WPBDF
Western Pennsylvania
Bleeding Disorders Foundation

HEMOGRAM

WESTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

SUMMER 2023

WPBDF
Western Pennsylvania Bleeding Disorders Foundation

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Staff office hours are Monday-Friday from 9 a.m. until 4 p.m. Every attempt will be made to return calls received during regular office hours on the same day.

MISSION STATEMENT

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

Hemogram is published quarterly by the Western Pennsylvania Bleeding Disorders Foundation.

DESIGNATE UNITED WAY GIFTS TO THE CHAPTER

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

WPBDF Contributor Agency Code Number is: 83

EVENTS CALENDAR

July 19, 2023
Hemgenix Program
The Cork 1794
Erie, PA

July 30 - August 4, 2023
Camp Hot-to-Clot
Camp Kon-O-Kwee
Fombell, PA

August 11, 2023
Back to School
Dave & Busters - North Hills
Pittsburgh, PA

August 17 - 19, 2023
NHF BDC
Gaylord National Resort & Convention Center
National Harbor, Maryland

August 26, 2023
Women's Wellness Day
Pittsburgh Botanic Garden
Pittsburgh, PA

September 9, 2023
Unite for Bleeding Disorders Walk & Run for Their Lives 5K
North Park Swimming Pool
Allison Park, PA

September 14, 2023
Hemgenix Program
Location TBA
Robinson Twp., PA

September 16, 2023
Pittsburgh Pirates Fundraiser
PNC Park
Pittsburgh, PA

September 23, 2023
New Parent Network
Kennywood
West Mifflin, PA

October 14, 2023
Fall Program
Fellowship Hall at Trinity Church
Wexford, PA

November 1, 2023
Insurance Program
Location TBD

November 4, 2023
WPBDF's Cornhole Tournament Fundraiser
Bottlerocket Social Hall
Pittsburgh, PA

November 21, 2023
Advocacy Stakeholder Meeting
Virtual

December 2, 2023
Take A Bough Fundraiser
Red Fox Winery
Hickory, PA

December 9, 2023
Winterfest
Shadow Lakes Country Club
Aliquippa, PA

February 18, 2024
Bowling for Bleeding Disorders
Paradise Island Bowl
Neville Island, PA

March 6 -8, 2024
NHF Washington Days
Wasington, D.C.

April 26-28, 2024
Education Weekend
Seven Springs Mountain Resort
Seven Springs, PA

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

COMMUNITY ANNOUNCEMENTS

MEET WPBDF'S SUMMER INTERN!

Hi! My name is Ally Smith. I am a rising Senior at Kent State University where I am pursuing a degree in marketing. At school, I am a part of Kent State Student Media, Delta Gamma Sorority, American Marketing Association, along with a few other organizations. In my free time, I enjoy working out, going on nature walks, and hanging out with friends. I am so excited for the opportunity to intern with WPBDF this summer. I look forward to helping Jess plan the Unite for Bleeding Disorders Walk as well as developing marketing materials for the Foundation.

CONTACT US

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@WPBDF
@WPABDF

LETTER FROM THE EXECUTIVE DIRECTOR AND BOARD PRESIDENT

Dear Foundation Members & Friends,

We hope everyone is having a great start to the summer! June marks the end of the Foundation's fiscal year and is a time we like to look back on what we accomplished and the work that lies ahead of us. This 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)! We had over 1,223 people register for these programs! We held 5 fundraisers, which raised over $88,000 for the bleeding disorders community. We provided nearly $35,000 in patient assistance to over 200 community members in need. Our grocery assistance program also 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.

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 – but our work is far from over. We are working hard to garner support for an increase to the hemophilia line item in the state budget and to get legislation passed to stop copay accumulators and maximizers. We need to continue building strong relationships with legislators and we need your help. If you would be interested in joining us in meeting with legislators, or would like to get involved by making phone calls or writing letters, please reach out to me at kara@wpbdf.org or 724-741-6160.

We have many upcoming events including our Back-to-School Program on August 11, Women's Wellness Day on August 26, the Unite for Bleeding Disorders Walk and Run for Their Lives 5k on September 9, our Fall Program on October 14, and we are very excited to be bringing back our Cornhole Tournament fundraiser on November 4! We hope to see you all there!

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

Sincerely,

Kara Dornish
Executive Director

Scott Domowicz
Board President

GENE THERAPY RESEARCH: UNDERSTANDING THE SCIENCE

BIOMARIN®

On Tuesday, May 2, 2023, the Western Pennsylvania Bleeding Disorders Foundation partnered with BioMarin to bring the community an educational program on Gene Therapy Research. Members gathered at the Grand Concourse to enjoy dinner as Tommy Russomano, Senior Account Manager Hemophilia Gene Therapy, led an engaging and interactive program on Gene Therapy Research. The program explained how gene therapy research is designed, what types of gene therapies are being researched, and why some people are better candidates for gene therapy than others. We thank BioMarin for sponsoring this event.

HEMGENIX

On November 22, the U.S. Food and Drug Administration approved Hemgenix (etranacogene dezaparvovec), an adeno-associated virus (AAV) vector-based gene therapy. It is approved for the treatment of adults with hemophilia B who currently use factor IX (FIX) prophylaxis therapy, or have current or historical life-threatening hemorrhage or have repeated, serious spontaneous bleeding episodes.

Safety and effectiveness of the therapy were evaluated via two clinical studies of 57 adult men, 18 to 75 years of age, with severe or moderately severe hemophilia B. According to a new FDA release, decreases in annualized bleeding rate (ABR) were a primary measure of the therapy's effectiveness. Results of one study showed that the 54 participants had increases in FIX activity levels, a decreased need for routine FIX replacement prophylaxis, and a 54% reduction in ABR compared to baseline.

The most common adverse reactions associated with Hemgenix treatment were liver enzyme elevations, headache, mild infusion-related reactions, and flu-like symptoms.

"Gene therapy for hemophilia has been on the horizon for more than two decades. Despite advancements in the treatment of hemophilia, the prevention and treatment of bleeding episodes can adversely impact individuals' quality of life," said Peter Marks, MD, PhD, director of the FDA's Center for Biologics Evaluation and Research. "Today's approval provides a new treatment option for patients with Hemophilia B and represents important progress in the development of innovative therapies for those experiencing a high burden of disease associated with this form of hemophilia."

In light of this FDA approval, Dr. Len Valentino, CEO of the National Hemophilia Foundation, said: "It's an exciting time for the bleeding disorders community as new and groundbreaking treatment options become available. It is great to see this innovation for people living with Hemophilia B, and we will continue our work to ensure all people with inherited bleeding and blood disorders have full access to Hemgenix and like products as they come to market. While this development is a significant step forward from bench to bedside for the hemophilia B community, receiving gene therapy is a decision that should be made with thoughtful consideration with one's family and medical team. [Source National Hemophilia Foundation: https://www.hemophilia.org/news/first-hemophilia-b-gene-therapy-approved-by-fda]

On April 6, 2023, the Western Pennsylvania Bleeding Disorders Foundation teamed up with the Eastern Pennsylvania Bleeding Disorders Foundation to hold a virtual program on Hemgenix. Corbett Reinbold, RN, BSN CCRCD led the discussion. Participants gained valuable information to gain a better understanding of Hemgenix through a live Q&A session. On May 24, 2023, the Western Pennsylvania Bleeding Disorders Foundation held an in-person program on Hemgenix at Atria's Tavern in Murrysville, PA. This program was presented by Dr. Richard Lemons, Medical Director, Division Chief, and professor of pediatrics in the Division of Pediatric Hematology/Oncology at the University of Utah in Salt Lake City. Dr. Lemons led a very engaging presentation and took the time to answer all participant questions. Everyone in attendance left with a better understanding of how this groundbreaking treatment works. We are planning additional programs this summer and fall. Be sure to check our events calendar at https://wpbdf.org/events.

HEMGENIX®
etranacogene dezaparvovec-drlb

No actual patients depicted.

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

AdynovateRealLife.com

HEMOPHILIA A IS A PIECE OF YOU.

NOT ALL OF YOU.

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

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

ADYNOVATE twice-weekly prophylaxis prevented or reduced the number of bleeds[2]

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

- **Children Under 12 Years**: This study evaluated the efficacy of ADYNOVATE twice-weekly prophylaxis and determined the ability to treat bleeding episodes for 6 months in 66 children under 12 years old who received 40–60 IU/kg of ADYNOVATE prophylaxis treatment[2]
  - During the 6-month study in children under 12, those receiving twice-weekly prophylaxis treatment experienced a median† overall ABR‡ of 2.0
  - 0 bleeds in 38% (25 out of 66 patients) during 6 months on twice-weekly prophylaxis
- **Adolescents and Adults 12 Years and Older**: This study evaluated the efficacy of ADYNOVATE in a 6-month study that compared the efficacy of a twice-weekly prophylactic regimen with on-demand treatment and determined hemostatic efficacy in the treatment of bleeding episodes in 137 patients. These adolescents and adults were given either ADYNOVATE prophylaxis twice-weekly at a dose of 40–50 IU/kg (120 patients) or on-demand treatment with ADYNOVATE at a dose of 10–60 IU/kg (17 patients). The primary study goal was to compare ABR between the prophylaxis and on-demand treatment groups[2]
  - 95% reduction in median overall ABR (41.5 median ABR with on-demand [17 patients] vs 1.9 median ABR with prophylaxis [120 patients])
  - 0 bleeds in 40% (40 out of 101 per-protocol§ patients) during 6 months on twice-weekly prophylaxis

†Median is defined as the middle number in a list of numbers arranged in numerical order.
‡ABR=annualized bleed rate, the number of bleeds that occur over a year.
§Per-protocol patients were assigned to the prophylactic group and treated with their originally assigned dose for the entire duration of the study.

ADYNOVATE Important Information

What is ADYNOVATE?

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

ADYNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADYNOVATE?

Do not use ADYNOVATE if you:

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

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

What should I tell my HCP before using ADYNOVATE?

Tell your HCP if you:

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

What important information do I need to know about ADYNOVATE?

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

What else should I know about ADYNOVATE and Hemophilia A?

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

What are possible side effects of ADYNOVATE?

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

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

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

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

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

US-ADY-0351v1.0 08/21

Takeda

ADYNOVATE
[Antihemophilic Factor (Recombinant), PEGylated]

Patient Important Facts about

ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

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

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

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

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

What is ADYNOVATE?

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

ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

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

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

How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

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

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

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

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

How should I use ADYNOVATE? (cont'd)

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

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

You should tell your healthcare provider if you:

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

What are the possible side effects of ADYNOVATE?

You can have an allergic reaction to ADYNOVATE.

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

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

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

What else should I know about ADYNOVATE and Hemophilia A?

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

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

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADYNOVATE. The FDA-approved product labeling can be found at www.ADYNOVATE.com or 1-877-TAKEDA-7.

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 www.takeda.com/en-us/patents/

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ADVOCACY UPDATE

STATE LEGISLATION

On Wednesday, June 7, 2023, Advocacy Ambassadors from both the Western and Eastern Pennsylvania Bleeding Disorders Foundations traveled to Harrisburg to take part in the Pennsylvania All Copays Count Coalition's State Advocacy Day in Harrisburg. Thank you to the following advocates for joining us at the state Capitol: Nora Bullock, Marissa Ferger, Cassandra Miller, John Christopher Ramsey, Joseph Smiles, Maria Shoemaker, and Christopher Templin.

The PA Bleeding Disorders Team had 20 meetings. They 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.

SIGN UP TO RECEIVE ACTION ALERTS!

By signing up for action alerts, the Western and Eastern Pennsylvania Bleeding Disorders Foundations will notify you when issues arise that impact the bleeding disorders community. We will notify you with ways you can take action and easily contact your legislators on important legislation impacting the bleeding disorders community.

SCAN ME!

OUR ASKS

Copay Accumulator Reform
During our visit to the state capitol, we asked our legislators to support ending the dangerous practice of copay accumulators in Pennsylvania. Drug manufacturers can offer copay assistance programs to assist patients with the purchase of their prescription medications. The goal is to alleviate a person's out-of-pocket expenses and have the assistance dollars count toward the deductible. The purpose of the assistance programs is defeated if/when insurers implement copay accumulator programs, preventing the drug manufacturer's assistance from counting toward the insurance deductible and out of pocket maximum.

Senator Judy Ward (R-Blair) introduced SB 372, which 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 on February 21, 2023.

Senate: Ask Senators to cosponsor SB 372.

House: Ask Representatives to sign onto Representative MaryLouise Isaacson's (D-Philadelphia) memo calling for accumulator reform in the House.

We need patient stories. If you are experiencing a copay accumulator

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How to file a complaint with the Insurance Commissioner.

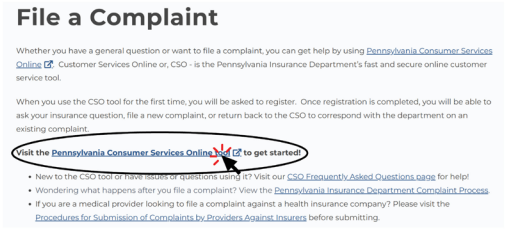
Step One:

Go to:

https://www.insurance.pa.gov/Consumers/insurance-complaint

Step Two:

Click on the Pennsylvania Consumer Service Online Tool (CSO) link.



Step Three:

Login in or, if this is your first time visiting the website, make an account. The CSO Tool will guide you step by step in filing your complaint.

If you prefer not to use the CSO tool, you can choose to download a complaint form and submit it to us using:

Fax:
(717) 787-8585

Email:
ra-in-consumer@pa.gov

Mail:
Pennsylvania Insurance Department
1209 Strawberry Square
Harrisburg, PA 17120

If you have any questions please feel free to reach out to the Pennsylvania Insurance Department toll-free at 1-877-881-6388.

ADVOCACY UPDATE

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or maximizer please reach out to Kara Dornish, WPBDF Executive Director, at kara@wpbdf.org or 724-741-6160.

Your stories are crucial as we work to get this legislation passed. If you are experiencing a copay accumulator or maximizer, It is also important that you file a complaint with the insurance commissioner.

Budget Line Item

As we begin the FY 2023-24 Pennsylvania budget process, we are requesting the following:

- Increase state support from $1,017,000 to $1,250,000.
- Include language in the fiscal code to maintain the existing distribution of funding to the 7 Hemophilia Treatment Centers.
- Maintain the hemophilia line item as a separate line item in the budget bill.

It is important to note that 100% of the Hemophilia Program line item goes directly to patient care (i.e., mostly for non-billable nursing and social work services vital for patient care) and it is critical to preserve the existing Hemophilia Treatment Center (HTC) model for the comprehensive and coordinated care for patients. A portion is also used as an emergency fund to help patients in financial hardship due to their bleeding disorder. This year, there has been an unprecedented number of requests, and the emergency assistance funds were used up before the end of the fiscal year.

There are approximately 33,000 patients with hemophilia and thousands more with other inherited bleeding disorders in the U.S. More than 3,000 reside and receive care in Pennsylvania at one of the seven-state supported hemophilia treatment centers, recognized as centers of excellence by the Commonwealth. The seven Pennsylvania HTCs are:

- Children's Hospital of Philadelphia
- St. Christopher's Hospital for Children
- Hospital of the University of Pennsylvania
- Penn State Hershey Medical Center
- Thomas Jefferson University Hospital
- Lehigh Valley Hospital
- Hemophilia Center of Western Pennsylvania

The seven-state supported HTCs are critical to the 3,000 Pennsylvanians who receive care at these facilities. Without this support, Pennsylvania will incur approximately 5x more costs for these citizens, from emergency and inappropriate care via Medicaid and lost tax revenue from those who become unable to remain gainfully employed. The Hemophilia Program saves Pennsylvania lives and saves Pennsylvania money.

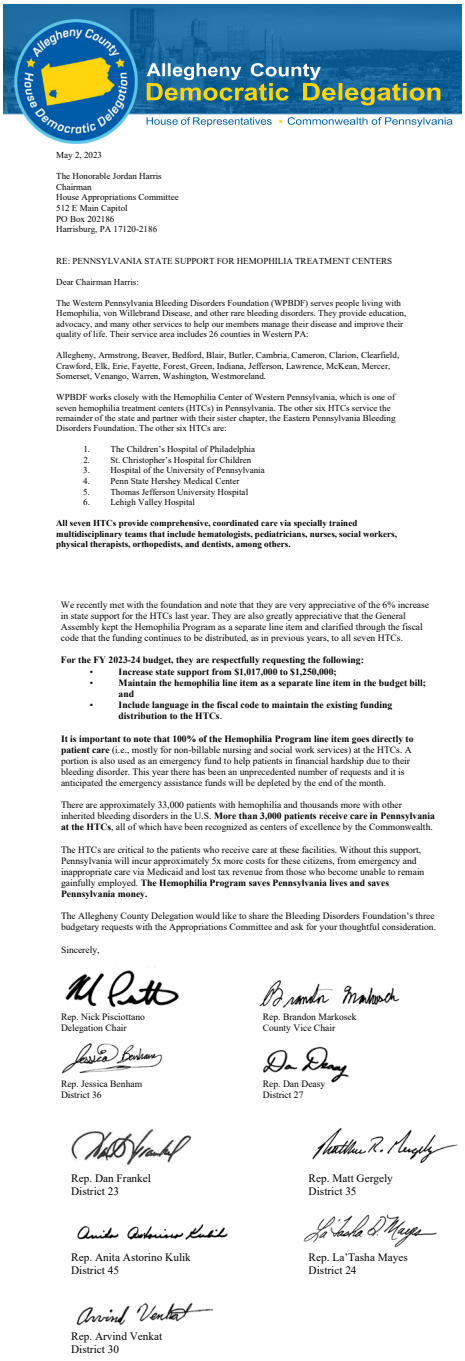
In May, the Allegheny Democratic Delegation shared a letter of support for the hemophilia line item with the Appropriations Committee.

On Monday, June 5, 2023, the House passed a General Appropriations budget vehicle, HB 611. Under the Department of Health's budget, the hemophilia line item is proposed to be funded at: $1,250,000. This is a 23% increase from the 2022 appropriation: $1,017,000. The bill passed the House with a vote of 102-101 and was sent to the Senate. This is just the beginning of budget negotiations, and the numbers could change again. In addition, the fiscal code language hasn't been negotiated yet.

We will continue to keep you updated on its status at wpbdf.org/advocacy.

NON-MEDICAL SWITCHING

Pennsylvania families carefully shop for a health plan with the pharmacy benefits they need (especially if a member of the family lives with a chronic or serious illness). Every insured family signs an annual contract with their health plan, with the expectation that pharmacy benefits will remain concrete throughout the year, but that health plan's pharmacy benefits can change at any time because of non-medical decisions made by insurance companies. A non-medical switch is a change to a patient's medication regimen for



Allegheny County Democratic Delegation
House of Representatives • Commonwealth of Pennsylvania

May 2, 2023

The Honorable Jordan Harris
Chairman
House Appropriations Committee
512 E Main Capitol
PO Box 202186
Harrisburg, PA 17120-2186

RE: PENNSYLVANIA STATE SUPPORT FOR HEMOPHILIA TREATMENT CENTERS

Dear Chairman Harris:

The Western Pennsylvania Bleeding Disorders Foundation (WPBDF) serves people living with Hemophilia, von Willebrand Disease, and other rare bleeding disorders. They provide education, advocacy, and many other services to help our members manage their disease and improve their quality of life. Their service area includes 26 counties in Western PA:

Allegheny, Armstrong, Beaver, Bedford, Blair, Butler, Cambria, Cameron, Clarion, Clearfield, Crawford, Elk, Erie, Fayette, Forest, Green, Indiana, Jefferson, Lawrence, McKean, Mercer, Somerset, Venango, Warren, Washington, Westmoreland.

WPBDF works closely with the Hemophilia Center of Western Pennsylvania, which is one of seven hemophilia treatment centers (HTCs) in Pennsylvania. The other six HTCs service the remainder of the state and partner with their sister chapter, the Eastern Pennsylvania Bleeding Disorders Foundation. The other six HTCs are:

1. The Children's Hospital of Philadelphia
2. St. Christopher's Hospital for Children
3. Hospital of the University of Pennsylvania
4. Penn State Hershey Medical Center
5. Thomas Jefferson University Hospital
6. Lehigh Valley Hospital

All seven HTCs provide comprehensive, coordinated care via specially trained multidisciplinary teams that include hematologists, pediatricians, nurses, social workers, physical therapists, orthopedists, and dentists, among others.

We recently met with the foundation and note that they are very appreciative of the 6% increase in state support for the HTCs last year. They are also greatly appreciative that the General Assembly kept the Hemophilia Program as a separate line item and clarified through the fiscal code that the funding continues to be distributed, as in previous years, to all seven HTCs.

For the FY 2023-24 budget, they are respectfully requesting the following:

- **Increase state support from $1,017,000 to $1,250,000;**
- **Maintain the hemophilia line item as a separate line item in the budget bill; and**
- **Include language in the fiscal code to maintain the existing funding distribution to the HTCs.**

It is important to note that 100% of the Hemophilia Program line item goes directly to patient care (i.e., mostly for non-billable nursing and social work services) at the HTCs. A portion is also used as an emergency fund to help patients in financial hardship due to their bleeding disorder. This year there has been an unprecedented number of requests and it is anticipated the emergency assistance funds will be depleted by the end of the month.

There are approximately 33,000 patients with hemophilia and thousands more with other inherited bleeding disorders in the U.S. **More than 3,000 patients receive care in Pennsylvania at the HTCs**, all of which have been recognized as centers of excellence by the Commonwealth.

The HTCs are critical to the patients who receive care at these facilities. Without this support, Pennsylvania will incur approximately 5x more costs for these citizens, from emergency and inappropriate care via Medicaid and lost tax revenue from those who become unable to remain gainfully employed. **The Hemophilia Program saves Pennsylvania lives and saves Pennsylvania money.**

The Allegheny County Delegation would like to share the Bleeding Disorders Foundation's three budgetary requests with the Appropriations Committee and ask for your thoughtful consideration.

Sincerely,

Rep. Nick Pisciottano
Delegation Chair

Rep. Brandon Markosek
County Vice Chair

Rep. Jessica Benham
District 36

Rep. Dan Deasy
District 27

Rep. Dan Frankel
District 23

Rep. Matt Gergely
District 35

Rep. Anita Astorino Kulik
District 45

Rep. La'Tasha Mayes
District 24

Rep. Arvind Venkat
District 30

reasons other than efficacy, side-effects, or poor adherence. This occurs when health plans drive stable patients to switch from their current medication to a less expensive one.

Insurers are increasingly making critical changes to their plans throughout the year – directly affecting the cost and accessibility of therapies for insured

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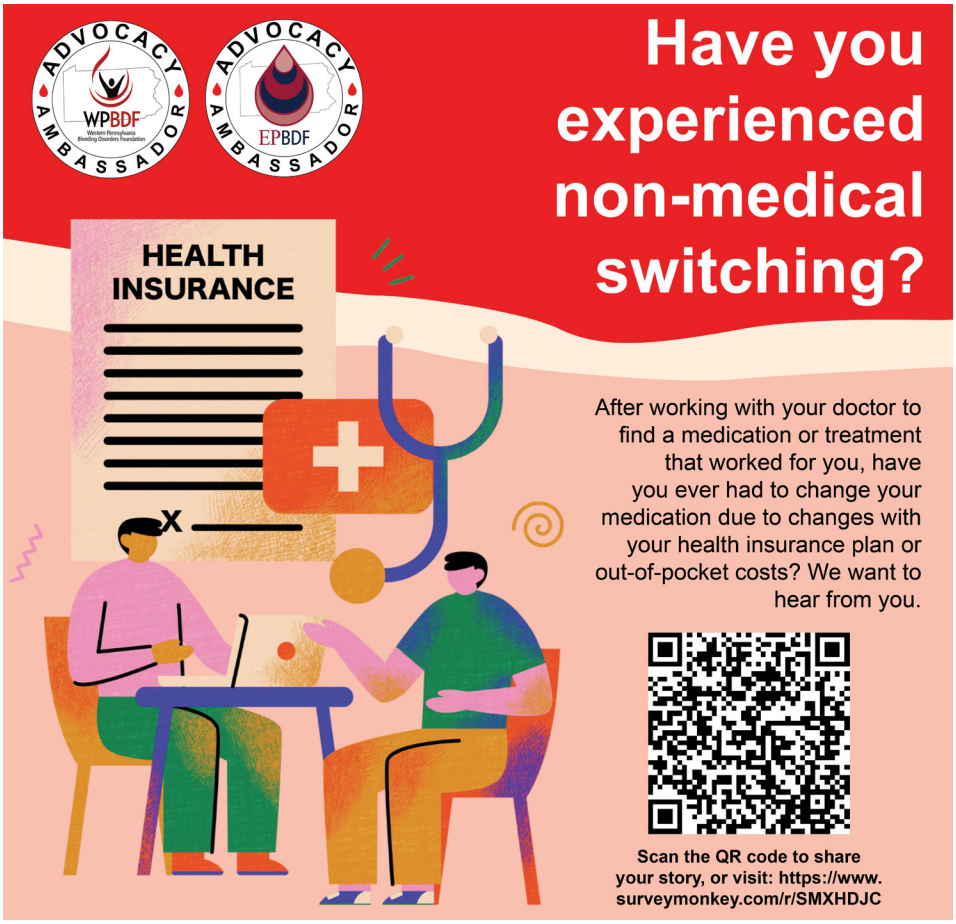

Pennsylvanians. Insurers are free to put additional restrictions on pharmacy coverage, raise out-of-pocket costs, or even remove coverage of a treatment altogether – at any time during the contract year.

Legislation has been re-introduced by Senator Judy Ward (SB348), the Unfair Insurance Practices Act, which would prohibit unfair methods of competition and unfair or deceptive insurance acts and practices. This bill was referred to the Senate Banking & Insurance Committee on February 10, 2023.

After working with your doctor to find a medication or treatment that worked for you, have you ever had to change your medication due to changes with your insurance plan or out-of-pocket costs? If you've experienced non-medical switching, please fill out our survey at: https://www.surveymonkey.com/r/SMXHDJC. Your story will help us better understand how non-medical switching affects the PA Bleeding Disorders community.

FEDERAL LEGISLATION

HELP Copays Act (S. 1375 and H.R. 830)

The sickest and most vulnerable patients—those who live with serious, complex chronic illness—are being targeted by health plan programs that undermine the benefits of copay assistance for medicines. The bipartisan Help Ensure Lower Patient (HELP) Copays Act eliminates barriers to treatment for patients ensuring that they can afford the necessary and life-saving medications prescribed by their doctors. The legislation requires health plans to count the value of copay assistance toward patient cost-sharing requirements. This would bring much-needed relief to vulnerable patients by ensuring that all payments— whether they come directly out of a patient's pocket or with the help of copay assistance—counts towards their out-of-pocket cost.

The Essential Health Benefit (EHB) loophole allows big companies to avoid paying for critical care for patients who need help. A loophole under the Affordable Care Act (ACA) allows many employer health plans to deem certain categories of prescription drugs as "non-essential," **even when they are life-saving or necessary for people with serious pre-existing and chronic conditions.** When a covered drug is deemed "non-essential," the insurer will not count any cost-sharing toward the patient's deductible and out-of-pocket maximum. This loophole also allows employers to simply not cover drugs that treat expensive health conditions. By falling into the EHB loophole, patients in these plans often must pay hundreds or thousands of dollars in out-of-pocket costs for life-saving medicines and never hit their out-of-pocket maximum.

The HELP Copays Act is a two-part solution that:

- Clarifies the ACA definition of cost sharing to ensure payments made "by or on behalf of" patients count towards their deductible and/or out-of-pocket maximum.
- Closes the EHB loophole to ensure that any item or service covered by a health plan is considered part of their EHB package and thus cost sharing for these must be counted towards patients' annual cost sharing limits.

Congressional action is needed to protect patients. The bipartisan HELP Copays Act can help end these harmful pricing schemes and bring much-needed cost savings to vulnerable patients.

PROTECT MEDICAID

A recently passed House bill would cut funding to Medicaid and create new barriers to coverage and care for millions of people including many who live with serious health conditions such as bleeding disorders.

So-called Medicaid work requirements would add new administrative hurdles and extra complexity to the Medicaid program, resulting in widespread coverage losses and harm to vulnerable patients. People who live with bleeding disorders and other serious health conditions cannot afford sudden gaps in their care.

Recent experiments with Medicaid "work and reporting" requirements (Arkansas 2018) led to drastic coverage losses and yet failed to boost employment. In fact, over 90% of Medicaid enrollees nationally already work, go to school, engage in caregiving, or would qualify for an exemption from the House-passed requirements due to age, illness, or disability. Yet they would be at serious risk of losing coverage under the new paperwork requirements. With the post-PHE Medicaid "unwinding" underway, now is a particularly bad time to layer on additional red tape and bureaucracy. We should not add new administrative hurdles and extra complexity to a program that's already hard to navigate!

URGE YOUR PENNSYLVANIA SENATORS TO ENSURE ALL CO-PAYS COUNT!

We need YOUR help!

Senators Marshall (R-KS), Kaine (D-VA), Murowski (R-AK), Markey (D-MA), and Ernst (R-IA) introduced Senate Bill 1375. This legislation would clarify the ACA definition of cost-sharing to ensure payments made "by or on behalf of" patients count towards their deductible and/or out-of-pocket maximum. S. 1375 needs more cosponsors! We want Senators to include the HELP Copays Act in the PBM reform package and vote in support!

Urge Senator Fetterman and Senator Casey to support Senate Bill 1375, which would help Pennsylvanians afford the treatments they need by ensuring all co-pay assistance counts towards out-of-pocket requirements.

SEND AN EMAIL WITH ONE CLICK:

HTTPS://P2A.CO/XTXCYVJ

Scan me to email your PA Senator's:

May 2023

The Devastating Consequences of Medicaid Cuts

Chairman Bob Casey, Senate Committee on Aging

Nearly 3.7 million Pennsylvanians rely on Medicaid & CHIP[1]

Cuts to Medicaid would disproportionately hurt children, older adults, people with disabilities, and people of color by eliminating their health care access and coverage.

Cutting Care for Children
Nearly 93% of eligible children in Pennsylvania are supported by Medicaid and/or CHIP.[2] Cuts would disproportionately hurt children with the lowest incomes and the highest health care needs.[2]

Blocking Access for Pregnant Women and Newborns
Nearly 43,700 births (33%) in Pennsylvania per year are covered by Medicaid. A cut to Medicaid would prevent mothers from obtaining the care they need.[3]

Increasing Disparities for Communities of Color
Medicaid covers more than 47% of adults of color in Pennsylvania ages 18-65.[4] A decrease in Medicaid funding would directly impact access to the communities that need it the most.

Curbing Health Care Access for People with Disabilities
Medicaid covers 45% of nonelderly adults with disabilities nationwide, roughly 10 million people.[5] They depend on Medicaid for services in order to thrive in their communities.

Cuts to Medicare Beneficiaries
Cuts to Medicaid could impact more than 485,500 dually-eligible Pennsylvanians who rely on the program to help pay their Medicare premiums and co-pays.[7]

Disrupting Nursing Home Care
Cuts to Medicaid could disrupt care for 63% of nursing home residents in Pennsylvania who use Medicaid as their primary payer to stay in a nursing facility.[6]

House Republicans' Proposed Cuts Threaten Care For Americans At Risk
The House Republicans' bill puts more than 1 million Pennsylvanians at risk of losing Medicaid coverage and could lead to gaps in health care coverage and undermine family economic security.[7]

AGING

The Devastating Consequences of Medicaid Cuts

Chairman Bob Casey, Senate Committee on Aging

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AGING

Please raise your voice to #ProtectMedicaid from cuts and counterproductive red tape. Go to https://act.newmode.net/action/noredtape – to send an email to your legislator today!

ADVOCACY AMBASSADOR RECAP: ALL COPAYS COUNT COALITION

CASSANDRA MILLER

On June 7, Advocacy Ambassadors from the Western and Eastern PA Bleeding Disorders Foundations came together with the All Copays Count Coalition to meet with our local Representatives and Senators in Harrisburg, PA, to ensure all copays count. We asked our Senators to support SB 372, which would require insurers to count the drug manufacturers' assistance towards the deductible and a patient's out-of-pocket costs. The Ambassadors told their stories and explained why copay accumulators and maximizers are detrimental to anyone with chronic illnesses, who often rely on copay assistance to afford their life saving medications. Many insurers have implemented Copay Accumulator Adjustment Programs (CAAPs) which means they accept copay assistance from manufacturers, nonprofits, or other patient support groups, but don't apply it to a patient's out of pocket maximum. The patient is on the hook for the full amount of their high deductible. Imagine you got a $10,000 scholarship for college to cover tuition, the school took the $10,000 from you, and still asked you to pay them the $10,000 for tuition! This is what copay accumulators do to patients.

You can help make all copays counts at the federal level, which will enact change to all

health insurance plans, by urging Pennsylvania Senators to support Senate Bill 1375! Send an email with one click at: https://p2a.co/xtXCYvj.

INHIBITOR RISK PAPER INFORMED BY GENOTYPING PROJECT

Between 2013-2017, the "My Life Our Future" (MLOF) project offered eligible individuals with hemophilia free genotyping, which is historically hard to access, expensive, and not covered by insurance. Conducted through the laboratory analysis of a single blood sample, genotyping can reveal the specific genetic mutation responsible for a patient's disease such as those located in the factor VIII and factor IX genes in the case of hemophilia A (HA) and hemophilia B respectively.

MLOF was a partnership between the hemophilia community, the National Hemophilia Foundation, American Thrombosis and Hemostasis Network (ATHN), Bloodworks Northwest, and Bioverativ/Sanofi (formerly Biogen). Individuals who participated in the program could also opt – via informed consent – to have a blood sample with their de-identified genome sequence data deposited into the MLOF Research Repository. Investigators could apply for access to the database to support their research, with acceptance contingent upon their ability to demonstrate both scientific merit and ultimate benefit to patients.

Ultimately, samples from more than 6,000 individuals were included in the repository to help advance the scientific understanding of the disorder. MLOF was a boon to researchers, particularly to those looking to better understand the genetic differences that affect bleeding severity and reactions to certain therapies. One such example is a new paper "Race, Ethnicity, F8 Variants, and Inhibitor Risk: Analysis of the 'My Life Our Future' Hemophilia A Database," published in the Journal of Thrombosis and Haemostasis.

Armed with ample collection of samples generated by MLOF, the authors of the paper sought to investigate some existing hypotheses related to inhibitor risk amongst individuals with HA.

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MENTAL HEALTH ROUND-UP

CHARLIE GILBERT, LCSW & BEN VILLAREAL, SOCIAL WORK STUDENT

Have you ever wondered what the effect of having a life-long bleeding disorder might be on your mental health? Are people with bleeding disorders subject to more stress and trauma than others and does that lead to anxiety or depression? These kinds of questions are at the forefront of efforts by clinical researchers across the country to compare the rates of anxiety and mood disturbance among various disorders and the general population. Recent and Post-pandemic data on these subjects and overall quality of life are now becoming available and suggest that indeed, people with bleeding disorders are at much greater risk of developing mental health disorders.

If you are a patient in a Hemophilia Treatment Center (HTC), chances are pretty good that you have been asked to be a part of a study of symptoms of anxiety and depression. Treatment Centers want to understand the relationship between age, race, bleeding disorder history and diagnosis, and treatment effects. While the mission of HTCs is to provide specialized, multi-disciplinary healthcare to meet the physical, psychosocial and emotional needs of persons with hemophilia (PWH), they also know the pain, suffering, disappointment, stress and frustration experienced by these same persons throughout their lives. What can we expect to be the outcome of this situation? Here's what the experts are beginning to see.

Although very little is known about the number or rate of PWH seeking or receiving treatment for depression and/or anxiety, the National Center for Health Statistics (NCHS) tracks the general population utilization of mental health services. In 2022, approximately 5% of Americans reported frequent feelings of depression and another 12.5% acknowledged feelings of worry, nervousness or anxiety. Looking at treatment, 12.6% of adults reported being counseled by a mental health professional. Among the US population in general, the percentage of adults (18> Yrs) reporting any mental health treatment by any provider in the past year increased from 4.7% since 2019 to 23.2% in 2021.

A recently published study by a national group of Hemophilia experts concluded that depression and anxiety rates in persons with von Willebrand disease (vWD) were much higher than that reported for the US population in general. In fact, while 7% of US adults reported high depression scores, 63.6% of vWD adults reported clinically significant depression scores on a standardized test (PHQ-9). When tabulating anxiety scores, 53.9% of vWD adults versus 6.1% of US adults tested (GAD-7) in the clinically significant range. Among those same vWD men and women, scores for depression were

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GETTING TO KNOW HCWP STAFF

BRIDGET WALBROWN
MEDICAL ASSISTANT

Birthplace: Philippines

First job: Burger King

Accomplishment you're proudest of: My family

What three words describe you best? Cheerful, easygoing, and resourceful

Dream vacation: Santorini, Greece

Things you can't do without: Dishwasher, designer handbags, jewelry, and fast food

Person you'd most like to have dinner with: My sister (it's been a while since the last time)

Movie you could see anytime: Big Daddy

TV show you try not to miss: Survivor

Three things that can always be found in your refrigerator: Milk, Shrimp paste, and salted eggs

Secret vice: I want to keep it a secret :)

Who would play you in the movies?: Sandra Bullock

Your pet peeve about Pittsburgh: People braking before the tunnels

People may be surprised to know: My real age

WHAT LIVING WITH VON WILLEBRAND DISEASE HAS TAUGHT ME ABOUT PROFITS TAKING PRIORITY OVER PATIENT LIVES

MARIA SHOEMAKER

Any person living with a chronic illness knows that we often must become our own advocates in the fight for our health and for fair and accessible treatment and insurance.

As someone with von Willebrand disease, a lifelong bleeding disorder characterized primarily by my blood failing to clot properly or perform as it should due to low levels of von Willebrand factor protein – I've spent years learning the ins and outs of the U.S. health care system, and the battles that patients like me go through to access lifesaving medications on a regular basis.

I was diagnosed with the disorder at age 23, after the birth of my first child due to a lot of bleeding complications. As the mother of five children, I've been concerned about what this disease means for them, and whether I've passed it on. Two of my children have been diagnosed with von Willebrand disease, and we're now waiting for confirmation about the third.

Like many people with chronic illnesses, my medications are expensive. Because I'm a severe type 1 von Willebrand disease patient with an allergy to DDAVP (desmopressin) — a common medication used to treat bleeding disorders — my only option is factor replacement therapy. I switched to a new factor medicine last year called VONVENDI, and each dose is around $14,000. Most months, I use two doses and occasionally a few extras for GI bleeds here and there, but there have also been times after surgeries where I've needed up to three doses per day for a week.

In the past, we were able to count on patient assistance programs to help with our expenses. The patient assistance helped us reach our deductible and helped cover a portion of the copays after. I always expected to pay some of it out-of-pocket, but the assistance helped with a large portion of the cost.

Since my husband switched jobs last year, and we're now with a different insurer, our situation has taken a turn for the worse.

I had a bad bleed in January of this year that left me in crisis, but I have not been able to access my factor

through my insurance at all this year. According to my new insurer's pharmacy benefit manager (PBM), my factor would no longer be available, and they would not help me pay for it.

The PBM said they could help me if I agreed to participate in a program they manage called SaveOnSP. I was told that the program would find $20K in patient assistance from the maker of my factor treatment. Then, I could get it through their PBM specialty pharmacy, Accredo. The PBM would take all the money from the manufacturer, but it would not apply toward my deductible or out-of-pocket maximums. Historically, they would have only collected roughly $2K that would have been counted towards my deductible.

If the patient assistance would not count, I would only be able to afford around one month of factor therapy, barring any unforeseen bleeding events. The PBM wanted all the money, but where was my benefit? I would still be left searching for additional support for my factor, and other medications to manage my bleeding disorder, that my insurance wouldn't provide. Why am I paying them?

Because of that, I've had to forego other health care priorities and procedures, like dental care and a biopsy. I cannot risk suffering another bleed that will put my life in jeopardy and cause me to become even more reliant on a medication that I can't access or afford right now.

There are millions of other people in this country who, like me, are holding out hope that our government will pass legislation that prioritizes fair cost-sharing for patients and requires that payments made by a patient, or on their behalf, count.

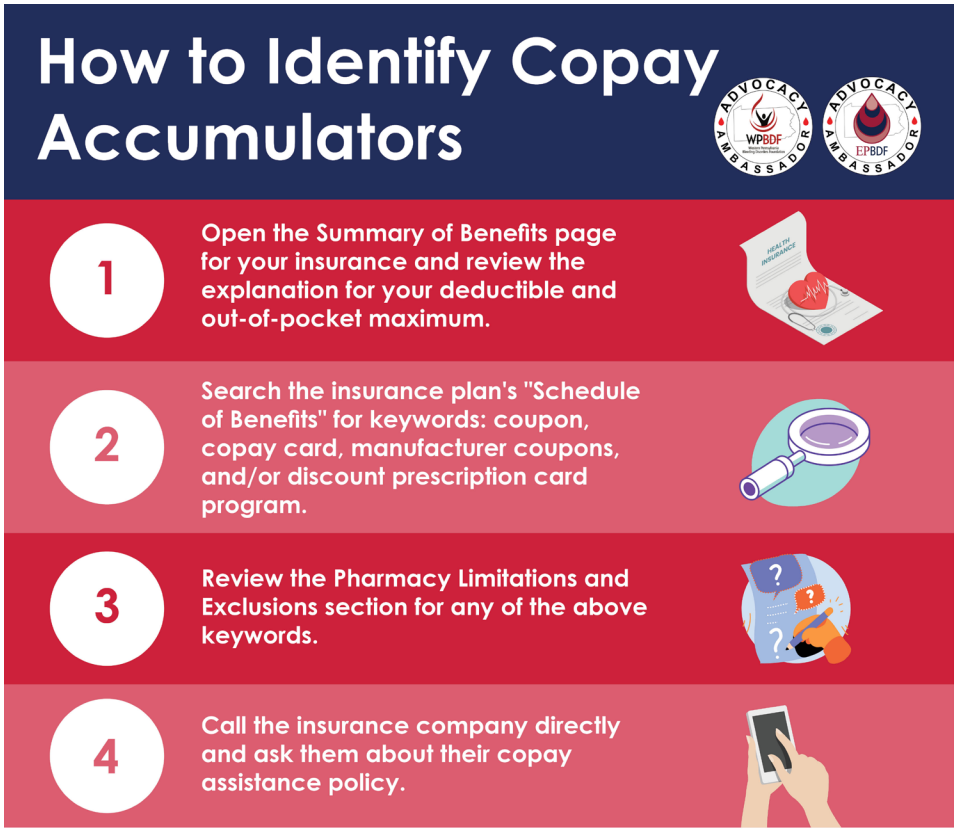
The Help Ensure Lower Patient (HELP) Copays Act (S. 1375) being considered right now by the U.S. Senate HELP Committee could have a life changing impact on access to medication for me and millions of others who rely on their employer-sponsored insurance.

Pennsylvania state lawmakers are looking at SB 372 to ensure state regulated plans also count all copays. 20 other states have already passed such laws to end harmful copay schemes and bring much-needed cost savings back to vulnerable patients.

The fight is far from over, and I urge fellow chronic disease patients and patient advocates to ask their elected officials to support these bills. I'll continue to share my voice and story like I've always done to advocate for myself and my family. I don't want my children to spend years fighting for funding sources acceptable to insurers in order to access the medications that help them stay healthy and alive.

Unless something changes, there will be too many families out there that will have their lives truly devastated by all this insanity just so greedy PBMs can make an extra dollar.

Maria Shoemaker is currently an accounting student at Community College of Allegheny County (CCAC). She resides in Vandergrift, Pennsylvania with her husband and five children.



NEW COMMUNITY GROUP FOR KIDS 7-12 YEARS OLD

EMILY NIKITHSER, SCHOOL-AGE CHILDREN'S GROUP – CO-COORDINATOR

Do you have an affected child or sibling aged 7-12? Are you looking for opportunities for your child to form bonds with others in their age group while also gaining knowledge and skills for the future? Then please consider joining the mailing list for our new School-Aged Children's Group!

In May, we held the first gathering for this new group and we're so excited to kick it off and gauge both interest in the group and hear about needs and concerns families have for their children in this age group. WPBDF offers so many amazing programs including New Parent Network, the Teen Group and adult groups as well. With this new group, we would love to provide our children in the tween age range opportunities to meet, share experiences, learn, and have fun! This also provides space and time for parents and families of children in this group to learn from each other and relate as well.

For our first meeting, we were so happy to have Kathaleen Schnur, LCSW, from the HCWP working with the kids. Everyone enjoyed talking about the excitement surrounding the upcoming Camp Hot-to-Clot summer camp. We discussed concerns about camp, but also discussed what each child is most looking forward to.

Next, the adult parents and family moved next door to chat about their interest in the new group and brainstorm ideas for future events. Kathaleen engaged the children in camp-related games and activities as well as conversations about what happens at camp. Former camper-turned-counselor, Julia Shoemaker, assisted with games and activities to generate excitement and ease any potential concerns.

Next door in the adult round table, Kelly Baker and I kicked things off by describing why we're hoping to get this new group off the ground. We are eager to give our children chances to get together and form

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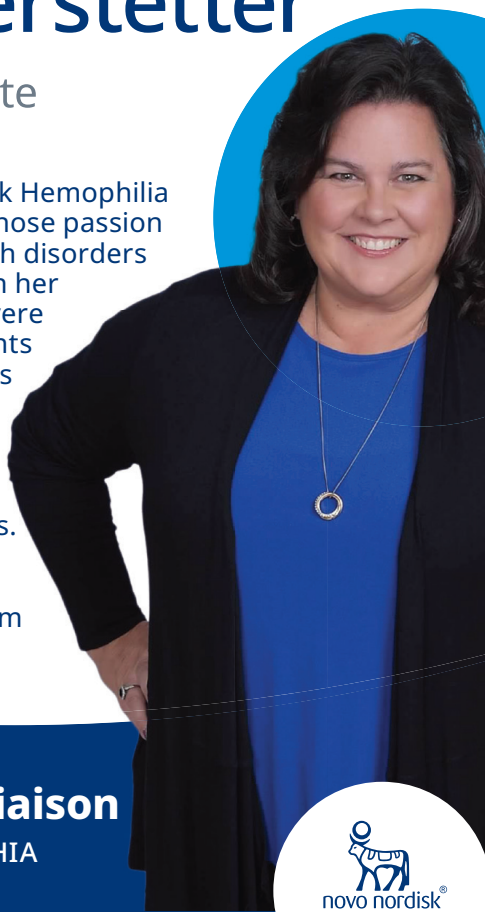
Lorie Kerstetter

Patient advocate



About Lorie

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

Connect with Lorie

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

Hemophilia Community Liaison

NORTHERN APPALACHIA
(WV, Western NY, PA)

novo nordisk®

Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

TAKE ME OUT TO THE BALL GAME!

On Sunday, June 11, members of WPBDF came together for a delicious brunch at the Renaissance Pittsburgh Hotel and heard from 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. We enjoyed a fun afternoon filled with sunshine, ballpark snacks, and community (plus a Pirates win)!

Pete is diagnosed with Hemophilia B and his love of sports has led him to become a high school basketball and baseball coach. He is also currently a certified basketball official and refs games just about every weekend. The challenges Pete faced due to his diagnosis made him stronger and helped him accomplish his dreams of being a part of the sports he's loved since he was a child. Pete reminded us that following our treatment regimen, maintaining a positive mindset, and finding support during difficult moments, allows us to live a life we love.

We thank CSL Behring for sponsoring this event!

CSL Behring

NEW COMMUNITY GROUP FOR KIDS 7-12 YEARS OLD

CONTINUED FROM PAGE 16...

bonds with others they can relate to. We're hoping by providing more opportunities for them to be together, we can encourage them to learn and gain confidence by sharing experiences and having fun. Next, we chatted about what we're envisioning for the group. At this time, we are hoping for at least two events per year. With the help of the WPBDF, we will plan a more structured program with educational benefits while also providing time to be together. The second event each year will be a social gathering, with an emphasis on FUN!

Some of the ideas for education programming included education for extended family members and other caregivers; taking ownership of their medical care; disclosing their bleeding disorder to friends; mental health topics for both children with a bleeding disorder and siblings of a child with a bleeding disorder, and more! Some ideas discussed for social activities include a pumpkin patch and bonfire, sporting event, bowling, mini golf, and playing video games together.

We would love to hear from you, our community members! Please reach out by sending an email to rsvp@wpbdf.org to join the mailing list for this group and keep an eye out for future communication surrounding our next event. We are also looking for feedback to better assess impact areas to focus on with our kids. What concerns do you have for your child(ren) in this age group? Would you or your child(ren) find this kind of group beneficial? Let us know!

If you can, please participate in a survey to help us identify and prioritize program needs and collect additional ideas for social events.

To take the survey, scan the QR code below or enter the following link: https://www.surveymonkey.com/r/XQN8YVR

WE WANT TO HEAR FROM YOU!

WPBDF would like to thank Emily Nikithser and Kelly Baker for taking the initiative to help form this new group in our bleeding disorders community and for agreeing to be co-coordinators to help plan and organize future events!

BACK TO SCHOOL PROGRAM

How to Communicate With Your Child's School

novo nordisk®

Friday, August 11
6:00 pm

Dave & Busters - North Hills
6260 Northway Mall Drive
Pittsburgh, PA 15237

Caregivers will learn strategies to improve communication with their child's school to help ensure a safe and nurturing environment.

Dinner and game cards will be provided to everyone who attends.

This program is for school aged children with a bleeding disorder and their caregivers/family members who live in the same household.

To register, send an email to rsvp@wpbdf.org or call the Chapter office at 724-741-6160. Be sure to include the total number of people you are registering for and if there are any food allergies. If children are attending, please be sure to include their ages.

Learn more at wpbdf.org/events

MENTAL HEALTH ROUND-UP

CONTINUED FROM PAGE 13...

roughly equal while women's scores for anxiety were considerably higher than men's scores. Also related to the higher rates of depression and anxiety among persons with vWD, were having specific symptoms of joint problems and spouse/partner status. As might be expected, persons experiencing joint pain and lacking a marital partner reported more depression and anxiety symptoms and lower quality of life scores.

In a recently published systematic review of 28 studies conducted over three decades, 2,926 persons with Hemophilia A and B, were assessed for the presence of depression, anxiety, both combined and ADHD. The prevalence was reported as follows:

Depression	41.7%
Anxiety	16%
Anxiety & Depression	39.7%
ADHD	15.3%

The above findings suggest, that 2 out of every 5 PWH may suffer from depression and/or anxiety and this is often linked to poor treatment adherence and additional functional impairments. Quite a few of the studies considered what might be the effect of comorbidities such as HCV, HIV and arthritis, but only HIV was studied extensively with a general consensus that it does not significantly increase the prevalence of depression.

One other study that bears mentioning looked at the relationship between depression, anxiety, pain and adherence to recommended treatment in Hemophilia A and B. In this report of a convenience sample of 200 participants attending Hemophilia-related educational meetings, respondents completed a battery of questionnaires including quality of life, depression, anxiety, pain and social support scales. Depending on whether the patient used on-demand or prophylaxis treatment regimen, they also completed the VERITAS-PRN or VERITAS-Pro to assess adherence to clotting factor replacement therapy. In short, the findings revealed that depression, anxiety, pain and low treatment adherence were significantly interrelated. No real surprises here for the bleeding disorder community. However, it was noted that 28% of participants reported moderate to severe depression and 13% had moderate to severe anxiety, and more than half of these individuals had never received a diagnosis for these illnesses.

This study points to the critical numbers of persons with undiagnosed depression and anxiety in this population and the need for additional surveillance, by individuals and families and our Hemophilia Treatment Centers. For many members of the bleeding disorder community, adding one more diagnosis seems burdensome and irrelevant, especially one that carries a certain stigma in our culture. Both depression and anxiety contribute to a lower quality of life for patients and families and this saps motivation, pain resistance, energy and self-concept. Treatment is available for these medical ailments and yet so many from this group fail to see the potential improvements in their lives and the lives of their families that would accrue from acceptance.

Why is this important to PWH or family of PWH? Research has identified PWH as an at-risk group for developing symptoms of depression and anxiety. It is important for PWH and their family members to be mindful of how these symptoms can present to best prevent the development of additional stressors and illness. People in the bleeding disorder community face a variety of adverse challenges that can lead to health complications that can make producing positive health outcomes more difficult. Getting to appointments at HTCs is a major component of treating these bleeding disorders, but without addressing the mental health side there can be gaps in overall quality of life. Comprehensive treatment combined with adequate mental health care when needed will lead to better health outcomes in PWH. Because of the overall risk for experiencing anxiety and depression, awareness of potential changes is crucial in preventing mental health disorders. Family members of PWH can be especially effective in helping identify significant behavioral and emotional changes which might lead to more severe problems. Here are a few that things that both PWH and family of PWH can do to help recognize depressive and anxious symptoms:

- Be mindful of your own internal feelings & mood.
- Look for changes in mood, sleep, or diet in family members with bleeding disorders.
- Get to appointments at the HTC to address any symptoms with the social worker.
- If you observe any noticeable symptoms, get help!

MENTAL HEALTH MATTERS TOO®

Mental Health Resource Guide for the Bleeding Disorders Community by Mental Health Matters Too - https://mentalhealthmatterstoo.com/wp-content/uploads/2022/02/mhmt-flyers-2022-v2.pdf

PARENTS & TINY TOTS

It was time to get out the toy medical kits and Shadow Buddies for some medical roleplay! Kathaleen Schnur, LCSW, a social worker at the Hemophilia Center of Western PA (HCWP), kicked off the New Parent Network Retreat on Friday, May 19, by discussing the importance of medical roleplay and leading families in a medical roleplay session. Each child received a Shadow Buddy and used toy medical kits for the roleplay. Shadow Buddies are dolls that are customized for medical conditions, and the children received a doll that had a tube in its arm for infusions. There were some very cute little caregivers in the room!

The next day, the kids spent time having fun in childcare, provided by Pittsburgh Event Childcare, while the parents participated in education programs. Dr. Frederico Xavier, hematologist at the HCWP and Children's Hospital of Pittsburgh, gave an introductory explanation of bleeding disorders, talked about how to identify and treat bleeds, and more. Michael Shulock, MS, CCLS, Child Life Specialist at Children's Hospital of Pittsburgh, discussed medical appointments, distraction techniques, and ways to help keep your child calm by phase of childhood. After the program, the families enjoyed the afternoon at the Carnegie Museum of Natural History!

New Parent Network events and the Parent Mentor program are open to families who have a child with a bleeding diagnosis, newborn – age 7. If you have a child with a bleeding disorder in this age range and would like to find out more about the programs or be connected with a mentor parent, please reach out to either Kathaleen Schnur (kschnur@vitalant.org / 412-209-7267) or Janet Barone (janet@wpbdf.org / 724-741-6160).

We thank the following for supporting the 2023 New Parent Network series of events:

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HCWP CORNER

KATHERINE BUSH, LCSW

Hello to all WPBDF Members and Your Families,

Summer weather seems to be on the way! We're hoping that you and your families get the chance to get out and enjoy it, but don't forget that allergy medicine if you need it! And your sunscreen! And stay hydrated!

As you make your summer plans, please remember to make sure that you are up-to-date with your clinic appointment. We want to make sure we know the info we need to help keep you safe on your travels and adventures. We can also provide you with documentation to take on your trips that can make it easier to travel with medications and (although we hope this isn't necessary) facilitate any needed care while you are away. Please remember to give us advance notice if possible so that we can get any medications and documents that you may need out to you in a timely manner.

We continue to offer pediatric appointments on Wednesdays and adult appointments on Mondays and Thursdays. Virtual appointments may be possible if necessary – please call the clinic to discuss this option. You can also request factor refills by phone or through our website (https://hcwp.vitalant.org/Home.aspx). We continue to have our on-call number (888-990-4297) available when the center is not open.

Whenever possible, please call us before you arrive to the emergency room. Also, if you have a planned procedure, please reach out to us at least 10 days in advance so that we can arrange a plan to help keep you safe during your procedure.

IF YOU HAVE ANY PLANNED INVASIVE PROCEDURES, PLEASE REACH OUT TO THE HCWP AT LEAST 10 DAYS IN ADVANCE SO THAT WE CAN ARRANGE A PLAN TO HELP KEEP YOU SAFE DURING YOUR PROCEDURE.

Invasive procedures are any that enters the body, usually by cutting or puncturing the skin, or by inserting instruments into the body. Please call us at 412-209-7280.

Camp is scheduled for July 30-August 4, 2023, for affected youth aged 7-17 and their siblings within the same age group, and we are so excited to be able to finally have this program once again. We have about 40 campers registered and we are sure that Hot-to-Clot will be an amazing time. We are also very pleased that we were once again able to hold outreach clinics to serve our Amish community.

The HCWP wishes a big thank you and a fond farewell to physical therapist, Cheri McShea. The education, care, and advocacy that she has brought to our patients has been invaluable. We are excited to welcome our new physical therapist, Clayton Kubrick, to the center. He is excited to meet and serve our bleeding disorder community.

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

Wishing you a wonderful summer full of laughter and relaxation,

The HCWP Staff

INFUSION TRAINING

On Saturday, June 3, the Western Pennsylvania Bleeding Disorders Foundation teamed up with the Hemophilia Center of Western Pennsylvania (HCWP) to provide education and infusion training to the Amish population in Punxsutawney, PA. The program began with coffee and donuts. Kathaleen Schnur, Social Worker at the HCWP, provided education on patient assistance programs available, insurance options, how to order more factor, and what to do in an emergency. Bruce Haas, Genetic Counselor at the HCWP, provided a very thorough presentation on the genetics of hemophilia. He did a wonderful job explaining how hemophilia is passed down and why siblings may present entirely different symptoms and have different severity in bleeding. He also explained that women can, and do, have hemophilia and what is known and unknown about hemophilia in women. After the morning education sessions, participants enjoyed a delicious lunch from Mary's Place. Carley Kalhammer and Kari Stepanik, nurses at the HCWP, led the infusion training session. They provided demonstrations and answered questions about home infusion. Each participant had the opportunity to practice infusing on each other. Participants left with a wealth of knowledge of their, or their loved one's, bleeding disorders and with more confidence to infuse on their own at home.

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WORLD HEMOPHILIA DAY

On Monday, April 17, 2023, the Western Pennsylvania Bleeding Disorders community came together to celebrate World Hemophilia Day. Dinner was held at the Monterey Bay Fish Grotto, located at the top of Mount Washington, which had 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.

The theme for World Hemophilia Day this year was, "Access for All: Prevention of bleeds as the global standard of care." The call to action for the community this year was to come together and advocate with local policy makers and governments for improved access to treatment and care with an emphasis on better control and prevention of bleeds for all people with bleeding disorders. This means the implementation of home-based treatment as well as prophylactic treatment to help those individuals have a better quality of life.

During the World Hemophilia Day event, 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. Carrie Koenig, Community Relations and Education Manager at Sanofi, led an interactive presentation on factor activity, pharmacokinetics and why they matter, bleed protection and lifestyle, telling your story as a form of self-advocacy, and the importance of community connection. Thank you to everyone who came out to celebrate and connect as one family, one community. We want to extend a huge thank you to Sanofi for sponsoring this event.

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CITY OF PITTSBURGH
OFFICE OF THE MAYOR

A PROCLAMATION

World Hemophilia Day

Access for All: Prevention of Bleeds as the Global Standard of Care

Monday, April Seventeenth, Two Thousand & Twenty Three

WHEREAS, Hemophilia is a rare genetic bleeding disorder in which one of the proteins that cause the blood to clot is missing or insufficient to work correctly, causing people to bleed longer. Without effective blood clotting, cuts and internal injuries have difficulty healing, and internal bleeding into the joints can result in pain and permanent damage; and

WHEREAS, Hemophilia is typically a lifelong condition that is primarily treated with infusions of a protein involved in blood clotting, and it is estimated that more than 400,000 people worldwide are living with hemophilia; and

WHEREAS, Approximately 20,000 people in the United States and more than 3,000 people in the Commonwealth of Pennsylvania live with hemophilia. It is found in all populations and people living with hemophilia, and those caring for and serving them, are firmly united in advocating for access to treatment and care; and

WHEREAS, The World Federation of Hemophilia (WFH) is an international nonprofit organization dedicated to improving people's lives with hemophilia and other bleeding disorders. The WFH was established by Frank Schnabel in 1963 and has member organizations in 147 countries; and

WHEREAS, World Hemophilia Day is held annually on April 17. It is an awareness day for hemophilia and other bleeding disorders, beginning in 1959. April 17 was chosen in honor of Frank Schnabel's birthday; and

WHEREAS, Western PA Bleeding Disorders Foundation (WPBDF) is a nonprofit consumer advocacy and service organization founded in the 1950s. It was established to help meet the extensive education and support needs of the bleeding disorders community in Western PA. Our mission is to enrich the lives of those with bleeding disorders in Western PA and respond to the community's needs in a dynamic environment;

NOW, THEREFORE, I, **Ed Gainey, Mayor of Pittsburgh**, do hereby proclaim **Monday, April 17, 2023**, as **World Hemophilia Day in the City of Pittsburgh** and call upon our residents to support people living with bleeding disorders in our communities, while promoting advocacy and collaboration.

Given under my hand and the Great Seal of the City of Pittsburgh at the City-County Building in the First Ward of the City of Pittsburgh, 414 Grant Street, Pittsburgh, PA, 15219 on this Fifteenth day of April in the year Two Thousand & Twenty-Three.

Ed Gainey
MAYOR OF PITTSBURGH

Governor Josh Shapiro proclaimed April 17, 2023, as World Hemophilia Day in Pennsylvania!

The Mayor of Pittsburgh, Mayor Ed Gainey, also issued a proclamation recognizing April 17 as World Hemophilia Day in The City of Pittsburgh!

Thank you for supporting the bleeding disorders community!

Commonwealth of Pennsylvania

Governor's Office

PROCLAMATION

WORLD HEMOPHILIA DAY
April 17, 2023

WHEREAS, hemophilia is a rare genetic bleeding disorder in which one of the proteins that causes the blood to clot is missing or there is not enough of it to work properly, causing people to bleed longer; and

WHEREAS, without effective blood clotting, cuts and internal injuries have difficulty healing, and internal bleeding into the joints can result in pain and permanent damage; and

WHEREAS, hemophilia is typically a lifelong condition that is primarily treated with infusions of a protein involved in blood clotting; and

WHEREAS, it is estimated that more than 1,125,000 people worldwide are living with hemophilia; and

WHEREAS, approximately 32,000 people in the United States – and more than 3,000 Pennsylvanians – are living with hemophilia; and

WHEREAS, hemophilia is found in all populations; and

WHEREAS, people living with hemophilia, and those caring for and serving them, are strongly united in advocating for access to treatment and care.

THEREFORE, I, Josh Shapiro, Governor of the Commonwealth of Pennsylvania, do hereby proclaim April 17, 2023, as WORLD HEMOPHILIA DAY. I strongly encourage all citizens to increase their awareness of hemophilia diagnosis and treatment.

GIVEN under my hand and the Seal of the Governor, at the City of Harrisburg, this fourth day of April two thousand twenty-three, the year of the Commonwealth the two hundred forty-seventh.

JOSH SHAPIRO
Governor

INHIBITOR RISK PAPER INFORMED BY GENOTYPING PROJECT

CONTINUED FROM PAGE 12...

A total of 4,169 subjects were included in the primary analysis, 2,443 with severe HA and 1,726 with mild or moderate HA – this analysis examined several key variables including demographic, clinical, factor VIII gene (F8) sequence data. Investigators found inhibitor incidences of 30.3% in those with severe HA and 7.9% in the mild/moderate group. In the severe group, 1075 (44%) had an intron-22 inversion mutation of the F8 gene, and of those, 388 (36.1%) developed an inhibitor.

The result of a crossing over between two linked gene pairs of the same chromosome, intron 22 inversions account for nearly 50% of severe hemophilia A cases. Investigators sought to determine whether inhibitor risk associated with these type mutations are similar to those associated with other large structural changes in the F8 gene. They ultimately found no difference in inhibitor risk amongst those severe HA participants with an intron-22 inversion vs. other large structural changes in the F8 gene.

The authors also looked at another hypothesis informed by earlier research which suggested that increased inhibitor risk could be caused by specific mutations known as non-HA causing, non-synonymous single nucleotide polymorphisms (nsSNPs). Often associated with disease, nsSNPs are caused by a change to the amino acid sequence of a genetically encoded protein. In fact, the analysis showed that nonpathogeic ns-SNPs in the F8 were not associated with inhibitor development.

The analysis also confirmed earlier studies suggesting an increased risk for FVIII inhibitor development in both Black/African American and Hispanic HA patients, relative to White non-Hispanic individuals with HA in the U.S.

Investigators signaled the potential implications of this study, and future research, in helping to inform therapeutic plans that better anticipate inhibitor risk.

"It is hoped that future studies, e.g., whole-genome sequence analyses to detect genetic variations contributing to inhibitor risk, will identify specific, clinically actionable genetic correlates indicating increased susceptibility to, or protection from, hemophilic inhibitor development and possibly suggesting novel therapeutic interventions to promote immune tolerance to FVIII," concluded the authors.

Article Courtesy of the Journal of Thrombosis and Haemostasis, April 2023.

CONGRATULATIONS TO THE 2023 GRADUATES!

Greetings! My name is Cameron Cedeno, and I just graduated from Penn State University with a B.S. in Plant Sciences. My major focused on studying plant genetics and biotechnology, and I minored in Plant Pathology. I spent nearly two years during my undergrad working as a Research Assistant in a field crop pathology lab that mainly investigates epidemiology of fungal pathogens on cereal and grain crops like wheat, corn, and soybeans. I also completed my own independent research project in this lab and got to present my poster at the American Phytopathological Society's national conference in Pittsburgh last year! I hope to continue working in plant pathology as a Research Technologist over the next couple of years before pursuing graduate school for a Master's degree in plant pathology or a related field. I hope to eventually work in either USDA research, international agriculture, or crop biotechnology in aims of protecting food systems and plant biodiversity from the damages of climate change.

Victoria Baker graduated from Slippery Rock University and received her Masters degree for Public Health with a concentration in Environmental and Occupational Health. She plans to continue working in public health and apply the new skills she learned. Victoria completed her program while working full-time and being a full-time student. She completed the program with a 4.0 GPA and was awarded the Master of Public Health Award.

Georgia Kathryn Ebsworth recently graduated from Moon Area High School and Parkway West Career and Technology Center. While at Moon, Georgia was a member of the Moon Gymnastics team and was a state winner. She proudly served as student mentor for Moon's Bocce Team.

During her junior year at Parkway West, she became a PA licensed Cosmetologist and was the first in her class to complete her hours for teaching certification. Georgia was a member of the National Technology Honor Society in both her junior and senior year. This year, Georgia was named Senior of the Year at Parkway West Career and Technology Center.

Georgia is a volunteer for the area chapter of Blue Star Mothers. She will be attending Slippery Rock University this fall as an Early Childhood/Special Education Major.

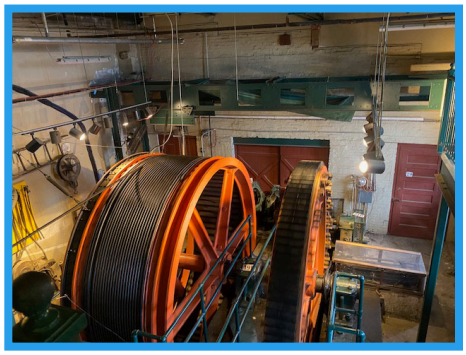
Raina Slater is a 2023 Hempfield High School Graduate. Raina graduated with honors and was a member of the National Honor Society, Science National Honor Society, Lady Spartans Tennis team, and Girls Lacrosse team. Raina will be attending Penn State University in the fall to study architectural engineering. Raina has been a member of the Western PA Bleeding Disorders Foundation Teen Group.

WPBDF'S COUPLE'S RETREAT

We were pleased to provide couples with an opportunity to spend quality time together to focus on their relationships, without distractions, at a retreat held just for couples on March 31-April 2, at Wyndham Grand Pittsburgh Downtown hotel. The retreat was designed for both couples in long-term relationships and those in newer, serious relationships. It can sometimes be tough to feel grateful when your life is full of challenges; and living with a chronic condition can certainly have an impact on relationships.

Dr. Gary McClain, PhD, a therapist, patient advocate, and author, specializing in helping clients deal with the emotional impact of chronic and life-threatening illnesses, kicked off the retreat on Friday with a session on being grateful. On Saturday, he continued with topics including validation and skills for couples who are living with a chronic condition. Kathaleen Schnur, LCSW, a social worker at the Hemophilia Center of Western PA presented a session on meaningful communication, and Lena Volland, PT, Ph.D (c), Director of Education, National Hemophilia Foundation, led a session that focused on self-care for caregivers. When the programming concluded, everyone enjoyed a tour of Pittsburgh on Molley's Trolleys, which included a ride on the historic Duquense Incline! The event concluded with an evening reception.

We thank the Colburn Keenan Foundation, Hemophilia Center of Western PA, Hemophilia Federation of America, and the National Hemophilia Foundation for supporting this event!



CK Colburn Keenan Foundation, Inc.

HFA Hemophilia Federation of America

THE HEMOPHILIA CENTER of Western Pennsylvania

NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

Unite for Bleeding Disorders

WPBDF
Western Pennsylvania Bleeding Disorders Foundation

Western Pennsylvania Bleeding Disorders Foundation's

15th Annual Unite for Bleeding Disorders Walk

Saturday, September 9, 2023

9:30 AM - 11:30 AM (Check-in begins at 9:00 AM)

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

HEMOPHILIA ALLIANCE

Takeda

Questions? Contact Pittsburgh Walk Manager Jessica Lee
jessica@wpbdf.org or call 724-741-6160

Register online at:

https://uniteforbleedingdisorders.org/event/wpa

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

WOMEN'S WELLNESS DAY

Saturday August 26
10:00 AM

Pittsburgh Botanic Garden
799 Pinkerton Run Road
Oakdale, PA 15071

Join us for lunch, wellness education, and a day enjoying the botanic garden. This event is open to women and people with the potential to menstruate, who have bleeding disorders, and are adults or mature teenagers or are a parent/caregiver or spouse/partner of someone with a bleeding diagnosis.

To register, send an email to rsvp@wpbdf.org or call the Foundation at 724-741-6160. Please let us know if you have any food allergies.

Learn more at wpbdf.org/events.

Thank you to our sponsors: CSL Behring COTTRILL'S PHARMACY, INC. HFA Hemophilia Federation of America

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