



OUR IMPACT

2022 - 2023 GRATITUDE REPORT





MISSION:

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.

SUPPORTERS, PATIENTS, AND FAMILIES
GATHER FOR THE 2022 UNITE FOR BLEEDING
DISORDERS WALK PINWHEEL CEREMONY.



LETTER FROM THE EXECUTIVE DIRECTOR

Dear Foundation Members & Friends,

We are happy to present our 2022 – 2023 “Gratitude Report”. This report is an overview of the programs, fundraisers, activities, and organizational milestones that took place over the last fiscal year. When I look back on the year, I am so proud of what we have been able to accomplish. This past year was a year of collaboration and coming together as a community. Over the past fiscal year, we held 29 educational programs (and we can’t forget our Education Weekend, which consisted of 28 different educational sessions in one weekend) and we had over 1,223 people register for these programs. We also held 5 fundraisers, which raised over \$88,000 for the bleeding disorders community.

We teamed up with the Eastern Pennsylvania Bleeding Disorders Foundation to hold our first ever joint Advocacy Ambassador Retreat, where 50 incredible Advocacy Ambassadors were trained and equipped with resources to advocate on behalf of the bleeding disorders community. We saw the passing of PA Senate Bill 225, which works to reform the prior authorization process to expedite approval of patient care and reduce administrative burdens for hospitals, physicians, and other health care providers. We saw a 6% increase to the hemophilia line item in the state budget. These funds go directly to patient care and a portion is also used as an emergency fund to help patients in financial hardship due to their bleeding disorder.

While rising rates of inflation are causing a hardship for many in the community, we have been able to keep our emergency financial assistance programs available. We provided nearly \$35,000 in patient assistance to over 200 community members in need. Our grocery assistance program helped more families this year than ever before. We provided over \$30,000 in grocery gift cards to 64 families struggling with food insecurity. In total, over the past year, we provided over \$65,000 in direct patient assistance.

I am proud of what we have been able to accomplish together but know that there is much more that needs to be done. I am so grateful for the continued service of our amazing volunteers, the passion and commitment of the incredible staff and board members, and the continued love and support the community offers one another. We care for you and are here for you every step of this journey. It is truly an honor to be leading this organization and I could not be more grateful.

Thank you,

Kara Dornish

Executive Director, WPBDF



2022 - 2023 IMPACTS

Provided over \$30,000 in grocery gift cards to 64 families.



Attended 33 legislative meetings.



1,223 people registered for programs.

Added 42 new families to our database.





**Received 16
proclamations.**

*(14 for Bleeding Disorders Awareness
Month, 2 for World Hemophilia Day)*



**Trained 50 Advocacy
Ambassadors.**

**Provided nearly
\$35,000 in patient
assistance to over
200 community
members in need.**



**Hosted
29 educational
programs.**

*(Including Education Weekend
which consisted of 28 different
educational sessions)*



**Hosted 5
fundraisers.**

*(Which raised over \$88,000 for the
bleeding disorders community)*





MARIA SHOEMAKER

I had a lot of bruises, nose bleeds, and (undiagnosed) joint bleeds as a child. My mother was told, "It was just who she is." She fully believed it since I was always quite an active child. In a way, educational outreach led to my diagnosis of von Willebrand disease. After the birth of my first child, my bleeding continued for over four months. The third gynecological specialist finally ordered the testing that caught my disease. Her medical training did not assist her decision to test for von Willebrand disease; instead, her sister-in-law speaking about her symptoms helped my gynecologist connect the dots. Who knows where I would be now if that woman had not dared to speak up? I try to take inspiration from her and believe sharing our stories is vitally important for many reasons. Since my diagnosis, I have dedicated my life to educating the public on the symptoms of the bleeding disorder, the difficulties we face due to our health issues, and the legislation that impacts us.

On April 28 of this year, I delivered five "gift bags" to local middle schools. Each bag contained new underwear, teen-sized menstrual pads, and information regarding bleeding disorders. I included a letter to each nurse explaining how children and adults can have undiagnosed bleeding disorders and how skilled professionals could help change a person's life by recognizing those symptoms. My goal was to help the information stand out by including those extras in the kits, and it appears my plan has worked! One nurse sent me a lovely email thanking me for the donation and for helping to share such important information.

On May 1, I was granted permission by the Community College of Allegheny County (CCAC) to set up an informational table at the Boyce Park location. During my time there, I had the pleasure of speaking with several people, including a wonderful gentleman going into the radiology field. We chatted for quite some time about the difficulties in diagnosing and treatment of bleeding disorders. Several staff members also came and got information on the Unite for Bleeding Disorder's walk, including a gentleman who has a sister with von Willebrand disease. I was pleased with the number of people that stopped by our booth. I plan to do more tables at other campuses as the year progresses, especially at colleges that offer nursing/medical programs.

Currently, we have several activities to assist ongoing educational outreach efforts. We are fundraising for our walk team, The Bloody Shoewalkers. On April 29 and May 7, we did a "tagging" event at Shop N' Save in Murraysville, PA. While the children were busy using their adorable smiles to raise money for the Western Pennsylvania Bleeding Disorder Foundation (WPBDF), I set up a table with information on bleeding disorders. I passed out handouts and some little goodies WPBDF happily provided. I was delighted to see many people stop by to discuss bleeding disorders. Additionally, I was very proud to listen to my children share their stories as they passed out pinwheels and collected funds for our cause. As a way of motivation, I told my children that the person who raised the most funds could choose the restaurant the next time we

dined out.

I also scheduled a booth at Pride in the Park at Kennedy Park in Vandergrift, PA, to share information on bleeding disorders as well as the legislation impacting many groups of people with serious health conditions. This sizable family-friendly event lasts all day and celebrates the diversity found in the world.

In the future, I plan on finding more ways to reach as many people as possible about bleeding disorders, such as von Willebrand disease. As I always tell my children, all knowledge is power! I am the mother of five exceptional children, four of whom may not have been here today without that one woman being open about her health struggles. I have heard some heart-breaking and unbelievably inspiring stories others have shared at WPBDF events. Those affected, either directly or indirectly, find their voice. Alone, we are but a whisper. Together, we are a chorus. Let us all sing!



BOARD OF DIRECTORS

July 2022 - June 2023



Scott Domowicz
President



John Yunghans
Vice President



Brittani Spencer
Secretary



Christina Miller
Treasurer



Melinda Perry-Stern
Board Member



Jennifer Smith
Board Member



Stephanie Shropshire
Board Member



Victoria Baker
Board Member

Thank you WPBDF Board of Directors for donating your time and talents! The Board of Directors is the governing body of WPBDF. Board members meet periodically to discuss and vote on the affairs of the organization, to support the work of WPBDF, and to provide mission based leadership and strategic governance.



THE CAPITOL BUILDING IN HARRISBURG LIGHTS UP RED FOR WORLD HEMOPHILIA DAY.

2023 VOLUNTEERS

VOLUNTEER OF THE YEAR

Maria Shoemaker



We are thrilled to present the volunteer of the year award to Maria Shoemaker! Maria has gone above and beyond in her volunteering, advocacy, and outreach efforts this year! She has volunteered at the Unite for Bleeding Disorders Walk and Take A Bough. When she found out her insurance policy was implementing a copay maximizer, she used her experience to educate others in the community and inform legislators about her experience. Maria is a strong advocate and works hard to create positive change. She spends her free time increasing awareness of women with bleeding disorders by delivering bags with menstrual products and information on bleeding disorders and the Foundation to local school nurses and community health clinics. She sets up displays at community events and outside local businesses to spread information about bleeding disorders and raise money for the Foundation. Maria is very passionate about the community and is always willing to lend a helping hand. We are so thankful for her leadership and dedication to the community.

TOP VOLUNTEERS

Linda Balog
Ryan Balog
Adam Boyle
Nancy Camp
Cameron Cedeno
Joseph Ebersohl
Cassandra Miller
Eileen Nikithser
Michelle Perry
Julia Shoemaker
Diane Standish
Maria Steele Voms Stein

COMMITTEE CHAIRS AND COORDINATORS

Victoria Baker, Program Committee Chair and Young Adult Group Co-Coordinator

Ethan Webb, Teens' Group Co-Coordinator

John Yunghans, Men's Group, Young Adult Group Co-Coordinator, and Governance Chair

Emily Nikithser, 2022 Unite Walk Chair and 7-12 Group Co-Coordinator

Maria Steele Voms Stein, Women's Group Coordinator and Take A Bough Co-Chair

Melinda Perry-Stern, Take A Bough Co-Chair, Fundraising Chair

Raina Slater, Teens' Group Co-Coordinator

Cassandra Miller, Advocacy Chair

Jennifer Smith, Finance Chair

Kelly Baker, 7-12 Group Co-Coordinator

Thank You! We are truly appreciative of our dedicated and hardworking volunteers! Our volunteers improve the lives of those living with bleeding disorders in Western Pennsylvania by spreading community awareness, leading support groups, championing advocacy efforts, and assisting with fundraisers and educational programs. For more information about upcoming volunteer opportunities, contact Jessica Lee at jessica@wpbdf.org.



ADVOCACY AMBASSADORS

Christina Bush
Jessamyn Butler
Angela Day
Ashley Day
Cheyenne Haslett
David Hiller
Matthew Hiller
Delores Johnson
Todd Kart
David Macharola

Sandy Macharola
Cassandra Miller
Jason Miller
Maria Shoemaker
Samantha Short
Melinda Perry-Stern
Steve Stern
Ethan Webb
Jodie White
Christopher White



WPBDF

Western Pennsylvania
Bleeding Disorders Foundation

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.

WPBDF serves families with bleeding disorders in 26 counties of Western Pennsylvania. Membership is free for people with bleeding disorders. We provide patient assistance to our members with bleeding disorders as well as hold a variety of educational events that cover a wide range of topics. Because bleeding disorders

impact nearly every area of our members lives, we strive to provide relevant and timely information about everything from raising affected children to dealing with financial stress to joint health and treatment concerns and much more.



Scan this code to donate to the Western Pennsylvania Bleeding Disorders Foundation!





MICHAEL CLANCEY

Born in 1947, during a time when the only treatment options for hemophilia were ice, pressure and whole blood transfusions, Mike has witnessed firsthand the challenges and advances in diagnosis and treatment for people with hemophilia. Mike was raised in the small town of Havre, MT. As a young child, he was often bruised and his mother would treat him with ice, pressure, and wrappings. He didn't experience his first bleed requiring hospitalization until he was approximately six years old and in first grade, when he developed a bleed in one of his legs for no apparent reason. Although hemophilia was known, it was a time when people were often misdiagnosed. His mother, who was originally from West

Virginia, had relatives back home who were "bleeders." She was a nurse and knew that blood transfusions could help Mike. After numerous attempts, she convinced the doctors that he might have a bleeding disorder and they treated him with blood transfusions. By the time they started the transfusions, the bleed had progressed and Mike's leg was very swollen. He spent several weeks in the hospital and missed the last 4-5 months of school while he recovered.

Within the next couple of years, Mike's family took a trip to visit relatives in West Virginia. While they were on that trip, Mike's father flew with him to Ohio, so he could be evaluated at the Cleveland Clinic. At the

time of his appointment, he wasn't experiencing an active bleed, so the doctors based their diagnosis on the symptoms and experiences that Mike and his father relayed to them. Mike's pattern of bleeds was inconsistent. He was a very active child and could go lengths of time without a serious bleed and then suddenly have a bleed for no apparent reason. The doctors suspected that he had Christmas Disease (hemophilia B/Factor IX Deficiency).

That diagnosis stayed with Mike until about 1972-1973, when Mike broke his foot. He was living near Chicago at the time. Advancements in diagnosis and treatment had been made over the years and he

was now diagnosed as having mild hemophilia A (Factor VIII Deficiency) and was successfully treated with factor.

Shortly thereafter, Mike moved to Ohio and then to Colorado. He was living in Denver, Colorado in 1982, when he developed spontaneous bleeds in both forearms and both calves. He received factor over an extended period and was hospitalized for a good part of that time. He was rehabilitated and received care from a Hemophilia Treatment Center for the first time.

Although treatment options improved over time and were increasingly more effective in helping to control bleeds, they came with some unwanted consequences. Mike had contracted Hepatitis B in 1973 and Hepatitis C in 1981, both of which were transmitted through the use of blood products. At one point in 1982, Mike was also told that he had developed an inhibitor. During the better part of the next decade, Mike avoided factor products unless they were absolutely necessary.

During the 1990's Mike experienced a severe GI bleed which resulted in the loss of a lot of blood. By this time, factor products had become safer as new screening and viral inactivation methods were implemented and new factor products were being developed using recombinant technologies. Mike was hospitalized for a few days, received blood to replace the blood he had lost, and received factor to control the bleed.

Mike is now 75 years old and is still very active. He experiences occasional bleeds and still has

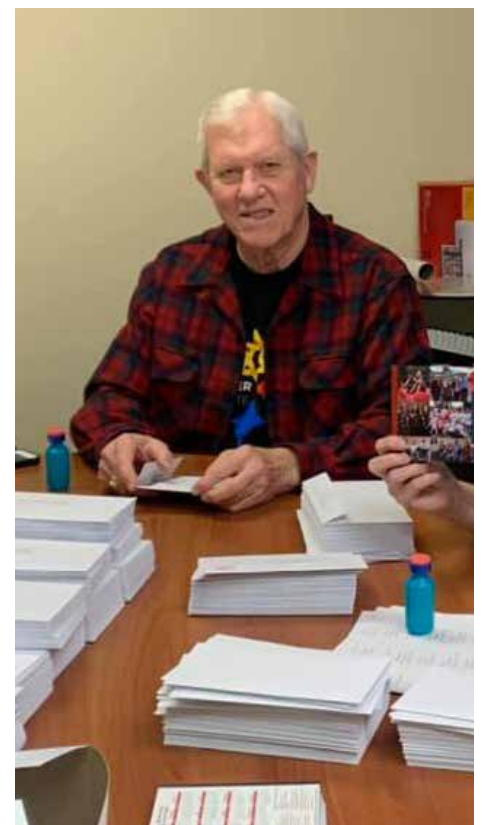


no set pattern for what triggers a bleed. Fortunately, he has no detectable viral loads for hepatitis and does not have an active inhibitor.

Mike is retired and resides in Grove City, PA, with his wife, Beth. They have lived in Grove City since 1986. They have two daughters, Sara and Jessica, and have four grandchildren. Two of their grandsons have hemophilia. Mike mentioned that one of his grandsons was life-flighted to receive care for a cranial bleed when he was born, but both boys are currently doing fine.

Although Mike is retired, he stays busy and has a full schedule. He frequently travels, enjoys fishing, does some consulting work, is involved with community work, and serves on the board of directors for several organizations. He serves on the advisory committee for ATHN (American Thrombosis & Hemostasis Network) and he serves on the Executive Committee for Region III Hemophilia Treatment Centers. Mike is also an active member and volunteer of the Foundation. He supports the Foundation's fundraisers, has participated in the Foundation's advocacy efforts, including traveling to Harrisburg on multiple occasions, and participates in the Men's Group.

When asked if he has any advice to share with our community, Mike said, "Don't over protect your kids." He said that when he was growing up, he was allowed to take part in almost all of the sports and activities he wanted. He thinks that sometimes when kids are told repeatedly that they can't do things, that message subconsciously carries over into other areas of their lives and they can become fearful of trying anything new. He suggests guiding them and giving them other options if necessary, but don't limit or over protect them.



WPBDF'S YEAR IN REVIEW

JULY 2022 - JUNE 2023



We were so excited to see our New Parent Network families at the Pittsburgh Zoo & PPG Aquarium on July 9! Kathaleen Schnur, LCSW, of the Hemophilia Center of Western Pennsylvania (HCWP) moderated a panel discussion on Early Childhood Safety and Precautions. Mentor parents shared their experiences and offered advice to new families. Our Annual Meeting was held in-person for the first time in 2 years! With over 120 people in attendance, it felt like a family reunion and was wonderful to reconnect with the community face-to-face. We ended July with a healthy food and fitness program for all our members, followed by a day at Kennywood Park!

In early August, we teamed up with our friends at the Eastern PA Bleeding Disorders Foundation (EPBDF) and held a state-wide Advocacy update. We shared an update on issues affecting the bleeding disorders community, how to become an advocacy ambassador, and simple steps community members can take to create change. Our Teen Group was busy this month at the Summer Teen Retreat where they reconnected with old friends, made new ones, and enjoyed a variety of crafts, camp activities, and sweet treats! Foundation staff attended NHF's Bleeding Disorders Conference, in Houston, TX, where they were able to connect with other Chapters and patients throughout the U.S. to learn best practices and ways to make the Western PA Chapter stronger. WPBDF's Men's Group also held their first in-person event since 2019 at the Tall Ships Festival in Erie, PA.



The Unite for Bleeding Disorders Walk and Run for Their Lives 5K was back in-person for the first time since 2019. The top fundraising team was Conor's Clan, who raised an incredible \$7,845! Thanks to the amazing support from sponsors, donors, and patrons, \$69,568 was raised to support the Western PA bleeding disorders community. Thank you to our amazing 2022 Walk Chair, Emily Nikithser!



Our Fall Program was held on Saturday, October 8, in Erie, PA. Members of our community gathered at the Erie Bayfront Convention Center to learn how to adapt physical activities for joint health. After the program, families were invited to enjoy the rest of the day having fun and staying active at Splash Lagoon.



laugh. On Saturday we offered programs on VWD, rare bleeding disorders, and hemophilia. We also focused on emotional wellness throughout the program tracks for both adults and children. While the grownups were attending their programs, four children's programs were running concurrently. The schedules varied by age group, but all included opportunities for education about bleeding disorders, emotional wellness, and fun games and activities, such as bowling and indoor mini-golf. Sunday morning brought a fresh batch of program topics, plus hands-on infusion training, for which 45 people registered. The infusion training was provided by nurses from the Hemophilia Center of Western PA. The weekend concluded with raffle basket drawings before everyone headed home. A huge thank you to our Education Weekend Committee: Victoria Baker, Janet Barone, Kara Dornish, Jessica Lee, and Kathaleen Schnur.



On November 3, 2022, SB 225 was signed into law. Thank you to everyone who sent letters, made calls, and attended meetings in support of this legislation! On the Senate floor, Senator Phillips-Hill noted that this is the first expansive change to the insurance and medical industry in over a decade. Over 78% of surveyed doctors noted that prior authorization delays led to patients walking away or delaying treatment. The system was broken, but SB 225 fixes it. Over 70 patient provider groups supported this bill.

After two postponements, due to COVID-19, we were finally

able to bring back the beloved Education Weekend at the Seven Springs Mountain Resort! It was wonderful to gather for a weekend of education and camaraderie after waiting 3 ½ years. Over 200 people attended this event! On Friday night, Dr. Federico Xavier led a program for parents in the New Parent Network. He talked about bleeding disorders, different types of bleeds, emergency situations, and emergency room visits. Concurrently, teens and their families attended a program led by Michael Garner. He explained to the families that everyone has their own personal "Clown Doctor Medical Bag," and we all have the tools to make someone

Shortly after Education Weekend, WPBDF's annual Take A Bough fundraiser returned in-person! Thanks to the support from our sponsors, donors, and patrons, we raised nearly \$10,000 for the

Western PA bleeding disorders community. Thank you to our amazing co-chairs, Melinda Perry-Stern and Maria Steele Voms Stein, and our WPBDF Fundraising Committee (Scott Domowicz, Kelly Baker, Emily Nikithser, Eileen Nikithser, and Michelle and Mike Perry) who helped gather trees, decorations, gifts, and raffle items leading up to the event.

The Western and Eastern PA Bleeding Disorders Foundations came together again to hold their Annual Advocacy Stakeholder Meeting. Kara Dornish, Executive Director, WPBDF, and Sarah Pilacik, Executive Director, EPBDF, gave Foundation updates, Miriam Goldstein of the Hemophilia Federation of America and Matt Delaney of the National Hemophilia Foundation



presented on federal issues, and Kerry Lange of Milliron and Goodman informed the group of state issues.

Finally, at the end of the month a virtual program was held on

Insurance. The program included an overview of insurance options, transitions that impact coverage, and insurance denials of coverage, led by Jan Martin, Community Education Specialist with Takeda.



We gathered in the National Aviary's beautiful Garden Room for WPBDF's Winter Program. At this program, our community learned more about the Foundation's community support groups and patient assistance programs, played games, made crafts, and enjoyed a visit from a parrot! After the program, everyone was welcome to enjoy the rest of the afternoon at the Aviary.



We kicked off 2023 with the Winter Teen Retreat! An amazing group of teens joined us for the weekend at the Promise Camp & Retreat Center in Clinton, PA. The teens learned important life skills while also playing games and catching up with old and new friends. We are so grateful to our counselors: Ryan Balog, Nicolette Cloutier, Julia Shoemaker, John Yunghans and junior counselors Trent Clayton and Georgia Ebsworth for keeping the fun and energy flowing all weekend!

On January 24, nearly 70 people came out to not

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only cheer on the Pittsburgh Penguins as they took on the Florida Panthers, but also show their support for WPBDF. A portion of all tickets sold through WPBDF's unique ticket link was donated back to the foundation. In total, we raised \$680 (and the Penguins took home a win that night)!

We ended the month by getting a bit cheesy with Chef Mike Hargett. Chef Mike taught us how to make a creamy broccoli cheddar soup and provided us with some cooking tips to use in the future!



Our annual Bowling for Bleeding Disorders also made a comeback in-person this month! We are extremely grateful for everyone who participated in this event as we raised over \$8,000 to provide emergency and medical patient assistance, educational programs, and support groups to benefit the bleeding disorders community in Western PA. At this event, we also recognized two individuals for their generosity and support of the bleeding disorders community. Mindy Perry-Stern and Lindsay McNany received WPBDF's Community Spirit Award. WPBDF would like to extend a huge thank you to these wonderful ladies.

We ended the month with a mindfulness program. Practicing mindfulness can lower stress, improve focus, and increase clarity. Jan Martin, Community Education Specialist with Takeda, led us through a series of breathing exercises and encouraged us to take the time to focus on our breath and how we are feeling.



March is Bleeding Disorders Awareness Month. The following counties and cities issued proclamations recognizing March 2023 as Bleeding Disorders Awareness Month: Allegheny, Beaver, Butler, Fayette, Greene, Lawrence, McKean, Somerset, Venango, and Westmoreland; and the Cities of: Altoona, Canonsburg, Erie, and Johnstown. We are so thankful for all the community advocates who attended committee meetings with us to accept the proclamations! Thank you to the counties, cities, and leaders for helping to raise awareness for bleeding disorders! We also invited everyone to decorate a tiny canvas to add to our collage celebrating Bleeding Disorders Awareness Month.

WPBDF and EPBDF teamed up to host the first ever state-wide Advocacy Ambassador Retreat on March 4. We were thrilled to have over 50 advocates from across PA participate in this retreat. Kerry Lange, of our lobbyist firm

Milliron & Goodman, started the education portion of the event with a presentation on Pennsylvania Policy. Miriam Goldstein, Interim Vice President, Public Affairs at the Hemophilia Federation of America, presented Hot Topics in Policy. Matt Delaney, Government Relations Specialist at the National Hemophilia Foundation, presented How to Advocate. Matt reviewed where we are in 2023 federally, in Pennsylvania, and on the local level. Jessica Graham, Coalition Coordinator at the New York State Bleeding Disorders Coalition, shared tips and stories of the success New York had in getting copay accumulator reform passed in New York state. Janet Barone, Program Director of WPBDF, explained how a photo book can be useful in legislative meetings. She shared her photo book and explained how powerful photos can be when telling your story and using it in a way to highlight the legislative issues. WPBDF staff and members of the community ran through some legislative role plays to give an example of best practices when meeting with lawmakers and their staff. At the end of the night we came together to play PA Advocacy Kahoot!



We participated in NHF's in-person Washington Days the weekend after our Advocacy Retreat! Advocates from Western PA included David Hiller, Matthew Hiller, Delores Johnson, Ethan Webb, Kyrie Holliday, Cassandra Miller, Samantha Short, Melinda Perry-Stern, Steve Stern, and Ryker Stern. We attended meetings with the offices of Senator Fetterman, Representative Cartwright, Representative Fitzpatrick, Representative Meuser, Senator Casey, Representative Deluzio, Representative Scanlon, Representative Thompson, and Representative Houlihan. 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 830) and members of the Senate to introduce a companion bill to ensure that all copays count for patients.

On March 22, Carrie Koenig, Community Relations and Education Manager with Sanofi, provided a detailed understanding about the importance of factor activity levels. She explained Pharmacokinetics and why factor levels are more than just peaks and troughs, during the program, Factor Fluency: Higher Factor Activity Levels Matter



We hosted our first Couple's Retreat since 2011 during the first weekend in April. Our Couples received helpful reminders to be grateful and ask for validation and learned some new communication techniques. We all got to learn more about the City of Pittsburgh and take a moment to enjoy each other's company during a ride on Molly's Trolleys!

WPBDF celebrated World Hemophilia Day on April 17, surrounded by community at the Monterey Bay Fish Grotto, located on the top of

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Mount Washington. This provided a beautiful view of the City of Pittsburgh. As the sun set, we could see the buildings in Pittsburgh light up red in honor of World Hemophilia Day. The buildings that lit up red in Pittsburgh included: Fifth Avenue Spire, the Koppers Building, Gulf Tower, the Heinz Hall Garden Plaza Waterfall, the City-County Building, and the Homestead Grays Bridge. During the event, hosted by Sanofi, there were different activity stations to make bracelets, share words of encouragement and make cards to send to those affected with bleeding disorders in third world countries. The capitol building in Harrisburg was also lit red for World Hemophilia Day. We received proclamations from Governor Josh Shapiro and Pittsburgh Mayor Ed Gainey, proclaiming April 17, 2023, World Hemophilia Day.



The month started with an educational program on Gene Therapy held at the Grand Concourse. This program was presented by Tommy Russomano of BioMarin. He discussed how gene therapy research is designed, what different types of gene therapies are being researched, and why are some people are better candidates than others.

We held a New Parent Network weekend program called Parents & Tiny Tots in Pittsburgh. Throughout the weekend, families roleplayed medical appointment visits, received an introductory explanation of bleeding disorders, and learned about comfort positions and distraction techniques when infusing their child. After the program, the families received tickets to spend the afternoon at the Carnegie Museum of Natural History! We also held the first meeting of our support group for children between the ages of 7 - 12. WPBDF held multiple educational programs about Hemgenix, the first FDA approved gene therapy for adults with Hemophilia B, presented by CSL Behring. Doctors were present at each program and thoroughly answered participant questions.





WPBDF started the month by teaming up with the HCWP to provide education and infusion training to the Amish population in Punxsutawney, PA.

In addition to the efforts being taken on the federal level to eliminate copay accumulators, advocacy is also happening on the state level. We participated in the PA All Copays Count Coalition Advocacy Day in Harrisburg. WPBDF staff attended along with two Advocacy

Ambassadors from Western PA, Maria Shoemaker and Cassandra Miller. The PA Bleeding Disorders Team had 20 meetings. We met with the offices of Representative Abby Major, Representative Valerie Gaydos, Representative Greg Vitali, Representative Tim Briggs, Representative Mark Gillen, Representative Scott Conklin, Senator Elder Vogel, Senator Lindsey Williams, Senator Marty Flynn, Senator Wayne Fontana, Senator Christine Tartaglione, Senator Lisa Boscola, Senator Joe Pittman, Senator Devlin Robinson, Senator Nikil Saval, Senator Anthony Williams, Senator Amanda Cappelletti, Senator Carolyn Comitta, Senator Judith Schwank, and Senator Wayne Langerholc. We asked our Senators to cosponsor SB 372 and asked our Representatives to sign onto Representative MaryLouise Isaacson's (D-Philadelphia) memo calling for accumulator reform in the House.

Finally, we kicked off the summer with a Pirates Game! Members joined us at the Renaissance Pittsburgh Hotel and heard from CSL Behring's Gettin' In the Game athlete, Pete Dyson! After Pete shared his amazing, inspirational story with us, everyone received tickets to attend the Pittsburgh Pirates vs. the New York Mets game at PNC Park.



BE THE RARE DIFFERENCE, BECOME A MONTHLY DONOR.

Make a monthly gift to be the Rare Difference – a special person who is committed to WPBDF's future by giving hope to those living with bleeding disorders. Your support will make a big impact to our families! **Sign up for a monthly gift today:**
<https://give.classy.org/wpcnhfdonate>.

Find out other ways to support the Western PA bleeding disorders community at wpbdf.org.

**SCAN ME TO DONATE
ONLINE!**





WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

775 4th Street
First Floor
Beaver, PA 15009



WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

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