

A vibrant background image featuring a clear blue sky filled with numerous cosmos flowers. Some flowers are in sharp focus, showing their delicate petals and green centers, while others are blurred in the background, creating a sense of depth. The flowers are in various stages of bloom, with some fully open and others as buds. The overall tone is bright and cheerful, evoking a summery atmosphere.

The Winning Spirit Newsletter

JOIN US!

Aug 17 - Bowling

Sep 10 - Golf

Sep 28 - Unite Walk

Nov 23 - Designer Bag BINGO

Summer 2024



EASTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

41 COUNTIES

1 MISSION

STAFF



Sarah Ross Pilacik
Executive Director
sarah@epbdf.org



Lisa Lee
Assistant Director
lisa@epbdf.org



NATIONAL
BLEEDING DISORDERS
FOUNDATION
Formerly NHF



BOARD OF DIRECTORS



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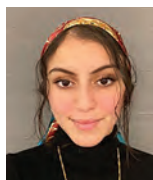
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Eastern PA Hemophilia Treatment Centers



DE Hemophilia Treatment Center



UPCOMING EVENTS

20 JULY
SATURDAY
ADVENTURES IN LEARNING

17 AUGUST
SATURDAY
BACK TO SCHOOL BOWLING

10 SEPTEMBER
TUESDAY
ANNUAL GOLF CLASSIC

12-14 SEPTEMBER
THURSDAY - SATURDAY
NBDF'S BLEEDING DISORDERS
CONFERENCE

28 SEPTEMBER
SATURDAY
UNITE WALK

For a complete list of events planned for this year, please visit our events page: epbdf.org/event

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Letter from Executive Director

Sarah Ross Pilacik

Dear EPBDF Community,

It has been wonderful seeing so many of you at our programs and events this first half of 2024! Thank you for your commitment and support of this chapter (otherwise known as Foundation).

We are excited to make the community aware of an important opportunity related to mental health needs. MoodRx provides “Affordable online therapy, executive coaching, and free self-assessments”. MoodRx is offering 10% Off Your First 6 Sessions For EPBDF Members and Their Families! Please review the advertisement found on page 18, and scan the QR code to learn more and get started.

Please continue to promote and build your teams for our Unite Walk on September 28th! Get your Unite team t-shirts designed and made for our first annual t-shirt contest. Other fundraisers include Back to School Bowling, Annual Golf Classic, the Inaugural Benefit for Christine M. Carroll, and Designer Bag Bingo for Bleeding Disorders. Check them out and register on our website!

We wish you a safe, relaxing, and fun summer.

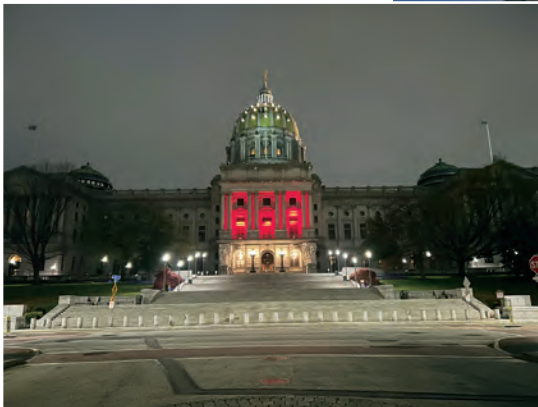
In Gratitude,

Sarah & Lisa



World Hemophilia Day

APRIL 17



Women's Wellness Day

MAY 18



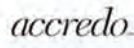
Sheep Snuggle

JUNE 8



Advocacy Ambassador Education & Training Event

MAY 6



Harrisburg Day

MAY 7



Spring Fling

JUNE 1



Annual Meeting

JUNE 12



REST IN PEACE



1979 - 2024

JOEY SMILES

**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!



ADVOCACY UPDATE

MG LEGISLATIVE UPDATE: PENNSYLVANIA BLEEDING DISORDERS FOUNDATION



HARRISBURG OVERVIEW

2024-25 Budget

With a constitutional deadline of June 30th, the Pennsylvania General Assembly is in prime budget season and closed-door leadership negotiations have begun.

Democrat Governor Josh Shapiro proposed a \$48.3 billion budget plan, \$3 billion more than the 2023-24 budget. It included an increase in public school funding by an additional \$1.1 billion.

However, legislators from the Republican caucuses argue that the Governor's proposal is unsustainable and will deplete the state's \$14 billion surplus within a few years.

In a counter proposal, Senate Republicans recently passed SB 269, which would provide for a \$3 billion tax cut, including cutting the personal income tax from 3.07% to 2.8%. Republican leadership maintains that if the state has significant reserves, it should go back to the taxpayer. Republicans estimate that their plan would save taxpayers \$13 billion over the next five years. They are also advocating for some school funding to be directed towards private schools.

The details of the final budget package remain to be seen. But the Milliron Goodman team remains actively involved and will keep you updated as negotiations progress.

House of Representatives

The House continues to operate with slim margins between the numbers of Democrats and Republicans. House Democrats currently hold 102 seats; Republicans hold 101.

Without an overwhelming majority, it's difficult for either caucus to successfully pass controversial bills through the chamber. So far this session, whenever a member resigned and a split ratio occurred (101-101), voting session was put on hold in the House.

Senate

Senate Republicans continue to hold the majority with 28 seats. Senate Democrats have 22 seats.

It's important to note that this is the final year of the 2023-24 legislative session, which means there is increasing pressure for legislators to address certain issues before they are out of time. All bills have until November 30th, 2024 to be signed into law, otherwise they are effectively dead and have to restart the legislative process in the next session.

2024 Elections

This year, all 203 seats of the Pennsylvania House of Representatives and half of the Senate seats (25) are up for election.

Between the upcoming election, the ending of the 2023-24 legislative session and the pending budget, tension continues to build in Harrisburg.

BUDGET LINE ITEM

As shown below, Governor Shapiro proposed level-funding for the hemophilia line item in the 2024-25 budget.

While a great starting point, BDF is requesting an increase up to \$1,250,000 and already made this request with the House and Senate Appropriations Committees as well as all legislators representing the seven treatment centers.

The Milliron Goodman team will continue to advocate for this increase.

28	For diagnosis and treatment	
29	for Canby's anemia.	
30	State appropriation.....	106,000
	202407682	- 51 -
1	For hemophilia services.	
2	State appropriation.....	1,017,000
3	for lupus programs.	
4	State appropriation.....	106,000
5	For sickle cell anemia	
6	services, including camps for	
7	children with sickle cell anemia.	

Continue on page 9

LEGISLATION

Accessibility to Menstrual Hygiene Products

Representative Darisha Parker (D-Philadelphia) sponsored **HB 851**, which amends the Public School Code by creating a grant program to provide eligible public-school entities with funding to acquire and distribute menstrual hygiene products at no expense to students. The bill appropriates \$3 million to the Department of Education for the grant program.

The bill recently passed the House with a vote of 117-85. It's now waiting for consideration in the Senate Education Committee. We'll continue to monitor.

Pharmacy Benefit Managers (PBM) Reform

Representative Jessica Benham (D-Allegheny) and Representative Valerie Gaydos (R-Allegheny) co-sponsored **HB 1993**, which amends the Pharmacy Audit Integrity and Transparency Act. The bill provides the state with more oversight over PBMs and limits or bans several practices by PBMs, including patient steering, spread pricing and retroactive recoupment of money paid by the PBM to the pharmacy. The was reported out of the House Health Committee in mid-June with unanimous support.

On a similar note, the companion bill, Senator Judy Ward's SB 1000, recently passed the Senate Health Committee with unanimous support.

We'll continue to monitor both bills and keep you updated on any developments.

Prohibiting Health Insurers from Altering Coverage or Premiums

In March, Representative Joe Hogan (R-Bucks) circulated a co-sponsorship memo indicating his intent to introduce legislation re: non-medical switching. His legislation would amend the Unfair Insurance Practices Act to prohibit health insurers from altering the coverage or premiums included in an insured person's health insurance policy during the policy term when an insured person has already received a specific treatment, service or prescription drug. We anticipate bill introduction soon.

Please continue to share your experiences with the BDF team so we can help advance this bill.

Co-Pay Accumulator

Senator Judy Ward's SB 372 amends the Insurance Company Law of 1921 by requiring insurers or pharmacy benefit managers to count any amounts paid, by the enrollee or paid on behalf of the enrollee by another party, towards the deductible or out-of-pocket limit. SB 372 is waiting for consideration by the Senate Banking and Insurance Committee.

In January, Representative Bridget Kosierowski (D-Lackawanna) indicated her intent to introduce companion bill in the House and circulated a co-sponsorship memo.

The Milliron Goodman team is continuing to stay engaged on this issue. Please continue to share your personal experiences with co-pay accumulators with the BDF team.

ADVOCACY DAY

The 2024 BDF Advocacy Day in the Pennsylvania State Capitol was a success!

This was another great and timely opportunity for the hemophilia community to meet directly with legislators/staff and share their personal experiences with hemophilia as well as educate legislators on the importance of HTC's.

Community members met with over 30 legislative offices! These face-to-face meetings are a critical component of advocacy and will help legislators remember the issue so they can assist with our line-item requests.

As part of the Advocacy Day, we also had an informational table in the main rotunda of the Capitol. Legislators, staff and other visitors who were walking through the building were able to learn about BDF there as well.

WORLD HEMOPHILIA DAY

In recognition of World Hemophilia Day, Milliron Goodman reserved the Capitol lights from April 16th-17th. The Capitol lights were red on those days.

THANK YOU

We look forward to continuing to represent you in the Capitol this year. Please reach out to our office with any questions or concerns.

Meet Our Advocacy Ambassadors



Advocacy Ambassadors are volunteers in a leadership position responsible for helping to establish and build a strong grassroots network of bleeding disorders advocates within Pennsylvania. The goal is to help increase awareness of Hemophilia, von Willebrand disease, and other factor deficiencies and the

challenges persons affected and their families face. Ambassadors serve as liaisons between the Pennsylvania Bleeding Disorders Foundations and the public, state agencies and officials working towards improving the quality of life of individuals and their families who are affected by bleeding disorders. Both Foundations are committed to our volunteer's engagement and contributions to the bleeding disorders community. We are committed to providing a worthwhile and impactful volunteer experience through the Advocacy Ambassador Program.



Brian Bullock
ARDMORE,
MONTGOMERY
COUNTY



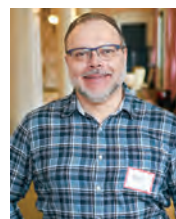
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MONTGOMERY
COUNTY



Joseph Butler
RED LION,
YORK COUNTY



Marisa Ferger
STATE COLLEGE,
CENTER COUNTY



Frank Lentini
ANNVILLE,
LEBANON COUNTY



Joe Pileri
PHILADELPHIA,
PHILADELPHIA
COUNTY



Chris Ramsey
BRYN MAWR,
DELAWARE COUNTY



Melanie Rosen
KING OF PRUSSIA,
MONTGOMERY
COUNTY



Jessica Neumann
CENTER VALLEY,
LEHIGH COUNTY



Victoria Selinsky
DELTA,
YORK COUNTY



Everett Upton
WHITE HAVEN,
LUZERNE COUNTY



Sherry Upton
WHITE HAVEN,
LUZERNE COUNTY



Constance Williams
DOVER DE,
KENT COUNTY

Copay Accumulator Adjuster Programs Clearing Up the Misconceptions

Copay Accumulator Adjustment Programs are affecting a tremendous number of patients with a diverse set of health conditions – most affected are those with chronic and/or rare disorders.

- Allowing Health Plans to utilize Copay Accumulator Adjuster programs leaves a lot of patients vulnerable and unable to access their medication. Patients are choosing between paying their rent/mortgage, putting food on the table, or paying for their medication.
- Bleeding Disorder patients meet their OOP maximum the first month or two of the year. They depend on Copay Assistance Programs to help them meet their deductible.
- Currently, over 63% of marketplace plans in Pennsylvania have copay accumulator adjustment policies.¹

How to Identify Copay Accumulators

1. Open the Summary of Benefits page for your insurance and review the explanation for your deductible and out-of-pocket maximum.
2. Search the insurance plan's "Schedule of Benefits" for keywords: coupon, copay card, manufacturer coupons, and/or discount prescription card program.
3. Review the Pharmacy Limitations and Exclusions section for any of the above keywords.
4. Call the insurance company directly and ask them about their copay assistance policy.

While not all insurances are implementing copay accumulator programs, many insurance plans include language that allows them to implement these programs at any time. Please look out for these programs before enrolling in an insurance plan. If you experience your insurance policy not allowing copay assistance to be counted toward your deductible or out of pocket maximum, please contact us at info@hemophiliasupport.org.

1. THE AIDS INSTITUTE. "TAI REPORT: COPAY ACCUMULATOR ADJUSTMENT PROGRAMS." FEBRUARY 2023.



VISITS AT THE CAPITOL

Jessica Neumann of Coopersburg, along with Samantha Short and Matthew Delaney visited me in Harrisburg to share their stories of the challenges of living with blood disorders. Jessica has been a lifelong champion of this cause while raising her wonderful 18-year-old son Nathaniel, who has hemophilia. Gratefully, he is doing well and is graduating from high school this year! I was so happy to meet with these remarkable people who persevere in spite of medical issues many of us cannot even begin to imagine.



Have you experienced non-medical switching?



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 health insurance plan or out-of-pocket costs? We want to hear from you.



Scan the QR code to share your story, or visit: <https://www.surveymonkey.com/r/SMXHDJC>

URGE SENATOR FETTERMAN TO ENSURE ALL CO-PAYS COUNT!

We need YOUR help!

Senators Kaine and Marshall have introduced a Senate companion bill, S.1375, with the goal of having it included in the upcoming HELP Committee mark-up on PBMs. 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.

We need you to urge Senator Fetterman 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 TO FETTERMAN'S OFFICE WITH ONE CLICK:

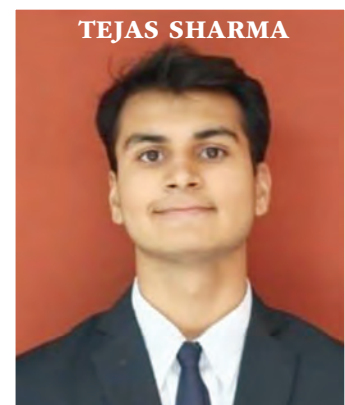
[HTTPS://P2A.CO/8BMIZUF](https://p2a.co/8BMIZUF)

Scan me to email Senator Fetterman's office!



Community Spirit

Congratulations to the 2024 Graduates





Period Product Support for Women with Bleeding Disorders

Feminine hygiene products, sanitary products, menstrual products, period products, whatever you call them, they're all the same--expensive! These products are a necessity, not a luxury, and they can put a strain on personal finances, causing many people to have to choose between purchasing products for their periods and purchasing food or other necessities. Having heavy or prolonged periods increases the need for these products, creating an even greater impact on personal and family budgets. This fund will provide gift cards for period products.



Eligibility:

1. The applicant is a member of the Eastern Pennsylvania Bleeding Disorders Foundation with a diagnosed bleeding disorder.
2. The cost of period products is making it difficult to afford essential household bills.

To apply, please fill out the application by scanning the QR code above or visiting: <https://forms.gle/qwVuyLxCpiJhvWpd8>

Questions? Contact Sarah Pilacik (sarah@epbdf.org/ 610-770-5215) or Lisa Lee (lisa@epbdf.org/ 610-883-3266)

How to Help

If you are in a position to help and would like to contribute, we welcome you to bring new, unopened packages of tampons, pads, period underwear, menstrual cups, etc., to EPBDF events, to donate. These items will be available for others to take home with them at no cost.

BACK
TO
SCHOOL



FUNDRAISER

\$25 per person
includes:

- 3 hrs of Unlimited Bowling
- Shoe Rental
- Food & Beverages

Saturday
August 17, 2024
2 PM - 5 PM

Thunderbird Lanes
3075 Holme Avenue
Philadelphia, PA 19136

RiverCrest Golf Club & Preserve

Phoenixville, PA



EPBDF

GOLF CLASSIC

SEPTEMBER 10, 2024

scan to
register




epbdf.org/events/golf-classic-2024/




**Join the fun by registering
your UNITE team today!**





The Carroll Family Presents:

The Inaugural Benefit Honoring Christine M. Carroll



October 6, 2024 | 2:00 pm

The Carroll's are pleased to announce the Inaugural Christine M. Carroll Fundraiser to benefit the Eastern Pennsylvania Bleeding Disorders Foundation, to be held at Crossing Vineyards & Winery, 1853 Wrightstown Rd, Washington Crossing, PA.

Featuring:



The Fabulous Greaseband



Space is limited. Purchase your tickets NOW!

Tickets: \$125 each or \$200 per couple

Ticket price includes: delicious food, fine wine & beer, and LIVE music!

SCAN QR code
for more info and to
purchase tickets



Proceeds to benefit:





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
EPBDF events, visit epbdf.org.



Affordable Online Mental Health Therapy

**10% Off Your First 6 Sessions For
EPBDF Members and Their Families!**

Are you or a family member suffering from bleeding disorders? You're not alone. Many people facing these conditions and their loved ones experience unique mental health struggles. But there's good news! We can connect you with qualified therapists on our staff who are willing to work with you on your specific needs. Take the first step towards a healthier, happier you with a free 15-minute consultation. Let's find the right therapist to guide you on your mental health journey.

Scan here to start!



Assessment

Sign up free
and take online
clinical self-
assessments



Awareness

Request a free
matching session
with a licensed
therapist



Action

Start affordable
virtual sessions
with your licensed
therapist

Sign up free today



<https://moodrx.com/register?referral=0QD6B5N>

Thank you!

We would like to express our sincere gratitude to the estate of Deena Tobias for a generous donation in the amount of \$50,000 in support of the Eastern Pennsylvania Bleeding Disorders Foundation.



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Fc-VWF-XTEN Fusion Protein-ehtl

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Lorie Kerstetter

Patient advocate

About Lorie

Lorie is a Novo Nordisk Rare Blood Community Liaison whose passion for helping people with bleeding disorders began years ago when her son was born with severe hemophilia A. Lorie loves traveling to experience new cultures, but she's also happy at home working on her flower gardens.

Connect with Lorie

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



Rare Blood Community Liaison

NORTHERN APPALACHIA (WV, Western NY, PA)

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

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NEVER MISS AN UPDATE!

