



WPBDF CELEBRATED HALLOWEEN THIS YEAR BY HOSTING A HALLOWEEN COSTUME CONTEST! YOU CAN CHECK OUT MORE ADORABLE PHOTOS ON PAGE 14!



ADVOCACY UPDATE

PAGE 5

TAKE A BOUGH RECAP

PAGE 7

GOT STRESS?

PAGE 16

WINTER PROGRAM

PAGE 19



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.

WPBDF Contributor Agency Code Number is: 83

EVENTS CALENDAR

January 8, 2022

Cooking with Chef Mike
Virtual Event

January 16, 2022

Teen Group
Virtual Program

January 20, 2022

Anatomy Workshop
Virtual Program

January 23, 2022

Teen Group
Virtual Event

January 27, 2022

Women's Group
Virtual Program

February 3, 2022

Gene Therapy Jeopardy
Virtual Program

February 10, 2022

Got Stress Workshop 1:
Strategies for Anxiety
and Worry
Virtual Program

February 17, 2022

Got Stress Workshop 2:
Strategies for Anxiety and Worry
Virtual Program

February 24, 2022

Got Stress Workshop 3:
Strategies for Anxiety and Worry
Virtual Program

March 1-2, 2022

Virtual NHF Washington Days

March 10, 2022

Drag Queen Bingo
Virtual Fundraiser

March 27, 2022

New Parent Network
Virtual Program

March 13, 2022

Cooking for Nutrition
Virtual Program

April 20-23, 2022

HFA Symposium
San Antonio, TX

June 12, 2022

Axe Out Bleeding Disorders
Fundraiser
Cranberry Twp, PA

July 21, 2022

Annual Meeting and Walk Kick-Off
Dave & Busters Waterfront
Homestead, PA

August 25-27, 2022

NHF Bleeding Disorders
Conference
Houston, TX

September 10, 2022

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

October 8, 2022

Fall Program
Erie, PA

November 4-6, 2022

Family Education Weekend
Seven Springs Mountain Resort
Champion, PA

VISIT [WPBDF.ORG](https://wpbdf.org) FOR MORE INFORMATION ON OUR UPCOMING EVENTS.

COMMUNITY ANNOUNCEMENTS

Would you like to submit a community announcement for our next issue? Please e-mail jessica@wpbdf.org.

Unite

for Bleeding Disorders

REGISTRATION FOR THE 2022 UNITE FOR BLEEDING DISORDERS WALK IS NOW OPEN! REGISTER YOURSELF OR YOUR TEAM TODAY AND HELP RAISE AWARENESS AND FUNDS FOR THE BLEEDING DISORDERS COMMUNITY!

Join us at beautiful North Park on Saturday, September 10, 2022 for a day of celebration for the bleeding disorders community.

Register today at: <https://uniteforbleedingdisorders.org/event/wpa>



CONTACT US

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

www.wpbdf.org
info@wpbdf.org

@WPBDF

@WPBDF

@WPABDF

LETTER FROM THE EXECUTIVE DIRECTOR AND BOARD PRESIDENT

Dear Community Members & Friends,

What a year it has been! We would have never imagined we would still be navigating through this health crisis, but we are so thankful for our community and our ability to adapt and make the best of these challenging times. To keep everyone safe, we are planning to keep things virtual the first quarter of 2022. We have many great educational programs and fun virtual activities planned. We hope you will join us and stay connected to the community.



So far, this fiscal year we have provided nearly \$26,000 to over 160 families in the community through our patient assistance fund. If you are experiencing hardship we are here to help. We realize times are tough and hardship can strike at any time. We will be continuing to offer a Grocery Assistance Program to anyone in the bleeding disorders community who is struggling with a financial hardship. This fund will provide gift cards for groceries, \$100 per family member, up to \$400 per family. You can apply for this assistance online at wpbdf.org/programs/patient-assistance or by calling us at the Chapter office 724-741-6160.

We are also very excited about the successful launch of our Stay In Motion program! This program is 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. As we go into 2022, this is a great program to help assist you in reaching your health goals. You can register for this program online



by going to wpbdf.org/sim or by calling us at the Chapter office at 724-741-6160.

We also want to hear from you! 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. If you have not yet completed our Needs Assessment, please do so here: <https://www.surveymonkey.com/r/B9VPBMY>. We will be leaving this open to get as much feedback from the community as possible.

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

Kara Dornish
Executive Director

R. Scott Domowicz
Board President

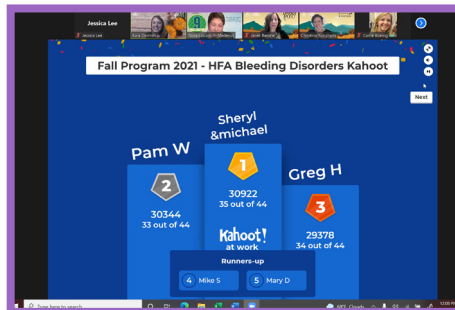
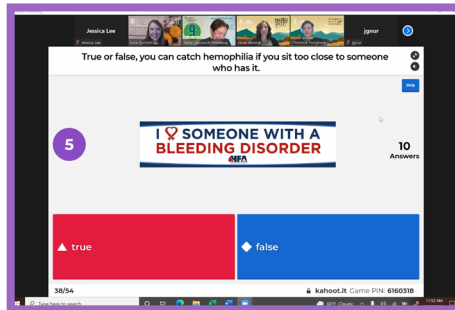
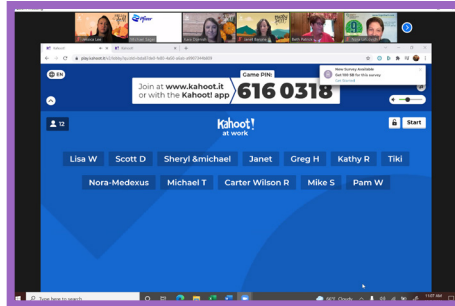
FALL PROGRAM

We enjoyed seeing everyone virtually for our Fall Program, which was held on October 9. We gathered for an educational and fun game of Bleeding Disorders Trivia, sponsored by the Hemophilia Federation of America, and hosted by one of our top volunteers, Christina Yunghans! Congratulations to the trivia winners: 1st Place: Sheryl & Michael, 2nd Place: Pam W, and 3rd Place: Greg H. Throughout the trivia game, our sponsors gave informative presentations on their companies, products, and/or services. We thank the following industry sponsors for presenting and supporting this event:



The learning and fun didn't stop there! Participants received a kit at home with ingredients and instructions for making ice cream "blood sundaes!" We thank the Colburn-Keenan Foundation for sponsoring the fun and educational ice cream sundae activity.

CK Colburn Keenan Foundation, Inc



BEING PREPARED FOR AN EMERGENCY

Do you think you're ready at a moment's notice for an emergency trip to the ER? Is your go-bag packed? Is your go-bag with you? Are you or your loved one with a bleeding disorder wearing a medical ID with important information such as the diagnosis and the on-call phone number for your hematologist? Are you in regular communication with your hematology team and informing them of upcoming procedures and surgeries, so they can create a plan with you for potential treatment pre and/or post procedure? These were just some of the things that were discussed during the program *Being Prepared for an Emergency*, which was held virtually on September 29. Amando Serrano, Hemophilia Community Consultant, Bayer Healthcare, presented the program, shared his experiences and encouraged others to do the same. We thank Bayer Healthcare for sponsoring this program.

Note: The Foundation provides medical ID jewelry free of charge to our members with a bleeding diagnosis. If you don't have a medical ID, please contact the Foundation for details on how to get one!



ADVOCACY UPDATE



The Annual PA Advocacy Stakeholders Meeting took place virtually on Tuesday, November 23, 2021. The Western and Eastern PA Chapters came together to hold this meeting. Kara and Janet gave Foundation updates, Miriam Goldstein of the Hemophilia Federation of America and Nathan Schaefer of the National Hemophilia Foundation presented on federal issues, and Erik Ross 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.



SNF Hemophilia Access Act

Policy solution: Allow SNFs to bill separately for bleeding disorders treatments and their administration

- Similar to current policy for other expensive, rare, and specialized treatments (i.e., chemotherapy, radioisotopes and prosthetic devices)
- Passed into law December 2020! Sponsors:
 - Senate: Menendez (D-NJ), Enzi (R-WY) and Whitehouse (D-RI)
 - House: Rep. LaHood (R-IL), Higgins (D-NY), Dingell (D-MI) and Bilirakis (R-FL)
- Went into effect October 1, 2021
- Issued communications to community members and providers

Our top priority this year will be keeping the hemophilia line item fully funded and keeping the language in the fiscal code

to ensure the state funds are distributed to all 7 federally funded Hemophilia Treatment Centers in Pennsylvania.

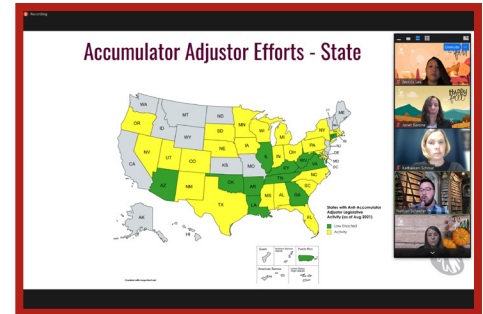
We are also in support of the following bills addressing issues that impact bleeding disorders patients in Pennsylvania. Please let us know if you have examples or patient stories regarding the following that could make our case for supporting these bills stronger.

CO-PAY ACCUMULATORS (HB 1664 AND SB

196): A copay accumulator – or accumulator adjustment program – is a strategy used by insurance companies and Pharmacy Benefit Managers (PBMs) that stop manufacturer copay assistance coupons from counting towards two costs: 1) the deductible and 2) the maximum out-of-pocket spending. We currently have one example of this occurring to a patient in Western PA. Please contact us if you have any examples of this happening to bleeding disorders patients in Pennsylvania.

PRIOR AUTHORIZATION AND STEP THERAPY (HB 225 AND SB 225):

Prior authorizations (PA) require a physician to request health insurer approval of a prescription drug or other health care services before such care is delivered. Health plans often use PA to restrict access to costly services and therapies—particularly newer treatments. Health plans may also use PA to ensure that a therapy is appropriate and safe for a specific patient. Fail First (also known as step therapy) requires patients to try, and fail, on one or more prescription drugs chosen by their insurance company – not their healthcare professional – before



gaining access to the drug that was recommended to treat their health condition. Please contact us if you have specific examples of a fully insured plan not providing timely prior authorization or continuity of care.

NON-MEDICAL SWITCHING (HB 599 AND SB

828): Non-medical switching of medication, whereby a patient's treatment regimen is changed for reasons other than efficacy, side effects, or adherence, is often related to drug formulary changes aimed at reducing drug costs. Please contact us if you have any examples of this happening to bleeding disorders patients in Pennsylvania.

Become an Advocacy Ambassador, your story matters! Join us in meeting with local legislators! We will provide training, schedule, attend and provide support with meetings, and provide all the tools and information needed for successfully contacting legislators. If you would like to become an Advocacy Ambassador of WPBDF please email Kara at kara@wpbdf.org for more information.

Sign up to receive action alerts from the Pennsylvania Bleeding Disorders Foundations here: <https://p2a.co/UDfKJur>

Let's get together to talk about IXINITY®

I have worked with members of the bleeding disorders community for many years; they feel like my extended family. It excites me to continue building those relationships and to forge new ones.

—Nora Latcovich, your resource for all things IXINITY



▶ Contact Nora at 814-483-9588 or nora.latcovich@medexus.com



▶ Scan me or visit ixinity.com today!

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GETTING TO KNOW HCWP STAFF



CARLEY KALHAMMER
NURSE

Birthplace: Pasadena, California

First job: Babysitting at age 12

Accomplishment you're proudest of: Owning my home and taking it and the garden from ordinary to special

What three words describe you best? Hard-working, efficient, friendly

Dream vacation: Anywhere involving a beach with warm water

Things you can't do without: my family, coffee, sunshine, and my kitty cats

Person you'd most like to have dinner with: Roger Federer

Movie you could see anytime: You've Got Mail

TV show you try not to miss: Steelers Football and Outlander

Three things that can always be found in your refrigerator: half and half (for my coffee), bottled water, and ketchup

Secret vice: If I told you, it would not be a secret!

Who would play you in the movies? Melissa McCarthy

Your pet peeve about Pittsburgh: The widely accepted use of improper grammar!!

People may be surprised to know that: I speak 4 languages.

BIDDING, WINE, AND CHOCOLATE – OH MY!

VIRTUAL 9TH ANNUAL TAKE A BOUGH

The 9th Annual Take A Bough was held virtually this year with online bidding and a delicious wine and chocolate tasting hosted over Zoom! Old York Cellar Winery joined us to lead the tasting and provided the kits.

The wine tasting kits included three hand selected wines, chocolate truffle parings from The Fudge Shoppe, a useful tasting profile wheel, and additional information about the winery. Laurin Dorman, a certified Sommelier and Wine Educator, taught us different techniques to taste wine and answered all our questions!



Thanks to the support from our sponsors, donors, and patrons, we raised over \$6,000 for the bleeding disorders community! We are extremely grateful for everyone



who participated in Take A Bough this year, even if we couldn't gather in person. This year's auction opened online on November 26 and the virtual Final Night Event took place on Saturday, December 4, at 7:00 PM.

Planning and preparation for this event began months before December. Our co-chairs, Mindy Perry-Stern and Maria Steele Voms Stein, and our amazing WPBDF Fundraising Committee (Scott

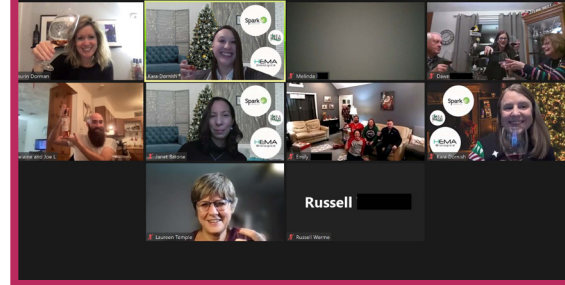
D., Kelly B., Emily N., Eileen N., and Michelle and Mike P.), helped gather trees, decorations, gifts, and raffle items leading up to the event.

Volunteers came to the office to help with the trees, but many community members decorated trees, wreaths, and centerpieces at their homes and dropped them off. Thank you so much for your continued support of this event and our auction!

In total, we had nine full-size trees, three tabletop trees, 27 wreaths (14 that were made by Michaelia A., Jessi B., Jen E., Emily N., JoAnn S., Maria S., MaryAnn A., Lisa W., and more!), and 13 centerpieces. Thank you to Michelle P., Tracy B., and Francine D. who handmade and donated five amazing glass snowmen to the auction to honor little 5-year-old Ryker! Thank you

to Georgann from Team Rolling for Ryker for beautifully decorating and donating two half trees to our auction! Thank you to Jessamyn Butler for her donation of the Fireball Tree, Lauren Temple for making and donating 6 beautiful centerpieces, Maria Steele Voms Stein for making and donating the lottery wreaths, and Melissa Kendrick, *Cottrill's Pharmacy*, for hosting the Winning Women's Group and creating and putting together materials for many of the wreaths up for bid. Finally, thank you to Mindy Perry-Stern for donating an amazing snowman tree and a rideable kids toy semi-truck to include in our auction!

In between the wine tastings, we showcased multiple items up for bid and pulled tickets for our Reverse Blood Drop Raffle! In a reverse raffle, you do NOT want your number to be called. The final five who survived to the last round could choose to split the winnings between them or keep pulling numbers until one number



was left standing. The final winner would take home the jackpot! The majority voted to keep pulling numbers. Thank you to Mindy and her family who helped sell tickets! Tickets were sold for \$10 each, and in total, we sold 72 tickets. Participants had the chance to win \$180!

Congratulations to the winner of the raffle, Mike P., who generously donated \$90 back to the Foundation! The total raised from the raffle was \$630. Thank you to Mindy and Team Rolling for Ryker for their support with the raffle! The wine tasting wrapped up around 8:30 PM and the auction ended at 9:00 PM. Participants were able to pay their invoices online or on the Handbid app on their phone and could arrange to pick up their items at the Chapter office starting Monday, December 6. The Western Pennsylvania Bleeding Disorders Foundation would like to thank Mindy and Maria for co-chairing the event, our amazing WPBDF Fundraising Committee, Old York Cellars Winery for hosting the tasting, and the many community members who donated their time and other items to the auction. We would also like to thank our sponsors:

OUR SILVER SPONSORS:



OUR BRONZE SPONSOR:



OUR SUPPORTER SPONSOR:

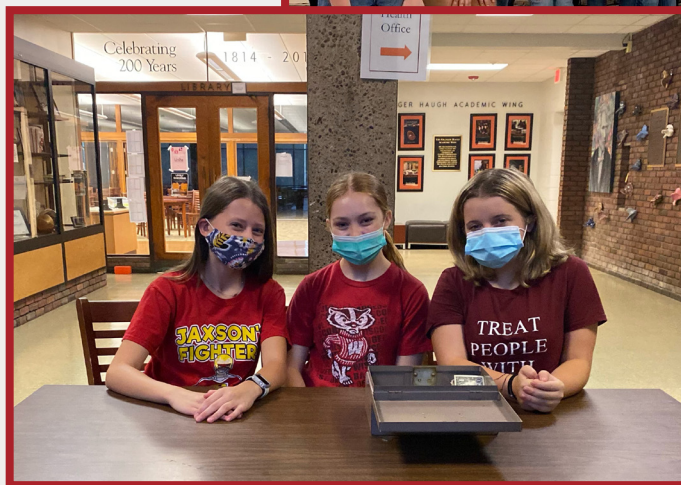


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LINSLY SCHOOL WEARS RED FOR BLEEDING DISORDERS!

On Thursday, October 7, the Linsly Middle School Leadership Council hosted their first fundraiser of the year to help raise awareness and funds for the Western PA Bleeding Disorders Foundation! Students could bring in a \$1 donation to dress down and wear red. Analise B. serves on the council and helped organize this event. Her little brother, Jaxson, is diagnosed with Hemophilia A, and her family participates in the Unite for Bleeding Disorders Walk every year.

In total, the students raised \$948 to benefit the bleeding disorders community of Western PA! We'd like to give a huge thank you to Analise and the entire leadership committee for their hard work in planning this fundraiser!



MEET FOX FACTOR!

ASHLEY FOX

"Come quick! Someone kidnapped Ashley!" My stepfather shouted frantically as he peered into my room. Instead of finding me asleep as per the usual weekday morning, he was startled to see my empty bed covered in blood. Awakened by the chaos, my mother rushed down the hallway in a daze. Before they could fully process the scene, 8 year old me moseyed out of the bathroom clutching a fistful of blood soaked tissues to my face.

Severe nosebleeds, among other vexing symptoms, were a common occurrence throughout my childhood. I can't count the times that family events and outings were interrupted because of them. I vividly remember one instance at the grocery store – my mother grabbing box after box of

tissues off the shelves trying to stop the bleeding while onlookers stared in horror.

Between my father having Hemophilia A and being labeled a symptomatic carrier myself, bleeding episodes were far from uncommon. I grew up watching him deal with the effects of this rare disorder from hematomas to life threatening complications. I was often told of the traumatic injuries he sustained as a child – specifically the story of a sledding accident that resulted in a blood transfusion.

Fast forward two decades. My husband and I welcomed our second baby boy into the world. He was beautiful and healthy at a whopping 8lb. 13oz. As planned, a cord blood sample was collected and we anxiously awaited the results. While we were well aware of the odds, we remained hopeful that he would

fall into the unaffected 50% like our first son.

That hope was quickly taken away when the genetic counselor called. "I regret to inform you that Rylen has inherited his grandfather's Hemophilia." His words sent me into a downward spiral. Suddenly this disorder that I was all too familiar with felt foreign and overpowering. The reality of my own child being affected changed my perception, and a feeling of helplessness set in.

After a week or two of tears and endless worry, my fear blossomed into determination. I vowed to be my son's biggest advocate. In between feedings, diaper changes, and newborn cuddles, I researched high and low, soaking up as much information as my postpartum brain could store.

CONTINUED ON PAGE 19...



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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**

WOMEN'S WREATH MAKING CLASS

MARIA STEELE VOMS STEIN
WOMEN'S GROUP COORDINATOR

On Tuesday, October 26, the WPBDF Winning Women's group hosted a virtual Winter Wreath Making Workshop event. The session moderator was Melissa Kendrick, Field Care Coordinator of Cottrill's Pharmacy, Inc. During the hands-on wreath making workshop, we were guided step-by-step on creating beautiful wreaths. Wreath making kits were sent to each person who registered for this event. The kits included decorations, wire, and lights!

Wreaths created by attendees during the event were donated to the chapter's Take A Bough fundraiser. Thank you to all that participated and so kindly donated your beautiful creations back to the chapter!

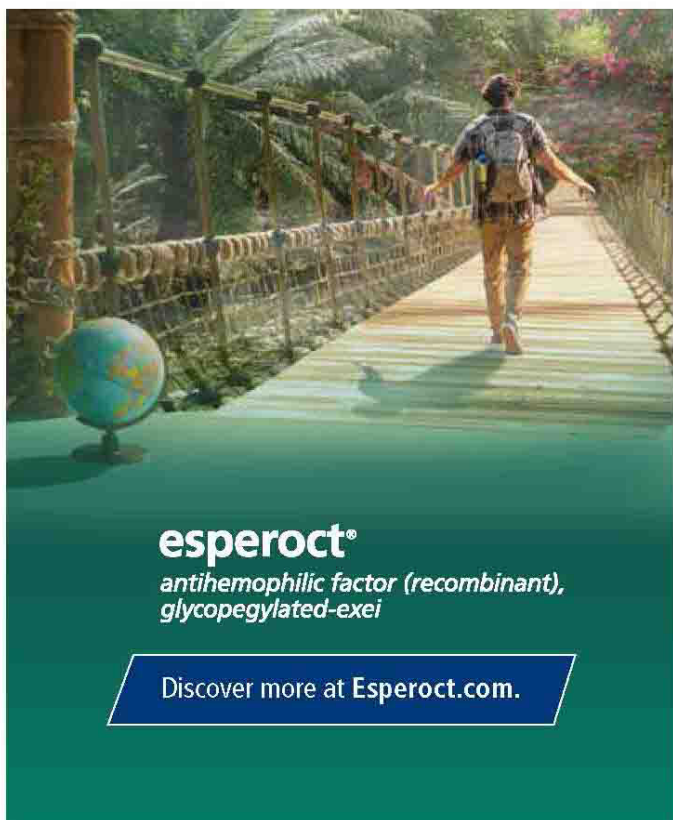


WPBDF's Winning Women's group is a great opportunity for the women of our chapter to network with other women in our community, learn about issues related to bleeding disorder management, and to have a lot of FUN! I hope to see you at an upcoming WPBDF Winning

Women's group or chapter event soon.

The Chapter thanks Cottrill's Pharmacy, Inc. for sponsoring this program.

COTTRILL'S 
PHARMACY, INC.



esperoct®
antihemophilic factor (recombinant),
glycopegylated-exei

Discover more at Esperoct.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)



HCWP CORNER

KATHERINE BUSH, LCSW

Hello to all WPBDF Members and Your Families,

Well, winter is here. Then it feels like spring again. Then fall-ish. Then, maybe, back to winter. The weather has been a bit up and down lately, and (for most of us) the past year has been up and down too. Sometimes it's hard to remember the "ups" when things are "down," but celebrating the holiday season has reminded us that there are also many things we have been thankful for this year. We were thankful to be part of such a vibrant community that has so many resources and so much compassion. We were thankful to have the chance to still connect, even in person on a couple of occasions! We were thankful that we were able to keep our doors open and keep serving you as best as we have been able. And we have been truly grateful for your patience and adaptability as we have done our best to keep

things on track during yet another remarkable year.

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 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. 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. You have the option for your appointment to be live or virtual, or even to see the doctor virtually and the rest of the team live. 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.

Unfortunately, in this time that is associated with celebration and plenty, we know that many people are still in very challenging

situations. Sometimes it seems that as the world returns to "normal" it highlights some of the bigger societal challenges we need to address. Please remember that we welcome your call, 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. Winter can be an expensive time. 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

TEEN GROUP

NICOLETTE C.
TEEN GROUP CO-COORDINATOR

These last couple months, the Teen Group has taken a step back to allow people a break from the Zoom mania that is our world currently. However, in late October, the Teen Group participated in a Goose Chase Game, where people submitted answers to questions for prizes and the chance to get to know people better! The next Teen Group events will be in January, where we will learn how to build and play the ukulele!

Happy New Year,
The Teen Group Coordinators



SEBASTIAN AND BELLA COMPLETE THE "BUNDLE UP" GOOSECHASE CHALLENGE!



TEEN GROUP! CREATE AND LEARN TO PLAY A UKULELE

These are virtual, private sessions exclusively for our Teen Group! Attend 1 or both sessions!

SESSION 1
Sunday, January 16, 2022, 3:00-5:00 PM
Build, Paint, and String a Ukulele!

This session will be led by a host from YayMaker! There's no cost to participate! WPBDF will purchase the supplies and they will be shipped to you directly from YayMaker.

To register, send your full name and mailing address to rvp@wpbdf.org or call 724-741-6160, by January 1, 2022. (Please note: your name and address will be shared with YayMaker for shipping purposes.)

SESSION 2
Sunday, January 23, 2022, 3:00-4:00 PM
Learn to play the Ukulele!

Join us for fun as we all learn how to play the ukulele! This session will be led by Mike Snyder, a musician and music teacher from Indiana who will be joining us virtually. You can check him out on Spotify! He has been playing and teaching music for many years, but also has a passion for working with youth. He is excited to work with us!

If you would like to participate in this session, but are unable to participate in session 1 and need a ukulele for this event, please let us know! To register, send an email to rvp@wpbdf.org. If you need a ukulele to participate in this event, please register by January 14, 2022, otherwise register no later than 3:00 PM on January 23rd.

The Western Pennsylvania Bleeding Disorders Foundation is an organization of acceptance and tolerance for all of its members and the patients it serves, regardless of race, color, ethnicity, national origin, religion, sex, sexual orientation, gender identity or expression, age or disability.



NHF'S WASHINGTON DAYS. 2022

MARCH 1 - 2



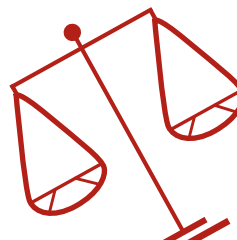
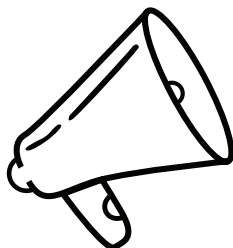
NHF's Washington Days is an opportunity for people affected by inherited blood disorders to advocate for issues that are important to them.



In 2021, Washington Days had more than 400 volunteer advocates from 44 states who met with legislators and staff to discuss federal funding for bleeding disorder programs and support policies that increase affordability of coverage and access to care. Washington Days 2022 will be an entirely virtual experience with programming and legislative meetings taking place on March 1st and 2nd. The issues and priorities for Washington Days 2022 will be announced at the start of the new year.

Training will be held on Tuesday, February 15th for Beginner Advocates (0-1 time attending prior Washington Days) at 2:00 PM and Advanced Advocates (2 or more times attending Washington Days) at 3:30 PM.

If you would like to join us in advocating for the bleeding disorders community, you can sign up by emailing rsvp@wpbdf.org, by Friday, February 4th.



**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.

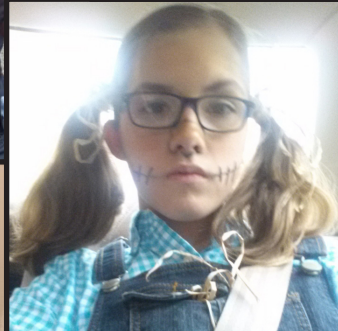
Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world,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

bleedingdisorders.com



HALLOWEEN COSTUME CONTEST

WPBDF celebrated Halloween this year by hosting a Halloween Costume Contest! This contest was open to Chapter members and Campers ages 0-18. Each person who submitted a photo received a prize! Thank you to everyone who submitted a photo. Check out the costumes below!



NEW YEAR

NEW YOU.



WPBDF and the HCWP are here to help you reach your 2022 fitness goals!

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 by the Western PA Bleeding Disorders Foundation and the Hemophilia Center of Western PA (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!

STAY IN MOTION

Western Pennsylvania Bleeding Disorders Foundation

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

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
- Weekly educational resources to keep you motivated
- Invitations to participate in physical wellness activities each month
- Fun, monthly activity challenges with chances to win prizes
- Community support and a safe space to share tips and get advice



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

Submit application form online at wpbdf.org/sim or email info@wpbdf.org for forms to be mailed to you!

Have you ever noticed the constant chatter going on in your mind?

Want to turn down the volume on anxiety and worry?

Got Stress: Strategies for Anxiety and Worry

Hemophilia Federation of America / Mental Health Matters Too Collaborative Workshop

What will you learn?

- The concept of mindset and how it creates excessive stress and worry
- The parts of an anxiety cycle
- Proven techniques to reduce the chatter in your mind and restore inner peace
- This program will be presented by Debbie de la Riva, Licensed Professional Counselor and Certified Mental Health First Aid Instructor.

This is a 3-part, virtual workshop. Dates and times:

Thursday,
February 10,
7:00 PM

Thursday,
February 17,
7:00 PM

Thursday,
February 24,
7:00 PM

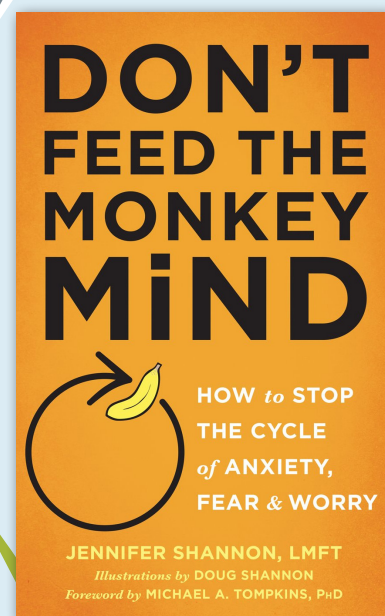
NOTE: In order to participate, you will need to attend all three (3) sessions of the workshop.

How to register:

This program is open to adults and mature teenagers who are members of WPBDF. Email rsvp@wpbdf.org or call 724-741-6160, by February 3, 2022. Be sure to include the name(s) of the person(s) participating and your mailing address. Zoom links for the sessions will be sent to those who register.

All participants will receive a free copy of the book *Don't Feed the Monkey Mind* for use throughout the workshop.

Each participating household will receive a stress relief care package from WPBDF.



YOGA PROGRAM



On Tuesday, October 12, we kicked off our first Stay In Motion activity with a virtual yoga night! Led by certified yoga instructor, Laura Jackson, she guided the group through an all-levels accessible yoga session. Rather than having to get on the floor to practice yoga, she led us through poses that can be done while sitting on a chair. She showed us many modifications to use to get the great benefits of yoga while still listening to and being gentle on our bodies.

WPBDF's Stay In Motion program encourages our bleeding disorders community to get up and get active in an easy and accessible way. For more information on how to participate in our Stay In Motion program visit wpbdf.org/sim.

REFRAMING YOUR MINDSET

Genentech

A Member of the Roche Group

As most of us have been exposed to much negativity and uncertainty over the past two years, it seemed like the perfect time to offer our members the program, *Your Time To Thrive: Reframe Your Mindset*. Genentech developed this program in partnership with the Positive Psychology Center at the University of Pennsylvania. Theresa Coia, from Genentech, led an interactive program on changing negative thinking patterns. The session included learning about different types of thinking traps and strategies to take control of them. We thank Genentech for sponsoring this program.

NO SURPRISES ACT IN EFFECT JANUARY 1

The No Surprises Act went into effect on January 1. Patients with health insurance will no longer receive as many unexpected medical charges from emergency visits and other out-of-network health care services. It requires patients to pay only the in-network cost-sharing amount in those situations.

- Patients will still be responsible for things like co-insurance payments and deductibles. But surprise out-of-network charges, which are exceptionally common, will effectively be banned.
- The law was approved by

STARBUCKS VOLUNTEERS



On Thursday, December 9, Jason M. and Adrienne B. from Starbucks stopped by the office to help the Foundation with a mailing. They stuffed, stamped, and sealed over 600 envelopes!

Jason is a member of the Foundation and helped to organize this volunteer opportunity with the Starbucks Volunteer Program! We are so thankful for your support!

Congress in late 2020 and gets rid of surprise medical billing, which happens when a person receives medical care by a provider outside their private insurer's network, even if the visit takes place at an in-network facility.

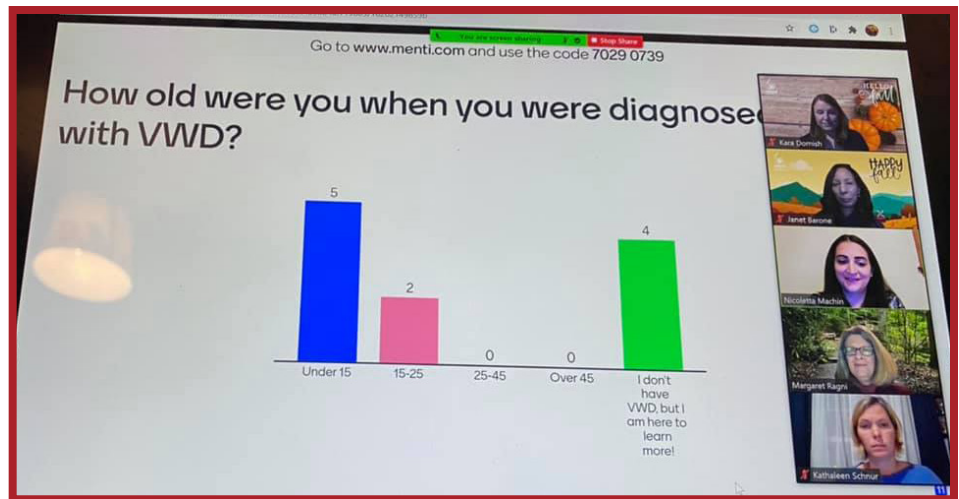
- Any outstanding charges will have to be settled between health insurers and out-of-network medical providers.
- Ground ambulances can still bill patients separately, but the law does offer protections from surprising billing from air medical transportation.
- The new law applies to almost all private health insurance plans provided by employers (including federal, state or local government), according to the Centers for Medicare and Medicaid Services.

HCWP DOCTOR SERIES

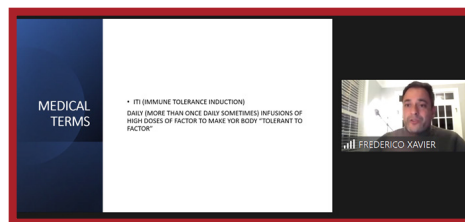
With the safety of our members in mind and the uncertainty surrounding the COVID-19 variants, we made the tough decision during the summer to postpone (for the second time) our most popular educational event, Education Weekend, which was scheduled to take place in November. Based on bleeding disorder education interests identified in our 2020 needs assessment and feedback from the previous Education Weekend, doctors from the Hemophilia Center of Western PA (HCWP) were slated to present programs at the event. Not wanting our members to wait another year to hear from the doctors on issues that are important to them, we discussed the possibility of offering virtual sessions led by the doctors. The hematologists at the HCWP were immediately onboard; and they prepared and presented a series of programs.

The series kicked off on Sunday, November 7. Dr. Margaret Ragni and Dr. Nicoletta (Niki) Machin teamed up to present: *What Ladies Really Need to Know About Von Willebrand Disease*. Highlights included information about iron deficiency, periods that just won't quit, and considerations if you have a baby on the way.

Dr. Frederico Xavier led the second program in the series, *What's on the Horizon?*, which took place on Sunday, November 14. This session began with a review of the history of treatment products and key medical terms,



which was very helpful leading up to an overview on how current products work and the types of products in research.

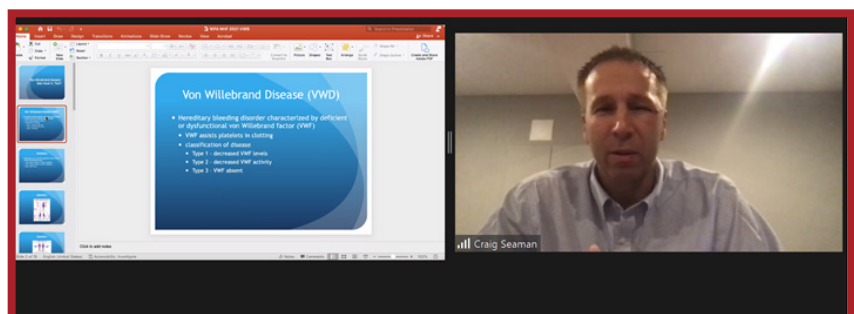


The series wrapped up on Thursday, November 18, with Dr. Craig Seaman leading the session: *Von Willebrand Disease: Men Have It Too?! Basic principles of von Willebrand Disease (VWD) and issues that are unique to men* were discussed. Dr. Seaman also addressed the concern about access to treatment products for patients who used to use Stimate, which has been recalled.

According to the HCWP: As of December 17, 2021 this is the most current and known

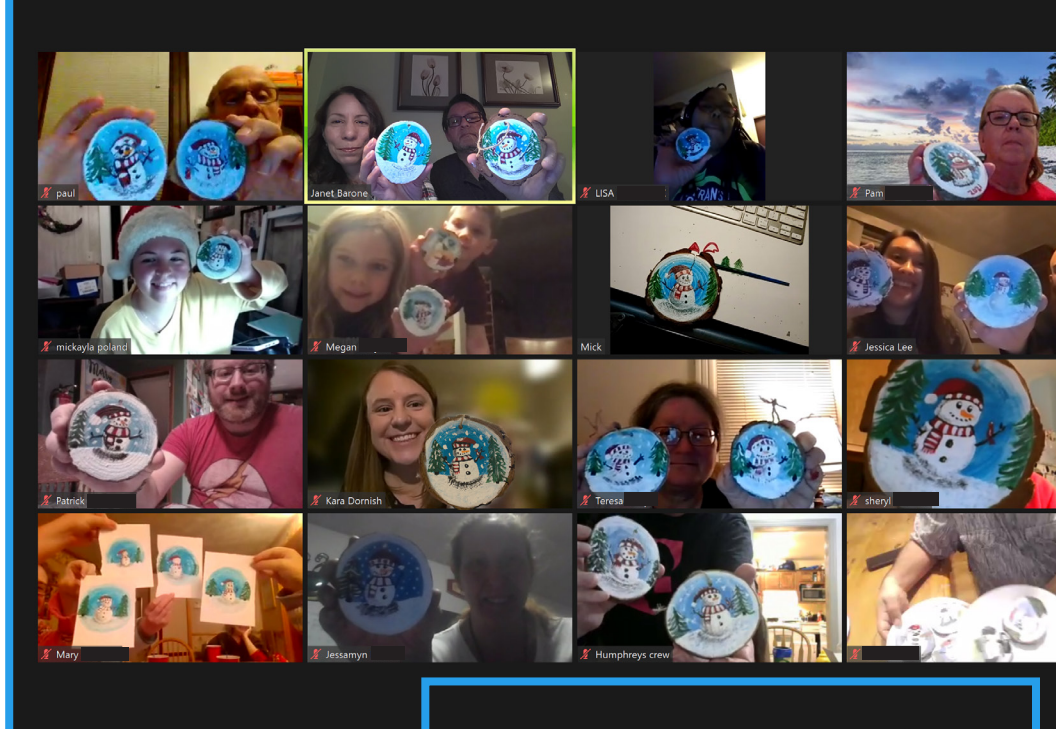
information available regarding our HCWP patients who used Stimate prior to the recall. The following therapies are currently available for individual discussion with your HCWP doctor; intravenous DDAVP, Lysteda or Amicar, and von Willebrand factor replacement (Vonvendi or Humate P). Additionally there is a new DDAVP intranasal spray produced by STAQ Pharmacy; however, there are ongoing challenges regarding cost, shelf life, and insurance barriers. We strongly encourage you to talk with your doctor for further information.

We are grateful to the HCWP for providing these programs. We feel so fortunate to have expert hematologists from the Hemophilia Center of Western PA serving patients in our region!



WINTER PROGRAM

On the evening of Sunday, December 12, families gathered virtually on zoom for WPBDF's Virtual Winter Family Program. The night started with a very engaging program sponsored by Sanofi Genzyme and led by Gretchen Hover on behavioral insights that may help you discuss managing hemophilia with your loved ones and health care team. This program explained how different parts of our brain work and how we make some of the choices we do. It also explored insights from the field of behavioral science and how they can be applied to conversations related to managing hemophilia. We were then joined by local artist, Mickayla Poland, who led us



through painting a wintery snowman ornament. Everyone did a fantastic job! We have such talented painters in our community!

SANOFI GENZYME

Finding Balance

Feeling +
Thinking =
Behaving



MEET FOX FACTOR!

CONTINUED FROM PAGE 8...



ASHLEY'S NEWBORN SON, RYLEN

In search of allies, I sought out support groups on social media. Before I knew it, I was making connections with other Hemo moms around the world. Some were veterans with a long family history while others were newly thrown into navigating the world of bleeding disorders. Despite our differences, we all shared the same passion and goal.

Our support system grew even more when our local HTC put us in contact with WPBDF. From day one, the staff made us feel welcomed and empowered. Coping with a life changing diagnosis is a little less overwhelming when you have a team behind you. They continue to remind us that no one has to walk this path alone. So from our family to yours, we're in this together.


BIDDING, WINE, AND CHOCOLATE - OH MY!

CONTINUED FROM PAGE 7...

Successful fundraisers like Take A Bough allow the Foundation to continue to carry out the mission of enriching the lives of those with bleeding disorders in Western Pennsylvania and respond to the needs of the community in a dynamic environment.

If you missed out on the tasting or would like to support the Foundation, you can purchase additional bottles of wine from Old York Cellars with custom WPBDF holiday labels! The Foundation will get \$8 back for each bottle of wine sold. Order today at: <https://shop.oldyorkcellars.com/Purchase/Fundraiser/Charity-Labels/WPBDF>.

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



HOW DOES
THIS FACTOR IN?

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



HOW TO TREAT BRUISES THAT COME WITH BLEEDING DISORDERS

FOR MEMBERS OF THE BLEEDING DISORDERS COMMUNITY, BRUISES ARE COMMON. BUT WHILE THEY'RE EASY TO GET, THERE ARE ALSO SEVERAL WAYS TO MANAGE THEM. USE THESE METHODS TO TREAT BRUISES.

MICHAEL HICKEY

Easy bruising is one of the most common and frequent symptoms of hemophilia. After all, a bruise occurs when an injury causes small blood vessels under your skin to bleed, and having hemophilia means your blood doesn't clot properly, so even small bumps can turn into large bruises.

Fortunately, there are methods to limit the extent of the bruise. Use these tips to manage bruises, and learn how to identify when bruises are a sign of something more serious that requires medical attention and needs clotting factor treatment. For severe bruises, contact your hemophilia treatment center (HTC) so you can get proper medical care.

USE THE R.I.C.E. METHOD FOR HEMOPHILIA BRUISING

This tried-and-true strategy stands for “rest, ice, compression and elevation,” and it's used to treat sprains, strains and bruises by slowing bleeding and reducing pain. The R.I.C.E. method is effective for minor bruises and should be started as soon as possible.

REST: After a bleed occurs, and while your body is healing, the

affected area should be rested and protected. Depending on where the bruise is, refrain from doing certain activities such as lifting heavy objects if your arm is bruised or walking around if the bleeding is in your legs.

If you're in pain, you may be tempted to massage the bruised area, but doing so could cause more blood vessels to break, making the bruise bigger.

ICE: Put an ice pack on your bruise; the cold temperature will slow blood flow in that area and reduce the amount of blood that leaks out of your vessels. Experts recommend applying ice for 15 to 20 minutes every two to three hours during the first 24 to 48 hours after your injury. Make sure to wrap the ice in a towel, as putting ice directly on your skin can cause ice burn or even frostbite.

COMPRESSION: Put pressure on the injured area using an elastic medical band to slow bleeding and reduce swelling caused by the bruise. Wrap the elastic band so that it's snug but not too tight. If the injured area changes color and becomes cool or numb, then you've likely wrapped the bandage too

tight. In this case, take the band off and re-wrap so it's not as tight. **Elevation:** Raise your injured limb so that it's higher than your heart. This keeps blood from pooling easily, which makes bruises larger.

SIGNS OF SEVERE BRUISING

Severe bruises require medical attention and possibly clotting factor treatment. But how can you tell the difference between a regular bruise that can be treated with the R.I.C.E. method and bruises that signal severe bleeding? There are signs, including:

- If the bruise is accompanied by swelling and extreme pain
- If the bruise doesn't go away after two weeks
- If pain remains days after injury
- If the bleed limits the movement and function of nearby joints

If you're unsure about the severity of a bruise, it's always best to contact your HTC.

*Article Courtesy of HemAware
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REMEMBERING VAL BIAS



On Thursday, December 30, Val Bias, former CEO of the National Hemophilia Foundation passed away. Val was a visionary, advocate and leader in the bleeding disorders community. He touched thousands of lives through his work and leaves a legacy for generations to come. We offer our deepest

condolences to his family, friends and the NHF staff. NHF looks to respect the Bias family's privacy at this time and will provide further information to the community at an appropriate time. All condolences and communications may be sent to communications@hemophilia.org.

How Can We Help You?

Your feedback is extremely important to help us create and offer programs, events, and services that are meaningful and beneficial to you.

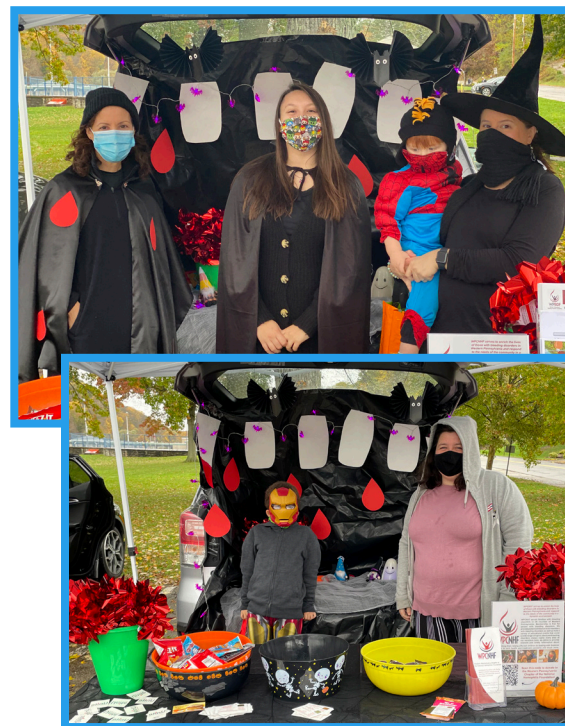
Please participate in the 2021 Needs Assessment.

You have the option to complete a printed version or an online version: <https://www.surveymonkey.com/r/B9VPBMY>

(Contact the Foundation at 724-741-6160 or info@wpbdf.org, to request a printed version.)



WPBDF'S FANG-TASTIC HALLOWEEN!



On Saturday, October 30, the Western PA Bleeding Disorders Foundation celebrated Halloween at the Park at a Trunk or Treat hosted by Beaver's Hometown Happenings. The event took place at Shaw Park and trick or treaters began arriving at 11:00 am. WPBDF staff handed out "blood drop" Hershey kisses and information about bleeding disorders. Janet and Jessica were dressed like Vampires and turned Janet's car into a spooky vampire mouth! Thank you to Hometown Happenings for this opportunity to raise awareness about bleeding disorders!



\$400

B:OMARIN®

GENE THERAPY JEOPARDY!

*An interactive game featuring the underlying principles of gene therapy research.
Join friends and play for points to become the next Jeopardy! gene-ius.*



**Thursday,
February 3, 2022**

7:00 PM



Virtual Event

Register Today!

*To register, email rsvp@wpbdf.org
or call
724-741-6160.*

Expand your gene therapy research knowledge in BioMarin's Gene Therapy Jeopardy Game! The Western Pennsylvania Bleeding Disorders Foundation (WPBDF) invites you to join a fun, new experience to make the science behind gene therapy research memorable and entertaining. Whether you're already a whiz or are just starting to explore, you and your friends can learn together and earn points to win prizes!

This program is for members of WPBDF and family members living in their household. To register, email rsvp@wpbdf.org or call 724-741-6160 by 3 PM on Thursday, February 3RD. Be sure to include the name(s) of the person(s) participating. The zoom link to join the program will be sent to everyone who registers for the program.

\$800



WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

775 4th Street
First Floor
Beaver, PA 15009

As we look forward to a new year with optimism and hope, we wish that this coming new year will be one that leaves your worries behind, and also one that gives you encouragement and hope.

From all of us at the HCWP-- we are looking forward to serving you in 2022. We thank you for trusting us to be a part of your care, and wish the best for you and yours in the new year!



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

