WPBDF
Western Pennsylvania
Bleeding Disorders Foundation

# HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

FALL 2023

WPBDF
Western Pennsylvania Bleeding Disorders Foundation

## BOARD OF DIRECTORS

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*Executive Director* Kara Dornish
*Program Director* Janet Barone
*Development Director* Jessica Lee

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.



## 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

**October 14, 2023**
Fall Program
Wexford, PA

**October 19, 2023**
Hemgenix Program
Bravo! Italian Kitchen
Pittsburgh, PA

**October 21, 2023**
Youth Group (Ages 7-12)
Iron Mill Farmstead
New Wilmington, PA

**November 1, 2023**
Insurance Program
Jackson's Restaurant
Hilton Garden Inn
Center Township, PA

**November 4, 2023**
WPBDF's Cornhole Tournament Fundraiser
Bottlerocket Social Hall
Pittsburgh, PA

**November 9, 2023**
Insurance Program
Virtual

**November 21, 2023**
Advocacy Stakeholder Meeting
Virtual

**December 2, 2023**
Take A Bough Fundraiser
Red Fox Winery
Hickory, PA

**December 9, 2023**
Winterfest
Shadow Lakes Country Club
Aliquippa, PA

**February 18, 2024**
Bowling for Bleeding Disorders Fundraiser
Paradise Island Bowl
Pittsburgh, PA

**March 6-8, 2024**
NBDF's Washington Days
Washington D.C.

**April 26-28, 2024**
Education Weekend
Seven Springs Mountain Resort
Seven Springs, PA

**July 18, 2024**
WPBDF Annual Meeting
Top Golf
Bridgeville, PA

**September 21, 2024**
Unite for Bleeding Disorders Walk
Run For Their Lives 5k
North Park, PA

**May 16-18, 2025**
Pennsylvania Bleeding Disorders Conference
Hershey Lodge

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

## COMMUNITY ANNOUNCEMENTS

*Submit a community announcement to jessica@wpbdf.org.*

### Do you have a great OBGYN?

**Please share with us if you have an OBGYN who provides the comprehensive care and understanding which you require for your or your daughters' bleeding disorder! We would like to know the providers in PA who are taking great care of our community.**

**Scan this QR code**
**OR**
**Follow this link to complete our form**

**https://forms.gle/nhcvrQjrSWzzwdfX8**

## CONTACT US

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@WPBDF
@WPBDF
@WPABDF

# LETTER FROM THE EXECUTIVE DIRECTOR AND BOARD PRESIDENT

Dear Foundation Members & Friends,

Happy Fall! Time to get out your favorite sweater and enjoy pumpkin spice everything! The summer always seems to go by so quickly, but fall is an exciting time for the Foundation. We are so excited to welcome Tim Ringgold to our Fall Program this year! He is an award-winning presenter, and we are sure you will enjoy his interactive music therapy session. Afterward, we invite you to head to Soergel Orchards to spend the day at the Fall Festival.

Thank you to everyone who came out to support the 15th Annual Unite for Bleeding Disorders Walk! We are so thankful for all the amazing volunteers, community members, donors, and sponsors. This was our best fundraising year yet!! The Unite for Bleeding Disorders Walk and Run for Their Lives 5K raised over $73,000, all of which stays local to support those living with bleeding disorders right here in Western PA.

We are looking forward to our Cornhole Tournament Fundraiser being held the first weekend in November. We are excited to work with Steel City Cornhole again on the first cornhole tournament since the pandemic! We hope you will join us at the Warehouse at Bottle Rocket Social Hall for a fun day of throwing bags and raising money for the bleeding disorders community.

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 be playing bingo and tasting wine at the Red Fox Winery in Hickory, PA! 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

# 2023 UNITE FOR BLEEDING DISORDERS WALK AND RUN FOR THEIR LIVES 5K

This year, our 15th Annual Unite for Bleeding Disorders Walk and 13th 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 $73,000 to support the bleeding disorders community in Western Pennsylvania.

Steely McBeam visited us at North Park to celebrate the finishers of our 5K Run and danced with the kids and families at the DJ booth! Everyone had a blast getting their face painted, snapping photos at the photo booth, and enjoying a delicious snack! Thank you to First Class Entertainment for the DJ and photo booth services and Face Paint Pittsburgh! Thank you to the following for providing so many amazing snacks: Wendy's (Gibsonia), Power Crunch, Trader Joe's, Eat' n Park, Texas Roadhouse, Ready Nutrition, Culligan Water, Super Bakery, and Cottrill's Pharmacy.

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 28 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 – $7,387
Rolling for Ryker – $3,910
Fox Factor – $3,856
Cameron's Walking Sticks – $2,325
Team Jaxson – $2,045
Clotting Cavaliers – $1,915
Factor 5 –$1,695.70
Maxwell House – $1,450
Gino's Gang – $1,300
Kara's Walkers – $1,190
Bloody Shoewalkers – $1,175

Congratulations to our top fundraising team, Conor's Clan, who raised an incredible $7,387! Thank you to the Team Captain of Conor's Clan, and the Top Team

Captain for 2023, Emily Nikithser. Conor is 7 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 $1,252! 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 Ashley Fox, of Fox Factor, who individually raised $1,733! Ashley unites for her 1-year-old son, Rylen. He is diagnosed with Hemophilia A and has his entire family celebrating him! 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, Jaxson B., who raised an incredible $1,280! Jaxson is the inspiration for his walk team, Team Jaxson. Jaxson is diagnosed with Hemophilia A and each year, his mom, dad, sister, and grandparents unite to raise awareness for bleeding disorders! Thank you and congratulations, Jaxson!

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:

- Cooper Aberegg of Aberegg's Army
- Brooke Aberegg of Aberegg's Army
- Gwen Austin of the Clotting Cavaliers
- Lincoln Austin of the Clotting Cavaliers
- Jaxson Baker of Team Jaxson
- Kelly Baker of Team Jaxson
- Janet Barone of Cameron's Walking Sticks
- Cameron Cedeno of Cameron's Walking Sticks
- Dave Clougherty of Conor's Clan
- Lisa Data of Conor's Clan
- Kara Dornish of Kara's Walkers
- Ashley Fox of Team Fox Factor
- Rylen Fox of Team Fox Factor
- Matthew Fox of Team Fox Factor
- Corey Glasgow of Finley's Crew
- Jessica Lee of Team Heart & Sole
- Lynda Maxwell of Maxwell House
- Conor Nikithser of Conor's Clan
- Eileen Nikithser of Conor's Clan
- Emily Nikithser of Conor's Clan
- Pat Nikithser of Conor's Clan
- Dawn Rotellini of Gino's Gang
- Gabbie Rose of the Clotting Cavaliers
- Micah Shropshire of Team Factor 5
- Samantha Shropshire of Team Factor 5
- Stephanie Shropshire of Team Factor 5
- Michael Perry of Rolling for Ryker
- Michelle Perry of Rolling for Ryker
- Melinda Perry-Stern of Rolling for Ryker
- Maurice Prendergast of Conor's Clan
- Maria Shoemaker of The Bloody Shoewalkers
- Ryker Stern of Rolling for Ryker
- Steve Stern of Rolling for Ryker
- Jen Werme of Conor's Clan
- Russell Werme of Conor's Clan
- Morgan Woods of TJ's First Walk

This year's event had 12 fabulous t-shirts designed by many of our walk teams. Thank you to Jamie

... CONTINUED ON PAGE 16

# FACTOR UP with ALTUVIIIO™

ALTUVIIIO™
Antihemophilic Factor (Recombinant), Fc-VWF-XTEN Fusion Protein-ehtl

## Higher-for-longer Factor VIII levels in the near-normal to normal range **(over 40%)** for most of the week

**HIGHER FACTOR LEVELS FOR LONGER**
Above 40% for most of the week (near-normal to normal range).*†

**48 HOUR HALF-LIFE IN ADULTS**
In a Phase 3 study,† ALTUVIIIO offered adults the longest half-life of any Factor VIII therapy.

**0.7 BLEEDS PER YEAR‡**
Mean annual bleed rate observed in 128 people previously treated with prophylaxis therapy.†

In people taking ALTUVIIIO in the XTEND-1 study, 21% of people had headache, 16% had joint pain, and 6% had back pain

*Average trough levels were 18% for adults 18 years and older, 9% for adolescents aged 12 years to under 18 years, 10% for children aged 6 years to under 12 years, and 7% for children aged 1 year to under 6 years.
†159 adults and adolescents with severe hemophilia (aged 12 years and older) were enrolled in the XTEND-1 study; 133 people were in Group 1 and switched to ALTUVIIIO prophylaxis from prior prophylaxis therapy. Efficacy of prophylaxis was evaluated in 128 of these patients.
‡Data based on treated bleeds.

## CONNECT WITH YOUR CoRe TODAY

Learn more about ALTUVIIIO, living with hemophilia, and treatment options from your local CoRe.

Carrie Koenig
carrie.koenig@sanofi.com
667-500-4326
Serving Western PA

## INDICATION

ALTUVIIIO™ [antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-ehtl] is an injectable medicine that is used to control and reduce the number of bleeding episodes in people with hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ALTUVIIIO when you have surgery.

## IMPORTANT SAFETY INFORMATION

**What is the most important information I need to know about ALTUVIIIO?**
Do not attempt to give yourself an injection unless you have been taught how by your healthcare provider or hemophilia center. You must carefully follow your healthcare provider's instructions regarding the dose and schedule for injecting ALTUVIIIO so that your treatment will work best for you.

**Who should not use ALTUVIIIO?**
You should not use ALTUVIIIO if you have had an allergic reaction to it in the past.

**What should I tell my healthcare provider before using ALTUVIIIO?**
Tell your healthcare provider if you have had any medical problems, take any medications, including prescription and non-prescription medicines, supplements, or herbal medicines, are breastfeeding, or are pregnant or planning to become pregnant.

**What are the possible side effects of ALTUVIIIO?**
You can have an allergic reaction to ALTUVIIIO. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called "inhibitors" against ALTUVIIIO. This can stop ALTUVIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

The common side effects of ALTUVIIIO are headache, joint pain, and back pain.

These are not the only possible side effects of ALTUVIIIO. Tell your healthcare provider about any side effect that bothers you or does not go away.

**Please see brief summary of Prescribing Information on the next page.**

sanofi



MAT-US-2301369-v1.0-03/2023

**Patient Information** **Rx Only**

**ALTUVIII™ (al too'vee oh)**
**[antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-ehtl] for intravenous use after reconstitution only**

**Single-dose vial**

Please read this Patient Information carefully before using ALTUVIII and each time you get a refill, as there may be new information. This Patient Information does not take the place of talking with your healthcare provider about your medical condition or your treatment.

**What is the most important information I need to know about ALTUVIII?**

Do not attempt to give yourself an injection unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for injecting ALTUVIII so that your treatment will work best for you.

**What is ALTUVIII?**

ALTUVIII is an injectable medicine that is used to control and reduce the number of bleeding episodes in people with Hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ALTUVIII when you have surgery.

**Who should not use ALTUVIII?**

You should not use ALTUVIII if you had an allergic reaction to it in the past.

**What should I tell my healthcare provider before using ALTUVIII?**

Talk to your healthcare provider about:

- Any medical problems that you have or had.
- All prescription and non-prescription medicines that you take, including over-the-counter medicines, supplements or herbal medicines.
- Pregnancy or if you are planning to become pregnant. It is not known if ALTUVIII may harm your unborn baby.
- Breastfeeding. It is not known if ALTUVIII passes into the milk and if it can harm your baby.

**How should I use ALTUVIII?**

You get ALTUVIII as an injection into your vein. Your healthcare provider will instruct you on how to do injections on your own, and may watch you give yourself the first dose of ALTUVIII.

Contact your healthcare provider right away if bleeding is not controlled after using ALTUVIII.

**What are the possible side effects of ALTUVIII?**

You can have an allergic reaction to ALTUVIII. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash or hives.

Your body can also make antibodies called "inhibitors" against ALTUVIII. This can stop ALTUVIII from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

The common side effects of ALTUVIII are headache, joint pain, and back pain.

These are not the only possible side effects of ALTUVIII. Tell your healthcare provider about any side effect that bothers you or does not go away.

**What are the ALTUVIII dosage strengths?**

ALTUVIII comes in seven different dosage strengths with 3 mL sterile water for injection (sWFI). The actual number of international units (IU) of Factor VIII activity in the vial will be imprinted on the label and on the box. The seven different strengths are as follows:

| Strength | Cap Color |
|---|---|
| 250 IU | Yellow |
| 500 IU | Red |
| 750 IU | Garnet |
| 1000 IU | Green |

**(continued)**

| Strength | Cap Color |
|---|---|
| 2000 IU | Royal Blue |
| 3000 IU | Mist Grey |
| 4000 IU | Orange |

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your healthcare provider.

**How should I store ALTUVIII?**

- Keep ALTUVIII in its original package.
- Protect it from light.
- Do not freeze.
- Store refrigerated 2°C to 8°C (36°F to 46°F) up to 48 months or at room temperature [not to exceed 30°C (86°F)], for a single period up to 6 months. Do not use ALTUVIII after the expiration date printed on the label and carton of each vial.
- When storing at room temperature:
  - Note on the carton the date on which the product is removed from refrigeration.
  - Use the product before the end of this 6-month period or discard it.
  - Do not return the product to the refrigerator.

After mixing with the diluent:

- Do not use ALTUVIII if the mixed solution is not clear and colorless to slightly yellowish.
- Use mixed product as soon as possible.
- You may store mixed ALTUVIII at room temperature, not to exceed 30°C (86°F), for up to **3 hours**. Protect the mixed ALTUVIII from direct sunlight. Discard any mixed ALTUVIII not used within 3 hours.

**What else should I know about ALTUVIII?**

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ALTUVIII for a condition for which it was not prescribed. Do not share ALTUVIII with other people, even if they have the same symptoms that you have.

Manufactured by:
Bioverativ Therapeutics Inc.
Waltham, MA 02451
A SANOFI COMPANY
US License Number 2078



AHF-PPI-SL-FEB23

# ADVOCACY UPDATE

KERRY LANGE, SENIOR ASSOCIATE MILLIRON GOODMAN

## HARRISBURG OVERVIEW

With a very divided state government (a one-seat Democratic-Majority in the House, a Republican-controlled Senate, and a Democratic Governor), the 2023 budget season was expected to be less amicable. Below is a brief recap on the most recent developments.

On June 30, the Constitutional deadline for a balanced budget, the Senate sent the House the general appropriations budget, HB 611. Senate Republicans claimed that they had a deal with Democrat Governor Josh Shapiro. They would support the spending bill, so long as he would support the $100 million line item for a school voucher program. So, the Senate amended HB 611 to include that voucher program.

Shortly after the Senate passed the bill and sent it over to the House, Governor Shapiro urged House support for the budget and promised that he would line-item veto the voucher program, arguing that there wasn't enough support for it in the House. With 86 Republicans in opposition, the House passed HB 611.

As part of standard operating procedures, each chamber is required to sign the bills that they've passed. Because Governor Shapiro reneged on his agreement with the Senate Republicans, Senate leadership refused to reconvene into session to sign the budget bill and send it to the Governor's desk. However, after mounting pressure from public schools, county human service program providers, and others who depend on state funding, the Senate reconvened on August 3rd, signed the bill and sent it to the Governor's desk.

Although the Governor signed HB 611 into law and many state departments can now start distributing some of the funding and prevent disruptions in schools and human services programs, the budget package is not yet finalized. The general appropriations budget bill is simply the spending portion of the budget package, detailing how much funding shall be allocated to each line item. However, many line items require additional authorization through a supplemental fiscal code bill, detailing how the money should be distributed within each line item. On August 30, the Senate reconvened to debate two fiscal code bills, HB 1300 and SB 757. HB 1300 directs funding to many non-controversial and bipartisan line items. SB 757 addresses the more controversial priorities, including funding for educational options for students in failing schools. Both bills were passed by the Senate and now await consideration by the House.

## BUDGET LINE ITEM

We are pleased to report that our advocacy work was successful again this year. We were able to protect the line item in HB 611 PN 1811 (Page 462). The state appropriation for hemophilia services in the 2023-24 state budget is $1,017,000. As previously noted, HB 611 was signed into law by Governor Shapiro on August 3rd. *(Figure 1)*

While the fiscal code language hasn't been considered by the House yet, the Senate's version, HB 1300, included our requested language, clarifying that there shall

```
    FOR ADULT CYSTIC FIBROSIS AND
OTHER CHRONIC RESPIRATORY
ILLNESSES.
        STATE APPROPRIATION.......                795,000
    FOR DIAGNOSIS AND TREATMENT
FOR COOLEY'S ANEMIA.
        STATE APPROPRIATION.......                106,000
    FOR HEMOPHILIA SERVICES.
        STATE APPROPRIATION.......              1,017,000
    FOR LUPUS PROGRAMS.
        STATE APPROPRIATION.......                106,000
    FOR SICKLE CELL ANEMIA
SERVICES, INCLUDING CAMPS FOR
CHILDREN WITH SICKLE CELL ANEMIA.
        STATE APPROPRIATION.......              1,335,000
```

*Figure 1*

be no changes to the hemophilia funding distribution formula. HB 1300 passed the Senate and is waiting for consideration in the House. *(Figure 2)*

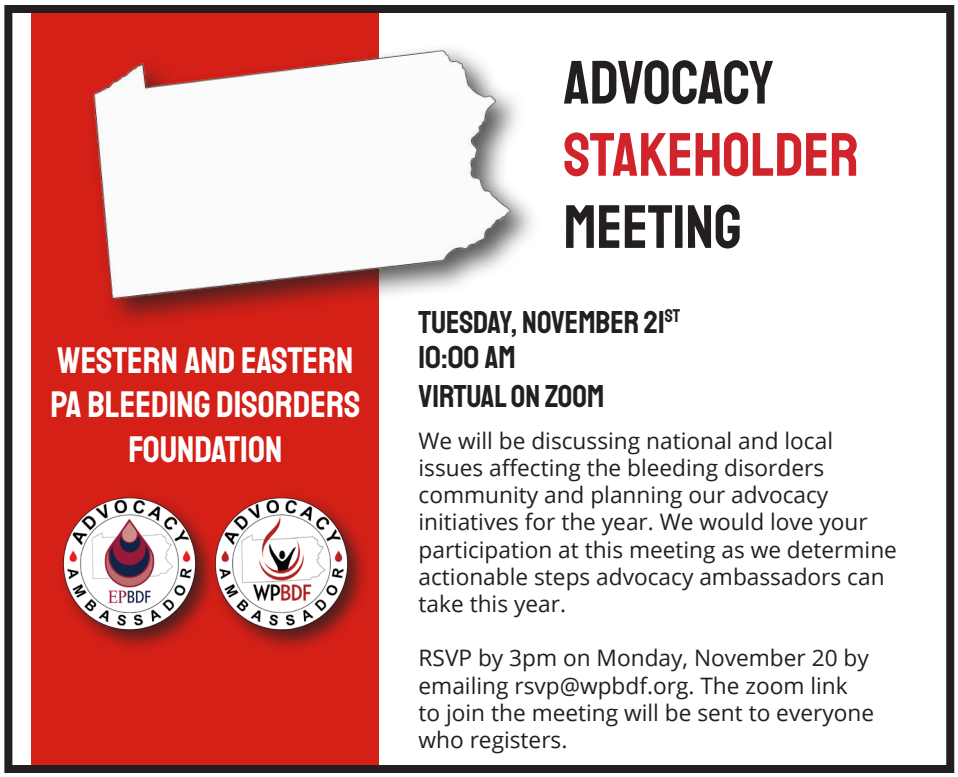
12 (7) MONEY APPROPRIATED FOR HEMOPHILIA SERVICES SHALL BE
13 DISTRIBUTED TO GRANTEES IN THE SAME PROPORTION AS DISTRIBUTED
14 IN FISCAL YEAR 2019-2020.

*Figure 2*

We'd like to give much deserved credit to all those who were able to come to Harrisburg on June 7, and make a grand finale push for the line item. It was a very productive day where members of the Bleeding Disorders Foundation were able to meet directly with legislators and staff and remind them about the importance of maintaining our line item in the annual budget.

### THANK YOU

On behalf of the Milliron Goodman team, thank you for choosing us to be your advocates in the Capitol. We look forward to continuing to partner with you and will keep you apprised on relevant legislative progress.




# TO THE MEMBERS OF CONGRESS

Many individuals in the bleeding disorders community rely on copay assistance from drug manufacturers and charities to maintain access to their high-cost treatments. Because blood factor drugs are biological products — in this case, a protein — there are no cheaper copies, called biosimilars, available. The cost of the life saving and life sustaining treatment for a person with a bleeding disorder such as hemophilia, can be several hundred thousand dollars per year and annual treatment costs of $1 million or more are not unheard of for patients with the most severe forms of the disease.

Copay assistance is often a lifeline to those with bleeding disorders and serious, chronic conditions. However, insurance companies are increasingly utilizing copay accumulator, maximizer, and copay diversion programs, which prevent copay assistance from being counted toward an individual's deductible or out-of-pocket maximum. For example, when an insurer applies a copay accumulator, the insurer collects double (or even more than double) the amount of a patient's required cost-sharing: once from the copay assistance program and then, when the assistance dollars are depleted, the full amount of the cost-sharing (again) from the patient. On the patient's side, all too often, the result is that the patient encounters an unexpected and unaffordable charge for their drug refill. If they are unable to pay, the patient may be forced to abandon their prescription, discontinue therapy, and potentially end up in the emergency room for treatment of an acute (and avoidable) health issue.

It is very important that copay assistance be used to assist patients as was originally intended. Federally, bills have been introduced in the House (H.R. 830) and Senate (S. 1375). If passed, this legislation will clarify the ACA definition of cost-sharing to ensure payments made "by or on behalf of" patients count towards their deductible and/or out-of-pocket maximum and close the essential health benefits loophole. In Pennsylvania, Senator Judy Ward and Senator Maria Collett are the prime sponsors of Senate Bill 372. If passed, this bill will protect

... CONTINUED ON PAGE 10

Pennsylvanians in state-regulated health plans by ensuring that all payments made by the patient or on behalf of the patient count toward the patient's deductible and out of pocket costs.

Maria Shoemaker, a Pennsylvania resident, and mother of five living with von Willebrand Disease, has written about her own experience with copay accumulators and the hardships she has continually faced as the result of a lack of medication access and affordability.

*July 26, 2023*

To (the members of Congress),

I overheard my child, on his 16th birthday, tell my husband that he has no hope for a happy life due to his chronic health conditions. He has seen me fight for months just to have the right to pay for his dental work. He has seen me have multiple bleeds that go untreated because of insurance problems. He has seen us struggle to survive financially despite our being above the medium income for the country. He has seen the hours and hours I have spent on emails and phone calls and meetings begging for help. He has seen me come out of my room after those hours with eyes swollen from crying and completely drained. How do I tell my child that he does have a chance at a decent future in a country that is rigged against people with chronic health conditions? I could hear the sadness and pain in his words that night and it broke me.

He is not being judged for his character or his value to the community, as is the same for all Americans with chronic health conditions. He is being judged on a genetic condition, von Willebrand Disease, that I had no idea was even present in my family tree before my first child was born. I wish I never had this disease or passed it along to my children. I wish that I did not have to worry about my bleeding or that of my children. I wish I had any other choice but to give myself intravenous medication over and over. I would give almost anything to be fully healthy, and for my children to have that future. That is not our reality.

I have this disease, as do two of my five children. While there are treatments to help us, access is out of reach. The insurance companies are literally middlemen for profit. They make money only when someone is the right kind of sick and wealthy enough to pay for it. So, they create policies to eliminate the high-cost patients that hurt their stockholder's earnings. Most legislators, both federal and in the state of Pennsylvania, are funded by these same insurance companies. Every time we make any progress with laws meant to protect people with chronic health issues, the insurance companies find loopholes to hurt the already disadvantaged even more. Now, when we ask Congress to simply hold the ACA mandates to the intent and stop the insane practices of copay accumulators/ maximizers/diversion policies, the very same protections our federal congressional members already have, we are told the cost to enforce the mandate is too high. How can something be considered too discriminatory for federal employees but not the average American? Why is it that enforcing ACA mandates only impacts the relatively small amount of profit insurance companies would be losing compared to their already record profits? Persons with chronic/serious health conditions in our country no longer carry value of simply being a human life. We are now a cost-benefit analysis. Does the government feel the individual in question, a person with a chronic or serious health condition, is worth the resources spent on them? Individuals like me are simply too expensive to keep alive. My factor replacement therapy is roughly $14,000 a dose and is very complex to create. I normally use two doses a month but need more for injuries or surgeries. I have more physical limitations due to my disease being undiagnosed for 23 years and the damage done over the years by chronic bleeds. I need to see doctors more frequently. I am currently a college student, so not contributing currently to the GDP. The government does not see the value we add to our community or the work we do. Our lives are now dollar signs and mine is in the red as far as the government is concerned.

Can anyone reading this tell me differently? Can you honestly tell me that my family is not being stripped of the intrinsic value of human life simply because of greed? Can any one of you look my son in the eye and promise him that the reality he is seeing with me is not going to be his life too? That he is not going to spend his life fighting for care and against the stigma that his life means less, or nothing at all, because he carries a genetic defect? These poor children are already facing such an uphill fight in our world. For my son to say he has nothing but fight in his future because he has seen how this country values people with any chronic health condition, it has broken me. I need to focus my efforts on ways to ensure my family's survival and it seems clear our government will not do anything to help us.

Maria Shoemaker
Vandergrift, Pennsylvania

# IN SEARCH OF:

## PA DENTISTS/ORAL SURGEONS WHO KNOW HOW TO TREAT PEOPLE WITH BLEEDING DISORDERS, AND DO IT WELL.

OR

bit.ly/padentalsurvey

EASTERN AND WESTERN PA BLEEDING DISORDERS FOUNDATIONS ARE CREATING A LIST OF THESE PROVIDERS SO THAT WE CAN HELP OTHERS WHO NEED IT.

**PLEASE CALL OR EMAIL YOUR CHAPTER IF YOU HAVE A REFERRAL, CLICK ON THE LINK, OR SCAN THE QR CODE. THANK YOU!**



The Western Pennsylvania Bleeding Disorders Foundation received The John Indence Award and the The Val Bias and Todd Smith Innovation in Camp Award at the National Bleeding Disorders Foundation's Bleeding Disorders Conference. 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 these awards.


# BACK TO SCHOOL WITH WPBDF

On Friday, August 11, members of the Western Pennsylvania Bleeding Disorders Foundation came together at Dave & Busters – North Hills, for a Back-to-School program called “How to Communicate With Your Child’s School." Cathy Tiggs, Social Worker for Adult/ Pediatric Hematology at the University Hospitals Case Medical Center in Cleveland, OH, led a very engaging conversation with both caregivers and children. Caregivers learned strategies to improve communication with their child’s school to help ensure a safe and nurturing environment. Thank you to Novo Nordisk for sponsoring this program.


novo nordisk®

## RITA T. WINTERMOYER

**MARCH 29, 1961 - APRIL 2, 2023**

Rita T. Wintermoyer, 62, formerly of North Huntingdon, resided in Grafton, WV, passed away Sunday, April 2, 2023. She was born March 29, 1961 in Braddock, resided in Pitcairn, a daughter of the late Harry Robert and Alice Waltz. Rita was a certified respiratory therapist and pharmaceutical representative and a former member of St. Edward Church. Rita was a graduate of Gateway High School and West Virginia University. She enjoyed boating, crocheting and fishing. She is survived by her husband, Todd Wintermoyer; sons, William Dull and his wife, Chrissy, Andrew Dull and his wife, Christine, Ryan Wintermoyer and his wife, Morgan; sister, Roberta Waltz; brothers, Gilbert (Debby), Joseph and Raymond Waltz; and many nieces, nephews, cousins and amazing friends. In lieu of flowers, donations may be made to National Hemophilia Foundation, www.hemophilia.org/who-we-are.

See Rita’s obituary or leave a tribute at: https://www.shirleyfuneralhome.com/obituaries/Rita-T-Wintermoyer?obId=27635641

# NATIONAL HEMOPHILIA FOUNDATION UPDATES NAME TO NATIONAL BLEEDING DISORDERS FOUNDATION

The National Hemophilia Foundation (NHF) has changed its name to the National Bleeding Disorders Foundation (NBDF). Foundation leaders announced the change during the 2023 Bleeding Disorders Conference, held in National Harbor, Maryland.

The foundation, created 75 years ago to help people living with hemophilia, has evolved to assist those living with other inheritable blood and bleeding disorders; these include von Willebrand disease, rare factor deficiencies, and platelet disorders. The foundation supports both patients and their families through research, education, and advocacy, according to a statement released to announce the name change.

In recent years the foundation has addressed health equity issues to eliminate barriers to care for underserved populations. According to the foundation's statement, the rebrand to include all blood disorders "aims to address concerns around diversity, inclusion, and equity to ensure every person and family facing an inheritable blood or bleeding disorder has access to the advanced care and support they need—regardless of gender, age, ethnicity, location, or socioeconomic background—so they can achieve their highest level of health."

The National Bleeding Disorders Foundation also released a new logo to represent a wide range of inheritable blood and bleeding disorders, as well as a new tagline: Innovate | Educate | Advocate.

"Our new name is one that's inclusive, trying to represent that entire blood and bleeding disorders community based on our past. We think that this really embraces what we're going to offer into the future by bringing everybody in and offering them something. No matter what disorder you have, you will find a home in the National Bleeding Disorders Foundation," said Len Valentino, MD, who is the CEO of the foundation.
NBDF retains its mission to support its network of more than 50 chapters, which channel funds into research on inheritable blood and bleeding disorders. The foundation will find ways to use its network to help patients with bleeding and blood disorders, many of which lack national support and advocacy network.

According to the group's statement, "This new name aligns with that vision for the future. The foundation's national and affiliate chapters will play an important role in introducing the rebrand to the community. The strong connections they foster and support they provide at the local level will be key to NBDF's success."

NBDF will continue to present its the new name and identity in the coming months. The group encourages patients and families to visit www.hemophilia.org, or follow these updated social media handles:

X, formerly known as Twitter: @NBDFoundation and @NBDFespanol

LinkedIn:@NationalBleeding DisordersFoundation

Facebook: @NationalBleeding DisordersFoundation

TikTok: @natlbdfoundation

Instagram: @natlbdfoundation

*Formerly NHF*
NATIONAL
**BLEEDING DISORDERS**
FOUNDATION

Innovate | Educate | Advocate


ADVATE has over 15 years of treatment experience in the real world and provides clinically proven bleed protection* for patients with hemophilia A.[1]

ADVATE
[Antihemophilic Factor (Recombinant)]

REAL LIFE. REAL BLEED PROTECTION.*

AdvateRealLife.com

### Prophylaxis with ADVATE prevented bleeds[1]

The ability of ADVATE to treat or prevent bleeds was evaluated in a clinical study using a standard prophylaxis, pharmacokinetic driven prophylaxis, and on-demand treatment.

53 previously treated patients (PTPs) with severe to moderately severe hemophilia A were analyzed. For the first 6 months of the study, patients received on-demand treatment. For the following 12 months of the study, patients received either standard prophylaxis every 48 hours or a pharmacokinetic-driven prophylaxis every 72 hours. The primary goal of the study was to compare annual bleeding rates between those receiving prophylaxis treatment and those receiving treatment on-demand. The number of bleeds per year for the 2 prophylaxis regimens were comparable.

- Those patients experienced a median of 1 overall bleed per year on either prophylaxis treatment vs 44 overall bleeds per year with on-demand treatment.† This represented a 98% reduction in overall bleeds per year.
- Zero bleeds were reported in 42% of patients (22 out of 53 patients) during 12 months on prophylaxis

†Median is the middle number in a group of numbers arranged from lowest to highest.

## ADVATE Important Information

### What is ADVATE?

- ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia).
- ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider (HCP) may give you ADVATE when you have surgery.
- ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

### DETAILED IMPORTANT RISK INFORMATION

### Who should not use ADVATE?

Do not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your HCP if you are pregnant or breastfeeding because ADVATE may not be right for you.

### What should I tell my HCP before using ADVATE?

Tell your HCP if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.

### What should I tell my HCP before using ADVATE? (continued)

- Are or become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

### What important information do I need to know about ADVATE?

- You can have an allergic reaction to ADVATE. Call your HCP right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADVATE unless you have been taught by your HCP or hemophilia center.

### What else should I know about ADVATE and Hemophilia A?

- Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

### What are possible side effects of ADVATE?

- Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, unusual taste, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash. Tell your HCP about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

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

**Please see Important Facts about ADVATE on the following page and discuss with your HCP.**

**For Full Prescribing Information, visit www.ADVATE.com.**

**Reference: 1.** ADVATE Prescribing Information.



Takeda

ADVATE
[Antihemophilic Factor (Recombinant)]

# Important facts about

**ADVATE [Antihemophilic Factor (Recombinant)]**

This leaflet summarizes important information about ADVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADVATE. If you have any questions after reading this, ask your healthcare provider.

### What is the most important information I need to know about ADVATE?

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADVATE so that your treatment will work best for you.

### What is ADVATE?

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.

Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

### Who should not use ADVATE?

You should not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your healthcare provider if you are pregnant or breastfeeding because ADVATE may not be right for you.

### How should I use ADVATE?

ADVATE is given directly into the bloodstream.

You may infuse ADVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADVATE to use based on your weight, the severity of your hemophilia A, and where you are bleeding.

You may have to have blood tests done after getting ADVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

Call your healthcare provider right away if your bleeding does not stop after taking ADVATE.

### What should I tell my healthcare provider before I use ADVATE?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

### What are the possible side effects of ADVATE?

You can have an allergic reaction to ADVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with ADVATE include:

| | | |
|---|---|---|
| cough | headache | joint swelling/aching |
| sore throat | fever | itching |
| unusual taste | dizziness | hematoma |
| abdominal pain | hot flashes | swelling of legs |
| diarrhea | chills | runny nose/congestion |
| nausea/vomiting | sweating | rash |

Tell your healthcare provider about any side effects that bother you or do not go away

These are not all the possible side effects with ADVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

### What else should I know about ADVATE and Hemophilia A?

Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ADVATE for a condition for which it is not prescribed. Do not share ADVATE with other people, even if they have the same symptoms that you have.

**The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADVATE. The FDA-approved product labeling can be found at www.ADVATE.com or 1-877-825-3327.**

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



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# 2023 UNITE FOR BLEEDING DISORDERS WALK AND RUN FOR THEIR LIVES 5K

CONTINUED FROM PAGE 5...

and Darin from Printeesweet for the printing of them, and for the many families that 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 $80!


Unite for Bleeding Disorders

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 over $8,000 was raised from the Run!

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

**Our Top Male Finishers:**


First Place Male Finisher: Jeff Smith


Second Place Male Finisher: Quintin Sano

WPBDF Western Pennsylvania Bleeding Disorders Foundation

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

**Thank You to Our Sponsors!**

**Pacesetter Sponsors**

Cigna. Takeda

**Gold Sponsors**

CSL Behring CoPilot

Third Place Male Finisher: Taylor Bizon

**Our Top Female Finishers:**


First Place Female Finisher: Jennifer Rose

Second Place Female Finisher: Erin McCandless

Third Place Female Finisher: Nicki Benvenuti

**And our Top Youth (under 17) Finishers:**


First Place Youth (under 17) Finisher, Enzo Urso, and Third Place Youth (under 17) Finisher, Lorelai Urso


Second Place Youth (under 17) Finisher: Gabbie Rose

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.


# GETTING TO KNOW HCWP STAFF

## CLAYTON KUBRICK PT, DPT

**Birthplace:** Pittsburgh, PA

**First job:** Kubrick Brother's Garden Center

**Accomplishment you're proudest of:** Becoming a father

**What three words describe you best?** Professional, Positive, Punctual

**Dream vacation:** Italy

**Things you can do without:** Negative attitudes

**Person you'd most like to have dinner with:** Grandfather

**Movie you could see anytime:** *The Departed*

**TV show you try not to miss:** *Ted Lasso*

**Three things that can always be found in your refrigerator:** Fruit, Eggs, Cheese

**Secret vice:** Dark chocolate peanut butter cups

**Who would play you in the movies?** Ryan Reynolds

**Your pet peeve about Pittsburgh:** Daily Traffic

**People may be surprised to know:** I am an avid fly fisherman

# HCWP CORNER

KATHALEEN SCHNUR, LCSW

Dear HCWP Patients, Families, and WPBDF Community:

One of my favorite fall quotes of late is, “Autumn shows us how beautiful it is to let things go” – Unknown. We collect a lot throughout the year, both literal and figurative. Fall seems a good time to purge things you are no longer using (the physical stuff) as well as any emotions that are no longer serving you, or even worse, weighing you down. I like to share an activity that we do in our own home, especially in the fall, when we enjoy a good fall fire (contained and safe, of course). Write down on pieces of paper those negative feelings, those situations that weigh heavy on your head and heart, any self-doubt, or whatever it is that you need to release from your mind, release it onto the paper and use it as kindling for your fire; let it go and give yourself a hug (and eat a s’more if you choose). I’d love to hear examples of how you “let things go” in the fall.

A check-in for yourself, when was the last time you were in to see us at the Center? More than a year? More than two years? Please call us and get scheduled. We understand that life gets busy (and stays there), but your health and overall well-being is important. Currently, we are scheduling nearly 3 months out. You must have a current appointment for medication refills as well as for surgical orders which include dental. If you are having challenges getting to the Center, please call so that we can listen to you and offer guidance to navigate those barriers. Additionally, do you have a PCP (primary care physician)? A PCP can provide preventive care, teach healthy lifestyle choices, identify and treat common medical conditions, and make referrals to medical specialists when needed. Ideally, if you find one you like, they can follow you long-term and have consistent records and family history on you which can be helpful. If you don’t have one and would like assistance, let us know at your next appointment.

Please note that cooler temps bring health insurance enrollment time. If you purchase a plan through Pennie (Pennsylvania's official health coverage marketplace), Pennie’s open enrollment period runs from November 1 to January 15 (https://pennie.com/). If you do not have a qualifying life event, there is no way to enroll in an ACA-qualified individual health insurance policy outside of normal open enrollment. Please do not wait.

... CONTINUED ON PAGE 23

THE HEMOPHILIA CENTER of Western Pennsylvania

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

**Factor Program Services**

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

**Patient Benefits**

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

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

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

# WOMEN'S WELLNESS DAY

We are grateful for the women who prioritized self-care and joined us for a Women's Wellness Day, on Saturday, August 26, at the Pittsburgh Botanic Garden. Taking care of your physical, emotional, and mental health can improve your overall health and wellbeing, and help you better manage stress, reduce risk of illness, and increase energy.

The day of wellness began with an ice breaker, led by Samantha Short, WPBDF Board Member, which gave everyone an opportunity to get acquainted with others in the room.

Angela Lambing, a nurse practitioner with over 30 years' experience, more than 20 years in bleeding disorders, presented the first session, *Managing Pain Alternatively*. Angela spent 15 years heading a hemophilia treatment center in Detroit, Michigan and has a wealth of knowledge regarding bleeding disorders and pain management. She touched on study results on pain that included persons with bleeding disorders and then discussed numerous non-pharmacological treatment options, including mind-body, manipulative and body-based, natural products, and energy therapies.

After lunch, the group learned about benefits of meditation and had an opportunity to practice meditation and learn how to make beaded bracelets. Many people find crafting to be therapeutic, as it can help relieve stress by taking one's mind off negative thoughts; and among other benefits, crafting can help build self-esteem as you learn a new skill. The women made lovely, beaded bracelets made of rose quartz and amethyst. Melissa Kendrick, a patient advocate with Cottrill's Pharmacy, led this session. Melissa has over 31 years of experience working in the Western PA bleeding disorders community, and she is passionate about promoting quality of life.

We wrapped up the day with a session on Tai Chi, led by Rick Starks. Rick is a motivational speaker and a Tai Chi instructor who has hemophilia. He presents programs and introduces people to Tai Chi at bleeding disorder-related programs across the country; and we were pleased to welcome him back to Western PA, to present the program, which was sponsored by CSL Behring. Rick shared his story about growing up with a bleeding disorder and pursuing his love for martial arts as an adult. Among other benefits, Tai Chi can help individuals improve balance and coordination through gentle, mindful movements. All participants had the opportunity to give Tai Chi a try as Rick led us through a gentle routine for novices, in the peaceful courtyard outside our meeting room.

Self-care looks different for everyone, and it can take some trial and error to figure out what works best for you. Take time to find what interests you and what works for you, and then find ways to incorporate self-care into your daily routine.

We thank the following for supporting the Women's Wellness Day:

COTTRILL'S PHARMACY, INC.

HFA Hemophilia Federation of America

CSL Behring

# NEW PARENT NETWORK FALL PICNIC

Each year, WPBDF hosts a series of educational and social events specifically designed for families who have a child aged 0-7 who has a bleeding disorder. These events are part of the New Parent Network program—an initiative that provides opportunities for families to learn together and build their support networks.

On September 23, we held a social event during Kennywood Park's Fall Fest. While we might not have had the beautiful fall weather that we had hoped for, we still enjoyed spending time together. We welcomed families to our picnic pavilion, and we had a fun time getting to know each other through a game of people bingo! Families also had a chance to share their current challenges and needs, as we gathered information for future training programs and events. To help make up for the not-so-nice weather, Kennywood gave everyone a free ticket to come back another day!

The New Parent Network also offers a mentor program. Families can be formally connected with other families who've been in their shoes before. If you would like to find out more about New Parent Network events or mentor program, contact either Kathaleen Schnur, LCSW, Social Worker, HCWP (kschnur@vitalant.org / 412-209-7267) or Janet Barone, Program Director, WPBDF (janet@wpbdf.org / 724-741-6160).

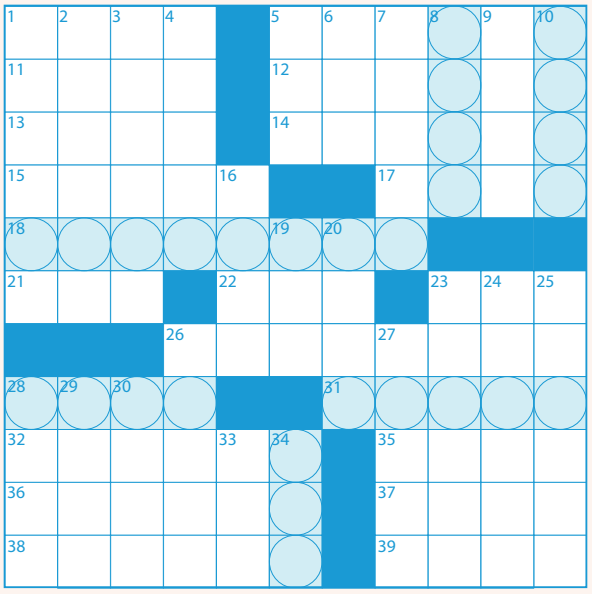
We thank the following for supporting the 2023 New Parent Network series of events:

CSL Behring · CVS specialty · Genentech A Member of the Roche Group · The Hemophilia Center of Western Pennsylvania · Takeda · novo nordisk · sanofi · Pfizer

CAN YOU SOLVE

# FOR A DIFFERENT HEMOPHILIA A TREATMENT?

## Test your HEMLIBRA knowledge



### ACROSS

**1.** Wine barrel
**5.** Deep fissures
**11.** Mideast gulf port
**12.** District
**13.** Ripped
**14.** Familiar with
**15.** Mean
**17.** Roost
**18.** The #1 prescribed prophylaxis for people with hemophilia A without factor VIII inhibitors*

*According to IQVIA claims data (various insurance plan types) from September 2021–August 2022 (refreshed November 2022), accounting for prophylaxis use in the US.

**21.** Calendar divs.
**22.** Regret
**23.** Banquet hosts (abbr.)
**26.** International travel necessity
**28.** Check out the _____ treated bleeds data with HEMLIBRA
**31.** Number of dosing options HEMLIBRA offers
**32.** Small hole in lace cloth
**35.** Central Plains tribe
**36.** Melodic
**37.** Towering
**38.** Reduce
**39.** Spanish cheers

### DOWN

**1.** Memorable, as an earworm
**2.** Devotee
**3.** Medical fluids
**4.** Prepare to propose, perhaps
**5.** PC's "brain"
**6.** Owns
**7.** Concert venue
**8.** See Medication Guide or talk to your doctor about potential _____ effects
**9.** Winter hrs. in Denver and El Paso
**10.** HEMLIBRA is the only prophylactic treatment offered this way under the skin
**16.** Pre-Euro currency in Italy
**19.** Subway alternative
**20.** Relax
**23.** Human
**24.** New Orleans cuisine
**25.** Mentally prepares
**26.** Collared shirts
**27.** Instagram post
**28.** Ardent enthusiasm
**29.** Brontë heroine Jane
**30.** Old Portuguese coins
**33.** Opposite of WNW
**34.** More than _____ thousand patients have been treated with HEMLIBRA worldwide†

† Number of people with hemophilia A treated as of October 2021.

### SOLUTIONS

**Across:** 1. cask, 5. chasms, 11. Aden, 12. parish, 13. tore, 14. used to, 15. cruel, 17. nest, 18. HEMLIBRA, 21. yrs, 22. rue, 23. MCs, 26. passport, 28. zero, 31. three, 32. eyelet, 35. Otoe, 36. arose, 37. tall, 38. lessen, 39. oles

**Down:** 1. catchy, 2. adorer, 3. serums, 4. kneel, 5. CPU, 6. has, 7. arena, 8. side, 9. MSTs, 10. shot, 16. lira, 19. bus, 20. rest, 23. mortal, 24. Creole, 25. steels, 26. polos, 27. photo, 28. zeal, 29. Eyre, 30. Reis, 33. ESE, 34. ten

## Discover more at HEMLIBRA.com/answers

### INDICATION & IMPORTANT SAFETY INFORMATION

**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.

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

**HEMLIBRA increases the potential for your blood to clot. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.**

**These serious side effects include:**

- **Thrombotic microangiopathy (TMA),** a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events),** which may form in blood vessels in your arm, leg, lung, or head

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects.**

HEMLIBRA®
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

# 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

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: 03/2023




Genentech
*A Member of the Roche Group*

# HCWP CORNER

CONTINUED FROM PAGE 18...

Medicare's open enrollment period is October 15 - December 7. Medicare health and drug plans can make changes each year—things like cost, coverage, and what providers and pharmacies are in their networks. October 15 to December 7 is when all people with Medicare can change their Medicare health plans and prescription drug coverage for the following year to better meet their needs. Please note that if you are living in PA, there is Pennsylvania Medicare Education and Decision Insight. PA MEDI is part of a nationwide network of State Health Insurance Assistance Programs, also known as SHIP. PA MEDI provides free, unbiased personalized help with detailed information about original Medicare, Medigap (Medicare supplement), Medicare Advantage plans, prescription drug plans, enrollment assistance, Medicare rules, notices, and billing concerns, Medicare financial assistance programs, Medicare appeals, long-term care insurance, and coordination of benefits. Please call the PA MEDI Helpline at 1-800-783-7067 Monday through Friday, 8 a.m. to 5 p.m. to schedule an appointment.

Medicaid/CHIP enrollment is available year-round for those who qualify. If your income drops to a Medicaid-eligible level later in the year, you'll be able to enroll at that point. A reminder that during the pandemic, (March 2020 through March 2023) states were not allowed to drop people from Medicaid. The continuous enrollment requirement ended March 31, 2023, and states resumed Medicaid disenrollments and regular eligibility redeterminations after that. People who are eligible for Medicaid are still able to enroll. However, people who are no longer eligible for Medicaid will not be able to stay enrolled in the program once their eligibility redetermination is complete. Furthermore, please make sure to complete your renewal paperwork or call the Consumer Service Center for Health Care Coverage at 1-866-550-4355 if you have any questions or need to confirm your address or renewal date.

If your employer coverage runs the calendar year, your open enrollment should be this fall as well. Please be aware of any changes in your plan. More and more patients are calling to report copay maximizer programs or other shifts that they were not anticipating. Please note that the language in these plans continues to change, and if you have questions, please feel free to contact us at the Center.

Finally, HCWP is on track for a November move to our new building. We will update you regarding the specifics as we get finalized information.

# MEET THE BOARD MEMBERS

## SAMANTHA SHORT

*Four newly elected WPBDF Board Members were introduced at the Annual Meeting on Sunday, July 16. Be sure to check out their profiles in our upcoming* Hemogram *issues!*

### WHAT INFLUENCED YOU TO GET INVOLVED WITH THE CHAPTER AND JOIN OUR BOARD OF DIRECTORS?

Our community, everyone has been so welcoming and helpful to me! I wanted to give back and help as many people as possible in our community.

### WHAT ARE YOU LOOKING FORWARD TO AS A NEW BOARD MEMBER?

Working with other board members to grow the foundation and make it even better!

### WHAT DO YOU LIKE TO DO FOR FUN?

I love traveling, especially road trips, reading and spending time with my family.

### WHAT IS YOUR BACKGROUND OR CURRENT OCCUPATION?

Small Business Ownership

# HEMGENIX

In the last issue of *Hemogram*, we shared information on Hemgenix, the first and only gene therapy to be approved by the FDA for adults with Hemophilia B. We encourage patients, their families and their trusted friends who would share in their decision making process, to become educated on gene therapy and learn about the results from the Hemgenix clinical trials.

WPBDF first partnered with the Eastern PA Bleeding Disorders Foundation to offer a virtual program, over Zoom, for all our members and their families. We then began holding programs in different areas of the Western PA region, so that patients and their loved ones can receive information and ask questions in person. In May, we held a program in Murrysville and, in July, we held a program in Erie. This fall, we are planning to hold a program west of Pittsburgh.

The discussions in the in-person programs have been invaluable to help gain a better understanding of gene therapy, potential eligibility, and potential benefits and risks. Dr. Beverly Schaefer, a clinical assistant professor of pediatrics at the Jacobs School of Medicine and Biomedical Sciences at State University of New York (SUNY)–Buffalo, an assistant professor of pediatric oncology at Roswell Park Comprehensive Cancer Center, and the pediatric medical director at Western New York BloodCare, presented the most recent program, in Erie. Dr. Schaefer gave an informative presentation on gene therapy and Hemgenix and welcomed all questions.

In addition to weighing the risks and benefits, it's important for people to understand the time commitment for follow-up appointments and tests, to help them determine if the timing is a good fit for their lifestyle. Here's what one of the attendees had to say after attending a session:

"I'm so thankful that CSL Behring and the WPDBF were able to hold the Hemgenix Gene Therapy program for me and my family to attend. Living with Severe Hemophilia B, I've always been excited about the prospect of gene therapy but never had the chance to really sit down and learn about any treatment in depth. I understood a bit of the science beforehand, but the hematologist at the educational event really helped me learn about it more and the information she gave me helped alleviate some of the doubts and fears I had. I encourage anyone who is interested in gene therapy to take advantage of learning opportunities and have discussions with their hematologist."

CSL Behring

# BLOOD, SWEAT, AND LIFT

On Saturday, August 6, 2023, Megan W. hosted a fundraiser for her senior project to help raise funds for the Western Pennsylvania Bleeding Disorders Foundation (WPBDF)! Megan is a member of WPBDF and is affected by von Willebrand Disease (VWD).

Blood, Sweat, and Lift was a CrossFit event that took place at Total Pursuit Athletics in Zelienople, PA. Megan raised $1,270 for the bleeding disorders community! Thank you so much for helping to spread awareness for bleeding disorders!


# A RETURN TO CAMP!

Camp Hot-to-Clot made its return after what felt like a very long three years. This was also a year of transition; the model of the camp looked a little different this year. While there was much excitement about the return to camp by staff, campers, and their families; there was also a collective pause anticipating the change. Our host camp, YMCA Kon-o-Kwee, continued to have significant staffing challenges, and to have the best chance of securing the counselors we needed to have camp at all, the safest option for us was to combine with their regular camp sessions. This meant that our campers shared the campus and the villages with campers who were not Hot-to-Clot, and they did activities with these campers as well. Our campers stayed together in cabins and had some activities with just Hot-to-Clot. While we still engaged with the larger group, we also maintained our own identity.

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. Additionally, the campers had some cabin reviews where specifics of their own (or their family's) bleeding disorder was discussed. The campers were able to connect and empower themselves and each other during these small sessions. Being in individual, age-based villages allowed connection with the other campers as well; the counselors engaged them and facilitated many village-based activities.

The overall response was

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# A RETURN TO CAMP!

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positive; however, there are some opportunities to improve this blended model. Our campers and their families have provided feedback, and we are working closely with KOK to continue to improve this experience. We are appreciative of the ongoing support and feedback as we continue to grow our camp within this model.


# WOMEN, GIRLS, AND THOSE WHO MENSTRUATE AND BLEEDING DISORDERS: JESSAMYN BUTLER

Before Jessamyn Butler received her bleeding disorder diagnosis, she had terrible, long, and miserable periods. Her family had a long history of bleeding issues, but once Jess started her period at age 11, she recalls her mother telling her, "Well, now it's your turn too, I feel bad for you." Both Jess' mother and grandmother suffered from symptoms of a bleeding disorder, and both suffered numerous hemorrhagic strokes.

Jess was officially diagnosed with von Willebrand Disease and Hemophilia A when she was 38 years old. Prior to her diagnosis, she suffered from several miscarriages that left her in a medical state of shock from extreme blood loss. Jess also had seven children, and she bled for six months after giving birth to each one. One of her children passed away, and she later learned it was due to complete placental abruption that was related to her bleeding disorder. By finally learning about her diagnosis, she was relieved that she could finally understand her health complications.

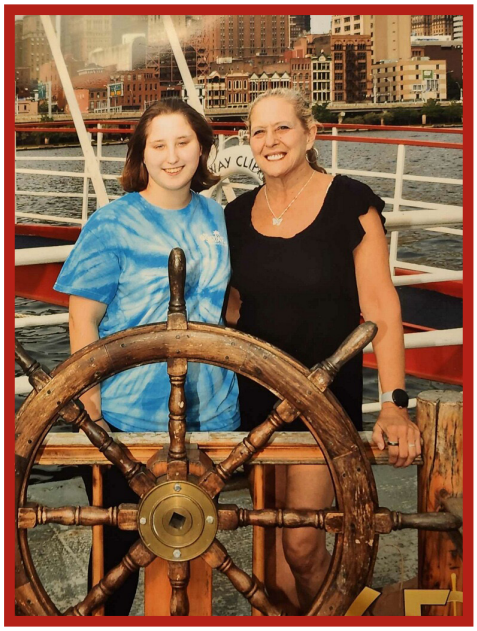
Day-to-day, Jess does not receive treatment for her bleeding disorder. She does have to be extremely careful not to cut herself or bump into things, as she will bleed heavily and bruise. Sometimes, she does get spontaneous nose bleeds and has desmopressin nasal spray and tranexamic acid for at home treatment when needed. Being a member of the Western Pennsylvania Bleeding Disorders Foundation (WPBDF) has given Jess the opportunity to join a large, supportive community of others affected by bleeding disorders. Even as large as the community is, Jess is surprised at the lack of awareness the general public has about this disease. "I can't believe one can go so long without getting diagnosed, just being told, 'Oh, that's normal bleeding for you,' by doctors, family, and others."

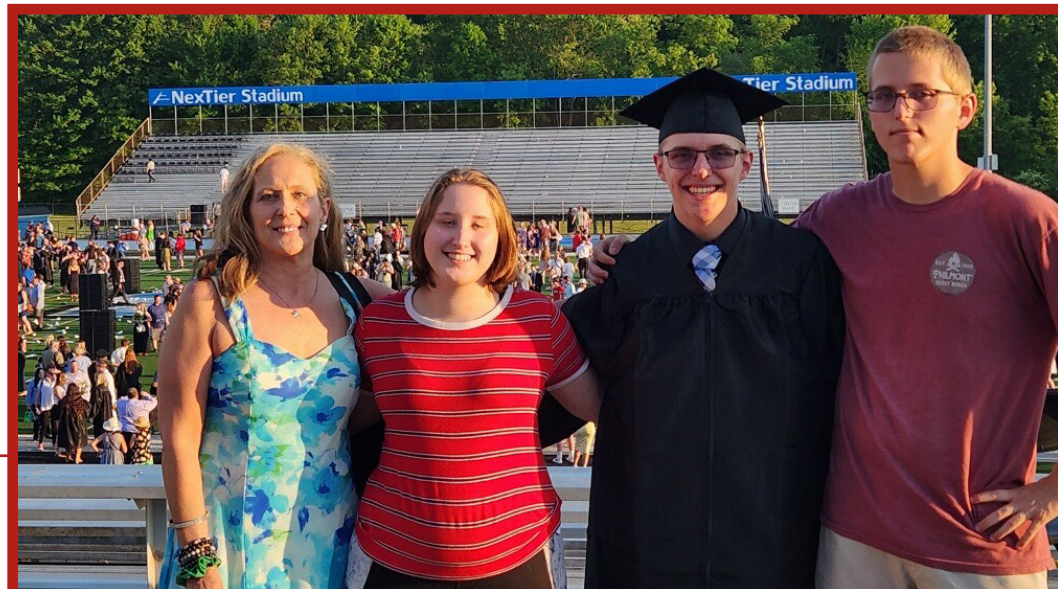
Four of Jess' six living children have a bleeding disorder. They are all very careful, as Jess says they can be a little clumsy and end up covered in bruises. Her daughters still have many years of periods to endure, and while they still live with heavy and long periods, they've found a tight-knit community filled with support and much needed education.

Jess believes that the most critical need for women, girls, and those who menstruate in our bleeding disorders community is awareness and advocacy. "The general public, and doctors, need to know that women, girls, and those who menstruate do have bleeding disorders," she says. "We do have symptoms, we are not going to be satisfied with, 'Oh that's your normal,' anymore!"

To all women in the community, Jess says, "Do not be afraid to question your doctor if you feel that they are either not listening to you or are shirking their responsibilities. It is okay to speak up!"

If you or someone you know has symptoms of a bleeding disorder, life can be better if you know. Better if you seek care. Better if you get treatment. Find out if you are at risk by visiting www.betteryouknow.org. If you already know you're at risk, you can still visit Better You Know to learn more about available resources.





# WPBDF'S ANNUAL MEETING


We were thrilled to have nearly 150 people join us for WPBDF's Annual Meeting! The event started off with exhibit displays and the room was buzzing with people from the moment the doors opened. The event was held at the Sheraton at Station Square, and after visiting with exhibitors and enjoying a buffet dinner, everyone settled in for the Annual Meeting presentations.

Scott Domowicz, Board President, led the business portion of the annual meeting, and he introduced four newly elected board members: Cassandra Miller, Samantha Short, Kristen Spezialetti, and Laureen Temple.

Kara Dornish, Executive Director, highlighted some of the accomplishments from the past fiscal year, which included providing our members with over $65,000 in assistance, through the Foundation's Emergency Patient Assistance Fund and Emergency Grocery Program. In addition, the Foundation held 29 educational programs—all at no cost to our members. She highlighted how the Foundation teamed up with the Eastern Pennsylvania Bleeding Disorders Foundation to hold the first ever joint PA Advocacy Ambassador Retreat where 50 incredible Advocacy Ambassadors were trained and equipped with resources to advocate on behalf of the bleeding disorders community. Because of these strong advocates, the hemophilia line item in the state budget was maintained at $1,017,000. These funds go directly to patient care and a portion is also used as an emergency fund to help patients in financial hardship due to their bleeding disorder. This past March, WPBDF received 14 proclamations from counties and cities all over Western PA, recognizing March 2023 as Bleeding Disorders Awareness Month. These included the counties of: Beaver, Allegheny, Butler, Fayette, Greene, Lawrence, Somerset, McKean, Venango, and Westmoreland; and the Cities of: Altoona, Canonsburg, Erie, and Johnstown. Kara thanked the community advocates who attended committee meetings to accept the proclamations and the counties, cities, and leaders for helping to raise awareness of bleeding disorders across Western Pennsylvania. Over the past fiscal year, 5 fundraisers were held which raised over $88,000 for the bleeding disorders community. WPBDF received the All-Star Chapter Award for the Unite for Bleeding Disorders Walk. Kara thanked and recognized the team captains and donors who support and raise funds year-round to make the Western PA Walk one of the most successful Walks in the nation.

Brittani Vuono, Board Secretary, announced the WPBDF academic scholarship winners for the 2023-2024 year. The following were recipients of WPBDF's Academic Scholarship:

Allison Shoemaker
Ashley Cynkar
Ashlyn Baptiste
Austin Baptiste
Banner Reed
Colin Domowicz
Erek Domowicz
Maria Shoemaker
Reese Miller

At the Western Pennsylvania Bleeding Disorders Foundation, we are lucky to have many hard working and passionate volunteers who are willing to donate their time and resources so that the Foundation can fulfill its mission. Volunteers are the lifeblood of our organization; we would not be able to succeed in our mission without them. John Yunghans, Board Vice President, recognized the top volunteers from our 2022-2023 fiscal year:

Linda Balog
Ryan Balog
Adam Boyle
Nancy Camp
Cameron Cedeno
Joseph Ebersohl
Cassandra Miller
Eileen Nikithser
Michelle Perry
Julia Shoemaker
Diane Standish
Maria Steele Voms Stein

Victoria Baker, Board Member and last year's volunteer of the year, was thrilled to present the volunteer of the year award to Maria Shoemaker!

Maria has gone above and beyond in her volunteering, advocacy, and outreach efforts this year! She has volunteered at the Unite for Bleeding Disorders Walk and Take A Bough. When she found out her insurance policy was implementing a copay maximizer, she used her experience to educate others in the community and inform legislators about her experience. Maria is a strong advocate and works hard to create positive change. She spends her free time increasing awareness of women with bleeding disorders

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# INSPIRING SHOTS GOLF CLINIC

Throughout July and August, the Wingmen Foundation held an Inspiring Shots Golf Clinic at Ironwood Golf Center in Aliquippa, PA. This golf clinic was held for individuals aged 18 years and over with a bleeding disorder or a caregiver of someone with a bleeding disorder. Each weekend, participants were able to get hands-on golf instruction and connect with others in the bleeding disorders community. On August 19, participants were able to meet and learn from Pro Golfer Perry Parker. Two participants from each clinic won a paid trip to the Junior National Championships (JNC) in Nevada. Congratulations to Josh Baker and Ben Meyer! Thank you for representing WPBDF at the JNC! We wish you luck as you compete to win a $2,500 donation for WPBDF.

# ANNUAL MEETING

**CONTINUED FROM PAGE 29...**

by delivering bags with menstrual products and information on bleeding disorders and the Foundation to local school nurses and community health clinics. She sets up displays at community events and outside local businesses to spread information about bleeding disorders and raise money for the Foundation. Maria is very passionate about the community and is always willing to lend a helping hand. We are so thankful for her leadership and dedication to the community.

Jessica Lee, Development Director, led the Walk Kickoff. She introduced the 2023 Walk Co-Chairs, Mindy Perry and Stephanie Shropshire. Mindy and Stephanie introduced themselves and shared information about the Unite for Bleeding Disorders Walk and invited others to sign up for the Walk. Jessica gave a shout out to some of our amazing teams and shared their stories including Conor's Clan, Team Factor 5, and TJ's First Walk.

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
Ethan Webb – Teen Group
Kelly Baker – Youth Group for those ages 7-12
Kathaleen Schnur – New Parent Network
Ally Smith – Stay In Motion
Jessica Lee – Hemogram Newsletter
Katherine Bush – Patient Assistance Programs and Camp Hot-to-Clot

At the end of the meeting, we surprised Janet with flowers and video messages from community members and staff thanking her for her 15 years of service to WPBDF. Janet puts her heart and soul into every program held by WPBDF. She dedicates countless hours to this community and truly paves the way for future leaders. Happy 15 Years, Janet – Here's to 15 more!

After the meeting, participants headed next door to the Gateway Clipper. Everyone who attended the meeting received tickets to enjoy the sightseeing tour with family and friends on the beautiful Sunday evening.

We are grateful to the following for supporting this event:

THE HEMOPHILIA CENTER
of Western Pennsylvania

We're MOVING!

# Projected Move Date is November 2023

**We are excited to announce that we are moving to a larger newly designed facility that will allow us to better serve our patients. Our new facility is in the North Oakland area and is approximately a mile and a half from our current location. The new site will increase our clinical exam space and will be able to accommodate patient events. Parking is available on site.**

***The Hemophilia Center's contact information will remain the same as it is today.***


**Phone Number: (412) 209-7280**

**Non-Operating Hours or On-Call Phone Number: 1-888-990-HCWP or 1-888-990-4297**

**FAX: (412) 209-7281**
**Website: hcwp.vitalant.org**

## NEW ADDRESS:

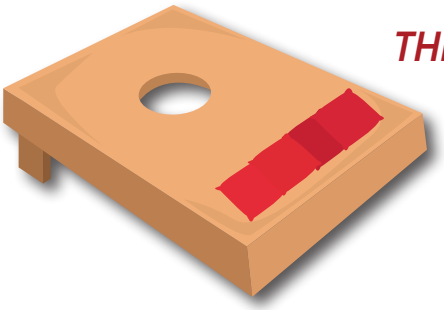
**201 N. Craig Street**
**Pittsburgh, PA 15213**

vitalant
Diversity · Equity · Inclusion

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION
775 4th Street
First Floor
Beaver, PA 15009

# WPBDF'S CORNHOLE TOURNAMENT

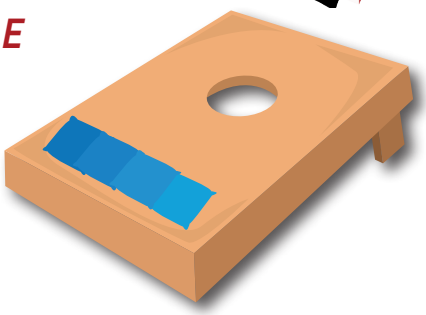
## NOVEMBER 4, 2023



*THE WAREHOUSE AT BOTTLE ROCKET SOCIAL HALL*

1226 ARLINGTON AVE
PITTSBURGH, PA 15210

**Registration:** 1:00 pm
**Tournament Start:** 1:30 pm



LEARN MORE REGISTER ONLINE AT:
GIVE.CLASSY.ORG/WPBDFCORNHOLE23

HEMOGRAM
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