Macharola, Sandra M., Martin T., Karen B.

ADVOCATES AT WASHINGTON DAYS 2025

MARIA SHOEMAKER

On March 6, 2025, I had the honor of traveling again to Washington DC with hundreds of our blood brothers and sisters. With 49 out of the 50 states represented there, it was a busy day of meetings and sharing our stories. I believe that our stories made an impact, discussing important matters such as Medicaid funding, copay accumulators/maximizers, and women and girls with bleeding disorders.

However, I believe we are all aware of how we are in perilous times. All people with disabilities have less rights than last year and the warning signs are all around us that more may be coming. Medicaid is under threat, and over a quarter of our community members rely on this for their family's medical needs. We are still fighting against maximizers and adjusters, both at state and federal levels. PBMs still make fists in profit for the sake of our care.

With that knowledge, I am begging each person that reads this to take action. I realize not all of us can miss work or school for three days and travel, but there is so much more each of us can do to help. Writing letters, making phone calls, and making appointments to visit local legislators' offices are all ways we can make a difference. WPBDF offers amazing resources and will help support you in your efforts.

Maria Shoemaker (right) and her son, Dexter (left), at NBDF's Washington Days.

I also encourage everyone to take all the advantages possible to get to know local legislators and candidates that are in your district. Above all, please share your stories. The more we spread awareness of how our medical issues impact our lives and our communities, the more change we can inspire!

ADVOCACY LUNCH & LEARN

On Tuesday, March 11, WPBDF partnered with the Eastern Pennsylvania Bleeding Disorders Foundation to host a virtual lunch & learn session to empower and educate advocates on key state and national issues impacting the bleeding disorders community.

Other topics at this session included:

- Exploring effective advocacy strategies and how to take meaningful action
- Learning how to schedule and prepare for meetings with legislators in their district offices
- Discussing various ways to advocate, from phone calls to emails and beyond

Kerry Lange, Senior Associate at Milliron Goodman, provided an update on state issues and discussed the importance of meeting legislators in their local district offices. Matthew Delaney, Government Relations Manager at the National Bleeding Disorders Foundation (NBDF), provided a recap of NBDF's Washington Days, highlighting the three priorities at the federal level: protecting federal programs dedicated to the bleeding disorders community, finding supporters for the HELP Copays Act, and rejecting health cuts and program changes to Medicaid and marketplace insurance coverage. The program ended with a mock-legislative meeting that highlighted the dos and don'ts when meeting with elected officials. This session was recorded and can currently be viewed online at: https://bit.ly/advocacy-lunch-learn.

Interested in becoming an advocate this year? We encourage you to schedule meetings with your legislators in their local district offices. Advocacy comes in many forms, whether it's meeting with legislators, making phone calls, or taking other actions. We can all take part in making a difference.

We're happy to provide one-on-one training, attend meetings with you, or connect you with other advocates in your area. Please email Kara at kara@wpbdf.org for more information!

STRIKE OUTS AND HIGH SCORES AT BOWLING FOR BLEEDING DISORDERS

THE WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION STRIKES OUT BLEEDING DISORDERS!

The Tenth Annual Bowling for Bleeding Disorders fundraiser was held at Paradise Island Bowl in Neville Island, Pennsylvania on Sunday, February 16, 2025. The cost to attend was $30 per person, which included shoe rental, bowling, pizza, wings, and unlimited soft drinks.

Nearly 50 bowlers competed for the most strikes, highest score, and the best style. The Highest Score Award went to Steve S., who rolled an impressive 226 game! The Most Strikes Award went to Joseph E., who got 16 strikes throughout the afternoon! The Best Style Award went to Kenny S. for his very stylish blue bowling shirt! Thank you to Cottrill's Pharmacy for sponsoring these awards!

At this event, WPBDF recognized an important member of the community with the Community Spirit Award. The recipient, Cassie Miller, is WPBDF's Advocacy Chair and a dedicated Board member. She works tirelessly to raise awareness of bleeding disorders, specifically in women, girls, and people with the potential to menstruate, and ensures the voices of the community are heard. Thank you, Cassie, for being an absolute rockstar!

Members of Unite for Bleeding Disorders Walk team, Rolling for Ryker, sold 50/50 raffle tickets and brought two amazing raffle baskets to raffle off. These raffles raised an additional $257 for the community! The winner of the 50/50 raffle, and team captain of Rolling for Ryker, Mindy Perry, generously donated back her $131 winnings! Thank you to Mindy and her entire team for their dedication to the bleeding disorders community!

We are extremely grateful for everyone who participated in this event. We are excited to report that over $2,000 was raised! The money raised will provide emergency and medical patient assistance, educational programs, and support groups to benefit the bleeding disorders community in Western PA.

WPBDF would like to thank all who participated in and sponsored this event. We can't wait to see you all at one of our future fundraisers!

THANK YOU TO OUR SPONSORS!

Spare Sponsor

CSL Behring

Award Sponsor

COTTRILL'S PHARMACY, INC.

Melinda Perry, of Rolling for Ryker, donates her 50/50 winnings back to WPBDF!

HIGHEST SCORE AWARD: STEVE S.

MOST STRIKES AWARD: JOSEPH E.

BEST STYLE AWARD: KENNY S.

COMMUNITY SPIRIT AWARD: CASSANDRA MILLER

RAISING AWARENESS: HELPING SCHOOL NURSES RECOGNIZE BLEEDING DISORDERS

The Western and Eastern Pennsylvania Bleeding Disorders Foundations are working hard to spread awareness and improve the diagnosis of bleeding disorders in women, girls, and individuals who menstruate (WGPPM). On average, it takes 16 years for WGPPM to receive a diagnosis and proper care. That's far too long, and we're determined to change it. By educating others about the signs and symptoms of bleeding disorders, we can help WGPPM get faster diagnoses and treatment, reducing pain, suffering, and permanent damage caused by untreated conditions.

On Saturday, March 22, we attended the Pennsylvania Association of School Nurses and Allied Practitioners Conference in State College, PA. Around 200 school nurses from across Pennsylvania came together for the event. School nurses are key in supporting the health of students, and they are likely to interact with students who experience chronic nosebleeds and/or heavy or prolonged periods, which are signs of potential bleeding disorders. Our goal is to provide school nurses with the information they need to recognize the signs of bleeding disorders and help students and their families find the right care and evaluation.

During the conference, we had the chance to speak with many school nurses and share helpful resources, including our Bleeding Disorders Toolkit, period packs, nosebleed kits, and information on the signs and symptoms of bleeding disorders. We also created and handed out an informational poster for nurses to display in their schools. This idea came from a suggestion we received last year, and we're excited to see it become a reality!

Together, we can make a difference and help ensure that bleeding disorders are diagnosed and treated more quickly, improving the quality of life for WGPPM.

YOU'RE INVITED!

Western Pennsylvania Bleeding Disorders Foundation's

2025 ANNUAL MEETING

When? Sunday, July 13, 2025
3:00 PM

Where?
Sheraton Station Square
300 W Station Square Drive
Pittsburgh, PA 15219

Join us for dinner, visit sponsor booths, and learn more about the services the Foundation offers! We will be celebrating our top volunteers and kicking off the 2025 Unite for Bleeding Disorders Walk!

Everyone who attends is invited to join us after the meeting for the Gateway Clipper's Three Rivers Sightseeing Cruise at 6:30 PM. Tickets for the cruise will be provided to attendees free of charge at the end of the meeting.

Space is limited, so be sure to register early! To register, send an email to rsvp@wpbdf.org or call the Chapter office at 724-741-6160. Be sure to include the total number of people you are registering for and if there are any food allergies. If children are attending, please be sure to include their ages. **Transportation assistance is available by request**.

WPBDF

The deadline to register for the Annual Meeting is Friday, June 6.

WPBDF'S YOUTH GROUP DISCUSSES BULLYING

EMILY NIKITHSER

On a snowy Saturday in January, the Carnegie Science Center in Pittsburgh became the backdrop for an important gathering of WPBDF's Youth Group. Despite the chilly weather, children aged 7-12 came together for an interactive and informative session titled "Being Different, Belonging Together", led by Kathaleen Schnur, LCSW, from the Hemophilia Center of Western PA.

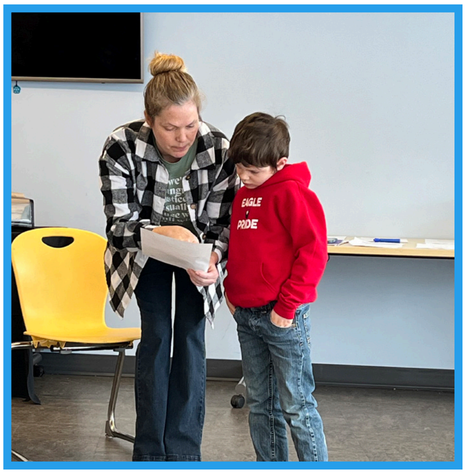
The program, designed to provide children with strategies for recognizing and dealing with bullying, was filled with creative prompts and activities that engaged the group in a fun and educational way. Through role-playing, discussions, and hands-on exercises, Kathaleen worked closely with the children to help them understand the impact of bullying and empower them with practical tools for responding to challenging situations.

The event not only focused on the seriousness of bullying but also highlighted the importance of empathy, confidence, and resilience. Children left the session equipped with valuable strategies to navigate social challenges with greater confidence, knowing they had the support of their peers and the guidance of trusted adults.

After the program, lunch was provided, giving families a chance to connect and spend time together. The day continued with everyone receiving tickets to explore and enjoy the exhibits at the Carnegie Science Center, making for an afternoon of fun and learning.

Thanks to the efforts of Kathaleen Schnur and the WPBDF, this snowy Saturday was not just about learning – it was about fostering kindness, courage, and community in the face of adversity.

We really hope you can join us for our next event! Please reach out with any ideas for program topics that you would like to see for our kids in this age group or locations that would be fun for a more casual get-together.



WHAT'S SO BLOODY FUNNY?

WPBDF'S COMEDY NIGHT FUNDRAISER

On Sunday, February 2, the bleeding disorders community laughed the night away at the Pittsburgh Improv with Samuel J. Comroe and JB Buchanan! In total, 32 people came out to support the Western Pennsylvania Bleeding Disorders Foundation and over $300 was raised to provide education and support to affected individuals throughout Western PA! Thank you to Samuel, JB, and the Improv for donating a portion of ticket sales back to us! A huge thank you to WPBDF Board Members, Mindy and Samantha, for organizing this amazing event.

GETTING TO KNOW HCWP STAFF

BREE MAINVILLE
PATIENT INSURANCE SPECIALIST

THE HEMOPHILIA CENTER of Western Pennsylvania

Birthplace: San Diego, CA

First job: Delia's in the Robinson Mall

Accomplishment you're proudest of: I just finished becoming a certified treatment foster parent!

What three words describe you best? Caring, Funny, and Dependable.

Dream vacation: I would love to stay in one of those huts on the water in Bora Bora or explore a lagoon in Albania.

Things you can do without: Social Media, Sparkling Water, and Coffee.

Person you'd most like to have dinner with: Sir Patrick Stewart. Always been a Star Trek fan.

Movie you could see anytime: Midsommar

TV show you could happily binge: 90 Day Fiancé and all of the spin-off's!

Three things that can always be found in your refrigerator: Dr. Pepper, Pierogies, and Chocolate Moose Tracks Ice Cream

Secret vice: Watching YouTube. It's constantly on even if I'm watching something else on the big TV.

Who would play you in the movies?: She looks nothing like me, but I'm currently obsessed with Sophie Thatcher, so I would choose her.

Your pet peeve about Pittsburgh: The traffic

People may be surprised to know: I have fostered 22 kittens and a bunny in just one year of fostering animals! It was very rewarding.

HCWP CORNER

KATHALEEN SCHNUR, LCSW

Dear WPBDF and HCWP Community,

As we transition into the vibrant season of spring, a time of growth and renewal, we reflect on the shared journey of the bleeding disorders community. Life, much like the seasons, presents both moments of growth and moments of challenge. As we continue navigating the landscape of living with bleeding disorders, one thing remains clear: we are all in this together.

In recent months, many have reached out with questions, particularly about insurance and other concerns. While there are no answers at this time, we want to assure you that we are staying closely attuned to the impact of these concerns and remain committed to monitoring the situation. We understand that this process can be overwhelming, and we are dedicated to staying engaged and aware as things continue to evolve. It's important to remember that life isn't always about resolving every challenge immediately; it's often about coping, supporting one another, and walking through difficulties together. The importance of human connection cannot be overstated, while each of us may walk a different path with unique experiences, we should never forget the power of leaning in and leaning on each other.

Recently, an update was sent to patients with necessary information regarding leadership transitions, location change, and expectations moving forward.

A key point emphasized was the importance of regular, comprehensive clinic visits. While this may seem like an additional responsibility, the intent is not to complicate matters but to ensure safe and continuous care. We can only provide care for patients we regularly see for safety reasons. If you have not had an appointment in the last year or two, it's strongly encouraged to contact the center to schedule a visit. Our team is committed to supporting patients and ensuring care is as seamless as possible. If there are difficulties attending the clinic, the HCWP Social Workers are available to assist with barriers.

The center has also welcomed new team members, including Denise Proakis, an additional Medical Assistant, and Bree Mainville, a new Insurance Specialist. Bree will be reaching out to patients ahead of appointments and is available for any insurance-related questions. This added support aims to make navigating insurance plans easier.

In exciting news, a new monthly HMB (Heavy Menstrual Bleeding) clinic will soon be offered with a local gynecologist as part of the HTC services. This initiative is an important step forward, and more details will be shared in the coming months. Additionally, the center is a qualified site for all FDA-approved gene therapy treatments, with the first patient already receiving an infusion. The future of gene therapy looks promising, and there is great optimism for its potential impact.

To further enhance care, a new patient satisfaction survey has been introduced, developed with input from the Consumer Advocacy Committee (CAC). This feedback will help assess how well the center is meeting the needs of the community and identify areas for improvement. For patients between the ages of 12 and 26, the focus continues on facilitating a smooth transition from pediatric to adult care, while also promoting autonomy and responsibility in managing bleeding disorder care. For younger patients under 12, a fun clinic BINGO game has been introduced to make appointments more engaging and enjoyable.

We look forward to continuing to support the community and appreciate your participation and feedback.

With warmth and support,
Kathaleen Schnur

PITTSBURGH PENGUINS FUNDRAISER

On March 18, the Pittsburgh Penguins took on the New York Islanders, and 38 people came out to not only cheer on the home team, but to show their support for WPBDF! A portion of all tickets sold through our unique ticket link was donated back to the Foundation. Additionally, the first 7,500 people at the game received a Pittsburgh Penguins beach towel. In total, we raised $380 that will go toward providing education, support groups, and patient assistance to individuals and families affected by bleeding disorders in Western PA. Unfortunately, the Islanders beat the Penguins 4-2, but we are so thankful for everyone's continued support of WPBDF!

WPBDF
Western Pennsylvania
Bleeding Disorders Foundation

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION'S

17th Annual Unite for Bleeding Disorders Walk

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

September 6
Saturday

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

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

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

Hemophilia Alliance

Takeda

National
Bleeding Disorders
Foundation

VON WILLEBRAND DISEASE DINNER PROGRAM

AN EVENING OF EDUCATION AND COMMUNITY

On Thursday, January 30, the Western PA Bleeding Disorders Foundation hosted a special von Willebrand Disease program, with Octapharma and InfuCare, at Bravo in Robinson Township. This engaging and informative evening brought together 27 attendees for an excellent presentation focused on von Willebrand Disease (VWD), led by patient advocate Mackenzie Fly and Dr. Claudio Sandoval.

Mackenzie Fly shared her personal journey, offering valuable insight into the challenges and triumphs of living with VWD. Dr. Sandoval provided expert medical knowledge, ensuring attendees walked away with a deeper understanding of the condition and its management. The discussion covered key aspects of treatment, advancements in care, and resources available to the bleeding disorders community.

Beyond education, the event fostered a sense of connection and support among attendees. It was an opportunity to ask questions, share experiences, and strengthen the community that makes our foundation so special.

A heartfelt thank-you to Octapharma and InfuCare for their partnership and support in making this program possible. We appreciate everyone who attended and look forward to more opportunities to learn and connect in the future!

Stay tuned for upcoming events and programs—your involvement makes all the difference!

InfuCare Rx

octapharma

NOSEBLEED KITS VOLUNTEER DAY

STEPHANIE SHROPSHIRE

Advocacy comes in all forms. I don't think of myself as well-versed on healthcare bills and issues within the political world – which is maybe what most people think of when discussing advocacy in the bleeding disorders community. One thing I'm really good at is advocating for my daughter, who has bled in various forms since she was 5 weeks old. After being accused of hurting my daughter and a 17 month journey to a diagnosis, I found myself working closely with the Foundation and ultimately on the Board of Directors.

With a Von Willebrand disease diagnosis, one common concern is frequent nosebleeds that require medical intervention to clot. While this is an issue we deal with often, we know other kids get nose bleeds too – sometimes because the air is dry, they pick it, or because they have a deficiency that effects their clotting. It has become my mission to help even just one child to get a diagnosis easier than what our family went through.

My first packing event was held at a small private school and we had a turnout of about 40 families, where we packed about 600 kits in only 30 minutes! It was a great test to see how big we could go! My next packing event was at another school, which is where I now work, and it was held on a Sunday. It was incredible to see kids as young as 3 years old, experiencing their first act of service for others, or a mitzvah, and that the foundation could make that possible for them-while we packed an impressive 800 kits with young families! It didn't stop there and my drive to pack even more became stronger.

This 2024-2025 school year, I held a recess nosebleed packing event for intermediate and middle school students (4-8 grades). Would you believe that we had 49 students pack 728 kits in only 18 minutes! In Judaism, 18 is a lucky number; it means chai, or life – and to know that these selfless kids helped to enhance lives by helping to find a route for a diagnosis for a child who may need it, is impressive and shows that I have the good fortune to be apart of two very special communities.

It's no secret that Community Day School spends Martin Luther King Jr. day as a "day on" where students in every grade level from the 3 years olds to the eighth graders volunteer doing service projects. I was honored and so incredibly excited when our Community Engagement Coordinator told me that our students enjoyed the nosebleed packing event during recess so much that they wanted to run a morning of packing for MLK day! We ambitiously came up with the goal of 3,000 kits! While we didn't hit that goal, it wasn't for lack of effort or time – but the distributor couldn't get the excessively high number of supplies to us fast enough! We did, however, pack, count and label over 2,600 kits!

I am so excited to have these kits distributed to schools across Western Pennsylvania in hopes of getting an easier diagnosis and really great education in the hands of kids who experience bleeds similar to my daughter. And as I'm sure you could have guessed, I'll be planning more events as the Foundation has a need to get more kits into schools!

The WPBDF
Scholarship

APPLICATIONS NOW OPEN!

Learn more and apply online at:
www.surveymonkey.com/r/wpa2026

Paper applications available upon request.
Email info@wpbdf.org.

Who is eligible for the WPBDF Scholarship?

Any person or immediate family member of a person with hemophilia, von Willebrand Disease, or other inherited bleeding disorder is eligible to apply for this scholarship. The person with the bleeding disorder must either be a member of the Foundation, living in one of the 26 counties served by the Foundation, or be a patient of the Hemophilia Center of Western PA. The candidate must provide proof of enrollment in an accredited college or vocational/technical center and must submit a completed application within the established deadline.

Scholarship Funds

One full award up to $3,000 per degree program or course of study will be granted. Partial awards may be granted. Individuals who have received a partial award (less than $3,000) from WPBDF in the past are welcome to reapply. The Foundation is delighted to be able to support our community in this way. We wish you the very best of luck as you pursue your education.

Applications must be received or postmarked by May 30, 2025. Winner(s) will be announced at the WPBDF Annual Meeting on July 13, 2025.

WPBDF
Western Pennsylvania Bleeding Disorders Foundation

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

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

Join the Western Pennsylvania Bleeding Disorders Foundation for our first ever Purse Bingo! Try for a chance to win one of our amazing brand name bags! Basket raffles, 50/50 raffles, and bonus games will be going on all evening, offering even more chances to win big!

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

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. Table reservations are available! Online registration ends 11/7/2025.

PURCHASE TICKETS AT: BIT.LY/WPBDFPURSEBINGO

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

RUN FOR THEIR LIVES

Bleeding disorders can't stop us.

REGISTER AT:
BIT.LY/RUNFORTHEIRLIVES2025

EARLY BIRD PRICING: $25
(until May 31st)

REGISTRATION FEE:
June 1 - September 5:
$30
Race Day fee:
$35

SATURDAY
SEPT 6
2025

NORTH PARK SWIMMING POOL

9901 S RIDGE DRIVE
GIBSONIA, PA 15044

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

HEMOGRAM

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

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