



HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

SPRING 2026



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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.

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

May 3-4

The Joey Smiles Advocacy Ambassador Education and Training
Hilton Harrisburg
Harrisburg, PA

May 16

New Parent Network
Pittsburgh Zoo & Aquarium
Pittsburgh, PA

May 21

Hympavzi Dinner Program
Il Pizzaiolo
Warrendale, PA

May 31

Backyard Brawl Cornhole Tournament WV vs WPA
Cobblehaus Brewing Co.
Coraopolis, PA

June 12-14

Stay In Motion Education Weekend
Seven Springs Mountain Resort
Champion, PA

June 17

Women's Empowerment Dinner Program
Location TBD

July 8

Rivers Club Happy Hour Fundraiser
Rivers Club
Pittsburgh, PA

July 11

Annual Meeting & Education Day
Bayfront Convention Center
Erie, PA

July 26-31

Camp Hot-to-Clot
Camp Kon-O-Kwee Spencer Fombell, PA

July 28

Hemlibra Dinner Program
Juniper Grill
Cranberry Township, PA

August 13-15

National Bleeding Disorders Conference
Orlando, FL

August 22

Regional Education Day
Oglebay
Wheeling, WV

September 1

Washington Wild Things Fundraiser
EQT Park
Washington, PA

September 19

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

October 2

New Parent Network Ambassador Center
Erie, PA

October 3

Fall Program
Ambassador Center
Erie, PA

October 24

Purse Bingo Fundraiser
Vanport Volunteer Fire Department
Beaver, PA

November 6-8

Teen Retreat
Promise Camp & Retreat Center
Clinton, PA

November 20 - 22

Women's Retreat
Hershey, PA

December 5

Winter Program
National Aviary
Pittsburgh, PA

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



SATURDAY, SEPTEMBER 19
NORTH PARK SWIMMING POOL LOOP
9901 S RIDGE DR, MCCANDLESS, PA 15044

Learn more and register at:
bit.ly/runfortheirives2026

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LETTER FROM THE EXECUTIVE DIRECTOR

Dear Community Members and Friends,

March once again brought us the meaningful opportunity to recognize Bleeding Disorders Awareness Month alongside Women's History Month, two observances that remind us of the strength, resilience, and advocacy within our community. This time of year is always inspiring, as individuals and families come together to share their stories, raise awareness, and push for progress.

From community members speaking with local officials to participating in proclamations declaring March as Bleeding Disorders Awareness Month, your voices are creating real impact. These moments of storytelling go beyond awareness. They are catalysts for understanding, compassion, and change. It is inspiring to witness the courage it takes to share your journey, and we are deeply grateful to everyone who stepped forward.

We have also expanded our outreach efforts in exciting ways

this year, including connecting with students and faculty at Penn State Beaver and new student groups at the University of Pittsburgh. Engaging with the next generation is critical to building broader awareness and fostering future advocates.

Advocacy continues to be at the heart of everything we do. Washington Days remains one of the most important opportunities we have to elevate the needs of our community on a national level. By coming together to meet with legislators and share our lived experiences, we help protect access to care, treatment, and vital resources. These efforts truly make a difference, and we encourage anyone interested to get involved. Your voice matters.

Looking ahead, we are excited to partner with the Eastern Pennsylvania Bleeding Disorders Foundation to host the Joey Smiles Advocacy Ambassador Education and Training in Harrisburg on May 3 and 4. This program is designed to empower community members with the tools, knowledge, and



confidence to become effective advocates. Whether you are new to advocacy or looking to deepen your involvement, we hope you will join us for this impactful experience.

As I reflect on the past few months, I am reminded that awareness is only the beginning. It is through continued advocacy, education, and connection that we create lasting change. Thank you for your passion, your voices, and your commitment to this community. Together, we are building something truly powerful.

With heartfelt gratitude,

Kara Dornish
Executive Director, WPBDF



Kara was featured in the March issue of *The Bridge* and was recognized as an Outstanding Woman of Beaver County! We are grateful for her leadership and passion for the Western Pennsylvania bleeding disorders community!

Read more at: <https://read.letterhead.email/the-bridge/rh7s1p0p61>

LETTER FROM THE BOARD PRESIDENT

It's one of my favorite times of year again, Washington Days! Washington Days is a collaborative event between chapters like ours, nationwide, and hosted by the National Bleeding Disorders Foundation (NBDF). For a few select days each spring, bleeding disorder advocates storm the capitol in an effort to further educate our federal lawmakers on the issues surrounding our community. Bright red ties can be seen by the dozen on Capitol Hill.

Each year, our Foundation selects a handful of Advocacy Ambassadors to embark on the trip. These ambassadors receive free training and are assigned appointments with legislators on Capitol Hill. This year, our Advocacy Ambassador scholarship recipients were strategically chosen based upon their legislative district and advocacy experience. Scholarships are supported by fundraisers hosted throughout the year. Events such as our annual

Unite for Bleeding Disorders Walk and our purse bingo help fund these legislative efforts, including covering travel fees and costs associated with attendance.

It's always fun to see how many people each state sends, but Pennsylvania tends to have one of the largest teams of advocates. This year, we had a total of 23!

Along with this event, NBDF also hosts numerous opportunities for the bleeding disorders community, including webinars and symposiums. They also provide special staff and board trainings. You may not be aware, but our staff and board is continually furthering their knowledge by attending education sessions year round. Our board of directors and staff are constantly working to make WPBDF bigger, better and stronger for our members.

Are you interested in taking your advocacy to the next level? Join



us May 3-4 in Harrisburg as we put advocacy into action! We start the event with a day of Advocacy Ambassador training, where new advocates and seasoned pros will learn about the issues facing our community. Then, on May 4, we will head to the capitol for meetings with our local legislators. Hotel and some meals are included; for more information, check out our events page on WPBDF.org. Hope to see you there!

Samantha Short
Board President, WPBDF

WPBDF Scholarship 2026-2027



NOW ACCEPTING APPLICATIONS!

Applications must be received or postmarked by May 30, 2026.

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.

Awards up to \$3,000!

Learn more and apply online at:
bit.ly/wpbfd-scholarship-2026
or scan this QR code!

Paper applications are available upon request.
Email info@wpbfd.org.



ADVOCACY UPDATE



KERRY LANGE, SENIOR ASSOCIATE
MILLIRON GOODMAN

HARRISBURG UPDATE

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

The House and Senate spring session schedules are as follows:

Senate

Jan 26, 27 & 28
Feb 2, 3 & 4
Mar 16, 17, 18, 23, 24
Apr 20, 21 & 22
May 4, 5 & 6

House

Jan 26, 27 & 28
Feb 2, 3 & 4
Mar 2, 3, & 4
Apr 13, 14, 15, 27, 28 & 29
May 4, 5 & 6

PA GENERAL ASSEMBLY

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

Here is the current breakdown:

- House: 102 D – 98 R
- Senate: 27 R – 23 D

A handful of representatives resigned from the House this year including:

1. State Rep. Torren Ecker (193): Elected to Adams County Court of Common Pleas
2. State Rep. Lou Schmitt (79): Elected to Blair County Court of Common Pleas
3. Rep. Seth Grove (196): Became President and CEO of the PA Concrete & Aggregates Association).

Special elections for Pennsylvania's 79th and 193rd House Districts were held on March 17. In the 79th District, Republican Andrea Verobish defeated Democrat Caleb McCoy. In the 193rd District, Republican Catherine Wallen won against Democrat Todd Crawley with 59.7% of the vote, keeping the seat in GOP control.

The special election for House District 196 is scheduled for Tuesday, May 19.

ELECTIONS

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

A growing list of members are announcing plans to resign/retire at the end of session in November 2026 including:

1. Rep. Mary Jo Daley (House of Representatives – 148)
2. Rep. Anita Kulik (House of Representatives – 45)
3. Rep. Bryan Cutler (House of Representatives – 100)
4. Rep. Sheryl DeLozier (House of Representatives – 88)
5. Rep. Eddie Day Pashinski (House of Representatives-121)
6. Rep. Stephanie Scialabba (House of Representatives-12)

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

REVENUE COLLECTIONS

The Independent Fiscal Office (IFO) released their Fiscal Outlook for FY 2025-2026 through FY 2030-2031. Here's a brief overview:

- General Fund surplus projected to be depleted in FY 2026-2027;
- Rainy Day Fund (currently \$4.7 billion) projected to be depleted by FY 2027-2028;
- FY 2025-2026 deficit is currently projected at \$3.7 billion and projected to grow to \$7.7 billion by FY 2030-2031; and
- \$1.3 billion temporary measures used in FY 2025-2026 must be back-filled next year.

2026-2027 BUDGET

In February, Governor Shapiro

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ADVOCACY UPDATE

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provided his 2026-2027 budget address and corresponding proposal. It is a \$53.3 billion plan. Similar to his 2025-2026 proposal, his plan would legalize and tax recreational marijuana as well as skill games, creating two new additional revenue sources to pay for his plan and help close the budgetary gap.

Specific to the annual hemophilia line item, we are off to a promising start this budget season. The Governor has proposed to fully fund the line item under the Department of Health at \$1,017,000.

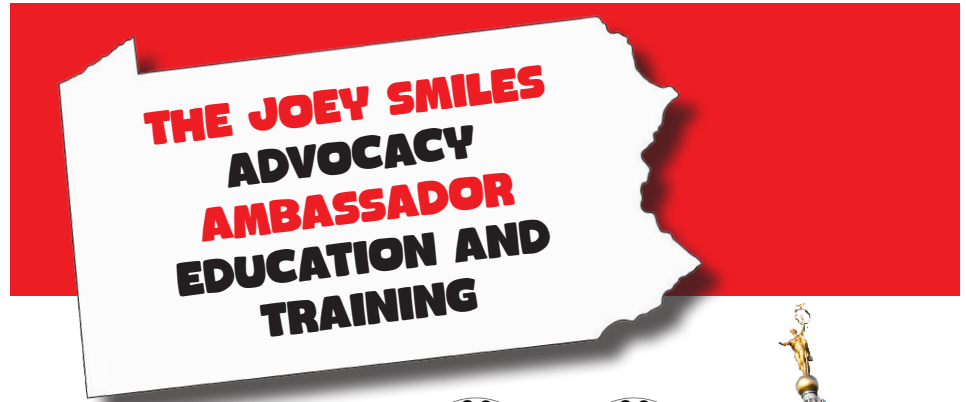
Milliron Goodman continues to advocate among House and Senate leadership and Appropriations Committees for an increase to the line item, keeping it separate from the other rare disease line items, and protecting the funding distribution formula to the HTC's.

However, given the fiscal outlook and deficit projections, we anticipate another contentious budget season.

The legislature has a constitutional deadline of June 30 to pass a balanced budget and send to the Governor's desk.

LEGISLATION

We will continue to monitor for any bills that could potentially harm the community, as well as for bills that could assist. **So far**



May 3-4, 2026

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

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

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

To register, email rsvp@wpbdf.org to receive the registration form.



this session (since January 1 2025), nearly 3,400 bills have been introduced.

Some of these bills include the co-pay accumulator companions, Senator Judy Ward's SB 268 and Representative Emily Kinhead's HB 2226, both of which await consideration in their respective Insurance Committees.

ADVOCACY DAY

WPBDF and EPBDF are hosting the next advocacy day in Harrisburg on Sunday, May 3 to Monday, May 4. Details regarding advocacy training and talking points will be available as we get closer.

Please let us know if you plan to attend and we will schedule meetings with your local legislators. As always, please feel

A red graphic containing two circular logos for "ADVOCACY AMBASSADOR" (one for WPBDF and one for EPBDF), the text "SIGN UP TO RECEIVE ADVOCACY ACTION ALERTS!", a QR code, and the text "SCAN THIS QR CODE!".

free to contact our office with any questions or concerns. We look forward to continuing to represent you this year.

MAKING A DIFFERENCE: VOICES OF IMPACT AT NBDF WASHINGTON DAYS 2026

DR. CHRISTY MILLER, ADVOCACY AMBASSADOR

Amidst the constant swirl of national headlines, a quieter but profound transformation took place in March on Capitol Hill. Advocates from across the country, including our dedicated delegation from the Western PA Bleeding Disorders Foundation, gathered for the National Bleeding Disorders Foundation's (NBDF) annual Washington Days. This event is more than just a series of meetings; it is a vital platform where personal stories become the catalyst for legislative change.

This year, our advocacy centered on three "big asks" essential to the health and financial stability of our community.

1. Sustaining the Foundation of Care

First, we urged legislators to continue their support for federal bleeding disorders programs through HRSA and CDC funding.



These programs are the backbone of our community, funding the network of Hemophilia Treatment Centers (HTCs) that provide comprehensive, life-saving care.

2. Ending Unfair Insurance Practices

Our second priority was the HELP Copays Act (H.R. 6423/S. 864). For three years, we have marched to the Hill to demand an end to "copay accumulators"—practices where insurance companies pocket copay assistance intended for patients without counting it toward their deductibles. This forces families into an impossible financial corner. Due to our collective advocacy, a legislator committed to bringing this act back to the floor. We are fighting to ensure that all payments made on behalf of a patient actually count toward their out-of-pocket maximums.

3. A Historic Win for the Underserved

The most emotional highlight of the week was our push for the FED Up Act (Fostering Effective Treatment and Diagnosis for Underserved Populations). This is a new, passion-driven initiative aimed at the estimated 30% of the ultra-rare community that remains undiagnosed as well as women and girls who are still being told they can't bleed because they are women. For too long, women and girls have faced diagnostic delays of up to 16 years due to outdated biases and a lack of clinical research.

In a moment of pure triumph, our advocacy efforts secured a new cosponsor for the bipartisan FED Up Act! This is a massive step forward in dismantling barriers

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WASHINGTON DAYS 2026

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to care for women and girls nationwide, as well as those with ultra-rare bleeding disorders.

Beyond the policy papers, the true heart of Washington Days is always the people. Along with 357 advocates from 49 NBDF chapters representing all 50 states, Puerto Rico, and Guam, we completed a total of 271 visits on Capitol Hill! I am incredibly proud of my children for having the courage to share their lived experiences with lawmakers. Seeing the impact of their voices firsthand is a reminder that advocacy is a

family affair. They then had the opportunity to explore the Capitol on Friday while I attended the Medical and Scientific Advisory Council (MASAC) meeting to hear about current issues and recommendations in the bleeding disorder community.

The ripples of this work are real. We learned during our visits that an individual we met with last year was finally able to secure their own diagnosis because of the information shared during that meeting. It is a powerful reminder that even when the world feels chaotic, we are doing essential work that changes lives.

Whether it is securing funding or changing the law, we proved once again that when the bleeding disorders community speaks with one voice, Washington listens. We



are making a difference, one story at a time.

WPBDF'S COMMUNITY LEARNS ABOUT HYMPAVZI

TORI BAKER, WPBDF BOARD OF DIRECTORS VICE PRESIDENT

On January 22, the Western Pennsylvania Bleeding Disorders Foundation, in partnership with Pfizer, hosted a community learning event for education on a treatment option for people living

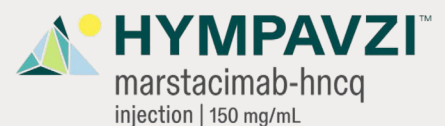
with hemophilia. The event was designed to provide educational information and support informed conversations between individuals and families. This educational program discussed HYMPAVZI, a new rebalancing treatment option for hemophilia. The event was held at the Grand Concourse in downtown Pittsburgh.

Attendees learned about the science behind rebalancing therapy, clinical trial data, safety information, information on administration and how it may fit within the current hemophilia treatment landscape. The discussion emphasized that treatment decisions are individualized and should be made in consultation with a qualified healthcare professional.

The event also highlighted

the importance of community connection and shared learning, offering a space for participants to ask questions and better understand evolving options in hemophilia care. No medical advice was provided.

Thank you to Pfizer for sponsoring this program and providing our community with this valuable information.



WPBDF'S WINNING WOMEN CELEBRATE GALENTINE'S DAY

**TAMARA FENTON, WOMEN'S GROUP CO-CHAIR,
ADVOCACY AMBASSADOR, & COMMUNITY
MEMBER**

On Thursday, February 12, WPBDF's Winning Women Group hosted a Galentine's celebration for the incredible women in our bleeding disorders community who have a bleeding disorder or are living with a family member with a bleeding disorder. Our evening began with conversation and celebration for each other.

Observing the interactions and the smiles, and hearing the cheerful conversation and laughter amongst new members and existing members, was very uplifting and heartwarming. I is incredible knowing friendships were made and seeing the support and love of the community is amongst the WPBDF members.

We gathered together to share a scrumptious Italian dinner followed by cheesecake, fresh fruits and toppings. The women put on their thinking-caps to try their luck at a Valentine's themed crossword puzzle to win prizes, and everyone had fun! We shared some "Victory



For Women" giveaways; NBDF offers educational programming and publications for women and girls with bleeding disorders as part of the "Victory For Women" program. You can learn more at: victoryforwomen.org.

A heartfelt thank you to Dawn Rotellini, Chief Operating Officer at the National Bleeding Disorders Foundation (NBDF), for answering our questions and for sharing her journey with a bleeding disorder, her advocacy, and her role in the documentary film *Dismissed*. *Dismissed* is a powerful documentary that follows five women living with Hemophilia, bringing to light their personal journeys and the systemic challenges women with bleeding disorders often face. Both educational and deeply moving, *Dismissed* serves as a call to action for healthcare providers, policymakers and communities to recognize and address the unique realities of women with bleeding disorders. The film has been widely praised for its focus on women's health and its potential to inspire meaningful change.

Throughout the remaining evening the women were able to be creative in a variety of activities. Melissa Kendrick helped us create beautiful beaded quartz bracelets as a special keepsake from the fun evening and one to donate back to the Foundation to support future fundraising efforts. Some of us also created a unique intention heart to take home as a reminder of our personal intentions for 2026. We finished our Galentine's Event at the Valentine's Photo Station; taking pictures with old and new friends, wearing smiles on our faces and in our hearts. With excitement in our voices and chatter amongst us about the next Winning Women and WPBDF community event, we all departed with more than we came with...the feeling of community in our hearts.

Thank you for the continued generosity of Cottrill's Pharmacy and Melissa Kendrick, Field Care Coordinator, for sponsoring the event.

COTTRILL'S 
PHARMACY, INC.



WPBDF IN THE COMMUNITY

Spreading awareness for bleeding disorders remains a top priority for WPBDF. Staff and volunteers braved the cold weather this winter season to stay involved with various student organizations at the University of Pittsburgh and Penn State Beaver. Keep reading to learn more about our awareness initiatives and hear from different volunteers who attended these events. Thank you to everyone who helped WPBDF make an impact!

Martin Luther King Day of Service at the University of Pittsburgh

DIANE STANDISH, WPBDF BOARD OF DIRECTORS

It won't be any surprise to you that a social worker would enjoy doing volunteer work, right? Over the course of my career, I've come to see that so many institutions, schools programs, and activities would just fall apart if it weren't

for volunteers. Like many of you, I take the opportunity to help when the call for volunteers comes around.

For two years, Foundation volunteers have partnered with the University of Pittsburgh for their Martin Luther King, Jr. Day of Service, Community, and Connection. As a proud Pitt grad, and spouse and Mom of Pitt grads, I love any chance to be back on campus, even in sub-freezing, snowy January weather. This year was the first time I participated in the event, and it was so interesting and rewarding.

Before the Pitt students arrived, Jessica, Justin, Stephanie, Sammi, Samantha, and I set up stations to assemble period packs. When the students joined us, there was an immediate infusion (haha) of energy and excitement in the room. About 25 students came, ready to WORK! How impressive they were—these volunteers could have stayed in bed on their day off, but they braved the bitter cold and the howling wind to help us. They jumped right



in and started putting all of the components together to make the period packs. These packs will make their way to school nurses in many Western PA schools for distribution to students—a terrific way to educate nurses and students about bleeding disorders and our Foundation.

When you live with a bleeding disorder or work in the

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LIVING WITH HEMOPHILIA

MARS TEEN COPE WITH BLEEDING DISORDER THROUGH CONSTANT OBSERVATION

EDDIE TRIZZINO, EAGLE COMMUNITY EDITOR

Eight years ago, Luke Miller might have been sent to the hospital after colliding with another player on the basketball court. This time, although he was a little worried, he went home with his parents instead of leaving in an ambulance.

Luke, 13, of Mars, was diagnosed with hemophilia when he was about 6 months old. The rare disorder prevents a person's blood from clotting in the typical way because it doesn't have enough blood-clotting proteins, also known as clotting factors, which can lead to a person bleeding for longer than someone without the disorder.

Since 2018, Luke has taken medicine via IV that helps bridge the gap between two clotting factors, which has prevented injuries on the court from ending up as hospitalizations.

Luke said he still gets a little alarmed when he takes a spill, but the worry about his collision on the basketball court was short-lived.

"I was worried when it happened," he said. "But after a little bit, once I realize nothing is really happening, then I don't really worry about it that much."



Butler County Commissioner Leslie Osche reads a proclamation recognizing March as Bleeding Disorders Awareness Month to Luke Miller, 13, of Mars, who has hemophilia, on Thursday, Feb. 26, in the Butler County Government Center. Photo by Eddie Trizzino/Butler Eagle.

Raising awareness

March is Bleeding Disorders Awareness Month, an awareness campaign promoted by the Western Pennsylvania Bleeding Disorders Foundation and other organizations like it. On Thursday, Feb. 26, Luke and his dad, Scott Miller, accepted a proclamation from the Butler County commissioners recognizing the month and the cause behind it.

Janet Barone, the foundation's program director, said that although awareness and treatment of bleeding disorders has grown in the past few years, many people still go years undiagnosed. Spreading information about diseases like hemophilia could lead people to be evaluated, preventing complications that could be caused by excessive bleeding, she said.

"On average it takes 16 years from the onset of symptoms for

a female to be diagnosed with a bleeding disorder. So we're trying to spread awareness to close that gap so women can receive care sooner," Barone said.

"We're getting into as many school districts as possible in Western Pennsylvania, we're sending them literature that lists the signs and symptoms of bleeding disorders so that they can familiarize themselves."

Living with hemophilia

Having a son diagnosed with hemophilia at 6 months old has led Miller and the rest of Luke's family to become familiar with its symptoms and effects, and also to become involved with the Western Pennsylvania Bleeding Disorders Foundation. Miller said Luke's treatment has taken place pretty much entirely at UPMC Children's Hospital of Pittsburgh.

Miller said it took a few trips to the emergency room for Luke

to be diagnosed, and he was misdiagnosed with another disease before doctors landed on hemophilia. Luke's original physician, Dr. Margaret V. Ragni, and his current physician, Dr. Frederico Xavier, taught the family a lot about hemophilia and how to help Luke live a typical life with the condition.

With no family history and little knowledge about bleeding disorders, the Millers relied on Children's Hospital and the foundation for information and support.

Luke still goes to the Hemophilia Center of Western Pennsylvania every six months and gets blood drawn. Luke's doctors also helped the family make the decision to use a new medicine that helps Luke's blood clot, preventing excessive bleeding. He takes the medicine weekly.

"He's missing Factor VIII, so when the cascade for proteins for clotting happens, he would go to VII and then nothing would come at VIII," Miller said. "This new injection doesn't use VIII — it's a bridge from VII to IX — so it skips VIII and goes over it and lets him clot. For him it works really well."

Since 2018, when Luke gained access to the medicine, he has not been hospitalized for bleeding. Luke used to get bleeds a lot in his youth, but he and his father said he lives a pretty typical life, even with hemophilia. It's his medicine that has helped make that happen.

Because he doesn't remember a time before having his condition, Luke said he feels the same as his classmates.

"It's not really much different,"

Luke said. "The only thing I wish I could do that I can't is play football, and if I didn't have hemophilia, I would. Besides that, there's really nothing."

However, the hospital visits and medicine make hemophilia an expensive condition. Miller said programs like the Affordable Care Act have helped pay for medicine. The foundation also has initiatives that help connect patients and their families to health care.

The foundation also offers support groups and activities that help show parents and patients they are not the only ones living with a bleeding disorder.

"We offer education programs and, for families that have especially a young child, a young newborn, we offer a new parent network program, and we partner with the Hemophilia Center of Western Pennsylvania on that," Barone said. "Education, and some social events too, so families can meet each other, build their own peer networks and know that they're not on this journey alone."

Advancements in treatments

Miller said there are "cures" for bleeding disorders like hemophilia that prevent regular bleeds from being an issue. But the cures are "10 times more unaffordable" than the treatments for hemophilia, Miller said.

Luke could decide one day whether to get a treatment that would get rid of many of hemophilia's effects, but Miller said there would still be some symptoms.

"A cure would turn him into a mild hemophiliac, which day-to-day

would be fine, but surgeries he would need more help with," Miller said. "He can make that decision when he's older."

Barone said pushing for awareness about bleeding disorders and their symptoms remains a priority for the Western Pennsylvania Bleeding Disorders Foundation.

She said the foundation has distributed period packs and nosebleed kits to school nurses, who are sometimes the first ones to recognize symptoms of a potential bleeding disorder in youths. The results of these distributions has already made a difference, Barone said.

"We did a survey at the end of this past school year, and of the nurses who participated with the nosebleed kits, 10 kids that they know of went on to seek evaluation, and one was diagnosed with a bleeding disorder," Barone said. "With the period packs, eight girls went on to receive evaluation, and three of them were diagnosed."

Miller said Luke doesn't often talk about his hemophilia with others, but wanted to help raise some awareness of it through accepting the proclamation alongside the bleeding disorders foundation.

He indicated it is possible to get rid of some of the risks associated with the condition with a little bit of treatment.

"The last one I got was in, I think, fourth grade," Luke said. "I haven't gotten one since."

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SHARED DECISION MAKING

Shared decision making is a collaboration between patients and their healthcare teams that helps them manage their condition. While the concept of Shared Decision making in the medical field isn't new, more and more healthcare providers and patients are embracing it and it has become a popular topic in recent years.

On February 21, WPBDF hosted a lunch program, giving patients and their families an opportunity to learn more about the shared decision-making process and the patient's role in it. Shaneka Storey, a Rare Disease Patient Navigator at Pfizer, led an interactive discussion about shared decision making, covering topics such as taking an active role as part

of your treatment team, finding quality sources of information, and discussing therapy considerations with your healthcare team. This led to a lively discussion between attendees on the various ways they've successfully and unsuccessfully implemented these techniques.

Effective shared decision making requires an open exchange of information between patients and providers. To help ensure productive conversations with medical providers, patients and caregivers should invest time preparing for appointments and be ready to share details that will inform the provider and aid in the decision-making process. Be prepared to discuss your goals and whether your current treatment plan is working well and is a good fit for your lifestyle.

It's a good idea to do some research ahead of time, especially if you want to speak with your provider about potentially changing therapies. However, be cautious about where you receive your

information online. If searching online, consider what the purpose of the website is and whether the information presented on it has been reviewed and is current.

Discuss the information you researched with your provider and ask them about new therapies. Prepare a list of questions you want to ask. Be ready to listen to what your provider says and take notes. It's also a good idea to bring a trusted family member or friend with you to listen and to help take notes.

Finally, you will likely need time to process everything you and your provider have discussed. Before you leave the appointment, ask who you should contact if you have any additional questions.

We thank Pfizer for sponsoring this informative program!



POWER PLAYS & POWERFUL SUPPORT

WPBDF AT THE PITTSBURGH PENGUINS!

On Monday, February 2, WPBDF hosted a fundraising game with the Pittsburgh Penguins! As the team took on the Ottawa Senators, our amazing donors, supporters, and Foundation members were helping to raise funds for crucial programs and services for the

bleeding disorders community here in Western PA!

A portion of all tickets sold through our unique ticket link was donated back to the Foundation. In total, we raised \$240 that will go toward providing education, support groups, and patient assistance to individuals and families affected by bleeding disorders! Unfortunately, the Senators beat the Penguins 3-2, but we are so thankful for everyone's continued support of WPBDF! Stay tuned for the next fundraising game, and check-out our other fundraising events at <https://wpbdf.org/events>.



THE POWERFUL IMPACT OF PROCLAMATIONS

CAMERON CEDENO

For the second year in a row, I was present to accept the Centre County Commissioners' proclamation of March 2026 as Bleeding Disorders Awareness Month. I've discovered that this is something I really enjoy participating in as I get a chance to spread awareness of bleeding disorders and advocate for my community at a very local level.

As someone who grew up attending advocacy trips to the state Capitol in Harrisburg, I feel I've always understood the importance and impact of advocating for yourself and your community. At the proclamation acceptance this year, I shared with the Commissioner the importance of spreading awareness for bleeding disorders, so impacted individuals can get diagnosed and have access to the life-changing medicine they need. Additionally, I shared awareness about the rise of women being diagnosed with bleeding disorders, the importance of funding for hemophilia treatment centers in PA, and I provided a resource for folks to learn more about diagnosis if they or a loved one might be experiencing symptoms of a bleeding disorder.

The Centre County Commissioners were very receptive of what I shared and asked great and engaging questions. I look forward to spreading awareness and accepting more proclamations in the future!



Cameron accepts a proclamation from the Centre County Board of Commissioners recognizing March 2026 as Bleeding Disorders Awareness Month!

Centre County wasn't the only place in Pennsylvania that recognized March 2026 as Bleeding Disorders Awareness Month! Counties and cities across the commonwealth showed their support for the bleeding disorders community. In Western Pennsylvania, we received proclamations from the following counties: Allegheny, Armstrong, Beaver, Butler, Cambria, Cameron, Crawford, Elk, Fayette, Greene, Lawrence, McKean, and Westmoreland. We also received a proclamation from Mayor Pacifico in Altoona!

Thank you to all the amazing volunteers who accepted proclamations on behalf of the Foundation and shared your story with your local communities.

Interested in getting involved next year? Please email jessica@wpbdf.org or call the Foundation office at 724-741-6160 to be added to our outreach list!

CHECK OUT MORE PHOTOS ON PAGE 26!



Mayor Pacifico presents Ashley D. with a proclamation from Altoona, PA.



The Armstrong County Commissioners present Tamara Fenton and Samantha Short with a proclamation for Bleeding Disorders Awareness Month.

GETTING TO KNOW HCWP STAFF



HOPE NOVAK
CLINIC NURSE



Birthplace: Fremont, California

First job: Hostess at Season's Restaurant.

Accomplishment you're proudest of: There are so many, but biggest: Having 3 children all becoming Engineers, Graduating Nursing School, Running a Marathon (both full and half), and Completing the Rachel Carson Challenge (a 37.5 mile hike)

What three words describe you best? Quiet (yes, it true), hardworking, and loyal

Dream vacation: I have 2: Santorini, Greece, and Machu Picchu, Peru

Things you can do without: Drama!!! Is that a thing????

Person you'd most like to have dinner with: Hmmmm. That's a great question..... I think my grandmother who passed away. I would love to sit and talk to her about life and her experiences.

Movie you could see anytime: Fiddler on the Roof

TV show or podcast you try not to miss: There is no TV Show or podcast I feel I must watch or listen to. I'm more of listening to music type of girl.

Three things that can always be found in your refrigerator: Coffee creamer, salsa, and eggs

Secret vice: CrossFit. It's my jam and when I can't attend class, I'm a very unhappy person.

Who would play you in the movies? Emma Stone

Your pet peeve about Pittsburgh: Maybe the potholes. I've transplanted here from California and though it was a culture shock, I do prefer it to California.

People may be surprised to know that: I served in the United States Air Force as an Immunology and Allergy Specialist. It's where I met my husband.

LEARNING ABOUT ALHEMO

DISCOVERING A SUBCUTANEOUS
PROPHYLAXIS TREATMENT IN A PEN FOR
HEMOPHILIA

KRISTEN SPEZIALETTI, WPBDF BOARD OF
DIRECTORS

On February 28, Novo Nordisk hosted an informational session about Alhemo, a subcutaneous prophylactic treatment option delivered through a prefilled injection pen. This program was held at the Wooden Angel in

Beaver, PA.

Rare Blood Community Liaison, Lorie Kerstetter, presented information about the clinical study behind Alhemo, including the safety and efficacy of the product. Alhemo is used to prevent or reduce the frequency of bleeding episodes in adults and children 12 years of age and older with hemophilia A or B. Following the presentation, attendees had the opportunity to check out how the injection pen works up close.

Lorie, whose son was diagnosed with Hemophilia A, shared her personal experience with medication management and opened the floor for attendees



to share as well. We thank Novo Nordisk for sponsoring this informative program!

THE WESTERN PENNSYLVANIA BLEEDING DISORDERS OFFICE

HAS MOVED!



**Western Pennsylvania
Bleeding Disorders Foundation**

WPBDF EDUCATION | ADVOCACY | SUPPORT

SAME TOWN, NEW SPACE!



NEW LOCATION!

AS OF JANUARY 21, 2026

In January we relocated from our office at 775 Fourth Street, Beaver, PA, to a bigger office just a few minutes down the road! This new space better fits our needs and allows us to serve you even better.

Our new address is:

**433 STATE AVENUE
SUITE #4
BEAVER, PA 15009**

Our email addresses, website, and phone numbers have not changed. If you have any questions you can reach us during office hours, 9 AM - 4 PM, Monday through Friday.

CONTACT US:

Phone: 724-741-6160

Email: info@wpbdf.org

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

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

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



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Alhemo® is a prescription medication.

Learn more at
Alhemo.com



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

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

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WPBDF IN THE COMMUNITY

CONTINUED FROM PAGE 10...

community, it's easy to forget that most people have no idea what "hemophilia" and "von Willebrand disease" are. So, while the students were helping the Foundation and school nurses, they were also taking in a lot of information. We hope that they will remember the Foundation and the hemophilia treatment center if they should ever encounter someone who is experiencing unexplained bleeding symptoms.

After assembling almost 1,000(!) period packs, the Pitt students were off to their next activity. Their enthusiasm was contagious, and we all left feeling inspired by, and grateful for, their commitment to honor the legacy of Martin Luther King, Jr. We hope to be back at Pitt again next year. As always, Hail to Pitt!

University of Pittsburgh Chapter of Days for Girls

We'd like to extend a huge thank you to the University of Pittsburgh's Chapter of Days for Girls for welcoming us on Monday, February 9, 2026, for a special evening of learning, conversation, and service.

During our visit, we had



the opportunity to share a presentation about bleeding disorders in women and how frequently these conditions go undiagnosed. Together, we talked about the importance of recognizing abnormal bleeding symptoms and ensuring that women and girls know when and

where to seek help.

Following the presentation, the group rolled up their sleeves to help us assemble more than 100 period packs that will be distributed across Pitt's campus. In addition to the packs, students are helping raise awareness by placing magnets and mirror clings in campus restrooms and distributing flyers with information about bleeding disorder symptoms and resources, including BetterYouKnow.org.

The evening sparked many thoughtful conversations about periods, women's health, and the barriers that often prevent people from seeking care. We were especially inspired by the student's dedication to addressing period poverty and supporting menstrual health for their campus community.

We are grateful for the opportunity to partner with such a passionate and committed group of students. Thank you, Days for Girls at Pitt, for helping us spread awareness and make a meaningful impact!

University of Pittsburgh's Environmental Honors Fraternity: Epsilon Eta Delta

WPBDF was proud to partner with the University of Pittsburgh's Environmental Honors Fraternity, Epsilon Eta Delta, on Monday, February 23, for an evening of bleeding disorders education, meaningful discussions, and impactful contribution.

More than 25 students joined us for an engaging presentation that highlighted the Foundation's mission, as well as the signs and symptoms of bleeding disorders. We also emphasized the importance of our Women, Girls,



University of Pittsburgh Chapter of Days for Girls (above)

and People with the Potential to Menstruate with Bleeding Disorders Initiative, and how our period packs play a vital role in supporting this effort.

Epsilon Eta Delta truly went above and beyond in their efforts to make a difference. Following the presentation, students stuffed and decorated over 100 period packs. These packs were left behind with the members of the organization, who offered to distribute them across Pitt's campus and in key on-campus resource areas. These packs play an important role in promoting awareness and providing accessible support to those who may be affected by bleeding disorders.

We are incredibly grateful for Epsilon Eta Delta's partnership and dedication. Their enthusiasm and commitment to spreading awareness are helping to create a more informed and supportive community. Thank you for making a meaningful impact!

Students help pack period packs at Penn State Beaver (right)

WPBDF at Penn State Beaver

Kara and Janet had two great visits to Penn State Beaver this spring, connecting with students and raising awareness about bleeding disorders. On February 25, they attended the campus Health Fair, sharing resources, education, and support services.

They returned on March 17 for another day of outreach. Students stopped by to learn the signs and symptoms of bleeding disorders while playing Plinko for fun prizes. Students and staff also helped pack period packs and create kindness cards, which will be distributed to school nurses across Pennsylvania.

Thank you to everyone who participated and helped make a meaningful impact.



HCWP CORNER

KATHALEEN SCHNUR, MSW, LCSW

As winter ends and spring begins, the season reminds us that growth often follows difficult times. Living with a bleeding disorder can feel similar to the changing seasons. There are periods of stability and times of uncertainty. During those moments, patience, planning, and resilience become especially important.

Many in our community have questions about insurance coverage, pharmacy processes, and medication access. The healthcare system can be confusing, and our team continues to monitor how these challenges may affect patients and families.

We encourage everyone to stay aware of deadlines, review coverage when needed, and keep track of medication refills and approvals. Staying informed and planning can help prevent unnecessary delays, and our team is always here to support you.

Regular clinic visits are essential. They keep treatment plans current, prescriptions active, and allow the care team to provide safe guidance. Being seen regularly is also critical when planning procedures, surgeries, or dental work. Without recent visits, we may lack the updated medical information needed for treatment recommendations or surgical clearance, which can lead to delays. Please know that emphasizing regular visits is not meant to create extra hurdles; we understand how important

timely procedures are. Staying up to date with appointments helps prevent delays and allows the team to respond quickly when you need support. If it has been more than a year since your last visit, we encourage you to contact the clinic to schedule an appointment.

The same applies to ordering factor and other medications. Because insurance plans, specialty pharmacies, and approvals can take time, delays may occur. Ordering factor early and staying in contact with your pharmacy can help prevent interruptions in treatment. Our team is here to help if problems arise.

Caring for your mental and emotional health is just as important as physical health. Living with a chronic condition takes resilience, and many people



THE HEMOPHILIA CENTER of Western Pennsylvania

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

Factor Program Services

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

Patient Benefits

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

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

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

are also navigating stress and uncertainty in the world. It is okay to acknowledge when things feel overwhelming. Taking a moment to step away, breathe, and focus on what you can control can help restore balance.

Looking ahead, a few reminders: our Amish Outreach Clinics will take place at the end of April and into May, and planning for summer camp is already underway. If your child is planning to attend camp, please make sure they are current with their clinic appointment or scheduled for one. We look forward to seeing many of you in clinic this spring and reconnecting during summer programming.

We also want to highlight an opportunity to get more involved. Our Consumer Advocacy Committee (CAC) welcomes input from patients and family members to view our services from new perspectives. CAC members provide suggestions, spark creativity, and offer thoughtful feedback when needed. While the CAC is advisory, the insight it provides is incredibly valuable. If you are interested in participating, please reach out to the center.

Spring reminds us that growth takes time. It happens gradually through regular care, thoughtful planning, and the support of others. One of the greatest

strengths of the bleeding disorders community is the connection we share. While every person's journey is different, no one has to face it alone.

If you have questions, concerns, or encounter challenges, please don't hesitate to call us. Reaching out early helps prevent small issues from becoming bigger ones. Thank you for staying connected and involved.

**LEARN MORE ABOUT
CAMP HOT-TO-CLOT ON
PAGE 27!**

MEET WPBDF'S NEW BOARD MEMBER



We would like to give a big welcome to WPBDF's newest member of our Board of Directors, Diane Standish! Diane is a longtime member of the bleeding disorders community. She previously worked as a social worker at the Hemophilia Center of Western Pennsylvania and has continued to volunteer with WPBDF and Camp Hot-to-Clot. Learn more about Diane below!

1. What influenced you to get involved with the Foundation and join our board of directors?

The Foundation has long been a favorite organization of mine, as a professional and as a volunteer. The staff members and board members are so committed to serving our bleeding disorders community, even though it often means working evenings and weekends, and repeatedly figuring out how to stretch limited dollars. When the opportunity arose to contribute to their efforts as a board member, I took it!

2. What is your background or current occupation?

I'm an adjunct faculty member at Butler County Community College, teaching psychology and social work classes since 2018. Prior to that, I was one of the social workers at the Hemophilia Center of Western PA for a long time.

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

I'm excited about supporting the high-quality programs that already exist, and helping to create new programs and events that meet the needs of people with bleeding disorders. And seeing familiar faces at Foundation events is always a reward!

4. What do you like to do for fun?

In no particular order: travel, try new restaurants, swim, go for walks, read, get together with friends, and did I mention travel? :)

WPBDF ATTENDS THE PASNAP CONFERENCE

Early diagnosis is key to reducing suffering, avoiding unnecessary procedures, and preventing long-term damage from untreated bleeds. We recognize that school nurses play a critical role in the health and well-being of students. When students who experience frequent or heavy nosebleeds, or heavy or prolonged menstrual bleeding, are seen by the school nurse, nurses are in a unique position to identify those who may be at risk of having a bleeding disorder. They can share information with parents who can seek further evaluation for their child.



As part of our continued effort to raise awareness among school nurses, the Western and Eastern Pennsylvania Bleeding Disorders Foundations hosted an exhibit at the Pennsylvania Association of School Nurses and Practitioners conference, held in State College, PA on Saturday, March 21. This was the third year the Foundations participated in the event.

This year, Janet Barone, WPBDF Program Director, Autumn

Moore, WPBDF Board Member, Sarah Pilacik, EPBDF Executive Director, and Lisa Lee, EPBDF Assistant Director, represented the Foundations and engaged with over 100 school nurses! Attendees received a package containing literature about bleeding disorders, including handouts they can share with students and their parents, as well as nosebleed kits, and period kits for students.

A POWERFUL DAY OF CONVERSATION, CREATIVITY, AND COMMUNITY: DISMISSED SCREENING RECAP

On Saturday, March 14, WPBDF partnered with Sanofi to host a special community screening of the documentary *Dismissed* at the Sheraton at Station Square. The film, which highlights the

experiences of women and girls with bleeding disorders and the challenges they often face in receiving recognition and care, sparked an important and meaningful conversation within our Western Pennsylvania community.

Following the screening, Katherine Bush, HCWP Social Worker, facilitated a thoughtful and open discussion about how the film resonated with attendees. Participants reflected on the emotional and physical impact of being dismissed in healthcare settings, the stigma that still surrounds menstruation and women's bleeding experiences, and the very real phenomenon

of impostor syndrome that many women with bleeding disorders face. The conversation also focused on how education, advocacy, and community support can help ensure women are heard, believed, and diagnosed earlier.

We were especially honored to welcome Dawn Rotellini, Chief Operating Officer of the National Bleeding Disorders Foundation and one of the stars of the film. Dawn shared her personal journey to diagnosis and offered powerful insight into the importance of amplifying the voices of women and girls within the bleeding disorders community. Her presence made

the conversation even more impactful, reminding us that progress happens when stories are shared and voices are lifted.

After the discussion, attendees continued connecting over lunch before participating in a series of creative and service-oriented activity stations. Community members worked together to assemble period packs that will be distributed to local school nurses, helping ensure students have access to essential menstrual supplies. Participants also wrote kindness cards that will be included in the packs to provide encouragement and support to students who may be navigating their periods or bleeding symptoms for the first time.

Additional activities included sharing experiences and messages on our *Dismissed* Wall, creating “My Voice” affirmation flags with messages like “I speak up” and “I matter,” and decorating mini canvases that will be displayed in the WPBDF office as a reminder of the strength and voices within our community.

The day was a powerful example of what happens when our community comes together to listen, learn, and support one another. The openness and honesty shared throughout the conversation demonstrated how important it is to continue creating spaces where women and girls with bleeding disorders feel seen, heard, and believed.

Strengthening Our WGPPM Initiative

This event is part of WPBDF’s ongoing commitment to strengthening our Women, Girls, and People with the Potential to



Menstruate (WGPPM) Initiative. Through this program, we aim to increase awareness, provide education, and support earlier recognition and diagnosis of bleeding disorders in women and girls.

Our WGPPM efforts focus on:

- Expanding education and outreach to school nurses and educators
- Providing resources and information to students and families
- Increasing awareness on college campuses
- Creating supportive spaces for women and girls in our community to share experiences and learn from one another

How You Can Get Involved

There are many ways you can help support and grow this important initiative:

- Volunteer to help assemble period packs or support future outreach efforts.
- Help connect us with

schools or school nurses who may benefit from education and resources.

- Share information about bleeding disorders in women and girls within your networks.
- Participate in future WGPPM events and discussions.

Every conversation, connection, and shared story helps move this work forward.

If you are interested in getting involved with our WGPPM initiative or learning more about upcoming opportunities, please contact Kara Dornish at kara@wpbdf.org.

Together, we can continue building a community where women and girls with bleeding disorders are recognized, supported, and empowered.





SUNDAY, MAY 31, 2026

**COBBLEHAUS BREWING COMPANY
1021 5TH AVE,
CORAOPOLIS, PA 15108**

**Check-in & Warm-up Begins at 1:00 PM
Tournament Begins: 1:30 PM**

SOCIAL DIVISION:

COST PER TEAM OF TWO

**Early Bird: \$40
(NOW THROUGH APRIL 1)**

Regular Price: \$50

**PRIZING: 1ST PLACE TEAM: \$100
(WINNER TAKES ALL)**

COMPETITIVE DIVISION:

COST PER TEAM OF TWO

**Early Bird: \$50
(NOW THROUGH APRIL 1)**

Regular Price: \$60

**PRIZING: 1ST PLACE TEAM: \$400
2ND PLACE TEAM: \$200
3RD PLACE TEAM: \$100**

Get ready for an afternoon of bags, brews, and bragging rights! Enjoy delicious brews made by Cobblehaus Brewing Company, with \$1 from each purchase of our special bleeding disorders brew being donated back to WPBDF and WVBDF! Participants who raise \$25 by Friday, April 24, will receive a commemorative event t-shirt as a thank-you for supporting the bleeding disorders community!

This is a double-elimination tournament, professionally managed by Steel City Cornhole.



Register online at: bit.ly/wpa_wv_cornhole



THE DANGERS OF DIETARY SUPPLEMENTS FOR PEOPLE WITH BLEEDING DISORDERS

Some common “natural” remedies can interfere with your body’s ability to clot.

RITA COLORITO

Supplements can seem like a harmless addition to your wellness routine. The reality is, unlike prescription medications, the U.S. Food and Drug Administration does not have the authority to approve dietary supplements for safety and efficacy before they hit store shelves. When it comes to bleeding disorders, some supplements may even prove harmful.

“We don’t always know the mechanism of harm for these supplements. And it’s not just patients with bleeding disorders, but all individuals,” says Rajiv Pruthi, MBBS, a hematologist at the Mayo Clinic in Rochester, Minnesota. As director of the Mayo Clinic’s hemophilia treatment center and co-director of the Special Coagulation Laboratory, Pruthi conducts both patient-centered clinical research and laboratory research.

However, most research on

supplements and bleeding focuses on people without bleeding disorders. Pruthi says that while there isn’t much clinical evidence on how specific supplements affect people with bleeding disorders and which they should avoid, research does find that certain supplements may cause harm in two different ways:

Supplements May Increase Surgical Bleeding

According to a **2021 report in Mayo Clinic Proceedings** on the preoperative management of surgical patients using dietary supplements, these include:

- Garlic extract
- Ginkgo biloba
- Glucosamine/chondroitin

Even people without bleeding disorders should avoid these supplements, especially before they’re scheduled to have surgery, Pruthi says.

Supplements Can Affect Platelet Function

These include:

- Flaxseed
- Grapeseed
- Melatonin

Both platelets and clotting factors make up your blood’s coagulation system – the process that stops bleeding when a blood vessel gets injured. “If you already have a compromised coagulation system, and then you’re just adding another variable that impacts your coagulation system, it has the significant potential to cause harm,” Pruthi explains.

How to Take Supplements Safely

Before you take any supplement, always talk to your primary care doctor and consult the hematologist at your hemophilia treatment center. “My general advice is not to take supplements, especially if there is no clear benefit and also because of the unknowns,” Pruthi says.

A daily multivitamin is one exception. “Most multivitamins are pretty straightforward and have micronutrients that are very important for bodily functions,” Pruthi says. “But usually you should get everything you need in a well-balanced diet.” To be on the safe side, read the label to make sure none of the ingredients that can affect bleeding are in your multivitamin.

Your primary care provider can also make sure that what you want to take is safe for you and your medical history. Through blood tests, they can also check for common vitamin deficiencies and recommend vitamin supplements that make sense for you to take. When in doubt, always ask.

NBDF’s **Steps for Living** website has more information about dietary supplements and bleeding disorders.

Article Courtesy of HemAware copyright 2026.

THE POWERFUL IMPACT OF PROCLAMATIONS

CONTINUED FROM PAGE 15...



Mason B. shared how he received his bleeding disorders diagnosis with the Beaver County Board of Commissioners and accepted a proclamation for Bleeding Disorders Awareness Month with his family, Heather K. and Ian S. (above).

Morgan and Corry W. attended the Westmoreland County Board of Commissioners meeting with their children to accept a proclamation on behalf of the Foundation (left).



Angela D. accepts a proclamation from the Cambria County Board of Commissioners.

IT TAKES A TEAM

A NEW PARENT NETWORK PROGRAM

New Parent Network families gathered virtually on March 22 for an educational program, *It Takes A Team*, designed specifically for caregivers of young children with bleeding disorders. The session covered various aspects of managing bleeding disorders in pediatric patients, aged 0-7 years. Dr. Frederico Xavier, Associate Professor of Pediatric Hematology/Oncology, University of Pittsburgh, UPMC Children's Hospital of Pittsburgh, and Pediatric Director, The Hemophilia Center of Western PA, presented the program.

Dr. Xavier addressed a wide range of topics including the different types of hemophilia and von Willebrand disease, prophylactic treatments, emergency care protocols, and the importance of effective communication with healthcare providers. He stressed that *everyone* bleeds

and emphasized that having a bleeding disorder doesn't make someone more fragile but rather affects how long bleeding lasts.

Dr. Xavier also answered specific questions from parents about managing mouth bleeding concerns, bruising concerns, and the appropriate use of medications such as Amicar (aminocaproic acid). He encouraged parents to share the Emergency Department letter provided by the HCWP with their child's primary care physician, in addition to bringing it with them to hospital emergency room visits.

The discussion also covered the role of hemophilia centers in providing comprehensive care and support for families, including coordination with daycares and other healthcare providers.

If you have a child aged 0-7 who has a bleeding disorder and would like more information about New Parent Network events or would like to be matched with a mentor

family, please contact either Janet Barone (janet@wpbdf.org) or Kathaleen Schnur (kschnur@vitalant.org).

We are grateful to the following for sponsoring the 2026 New Parent Network series of events.

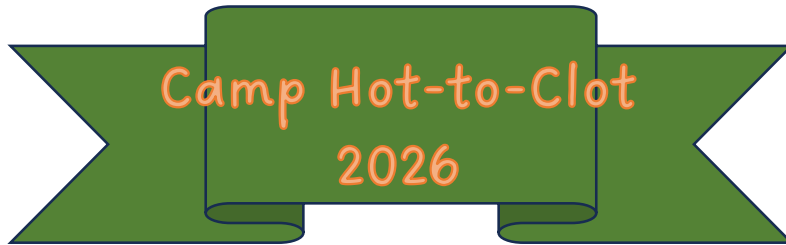
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of Western Pennsylvania


novo nordisk®

sanofi



What is it? Camp Hot-to-Clot is a *free overnight summer camp* in Western Pennsylvania for youth (aged 7-17 years) with a bleeding disorder or a sibling with a bleeding disorder. Affected campers must have a current clinic appointment on file, and if space is limited, preference is given to HCWP patients.

When is it? July 26-July 31, 2026

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

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

How do I sign up? The YMCA is using new registration software this year. Follow the steps below:

STEP 1

Register for a CORE account. Enter the following web address or scan the QR Code.

<https://bit.ly/core-account>



STEP 2

Watch this video to see a sample registration (the example mentions a fee, but please note our camp has no fees)

<https://bit.ly/h2c-reg-video>



STEP 3

Complete the Camp Hot-to-Clot registration. Enter the following web address or scan the QR Code.

<https://bit.ly/campH2C-2026>



Please email the camp at campkon-o-kwee@ymcapgh.org with questions about this process & email Katherine (kbush@vitalant.org) if you would like these links emailed to you. We will complete the bleeding disorder health form for all HCWP patients, and you may need additional forms for other significant healthcare/behavioral needs to determine if your youth is a good fit for camp.

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

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



WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

443 State Avenue
Suite 4
Beaver PA 15009



ALL AGES ARE WELCOME!



STAY IN MOTION

Western Pennsylvania Bleeding Disorders Foundation

EDUCATION WEEKEND

JUNE 12-14, 2026

SEVEN SPRINGS MOUNTAIN RESORT

777 Water Wheel Drive
Champion, PA 15622

**REGISTRATION
NOW OPEN!**

To request a registration form, send an email to rsvp@wpbdf.org or call 724-741-6160. Once approved, you will receive a link to fill out your registration form online.

**LEARN MORE AT:
WPBDF.ORG/EVENTS**



HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

433 State Avenue, Suite 4
Beaver, PA 15009
Phone: 724-741-6160
info@wpbdf.org