



HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

SPRING 2024



WASHINGTON DAYS

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CONFERENCE**

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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

April 26-28

Education Weekend
Seven Springs Mountain Resort
Seven Springs, PA

May 6-7

Advocacy Ambassador
Education and Training
Harrisburg, PA

May 22

Insurance & Anime Program
Luciano's Italian Brick Oven
Mars, PA

June 22

Pirates Game Fundraiser
PNC Park
Pittsburgh, PA

June 28-30

Couples Retreat
Liberty Mountain Resort
Fairfield, PA

July 18

WPBDF Annual Meeting
Top Golf
Bridgeville, PA

July 28 - August 2

Camp Hot-to-Clot
Camp Kon-o-Kwee Spencer
Fombell, PA

August 1

Back to School Program
Location TBD

August 10

New Parent Network Picnic
Idlewild
Ligonier, PA

September 12-14

NBDF's Bleeding Disorders
Conference
Atlanta, GA

September 21

Unite for Bleeding
Disorders Walk
Run For Their Lives 5k
Cornhole Tournament
North Park, PA

October 5

Fall Program
Ambassador Banquet and
Conference Center
Erie, PA

November 1-3

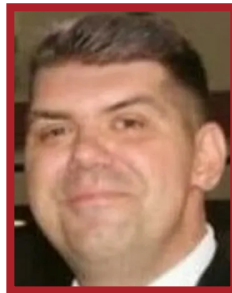
Teen Retreat
Promise Camp
Clinton, PA

November 16

Take A Bough
Red Fox Winery
Hickory, PA

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

COMMUNITY ANNOUNCEMENTS



It is with great sadness to announce beloved community member, Guy Law, passed away peacefully at home surrounded by his parents, wife, and other loved ones, on Monday, January 22, 2024. Guy was kind beyond measure and an inspiration to everyone who had the pleasure of knowing him.

Pittsburgh Pirates Baseball Fundraiser

Saturday

June 22ND

4:05 PM

PNC Park

\$10 of each ticket sold will help provide education, advocacy, and support. Plus, the first 20,000 fans will receive a Pirates bobblehead at the game!

Seat location: 131

Pick your row online!



Scan me for tickets!



\$36
Per Person

fevo-enterprise.com/event/WPBDF2024

CONTACT US

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LETTER FROM THE EXECUTIVE DIRECTOR AND BOARD PRESIDENT

Dear Foundation Members and Friends,

As we bid farewell to March, we are compelled to reflect on the significance of the month that just passed. March marks not only Bleeding Disorders Awareness Month but also Women's History Month. Bleeding Disorders Awareness Month provides a platform for raising awareness about hemophilia, von Willebrand disease, and other bleeding disorders that affect millions worldwide. It serves as a time to educate, advocate, and unite in support of individuals and families impacted by these conditions. Women's History Month gave us an even bigger platform to shine a light on women with bleeding disorders who often face delayed diagnosis and inadequate treatment due to misconceptions about the prevalence and presentation of these conditions in females.

The support from our community members in requesting resolutions and attending local commissioner meetings to proclaim March as Bleeding Disorders Awareness Month is truly commendable. Community members shared their stories, successes, and struggles at these meetings which have been instrumental in raising awareness and fostering understanding of the challenges faced by individuals and families affected by bleeding disorders. In Pennsylvania, we received 21 proclamations from the following counties: Allegheny, Beaver, Berks, Bradford, Butler, Carbon, Chester, Crawford, Cumberland, Dauphin, Elk, Fayette, Greene, Lackawanna, Lancaster, McKean, Northampton, Northumberland, and Washington, as well as the Cities of Altoona and Erie. If you would like to learn how you can receive a proclamation from your local government, reach out to Jessica at jessica@wpbdf.org.

The Western and Eastern Pennsylvania Bleeding Disorders Foundations have teamed up on an initiative to increase diagnosis and support for women, girls, and those with the potential to menstruate who have bleeding disorders. We have received the Innovation Grant from the Hemophilia Alliance Foundation and with their support, we have been creating and distributing period packs and resources to university health centers, school nurses, local health clinics, and OB/GYNs throughout Pennsylvania. So far, we have distributed over 1,500 period



packs to 150 school districts, 15 universities, and 20 health clinics all throughout Pennsylvania! Our work is far from over and we are always looking for volunteers. Please reach out to Kara at kara@wpbdf.org or 724-741-6160 if you would like to help.

Together, we can make a real difference. Let us commit to amplifying the voices of those with bleeding disorders, advocating for access to comprehensive care, and fostering a more inclusive and supportive community for all.

Thank you for your continued dedication and support.

Kara Dornish
Executive Director

Scott Domowicz
Board President



ADVOCACY UPDATE



KERRY LANGE, SENIOR ASSOCIATE MILLIRON GOODMAN

HARRISBURG OVERVIEW

Budget

While the 2023-24 budget was just recently completed, Governor Josh Shapiro delivered the 2024-25 budget proposal in February. This officially started the next budget season.

The Governor's 2024-25 budget proposal is a \$48.3 billion plan, a 7.5% increase over last year's budget. For some highlights, Governor Shapiro called for:

- \$1.5 billion in new funding for K-12 basic education;
- \$3 million to support a new student meal program for the summer months; and
- An increase of the minimum wage to \$15/hour beginning on July 1, 2024.

To support this plan (in part), Governor Shapiro proposes to utilize \$3 billion from the state's rainy-day fund, legalize and tax recreational marijuana (20%) and tax skill games (42%).

For the past few weeks, the House and Senate Appropriations Committees hosted budget hearings with the state agencies. Budget hearings allow each state agency the public opportunity to promote their successes over the past year, discuss upcoming projects and costs, and pending legislation with legislators. Legislators will incorporate this feedback into the ongoing budget negotiations.

House of Representatives

The House continues to operate with slim margins between Democrats and Republicans. Without a clear majority, it's difficult for either caucus to successfully pass controversial bills through the chamber. So far this session, whenever a split ratio occurred, voting session was put on hold in the House.

House Democrats recently picked up a vacant seat (Galloway, D-Bucks) and brought their number back up to 102.

Shortly after that special election, Representative Joe Adams (R-Pike) announced his resignation. The election to fill that seat is scheduled for April 23 (Primary Day). Republicans currently hold 100 seats.

Senate

Senate Republicans continue to hold the majority with 28 seats. Senate Democrats have 22 seats.

28	For diagnosis and treatment	
29	for Cooley's anemia.	
30	State appropriation.....	106,000
2024D07682 - 81 -		

1	For hemophilia services.	
2	State appropriation.....	1,017,000
3	For lupus programs.	
4	State appropriation.....	106,000
5	For sickle cell anemia	
6	services, including camps for	
7	children with sickle cell anemia.	

All bills have until November 30, 2024, to be signed into law, otherwise they are effectively dead and have to restart the legislative process in the next session. So far, less than 3% of introduced bills have made it across the Governor's desk and signed into law.

BUDGET LINE ITEM

As pictured below, Governor Shapiro is proposing level-funding for the hemophilia line item in the 2024-25 budget.

While a great starting point, the PA Bleeding Disorders Foundations are requesting an increase up to \$1,250,000 and has already made this request with the House and Senate Appropriations Committees as well as all legislators representing the seven treatment centers.

The legislature has until June 30 to pass a balanced budget. The Milliron Goodman team will continue to advocate for this increase.

LEGISLATION

Medical Screenings for Women with Suspected Bleeding Disorders

The Milliron Goodman team is coordinating a conversation with the PA Chapter of the American College of Obstetricians and Gynecologists (ACOG) and the leaders of the PA Bleeding Disorders Foundations. There are concerns that OBGYN patients are under diagnosed for potential bleeding disorders. There might be an opportunity to address these concerns with some educational components through the Department of Health. Stay tuned.

Prohibiting Health Insurers from Altering Coverage or Premiums

Representative Joe Hogan (R-Bucks) recently circulated a co-sponsorship memo indicating his intent to introduce legislation re: non-medical switching. His legislation would amend the Unfair Insurance Practices Act to prohibit health insurers from altering the coverage or premiums included in an insured person's health insurance policy during the policy term when an insured person has already received a specific treatment, service or prescription drug. We anticipate bill introduction soon.

Please continue to share your experiences with the PA Bleeding Disorders Foundations team so we can help advance this bill.

Co-Pay Accumulator

Senator Judy Ward's SB 372 amends the Insurance Company Law of 1921 by requiring insurers or pharmacy benefit managers to count any amounts paid, by the enrollee or paid on behalf of the enrollee by another party, towards the deductible or out-of-pocket limit. SB 372 is waiting for consideration by the Senate Banking and Insurance Committee.

Have you experienced non-medical switching?

After working with your doctor to find a medication or treatment that worked for you, have you ever had to change your medication due to changes with your health insurance plan or out-of-pocket costs? We want to hear from you.

Scan the QR code to share your story, or visit: <https://www.surveymonkey.com/r/SMXHDJC>

Representative Bridget Kosierowski (D-Lackawanna) is planning to introduce a companion bill in the House.

The Milliron Goodman team is continuing to stay engaged on this issue. Please continue to share your personal experiences with co-pay accumulators with the PA Bleeding Disorders Foundations team.

ADVOCACY DAY

We are excited to announce that the 2024 Bleeding Disorders Foundation's Advocacy Day is scheduled for Tuesday, May 7, in the Pennsylvania State Capitol.

This is another great and timely opportunity for the hemophilia community to meet directly with their legislators/staff and share

their personal experience with hemophilia as well as the benefits of the treatment centers. We want to continue to educate legislators about this disease and request their support of our budget line-item requests.

WORLD HEMOPHILIA DAY

In recognition of World Hemophilia Day, Milliron Goodman was able to secure the Pennsylvania State Capitol lights from April 16th-17th. The Capitol lights will be red on those days.

THANK YOU

We look forward to continuing to represent you in the Capitol this year. Please reach out to our office with any questions or concerns.

NBDF'S WASHINGTON DAYS

CHRISTINA MILLER

In February, I defended my dissertation that focused on social-emotional learning for young children with bleeding disorders. At the conclusion of my defense, I was asked, "What's next on your advocacy journey?" The answer was a trip to Washington D.C. with my family and many others from Pennsylvania for Advocacy Days!

Annually, the National Bleeding Disorders Foundation hosts an event where people with varying bleeding disorders from all over the country convene in Washington D.C. to meet with legislators to advocate for issues that impact the bleeding disorders community. This year, we were focusing on two important concerns. First, we discussed the impact of narrow formularies that limit access to medications for people with bleeding disorders, despite guidance that is in place through other laws that should not allow such limitation. The Help Copays Act (H.R. 830) was the second advocacy ask during this event. This bipartisan act is designed to eliminate copay accumulators, a huge burden to many with rare diseases, but especially for those in our community. Happily, Summer Lee, one of our local representatives, recently agreed to support this bill as a result of our advocacy efforts!

This was our family's first time attending the Washington Advocacy Days and it is an



event we are excited to continue to attend in the future. Being a part of such important work is empowering. It was also an amazing learning experience for Seth, Xavier, Spencer, and Scarlett, who got to speak with our representatives about how bleeding disorders impact them. Spencer became more comfortable throughout the day and spent some time during our last meeting of the day showing off his factor kit and explaining to the representative what kids with bleeding disorders live through, which opened the door to explaining the importance of having access to the medications they need.

We were so lucky to be surrounded



by other amazing advocacy ambassadors from Western PA! Maria S., Cassie Miller, Delores J. with her children, and the Perry-Stern family were all in attendance. Of course, our amazing Western PA Bleeding Disorders Foundation staff also were there to provide support as well as other Pennsylvania ambassadors. We are so thankful for this opportunity and hope you all consider joining advocacy efforts to improve care for everyone in the bleeding disorders community!

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Fc-VWF-XTEN Fusion Protein-ehtI

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with **ALTUVIIIIO™**

Sanofi Community Relations and Education (CoRe) Managers are dedicated professionals who can provide personalized education about ALTUVIIIIO, and point you toward helpful support and resources.



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YOUR CoRe TODAY



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MAT-US-2305908-v1.0-07/2023

FIGHTING COPAY ACCUMULATOR ADJUSTOR PROGRAMS AND ENSURING ACCESS TO CARE

What does the Help Ensure Lower Patient (HELP) Copays Act (H.R. 830/S. 1375) do?

The HELP Copays Act bans harmful insurer and PBM practices called copay accumulator adjustor policies (CAAPs) and copay maximizer programs by:

- Clarifying the Affordable Care Act (ACA) definition of cost sharing to ensure payments made “by or on behalf of” patients count towards their deductible and out-of-pocket (OOP) maximum.
- Closing the essential health benefit (EHB) loophole to ensure that any items or services covered by a health plan is part of the EHB package so that all related cost sharing counts towards a patient’s cost sharing limits.

How do CAAPs and Maximizers Impact Patient Access?

When they implement CAAPs, plans accept co-pay assistance but then don’t allow those dollars to count towards a patient’s deductible and OOP max. In copay maximizers, plans say that a covered drug is not an EHB. Then, patient protections don’t apply and plans set cost-sharing amounts artificially high to get more patient-assistance dollars. None of the payments count towards a patient’s deductible and OOP max. Many patients cannot afford their treatments and interrupt their care when they face CAAPs and maximizers. This leads to complications and expensive and harmful unintended consequences (i.e., increased ER visits, avoidable joint bleeds).

THE IMPACT OF TREATMENT MISCLASSIFICATION AND NARROW FORMULARIES ON THE BLEEDING DISORDER COMMUNITY

What policies govern health plan formularies?

The Affordable Care Act (ACA) created the essential health benefits (EHB) to define what services must be covered by health plans. EHB rules state that individual and small group health plans must cover at least: one prescription drug in every therapeutic category and class; or the same number of drugs in each category and class as the state’s EHB-benchmark plan.

What players are involved?

The United States Pharmacopeia (USP), a non-governmental organization, defines drug categories and classes. Today, USP combines treatments for hemophilia A, hemophilia B, hemophilia with inhibitors, von Willebrand Disease and deficiencies of Factor VII, X, and XIII into a single category and class.

How does this harm people with bleeding disorders?

Narrow formularies are when health plans significantly limit the medications they cover. For people living with bleeding disorders, narrow formularies may offer as few as one treatment option across all bleeding disorders.

NBDF is calling on Members of Congress to sign a letter to HHS requesting enhanced enforcement of current essential health benefits (EHB) policies that would prevent narrow formularies that don’t cover treatments for all bleeding disorders.

NEW YEAR, NEW HEALTH PLAN

WPBDF partnered with the National Bleeding Disorders Foundation (NBDF) on Thursday, February 8, to host a discussion on surprises that can happen at the beginning of insurance plan years. This session was led by Ryan Faden, Director, Patient Access at the National Bleeding Disorders Foundation. Topics included copay accumulator adjusters, copay maximizers, and formulary exclusions/limitations.

COPAY MAXIMIZERS EXPLAINED

A copay accumulator is a program or policy implemented by health

insurance companies that restricts the ability of patients to use copay assistance programs to cover their out-of-pocket costs for prescription medications. Copay assistance

programs are often offered by pharmaceutical companies to help patients afford expensive

... CONTINUED ON PAGE 18

Patient is exposed to a Copay Accumulator

Month	January	February	March	April	May	June	July	August	September	October	November	December	Cost to Patient	Cost to Insurer
Patient Cost Share	\$0	\$0	\$0	\$0	\$0	\$0	\$1,000	\$1,000	\$1,000	\$0	\$0	\$0	\$3,000	\$3,000
Manufacture Assistance	\$1,000	\$1,000	\$1,000	\$1,000	\$1,000	\$1,000	\$0	\$0	\$0	\$0	\$0			
Insurer Share	\$0	\$0	\$0	\$0	\$0	\$0	\$0	\$0	\$0	\$1,000	\$1,000	\$1,000		
Patient Remaining Deductible	\$3,000	\$3,000	\$3,000	\$3,000	\$3,000	\$3,000	\$2,000	\$1,000	\$0	\$0	\$0	\$0		

Coupon Limit: \$6,000 Patient Deductible: \$3,000 Cost of Medication: \$1,000/month

WPBDF WINNING WOMEN

MARIA S., WOMEN'S GROUP COORDINATOR

On Monday, March 11, the WPBDF Winning Women group hosted a social dinner at Bravo! Cucina in Robinson Township with the opportunity to volunteer to make period packs for one of the Foundation's current initiatives. The initiative, through a Hemophilia Alliance Foundation grant, is an outreach program aimed at improving diagnosis of bleeding disorders and improving the quality of life in women, girls, and individuals with the potential to menstruate. Over 400 period packs were assembled by the 24 women in attendance at the event. A lovely gift basket, donated by Samantha Short, was raffled off and won by Amanda S. The women also received a bloodstone bracelet kit graciously donated by Melissa Kendrick.

We would like to thank Cottrill's Pharmacy for generously sponsoring the event and their willingness to commit to a 2024 sponsorship for the WPBDF Winning Women! An extra special word of thanks to Melissa Kendrick, Field Care Coordinator,



for her unwavering support of the Winning Women group, our Foundation and the wonderful people that make up our amazing community.

WPBDF's Winning Women group is a great opportunity for the women of our chapter to network with other women in our community, learn about issues related to

bleeding disorder management and to have a lot of FUN! I hope to see you at an upcoming WPBDF Winning Women group or chapter event soon.

COTTRILL'S 
PHARMACY, INC.

YOUTH GROUP

EMILY N., YOUTH GROUP CO-COORIDNATOR

On March 23, the WPBDF Youth Group had the exciting opportunity to meet and spend time together at the Children's Museum of Pittsburgh. There was a great turnout with seven families of a child aged 7-12 affected by a bleeding disorder in attendance, including siblings!

Kathaleen Schnur, from the Hemophilia Center of Western PA, led an informative and interactive discussion with the kids, helping them to understand the importance of being mindful of their own bleeding disorder or that of their sibling. I know that I personally loved this discussion and felt that it was meaningful for the kids. With the many advancements in care and management today, my own child

often struggles with understanding the importance of his medical care and WHY it is significant. The session was a great reminder and Kathaleen did a wonderful job (as always) connecting with the group.

She began by discussing with the group what self-respect is and the importance of taking care of ourselves both emotionally and physically. Not only is it valuable

... CONTINUED ON PAGE 16

FULL HOUSE AT BOWLING FOR BLEEDING DISORDERS

THE WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION STRIKES OUT BLEEDING DISORDERS!

The Ninth Annual Bowling for Bleeding Disorders fundraiser was held at Paradise Island Bowl in Neville Island, Pennsylvania on Sunday, February 18, 2024. The cost to attend was \$25 per participant, which included shoe rental, bowling, pizza, wings, and unlimited soft drinks.

Eighty bowlers competed for the most strikes, highest score, and the best style. Congratulations to Randy, from Cassie's Team, for winning the award for most strikes, Joseph, from Team Heart and Sole, for winning highest score, and congratulations to Kristen and Minter, who won best style for being dressed as Paradise Island Bowlers!

At this event, we also recognized Lindsay M. for her generosity and support of the bleeding disorders community by presenting her with WPBDF's Community Spirit Award. Lindsay brought a bus full of bowlers to fill three lanes!

We are extremely grateful for everyone who participated in this event. We are excited to report that over \$8,000 was raised! The money raised will provide emergency and medical patient assistance, educational programs, and support groups to benefit the bleeding disorders community in Western PA.

Thank you to our sponsors:

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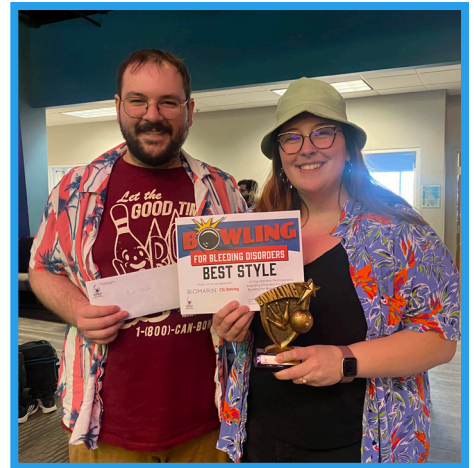
WPBDF would like to thank all who participated in and sponsored this event. We can't wait to see you all at one of our future fundraisers!



Joseph, from Team Heart and Sole, wins the award for highest score.



Randy, from Cassie's Team, wins the award for most strikes.



Kristen and Minter, from Team Heart and Sole, win the award for Best Style.

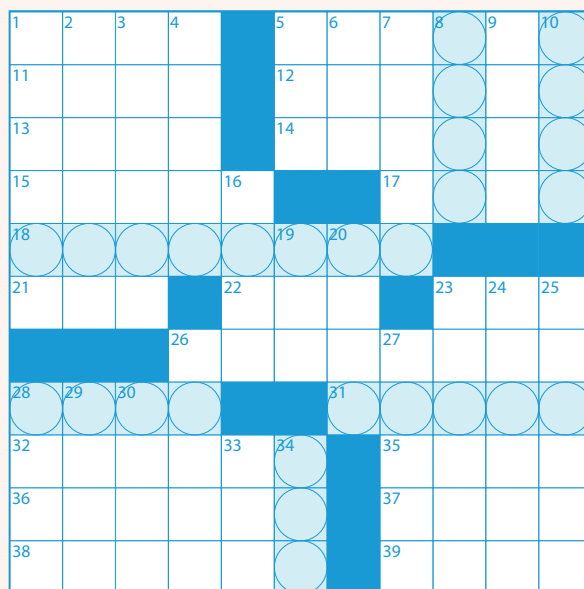
Lindsay M.'s team celebrates her Community Spirit Award!



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. eyelid; 35. Oloz; 36. anozse; 37. tall; 38. lessen; 39. oles
 Down: 1. catny; 2. adores; 3. surms; 4. kneel; 5. CPU; 6. has; 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. Eye; 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**.



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: 03/2023



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Genentech
A Member of the Roche Group

GIRL SCOUTS WORKING TO SPREAD AWARENESS OF BLEEDING DISORDERS

On Thursday, January 25, Samantha Short, WPBDF Board Member, was invited to attend the meeting of Girl Scout Troop 60029. She led a presentation educating the girls about bleeding disorders and the girls put together 100 nosebleed kits!

Samantha also attended a Girl Talk Meeting with the Best of the Batch Foundation where she led a presentation discussing what a bleeding disorder is, signs of a bleeding disorder, and how to advocate for yourself at doctors appointments. They then put together 150 period packs.



On March 3, Samantha visited Girl Scout Troop 16842 to pack even more nosebleed kits. All these kits will be distributed to local elementary schools in the area. We are working to spread awareness of bleeding disorders throughout Pennsylvania and believe these kits will aid in the detection of undiagnosed bleeding disorders in those experiencing frequent, heavy nosebleeds. A huge thank you to Samantha, the girls of Troop 60029, the girls of



Troop 16842, and the Best of the Batch Foundation for allowing us to partner with you and helping us spread awareness of bleeding disorders in women!

WPBDF'S TRIVIA NIGHT

On Monday, March 25, board member, Kristen Spezialetti, hosted a trivia night to raise awareness and funds for the bleeding disorders community! Trivia Night was hosted at Greensburg Tavern, located in Darlington, PA. The night was hosted by Kristen and volunteer, Joseph E.

The night consisted of four rounds of seven questions each and

one lightning round. Categories included historical figures, sports, places, and pop culture.

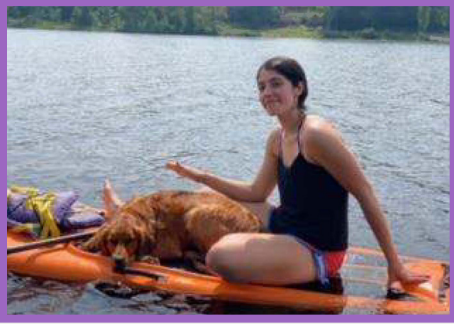
Each person who attended received a raffle ticket for a chance to win a fun, bleeding disorder prize. Congratulations to the winning team, Eff & Crew! In total, Kristen raised over \$600 dollars for the bleeding disorders community!

Thank you to Greensburg Tavern for donating their space for the night as well as WPBDF Board Member, Kristen Spezialetti, for organizing this event, and Joseph

E. for volunteering to help host and create the trivia questions!



GETTING TO KNOW HCWP STAFF



JESSIE CHATTA

HCWP CHP NURSE COORDINATOR

Birthplace: Seattle, WA

First job: Waitress

Accomplishment you're proudest of: Surviving my first year of nursing (2020)

What three words describe you best? Curious, calm, hungry

Dream vacation: A small Italian seaside village

Things you can do without: Early wake up calls

Person you'd most like to have dinner with: My grandma

Movie you could see anytime: *Kill Bill*

TV show you try not to miss: *SNL*

Three things that can always be found in your refrigerator: Pickles, lemons, and cheese

Secret vice: *New York Times* word games

Who would play you in the movies?: Gal Gadot

Your pet peeve about Pittsburgh: The lack of sunshine

People may be surprised to know: I paddle board with my dog :)

NOSE BLEED KIT PACKING EVENT

STEPHANIE SHROPSHIRE

Advocacy comes in many forms. Many times, we see our Foundation members reaching out to Congress for help with insurance difficulties surrounding access for all with bleeding disorders. For my family, advocacy has come in the form of helping families who may have a bleeding disorder more easily and accessibly get a diagnosis; as it was a grueling process for our family six years ago.

With von Willebrand Disease, many patients experience frequent nose bleeds; that is true for my daughter, Sammi, who has had several dozen in the last few years, many which have required medical interventions to clot.

In our Board meeting, the idea of distributing nosebleed kits to nurses in our Western PA school districts came up, and immediately I knew this was the type of advocacy that was a right fit for



our family.

Held at Kentucky Avenue School in the Shadyside section of Pittsburgh, families of students, friends of ours, and even Sammi's school nurse came to pack nosebleed kits! They consist of two nose clamps, 2 petroleum jelly packets, a mini pack of tissues, an informational card on what to do if you have a nose bleed and if they happen frequently, who to call, and it's all zipped up in a reusable pouch.

Our youngest volunteer was only 3 years old! This event was 100% family friendly and a great way to introduce acts of kindness and helping out others to our youngest



community members. We set out for an ambitious goal of 800 nose bleed kits packed in 2 hours, but with so much support from our incredible community, both with and without bleeding disorders, we crushed that goal! We packed 806 kits in only 30 minutes!

These kits are in the process of being delivered to school nurses in many school districts. If one child is able to have an easier route to a diagnosis of a bleeding disorder, then this event will have been even more of a success and certainly a meaningful one!

More events are coming soon to pack nose bleed kits for our community!

Supporting our community is the foundation of what we do



That's why Novo Nordisk goes beyond offering a broad range of treatments and is dedicated to providing educational resources and one-on-one support!

We have **resources** for people living with:

- Hemophilia A
- Hemophilia B
- Hemophilia A with inhibitors
- Hemophilia B with inhibitors
- Glanzmann's thrombasthenia when platelets don't work
- Factor VII deficiency
- Factor XIII A-subunit deficiency

Get connected locally with one of our Hemophilia Community Liaisons (HCL) to see how they can help you!



Scan to connect



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PENNSYLVANIA SCHOOL NURSES CONFERENCE

SAMANTHA SHORT

When I joined our advocacy committee, led by Cassie Miller, last year, we started brain storming ideas on how to bring more bleeding disorder awareness into our local communities. I reflected back on my own personal experiences growing up with a bleeding disorder, particularly during my high school years when my VWD was not well controlled.

During that time, I was lucky enough to have an amazing school nurse who was willing to go above



and beyond to help me achieve my educational goals while still prioritizing my health.

Last November, I reached out to

PASNAP, the Pennsylvania School Nurses and Practitioners, to inquire if they had any opportunities to work with us on expanding

... CONTINUED ON PAGE 19

Couples Retreat

ATTENTION COUPLES!

Whether you are a couple in a newer, serious relationship and want tools to start off successfully, or you are a couple in a long-term, committed relationship who wants a deeper connection, and whether you are in a relationship where one partner has a bleeding disorder or you are a couple raising a child with a bleeding disorder, this retreat is for you!

This retreat is available to all couples (dating, engaged, or married) regardless of orientation, ages 21 and up, and are members of the Western or Eastern Pennsylvania Bleeding Disorders Foundations.

To register, send an email to rsvp@wpbdf.org. The final day to register is Friday, May 24!

June 28-30

Liberty Mountain Resort
78 Country Club Trail
Fairfield, PA 17320



YOUTH GROUP

CONTINUED FROM PAGE 9...

to eat healthy and exercise, but how we speak to ourselves can be equally meaningful. Treating our minds and bodies with kindness can help motivate us to be healthy. She also spoke with the children about the value of knowing their or their sibling's diagnosis or medication and reminding them that it is always important to tell someone when they get hurt. Feeling comfortable talking to family and your healthcare team can be a significant first step in advocating for yourself and setting you up for a long, healthy experience with or without a bleeding disorder. As a reminder, each child was given a thank you card to write to themselves.

After the presentation, we enjoyed a meal and socialization time. It's always fun to have the kids together and spend time catching up. A staff member from the

museum then assisted with a fun activity, decorating planters, and each child received seeds to take home to plant and watch grow. Then everyone was free to enjoy the museum for the afternoon.

I know that my son loves the Children's Museum, especially the areas that involve climbing and sliding. There was even a neat exhibit with Rube Goldberg machines that he loved. Having experiences with other community members is what drove the formation of the youth group, and we really enjoyed our time.



We can't wait to see what is next for our new group and we would love to have more community members join! Please reach out by sending an email to rsvp@wpbdf.org to join the mailing list for the group. We are always looking for feedback on events and focus areas that will be most significant to our kids in this age group. We are also seeking ideas for social activities or meet-ups.

Thank you so much to Kathaleen, Janet and WPBDF for supporting our kids and allowing us this opportunity!



Scan this QR code to join the Youth Group mailing list or visit: <https://www.surveymonkey.com/r/RYZRWKG>

PITTSBURGH PENGUINS FUNDRAISER

On Thursday, March 28, 46 people came out to not only cheer on the Pittsburgh Penguins as they took on the Columbus Blue Jackets, but to show their support for the Western PA Bleeding Disorders Foundation! A portion of all tickets

sold through WPBDF's unique ticket link was donated back to the Foundation. Additionally, the first 10,000 people at the game received a patterned Pittsburgh Penguins shirt. In total, we raised \$460 that will go toward providing education, support groups, and patient assistance to individuals and families affected by bleeding disorders in Western PA. The Penguins took home a win that night, beating the Blue Jackets 3-2! It was an exciting game, and we are so thankful for everyone's

continued support of WPBDF!

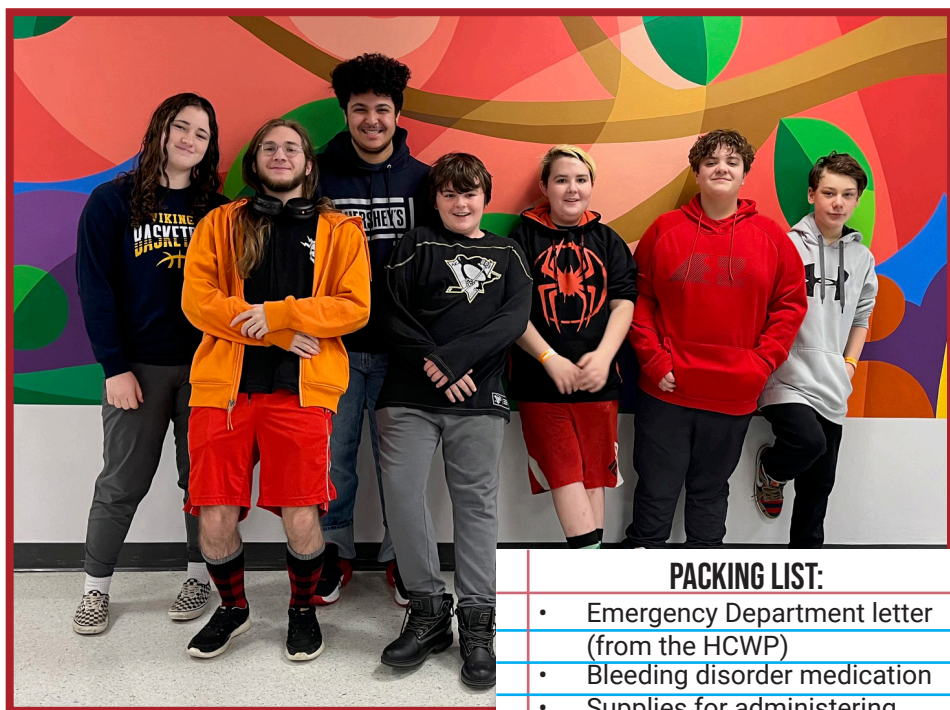


TEEN GROUP WINTER MEET-UP

Winter was the perfect time for teens to come together and regroup! Some had not seen each other since camp last summer. On January 27, 2024, a mild winter day, we gathered at the Carnegie Science Center for a program and some fun!

Ethan W., a teen who is also one of the Teen Group Coordinators, created an ice breaker, based on four elements: Wind, Water, Fire, Earth, which was very fitting for an event at a science center! The program focused on transitioning teens to independent medical care, as they spend more time away from home. To help teens become prepared to make calls to their medical team, parents and teens roleplayed phone calls to a doctor's office and each family could customize the experience, based on their diagnosis or needs.

Participants were also given a scenario to imagine that the teens had an upcoming overnight school trip and to create of list of things they should do to prepare for it. The parents gathered and created a list together and the teens did the same. The two groups then



compared and discussed the lists.

After the program, the group had lunch and attended a show together at the science center! Teen Group events are for teenagers in middle school and high school, who either have a bleeding disorder or are a sibling of someone with a bleeding disorder. If you have questions about the Teen Group, please contact Katherine Bush, LCSW, from the Hemophilia Center of Western PA (kbush@vitalant.org) or Janet Barone, Program Director, from WPBDF (janet@wpbdf.org).

PACKING LIST:

- Emergency Department letter (from the HCWP)
- Bleeding disorder medication
- Supplies for administering medication
- First aid supplies
- Medical ID (i.e., bracelet, necklace)
- Knee/Elbow braces, etc.
- Information that will be useful in an emergency:
 - Date/time of most recent dose of medication
 - Bleeding disorder medication dose
 - Emergency contact information
 - Name and Contact information for the local HTC

NEW YEAR, NEW HEALTH PLAN

CONTINUED FROM PAGE 8...

medications by covering some or all of their copayments or coinsurance.

With a copay accumulator program, the funds provided by pharmaceutical companies through copay assistance programs are not counted toward the patient's deductible or out-of-pocket maximum. This means that even though the patient may be receiving financial assistance for their copayments, they are still responsible for paying the full amount of their deductible or out-of-pocket maximum before their insurance coverage kicks in. Manufacturer copay assistance funds prescriptions until the maximum value on the copay assistance is reached. After that, the patient's out-of-pocket costs begin counting toward their annual deductible and out-of-pocket maximum.

COPAY MAXIMIZERS EXPLAINED

A copay maximizer is a feature or program within an insurance plan whereby a manufacturer's payments do not count toward the patient's deductible and out-of-pocket maximum. The maximum value of the manufacturer's copay assistance is applied evenly throughout the benefit year. Copay maximizers can result in patients paying more for other care.

ALTERNATIVE FUNDING PROGRAMS

Alternative Funding Programs are targeted to employer self-funded health plans attempting to reduce their specialty drug spend and catastrophic claims exposure by partially or fully excluding coverage of specialty medications from their prescription drug benefit.

Patient is exposed to a Copay Maximizer														
Month	January	February	March	April	May	June	July	August	September	October	November	December	Cost to Patient	Cost to Insurer
Patient Cost Share	\$0	\$0	\$0	\$0	\$0	\$0	\$0	\$0	\$0	\$0	\$0	\$0	\$0	\$6,000
Manufacture Assistance	\$500	\$500	\$500	\$500	\$500	\$500	\$500	\$500	\$500	\$500	\$500	\$500		
Insurer Share	\$500	\$500	\$500	\$500	\$500	\$500	\$500	\$500	\$500	\$500	\$500	\$500		
Patient Remaining Deductible	\$3,000	\$3,000	\$3,000	\$3,000	\$3,000	\$3,000	\$3,000	\$3,000	\$3,000	\$3,000	\$3,000	\$3,000		
Coupon Limit: \$6,000 Patient Deductible: \$3,000 Cost of Medication: \$1,000														

The prior authorization request is automatically denied by the PBM when a plan participant is seeking to obtain one or more of the carved-out meds. The participant is then referred to work with an alternative funding vendor that helps them pursue coverage of their drug(s) from another source, primarily manufacturer free-drug programs, charitable foundations, importation and medical tourism, with the hope that one of those options can help their members access the drug they need while avoiding the expense for the plan.

This can be highly disruptive to impacted members.

FORMULARY CHANGES

Plans use formulary exclusions (or the threat of formulary exclusions) as a negotiating lever for maximizing their revenues (usually in the form of rebates) from manufacturers whose drugs are INCLUDED in the formularies. Recent examples of large-scale exclusions include:

- CVS national formulary excluding all standard half-life factor IX products
- Blue Cross Blue Shield of Tennessee excluding ~18 bleeding disorders products from formulary in 2023 and again in 2024, including *all

available products* for certain conditions

Formulary exclusions create access problems for patients who rely on the excluded medications. Patients and their doctors must invest time and effort in trying to obtain an "exception" – permission from the health plan/PBM to continue using the product originally prescribed by the doctor. Even if these efforts are successful, patients experience delays and interruptions in getting their prescriptions filled. Interruptions to therapy can lead to patients being harmed by having break through bleeds and other complications which may result in emergency room visits. Patients may end up being required to switch to a different product, for non-medical reasons – one that may not work as well for them. If the new product is less effective, harder to self-administer, or has side effects, then patient health may suffer and spending may increase due to emergency room visits, hospitalization, and other interventions.

Missed this program? You can watch the recording of this presentation at: https://youtu.be/jt_qgWcipuo

ROCTAVIAN EDUCATIONAL PROGRAM

On March 27, BioMarin sponsored an educational program on ROCTAVIAN, the first and only FDA approved gene therapy for Hemophilia A. ROCTAVIAN is a one-time gene therapy used to treat adults who have severe hemophilia A. Participants gathered at the Grand Concourse for the dinner program and had the opportunity to ask questions and deepen their understanding of gene therapy and ROCTAVIAN. We thank BioMarin for bringing this education program to Western PA.



PENNSYLVANIA SCHOOL NURSES CONFERENCE

CONTINUED FROM PAGE 15...

bleeding disorders education.

On Saturday, March 23, PASNAP held their annual conference at the Hershey Lodge in Hershey, PA with over 270 Pennsylvania school healthcare professionals in attendance. We were fortunate enough to be able to have an exhibitor booth and interact directly with these valuable caretakers along with the Eastern Pennsylvania Bleeding Disorders Foundation.

As many in our community know, school nurses are on the front lines of healthcare.

THE JOINT MOVEMENT

On Thursday, January 25, community members came together at Il Pizzaiolo in Warrendale for a program called *The Joint Movement: Keep It Together: The Value of Family Connectivity*. This program was sponsored by Sanofi and Optum and led by Carrie Koenig, Community Relations and Education Manager at Sanofi, and Kim Baumann, Associate Director of Optum Physical Therapy Collaborative. During Carrie's presentation, we viewed a short film about a family affected by hemophilia A. The son was diagnosed with severe hemophilia A at birth and the mother was diagnosed with hemophilia as an adult. We reflected on the film and participants shared experiences they have had that are similar to the family in the film.

A pediatrician might see their patient every six months, but school healthcare professionals get to know their students on a daily basis, creating a very powerful relationship. Many school nurses we talked to had students they already identified as having signs of a bleeding disorder and we were able to provide them with additional educational material.

CASSANDRA MILLER

During the conference, we were able to tell our stories and advocate for women and girls with bleeding disorders, explaining the importance of diagnosing girls and young women early. Samantha and I explained the initiative that both the Eastern and Western Bleeding Disorder Foundations are doing to raise awareness, and in doing so, we gave out period packs and

We discussed the importance of self-care and advocating for yourself and your child. We talked about the importance of women receiving a diagnosis for their bleeding disorder. For so long, women have been brushed off as symptomatic carriers and were told they could not have hemophilia. Women can and do have bleeding disorders. We want to make sure women have the tools to advocate for themselves. The second half of the evening, Kim Baumann led a very engaging presentation on joint health. With illustrations, she explained what happens when a joint bleed occurs, what a target joint is, and the importance of movement and staying active to keep joints healthy. Participants walked away with a book of exercises, called *The Mobility Manual*, and a better understanding of the importance of self-care, self-advocacy, and ways to keep their joints healthy.



nosebleed packs to many school nurses that included an info packet about bleeding disorders. I believe each person who visited our booth received a great introduction to bleeding disorders and were even able to get first hand accounts on how bleeding disorders affect women and girls.

A special thanks to Sarah Pilacik and Lisa Lee for representing Eastern Pennsylvania Bleeding Disorder Foundation and making this conference become a reality!



MARCH IS BLEEDING DISORDERS AWARENESS MONTH!

Each year, we celebrate March as Bleeding Disorders Awareness Month to bring much needed attention to inheritable blood and bleeding disorders. This month shines a light on patients and families with hemophilia, von Willebrand disease, rare factor disorders, and platelet disorders to share their lives, stories, struggles, and successes.

In Western PA, we received Bleeding Disorders Awareness Month proclamations from the following counties in Western Pennsylvania: Allegheny, Beaver, Butler, Crawford, Elk, Fayette, Greene, McKean, and Washington;



and the cities of Altoona and Erie.

Our goal is to get every county in Pennsylvania to recognize March as Bleeding Disorders Awareness month! Do you know someone in your local county or city government? Are you looking for a way to get involved during Bleeding Disorders Awareness Month? You can reach out to your own local government and ask them to issue a proclamation! Reach out to Jessica, jessica@wpbdf.org, to learn how you can help next year!



RUN FOR THEIR LIVES

Bleeding disorders can't stop us.

**SATURDAY,
SEPTEMBER 21, 2024**

**NORTH PARK SWIMMING POOL
S. RIDGE DRIVE,
ALLISON PARK, PA 151010**

REGISTRATION FEE

Early Bird Price!

\$25

Virtual and In-Person
(until May 31st)

June 1 - September 20:

\$30

Race Day fee: **\$35**



Scan me to register!



**Learn more at:
bit.ly/runfortheirlives2024**



Y'ALL YETI FOR THIS?

After a long day of traveling across the country, we were greeted by smiling, familiar faces in the Portland, Oregon airport. Our friends (old and new), dressed in “Y'ALL YETI FOR THIS?” t-shirts, set the tone for an exciting weekend! YETI is an experiential train-the-trainer conference, hosted by Pacific Northwest Bleeding Disorders, held for teens and adults who run teen programs in their local bleeding disorders community. YETI is an acronym for Youth Effectively Transitioning to Independence and the program promotes confidence and supports teens in the bleeding disorders community. Teen programming teams attend the conference together. Ideally, the teams consist of a bleeding disorders Chapter representative, a Treatment Center representative, and a teen who is active in teen programs. Our

team consisted of our Teen Group Coordinators: Ethan W. (teen), Katherine Bush, LCSW (Hemophilia Center of Western PA), and Janet Barone, Program Director (WPBDF). The event began on Thursday, February 22 and ended on Sunday, February 25.

The teens and adults were in separate programs for a good amount of the time, but they came together on Saturday to go on a day trip the teens planned and again on Sunday to work in their local teams to discuss ideas gained from the experience and make plans for future events.

Ethan W. wrote a detailed report about his experience. Below are a few excerpts. To read about his entire experience, go to WPBDF's blog or visit the link at the bottom of the article.

In the words of Ethan:

“...Our first take off from Pittsburgh to Minnesota was a little scary for me. The last time I've felt g-force like that was going down the Black Hole water slide in Erie's Splash Lagoon. The flight was two-and-a-half hours and was a little crowded. I spent most of the flight getting used to air travel again. Once we landed the flying microwave of an airplane, we found out it isn't always snowing in Minnesota; in fact, they too have their summer days in winter. After exploring the airport, we decided to eat at Smashburger. After we ate, we explored the gift shops and grabbed snacks and drinks. I also ended up getting the new Percy Jackson book, which I was really excited about, and a few other things. We boarded the next plane which felt like first class, or the closest I'll ever get to it. Instead of two seats on each side there were three and in plane math that somehow equals a bit more space. The best part was there were video screens on the back of the chairs that had almost every single movie for free. It also had a flight tracker which I found more appealing; I don't know why. I spent most of this three-and-a-half-hour trip reading *The Heroes of Olympus: The House of Hades*, which is a sequel to the Percy Jackson series. When we landed it was WAY past my bedtime, but only like eight o'clock over in Oregon. We met up with some staff and other members of YETI to board a bus to take us to Camp Collins. This is where we met Nikole, who is an old friend of mine and she had way too much energy for being up all day. Her presence helped me get out of my shell a little bit and gave me the feeling that it was going to be a fun four days. Our bus turned out to be the last bus, so we ended up joining a little late, but in time for the last activity. I was a little happy though, because

... CONTINUED ON PAGE 22

Y'ALL YETI FOR THIS?

CONTINUED FROM PAGE 21...

even though camp beds usually suck, I was ready for mine. For the activity, we had to put important dates of things that happened in the bleeding disorder community in the correct order on a timeline. My chapter people, Janet and Kit, excelled at it from the 1980's up. After that, they gave us stuff to make our beds and we headed up to the cabins, and these weren't any normal cabins. They were Hobbit houses with a 5 foot round door and a normal door on the side."

"...The trail led to a beautiful beach with a river going through it and a little waterfall. For a person who's always been surrounded by rivers, I was starstruck. The morning atmosphere, the fog, and the tranquility of the waterfall was enough to make me wanna

live there. I also got some foreshadowing of the trip to come. After breakfast we went into a little side room off the cafeteria where we learned about the HIV crisis in the early 1980's for about 3 hours. This was completely new to me, and I had no idea that it happened till that day."

"...This is where I was able to make new friends and find out a little bit more about other people's chapters and how they were different from mine. When we were done communicating, we headed to the shower house then came back a little before the talent show was ending. The next day, after breakfast, we talked about how medication in the bleeding disorder community grew and improved over the years. Thankfully it was only 30 minutes, but I learned a few things, like a little more about how proph doses weren't always a thing and the struggles of women getting treated for a bleeding

disorder. I also learned how common bleeding disorders really are, but they are just not diagnosed until something big happens in a person's life. I also learned more about how other people's chapters aren't as advanced or don't have the same things mine does, which made me realize how truly thankful I am for the position and location I'm in."

Read about Ethan's entire experience here: <https://wpbdf.org/yall-yeti-for-this/>



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.

HCWP CORNER

KATHALEEN M. SCHNUR, MSW, LCSW

Dear WPBDF and HCWP communities,

Spring has sprung, Punxsutawney Phil predicted an early spring but the day-to-day confusion of what to wear and sometimes experiencing all four seasons in a day still seems to be our newer baseline in Western PA and the extended areas.

We are settling in well at our new facility. As many of you know, we FINALLY made the move to a new place this past November. The Hemophilia Center of Western PA is now located at 201 N Craig St, Suite 500, Pittsburgh, PA 15213, and parking is still available as there is a parking garage beneath the building. It is valet parking and we validate your ticket.

Some staffing changes are happening at the center as well, we have a new nurse Jaspreet (Jessie) Chatta who will be replacing Sandra Fleck. Jessie will be responsible for helping with the coordination of care between HCWP and Children's Hospital of Pittsburgh (CHP). Like Drs Ritchey and Xavier, Jessie will have access to both EMR systems (HCWP and CHP) and can help navigate your pediatric patient's care when you need imaging, labs, and outpatient

or urgent visits to CHP clinics or emergency rooms. Remember that your primary care for your bleeding disorders will always be at HCWP, always reach out to us first.

Dr. Olubusola (Bosula) Oluwole is new to the center and will be seeing inherited thrombophilia patients. She specializes in benign hematology and is board-certified in hematology and internal medicine by the American Board of Internal Medicine. She practices Benign Hematology and is affiliated with UPMC Magee-Womens Hospital, UPMC Shadyside, and UPMC Presbyterian. Dr. Oluwole completed her fellowship at University of Washington School of Medicine and residency and medical education at University of Pittsburgh School of Medicine.

Sadly, nurse Jonathan Morris left the Center as a wonderful opportunity surfaced for him a few states away. He was impactful in his time here, and while we will miss him, we wish him the best.

A gentle reminder to our Center patients and families, please make sure you are current on your clinic appointments. It is not best care to prescribe medication or make surgical or dental recommendations for patients we have not seen. Most of our patients should be seen yearly unless otherwise directed by the doctor. If you aren't sure, give us a call, and if you are struggling to get

to us, give social work a call to help navigate those barriers.

Some important notes, our three Amish Outreach events are in May so while staffing will be available during those weeks, we will not have our usual clinics. Camp Hot-to-Clot registration is open for our affected kiddos and their siblings. Lots is happening in the community over the next few months and we look forward to seeing you in the community and in the clinic.

To our bleeding disorder community looking to pursue post-secondary education or training, please look at the available bleeding disorder scholarships, deadlines are rolling out between May and through the summer months: <https://www.hemophilia.org/community-resources/financial-assistance/scholarships>.

Dr. Xavier asked to share that HCWP is an enrollment site for the new medication to be given subcutaneously (underneath the skin) for patients 12 years old and older, with severe hemophilia, and on prophylactic infusions to prevent bleeding. Please contact our research team at (412)-209-7563 if interested in hearing more about it.

As always, we are here for you!

Sincerely,
Kathaleen M. Schnur, MSW, LCSW

WPBDF'S CORNHOLE TOURNAMENT

SATURDAY, SEPTEMBER 21

**NORTH PARK SWIMMING POOL
S. RIDGE DRIVE
ALLISON PARK, PA 15101**



TEAM COST: (PER TEAM OF TWO)

EARLY BIRD: \$50

Now through August 2nd

REGULAR: \$60

Register online at:

**WPBDF.ORG/
EVENT/CORNHOLE**



The Fourth National HTC Patient Satisfaction Survey is now open!

Your experience is important to us! If you visited your HTC last year, we need your voice!

Use this QR code, take the survey online at www.htcsurvey.com, or fill out and return the survey you received in the mail.

**Surveys must be completed
by May 31, 2024**

LIVING WITH HEMOPHILIA THINGS YOU REALLY NEED TO KNOW

BILL JAMISON

Living with hemophilia, or any chronic condition, requires you to learn as much as you possibly can about your condition – to make sure you have the best health outcome to live a long and healthy life.

So, what qualifies me to speak on this topic? Well, I have Severe Hemophilia Type “A”, Factor VIII Deficiency and have been living with hemophilia for almost 70 years.

Growing up in the 1950’s and 1960’s, the available treatments for hemophilia were very limited and did not work very well. Factor concentrates were decades away and bleeds involving joints and muscles were serious business. For the most part, the treatments available were whole blood, fresh frozen plasma, lyophilized plasma and in the early 1960’s, cryoprecipitates. None of them worked very well, but that’s all we had at that time.

Resolving bleeds was often a long and painful process requiring multiple hospitalizations, sometimes for months on end. Joint and muscle damage was common, often leading to joint replacements later in life. I am a living example of that.

Treating a bleeding disorder today is 180 degrees different than what people of my generation experienced. Today, we have factor concentrates, gene therapy and other treatment options that can usually resolve a bleed quickly with one or two doses or prevent you from bleeding all together in some cases.

I was very fortunate to be in some of the first clinical trials back in 1968 to test this new “Miracle Drug” called factor VIII concentrate. No longer did it take thousands and thousands of cc’s of plasma to resolve a bleed. No longer did my treatment require months long hospitalizations to stop me from bleeding. Treatment now consisted of injecting 50-60 cc’s of this Miracle Juice, as I called it, to resolve a bleeding episode.

I was 14 years old when I got my first infusion of factor VIII concentrate and even at that young age, I knew this was going to be the “hot ticket” to treat my hemophilia and would change my life for the better. It did just that!

Back in 1971, I had a very forward-thinking hematologist that had some groundbreaking thoughts on treating my hemophilia. He decided to have me infuse factor VIII three times a week to see how much it reduced my spontaneous bleeding. He didn’t have to twist my arm to agree with this treatment option. After being in the clinical trial, I absolutely knew this would be a positive life changing treatment for me, and it worked! As far as I know, prophylactic treatment was not the treatment of choice until many years later, but it was my choice, and that’s exactly what I did.

Prophylactic infusion of factor VIII three times a week enabled me to lead a full and productive life. I

was married for 47 years until my wife passed. I have two wonderful adult kids, a boy and a girl, and four grandchildren including a set of twin boys! So, for me, prophylactic treatment and adhering to my treatment protocol made a positive difference in my life.

I attribute my positive outcome to a few things. Living with a bleeding disorder has not been easy at times. Worrying about your job, your insurance, your family and all the crazy things that seem to challenge us that we all face every day have an influence on your overall health. I’m sure all of you would know that.

I made it my goal to learn as much as I could about my hemophilia to have the best healthy outcome as I go through life’s journey.

Here’s a list that I have used over the years that might be of some help to you to navigate this sometimes confusing maze of living with a bleeding disorder. These are in no particular order:

- What’s the name of my factor product or medication?
- What’s my usual dose?
- What’s the name of my insurance company?
- If you use a Specialty Pharmacy, what’s their name and phone number?
- Who’s the contact person if you need meds or services? Is there an after hours number?
- Know your HTC! Who’s your contact person? What’s their phone number? Is there an emergency number to call after hours? Do you know your HTC doctors and nurses name?
- Get some kind of Medic-Alert
- Get a copy of your treatment protocol. Keep a copy in your vehicle, wallet or purse.
- Pennsylvania has the Yellow Dot program. Use it!



The WPBDF
Scholarship

NOW ACCEPTING APPLICATIONS!



*Scan here to apply
and find out more!*

Apply now by going to bit.ly/wp24scholarship

Applications must be received by May 30, 2024.

Questions? Reach out to us at info@wpbdf.org

- Know who your legislators are for your area.
- Get involved with your Bleeding Disorders Chapter
- Volunteer if you're able
- Advocate for yourself and others with bleeding disorders

I hope this information is useful to you. By no means is this a complete list of all the things you can do to help yourself navigate through the challenges we face every day living with a bleeding disorder.

The future of treating bleeding disorders is very bright and getting better all the time. The choices that

are available today are something I could only dream of as a child. You can do "this" thing of living with a bleeding disorder! Just be smart about it. Sometimes it's hard and sometimes it's easy. Just stay ever vigilant of what's going on in the bleeding disorders community and never forget what happened to our community in the 1980's. Over 10,000 men were infected with HIV, and most have died because the focus was lost on what was moral and correct. Never let this happen again! Advocate, initiate, participate.

In closing, the most important thing you can do, in my opinion, is

**Insurance Basics:
Everything You
Didn't Know You
Needed to Know**

**WEDNESDAY, MAY 22, 2024
6:00 PM - 8:30 PM**

**LUCIANO'S ITALIAN BRICK OVEN
161 SCHARBERRY LANE
MARS, PA 16046**

This interactive question and answer style program will address a number of insurance challenges such as prior authorizations, step therapy, specialty tiers, and copay accumulators. You bring the question, we provide the answer! After the program, join us for a drawing class!

Children are welcome to attend. To register, send an email to rsvp@wpbdf.org or call 724-741-6160.

educate yourself on your condition. This is a life-long process. There is always something new to learn. New medications, new procedures, new treatment protocols and much more to help you have a better health outcome.

...Just some thoughts from some old guy that's been around the track a few times.

Be kind,
be safe,
be well!

Bill





THE WESTERN PA BLEEDING DISORDERS FOUNDATION IS SEEKING NEW BOARD MEMBERS



ARE YOU PASSIONATE ABOUT THE BLEEDING DISORDERS COMMUNITY?

WOULD YOU LIKE TO USE YOUR TIME AND TALENTS TO MAKE A POSITIVE DIFFERENCE?

Help support WPBDF's mission by joining our board of directors.



Scan this QR code to apply or go to <https://www.surveymonkey.com/r/QMM7TFW>



EMERGENCY SITUATIONS



On January 28, 2024, Dr. Frederico Xavier presented a virtual program to families who have a child aged 0-7, who has a bleeding disorder. Topics included knowing when to call your hematologist; tips for talking to the doctor on-call, preparing for emergency room visits, and a variety of methods for treating different types of bleeds at home.

After the program, each participating household received

a go-bag (a red backpack) to have packed and on-hand for emergency trips to the hospital or treatment center. The go-bag contained a few items that parents will want to have with them in an emergency, along with a laminated checklist attached to the go-bag on a key



ring. During the program, parents contributed their ideas for items to include in an emergency go-bag.

New Parent Network events are open to families who have a child aged 0-7, who has a bleeding disorder. For more information, please contact Kathaleen Schnur, LCSW, at the Hemophilia Center of Western PA (kschnur@vitalant.org) or Janet Barone at the WPBDF (janet@wpbdf.org).

We thank the following for sponsoring the 2024 New Parent Network Series of Events:





WPBDF'S 2024 ANNUAL MEETING



TOPGOLF
400 Presto-Sygan Road
Bridgeville, PA 15017

THURSDAY, JULY 18, 2024
6:00 PM

Join us for dinner, visit sponsor booths, and learn more about the services the Foundation offers! We will be celebrating our top volunteers and kicking off the 2024 Unite for Bleeding Disorders Walk!

After the meeting, everyone is invited to stay and golf! This program is open to members of the Western Pennsylvania Bleeding Disorders Foundation and family members living in their household. This is an all ages event. Adult supervision is required at all times for those ages 16 & under.

The deadline to register is Monday, July 1, 2024.

Space is limited, so be sure to register early! To register, send an email to rsvp@wpbdf.org or call the Chapter office at 724-741-6160. Be sure to include the total number of people you are registering for and if there are any food allergies. If children are attending, please be sure to include their ages.



WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

775 4th Street
First Floor
Beaver, PA 15009



Unite

for Bleeding Disorders

16th Annual Unite for Bleeding Disorders Walk

9:00 to 11am
(CHECK-IN: 8:00 - 9:00 AM)

SEPT 21
SATURDAY

NORTH PARK SWIMMING POOL
S. Ridge Drive
Allison Park, PA

CONTACT US:

Jessica Lee: 724.741.6160
jessica@wpbdf.org

www.uniteforbleedingdisorders.org/event/wpa



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

