

*The
Winning
Spirit
Newsletter*



EPBDF

Fall 2024



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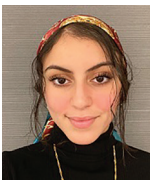
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UPCOMING EVENTS

6 OCTOBER
SUNDAY
TOAST TO A LEGACY BENEFIT

11-13 OCTOBER
FRIDAY – SUNDAY
FAMILY CAMP

2 NOVEMBER
SATURDAY
COMMUNITY EMPOWERMENT DAY

23 NOVEMBER
SATURDAY
DESIGNER BAG BINGO FOR BLEEDING DISORDERS

7 DECEMBER
SATURDAY
HOLIDAY PARTY

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

Eastern PA Hemophilia Treatment Centers



DE Hemophilia Treatment Center



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Letter from Executive Director

Fall Greetings!

As the leaves turn and we move swiftly toward the end of the year, I'm reminded how quickly time flies. We've been hard at work, and I'm excited to share some important updates with you.

HTC Connections and Community Engagement

In August, I had the privilege of meeting one-on-one with the six Hemophilia Treatment Center (HTC) social workers within our 41 county coverage area. It was an invaluable opportunity to learn about each HTC's unique contributions, explore future community event ideas, and discuss how they can participate in our inaugural Pennsylvania Bleeding Disorders Conference, set for May 2025. It was a true honor to see the dedication these incredible women bring to our community daily. Shortly after, we hosted our Back-to-School Bowling event at Thunderbird Lanes. A heartfelt thank you to everyone who donated school supplies, which have been delivered to three of our HTC locations. Your generosity is deeply appreciated!

Excitement for the PA Bleeding Disorders Conference

Speaking of our first-ever Pennsylvania Bleeding Disorders Conference, don't miss your chance to stay updated! Visit our website and sign up for notifications—you'll be among the first to know when registration opens. We've been working closely with the Western PA Bleeding Disorders Foundation (WPBDF) all summer to make this event truly special. Here are a few key details:

- **Dates:** May 16-18, 2025, at The Hershey Lodge
- **Childcare:** Available during the event
- **Program:** Multiple tracks, including those for children and teens
- **Accommodations:** Rooms and meals are covered, with only a small registration fee possible
- **Transportation:** Provided to ensure all community members can attend
- **HTC Staff Participation:** You'll see staff from both chapters and HTCs!

We are committed to removing any barriers preventing attendance. If you have concerns, please reach out to your social worker or me—we'll do everything we can to help.

National Conference Highlights Lisa and I recently returned from the National Bleeding Disorders Foundation (NBDF) Bleeding Disorders Conference in Atlanta. We were thrilled to send some of our community members on scholarship, while others attended through the NBDF scholarship program. Pennsylvania was well represented with participants from five out of the seven HTCs. During the event, Kara Dornish, Executive Director of WPBDF, and I gave a brief presentation on the collaborative work our

chapters have been doing around the **Women, Girls, and People with the Potential to Menstruate** initiative.

This project has taken off thanks to a grant from the Hemophilia Alliance Foundation, donations from CVS, and the tireless commitment of volunteers throughout the year. Our work is only beginning, and we look forward to continuing to make an impact for this important cause!

Honoring Joey Smiles

I'm also proud to share that our dear friend and board member, Joey Smiles, who passed away this spring, was posthumously awarded the **Chapter Volunteer of the Year** award at the NBDF conference. A special thanks to Samantha Short, Board Member at WPBDF, who accepted the award on his behalf. Joey's dedication and contributions to our chapter are irreplaceable, and this honor is a testament to the lasting impact he made on our community.



Volunteer Committees in Action On the topic of volunteers, I'm thrilled to report that we've successfully launched volunteer committees to help plan and execute some of our major events this year. Working alongside such passionate, dedicated individuals has been a true privilege. I sincerely thank each of you for your time, energy, and commitment to our community.

Looking Ahead Though October is just around the corner, we're far from finished with our 2024 events! Please check out our website for details on our upcoming fundraisers, Family Camp, Community Empowerment Day, and our Holiday Party. We look forward to seeing you there!

Special Thank You to Tom Carroll Sr. and Tom Carroll Jr., owners of Crossing Vineyards and Winery, for their giving hearts as we work together to plan the Inaugural Benefit for their wife and mother, Christine M. Carroll. We are excited to celebrate the life and legacy of Christine on October 6th with her family, friends, providers, and the EPBDF community.

And finally, to my fellow Philadelphia sports fans: Let's hope my next newsletter includes a celebration of a Phillies World Series win, the Eagles in playoff contention, and strong starts from the rest of our teams!

Be well,

Sarah Pilacik

Sarah Pilacik
Executive Director, EPBDF

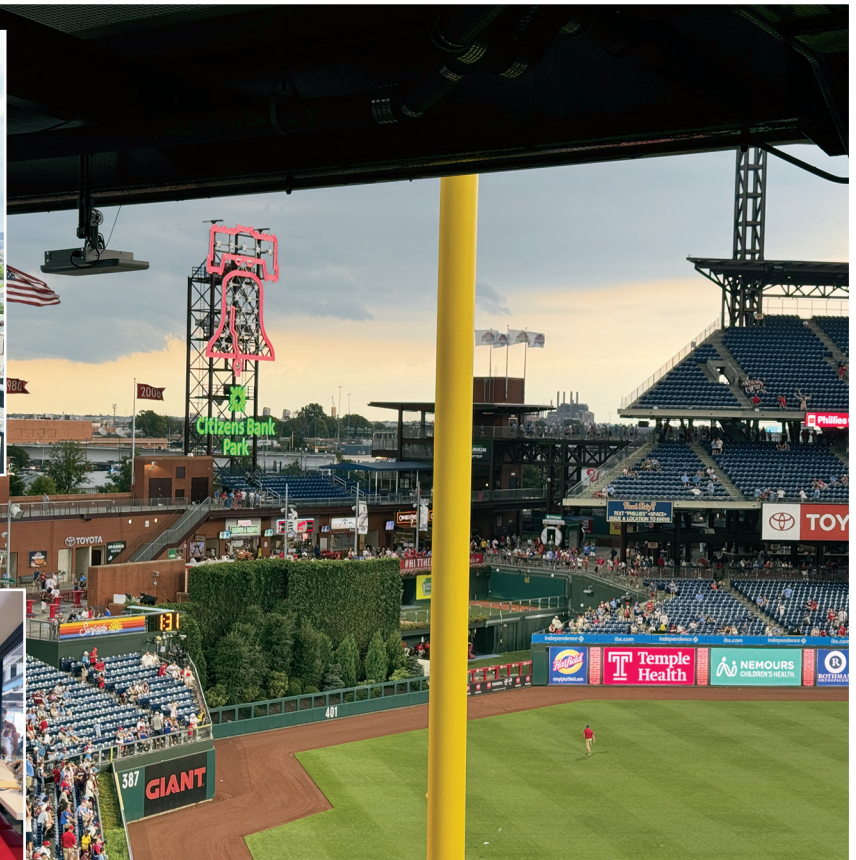
Couples Retreat

JUNE 28



Living With Hemophilia - Phillies Game

JULY 14



Adventures in Learning at Adventure Sports

JULY 20



Back to School Bowling

AUGUST 17



These school supplies were collected and donated to 3 of our HTC's (CHOP, St. Chris, and Lehigh Valley).

Annual Golf Classic

SEPTEMBER 10



National Bleeding Disorders Foundation (NBDF) Bleeding Disorders Conference

SEPTEMBER 12-14



ADVOCACY UPDATE



MG LEGISLATIVE UPDATE: PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

HARRISBURG OVERVIEW

The 2023-24 session will officially conclude on November 30th, leaving limited session days to move outstanding bills through the legislative process and across the Governor’s desk. If they don’t make it through the finish line, the bills will have to be reintroduced for consideration during the next session.

This fall, the House plans to gavel-in for 11 session days and the Senate for 14 days.

House of Representatives

The House continues to operate with slim margins between Democrats and Republicans. Without a clear majority, it’s difficult for either caucus to successfully pass controversial bills through the chamber.

At full complement, the House has 203 Representatives. Right now, there are 201 members. Two Democrats recently resigned, bringing their numbers down from 102 to 100 seats. Republicans are technically in the majority with 101 seats. The special election to fill those two seats is scheduled for September 17th and it is generally expected that both seats will be filled by Democrats, putting them back in the majority (102) for the remainder of the session.

Senate

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

2024 Elections

On November 5th, all 203 seats of the Pennsylvania House of Representatives and 25 out of the 50 Senators are up for election. All odd-numbered Senate district seats are up for election this year.

On your ballots, you’ll also find three state row offices: Attorney General, Auditor General and Treasurer. The major party candidates for each office are as follows:

- Attorney General
 - Republican Dave Sunday
 - Democrat Eugene DePasquale
- Auditor General
 - Incumbent Republican Tim DeFoor
 - Democrat Malcolm Kenyatta

- Treasurer:
 - Incumbent Republican Stacy Garrity
 - Democrat Erin McClelland

BUDGET LINE ITEM

Each year, our priorities for the Bleeding Disorders Foundation are to protect the hemophilia line item in the state budget and ensure that the funding distribution formula remains as is.

This year, we were able to secure \$1,017,000 in the General Appropriations bill (SB 1001) and protect the distribution formula with language in the fiscal code (HB 2310), as follows.

SB 1001 (General Appropriations):

20	FOR ADULT CYSTIC FIBROSIS AND	
21	OTHER CHRONIC RESPIRATORY	
22	ILLNESSES.	
23	STATE APPROPRIATION.....	795,000
24	FOR DIAGNOSIS AND TREATMENT	
25	FOR COOLEY'S ANEMIA.	
26	STATE APPROPRIATION.....	106,000
27	FOR HEMOPHILIA SERVICES.	
28	STATE APPROPRIATION.....	1,017,000
29	FOR LUPUS PROGRAMS.	
30	STATE APPROPRIATION.....	106,000
20240SB1001FN1817		- 270 -

HB 2310 (Fiscal Code):

13 (7) MONEY APPROPRIATED FOR HEMOPHILIA SERVICES SHALL BE
 14 DISTRIBUTED TO GRANTEEES IN THE SAME PROPORTION AS DISTRIBUTED
 15 IN FISCAL YEAR 2019-2020.
 16 (8) MONEY APPROPRIATED FOR LUPUS PROGRAMS SHALL BE
 17 DISTRIBUTED PROPORTIONATELY TO EACH ENTITY THAT RECEIVED
 18 FUNDING IN FISCAL YEAR 2018-2019.
 19 (9) FROM MONEY APPROPRIATED FOR SICKLE CELL ANEMIA
 20 SERVICES, INCLUDING CAMPS FOR CHILDREN WITH SICKLE CELL
 21 ANEMIA, THE FOLLOWING SHALL APPLY:
 22 (I) GRANTEEES WHICH RECEIVED AMOUNTS IN FISCAL YEAR
 23 2019-2020 SHALL RECEIVE AN AMOUNT WHICH IS IN THE SAME
 24 PROPORTION AS DISTRIBUTED IN FISCAL YEAR 2019-2020.
 25 (II) \$75,000 SHALL BE DISTRIBUTED TO A QUALIFYING
 26 ACADEMIC MEDICAL CENTER LOCATED IN A COUNTY OF THE THIRD
 27 CLASS WITH A POPULATION BETWEEN 280,000 AND 300,000 UNDER
 28 THE MOST RECENT FEDERAL DECENNIAL CENSUS FOR EXPANDED
 29 CARE OF ADULT SICKLE CELL DISEASE.
 30 (10) MONEY APPROPRIATED FOR LYME DISEASE INCLUDES
 20240HB2310FN3506 - 78 -

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LEGISLATION

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. In short, 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.

More specifically, it prohibits PBMs from:

- Reimbursing a retail pharmacy less than the amount that the PBM reimburses a PBM-affiliated pharmacy;
- Unilaterally altering the terms of the original contract;
- Designating a prescription drug as a specialty drug or requiring a prescription drug to be dispensed exclusively at a specialty pharmacy.
- In addition, health insurers and their contracted PBMs are prohibited from:
- Requiring covered individuals to purchase prescription drugs exclusively through a mail-order pharmacy or PBM-affiliated retail pharmacy.
- Prohibiting or limiting a covered individual from selecting an in-network pharmacy of the individual's choice.

After several rounds of amendments, the bill passed the House with a vote of 172-30, the Senate with a vote of 48-1 and was signed by the Governor as **Act 77 of 2024**.

Telemedicine

For nearly a decade, legislators have been attempting to address and expand access to telemedicine. This session, Senator Elder Vogel (R-Beaver) can say he accomplished it.

SB 739 was signed into law as **Act 42 of 2024**. The law requires health insurance companies to pay or reimburse participating network providers for covered health care services that were delivered via telemedicine, per the terms and conditions of the contract.

Note that the law doesn't specifically address payment parity, but rather leaves the details open-ended for individual contracts, likely in an intentional move to keep insurers neutral on the bill.

Act 42 will take effect on October 1st, 2024.

Access 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 was sent to the Senate.

Somewhat simultaneously, Governor Shapiro suggested similar funding in his budget proposal. His proposal was included in the final budget package.

The Bleeding Disorders Foundation was instrumental in the success of this initiative. We shared letters of support for this with the Governor's office as well as the House and Senate Appropriations Committees. Congrats team!

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.

THANK YOU

We look forward to continuing to represent you in the Capitol. 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



Nora Bullock
ARDMORE,
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.

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!



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

COLE HAMSTEAD 2024

One of the greatest needs in the hemophilia community today is to motivate the younger generation to get involved in advocating for the issues that impact our community and “Pay it Forward”. We are so fortunate today to have safe hemophilia treatments. Even with my diagnosis of severe Hemophilia A, I can say that I am living my life to the fullest as a 3-sport high school athlete (baseball, soccer and basketball) and being able to complete my Eagle Scout Rank.

In the 1980’s, most young men with severe hemophilia died from AIDS due to medications affected by the tainted blood supply. In 2005, when I was born, a person with severe hemophilia could live a normal life. At that time, it was reassuring to learn that there were great strides being made in genetic research and improved treatments. As I got older, I was inspired to be a part of driving forward these exciting initiatives in the bleeding disorders community.

My journey to “Pay it Forward” started at the age of 5 years old when I began attending the annual National Bleeding Disorders Foundation’s (NBDF) Washington D.C. Advocacy Day with my mother. At that time, we had learned that there were no families visiting the Delaware lawmakers in D.C., so we decided to take on that role. Although we lived in PA, we were so close to Delaware that we went the HTC at Christiana until I was 7. Over the next 14 years I would annually meet with the senators and congressmen of Delaware in Washington D.C. to discuss issues that impacted the bleeding disorders community like ensuring access to our specialty medications and addressing

insurance company tactics that can threaten that access (i.e. copay accumulators). As I developed these relationships, my confidence increased I was able to be more effective in encouraging them to co-sponsor legislation (like the HELP Copays Act of 2023 and the Skilled Nursing Facility act of 2019) and continue to support funding for the federal hemophilia programs. Through this experience I have developed skills in speaking persuasively and learned to build an effective argument for my ‘ask’ backed by data, reason, and compelling examples. By working with the National Bleeding Disorders Foundation on these advocacy initiatives I was able to broaden my knowledge of the issues impacting this community beyond my personal experiences. I have benefited from the medical progress and strong advocacy that resulted from the crisis in the 80’s and I want to ‘pay it forward’ to further benefit the hemophilia community.

I have been able to take the learnings from my federal advocacy and apply it at the state and local level. One example of this is when I shared my testimony at Pennsylvania State legislative hearing about the high cost of specialty prescription drugs. Additionally, I worked with the Governor’s Office in Delaware to have March designated as Bleeding Disorders Awareness Month. Another example was the ‘Genetics of Hemophilia’ presentation I did at my school. For 4 years I was able to do this presentation for the entire 7th grade class in my school as a part of the science curriculum regarding x-linked disorders. The presentation provided an education of what hemophilia is, how it is treated, how it is genetically

Federal Advocacy:



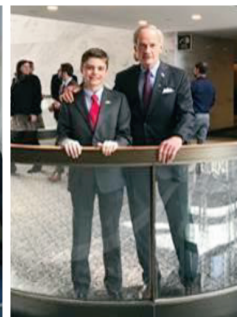
Wash Days Presentation 2016



Meeting with Senator Coons 2017



Meeting with VP Biden 2016



With Sen. Carper 2020



With Sen. Carper 2024

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State Advocacy:



With PA Rep. Sappey 2019



Speaking at Harrisburg Hearing – 2016



Giving a speech before the DE Gov.



DE Gov. Carney with the proclamation

passed as an x-linked chromosome and the example of how it was passed within my family.

In 2023 I was a Junior Camp Counselor at the Hole in the Wall Gang Camp created by Paul Newman. Throughout my childhood I had the opportunity to attend this special summer ‘sleep away’ camp for kids with chronic health conditions. The affirming and supportive atmosphere created a ‘camp magic’ that enabled campers to step outside of their comfort zone and have fun engaging in activities they may not normally try, like self-infusing. It was rewarding for me to take the journey full circle from experiencing the ‘camp magic’ as a camper to creating the ‘camp magic’ and bringing that same joy to the new campers as a Junior Camp Counselor.

My cousin, who also has severe hemophilia, and I started a walk team together called Cousins for a Cure to raise money for hemophilia research. Over ten years we raised over \$130,000. The funds were used to make donations to bleeding disorders research programs, various hemophilia camps in the area, hemophilia treatments centers in Pennsylvania and Delaware and to families experiencing financial crisis

due to their bleeding disorder. We were recognized as the top fundraising team at the Eastern PA Chapter Walk from 2010 to 2017.

I was honored to receive the Outstanding Advocacy Award (2014) from the Eastern PA Chapter, Ryan White Youth Leadership Award (2017) from the National Bleeding Disorders Foundation and the Future Leaders Award from the Hemophilia Federation of America (2022). I feel these youth awards are a great way to bring visibility to the ways that young people can get involved in this community to drive change.

The Eastern PA Bleeding Disorders Foundation Scholarship will help me achieve my academic goals by providing very helpful financial support. My years of giving back to the bleeding disorders community will help me succeed in my pursuit of a Business Degree at Southern Methodist University because these experiences have given me the chance to develop my skills of leadership, project management, public speaking, an appreciation for the financial/insurance challenges of costly biologic medications and a deeper understanding of the legislative process.

Local Advocacy:



“Genetics of Hemophilia” Presentation



Walk donation to CHOP



Jr. Camp Counselor at Hole in the Wall

Community Spirit

WRITTEN AND ARRANGED BY: BRYANT E. CULPEPPER SR.

JESSICA, THE PERSON, THE ♥ HEART

Before I began my story, just magnify the notion that this is what I truly believe now in my heart of hearts. My story is of a person that I recently met through her field of work. Her name is Jessica. And the reason that I chose this particular young lady, is truly not any of the tangibles she has so gratefully assisted me with. But of one of the purest hearts that I ran across in a very long time.

Let me take you back so you see and understand the crux of my story. On the date of, October 12th of 2023, I underwent a total shoulder replacement with my favored arm. And the residuals that occurred post- OP, has taken me into some very strenuous financial waters in which I thought I was surely going to drown in for a season. But for some reason I thought. Maybe I could write a letter to the social service department of the Hemophilia Cardezia clinic, under the coats of Jefferson hospital here in Philadelphia.

But I said to myself, Bobby the former social worker in that department is no longer there. With knowing that I decided to call Cardezia to find out who was the new worker there.

After gaining my information, I decided to write a letter to Jessica being as transparent and humble in my times of need. And I BELIEVE now that God has sent an angel into the very midst of my troubles. This young lady started out the gates with a type of caring and understanding that truly amazed me to the point I was startled at first. She understood just about ninety percent of my current troubles.

Jessica never for one minute made me to feel uncomfortable in my present situation. However, it was just the opposite.

And as a man that has been independent since the age of sixteen, my ego took the reigns of my self pride. But even then, Jessica's humanitarianism of good deed seemed to steep further and further into the angel that I believe she is. She helped me with food, getting my utilities in order, as well as enlightening me with resources I never knew of. But allow me to incorporate a fact that there were just a few times that I thought she was becoming to be a bit pushy in her work. Notice I said work, not character. You see because from past experiences in my life, there were situations I endured that caused me to be afraid when folk start to be too much of a help. It's then I become to feel obligated. And trust me, I truly hate being obligated to anyone on this earth.

But Jessica kept coming on strong in which led me to believe that yes, this young lady is truly sincere in good character. I'm a bit of a spiritual soul, and most times I can spot a phoney. But this young lady was no fraud. I say that because, by Jessica being so young, she's truly innocent in good character while dealing with her clients. And today it could be hard to find good genuine young folk. Let me be very clear, that this story has nothing, and I say nothing to do with any of the tangibles that Jessica has helped me with. And most times I'm a good judge of character. This story is riding on the tracks of a kind sincere and truly, a very big heart. And I believe Jessica fits this title to the tee. Jessica has won my vote for humanitarian woman of 2024 and many many more to come. A man would love to have a daughter with such sincereness and dedication not to her job only, but to the people she serves. So in conclusion, I just want to say. Thank you Jessica, for being a very special part in making this flower bloom again. You will go far in what you do. And to all that reads this story. This is exactly why I entitled it, "Jessica, the person, the ♥ heart".

END

Congratulations

2024-2025 Scholarship Recipients

EPBDF is thrilled to award college scholarships to each of the talented students below.
*Generously supported by a charitable donation through the annual Matthew Thomas Scholarship Fund.
On behalf of the EPBDF and scholarship recipients, thank you.*



ELIZABETH AIELLO
Freshman
College for Creative Studies



MEREDITH BROWNHILL
Freshman
Elizabethtown College



JORDAN DAVIS
Freshman
University of Maryland Eastern Shore



CALEB DEFRANK
Junior
Alvernia University



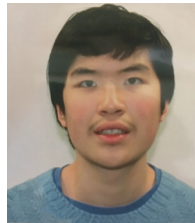
ZACHARY GLAVIN
Sophomore
University of Pittsburgh



COLE HAMSTEAD
Freshman
Southern Methodist University



ISAAC HEILMAN
Junior
Saint Joseph's University



STEVEN HUANG
Sophomore
Lycoming College



JUSTINE LAMPE
Senior
Indiana University



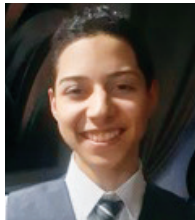
JASPER MCHUGH
Sophomore
West Chester University



NICHOLAS MCKEEN
Junior
Harford County Electrical Contractors Assn



HANNAH MILLER
Junior
Cairn University



JOSE PEREZ
Junior
Community College of Philadelphia



COURTNEY ROWE
Sophomore
West Chester University



MATTHEW WINARTO
Junior
St. Joseph's University

ATTENTION COLLEGE STUDENTS!

Don't forget

When you go to school, make sure to locate your nearest HTC and local chapter.





EPBDF

Period Product Support for Women, Girls and People with the Potential to Menstruate

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:



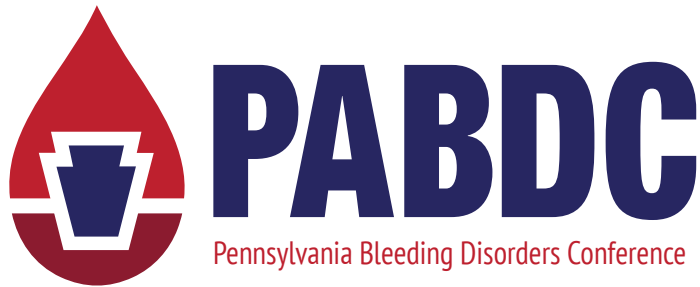
1. The applicant is a member of the Eastern Pennsylvania Bleeding Disorders Foundation with a diagnosed bleeding disorder.
2. The cost of period products is making it difficult to afford essential household bills.

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.



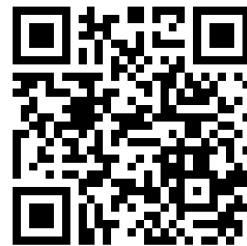
Save the Date



Pennsylvania Bleeding Disorders Conference

May 16 - 18, 2025

Hershey Lodge
325 University Dr,
Hershey, PA 17033



Be the first to know when PABDC registration opens! Scan the QR code to join the PABDC mailing list.



EPBDF
2024
Annual Campaign

**Please Support the Eastern Pennsylvania
Bleeding Disorders Foundation Annual Campaign**

With your support, the Eastern Pennsylvania Bleeding Disorders Foundation can continue the mission of serving those affected by bleeding disorders across our 41-county coverage area. Your contribution fosters a sense of connection and support through education, programming, advocacy, and financial assistance.

Donate Today and Make a Difference

Every gift directly impacts individuals and families, ensuring we can continue to provide critical resources and services. Together, we can create a stronger, more supported future for those living with bleeding disorders.

please scan
to donate





EASTERN PENNSYLVANIA
BLEEDING DISORDERS FOUNDATION

C O M M U N I T Y

Empowerment
DAY

At The Mill
810 Old West Chocolate Avenue
Hershey, PA 17033

SATURDAY
NOVEMBER 2, 2024
11 - 4:00 PM

SCAN CODE TO REGISTER



DESIGNER BAG BINGO

FOR BLEEDING
DISORDERS

FUNDRAISER



**SATURDAY,
NOVEMBER 23
1:00 – 4:00 PM**

**TYLERSPORT FIRE COMPANY
125 RIDGE ROAD
TYLERSPORT, PA 18971**



- Tickets = \$30
- 15 Games
- Door Prizes
- 50/50 Drawing
- Raffle Baskets
- BYO food and beverages.



scan to register

**EARLY BIRD
DISCOUNT**

\$25 for tickets purchased
by November 13



EASTERN PENNSYLVANIA
BLEEDING DISORDERS FOUNDATION

*This holiday season please join us to
celebrate our community!*

Holiday Party

Saturday, December 7
Starting at 12 PM

Cannstatter Volksfest Verein
9130 Academy Road
Philadelphia, PA 19114

SCAN CODE
TO REGISTER




NEVER MISS AN UPDATE!



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.




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>



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Supporting our community is the foundation of what we do



That's why Novo Nordisk goes beyond offering a broad range of treatments and is dedicated to providing educational resources and one-on-one support!

We have **resources** for people living with:

- Hemophilia A
- Hemophilia B
- Hemophilia A with inhibitors
- Hemophilia B with inhibitors
- Glanzmann's thrombasthenia when platelets don't work
- Factor VII deficiency
- Factor XIII A-subunit deficiency

Get connected locally with one of our Hemophilia Community Liaisons (HCL) to see how they can help you!

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Fc-VWF-XTEN Fusion Protein-ehl

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Connect with
Alexis Akins
alexis.akins@sanofi.com
215-449-9121



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scanning the QR code

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Fc-VWF-XTEN Fusion Protein-ehl

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