



HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

FALL 2024



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

MISSION STATEMENT

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

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

DESIGNATE UNITED WAY GIFTS TO THE CHAPTER

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

WPBDF Contributor Agency Code Number is: 83

EVENTS CALENDAR

October 19

Mead and Bleed
Greene Township Building
Erie, PA

November 1-3

Teen Retreat
Promise Camp
Clinton, PA

November 6

Insurance Program
Bravo! Italian Kitchen
Robinson Township

November 16

Take A Bough
Red Fox Winery
Hickory, PA

November 18-21

National Bleeding Disorders
Chapter Leadership Seminar
Dallas, TX

December 3

Advocacy Stakeholder
Meeting
Harrisburg, PA

December 7

Winter Program
Dave & Busters
Homestead, PA

January 30, 2025

VWD Dinner Program
Bravo! Italian Kitchen
Robinson Township

February 16, 2025

Bowling for Bleeding
Disorders
Paradise Island Bowl
Pittsburgh, PA

March 5-7, 2025

NBDF's Washington Days
Washington D.C.

March 18, 2025

Pittsburgh Penguins
Fundraiser
PPG Paints Arena
Pittsburgh, PA

March 27-29, 2025

HFA Symposium
San Diego, CA

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

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 9, 2025

Education Day
Oglebay Resort
Wheeling, WV

August 21-23, 2025

National Bleeding Disorders
Conference
Denver, CO

VISIT [WPBDF.ORG](https://www.wpbdf.org) FOR MORE INFORMATION ON OUR UPCOMING EVENTS.

Do you have a great OBGYN?

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



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

<https://forms.gle/nhcvrQjrSWzzwdfX8>

CONTACT US

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LETTER FROM THE EXECUTIVE DIRECTOR AND BOARD PRESIDENT

Dear Foundation Members & Friends,

As summer gives way to the vibrant hues of fall, it's a wonderful time to embrace the season's cooler weather, festive gatherings, and, of course, everything pumpkin spice! We want to express our heartfelt gratitude to everyone who supported the 16th Annual Unite for Bleeding Disorders Walk! It was a beautiful day, filled with the spirit of community and togetherness. Thanks to our incredible volunteers, generous donors, and devoted sponsors, we achieved our best fundraising year yet, raising over \$79,000 to support individuals with bleeding disorders right here in Western PA.



We're excited to share updates on our initiative aimed at raising awareness and improving diagnosis for women, girls, and people with the potential to menstruate (WGPPM). So far, we've distributed period packs to over 200 school districts across every county in Western PA. Early survey results from 36 school nurses show that at least 7 students have been evaluated for a bleeding disorder, with 1 diagnosis confirmed. These results highlight the significant impact of our work, making a real difference in the lives of young individuals who might otherwise remain undiagnosed. We will be sending out a toolkit this month to help you get involved, and if you'd like to assist with distributing resources, please reach out to Kara at kara@wpbdf.org or give us a call at the Foundation office, 724-741-6160.

We're also thrilled to invite you to our upcoming Take A Bough fundraiser at Red Fox Winery in Hickory, PA, on November 16th! Join us for an evening of bidding on beautiful holiday trees, wreaths, and centerpieces, along with engaging games of chance. Let's come together to celebrate the incredible volunteers who make our WGPPM Initiative a success.



Looking ahead, we are hard at work planning the Pennsylvania Bleeding Disorders Conference. This conference will be held at the Hershey Lodge on May 16-18, 2025. We're excited to partner with the Eastern PA Bleeding Disorders Foundation to host the largest educational event for bleeding disorders in Pennsylvania, supported by all seven Hemophilia Treatment Centers in the state. We hope to see you there!

Thank you for all that you do on behalf of the Western Pennsylvania Bleeding Disorders Foundation.

Much Love and Appreciation,

Kara Dornish
Executive Director, WPBDF

Scott Domowicz
Board President, WPBDF



WALK, RUN, AND CORNHOLE FOR BLEEDING DISORDERS!

**WPBDF'S 2024 UNITE FOR BLEEDING
DISORDERS WALK, RUN FOR THEIR LIVES 5K,
AND CORNHOLE TOURNAMENT**

This year, our 16th Annual Unite for Bleeding Disorders Walk, 15th Annual Run for their Lives 5k, and WPBDF's Cornhole Tournament was held in-person at the North Park Swimming Pool! These events brought friends and families together to raise over

\$79,000 to support the bleeding disorders community in Western Pennsylvania.

Everyone had a blast getting their faces painted, snapping photos at the photo booth, and enjoying a delicious snack! Thank you to First Class Entertainment for the DJ and photo booth services and Face Paint Pittsburgh! Thank you to the following for providing so many amazing snacks: Cottrill's Pharmacy, Culligan Water, Eat' n Park, McDonald's (Allison Park), and Soleo Health.

This day would not be possible without the support of our many team captains who rallied their runners and walkers and went above and beyond in all that they did. Thank you to all 27 of our

Walk Teams! A special shout out to the teams who really went above and beyond and raised \$1,000 or more:

Cameron's Walking Sticks - \$6,382
Conor's Clan - \$5,960.72
Rolling for Ryker - \$5,124.00
Fox Factor - \$4,000.00
Red N' Plenty - \$2,045.00
Team Jaxson - \$1,721.31
Clotting Cavaliers - \$1,705.00
Maxwell House - \$1,550.00
TJ's Team - \$1,230.00
Blake's Bloodline - \$1,025.00

Our top fundraisers, as of 9/21/24, were recognized and honored at the Walk. Congratulations to Conor's Clan who raised an incredible \$5,960.72, and received the Top Fundraising Team Award!

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ADVOCACY UPDATE



**KERRY LANGE, SENIOR ASSOCIATE
MILLIRON GOODMAN**

HARRISBURG OVERVIEW

The 2023-2024 session will officially conclude on November 30, leaving limited session days to move outstanding bills through the legislative process and across the Governor's desk. If they don't make it through the finish line, the bills will have to be reintroduced for consideration during the next session.

This fall, the House plans to gavel-in for 11 session days and the Senate for 14 days.

House of Representatives

The House continues to operate with slim margins between Democrats and Republicans. Without a clear majority, it's difficult for either caucus to successfully pass controversial bills through the chamber.

Democrats retain a one-vote majority in the PA House after winning two uncontested special elections in North Philadelphia in September.

Senate

Senate Republicans continue to hold the majority with 28 seats; Democrats hold 22 seats.

2024 Elections

On November 5, all 203 seats of the Pennsylvania House of Representatives and 25 out of the 50 Senators are up for election. All odd-numbered Senate district

seats are up for election this year.

On your ballots, you'll also find three state row offices: Attorney General, Auditor General and Treasurer. The major party candidates for each office are as follows:

Attorney General

- Republican Dave Sunday
- Democrat Eugene DePasquale

Auditor General

- Incumbent Republican Tim DeFoor
 - Democrat Malcolm Kenyatta
- ### Treasurer
- Incumbent Republican Stacy Garrity
 - Democrat Erin McClelland

BUDGET LINE ITEM

Each year, our priorities for the PA Bleeding Disorders Foundation are to protect the hemophilia line item in the state budget and ensure that the funding distribution formula remains as is.

This year, we were able to secure \$1,017,000 in the General Appropriations bill (SB 1001) and protect the distribution formula with language in the fiscal code (HB 2310), as follows.

SB 1001 (General Appropriations)

20	FOR ADULT CYSTIC FIBROSIS AND	
21	OTHER CHRONIC RESPIRATORY	
22	ILLNESSES.	
23	STATE APPROPRIATION.....	795,000
24	FOR DIAGNOSIS AND TREATMENT	
25	FOR COOLEY'S ANEMIA.	
26	STATE APPROPRIATION.....	106,000
27	FOR HEMOPHILIA SERVICES.	
28	STATE APPROPRIATION.....	1,017,000
29	FOR LUPUS PROGRAMS.	
30	STATE APPROPRIATION.....	106,000

202408B1001PW1817 - 270 -

HB 2310 (Fiscal Code):

13 (7) MONEY APPROPRIATED FOR HEMOPHILIA SERVICES SHALL BE
14 DISTRIBUTED TO GRANTEEES IN THE SAME PROPORTION AS DISTRIBUTED
15 IN FISCAL YEAR 2019-2020.
16 (8) MONEY APPROPRIATED FOR LUPUS PROGRAMS SHALL BE
17 DISTRIBUTED PROPORTIONATELY TO EACH ENTITY THAT RECEIVED
18 FUNDING IN FISCAL YEAR 2018-2019.
19 (9) FROM MONEY APPROPRIATED FOR SICKLE CELL ANEMIA
20 SERVICES, INCLUDING CAMPS FOR CHILDREN WITH SICKLE CELL
21 ANEMIA, THE FOLLOWING SHALL APPLY:
22 (I) GRANTEEES WHICH RECEIVED AMOUNTS IN FISCAL YEAR
23 2019-2020 SHALL RECEIVE AN AMOUNT WHICH IS IN THE SAME
24 PROPORTION AS DISTRIBUTED IN FISCAL YEAR 2019-2020.
25 (II) \$75,000 SHALL BE DISTRIBUTED TO A QUALIFYING
26 ACADEMIC MEDICAL CENTER LOCATED IN A COUNTY OF THE THIRD
27 CLASS WITH A POPULATION BETWEEN 250,000 AND 300,000 UNDER
28 THE MOST RECENT FEDERAL DECENTENAL CENSUS FOR EXPANDED
29 CARE OF ADULT SICKLE CELL DISEASE.
30 (10) MONEY APPROPRIATED FOR LYME DISEASE INCLUDES

202408B2310PN3506

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LEGISLATION

Pharmacy Benefit Managers (PBM) Reform

Representative Jessica Benham (D-Allegheny) and Representative Valerie Gaydos (R-Allegheny) co-sponsored HB 1993, which amends the Pharmacy Audit Integrity and Transparency Act. In short, the bill provides the state with more oversight over PBMs and limits or bans several practices by PBMs, including patient steering, spread pricing and retroactive recoupment of money paid by the PBM to the pharmacy.

More specifically, it prohibits PBMs from:

- Reimbursing a retail pharmacy less than the amount that the PBM reimburses a PBM-affiliated pharmacy;
- Unilaterally altering the terms of the original contract;
- Designating a prescription drug as a specialty drug or

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ADVOCACY UPDATE

CONTINUED FROM PAGE 5...

requiring a prescription drug to be dispensed exclusively at a specialty pharmacy.

In addition, health insurers and their contracted PBMs are prohibited from:

- Requiring covered individuals to purchase prescription drugs exclusively through a mail-order pharmacy or PBM-affiliated retail pharmacy.
- Prohibiting or limiting a covered individual from selecting an in-network pharmacy of the individual's choice.

After several rounds of amendments, the bill passed the House with a vote of 172-30, the Senate with a vote of 48-1 and was signed by the Governor as Act 77 of 2024.

Telemedicine

For nearly a decade, legislators have been attempting to address and expand access to telemedicine. This session, Senator Elder Vogel (R-Beaver) can say he accomplished it.

SB 739 was signed into law as Act 42 of 2024. The law requires health insurance companies to pay or reimburse participating network providers for covered health care services that were delivered via telemedicine, per the terms and conditions of the contract.

Note that the law doesn't

specifically address payment parity, but rather leaves the details open-ended for individual contracts, likely in an intentional move to keep insurers neutral on the bill.

Act 42 took effect on October 1, 2024.

Access to Menstrual Hygiene Products

Representative Darisha Parker (D-Philadelphia) sponsored HB 851, which amends the Public School Code by creating a grant program to provide eligible public-school entities with funding to acquire and distribute menstrual hygiene products at no expense to students. The bill appropriates \$3 million to the Department of Education for the grant program. The bill recently passed the House with a vote of 117-85. It was sent to the Senate.

Somewhat simultaneously, Governor Shapiro suggested similar funding in his budget proposal. His proposal was included in the final budget package.

The PA Bleeding Disorders Foundations were instrumental in the success of this initiative. We shared letters of support for this with the Governor's office as well as the House and Senate Appropriations Committees. Congrats team!

Prohibiting Health Insurers from Altering Coverage or Premiums

In March, Representative Joe Hogan (R-Bucks) circulated a co-sponsorship memo indicating his intent to introduce legislation re: non-medical switching. His legislation would amend the

Unfair Insurance Practices Act to prohibit health insurers from altering the coverage or premiums included in an insured person's health insurance policy during the policy term when an insured person has already received a specific treatment, service or prescription drug. We anticipate bill introduction soon.

Please continue to share your experiences with the WPBDF team so we can help advance this bill. Scan this QR to share your story or visit <https://www.surveymonkey.com/r/VFQYMN2>.



Co-Pay Accumulators

Senator Judy Ward's SB 372 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. SB 372 is waiting for consideration by the Senate Banking and Insurance Committee.

The Milliron Goodman team is continuing to stay engaged on this issue. Please continue to share your personal experiences with co-pay accumulators with the WPBDF team. Scan this QR code or visit: <https://bit.ly/copayspa>.



THANK YOU

We look forward to continuing to represent you in the Capitol. Please reach out to our office with any questions or concerns.

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ADYNOVATE
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HEARTWARMING HIGHLIGHTS FROM OUR ANNUAL MEETING

We were delighted to welcome over 120 community members to the WPBDF Annual Meeting on July 18 at Top Golf. The evening began with engaging exhibit displays and lively conversations, setting a vibrant tone for the event.

Executive Director, Kara Dornish, shared our significant accomplishments over the past fiscal year, emphasizing our outreach efforts that reached diverse communities. We were honored to receive the Hemophilia Alliance Foundation's Innovation Grant, which allowed us to raise awareness about undiagnosed bleeding disorders, particularly among women, girls, and people with the potential to menstruate. Through 16 outreach events and the distribution of educational materials, we have made strides in enhancing understanding and support for bleeding disorders across Western Pennsylvania. We also celebrated the distribution of over 2,000 period packs and nosebleed kits to school nurses, empowering them to identify and assist students in need. Our community's generosity enabled us to provide more than \$60,000 in direct patient assistance this year, supporting over 250 individuals facing financial hardship.

During the business segment,



Board President, Scott Domowicz, introduced newly elected board members Jason Miller and Maria Shoemaker, our new Treasurer. He also thanked outgoing members Brittani Vuono and Christina Miller for their dedicated service.

We recognized 13 exceptional students and distributed \$12,000 in scholarships. Congratulations to our scholarship award winners: Claire Murphy, Ashley Cynkar, Mikaela Kottelich, Raina Slater, Katherine Berry, Willow Reed, Elijah Shropshire, Georgia Ebsworth, Cailin Stukus, Megan Wharton, Rochelle Lynn Hetrick, Haley M. Dunaway, and Amanda Steele Voms Stein. We wish them the best as they pursue their education.

Volunteers are the backbone of our organization, and we honored several for their unwavering commitment: Victoria Baker, Adam Boyle, Joseph Ebersohl, Cassie Miller, Claire Murphy, Eileen Nikithser, Maria Shoemaker, Stephanie Shropshire, and Judy Walsh. Last year's Volunteer of the

Year, Maria Shoemaker, introduced this year's recipient, Samantha Short.



WPBDF's 2024 Volunteer of the Year, Samantha Short (middle), with Executive Director, Kara Dornish (left) and Development Director, Jessica Lee (right).

Jessica Lee, our Development Director, led the Walk Kickoff, introducing the 2024 Walk Co-Chairs, Kelly Baker and Ashley Fox. Kelly invited everyone to sign up for the Unite for Bleeding Disorders Walk. Inspiring teams were highlighted, including Fox Factor, Conor's Clan, and Rolling for Ryker. Everyone who registered for the Walk received a red light-up bracelet to show their support,

fostering a sense of unity for the cause. Our summer intern, Shae McKoen, introduced a lively western-themed Team Week for the Walk, designed to both celebrate our community spirit and raise awareness for the Walk.

The evening concluded with an inspiring talk from professional golfer Perry Parker, who shared his journey living with a bleeding disorder, reminding us that challenges do not define us. As we practiced our swings at the golf bays, the sense of community and shared purpose was palpable. Thank you to everyone who contributed to making this event a success. Together, we continue to support and uplift the bleeding disorders community.

Thank you!

to the sponsors of
WPBDF's Annual Meeting!

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ADVOCACY AND ACTIVISM

SAMANTHA SHORT HONORED AS WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION'S VOLUNTEER OF THE YEAR

In a heartfelt recognition of dedication and compassion, Samantha Short has been named the Western Pennsylvania Bleeding Disorders Foundation's (WPBDF) Volunteer of the Year for her exceptional advocacy within the bleeding disorders community. Samantha, a valued member of the WPBDF's Board of Directors, serves as co-coordinator for both the Women's Group and Young Adult Group, and is recognized as a Pennsylvania Advocacy Ambassador. Her commitment to raising awareness about bleeding disorders and advancing WPBDF's mission has been nothing short of inspiring.

One of Samantha's most significant contributions has been her outreach efforts to educate Girl Scout troops about bleeding disorders and working with them to assemble nosebleed kits for school nurses across Pennsylvania. This initiative not only spread crucial knowledge to the young girls but also instilled in them a sense of community service and giving back. Her proactive approach in forging community connections has been invaluable. Through collaborations with organizations like the Best of the Batch Foundation, Samantha led educational sessions about bleeding disorders in women and worked to destigmatize discussions around menstrual health. She led the group in constructing period packs which were then distributed to school nurses across Pennsylvania.

Samantha is deeply passionate about sharing her story and consistently leverages her

knowledge and experiences to support others. She is a strong advocacy ambassador and has been instrumental in representing WPBDF at outreach events. Samantha consistently leads by example, eagerly stepping forward as one of the first volunteers to sign up for these important initiatives. Her efforts have fostered connections with numerous nurses, community members, and nonprofit leaders, further strengthening our network and expanding WPBDF's outreach capabilities. Samantha's passion, initiative, and commitment have had a profound impact on WPBDF and the community at large. Her efforts have not only raised awareness about bleeding disorders but have also empowered individuals and organizations to take meaningful action. Samantha's contributions embody the spirit of volunteerism and serve as an inspiration to us all.



WALK, RUN, AND CORNHOLE FOR BLEEDING DISORDERS!

CONTINUED FROM PAGE 4...

Thank you to the Team Captain of Conor's Clan, and the Top Team Captain for 2024, Emily Nikithser. Conor is 8 years old, and Conor's Clan has been participating in the Unite for Bleeding Disorders Walk ever since he was born. This year, Emily tapped into her personal connections to find local and family businesses to sponsor the team, as well as utilizing social media to share Conor's story and help raise additional funds. We are so thankful for Emily, Conor's Clan, and all of the people who rally to support Conor each year. Thank you for all you do!

This year's Top Individual Fundraiser was Kim Ebsworth, who raised \$5,000! Kim is very passionate about the bleeding

Conor's Clan accepting the Top Team Captain and Top Fundraising Team Award at the Unite for Bleeding Disorders Walk.

disorders community and connected with her work to secure a large sponsorship for the Unite for Bleeding Disorders Walk. Kim was unable to attend the Walk this year, so her daughter, Nikole, and her granddaughter, Keely, accepted it on her behalf. Thank you for everything you do for the community! Congratulations!



WPBDF Executive Director, Kara Dornish (left) presenting Keely (middle) and Nikole (right) with Kim's Top Individual Fundraising Award.

Finally, a big congratulations to the winner of the Awesome John Eyrolles Top Youth Fundraiser Award, Damon F. of Team Fox Factor. Damon raised an incredible \$3,950! Damon walks in honor of his little brother, Rylen, and loves coming to the Walk each year. Thank you and congratulations, Damon!



Damon (right) and mom, Ashley (left) at the Unite for Bleeding Disorders Walk.

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

Brooke Aberegg
Cooper Aberegg
Gwen Austin
Lincoln Austin
Jaxson Baker
Kelly Baker
Janet Barone
Kara Dornish
Lisa Data
Kim Ebsworth
Kaleb Farmer
Ashley Fox
Damon Fox
Lynda Maxwell
Conor Nikithser
Eileen Nikithser
Emily Nikithser
Melinda Perry
Michael Perry
Michelle Perry
Blake Rhodes
Lauren Rhodes
Gabbie Rose
Dawn Rotellini
Robert Sethman

Unite

for Bleeding Disorders

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National Community Partner

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Virtual Partners

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Samantha Shropshire
Stephanie Shropshire
Ryker Stern
Steve Stern
Jen Werme
Russell Werme
Morgan Woods
Tristen Woods



2024 Unite for Bleeding Disorders Factor Club

This year, nine walk teams designed their own team t-shirt to celebrate a year of hard work fundraising. Thank you to Jamie and Darin from Printeesweet for the printing of them, and for the many families that took the time to vote for their favorite t-shirt. This year, team t-shirt voting opened online one week before the in-person walk and allowed teams to share their designs with loved ones who may not have made it on Walk Day. In total, the Team T-Shirt Contest raised \$386.64! Congratulations to Team Jaxson as the official Team T-shirt Winner, raising over \$200! Team Jaxson is the undefeated Team T-Shirt champions since 2022.



Program Director, Janet Barone, accepting the Top Team T-Shirt Award on behalf of Team Jaxson.

The captain of Team Jaxson, Kelly, was in Henderson, Nevada over the weekend, supporting Jaxson, and her husband, Josh, at the Junior National Championship! Janet Barone, WPBDF Program Director, accepted the award on their behalf. Keep it up, Team Jaxson!

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

the members of WPBDF.

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

Our Top Male Finishers:



First Place: Christopher Rossitto

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WALK, RUN, AND CORNHOLE FOR BLEEDING DISORDERS!

CONTINUED FROM PAGE 11...



Run for Their Lives 5K Registration

Thank You to Our Sponsors

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Second Place: Quintin Sano



Third Place: Jake Smith

Our Top Female Finishers:



First Place: Nicki Benvenuti



Second Place: Elaine Miller



Third Place: Jessica Papcunik
And our Top Youth (under 17)
Finishers:



First place: Enzo U.



Second place: Gabbie R.



Third Place: Noelle B.



WPBDF's Cornhole Tournament Registration



Thank You to Our Sponsors

Corn in the Hole Sponsor



Corn on the Cob Sponsor

CSL Behring



Thank you to Joe Castellano from Steel City Cornhole for running our Annual Cornhole Tournament! WPBDF's Cornhole Tournament brought in nearly \$4,000, all of which will stay local to support individuals with bleeding disorders in Western PA. Congratulations to the winners of the tournament!



First Place: Jeremy Lucas and Lucas Householder, Team Lucas Squared



Third Place: Chris and Cindy McCrea, Team C+C Cornhole Factory

braces and other medical devices, provide medical ID jewelry to our members at no cost to them, provide local educational programming throughout the year, provide a support network to all our community members, and create and increase awareness about bleeding disorders.



Second Place: Ryan Kosylo and Jesse Henderson, Team BackPack

Lastly, and most importantly, thank you to each and every one of you who came together with us to Unite for Bleeding Disorders. 100% of the money raised from the Walk, Run, and Cornhole Tournament will stay local to promote patient advocacy, support families in need by offering assistance with medical bills, travel, knee/elbow

SAVE THE DATE

Unite
for Bleeding Disorders

**SATURDAY,
SEPTEMBER 6, 2025**

**9:00 AM
NORTH PARK
SWIMMING
POOL**

**STAY UP-TO-DATE WITH
UPCOMING EVENTS AT
WPBDF.ORG.**



BACK TO SCHOOL DINNER: A SUCCESSFUL EVENING OF LEARNING AND COMMUNITY

On Thursday, August 1, we gathered for an informative Back to School Dinner at the Grand Concourse. This event was made possible through the support of Takeda. Our heartfelt thanks go out to Jan Martin, MSN, RN-BC, CPN, from Takeda, who delivered an insightful presentation and shared Takeda's Back to School

Guide with attendees.

The evening was filled with important discussions on how to effectively communicate with your child's school and how to foster a collaborative environment between students, parents, family members, and school staff. Jan Martin provided clarity on essential topics, including the distinctions between Individualized Education Programs (IEPs) and 504 Plans, and what each requires to ensure that students with bleeding disorders receive the support they need. If you weren't able to pick up a Back to School Guide at the event, don't worry! Simply reach out to Kara at kara@wpbdf.org, and we'll make sure you receive one promptly.

For even more back to school

resources, be sure to check out HFA's Back to School Toolkit. It's packed with valuable information to help make this school year as smooth and successful as possible: <https://www.hemophiliafed.org/resource/back-to-school/>.

Here's to a fantastic school year ahead, filled with learning and growth!

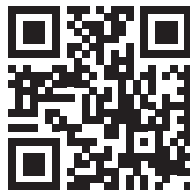




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- Hemophilia B
- Hemophilia A with inhibitors
- Hemophilia B with inhibitors
- Glanzmann's thrombasthenia when platelets don't work
- Factor VII deficiency
- Factor XIII A-subunit deficiency

Get connected locally with one of our Hemophilia Community Liaisons (HCL) to see how they can help you!

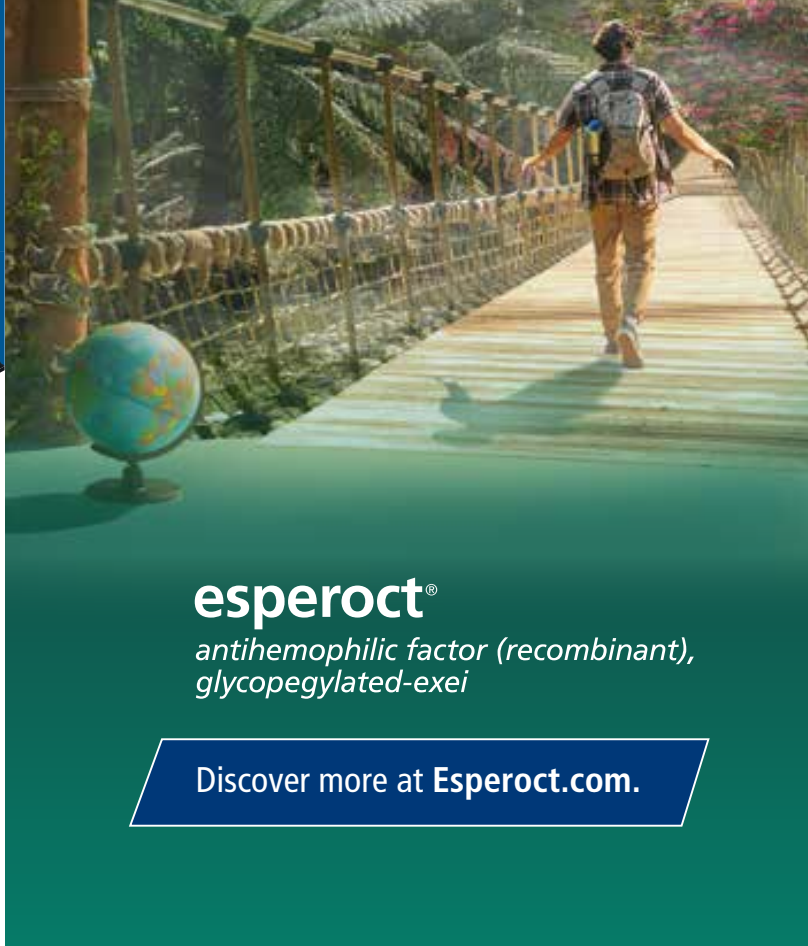


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WOMEN'S GROUP CANDLE MAKING WORKSHOP

SAMANTHA SHORT

After an unexpected rescheduling, we were finally able to gather for our winning women's group summer night activity. In an effort to expand our reach, we selected the Vandergrift area for our summer event this year! We were joined by several new members as well as our newest board member and Vandergrift local, Maria Shoemaker.

The night started with selecting our "signature scent" and hand

pouring our own candles at Honey and Heart Candle Company. While waiting for our candles to set Melissa Kendrick, from Cottrill's Pharmacy (who sponsored the 2024 series of women's events), lead us through a guided meditation.

We then discussed as a group the importance of self care while enjoying a beautiful picnic-like spread of fried chicken with all the accompaniments. The groups self care strategies ranged everywhere from an evening spent with friends to reading a favorite book. The night itself was a great show of self care - bonding with new and old friends while crafting our candles! Thank you to all who attended, your attendance is what makes our group so amazing!

We are always looking to expand our Winning Women's Group to new members and locations! Feel free to email us with any suggestions on new areas/locations! Shoot me an email at samanthalshort@yahoo.com.



COTTRILL'S 
PHARMACY, INC.

HCWP CORNER

KATHAELEEN SCHNUR, LCSW

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

As autumn paints the world in rich hues of gold and crimson, we find ourselves reflecting on the transitions and changes that this season represents. The crisp, cool air and the soft fall of leaves remind us that change is not only a natural part of life but can also be a beautiful opportunity for growth and renewal. As we embrace this season, it's a perfect time to also think about our health and well-being, especially with the arrival of open enrollment for health insurance.

Autumn can be a particularly challenging time for mental health. With less sunshine and shorter days, people can experience seasonal affective disorder (SAD), which can affect mood and energy levels. To combat these effects, consider embracing the season's offerings: enjoy the vibrant fall foliage, engage in cozy activities like baking or crafting, and connect with loved ones. Simple joys like a walk in the crisp autumn air or a warm cup of cider can make a big difference. Remember, maintaining connections and engaging in activities you enjoy can be powerful ways to support your mental health. Also, if you aren't aware, the 988 Suicide & Crisis Lifeline is available 24/7/365. Whether someone is facing

mental health issues, emotional distress, substance use concerns, or simply needs someone to talk to, compassionate counselors are available to provide support.

As you prepare for open enrollment, it's crucial to understand any changes to your health insurance plan. Each year, insurance companies may alter their plans, affecting coverage, costs, and provider networks. Take this time to review your current plan, explore your options, and ensure you choose the plan that best meets your needs. If you need guidance or have questions about your health insurance options, please reach out to us. We are here to help you navigate these changes. Open enrollment for the 2025 Affordable Care Act (ACA) in Pennsylvania (<https://pennie.com/>) will be from November 1, 2024 to January 15, 2025. Open enrollment for Medicare in 2025 will run from October 15, 2024 to December 7, 2024. New Medicare coverage will begin on January 1, 2025.

Additionally, I want to gently remind you that our center, which relocated last November, is still located in Oakland and offers free parking beneath the building. We are committed to making your visits as comfortable and accessible as possible. If it's been a while since your last appointment, please consider scheduling a visit. Regular check-ups are essential for managing your health and ensuring that you receive the care and support you need.

I wanted to let you know that

earlier this year, we introduced an enhanced approach to patient transition at our comprehensive care clinic, as part of our grant from the Health Resources and Services Administration (HRSA) through the National Hemophilia Program Coordinating Center. With a focus on individuals aged 12 years through 26 years, this initiative aims to improve the healthcare transition process, particularly for the transition from pediatric to adult healthcare. Our goal is to provide structured and supportive resources to help young adults take control of their healthcare needs, foster autonomy, and encourage responsible health management. The transition planning resources we have introduced are designed to make this shift smoother and ensure ongoing communication with our care team at HCWP. Research has shown that well-structured transition care interventions can significantly impact health outcomes and enhance the quality of life, and we are committed to offering the guidance and support necessary to ensure a successful transition.

As we embrace the beauty and change of fall, let's also focus on taking care of ourselves and our loved ones. Reach out to us for appointments, insurance support, or any additional needs. Together, we can navigate this season and its transitions with confidence and care.

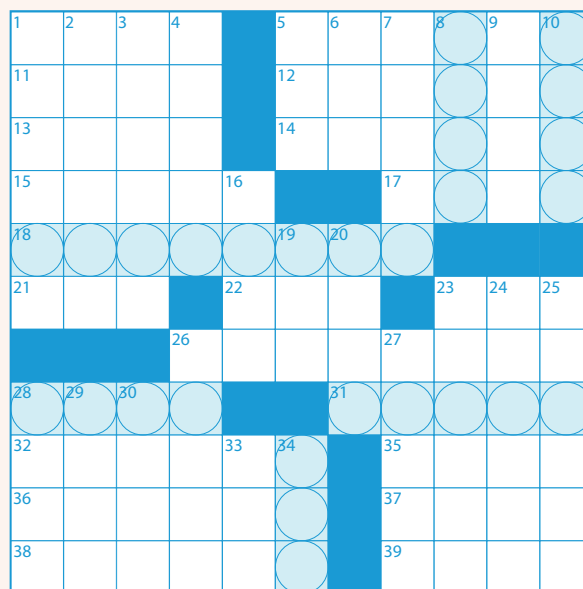
Warmest wishes for a healthy and fulfilling fall,

Kathaleen Schnur

CAN YOU SOLVE **FOR A DIFFERENT** **HEMOPHILIA A**

TREATMENT?

Test your HEMLIBRA knowledge



ACROSS

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

*According to IQVIA claims data (various insurance plan types) from September 2021–August 2022 (refreshed November 2022), accounting for prophylaxis use in the US.

21. Calendar divs.
22. Regret
23. Banquet hosts (abbr.)
26. International travel necessity
28. Check out the _____ treated bleeds data with HEMLIBRA
31. Number of dosing options HEMLIBRA offers

32. Small hole in lace cloth
35. Central Plains tribe
36. Melodic
37. Towering
38. Reduce
39. Spanish cheers

DOWN

1. Memorable, as an earworm
2. Devotee
3. Medical fluids
4. Prepare to propose, perhaps
5. PC's "brain"
6. Owns
7. Concert venue
8. See Medication Guide or talk to your doctor about potential _____ effects
9. Winter hrs. in Denver and El Paso
10. HEMLIBRA is the only prophylactic treatment offered this way under the skin

16. Pre-Euro currency in Italy
19. Subway alternative
20. Relax
23. Human
24. New Orleans cuisine
25. Mentally prepares
26. Collared shirts
27. Instagram post
28. Ardent enthusiasm
29. Brontë heroine Jane
30. Old Portuguese coins
33. Opposite of WNW
34. More than _____ thousand patients have been treated with HEMLIBRA worldwide*

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

SOLUTIONS

Across: 1. cask, 5. chasms, 11. Aden, 12. parish, 13. tore, 14. used to, 15. cruel, 17. nest, 18. HEMLIBRA, 21. yrs, 22. rue, 23. MCS, 26. passport, 28. zero, 31. three, 32. eyelid, 35. Oloz, 36. arioso, 37. tall, 38. lessen, 39. oles, 40. CPU, 6. has, 7. arena, 8. side, 9. MSTs, 10. shot, 16. lira, 19. bus, 20. mortal, 24. Creole, 25. steels, 26. polos, 27. photo, 28. zeal, 29. Eyre, 30. Reis, 33. ESC, 34. ten

Down: 1. catchy, 2. adores, 3. serums, 4. kneel, 5. PC's, 6. owns, 7. concert, 8. See Medication Guide or talk to your doctor about potential _____ effects, 9. winter, 10. HEMLIBRA, 11. Mideast, 12. district, 13. ripped, 14. familiar with, 15. mean, 16. pre-Euro, 17. roost, 18. HEMLIBRA, 19. subway, 20. relax, 23. human, 24. New Orleans, 25. mentally, 26. collared, 27. Instagram, 28. ardent, 29. Brontë, 30. old Portuguese, 33. opposite, 34. more than _____ thousand patients have been treated with HEMLIBRA worldwide*

Discover more at HEMLIBRA.com/answers

INDICATION & IMPORTANT SAFETY INFORMATION

What is HEMLIBRA?

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

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

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

These serious side effects include:

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

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



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

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

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

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

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

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

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

See “What are the possible side effects of HEMLIBRA?” for more information about side effects.

What is HEMLIBRA?

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

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

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

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

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

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

How should I use HEMLIBRA?

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

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.

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

What are the possible side effects of HEMLIBRA?

- See “What is the most important information I should know about HEMLIBRA?”

The most common side effects of HEMLIBRA include:

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

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

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

How should I store HEMLIBRA?

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

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

General information about the safe and effective use of HEMLIBRA.

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

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

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

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 03/2023



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RAIN CAN'T STOP HOT-TO-CLOT!

KATHERINE BUSH, LCSW

The Hemophilia Center of Western Pennsylvania (HCWP) hosted its annual Hot-to-Clot camp in August.

Growing up with a bleeding disorder is a rare experience, and patients can go years without meeting another affected person - unless they are provided with the opportunity. Through Camp Hot-to-Clot, HCWP is honored to offer that chance!

Together with YMCA Camp Kon-o-Kwee (KOK) and the Western Pennsylvania Bleeding Disorders Foundation, HCWP runs a 5-day overnight camp for patients ages 7-17 and their siblings. At camp, patients swim, play soccer, learn archery, build forts, and do many other fun camp activities. They also spend time learning about their bleeding disorder and, most importantly, forming relationships with each other. These relationships encourage engagement with the bleeding disorder community, and by extension, participation and independence in care. As one camper said, "Camp was the first place I realized that there were other people like me out in the world, and the first place to help me live with it."

The YMCA provides general camp staff. HCWP provides additional medical staff including doctors, nurses, physical therapist, and social workers to meet our patients' specific needs. Although camp week is intense, our staff enjoys getting out of the office and making unique and meaningful



memories together.

Fifty-two (52) campers attended this year's camp. Despite heavy rain and extremely hot weather, good times were had by all! We are already excitedly planning for next summer and all the fun we'll have; so be sure to mark your calendars for August 27- July 1, 2025, and be on the lookout for registration to start at the beginning of November on the KOK website (<https://www.ycampkok.org/summer-camp/>). We can't wait to see the smiles and excitement from our campers!





WINTER PROGRAM

SATURDAY, DECEMBER 7, 2024

10:00 AM

DAVE & BUSTER'S
THE WATERFRONT
180 E WATERFRONT DRIVE
HOMESTEAD, PA 15120



WPBDF
Western Pennsylvania
Bleeding Disorders Foundation

Join us for exhibits, an educational program, and buffet lunch. After the program, participants will receive game cards to enjoy the rest of the afternoon at Dave & Buster's.

This program is for members of WPBDF with bleeding disorders and immediate family members living in their household.

RSVP by Monday, November 25 by emailing rsvp@wpbdf.org or calling 724-741-6160. Please be sure to include the number of people who will be attending, the ages of children who will be attending, and if you have any food allergies or dietary restrictions.



GETTING TO KNOW HCWP STAFF



NICHOLAS PALUSELLI
HCWP NURSE

Birthplace: Pittsburgh, PA

First job: Pool Cleaner

Accomplishment you're proudest of: Bachelor's Degree

What three words describe you best? Friendly, accountable, and shy

Dream vacation: Greek Islands

Things you can do without: Fruit Danishes/Donuts

Person you'd most like to have dinner with: Post Malone

Movie you could see anytime: Good Fellas

TV show you try not to miss: Anything on the History Channel

Three things that can always be found in your refrigerator: Veggies, cheese, and water

Secret vice: Romcom movies

Who would play you in the movies?: Chris Hemsworth

Your pet peeve about Pittsburgh: Construction... all the time!

People may be surprised to know: I have heterochromia (two different colored eyes)



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

Factor Program Services

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

Patient Benefits

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

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

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

**WE'RE IN THIS
TOGETHER.**

Friday 6:26 pm

Sharing stories by the
campfire with friends

Isaac, living with
hemophilia B



Not an actual patient

Let's make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world, is stronger than ever.

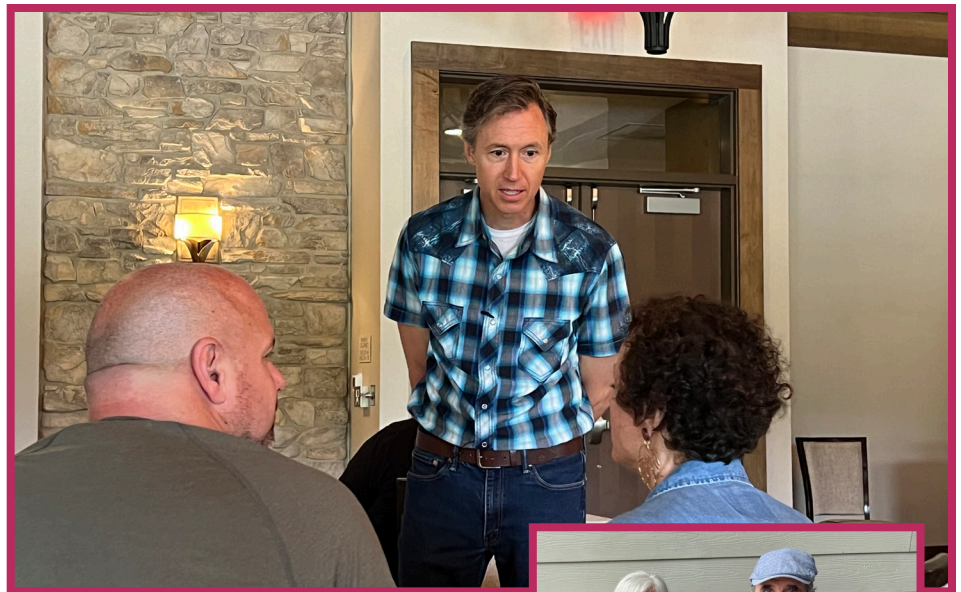
bleedingdisorders.com



REKINDLING CONNECTIONS: A MEMORABLE COUPLES RETREAT

On June 28-29, the Western Pennsylvania Bleeding Disorders Foundation joined forces with the Eastern Pennsylvania Bleeding Disorders Foundation to host an enriching Couples Retreat at Liberty Mountain Resort in Fairfield, PA. We were delighted to welcome 22 couples for a transformative experience.

The retreat, expertly guided by Dr. Wyatt Fisher, featured a comprehensive 6-step workshop designed to strengthen relationships. Over the course of the weekend, couples were immersed in focused activities aimed at addressing resentments, enhancing communication, and deepening intimacy. This dedicated time away from everyday



distractions allowed participants to reconnect and rejuvenate their bonds with their partners.

A heartfelt thank you goes out to everyone who attended and contributed to the success of our Couples Retreat. We are especially grateful to Dr. Wyatt Fisher for leading such an impactful workshop and equipping our attendees with valuable skills and strategies for nurturing lasting and fulfilling relationships. We'd like to say thank you to the Eastern Pennsylvania Bleeding Disorders Foundation for your partnership!



Thank you to sponsors that made this possible:



Tickets on sale now!

Learn more at:

bit.ly/takeabough24

or scan this QR code with your phone!



November 16, 2024
5:30 PM - 8:30 PM

Red Fox Winery
80 Red Fox Road
Hickory, PA 15340

NBDF'S BLEEDING DISORDERS CONFERENCE

The National Bleeding Disorders Foundation hosted the 76th Annual Bleeding Disorders Conference in Atlanta, Georgia, from September 12-14, 2024.

At NBDF's Annual Awards of Excellence Ceremony, Kathaleen Schnur, a social worker at the Hemophilia Center of Western Pennsylvania, was awarded Social Worker of the Year! We are so grateful for her dedication to the bleeding disorders community. Her commitment and tireless efforts have made a difference in the lives of so many.



Additionally, we are deeply grateful that Joey Smiles was honored as the Volunteer of the Year. Joey was a beacon of warmth, resilience, and unwavering dedication within our community. His familiar smile was a comforting presence at every advocacy event, and he quickly became a cherished friend to us all.



As a beloved member and dedicated board member of the Eastern Pennsylvania Bleeding Disorders Foundation, Joey's impact was nothing short of extraordinary. With a natural gift for teaching, he shared his own experiences, lifting others up and empowering them. Despite his own challenges, Joey's boundless spirit was a wellspring of inspiration, encouraging us all to face our own trials with courage and compassion.

Joey's unexpected passing in April left a profound void in our hearts. Though Joey is no longer with us, his legacy of compassion, strength, and advocacy will forever echo within our community. We are deeply thankful for the time we were privileged to share with him. Joey's award was accepted by his dear friend and fellow advocate, Samantha Short.

If you would like to make a contribution in memory of Joey,

you can do so here:
<https://bit.ly/joeysmiles>.

Donations will go toward the Western and Eastern Pennsylvania Bleeding Disorders Advocacy Efforts, and to the Penn State Health Hemophilia Treatment Center of Central Pennsylvania.

This year, three families were able to attend the conference through an educational grant provided by WPBDF. Melinda Perry and Ethan W. share their experiences below.

MELINDA PERRY

Ryker, Steve and myself were graciously afforded the opportunity to attend the National Bleeding Disorders Conference in Atlanta, Georgia.

Some of the classes Steve and myself attended either together or separate were:

- Patient Assistance
- How to be an Educated Advocate
- Leveling the Playing Field: Sports Participation Clinical Considerations
- Treatment Basics
- Campfire Session: Keep it up with Factor Levels
- Super Parenting
- Treatment Products Keeping them Safe
- Lets Talk About S*x
- Before the Fur Hits the Fan

Even though the Sports Participation Clinical Considerations session was a session aimed at medical professionals, I really enjoyed it. This session navigated which sports are acceptable for people with hemophilia, which ones have the highest injury rates versus the worst type of injuries by sport. I felt this session should be open to all

as it was very helpful in deciding what sports I will allow Ryker to play in the future.

The mental health discussion was by far my favorite session and I hope to bring this class to our local Foundation for our Teen Group and even Women's Group. This was informative and helped me to navigate some of the struggles I face raising a child with hemophilia. The tools we were given, such as setting hope-filled short term goals, will stick with me forever.

From there, we went to many other sessions; however, the one session that stuck out to me was Before the Fur Hits the Fan. This session explored every possible way you can be prepared in the event of an emergency with hemophilia. You can be prepared by alerting your local EMS that you have someone

in the home with hemophilia to have your address flagged in their system, to having an emergency hospital go bag, to addressing hemophilia with your child's school.

Every session gave important information that I am grateful to have learned. Our family is also very grateful that we were given the opportunity to go to this conference and get more education as raising an almost 7 year old with hemophilia is not always easy.



ETHAN W.

BDC was an interesting event that reminded me of the Seven Springs event the Foundation holds, but I also liked that I was able to learn about more stuff than just having a bleeding disorder as a teen. The opening event I didn't attend cause I watched my little brother and other kids play, but I heard it explained the fun things that will happen the rest of the weekend and got people motivated. Next, we got to explore the exhibit hall where all the sponsors and companies that help with bleeding disorders show us their products with some sweet treats and educational games to go with it. We had dinner in the hall and then went back to the hotel for the night. At breakfast, the Foundation influenced me to take a bunch of teen programs, one of which was



Teens: Transitioning to Adulthood. This program had a panel of college students that taught us their mistakes and successes of their college lives so far. The next session I went to was Teens: Self Advocacy, which taught us how to advocate for ourselves as teens. This was pretty much a

review for me. Then, I went to the exhibit hall again for lunch and explored more companies. After lunch, I went to sessions with my mom. The first one was Breaking Barriers: How LEEs are Shaping Bleeding Disorders Research.

... CONTINUED ON PAGE 27

NEW PARENT NETWORK PICNIC

Saturday, August 10, 2024, was a perfect day for a picnic, and we were thrilled to welcome both new and returning families to the New Parent Network gathering! The beautiful weather set the stage for a day of fun and connection!

Families came together for a picnic where they had the chance to meet and bond over a spirited game of People Bingo. This engaging activity helped everyone get to know one another, creating a warm and welcoming atmosphere.

The event included a resource table, packed with valuable materials designed to inform and support families living with bleeding disorders. We hope everyone found these resources helpful and encouraging as they navigate their journeys.

Lunch featured a picnic buffet. After enjoying their meals, families participated in a creative and educational cookie-decorating activity. Each treat represented a different component of the blood clotting process, with toppings symbolizing plasma, red blood cells, white blood cells, platelets, clotting factors, von Willebrand factor, and fibrin. It was both a tasty and informative experience!

As the picnic wrapped up, families were excited to enjoy the rest of the day at Idlewild & SoakZone, making even more wonderful memories together.



We want to remind families that our New Parent Network events are open to those with children who have a bleeding diagnosis, from newborn to age 7. If you're interested in learning more about the New Parent Network or connecting with a mentor parent, please reach out to Kathaleen Schnur at kschnur@vitalant.org / 412-209-7267 or Janet Barone at janet@wpbdf.org / 724-741-6160.

How to Make Blood Clot Cookies

<p>Step 1: Frosting Frosting represents plasma. Plasma carries red blood cells, white blood cells, platelets, and more, throughout the body.</p>	<p>Step 2: Red Sprinkles or Red Sugar Red Sprinkles or Red Sugar represent red blood cells. Red blood cells carry oxygen and give you energy!</p>	<p>Step 3: Mini Marshmallows Mini Marshmallows represent white blood cells. They fight germs and help you get better when you are sick.</p>
<p>Step 4: Cheerios Cheerios represent platelets, which help your blood clot. When you get cut, they clump together and help stop a bleed.</p>	<p>Step 5: Rainbow Sprinkles Rainbow Sprinkles represent 13 clotting factors in your blood that work together to form a clot.</p>	<p>Step 6: Gummy Worms Gummy Worms represent VWF (von Willebrand Factor). VWF acts like glue and makes platelets stick together. It also carries one of the clotting factors (8) to where it needs to go.</p>
<p>Step 7: Pretzels or Corn Chex Pretzels or Corn Chex represent fibrin. Fibrin forms a mesh to hold a platelet plug in place and help form a clot to stop a bleed.</p>	<p>Sugar Cookie</p>	

A huge thank you to all who supported the 2024 New Parent Network series of events.

CSL Behring

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THE HEMOPHILIA CENTER
of Western Pennsylvania

novo nordisk

sanofi

CONTINUED FROM PAGE 25...

exhibit hall, so I got to walk around and get more sweets. Then, when she was finished, we went back to the hotel to get ready to have dinner with our Foundation friends at Margaritaville and we got to ride a Ferris wheel and explore the park. The next morning, I walked with my mom and little brother to infusion training, then went down to join a session that my mom couldn't attend because of the infusion training. I found my mom someone to talk to, whose story was fairly similar to hers, in a session called Unlocking the Future. Then, I went to a session called, Black and African Voices, which I thought was cool to attend cause I was

able to see what challenges I might face in my adulthood with my mom not in the ER room with me. I went to lunch with my mom, and then we went back to the hotel for some down time. Later, we went to the closing ceremony and went to the party for a bit before heading back to the hotel. BDC was definitely a 10/10 experience for me and really showed me how amazing life out of Pittsburgh really is because it was my first time out of Pennsylvania where I didn't go sight seeing and was actually able to visit an aquarium. And I was also able to learn some more things about the bleeding disorder community.

about the signs and symptoms of bleeding disorders with hundreds of individuals. Thank you to the following community members for volunteering their time to staff the booth during this weekend long event: Melissa K, Paul L., Mindy Perry, Michelle P., Samantha Short, Lenore H., Scott Domowicz, and Cassie Miller.

Finally, Executive Director, Kara Dornish, and Development Director, Jessica Lee, were invited to display at the Wellness4Schools Summer Symposium on August 1. Kara and Jess had the chance to spread

awareness for bleeding disorders and provide multiple period packs, nosebleed kits, and resources to many schools in the Pittsburgh area!

Interested in volunteering with this initiative? Be on the lookout for volunteer opportunities to staff booths or stuff period packs. If you know of a local festival or health fair in your community, let us know! We can provide you with resources to run your own WPBDF booth and help raise awareness for bleeding disorders! Email kara@wpbdf.org for more information.

GETTING TO KNOW THE WPBDF BOARD



JASON MILLER

WHAT INFLUENCED YOU TO GET INVOLVED WITH THE FOUNDATION AND JOIN OUR BOARD OF DIRECTORS?

Overall, my decision to get involved with the Foundation was centered around my appreciation of the Foundation. My wife and all four of my children are affected by bleeding disorders, with my oldest (12) just getting diagnosed two weeks before Camp Hot-to-Clot this year. Because of the experiences we have had participating in all the events, attending camp, and engaging with

the members of the community, his new diagnosis was not as big of a shock for him. Upon finding out that not only did he have a bleeding disorder, but a more rare factor deficiency, there wasn't shock. He just calmly declared that now he actually belonged because up to this point he had been an unaffected sibling. Even as a sibling, he was always learning about bleeding disorders during the events. At Camp Hot-to-Clot, one of the activities they complete is to identify their disorder and treatment, and because of the education he has had over the years, he was able to answer most of the questions less than two weeks after receiving the diagnosis.

I also see tremendous value in events like Harrisburg Days and the national advocacy days in Washington D.C. This past year was the first time we had the opportunity to participate, and our kids came with us. For me, that was one of the most powerful experiences, because it showed how we as a community, and especially our kids, need to advocate for their own needs. Ultimately, this event, and seeing my kids participate and discuss their conditions with the legislators, is one of the main reasons I decided to take a more active role in supporting the community. Because preparing them to advocate, and showing them why they need to, is so important to the future of the community.

WHAT IS YOUR BACKGROUND OR CURRENT OCCUPATION?

Currently, I am a Technology Engineer for Just Between Friends Franchise System. In my role, I manage and support our technology platforms, including development and configuration of a broad range of systems. I have worked to plan and implement several updated systems for release to our franchisees across the system. Prior to this role, I spent 20 years in retail management roles spanning various industries including home improvement, general merchandise, grocery, and specialty food service.

WHAT ARE YOU LOOKING FORWARD TO AS A NEW BOARD MEMBER?

I am looking forward to helping to further support our advocacy efforts and the general strategic direction of the Foundation as a whole. In addition, I plan to help support our programming for the men within our community, to ensure that the programming remains relevant for all members of the community.

WHAT DO YOU LIKE TO DO FOR FUN?

I enjoy traveling and taking regular trips to Legoland in New York with my kids. In addition, I am a long time video game player. My current games of choice are the Pokemon and Legend of Zelda series on the Nintendo Switch.

PITTSBURGH PENGUINS FUNDRAISER

Support WPBDF by attending a Pittsburgh Penguins Game! See the Penguins battle the Islanders!



When: Tuesday, March 18th, 2025

Game Time: 7:00 PM

Where: PPG Paints Arena
1001 Fifth Ave
Pittsburgh, PA 15219

\$10 from every ticket will be donated to the Western PA Bleeding Disorders Foundation. Plus, the first 7,500 fans will receive a Penguins beach towel! You can help provide education, support groups, and patient assistance to our families and individuals in need!

Learn more and grab tickets at:
bit.ly/wpbd-f-penguins



CELEBRATING EMPOWERMENT

On Thursday, September 26, the spirit of empowerment and camaraderie filled the air as WPBDF's Winning Women's Group came together for a Safety Skills Workshop. This gathering was more than just a workshop; it was a celebration of strength, resilience, and the support we provide one another.



The workshop was led by Lioness Martial Arts and provided participants with invaluable strategies to reduce risk and enhance personal safety. Through engaging discussions and practical exercises, the women learned how to harness the power of their voices and adopt effective attitudes that promote confidence. The expert facilitators guided the group through essential physical techniques, equipping everyone with the tools they need to navigate the world with greater assurance.

After gaining these empowering skills, the women gathered for a delicious meal that fostered connection and friendship. As the evening progressed, creativity took center stage. Together, the women crafted beautiful bracelets, pins, and wine charms, each piece a

VOICES FOR CHANGE

At the National Bleeding Disorders Foundation's Bleeding Disorders Conference, a new resource called Voices for Policy Change! was unveiled. Voices for Policy Change! is a vital resource aimed at educating and mobilizing advocates around key legislative issues affecting individuals with bleeding disorders. There are a series of videos you can view and share by going to: <https://www.bleeding.org/advocacy/how-you-can-take-action/voices-for-policy-change>.

Here's how you can make the most of the available videos:

1. Patient Experience Videos

These videos showcase personal stories that help individuals craft their narratives.

2. Advocate Expert Videos

Gain insights on critical issues like

Copay Accumulation Adjustment Programs (CAAPs) and Copay Maximizers. These videos can be utilized in both individual study and group settings to foster informed advocacy.

3. Insurance Expert Videos

Understand the key language used by insurance companies to navigate your coverage effectively. These resources empower patients to advocate for themselves confidently.

By utilizing these tools, we can collectively advocate for change and support one another in our journeys. Explore Voices for Policy Change today and let your voice be heard! Together, we can make a difference!

SCAN THE QR CODE TO LEARN MORE ABOUT VOICES FOR CHANGE AND WATCH VIDEOS FROM PATIENT ADVOCATES.



symbol of our solidarity and shared journey. These creations serve as lasting reminders of the strength we find in our community.

A heartfelt thank you goes out to Cottrill's Pharmacy for sponsoring



this event. Your support plays a vital role in helping us empower women and create safe spaces for learning and growth.

COTTRILL'S 
PHARMACY, INC.

2024 General Election Important Dates



**Last day to register to vote
in the general election.**
vote.pa.gov/Register



**Last day to apply
for a mail ballot.**
vote.pa.gov/MailBallot



**Election Day. Polls are
open from 7 a.m. to 8 p.m.**
vote.pa.gov/Polls



**Completed mail ballots
must be received by 8 p.m.**
vote.pa.gov/County

Visit vote.pa.gov



You are invited to an informative presentation to help you understand your health insurance options!



**WEDNESDAY,
NOVEMBER 6, 2024
6:00 PM
BRAVO! ITALIAN KITCHEN
211 SUMMIT PARK DR
PITTSBURGH, PA 15275**



Sponsored by Genentech
Genentech
A Member of the Roche Group

Join us for an informative session to learn about health insurance options and how health insurance changes may affect your coverage and treatment costs.

We understand health insurance can be confusing. We are here to help you understand your insurance options so you can identify the best plan for you.

Please RSVP by Monday, October 28 to: rsvp@wpbdf.org or 724-741-6160. Please be sure to include the total number of adults and children attending and any food allergies or dietary restrictions.



WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

775 4th Street
First Floor
Beaver, PA 15009



PABDC

Pennsylvania Bleeding Disorders Conference

Save the Date



Pennsylvania Bleeding Disorders Conference

May 16 - 18, 2025



Hershey Lodge
325 University Dr,
Hershey, PA 17033

Be the first to know when PABDC registration opens! Scan the QR code to join the PABDC mailing list!



HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

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