



EPBDF

*The
Winning
Spirit
Newsletter*

Winter 2024



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UPCOMING EVENTS

7-9 February
FRIDAY – SUNDAY
WOMEN'S RETREAT

1 March
SATURDAY
BOWLING FOR BLEEDING DISORDERS

26 April
SATURDAY
UNITE WALK

16 – 18 May
FRIDAY – SUNDAY
PA BLEEDING DISORDERS
CONFERENCE

26 June
THURSDAY
EPBDF ANNUAL MEETING

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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Wishing You



A Happy New Year

2025

Board



EASTERN PENNSYLVANIA
FEEDING DISORDERS FOUNDATION

Staff

Unite Walk

SEPTEMBER 28



Toast to Legacy

OCTOBER 6



Family Camp

OCTOBER 11 – 13



Designer Bag Bingo

NOVEMBER 23



Holiday Party

DECEMBER 7



ADVOCACY UPDATE



MG LEGISLATIVE UPDATE: PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

HARRISBURG OVERVIEW

On November 30, 2024, the 2023-24 session will officially come to an end. This means that any bills that haven't made it through the legislative process and across the Governor's desk, are officially dead. For future consideration, those bills will have to be reintroduced in the next session. The 2025-26 session begins on January 7th.

The November elections did not lead to changes to control of the House and Senate. The ratios between Republicans and Democrats in both the House and Senate will remain the same. Democrats will continue to hold a one-seat majority in the House with 102 seats. Republicans hold 101 seats. The Senate will continue with a Republican majority (28R; 22D).

Keep in mind there were 19 retirements (3 in the Senate and 16 in the House), so there will be plenty of new members in the upcoming session. In addition, a Senate incumbent was defeated for re-election. These retirements will create openings in the seniority-based committee chairmanships and could have a cascading effect as senior members look to bump up to chair a different committee to match their interests or expertise. We will see committee chairs and rank-and-file committee membership lists in January.

In the meantime, all four legislative caucuses have elected their leadership teams for the new session, as follows:

2025-26 Senate Republican Leadership:

President Pro Tempore: Kim Ward (R-Westmoreland)
Leader: Joe Pittman (R-Indiana)
Whip: Ryan Aument (R-Lancaster)
Appropriations Chair: Scott Martin (R-Lancaster)
Caucus Chair: Kristin Phillips-Hill (R-York)
Caucus Secretary: Camera Bartolotta (R-Washington)
Policy Chair: *TBD through appointment.*
Caucus Administrator: *TBD through appointment.*

2025-26 Senate Democratic Leadership:

Leader: Jay Costa (D-Allegheny)
Appropriations Chair: Vincent Hughes (D-Philadelphia)
Whip: Tina Tartaglione (D-Philadelphia)
Caucus Chair: Maria Collett (D-Montgomery)
Caucus Secretary: Steve Santarsiero (D-Bucks)
Policy Chair: Nick Miller (D-Lehigh/Northampton)
Caucus Administrator: Judy Schwank (D-Berks)

2025-26 House Republican Leadership:

Leader: Jesse Topper (R-Bedford/Fulton)
Whip: Tim O'Neal (R-Washington)
Appropriations Chair: Jim Struzzi (R-Indiana)
Caucus Chair: Martina White (R-Philadelphia)
Caucus Secretary: Clint Owlett (R-Bradford/Tioga)
Policy Chair: David Rowe (R-Juniata/Mifflin/Snyder/Union)
Caucus Administrator: Sheryl Delozier (R-Cumberland)

2025-26 House Democratic Leadership:

Speaker: Joanna McClinton (D-Philadelphia)
Leader: Matt Bradford (D-Montgomery)
Appropriations Chairman: Jordan Harris (D-Philadelphia)
Whip: Mike Schlossberg (D-Lehigh)
Caucus Chair: Rob Matzie (D-Beaver)
Caucus Secretary: Tina Davis (D-Bucks)
Policy Chair: Ryan Bizzarro (D-Erie)
Caucus Administrator: Leanne Krueger (D-Delaware)

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).

These line-item requests will continue to be our priority for BDF in the new session, as it is crucial for the patients and treatment centers. However, we are preparing for a difficult budget season. The Independent Fiscal Office (IFO) published a five-year projection of Pennsylvania's General Fund revenues and expenditures and found that the rainy day fund's surplus will likely disappear next year. In addition, the fiscal year 2025 deficit is projected to increase to \$3.3 billion. And the fiscal year 2026 deficit is now projected to reach \$4.5 billion.

With these deficit predictions, the state budget process will likely become a much more heated and competitive process this year. Lobbying and grassroots advocacy will become more critical. Legislators will need to know their constituents to make their requests top priority.

Continue on page 8

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 became effective 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 for "period poverty" in his budget proposal. Ultimately, the funding 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!

Keep in mind, this was a one-time funding pledge by the legislature, so it will have to be proposed again for consideration in the 2025-26 budget.

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. While the bill was never introduced, we anticipate bill introduction in the upcoming session.

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 was introduced and referred to the Senate Banking and Insurance Committee, where it effectively died on November 30th. For future consideration, the bill language will need to be reintroduced.

In January 2024, Representative Bridget Kosierowski (D-Lackawanna) indicated her intent to introduce companion bill in the House and circulated a co-

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.



Joseph Butler
RED LION,
YORK COUNTY



Marisa Ferger
STATE COLLEGE,
CENTER COUNTY



Frank Lentini
ANNVILLE,
LEBANON COUNTY



Joe Pileri
PHILADELPHIA,
PHILADELPHIA
COUNTY



Chris Ramsey
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DELAWARE COUNTY



Melanie Rosen
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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.

sponsorship memo. The bill was not introduced this session, but the issue could receive more momentum in the new session.

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

GRASSROOTS ADVOCACY

As with most professional relationships, the best time to meet with your legislators (Representative and Senator) is before you have a request, before you are asking for their support/opposition on an issue. We urge you to get to know your legislators if you haven't already. There are plenty of options: from a district office meeting to simply attending an event that the legislator is hosting, such as a town hall. Introduce yourself and make it simple to start.

For the more formal meetings where a request is being made, here are some tips:

- Do some homework. Research your legislators, committee assignments, co-sponsorship memos and sponsored legislation. This offers insight into their legislative interests.

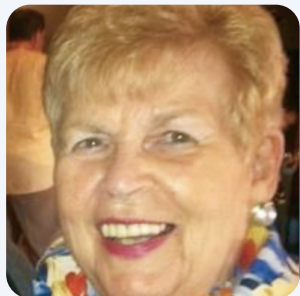
- Always identify yourself as a constituent.
- You are the expert on your issue and know what you or the bleeding disorders community needs. You do not have to be an expert in the legislative process!
- Be clear, brief and accurate! Sharing your story and experiences is very persuasive!
- Your legislator might not agree with your position. Be persistent, but not argumentative. Provide points to support your position. Remember – legislators might not support an issue now, but might support another issue in the future!
- Get to know staff! Staff play a critical role in the legislative offices and can often help legislators remember the issues and next steps.
- Express appreciation.
- Continue to build the relationship!

THANK YOU

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

In Loving Memory

GLADYS BURKE
1933-2024



For more than forty years, Gladys was a member of the Ladies Fashion Show Committee of the Delaware Valley Chapter of the National Hemophilia Foundation. As the mother of three sons with hemophilia, she understood the challenges of our community. We will always remember Gladys and the light she brought to each of us, especially in our darkest times. Rest in peace, dear friend.

Community Spirit

AN ODE TO COLE HAMSTEAD

WRITTEN AND ARRANGED BY; BRYANT E. CULPEPPER SR.

Before I begin this piece, I first like to assure the readers that I'm a hemophiliac, moderate factor eight deficiency. And the Crux of my story birdseye on the wonderful works of a young man named, Cole Hamstead. As a vivid reader of the "Winning spirit newsletter", a medium that's published quarterly by the Eastern Pennsylvania bleeding disorders foundation. I stumbled across an article that was featured in the community spirit section of that medium.

It was of the wonderful works within the purpose of the bleeding disorders foundation. I was so amazed by the dedication and hard work that this young man has put into his learnings of his federal advocacy and applied it to the state and local level. And of how he incorporated his love of sports while being a sever hemophiliac. I can relate, because as a young man growing up in the streets of North Philadelphia, I too being a hemophiliac had the love of sports. And believe me, it was a struggle. I remember being hospitalized in C.H.O.P., The children's hospital of Philadelphia for a very long period of time, due to a torn ligament in my right knee at the age of around fourteen while playing sports. I'm sixty years of age now. But back then, technology regarding hemophiliacs wasn't as advanced as they are today. And so, through that period, that's when I really started to be an inquisitive for the history of hemophilia. What I'm saying is that

we as hemophiliacs now have a platform that we can enlighten the minds of folk that just don't know the severity of being hemophilia and living a normal life in our everyday activity. And I believe Cole Hamstead has taken the lane through his efforts of sharing such a wonderful and enlightening experience of his works within the foundation.

Also, it's such an amazing power move as a young person to reach out to, not only the minds of adults, but to our younger generation of whom we as adults must have an open ear to. Especially in these days and times. And to me, as being a writer of encouragement to others. I take pride in magnifying the wonderful works of our youth in their particular lanes on such platforms. This is the second article I've written about the younger generation and their works within the Eastern Pennsylvania bleeding disorders foundation. Although I haven't met many people face to face in the foundation, I truly take joy in reading about them in the Winning spirit newsletter. And not just the youth, but all the wonderful staff such as Sarah Ross Pilacik, Lisa Lee, and many others within the board of directors. In closing, I want to again thank Cole Hamstead, in his wonderful works as such a young man, for the encouragement he's given me through his story in the Winning spirit newsletter. And that encouragement was to give me another story to write about the good heart of others.

END

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!



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>

Community Spirit



JNC 2024 GRIFFIN SANDFORD

"This past September, I had the unique opportunity to represent our chapter at the Junior National Championship in Henderson, Nevada. It truly was an amazing experience - from meeting new friends and learning more about living a successful life with a bleeding disorder to showcasing my basketball abilities in the skills competition. Sharing this experience with other individuals

with bleeding disorders was very meaningful and reminded me that I have much to be thankful for. I came home feeling energized and proud to be a part of such a talented and hopeful community. Thank you to our chapter for giving me the experience of a lifetime. I had a blast and will never forget it!"



JNC 2024 JARED FORD

" I would like to thank the Eastern Pennsylvania Bleeding Disorders Foundation for nominating me to go to the CSL Gettin' in the Game National Championships in Nevada. It was one of the best trips of my life. My dad and I were even picked up at the airport in a limo! Everything about the trip was great - the hotel was nice, the scenery was incredible, and the people were really friendly. All of the basketball coaches were really helpful and made the experience a lot of fun. Coach Bob offered pointers

on my shooting that I plan to use this winter when I play ball for my school. This was also the first time I was around other kids with bleeding conditions like mine. The sense of community was reassuring, and I even met some new friends from other states. My dad appreciated the tips and information offered throughout the weekend. I am sure I will carry the memories of this once-in-a-lifetime trip with me for the rest of my life. "

Jared Ford



Community Spirit

LARRY MCHUGH

EPBDF BOARD MEMBER

GETTING IN THE GAME AND WINGMAN

Each year, CSL Behring hosts a National Championship for children with bleeding disorders from around the country. Children are selected by their chapters to go complete against kids of similar skill levels in golf, basketball, baseball and swimming. It is an amazing program where many CSL employees volunteer to help each child in their sport. Personally, I experienced the impact it has had on my son's life. After attending his first tournament in Arizona that introduced him to golf at the competitive level; he came home and became focused on improving his game as well as taking more lessons. When he began high school, he played for his school's golf team and became a caddy at a local golf club which exposed him up to a whole new world of golf. Recently, I spoke with one of the members who often requests Jasper to caddy for her. She said the first time he caddied for her in a competition he gave her a pep talk to win the competition which she was behind by 3 strokes. She said he got her all pumped up and she ended up winning the match. Jasper went on to receive a scholarship for college through the work at his golf course. The Golf Association of Philadelphia's, J Wood Platt Trust program is an amazing experience that has allowed Jasper to build relationships with members of other clubs as well as meet new friends among caddies at other clubs. Through the Platt trust, he was invited to caddy for the LPGA tour last year. We will

be forever grateful to CSL Behring and Perry Parker for the impact the tournament has had on his life as a golfer.

In addition to the CSL Jr National Getting in the Game championship, I am also involved with The Wingman organization who partners with CSL to provide lessons and a national tournament for adults with a bleeding disorder or their family members. Through this program, Jasper and I received lessons with a professional and competed with other participants locally. I was selected for the national tournament and in our second-year competition we were able to bring the trophy home for our Chapter. This year I got to go back as an alumni golfer in the Wingman tournament to play against other alumni golfers from around the country. We were not able to keep the trophy this year, but had an amazing time growing relationships with friends from the Wingman program.

This fall, for the first time Getting in the Game paired Wingman alumni as caddies for the children playing in the National Getting in the Game tournament. It was an honor to serve as caddy and complete the circle of giving back for what Getting in the Game and CSL Behring gave to my son. A priceless love for the game of golf!

Please reach out to Sarah about how to have your child apply for this wonderful tournament. It will be a life changing weekend for you and your child!

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!



EPBDF
2024
Annual Campaign

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

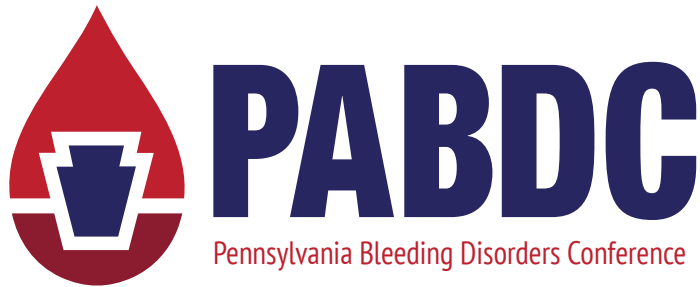
With your support, the Eastern Pennsylvania Bleeding Disorders Foundation can continue the mission of serving those affected by bleeding disorders across our 41-county coverage area. Your contribution fosters a sense of connection and support through education, programming, advocacy, and financial assistance.

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





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

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.

Women's Retreat

February 7 - 9

Normandy Farm

Hotel and Conference Center

SCAN ME!



Or register here:
epbdf.org/event/

**Limited Number of Rooms Available
Register Today!**



**Registration Closes
January 10**

SCAN ME!



EPBDF

EASTERN PENNSYLVANIA
BLEEDING DISORDERS FOUNDATION

BOWLING

Fundraiser

SATURDAY
MARCH 1
2-5 PM

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300 LANCASTER AVE
DEVON, PA 19333

\$25
PER PERSON

INCLUDES:
BOWLING
SHOE RENTAL
FOOD & BEVERAGES

Unite

for Bleeding Disorders

SAVE THE DATE

APRIL 26
2025

Details regarding the NEW location is coming soon!



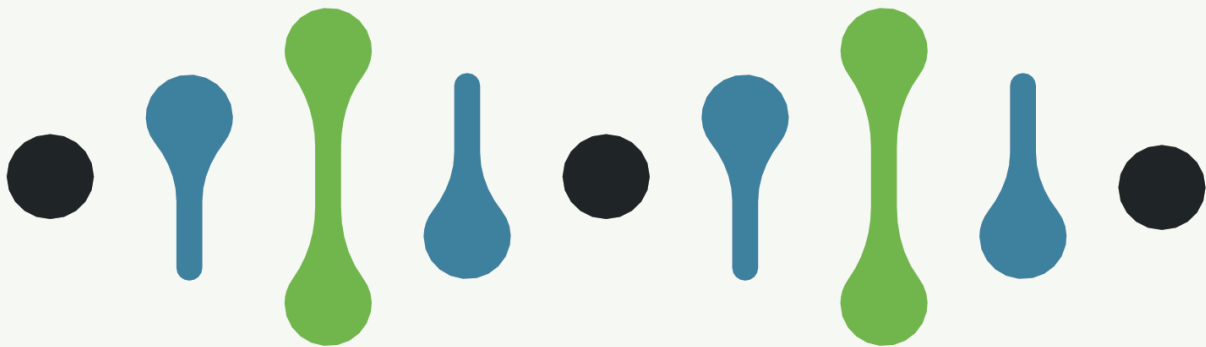


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Supporting our community is the foundation of what we do



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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NEVER MISS AN UPDATE!

