



Western Pennsylvania
Bleeding Disorders Foundation

HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

FALL 2021



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BOARD OF DIRECTORS

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

MISSION STATEMENT

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

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

DESIGNATE UNITED WAY GIFTS TO THE CHAPTER

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

WPCNHF Contributor Agency Code Number is: 83

EVENTS CALENDAR

October 12, 2021

All Levels Yoga
Virtual Event

October 18-28, 2021

HFA Symposium
Virtual Program

October 21, 2021

Reframe Your Mindset
Virtual Program

October 24, 2021

Teen Group
Virtual Event

October 24 - November 3, 2021

Halloween Costume Contest
Teen Group Goosechase
Virtual Program

October 26, 2021

Women's Group Wreath Making
Virtual Program

November 3, 2021

Reconnecting the Mind &
Body Through Fitness
Virtual Program

November 7, 2021

Women and VWD
Virtual Program

November 14, 2021

What's new and upcoming
in treatment?
Virtual Program

November 18, 2021

Von Willebrand Disease:
Men have it too?!
Virtual Program

November 23, 2021

Advocacy Stakeholder Retreat
Virtual Program

November 26 - December 4, 2021

Take A Bough Auction
Virtual Fundraiser

November 30, 2021

Giving Tuesday
Virtual Fundraiser

December 4, 2021

Take A Bough Final Night
Event
Virtual Fundraiser

December 12, 2021

Positive Self Talk &
Winter Craft Making
Virtual Program

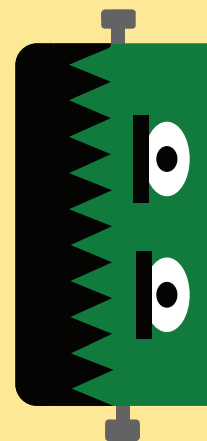
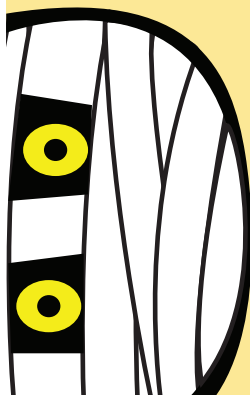
VISIT WPBDF.ORG FOR MORE INFORMATION ON OUR UPCOMING EVENTS.

WPBDF'S COSTUME CONTEST!

Celebrate Halloween with WPBDF's Teen Group by entering our Costume Contest! The Teen Group is inviting all children from the Chapter and Camp Hot-to-Clot to join them this year in a virtual costume contest!

This contest is open to Chapter members and Campers ages 0-18. To enter, submit photos of yourself or your children in costume to info@wpbdf.org. The deadline to submit your photo is Thursday, November 3rd!

Prizes will be awarded to the winners! **Remember to submit your photo by November 3rd!** Winners will be announced on November 8th!



CONTACT US

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@WPBDF

@WPBDF

@WPABDF

LETTER FROM THE EXECUTIVE DIRECTOR AND BOARD PRESIDENT

Dear Chapter Members and
Friends,

Happy Fall! The summer seemed to go by so quickly! We know this has been tough! We had high hopes of being able to hold in-person events this Fall but with the increase in COVID-19 cases and the delta variant, we need to do all we can to keep the community safe. Please remember we are all in this together. Do not hesitate to reach out or ask for help if you need it.

We are planning to keep things virtual through the rest of 2021. We have a full line up of educational programs and fun virtual activities planned. We are especially looking forward to a new program we are launching this month in partnership with the Hemophilia Center of Western Pennsylvania called

Stay In Motion.

The *Stay In Motion* program was designed to provide all members with the education and tools for assessing their current physical condition, talking with their healthcare team, setting goals, and creating a plan for physical activity. We will be providing access to a variety of physical activities to enable you to reap both the mental and physical benefits of exercise!

Updated information and upcoming events can also always be found on our website at www.wpbdf.org on the events tab. As we begin to plan for next year, if there is a topic that you would like to learn more about, or something you think would be interesting to others, please let us know and we'll do our best to bring those programs to you.

Thank you to everyone who worked hard to make this year's Unite for Bleeding Disorders Walk a success! Moving the Walk virtual for the second year in a row was a difficult decision to make but we knew it was the best decision to keep everyone safe. We had a great time playing virtual Unite Trivia with everyone and loved seeing photos of the walk teams who enjoyed the beautiful day walking with family and friends. Thank you to everyone who continued to spread awareness, raise critical funds for the bleeding disorders community, and proved that even while apart, we are resilient

and we UNITE for bleeding disorders.

We hope to see you all at our virtual Take A Bough event this year! Beautiful holiday trees, wreaths, and tabletop displays will be up for bid the day after Thanksgiving. The online auction will be up for the week and a virtual final night event will be held on Saturday, December 4th. 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 Appreciation,

Kara Dornish
Executive Director

R. Scott Domowicz
Board President



CAMP HOT-TO-CLOT

KATHALEEN SCHNUR, LCSW

Many of us had some big feelings about another summer without being at camp Hot-to-Clot with our friends, our community, and our people. We still wanted to offer ways to connect to camp and each other. Camp kit boxes were sent out to all registered campers filled with camp goodies including crafts, instructions, playing cards, and even a gift card to pick up the ingredients to make s'mores!

Two virtual events were offered to our camp community. The first one was on Monday, August 9th. During this event, campers shared summer experiences, reviewed camp box contents, played virtual scavenger hunt games and created a collaborative story. We even had breakout rooms and played UNO together! Campers were encouraged to use their creativity to show us what camp means to them or what they imagine camp to

be in an art project, story, song, etc. We requested the campers to send us a picture or an email of their "work." We received a spectacular representation from our soon-to-be camper Jaxson B.



Our other virtual event was held on Friday, August 13th. We had a special guest lead this activity; our very own H2C creative arts specialist, Jamie Geiser. Jamie led all of us in creating our own masterpiece of mountains and happy trees using acrylic paints, paint brushes, and a canvas from the camp kit box. Everyone did a beautiful job and there was much laughter which was equally as beautiful.



While this was not the camp experience we were expecting, it was nice to see so many of your smiling faces!

NEW STUDY LOOKS AT BLEEDING DISORDER CAMPS

While it has been well established that bleeding disorders camps (BDCs) in the U.S. have played a key part in empowering affected children for decades, comprehensive knowledge of their capacity and functioning is historically lacking.

In order to fill these knowledge gaps, a pair of national surveys were designed, one for BDC administrators (CAs) and one for healthcare providers (HCPs). Analysis of the results, "A Descriptive Study of United States Bleeding Disorder Camps," were published in The Journal of Haemophilia Practice (JHP).

Developed through a collaborative

effort by both the National Hemophilia Foundation's (NHF's) Research Team and members of its Nursing and Physical Therapy Working Groups, the surveys were designed, in part, to uncover the types of inconsistencies and vulnerabilities in the BDC system that could jeopardize the current model's long-term viability.

While every effort was made to cast a wide net by including all U.S. BDCs in the survey process, the authors ran up against certain limitations such as undeliverable emails, firewalls, and non-responses. Despite these and other limitations, a 30.5% response was achieved, encompassing 121 respondents (101 HCPs and 20 CAs).

Of the total 59 BDC camps in the US, 46 (78%) were represented in the study; 19 camps were represented by the 20 CA respondents; 37 camps were represented by the 75 HCPs who

had participated in camp during the past five years. The number of HCPs per camp who completed the survey ranged from 1 to 12. Eighteen out of 73 (24.7%) HCPs reported participation in multiple camps.

The surveys gleaned a wealth of information relevant to BDC policies and procedures, camp composition, funding, administration, plus HCP staffing expectations of their HTC, among other topics.

The authors identified certain disparities and financial challenges that have direct impact on HCP participation in BDCs. "In general, diminishing financial resources threaten the existence of BDCs. Fifty percent of the CAs identified a combination of funding sources, with chapters and HTCs holding a significant responsibility. All HCP respondents who participated

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New Name. New Location. **Same Dedication.**



**Western Pennsylvania
Bleeding Disorders Foundation**

WPBDF EDUCATION | ADVOCACY | SUPPORT

On behalf of the Board of Directors and Staff, we are pleased to share an exciting change to our Foundation. In order to be more inclusive of the community we serve, we have updated our name to the **Western Pennsylvania Bleeding Disorders Foundation**. Our organization not only serves individuals living with hemophilia, but all bleeding disorders including von Willebrand Disease, factor deficiencies, and platelet disorders. We are happy to have a name that reflects who we are and who we serve.

Our office has moved!

In September we relocated from our office in Cranberry Township, to a bigger office just 25 minutes away in Beaver, PA. This office is on the ground level making it more accessible for all.

Our new address is:

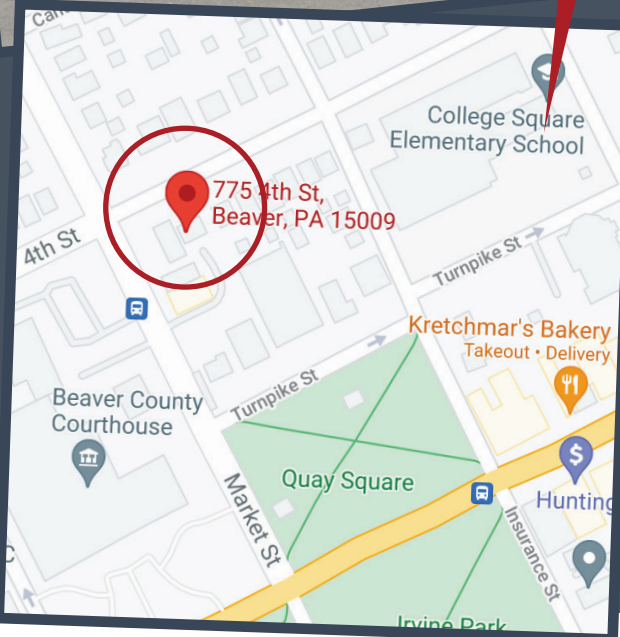
**775 4th Street, First
Floor, Beaver, PA 15009**

Our email addresses, website, and phone numbers have not changed. If you have any questions you can reach us during office hours 9 AM - 4 PM Monday through Friday.

Contact Us:

Phone: 724-741-6160

Email: info@wpbdf.org



ADVOCACY UPDATE

WE REPRESENT YOU!

Advocacy is a key component of the Foundation's mission. Our overarching goal is to preserve access to care for our community members in Pennsylvania. As such, we are involved with budgetary, policy and legislative issues that arise in Harrisburg. We are strategically positioned to be proactive in our advocacy efforts, while also being nimble enough to react when needed.

Under the leadership of both the Western and Eastern PA Bleeding Disorders Foundations, a coalition was formed that includes the seven HTC's in the state, the National Hemophilia Foundation, the Hemophilia Federation of America, and Milliron & Goodman Government Relations. This collaborative group is proud to represent You!

UNDERSTAND THE ISSUES

MAINTAIN FUNDING TO ALL 7 HEMOPHILIA TREATMENT CENTERS IN PENNSYLVANIA

The Pennsylvania General Assembly passed the budget and fiscal code bills on June 28th, 2021 and Governor Wolf signed them into law on June 30th, 2021. We are happy to let you know the Pennsylvania budget has passed with hemophilia fully funded at \$959,000. In addition, the language in the fiscal code reads as follows: "FUNDS APPROPRIATED FOR

HEMOPHILIA SERVICES SHALL BE DISTRIBUTED TO GRANTEE'S IN THE SAME PROPORTION AS DISTRIBUTED IN FISCAL YEAR 2019-2020." This ensures hemophilia funding in the budget must be distributed to the 7 Hemophilia Treatment Centers in the same way it was last fiscal year and not based on a regional approach.

END CO-PAY ACCUMULATORS IN PENNSYLVANIA

Several states have already eliminated accumulator programs, and we are working to eliminate them in Pennsylvania. Bipartisan legislation has been introduced that would protect patients from having their prescription drug co-pay assistance programs undercut by their health insurer or pharmacy benefit managers. Introduced by Reps. Barbara Gleim (R-Cumberland County) and Mark Longietti (D-Mercer County), HB 1664 along with Senate Bill 196, would eliminate co-pay accumulator programs statewide.

IMPROVE PRIOR AUTHORIZATION AND FAIL FIRST FOR PENNSYLVANIANS

SB 225: Amends the Insurance Company Law by including a standard definition of prior authorization. It will also significantly streamline the process by requiring insurers to make available an electronic communications network that permits prior authorization requests to be submitted electronically, and authorizations and adverse determinations to likewise be returned electronically. On June

23, 2021, SB 225, as amended, passed unanimously out of the Senate Banking and Insurance Committee. We will be sending out action alerts and have phone scripts available to urge your legislators to support this bill when it is up for a vote in the full Senate.

WHAT YOU CAN DO TO HELP

YOU ARE YOUR OWN BEST ADVOCATE. LET YOUR VOICE BE HEARD.

Become an Advocacy Ambassador
Please contact Janet at janet@wpbdf.org or call the Foundation office at 724-741-6160. We can help set up meetings with your legislators, coach you on key issues, and provide you with everything you need to have a successful meeting.

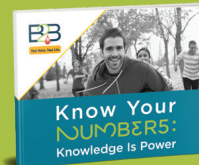
Sign up to receive action alerts at: <https://p2a.co/udfkjur>

By signing up for action alerts, the Western and Eastern Pennsylvania Bleeding Disorders Foundations will notify you when issues arise that impact the bleeding disorders community. We will notify you with ways you can act and easily contact your legislators on important legislation impacting the bleeding disorders community.



The Power In Knowing Your Numbers

This content is brought to you by Pfizer.



For more information, scan the QR code with your smartphone camera to access *Know Your Numbers: Knowledge Is Power.*



This information is provided for educational purposes only and is not intended to replace discussions with a health care provider. Speak to your treatment team if you have any questions about your/your child's care.

For those who live with hemophilia and their caregivers and families, it's important to understand how specific sets of numbers, test values, and data about the condition can impact patients throughout their lifetimes. It's important for all people with hemophilia to understand their numbers in order to communicate effectively with their health care professionals (HCPs).

Replacement Factor

One important number to know is how the dose of replacement factor is calculated and how that number may vary from person to person:

- For treating hemophilia A, the factor VIII dosage = body weight (kg) × desired factor VIII level increase (%) × 0.5¹
- For treating hemophilia B, the number of factor IX units required = body weight (kg) × desired factor IX increase (%) × product-specific multiplier (varies by factor IX replacement product)^{2,3}
- For severe bleeding associated with both hemophilia A and B, an appropriate dose of factor should yield a factor level of 80% to 100%¹⁻³
- Because of the wide variation in recovery time, further adjustments may be needed. Talk to your treatment team to determine the right treatment³

"I have encouraged my patients with hemophilia to communicate with the hemophilia treatment team about all aspects of their condition. When it comes to test results and what they mean, patients should never hesitate to seek a discussion with the health care team."

-PATRICK F. FOGARTY, MD

Drug Half-life

The half-life of a drug is important because it can help guide the appropriate drug dosage.³ The drug half-life is helpful for HCPs when recommending a particular dose regimen.

- The half-life is the length of time it takes for the body to eliminate 50% of the amount of drug in the bloodstream⁴
- The half-life measures how quickly or slowly the factor breaks down in the body
- The amount of factor in the bloodstream is highest right after an infusion and then subsequently decreases

Keep a Log

As part of a total self-management program, keep a log that includes all your health information such as dates of bleeds, types of bleeds, how bleeds were treated, factor levels when known, and the dosage of any other medications you are taking. Tracking day-to-day information may help your health care professional or treatment team develop a treatment plan. Knowing how many bleeds you have had or your child has had will provide important information to your health care professional or HTC treatment team.

Know Your Numbers—Know Yourself

Being an active advocate for your health care can be part of living with hemophilia. Part of effective communication with your treatment team is knowing and understanding your numbers. Finally, making sure family members and caregivers also understand your numbers can be part of a comprehensive plan for living with hemophilia.

References: 1. Hemophilia A. ClinLab Navigator website. <http://www.clinlabnavigator.com/hemophilia-a.html>. Accessed April 8, 2020. 2. Hemophilia B. ClinLab Navigator website. <http://www.clinlabnavigator.com/hemophilia-b.html>. Accessed April 5, 2020. 3. Srivastava A, Brewer AK, Mauer-Bunschoten EP, et al. Guidelines for the management of hemophilia. *Haemophilia*. 2013;19:e1-e47. doi:10.1111/j.1365-2516.2012.02909.x 4. Half-life definition. Beltina.org Encyclopedia of Health website. <https://www.beltina.org/half-life-definition>. Accessed April 5, 2020.



Patient Affairs Liaisons are Pfizer employees who are dedicated solely to providing support to the community. Your Pfizer Patient Affairs Liaison is available to help you access the support and information you need. To find your Patient Affairs Liaison, go to pfizerpalfinder.com or call Pfizer Hemophilia Connect at 1.844.989.HEMO (4366).

NEW STUDY LOOKS AT BLEEDING DISORDER CAMPS

CONTINUED FROM PAGE 4...

in camp indicated some form of compensation. Those who did not participate in camp cited barriers associated with the use of personal time, employers not compensating or allowing time to participate, and not being licensed in the state where the BDC was held. This may explain why 70% of camps allow specialty pharmacy, specialty homecare, or industry representatives to serve as camp staff," explained the authors.

Another theme of these surveys was an uneven adherence to available BDC guidelines, which include instructions for formal trainings for camp staff on a host of matters, such as proper medication storage.

According to the JHP article, "Despite the existence of state, national, NHF, and American Camp Association guidelines, adherence is variable. Approximately half of the CAs reported following these guidelines. NHF's 2017 Health Center Guidelines for Camps Serving Persons with Bleeding Disorders indicate that all staff should receive education, which the authors interpret as at least an 'orientation'. Despite this recommendation, many respondents reported no official orientation."

Another eye-opening finding was relevant to self-infusion education, a fundamental component of BDC programs for many years, whereby children learn to administer their own factor under the guidance of expert camp staff. While this practice can offer tremendous benefits for affected children, feedback suggests that in many instances there is little-to-no post-instruction follow up with children. In fact, 70% of CAs and

44.4% HCPs surveyed reported zero follow-up. This represents a lost opportunity to reinforce educational gains and to monitor a child's fledgling progress towards independence.

Instead, the authors encourage HTC's and parents to work closely post-BDC to develop a follow-up program, complemented with practical educational resources such as a self-infusion tip sheet for parents. They also recommend implementation of a "standardized quality improvement" (QI) program to increase the effectiveness of self-infusion education programs at camps.

The authors go on to suggest that a positive correlation between camp participation and enhanced independence will cultivate the value of BDCs, with positive implications for funding moving forward. Challenges notwithstanding, the authors see ample opportunities for further study of, and enhancements to, BDCs.

"While BDCs are known by reputation to be very successful, this survey demonstrates opportunities for continued growth and research. Future studies should focus on assessing the multiple benefits BDCs provide to those who attend them, not only to understand how camps can better serve the BD community in the future, but also to improve the experience of the camper addressing their increasing psychosocial and medical complexity," concluded the authors.

Access the full article at: <https://sciendo.com/de/article/10.17225/jhp00171>

Santaella, Maria E., Nichols, Cynthia and Witkop, Michelle. "A descriptive study of United States bleeding disorders camps" *The Journal of Haemophilia Practice*, vol.8, no.1, 2021, pp.1-10. <https://doi.org/10.17225/jhp00171>

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BOMBARDIER BLOOD MOVIE NIGHT

On Thursday, July 15th, WPBDF held a special outdoor movie screening of Believe Limited's **Bombardier Blood!** Check-in began at the Rotary Amphitheater in the Cranberry Township Community Park at 8:30 pm. The movie started around 9:00 pm. This event was free to attend and was open to the public. Everyone who attended received a picnic blanket with the Foundation logo!

Thank you to Octapharma for sponsoring this event and providing **Bombardier Blood** raffle prizes! Thank you to everyone who came out to watch with us!



Chris Bombardier is on a mission to become the first person with severe haemophilia to climb the Seven Summits, the highest mountain on each continent. He has completed five of the climbs already, but he next faces the big one: Everest.

Bombardier Blood is available to buy, rent, or stream everywhere! Check bombardierblood.com for more information.

VIRTUAL UNITE FOR BLEEDING DISORDERS WALK AND RUN FOR THEIR LIVES 5K!

Unite for Bleeding Disorders

This year, we celebrated our 13th Annual Unite for Bleeding Disorders Walk virtually! The Walk was held on Saturday, September 18th and coincided with the National Hemophilia Foundation's (NHF) nationwide Unite Day. This year, our Unite Walk moved virtual and friends, family, and supporters still came together to raise nearly \$50,000 to support the bleeding disorders community of Western Pennsylvania!

Our virtual event started at 10:00 am with a thank you to our amazing national and local sponsors, a special shoutout to our Walk teams, and the announcement of our top fundraising awards and factor club winners.

Congratulations to our top fundraising team, Conor's Clan, who raised an incredible \$6,348.38! This year, Conor's Clan hosted their annual car wash again after taking a break last year and raised over \$500 for the Foundation! They also gathered vases of pinwheels and set them up in local businesses around Beaver. Many people threw their extra change into these vases throughout the summer and Conor's Clan raised nearly \$250 by just setting the vases out! Thank you so much for your continued support and congratulations to your entire team!

Congratulations to our Top

Individual Fundraiser and 2021 Top Team Captain, Kelly of Team Jaxson! Kelly raised an amazing \$3,744! She utilized social media to share her family's story and encourage her friends and family to donate in honor of her son, Jaxson. Kelly also hosted a fundraiser at Back Deck Grill where a portion of every meal sold that night was donated back to the Foundation. She ended up raising nearly \$1,500 for the Unite for Bleeding Disorders Walk! Kelly is also our 2021 Walk Chair! Congratulations, Kelly. We are so grateful to have you as our 2021 Walk chair and in our community.

Finally, a huge congratulations to our 2021 Awesome John Eyrolles Top Youth Fundraiser, Jaxson of Team Jaxson! This year, Jaxson walked surrounded by his new friends from school. All of us at the Foundation hope you had an amazing day! Jaxson was diagnosed with Hemophilia A when he was seven months old. His parents and big sister, Analise, always join the walk to support him each year. Thank you and congratulations again, Jaxson!

Thank you to all 19 of our Walk Teams! We'd like to give a special shout out to the teams who really



CONOR'S CLAN

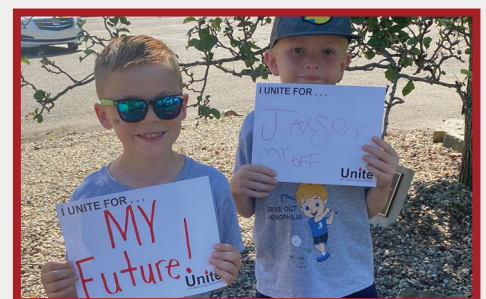
went above and beyond and raised \$1,000 or more:

Conor's Clan - \$6,348.38
Team Jaxson - \$3,744
Rolling for Ryker - \$3,730
Gino's Gang - \$1,550
Cameron's Walking Sticks - \$1,505
Charlotte's Hemo Heroes - \$1,500
Maxwell House - \$1,450
Aberegg Army - \$1,220
Red N' Plenty - \$1,165
Clotting Cavaliers - \$1,000

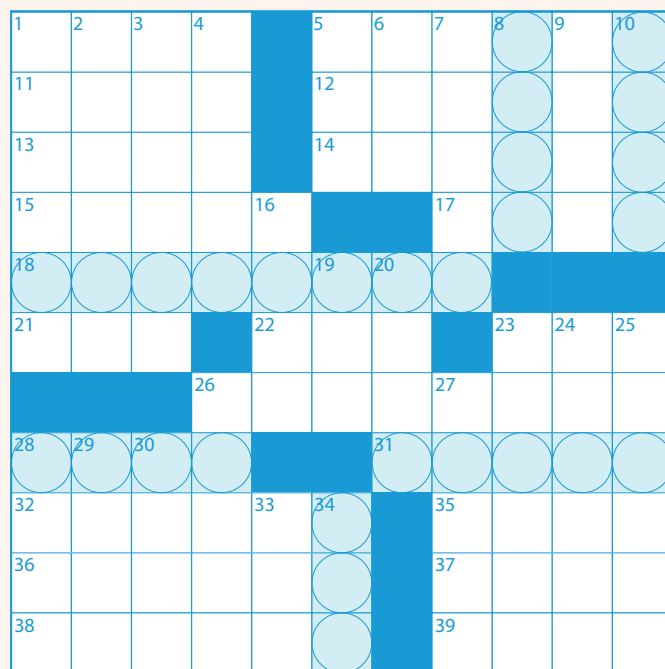
Thank you to all of our Factor Club

CONTINUED ON PAGE 12...

TEAM JAXSON



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 hemophilia A*

*According to IQVIA claims data from various insurance plan types from October 2019 to November 2020 and accounts for usage in prophylaxis settings 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. _____ thousand patients have been treated with HEMLIBRA worldwide†

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. Oloé, 36. arose, 37. tall, 38. lessen, 39. oles, 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

Down: 1. catchy, 2. adorer, 3. serums, 4. kneel, 5. PC's, 6. has, 7. arena, 8. side, 9. MSTs, 10. shot, 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. Oloé, 36. arose, 37. tall, 38. lessen, 39. oles, 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

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

Discover more at [HEMLIBRA.com/answers](https://www.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.

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: 10/2018



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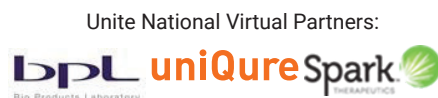
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VIRTUAL UNITE FOR BLEEDING DISORDERS WALK!

CONTINUED FROM PAGE 9...

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

Brooke Aberegg of Aberegg Army, Charlotte Rosborough of Charlotte's Hemo Heroes, Conor Nikithser of Conor's Clan, Cooper Aberegg of Aberegg Army, Dawn Rotellini of Gino's Gang, Eileen Nikithser of Conor's Clan, Emily Nikithser of Conor's Clan, Janet Barone of Cameron's Walking Sticks, Janice Wyatt of Team Heart and Sole, Jaxson Baker of Team Jaxson, Jen Rose of Clotting Cavaliers, Jen Werme of Conor's Clan, Kara Dornish of Kara's Walkers, Kathaleen Schnur of Bubble Brigade, Kelly Baker of Team Jaxson, Lynda Maxwell of Maxwell House, Maurice Prendergast of Conor's Clan, Melinda Perry-Stern of Rolling for Ryker, Michelle Perry of Rolling for Ryker, Patrick Nikithser of Conor's Clan, Robert Sethman of Team Red N' Plenty, Russell Werme of Conor's Clan, Ryker Stern of Rolling for Ryker, Steve Stern of Rolling for Ryker, and Tracy Sethman of Team Red N' Plenty

This year, our community came together to create an inspirational video version of our Pinwheel

Ceremony. Each line of the ceremony was read by one member of our Walk community. Thank you to every who submitted a video. You can see our Pinwheel Ceremony at: <https://youtu.be/-5yrYvtqYCw>

The Unite for Bleeding Disorders Walk would not have been possible without the extremely generous support of our National & Local Sponsors. Our National Sponsors Include: National Presenting Partners, Takeda and the Hemophilia Alliance, Our National Community Partners: Sanofi Genzyme, Pfizer and, BioMarin, Our National Partners: AscellaHealth, Bayer, Grifols, and Optum, Our Unite National Virtual Partners: Spark, Uniqure, and Bio Products Laboratory, Our Local Gold Sponsor: UPMC, Our Bronze Sponsors: CSL Behring, Drug Co, Genentech, and Octapharma, Our Pittsburgh Sponsors: Auto Owners Insurance and M&M Cabinets, Our Supporter Sponsors: American Electric Power, My Hero's Sub Shop, the Beaver Area Jaycees and Spanos Group of Raymond James, Our Kilometer Sponsor: Bookminders, and all of our in-kind sponsors who provided coupons and snacks for our Walk event boxes! Please take a few minutes to check out their virtual booths by going to <https://nhf.swoogo.com/uniteday2021/WPBDF>.

The 12th Annual Run for Their Lives 5K was also moved virtual. Runners were encouraged to run on September 18th to raise awareness for bleeding disorders!

This year, Dick's Sporting Goods generously donated gift certificates for our 1st, 2nd, and 3rd place winners in the men's and women's categories. Runners could submit their virtual times online, and the fastest times in each category was sent a prize! Runners had from September 18th until September 30th to submit their times. Thank you to the generous sponsors of our run: Our Pacesetter Sponsor: Takeda, Our Platinum Sponsor: Bayer, and our Silver Sponsor: CSL Behring. We raised over \$3,500 for the bleeding disorders community through our run. Thank you to all our amazing runners who donated and ran to raise awareness for our community!

All of the money raised from the Walk and Run stays local to promote patient advocacy, provide educational programming and support groups, and provide financial assistance to families in need. The Foundation offers

financial assistance with medical bills, travel to medical appointments, medical devices, medical ID jewelry, and more. The Foundation also uses the money raised to create and increase awareness of bleeding disorders. Mark your calendar now for next year's Unite for Bleeding Disorders Walk, Run For Their Lives 5k, and Cornhole Tournament taking place at the North Park Pool on Saturday, September 10, 2022!



RUN FOR THEIR LIVES

THANK YOU TO OUR SPONSORS

Silver Sponsor:

CSL Behring
Biotherapies for Life™

Platinum Sponsor:

Takeda

Platinum Sponsor:





VIRTUAL ANNUAL MEETING

On July 22, we held out Annual Meeting virtually over Zoom. Over 100 individuals joined us to hear our annual report, help us recognize top volunteers, congratulate scholarship winners, kick off the Unite for Bleeding Disorders Walk, and hear about all the programs the Chapter offers throughout the year. We are grateful for the following organizations that supported this event: Accredo, Bayer Healthcare, Biomarin, CSL Behring, CVS Specialty, Drug Co., Genentech, Hemophilia Center of Western PA, Sanofi Genzyme, Spark Therapeutics, Takeda.

Brittani Spencer, Board Secretary, conducted the businesses portion of the Annual Meeting. Each board member who was present introduced themselves to the members and spoke about their vision for the future of the Foundation. Board members who could not be there live sent in videos that were shown. The Foundation is grateful to be in a position to support

TEEN GROUP

NICOLETTE C., TEEN GROUP CO-COORDINATOR

The Western PA Bleeding Disorders Foundation is back in full swing. Due to the cancellation of Camp Hot-to-Clot, during the week of camp, the teens and other kids met virtually for multiple crafts and other fun activities. At the end of the week, the teen group held an impromptu get together at South Park. The teen group is looking forward to having more virtual events, and will hopefully meet in person again soon, depending on COVID-19.

so many of our members. Last year, the Foundation provided over \$32,000 in patient assistance to over 200 members in need. This included emergency financial assistance for bills, elbow/knee/ankle braces, medical ID jewelry, durable medical equipment (that insurance didn't cover), and transportation to medical appointments. In addition, we were able to support 36 families, who were impacted by COVID-19, with \$13,900 for emergency grocery assistance.



Kara Dornish, Executive Director, gave an overview of the Foundation's accomplishments over the past fiscal year, which included 25 virtual education programs, 1 in-person retreat, 7 virtual fundraisers, and 1 in-person fundraiser! The Foundation wouldn't be able to accomplish the things that it does without the help of volunteers. Time was taken to recognize this past year's top volunteers: Victoria Baker,

CONTINUED ON PAGE 18...

THIRD ANNUAL BALLERS FOR BLEEDING DISORDERS

On September 11, 2021, WPBDF hosted their third annual Ballers for Bleeding Disorders charity paintball fundraiser at Three Rivers Paintball in Freedom, PA.

Eighteen people played in the tournament. The cost was \$40 per person and included admission, rental paintball gun, all day air, goggles, and 200 paintballs. Registration began at 11:30 a.m. and the players were on the field by 12:30. The tournament lasted until

4:30 p.m. Spectators were able to get in on the action and try their hand at target practice for \$10 per person.

WPBDF once again sold Ballers for Bleeding Disorders t-shirts and velcro patches to help raise awareness and additional funds for the Foundation. Thank you to Ere and Scott Domowicz for their hard work selling patches and shirts and for their assistance in planning this awesome event! Thank you to Three Rivers Paintball for hosting this event and continuing to support our community.

Thank you to our Bronze Sponsor, Octapharma, for supporting this event!

This year, over \$1,000 was raised to support emergency and medical patient assistance, educational programs, and support groups to benefit the bleeding disorders community in Western PA. We hope to see everyone at our next Ballers for Bleeding Disorders fundraiser!



YOUNG ADULT RETREAT

TORI BAKER, YOUNG ADULT GROUP CO-COORDINATOR



On June 26, 2021, the Young Adult Group held our first in-person event at Seven Springs Mountain Resort.

Our day started with a fun icebreaker activity - the Oreo Tower Battle! The goal of the activity was to see who could build the tallest Oreo Tower within 2:00 minutes. Kara and Kat tied for the tallest tower and won all you can eat Oreos and bragging rights. Once we were all filled with Oreos,

we participated in our second icebreaker where we all pondered the question, "What is your desert island snack?". My personal favorites are a salty-sweet combination of salt-and-vinegar chips and peach rings.

We then moved outside to the patio to participate in a casual discussion about tips to balance life, stress, and mental health led by social worker extraordinaire, Kathaleen Schnur. The presentation concluded with a balancing activity that compared the stress of our everyday lives to balancing objects on a wooden board. The activity ended with us working on some ways we can practice self-care to lower our stress levels. Some examples include, taking time to read a book, practicing yoga, or spending time outside.

After lunch, we spent some time enjoying the amenities offered by Seven Springs. We went bowling,



rode the chairlifts down the mountain, slid down the alpine slide, and enjoyed the lake on hydro-bikes and paddles boats.



Our day ended with dinner and a debrief of the day. We are looking forward to more fun events like this one. If you are between the ages 18-35 and are looking for a fun group to join, keep an eye out for an invitation to our next event! We look forward to meeting you!

SPARK YOUR CURIOSITY

On Thursday, July 8th the Western and Eastern Pennsylvania Bleeding Disorder Foundations came together to hold a virtual educational program, Understanding Gene

Therapy Research and Its Potential Application to Hemophilia. This program was led by Laureen Temple, Patient Education Lead, at Spark Therapeutics. The presentation started with the basics of genetics and the role genetics

play in hemophilia. Gene therapy research began over 50 years ago and Laureen explained how gene therapy is meant to work. Finally, we considered the potential for and the challenges of gene therapy research in hemophilia today.





LIFE HAPPENS

AND ADVATE WILL BE THERE WHEN IT DOES

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



[Antihemophilic Factor (Recombinant)]

REAL LIFE. REAL BLEED PROTECTION.*

AdvateRealLife.com

***In clinical trials, ADVATE demonstrated the ability to help prevent bleeding episodes using a prophylaxis regimen.**

Not an actual patient.

Prophylaxis with ADVATE prevented bleeds¹

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.

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[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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Michael Sager

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O: 330-413-9755

"I'm dedicated to connecting you with the resources and information you need. Feel free to contact me at any time in English, Spanish, or Portuguese. I look forward to serving you!"

My work is guided by:

Compassion—Listening to your needs and addressing questions and concerns that you may have

Commitment—Educating you about Pfizer's tools and resources, including the Pfizer Community Connections Program, the HemMobile® app for logging bleeds and infusions, B2B materials, and more

Connection—Connecting you with hemophilia advocacy groups and programs like Leading Edge, the National Hemophilia Foundation, The Coalition for Hemophilia B, and others

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GETTING TO KNOW HCWP STAFF



NICOLETTA (NIKI) MACHIN
PHYSICIAN

Birthplace: Pittsburgh, PA

First job: Ace Hardware cashier. I can tell you anything you need to know about rock salt.

Accomplishment you're proudest of: My time in Teach for America as a high school science teacher and now watching my students grow-up and accomplish big things!

What three words describe you best? Nerdy, Cautious, and Diligent

Dream vacation: New Zealand

Things you can't do without: The Internet/my phone

Person you'd most like to have dinner with: Brandon Sanderson, my favorite author. Yes, I'm a sucker for fantasy novels.

Movie you could see anytime: *How to*

Train Your Dragon (judge away I love it)

TV show you try not to miss: I don't watch much TV but *The Office* is always on repeat in my house for unknown reasons.

Three things that can always be found on your refrigerator: My kid's pictures, their drawings and a to-do list

Secret vice: Stealing my kid's chocolate...they really don't need all of that, right?

Who would you play in the movies? The mage or someone who's around for counsel/backdoor dealing not so much adventuring.

Your pet peeve about Pittsburgh: Like everyone else, I hate tunnel traffic.

People may be surprised to know that: Despite my cautious nature, I love a good thrill and have been skydiving and bungee jumping.

VIRTUAL ANNUAL MEETING

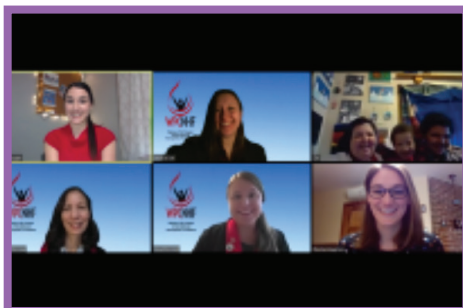
CONTINUED FROM PAGE 13...

Cameron Cedeno, Colin Domowicz, Erek Domowicz, Tracy Sethman, Diane Standish, Ronald Weisser, and Christina Yunghans; and the recipient of the Top Volunteer of the Year award was John Yunghans! John has done an amazing job this past year leading the Men's Group and Blood Brotherhood program for the Chapter. He is the Co-Chair of the Young Adult Group and did a fantastic job in planning and implementing our first Young Adult Retreat at Seven Springs in June. He has served on the Board of Directors as Secretary and dedicates much of his time leading special projects on the Board to make the Chapter stronger. John is very passionate about the community, is always willing to lend a helping hand, and we are thankful for his leadership and dedication to the Chapter. Thank you and congratulations John!



The Foundation's staff and volunteers have also been involved in numerous advocacy meetings and other advocacy-related activities. Our volunteer Advocacy Ambassadors were also recognized for their time and commitment to making Pennsylvania a better place for people living with bleeding disorders: Ashley Cramer, Ashley

Lohr, Cassandra Miller, Charles Thayer, Christina Yunghans, Christopher Templin, Delores Johnson, Ethan Webb, Heather Kosto, John Yunghans, Julia Shoemaker, Kathaleen Schnur, Kyrie Holliday, Lenore Hiller, Maria Shoemaker, Marty Bobro, Mason Bobro, Matthew Hiller, Melinda Perry-Stern, Michael Clancey, Michelle Perry, and Ryker Stern.



This event also served as the 2021 Unite for Bleeding Disorders Walk kickoff. Jessica Lee, Development Director, introduced this year's Walk Chair, Kelly Baker, and provided information on the Walk, which is the Foundation's largest, annual fundraising event.

Janet Barone, Program Director, provided an overview on the Foundation's programs and services and introduced a number of our program committee members, who provided details about specific activities over the past year and plans for the following year. In addition, the Foundation partners on some programs with the Hemophilia Center of Western PA, and social workers Kathaleen Schnur and Katherine Bush also provided updates.

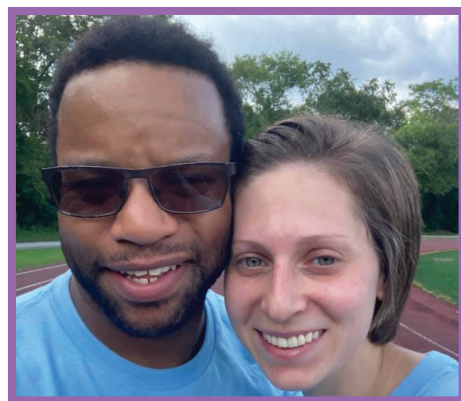
We are grateful for our members who served this past year on fundraiser and/or program committees, and all were recognized during the Annual Meeting:

- Victoria Baker, Program Committee Chair and Young Adult Group Co-Coordinator
- John Yunghans, Men's Group and Young Adult Group Co-Coordinator

- Maria Voms-Stein, Women's Group Coordinator and Take A Bough Co-Chair
- Nicolette Cloutier, Teen's Group Co-Coordinator
- Raina Slater, Teen's Group Co-Coordinator
- Ziola Jevack, Teen's Group Co-Coordinator
- Jennifer Miller, 2020 Unite Walk Chair
- Melinda Perry-Stern, Take A Bough Co-Chair

We were pleased to announce the recipients of the Foundation's annual education scholarship:

1ST PLACE - \$2,500 - ELIJAH SHROPSHIRE



2ND PLACE - \$1,500 - JASON MILLER



3RD PLACE - \$1,000 - AMANDA STEELE VOMS STEIN



WPBDF'S NEW PARENT NETWORK PICNIC



On Saturday, July 17th families in our New Parent Network program came together for a picnic at Idlewild & Soak Zone! Our New Parent Network program is open to families with a child ages 0-7 with a bleeding diagnosis. It was a beautiful day for families to network and have fun! A delicious catered lunch was set up at a pavilion just outside the Storybook



Forest. After lunch, families played fun icebreaker games such as People Bingo and Minute to Win It. People Bingo was a fun way for families to get to know each other better. Everyone was given a bingo card and had to find someone who matched the characteristics listed in the bingo squares. Characteristics included things such as "Likes Disney movies", "Doesn't mind wearing mismatched socks", and "Likes to play in the rain". The Minute to Win It game was hilarious as participants placed an Oreo cookie on their forehead and had to



make it into their mouths without touching it. After the picnic, families were invited to spend the rest of the day enjoying the park with their families. Shortly after the picnic ended, clouds filled the sky and the beautiful sunny day turned into rain. Idlewild graciously gave all families who attended rain day tickets that could be used any day for the rest of the season.

Thank you to our sponsors for their support of this program!



HCWP CORNER

KATHALEEN SCHNUR, LCSW

Fall is synonymous with change; the weather, nature, colors, activities, daylight, etc., all shifting around us and to us. We continue to change and adapt to our situations the best we can. It's been about a year and a half since our lives were changed by the impact of COVID-19 and still we pivot. This has not been easy, our ability to cope with stress and recover from adversity has been in overdrive. There are studies that show an increase in adults experiencing symptoms of anxiety and depression since the start of COVID. Many households are still struggling with finances, employment, childcare, transportation, health care, and overall wellbeing. When basic needs are unstable, it can be overwhelming and distracting to address other unmet needs including both physical and mental health. Your HTC team can offer guidance and help navigate

available resources. We want to connect with you to let you know that you matter and remind you that your comprehensive care team continues to care for you as a whole person.

Many schools are in-session right now. Please know that we at the center can offer many supports including diagnosis documentation, educational materials, in-services for staff, as well as other considerations when your child is in school. Our post-secondary students should know that we can also offer supports such as awareness of bleeding disorder specific scholarships, medical documentation, insurance concerns, etc. If you are not sure, we can develop a plan and review processes with you.

We want our patients and families to be aware that open enrollment for the Health Insurance Marketplace (healthcare.gov) begins Monday, November 1, 2021–Saturday, January 15, 2022. You must enroll by December

15, 2021 for coverage that starts January 1, 2022. Medicare open enrollment for 2022 coverage starts on October 15, 2021 and continues through December 7. Patients on these plans will sometimes reevaluate their coverage to determine if they need to look at a different plan. If you need assistance with this, please outreach the center for help. Additionally, if you have any questions or need assistance understanding your current plan, the center can help. Please know that if you do not have health insurance or suddenly lose your health insurance, please call the center for support.

Please make sure to call the center and schedule your appointment (412-209-7411). Current and accurate records are necessary for best care. We need to see most of you yearly or at least every other year. If you're not sure when you were in last, call to say "hi" and check-in. We always enjoy hearing from our patients.

Stay Safe, Stay Well!



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ADYNOVATE[®]

PK (Pharmacokinetics) Study Data



Talk to your doctor
about the study.



Scan the QR code to learn more
about PK at **UnderstandingPK.com**

REMEMBERING NORMAN ROLAND

Many years ago, when the Foundation used to host an annual Holiday Party at Wildwood Highlands, Norman Roland would volunteer his time to be our Santa Clause. He would give away little presents or candy canes and always enjoyed being with the families.

Norm was a volunteer for the Ohio Twp. Fire Department and was an Air Force and Navy veteran. Around the holidays, he rode around in the fire truck in Ohio Township, dressed as Santa, and would pass out candy to the kids.

"He loved to dance," Lynda, his niece, said. "At every event we'd go to, the whole family would be there and he'd be trying to get people to dance with him. He was just a

friendly person."

Norm passed away in January of this year due to complications from COVID-19. Our hearts go out to Lynda and her family. Thank you to Norm for bringing joy to many of our families.



MEET THE BOARD MEMBER

CHRISTINA MILLER, TREASURER



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

I volunteered at the Walk and Cornhole tournament a few years ago and really enjoyed the experience! I was excited to get more involved and with a background in Finance, I welcomed the opportunity to assist in the budgeting process!

WHAT IS YOUR BACKGROUND OR CURRENT OCCUPATION?

Finance and Risk Management

WHAT IS YOUR FAVORITE PART ABOUT BEING A WPBDF BOARD MEMBER?

I like everything about it, but I especially love that I can make a difference doing what I love the most which is helping to make sure we have a strategic direction for the Chapter's finances.

WHAT DO YOU LIKE TO DO FOR FUN?

Soccer and spending time with my family, especially my husband and two young daughters.



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.

To me, it's personal.

As a Community Relations and Education Manager for Sanofi Genzyme, I'm here to help provide education and resources for you and the hemophilia community.

Carrie Koenig
CoRe Manager for Pennsylvania and West Virginia



Let's connect.

Call, text, video chat: 667-500-4326
Email: carrie.koenig@sanofi.com
Facebook: @HemophiliaCoRes



www.rareblooddisorders.com

SANOFI GENZYME 



Western Pennsylvania Bleeding Disorders Foundation



INDIVIDUALIZED PHYSICAL ACTIVITY IMPROVEMENT



SUPPORT FOR SETTING GOALS AND CHANGING BEHAVIOR



MONTHLY COMMUNITY WELLNESS ACTIVITIES

If you have a bleeding disorder and are questioning whether you should be physically active, the answer is a definite “Yes!” Regular physical activity has great benefits, such as improved cardiovascular fitness and healthy weight. It also can lower the risk of spontaneous joint bleeds, reduce feelings of anxiety and depression, and help you sleep better. The Stay In Motion program was designed with the Hemophilia Center of Western Pennsylvania (HCWP) to provide all members with the education and tools for assessing their current physical condition, talking with their healthcare team, setting goals, and creating a plan for physical activity. In addition, we want to provide access to a variety of physical activities to enable YOU to reap both the mental and physical benefits of exercise!

This program is designed for ALL individuals in the bleeding disorders community regardless of mobility and physical fitness level.



When you register for this program you will receive:

- Checklist with resources to help you get started
- Access to educational videos
- Motivational time marker water bottle and infuser
- Journal to make and track goals
- Support from the HCWP Physical Therapist and Social Worker
- Invitations to participate in physical wellness activities each month
- Weekly educational resources to keep you motivated
- Fun, monthly activity challenges with chances to win prizes
- Community support and a safe space to share tips and get advice

This program is open to:

- individuals diagnosed with a bleeding disorder and living in one of the 26 counties of Western PA or treated at the Hemophilia Center of Western PA; or
- parents living in the same household as an individual with the diagnosed bleeding disorder; or
- friend or family member of the parent or person diagnosed with a bleeding disorder who is enrolled in the program; and
- are at least 13 years old

All individuals affected by a bleeding disorder who enroll in this program are highly encouraged to speak with the treatment center's physical therapist. Those not affected by bleeding disorders are encouraged to consult their primary care physician before participating.

**Submit application form online at wpbdf.org/sim or request printed forms to fill out and mail to
WPBDF 775 Fourth Street, 1st Floor Beaver, PA 15009**



WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

775 4th Street
First Floor
Beaver, PA 15009



**TAKE A
BOUGH**

HOLIDAY TREE AUCTION TO BENEFIT WPBDF

Holiday Tree and Wreath Auction

*Save the
Date*

December 4, 2021

Online Auction:

November 26 - December 4, 2021

More information: WPBDF.ORG



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

