WPBDF
Western Pennsylvania
Bleeding Disorders Foundation

HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

FALL 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

November 6-8, 2026
Teen Retreat
Promise Camp & Retreat Center
Clinton, PA

November 20 - 22, 2026
Women's Retreat
Hershey Lodge
Hershey, PA

December 5, 2026
Winter Program
National Aviary
Pittsburgh, PA

December 8, 2026
Stakeholder Meeting
Hilton Harrisburg
Harrisburg, PA

March 3-5, 2027
NBDF's Washington Days
Washington D.C.

March 18, 2027
Paint and Sip Fundraiser
The Hive on 3rd
Conway, PA

March 20, 2027
Pediatric Infusion Education & Hands-On Training
Hemophilia Center of Western PA
Pittsburgh, PA

April 17, 2027
World Hemophilia Day Event
Monterey Bay Fish Grotto
Pittsburgh, PA

May 2-3, 2027
Advocacy Ambassador Education & Training
Hilton Harrisburg
Harrisburg, PA

May 16, 2027
Cornhole Tournament
Cobblehaus Brewing Company
Coraopolis, PA

June 11, 2027
New Parent Network
Oglebay Resort
Wheeling, WV

June 12, 2027
Regional Summer Education Day
Oglebay Resort
Wheeling, WV

July 10, 2027
Annual Meeting
Discovery Church
Mars, PA

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

COMMUNITY ANNOUNCEMENTS

OUR NEWSLETTER IS GOING DIGITAL IN 2027!

Beginning in Spring 2027, our newsletter will transition to a digital format. This change will help us reduce printing and mailing expenses, allowing us to be thoughtful stewards of the resources entrusted to us while continuing to share the news, stories, and updates that keep our community connected.

We recognize that some of our readers prefer receiving a printed newsletter, and we want to honor that preference. If you would like to continue receiving a physical copy by mail, please let us know!

To request a printed copy, please call the Foundation office at 724-741-6160, email info@wpbdf.org with your name and mailing address, or complete our short online form by scanning the QR code below.

Scan the QR code or visit:

bit.ly/hemogramprint

Thank you for your continued interest, support, and commitment to our mission. We look forward to staying connected with you in 2027!

CONTACT US

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LETTER FROM THE EXECUTIVE DIRECTOR



Dear Foundation Members and Friends,

What an incredible few months it has been for our Foundation! As I reflect on everything we've been doing, I am reminded of just how special our bleeding disorders community is and how grateful I am for the people who make it all possible.

We had some exciting news at this year's National Bleeding Disorders Foundation's Bleeding Disorders Conference (BDC)! Our Teen Retreat received the Ziggy Douglas Innovation in Youth Programming Award! I couldn't be prouder of Janet Barone, our Program Director, and Katherine Bush, Clinical Social Worker at the Hemophilia Center of Western Pennsylvania, for the heart and dedication they put into making this program such a meaningful experience for our teens. What an honor to see their hard work recognized nationally!

We also had the opportunity at BDC to present a poster highlighting our school nurse outreach through our Women, Girls, and People with the Potential to Menstruate (WGPPM) initiative. It was wonderful to connect with bleeding disorders foundations from across the country and share our resources and experiences. Our hope is that similar outreach efforts will grow in communities nationwide, and we are always happy to share what we've learned and help others get started!

And what an amazing day we had at our Unite for Bleeding Disorders Walk and Run for Their Lives 5K! Our community showed up in such a big way, helping us raise close to $70,000! A huge thank you to Jessica Lee, our Development Director, for all the hard work she put into making this event such a success. Seeing so many families, friends, and supporters come together was such a wonderful reminder of what makes our bleeding disorders community so special. Thank you to everyone who made the day possible!

We've also been busy spreading awareness throughout Western Pennsylvania! From health fairs and community events to connecting with school nurses throughout our 26 counties, we are working hard to reach more individuals and families. Some of our recent outreach has taken us to Penn State Beaver, Penn State DuBois, Midland School District, Penn Hills School District, and Westmont Hilltop School District, just to name a few! Every opportunity to connect with new people helps us spread awareness and share the resources available to our community.

We've been fortunate to have some wonderful community partners join these efforts! After connecting at a University of Pittsburgh volunteer fair, we partnered with GIFT (Giving It Forward, Together), an organization that brings seniors and students together to build meaningful relationships. Together, they assembled period packs to support this important outreach initiative! Volunteers from Carnegie Mellon University also assembled period packs, while the amazing staff at Precision Copy Products put together nosebleed kits. A special thank you to all the incredible volunteers who have joined us at outreach events, helped assemble kits, and delivered resources. We couldn't do nearly as much without you!

I also want to remind everyone about upcoming Medicaid changes that could have a very real impact on individuals and families. If you or a loved one receives Medicaid, please keep your contact information updated, watch for renewal notices, and respond to requests for information. Visit https://wpbdf.org/advocacy for updates and resources. We are here to help connect you with support if you have questions!

As we head into the final months of the year, I just want to say thank you. I am so proud of our small but mighty team and the incredible community we are fortunate enough to serve. We have so much to be grateful for, and I look forward to all that we will accomplish together!

With gratitude,

Kara Dornish
Executive Director, WPBDF

LETTER FROM THE BOARD PRESIDENT



In the bleeding disorder industry, the latest hot topic has been the care and diagnosis of women. I can't look at my inbox or news feed without seeing an article about the never-ending challenges women face within our community. I love that this topic is finally getting the attention it deserves, but this isn't new for us in Western Pennsylvania. We've been working both behind the scenes and publicly for years on this initiative—particularly with our Women, Girls, and People with the Potential to Menstruate (WGPPM) initiative, which has reached over 293 schools, 6 college campuses, and 53 local libraries. Propelling WPBDF into one of the top allies for women with bleeding disorders!

In 2023, we officially launched our WGPPM initiative by empowering some of the best allies we could think of: school nurses. School nurses are the front line responders when it comes to our children's health. They often know our children's "baseline" health better than their pediatricians because they see them daily.

I remember when we first started discussing this program and feeling a special connection to it. My high school nurse went above and beyond to make sure I was well taken care of during my time at school. Keeping a copy of *A Guide to Living with Von Willebrand Disease* by Laureen A. Kelley and Paul Clement on her bookshelf and coming up with creative solutions to my bleeding issues.

WPBDF's goal is to continue empowering our local community leaders with educational information about bleeding disorders, ultimately ensuring those living with a bleeding disorder get diagnosed sooner. Earlier diagnoses improve outcomes and quality of life. And it's working! Since launching this initiative, we have received confirmation of eight bleeding disorder diagnoses among individuals reached through our outreach kits.

This summer, Kara Dornish had the opportunity to present an abstract poster on our initiative at NBDF's annual Bleeding Disorders Conference in Orlando, Florida, helping bring national recognition to this effort. This program is one of the first of its kind, and other local chapters are already interested in starting their own versions.

From a financial perspective we have been able to keep the cost of each kit low thanks to volunteers who donate their time to assemble them. With the current rising cost of goods (and, well, everything!), volunteers are essential to keeping this mission going.

We're also very thankful to our sponsors for investing in women's health and providing the funds needed to supply these kits.

While industry sponsorship is ever changing, WGPPM continues to generate strong interest, and we're hearing a lot of excitement from our sponsorship partners. Please take a look at our acknowledgments page by scanning the QR code below.

As the board remains committed to addressing the evolving needs of our community, I hope you are as excited as I am about the huge strides we've been able to make right here in Western PA!

Samantha Short
Board President, WPBDF

To learn more about our WGPPM Initiative and our supporters, please scan this QR code or visit:

bit.ly/wgppm-acknowledgments

ADVOCACY UPDATE

AMERICAN SOCIETY OF HEMATOLOGY LETTER TO CDC DIRECTOR DR. ERIKA SCHWARTZ

The Western Pennsylvania Bleeding Disorders Foundation joined the American Society of Hematology and more than 50 organizations representing the blood disorders community in sending a letter to newly appointed CDC Director Dr. Erika Schwartz.

Together, we are urging CDC leadership to fully restore the Division of Blood Disorders and Public Health Genomics to full operational capacity, address recent disruptions, and ensure the continuity of its critical programs and services.

A copy of the letter has been reprinted in this article for your convenience.

September 4, 2026
Erika Schwartz, MD, MPH, JD
Director
Centers for Disease Control and Prevention
1600 Clifton Road
Atlanta, GA 30329

Dear Dr. Schwartz,

The undersigned organizations, representing individuals living with blood disorders, health care providers, researchers, and public health professionals, congratulate you on your confirmation as Director of the Centers for Disease Control and Prevention (CDC). As you begin your tenure and assess the agency's priorities, we welcome the opportunity to support your efforts to strengthen CDC programs that support Americans living with blood disorders. We look forward to working with you and your team to advance the CDC's public health mission and improve outcomes for patients and communities across the country.

For more than 50 years, the CDC's Division of Blood Disorders & Public Health Genomics (DBDPHG), housed within the National Center on Birth Defects and Developmental Disabilities (NCBDDD), has played a unique and critical role in supporting people living with blood disorders. The Division works with states, health care providers, treatment centers, researchers, patients, and families to advance surveillance, data collection, laboratory services, technical assistance, and public health programs addressing conditions including sickle cell disease (SCD), hemophilia, thalassemia, blood clots, and other inherited and acquired blood disorders.

DBDPHG's work has produced meaningful public health and patient benefits. For example, the Sickle Cell Data Collection (SCDC) Program has helped states and other grantees collect and analyze longitudinal data on health care utilization, complications, treatment, and outcomes among people living with SCD. These data help providers and public health officials identify gaps in care, improve coordination, and better understand the needs of individuals living with SCD. Similarly, CDC supported hemophilia programs and research have contributed to improvements in the early identification and management of inhibitors, which can cause serious and potentially life-threatening complications for people with hemophilia. Additionally, people at highest risk for blood clots are using CDC supported or developed tools to recognize symptoms and seek timely care, improving outcomes for nearly 900,000 people each year.

These successes demonstrate why sustained federal leadership and expertise are essential. DBDPHG's programs depend on experienced staff who possess the technical knowledge, institutional expertise, and relationships necessary to administer grants, maintain surveillance systems, analyze data, provide technical assistance, and coordinate with states, providers, and communities. Funding alone cannot ensure that these programs function effectively without the personnel necessary to carry out this work. Unfortunately, DBDPHG has not been operating at full capacity for more than a year following significant staffing disruptions. With 29 of the Division's 32 staff placed on administrative leave, the resulting loss of institutional knowledge, technical expertise, and leadership has affected the states, grantees,

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ADVOCACY UPDATE

CONTINUED FROM PAGE 5...

providers, and patients that rely on the Division.

The consequences are already being felt across the blood disorders community. The SCDC Program has experienced disruptions affecting the flow of aggregated data to clinics, including information that may not be available through other sources, such as prescription fills and emergency department utilization. In hemophilia, Community Counts supports surveillance across more than 140 Hemophilia Treatment Centers and provides free inhibitor testing to eligible patients. Inhibitors prevent clotting factor treatments from working effectively and are among the most serious complications of hemophilia. People with hemophilia who develop an inhibitor are twice as likely to be hospitalized for a bleeding complication and are at increased risk of death, underscoring the importance of maintaining access to regular inhibitor testing. For individuals living with thalassemia, DBDPHG provides clinical education and strategic planning that help providers deliver appropriate care to patients who require lifelong transfusions. The Division's monitoring of blood and blood products and transfusion-related complications also helps promote safer transfusions and prevent infections. More broadly, disruptions to federal coordination, surveillance, data collection, grant administration, and technical assistance risk creating gaps in care and public health infrastructure that cannot be quickly or easily restored.

These challenges are particularly concerning because the Division and its programs continue to receive congressional support. Congress has appropriated funding for these activities because they provide unique public health functions that are not readily replicated elsewhere. The issue is therefore not simply whether these programs are funded, but whether the Division has the staffing, leadership, and expertise necessary to ensure that those federal investments are used as Congress intended.

As you assess the CDC's structure and priorities, we respectfully ask you to:

- **Restore DBDPHG to full operational capacity** by ensuring that the Division has sufficient qualified staff, leadership, and technical expertise to fulfill its statutory mission.
- **Ensure continuity of DBDPHG's core programs and functions,** including surveillance, data collection, laboratory services, grant administration, technical assistance, and coordination with states, providers, researchers, and patient communities.
- **Assess and address the disruptions that have occurred over the past year**, including gaps in surveillance, data collection, grant implementation, laboratory services, and technical assistance, and take steps to restore continuity where necessary.
- **Engage directly with patients, providers, grantees, states, and other stakeholders** to understand the impact of these disruptions and ensure that the Division's programs continue to address the needs of the communities they serve.

The blood disorders community stands ready to work with you and the CDC to ensure that DBDPHG can continue its longstanding work to prevent complications, improve health outcomes, strengthen public health surveillance, and support the patients and families who depend on these programs.

We urge you to restore DBDPHG's staffing, leadership, and operational capacity as an early priority of your tenure. Congress has recognized the importance of these programs through continued authorization and funding.

Thank you for your leadership and consideration. We look forward to working with you and your team to strengthen the CDC's efforts on behalf of people living with blood disorders.

To see the full list of organizations that signed onto this letter, please visit: https://wpbdf.org/blood-group-letter-to-cdc-director-dr-erica-schwartz/

SIGN UP TO RECEIVE ADVOCACY ACTION ALERTS!

SCAN THIS QR CODE!

FED UP ACT TARGETS BARRIERS FACED BY WOMEN AND GIRLS WITH BLEEDING DISORDERS

On May 22, Representatives Julie Johnson (D-TX-32), Joe Wilson (R-SC-02), and Rep. Sarah McBride (D-DE-At Large) introduced the Fostering Effective Diagnosis and Treatment for Underserved Populations with Bleeding Disorders Act (FED UP with Bleeding Disorders Act, H.R. 8794), federal legislation introduced in the United States Congress aimed at improving diagnosis, treatment, and research equity. The bill is a key advocacy priority of the National Bleeding Disorders Foundation (NBDF).

Women and Girls Face Delayed Diagnosis of Bleeding Disorders

For decades, bleeding disorders—particularly hemophilia—have been commonly associated with men by both medical professionals and the general public. At the same time, women and girls with bleeding disorders ranging from hemophilia to von Willebrand disease (the most common inherited bleeding disorder), have faced a different but significant challenge: their symptoms are frequently overlooked or misattributed. Heavy menstrual bleeding, one of the most common symptoms of bleeding disorders in women, is often normalized or not recognized as a sign of an underlying condition, which can contribute to delayed diagnosis and gaps in care.

"I was 27 years old when I was diagnosed with von Willebrand disease, after years of symptoms and inadequate care," said Candi Mitchum, Vice President of the Bleeding Disorders Association of South Carolina, who is a constituent of Representative Wilson and who advocated for the legislation at Washington Days. "No one should have to wait that long for answers."

The National Bleeding Disorders Foundation and advocates across the bleeding disorders community have worked to address this longstanding misconception, raising awareness of the unique ways bleeding disorders present in women and girls and promoting earlier diagnosis and improved access to care.

"NBDF and the bleeding disorders community have worked tirelessly to bring visibility to the unique challenges faced by women and girls," said Dawn Rotellini, chief operating officer of the National Bleeding Disorders Foundation. "For far too long, women and girls have been blocked from timely diagnosis, comprehensive care, and inclusion in clinical research."

FED UP Act Targets Research, Treatment, and Awareness Gaps

The Fostering Effective Diagnosis and Treatment for Underserved Populations with Bleeding Disorders Act reflects these sustained advocacy efforts. The legislation calls for a coordinated, interagency review across federal health programs and agencies to evaluate and update programs, activities, and strategic plans related to women and girls with bleeding disorders. Key focus areas include scientific research, access to care, provider training and education, and inclusion in clinical trials. The bill also requires the development of a national public education and awareness campaign aimed at improving recognition, diagnosis, and treatment among both patients and healthcare providers.

Momentum for this legislation has been supported by ongoing engagement between the bleeding disorders community and policymakers in the United States Congress. In April 2025, the National Bleeding Disorders Foundation convened a Capitol Hill Day dedicated to women and girls with bleeding disorders, bringing advocates to Washington to share their experiences and outline urgent needs. Building on that effort, community members continued their advocacy during Washington Days 2026, educating Congressional offices and urging action on this issue.

"This legislation represents meaningful progress toward breaking down those barriers and ensuring future generations receive the care and recognition they deserve," said Rotellini.

How You Can Help

Send a message to your Representative today asking that they cosponsor H.R. 8794, the FED UP with Bleeding Disorders Act. This bipartisan legislation is currently only introduced in the House of Representatives, but NBDF will expand this action alert to the Senate once the bill is introduced there.

You can send an email with one, easy click at: https://bleeding.quorum.us/campaign/FEDUpAct/

This press release was published by the National Bleeding Disorders Foundation on May 22, 2026.

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POURS FOR A PURPOSE AT THE RIVERS CLUB!

WPBDF partnered with the Rivers Club to host our Purpose & Pours Happy Hour on Wednesday, July 8, and what an incredible evening it was!

Our celebrity bartender, Mindy P., served up a delicious blood orange margarita while sharing her personal connection to the bleeding disorders community and why WPBDF has been so important to her family. Her son, Ryker, even joined in on the fun by pouring the mocktail version of the margarita!

Together, we celebrated the incredible strength and resilience of the bleeding disorders community while raising awareness and funds to support WPBDF's mission. Thanks to the generosity of our guests and supporters, we raised an incredible $958!

Thank you to everyone who joined us for an evening filled with connection, community, and purpose. Your support helps WPBDF continue providing education, advocacy, and resources to individuals and families affected by bleeding disorders across Western Pennsylvania.

A special thank you to Mike and Michelle P. for donating an amazing Steelers raffle basket featuring items signed by Rocky Bleier, and for selling tickets for our 50/50 raffle!

We're so grateful to everyone who helped make this event a success. Cheers to community, connection, and making a difference together!









CELEBRATING 25 YEARS OF CAMP HOT-TO-CLOT!

KATHERINE BUSH, LCSW

We at HCWP are so happy to share that another wonderful experience was had at Camp Hot-to-Clot this year! A total of 50 campers ages 7 to 17 years old attended, including both patients and their unaffected siblings. We had some of the most beautiful camp weather we have ever had, and this meant we got to enjoy the full range of camp activities- such as gaga, BBs, campfires, fishing, and so much more!

This was an incredibly special year in so many ways–the 25th year since the beginning of Camp Hot-to-Clot, the 100th year since the beginning of Camp Kon-o-Kwee (our host camp), and the 100th year since the discovery of von Willebrand Disease. We took time to recognize how much treatment for bleeding disorders has improved, explored how kids spent their free time 100 years ago, and celebrated the relationships that have formed during our camp years and that we continue to grow today. We even planted a tree as a symbol of our roots in this community, and to provide us with beautiful shade as we continue to experience many more years of camp together.

We always say that camp is a place not only to have fun (and we do have a lot of fun!), but also to grow in independence, grow in relationships, and grow in knowledge of bleeding disorders. This year, our campers integrated with some of the Kon-o-Kwee general session campers in more activities than they have in past years, while also spending time with other Hot-to-Clot campers in dedicated activities for our group and in their cabin/lodge. This gave our campers the chance to spend time building relationships with other youth with bleeding disorders (a rare opportunity) while also teaching them to navigate activities outside of our small group. It taught the rest of the camp about bleeding disorders, and the other counselors and campers got to see just what our campers are capable of–which is just about anything they put their minds to! Also, our campers spent some time both as a large group and in small groups learning about bleeding disorders in general as well as their specific diagnosis and how to manage it.

The staff at HCWP thank the staff of WPBDF and all of the amazing volunteers who support camp. It wouldn't be possible without you! We also thank all the parents and guardians who entrusted us with their children for a week of camp.

We had a fantastic time! Camp is a great opportunity for our HCWP staff to know your children outside of the clinic walls and see them in an atmosphere where they get to learn, grow, and have fun! We are already looking forward to next year!



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Blood unites us in powerful ways. As a Community Relations and Education (CoRe) Manager for Sanofi, I'm here to be a source of education for you and others living with hemophilia.

Paul Brayshaw
CoRe Manager
Maryland and Western PA



Let's connect.

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CELEBRATING OUR COMMUNITY AT THE 2026 ANNUAL MEETING

On July 11, nearly 100 community members gathered at the Erie Bayfront Convention Center for our 2026 Annual Meeting, a day dedicated to celebrating our community, reflecting on the Foundation's accomplishments over the past year, and looking ahead to all that is still to come.

During the Annual Meeting, we shared highlights from another busy year of education, support, advocacy, outreach, and community connection. We also officially kicked off the 2026 Unite for Bleeding Disorders Walk! A special thank you to our Walk Co-Chair, Lauren Rhodes, for helping lead the excitement and sharing during the Walk Kick-Off. We are so grateful for Lauren's enthusiasm and commitment to making this year's Walk a success!

Following the meeting, attendees took part in a special panel discussion reflecting on the legacy of the bleeding disorders community and just how far we have come. Panelists shared personal stories and perspectives on the incredible advancements in treatment, diagnosis, and care that have transformed what it means to live with a bleeding disorder.

A special thank you to Diane Standish for serving as our moderator and to our wonderful panelists, Nikole, Justin, Trina, Sheryl, and Dave, for sharing their experiences so openly. Hearing from different generations of our community was a powerful reminder of the progress that has been made, the challenges that remain, and why continuing this work matters.



Our wonderful panelists and moderator (from left to right): Dave Macharola, Diane Standish, Sheryl B., Trina G., Justin N., and Nikole S.





After the program, families received Wally Cards and headed to Waldameer Park to enjoy an afternoon of rides, games, and time together!

Thank you to everyone who attended, volunteered, presented, and helped make this year's Annual Meeting such a meaningful day. Most importantly, thank you to our community for continuing to believe in and support our mission. Together, we are honoring the legacy of those who came before us while building an even stronger future for the bleeding disorders community.

Thank you to our sponsors!

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SUMMER LEARNING, CONNECTION & FUN AT OGLEBAY!

What a great day at Oglebay! On August 22, nearly 100 members of the bleeding disorders community came together at Oglebay Resort for our Regional Summer Education Day, hosted in partnership with our friends at the West Virginia Chapter of the National Bleeding Disorders Foundation.

The day offered a great mix of education, connection, and summer fun. Attendees began the morning visiting with sponsors and exhibitors before taking part in educational sessions designed to provide practical information for living well with a bleeding disorder.

Aaron Blocker from the National Bleeding Disorders Foundation helped families better understand and navigate insurance, while Clayton Kubrick, PT, discussed participation in sports in the era of novel therapies and how advances in treatment are changing possibilities for people with bleeding disorders. Attendees also participated in a mental wellness session focused on navigating difficult conversations, offering helpful strategies for communicating through challenging situations.

After enjoying lunch together, families received activity wristbands and headed out to explore Oglebay. From swimming and mini golf to the zoo and aerial challenge course, there was something for everyone to enjoy.

One of our favorite parts of this event is the opportunity to bring our Western Pennsylvania and West Virginia communities together. The connections made with other families are just as important as the information shared during the educational sessions.

We are incredibly grateful to the families, speakers, sponsors, exhibitors, volunteers, and our friends in West Virginia who helped make the day possible. We love working together to create more opportunities for education, support, and connection throughout our region!

Thank You to Our Sponsors!



NEW PARENT NETWORK BRINGS FAMILIES TOGETHER IN ERIE

On Friday, October 2, seven families joined us at the Hilton Garden Inn in Erie for our New Parent Network, a program for families of newly diagnosed children ages 0–7 who are affected by a bleeding disorder. Families started the evening by breaking the ice with conversation cards, giving everyone an opportunity to get to know one another and begin making connections.

We were grateful to have Kathaleen Schnur, Clinical Social Worker at the Hemophilia Center of Western Pennsylvania (HCWP), present the evening's program. Kathaleen shared helpful insights about navigating a new diagnosis, finding support, and building connections within the bleeding disorders community.

One of the biggest takeaways of the evening was that everyone belongs. Every family's experience is different, and there is no need to compare diagnoses, severity, treatments, or individual journeys. Our community is here to support one another, deepen connections,

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GETTING TO KNOW HCWP STAFF



CHRISTINA CHERKES
CLINIC NURSE

Birthplace: Jacksonville, FL

First job: Dishwasher in a small-town restaurant

Accomplishment you're proudest of: Graduating nursing school with four small children at home

What three words describe you best? Kind, compassionate and passionate

Dream vacation: Bora Bora or the Maldives

Things you can do without: All the hatred we see in the world

Person you'd most like to have dinner with: Nikola Tesla

Movie you could see anytime: *Interstellar*

TV show or podcast you try not to miss: Oldie re-runs

Three things that can always be found in your refrigerator: Water, pickles and ketchup

Secret vice: Music

Who would play you in the movies? No clue

Your pet peeve about Pittsburgh: Driving in the city

People may be surprised to know that: I was raised in Kentucky and am a huge Kentucky Wildcats basketball fan.

A NIGHT TO REMEMBER: WPBDF CELEBRATES RED OUT NIGHT!

WPBDF had an incredible time celebrating Red Out Night at EQT Park with the Washington Wild Things! We're so thankful to the Wild Things for inviting us to be part of this special evening and for helping us spread awareness and education about bleeding disorders throughout the community.

On Tuesday, September 1, the Wild Things took on the Gateway Grizzlies, and WPBDF staff and volunteers were there to join in the fun! Our team welcomed fans to the park with awesome giveaways, educational resources, and plenty of opportunities to chat about bleeding disorders and the importance of awareness. A huge thank you to Diane Standish, Sandy F., Kimmy W., Adam B., Gus B., and Joseph E. for volunteering at our booth and helping make the evening such a success! We couldn't have done it without you!

Fans were encouraged to wear red in support of heart health and bleeding disorder awareness, creating an amazing sea of red throughout the ballpark. There was even more reason to celebrate, as $5 from every ticket purchased for the Red Out game through our unique link was donated back to WPBDF!

We are incredibly grateful to the Washington Wild Things for shining a spotlight on WPBDF and other important charities throughout Western Pennsylvania. It was an honor to be part of such a fun and meaningful event, and we're already looking forward to joining the Wild Things again next year!

Thank you to everyone who stopped by, wore red, shared their support, and helped make Red Out Night one to remember!





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FALL PROGRAM BRINGS EDUCATION AND FUN TO ERIE







On Saturday, October 3, we welcomed nearly 130 members of the bleeding disorders community to our Fall Program at the Ambassador Banquet & Conference Center in Erie, PA!

The day featured an educational session on clinical research and the important role it plays in advancing bleeding disorders care. Dana Ivanco, CCRC, Senior Clinical Research Coordinator at the Hemophilia Center of Western Pennsylvania, provided an overview of the clinical research process and helped families better understand what it means to participate in a research study.

Families learned about the different types and phases of clinical research, why clinical studies are important, protections for research participants, and current and emerging studies involving people with bleeding disorders. Dana's presentation offered valuable insight into how research helps shape the future of treatment and care for our community.

Of course, we made plenty of time for fun and connection, too! Families participated in a fall-themed People Bingo activity, encouraging everyone to mingle, meet someone new, and discover fun facts about others in our community. Following the program and lunch, families received tickets to Splash Lagoon, where they could continue spending time together and enjoy the rest of the day!

Thank you to Dana for sharing her expertise with us and to all of the families and volunteers who joined us in Erie. We are grateful for opportunities like these to bring our community together to learn, connect, and have fun.

A special thank you to our Fall Program sponsors: CSL Behring, Genentech, HemaBiologics, Novo Nordisk, Pfizer, Sanofi, Cottrill's Specialty Pharmacy, InfuCare RX, and the Hemophilia Center of Western Pennsylvania. We look forward to continuing to create opportunities for our bleeding disorders community to connect, learn, and grow together!



HCWP CORNER

KATHALEEN SCHNUR, MSW, LCSW

Hello to all WPBDF Members and Your Families,

There's something about fall that makes change feel a little more noticeable. The leaves start to change, routines shift, kids go back to school, schedules get busier, and suddenly we're wondering how the holidays are already around the corner.

There's a lot of change happening in the bleeding disorder community, too. Treatment options continue to change. Insurance rules and healthcare systems change. Families move through different stages of life. Young people become more independent, and adults take on new jobs, relationships, and responsibilities. And sometimes, what worked for us five years ago, or even last year, may not be what works best today.

Change can be exciting, but it can also feel overwhelming. As a social worker, I often see the parts of living with a bleeding disorder that don't always come up during a medical visit: the phone calls, paperwork, insurance questions, school concerns, financial stress, family issues, and the emotional energy that comes with managing something that doesn't just go away when you leave the clinic.

That's one reason shared decision-making is so important. Your care should not simply happen to you. Your experiences, concerns, priorities, and goals should be part of the conversation.

Maybe you're excited about a new treatment option. Maybe you're not sure about making a change. Maybe what you're doing now is working well for you. Or maybe your biggest concern has nothing to do with treatment. It might be getting medication on time, remembering another appointment, managing work, or figuring out how to explain your bleeding disorder to your kiddo's school.

All of those things matter. Shared decision-making means asking questions, talking about what matters to you, and working with your healthcare team to find an approach that fits your life. There isn't one "right" answer for everyone. Sometimes the right choice is to make a change. Sometimes it's to stay with what is working. Sometimes you need more information before deciding. And as a social worker, I want to remind you that what is happening outside of the clinic matters, too. If stress, finances, transportation, family responsibilities, work, school, mental health, or simply feeling overwhelmed is making it harder to manage your bleeding disorder, please tell us. These aren't separate from your health. They are part of it.

Fall Is a Good Time for a Health Insurance Check-In

Fall is also a good time to take a look at your health insurance. Insurance can be confusing, and there are some important changes coming in 2027.

Medicare Open Enrollment: October 15–December 7, 2026

If you have Medicare, Open Enrollment is a good time to review your coverage for next year. You can look at your Medicare Advantage or prescription drug coverage and make changes if needed. Changes made during Open Enrollment generally begin January 1. You don't have to figure it out by yourself. PA MEDI provides free help with Medicare questions and plan choices. PA MEDI Helpline: 1-800-783-7067- Monday–Friday, 8 AM–5 PM.

Pennie Open Enrollment: November 1, 2026–January 15, 2027

If you get your health insurance through Pennie, Pennsylvania's health insurance marketplace, this is the time to review your plan or choose a plan for 2027. If you want coverage to start January 1, you need to enroll by December 15, 2026. If you enroll between December 16 and January 15, your coverage will generally start February 1. You may also be able to get coverage outside of Open Enrollment after certain life changes, such as losing other health insurance, getting married, having a baby, or moving.

Changes Coming to Medicaid in 2027

Some people with Medicaid will have new rules beginning January 1, 2027.

- **Some people will need to renew Medicaid every six months:** Beginning in 2027, some adults ages 19-64 who receive Medicaid through the expansion program will need to renew their coverage every six months instead of annually. For current recipients, this change will take effect after their next scheduled renewal. You can check your renewal date through COMPASS or the myCOMPASS PA app.
- **Some adults will need to**

meet work or community engagement requirements: Beginning January 1, 2027, certain Medicaid recipients ages 19-64 will need to meet new work, education, or community engagement requirements. However, exemptions are available, including for individuals with certain disabilities, serious or complex medical conditions, and care giving responsibilities. Current recipients will generally need to report that they meet the requirements or qualify for an exemption at their next Medicaid renewal in 2027. If these changes apply to you, PA DHS will send information about what you need to do. Be sure to read and respond to any notices you receive.

- **Medicaid may cover fewer months of past medical bills:** Starting January 1, 2027, Medicaid will cover a shorter period of medical bills from before you applied. For adults ages 19-64 covered through Medicaid expansion, Medicaid may cover up to one month before the application. For other Medicaid recipients, it may cover up to two months.

Insurance changes can be confusing. If you aren't sure what applies to you, please call us. We can help you understand what is happening and connect you with the right resources.

Don't Forget Your Annual Appointment

Fall is also a good time to make sure you have your annual bleeding disorder appointment scheduled. Your annual visit is more than checking a box. It gives you and your care team a chance to step back and look at the bigger picture.

- What is working?
- What has changed?
- Are there new concerns?
- Is your treatment still meeting your needs?
- Are there insurance or financial issues we should know about?
- Do you need help with school, work, transportation, medication, or something else?
- What questions do you have for your care team?

If you haven't been seen in the past year, please call us to schedule your appointment. And if something is making it difficult to come in, call us anyway. Let us know what's getting in the way. We may be able to help.

Your Care Is a Partnership

You don't have to come to your appointment with all the answers. Sometimes the most important thing you can bring is a question. Your healthcare team brings medical knowledge and experience. You bring knowledge about your own life, your priorities, your concerns, your challenges, and what matters most to you. Both are important.

We are here to do more than treat a bleeding disorder. We are here to help you navigate the things that can make living with one more complicated. If you have a question, a concern, an insurance problem, or simply aren't sure where to start, please reach out. You don't have to figure everything out on your own. We are your partners in care, and we're here to help you navigate the changes along the way.

NEW PARENT NETWORK BRINGS FAMILIES TOGETHER IN ERIE

CONTINUED FROM PAGE 12...

and remind families that they are not alone.

Families also reflected on how much bleeding disorders care has changed over the generations. Research, advocacy, comprehensive care, and advances in treatment have created new possibilities for children growing up today. Our community continues to grow and evolve, with each generation helping to make things better for the next.

Thank you to Kathaleen and all of the families who joined us! We are also incredibly grateful to our New Parent Network sponsors. Their support helps us continue creating opportunities for families to learn, connect, and grow together.



WE UNITE: CELEBRATING AN INCREDIBLE 2026 WALK & RUN!



We're excited to share that the 18th Annual Unite for Bleeding Disorders Walk and 17th Annual Run for Their Lives 5K raised more than $69,500—surpassing our $60,000 fundraising goal!

On September 19, our community gathered at the North Park Swimming Pool for a day filled with family, friends, fun, and, most importantly, community. We are incredibly grateful to every walker, runner, sponsor, volunteer, and team captain who helped make this year's event such a success.

From face painting and photo booth fun to carnival games, snacks, and a special visit from Princess Belle, there was truly something for everyone! A huge thank you to DJEN4k, Photo Frenzy, Face Paint Pittsburgh, and Enchanted Experiences for helping make the day extra special. Team Rolling for Ryker also brought back the UNITE Carnival, giving attendees the chance to play classic carnival games and win prizes.

We also highlighted our Women and Girls Initiative by sharing empowerment flags with attendees and celebrating the strength of women and girls in our bleeding disorders community.

So. Many. Snacks! Our snack tent was definitely one of the most popular stops of the day! Thank you to Cottrill's Pharmacy, Culligan Water, Eat'n Park, Heartland Restaurant Group, Santonastasso Enterprises LLC, and Soleo Health for keeping everyone fueled with fresh fruit, coffee, water, Smiley Cookies, donuts, breakfast sandwiches, and granola bars!

Our 27 Walk Teams worked hard all year to raise funds and rally their communities. We are so grateful for every team captain and team member who helped make this year's Walk possible.

Our top fundraisers were also recognized on Walk Day. Congratulations to Conor's Clan, our Top Team, which raised an incredible $5,947! Team captain Emily Nikithser accepted the award and shared her story. Emily walks for her ten-year-old son, Conor, and has been participating since the year he was born. We are so grateful to Emily, Conor's Clan, and

Congratulations to the teams who raised $1,000 or more!

- Conor's Clan - $5,947
- Fox Factor - $3,397
- Rolling for Ryker - $3,046
- WPBDF Board of Directors - $2,652
- RED n' PLENTY - $2,555
- Cameron's Walking Sticks - $2,336
- TJ's Team - $2,309
- Blake's Bloodline - $2,227
- Kara's Crew - $1,955
- Clotting Cavaliers - $1,870
- Maxwell House - $1,768
- Factor 9 KnightCrew - $1,454
- Factor 5 - $1,069



everyone who continues to rally around Conor each year!

Congratulations to our Top Team Captain, Morgan Woods of TJ's Team! Morgan has walked with us since 2023 for her son, TJ, who was diagnosed with Hemophilia A at just six days old. Thank you, Morgan, for your leadership, passion, and dedication to your team and our community!

Our Top Individual Fundraiser was Tracy Sethman, who raised more than $2,500! Tracy and her family are affected by von Willebrand Disease, and they have been walking with us since 2013. From creating raffle baskets and securing team sponsors to volunteering on Walk Day, Tracy gives so much to the Unite Walk. Thank you, Tracy, for all you do!

Finally, our Awesome John Eyrolles Top Youth Fundraiser Award went to Damon and Rylen Fox of Fox Factor, who raised more than $3,000! Damon received this award for the third year in a row, and this year, he shared the honor with his little brother, Rylen. Together, they remind us that you're never too young to make a difference!

We are incredibly grateful to our 2026 Unite for Bleeding Disorders Walk Co-Chairs, Lauren Rhodes and Stephanie Shropshire. Thank you for bringing our community together, championing our mission, and helping make this such a special day!

Our 2026 Top Team T-Shirt contest was another highlight! Ten teams designed their own shirts to

...CONTINUED ON THE NEXT PAGE



Top Team Captain: Morgan Woods



Top Fundraiser: Tracy Sethman



Awesome John Eyrolles Top Youth Fundraiser: Damon and Rylen Fox



Top Team T-Shirt: Blake's Bloodline





Our 2026 Unite for Bleeding Disorders Walk Co-Chairs: Lauren Rhodes and Stephanie Shropshire





celebrate their hard work and fundraising efforts. Thank you to Instant Imprints in Cranberry Township for printing the shirts, UPMC for sponsoring them, and everyone who voted for their favorite design. Congratulations to Blake's Bloodline, our 2026 Top Team T-Shirt! Together, our teams raised more than $300 through the contest!



A special thank you also goes to everyone who earned a place in our Factor Club by raising $500 or more. Medals were awarded to:

- Mandy Aberegg
- Gwen Austin — Clotting Cavaliers
- Lincoln Austin — Clotting Cavaliers
- Fleury Barone — Cameron's Walking Sticks
- Janet Barone — Cameron's Walking Sticks
- Gus Boyle — Kara's Crew
- David Clougherty — Conor's Clan
- Jimmy Cohen — Team Factor 5
- Susie Cohen — Team Factor 5
- Lisa Data — Conor's Clan
- Angela Day — Team Zhi
- Kara Dornish — Kara's Crew
- Kaleb Farmer — Kaleb's Crew
- Damon Fox — Fox Factor
- Rylen Fox — Fox Factor
- Finley Glasgow — Factor 9 KnightCrew
- Grayson Glasgow — Factor 9 KnightCrew
- Lynda Maxwell — Maxwell House
- Jason Miller — 4 Rare Kids
- Autumn Moore — WPBDF's Board of Directors Team
- Conor Nikithser — Conor's Clan
- Eileen Nikithser — Conor's Clan
- Emily Nikithser — Conor's Clan
- Mindy Perry — Rolling for Ryker
- Maurice Prendergast — Conor's Clan
- Blake Rhodes — Blake's Bloodline
- Lauren Rhodes — Blake's Bloodline
- Gabbie Rose — Clotting Cavaliers
- Tracy Sethman — Team Red N' Plenty
- Samantha Short — WPBDF's Board of Directors Team
- Lev Shropshire — Team Factor 5
- Micah Shropshire — Team Factor 5
- Sammi Shropshire — Team Factor 5
- Ryker Stern — Rolling for Ryker
- Ron Weisser — Factor 9 KnightCrew
- Jen Werme — Conor's Clan
- Russell Werme — Conor's Clan
- Morgan Woods — TJ's Team
- Tristen Woods — TJ's Team

RUN FOR THEIR LIVES
Bleeding disorders can't stop us.

Thank you to Miles of Smiles Timing for managing our Run for Their Lives 5K and to everyone who laced up and participated!

We're excited to share that the 5K raised more than $4,000 to support individuals and families affected by bleeding disorders in Western Pennsylvania.

The race was kicked off by Sammi, a 9-year-old who was diagnosed with von Willebrand Disease when she was just 18 months old. We shared a bit of Sammi's story with our runners, and she had the special honor of blowing the starting horn and signaling the start of the race!

Congratulations to our 2026 winners!

Men's Division:
First Place: Robert Rutkowski
Second Place: Brendan Gesselman
Third Place: Rod Clark

Women's Division:
First Place: Kaimakani Digioia
Second Place: Nicki Benvenuti
Third Place: Britt Cranmer

Youth Division (17 and under):
First Place: Jack Glinski
Second Place: Charlie Weiler
Third Place: Julia Weiler

A special thank you to the Appalachian Running Company for providing the awards for our runners!

Most importantly, thank you to everyone who came together to UNITE for bleeding disorders!

100% of the money raised through the Walk and Run stays local, helping us provide patient advocacy, financial assistance for medical bills and travel, knee and elbow braces and other medical devices, free medical ID jewelry, educational programs, community support, and increased awareness of bleeding disorders throughout Western Pennsylvania.

We couldn't do it without you. Thank you for helping us UNITE!







RUN FOR THEIR LIVES
Bleeding disorders can't stop us.

Thank You to Our Sponsors!

Gold Sponsors

BAYER CSL Behring

Special Thanks to

Appalachian Running Company · Culligan Water · Finn Chiropractic

Save the Date!

Unite for Bleeding Disorders

2027 Unite for Bleeding Disorders Walk & Run

September 18, 2027
North Park Swimming Pool
Gibsonia, PA

We can't wait to UNITE with you!

WPBDF OUT IN THE COMMUNITY!

WPBDF has been out and about spreading bleeding disorders awareness! At these events, we shared information about the signs and symptoms of bleeding disorders, as well as the many resources and programs available through WPBDF. Events like these are a great opportunity to reach people who may not know about bleeding disorders or realize that support is available right here in Western Pennsylvania.

We love getting out into our communities, making new connections, raising awareness, and spreading the word that WPBDF is here to help!

If you know of a health fair in your area or are interested in volunteering at our booth in the future, please reach out to us at info@wpbdf.org and let us know!



Community Day 2026 at Community College of Beaver County, Saturday, August 1



Wellness4Schools Symposium, Wednesday, August 19



Carnegie Mellon Volunteer Engagement Fair, Friday, August 28



University of Pittsburgh Pitt Serves Volunteer Fair, Monday, September 14



The Settlers Ridge Health Expo, Saturday, July 25, 2026



Penn State DuBois Health Fair, Wednesday, September 30



Westmont Hilltop School District Health Fair, Monday, October 5

MEET WPBDF'S NEWEST BOARD MEMBER



DAVE MACHAROLA
WPBDF BOARD OF DIRECTORS

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

I decided to join the board after advocating for the bleeding disorders community on critical issues with local representatives, as well as in Harrisburg and Washington, D.C. I have a daughter and grandson with bleeding disorders; advocacy is important because we represent you and your voice to legislators to discuss the issues that are critically important to the bleeding disorders community. We present each issue respectfully, with clear, informative explanations of our position, our request for legislative support, and why adverse decisions may affect the lives of people with bleeding disorders.

2. What is your background or current occupation?

I'm semi-retired, but still practicing as a registered architect and owner of David Macharola Architects.

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

I'm married to Sandy, who advocates with us, and we have three children and six grandchildren. I look forward to serving and giving back to the community that, for my lifetime, provided me with the care I needed because of severe hemophilia B, along with the supportive services that helped me maintain my health and achieve my goals.

4. What do you like to do for fun?

For fun, we love to travel, spend time with family, and enjoy all types of food. To stay in better physical shape, I joined the local gym and do aquatic exercises in a warm pool.

WPBDF RECEIVES THE ZIGGY DOUGLAS INNOVATION IN YOUTH PROGRAMMING AWARD

WPBDF received the Ziggy Douglas Innovation in Youth Programming Award for our Teen Retreat at the National Bleeding Disorders Foundation's Bleeding Disorders Conference, held in Orlando August 13–15! WPBDF Vice President Jason Miller and his daughter, Scarlett, accepted the award on behalf of the Foundation.

This award recognizes chapters that champion, develop, and support the spirit of youth. Donald "Ziggy" Douglas, the former Executive Director of the Hawaii Chapter of NBDF, was a beloved leader who was sadly lost too soon. This award honors his legacy by celebrating chapters that prioritize nurturing the next generation of leaders.

This amazing program is led by two passionate and dedicated individuals, our Program Director, Janet Barone, and Katherine Bush, Cinical Social Worker at the Hemophilia Center of Western PA. Their creativity, commitment, and passion for supporting young people in our community are what make the Teen Retreat so special. We are incredibly proud of Janet and Katherine and grateful for all they do to create meaningful experiences, build connections, and empower the next generation of leaders in the bleeding disorders community. Congratulations, Janet and Katherine, on this well-deserved recognition!



WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION
433 State Avenue
Suite 4
Beaver PA 15009

This event is open to members of WPBDF. Registration is limited to immediate family members living in the household with the person who has a bleeding disorder.

Winter Program

Transportation assistance, in the form of a gas card, is available upon request.

Saturday, December 5, 2026

Join us for a fun-filled day at the National Aviary!

Admission to the Aviary is included!

There's no cost to attend, but registration is required. To register, send an email to rsvp@wpbdf.org or call the Foundation office at 724-741-6160 by Wednesday, November 18. Please provide the following information: first and last name, number of adults, number of children and their ages, and any food or dietary restrictions.



Where? National Aviary, 700 Arch St., Pittsburgh, PA 15212

When? 11:00 AM - 1:30 PM

HEMOGRAM
WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION
433 State Avenue, Suite 4
Beaver, PA 15009
Phone: 724-741-6160
info@wpbdf.org

OUR NEWSLETTER IS GOING DIGITAL IN 2027!

Beginning in Spring 2027, our newsletter will transition to a digital format. If you would like to continue receiving a printed copy, please call the Foundation office at 724-741-6160, email info@wpbdf.org with your name and mailing address, or complete our short online form at bit.ly/hemogramprint.