

OUR IMPACT



WPBDF

Western Pennsylvania
Bleeding Disorders Foundation



WWW.WPBDF.ORG



INFO@WPBDF.ORG



724-741-6160

2024 - 2025 GRATITUDE REPORT

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

TABLE OF CONTENTS

LETTER FROM WPBDF'S EXECUTIVE DIRECTOR	3
2024 - 2025 IMPACT	4
COMMUNITY SPOTLIGHT: TRINA & ORAIA	6
BOARD OF DIRECTORS	8
VOLUNTEER OF THE YEAR	9
TOP VOLUNTEERS	10
SCHOLARSHIP WINNERS	11
WPBDF'S YEAR IN REVIEW	14



LETTER FROM THE EXECUTIVE DIRECTOR

Dear Foundation Members and Friends,

Each year, as we reflect on the work of the Western Pennsylvania Bleeding Disorders Foundation, I am reminded of the strength, compassion, and resilience that define our community. This past year has been no exception. We made meaningful progress together by supporting one another, expanding access to critical resources, and ensuring that individuals and families living with bleeding disorders never feel alone.

One of our most significant milestones this year was the launch of the inaugural Pennsylvania Bleeding Disorders Conference, held in partnership with the Eastern Pennsylvania Bleeding Disorders Foundation. Hosted in Hershey, this landmark event welcomed nearly 400 attendees from across the state and offered 40 dynamic educational sessions tailored for both adults and children. It was a powerful weekend of learning, connection, and community building that left a lasting impact. We are incredibly proud of this achievement and excited to build on its success in the years to come. Throughout the year, we also remained committed to

meeting urgent community needs. We provided over \$50,000 in direct patient assistance to more than 300 individuals, helping cover essential needs such as rent, utilities, transportation to medical appointments, medical ID jewelry, and other critical expenses to ensure uninterrupted access to care. Recognizing that food insecurity remains a significant concern, we continued this vital program and provided nearly \$15,000 in grocery assistance to 36 families, helping to ease a critical burden for those facing financial hardship.

Education and advocacy were key pillars of our work. We trained 28 Advocacy Ambassadors, giving them the tools and confidence to share their stories and advocate for important policy changes. In March, we proudly received 13 proclamations from counties and municipalities across Western Pennsylvania in recognition of Bleeding Disorders Awareness Month. We also continued expanding our Women, Girls, and People with the Potential to Menstruate with Bleeding Disorders Initiative, reaching 258 school districts throughout the region. This initiative is helping to identify those who may be living with undiagnosed bleeding disorders and

connecting them with the resources and care they need.

None of these achievements would be possible without the compassion of our volunteers, the leadership of our board, and the generosity of our supporters and partners. You are the heart of this foundation, and your belief in our mission moves us forward every day.

As we look ahead, I am filled with gratitude and optimism. Together, we are building a stronger, more informed, and more connected bleeding disorders community across Pennsylvania. I cannot wait to see what we will accomplish next.

With heartfelt gratitude,



Kara Dornish

**KARA DORNISH
EXECUTIVE DIRECTOR**

OUR IMPACT

Welcomed **71 new families** as members of our Foundation.

1098 Foundation members registered for programs.

Provided nearly **\$15,000** in grocery assistance to **36 families facing food insecurity.**

Trained **28 Advocacy Ambassadors.**

Attended **17 legislative meetings.**



Provided over **\$50,000** in patient assistance to over **300 individuals.**

Distributed over **2,000 nose bleed kits** to 173 school districts.

Hosted 8 fundraisers (which **raised nearly \$100,000** for the bleeding disorders community).

Received **13 proclamations** in Western PA (12 recognizing March as Bleeding Disorders Awareness Month and 1 recognizing April 17 as World Hemophilia Day.)



Attended **18 community outreach events** to educate about the signs and symptoms of bleeding disorders in women, girls, and people with the potential to menstruate.

Reached **258 school districts in Western Pennsylvania** through our Women, Girls, and People who have the Potential to Menstruate with Bleeding Disorders Initiative, and at least one school in each of the 26 counties we serve.

Hosted **20 educational programs** (plus **40 different educational sessions** at the inaugural Pennsylvania Bleeding Disorders Conference).

MEASURING OUR IMPACT: TWO YEARS OF THE WOMEN, GIRLS, AND PEOPLE WITH THE POTENTIAL TO MENSTRUATE INITIATIVE

In the two years since the launch of our Women, Girls, and People with the Potential to Menstruate (WGPPM) Initiative, we've distributed period packs and nosebleed kits to school nurses across the region. We conducted a survey to evaluate the reach and health impact of these resources. We outreached 258 school districts and received 88 responses. Here's what we learned.



"TO YOUR KNOWLEDGE, IS ANYONE WHO HAD RECEIVED A PERIOD PACK SEEKING EVALUATION OF A POTENTIAL BLEEDING DISORDER WITH A MEDICAL PROFESSIONAL, AS A RESULT?"

8 ANSWERED YES.

"TO YOUR KNOWLEDGE, HAS ANYONE WHO HAD RECEIVED A PERIOD PACK BEEN DIAGNOSED WITH A BLEEDING DISORDER, SINCE RECEIVING THE PERIOD PACK?"

3 ANSWERED YES.

"TO YOUR KNOWLEDGE, IS ANYONE WHO HAD RECEIVED A NOSEBLEED KIT SEEKING EVALUATION OF A POTENTIAL BLEEDING DISORDER WITH A MEDICAL PROFESSIONAL, AS A RESULT?"

10 ANSWERED YES.

"TO YOUR KNOWLEDGE, HAS ANYONE WHO HAD RECEIVED A NOSEBLEED KIT BEEN DIAGNOSED WITH A BLEEDING DISORDER, SINCE RECEIVING THE KIT?"

1 ANSWERED YES.

These findings suggest meaningful impact: earlier diagnoses, better awareness, and healthier futures. We're using this data to refine our outreach strategy and expand support for school health professionals in the coming year.



COMMUNITY SPOTLIGHT: TRINA & ORAIA

Eleven-year-old Oraia grew up covered in bruises, even after minor injuries, and had a history of heavy nosebleeds. Her mother, Trina, raised concerns with their pediatrician multiple times, and each time, bloodwork was ordered. But the results always came back normal. The doctor reassured Trina that some people simply bruise easily and told her not to worry. It wasn't until Oraia was 8 years and 8 months old that she finally received an official diagnosis: severe Type 1C von Willebrand Disease (VWD).

In January of 2023, Trina recalls picking Oraia up from a birthday party where she bumped her

head on a lamp. There was no bump or pain, so she wasn't too concerned at the time. "We headed to pick up my son from a visit with his father," Trina said. "About halfway there, Oraia's nose started to bleed heavily. It wasn't stopping, so once I had my son, I dropped him off at home and headed to the Emergency Room."

Oraia's nose had been bleeding heavily for nearly an hour by the time they arrived and registered at the emergency room. During this visit, Trina was told her daughter most likely had VWD but needed to follow-up with a hematologist at the Children's Hospital of Pittsburgh. At their next appointment, more blood

was taken. The doctor provided more information about VWD, and assured Trina that the most common type of VWD, Type 1, typically did not cause a significant impact on most people's lives, and it would just require some extra caution with certain things, like surgery.

"I felt relieved after that appointment. Three days later, at 4pm on a Friday afternoon, Dr. Cooper's office called me. They told me that Oraia had Von Willebrand Type 3 and that hers was too severe for their office. They advised me to schedule an appointment with the Hemophilia Center of Western Pennsylvania (HCWP)."

Trina was in shock, but her long list of questions didn't begin to form until after she hung up the phone. What would life look like for her daughter? For her family? The more pressing issue on her mind was what activities could Oraia safely participate in? Could she play in her basketball game tomorrow? With the doctor's offices closed for the evening, Trina, despite knowing it wasn't the best source for information, turned to the internet. She found the VWD Connect website and got her first taste of how supportive the bleeding disorders community could be.

One week later, Oraia had her first appointment at the HCWP, where they learned more about VWD and what a severe diagnosis meant. They also finally received their correct diagnosis, VWD Type 1c. Trina said, "I have since learned that there are issues with the testing for VWD... doctors don't necessarily know that repeat testing is sometimes needed, doctors don't always order the correct tests, and

sometimes there are issues when it comes to completing the testing."

VWD can be difficult to test for initially because the symptoms can be mild and go undetected. There are multiple types of tests that measure protein levels or clotting activity, but the results of these tests can fluctuate in the same person over time due to factors such as stress, exercise, infection, pregnancy and medications. These tests may need to be repeated to get an accurate diagnosis.

In the summer of 2023, Oraia attended her first year at camp Hot-to-Clot, an overnight summer camp in Western Pennsylvania for youth aged 7-17, who have a bleeding disorder or who have a sibling with a bleeding disorder, and who live in Western Pennsylvania or the surrounding area. At camp, she was able to take part in fun activities, such as swimming, gaga, fishing, and canoeing while connecting with other kids in the bleeding disorders community. In the fall after camp, Trina and her family officially became members of the Western Pennsylvania Bleeding Disorders Foundation (WPBDF).

Since then, Trina and her family have attended as many Foundation events as possible—eager to learn everything they can about bleeding disorders and to build a strong support network with other affected families across Western Pennsylvania. Oraia's siblings, Ruthie, Caleb, Jordan, and Angelo, as well as Trina herself, have all been tested for a bleeding disorder, but Oraia remains the only one in her immediate family with a diagnosis.

"I think it is so wonderful that we have a chance to get to know the bleeding disorders community. It is so important for these kids to get to know other kids who are going through the same thing," Trina said. "Oraia has made multiple friends, and I think that is wonderful. Angelo has also made friends, and in doing so, I think he has been able to understand more about Oraia's diagnosis. Getting to know other parents and learning from them or giving them pointers from my experience has been really nice. I think all of these fun things that Oraia gets to do because of her diagnosis helps her get through the times when she misses out on other things because of it."

On March 25, 2024, Trina and Oraia reached a new milestone on their journey, completing their first at home infusion! Until then, Oraia went to the ER for her infusions anytime they were needed. This became taxing on the family as visits to the ER would take hours, especially when the staff wouldn't listen to the on-call hematologist. After a joint bleed in her knee in March, the HCWP decided Oraia would start prophylactic treatment. "Her nosebleeds usually last less than 5 minutes now and have little blood, when in the past it would be 45 minutes to an hour and lead to needing many towels due to the amount of blood. Ever since she started prophy, the effects that her VWD has on our day to day lives have decreased," Trina added.

WPBDF has become a true lifeline for Trina and her family. As Oraia enters her teenage years, Trina finds comfort in knowing her daughter has a strong support system to lean on—one where she can openly

share her experiences and challenges. Oraia is already passionate about the bleeding disorders community and is using her own voice and talents to make a difference. In December 2024, Oraia and her classmates in her school's gifted program participated in a Holiday Market organized by Range Resources. Students demonstrated incredible creativity and compassion by crafting and selling handmade items made from recycled materials. Oraia wrote a persuasive essay about the Western PA Bleeding Disorders Foundation (WPBDF), which led to the Foundation being selected as one of the event's beneficiaries. Fueled by the students' enthusiasm and hard work, the Holiday Market raised an impressive \$214 for WPBDF.

"The Foundation does so much for the community, and donations help make that possible," Trina said. "WPBDF supports families with groceries, utilities, transportation to medical appointments, Christmas gifts for children, and period products. They also advocate for the bleeding disorders community, which is especially important in these uncertain times. Their events offer education and create opportunities to connect with others who truly understand what you're going through. And Camp Hot-to-Clot means so much. It gives kids a chance to have a normal camp experience, and parents the peace of mind knowing their children are safe and cared for by trained staff. The WPBDF programs that we have attended have made such a difference in our lives. We have learned so much, and we have gotten to know other people with bleeding disorders."

WPBDF'S BOARD OF DIRECTORS

JULY 2024 - JUNE 2025

Thank you WPBDF Board of Directors for donating your time and talents!

The Board of Directors is the governing body of WPBDF. Board members meet periodically to discuss and vote on the affairs of the organization, to support the work of WPBDF, and to provide mission based leadership and strategic governance.



R. SCOTT DOMOWICZ
President



JOHN YUNGHANS
Vice President



VICTORIA BAKER
Secretary



MARIA SHOEMAKER
Treasurer



CASSANDRA MILLER



JASON MILLER



MELINDA PERRY



ASHLEY LYNN PRIORE



SAMANTHA SHORT



STEPHANIE SHROPSHIRE



KRISTEN SPEZIALETTI



LAUREEN TEMPLE

VOLUNTEER OF THE YEAR

CASSANDRA MILLER



We are proud to honor Cassie Miller as the 2025 Volunteer of the Year. As the Advocacy Chair for the Western Pennsylvania Bleeding Disorders Foundation, Cassie goes above and beyond in her dedication to advancing our mission. She is a tireless advocate, recruiting and mentoring others to join in grassroots efforts, meeting with legislators, and representing the community at key events throughout the year.

Cassie's passion especially shines in her work to raise awareness for women with bleeding disorders. She frequently attends events on behalf of the Foundation, sharing her story, connecting with others, and helping build a stronger, more informed community. Cassie also actively reaches out to local businesses and coffee shops to distribute educational materials and raise awareness in everyday spaces where it matters most.



In addition to her advocacy work, Cassie donates the proceeds from her handmade crafts to support our programs and services. This incredible gesture of generosity speaks to her selfless spirit. Her leadership, commitment, and heartfelt support make a lasting impact on the bleeding disorders community.

We are deeply grateful for all she does and are thrilled to recognize her as our 2025 Volunteer of the Year.

THANK YOU!

TOP VOLUNTEERS

JULY 2024 - JUNE 2025

Thank You! We are truly appreciative of our dedicated and hardworking volunteers! Our volunteers improve the lives of those living with bleeding disorders in Western Pennsylvania by spreading community awareness, leading support groups, championing advocacy efforts, and assisting with fundraisers and educational programs. For more information about upcoming volunteer opportunities, contact Jessica Lee at jessica@wpbdf.org.

2023 - 2024 TOP VOLUNTEERS

Volunteer of the Year:
Cassandra Miller

Top Volunteers:
Adam Boyle
Joseph Ebersohl
Melissa Kendrick
Eileen Nikithser
Michael Perry
Michelle Perry
Dexter Shoemaker
Larry Short
Maria Shoemaker
Samantha Short
Melinda Perry
Stephanie Shropshire



ADVOCACY AMBASSADORS

Advocacy Ambassadors are volunteers in a leadership position responsible for helping to establish and build a strong grassroots network of bleeding disorders advocates within Pennsylvania.

Jessamyn Butler
Angela Day
Ashley Day
Tamara Fenton

COMMITTEE CHAIRS AND COORDINATORS

Kelly Baker , Youth Group Co-Coordinator and 2024 Unite for Bleeding Disorders Walk Co-Chair	Fundraising Chair
Victoria Baker , Young Adult Group Co-Coordinator and Scholarship Committee Chair	Samantha Short , Women's Group Co-Coordinator and Young Adult Group Co-Coordinator
Erek Domowicz , Men's Group Co-Coordinator	Maria Shoemaker , Finance Chair and Take A Bough Planning Committee
Maggie Egenlauf , Teen Group Co-Coordinator	Maria Steele Voms Stein , Women's Group Co-Coordinator and Take A Bough Planning Committee
Ashley Fox , 2024 Unite for Bleeding Disorders Walk Co-Chair	Laureen Temple , Take A Bough Planning Committee
Cassandra Miller , Advocacy Chair	Ethan Webb , Teen Group Co-Coordinator
Emily Nikithser , Youth Group Co-Coordinator	John Yunghans , Men's Group Co-Coordinator and Governance Chair
Melinda Perry , Take A Bough Planning Committee and	Mary Heards Kyrie Holiday Delores Johnson David Macharola Sandy Macharola Seth Martin Cassandra Miller Christy Miller Jason Miller Scarlett Miller Seth Miller Spencer Miller Xavier Miller
	Claire Murphy Justin Najmian Melinda Perry Kingsley Reese Teresa Reilly Maria Shoemaker Dexter Shoemaker Samantha Short Ryker Stern Steve Stern Ethan Webb Lisa Wilson

2025 SCHOLARSHIP WINNERS



CONGRATULATIONS TO THE RECIPIENTS OF WPBDF'S 2025 ACADEMIC SCHOLARSHIP!

\$2,250 SCHOLARSHIP WINNERS

Justin Najimian
Billie Rolle



\$2,000 SCHOLARSHIP WINNERS

Mary Laughlin



\$1,000 SCHOLARSHIP WINNERS

Maggie Egenlauf
Jason Miller
Ryan Palmer

\$750 SCHOLARSHIP WINNERS

Ava Bush
Mackenzie Cloutier



\$500 SCHOLARSHIP WINNERS

Whes Ebsworth
Robert Weaver

JUSTIN NAJIMIAN

As a genetic counseling student at the University of Pittsburgh, I am excited to enter the workforce as a genetic counselor. I look forward to being able to serve those with genetic conditions on a daily basis and assist them in becoming their own best advocates.

BILLIE ROLLE

I'm a licensed Cosmetology Instructor and am passionate about education, community service, and mentorship. I aim to open a diverse full-service salon that doubles as a training center. My vision is to empower future professionals, offering free services to those in need, while using beauty to uplift individuals and strengthen my community.

MARY LAUGHLIN

I'm close to earning my Bachelor's Degree in Art Education at Indiana University of Pennsylvania. I'll be certified to teach Kindergarten through twelfth grade. I've enjoyed exploring many different art mediums and am excited to offer my future students a wide range of techniques to learn. Thank you so much to the WPBDF for this scholarship, it's going to be a big help in reaching my educational goal!



MAGGIE EGENLAUF

My career goals will begin at Indiana University of Pennsylvania this fall majoring in Family Consumer Science Education. I plan to complete my education there, and become a high school FCS teacher. Along my way, I plan to keep close to the bleeding disorder community and hold my values.



JASON MILLER

I'm currently earning my MBA in IT Management as I prepare to shift from day-to-day development work into a future role in software architecture, combining my technical background with a broader strategic perspective to support innovation and growth.



RYAN PALMER

Thank you for providing me with this scholarship! I plan to attend Slippery Rock University in the fall and major in Computer Science. I am excited for this opportunity because it will give me the chance to really feel like an adult living independently, despite my Autism diagnosis.



AVA BUSH

Hello, my name is Ava Bush. I am a fourth generation Dairy Farmer who is currently enrolled in Gannon Universities 5-year Physician Assistant program. I hope to enter the Emergency Department or NICU after graduation, unless I find a field during clinical rotations that I love.



MACKENZIE CLOUTIER

In the future, I plan to pursue a Master's degree in both Cello Performance and Orchestral Conducting, with the goal of utilizing music as a tool for social growth and community building. I also plan on bringing music education—especially string education—to communities typically underrepresented and underfunded in music and arts opportunities.



ROBERT WEAVER

Robert will be pursuing his dream of studying science and technology, data analytics, and agricultural science. He hopes that through technology, agricultural, and industrial integration we can have a more sustainable and fruitful future, not only here on Earth but as we look out to the stars.



WPBDF

Western Pennsylvania
Bleeding Disorders Foundation

impact nearly every area of our members' lives, we strive to provide relevant and timely information about everything from raising affected children to dealing with financial stress to joint health and treatment concerns and much more.



**Scan this code to donate to
the Western Pennsylvania
Bleeding Disorders
Foundation!**



OUR YEAR IN REVIEW

JULY 2024 - JUNE 2025



Families teed off with Perry Parker at Topgolf after WPBDF's 2024 Annual Meeting!

JULY

July was filled with sunshine, connection, and community outreach. From July 11–13, we took part in Cranberry Township Community Days, where our amazing volunteers helped us raise awareness about bleeding disorders and share vital information with hundreds of community members. We are so grateful to everyone who gave their time to help make this outreach so impactful.

On July 18, we welcomed nearly 120 community members to our Annual Meeting at Top Golf. It was a wonderful evening of recognition, connection, and inspiration. We celebrated our top volunteers, officially kicked off our Unite for Bleeding Disorders Walk campaign, and heard an empowering message

from professional golfer, Perry Parker. Guests stayed afterward to enjoy the golf bays, with tips from Perry himself!

On July 24, the women of our Foundation gathered in Vandergrift for a candle-making workshop as part of our ongoing Women's Initiative. Together, we poured candles, shared a delicious meal, and talked about the importance of self-care while spending a relaxing and meaningful evening surrounded by old and new friends.

We closed the month with Camp Hot-to-Clot from July 28–August 2, where campers living with bleeding disorders came together for a week of friendship, growth, and summertime adventure.



Stephanie and her son learned about the clotting process through a hands-on cookie decorating activity at the New Parent Network in Idlewild!

AUGUST

August began with a focus on advocacy and education. On August 1, Kara and Jess represented the Foundation at the Wellness4Schools Summer Symposium, sharing nosebleed kits, period packs, and resources with schools across the region. That evening, we hosted a Back-to-School Dinner at the Grand Concourse, where families gathered to learn how to build strong relationships with school staff and advocate for their children's needs.

On August 10, we held a New Parent Network picnic at Idlewild Park. Families enjoyed food, fun, and fellowship, including a cookie-decorating activity that cleverly taught the clotting process. It was a joyful day filled with learning, laughter, and connection.

At the end of the month, we said goodbye and thank you to our summer intern, Shae, who played an essential role in outreach and walk preparations. We are so thankful for her contributions!



Grant recipients attend the 2024 National Bleeding Disorders Conference.



The Miller family proudly holds their pinwheels at the Unite for Bleeding Disorders Walk Pinwheel Ceremony!



Teens explored an ambulance while meeting local EMS at the Fall Program in Erie.



Pitt students packed over 800 period packs during the University of Pittsburgh's Civic Action Week.

SEPTEMBER

September started on a joyful note as we celebrated the wedding of our Development Director, Jessica! Congratulations to her and Joe!

The following week, Janet and Kara, along with three local families, traveled to Atlanta for the NBDF Bleeding Disorders Conference. While there, Kara had the opportunity to co-present alongside Sarah, Executive Director of the Eastern PA Bleeding Disorders Foundation, to share the impactful work of our Women and Girls Initiative. We were proud to highlight this important effort and offer tools and resources with the hope that similar programs will be adopted nationwide to help more women receive earlier diagnoses. We were also overjoyed to celebrate two national award recipients from our community: Kathleen Schnur, honored as Social Worker of the Year, and the

late Joey Smiles, posthumously recognized as Volunteer of the Year. Their dedication and compassion continue to inspire us all.

On September 21, we gathered at North Park for one of our biggest events of the year, the 16th Annual Unite for Bleeding Disorders Walk, 15th Annual 5K Run, and Cornhole Tournament. With over 27 teams participating, the day raised more than \$79,000 to support our mission. It was a powerful day of unity, celebration, and purpose.

We closed the month on September 26 with our Winning Women's Safety Skills Workshop. Led by Lioness Martial Arts, this empowering evening gave women practical tools and confidence to stay safe and advocate for themselves in any environment.

OCTOBER

October brought meaningful opportunities to educate, connect, and empower. On October 5, we held our Fall Program in Erie, welcoming families for a day of learning and connection. Darlene Shelton from Danny's Dose delivered a powerful presentation on emergency medical access for individuals with rare disorders, while local EMS offered ambulance tours and kids built their own "go bags," making emergency preparedness personal and fun.

Just days later, on October 9, WPBDF took part in two outreach events, one at Penn State DuBois and another with school nurses in Pittsburgh. We raised awareness around bleeding disorders in women, girls, and those who

menstruate, and distributed period packs, nosebleed kits, and vital educational materials. On October 17, in collaboration with the Eastern PA Foundation, we visited the Blair County School Nurses' Association to continue spreading awareness and sharing tools to better support students.

October 19 was a big day of action and fun. At the University of Pittsburgh's Civic Action Week, over 25 student volunteers helped us pack more than 800 period packs for school nurses across the state. That same day in Erie, we hosted our first-ever Mead & Bleed event, bringing the community together for a craft show and tasting at Iron Stone Meadery.



Teens learned first aid skills from Nurse Kimmy at the Teen Retreat.



Maria Shoemaker is named WPBDF's Advocate of the Year at Take A Bough.



Pennsylvania Insurance Commissioner, Michael Humphreys, and his team attended our Stakeholder Meeting to listen to treatment center social workers about pressing issues facing the bleeding disorders community.



Santa stopped by for a visit at WPBDF's Winter Program!

NOVEMBER

In early November, our Teen Group spent a weekend together at the Promise Camp & Retreat Center, learning life skills, making s'mores, and growing closer through games, meals, and shared laughter. From budgeting workshops to escape rooms, the weekend offered connection, education, and unforgettable memories.

On November 6, Tony Paciucci from Genentech led a helpful program on understanding health insurance by breaking down coverage changes, terminology, and how to advocate for care.

DECEMBER

We wrapped up 2024 with community, collaboration, and celebration. On Tuesday, December 3, 2024, the Eastern and Western Pennsylvania Bleeding Disorders Foundations teamed up to hold the 2024 Advocacy Stakeholder Meeting. We were joined by 21 individuals including representatives from each of the 7 Pennsylvania Hemophilia Treatment Centers, individuals from both national organizations (National Bleeding Disorders Foundation and Hemophilia Federation of America), Kerry Lange of Milliron and Goodman, PA Insurance Commissioner Michael Humphreys, advocacy ambassadors, and Eastern and Western PA Foundation staff and board members.

On December 7, families gathered

JANUARY

A snowy Saturday on January 11 brought warmth and connection as WPBDF's Youth Group gathered at the Carnegie Science Center. Children ages 7 to 12 explored the theme "Being Different, Belonging Together" with Kathaleen Schnur, LCSW, through hands-on activities

On Saturday, November 16, we gathered for our 12th Annual Take a Bough fundraiser at Red Fox Winery. The evening was full of warmth, music, and generosity, raising over \$12,000 to support families in our community.

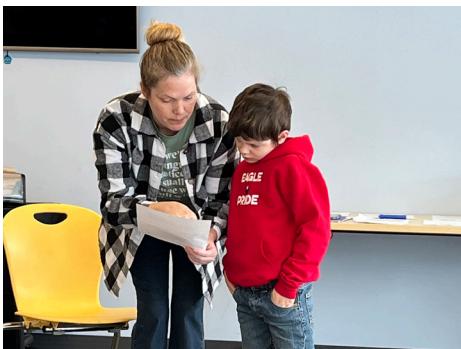
The following week, Janet and Kara traveled to San Antonio to attend the NBDF Chapter Leadership Seminar, connecting with leaders from across the country to exchange ideas and strengthen our mission.

at Dave & Buster's for our Winter Program. From visiting sponsor booths and writing holiday hopes to taking photos with Santa and enjoying a festive lunch, the day was full of joy and togetherness. Sanofi's Carrie Koenig closed the program with an inspiring presentation on the power of connection in our community.

Finally, on December 19, Kara and WPBDF Board Member Samantha Short, visited Riverside High School to speak with students in the Health Career Club. Together, they assembled period packs while sparking meaningful conversations about bleeding disorders, inspiring awareness, curiosity, and compassion among the next generation of healthcare professionals.

that built confidence and tools for navigating bullying.

Later in the month, on January 20, WPBDF Board Member, Stephanie Shropshire led an incredible



HCWP Social Worker, Kathaleen Schnur, discusses bullying with WPBDF's Youth Group.



WPBDF's Winning Women celebrate Galentine's day together at AR Workshop.



Sarah and Janet hand out period packs and nose bleed kits to school nurses at the Pennsylvania Association of School Nurses and Allied Practitioners Conference.



Nicole R. (left) poses with her son, Elijah (middle) and fellow community member, Kingsley R. (right) after receiving a proclamation for Bleeding Disorders Awareness Month from the McKean County Board of Commissioners.

JANUARY (CONTINUED)

community project at Community Day School. The students put together over 2,600 nosebleed kits that will raise awareness and promote early diagnosis throughout local schools.

We closed out January with a

special evening on the 30th focused on von Willebrand Disease, hosted in partnership with Octapharma and InfuCare. Mackenzie Fly shared her personal journey, while Dr. Claudio Sandoval offered expert medical insights to our engaged group of attendees.

FEBRUARY

Laughter echoed through the Pittsburgh Improv on February 2 as comedian Samuel J. Comroe took the stage in support of WPBDF, helping raise funds and spirits in equal measure.

Just two days later, our Winning Women's Group celebrated Galentine's Day with an evening of creativity, connection, and intention

setting—complete with handcrafted signs, shared stories, and beautiful keepsakes.

On February 16, our community came together once again for the 10th Annual Bowling for Bleeding Disorders fundraiser. With nearly 50 bowlers and a lot of friendly competition, we raised over \$2,000 in support of local families.

MARCH

March was a powerful month of advocacy and awareness in honor of Bleeding Disorders Awareness Month. We were proud to receive proclamations from 12 counties and the City of Erie, each helping to shine a light on the needs of those living with bleeding disorders. As part of the celebration, our community contributed to the annual mini canvas art project. Each small canvas reflected a personal journey, and together they now fill our office with vibrant reminders of strength, resilience, and hope.

On March 6, fourteen passionate advocates from Western Pennsylvania traveled to Washington, DC to meet with lawmakers and share their stories, helping to advance critical policy efforts on a national level. Just a few days later, on March 11, we partnered with the Eastern Pennsylvania Bleeding Disorders Foundation for a virtual Lunch & Learn to educate advocates on

key state and federal issues. That evening, WPBDF Board Member Samantha Short visited the Best of the Batch Foundation's Girl Talk program to lead an interactive session focused on menstrual health, self-advocacy, and reducing stigma. The girls wrapped up the evening by assembling period packs which will be distributed to school nurses and rural health clinics throughout the region.

On March 13, Executive Director Kara Dornish, along with Board Members Samantha Short and Ashley Lynn Priore, appeared on Talk Pittsburgh to raise awareness about bleeding disorders, especially in women, girls, and those with the potential to menstruate. Kara shared information about the Foundation's work and resources, while Samantha and Ashley offered heartfelt insights into their personal experiences.

Later in the month, 38 supporters gathered at PPG Paints Arena



Attendees showcased the bleeding disorders community's unbreakable bond by building a chain out of pipe-cleaners.



Phipps Conservatory in Pittsburgh lights up red for World Hemophilia Day 2025!



WPBDF Board Member, Kristen Spezialetti, prepares for her 2nd annual Trivia Night Fundraiser!

MARCH (CONTINUED)

on March 18 to cheer on the Pittsburgh Penguins and support WPBDF. A portion of the ticket sales benefited the Foundation, and the event raised \$380.

We wrapped up the month in State College at the Pennsylvania Association of School Nurses and Allied Practitioners Conference, where Janet and Sarah engaged with nearly 200 school nurses. Many of these professionals

APRIL

April was a month of connection, education, and celebration. On April 7, WPBDF Board Member, Kristen Spezialetti, hosted her 2nd annual Trivia Night fundraiser. Thanks to the incredible generosity of all attendees and sponsors, the event raised over \$500 to fund vital education, advocacy, and support programs for the bleeding disorders community in Western Pennsylvania!

On April 10, families gathered for a program on Family Connections, sponsored by Pfizer. Led by Kurt Feldmann, the conversation focused on how to navigate communication outside the home—whether at work, school, or online. Attendees shared personal stories, offering support and insights that reminded us how powerful community can be.

That same day, WPBDF participated in Chatham University's Public Health Week. We spoke with students about bleeding disorders,

MAY

May was a month of milestones. We began by participating in Representative Dan Miller's Disability and Mental Health Summit, sharing resources and raising awareness about bleeding disorders with attendees across

work with students experiencing frequent nosebleeds or heavy periods, which can be signs of an undiagnosed bleeding disorder. We shared our Bleeding Disorders Toolkit, period packs, nosebleed kits, and a new informational poster for display in schools, which was an idea inspired by feedback from last year's conference. We were thrilled to see it come to life and begin making an impact.

shared resources, and encouraged them to take a free risk assessment at betteryouknow.org.

On April 17, we marked World Hemophilia Day in a big way. Across Pittsburgh, iconic buildings lit up red to show support for the bleeding disorders community. That evening, more than 70 attendees gathered at Monterey Bay Fish Grotto for a special dinner program sponsored by Sanofi. With sweeping views of the glowing city skyline, we celebrated our community's strength and unity. Guests created symbolic pipe cleaner chains to reflect their personal journeys and the unbreakable bonds that connect us. Activity stations, heartfelt stories, and shared laughter made the evening especially meaningful.

Also on April 17, Kara attended the Kane Health Expo to raise awareness and share resources with the broader community, continuing our mission to educate and advocate.

Western Pennsylvania. Later that month, we officially launched the first-ever Pennsylvania Bleeding Disorders Conference with our Advocacy Pre-Con. It was years in the making, and the hard work

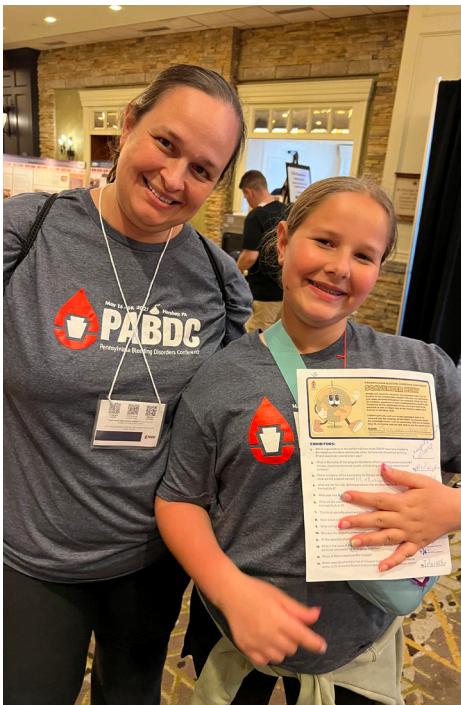


MAY (CONTINUED)

of staff and board members from both Eastern and Western Pennsylvania truly brought it to life. Thirty advocates joined us to hear updates on state and federal issues from advocacy leaders Kerry Lange and Matt Delany. We were especially honored to welcome Representative Tom Mehaffie, who shared his personal connection to our cause and inspired us with his continued support.

From May 16 to 18, nearly 400

attendees representing over 120 families came together in Hershey for the inaugural Pennsylvania Bleeding Disorders Conference. With more than 40 educational sessions for adults and children, the weekend was packed with meaningful learning, connection, and community. We are so grateful to our conference planning team, speakers, volunteers, and families who made this historic event possible.



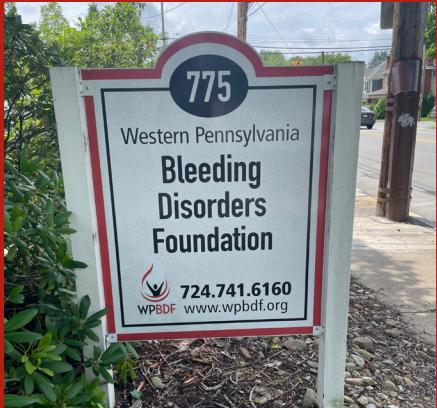
Never fear! The WPBDF's New Parent Network super team is here to save the day!

JUNE

June began with smiles and superhero capes as our New Parent Network gathered at the Children's Museum of Pittsburgh. Families—both new and familiar—spent the day connecting over crafts, laughter, and shared experiences. The kids designed their own superhero characters, and by the end of the day, we were all reminded of just how strong this community truly is. Throughout the month, WPBDF participated in the

Wellness4Schools Summer Symposium, Beaver's Garrison Day, and Bridgeville's Day on the Avenue. These outreach events gave us a chance to share information, distribute resources, and connect with individuals who may be experiencing symptoms of an undiagnosed bleeding disorder. We are deeply thankful to the volunteers who helped us spread awareness and make our presence felt at these vibrant community gatherings.

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION



WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

775 Fourth Street, First Floor
Beaver, PA 15009

Website: wpbdf.org

Email: info@wpbdf.org

Phone: 724-741-6160

Fax: 724-741-6167

Foundation Staff:



Kara Dornish

Executive Director
kara@wpbdf.org



Janet Barone

Program Director
janet@wpbdf.org



Jessica Lee

Development Director
jessica@wpbdf.org



Laurie Sano

Office Assistant
laurie@wpbdf.org

The Western Pennsylvania Bleeding Disorders Foundation is a nonprofit consumer advocacy and service organization founded in the 1950's and incorporated as a 501(c)(3) nonprofit organization in 1976. We were founded to help meet the vast education and support needs of the bleeding disorders community in Western Pennsylvania.

WPBDF serves families with bleeding disorders in 26 counties of Western Pennsylvania. Membership is free for people with bleeding disorders. We provide patient assistance to our members with bleeding disorders as well as hold a variety of educational events that cover a wide range of topics. Because bleeding disorders impact nearly every area of our members' lives, we strive to provide relevant and timely information about everything from raising affected children to dealing with financial stress to joint health and treatment concerns and much more.

