



# HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

SUMMER 2022



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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 Foundation.

**WPBDF Contributor Agency Code Number is: 83**

## EVENTS CALENDAR

### July 21, 2022

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

### July 30, 2022

Stay In Motion: Food & Fitness  
Monroeville, 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 1, 2022

Wheels for the World  
Save One Life Fundraiser  
Leesport, 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

Education Weekend  
Seven Springs  
Mountain Resort  
Champion, PA

### November 19, 2022

Take A Bough  
Gaetano's  
Pittsburgh, PA

### December 10, 2022

Winter Program  
National Aviary  
Pittsburgh, PA

VISIT [WPBDF.ORG](http://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](mailto:jessica@wpbdf.org).

## Donations Needed!

The Western Pennsylvania Bleeding Disorders Foundation is in need of donations for their holiday auction fundraiser. Donations such as unlit artificial Christmas trees, string lights, ornaments, centerpieces, wreaths, holiday decor, and themed gift baskets or gift cards are great contributions. You can also sponsor a tree or wreath with a monetary donation.

If you would like to help, please e-mail Jessica Lee at [jessica@wpbdf.org](mailto:jessica@wpbdf.org) or call 724-741-6160 to schedule a time to drop off items at the Foundation office! Our office is located at 775 Fourth Street, First Floor, Beaver PA 15009.



Save the date! Saturday, November 19, 2022

### Take A Bough:

Holiday Auction to Benefit  
the Western PA Bleeding  
Disorders Foundation

Gaetano's  
1617 Banksville Road  
Pittsburgh, PA 15216

Learn more at [wpbdf.org](http://wpbdf.org)



## CONTACT US

### Western Pennsylvania Bleeding Disorders Foundation

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

Phone: 724-741-6160  
Toll Free: 800-824-0016  
Fax: 724-741-6167

[www.wpbdf.org](http://www.wpbdf.org)  
[info@wpbdf.org](mailto:info@wpbdf.org)

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# LETTER FROM THE EXECUTIVE DIRECTOR AND BOARD PRESIDENT

Dear Foundation Members & Friends,

We hope everyone is having a great start to the summer! After many months of virtual programming, it feels so good to be holding in-person events again. June marks the end of the Foundation's fiscal year and is a time we like to look back on what we accomplished and the work that lies ahead of us.

This fiscal year we held 27 virtual programs, 6 in-person programs, 6 virtual fundraisers, and 1 in-person fundraiser. We increased our ability to provide emergency financial assistance to community members in need. We provided over \$36,800 in patient assistance to over 200

community members in need. We made our Grocery Assistance Program a permanent program as it has created a streamlined way for us to get grocery gift cards to those in the community struggling with food insecurity. We provided over \$30,600 in grocery gift cards to 60 families in need. In total, we've provided over \$66,000 in direct patient assistance, which is more than double what we have been able to provide in the past.

We have continued to keep our Advocacy Ambassador program going strong. We have secured a 6% increase to the hemophilia line item in the Pennsylvania state budget! These funds are split among the 7 Hemophilia Treatment Centers in Pennsylvania and are used to support patient centered care including the Consumer Advisory Council, mental health support, unified care plan, and patient assistance. We are working hard to end co-pay accumulators and improve prior authorization and fail first policies for Pennsylvanians.

We need to continue

building strong relationships with legislators and we need your help. If you would be interested in joining us in meeting with legislators or would like to get involved by making phone calls or writing letters, please reach out to me at [kara@wpbdf.org](mailto:kara@wpbdf.org) or 724-741-6160.

We have many upcoming events including the Unite for Bleeding Disorders Walk and Run for Their Lives 5k on September 10<sup>th</sup>, our Fall Program in Erie on October 8<sup>th</sup>, Education Weekend at Seven Springs Mountain Resort taking place November 5<sup>th</sup>-6<sup>th</sup>, and our Winter Program at the National Aviary on December 10<sup>th</sup>. We hope to see you all there!

As always, please contact the office with any questions or concerns. It is truly an honor to be leading this organization.

Sincerely,  
Kara Dornish  
Executive Director

R. Scott Domowicz  
Board President



# One Family.

This World Hemophilia Day, help us harness the power of the hemophilia community to raise awareness for joint health with our blood brothers and sisters around the world.



## WPBDF CELEBRATES WORLD HEMOPHILIA DAY



sanofi

On the evening of Tuesday, April 12<sup>th</sup>, we held a World Hemophilia Day program virtually over Zoom to celebrate World Hemophilia Day on April 17<sup>th</sup>.

Thank you to everyone who joined us and to Sanofi for bringing this program to our community. We participated in hands-on activities to simulate joint damage and were then asked to perform daily activities that we often take for granted such as brushing our hair, buttoning up a shirt, eating, and writing our name. It brought awareness to the struggles that

those with bleeding disorders in developing countries, without proper treatment, face every day. We then took time to write cards with words of encouragement to our blood brothers and sisters around the world. Sanofi partnered with Save One Life to mail out the cards to those affected with bleeding disorders around the world. We discussed different ways we can make a difference such as making monetary donations, donating factor, spreading awareness, and advocating for the community.

## WPBDF RECEIVES HFA'S YOU MATTER AWARD

The Western Pennsylvania Bleeding Disorders Foundation is honored to have received HFA's You Matter Award for Mental Health Awareness.

We are grateful to HFA and Debbie De La Riva for creating mental health programming that we have

been able to bring to the Western PA community. Two of our staff members, Kara and Janet, have been certified in Mental Health First Aid. The Mental Health First Aid course and training was provided to us free of charge by HFA.





# ADVOCACY UPDATE



Advocacy is a key component of the Foundation's mission. Our overarching goal is to preserve access to care for our community members in Pennsylvania.

As such, we are involved with budgetary, policy and legislative issues that arise in Harrisburg. We are strategically positioned to be proactive in our advocacy efforts, while also being nimble enough to react when needed.

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

## Understand the Issues

### MAINTAIN FUNDING TO ALL 7 HEMOPHILIA TREATMENT CENTERS IN PENNSYLVANIA

On Friday, July 8<sup>th</sup>, Governor Tom Wolf signed the Pennsylvania state budget into law. We are very happy to report that we have secured a 6% increase to the hemophilia line item in the Pennsylvania state budget (from \$959,000 to \$1,017,000). In addition, fiscal code language has passed to ensure distribution among all 7 Hemophilia Treatment Centers in Pennsylvania!

The funds appropriated for hemophilia services in the state budget are split among the 7 Hemophilia Treatment Centers in Pennsylvania and are used to support patient centered care including the Consumer Advisory Council, mental health support, unified care

plans, and patient assistance. This could not have happened without your help. Thank you to everyone who contacted your legislators and shared your stories of the importance of the Hemophilia Treatment Centers in Pennsylvania.

### END CO-PAY ACCUMULATORS IN PENNSYLVANIA

Several states have already eliminated accumulator programs, and we are working to eliminate them in Pennsylvania. Bipartisan legislation has been introduced that would protect patients from having their prescription drug co-pay assistance programs undercut by their health insurer or pharmacy benefit managers. Introduced by Reps. Barbara Gleim (R-Cumberland County) and Mark Longietti (D-Mercer County), House Bill (HB) 1664 along with Senate Bill (SB) 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. 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 Foundation office at 724-741-6160. Your personal stories are very important right now as we work on getting this legislation moved out of the Banking and Insurance Committees.

### IMPROVE PRIOR AUTHORIZATION AND FAIL FIRST POLICIES FOR PENNSYLVANIANS

SB 225 (Phillips-Hill, R-York): Amends Insurance Company Law of 1921 by:

Not requiring prior authorization for emergency services, including

testing and other diagnostic services that are medically necessary to evaluate or treat an emergency medical condition prior to the point at which the conditions are stabilized;

Allowing one FDA-approved prescription drug classified as medication assisted treatment without initial prior authorization;

Requiring insurers, Managed Care Organizations (MCO) or contractors to establish a provider portal for electronic submission of prior authorization;

Requiring a list of all health services for which prior authorization is required to be posted on the insurer, MCO or contractor's website;

Requiring medical policies that incorporate step therapy for prescription drugs to be reviewed in accordance with the standards set forth in prior authorization review; The review shall also take into consideration the enrollee's individualized clinical condition with respect to contraindications, clinical effectiveness or ineffectiveness of the required prerequisite prescription drugs, past clinical outcomes, expected clinical outcomes of the prescribed prescription drug and, for new enrollees, whether the enrollee has already satisfied a step therapy protocol with their previous health plan that required trials of drugs similar to those currently required in a step therapy protocol.

SB 225 passed unanimously out of the Senate on June 29<sup>th</sup>, 2022.

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# ADVOCACY UPDATE

CONTINUED FROM PAGE 5...

The bill will be sent to the House for consideration.

Visit <https://www.wpbdf.org/getinvolved/advocacy> to stay up to date on advocacy issues and sign up for action alerts.

## ADVOCACY AMBASSADOR PROGRAM



Advocacy Ambassadors are volunteers in a leadership position, responsible for helping to establish and build a strong grassroots network of bleeding disorders advocates within Pennsylvania. The goal is to increase awareness of Hemophilia, von Willebrand disease, and other factor deficiencies and the challenges persons affected and their families face. Ambassadors serve as liaisons between the Pennsylvania Bleeding Disorders Foundations and the public, state agencies and officials working towards improving the quality of life of individuals and their families who are affected by bleeding disorders.

### WHAT IS THE ROLE OF AN AMBASSADOR?

Advocacy Ambassadors are volunteers interested in helping to lead our state's grass root advocacy efforts and promote the importance of becoming an advocate within our community.

### LEARN MORE ABOUT BECOMING AN ADVOCACY AMBASSADOR AT:

[HTTPS://WWW.WPBD.F.ORG/GETINVOLVED/](https://www.wpbdf.org/getinvolved/)

# A GUIDE TO GRASSROOTS ADVOCACY FOR THE BLEEDING DISORDERS FOUNDATIONS

**ERIK ROSS**

**SENIOR ASSOCIATE**

**MILLIRON & GOODMAN GOVERNMENT RELATIONS**

On January 5, 2021, the Pennsylvania General Assembly began a new two-year legislative session and we are midway through the second year, which is an election year, so the legislative calendar and opportunity to get issues approved tightens. Over the course of a legislative session, our state legislators will consider multiple pieces of legislation that could have a significant impact – positive or negative – on the Eastern and Western PA Bleeding Disorders Foundations. Whether you're supporting or opposing a bill, regulation or budget item, grassroots advocacy is now more important than ever.

Once upon a time, it was not out of the ordinary for incumbents to serve twenty or thirty plus years. Long-serving veteran members were often valued not only for their experience and expertise on issues, but also as legislative champions. However, politics, retirements and frustration with the legislative process have paved the way for an influx of new members. Since 2010, both chambers of the General Assembly have seen historic turnover; 75% of the House and nearly 70% of the Senate have a decade or less experience.

With every freshman class,

challenges lie ahead. There is a learning curve, new set of priorities, and competing interests. Without outspoken advocates, issues can quickly get lost in the thousands of bills introduced each legislative session.

Elected officials want to hear from their constituents – the people that elected them and can re-elect them. Building strong, personal relationships with legislators and their staff is one of the most important, yet overlooked, aspects of working in the public utility or authority arena.

In the short-term, you are putting a face on an issue that allows legislators to connect beyond the facts and figures. In the long-term, you are developing legislative champions that will seek your advice before addressing issues affecting the bleeding disorders community.

We strongly encourage you to get to know your legislators – whether it's coffee to introduce yourself, a meeting (in-person or virtual) to discuss an issue or inviting your legislator on a tour of your hemophilia treatment center (HTC). All are examples of community and grassroots advocacy and effective ways to build relationships with your legislators.

Finally, we'd like to share a few grassroots tips we've learned along the way:

### 10 TIPS ON EFFECTIVE GRASSROOTS ADVOCACY

1. Before contacting your legislators, do a little homework. Research their biography, committee assignments, cosponsor memos and legislation sponsored. This will offer some insight into their legislative interests. You might also discover that you attended the same school or have a hobby in common. The Pennsylvania General Assembly website is

- also a great place to start.
2. If you do not know or have never met your legislators, you should attempt to make your first meeting a friendly, get-acquainted occasion. This could be as simple as introducing yourself as a constituent at a town hall meeting or local event. Follow-up by scheduling a personal meeting in their office or a virtual meeting through ZOOM or TEAMS.
  3. Take advantage of additional opportunities to connect with your legislators – whether inviting your legislators to attend an open house, an award ceremony, or a Foundation event. Likewise, opportunities might arise through involvement with professional organizations, civic or charitable organizations, or political parties.
  4. The hometown connection is essential to getting a legislator's attention, so

always identify yourself as a constituent – where you live and how you are connected to the community.

5. You are the expert on your issue and knowing what you or the bleeding disorders community needs. You are meeting with the legislator as a constituent. You do not have to be an expert in the legislative or regulatory process.
6. If discussing an issue, be brief, clear, and accurate. Telling your story by sharing your experiences, struggles and solutions is the most persuasive message. Allow the legislator to offer his or her view on the issue and ask questions. If the legislator asks questions that you cannot answer, be honest and provide the requested information later.
7. Your legislator may not always agree with your position. Be persistent, but not argumentative. Provide points supporting your issue. Ask thought provoking questions

that will encourage him or her to contemplate your position. Keep in mind that a legislator who opposes you on an issue today may become a valued ally on a different issue tomorrow.

8. Get to know your legislator's staff. They usually have more time to devote to your issues and have more time to learn the details of an issue before briefing their legislator.
9. Always express appreciation. Follow-up with a thank you letter or e-mail that briefly restates your main points and includes any information you offered to provide.
10. Once acquainted with your legislators, it is important to maintain an ongoing relationship. Stay informed about your legislator's activities by subscribing to his or her newsletter. Attend and participate in town hall meetings. Invite your legislators to your office to meet with your colleagues.



# SAVE THE DATE

**Saturday, October 8, 2022**

**Bayfront  
Convention Center**

1 Sassafras Pier,  
Erie, PA 16507

**10:00 AM - 1:00 PM**

Join us for exhibits, an  
educational program and lunch.

Spend the rest of the day at  
Splash Lagoon!

**LEARN MORE AT WPBDF.ORG OR  
CALL THE FOUNDATION OFFICE AT  
724-741-6160.**

WPBDF'S  
**FALL  
PROGRAM**



# Education Weekend

The Western Pennsylvania Bleeding Disorders Foundation's Education Weekend benefits patients and their families living with hemophilia, von Willebrand Disease, and other rare bleeding disorders.



“ I'm the mom of a eight-year old boy with Severe Type A Hemophilia, and I'm also a carrier of Hemophilia. I'm excited to learn more about treatment options for bleeding disorders. I'm also looking forward to connecting with other bleeding disorder families. ”

- Kelly

## Program Information:

The weekend will include sessions for adults with bleeding disorders and parents of children with bleeding disorders. Special programs and activities are provided for children ages 5-18 and daycare is provided for children ages 0-4.

Sessions include:

- Controlling Bleeding -- The basic and the new
- Infusion Training
- Mental Health
- Social Activities

Fun, educational sessions and activities will be provided for children, based on age group. Activities may include bowling, indoor mini-golf, scavenger hunt, and game room.

Two special pre-conference programs will be offered for Friday evening, November 4: Teen & Parent and New Parent Network. Invitations for those programs will be sent to eligible members.



**All ages are welcome!**  
**November 5-6, 2022**

**SEVEN SPRINGS MOUNTAIN RESORT**  
777 Waterwheel Dr.,  
Seven Springs, PA 15622

## Registration Information:

- To request registration forms, send an email to [rsvp@wpbdf.org](mailto:rsvp@wpbdf.org) or call 724-741-6160.
- The deadline to request registration forms and a scholarship application is September 7, 2022.
- WPBDF must receive completed registration forms and deposit (or scholarship application) by **September 21, 2022.**



*The only cost to attend this event is a \$25 non-refundable registration fee, per family (due at time of registration). If the \$25 registration fee and/or cost of transportation would present a hardship that would prevent you from attending, you may apply for a scholarship.*

*Registration is limited to immediate family members living in the household with the person who has a bleeding disorder.*

**Learn more at:**  
[wpbdf.org/event/education-weekend-4](http://wpbdf.org/event/education-weekend-4)



# HOW TO KEEP SUMMER ACTIVITIES SAFE FOR KIDS WITH BLEEDING DISORDERS

## LEARN WHY A POPULAR PIECE OF BACKYARD PLAY EQUIPMENT IS RISKIER THAN YOU MIGHT THINK

### DONNA BEHEN

It's summertime, and kids are out of school and excited to have fun in the great outdoors. After a year of remote learning, social isolation and so much uncertainty, probably more than ever!

But if you're the parent of a child with hemophilia or another bleeding disorder, your eagerness for your child to get outside and be active is tempered by the concern that the sport they are playing or another activity they're doing might put them at risk for a serious injury.

What can you do to help make this summer an enjoyable and active one for your child while also keeping him or her safe from injuries?

For advice about hemophilia

and sports, we turned to Alice Anderson, PT, DPT, PCS, a co-author of the National Hemophilia Foundation's (NHF's) *Playing It Safe: Bleeding Disorders, Sports and Exercise* guide. Here's what she recommends:

### CHECK WITH YOUR HTC

A good first step is to talk to your child's hemophilia treatment center (HTC), Anderson says. "You can find out if they recommend that your child be on prophylaxis, and if your child has a problem joint, you can determine if there are specific sports that would be safer for them than others," she says. You can also talk about any measures you can take to make the sport or activity safer. "Clearly, it's a no-brainer that everybody should use the appropriate safety gear for each sport," she adds.

### STEER CLEAR OF ACTIVITIES WITH A 3 RATING

In the *Playing It Safe* guide, sports that are rated 3 for "high risk"

include BMX racing, boxing, tackle football, rugby and wrestling. "These are sports that can be dangerous for anyone, regardless of whether they have a bleeding disorder, because they are considered high velocity and/or at high risk for collision," Anderson says. "The most important thing we want to prevent is a blow to the head, which at the very least can cause a concussion and at the very worst, a head bleed."

### BE CAUTIOUS WITH TRAMPOLINES

Sales of backyard trampolines jumped last summer as families looked for ways to keep their kids occupied at home during the pandemic.

But the American Academy of Pediatrics strongly discourages the use of home trampolines for any child, citing the high rate of injuries that can occur, including fractures and dislocations. In the *Playing It Safe* guide, trampoline use has a

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# WPBDF GETS CREATIVE FOR MOTHER'S DAY!

On Sunday, May 8<sup>th</sup>, WPBDF celebrated Mother's Day with a virtual Paint 'N Sip fundraiser! Angela Dragich, a local artist based in Brockway, PA, spent the afternoon with us and showed us how to paint a beautiful flowery field on our wine glasses. The cost to participate was \$25 to pick-up your painting kit at the Foundation office or \$35 and your kit would be shipped to your home. Each kit included a wine glass, 2 paint brushes, 6 paint cups, and care instructions for the finished glass. Participants could bake their glasses in the oven once the event was over to cure the paint or leave it out to air dry for 21 days.

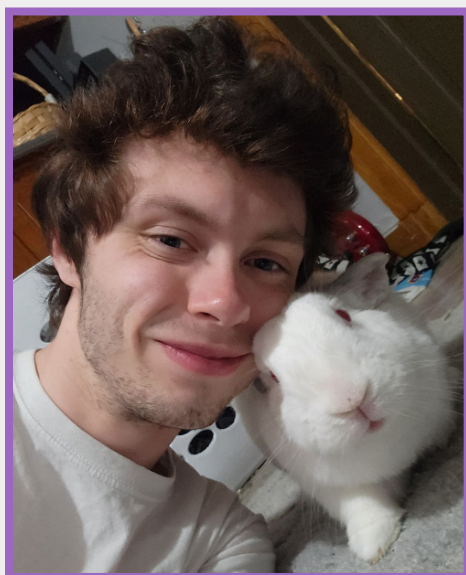
Together, we raised nearly \$600

for the bleeding disorders community of Western Pennsylvania! All the money raised from this event will go toward providing free educational programs, support groups, and medical and emergency assistance to anyone affected by bleeding disorders in Western PA!

Thank you to everyone who joined us at this event! We are so grateful you joined us to celebrate the amazing women in your lives. We hope to see you at one of our events in the future!



# GETTING TO KNOW HCWP STAFF



**BRANDON LAWRYK**  
RESEARCH ASSOCIATE

**Birthplace:** Pittsburgh, PA

**First job:** Target Team Member

**Accomplishment you're proudest of:** This year, my first research study will be published and it will be my first publication!

**What three words describe you best?** Introverted, Nerdy, Observant

**Dream vacation:** Japan

**Person you'd most like to have dinner with:** Dwayne Johnson

**Movie you could see anytime:** Toy Story 2

**TV show you try not to miss:** One Piece

**Three things that can always be found in your refrigerator:** Iced Coffee, leftover pizza, and bacon

**Secret vice:** Milkshakes on a summer day!

**Who would play you in the movies?**  
Tom Holland

**Your pet peeve about Pittsburgh:** Rainy Weather

**People may be surprised to know that:** Despite my quiet personality, I enjoy Pittsburgh's nightlife and going to public events!



# STAY IN MOTION HIKE

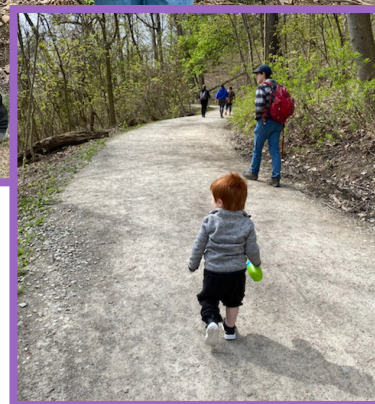
Saturday, April 30<sup>th</sup> was the perfect sunny, 65° day for a hike! WPBDF's first in-person Stay In Motion (SIM) program was an outdoor hike at the Frick Park Clayton Loop. The trail was an all levels, 1-mile loop route that encompasses Clayton Hill. Guides from Venture Outdoors lead the group and helped navigate the path, answered questions, and pointed out unique landmarks around the park. Thank you to Venture Outdoors for providing us with an amazing adventure!

We hope to see you at one of our upcoming SIM programs! SIM provides monthly opportunities to participate in virtual and in-person group fitness and support activities to encourage physical activity.

You can learn more about SIM and



register online at:  
<https://wpbdf.org/sim/>.



# STAY IN MOTION STORIES

## PAUL AND PAT



Active lifestyles have many benefits for individuals diagnosed with a bleeding disorder. Physical activity can help you maintain a healthy weight, strengthen the muscles around your joints, and improve your mental and emotional health. The Stay In Motion (SIM) program was designed in partnership with the Hemophilia Treatment Center of Western Pennsylvania (HCWP) to provide all members with the education and tools for assessing their current physical condition, talking with their healthcare team, setting goals, and creating a plan for physical activity.

In addition, we want to provide access to a variety of physical activities to enable YOU to reap both the mental and physical benefits of exercise!

Paul was diagnosed with Hemophilia B when he was 63

years old, and his doctors strongly encouraged him to take charge of his health. Prior to 2020, Paul and his wife, Pat, would visit their local YMCA three times a week. They have not yet returned because of COVID, but through the SIM program, Paul and Pat have been able to keep up with regular exercise. 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! Paul and Pat share their experience with the SIM program, and you can read their answers below:

### WHY DID YOU CHOOSE TO PARTICIPATE IN THE STAY IN MOTION PROGRAM?

**Paul:** I want to age as healthily as possible, not only because of the Hemophilia B, but also due to signs of having vascular problems. All of my doctors strongly encourage physical activity as a way to

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## WE'RE IN THIS TOGETHER.

**Saturday 1:22pm**

Swinging in the  
backyard with mom

Evan, living with  
hemophilia A

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](https://bleedingdisorders.com) | 



# HCWP CORNER

KATHERINE BUSH, LCSW

Hello to all WPBDF Members and Your Families,

It's so lovely to be able to walk outside and see the flowers blooming! The high pollen counts have been another story, though... here's hoping no one is too allergy ridden!

We are so excited about some of the in-person events that are slated to occur over the summer. We have been missing each other, and it will be wonderful to have some in-person contact at long last. We also remain hopeful that we will be able to provide outreach clinics to our Amish population in the fall. We also want our camp families to know what we have begun to plan camp for summer 2023, and that we may be reaching out to you for feedback. Right now,

the camp world is facing many challenges - staffing, supplies, and financial security - that make camp planning more challenging than we have experienced in past years. However, camp is important to us and we are trying our hardest to make it work.

As you make your summer plans, please remember to make sure that you are up-to-date with your clinic appointment. We want to make sure we know the info we need to help keep you safe on your travels and adventures. We can also provide you with documentation to take on your trips that can make it easier to travel with medications and (although we hope this isn't necessary!) facilitate any needed care while you are away.

We continue to offer appointments both in-person and virtually, and we have welcomed a new hematologist, Dr. Nicoletta Machin, to our clinic. You can also request

factor refills through our website (<https://hcwp.vitalant.org/Home.aspx>). We continue to have our on-call number (888-990-4297) available when the center is not open. Whenever possible, please call us before you arrive to the emergency room. Also, if you have a planned procedure, please reach out to us at least 10 days in advance so that we can arrange a plan to help keep you safe during your procedure.

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.

Wishing you a wonderful summer full of laughter and relaxation,

*The HCWP Staff*

## HOW TO KEEP SUMMER ACTIVITIES SAFE FOR KIDS WITH BLEEDING DISORDERS

CONTINUED FROM PAGE 9...  
2.5 to 3 rating.

"If you choose to allow your child to be on a trampoline, the things that are going to make it safer are ensuring there's adult supervision and no flips or somersaults and, most importantly, having only one child jump at a time," Anderson says. "You want to avoid the risk of two heads hitting each other really hard."

### DON'T OVERLOOK NEIGHBORHOOD PICKUP GAMES

While tackle football is a definite high-risk sport, what about a friendly neighborhood game of

touch football?

Anderson says these kinds of impromptu pickup games can often be a lot riskier than you realize, because there's usually little to no adult supervision. "With league play or a game at the Y, you're going to have refs that are watching, but if it's just a bunch of kids playing up the street, it's possible that a player could go rogue and do something really dangerous," she says.

### KEEP YOUR CHILD'S INTERESTS IN MIND

Don't make the mistake of limiting your child's activities to only those rated 1 for "low risk," Anderson says. It's important to allow kids to have a say in the sports or activities they're interested in.

Some activities are actually less risky for kids with bleeding disorders than parents might think.

Take rock climbing, for instance. While outdoor rock climbing gets a 2 to 3 rating in the Playing It Safe guide, indoor rock climbing, with proper safety equipment such as ropes and harnesses, is 1.5 to 2. "Back in the day before we had such good treatment, every kid was encouraged to swim because it's not a high-impact sport, but what if your kid doesn't like swimming?" Anderson says. "Forcing your kid to do a level 1 sport they hate is not helpful, and they're not going to get any fun out of it."

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**rebinyn.com**

# Lorie Kerstetter

Patient advocate

## About Lorie

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

## Connect with Lorie

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

## Hemophilia Community Liaison

NORTHERN APPALACHIA  
(WV, Western NY, PA)



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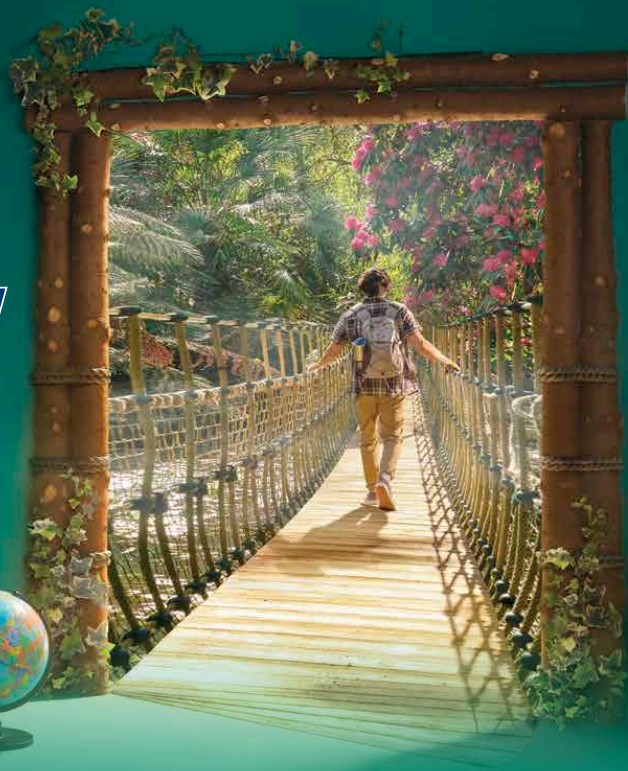
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# Unite

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 or call 724-741-6160*



**HEMOPHILIA  
ALLIANCE**

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





# AXE OUT BLEEDING DISORDERS

## LUMBERJAXES

The first Axe Out Bleeding Disorders fundraiser was held at Lumberjaxes in Cranberry Township, Pennsylvania on Sunday, June 12<sup>th</sup>, 2022. The cost to attend was \$40 per participant and included two hours of axe throwing, a personal axe throwing coach for the lane, food, and prizes. WPBDF would like to thank Philly Pretzel Factory of Cranberry Township and Peppino's Pizza for donating food and snacks for our throwers!

Twenty-five throwers joined us to "Axe Out" Bleeding Disorders! Congratulations to Emma for winning the best style award! Congratulations to Joseph for hitting the most bullseyes and winning the title of Bull Master! Finally, a huge congratulations to Zach for winning 3rd in our tournament, Jack for taking 2nd, and Jim for winning 1st and being WPBDF's Grand Champion! Thank you to Lumberjaxes for providing trophies to our winners!

We are extremely grateful for everyone who participated in this event. We are excited to report that nearly \$4,000 was raised from this event! All the money raised will provide emergency and medical patient assistance, educational programs, and support groups to benefit the bleeding disorders community in Western PA.

Thank you to our sponsors:

**GOLD SPONSOR:**

**Optum**

**SILVER SPONSOR:**

**CSL Behring**

**BRONZE SPONSOR:**

**InfuCare Rx**

**FOOD SPONSORS:**



Because of individuals like you, we are making Pennsylvania a better place for those with bleeding disorders. We hope to see you at one of our upcoming events!



# YOUNG ADULT TRIVIA SLAM

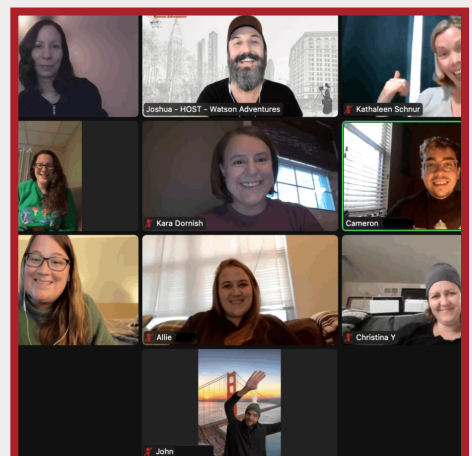
**VICTORIA BAKER, YOUNG ADULT GROUP CO-COORDINATOR**

The young adult group participated in an online trivia night on Tuesday, April 5<sup>th</sup> hosted by Watson Adventures. The young adults were joined by the Western Pennsylvania Bleeding Disorder Foundation and Hemophilia Treatment Center of Western Pennsylvania staff. The group was split up and competed

to see who the king or queen of trivia could be. Trivia questions ranged in topics from sports trivia to current events. In the end, the young adults were beat in trivia by the Foundation and Center staff. A fun time was had by all.

If you or someone you know are interested in joining the Young Adult Group. Please contact the Foundation. The Young Adult Group is open to members of WPBDF who are between the ages of 18-35. Young adults who have a bleeding disorder or are the partner/spouse or a sibling

of someone with a diagnosis are welcome to join. We are currently brainstorming ideas for our next event!







**ADYNOVATE**  
[Antihemophilic Factor  
(Recombinant), PEGylated]  
REAL LIFE, REAL BLEED PROTECTION.\*

AdynovateRealLife.com

## HEMOPHILIA A IS A PIECE OF YOU. NOT ALL OF YOU.

ADYNOVATE® is a treatment that can be personalized to fit your lifestyle so you have more time to spend doing the other things that also make you, you. It has a simple, twice-weekly dosing schedule on the same 2 days every week.<sup>1,2</sup>

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

No actual patients depicted.

### ADYNOVATE twice-weekly prophylaxis prevented or reduced the number of bleeds<sup>2</sup>

ADYNOVATE was proven in 2 pivotal clinical trials to prevent or reduce the number of bleeding episodes in children and adults when used regularly (prophylaxis)<sup>2</sup>

- **Children Under 12 Years:** This study evaluated the efficacy of ADYNOVATE twice-weekly prophylaxis and determined the ability to treat bleeding episodes for 6 months in 66 children under 12 years old who received 40–60 IU/kg of ADYNOVATE prophylaxis treatment<sup>2</sup>
  - During the 6-month study in children under 12, those receiving twice-weekly prophylaxis treatment experienced a median<sup>1</sup> overall ABR<sup>3</sup> of 2.0
  - 0 bleeds in 38% (25 out of 66 patients) during 6 months on twice-weekly prophylaxis

<sup>1</sup>Median is defined as the middle number in a list of numbers arranged in numerical order.

<sup>2</sup>ABR=annualized bleed rate, the number of bleeds that occur over a year.

<sup>3</sup>Per-protocol patients were assigned to the prophylactic group and treated with their originally assigned dose for the entire duration of the study.

### ADYNOVATE Important Information

#### What is ADYNOVATE?

- ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital factor VIII deficiency).
- Your healthcare provider (HCP) may give you ADYNOVATE when you have surgery.
- ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

#### DETAILED IMPORTANT RISK INFORMATION

##### Who should not use ADYNOVATE?

Do not use ADYNOVATE if you:

- Are allergic to mouse or hamster protein.
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)].

Tell your HCP if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

##### What should I tell my HCP before using ADYNOVATE?

Tell your HCP if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
- Are or become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

- **Adolescents and Adults 12 Years and Older:** This study evaluated the efficacy of ADYNOVATE in a 6-month study that compared the efficacy of a twice-weekly prophylactic regimen with on-demand treatment and determined hemostatic efficacy in the treatment of bleeding episodes in 137 patients. These adolescents and adults were given either ADYNOVATE prophylaxis twice-weekly at a dose of 40–50 IU/kg (120 patients) or on-demand treatment with ADYNOVATE at a dose of 10–60 IU/kg (17 patients). The primary study goal was to compare ABR between the prophylaxis and on-demand treatment groups<sup>2</sup>
  - 95% reduction in median overall ABR (41.5 median ABR with on-demand [17 patients] vs 1.9 median ABR with prophylaxis [120 patients])
  - 0 bleeds in 40% (40 out of 101 per-protocol<sup>3</sup> patients) during 6 months on twice-weekly prophylaxis

#### What important information do I need to know about ADYNOVATE?

- You can have an allergic reaction to ADYNOVATE. Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADYNOVATE unless you have been taught by your HCP or hemophilia center.

#### What else should I know about ADYNOVATE and Hemophilia A?

- Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

#### What are possible side effects of ADYNOVATE?

- The common side effects of ADYNOVATE are headache, diarrhea, rash, nausea, dizziness, and hives. These are not all the possible side effects with ADYNOVATE. Tell your HCP about any side effects that bother you or do not go away.

**You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.**

**Please see Important Facts about ADYNOVATE on the following page and discuss with your HCP.**

**For Full Prescribing Information, visit [www.adynovate.com](http://www.adynovate.com).**

**References:** 1. Valentino LA. Considerations in individualizing prophylaxis in patients with haemophilia A. *Haemophilia*. 2014;20(5):607-615. 2. ADYNOVATE Prescribing Information.

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## Patient Important Facts about

### **ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]**

This leaflet summarizes important information about ADYNOVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADYNOVATE. If you have any questions after reading this, ask your healthcare provider.

#### **What is the most important information I need to know about ADYNOVATE?**

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADYNOVATE so that your treatment will work best for you.

#### **What is ADYNOVATE?**

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

#### **Who should not use ADYNOVATE?**

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)]

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

#### **How should I use ADYNOVATE?**

ADYNOVATE is given directly into the bloodstream.

You may infuse ADYNOVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADYNOVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADYNOVATE to use based on your individual weight, level of physical activity, the severity of your hemophilia A, and where you are bleeding.

Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

You may have to have blood tests done after getting ADYNOVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

#### **How should I use ADYNOVATE? (cont'd)**

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

#### **What should I tell my healthcare provider before I use ADYNOVATE?**

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

#### **What are the possible side effects of ADYNOVATE?**

You can have an allergic reaction to ADYNOVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

The common side effects of ADYNOVATE are headache, diarrhea, rash, nausea, dizziness, and hives. Tell your healthcare provider about any side effects that bother you or do not go away.

These are not all the possible side effects with ADYNOVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

#### **What else should I know about ADYNOVATE and Hemophilia A?**

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

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ADYNOVATE for a condition for which it is not prescribed. Do not share ADYNOVATE with other people, even if they have the same symptoms that you have.

#### **The risk information provided here is not comprehensive.**

**To learn more, talk with your health care provider or pharmacist about ADYNOVATE. The FDA-approved product labeling can be found at [www.ADYNOVATE.com](http://www.ADYNOVATE.com) or 1-877-TAKEDA-7.**

**You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.**

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US-ADY-0034v2.0 06/21



# STAY IN MOTION STORIES

CONTINUED FROM PAGE 11...

prolong life, prevent dementia, and stay energized.

**Pat:** I like the encouragement of exercise and fitness... this new program prompts/reminds us to keep up with exercise and do the best we can. I try to keep my joints as limber as possible; in 1990 I had a full knee cap realignment (via the legendary Dr. Freddie Fu) due to having a dislocating kneecap since childhood (second surgery on the knee). To this day, I can't use my knee normally so I must do all I can to keep strength and flexibility in the joint.

**CAN YOU TELL ME A LITTLE ABOUT YOUR DAY-TO-DAY AND HAS STAY IN MOTION ENCOURAGED YOU TO MAKE ANY CHANGES OR KEPT YOU MOTIVATED WITH YOUR ROUTINE?**

**Paul:** Since I have a desk job, I try to stand at my desk as much as possible. I do knee squats at my desk. I take two 15-minute breaks each day and luckily there is a community park right behind the building where I work. I take a walk on the trail overlooking the Monongahela River. If the weather is bad, I walk on the sidewalk in the front of the building; the sidewalk is covered by a canopy. Since I work in a large building, when it is cold or raining, I can get exercise indoors by just walking down different hallways.

**Pat:** Since I am an early riser (usually by 5:30 a.m.), I try to walk at least 20 minutes by 8 a.m. Since I have some balance issues, I stay close to home when I am walking. There is a walkway to my garage that I use and then I walk around the garage and go back and forth. It works for me. I also walk indoors and anytime I am on the phone I am walking as I talk. I use hand barbells for strengthening exercises.

**WHAT DOES PHYSICAL ACTIVITY MEAN TO YOU? WHY IS IT IMPORTANT TO YOU?**

**Paul:** Physical activity makes me feel alive and in a better mood. It lifts my spirit and reminds me that I am doing something good for my body and mind. It is important to me because I want to control my weight, keep joints as healthy as possible, keep muscle strength and do something positive for my health.

**Pat:** Physical activity helps me to feel better not only physically but also mentally. It is a great stress reducer for me and gives me a feeling of accomplishment. It helps me to relax and sleep better. When I walk outdoors, I find it soothing to hear the birds and feel a breeze or wind.

**WHAT HAS BEEN YOUR FAVORITE THING ABOUT THE PROGRAM SO FAR?**

**Paul:** After movement and exercise, I feel satisfied that I did something positive for myself. I like the reminders to keep going and I feel like I can go at my own pace.

**Pat:** I like the encouragement to keep fit and stay healthy; I enjoy and appreciate the programs offered to exercise and maintain a fitness schedule.

**WHAT IS THE BIGGEST WAY STAY IN MOTION HAS SUPPORTED YOU IN YOUR FITNESS JOURNEY?**

**Paul and Pat:** Email reminders and encouragement to exercise, programs to support fitness, and knowing our local HTC recommends staying fit.

**WHAT ARE YOU LOOKING FORWARD TO WITH THE PROGRAM IN THE FUTURE?**

**Paul and Pat:** Continuing on the journey of taking care of our health and fitness; making healthy choices a daily part of our lives; choosing to be up and about as much as our bodies allow.

**WHAT WOULD YOU SAY TO SOMEONE WHO WAS THINKING ABOUT JOINING THE STAY IN MOTION PROGRAM?**

**Paul:** Just sign up and take it one day at a time; just do what you can; something is better than nothing. Just standing by the sink and rinsing vegetables or doing laundry is movement and a form of exercise. It is simple but it is movement.

**Pat:** Just try it; exercise and movement are different for everyone. It is the little things that add up and count as movement – the everyday tasks and things that we are sometimes not even aware of. Five to ten minutes count.

Are you interested in joining the Stay In Motion Program? Visit <https://wpbdf.org/sim/> to fill out your online application. If you have any questions about this program, please contact the Foundation at 724-741-6160 or email [info@wpbdf.org](mailto:info@wpbdf.org).

## CHRISTMAS IN JULY AT THE MALL AT ROBINSON



From July 1st - 31st, you can visit Christmas in July Tree Land at the Mall at Robinson (Pittsburgh, PA), located on the lower-level Macy's wing across from Chocolate Boutique. Check out WPBDF's tree and vote for it to win the Best Tree Award! The winning tree will receive \$500.



# WPBDF'S WOMEN'S RETREAT

MARIA STEELE VOMS STEIN, WOMEN'S  
GROUP COORDINATOR



The WPBDF Winning Women's group hosted our first in-person Women's Retreat on Saturday, May 14, 2022, at the Wyndham Pittsburgh University Center.

The event opened with a welcome to the participants, fun ice breakers and exhibit displays. Our keynote speaker, Dr. Nicoletta Machin, presented "Be Your Best Advocate – Making Sure You are Heard." A delicious lunch was served by the Wyndham Pittsburgh University Center.

After lunch, participants chose one of two breakout sessions. "A Pathway for Best Care; The Reproductive Years" was presented by Dr. Nicoletta Machin; in this session, attendees learned about how to effectively manage menorrhagia, family planning and childbirth. "Women With Bleeding Disorders, What Does Age Have to Do with It?" presented by Dr. Margaret Ragni; provided a brief overview of bleeding disorders and what this means for bleed risks as we age.



Each breakout session was accompanied by a rap session moderated by Kathaleen Schnur, LCSW and Katherine Bush, LCSW.

WPBDF Winning Women's group would like to thank, Dr. Nicoletta Machin, Dr. Margaret Ragni, Kathaleen Schnur, LCSW and Katherine Bush, LCSW for their participation during our event and the ongoing support of the women of our chapter.

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.

WPBDF would like to give a huge thank you to Maria Steele Voms Stein and Victoria Baker for co-coordinating this amazing event! We couldn't have done it without you!

## THANK YOU TO OUR SPONSORS



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Takeda



# A GREAT DAY AT THE PENGUINS GAME!

On Tuesday, April 26<sup>th</sup>, the Pittsburgh Penguins took on the Edmonton Oilers. Nearly 70 people came out to not only cheer on the Pens, but also showed their support for the Western PA Bleeding Disorders Foundation! Thank you to Mindy P. for setting up this fundraising night with the Penguins. A portion of all tickets sold through WPBDF's unique ticket link was donated back to the Foundation. In total, we raised \$840 that will provide education, support groups, and patient assistance to individuals and families affected by bleeding disorders in Western PA. The Penguins may have lost, but our community won big thanks to your continued support of the bleeding disorders community!



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.



# TOP GOLF WITH PERRY PARKER

Saturday, June 25<sup>th</sup>, was a day filled with inspiration and fun! Participants at the TopGolf event, in Bridgeville, PA, had plenty of opportunity to meet and talk with Perry Parker! Perry, a pro golfer who has hemophilia, shared his amazing, inspirational story with us and then spent the next two hours joining us in the golf bays and giving us tips to improve our golf swings.

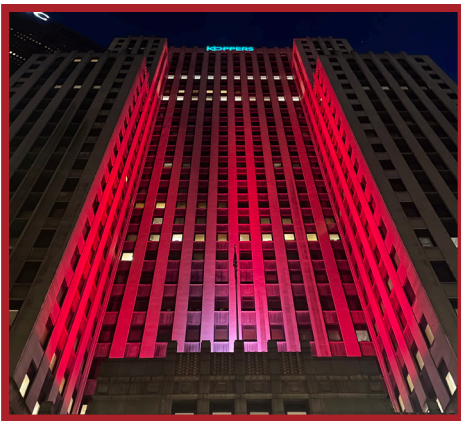
When Perry was a child, he was told by doctors that he couldn't participate in sports. With the support of his parents, Perry explored options and he found a passion for golf. He became a professional golfer in 1988 and has played on the Asian, Australian, Canadian, Japanese, Nike and PGA tours. He has five Canadian tour event titles, more than 30 victories in California and participated in three U.S. Open tournaments. Perry encouraged us to believe in ourselves, find our passion, and do what we want to do!

We thank CSL Behring for sponsoring this event!

## CSL Behring

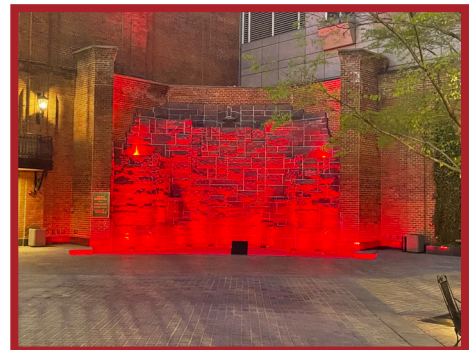
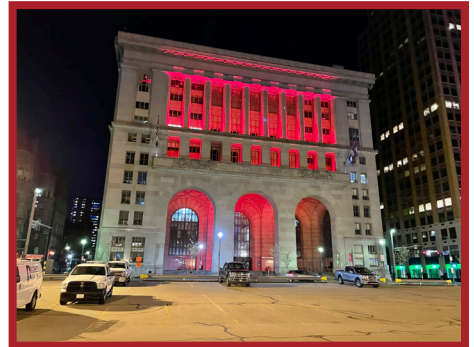
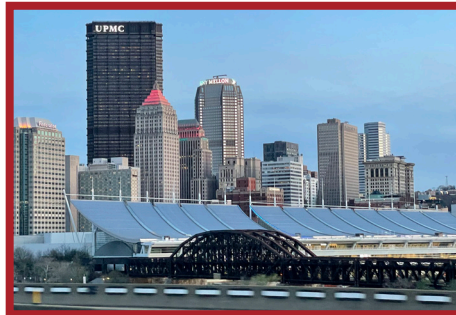






On World Hemophilia Day, buildings and landmarks in Harrisburg and Pittsburgh were lit red in honor of World Hemophilia Day.

In Pittsburgh, landmarks lit red included Pittsburgh's City-County Building, Gulf Tower, Koppers Building, Fifth Avenue Place spire, Heinz Hall's garden plaza waterfall, and the Homestead Grays bridge.



To celebrate World Hemophilia Day, community members painted small canvas squares for our World Hemophilia Day Canvas Collage! We combined squares made by our community in 2021 and 2022 to spread awareness for bleeding disorders and share each person's story.

Governor Tom Wolf also issued a proclamation declaring April 17<sup>th</sup> as World Hemophilia Day in Pennsylvania!







WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

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

# RUN FOR THEIR LIVES

September 10, 2022

North Park Swimming  
Pool Parking Lot  
S. Ridge Drive  
Allison Park, PA 15101

**Distance:** 5K (3.1 miles)

**Registration fee (Virtual and In-Person):** \$25 (until September 9th)

**Race Day fee:** \$30

*Registration includes a race bib, finishers medal, technical t-shirt, goody bag, and access to virtual race results.*

Your participation will help raise awareness of bleeding disorders and help raise needed funds for education and advocacy!



**Learn more at: [bit.ly/runfortheirlives2022](https://bit.ly/runfortheirlives2022)**

*A portion of proceeds will support the Western Pennsylvania Bleeding Disorders Foundation!*



# HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

775 4<sup>th</sup> Street, First Floor

Beaver, PA 15009

Phone: 724-741-6160 Toll Free: 800-824-0016 Fax: 724-741-6167

[info@wpbdf.org](mailto:info@wpbdf.org)

