WPBDF
Western Pennsylvania
Bleeding Disorders Foundation

HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

WINTER 2024

WPBDF
Western Pennsylvania
Bleeding Disorders Foundation

BOARD OF DIRECTORS

STAFF

Executive Director Kara Dornish

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.

DESIGNATE UNITED WAY GIFTS TO THE CHAPTER

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

WPBDF Contributor Agency Code Number is: 83

EVENTS CALENDAR

January 25
The Joint Movement
Il Pizzaiolo
Warrendale, PA

January 27
Teen Group
Carnegie Science Center
Pittsburgh, PA

January 28
New Parent Network
Emergency Situations
Virtual Program

February 18
Bowling for Bleeding Disorders Fundraiser
Paradise Island Bowl
Pittsburgh, PA

March 6-8
NBDF's Washington Days
Washington D.C.

March 28
Pittsburgh Penguins Fundraiser
PPG Paints Arena
Pittsburgh, PA

April 17
World Hemophilia Day

April 26-28
Education Weekend
Seven Springs Mountain Resort
Seven Springs, PA

May 6-7
Advocacy Ambassador
Education and Training
Harrisburg, PA

June 22
Pirates Game Fundraiser
PNC Park
Pittsburgh, PA

June 28-30
Couples Retreat
Liberty Mountain Resort
Fairfield, PA

July 18
WPBDF Annual Meeting
Top Golf
Bridgeville, PA

July 28 - August 3
Camp Hot-to-Clot
Camp Kon-o-Kwee Spencer
Fombell, PA

August 1
Back to School Program
Location TBD

August 10
New Parent Network Picnic
Idlewild
Ligonier, PA

September 21
Unite for Bleeding Disorders Walk
Run For Their Lives 5k
Cornhole Tournament
North Park, PA

November 1-3
Teen Retreat
Clinton, PA

November 16
Take A Bough
Red Fox Winery
Hickory, PA

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

PITTSBURGH PENGUINS FUNDRAISER

When: Thursday, March 28TH, 2024
Game Time: 7:00 PM
Where: PPG Paints Arena
1001 Fifth Ave
Pittsburgh, PA 15219

Get tickets at:
bit.ly/penguinsbdf23

Upper Bowl: $53
Lower Bowl: $92

$10 from every ticket will be donated to the Western PA Bleeding Disorders Foundation.

CONTACT US

Western Pennsylvania Bleeding Disorders Foundation

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First Floor
Beaver, PA 15009

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

www.wpbdf.org
info@wpbdf.org

@WPBDF

@WPBDF

@WPABDF

LETTER FROM THE EXECUTIVE DIRECTOR AND BOARD PRESIDENT

Dear Community Members & Friends,

Happy New Year! As we ring in the New Year, we are so grateful for our members, volunteers, community partners, and everyone who has supported us over the year. Because of you, we provided patient assistance, education, advocacy, and support to those affected by bleeding disorders in western Pennsylvania.

The holidays are a special time, and we believe each child deserves to experience the joy of gifts during the holiday season. Because of your support, we granted over $3,300 in holiday gifts to 89 children in the community. Since July, we granted nearly $10,000 in grocery assistance, providing assistance to over 25 families. Emergency assistance funds have been granted to over 125 individuals, providing over $26,000 in assistance. We are truly grateful to be in the position to help community members experiencing hardship. If you are experiencing hardship, we are here to help. We realize times are tough and hardship can strike at any time. For more information about the programs and their application processes, visit https://wpbdf.org/patient-assistance, or by calling us at the Foundation office 724-741-6160.

We are excited to have been awarded the Innovation Grant from the Hemophilia Alliance Foundation for our Women with Bleeding Disorders Initiative. We have teamed up with the Eastern Pennsylvania Bleeding Disorders Foundation to improve the diagnosis of bleeding disorders and quality of life in women, girls, and those with the potential to menstruate. We are creating and distributing period bags to university health centers, school nurses, local health clinics, and OB/GYNs throughout Pennsylvania.

We have created, and are working on distributing, magnets, stickers, and flyers, which list the symptoms of bleeding disorders in women and where to go for more information. We are planning to distribute them to major universities and local colleges to be given out to women's dorms and placed in the stalls of women's bathrooms on campus.

We are also hosting booths at health fairs and community events to raise awareness of bleeding disorders in women.

We need your help!

1. If you know of community events that have booth or exhibit opportunities, please let us know. Better yet, if you would be willing to display at the booth, we can provide you with all the resources you need.
2. If you have connections with your local school nurses, high schools, universities, health clinics, or OB/GYNs, we need your help to get these resources to them!

Please reach out to Kara at kara@wpbdf.org or 724-741-6160 if you would like to help.

We are truly honored to be leading this organization into 2024. We look forward to continuing to serve this community and we hope to see you at one, or many, of our upcoming events!

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

Kara Dornish
Executive Director

Scott Domowicz
Board President

ADVOCACY UPDATE

KERRY LANGE, SENIOR ASSOCIATE MILLIRON GOODMAN

HARRISBURG OVERVIEW

With a very divided state government (a one-seat Democratic-Majority in the House, a Republican-controlled Senate, and a Democratic Governor), the 2023 budget season was expected to be less amicable. Below is a brief recap on the most recent developments.

On June 30, the Senate amended the general appropriations budget bill, HB 611. Senate Republican leadership claimed that they had a deal with Governor Josh Shapiro. They would support a significant portion of the Democrat's requested line items, so long as he would support the inclusion of a $100 million dollar line item for a school voucher program.

Shortly after the Senate passed the bill and sent it over to the House, Governor Shapiro reneged on his agreement and promised the Democratic-led House that he would line-item veto the school voucher program. To Senate Republicans, he argued that there wasn't enough support for the voucher program. He argued that to pass an on-time budget, they would have to disregard the school voucher program. With 86 Republicans in opposition, the House passed HB 611.

As part of normal operating procedure, each chamber is required to sign the bills that they've passed. Because Governor Shapiro reneged on his agreement with the Senate Republicans, Senate leadership refused to reconvene to sign the bill and send it to the Governor's desk. However, after mounting pressure from public schools, county human service program providers, and others who depend on state funding, the Senate reconvened on August 3, signed the bill and sent it to the Governor's desk.

The Governor quickly signed HB 611 into law, allowing state departments to start distributing some of the funding and prevent various disruptions in schools and human services programs.

On August 30, the Senate reconvened to debate two separate fiscal code bills, HB 1300 and SB 757. HB 1300 directs funding to many non-controversial and bipartisan line items. SB 757 addresses the more controversial priorities, including funding for educational options for students in failing schools. Both bills were passed by the Senate and sent over to the House. On October 4, the House amended HB 1300 and sent it back to the Senate.

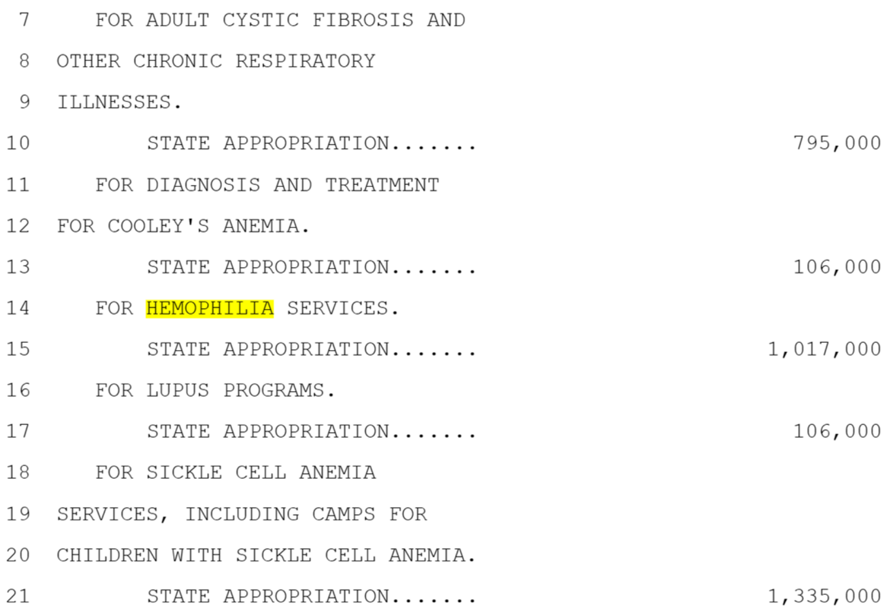
We are about half-way through the two-year legislative cycle.

BUDGET LINE ITEM

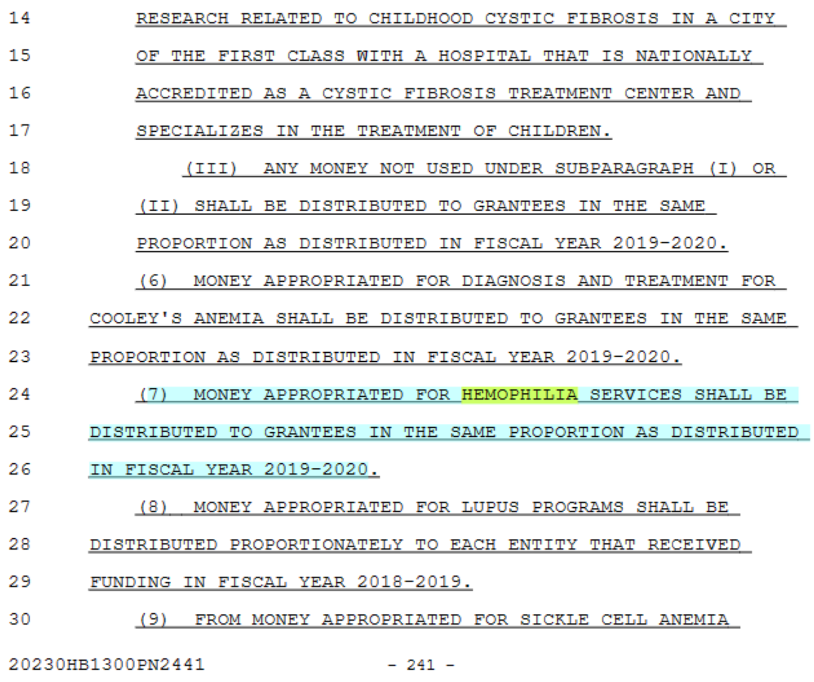
We are very pleased to report that our advocacy work was successful again this year. We were able to protect the line item in HB 611 PN 1811 (Page 462). The state appropriation for hemophilia services in the 2023-2024 state budget is $1,017,000. As previously noted, HB 611 was signed into law by Governor Shapiro on August 3.

The hemophilia language was included in the final version of the fiscal code bill, HB 1300. It was passed in the House and Senate on December 14, 2023, and was signed by the Governor as Act 34 of 2023.

We'd like to give much deserved credit to all those who were able to come to Harrisburg in June and make a grand finale push for the line item. It was a very productive



FOR ADULT CYSTIC FIBROSIS AND OTHER CHRONIC RESPIRATORY ILLNESSES.	
STATE APPROPRIATION.......	795,000
FOR DIAGNOSIS AND TREATMENT FOR COOLEY'S ANEMIA.	
STATE APPROPRIATION.......	106,000
FOR HEMOPHILIA SERVICES.	
STATE APPROPRIATION.......	1,017,000
FOR LUPUS PROGRAMS.	
STATE APPROPRIATION.......	106,000
FOR SICKLE CELL ANEMIA SERVICES, INCLUDING CAMPS FOR CHILDREN WITH SICKLE CELL ANEMIA.	
STATE APPROPRIATION.......	1,335,000



RESEARCH RELATED TO CHILDHOOD CYSTIC FIBROSIS IN A CITY OF THE FIRST CLASS WITH A HOSPITAL THAT IS NATIONALLY ACCREDITED AS A CYSTIC FIBROSIS TREATMENT CENTER AND SPECIALIZES IN THE TREATMENT OF CHILDREN.

(III) ANY MONEY NOT USED UNDER SUBPARAGRAPH (I) OR (II) SHALL BE DISTRIBUTED TO GRANTEES IN THE SAME PROPORTION AS DISTRIBUTED IN FISCAL YEAR 2019-2020.

(6) MONEY APPROPRIATED FOR DIAGNOSIS AND TREATMENT FOR COOLEY'S ANEMIA SHALL BE DISTRIBUTED TO GRANTEES IN THE SAME PROPORTION AS DISTRIBUTED IN FISCAL YEAR 2019-2020.

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

(8) MONEY APPROPRIATED FOR LUPUS PROGRAMS SHALL BE DISTRIBUTED PROPORTIONATELY TO EACH ENTITY THAT RECEIVED FUNDING IN FISCAL YEAR 2018-2019.

(9) FROM MONEY APPROPRIATED FOR SICKLE CELL ANEMIA

20230HB1300PN2441 - 241 -

day where members of the PA Bleeding Disorders Foundations (BDFs) were able to meet directly with legislators and staff and remind them about the importance of maintaining our line item in the annual budget.

Soon, we will begin our meetings and advocacy for the 2024-2025 budget line item.

CO-PAY ACCUMULATORS

SB 372 (Ward, R-Blair): Amends the Insurance Company Law by requiring insurers to count the drug manufacturers' assistance program towards the deductible and out-of-pocket costs.

The bill was introduced and referred to the Senate Banking & Insurance Committee, where it currently waits for consideration. The PA BDFs circulated a letter of support.

Please note that the previous Executive Director for the Senate Banking & Insurance Committee recently resigned, and we are anticipating a new Executive Director shortly. Once that position is filled, we will coordinate a meeting with the PA BDFs. This will allow the PA BDFs to bring the new person up-to-speed and directly advocate for committee consideration.

We are currently collaborating with the Immune Deficiency Foundation and their government relations team. We've agreed to divert from Representative Mary Isaacson (D-Philadelphia) to Representative Bridget Kosierowski (D-Lackawanna) for the introduction of a companion bill in the House. Representative Kosierowski is a Registered Nurse and a member of the House Insurance Committee. We are prepared to circulate a letter of support once the bill is introduced.

OTHER LEGISLATION

Legislators have introduced several bills relating to menstrual education (HB 354) and menstrual product access (HB 850) and we plan to engage on a few of them.

- HB 354 (Isaacson, D-Philadelphia): Amends the Public School Code by requiring the Pennsylvania Department of Education to develop a curriculum for menstrual education that school districts can implement into their instruction for students. This curriculum would include topics related to the menstrual cycle, menstrual hygiene management, menstrual disorders, and more. This legislation will expand access to menstrual education for all students in Pennsylvania, regardless of gender, and ensure that students who menstruate are better equipped to manage their periods.
    - *Introduced and referred to the House Health Committee on 3.13.23.*
- HB 850 (Parker, D-Philadelphia): Amends the Human Services Code by requiring our Department of Human Services to apply to the federal government if a waiver is made available to states to allow those receiving Supplemental Nutrition Assistance Program (SNAP) and Women, Infants, and Children (WIC) to use the two programs for menstrual hygiene products. Currently, these programs do not allow for the purchase of menstrual hygiene products, despite being a necessity.
    - *(D-Berks) has also announced her intent to introduce a Senate companion bill to HB 850 and recently circulated a co-sponsorship memo.*

... CONTINUED ON PAGE 7

ADVOCACY AMBASSADOR EDUCATION AND TRAINING

May 6 - 7, 2024

Harrisburg Hilton
One N 2nd St,
Harrisburg, PA 17101

We are looking for individuals who are interested in supporting the advocacy efforts of the Pennsylvania Bleeding Disorders Foundations throughout the year. Do you have a desire to meet with legislators to help influence decisions on policies that affect individuals and families living with bleeding disorders?

If you answered yes, we would like you to join us in Harrisburg, on Monday, May 6 and Tuesday, May 7, 2024!

On Monday, May 6, you will receive training to become a Volunteer Advocacy Ambassador and learn about the issues we will be discussing with legislators the following day.

On Tuesday, May 7, we will head to the capitol to meet with legislators to advocate for the needs of the bleeding disorders community. Each advocate will be teamed up with other advocates to attend meetings in small groups.

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

This training is open to individuals 18 years and older and mature adolescents and teens. No childcare will be provided at this event.

This is an overnight training and advocacy day. Training begins at 3 PM on Monday, May 6. On Tuesday, May 7, we will head to the PA state capitol where you will have the opportunity to meet with your local legislators.

The Foundations will provide dinner on Monday, a hotel room at the Harrisburg Hilton on Monday night, and breakfast on Tuesday morning.

Transportation assistance is available upon request.

To register, scan the QR code or visit:

bit.ly/advocacytrainingpa

The final day to register is Friday, April 5!

ADVOCACY UPDATE

CONTINUED FROM PAGE 5...

2024 STATE ADVOCACY DAY

Milliron Goodman is excited to host the bleeding disorder community for a revitalized advocacy day in Harrisburg, Pennsylvania. The Advocacy Ambassador Education and Training will take place on May 6 and 7, 2024.

Advocacy days are critical opportunities for the community. Attendees are guaranteed to have facetime with legislators and staff. This allows legislators (the decision makers!) to become more attuned to the current issues impacting the community and their voting constituents.

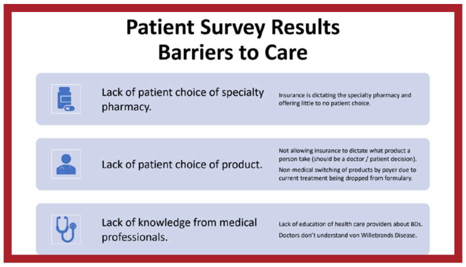
Registration is now open for the Advocacy Ambassador Retreat and Training. Register at bit.ly/advocacytrainingpa!

THANK YOU!

On behalf of the Milliron Goodman team, thank you for choosing us to be your advocates in the Capitol. We look forward to continuing to partner with you and will keep you apprised of relevant legislative progress.

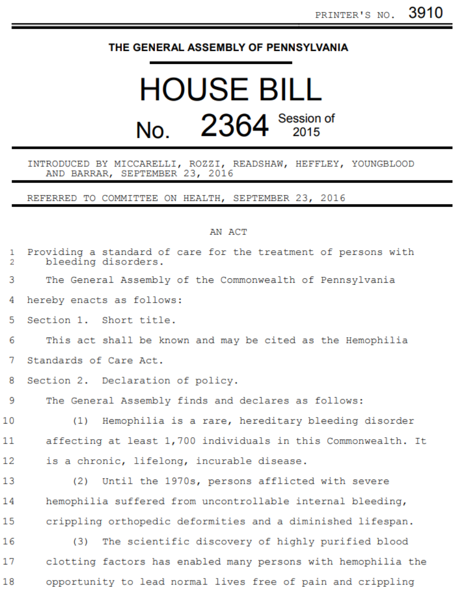
ADVOCACY STAKEHOLDER RETREAT

On Tuesday, November 21, 2023, the Eastern and Western Pennsylvania Bleeding Disorders Foundations teamed up to hold the 2023 Advocacy Stakeholder Meeting. We were joined by 30 individuals including representatives from the 7 Pennsylvania Hemophilia Treatment Centers, individuals from both national organizations (National Bleeding Disorders Foundation and Hemophilia Federation of America), Kerry Lange of Milliron and Goodman, advocacy ambassadors, and Eastern and Western PA Foundation staff and board members. Matt Delaney, of the National Bleeding Disorders Foundation, and Miriam Goldstein, of the Hemophilia Federation of America, presented on Federal Issues. Kerry Lange, of Milliron and Goodman, presented issues happening here in Pennsylvania. Robust conversations were had determining what our advocacy approach should be next year. We are planning to work on the Standards of Care Bill, which was last introduced in 2015, and legislation that addresses period poverty and women's health education. Our top priorities remain copay accumulator reform, increasing funding to the hemophilia line item in the state budget and ensuring distribution of those funds to all 7 HTCs.



Patient Survey Results
Barriers to Care

Lack of patient choice of specialty pharmacy.	Insurance is dictating the specialty pharmacy and offering little to no patient choice.
Lack of patient choice of product.	Not allowing insurance to dictate what product a person take (should be a doctor / patient decision). Non-medical switching of products by payer due to current treatment being dropped from formulary.
Lack of knowledge from medical professionals.	Lack of education of health care providers about BDs. Doctors don't understand von Willebrands Disease.



PRINTER'S NO. 3910

THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE BILL

No. 2364 Session of 2015

INTRODUCED BY MICCARELLI, ROZZI, READSHAW, HEFFLEY, YOUNGBLOOD AND BARRAR, SEPTEMBER 23, 2016

REFERRED TO COMMITTEE ON HEALTH, SEPTEMBER 23, 2016

AN ACT

Providing a standard of care for the treatment of persons with bleeding disorders.

The General Assembly of the Commonwealth of Pennsylvania hereby enacts as follows:

Section 1. Short title.

This act shall be known and may be cited as the Hemophilia Standards of Care Act.

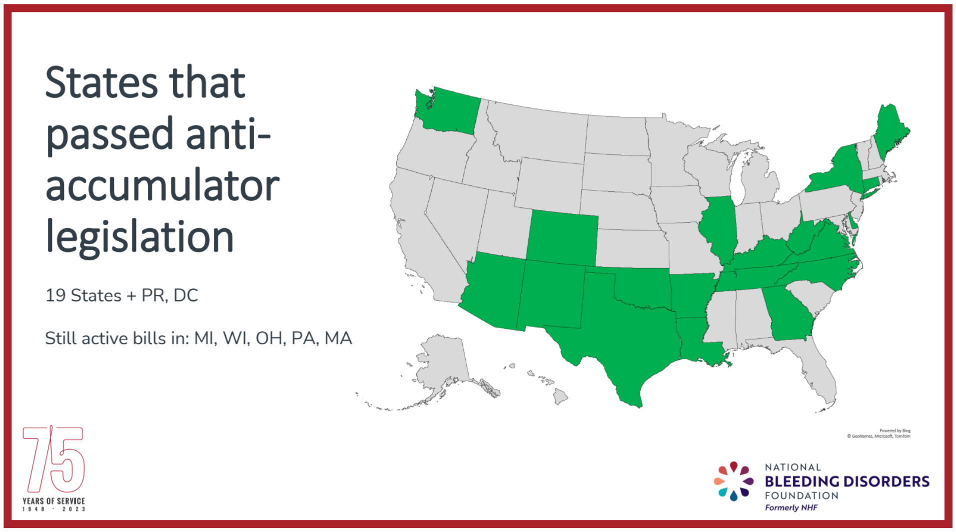
Section 2. Declaration of policy.

The General Assembly finds and declares as follows:

(1) Hemophilia is a rare, hereditary bleeding disorder affecting at least 1,700 individuals in this Commonwealth. It is a chronic, lifelong, incurable disease.

(2) Until the 1970s, persons afflicted with severe hemophilia suffered from uncontrollable internal bleeding, crippling orthopedic deformities and a diminished lifespan.

(3) The scientific discovery of highly purified blood clotting factors has enabled many persons with hemophilia the opportunity to lead normal lives free of pain and crippling



States that passed anti-accumulator legislation

19 States + PR, DC

Still active bills in: MI, WI, OH, PA, MA

WINTER PROGRAM

On Saturday, December 9, 2023, families and community members came together at the Club at Shadow Lakes for WPBDF's Winter Program. The first hour was spent playing games, making holiday crafts, and visiting the sponsor booths. Every child received a gift of a new Lego set as they arrived. The Shropshire Family taught everyone how to play dreidel and Stephanie led a craft of making your own edible dreidel with pretzel rods, marshmallows, and a Hershey kiss. The Shoemaker Family led the holiday craft table and allowed attendees to color their own wooden ornaments and put together holiday picture frames. Maria Shoemaker donated a basket of toys and each child who attended received a ticket for a chance to win. Santa made a special appearance and families could get their photo taken with him. A surprise visit from the Grinch thrilled the children as holiday music played in the background. Attendees enjoyed a brunch buffet of French toast, scrambled eggs, bacon, crepes, potatoes, and fruit. After brunch, a program was held on nutrition and how to stay active this winter. Everyone left with a workbook full of healthy recipes, simple exercises, and tips on how to stay healthy and active. Thank you to everyone who attended this program and celebrated the holiday season with us! We wish everyone a happy and healthy new year!

Thank you to our sponsors:

promptcare
BIOMARIN
DrugCo Health
The Hemophilia Center of Western Pennsylvania
Medexus Pharma
Cottrill's Pharmacy, Inc.
sanofi
Pfizer
Takeda
novo nordisk

LIFE HAPPENS

AND ADVATE WILL BE THERE WHEN IT DOES

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

Not an actual patient.

ADVATE has over 15 years of treatment experience in the real world and provides clinically proven bleed protection* for patients with hemophilia A.[1]

ADVATE

[Antihemophilic Factor (Recombinant)]

REAL LIFE. REAL BLEED PROTECTION.*

AdvateRealLife.com

Prophylaxis with ADVATE prevented bleeds[1]

The ability of ADVATE to treat or prevent bleeds was evaluated in a clinical study using a standard prophylaxis, pharmacokinetic driven prophylaxis, and on-demand treatment.

53 previously treated patients (PTPs) with severe to moderately severe hemophilia A were analyzed. For the first 6 months of the study, patients received on-demand treatment. For the following 12 months of the study, patients received either standard prophylaxis every 48 hours or a pharmacokinetic-driven prophylaxis every 72 hours. The primary goal of the study was to compare annual bleeding rates between those receiving prophylaxis treatment and those receiving treatment on-demand. The number of bleeds per year for the 2 prophylaxis regimens were comparable.

- Those patients experienced a median of 1 overall bleed per year on either prophylaxis treatment vs 44 overall bleeds per year with on-demand treatment.[†] This represented a 98% reduction in overall bleeds per year.
- Zero bleeds were reported in 42% of patients (22 out of 53 patients) during 12 months on prophylaxis

[†] Median is the middle number in a group of numbers arranged from lowest to highest.

ADVATE Important Information

What is ADVATE?

- ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia).
- ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider (HCP) may give you ADVATE when you have surgery.
- ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADVATE?

Do not use ADVATE if you:

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

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

What should I tell my HCP before using ADVATE?

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 ADVATE passes into your milk and if it can harm your baby.

What should I tell my HCP before using ADVATE? (continued)

- Are or become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What important information do I need to know about ADVATE?

- You can have an allergic reaction to ADVATE. Call your HCP 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 ADVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADVATE 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 ADVATE 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 ADVATE?

- Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, unusual taste, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash. Tell your HCP about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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

For Full Prescribing Information, visit www.ADVATE.com.

Reference: 1. ADVATE Prescribing Information.

Takeda

ADVATE
[Antihemophilic Factor (Recombinant)]

Important facts about

ADVATE [Antihemophilic Factor (Recombinant)]

This leaflet summarizes important information about ADVATE. 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 ADVATE. If you have any questions after reading this, ask your healthcare provider.

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

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 ADVATE so that your treatment will work best for you.

What is ADVATE?

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.

Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

Who should not use ADVATE?

You should not use ADVATE if you:

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

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

How should I use ADVATE?

ADVATE is given directly into the bloodstream.

You may infuse ADVATE 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 ADVATE by themselves or with the help of a family member.

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

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

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

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

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

What are the possible side effects of ADVATE?

You can have an allergic reaction to ADVATE.

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

Side effects that have been reported with ADVATE include:

cough
sore throat
unusual taste
abdominal pain
diarrhea
nausea/vomiting
headache
fever
dizziness
hot flashes
chills
sweating
joint swelling/aching
itching
hematoma
swelling of legs
runny nose/congestion
rash

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 ADVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADVATE 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 ADVATE 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 ADVATE for a condition for which it is not prescribed. Do not share ADVATE 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 ADVATE. The FDA-approved product labeling can be found at www.ADVATE.com or 1-877-825-3327.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Patented: see https://www.takeda.com/en-us/patents/

U.S. License No. 2020
Issued: 12/2018

US-ADV-0030v1.0 02/20

Takeda

GETTIN' IN THE GAME JUNIOR NATIONAL CHAMPIONSHIP

JAXSON B.

On October 5, I traveled with my mom to Las Vegas, NV to attend CSL Behring's 2023 Gettin' in the Game Junior National Championship. We stayed at the Hilton Lake Las Vegas Resort, and I loved it there. It was so awesome!

On the first night, there was a Welcome Dinner, where I met two new friends who were both from West Virginia and have Hemophilia, like me. We had fun that night playing in the game room. The next day, we had some free time and my parents and I visited the Hoover Dam. Then, we headed to a golf clinic at Chimera Golf Club. We met Perry Parker and other golfers who helped me in the clinic. We practiced chipping, putting, and spent time at the driving range. I learned a lot of new golf skills and how to improve my golf game.

On Saturday morning, we had a golf competition and I had my very own caddy. I felt a little nervous when I got there, but everyone was cheering and clapping for us when we got off the bus and that made me feel happy. My caddy was kind and he helped me do better in the competition. He even let me drive the golf cart!

Later that afternoon, we had a Rap Session with Perry Parker and the rest of the Pro Sports Athletes. Then, we did a community service project to provide food to the homeless. That evening, there was an awards dinner and a fun after party. We had ice cream and I got to dance with my new friends.

I had so much fun on this trip, and I loved golfing in Las Vegas! Thank you to CSL Behring and the WPA Bleeding Disorders Foundation for sending me on this trip.

MEET THE BOARD MEMBERS

KRISTEN SPEZIALETTI

WHAT INFLUENCED YOU TO GET INVOLVED WITH THE CHAPTER AND JOIN OUR BOARD OF DIRECTORS?

I have seen how challenging chronic medical conditions can be to a family. I have also seen the goodness embodied by organizations like the Western Pennsylvania Bleeding Disorders Foundation, and I wanted to be a part of that.

WHAT ARE YOU LOOKING FORWARD TO AS A NEW BOARD MEMBER?

I am looking forward to cultivating relationships with the bleeding disorders community. I want to use my skills, experiences, and network to serve the community and have a positive impact on families affected by bleeding disorders through advocacy, fundraising, education, and fellowship. To experience individuals and families gathering with one common goal is powerful, and it's a true testament to the kindness and strength of the bleeding disorders community.

WHAT DO YOU LIKE TO DO FOR FUN?

I love painting and creating floral arrangements. I also love trivia... especially geography and history.

WHAT IS YOUR BACKGROUND OR CURRENT OCCUPATION?

I work in communications, and I have professional experience in fundraising, social media management, and event planning/coordination.

MAKING A DIFFERENCE ON THE MOUNT

ASHLEY F.

A blend of sweet and savory scents waft through a snug Mount Washington pub as an energetic crowd gathers inside. Each fall, Pittsburgh locals flock to Cafe Nikos on Shiloh Street to sample chili and support their community.

For the past 11 years, Nick Hages, Dena Milesky, and the team at Cafe Nikos have hosted their annual Chili Cook Off benefiting a local charity or family in need. The 'day drinking for a cause' event involves 15 chili contestants, a panel of judges comprised of local chefs, an expansive bake sale, raffles, and a DJ.

One of the returning judges is Prep/Catering Manager of North Shore Tavern and long time Nikos customer, Maggie Conroy. When asked about the collective impact of the event, she stated that, "... year after year, the cause is so deserving...When you have an establishment that lifts up its community, it feels like home."

This year, Cafe Nikos decided to shift their focus to a lesser known cause — the bleeding disorders community. "It hits close to home because my grandson has Hemophilia, so I've seen firsthand the obstacles of living with this condition," said Dena Milesky, Cafe Nikos manager.

Dena's two year old grandson, Rylen, was diagnosed with Hemophilia A shortly after birth. Within the first year of his life, he had already spent quite some time in Children's Hospital receiving factor infusions, CT scans, and overnight monitoring.

Unifying as Team Fox Factor, Rylen and his family participate in the annual Unite Walk, collecting donations and organizing various benefits. Their fundraising was kicked into high gear when they were selected as Cafe Nikos' 2023 beneficiary. In total, $3,650 was raised at the Chili Cook Off. All proceeds directly benefit Western PA Bleeding Disorders Foundation and its mission.

"The Chili Cook Off is always such a great event and is a wonderful opportunity for all of us to come together and support a good cause," said Katy Hibbard, Cafe Nikos employee.

Rylen's family looks forward to continuing to raise funds and awareness for those living with bleeding disorders in the years to come.

11TH ANNUAL TAKE A BOUGH

The 11th annual Take A Bough was held on Saturday, December 2, at the Red Fox Winery in Hickory, PA. Thanks to the support from our sponsors, donors, and patrons, we raised over $8,500! We are extremely grateful for everyone who participated in Take A Bough this year, as this fundraiser would not have been successful without you.

This year's auction opened online on Friday, November 24, one week prior to the live event. Planning and preparation for this event began months before December. Many supporters and community members handmade and generously donated all of the items featured in the auction this year.

Thank you to:

Laureen T.
Kara D.
Dalton D.
Maria S.
Janet B.
Kristen S.
Jessica L.
Cassie M.
Delaine L.
Absolute Kitchens
Tracy S.
Julie L.
Jeanne S.
Francine D.
Maria Steele-Voms Stein
Trinity Jewelers

We'd also like to thank our co-chairs, Mindy Perry-Stern and Maria Steele-Voms Stein! These ladies helped with planning and preparation for this event and collected numerous donations for our auction and basket raffles! In total, we had three full size trees, eight tabletop trees, 13 wreaths, 10 centerpieces, 19 raffle baskets, and six additional auction items! Michael P. and Tracy B. sold tickets for the 50/50 raffle and donated a signed Kris Letang jersey! These raffles raised $829!

Thank you to our amazing volunteers who helped make this event successful:

Samantha S.
Larry S.
Maria S.
Todd S.
Joseph E.
Delaine L.
Victoria B.
Judy W.
Tracy B.
Michael P.
Adam B.

Red Fox Winery provided wine samples to our guests and ran a fun and exciting bingo game for us! This year, Take A Bough also featured a delicious Italian dinner. WPBDF also hosted an Ugly Sweater Contest and encouraged all our participants to come wearing their ugliest holiday sweater. Laureen T. was the winner and took home a $50 gift card to LeMont along with a holiday cheer basket! You can check out all the sweaters we saw at Take A Bough below!

The auction ended online and in-person at 9:00 PM. Participants

... CONTINUED ON PAGE 18

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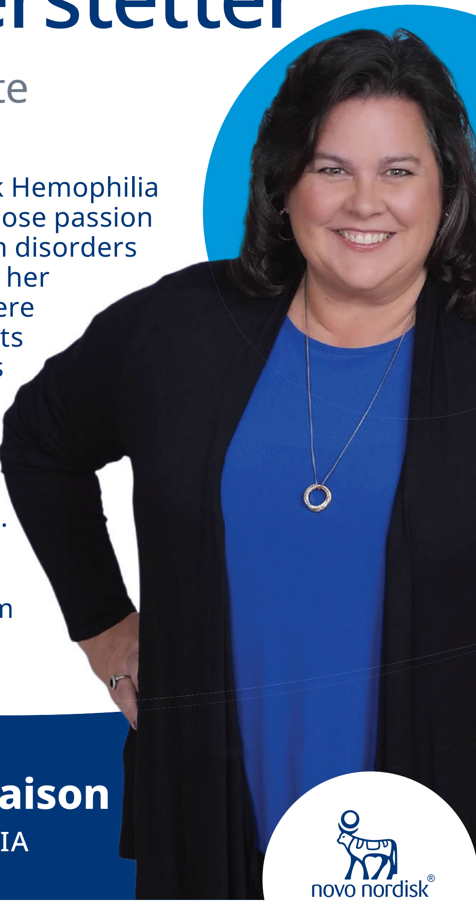
DINE 2 DONATE AT PRIMANTI'S

On Wednesday, October 4, Primanti Brothers of Center Township hosted a Dine 2 Donate to benefit the Western Pennsylvania Bleeding Disorders Foundation. 20% of all purchases that day were donated back to the Foundation. Thank you to WPBDF board member, Kristen Spezialetti, for organizing this event for us! In total, we raised over $100! Thank you to everyone who came out to enjoy a delicious meal and support the bleeding disorders community of Western PA!



THE BEAUTY BOOST

WPBDF'S WOMEN, GIRLS, AND THOSE WITH THE POTENTIAL TO MENSTRUATE WITH BLEEDING DISORDERS INITIATIVE

On Saturday, November 11, 2023, Executive Director, Kara Dornish, Development Director, Jessica Lee, and patient advocate Maria S. attended The Beauty Boost Pittsburgh's Fitness Sampler! This event featured 25-minute back-to-back workout sessions lead by local fitness studios and focused on women's health. WPBDF displayed a table at the event and passed out information about the Foundation, explained what bleeding disorders are, and directed women who may be experiencing symptoms to betteryouknow.org. Maria, who is affected by von Willebrand Disease, shared her story with those who stopped by the booth. Over 300 women attended this event! Thank you to Michelle Colella, owner of The Beauty Boost Pittsburgh, for allowing us to share information about bleeding disorders at this event!

HOW YOU CAN HELP?

If you know of community events that have booth or exhibit opportunities, please let us know. Better yet, if you would be willing to display at the booth or exhibit we can provide you all the resources you need! If you have connections with your local school nurses, high schools, universities, health clinics, or OB/GYNs, we need your help to get resources to them! Questions? Please reach out to Kara at kara@wpbdf.org.

WPBDF'S CORNHOLE TOURNAMENT

WPBDF'S
CORNHOLE TOURNAMENT

WPBDF held their first in-person cornhole tournament since 2019 on Saturday, November 4, 2023, at the Warehouse at Bottle Rocket Social Hall. This double elimination tournament was managed by Steel City Cornhole. Warm up and registration started at 1:00 PM and the tournament began at 1:30 PM. We had three competitive teams and eight social teams. WPBDF raffled off some amazing items such as a Steeler's Basket, a $50 gift card to the Cheesecake Factory, and a set of hand painted, superhero cornhole boards! Congratulations to the winners of our Competitive Division:

First Place: Mike and Justin

Second Place: Dana and Eddie

Third Place: Joe and Stuart

And congratulations to the first-place winner of the Social Division, Steve S. and Steve E.!

First place winners of the Competitive Division, Mike and Justin, donated $100 of their winnings back to the Foundation. Justin also won the 50/50 and donated all of his winnings back! Thank you to Michelle from Rolling for Ryker for helping to sell 50/50 raffle tickets! The 50/50 raised a total of $126. Special thanks to Joe Castellano of Steel City Cornhole for doing an amazing job running the tournament.

Thank you to our sponsors!

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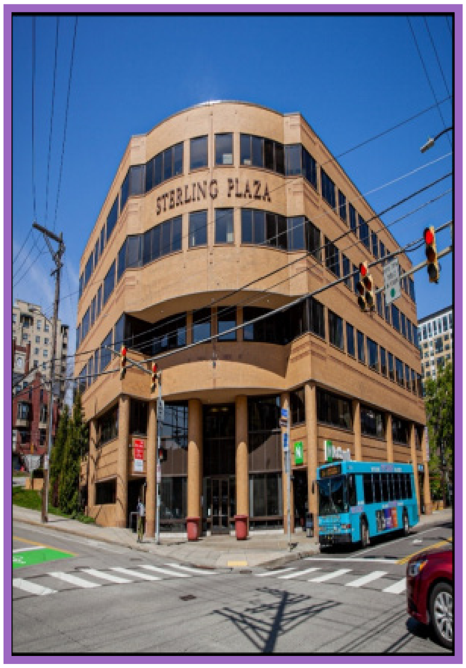
CSL Behring

We are excited to report that over $4,000 was raised! 100% of this money will stay local to support the members of the Western PA Bleeding Disorders Foundation.

Steve E. not pictured.

GETTING TO KNOW HCWP STAFF



We are pleased to introduce our newest face at the Center: 201 North Craig Street, Suite 500!

She is excited to join us and serve our beautiful community.

Here is some information so you can get to know her!

Birthplace: Sterling Plaza, Pittsburgh, PA

First job: Proudly serving the bleeding disorders community

Accomplishment you're proudest of: Having a lot of space to accommodate meetings, appointments, and staff! Just look at my spacious waiting room!

What three words describe you best? Comfortable, fresh, welcoming

Dream vacation: Why would I want to be anywhere else??

Things you can do without: Empty hallways... they make me sad.

Person you'd most like to have dinner with: Dr. Margaret Ragni. She's a legend. Or any of the WPBDF staff, really. All legends!

Movie you could see anytime: It's not a movie, but I really love *The Office.* Dwight cracks me up!

TV show you try not to miss: *Grey's Anatomy*. I love a medical drama- and I'm learning so much with my work here!

Three things that can always be found in your refrigerator: Whatever the HCWP staff put in there! They seem to really enjoy a variety of condiments and Diet Coke.

Secret vice: Watching people get surprised by the motion sensor lights (pretty funny)!

Who would play you in the movies?: The Eiffel Tower... a girl can dream, right?

Your pet peeve about Pittsburgh: I look best in the sunlight- so I'd say too many gray skies!

People may be surprised to know: I have my very own garage, with validated parking!

WPBDF OPEN HOUSE

On Sunday, October 1, we invited the community to visit the Western Pennsylvania Bleeding Disorders Foundation office, located at 775 Fourth St., in Beaver, PA. Participants enjoyed light refreshments and met with members of the WPBDF Board of Directors and Staff. Everyone who attended had the opportunity to learn about bleeding disorders and the services we provide. We shared information about our upcoming events and all the different ways to get involved as a member or volunteer. We would like to extend a huge thank you to everyone who attended! Thank you for making our first open house a success!

11TH ANNUAL TAKE A BOUGH

CONTINUED FROM PAGE 13...

were able to take their winnings home that night, while online participants could pick them up at the Foundation office starting Monday, December 4. The Western Pennsylvania Bleeding Disorders Foundation would like to thank Mindy and Maria once again for co-chairing the event, the community members who handmade and generously donated items for the auction, and the many volunteers who helped transport items to Red Fox Winery, set up the venue, and helped during the event. Successful fundraisers like Take A Bough allow the Foundation to provide education, support groups, and patient assistance to our members in need – all at no cost to them.

We hope to see you at our next event!

Thank you to our sponsors!

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CSL Behring

Our Dessert Sponsor:

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HCWP CORNER

KATHRINE BUSCH, LCSW

Hello to all WPBDF Members and Your Families,

It's been a great year! We have been able to resume our Amish outreach clinics, resume camp, and move to our beautiful new HCWP location! The year 2023 has certainly had a lot to celebrate, and we are feeling positive and hopeful as we head into 2024. We are hopeful for all of you that you have had reason to celebrate in 2023 as well; and if it was a tough time for you, we are hopeful for brighter times ahead.

As you are out and about with your holiday visits, please remember to contact us for a travel/Emergency Department letter if you need an updated one, and to make sure you have plenty of factor on hand (don't forget, you can leave a message after hours or order factor online). Make sure that go-bag is ready to go with all needed supplies.

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

We know that the holidays, and winter in general, can be a financially hard time for many; and it certainly doesn't seem that life is getting any cheaper. Please remember that we are glad to speak with you about any assistance or resources we can provide, and that the bleeding disorder community is truly a generous community that wants to make sure everyone who is a part of it receives what they need. Please reach out to us if things are tough. We cannot stress enough how very thankful we are to have real, concrete, readily available support for our patients. We do want to be wise stewards of these resources, however, so please be mindful of our policies and limits. These policies are available upon request.

We are excited to announce that camp Hot-to-Clot 2024 is being held from July 28-August 2, 2024. Registration for camp opened January 3. The registration link is: https://konokweespencer.campbrainregistration.com/. Select Hot-to-Clot as your session. Please remember that camp is for youth ages 7-17 years old with a bleeding disorder, as well as their siblings in the same age range. If you are interested in volunteering or being a counselor, please reach out to the center at 412-209-7344 and let us know. We're already looking forward to it!

Additionally, Dr. Xavier wanted to pass along this information: *HCWP and UPMC Children's Hospital of Pittsburgh have opened a new clinical trial studying a new hemostatic drug given subcutaneously (underneath the skin) for patients12 years and older with severe hemophilia A or B. If this interests you, please call 412-209-7564 for more information.*

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

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

The HCWP Staff

FALL PROGRAM

Tim Ringgold, an award-winning international speaker and board-certified music therapist, presented a program on music therapy during our Fall Program, on October 14, 2023. As a music therapist, Tim has helped people leverage the power of music to cope with challenges associated with medical conditions and addiction. Realizing that many people weren't even aware of music therapy as an option to address pain, stress, behavior, etc., Tim began giving formal talks on the subject. We are grateful that we were able to arrange a program with Tim to speak to members of the Western Pennsylvania bleeding disorders community.

Through the years, Tim learned to overcome adversity and has become resilient. He shared his own story, which included some incredibly personal losses and challenges, including the loss of his own special needs daughter.

He shared with us how he and his wife used music to create a peaceful atmosphere for them and their daughter during her daily care and treatment, which took hours at a time.

We were introduced to techniques in music therapy and were given an opportunity to practice. Everyone received an egg shaker at the start of the program to join in on making music. Tim played his guitar and guided us through a meditation, and he ended the program by leading a sing-along. One attendee later mentioned that they felt the benefit of the program that very day. Another mentioned that the program far exceeded their expectations!

We thank our sponsors for supporting this event:

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WPBDF
Western Pennsylvania
Bleeding Disorders Foundation

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION'S

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.

All ages are welcome!

April 26 - 28, 2024

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

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 aged 5-17 (or 18 and in high school) and daycare is provided for children aged 0-4.

Sessions include:

- Bleeding Disorders 101
- Musculoskeletal
- Hands-on Infusion Training
- Childbearing Years and Childbirth
- Preparing for Surgery and After-Surgery Support

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

We are excited to announce that this year, Education Weekend will begin on Friday, April 26, for all registered participants!

Registration Information:

- To request a registration form, send an email to rsvp@wpbdf.org or call 724-741-6160. Once approved, you will receive a link to fill out your registration form online.
- The $50 registration fee can be paid with a check, money order, or credit card.
- The deadline to request a registration form and a scholarship application is March 14, 2024.
- Completed registration form (including all signed documents) and the registration fee (or scholarship request) **must be received by March 17, 2024.**

Education Weekend Includes:

- 2 Night Hotel Stay
- Meals and Snacks
- Education Sessions for Adults
- Supervision, Education Sessions, and Activities for Children
- Daycare for Infants and Preschoolers

The only cost to attend this event is a $50 non-refundable registration fee, per family (due at time of registration). If the $50 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.

Completed registration forms and $50 registration fee (or scholarship request) must be received by March 17, 2024.

You are encouraged to register early!

Please note: Any family that has registered for and no-showed this event in the past or has no-showed multiple events in the last 18 months (without a medical reason) may be placed on a waiting list.

NEW STUDY LOOKS AT HEMOPHILIA SURVIVAL RATE DISPARITIES

Results of a new study published in the journal Haemophilia are illustrative of persistent health disparities existing within the U.S. hemophilia population.

The data that informed the study was drawn from National Vital Statistics System (NVSS), which generates comprehensive statistics on births and deaths in the United States. The authors looked at the NVSS' 1999–2020 Multiple Cause-of-Death data set to learn more about rates of hemophilia-related death (rHD).

Investigators ultimately identified 3,115 males associated with a rHD. Data showed that approximately 76.1% of deaths occurred in White men (2370), 13.3% in Black men (413), 7.4% in Hispanic men (233), 2.2% in Asian men (69), and 0.9% in American Indian/Alaska Native men (28), while race and ethnicity data were missing in two cases. A review of the data revealed a noteworthy reduction in overall age-adjusted rHD rates for all race and ethnic groups, with a decrease from 1.37 per 1 million males in 1999-2004 to 0.76 per 1 million males in 2015-2020.

This improvement in rHD rates, driven in part by the evolution of treatment and access to better therapies, represents a positive overall trend. However, the most recent decade's worth of data (2010-2020) also revealed a troublesome disparity as Blacks and Hispanics showed a median rHD of 56 years, putting them significantly behind their white counterparts who experienced a mean age of 68 years.

"Our observation that Black men had a lower median age at death and that HIV continues to be a leading cause of death among Black males with hemophilia listed in their death certificate in both earlier and recent years could signal ongoing survival disparities among Black people with hemophilia and an HIV infection,"

While the data suggest that HIV has a major impact on rHD in Black males, further research is necessary to identify additional inequities contributing to poorer health outcomes in underserved populations.

"Reported haemophilia-death rates improved in males across all race/ethnicities, but rates were higher Black versus White males. Given the inherent limitations of the current study's data source, further investigation of survival rates and disparities in haemophilia are needed," the authors concluded.

The study, "Racial and ethnic differences in reported haemophilia death rates in the United States," was published online in Haemophilia on September 23, 2023.

Source: The American Journal of Managed Care, September 23, 2023

Article Courtesy of HemAware *copyright 2023*

HEMGENIX

On October 19, 2023, a program on Hemgenix, the first and only approved gene therapy for Hemophilia B, was held in Mt. Lebanon. Dr. Beverly Schaefer, a clinical assistant professor of pediatrics at the Jacobs School of Medicine and Biomedical Sciences at State University of New York (SUNY) – Buffalo, an assistant professor of pediatric oncology at Roswell Park Comprehensive Cancer Center, and the pediatric medical director at Western New York BloodCare, presented the educational program. Throughout the evening, Dr. Schaefer answered questions about the clinical trials and results, how gene therapy works, eligibility, and more. Everyone walked away with a deeper understanding of gene therapy.

We encourage patients and those who would share in their decision-making progress, to become educated on gene therapy and the results from the Hemgenix clinical trials. We thank CSL Behring for bringing this program to Western Pennsylvania.

CSL Behring

As we say farewell to 2023 and hello to 2024, we are thankful for all the opportunities you gave us to serve you over the past year. We wish you a warm and cozy holiday season!

From all of us at the HCWP – we are looking forward to serving you in 2024. We thank you for trusting us to be a part of your care, and wish the best for you and yours in the coming year!

Save the Date

Pennsylvania Bleeding Disorders Conference

May 16 - 18, 2025

Hershey Lodge
325 University Dr,
Hershey, PA 17033

More information coming soon!
To stay up-to-date on all upcoming WPBDF events, visit wpbdf.org.

HEALTH INSURANCE ROADMAP

We can't stress enough how important it is to understand your health insurance coverage, especially when you are choosing or renewing a policy. On November 9, 2023, we offered a virtual insurance program for our members, the *Health Insurance Roadmap*. Jan Martin, Community Education Specialist with Takeda, presented the program. Jan has 40 years of nursing experience, including 16 years in the Hemostasis and Thrombosis Center at University Hospitals in Cleveland. She is very familiar with insurance issues that patients in the bleeding disorders community encounter. Jan's presentation included an overview of insurance options, transitions that impact coverage, and insurance denials. We thank Takeda for sponsoring this program.

It's so important to stay on top of insurance issues and to do your best to be aware of any changes in your policy from year to year, such as the addition of a Copay Accumulator Adjustor Program. When an insurance policy has this, any financial assistance a patient receives toward their copay does not count toward their out-of-pocket maximum. Only dollars paid directly by the patient count.

It's not always easy to be able to identify Copay Accumulator Adjustor Program language in an insurance plan. The language varies from plan to plan and sometimes it's phrased in a way that sounds like it's a benefit to the patient, when the patient is not the one benefiting. In addition, it's important to be aware that copay accumulator language might exist in a plan one year, but not be enacted, and the next year the company might choose to enact it. When selecting an insurance policy, it's really important ask lots of questions!

Takeda

MEET THE BOARD MEMBERS

LAUREEN TEMPLE

WHAT INFLUENCED YOU TO GET INVOLVED WITH THE CHAPTER AND JOIN OUR BOARD OF DIRECTORS?

It has been an honor to be part of this community for over 20 years. I came to the community through my position in the industry, but quickly realized that my work would be fueled by a passion to support the warm, courageous and welcoming members. I have seen so many face challenges, conquer fears, embrace others and genuinely show up for each other. This is the heart of the community and I will always be proud to be allowed to stand in.

WHAT ARE YOU LOOKING FORWARD TO AS A NEW BOARD MEMBER?

I am looking forward to my time as a board member to serve this community in new ways. I hope that my science background and understanding of the industry will combine to enhance our understanding of future advances and find new ways to grow financial and medical support.

WHAT DO YOU LIKE TO DO FOR FUN?

So, what I like to do for fun has greatly expanded recently and I am trying all new things. I really enjoy traveling, reading, baking, dancing, biking and even a little pickleball. Mostly I am enjoying the time to be able to spend it with those that I love. I am so grateful.

WHAT IS YOUR BACKGROUND OR CURRENT OCCUPATION?

My background has been in medical sales, patient education and advocacy. My focus has been striving to always be present, and to support the community with the education needed to be able to understand bleeding disorders and the products and services available. Although retired now, my big nerd tendencies prevail and I love to explain just how the clotting cascade works and how new innovations may impact the treatments of the future.

WPBDF
Western Pennsylvania Bleeding Disorders Foundation

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION
775 4th Street
First Floor
Beaver, PA 15009

FOR BLEEDING DISORDERS

Sunday, February 18, 2024

Paradise Island Bowl
7601 Grand Avenue
Pittsburgh, PA 15225

bit.ly/bowlingforbleedingdisorders24

WPBDF
Western Pennsylvania Bleeding Disorders Foundation

HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION
775 4th Street, First Floor
Beaver, PA 15009
Phone: 724-741-6160 Toll Free: 800-824-0016 Fax: 724-741-6167
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