



HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

WINTER 2023



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BOARD OF DIRECTORS

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

MISSION STATEMENT

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

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

DESIGNATE UNITED WAY GIFTS TO THE CHAPTER

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

WPBDF Contributor Agency Code Number is: 83

EVENTS CALENDAR

January 13-15, 2023

Teen Retreat
Promise Camp & Retreat
Center
Clinton, PA

January 24, 2023

Penguins Game Fundraiser
PPG Paints Arena
Pittsburgh, PA

January 29, 2023

Family Cooking Program
Virtual

February 12, 2023

Bowling for Bleeding
Disorders
Paradise Island Bowl
Pittsburgh, PA

February 23, 2023

Mindfulness
Takeda Hello Talk
Virtual

February 28, 2023

Rare Disease Day

March 4-5, 2023

Advocacy Ambassador
Retreat
Bedford Springs Resort
Bedford, PA

March 8-10, 2023

NHF Washington Days
Washington, DC

April 13-16, 2023

HFA Symposium
Orlando, FL

April 17, 2023

World Hemophilia Day

July 16, 2023

WPBDF Annual Meeting
Sheraton Station Square
Pittsburgh, PA

September 9, 2023

Unite for Bleeding Disorders
Walk & Run for Their Lives 5K
North Park Swimming Pool
Allison Park, PA

October 14, 2023

Fall Program
Wexford, PA

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

COMMUNITY ANNOUNCEMENTS

Jaxson Baker was selected to attend CSL Behring's Gettin' In The Game Junior National Championship in Phoenix, Arizona this year! Jaxson represented the Western Pennsylvania Bleeding Disorders Foundation in golf.

He participated in friendly competition and connected with his peers. Educational seminars focusing on the importance of physical fitness and other related topics were provided on site. Congratulations to Jaxson for hitting the longest drive! Way to go "Iron" Jaxson! We are so proud of you!



Submit a community announcement to jessica@wpbdf.org.

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LETTER FROM THE EXECUTIVE DIRECTOR AND BOARD PRESIDENT

Dear Community Members & Friends,

Happy 2023! It always amazes us how fast the year goes by. The new year is a good time to reflect on what we have accomplished and the work that lies ahead.

Over the past year, we have held 52 educational events at no cost to our members. This included an Education Weekend with 2 days of educational programming. Our Unite for Bleeding Disorders Walk was finally back in-person this year! It was a day of celebration and was incredible to see this resilient community UNITE to raise over \$68,000 to support our local programs and services! Our Unite

for Bleeding Disorders Walk also received NHF's 2022 All Star Chapter Award! It was wonderful to see many of you at our Take A Bough Holiday Auction which raised over \$9,000, all of which stays local to support the bleeding disorders community in Western PA. Over the past year, we have provided over \$50,000 in patient assistance to community members in need. We continue to keep our Grocery Assistance Program open which provides an accelerated way for us to assist those in the community struggling with food insecurity. We were also happy to be able to provide a Holiday Gift Program this year to ensure that every child could experience the joy of gifts this holiday season.

We continued to work hard advocating for the community, and received a 6% increase to the hemophilia line item in the state

budget! We are excited to partner with the Eastern Pennsylvania Bleeding Disorders Foundation to take our advocacy to the next level by holding a state-wide Advocacy Ambassadors Retreat this March. We hope you will join us in this endeavor as your participation is what will make a real difference in ensuring patient protection and affordable

healthcare for the entire bleeding disorders community.

We are truly honored to be leading this organization into 2023. We look forward to continuing to serve this community and I hope to see you at one of our many upcoming events!

Wishing you good health and happiness in the coming year and always,

Kara Dornish
Executive Director

Scott Domowicz
Board President



WPBDF'S EDUCATION WEEKEND RETURNS!



Finally! After two postponements, due to COVID-19, we were able to bring back Education Weekend! We were so grateful to be joined by 50 parties from the bleeding disorders community, representatives from 20 sponsoring organizations, plus speakers. All in all, 212 people registered to attend this event! The space quickly filled with smiling faces, excitement, and lots of chatter as the event kicked off and people reconnected. It was wonderful to gather for a weekend of education and camaraderie after waiting 3 ½ years for this event to return.

In addition to programs on different types of bleeding disorders, including VWD, rare bleeding disorders, and hemophilia, this year's programming also offered a focus on emotional wellness throughout the program tracks for both adults and children. Since the pandemic, there has been an increase in the awareness on the importance of mental health, and we recognize that both physical and mental health are critical to overall health.

On Saturday afternoon, we offered optional social events to give participants time to connect and build their peer networks, as well as to give everyone a mental break from the programming. Options included a hike, axe throwing, and wreath & bracelet making.

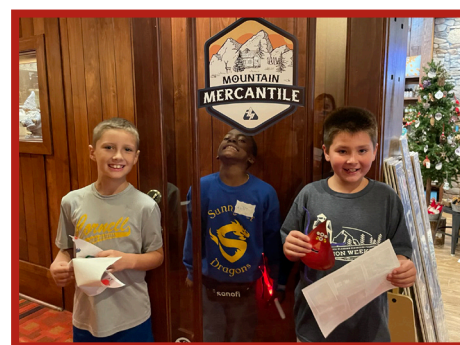
While the grownups were



attending their programs, four children's programs were running concurrently. Age-appropriate programs were offered for children ages 5-12 and for teenagers (see the Teen Group article on page 6 to learn more about their weekend experience). The schedules varied by age group, but all included opportunities for education about bleeding disorders and fun games and activities, such as bowling and

indoor mini-golf.

Sunday morning brought a fresh batch of program topics, plus hands-on infusion training, for which 45 people registered. The infusion training was provided by nurses from the Hemophilia Center of Western PA. The weekend concluded with raffle basket drawings before everyone headed home.



The Education Weekend planning committee is grateful for everyone who participated in this event. We were excited to see many new families, as well as returning families, speakers, and sponsors. We are encouraged by the energy and feedback from this event and are excited to plan the next one—stay tuned!

Thank you to our Education Weekend Planning Committee: Victoria Baker, Janet Barone, Kara Dornish, Jessica Lee, and Kathaleen Schnur

Thank You to Our Education Weekend Sponsors:

Platinum Sponsor: Hemophilia Center of Western Pennsylvania

Gold Sponsors: Novo Nordisk, Sanofi, and Takeda

Silver Sponsors: CSL Behring, Hema Biologics, Octapharma, Pfizer, and Spark Therapeutics

Bronze Sponsors: Accredo, BioMarin, Cottrill's Pharmacy, CSI Pharmacy, CVS Specialty, DrugCo Health, Genentech, Infucare Rx, Medexus, and Wellpha Pharmacy

Special Thanks to: Hemophilia Alliance, Hemophilia Federation of America and National Hemophilia Foundation.

FALL NEW PARENT NETWORK

We were pleased to have had Dr. Frederico Xavier lead a program for parents in the Fall New Parent Network Program, which was held at Seven Springs Mountain Resort, on Friday, November 4. Dr. Xavier has an academic appointment at the University of Pittsburgh



Blood Brotherhood

BLOOD BROTHERHOOD MEET UP AT EDUCATION WEEKEND!

JOHN YUNGHANS, BLOOD BROTHERHOOD GROUP COORDINATOR

Education weekend is an invaluable space for strengthening relationships and discovering new friendships. Fifteen men from across our Chapter's Blood Brotherhood support network came together Saturday night to throw axes, pulverize some targets, develop new skills, and determine which of us had that competitive edge (shout out to

Erek)! After throwing, we gathered at the Bavarian Lounge to enjoy a meal, drinks, and conversation. We discussed ways our community could better support one another, advocate for better treatment in the emergency room setting, and grow our Blood Brotherhood program in our chapter. The night was fulfilling and super fun. I would like to thank WPBDF for sponsoring Axe Throwing and Cottrill's Pharmacy for sponsoring our Bavarian Lounge gathering. If you would like to learn more about Blood Brotherhood, please email info@wpbdf.org. We can't wait to get our next event on the books!



as Associate Professor in the Department of Pediatrics, Division of Pediatric Hematology/Oncology, and also is the Associate Clinical Director at the Hemophilia Center

of Western Pennsylvania. Dr. Xavier talked about bleeding disorders, different types of bleeds, emergency situations, and

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TEEN GROUP

RAINA S. AND ETHAN W.
TEEN GROUP CO-COORDINATORS

Education Weekend brought both opportunities to learn about living with a bleeding disorder and opportunities to connect with other teens from the community and have some fun!

Programming for teens began with a pre-conference program, on Friday, November 4. Raina S., Teen Group Co-Coordinator, shares her experience:

As teens and their families filled the room, temptation rose as to what event they would be a part of for the night. As they finished their dinners, the sound of a ukulele strummed through the air. With the music came a clown, but not just an ordinary clown – a regular looking man walked through the doorway while balancing a feather on his nose and playing at the same time! Michael Garner paraded around the room to introduce himself and explain what he does as a clown. From performing for Cirque Du Soleil, Mr. Garner found his passion in making others laugh. To do so, he brought his work to hospitals to brighten sick children's days. He opened up about his experiences and how we can make a positive impact on others' lives. Mr. Garner explained that everyone has their own personal "Clown Doctor Medical Bag" where we have all the tools to make someone laugh. We can use our own humor, or instruments such as gum wrapper or rubber gloves to make silly jokes.

On Saturday morning, Education Weekend kicked off and the teens had a full day of programming and



activities. On Sunday, the teens attended program sessions with the adults and were able to select from a choice of breakout sessions and hands-on infusion training. Ethan W., Teen Group Co-Coordinator, shares his weekend experience:

Education Weekend was an enjoyable experience. Saturday started off with breakfast, which is always delicious no matter the event! There were a lot of people I knew from Camp Hot-to-Clot and a lot of new faces as well. We got our event schedules and headed off to our programs. I went to a room with teens where we talked about bleeds and how they affect our bodies. The session, called *Anatomy ABCs*, was led by Angela Forsyth, a physical therapist. After, we participated in a team-building activity called Build a Boat, which was led by staff from Seven Springs Mountain Resort. We were split into teams and made boats out of cardboard, duct tape, and trash bags. We had 30 minutes to build our boats then we went to the pool and tested them out! After what seemed like hours in



the pool, we dried off and went back to the room and had lunch. Next, Katherine Bush, a social worker with the Hemophilia Center of Western PA, led a program called *Mental Health for Teens*, which focused on identifying and managing stress. Then, we were reacquainted with Mr. Garner. We were split into groups for a program called Taskmaster. Taskmaster is a game where you are assigned a bunch of random activities and the winner got a special candy, which I'm a little sad I didn't get to try! We concluded the day with bowling.

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ADVOCACY UPDATE



MILLIRON & GOODMAN LEGISLATIVE UPDATE

HARRISBURG OVERVIEW:

On November 30, the 2021-22 legislative session officially ended. Any outstanding bills that did not pass through the legislature and get signed into law by the Governor will have to be reintroduced in the upcoming session.

ELECTIONS:

On November 8, Attorney General Josh Shapiro secured his seat as the next Governor of Pennsylvania with over 56% of the vote; Senator Doug Mastriano (R-Franklin) trailed behind at about 43%. Shapiro's inauguration is scheduled for January 17, 2023.

In addition to the gubernatorial race, all House district seats were up for election as well as half of the Senate districts (even numbered districts). Prior to election day, Republicans held a safe majority in both the House (113-89) and Senate (29-21). However, for the first time in over a decade, Democrats secured a majority of seats (102) in the House. Republicans lost 12 seats, bringing them down to 101 seats.

It's important to note that three seats will be vacant when the new session begins:

- Representative Tony DeLuca (D-Allegheny) *Passed away on October 9, 2022.*
- Representative Summer Lee (D-Allegheny) *Elected to Congress.*
- Representative Austin Davis

(D-Allegheny) *Elected as the next Lieutenant Governor.*

These three vacancies would bring Democrats back down to 99 seats and bring Republicans temporarily back in the majority with 101 seats. However, it is anticipated that these three seats will be filled by Democrats in a special election in the spring. The House Majority would then likely go back to the Democrats.

Republicans will continue to hold the majority in the Senate (28-22). They recently announced their 2023-24 leadership team:

- Senator Kim Ward (Westmoreland) - President Pro Tempore
- Senator Joe Pittman (Indiana) - Majority Leader
- Senator Ryan Aument (Lancaster) - Majority Whip
- Senator Scott Martin (Lancaster) - Majority Appropriations Chair
- Senator Kristin Phillips-Hill (York) - Majority Caucus Chair
- Senator Camera Bartolotta (Washington) - Majority Caucus Secretary

On the Democratic side, the leadership team is comprised of the following members:

- Senator Jay Costa (Allegheny) - Minority Leader
- Senator Tina Tartaglione (Philadelphia) - Minority Caucus Whip
- Senator Vincent Hughes (Philadelphia) - Minority Appropriations Chair

- Wayne D. Fontana (Allegheny) - Minority Caucus Chair
- Maria Collett (Montgomery) - Minority Caucus Secretary

We anticipate a great deal of leadership changes at the Departments of Health and Insurance as well as legislative committee chairmanships, rank-and-file membership, and personnel.

We'll make introductions (either virtually or in-person) with the appropriate government officials, legislators and staff and ensure that they are familiar with the hemophilia community and any legislative concerns.

One of our many roles as your lobbyist is to ensure that you continue to have an active voice in the Capitol and relevant state agencies. This becomes even more critical during transition times!

LEGISLATION:

Prior Authorization:

- SB 225 (Phillips-Hill, R-York): Amends Article 21 of the Insurance Company law to provide for prior authorization. Prior authorization is the process that health insurers, Children's Health Insurance Program (CHIP) managed care plans, and Medical Assistance (MA) managed care plans use to grant pre-approval for certain health care services as a condition of payment.
- Senate Bill 225 would make an electronic portal with all pre-authorizations and the

... CONTINUED ON PAGE 8

accompanying paperwork flow into one site. Standardizing the paperwork and expectations will make a more transparent process.

- If insurers question the validity or necessity of the test or treatment, Senate Bill 225 calls for a peer review by a doctor from the specialty in question, not just any physician.
- STATUS: Passed the House and Senate with unanimous support and was signed into law as Act 146 of 2022.
- The foundation authored a letter of support, which was circulated to House and Senate leadership.
- Many different stakeholders were involved in the negotiation process, including PA Medical Society, Department of

Insurance, among others. Congratulations to all!

BUDGET:

We were able to secure a 6% increase in the hemophilia line item in the 2022-23 budget bill (SB 1100). In addition, we were able to insert language in the fiscal code (HB 1421) to maintain the current funding distribution.

General Appropriations Language (SB 1100, Page 265)

Section 221. Department of Health
FOR HEMOPHILIA SERVICES
STATE APPROPRIATION.....
1,017,000

Fiscal Code Language (HB 1421, Page 120)

Section 1726- F.1. Department of Health

7) MONEY APPROPRIATED FOR HEMOPHILIA SERVICES SHALL BE DISTRIBUTED TO GRANTEEES IN THE SAME PROPORTION AS DISTRIBUTED IN FISCAL YEAR 2019-2020

Over the next few months, we're going to start our advocacy for the 2023-24 hemophilia line item. We'll advocate with Senate Appropriations Chairmen Martin and Hughes as well as the new House Appropriations Chairs (once they are announced). We'll also request letters of support again from the Senators and Representatives who directly represent the hemophilia treatment centers.

ADVOCACY STAKEHOLDER RETREAT

On Tuesday, November 22, the Western and Eastern Pennsylvania Bleeding Disorders Foundations held their annual Advocacy Stakeholder Meeting. Kara Dornish, Executive Director, WPBDF, and Sarah Pilacik, Executive Director, EPBDF, gave Foundation updates, Miriam Goldstein of the Hemophilia Federation of America and Matt Delaney of the National Hemophilia Foundation presented on federal issues, and Kerry Lange of Milliron and Goodman informed the group of state issues. We were joined by representatives from multiple Pennsylvania Hemophilia Treatment Centers and Foundation Advocacy Ambassadors. We are



looking forward to building our Advocacy Ambassador Program and continuing the strong partnership with the Eastern



PA Chapter. The Western and Eastern PA Chapters will be joining forces to hold a state-wide Advocacy Ambassador Retreat at the Omni Bedford Springs Resort March

4-5, 2023. Learn more about the Advocacy Ambassador Retreat on page 9!

ADVOCACY AMBASSADOR RETREAT



Saturday, March 4 - Sunday, March 5

**Omni Bedford Springs Resort
2138 Business, 220
Bedford, PA 15522**

We are looking for individuals who are interested in supporting the advocacy efforts of the Pennsylvania Bleeding Disorders Foundations throughout the year. Do you have a desire to meet with legislators to help influence decisions on policies that affect individuals and families living with bleeding disorders? Are you willing to make phone calls or write letters to your legislators asking them to support legislation that could have a positive impact on the bleeding disorders community and vote against legislation that could have a negative impact? If you've answered yes to any of the above questions, we would like you to join us at the Omni Bedford Springs Resort to receive training to become a Volunteer Advocacy Ambassador!

This is an overnight retreat open to adults and mature teenagers. The retreat begins at 11 am on Saturday, March 4th and ends after breakfast on Sunday, March 5th. The Foundations will provide all meals and hotel room for Saturday night. Transportation assistance is available upon request. To register go to: <https://forms.gle/PVR2N7RZ9nH3aVxE6>

If you have any questions call 724-741-6160 or send an email to info@wpbdf.org.



Scan this QR Code with your phone to register!

LEARN ABOUT:

Current issues that impact the bleeding disorders community

Effectively talking with legislators

How to tell your story

Perfecting your elevator speech

Phone calls & letter writing

Jivi[®], now with up to **7 YEARS OF DATA.**

Talk to your doctor about the study.



Scan this QR code to learn
more about the data at
JiviExtensionStudy.com

ERIE FALL PROGRAM

On Saturday, October 8, community members came together at the Erie Bayfront Convention Center for our Fall Program. We were thrilled to have Debra Shijo, PT, MPT present on Adapting Physical Activities for Joint Health. Debbie is a staff therapist at Akron's Children's Hospital where she has been employed for 21 years. She discussed the importance of physical activity and introduced ways to adapt activities to everyone's physical condition. She demonstrated how you don't need expensive exercise equipment to stay physically active. Participants demonstrated how to use common household items such as canned goods and water jugs to exercise. Everyone was invited to get up and run through an exercise circuit which could be adapted to each individual's physical condition. After the program, we enjoyed lunch and thanks to the Colburn



Keenan Foundation, families were invited to enjoy the rest of the day having fun and staying active at Splash Lagoon.

This interactive and informative program was offered as part of our Stay In Motion program. Stay In Motion encourages our bleeding disorders community to get up and get active in an easy and accessible way. All members are invited and encouraged to participate. For more information, visit wpbdf.org/sim.

Special thanks to all our sponsors:



CK Colburn Keenan Foundation, Inc.

STAY IN MOTION STORIES

JEANNE



Jeanne joined the Stay In Motion (SIM) program in April 2022, when she received an email about it from WPBDF. When she first got out of college, Jeanne knew she wasn't walking nearly as much as she used to. She made it a point to keep walking and stay moving as she got older.

"People make excuses as to why they don't keep up with [staying active], but Stay In Motion was very encouraging by the very title," Jeanne says. "Having a group during the pandemic and having WPBDF send out tasks every month helps keep you focused on making good choices."

Her favorite SIM events have been the virtual cooking programs

and the monthly Goosechase challenges. Jeanne won a gift card from one of the monthly challenges and could buy herself a new pair of sneakers to continue walking! She also loves that the information this program provides is specific to the bleeding disorders community.

All in all, Jeanne says she hasn't lost any weight since joining the program but is so happy that it's helped her stop gaining weight!

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

COPAY ACCUMULATORS

Whether insurers refer to these programs as Copay Accumulators, Out-of-Pocket Protection Programs, or True Accumulation, the bottom line is that these insurer-mandated forms of utilization management present a serious hurdle for patients looking to access crucial medication through their marketplace insurance. Insurers use copay accumulators to accept third-party copay assistance for a patient's medication without counting these payments towards a patient's cost-sharing obligations, lulling patients into a false sense of security before hitting them with bills running into the thousands of dollars for essential medications that patients often cannot afford alone. Even though patients with chronic illnesses can experience worsened symptoms, permanent complications, and even hospitalizations without uninterrupted access to their medication, these copay accumulators have only become more common in marketplace health plans over the last few years.

Senator Judy Ward will be reintroducing legislation to ensure that all copays count in Pennsylvania. We will be working diligently to educate members of the Pennsylvania state legislature about copay accumulators and ask them to support reform in the coming session.

HOW TO IDENTIFY COPAY ACCUMULATORS

1. Open the Summary of Benefits page for your insurance and

How to Identify Copay Accumulators



1

Open the Summary of Benefits page for your insurance and review the explanation for your deductible and out-of-pocket maximum.



2

Search the insurance plan's "Schedule of Benefits" for keywords: coupon, copay card, manufacturer coupons, and/or discount prescription card program.



3

Review the Pharmacy Limitations and Exclusions section for any of the above keywords.



4

Call the insurance company directly and ask them about their copay assistance policy.



While not all insurances are implementing copay accumulator programs, many insurance plans include language that allows them to implement these programs at any time. Please look out for these programs before enrolling in an insurance plan. If you experience your insurance policy not allowing copay assistance to be counted toward your deductible or out of pocket maximum, please contact us at 724-741-6160 or email info@wpbdf.org.

SB 196 AND HB 1664 HISTORY

SB 196 INTRODUCED IN PA SENATE IN 2021

Introduced on February 10, 2021, with a bipartisan group of 13 sponsors.

REFERRED TO COMMITTEE

SB 196 was immediately referred to the Senate Banking and Insurance Committee.

HB 1664 INTRODUCED IN THE SENATE IN 2021

Complementary legislation was introduced in the House on June 12, 2021, with a bipartisan group of 17 sponsors.

REFERRED TO THE SENATE

HB 1664 was immediately referred to the House Insurance Committee.

16 STATES HAVE ALREADY PASSED COPAY ACCUMULATOR REFORM. PA CAN TOO!

1. review the explanation for your deductible and out-of-pocket maximum.
2. Search the insurance plan's "Schedule of Benefits" for keywords: coupon, copay card, manufacturer coupons, and/or discount prescription card program.
3. Review the Pharmacy

Limitations and Exclusions section for any of the above keywords.

4. Call the insurance company directly and ask them about their copay assistance policy.

Language may include:
"The following amounts may not be used to satisfy the Benefit Period

SIGN UP TO RECEIVE ACTION ALERTS!

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 take action and easily contact your legislators on important legislation impacting the bleeding disorders community.



SCAN ME!



HEALTH INSURANCE ROADMAP

On Wednesday, November 30, Jan Martin, Community Education Specialist with Takeda, led a virtual program with us on health insurance. The program included an overview of insurance options, transitions that impact coverage, and insurance denials of coverage. One of the main resources Jan mentioned throughout the program was NHF's Healthcare Toolkit. You can access it here: <https://www.hemophilia.org/bleeding-disorders-a-z/healthcare-coverage/personal-health-insurance-toolkit>.

Jan stated throughout the program how important it is to document everything especially when you are dealing with insurance denials of coverage. Be sure to note the date you are calling and get the name of the person you are speaking to. Don't hesitate to reach out to WPBDF or the HCWP with any questions or concerns.



Deductible:

Discounts, coupons, or other amounts from third parties, including manufacturer coupons and discount prescription card program.

We reserve the right not to apply manufacturer or provider cost share assistance program payments (e.g., manufacturer cost share assistance, manufacturer discount plans, and/or manufacturer coupons) to the Deductible or Out-of-Pocket maximums.

Please note, Cost Sharing reduction for any prescription drugs obtained by you through the use of a discount card or coupon provided by a prescription drug manufacturer will not apply toward any Deductible or the Annual Out-of-Pocket Maximum under your Plan."

While not all insurances are implementing copay accumulator programs, many insurance plans include language that allows them to implement these programs at any time. Please look out for these programs before enrolling in an insurance plan. If you experience your insurance not allowing copay assistance to be counted toward your deductible or out of pocket maximum, please contact us at 724-741-6160 or info@wpbdf.org.

Q: Doesn't copay assistance push patients towards high-cost drugs when generic alternatives are available?

A: 99.6% of copay assistance is used on drugs that do not have generic alternatives. Insurers say that copay accumulators push patients off high-cost drugs and onto cheaper alternatives, but in most cases these cheaper alternatives do not exist.



WE'RE IN THIS TOGETHER.

Friday 6:26 pm

Sharing stories by the campfire with friends

Isaac, living with hemophilia B

Not an actual patient

Let's make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world is stronger than ever.

 bleedingdisorders.com | 

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TAKE A BOUGH RETURNS IN-PERSON!

The 10th annual Take A Bough was held on Saturday, November 19, at Gaetano's Banquet Center on Banksville Road. This year marked the return of this beloved event after being held virtually for two years.

Thanks to the support from our sponsors, donors, and patrons, we raised nearly \$10,000! We are extremely grateful for everyone who participated in Take A Bough this year, as this fundraiser would not have been successful without them.

This year's auction opened online on November 14, one week prior to the live event. The night featured a wine tasting from Deer Creek Winery of South Hills Village. Bryan P. Keenan & Associates sponsored additional wine samples at the bar. Thank you to both Irania of Deer Creek Winery and Bryan P. Keenan for supporting this event!



Planning and preparation for this event began months before November 19. Members of the Western PA bleeding disorders community joined us for a wreath making class during WPBDF's Education Weekend and hand-made and decorated many of the wreaths featured in the auction. Many supporters and community members also dropped by the Foundation office to donate centerpieces, additional wreaths, trees, and raffle baskets. Our co-chairs, Mindy Perry-Stern and Maria Steele Voms Stein, helped



contact wineries and gather donations and other decorations for the event. In total, we had 12 trees, 37 wreaths, six centerpieces, and four extra auction items!

At the event, there were 12 raffle baskets donated by community members and a 50/50 raffle ran by Michael Perry. Maria Steele-Voms Stein was the winner of the 50/50 raffle and donated her winnings back to the Foundation!

Maria also ran a reverse raffle using small blood drop ornaments made by our young community members at Education Weekend. Tickets for the Reverse Raffle were sold for \$5 each and participants had the chance to win \$250! Jeff L. was the last number standing at the end of the night and donated a portion of his winnings back to the Foundation! Her raffle raised \$350!

The auction ended online and in-person at 9 PM. Participants were able to take their winnings home that night, while online participants could pick them up at the

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CAMP HOT-TO-CLOT UPDATE



Dear Camp Families, Staff, and Volunteers,

We are moving forward on planning camp for summer 2023. At this time, our tentative dates are July 30 – August 4, at YMCA Camp Kon-O-Kwee. Please note that camp begins on a Sunday and ends on a Friday.

As we have shared with you before, there are a few reasons that camp may need to look different next summer in order for us to have camp at all. Kon-O-Kwee continues to have significant staffing challenges; and in order to have the best chance of securing the counselors we need; the safest option is for us to combine Camp Hot-to-Clot with one of Camp Kon-O-Kwee's regular camp sessions. These sessions have the highest staff numbers and most reliable staff engagement.

This means that your campers will be sharing the campus with other youth who are not there for Camp

Hot-to-Clot, and they will be doing some of their activities with these other campers as well. However, we have been having extensive discussions with Kon-O-Kwee to ensure that we are able to have our campers together in cabins, to have some activities with just our campers, and to maintain the safety standards we need. We hope to achieve a "camp within a camp" – meaning that while we will still engage with the larger group, we will also maintain our own identity.

Following this strategy will mean changes to how you register for camp – you will register through the YMCA, and we will provide further information on this. You will also register earlier than usual. Counselors will also apply directly through the YMCA (as they have in previous years). If you are interested in being a counselor, please let us know, as the more counselors we have the more we are ensuring that we will have camp.

Another change is that we will likely have to place a limit on our number of campers, so that Kon-O-Kwee is able to effectively plan for the summer. We do not yet have concrete information on this, but we'll be using our camper numbers from past years as well as our current patient data to make these decisions. This means that when

registration for Camp Hot-to-Clot opens, it will be important to enroll your campers as soon as possible to help ensure their spots.

We know that change can be uncomfortable and difficult (even for us), but we are doing our best to ensure that camp will continue. We want to provide your campers with an experience that is both safe and educational in a setting where they can build community and develop their strengths.

We know that this letter contains a lot of information and may leave you with a lot of questions. We will share further information as it becomes available and hope to also plan a virtual meeting in January to provide information & answer questions as we move through the planning process. In the meantime, please feel free to reach out.

Kathaleen Schnur
Camp Co-Director

Katherine Bush Camp
Co-Director

Janet Barone
Camp Activities Coordinator

SPLATTER ME CRAZY!

Camp Hot-to-Clot photographer, Dominique Murray, hosted her annual fundraiser, Splatter Me Crazy, on Sunday, October 2 at the Art Room in the Strip District. The event featured music, a photo booth, raffles, kids activities, and the opportunity to throw paint at

canvases and volunteers! The cost was \$1 to throw and they raised a total of \$1,500!

The proceeds supported Magee's Women's Hospital & Research Institute, The Magic Yarn Project, and The Western PA Bleeding Disorder Foundation.

Thank you so much to Dominique for hosting this event to support WPBDF!



TEEN GROUP

CONTINUED FROM PAGE 6...

On the final day we had breakfast with everyone and then I split off from my friends and attended programs with my mother. We dropped my little brother off in one of the children's programs and my mother and I went to Tai-Chi with Rick Starks. Mr. Starks taught us some basic tai-chi moves and taught us how to breathe during the process. Then we attended *Let's Talk: Real Talk, Real Solutions*, a mental health program led by Debbie da la Riva, LPC, where three panelists shared their experiences with us. Mrs. de la Riva asked the panelists questions about how bleeding disorders have affected their lives and how they overcame their struggles. Lastly, we learned about self-advocacy with Rachel Cooper-Leal who led the program, *Adversity, Strength, and Resilience*.



We learned about advocating for ourselves and how to talk with our doctors. Then we went to the ballroom where the event wrapped up with raffle basket drawings. My mother won the first place Goose Chase prize, plus another basket! I said my goodbyes and then we headed home.



GETTING TO KNOW HCWP STAFF



RICHARD (RICK) YOST
NURSE

Birthplace: Pittsburgh, PA

First job: Landscaping

Accomplishment you're proudest of: Raising my son RJ

What three words describe you best? Dependable, Compassionate, and Fun

Dream vacation: Fiji

Person you'd most like to have dinner with: Kris Letang

Movie you could see anytime: Snatch

TV show you try not to miss: Impractical Jokers

Three things that can always be found in your refrigerator: Lunch meat/cheese, Ice Cream, Mustard

Secret vice: Fishing/Camping

Who would play you in the movies?
Sal Vulcano

Your pet peeve about Pittsburgh:
Potholes

People may be surprised to know that: The first time I played the PA lottery I won \$45 on a 50 cent ticket



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rebinyn.com

Lorie Kerstetter

Patient advocate

About Lorie

Lorie is a Novo Nordisk Hemophilia Community Liaison whose passion for helping people with disorders began years ago when her son was born with severe hemophilia A. She wants to advocate for families in the hemophilia community and is excited to educate them about Novo Nordisk products.

Connect with Lorie

LOKS@novonordisk.com
(717)-368-2851

Hemophilia Community Liaison

NORTHERN APPALACHIA
(WV, Western NY, PA)



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WINTERFEST

Time flew by as we wrapped up the final event for 2022, on December 10, with WPBDF's Winter Program! We gathered in the National Aviary's beautiful Garden Room to learn more about the Foundation's peer support groups and patient assistance programs, play games, make crafts, and enjoy a buffet lunch together. We also enjoyed a visit and photo opportunity with a parrot! After the program, everyone was welcome to enjoy the rest of the afternoon touring the National Aviary.

During the event, Kara Dornish shared highlights of the Foundation's accomplishments in 2022 and gave an update on important advocacy issues. Jessica Lee informed everyone of fundraisers that are currently open for registration. Janet Barone introduced volunteers who shared information on support groups and patient assistance programs:

Blood Brotherhood – Scott Domowicz
WPBDF Winning Women – Janet Barone, on behalf of Maria Steele Voms Stein
Young Adult Group – Victoria (Tori) Baker
Teen Group – Raina Slater
New Parent Network – Kathaleen Schnur, LCSW
Patient Assistance Programs and update on Camp Hot-to-Clot – Katherine Bush, LCSW

Each support group sponsored a table with a game or craft and provided additional information about the group and/or relevant literature. Games included Grinch ring toss, snowman bean bag toss, snowman bowling; and crafts included making a picture frame



and making a snowman ruler to measure snow!

The event also included exhibit displays and we thank the following organizations for supporting this event:

BIOMARIN **CSL Behring**

BIOMATRIX

THE HEMOPHILIA CENTER
of Western Pennsylvania

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MY DECIDING FACTOR:

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vonvendi
[von Willebrand factor
(Recombinant)]

Erica

VONVENDI Use: On-Demand & Surgery

- VONVENDI® is the **first and only treatment approved for routine use (prophylaxis)** in adults with severe Type 3 VWD who previously received on-demand therapy
- VONVENDI is **also approved for on-demand and surgical bleed management** in adults with all types of VWD
- VONVENDI **replaces VWF** (the main issue behind VWD), and **may be used with or without recombinant factor VIII** as instructed by your healthcare provider



Are you ready to ask about VONVENDI for your VWD? Visit VONVENDI.com to learn more, and talk to your healthcare provider.

VWD=von Willebrand disease; VWF=von Willebrand factor.

VONVENDI [von Willebrand factor (Recombinant)] Important Information

What is VONVENDI?

VONVENDI is used in adults (age 18 years and older) diagnosed with von Willebrand disease to:

- treat and control bleeding episodes
- prevent excessive bleeding during and after surgery
- reduce the number of bleeding episodes when used regularly (prophylaxis) in adults with severe Type 3 von Willebrand disease receiving on-demand therapy

Detailed Important Risk Information

Who should not use VONVENDI?

You should not use VONVENDI if you:

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

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

How should I use VONVENDI?

Your first dose of VONVENDI for each bleeding episode may be administered with a recombinant factor VIII as instructed by your healthcare provider.

Your healthcare provider will instruct you whether additional doses of VONVENDI with or without recombinant factor VIII are needed.

What should I tell my healthcare provider before I use VONVENDI?

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 VONVENDI passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if VONVENDI can harm your unborn baby.
- Have been told that you have inhibitors to von Willebrand factor (because VONVENDI may not work for you).
- Have been told that you have inhibitors to blood coagulation factor VIII.

What else should I know about VONVENDI and von Willebrand Disease?

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

What are the possible side effects of VONVENDI?

You can have an allergic reaction to VONVENDI.

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 VONVENDI include: headache, nausea, vomiting, tingling or burning at infusion site, chest discomfort, dizziness, joint pain, joint injury, increased liver enzyme level in blood, hot flashes, itching, high blood pressure, muscle twitching, unusual taste, blood clots and increased heart rate.

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

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 the VONVENDI Consumer Brief Summary on the following page and talk to your healthcare provider.



Important facts about VONVENDI® [von Willebrand factor (Recombinant)]

This leaflet summarizes important information about VONVENDI. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider.



What is VONVENDI?

VONVENDI is a recombinant medicine used to replace low levels or not properly working von Willebrand factor in people with von Willebrand disease. Von Willebrand disease is an inherited bleeding disorder in which blood does not clot normally.

VONVENDI is used in adults (age 18 years and older) diagnosed with von Willebrand disease to:

- Treat and control bleeding episodes
- Prevent excessive bleeding during and after surgery
- Reduce the number of bleeding episodes when used regularly (prophylaxis) in adults with severe Type 3 von Willebrand disease receiving on-demand therapy.

Who should not use VONVENDI?

You should not use VONVENDI if you:

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

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

What should I tell my doctor before I use VONVENDI?

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 VONVENDI passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if VONVENDI can harm your unborn baby.
- Have been told that you have inhibitors to von Willebrand factor (because VONVENDI may not work for you).
- Have been told that you have inhibitors to blood coagulation factor VIII.

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

VONVENDI can cause blood clots particularly in patients with known risk factors for blood clots. Discuss this risk with your healthcare provider.

You can have allergic reactions to VONVENDI. Symptoms may include generalized itching; rash or hives; rapid swelling of the skin or mucous membranes; chest pain or tightness; tightness of the throat; low blood pressure; shock; drowsiness; nausea; vomiting; tingling, prickling, burning, or numbness of the skin; restlessness; wheezing and/or difficulty breathing; lightheadedness; dizziness; or fainting. If symptoms occur, stop using VONVENDI immediately and get emergency treatment right away.

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

What are the possible side effects of VONVENDI?

Side effects that have been reported with VONVENDI include: headache, nausea, vomiting, tingling or burning at infusion site, chest discomfort, dizziness, joint pain, joint injury, increased liver enzyme level in blood, hot flashes, itching, high blood pressure, muscle twitching, unusual taste, blood clots and increased heart rate. These are not all the possible side effects with VONVENDI. You can ask your healthcare provider for information that is written for healthcare professionals.

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

What else should I know about VONVENDI and von Willebrand Disease?

Consult with your healthcare provider to make sure you are carefully monitored with blood tests to measure levels of von Willebrand factor and factor VIII so they are right for you.

You may infuse VONVENDI at a hemophilia treatment center (HTC), at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or HTC. Many people with von Willebrand disease learn to infuse VONVENDI by themselves or with the help of a family member.

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

Medicines are sometimes prescribed for purposes other than those listed here. Do not use VONVENDI for a condition for which it is not prescribed. Do not share VONVENDI 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 healthcare provider or pharmacist about Vonvendi. The FDA approved product labeling can be found at https://www.shirecontent.com/PI/PDFs/VONVENDI_USA_ENG.pdf or call 1-877-TAKEDA-7 (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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US-VON-0657v1.0 04/22



FALL NEW PARENT NETWORK

CONTINUED FROM PAGE 6...

emergency room visits.

Dr. Xavier proceeded to lead a casual discussion which allowed opportunity for parents to ask questions and share experiences in a group conversation.

New Parent Network events and the Parent Mentor program are open to families who have a child with a bleeding diagnosis, newborn – age 7. If you have a child with a bleeding disorder in this age range and would like to be connected with a mentor parent, please reach out to either Kathaleen Schnur (kschnur@vitalant.org / 412-209-7267) or Janet Barone (janet@wpbdf.org / 724-741-6160).

We are grateful to the following organizations for sponsoring the 2022 New Parent Network series of events:

CSL Behring **Genentech**
A Member of the Roche Group

Optum **sanofi**

Takeda **THE HEMOPHILIA CENTER**
of Western Pennsylvania



TAKE A BOUGH RETURNS IN-PERSON!

CONTINUED FROM PAGE 15...

Foundation office starting Monday November 21.

The Western Pennsylvania Bleeding Disorders Foundation would like to thank Mindy and Maria for co-chairing the event, our amazing sponsors and wineries, and the many volunteers who decorated in the office, transported items to Gaetano's, set up the venue, and helped during the event. Successful fundraisers like Take A Bough allow the Foundation to provide education, support groups, and patient and grocery assistance to our members in need – all at no cost to them.

Thank you to our sponsors:

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referral or scan the QR code. Thank you!**

HCWP CORNER

KATHERINE BUSH, LCSW

Hello to all WPBDF Members and Your Families,

We are definitely starting to feel the chill in the air as winter comes again! We hope that 2022 has been a good year for you, and we are so glad that things started to feel a bit more normal-ish this year. We were so excited to see people at some in-person events with WPBDF and we were also thrilled to be able to resume our outreach clinics with our Amish community. We also are planning a very hopeful return to our summer camp - please see the letter regarding camp for more information on page 16.

Please remember, if you travel for the holidays (or any other time), to contact us for a travel letter and to make sure you have plenty of factor on hand (don't forget – you can leave a message after hours or order factor online)! Also, if it has

been outside of our recommended time-frame for your appointment, please get an appointment scheduled so that we are safely and accurately able to meet your needs. We have two adult providers you can see (Dr. Machin and Dr. Seaman) in addition to two pediatricians (Dr. Xavier and Dr. Ritchey). No one wants an emergency, but we do want to be ready if there is one. Keeping up with appointments allows us to be ready to meet your needs. Although in-person appointments do generally give us the best information, you do still have the option of a virtual appointment if it is determined to be appropriate to your needs. We do ask that you come in for a live clinic at least occasionally, however, as this is the best way to get a truly accurate assessment of your health.

We do know that the holidays, and winter in general, can be a financially hard time for many; and recent world situations haven't made it any easier.

Please remember that we are glad to speak with you about any assistance or resources we can provide, and that the bleeding disorder community is truly a generous community that wants to make sure everyone who is a part of it receives what they need. Please reach out to us if things are tough. We cannot stress enough how very thankful we are to have real, concrete, readily available support for our patients.

And as always, please continue to reach out to us with any questions or concerns that you may have about your care or barriers that may keep you from receiving care. Please let us know what would make us better and what has been going well with your care. The more we know, the better we can be.

Sending our best wishes for a healthy and happy year to all of you,

The HCWP Staff

As we usher out 2022 and welcome 2023, we are filled with a spirit of hopeful optimism and peace for the new year and for all of us.

From all of us at the HCWP – we are looking forward to serving you in 2023. We thank you for trusting us to be a part of your care, and wish the best for you and yours in the coming year!



WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

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Sunday, February 12, 2023
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\$25 per person. Includes 3 hours of bowling, shoe rental, pizza, and unlimited soft drinks! A portion of proceeds raised at this event will provide education, support groups, and patient assistance to the bleeding disorders community of Western PA!

GET TICKETS AT: [GIVE.CLASSY.ORG/BOWLINGFORBLEEDINGDISORDERS](https://give.classy.org/bowlingforbleedingdisorders)



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

