



HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

FALL 2022



NEW PARENT NETWORK

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DISORDERS WALK**

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BOARD OF DIRECTORS

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Staff office hours are Monday-Friday from 9 a.m. until 4 p.m. Every attempt will be made to return calls received during regular office hours on the same day.

MISSION STATEMENT

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

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

DESIGNATE UNITED WAY GIFTS TO THE CHAPTER

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

WPBDF Contributor Agency Code Number is: 83

EVENTS CALENDAR

November 4, 2022

New Parent Network
Seven Springs Mountain
Resort
Champion, PA

November 4, 2022

Teen Group
Seven Springs Mountain
Resort
Champion, PA

November 5-6, 2022

Education Weekend
Seven Springs Mountain
Resort
Champion, PA

November 19, 2022

Take A Bough
Gaetano's
Pittsburgh, PA

November 22, 2022

Stakeholder Advocacy
Meeting
Virtual

November 29, 2022

Giving Tuesday

November 30, 2022

Insurance Road Map
Virtual

December 5-8, 2022

Unite Rally
Virtual

December 10, 2022

Winterfest
National Aviary
Pittsburgh, PA

January 13 - 15, 2023

Teen Retreat
Promise Camp & Retreat
Center
Clinton, PA

January 24, 2023

Penguins Game Fundraiser
PPG Paints Arena
Pittsburgh, PA

February 12, 2023

Bowling for Bleeding
Disorders
Paradise Island Bowl
Pittsburgh, PA

March 4-5, 2023

Advocacy Ambassador
Retreat
Bedford Springs Resort
Bedford, PA

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

COMMUNITY ANNOUNCEMENTS



Shirley L. Pfaffle went home to her Heavenly Father on July 8, 2022. Shirley was born on February 11, 1933 and preceded in passing by her loving parents Fred Pfaffle and Charlotte Greer.

Shirley could sing like a pro after surviving a stroke in 2020 and wanted to volunteer to work with other stroke patients/survivors by using her singing, drawing and artistic ability to help others overcome the challenges of life after a stroke and to demonstrate God's healing power!

She is survived and greatly missed by her loving daughter Lisa C. Nicolette of McCandless, brother Robert Pfaffle of Huron, Ohio, her little dog (Roxy), nephew Lee Pfaffle, niece Elizabeth Pfaffle, her cousin Susan Grieve (often referred to as her sister cousin) and many relatives and friends that reside throughout the US.

Shirley's full obituary may be found at: www.healyhahnfuneralhomes.com

Submit a community announcement to jessica@wpbdf.org.

CONTACT US

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@WPBDF

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@WPABDF

LETTER FROM THE EXECUTIVE DIRECTOR AND BOARD PRESIDENT

Dear Foundation Members and Friends,

Happy Fall! Can you believe it is October already?! The summer seemed to go by so quickly, but fall is an exciting time for the Foundation. We are so excited to be holding in-person events with our Fall Program in Erie and Education Weekend and Take A Bough coming up in November.

Thank you to everyone who came out to support the 14th Annual Unite for Bleeding Disorders Walk! It feels amazing to be back in-person raising funds and awareness for the bleeding disorders community. We are so thankful for all the amazing

volunteers, community members, donors, and sponsors. The Unite for Bleeding Disorders Walk and Run for Their Lives 5k raised over \$68,000, all of which stays local to support those living with bleeding disorders right here in Western PA.

We are looking forward to Education Weekend which will be held at Seven Springs Mountain Resort the first weekend in November. After having to postpone the event for the past two years, we are beyond excited to be holding this weekend. The Education Weekend Committee has been hard at work planning a full weekend of education, support, and fun. We can't wait to see you there!

We hope to see you all at our Take A Bough fundraiser event this year! In addition to bidding on beautiful holiday trees, wreaths,

and centerpieces, we will once again be inviting local wineries to offer samples of their wine. It will be a fun evening as we cheer each other on and raise awareness and funds for the bleeding disorders community.

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

Much Love and Appreciation,

Kara Dornish
Executive Director

Scott Domowicz
Board President





EARLY CHILDHOOD SAFETY & PRECAUTIONS

Families gathered at the Pittsburgh Zoo & PPG Aquarium, on Saturday, July 9, for a New Parent Network program. Mentor parents shared their experiences and offered their advice, as Kathaleen Schnur, LCSW moderated a panel discussion on Early Childhood Safety and Precautions. While the parents were participating in the program, the children experienced two animal encounters in a separate room and got to learn about and see a chinchilla and a bearded dragon up close! When the children rejoined their parents, they went on a short scavenger hunt in the Zoo where mentor parents were stationed to share additional information with families and give prizes to the children! The event concluded with all families assembling a giant puzzle that read Unite for Bleeding Disorders.

New Parent Network programs are open to families who have a child, newborn to age seven, who has a bleeding disorder. For more information on New Parent

Network programs, contact Janet Barone (janet@wpbdf.org / 724-741-6160) or Kathaleen Schnur (kschnur@vitalant.org / 412-209-7267).

We thank the following for sponsoring the 2022 New Parent Network series of events:

CSL Behring

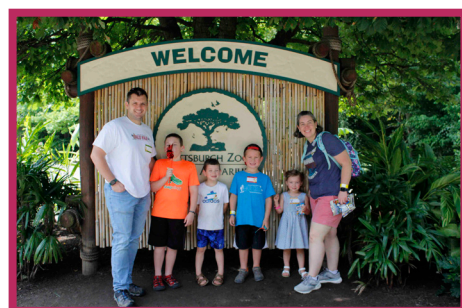
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THE HEMOPHILIA CENTER
of Western Pennsylvania

sanofi

Takeda



ADVOCACY UPDATE



Pennsylvania's Medicaid program has a Preferred Drug List. Not all products used to treat bleeding disorders are on the preferred drug list. If a doctor wants to prescribe a medication that is on the non-preferred list, they need to seek authorization and may or may not receive approval from the insurance company. We advocate for open access for every FDA Approved product for treating bleeding disorders to be placed on the preferred drug list.

On September 14 and 15, Pennsylvania Medicaid's Pharmaceuticals & Therapeutics (P&T) committee reviewed a variety of hemophilia agents. The Western Pennsylvania Bleeding Disorders Foundation along with the Eastern Pennsylvania Bleeding Disorders Foundation, the National Hemophilia Foundation, and the Hemophilia Federation of America submitted a joint written testimony urging the P&T Committee to allow patients access to all FDA-approved therapies available to treat hemophilia and related bleeding disorders. You can view the PA Preferred Drug List at: <https://papdl.com/preferred-drug-list>. If you or anyone in your family is experiencing access issues, please contact us at 724-741-6160.

STATE SENATE BILL 225

On June 19, 2022 State Senate Bill 225 passed the Senate unanimously, bringing patients one step closer to having better access to care. Now, we're racing toward the finish line, and the House has a limited number of session days to schedule a vote

and pass the bill.

This legislation will create a quicker, more efficient prior authorization process. The bill also provides a clearer route to request an override from the step therapy process. Health insurance practices such as prior authorization and step therapy allow insurers to deny a prescribed medication or treatment, requiring patients to try and fail different treatment(s) before approving the original. Additionally, these practices undermine the patient-provider relationship and delay access to needed treatment which may result in worsened symptoms and associated higher healthcare costs.

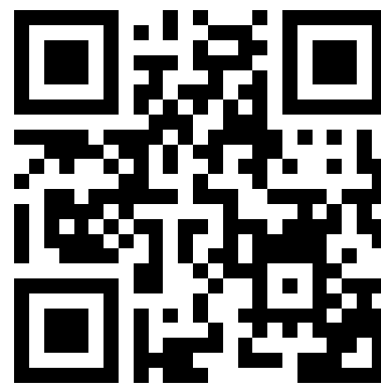
On Tuesday, September 20, 2022, SB 225 passed the House Insurance committee unanimously. We are now working towards a floor vote. Be sure to stay up to date on issues affecting the bleeding disorders community and what you can do to take action by signing up for our Advocacy Action Alerts here: <https://p2a.co/udfkjur>

HELP COPAYS ACT HR 5801

We continue to look for additional co-sponsors for H.R.5801 (HELP Copays Act), addressing co-pay accumulator adjuster programs on the federal level. NHF has an action alert to directly send a request to your Representative to support this legislation. Please use the following link to urge your Representative to support for H.R. 5801 today: <https://p2a.co/7jWIBtF>

NHF RESPONDS TO POTENTIAL CONTRACEPTION BANS

Following the June 24th Supreme Court decision overturning *Roe v. Wade*, NHF has reiterated our mission to ensure that the bleeding disorders community has access to the healthcare that they need. For the bleeding disorders community, safe and effective medical contraceptive tools can serve as a crucial aid to control bleeding and is one of many communities that may use these tools for medical purposes beyond reproductive rights. Read NHF's statement at: <https://www.hemophilia.org/news/nhf-addresses-potential-contraception-bans>.



SCAN THIS QR CODE TO SIGN UP FOR OUR ACTION ALERTS!



ADVANCED ADVOCACY TRAINING

JOHN YUNGHANS

In June, I had the opportunity to participate in the National Hemophilia Foundation's Advanced Chapter Advocacy Training in Washington D.C. I am so thankful that the Foundation could send Cassandra Miller and me to attend an intensive weekend about advocating for the

bleeding disorders community.

My advocacy journey started with Harrisburg Days. I joined a small group of people at the capital of Pennsylvania, and we shared our stories with our representatives. After that experience, and seeing the impact of my actions, I caught the advocacy bug. These activities had positive outcomes and helped further the legislative goals of the Foundation to protect those in Pennsylvania affected by bleeding disorders.

I had an amazing experience in D.C. We were taught ways to be proactive on the ground level

from home and learned that every point of contact - be it a letter, a phone call, or an email - with our political leaders matters. Building relationships with their staffers and partnering with other groups in coalitions are also equally important.

I'm thankful for this experience, and I know the Foundation's advocacy efforts will be more effective because of the knowledge I received that weekend. I encourage everyone to consider attending one of our meetings, virtually or in person, because every voice makes a difference. Your voice matters!

TEEN RETREAT 2022

NICOLETTE C., TEEN GROUP
CO-COORDINATOR

The WPBDF teen group has been busy! This August, the teen group held a weekend retreat for teenagers aged 13-18. After the teens registered, they got to meet new friends and reconnect with old friends through icebreakers. After making wooden disc nametags, the group headed to the dining hall for dinner.

Over the weekend, many activities were done, including classic camp activities like group bonding games, archery, fishing, and campfires. Along with this, the teen group was able to try out a brand-new activity at Camp Kon-O-Kwee: tubing on the creek!

Along with this, educational activities were done. The group was taught about joint and muscle bleeds and learned how to wrap injured joints with Coban.

The weekend ended with a movie and ice cream night--a sweet



send-off for a sweet weekend.

Look out for future teen group events that are being planned and consider going to Education Weekend this November.

This was Nicolette's last event as a Teen Group Co-Coordinator. Nicolette has graduated high school and is off to college. We couldn't be more proud of her and we are thankful for her dedication and contributions to the Teen Group over the years.

In addition to Nicolette, we would also like to thank and recognize Raina S. (Teen Group Co-Coordinator) and Tori Baker for their assistance with planning and implementing this event. A



special shout out to our Alumni Counselors for their support with the Teen Retreat: Tori Baker, Julia Shoemaker, Cameron Cedeno, and John Yunghans. And a special thank you to Nurse Kim Walsh for her support throughout the weekend. If you have any questions about the Teen Group or future Teen events, please contact Janet Barone (janet@wpbdf.org / 724-741-6160 or Katherine Bush (kbush@vitalant.org / 412-209-7286).

Winter Teen Retreat



JANUARY 13-15

Drop Off: 6pm-7pm January 13

Pick Up: 11am January 15

Heated Cabins, with showers and bathrooms inside!

For questions or to pre-register, contact Janet Barone, WPBDF Program Director (janet@wpbdf.org, 724-741-6160, Option 3) or Katherine Bush, HCWP Social Worker (kbush@vitalant.org, 412-209-7286).

PROMISE CAMP & RETREAT CENTER

227 LANCE RD, CLINTON, PA 15026

THIS RETREAT IS FOR TEENS ONLY! MIDDLE SCHOOL AND HIGH SCHOOL STUDENTS WHO HAVE A BLEEDING DIAGNOSIS OR ARE A TEENAGE SIBLING OF SOMEONE WITH A BLEEDING DIAGNOSIS AND ARE A MEMBER OF THE WESTERN PA CHAPTER OR THE WEST VIRGINIA CHAPTER.

HCWP CORNER

KATHLEEN SCHNUR, LCSW

Happy Fall Y'All!

It's been wonderful seeing so many of our patients and their families at Foundation events over the last few months. And we're also glad to have so many of you making appointments and coming to the center for your bleeding disorder well visits. We recognize that life can be busy, so we do our best to send reminder cards and letters and make phone calls. We promote optimal health and well-being for our patients and their families, and we must see our patients in the clinic to achieve this.

We welcomed a new Medical Assistant, Bridget Walbrown here at the center. While Bridget is

new to the center, she has been employed by Vitalant for the last five years. Fun fact about Bridget, she moved to Seattle from the Philippines 20 years ago and then moved to PA in 2017.

As we are moving into fall, we are entering open enrollment for many health insurance plans. Marketplace health insurance open enrollment for 2023 runs from November 1, 2022 – January 15, 2023. Medicare open enrollment for 2023 goes from October 15 – December 7, 2022. Please feel free to reach out to your HTC social worker if you have any questions. Additionally, NHF has a Personal Health Insurance Toolkit that is helpful when considering plans: <https://www.hemophilia.org/bleeding-disorders-a-z/healthcare-coverage/personal-health-insurance-toolkit>.

In exciting treatment news, FVIII gene therapy was approved by the European Union on August 24, 2022, and is expected to be reviewed in the United States in the next months. If you would like to learn more about gene therapy, there are many resources through the NHF website (<https://www.hemophilia.org/bleeding-disorders-a-z/treatment/future-therapies/frequently-asked-questions>) (<https://www.hemophilia.org/bleeding-disorders-a-z/treatment/future-therapies>). As always, feel free to ask your doctor.

Wishing you all a cozy and happy fall!



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Talk to your doctor about the study.



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more about the data at
JiviExtensionStudy.com

WPBDF'S ANNUAL MEETING

We were thrilled to have over 100 people join us for WPBDF's Annual Meeting – our largest in-person event since 2019! The event started off with exhibit displays and the room was buzzing with people from the moment the doors opened. There was much excitement as people were reconnecting in person for the first time in several years; and it was just as exciting to meet our newer members in person for the first time!

The event was held at Dave 'n Buster's, and after a buffet dinner, everyone settled in for the Annual Meeting presentations.

John Yunghan's, Board Vice President, led the business portion of the annual meeting, and he introduced two newly elected board members, Victoria (Tori) Baker and Stephanie Shropshire.



From left to right: Tori Baker, Stephanie Shropshire, John Yunghans, and Mindy Perry Stern.

Kara Dornish, Executive Director, highlighted some of the accomplishments from the past fiscal year, which included providing our members with over \$66,000 in assistance, through the Foundation's Emergency Patient Assistance Fund and Emergency Grocery Program. This is the most assistance the

Foundation has provided in one year, to date, and we are grateful we were able to provide this support to our families in need. In addition, the Foundation held 27 virtual programs and 6 in-person programs – all at no cost to our members. We held 6 virtual and 1 in-person fundraising events; and WPBDF received the Rising Star Chapter Award for our Unite for Bleeding Disorders Walk and continued to have one of the most successful Walks in the nation. Kara also shared highlights of the Foundation's advocacy efforts. With the support of dedicated Advocacy Ambassadors, we secured a 6% increase to the hemophilia line item in the Pennsylvania state budget and are continuing to address legislative issues that impact people living with a bleeding disorder.

Jessica Lee, Development Director, led the Walk Kickoff. She introduced Emily Nikithser, 2022 Walk Chair, and Emily shared information about the Unite for Bleeding Disorders walk and invited others to sign up.

Jessica gave a shout out to some of our amazing team captains and shared their stories: Mindy Perry Stern (Rolling for Ryker), Ashley Fox (Fox Factor), and Emily Nikithser (Conor's Clan)!

Janet Barone, Program Director, led the Chapter Services presentation and introduced the following volunteers and staff, who provided information about support groups and programs:

- John Yunghans – Blood Brotherhood / Men's Group
- Maria Steele Voms Stein – WPBDF Winning Women
- Tori Baker – Young Adult Group
- Janet Barone (on behalf of Raina S. & Nicolette C.) – Teen Group
- Kathleen Schnur – New Parent Network
- Stephanie Shropshire – Stay In Motion
- Jessica Lee – Hemogram Newsletter

...CONTINUED ON PAGE 20



From left to right: Emily Nikithser, Eileen Nikithser, Jason Miller, and Tori Baker. Not pictured: Maria Steele Voms Stein

UNITE FOR BLEEDING DISORDERS WALK BACK IN-PERSON!

This year, our 14th Annual Unite for Bleeding Disorders Walk and 12th Annual Run for their Lives 5K was held in-person at the North Park Swimming Pool! These events brought friends and families together to raise over \$68,000 to support the bleeding disorders community in Western Pennsylvania.

Anna, Elsa, and Mirabel visited us at our KidsZone along with Darth Vader and his Storm Troopers and the Eat N' Park Smiley Cookie! The characters talked, colored, and did crafts with the children and families who stopped by. The KidsZone featured a face painter, a balloon artist, crafts, and fun games provided by Angels from the Heart. There was also a DJ and a photo booth so everyone could capture their favorite memories from the day. Thank you to First Class Entertainment for the DJ and photo booth services, Face Paint Pittsburgh, Dragonfly Balloons, the 501st Starkiller Garrison, Eat N' Park, and Angels from the Heart.

This day would not be possible without the support of our many team captains who rallied their runners and walkers and went above and beyond in all that they did. Thank you to all 25 of our Walk Teams! A special shout out to the teams who really went above and beyond and raised \$1,000 or more:

Conor's Clan – \$7,845
Rolling for Ryker – \$3,470
Team Jaxson – \$2,390

Cameron's Walking Sticks – \$1,943
Fox Factor – \$1,904.52
Charlotte's Hemo Heroes Inc – \$1,650
Clotting Cavaliers – \$1,405
Maxwell House – \$1,350
Kara's Walkers – \$1,271.39
Red N' Plenty – \$1,240
Gino's Gang – \$1,195
Team Heart and Sole – \$1,000

Congratulations to our top fundraising team, Conor's Clan, who raised an incredible \$7,845! Thank you to the Team Captain of Conor's Clan, and the 2022 Unite for Bleeding Disorders Walk Chair, Emily Nikithser. Conor is 6 years old, and Conor's Clan has been participating in the Unite for Bleeding Disorders Walk ever since he was born. Each year, Conor's Clan hosts a car wash fundraiser. This year the car wash raised over \$1,200! Conor's friends united around him and raised even more funds by holding a lemonade stand! We are so thankful for Emily, Conor's Clan, and all of the people who rally to support Conor each year. Thank you for all you do!

This year's Top Individual Fundraiser was Eileen Nikithser, of Conor's Clan, who individually raised \$1,450! Eileen unites for her grandson, Conor, and raised funds by sharing her family's story. Thank you for your hard work and dedication to the bleeding disorders community. Congratulations!

Finally, a big congratulations to the winner of the Awesome John Eyrolles Top Youth Fundraiser Award, Conor Nikithser, who raised an incredible \$1,700! Conor is the inspiration for his walk team, Conor's Clan. Conor is diagnosed with Hemophilia A and each year, his mom, dad, grandparents, aunts, uncles, and friends Unite to raise awareness for bleeding disorders! Thank you and congratulations, Conor!

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

CONTINUED ON PAGE 12...

CONGRATULATIONS CONOR'S CLAN!



A **ONCE-WEEKLY** TREATMENT OPTION FOR HEMOPHILIA B.



HOW DOES
THIS FACTOR IN?

To find out about a prescription
option, talk to your doctor or visit
[OnceWeeklyForHemophiliaB.com](https://www.OnceWeeklyForHemophiliaB.com)

Unite for Bleeding Disorders

National Presenting Partners



National Community Partners



Thank You to Our Local Sponsors!



UNITE FOR BLEEDING DISORDERS WALK

CONTINUED FROM PAGE 10...

Cooper Aberegg of Aberegg Army, Brooke Aberegg of Aberegg Army, Kelly Baker of Team Jaxson, Jaxson Baker of Team Jaxson, Janet Barone of Cameron's Walking Sticks, Dave Clougherty of Conor's Clan, Lisa Data of Conor's Clan, Scott Domowicz of WPBDF's Board of Director's Team, Kara Dornish of Kara's Walkers, Ashley Fox of Team Fox Factor, Jessica Lee of Team Heart and Sole, Lynda Maxwell of Maxwell House, Jason Miller of 4 Rare Kids, Conor Nikithser of Conor's Clan, Eileen Nikithser of Conor's Clan, Emily Nikithser of Conor's Clan, Pat Nikithser of Conor's Clan, Michael Perry of Rolling for Ryker, Michelle Perry of Rolling for Ryker, Melinda Perry-Stern of Rolling for Ryker, Charlotte Rosborough of Charlotte's Hemo Heroes Inc, Marilyn Rosborough of Charlotte's Hemo Heroes Inc, Dawn Rotellini of Gino's Gang, Gabbie Rose of Clotting Cavaliers, Gwen Austin of Clotting Cavaliers, Lincoln Austin of Clotting Cavaliers, Tracy Sethman of Team Red N' Plenty, Stephanie Shropshire of Team Factor 5, Samantha Shropshire of Team Factor 5, Micah Shropshire of Team Factor 5, Steve Stern of Rolling for Ryker, Ryker Stern of Rolling for Ryker, Jen Werme of

Conor's Clan, and Russell Werme of Conor's Clan.

This year's event had fabulous t-shirts designed by many of our walk teams. Thank you to Jamie and Darin from Printeesweet for the printing of them, and for the many families who took the time to vote for their favorite t-shirt the day of our Walk. Congratulations to Team Jaxson as the official Team T-shirt Winner, raising nearly \$90!



Thank you to Miles of Smiles Timing for the great job they did managing the Run for Their Lives 5k and to everyone who participated in the run. We are excited to announce that nearly \$8,000 was raised from the Run! All the money raised will stay local to support the members of WPBDF.

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

Our Top Male Finishers:



First place: Michael Klapper



Second place: Matthew Rose



Third Place: Douglas Basinski



Our Top Female Finishers:



First place: Megan Broman



Second place: Jennifer Rose

Third Place: Caitlin Gates

And our Top Youth (under 17) Finishers:



First place: James Christian



Second place: Enzo Urso

Unite
for Bleeding Disorders



Third Place: Lorelai Urso



Lastly, and most importantly, thank you to each and every one of you who came together with us to Unite for Bleeding Disorders. 100% of the money raised from the Walk and Run will stay local to promote patient advocacy, support families in need by offering assistance with medical bills, travel, knee/elbow braces and other medical devices, provide medical ID jewelry to our members at no cost to them, provide local educational programming throughout the year, provide a support network to all our community members, and create and increase awareness about bleeding disorders.

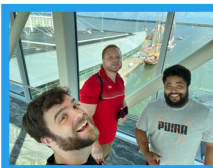
Mark your calendar now for next year's Unite for Bleeding Disorders Walk and Run For Their Lives 5k taking place at the North Park Pool on Saturday, September 9, 2023!



MEN'S GROUP

JOHN YUNGHANS

WPBDF's Blood Brotherhood held their first in-person event since 2019, on August 27, and it was a smashing success! We traveled to Erie and rallied around our old friends and new brothers by the Great Lakes. After an amazing breakfast, we launched out with our families to enjoy the tall ships together. Axes were thrown and tall sailing ships off the line were toured, but thankfully no one had to walk the plank! If you have not attended a blood brotherhood event yet and you're over 18 with a bleeding diagnosis - then you're missing out! We can't wait to meet you at the next one.





Saturday, November 19, 2022 | 6:30 PM

Gaetano's Banquet Center and Restaurant

1617 Banksville Rd, Pittsburgh, PA 15216

Holiday Tree and Wreath Auction and Wine Tasting Event

Tasting Ticket: \$30

Includes: Commemorative wine glass, two tastings at each winery, appetizers, and unlimited soft drinks

Designated Driver Ticket: \$15

Includes: Appetizers and unlimited soft drinks and one complimentary mocktail

The Western Pennsylvania Bleeding Disorders Foundation (WPBDF) invites you, your family, and friends to attend our holiday tree and wreath auction. It's a great way to kick off your holiday season!

This auction will showcase decorated trees, wreaths, and tabletop centerpieces that are all available for bid. Bidding will open online on Monday, November 14, 2022 and end on Saturday, November 19, 2022 at the conclusion of our Final Night Event. Auction items can be taken home the night of the event. ***You do not need to purchase a ticket to our Final Night Event to participate in the auction!*** You can register to be a virtual bidder online and bid from the comfort of your own home! Items can be picked up at the Foundation office (775 Fourth Street, Beaver, PA 15009) starting Monday, November 21st. Please contact jessica@wpbdf.org for more information and to coordinate item pick-ups.

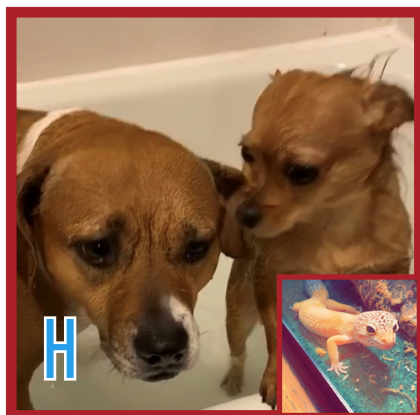
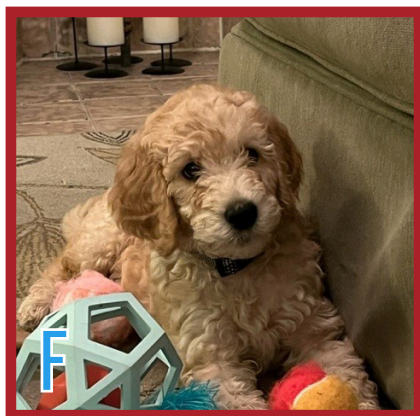
Questions? Contact Jessica at jessica@wpbdf.org or call 724-741-6160.

<https://bit.ly/wpatab2022>

GETTING TO KNOW HCWP STAFF'S PETS!

Can you match these adorable pet photos to their HCWP staff owners? The answer key is at the bottom of this page!

- | | |
|---------------------------------|---|
| 1. Nurse Kari Stepanik | 8. Research Associate Brandon Lawryk |
| 2. Dr. Craig Seaman | 9. Social Worker Kathaleen Schnur |
| 3. Dr. Frederico Xavier | 10. Administrative Assistant Patty Linn |
| 4. Genetic Counselor Bruce Haas | |
| 5. Nurse Deb Solvay, | |
| 6. Research Nurse Deb Vehec | |
| 7. Social Worker Kit Bush | |



Answers: A - Research Associate Brandon Lawryk; B - Social Worker Kathaleen Schnur; C - Nurse Deb Solvay; D - Dr. Craig Seaman; E - Research Nurse Deb Vehec; F - Social Worker Kit Bush; G - Dr. Frederico Xavier; H - Nurse Kari Stepanik; I - Administrative Assistant Patty Linn; J Genetic Counselor Bruce Haas

STAY IN MOTION STORIES

DELORES



**"FIGHT FOR EVERYTHING YOU WANT TO
ACHIEVE CAUSE YOU ARE WORTH IT AND
YOU OWE HAPPINESS TO YOURSELF."**

Delores joined the Stay In Motion (SIM) program in July 2022 along with her sister-in-law as an added layer of support! The SIM program was designed in partnership with the Hemophilia Treatment Center of Western Pennsylvania (HCWP) to provide all members with the education and tools for assessing their current physical condition, talking with their healthcare team, setting goals, and creating a plan for physical activity. SIM allows those affected by bleeding disorders to join with a friend or a family member as extra motivation!

Her favorite ways to exercise are swimming and riding bikes with her two sons, one 15-year-old and one 7-year-old. Delores also works at Kennywood and throughout the summer, she averaged between 4,000 and 13,000 steps a day! Her promotion at work was the push for her to be more active as it required a lot of walking

throughout the park.

While on her journey, Delores says the support she's received from WPBDF through weekly check-ins, monthly challenges, and fitness events has been nothing but positive for her. "I am motivated to keep exercising and eat healthier," she says. "It feels good mentally and physically to reach small milestones that I didn't think I'd be achieving yet."

Are you interested in joining the Stay In Motion Program? Visit <https://wpbdf.org/sim/> to fill out your online application. If you have any questions about this program, please contact the Foundation at 724-741-6160 or email info@wpbdf.org.



STAY IN MOTION AT KENNYWOOD!

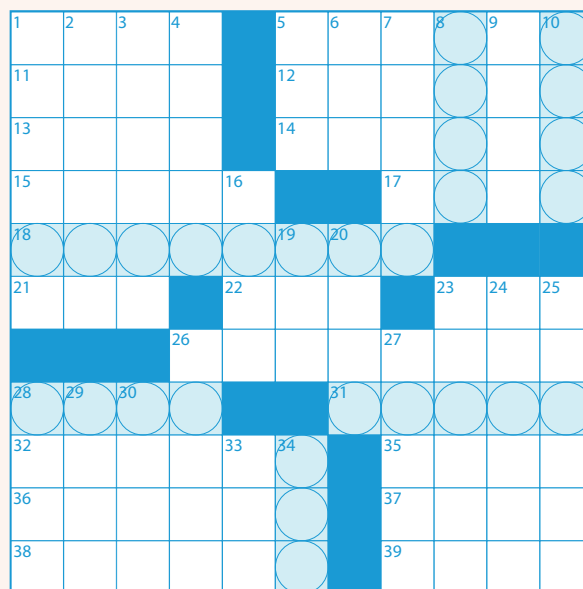
On Saturday, July 30, over 100 members came together for a program on food and fitness basics followed by a day at Kennywood Park! We had a great morning enjoying a healthy breakfast and learning about nutrition and the benefits of being physically active. The rest of the day was spent at Kennywood where we had healthy food swap stations and enjoyed a healthy lunch. We held a scavenger hunt in Kennywood and loved seeing everyone's yoga poses and creative ways of Staying In Motion and eating healthy! This program was offered as a part of WPBDF's Stay In Motion initiative. All members are invited and encouraged to participate. Stay In Motion encourages our bleeding disorders community to get up and get active



in an easy and accessible way. For more information, visit wpbdf.org/sim.

FOR A DIFFERENT **HEMOPHILIA A**

Test your HEMLIBRA knowledge



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

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

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

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

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

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

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

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

What is HEMLIBRA?

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

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

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

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

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

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

How should I use HEMLIBRA?

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

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

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

What are the possible side effects of HEMLIBRA?

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

The most common side effects of HEMLIBRA include:

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

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

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

How should I store HEMLIBRA?

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

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

General information about the safe and effective use of HEMLIBRA.

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

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

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

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

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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.

This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 12/2021



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WPBDF'S ANNUAL MEETING

CONTINUED FROM PAGE 9...

- Katherine Bush – Patient Assistance Programs and Camp Hot-to-Clot

One of the highlights of the evening was announcing our scholarship winners for the 2022-2023 academic year. The following were recipients of WPBDF's Education Scholarship:

- Anna Bailes
- Nicolette Cloutier
- Colin Domowicz
- Erek Domowicz
- Christy Miller
- Julia Shoemaker
- Maria Shoemaker

We've said it before, but it's so

true—we could not accomplish the things we do without the help of dedicated volunteers. It was our honor to recognize the top volunteers from our 2021-2022 fiscal year:

- Victoria Baker
- Jason Miller
- Eileen Nikithser
- Emily Nikithser
- Maria Steele Voms Stein

Victoria Baker was also the recipient of the Top Volunteer of the Year award!

We are grateful to the following for supporting this event:



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

Factor Program Services

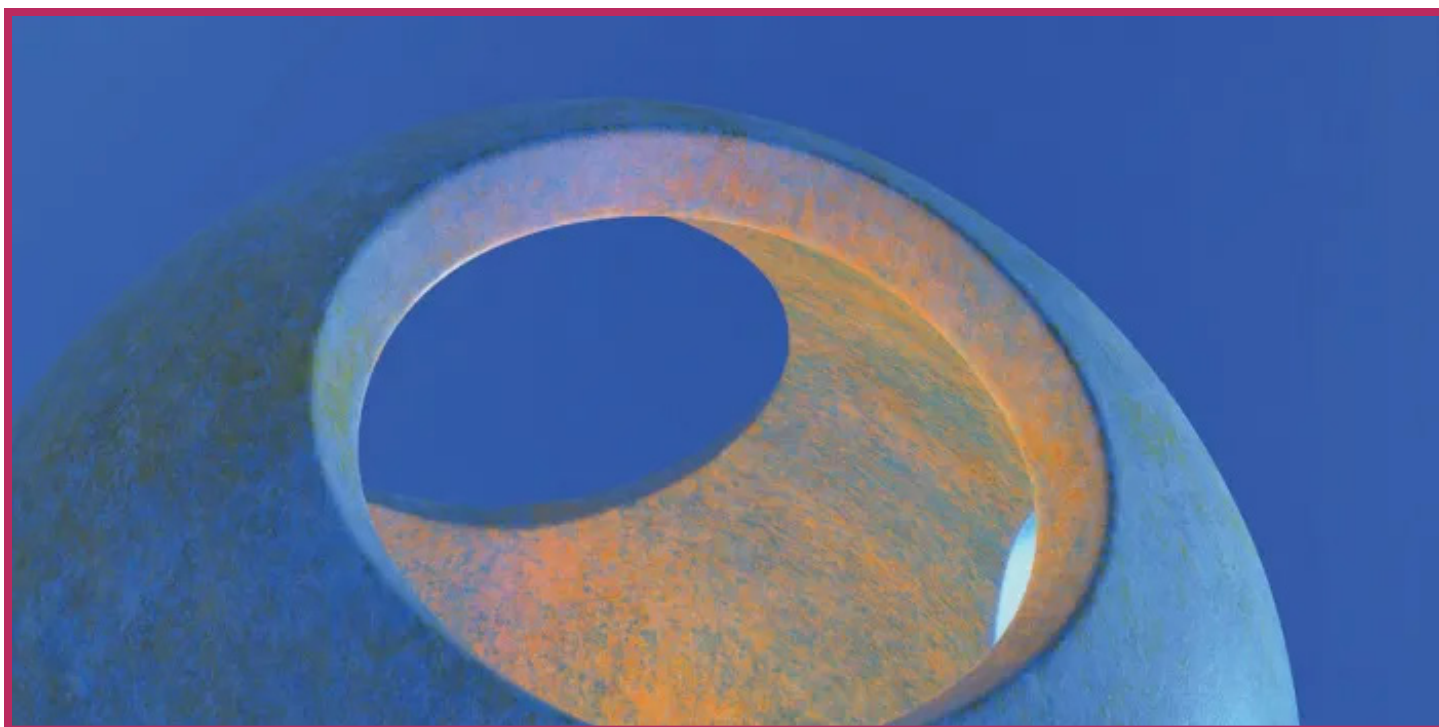
- All factor product brands available
- Online factor ordering available
- 24 – 48 hour delivery
- Same day courier service for emergent needs
- On-call services, 24/7
- Home treatment supplies
- Lot tracking for recall notification
- Online home treatment records
- Insurance benefit information assistance

Patient Benefits

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

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

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



OVARIAN CYSTS: NORMAL OR NOT?

WHAT WOMEN WITH BLEEDING DISORDERS NEED TO KNOW ABOUT OVARIAN CYSTS.

KATHRYN ANNE STEWART

Jillian Vilardo was a sophomore in high school when she first experienced a painful ovarian cyst, a fluid-filled sac that forms within or on the surface of the ovary. She was familiar with intense periods, as a result of having von Willebrand disease and factor V Leiden. But this pain was significantly worse.

"I couldn't even lift my leg to get in my mom's car," she explains.

Doctors determined that the cyst was large and likely to rupture. She was rushed into surgery to remove it. Now 28 and a registered nurse in Snyder, New York, Vilardo hasn't had any issues with cysts since. She and her husband welcomed a baby girl in May 2021.

WHAT CAUSES OVARIAN CYSTS?

One of Vilardo's physicians is Shaveta Malik, MD, an obstetrician/gynecologist and co-director of the Specialized Hematology Experts (S.H.E.) Clinic at Western New York BloodCare, in Buffalo, New York.

During the normal process of ovulation, she explains, each month the ovary releases a tiny follicle containing an egg. The follicle grows to about an inch wide, then releases the egg, along with a small amount of blood. Once in a while, the follicle continues to grow, becoming a larger cyst. Some cysts cause no symptoms, and others lead to tremendous pain or discomfort.

"Having a small cyst is very normal in reproductive-age women," Malik says.

Some data suggests that they are more common in women with bleeding disorders. In one Centers for Disease Control and Prevention study, 52% of women with von Willebrand disease had a history of ovarian cysts, compared with just 22% of women without a bleeding disorder. However, this may be because women with bleeding disorders are more likely to have symptoms.

DIAGNOSIS AND TREATMENT

First, a doctor will feel the size of your ovaries and check for

tenderness. Then, an ultrasound determines the size of the cyst and what kind it is.

Many cysts resolve on their own, according to Malik. Surgery is only necessary if there is significant bleeding and/or pain, or if the cyst is large (8 centimeters or more). To prevent new cysts from forming, oral contraceptives are often prescribed, Malik says.

Cysts related to ovulation don't typically affect a woman's fertility. Even if surgery is needed, it's possible to remove the cyst, leaving the ovary intact. Vilardo and her husband were able to conceive after eight months of trying. "Of course, I was convinced that there was an issue," she says. She spoke to Malik, who provided reassurance.

WHEN TO CONTACT YOUR DOCTOR ABOUT A CYST

Nausea and abdominal pain, especially if they occur suddenly after strenuous activity, could be signs to see a doctor. Fortunately, Malik's advice is simple: "Contact your ob/gyn if you don't feel well," she says.

*Article Courtesy of HemAware
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MEET THE BOARD MEMBERS



STEPHANIE SHROPSHIRE

What influenced you to get involved with the Chapter and join our board of directors?

My daughter woke up at 5 weeks old with bruising on her. It became a long journey of getting her diagnosis and ultimately finding a great group to support her and our family while we learn and navigate her bleeding disorder. A few years later, the Chapter has given so much to our family, it only seemed natural to join the board of directors and help support other families in similar situations to our own.

What is your background or current occupation?

I am a stay at home mom of three, a graphic designer and I also teach art at a private school in Pittsburgh.

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

I'm looking forward to helping families like mine help navigate their new diagnosis, to help support people who don't have access to life saving medications and to make a difference in the bleeding disorders community.

What do you like to do for fun?

I love to read, sew and spend time with my husband, children, our two dogs (chihuahua and German shepherd), and our four chickens!

Stephanie joined the WPBDF Board of Directors in July 2022.

WPBDF's

Winterfest

SATURDAY, DECEMBER 10, 2022

National Aviary

700 Arch Street
Pittsburgh, PA 15212



11:00 AM - 1:30 PM

Join us in the Garden Room at the National Aviary to learn more about the Western Pennsylvania Bleeding Disorders Foundation and the services offered! Enjoy a lunch buffet, exhibits, games, an animal encounter, and a day of fun exploring the National Aviary!

This program is for members of the Western PA Bleeding Disorders Foundation and family members living in their household. This is an all ages event.

To register, send an email to rsvp@wpbdf.org or call the Foundation office at 724-741-6160, by Wednesday, November 23rd. Let us know the number of people in your party and if there are any food allergies. If children will be attending please include their ages.





A BOWLING FUNDRAISER TO BENEFIT THE WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION!

Sunday, February 12, 2023
2:00 PM - 5:00 PM

Paradise Island Bowl
7601 Grand Avenue
Pittsburgh, PA 15225

\$25 per person. Includes 3 hours of bowling, shoe rental, pizza, and unlimited soft drinks! A portion of proceeds raised at this event will provide education, support groups, and patient assistance to the bleeding disorders community of Western PA!

TICKETS ON SALE SOON! LEARN MORE AT: WPBDF.ORG

PITTSBURGH PENGUINS FUNDRAISER



Scan the QR code for
tickets!

**Support WPBDF by attending a
Pittsburgh Penguins Game!**

When: Tuesday, January 24TH, 2023

Game Time: 7:00 PM

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

Upper Bowl: \$45
Lower Bowl: \$75

Get tickets at: <https://fevo.me/penguinsnhf23>

*A maximum of six (6) tickets can be
purchased at a time. For larger groups,
please email Derick at
dwoodard@pittsburghpenguins.com.*

**\$10 from every ticket will be donated
to the Western PA Bleeding Disorders
Foundation.** You can help provide
education, support groups, and patient
assistance to our families and individuals
in need!





WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

775 4th Street
First Floor
Beaver, PA 15009



Winter Flower Fundraiser

Order your winter flowers and support the Western PA Bleeding Disorders Foundation!



A portion of every plant purchased will be donated back to support the Western PA bleeding disorders community. The more we sell, the higher percentage is donated back to our community! Share this with your friends, family, and loved ones to help us raise funds to provide education, support groups, and patient and grocery assistance to families and individuals in need.

Scan this QR code to order your winter flowers or visit: <https://give.classy.org/wpbdfwinterflowers>



HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

775 4th Street, First Floor

Beaver, PA 15009

Phone: 724-741-6160 Toll Free: 800-824-0016 Fax: 724-741-6167

info@wpbdf.org

