



WPBDF

Western Pennsylvania
Bleeding Disorders Foundation

OUR IMPACT

2023 - 2024 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.



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Kara Dornish
Executive Director, WPBDF

LETTER FROM THE EXECUTIVE DIRECTOR

DEAR FOUNDATION MEMBERS & FRIENDS,

We are thrilled to present our 2023-2024 “Gratitude Report,” celebrating a year of extraordinary achievements and heartfelt outreach. This report encapsulates the remarkable progress and impactful initiatives that have defined our journey over the past fiscal year.

Throughout this period, we have cultivated an unwavering spirit of outreach, supported by the dedication of our volunteers who have tirelessly extended our reach into new communities. Together, we orchestrated 16 impactful outreach events, spanning schools, college campuses, and rural health clinics across Pennsylvania. We conducted a total of 28 educational and outreach programs, including our Education Weekend which was comprised of 28 distinct educational sessions.

In our commitment to directly assist those in need, we provided over \$43,000 in patient assistance to

over 250 individuals, along with grocery gift cards totaling nearly \$15,000 to 40 families facing food insecurity. We also distributed over \$2,500 worth of gift cards to women, girls, and people who have the potential to menstruate who have bleeding disorders and are struggling with period poverty. In total, our direct patient assistance efforts amounted to over \$60,000 in the past year alone.

None of these achievements would have been possible without the unwavering support of our community. Through nine successful fundraisers, we collectively raised over \$103,000 to empower and uplift the bleeding disorders community.

In collaboration with the Eastern Pennsylvania Bleeding Disorders Foundation, we organized an advocacy education and training at the state capitol in Harrisburg. Together, 22 Pennsylvania Advocacy Ambassadors made their way to the Capitol to meet with the offices of 33 Pennsylvania legislators. Advocates shared their stories and worked hard to garner support for an increase to the Hemophilia line item in the state budget, support for copay accumulator legislation (SB 372), and support for menstrual product access legislation that would help end period poverty in Pennsylvania (SB 1016).

I am immensely proud of what we have accomplished, yet recognize the ongoing challenges ahead. I am deeply grateful for the tireless dedication of our volunteers, the passion of our remarkable staff and board members, and the enduring support of our community. Your steadfast commitment and generosity propel us forward as we continue our mission to advocate, educate, and support those affected by bleeding disorders.

It is truly an honor to be leading this organization and I am profoundly grateful for your continued support of our Foundation. Together, we will forge ahead, driven by our shared commitment to make a meaningful difference in the lives of those with bleeding disorders.

With heartfelt gratitude,

Kara Dornish

Executive Director

2023 - 2024 IMPACT

Welcomed **46 new families** as members of our Foundation.

916 Foundation members registered for programs.



Provided nearly **\$15,000** in grocery assistance to **40 families facing food insecurity.**



Attended **43 legislative meetings.**

Trained **36 Advocacy Ambassadors.**



Distributed over **1,000 nose bleed kits** to 85 school districts to increase awareness of bleeding disorders.

Attended **16 community outreach events** to educate about the signs and symptoms of bleeding disorders in women, girls, and people with the potential to menstruate.

Received **13 proclamations** in Western PA (11 recognizing March as Bleeding Disorders Awareness Month and 2 recognizing April 17 as World Hemophilia Day).

Provided over **\$43,000** in patient assistance to over **250 individuals.**

Hosted **9 fundraisers** (which raised **over \$103,000** for the bleeding disorders community).

Hosted **28 educational programs (plus 28 different educational sessions at Education Weekend).**



Provided over **\$2,500 in assistance to Women, Girls, and People who have the Potential to Menstruate with Bleeding Disorders** and are struggling with period poverty.

Reached over **170 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.

Distributed over **2,000 period packs** to elementary and high schools, colleges, universities, and rural health centers to increase awareness for bleeding disorders in Women, Girls, and People who have the Potential to Menstruate.



MEET THE MILLER FAMILY

Jason and Christy have their hands full with four kids, ages 12, 9, 7, and 5, who are all participating in multiple extracurricular activities this year from soccer, to swimming, to baseball, to even karate. It's tough enough to balance family life every day, but this family has overcome the added challenges of living with a rare bleeding disorder, Factor VII (7) Deficiency, and Platelet Function Disorder.

Out of the six members of the family, Christy and their three youngest children, Xavier, Spencer, and Scarlett, have confirmed bleeding disorders. The children are diagnosed with Platelet Function Disorder and Christy and Spencer also have Factor VII (7) Deficiency. Christy received her diagnosis in 2007 before having her tonsils removed. At the time, she was experiencing

“FROM THE BOTTOM OF OUR HEARTS, THANK YOU. WE HAVE NO WAY TO REPAY THE INFLUENCE OF EVERYTHING THE CHAPTER HAS DONE FOR US, BUT THEY HAVE BEEN ABLE TO REMOVE OR REDUCE WHAT HAVE SOMETIMES BEEN INSURMOUNTABLE BARRIERS.”

bleeding symptoms and was being monitored by her rheumatologist. She lived in rural, upstate New York and had no idea what a Hemophilia Treatment Center (HTC) was, nor did she have any family history of a bleeding disorder.

“When the hematologist in NY called me, he initially told me that he thought I had hemophilia and I laughed at him,” Christy recalls. “I told him there was no possible way – there was no family history, and I was a female. Obviously, I now know that those things don't matter, but at the time with the little information that I knew about bleeding disorders, I thought he

was off his rocker.” Many years later, after the children received their diagnoses, Christy's mother told her that her grandfather “was a bleeder.”

Christy would eventually be diagnosed with von Willebrand Disease (VWD). At first, Christy remembers feeling young, dumb, and invincible, so she didn't give her new diagnosis a lot of thought. It wasn't until her first pregnancy did her bleeding disorder diagnosis gain more relevance.

Christy hemorrhaged during childbirth with her first son. Doctors assured her hemorrhaging was uncommon and it wouldn't happen again; however, when she had her second child, she nearly died. Christy spent several days in the ICU from blood loss and was sent to the HTC for treatment.

“That was when [my bleeding disorder] became a ‘bigger deal’ to me,” Christy says. “I had severe hemorrhages with each pregnancy, which were very scary.”

Xavier, Spencer, and Scarlett were all diagnosed with VWD and were treated as such for many years. VWD can be extremely hard to test for, as factor levels can be influenced by multiple outside factors, such as stress. Luckily, through the years, technology has improved greatly and allowed for more accurate testing and diagnosis for bleeding disorders patients. After more tests and discussions with doctors, the families VWD diagnosis was changed to a Platelet Function Disorder diagnosis.

“The VWD diagnosis had always been a little bit uncertain due to the shifting factor levels. After retesting and getting positive confirmation of the Platelet Function Disorder, it signified a solid diagnosis that was much more certain,” Jason says. Due

to the new diagnosis, this meant new treatment options for Christy and the kids. Instead of IV Factor replacement, they were able to use the desmopressin nasal spray, DDAVP.

Through retesting, the family also found out that Spencer and Christy had Factor VII deficiency as well. This shifted them back to IV factor replacement, but also gave Spencer a game changing option for prophylactic treatment. With the solid treatment plan managed by the Hemophilia Center of Western Pennsylvania (HCWP), all the kids have joined the local swim team, Scarlett is playing soccer, and Spencer is playing baseball and is currently a Yellow/White belt in karate. Because of Spencer's choice of activities, he treats prophylactically three times a week. He has the freedom to choose what he wants to do and can do them safely.

Jason and Christy's oldest son, Seth, shows some signs of a bleeding disorder but has never been positively diagnosed. With the improvements in testing ability, the family plans to have him retested.

"Being a part of the bleeding disorders community and having strong support helped Christy advocate to find the correct diagnosis," Jason adds. "Finding out about her grandfather's bleeding tendencies several years after asking about bleeding and being told there was no history also speaks to the stigma both within and outside the bleeding disorders community."

The first event the family attended was WPBDF's Education Weekend in 2019. The HCWP recommended they attend the event. They were intimidated but found an immense community full of support –

something they lacked for so long.

"I just remember going and meeting so many other families that were like ours," Christy states. "Being included in this community has been very valuable in helping us navigate everything from insurance approvals, to activities, to navigating school for the kids. They have provided so much support in so many ways, it is difficult to list everything. When COVID shut everything down, and both Jason and I were out of work for a period of time, the Foundation was able to help support us through their generous assistance programs. They also have been supportive in helping with not only our bleeding diagnosis but managing some of the other intricacies of having medically complex children. They also have helped us realize that there are some other national organizations as well that have provided resources to us, like the One Drop Conference for people with ultra rare bleeding disorders that Spencer was able to attend last year."

For the Millers, WPBDF is there to provide education, resources, and a tight-knit community, which alleviates much of their day-to-day

stress. They actively participate in many of the programs the Foundation has to offer such as the New Parent Network, a support group focused on families with children under the age of 7; the Youth Group, a support group for families with children between the ages of 7 – 12; and our Advocacy Ambassador Program. The entire family traveled to Washington D.C. this year to participate in the National Bleeding Disorders Foundation's Washington Days and advocate on behalf of the entire bleeding disorders community. Jason recently joined the WPBDF Board of Directors as well.

"We want to give back," Jason says. "This community and the Foundation have given us so much that we can never repay, but we can provide support in a way that we know how. We also want to advocate for others so that they can be a part of this community if they need to be and so that others know that this community exists. From the bottom of our hearts, thank you. We have no way to repay the influence of everything the chapter has done for us, but they have been able to remove or reduce what have sometimes been insurmountable barriers."



BOARD OF DIRECTORS

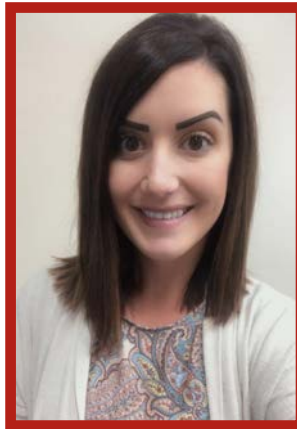
JULY 2023 - JUNE 2024



R. Scott Domowicz
President



John Yunghans
Vice President



Brittani Vuono
Secretary



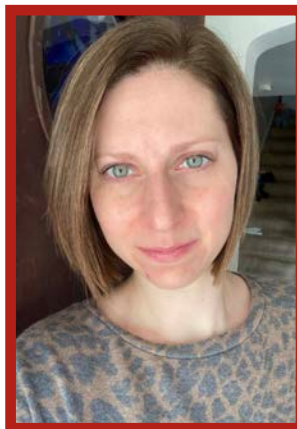
Christina Miller
Treasurer



Melinda Perry



Victoria Baker



Stephanie Shropshire



Cassandra Miller

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.



Samantha Short



Kristen Spezialetti



Lauren Temple

VOLUNTEER OF THE YEAR



Samantha Short

Samantha has truly exemplified the spirit of dedication and compassion as our Volunteer of the Year. Since joining our board of directors last year, her impact has been nothing short of remarkable. Her commitment to raising awareness about bleeding disorders and advancing our mission has been inspiring to witness.

One of Samantha's most significant contributions has been her outreach efforts to educate Girl Scout troops about bleeding disorders and working with them to assemble nosebleed kits for school nurses across Pennsylvania. This initiative not only spread crucial knowledge to the young girls but also instilled in them a sense of

community service and giving back.

Her proactive approach in forging community connections has been invaluable. Through collaborations with organizations like the Best of the Batch Foundation, Samantha led educational sessions about bleeding disorders in women and worked to destigmatize discussions around menstrual health. She led the group in constructing period packs which were then distributed to school nurses across Pennsylvania.

Samantha is deeply passionate about sharing her story and consistently leverages her knowledge and experiences to support others. She is a strong advocacy ambassador and has been instrumental in representing our foundation at outreach events. Samantha

consistently leads by example, eagerly stepping forward as one of the first volunteers to sign up for these important initiatives. Her efforts have fostered connections with numerous nurses, community members, and nonprofit leaders, further strengthening our network and expanding our outreach capabilities.

Samantha's passion, initiative, and unwavering commitment have had a profound impact on our foundation and the community at large. Her efforts have not only raised awareness about bleeding disorders but have also empowered individuals and organizations to take meaningful action. Samantha's contributions embody the spirit of volunteerism and serve as an inspiration to us all. We are incredibly grateful for her outstanding service and proud to honor her as our Volunteer of the Year.



2023-2024 VOLUNTEERS

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.

COMMITTEE CHAIRS AND COORDINATORS

Kelly Baker, Youth Group Co-Coordinator

Victoria Baker, Young Adult Group Co-Coordinator

Erek Domowicz, Men's Group Co-Coordinator

Maggie Egenlauf, Teen Group Co-Coordinator

Cassandra Miller, Advocacy Chair

Christina Miller, Finance Chair

Emily Nikithser, Youth Group Co-Coordinator

Melinda Perry, Take A Bough Co-Chair, 2023 Unite for Bleeding Disorders Walk Co-Chair, and Fundraising Chair

Samantha Short, Women's Group Co-Coordinator and Young Adult Group Co-Coordinator

Stephanie Shropshire, 2023 Unite for Bleeding Disorders Walk Co-Chair

Maria Steele Voms Stein, Women's Group Co-Coordinator and Take A Bough Co-Chair

Brittani Vuono, Scholarship Chair

Ethan Webb, Teen Group Co-Coordinator

John Yunghans, Men's Group Co-Coordinator and Governance Chair



ADVOCACY AMBASSADORS

Tamara Fenton
Kyrie Holiday
Delores Johnson
David Macharola
Sandy Macharola
Claire Murphy
Cassandra Miller
Christy Miller
Jason Miller
Scarlett Miller
Seth Miller

Spencer Miller
Xavier Miller
Melinda Perry
Kingsley Reese
Maria Shoemaker
Dexter Shoemaker
Samantha Short
Ryker Stern
Steve Stern
Ethan Webb



2023 - 2024 TOP VOLUNTEERS

Samantha Short - Volunteer of the Year

Tori Baker
Adam Boyle
Joseph Ebersohl
Claire Murphy

Eileen Nikithser
Maria Shoemaker
Stephanie Shropshire
Judith Walsh

Thank you!



WPBDF

Western Pennsylvania
Bleeding Disorders Foundation

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

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.



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



2024 SCHOLARSHIP WINNERS

CONGRATULATIONS TO OUR 2024 SCHOLARSHIP WINNERS!

\$3,000 SCHOLARSHIP WINNER

Claire Murphy

\$1,100 SCHOLARSHIP WINNERS

Ashley Cynkar
Mikaela Kottelich
Raina Slater
Katherine Berry
Willow Reed

\$500 SCHOLARSHIP WINNERS

Elijah Shropshire
Georgia Ebsworth
Cailin Stukus
Megan Wharton
Rochelle Lynn Hetrick
Haley M. Dunaway
Amanda Steele Voms Stein



CLAIRE MURPHY

I will be continuing my dental education at Boston University to obtain my Master of Science in Oral Health Sciences. Upon my completion of this one year program, I will enroll in dental school for another four years. My ultimate goal is to specialize, and continue for an additional three years in a dental anesthesiology residency. At the core of all these accolades is my continuity of advocacy for patients with bleeding disorders in the dental community and beyond. I aspire to implement coursework in dental schools that encompasses what it means to have a bleeding disorder. More providers that confidently and successfully treat these patients means more access to care for our community.



ASHLEY CYNKAR

I am currently in my sixth and final year of Pharmacy School at Duquesne University. I am beyond excited for the opportunities that lay ahead in my career. As of now, I am interested in pursuing a post graduate residency in critical care and desire to help patients in the hospital setting. I am beyond grateful for the generous scholarship awarded to me by the Western Pennsylvania Bleeding Disorders Foundation and will use the funds to achieve my academic goals.



MIKAELA KOTTELICH

My name is Mikaela Kottelich and I am entering my third and final year at the University of Akron majoring in Biomedical Science. This past April, I found out that I was accepted into Northeast Ohio Medical School through my university's early assurance program. I will be taking a gap year before matriculating, in which I hope to continue to do research. After that, I will begin a Master's program at NEOMed for one year and then officially start medical school. I am looking forward to continuing my education to one day become a physician. I am very grateful that WPBDF has granted me this wonderful scholarship that allows me to fund my educational goals.

2024 SCHOLARSHIP WINNERS



RAINA SLATER

Thank you for the scholarship! This award is going to help aid me through my academic career at Penn State University. I study architectural engineering in the 5 year masters program. I love Penn State, and more importantly, I love learning!



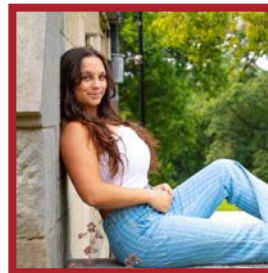
CAILIN STUKUS

I am super excited to continue and complete my bachelor's degree in chemical engineering and minor in environmental engineering at the Swanson School of Engineering at the University of Pittsburgh! I plan to graduate in May 2026!



KATHERINE BERRY

After completing my Biomedical Engineering undergraduate degree, I plan on pursuing my Master of Science degree in Biomedical Engineering as well. My goal is to work in an environment where I can manufacture prosthetics and in vitro devices to improve the healthcare quality in my community. After years of being looked after from medical professionals and the community, it is time to return the favor.



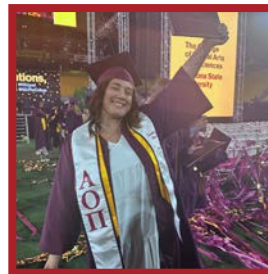
MEGAN WHARTON

For my academic future, I am attending Chatham University and majoring in nursing. I am going to specialize in labor and delivery and hopefully be able to give back to WPBDF.



WILLOW REED

In the fall, I plan to attend Indiana University of Pennsylvania as a biology major with a focus in pre-medicine and a minor in a health-related subject. Afterwards, I plan to attend medical school and become a physician.



**AMANDA STEELE
VOM STEIN**

My academic plans are to graduate from the University of Pittsburgh with a Masters in Social Work, concentration in Gerontology. I am hoping to get a job within the VA hospital system following graduation in May of 2025.

The Foundation is delighted to be able to support our community in this way. We wish all of our scholarship award winners the very best of luck as they pursue their education.



WPBDF'S YEAR IN REVIEW

JULY 2023 - JUNE 2024

JULY 2023

On July 16, 2023, the bleeding disorders community gathered for WPBDF's Annual Meeting! We highlighted our programs and services, recognized our top volunteers, and kicked off the Unite for Bleeding Disorders Walk! After the meeting, over 100 of us walked over to the Gateway Clipper Cruise for an evening sightseeing cruise!

Camp Hot-to-Clot made its return after what felt like a very long three years. Camp kicked off on July 30 and lasted through August 4. The day-to-day camp activities included swimming, archery, gaga, fishing, arts and crafts, indoor rock climbing, outdoor living skills, as well as many sports and performance options. We had a few specific bleeding disorder evening programs where the kids were all brought together to learn and connect as a community.

July ended with an educational program from CSL Behring on Hemgenix, the first FDA approved gene therapy for patients with Hemophilia B. This program was held in Erie and provided our Hemophilia B community members with more information about gene therapy.



AUGUST 2023

In early August, we said goodbye to our 2023 Summer Intern, Ally. She took charge of our Stay In Motion program and created many fun challenges for our community to try out. She was also instrumental in preparing for the Unite for Bleeding Disorders Walk. Thank you so much for all your help, Ally!

On Friday, August 11, families joined us for a Back-to-School program to learn how to communicate with their child's school.

The following week, Foundation staff, along with 4 families from Western Pennsylvania, attended NBDF's Bleeding Disorders Conference in National Harbor, MD. Staff connected with other chapter leaders and our families had a chance to learn from and connect with other families from across the country! At the National Bleeding Disorders Foundation's Bleeding Disorders Conference, the Western Pennsylvania Bleeding Disorders Foundation received The John Indence Award and the The Val Bias and Todd Smith Innovation in Camp Award. We are grateful for the passion and dedication of our Advocacy Ambassadors, the support of NBDF's Advocacy Team, and the incredible community we have in Western PA who help raise awareness of bleeding disorders and offer support to one another. Staff from the Western PA Bleeding Disorders Foundation and the Hemophilia Center of Western PA frequently collaborate to keep our youth and teens engaged and connected through Camp Hot-to-Clot and Retreats throughout the year. We are honored to receive this recognition.

August ended with Women's Wellness Day at the Pittsburgh Botanical Gardens. We learned alternative ways to manage pain and practiced self-care by making jewelry, meditating, and participating in a Tai Chi session! It was a wonderful reminder to make sure we take care of ourselves.

SEPTEMBER 2023

The Unite for Bleeding Disorders Walk and Run for Their Lives 5K invited friends, family, and loved ones to North Park for a day of celebration on September 9! The top fundraising team was Conor's Clan, who raised an incredible \$7,387! Thanks to the amazing support from sponsors, donors, and patrons, \$73,970 was raised to support the Western PA bleeding disorders community. Thank you to our amazing 2023 Co-Walk Chairs, Melinda Perry and Stephanie Shropshire!



The weekend after the Walk, WPBDF partnered with the Pittsburgh Pirates to host a fundraiser game. For every ticket sold through our unique ticket link, \$10 was donated back to the Foundation, raising \$300 for the Foundation.

September ended with our New Parent Network (NPN) families on a cold and rainy day at Kennywood Park's Fall Festival. Families joined us for a picnic and bingo and had the chance to share their current challenges and needs to help plan future NPN events.



OCTOBER 2023

We kicked off October with the first ever WPBDF Open House! We invited Foundation members and members of the Beaver community to visit our office and learn more about our programs and services. Thank you to everyone who stopped by to say hello!

Our Fall Program filled our ears with song as our community gathered for a morning of music therapy led by Tim Ringgold. We were introduced to techniques in music therapy and were given an opportunity to practice. Everyone was given an egg shaker at the start of the program to join in on making music. Afterwards, they went to Soergel Orchards for the Fall Festival.



NOVEMBER 2023

We kicked off November with our beloved Cornhole Tournament! This is the first time we've hosted an in-person cornhole tournament since 2019. Thanks to our sponsors and players, we raised over \$4,000 to support the bleeding disorders community!

On November 9, we offered a virtual insurance program for our members, the *Health Insurance Roadmap*. Jan Martin, Community Education Specialist with Takeda, presented the program. She is very familiar with insurance issues that patients in the bleeding disorders community encounter. Jan's presentation included an overview of insurance options, transitions that impact coverage, and insurance denials.

On Saturday, November 11, Executive Director, Kara Dornish, Development Director, Jessica Lee, and patient advocate, Maria Shoemaker, attended The Beauty Boost Pittsburgh's Fitness Sampler! This event kicked off the community side of our initiative to raise awareness of bleeding disorders in women, girls, and people who have the potential to menstruate (WGPPM). Kara, Jessica, and Maria had a chance to talk to over 300 women about the symptoms of a bleeding disorder.

Kara and Jessica then headed to Seattle for the Chapter Leadership Seminar put on by the National Bleeding Disorders Foundation. There, they connected with Chapter leadership around the nation to share ideas and best practices.

Finally, November ended with our Advocacy Stake Holder Meeting where Matt Delaney, of the National Bleeding Disorders Foundation, and Miriam Goldstein, of the Hemophilia Federation of America, presented on Federal Issues. Kerry Lange, of Milliron Goodman, presented on the local issues happening here in PA.



DECEMBER 2023

Take A Bough saw beautifully decorated holiday items and bingo winners galore this year! Thanks to the support from our sponsors, donors, and patrons, we raised over \$8,500! Thank you to all our amazing volunteers who helped gather trees, decorations, gifts, and raffle items leading up to the event. Thank you to our co-chair, Melinda Perry and Maria Steele Voms Stein.

The final event for 2023 was WPBDF's Winter Program, which included games, holiday crafts, and special visits from the Grinch and Santa Claus. Board member, Stephanie Shropshire, and her family also taught everyone how to play dreidel and taught everyone how to make their own edible dreidel with pretzel rods, marshmallows, and a Hershey kiss. After the festivities, families enjoyed a program about nutrition and how to stay active in the winter.

We ended the month feeling like winners as NBDF awarded us with the 2023 Rising Star Chapter award for our successful Unite for Bleeding Disorders Walk!



JANUARY 2024

On Thursday, January 25, community members came together at Il Pizzaiolo in Warrendale for a program called The Joint Movement: Keep It Together: The Value of Family Connectivity. This program was sponsored by Sanofi and Optum and led by Carrie Koenig, Community Relations and Education Manager at Sanofi, and Kim Baumann, Associate Director of Optum Physical Therapy Collaborative. Participants walked away with a book of exercises, called *The Mobility Manual*, and a better understanding of the importance of self-care, self-advocacy, and ways to keep their joints healthy.

WPBDF's Teen group kicked off the new year with a gathering at the Carnegie Science Center. The program focused on transitioning teens to independent medical care, as they spend more time away from home. Parents and teens separated into two groups to create a list of things they should do to prepare for a hypothetical overnight school trip and then came together to compare and discuss their ideas. It was quite an eye-opening experience for everyone!

WPBDF's New Parent Network group also celebrated the new year together with a virtual program on emergency situations, led by Fredrico Xavier, M.D., M.S., HCWP Clinical Director of Pediatric Services. Each household received a go-bag to have packed and on-hand for emergency trips to the hospital or treatment center.



FEBRUARY 2024

With the new year, comes new questions about insurance. WPBDF partnered with EPBDF to host the virtual program, *New Year, New Health Plan*, with NBDF. This program discussed the surprises that can happen at the beginning of the insurance plan year and included information about copay accumulator adjusters, copay maximizers, and formulary exclusions/limitations.

We saw a full house at Bowling for Bleeding Disorders this year, too! Eighty bowlers joined us to strike out bleeding disorders. In total, we raised over \$8,000 to provide education, advocacy, and support for the bleeding disorders community!

At the end of the month, Janet Barone, WPBDF Program Director, Katherine Bush, LCSW, HCWP, and Ethan Webb, Teen Group Co-Coordinator, traveled to Oregon to attend the YETI conference, hosted by Pacific Northwest Bleeding Disorders. YETI is an experiential train-the-trainer conference, held for teens and adults who run teen programs in their local bleeding disorders community. YETI is an acronym for Youth Effectively Transitioning to Independence and the program promotes confidence and supports teens in the bleeding disorders community.



MARCH 2024

March is Bleeding Disorders Awareness Month. The following counties and cities issued proclamations recognizing March 2024 as Bleeding Disorders Awareness Month: Allegheny, Beaver, Butler, Crawford, Elk, Fayette, Greene, McKean, and Washington; and the cities of Altoona and Erie. We are so thankful for all the community advocates who attended committee meetings with us to accept the proclamations! Thank you to the counties, cities, and leaders for helping to raise awareness for bleeding disorders! We invited everyone to decorate a tiny canvas to add to our collage celebrating Bleeding Disorders Awareness Month.

We participated in NBDF's in-person Washington Days, March 6 – March 8! Advocates from Western PA included: Delores Johnson, Ethan Webb, Kyrie Holliday, Cassie Miller, Mindy Perry, Steve Stern, Ryker Stern, Maria Shoemaker, Jason Miller, Christy Miller, Seth Miller, Spencer Miller, Xavier Miller, and Scarlett Miller. We attended meetings with the offices of Representative Meuser, Representative Reschenthaler, Senator Casey, Representative Perry, Representative Deluzio, Representative Lee, Representative Scanlon, Representative Cartwright, and Senator Fetterman. We asked members of the House and Senate to co-sponsor the HELP Copays Act (HR

830/S 1375). We also called on Members of Congress to sign a letter to HHS requesting enhanced enforcement of current essential health benefits (EHB) policies that would prevent narrow formularies that don't cover treatments for all bleeding disorders.

Following Washington Days, WPBDF's Winning Women group hosted an event at Bravo! Italian Kitchen in Robinson. It was a great night of connection and volunteering as the women had a chance to catch up with each other and assemble over 400 period packs for our Women, Girls, and People who have the Potential to Menstruate with Bleeding Disorders Initiative. We are so thankful for everyone who joined us!

WPBDF's new Youth Group held a program this month at the Children's Museum of Pittsburgh. Seven families attended and listened to HCWP social worker, Kathaleen Schnur, LCSW, give a presentation on the importance of being mindful of your own bleeding disorder. This session focused specifically on the children and their siblings to help them better understand their own, or their siblings, bleeding disorder.

On Saturday, March 23, Pennsylvania Association of Staff Nurses and Allied Professionals (PASNAP) held their annual conference at the Hershey Lodge in Hershey, PA, with over 270 Pennsylvania school healthcare professionals in attendance. We

were fortunate to have an exhibitor booth and interact directly with these valuable caregivers, along with the Eastern Pennsylvania Bleeding Disorders Foundation. WPBDF Board Members, Cassie Miller and Samantha Short, attended this meeting along with Sara Pilacik and Lisa Lee, leadership staff from the Eastern Pennsylvania Foundation. As many in our community know, school nurses are on the front lines of healthcare. A pediatrician might see their patient every six months, but school healthcare professionals get to know their students daily, creating a very powerful relationship. Many school nurses we talked to had students they already identified as having signs of a bleeding disorder and we were able to provide them with additional educational material.

On March 27, we hosted a dinner program with BioMarin that offered members of the community the opportunity to learn more about ROCTAVIAN, the first FDA approved gene therapy for Hemophilia A. The month ended with a fun trivia night, organized by board member Kristen Spezialetti, raising over \$600 for the bleeding disorders community and a fundraising night at a Pittsburgh Penguins Game raising \$460.

April started with the University of Pittsburgh's PittServes Day of Service, Be A Good Neighbor Day, inspired by Fred Rogers. Over 30 students volunteered with us and helped put together 1,500 period packs, 100 resource folders for school nurses, a 6-piece mailer to over 570 community members, and over 100 bleeding disorder fact candy bags!

We actively participated in outreach events at Chatham University, Kane Area High School's Health Expo, Slippery Rock University, and Robert Morris University, aiming to raise crucial awareness about bleeding disorders in women, girls, and people with the potential to menstruate.

WPBDF celebrated World Hemophilia Day, on April 17, surrounded by community at the Monterey Bay Fish Grotto, located on the top of Mount Washington. This provided a beautiful view of the City of Pittsburgh. As the sun set, we could see the buildings in Pittsburgh light up red in honor of World Hemophilia Day. The buildings that lit up red in Pittsburgh included: Fifth Avenue Spire, the Koppers Building, Gulf Tower, the Heinz Hall Garden Plaza Waterfall, the City-County Building, One Oxford Center, and the Homestead Grays Bridge. During the event, hosted by Sanofi, there were different activities that encouraged the community, such as a selfie station,



making personal time capsules, and creating wish ribbons. The capitol building in Harrisburg, along with the Walnut Bridge and Market Street Bridge, were lit red for World Hemophilia Day. We received proclamations from Pittsburgh Mayor Ed Gainey and the Mayor of Whitehall Borough, James Nowalk, proclaiming April 17, 2024, World Hemophilia Day.

We ended the month with the largest gathering of our community at WPBDF's Education Weekend! We were back at Seven Springs Mountain Resort from April 26 - 28. This year, we welcomed over 200 people from the bleeding disorders community! On Friday night, Michael Garner kicked off the weekend with a keynote about the four different types of luck and how to change your mindset.

On Saturday, while adults were busy learning about everything from bleeding disorders basics to gene therapy and more, children were busy making new friends, learning about bleeding disorders, and enjoying activities together. The children's programs had a summer camp theme woven through them. Sunday morning brought a fresh batch of program topics, plus hands-on infusion training! The infusion training was provided by nurses from the Hemophilia Center of Western PA. The weekend concluded with raffle basket drawings before everyone headed home. A huge thank you to our Education Weekend Committee: Victoria Baker, Janet Barone, Kara Dornish, Jessica Lee, and Kathaleen Schnur.

MAY 2024

To kick off the month of May, we participated in the Montour Valley School District Health Fair to help raise awareness of bleeding disorders and the services the Foundation offers.

We were so excited to partner with the Eastern PA Bleeding Disorders Foundation to host a state-wide Advocacy Retreat in Harrisburg! Kerry Lange, of Milliron Goodman, joined us to discuss Pennsylvania Policy, and Matt Delaney, of the National Bleeding Disorders Foundation, provided an update on federal policy and taught us how to advocate. The training concluded with an educational trivia game, hosted by Keyai Lee, of EPBDF. The next day, 22 PA Advocacy Ambassadors made their way to the Capitol to meet with the offices of 33 Pennsylvania legislators. Advocates talked about the importance of the Hemophilia Line Item and asked for an increase from \$1,017,000 to \$1,250,000. Additionally, we asked members of the PA Senate to co-sponsor copay accumulator legislation (SB 372) and support menstrual product access legislation that would help end period poverty in Pennsylvania (SB 1016).

WPBDF also partnered with BioMatrix and HemaBiologics to bring an insurance program to the community. Attendees departed armed with not only answers to their queries but also a deeper understanding of the intricacies of insurance.

On behalf of the Foundation, Janet Barone attended the 2nd National Bleeding Disorders Foundation (NBDF) Health Equity (HE) Summit, Every Hour, Every Day: Access and Political Determinants of Health, on May 30-31, in New Orleans, LA. Stakeholders, which included members from the inheritable bleeding and blood disorders community, other organizations in the blood disorder and rare disease community, providers, health equity champions, and industry, gathered to learn and discuss equitable access and quality treatment for those living with inheritable bleeding and blood disorders.

JUNE 2024

Throughout June, we continued our community outreach efforts by participating in Garrison Days in Beaver and the Babesburgh Bash in Pittsburgh. We are so thankful for the volunteers who attended our community booths to tell their stories and discuss bleeding disorder signs and symptoms. We also partnered with the Pittsburgh Pirates to host a fundraising night this month! Over 38 people came to not only cheer on the Pirates, but to also support WPBDF. We raised a total of \$380 from this fundraiser, and the Pirates took home a win!

To end the month, EPBDF and WPBDF partnered to host a Couples Retreat at Liberty Mountain Resort in Fairfield, PA. Dr. Wyatt Fisher, a licensed therapist that specializes in couples therapy, flew all the way from Colorado to lead us through a six-part workshop that focused on deepening your connection with your partner. Twenty-two couples joined us for this weekend and left with many tools and strategies to have a lasting and fulfilling relationship.





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