



# HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

SPRING 2022



**MULTIPLE CITIES AND COUNTIES DECLARED MARCH 2022 AS BLEEDING DISORDERS AWARENESS MONTH! READ MORE ABOUT OUR PROCLAMATIONS ON PAGE 26!**

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## BOARD OF DIRECTORS

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**Program Director** Janet Barone  
**Development Director** Jessica Lee  
 Staff office hours are Monday-Friday from 9 a.m. until 4 p.m. Every attempt will be made to return calls received during regular office hours on the same day.

## MISSION STATEMENT

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

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

### April 20-23, 2022

HFA Symposium  
 San Antonio, TX

### April 26, 2022

Pittsburgh Penguins Game Fundraiser  
 PPG Paints Arena  
 Pittsburgh, PA

### April 30, 2022

Stay In Motion Hike  
 Frick Park  
 Pittsburgh, PA

### May 4, 2022

Food and Fitness Basics  
 Crate Cooking School  
 Pittsburgh, PA

### May 8, 2022

Mother's Day Paint and Sip  
 Virtual Fundraiser

### May 14, 2022

Women's Retreat  
 Wyndham Pittsburgh  
 University Center  
 Pittsburgh, PA

### June 12, 2022

Axe Out Bleeding Disorders Fundraiser  
 Cranberry Twp, PA

### July 9, 2022

New Parent Network  
 Pittsburgh Zoo  
 Pittsburgh, PA

### July 21, 2022

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

### August 6-8, 2022

Teen Retreat  
 Camp Kon-O-Kwee  
 Fombell, PA

### August 25, 2022

Men's Group  
 Sheraton Erie Bayfront  
 Erie, 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, 2022

New Parent Network  
 Seven Springs Mountain Resort  
 Champion, PA

### November 4, 2022

Teen Group Seven Springs Mountain Resort  
 Champion, PA

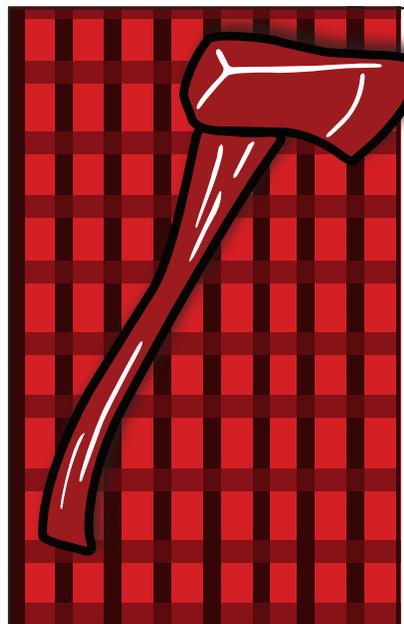
### November 5-6, 2022

Family Education Weekend  
 Seven Springs Mountain Resort  
 Champion, PA

### November 19, 2022

Take A Bough  
 Gaetano's  
 Pittsburgh, PA

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



## Axe Out Bleeding Disorders

A "badaxe" fundraiser to support the Western PA Bleeding Disorders Foundation

**When: Sunday, June 12, 2022**

**2 pm - 4 pm**

**Where: LUMBERJAXES  
 CRANBERRY**

**20111 Rte 19, Room 302-B  
 Cranberry Twp, PA 16066**

**Learn more at:  
[bit.ly/wpbdfaxethrowing](http://bit.ly/wpbdfaxethrowing)**

## CONTACT US

### Western Pennsylvania Bleeding Disorders Foundation

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 First Floor  
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# LETTER FROM THE EXECUTIVE DIRECTOR AND BOARD PRESIDENT

Dear Chapter Members & Friends,

Spring is here! We hope everyone takes time to enjoy the fresh air and sunshine. We made it through another challenging season, and we cannot express how thankful we are for this amazing community.

March was Bleeding Disorders Awareness Month, and we started off the month advocating for the community by participating in NHF's Virtual Washington Days. We received proclamations from all over Western Pennsylvania which worked to spread awareness and recognition of bleeding disorders. We are continuing to meet with

local legislators to ensure funding to all seven Hemophilia Treatment Centers in Pennsylvania and we would love your participation. Please email [kara@wpbdf.org](mailto:kara@wpbdf.org) to receive more information on how to get involved in our Advocacy Ambassador Program.

We have increased our ability to provide emergency financial assistance and have made our Grocery Assistance Program permanent and ongoing. This year, and through this program alone, we have assisted 52 households by granting over \$24,000 in grocery gift cards. If you need assistance, please do not hesitate to reach out. We are here to help.

Every day, through many different obstacles, your kindness makes our work possible. When you donate, volunteer, or advocate, your work makes a lasting impact for people right here in Pennsylvania. We simply cannot do it without you! Your support means the world to us.

Thank you for all you do on behalf of the bleeding disorders community.

Sincerely,  
Kara Dornish  
Executive Director

R. Scott Domowicz  
Board President

## WPBDF'S NEW PARENT NETWORK CELEBRATES SPRING!

On Sunday, March 27, we held a New Parent Network program to help families recognize the impact on family life when raising a child with a bleeding diagnosis, and to remind families of available resources.

The program "Survey Says!" was held in a game style format where participants were asked to provide answers. Kathaleen Schnur, LCSW, HCWP and Janet Barone, Program Director, WPBDF facilitated the event. This event included a special set of questions for the kiddos, who received an event box filled with prizes and snacks in the mail prior to the event for use during and after the program.



209-7267) or Janet Barone ([janet@wpbdf.org](mailto:janet@wpbdf.org) / 724-741-6160).

We are grateful to our sponsors for supporting these programs. The 2022 New Parent Network series of events are sponsored by:

**CSL Behring**

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](mailto:kschnur@vitalant.org) / 412-

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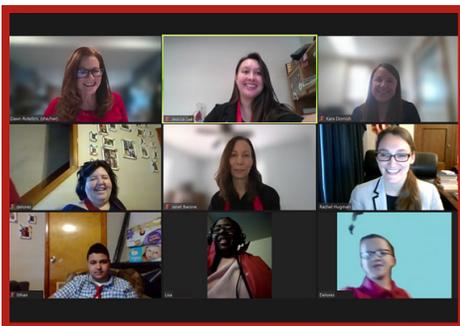
**Takeda**

# ADVOCACY UPDATE



## NHF WASHINGTON DAYS

On Wednesday, March 2, the Western Pennsylvania Bleeding Disorders Foundation participated in the National Hemophilia Foundation's virtual Washington Days. Advocates from Western PA included Lisa Gonzalez, Delores Johnson, Ethan Webb, Kyrie Holliday, Jessica Lee, Janet Barone, Kara Dornish, and Dawn Rotellini. We attended meetings with Kate Werley, Representative Mike Doyle's Legislative Director; Rachel Hugman, Representative Conor Lamb's Legislative Assistant; and Kate Samuelson, Policy Advisor for Senator Bob Casey. We asked them to maintain support for federal bleeding disorders programs at NIH, CDC, and HRSA. We asked members of the House to co-sponsor the HELP Copays Act (HR 5801) and members of the Senate to introduce a companion bill to ensure that all copays count for patients.



Meeting with Rachel Hugman from Representative Lamb's office.

## FEDERAL BLEEDING DISORDERS PROGRAMS

We explained that there are

federal programs that support our community and asked for their continued support of the following programs:

- National Institutes of Health (NIH): Funds biomedical research on bleeding disorders. NIH is working to implement a national blueprint for research on inhibitor prevention and eradication.
- Centers for Disease Control and Prevention (CDC): Funds HTC surveillance and prevention activities, and supports outreach and education programs provided by national bleeding disorders patient organizations.
- Health Resources and Services Administration (HRSA): Provides funding for HTCs to provide multi-disciplinary services not typically covered by insurance, such as PT and social work services. Also, as HRSA grantees, most HTCs participate in the 340B Drug Discount Program, which supports comprehensive care offered to all their patients.

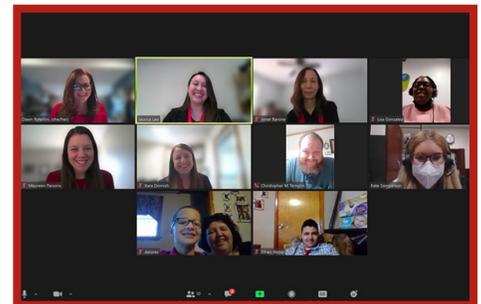
## BLEEDING DISORDERS CONCERNS ABOUT AFFORDABILITY

People with bleeding disorders must have access to comprehensive health insurance that covers their life-saving treatments and expert care provided at hemophilia treatment centers (HTCs). Annual treatment costs exceed \$350,000 per year for a person with severe hemophilia. Therefore, many people with bleeding disorders hit their annual out-of-pocket

(OOP) maximum each year. For 2022, the OOP limit is \$8,700 for an individual and \$17,400 for a family.

Thus, many community members worry about:

- Having access to and affording comprehensive insurance coverage
- Paying their OOP costs for treatment
- Hitting their OOP limit, often in the first month
- Needing financial assistance to afford their OOP costs



Meeting with Kate Samuelson from Senator Casey's office.

## WHAT ARE COPAY ACCUMULATOR ADJUSTER PROGRAMS AND HOW DO THEY IMPACT PATIENT ACCESS?

- Many people with bleeding disorders and other chronic conditions need copay assistance programs to help them afford their high OOP costs.
- An increasing number of private health insurance plans are implementing copay accumulator adjuster programs that disallow copay assistance from counting towards a patient's deductible and OOP maximum.
- When copay assistance is not allowed, many patients cannot

afford their treatments and stop taking them or reduce the prescribed dosage. This often leads to complications and has unintended consequences (i.e., increased ER visits, joint bleeds/damage, and missed days from work/school) that harm patients and increase overall costs.

- This also affects people with other expensive conditions. NHF helps lead the All Copays Count Coalition, which has 120+ members representing people with cancer, MS, HIV/AIDS, arthritis, lupus, and other rare and chronic conditions. Plans should be required to count

### THE HELP COPAYS ACT

all copays (regardless of who pays) towards a person's OOP maximum. The Help Lower Patient Copays Act (HELP Copays Act) is a bipartisan, two-part solution that:

- Clarifies the ACA definition of cost sharing to ensure payments made "by or on behalf of" patients count towards their deductible and OOP max.
- Closes the Essential Health Benefit (EHB) loophole to ensure that any item or service covered by a health plan is part of the EHB package so that all related cost sharing counts towards a patient's cost sharing limits.

In the House, HR 5801 was introduced by Reps. McEachin (D-VA) and Davis (R-IL). We are asking Representatives to co-sponsor the bill. In the Senate, we are asking Senators to introduce a companion bill.



## LOCAL ADVOCACY

There are approximately 30,000 patients with hemophilia and thousands more with other inherited bleeding disorders in the United States. More than 3,000 of these individuals reside in Pennsylvania and receive care at one of the 7 Hemophilia Treatment Centers. We have Centers all throughout PA with 4 in Philadelphia County, 1 in Allegheny County, 1 in Dauphin County, and 1 in Lehigh County. We all know how important the HTC's are to us and the multidisciplinary care received there. CDC studies even demonstrate a 40% reduction in mortality and medical complications in patients who receive their care at an HTC and the overall costs of care are reduced as well.

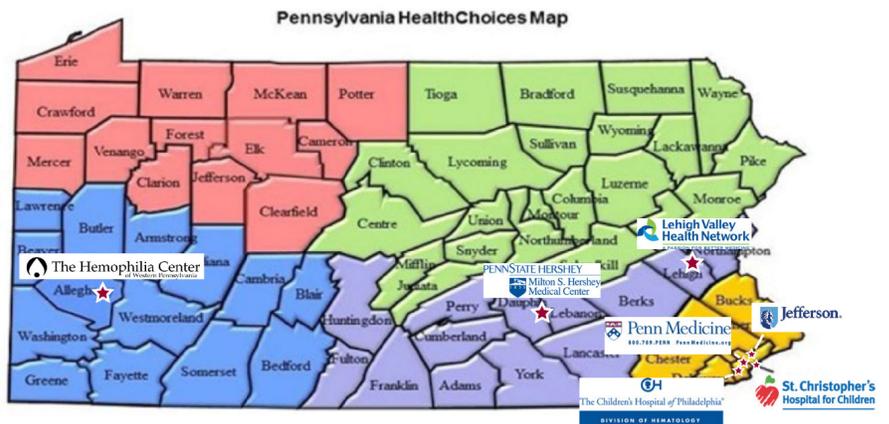
In 1974, we were one of the first states in the United States to establish a state hemophilia program. If you have ever advocated with us in the past, you know we have always asked for that line item to be maintained at \$959,000 – it has been over a decade since we have seen an increase in the line item. This year we are asking the General Assembly to increase the \$959,000 line item by \$41,000 to \$1,000,000. These funds are used to support patient centered

care including the Consumer Advisory Council, mental health support, unified care plan, and direct patient assistance. Going into another year of the COVID-19 pandemic, patient barriers have increased and the need for direct patient support is greater now than ever before.

The Department of Health is once again trying to implement the HealthChoices Five Regions this year. The Specialty Care Programs funds have been distributed in previous years through a state procurement process known as a Sole Source request. This ensured that if the hemophilia line item was in the state budget, all 7 hemophilia treatment centers in Pennsylvania received state funding. The Department of Health is trying to replace this with a new grant process called Request for Applications (RFAs). The RFAs will use a regional approach, based on the Pennsylvania HealthChoices five regions.

Problems with this model:

- There are 7 federally supported hemophilia treatment centers (HTCs) but only 5 HealthChoices regions, with 4 HTCs located in Philadelphia.
- While applicants may apply for multiple regions, having only one grant awarded per region is problematic when four world



CONTINUED ON PAGE 7...



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"The resilience and tenacity of the hemophilia community are what inspire me most."

[carrie.koenig@sanofi.com](mailto:carrie.koenig@sanofi.com)  
(667) 500-4326



**Scan with your phone to  
contact your local CoRe.**

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# LOCAL ADVOCACY

CONTINUED FROM PAGE 5...

class HTC's are in one region (Philadelphia). As proposed, the four HTC's in Philadelphia will be pitted against each other competing for funding.

- When we voiced this concern in the meeting with the Department of Health they told us they expect the Treatment Centers to team up to apply for funding. But this only creates more problems as who will be responsible for the administrative burden and how will the funding be divided between them? This one-size fits all approach that the Department of Health is requiring for all specialty care programs clearly doesn't work for hemophilia and will only jeopardize our HTC's' funding. Lost funding can result in staff positions being eliminated which could ultimately result in loss of comprehensive care.

Luckily, we did find a way to avoid this. We were able to get language in the fiscal code that reads: "FUNDS APPROPRIATED FOR HEMOPHILIA SERVICES SHALL BE DISTRIBUTED TO GRANTEES IN THE SAME PROPORTION AS DISTRIBUTED IN FISCAL YEAR 2019-2020." This language guaranteed that all 7 Hemophilia Treatment Centers received funding.

This year we are asking the General Assembly to:

1. Keep the Hemophilia Program as a separate line item
2. Increase the fiscal year amount from \$959,00 to \$1,000,000
3. Keep the distribution of funds, as in previous years, to all seven-state supported hemophilia treatment centers

On February 8, Governor Tom Wolf

announced his proposed budget plan. We were happy to see the Hemophilia line item separated out at level funding of \$959,000 which gives us a good starting point. In preparation for that, we had sent letters and met with Representative Dan Frankel and Senator Jay Costa asking them to reach out to the Governor's office in support of our three asks. Both are very supportive of our asks and did agree to reach out to the Governor's office as well as the Appropriation Chairs. For us to move forward in our advocacy initiatives for the year, we need community members

like you to join us in meetings with your local legislators. We would be happy to assist in getting the meeting scheduled and provide all the resources needed to ensure a successful meeting. We would meet with you ahead of time to run through your talking points and make sure you feel comfortable, prepared, and understand the issues; all of this can be done virtually. If you are interested, please email Kara at [kara@wpbdf.org](mailto:kara@wpbdf.org) or call the Chapter office at 724-741-6160.

## MEETINGS HELD THIS YEAR:



**Senator Scott Hutchinson**  
Butler County  
Advocacy Ambassador:  
Jessica Lee



**Senator Wayne Fontana**  
Allegheny County  
Advocacy Ambassador:  
Cassandra Miller



**Senator Camera Bartolotta**  
Beaver County  
Advocacy Ambassador:  
Kara Dornish



**Senator Jay Costa**  
Allegheny County  
Advocacy Ambassador:  
Kathaleen Schnur



**Representative Dan Frankel**  
Allegheny County  
Advocacy Ambassador:  
Kathaleen Schnur



**Representative Jessica Benham**  
Allegheny County  
Advocacy Ambassadors: Lisa Gonzalez and Cassandra Miller



Virginia, enacted similar laws requiring co-pay assistance to count towards an enrollee's deductible and out-of-pocket limit. We believe PA should be next.

If you are experiencing a copay accumulator and would like to share your story with us, please email Kara at [kara@wpbdf.org](mailto:kara@wpbdf.org) or call the Chapter office at 724-741-6160.

## SUPPORTING PATIENTS WITH RISING OUT-OF-POCKET COSTS

### ENSURING ALL CO-PAYS COUNT

In addition to the efforts being taken on the federal level to eliminate copay accumulators, advocacy is also happening on the state level. In Pennsylvania, bipartisan legislation has been introduced that would protect patients from having their prescription drug co-pay assistance programs undercut by their health insurer or Pharmacy Benefit Managers (PBMs). House Bill (HB) 1664 along with Senate Bill 196, would eliminate co-pay accumulator programs statewide. Currently, HB 1664 is in the Insurance Committee and SB 196 is in the Insurance and Banking Committee.

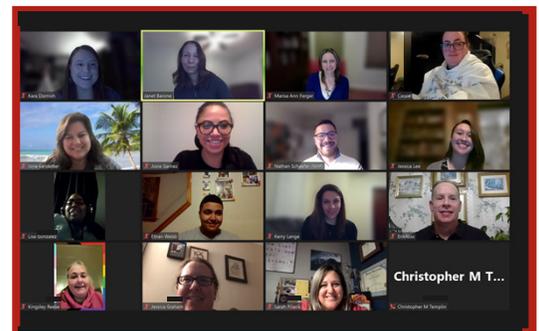
On Wednesday, March 16, WPBDF participated in the PA All Copays Count Coalition Advocacy Day. Many individuals we serve who have bleeding disorders rely on copay assistance to access their high-cost medication. Over the past several years, many insurance companies have instituted copay accumulator programs, which do not allow

copay assistance to count toward deductibles or out-of-pocket maximums, as it traditionally has. Copay accumulator programs allow health insurers and Pharmacy Benefit Managers (PBMs) to take the benefit of the copay assistance rather than passing it on to consumers, as it was intended. Copay accumulators are a barrier to access to care in Pennsylvania, and we must ensure that all copays count.

We met with Senator Kim Ward, Senator Jay Costa, Senator John DiSanto, Senator Christine Tartaglione, Senator Elder Vogel, Senator Camera Bartolotta, and Representative Josh Kail to garner their support for Senate Bill 196 and House Bill 1664 to ensure all copays count in Pennsylvania. These bills would require health insurers and PBMs to count aid enrollees get through copay assistance programs toward their cost-sharing requirements, including their deductible or out-of-pocket maximum. The changes from this legislation will protect Pennsylvanians from surprise bills and treatment delays, as well as allow individuals to utilize the full benefit of co-pay assistance programs. In recent years, many states, including neighbor West

Your personal stories are very important right now as we work on getting this legislation moved out of the Banking and Insurance Committees.

## ADVOCACY AMBASSADOR TRAINING



On Wednesday, February 23, the Western and Eastern Pennsylvania Bleeding Disorders Foundations teamed up to hold a statewide Advocacy Ambassador Training.

We went over local issues, shared ten tips for effective legislative meetings, heard from experienced advocates, and performed a mock meeting where we demonstrated what to do and what not to do in legislative meetings. If you would like to get involved and advocate for the needs of the bleeding disorders community, please email [kara@wpbdf.org](mailto:kara@wpbdf.org) to learn more.

# COOKING WITH CHEF MIKE

What a wonderful way to spend a cold winter's night – cooking with friends over Zoom, while listening to an entertaining and compassionate individual, Chef Mike Hargett, tell his story!

The theme was Hawaiian, and Chef Mike taught us how to make Loco Moco, a delicious and popular Hawaiian dish. Everyone received an ingredient list and a gift card to purchase the ingredients prior to the event and most of us cooked along with Mike as he instructed us through each step of the recipe. It was the first time the majority ever tasted or made this recipe and it was a hit!

Chef Mike has severe Hemophilia A; he is the first patient with hemophilia, in the United States,



to receive a heart transplant; and he is also the recipient of a kidney transplant. While cooking, Chef Mike told us his story and welcomed questions about both his life experiences and the recipe.

We enjoyed the engagement of everyone who joined the event! Many of the participants

wore Hawaiian-themed shirts and accessories, many cooked along and asked questions or offered suggestions for dietary substitutions. It was a wonderful experience, and we thank the Hemophilia Federation of America for bringing us this amazing program, which was held on January 8.

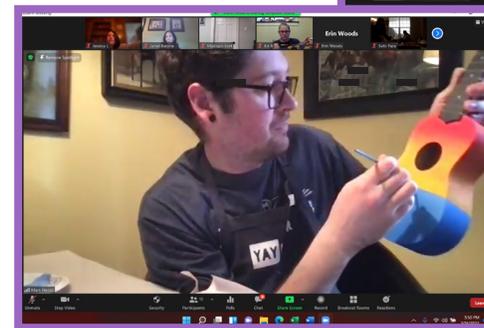
# WPBDF'S TEEN GROUP LEARNS TO PLAY THE UKELELE



## RAINA S., TEEN GROUP CO-COORDINATOR

The teen group hosted an online ukulele event on Sunday, January 16, that demonstrated the wonders of the ukulele. Each participant received a bare ukulele in the mail where they were given the freedom to paint it however they pleased.

Mark Hecox, from Yaymaker, taught everyone how to paint a beach-y sunset as a background for their ukulele, as well as how to string and tune the ukulele. After everyone was tuned up and ready to go, we all learned some small chords and sounds of the ukulele.



The following Sunday, January 23, Mike Snyder, a musician and music teacher from Indiana, instructed us on how to play the ukulele. Participants received sheet music in the mail to play along to, and we learned how to play several songs, strums, and notes.



# Trust the Experience



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## GETTING TO KNOW HCWP STAFF



**CHRISTINA EKEKWE**  
**RESEARCH NURSE**

**Birthplace:** Ovim, Nigeria

**First job:** Health Program Manager at AFRIT

**Accomplishment you're proudest of:** Developing a health intervention program which saved lives of thousands of women and kids in rural Africa

**What three words describe you best?** Focused, disciplined, and Amiable

**Dream vacation:** A month touring Safari in East Africa (minus the snakes!!!)

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

**Movie you could see anytime:** Shrek

**TV show you try not to miss:** Grey's Anatomy

**Three things that can always be found in your refrigerator:** Rice, chicken wings, Coca-Cola

**Secret vice:** I snack more than an average person

**Who would play you in the movies?** Jada Pinkett Smith

**Your pet peeve about Pittsburgh:** Potholes!!!!

**People may be surprised to know that:** I earned a bachelor's degree in engineering



# WHAT WOMEN WITH BLEEDING DISORDERS NEED TO KNOW ABOUT JOINT PROBLEMS

RESEARCH IS RECOGNIZING MORE JOINT ISSUES IN WOMEN WITH BLEEDING DISORDERS, INCLUDING CARRIERS. HERE'S HOW TO GET YOUR CONCERNS ADDRESSED.

## KATHRYN ANNE STEWART

Kolbie Clarke, 17, has mild hemophilia A and low von Willebrand factor, and when she started having joint issues playing soccer five years ago, she wasn't surprised. Her father and uncle have severe hemophilia, and Kolbie saw them deal with repeated knee and ankle bleeds.

Until recently, the medical community wouldn't have expected joint issues like Kolbie's. Now, that is changing.

A leading researcher in this area is Robert Sidonio Jr., MD, director of hemostasis and thrombosis clinical operations at the Aflac Cancer and Blood Disorders Center of Children's Healthcare of Atlanta. Sidonio attended patient advocacy group meetings where carriers shared stories of joint bleeding. "It

really hadn't been known that the carriers would be at any significant risk for joint bleeds," he says. Since then, his research has uncovered evidence that indicates prior joint bleeding in hemophilia carriers, particularly those with levels less than 60%.

For women with bleeding disorders, seeking care from a hemophilia treatment center (HTC) is the first step to progress. Data collected by HTCs populates the registries of groups such as the Centers for Disease Control and Prevention and the American Thrombosis and Hemostasis Network. "If you don't become an active part of those datasets, then it's really hard for us to do any research," Sidonio notes.

He urges all carriers, even those without a confirmed bleeding disorder diagnosis, to consider

being evaluated at an HTC. It's possible that many carriers have mild hemophilia based on their clotting factor levels.

## HOW TO RECOGNIZE JOINT ISSUES

Joint bleeds are most likely in the knees and ankles in males and females with hemophilia, Sidonio says, and sometimes in the elbows. "It typically starts off as a tingling, pins-and-needles sensation," he explains. "Then it progresses to warmth."

The joint may also look different, as swelling obscures typical contours of bones. Often the range of motion will decrease, and there will be pain.

To help tell the difference between a strain or sprain and a joint bleed, Sidonio encourages people to take

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# Unite

for Bleeding Disorders



## Western Pennsylvania Bleeding Disorders Foundation's

### 14th Annual Unite for Bleeding Disorders Walk

Saturday, September 10, 2022

9:30 am to 11:30 am | Check-in 9:00 am to 10:00 am

North Park Swimming Pool Parking Lot

S Ridge Dr, Allison Park, PA 15101

Questions? Contact Pittsburgh Walk Manager Jessica Lee

[jessica@wpbdf.org](mailto:jessica@wpbdf.org) or call 724-741-6160



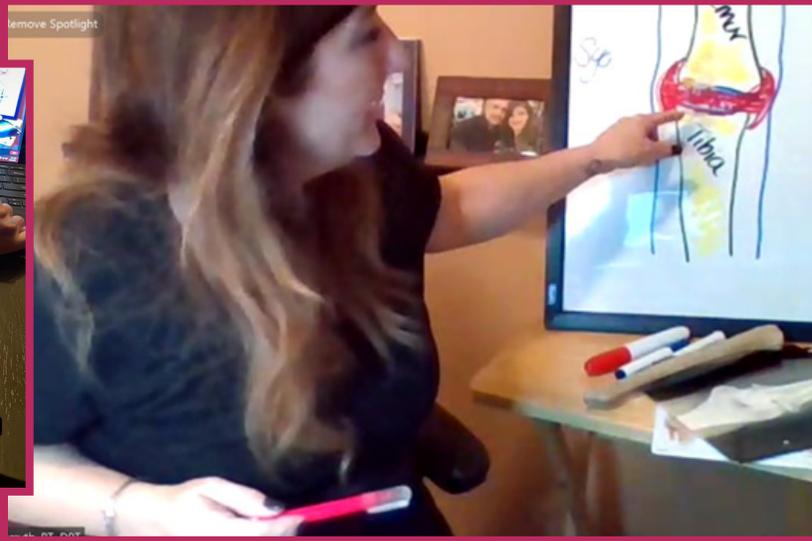
[www.uniteforbleedingdisorders.org/event/wpa](http://www.uniteforbleedingdisorders.org/event/wpa)



## ANATOMY WORKSHOP

This engaging session was perfect for people who learn best when they participate in an activity! Angela Forsyth, PT, DPT had everyone participating from the moment the program started. She gave us the option to draw on paper, ourselves, or a family member, with body crayons that we received prior to the event. Everyone chose the body part they would work on (hand, arm, or knee) and she guided us in drawing the bones and joints. She then explained how joint bleeds affect the health of joints and instructed us on how to modify our drawings to illustrate a joint bleed and damage.

This virtual anatomy workshop was held over Zoom and the chat box was active throughout the program with many great



questions from the participants. Angela responded to the questions as we progressed through the session and was available to answer additional questions at the end.

Angela Forsyth, PT, DPT has more than 25 years of experience

specializing in bleeding disorders and orthopedics, including time spent working at hemophilia treatment centers. We thank Optum for sponsoring this program.

**Optum**

# 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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## HCWP CORNER

**KATHALEEN SCHNUR, LCSW**

Happy Spring to our Bleeding Disorders Community!

As I'm typing, my windows are open, the sun is shining, and I am hopeful I won't have to turn on the furnace again. I'm especially excited for all the colors that spring brings. Pause for a moment... what is something you are excited about as we move into springtime? I hope that thought brought a smile to your face!

We have some exciting news to share. As many of you know, in response to the STIMATE nasal spray recall, the Hemophilia Alliance partnered with STAQ Pharma to provide an alternative source of desmopressin acetate nasal spray, 1.5 mg/mL, for its members' patients. STAQ Pharma is an FDA registered 503B Outsourcing Facility located in Denver, CO. As a member of the Hemophilia Alliance, the Hemophilia Center of Western Pennsylvania (HCWP) is currently working on obtaining this product through STAQ Pharma and is anticipating receiving its initial shipment in April 2022. We will work with your health insurance

carrier to seek coverage for this product.

HCWP is participating in the clinical trials of Fitusiran (a novel therapy not yet FDA approved) for patients with hemophilia A or B with or without inhibitors. It acts by reducing antithrombin (a clot inhibitor) to promote clots lasting longer. It is given every month or every other month under the skin (SQ). If you have questions, or would like more information, please contact the center and ask to speak with research staff.

To patients and families using the center's 340B pharmacy, the courier situation has notably improved; however, we still encourage families to order ahead of time whenever possible. Additionally, the new year brings new insurance hoops to jump through, so sometimes prior authorizations are slow to come through. Shortages in medical supplies continue to happen at different times, so occasionally the rationing will cause lower quantities to be sent out. We are trying to stay ahead of it. Please feel free to call with any questions or concerns.

We've recently had some families ask us why treatment logs are important. A treatment log is a

place to track your treatments and when you have any bleeds. Tracking this information is important for many reasons, including treatment adjustments if needed (maybe your occasional extra dose isn't so occasional anymore), insurance purposes, recalls, etc. It's difficult to keep so much information in one's brain, write it down. There are many digital options available as well. Check out this link on NHF's Steps for Living (<https://stepsforliving.hemophilia.org/basics-of-bleeding-disorders/treatment-basics/treatment-logs>). If you are a HCWP patient, you can upload your treatment logs on the website; <https://hcwp.vitalant.org/Services/Patient-Upload.aspx>. While we're discussing treatment, make sure to take a look at the expiration dates on your home storage products, give us a call if you are expired or near expired.

NHF has an updated list of bleeding disorder scholarships with listed deadlines: <https://www.hemophilia.org/community-resources/financial-assistance/scholarships>

We hope all of you have a wonderful springtime, and we look forward to seeing you in the clinic and at community events!

## VIRTUAL DRAG QUEEN BINGO RETURNS!

On Thursday, March 10, WPBDF once again hosted a Virtual Drag Queen Bingo Fundraiser to help raise funds and awareness for the bleeding disorders community. Thirty people joined local Pittsburgh Drag Queen, Alora Chateaux, for an evening of entertainment and prizes. The cost to participate was \$20 per person and included the Zoom link to watch Alora's performance, a bingo card, and four rounds

of bingo. Additional bingo cards were available for purchase for \$5 per card. Prizes included a coffee basket, Bath and Body Works basket, game night basket, summer adventure basket, family scavenger hunt basket, and an arts and crafts basket. Prizes were awarded to the first person to call out or type BINGO in the chat box!

We are extremely grateful for everyone who participated in this event and are pleased to announce over \$600 was raised! All the money raised supports our emergency and medical patient assistance fund, educational

programs, and support groups that benefit the bleeding disorders community in Western PA. WPBDF would like to give a huge thank you to Alora for her constant support of our community. We are truly grateful for your continued support!



# 'IT GAVE ME MY LIFE BACK': AFTER YEARS OF PAIN FROM HEMOPHILIA, PITT STUDY CHANGED HIS LIFE

ANYA SOSTEK



About six years ago, Dan Price and his family attempted a short vacation to the Columbus Zoo. Because it was relatively close to home, Mr. Price didn't bring medicine to treat his hemophilia. But by 3 a.m., he was suffering from ankle pain so unbearable that he left his hotel room to find a hospital in Columbus that could inject him with a clotting factor. When Mr. Price tells stories of his life more than five years ago, he often prefaces them with "before." As in, before he was able to kick a soccer ball with his sons. Before, when he worried that he wouldn't be physically able to continue doing his job as a paramedic. Before he enrolled in a study about gene therapy and hemophilia through the University of Pittsburgh.

Five years after receiving one gene therapy injection in a room at UPMC Montefiore as part of the study, Mr. Price hasn't needed a single hemophilia treatment. His

body now knows how to produce a clotting factor on its own, essentially curing his hemophilia. "It's been amazing," said Mr. Price, 50, of South Franklin in Washington County. "It gave me my life back."

Mr. Price has hemophilia A, the most common type, which affects roughly 1 out of every 5,000 males worldwide. Those with severe hemophilia A produce less than 1 percent of normal levels of a protein called factor VIII, meaning that their blood doesn't clot normally, which results in uncontrolled bleeding, severe joint pain and a higher risk of death. Results of the study that Mr. Price took part in, which involved researchers at the University of Pittsburgh, the University of Pennsylvania and Penn State – as well as in Australia, Mississippi, Massachusetts, New York and Oregon – were published in November in the *New England Journal of Medicine*. Of the 18

patients who participated, all but two had lasting effects from the gene therapy that enabled their bodies to produce their own factor VIII. The participants had more than a 90 percent reduction in bleeding episodes, from an average of 8.5 each per year before the gene therapy to an average of 0.3 each per year after.

"This is the first time that gene therapy has been shown to correct hemophilia A with a safe and effective outcome," said Dr. Margaret Ragni, an author of the study and a professor of medicine and clinical translational research at the University of Pittsburgh. "It provides promise for other genetic disorders."

Because hemophilia A is a genetic disease, passed from mother to son, Mr. Price's parents knew even before he was born that there was a chance he'd inherit the disease. He remembers long, regular trips as a child from his home in rural Washington County to Children's Hospital of Pittsburgh, where he would spend hours getting infusions of a plasma product and other therapies. Mr. Price was never permitted to play sports as a child because of the dangers of bleeding and joint pain, although he was active in marching band and on his parents' and grandparents' farms.

While hemophilia can be painful and dangerous, it's not necessarily in the way that people think. "The common misconception is that if you cut yourself shaving you're going to bleed to death," he said. And while that's not true – Mr. Price suffered serious cuts growing up on a farm without major consequences – certain

CONTINUED ON PAGE 20...

# WHAT WOMEN WITH BLEEDING DISORDERS NEED TO KNOW ABOUT JOINT PROBLEMS

CONTINUED FROM PAGE 11...

pictures and talk about joint issues with their physicians, who may suggest an X-ray or a point-of-care musculoskeletal ultrasound. These tests can reveal a lot, especially if done within 12 to 24 hours of the injury, he says.

## WHAT YOU CAN DO

Sidonio recommends you document joint issues with a bleeding diary to record details such as the date, the duration and what makes it feel better. You can keep track on paper, download a bleeding app or use your phone's notes feature, as Kolbie Clarke does.

If you have lingering joint injuries, your HTC can help. Most have a dedicated physical therapist, and some have an orthopedic surgeon who visits throughout the year. You can also request that your joint range of motion be followed. Information like this helps the medical community further its knowledge of women and joint issues. Sidonio says, "That's what really makes a difference." Women with bleeding disorders are also encouraged to join the National Hemophilia Foundation's registry, Community Voices in Research (CVR). CVR connects the experiences of people with bleeding disorders to researchers investigating improving treatments and care.

Article Courtesy of HemAware copyright 2022

# MAX FEINSTEIN SHARES HIS WORLD

ON THE NEW HEMOPHILIA-INSPIRED CONCEPT ALBUM *REDEFINE*  
**OUT EVERYWHERE MARCH 25<sup>TH</sup>**  
 IN HONOR OF **BLEEDING DISORDER AWARENESS MONTH**



Whether on stage or on record, **MAX FEINSTEIN** is bent on spilling his guts while encouraging others to do the same. The Jersey City songwriter's "progressive grunge" sensibilities and chameleonic voice combine to create a thoughtful and immediate brand of rock that celebrates vulnerability.

While repairing an elbow heavily damaged by hemophilia, Max was forced to confront the ways in which

the rare bleeding disorder had impacted his mental health. It was during this process that he began to redefine his relationship with his body and mind.

Full of righteous guitars and theatrical vocals, Feinstein's third collection of music, **REDEFINE**, is an emotional rollercoaster of self-talk and self-determination that transcends its chronic illness origins.

### FOR FANS OF

Paul McCartney, Mike Patton, Ween, Steven Wilson, King Gizzard & the Lizard Wizard, Mastodon, The Mars Volta, Frank Zappa, Primus, working through some stuff, blowing off steam

### "FEINSTEIN DOES NOT PLAY A ROLE HERE."

From what I can hear, this is a piece of the puzzle that he is. This honesty cannot be staged; these outbursts of passion and feeling are real."

-KMS REVIEWS

"An aesthetic unlike anything we've heard, with a unique vocal timbre and a frenetic interpretation that sounds great through the complex guitar riffs and a dose of psychedelia."

-BOTECO INDIE

"The message couldn't be clearer. Don't hide behind your affliction; use it to inspire yourself and others."

-JIM TESTA, THE JERSEY JOURNAL

"This is an impressive amount of damage. Someone with this degree of elbow damage typically wouldn't be able to play guitar like this."

-SIDDHANT MEHTA, MD

"An epic soundscape that is every bit as complex, vulnerable, creative, and honest as the masterful musician that molded it."

-YACK! MAGAZINE

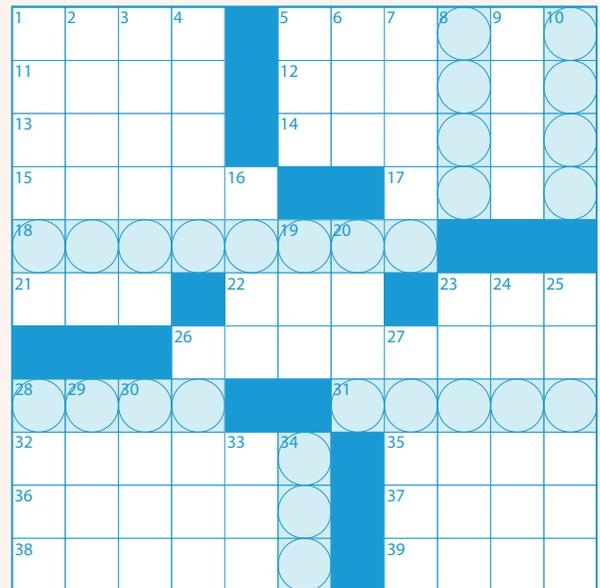


Jason Miller, Assistant Store Manager at Starbucks, nominated WPBDF to receive a \$1,000 grant from the Starbucks Foundation! WPBDF met with Jason and other Starbucks leadership to share the news on January 20. We are so thankful for Jason's constant support in helping to raise awareness and funds for the bleeding disorders community!

**CAN YOU SOLVE**

**FOR A DIFFERENT  
HEMOPHILIA A  
TREATMENT?**

**Test your HEMLIBRA knowledge**



**ACROSS**

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

\*According to IQVIA claims data from various insurance plan types from April 2020 - May 2021 and accounts for usage in prophylaxis settings in the US.

- 21. Calendar divs.
- 22. Regret
- 23. Banquet hosts (abbr.)
- 26. International travel necessity
- 28. Check out the \_\_\_\_\_ treated bleeds data with HEMLIBRA
- 31. Number of dosing options HEMLIBRA offers

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

- 32. Small hole in lace cloth
- 35. Central Plains tribe
- 36. Melodic
- 37. Towering
- 38. Reduce
- 39. Spanish cheers

**DOWN**

- 1. Memorable, as an earworm
- 2. Devotee
- 3. Medical fluids
- 4. Prepare to propose, perhaps
- 5. PC's "brain"
- 6. Owns
- 7. Concert venue
- 8. See Medication Guide or talk to your doctor about potential \_\_\_\_\_ effects
- 9. Winter hrs. in Denver and El Paso
- 10. HEMLIBRA is the only prophylactic treatment offered this way under the skin

- 16. Pre-Euro currency in Italy
- 19. Subway alternative
- 20. Relax
- 23. Human
- 24. New Orleans cuisine
- 25. Mentally prepares
- 26. Collared shirts
- 27. Instagram post
- 28. Ardent enthusiasm
- 29. Brontë heroine Jane
- 30. Old Portuguese coins
- 33. Opposite of WNW
- 34. More than \_\_\_\_\_ thousand patients have been treated with HEMLIBRA worldwide†

**SOLUTIONS**

Across: 1. cask, 5. chasms, 11. Aden, 12. parish, 13. tore, 14. used to, 15. cruel, 17. nest, 18. HEMLIBRA, 21. yrs, 22. rue, 23. M.C.s, 26. passport, 28. zero, 31. three, 32. eyelid, 35. Ctoe, 36. arose, 37. tall, 38. lessen, 39. oles  
 Down: 1. catchy, 2. adorer, 3. serum, 4. kneel, 5. CPU, 6. has, 7. arena, 8. side, 9. MSTs, 10. shot, 16. lira, 19. bus, 20. rest, 23. mortal, 24. Creole, 25. steels, 26. polos, 27. photo, 28. zeal, 29. Eyre, 30. Reis, 33. ESE, 34. ten

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

**INDICATION & IMPORTANT SAFETY INFORMATION**

**What is HEMLIBRA?**

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

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

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

**These serious side effects include:**

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

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



**Medication Guide**  
**HEMLIBRA® (hem-lee-bruh)**  
**(emicizumab-kxwh)**  
**injection, for subcutaneous use**

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

**HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.**

**HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:**

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

**If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.**

**Your body may make antibodies against HEMLIBRA, which may stop HEMLIBRA from working properly. Contact your healthcare provider immediately if you notice that HEMLIBRA has stopped working for you (eg, increase in bleeds).**

See “**What are the possible side effects of HEMLIBRA?**” for more information about side effects.

**What is HEMLIBRA?**

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

**Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:**

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

**Tell your healthcare provider about all the medicines you take,** including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

**How should I use HEMLIBRA?**

**See the detailed “Instructions for Use” that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.**

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.

- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

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

- See “**What is the most important information I should know about HEMLIBRA?**”

**The most common side effects of HEMLIBRA include:**

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

**How should I store HEMLIBRA?**

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

**Keep HEMLIBRA and all medicines out of the reach of children.**

**General information about the safe and effective use of HEMLIBRA.**

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

**What are the ingredients in HEMLIBRA?**

**Active ingredient:** emicizumab-kxwh

**Inactive ingredients:** L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,  
1 DNA Way, South San Francisco, CA 94080-4990  
U.S. License No. 1048

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For more information, go to [www.HEMLIBRA.com](http://www.HEMLIBRA.com) or call 1-866-HEMLIBRA.  
This Medication Guide has been approved by the U.S. Food and Drug Administration  
Revised: 12/2021



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**Genentech**  
A Member of the Roche Group

# GOT STRESS: STRATEGIES FOR ANXIETY AND WORRY



HFA and Mental Health Matters Too collaborated to offer a workshop to HFA member organizations throughout the United States on how to manage anxiety and worry. On February 10, 17, and 24 the Western PA Bleeding Disorders Foundation brought this workshop to the Western PA community. Led by Debbie de la Riva, Licensed Professional Counselor and Certified Mental Health First Aid Instructor, and using the techniques explained in the book, *Don't Feed the Monkey Mind: How to Stop the Cycle of Anxiety, Fear, & Worry* by Jennifer Shannon, LMFT, participants were taught

the concept of mindset and how it sometimes creates excessive worry and fear. Participants took quizzes to find out which monkey mindset they most recognized in themselves. These monkey mind-sets included Intolerance of Uncertainty, Perfectionism, and Over-responsibility. Once those mindsets were discovered, participants were put into breakout rooms to deep dive into further discussion about how the mindsets affect their lives. Participants discovered that when they respond to anxiety with safety strategies, they confirm the perception of threat and further feed the monkey. To thrive, we all

must replace safety strategies with expansive strategies. Participants discussed and shared expansive mindsets and how they can incorporate them in their day-to-day life. It was also discussed how worry will dissipate if it is welcomed and tolerated, rather than resisted or acted upon. Participants also took the time to reflect upon what values are important to them and how they can override the monkey's value of safety when focusing on honoring those values. They were taught that Anxiety x Welcoming = Resilience and with resilience to anxiety, peace and presence can be claimed.



## WPBDF's Mother's Day Paint N' Sip

*Virtual Wine Glass Painting*

Sunday, May 8, 2022 • 3:00 PM - 5:00 PM

**Cost:**

**Registration with kit pick-up: \$25 | Registration with kit shipping: \$35**

Celebrate Mother's Day while supporting the Western Pennsylvania Bleeding Disorders Foundation! Join us on Sunday, May 8<sup>th</sup> from 3-5 pm. Local artist, Angela Dragich, will provide step-by-step instruction on how to create a beautiful spring scene on a wine glass.

Painting kits will include one wine glass, 2 paint brushes, 6 paint colors, and instructions to care for your glass. Kits can be picked up at the Foundation office or shipped to you.

**Learn more and register today at:  
<https://give.classy.org/wpbdpaint>**

## 'IT GAVE ME MY LIFE BACK': AFTER YEARS OF PAIN FROM HEMOPHILIA, PITT STUDY CHANGED HIS LIFE

CONTINUED FROM PAGE 15...

injuries like cuts in the mouth can be dangerous because of difficulty healing, as well as what he calls "epic nosebleeds."

As with many hemophiliacs, the biggest impact on Mr. Price's quality of life came from joint pain, caused by internal bleeding. By his early to mid 40s, "every time I got out of a chair it was pain. I woke up, pain. It was just pain 24/7," he said. "My ankle had deteriorated to the point where I was ready to saw the darn leg off. I thought, having an artificial foot has got to be better than this."

He would sometimes work his entire shifts at his job as a Peters Township paramedic from the garage rather than face the pain of walking up steps to the office. Doctors were considering fusing Mr. Price's ankle because he didn't have much mobility anyway. He was also getting time-consuming infusions of factor VIII multiple times per week to dull the pain caused by internal bleeding. And while he no longer had to go to the hospital for treatment, as he did as a child, he would often drive to his work to have one of his co-workers do it rather than limit himself to the veins he could find at home one-handed.

Even before gene therapy, hemophilia treatment had come a long way. In the early 1900s, when the life expectancy for a hemophiliac was just 12 years old and there was no way to store blood, treatment was limited to whole blood donations from family members. Various treatments were tried in the years since, from diluted snake venom to peroxide to

gelatin, until scientists discovered transfusions of plasma, which became common in the 1940s and 1950s. But even in 1960, the life expectancy for a hemophiliac was less than 20 years old.

The 1970s and 1980s brought advances in using thawed frozen plasma, as well as freeze-dried

many doctors' appointments and treatments over the years, he would always ask about new treatments on the horizon.

Scientists had been talking about the possibility of using gene therapy for hemophilia since the late 1990s, and while some experiments showed early promise



DANIEL PRICE AND HIS WIFE, STACEY, WITH THEIR SONS SAMUEL, 10, LEFT, AND NOAH, 7, IN SOUTH FRANKLIN PARK ON DEC. 30. (PITTSBURGH POST-GAZETTE)

powder concentrates that could be administered at home. But hemophiliacs in the 1980s were devastated by the AIDS epidemic, with HIV transmissible through blood products. About half of the hemophiliacs in the United States contracted HIV and thousands died, according to the National Hemophilia Foundation. Although Mr. Price never contracted HIV, he did get hepatitis C through donated blood, which was later cured with treatments of interferon.

At 50, Mr. Price has outlived the other hemophiliacs in his family. A cousin in Texas died of AIDS. His uncle likely died of a brain hemorrhage. One of his grandmother's brothers died as a toddler, and another committed suicide in his 20s.

When Mr. Price would go to his

in encouraging the body to produce Factor VIII, the results weren't durable. After a year or less, the body would go back to being unable to produce factor VIII, and bleeding episodes would resume. Then, about five years ago, Mr. Price got a call from the Hemophilia Center of Western Pennsylvania asking if he wanted to be part of a new study. "They said, 'If this works, you may possibly be cured.' I said, 'What hospital and what time do I have to be there?'"

Gene therapy works by using a virus to introduce new genetic material into the body that takes over existing genes. "You can think of the virus like a truck carrying cargo," said Dr. Ragni. "It goes into a cell, puts a copy of itself into the nucleus and takes over the genetic

material of the cell, which allows it to make factor VIII, and it goes into the blood stream.”

Gene therapy is under experimentation to help treat numerous genetic diseases, from sickle cell anemia to cystic fibrosis to forms of blindness.

Mr. Price expected that getting injected with genetic material would be a major procedure, and he packed expecting to stay the night at UPMC. Instead, he got the shot and was told he could leave after half an hour. He suffered no side effects whatsoever. And he hasn't had to do a single infusion of factor VIII since.

“There were no negative results from the genetic stuff at all – It was all positive. How often does that happen?” he said. “They just put stuff in there that told my body, hey dummy, start making factor VIII. You've been slacking for 45 years now. [It's] Time to pick up the pace.”

Most participants in the study were given steroids along with the gene therapy to reduce the change of their bodies mounting an immune reaction to the genetic material. Two of the study subjects stopped making factor VIII, presumably because of an immune response. But the other 16 continued to produce factor VIII as long as they were followed by the study.

Dr. Ragni said that participants in the study averaged factor VIII levels at only 12 percent of what a non-hemophiliac would produce, but that amount was enough to virtually eliminate bleeding episodes. The lower level may have been what made the study more successful than previous ones, she said.

For Mr. Price, it's been absolutely life changing. He still can't run any distance and still has lingering joint damage, but he has been able to play soccer with his sons, ages 7 and 10, and take them to Colonial Williamsburg and two trips to

Disney World, spending entire days walking.

“One wanted to go hunting this year, so I took him deer hunting, and whenever we got bored sitting, we walked through the woods and talked,” he said. “I couldn't have done that before. There's no way – I would have had to drive my truck up to the field.”

The hardest part at times is convincing himself that it's going to last.

“It's been five years and I still feel like this is going to end, that I'll wake up and my ankle will be exploded out and in pain,” he said. “But it hasn't happened yet.”

*Anya Sostek: asostek@post-gazette.com. First Published January 17, 2022, 6:00am*

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

#### **Factor Program Services**

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

#### **Patient Benefits**

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

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

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

**rebinyn<sup>®</sup>**  
 Coagulation Factor IX  
 (Recombinant), GlycoPEGylated

Learn more at  
[rebinyn.com](http://rebinyn.com)

**esperoct<sup>®</sup>**  
 antihemophilic factor (recombinant),  
 glycopegylated-exei

Discover more at [Esperoct.com](http://Esperoct.com).

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# KEEP CALM AND GET YOUR HOT COCOA ON!

**MARIA STEELE VOMS STEIN, WPBDF'S WOMEN'S GROUP COORDINATOR**

On Thursday, January 27, the WPBDF Winning Women's group hosted a virtual Hot Cocoa Bomb Making event. Women who registered for the event received a box of supplies from Yaymaker that included all of the tools needed for our creations. During the event, Cathy of Yaymaker guided us with step-by-step instructions on creating beautiful and delicious hot cocoa bombs.

The WPBDF 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.



# REBUILDING THE BODY WITH DIET

Myles Ganley, a long-time member of the bleeding disorders community, enjoys helping others in the community in as many ways as possible. Myles, a fitness enthusiast and amateur chef, has hemophilia B and is a Community Liaison with Medexus Pharma. On March 13, Myles led a virtual cooking demonstration, as a component of Medexus Pharma's BActive™ program, *Rebuilding the Body with Diet*. Myles taught us how to cook a delicious meal—chicken parmesan with homemade sauce (vegetarian alternatives were eggplant and portabella mushroom)! Many of the program participants followed along and cooked their dinners with Myles who was quick to answer questions and offer cooking advice. Prior to the event, participants received a list of ingredients and a gift card to purchase them.

This family-friendly event was co-sponsored by Optum and Medexus Pharma. Optum provided aprons for children ages 12 and under. We thank Evan Kerstetter, Patient Liaison, Optum and Nora Latcovich, RN, MSN, Hemophilia Territory Manager, Medexus Pharma for sponsoring this event.



**Optum**

**MEDEXUS PHARMA**

# GENE THERAPY JEOPARDY

For those who enjoy learning or testing their knowledge in a game environment, Gene Therapy Jeopardy was the perfect fit! BioMarin's Gene Therapy Jeopardy game was a new approach to learning the science behind Gene Therapy. No previous knowledge was required. Contestants chose the categories and question levels and then everyone had the opportunity to select the correct answer on their device. Tommy Russamano, BioMarin Sr. Account Manager, hosted the event and provided the education behind the answer to each question. This event was held virtually on February 3, and we thank BioMarin for sponsoring this program.



JEOPARDY! LEADERBOARD		
Rank	Player	Score
1	Cameron	\$1,800
2	sarah	\$1,620
3	Sheryl b	\$1,085
4	Tommy BioMarin	\$600
5	Sophia Herndon	\$600
6	Jessica L	\$200
7	Lies W	-\$910
8	Jeanne	-\$1,100
9	teresa	-\$1,216
10	Jessica L	-\$1,400



# STAY IN MOTION STORIES

## SHERYL AND MICHAEL



Western Pennsylvania Bleeding Disorders Foundation

Sheryl and her son Michael joined Stay In Motion in October 2021 when the program was first announced. Stay In Motion allows those affected by bleeding disorders to join with a friend or a family member to add an extra layer of support and motivation!

“We like to learn!” Sheryl says. Her and her son value the educational opportunities provided by the Foundation and wanted to join Stay In Motion because it offers virtual education activities.

Stay in Motion provides access to educational videos, support from the HCWP physical therapist and social workers, invitations to monthly physical fitness and educational programs, weekly educational resources, monthly fitness challenges, support from your Western PA bleeding disorders community, and a fun, motivational care package upon

registration. “My favorite thing about the program so far is the videos,” Sheryl says. “I liked the goal setting video. It helped me set a realistic goal and reminded me that it is ok to adjust the goal if needed.”

Sheryl’s first goal was to replace a glass of pop with a glass of water. While it may sound like a simple goal, it was a huge accomplishment for her. “I drink way too much diet coke, but now, I’ve really reduced my pop consumption.”

The Stay In Motion program helps to hold you accountable by helping you set a weekly goal. Each participant receives a daily goal journal that helps you stay on track and focuses on your mental health as much as your physical health. Sheryl adds, “I don’t always meet the goal, but then I adjust for the next week. I keep my journal right on the counter where it’s always in sight.”

Four days a week, Sheryl takes part in group fitness classes at her local gym. One day is stretching and the other classes are HIIT workouts (high intensity interval training). “Some days after work, my ‘high intensity’ isn’t really high, but I go anyway,” she adds. “Selecting a lower weight or making an exercise low impact is better than not moving at all. I feel better when I exercise.”

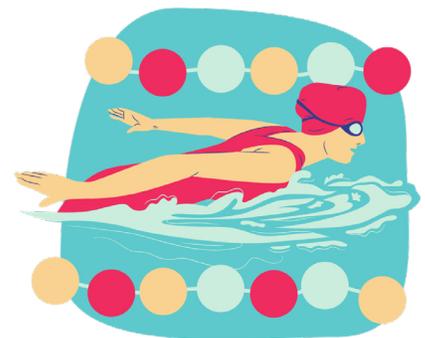
Michael was diagnosed with severe Hemophilia A when he was 11 months old, and the doctors at HCWP stressed the importance of physical activity. He works late shifts, from 3:00 PM to midnight, but he is disciplined and closely follows his weekly routine. He swims three days a week and strength trains two days a week. At work, he takes the stairs instead of the elevator and parks farther away from the door at the grocery store.

“Having hemophilia, I know that it is important to have strong joints and muscles,” Michael says. “I also know it is important to maintain a healthy weight.” Michael’s been swimming since he was just two years old.

In addition to the physical benefits, swimming provides a stress release component for Michael. Strength training is also an important part of his physical activity. Michael spoke to his doctor at HCWP and met with a personal trainer in Erie. His trainer designed a program that involves body weight exercises as well as lifting. Michael has learned over the years to modify his exercises when needed.

“The Physical Activity Guidelines video was a good reminder that while having Hemophilia may limit some activities, like not being able to play football, there are still plenty of physical activities that I can participate in to stay healthy,” Michael adds. “I know all this, but it is still important to hear and the video is a good reminder.”

Sheryl and Michael are looking forward to future events and resources in the Stay In Motion program! You can join them today by visiting <https://wpbdf.org/sim/>. If you have any questions about this program, please contact the Foundation at 724-741-6160 or email [info@wpbdf.org](mailto:info@wpbdf.org).



The Western Pennsylvania Bleeding Disorders Foundation invites you to attend an **IN PERSON**

# Women's Retreat

**Saturday, May 14, 2022**

**9:30 AM - 3:00 PM**

**Wyndham Pittsburgh University Center**

100 Lytton Avenue

Pittsburgh, PA 15213

Join us for lunch and a special day of interaction and education!

This event is open to women of the Foundation who are adults or mature teenagers who have a bleeding diagnosis or are a parent/caregiver or spouse/partner of someone with a bleeding disorder.

## Keynote

*Be Your Best Advocate: Making Sure You're Heard*

**Speaker:** Dr. Nicoletta Machin

## Choice of breakout session:

*Women with Bleeding Disorders: What does Age have to do with it?*

**Speaker:** Dr. Margaret Ragni

This talk will be interactive and feature a brief review of VWF, FVIII and FIX as we age and what this means for bleed risk as we age.

*A Pathway for Best Care: The Reproductive Years*

**Speaker:** Dr. Nicoletta Machin

OR

In this session, attendees will learn about how to identify the symptoms of a bleeding disorder and how to effectively manage the onset of menorrhagia, family planning and childbirth.

**RSVP by Monday, May 2 here:**

<https://www.surveymonkey.com/r/96LVVF2>

or by calling the Foundation office at 724-741-6160.

If there's more than one person attending from the same household, a separate registration form must be filled out for each person.

Travel grants are available for participants when the expense of traveling could create a hardship.

*Masks are strongly encouraged and may be required, depending on the rate of COVID -19 infections and recommendation of the department of health.*

**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.**







# STAY IN MOTION HIKE

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**When:** Saturday, April 30<sup>th</sup>  
10:30am-12:30pm

**Where:** Frick Park  
**Clayton Loop**  
Trail entrance is located near  
the Frick Environmental Center  
located at:  
2005 Beechwood Blvd,  
Pittsburgh, PA 15217

Join us for a hike on the Clayton Loop at Frick Park! This is an all-levels, 1-mile trail that encompasses Clayton Hill.

Rain or Shine. Family and stroller friendly! Sorry, no pets allowed. This program is for members of the Western Pennsylvania Bleeding Disorders Foundation and family members living in their household.

To register, email [rsvp@wpbdf.org](mailto:rsvp@wpbdf.org) or call  
724-741-6160.



WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

775 4<sup>th</sup> Street  
First Floor  
Beaver, PA 15009

# WPBDF's ANNUAL MEETING

Thursday, July 21, 2022  
Dave & Buster's  
180 E Waterfront Drive  
Homestead, PA 15120

Learn more about the services the Foundation offers, help us recognize our top volunteers, visit our sponsor booths, and help us kick off the Unite for Bleeding Disorders Walk!

Keep an eye out for more information coming soon! Stay up to date with all Foundation events at:  
<https://wpbdf.org/events/>

*Save the Date*



# HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

775 4<sup>th</sup> Street, First Floor  
Beaver, PA 15009

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