



























The Winning Spirit Newsletter

Spring / Summer 2025

EASTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

1 MISSION

STAFF



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UPCOMING EVENTS



BLEEDING DISORDERS

NATIONAL

ANNUAL FAMILY DINNER

ADVENTURES IN LEARNING

9 August



21 – 23 August THURSDAY – SATURDAY

NBDF'S BLEEDING DISORDERS CONFERENCE

9 September

EPBDF ANNUAL GOLF CLASSIC

2 November

TOAST TO A LEGACY

22 November SATURDAY

DESIGNER BAG BINGO FOR BLEEDING DISORDERS

6 December

HOLIDAY PARTY

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

BOARD OF DIRECTORS



Marisa Ferger President



Anthony Deni Vice President



Tammy Jones Secretary



Mike Wood Treasurer



Hajar Abusief **Board Member**

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Board Member



Larry McHugh **Board Member**

Eastern PA Hemophilia Treatment Centers











DE Hemophilia Treatment Center





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Letter from Our Executive Director

Dear Friends.

As summer unfolds, I want to take a moment to reflect on the incredible momentum we've built together and to thank you for being such a vital part of it.

We are still celebrating the success of the inaugural Pennsylvania Bleeding Disorders Conference (PABDC), held this May at the wonderful Hershey Lodge. The event brought together more than 400 individuals from across the Commonwealth for a weekend of education, connection, and empowerment. From our dedicated Board of Directors, volunteers and engaged attendees, to our HTC partners, to our generous sponsors and inspiring speakers—thank you.

A special note of gratitude goes to our partners at the Western Pennsylvania Bleeding Disorders Foundation (WPBDF). Their leadership, collaboration, and shared vision were instrumental in launching this meaningful new statewide tradition. We are proud of what we accomplished together and excited to carry this energy into the months ahead.

I also want to give a heartfelt thank-you to **Lisa and Kevai** for their incredible dedication and attention to detail throughout the planning and execution of PABDC. Their commitment behind the scenes—along with their daily contributions to this foundation ensures that our mission is carried out with excellence and heart. I'm deeply grateful for their partnership.

We're also excited to recognize and celebrate the Class of 2025! Whether you're graduating from high school, college, a vocational program, or another milestone congratulations! You are featured in this newsletter and will also be honored at our Family Dinner on June 25. We are so proud of your achievements and can't wait to welcome you into our community as adults. Your voice, experience, and leadership will help shape the future of EPBDF, and we're eager to see how you'll grow with us in the years to come.

In support of those pursuing higher education, EPBDF is proud to offer a scholarship program that helps individuals in our bleeding disorders community reach their academic goals. We extend our heartfelt thanks to the family of Matthew Thomas for their generous annual contribution, which helps make this program possible.

If you'd like to support the scholarship fund, donations may be made online or by mailing a check to the

address below. For more information, please don't hesitate to reach out—we'd love to connect with you.

As always, we remain committed to supporting families beyond education. Thanks to a \$50,000 grant from the Foxwynd Foundation, EPBDF recently launched the EPBDF | Foxwynd Financial Assistance Fund, which provides critical help to individuals and families in crisis. As part of the grant, EPBDF committed to raising an additional \$10,000—and we're thrilled to share that an anonymous donor is matching every gift up to that amount!

This is a powerful opportunity to double your impact and ensure no one in our community has to navigate financial strain alone.

Scan the QR code below or mail your matched gift to: Eastern PA Bleeding Disorders Foundation 148 W. State Street, Suite 305 Kennett Square, PA 19348 Memo: Special Campaign

If you or someone you know is interested in becoming a matching donor, we would love to hear from you.



Every dollar makes a difference, and every act of generosity helps strengthen the EPBDF family.

We look forward to seeing you at our upcoming events for the second half of 2025! Please visit our calendar at www.epbdf.org. Wishing you a joyful, healthy, and safe summer.

With gratitude,

Sarah Pilacik

Sarah Pilacik **Executive Director** Eastern Pennsylvania Bleeding Disorders Foundation



Bowling for Bleeding Disorders





World Hemophilia Day



Advocacy Ambassador Education and Training



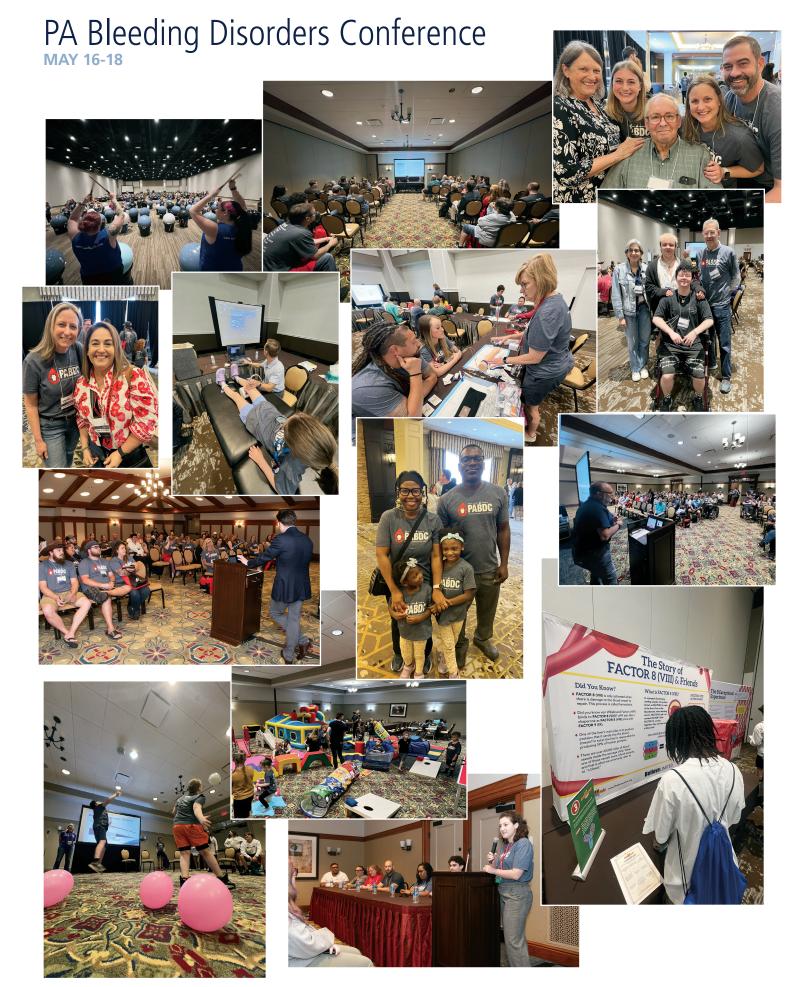




PA Bleeding Disorders Conference



PA Bleeding Disorders Conference MAY 16-18



ADVOCACY UPDATE

EPBDF OO

MG LEGISLATIVE UPDATE: PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

HARRISBURG OVERVIEW

The Pennsylvania General Assembly is approaching the second quarter of the two-year legislative cycle. All bills have until the end of the session, November 30th, 2026, to get through the legislative process and across the Governor's desk.

Two special elections were held at the end of March:

- House: Representative Matt Gergely (D-Allegheny)
 passed away in January and left a vacancy in the 35th
 House district seat. Dan Goughnour, a Democrat from
 McKeesport, won the special election.
- Senate: Senator Ryan Aument (R-Lancaster) resigned to work for U.S. Senator Dave McCormick, leaving a vacancy in the 26th Senate district seat. In a major unexpected shake-up, *Democrat* James Malone won the special election. He is the first Democratic State Senator from Lancaster since 1889.

The new ratios in the House and Senate are as follows:

House: 102 Democrats; 101 Republicans
Senate: 27 Republicans; 23 Democrats.

Democrats maintain a slim majority in the House and Republicans maintain a slightly less comfortable majority in the Senate.

Below are some committee chairs of interest to the Bleeding Disorders Foundation (BDF):

- Senate Health & Human Services Committee:
 - Majority Chair Michele Brooks (R-Mercer)
 - Minority Chair Art Haywood (D-Montgomery)
- Senate Banking & Insurance Committee:
 - Majority Chair Chris Gebhard (R-Lebanon)
 - Minority Chair Sharif Street (D-Philadelphia)
- House Health Committee:
 - Majority Chair Dan Frankel (D-Allegheny)
 - Minority Chair Kathy Rapp (R-Crawford)
- House Insurance Committee:
 - Majority Chair Perry Warren (D-Bucks)
 - Minority Chair Tina Pickett (R-Bradford)

BUDGET

In February, Governor Josh Shapiro provided his 2025-26 budget address and corresponding proposal.

It was a \$51.3 billion spending plan, a 7.5% increase over last year's budget.

Once again, it did not include any increases to the personal income tax (PIT) rates or sales & use (S&U) tax rates.

However, to help offset the state's current \$3.4 billion operating deficit, the Governor proposed the legalization and taxation of recreational marijuana, taxed at 20%, and skill games, taxed at 52%. The projected revenue from both recreational marijuana and skill games in the first fiscal year (if passed) would be just shy of \$1 billion.

The Independent Fiscal Office (IFO) projects the state's operating deficit to increase from \$3.4 billion to \$6 billion by next year.

The legislature has a constitutional deadline for passing a balanced budget by June 30th.

BUDGET LINE ITEM

Each year, our priority for BDF is a three-part budget request:

- Protect/increase the hemophilia line item in the state budget;
- Separate it out from the other rare disease line items; and
- Ensure that the funding distribution formula remains as is.

Last year, we successfully secured \$1,017,000 in the General Appropriations bill (SB 1001), kept it separated from other line items, and protected the distribution formula with language in the fiscal code (HB 2310).

These budget requests will continue to be our priority for BDF this session, as they are most critical for the patients and treatment centers. Ideally, we are advocating for an increase from \$1,017,000 to \$1,250,000.

We emphasize that we are preparing for a difficult budget season. With these IFO predictions, the state budget process will likely become a much more heated and competitive process.

We note that several legislators representing HTCs across the state, including Representative Tom Mehaffie (R-Dauphin), Senator Tina Tartaglione (D-Philadelphia) and Senator Nikil Saval (D-Philadelphia), have authored

supplemental letters of support for our requests and shared with their leadership teams in the House and Senate.

But your legislators need to hear from you as well! Legislators need to know their constituents to make this three-part budget request a top priority.

GRASSROOTS ADVOCACY

Now is the time to start meeting with your personal legislators (Representative and Senator) to help advocate for the budget line-item requests. Please reach out to the district offices to schedule an in-person meeting.

We need to ensure that your legislators:

- Know you are a constituent;
- Are familiar or become more educated on hemophilia and other bleeding disorders; and hopefully
- Are supportive of the hemophilia line item and are willing to make it a budget request with their leadership in the House and Senate.

Because the budget process will likely be more competitive this year, legislators are asking for more details on how each line item (including hemophilia) is spent. We shared the below HTCs responses with legislative offices, but it might be helpful for you to share with your legislators as well.

Funding is applied to:

- Unified Care Protocol, which helps eliminate barriers to care:
- Consumer Advocacy Council, which provides a platform for patients to voice concerns and suggestions;
- Mental health support, including routine screenings; and
- Initiatives for job readiness and vocational training.

LEGISLATION

We continue to monitor for any bills that could potentially harm the community, as well as for bills that could support the community. Our firm coordinates directly with Kara and Sarah (and team!) to review the bills introduced and determine levels of engagement (support/oppose/amend/neutral).

So far this session (since January 1st), over 2,000 bills have been introduced!

Access to Menstrual Hygiene Products

Representative Roni Green (D-Philadelphia) introduced HB 337, which requires the Department of General Services to provide menstrual hygiene products, with a dispensing machine and disposal receptables, in at

least 50% of bathrooms in all state buildings.

We all know that these products are especially critical for women who have bleeding disorders. Women with bleeding disorders often have prolonged periods, heavy bleeding, and disruptions to everyday activities. These challenges are further exacerbated for those who struggle to afford or simply forget to bring feminine hygiene products with them to work. By providing more access to these products, Pennsylvania can truly help make a difference for women with bleeding disorders and improve overall office work productivity.

BDF sent a letter of support for HB 337 to the House State Government Committee, where it recently passed with a party-line vote (14-12). It will now go to the full House for a floor vote before going to the Senate for its consideration.

Co-Pay Accumulator

Senator Judy Ward reintroduced the co-pay accumulator bill as SB 268. It was referred to the Senate Banking & Insurance Committee.

Again, the bill 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.

The Milliron Goodman team is continuing to stay engaged on this issue. In fact, over the past six months, we've been able to establish an on-going dialogue directly with Insurance Commissioner Michael Humphreys and his leadership team.

Please continue to share your personal experiences regarding co-pay accumulators and any other insurance related concerns with the BDF team.

Other

BDF is partnering with the Bleeding Disorders Substance Use & Mental Health Access Coalition (BDSUMHAC) to focus on the intersection of bleeding disorders, substance use and mental health. At the state level, we are meeting with the Shapiro Administration, including leadership within the Department of Human Services and the Department of Drug & Alcohol, to advocate for improved access to services, increase overall awareness, etc.

THANK YOU

As always, please feel free to contact our office with any questions or concerns. We look forward to continuing to represent you in the 2025-26 legislative session. Melonie

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.

	Town	County
Michelle Bennage	Elizabethtown PA	Lancaster
Marisa Ferger	State College PA	Center
Lorie Kerstetter	Lititz PA	Lancaster
David Melendez	Philadelphia PA	Philadelphia
Jessica Neumann	Center Valley PA	Lehigh
Chris Ramsey	Bryn Mawr PA	Delaware
Melanie Rosen	King of Prussia PA	Montgomery
Allison Sandford	Thornton PA	Delaware
Sara Serrano	Milford PA	Pike
Amber Szagola	Levittown PA	Bucks
Kathryn Szagola	Levittown PA	Bucks
Samantha Tomascik	Levittown PA	Bucks
Joseph Butler	Red Lion PA	York
Frank Lentini	Harrisburg PA	Dauphin
Joe Pileri	Philadelphia PA	Philadelphia
Victoria Selinsky	Delta PA	York
Everett Upton	White Haven PA	Luzerne
Sherry Upton	White Haven PA	Luzerne
Constance Williams	Dover DE	Kent

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



Open the Summary of Benefits page for your insurance and review the lanation for your deductible and out-of-pocket maximum.



of Benefits" for keywords: coupon, copay card, manufacturer coupons, and/or discount prescription card



Review the Pharmacy Limitations and Exclusions section for any of the above keywords.



Call the insurance company directly assistance policy



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

Advocacy

BLEEDING DISORDERS AWARENESS MONTH COUNTY PROCLAMATION



City Of Philadelphia Cherelle L. Parker, Mayor

PROCLAMATION

The City of Philadelphia holds the health and well-being of its residents to be a top priority. Everyone deserves to have the opportunity to live a full, healthy life despite any obstacles they may encounter in diagnosis or treatment. In addition, health care professionals should have the necessary resources to help treat all illnesses.

Hemophilia is a rare genetic bleeding disorder in which one of the proteins that cause the blood to clot is missing or there is not enough of it to work properly, 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. It is typically a lifelong condition that is primarily treated with infusions of protein involved in blood clotting.

Hemophilia is found in all populations and it is estimated that more than 400,000 people worldwide are living with it. Approximately 20,000 people in the United States, including more than 3,000 people in Pennsylvania, are living with hemophilia. They are strongly united in advocating for access to treatment and care, along with those caring for and serving them.

THEREFORE...

I, Cherelle L. Parker, Mayor of the City of Philadelphia, do hereby proclaim Thursday, April 17, 2025, to be

WORLD HEMOPHILIA DAY

in Philadelphia, and urge all residents to be aware of the importance of advocating for access to treatment and care for those living with hemophilia, and commend all those whose efforts are contributing to improving their quality of life.



Charle L. Parker Cherelle L. Parker

> Given under my hand and the seal of the City of Philadelphia on this seventeenth day of April, two thousand and twenty-five

PHILADELPHIA PROCLAMATION WORLD HEMOPHILIA DAY

Advocacy

CANCER ADVISORY (provided by community member)

I am 67 years old and I have Factor VIII hemophilia – severe. I received my first dose of Factor VIII concentrates in 1968. At that time the package inserts warned of the risk of "non A non B hepatitis." Given the risks of living with hemophilia at that time and the vast therapeutic improvement that factor concentrates represented over fresh frozen plasma or cryoprecipitate, we accepted the hepatitis risks. While the hepatitis warnings implied that there was a risk of contracting this "new" hepatitis, the process of acquiring plasma from thousands of donors (often paid) and pooling it together in the factor concentrate processing, it almost certainly guaranteed infection. By that logic I calculate that I was infected with hepatitis C from the age of ten until I cleared the virus with a course of the new antiviral drugs in 2018 at the age of 60.

During those fifty years of infection and the seven years since, my liver enzyme levels never registered levels of concern. The prevailing wisdom had been that once cleared of hepatitis C, with no evidence of additional liver disease and normal liver enzyme levels that there was no need for additional concern for cirrhosis or cancer. Apparently, that is not true. Last fall I was diagnosed with advanced liver cancer.

It is likely that annual or biennial liver scans would have detected my cancer at an earlier stage. Much of my life has been pushing the boundaries of hemophilia care and treatment, blazing a path for those who have come after me. At this point in my life, I would like to encourage all of my blood brothers and sisters who have ever been diagnosed with hepatitis C to request liver scans annually or biennially as part of their regular visits to their health care providers. Advocate for the care that you deserve. - JCR



Advocacy

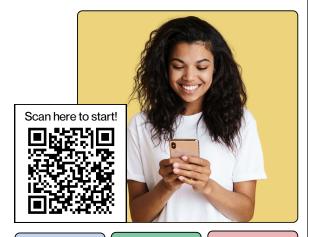




Affordable Online Mental Health Therapy

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 selfassessments



Awareness

Request a free matching session with a licensed therapist



Start affordable virtual sessions with your licensed therapist

Sign up free today



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

Community Spirit

Jefferson Hemophilia Treatment Center Meet & Greet



Crossroads

Meet me at the crossroads, where decisions must be made. Should I burn in the blazing sun, or should I just rest in the shade. They say don't straddle the middle, you must make up your mind. Because if you're stuck between, truth may be hard to find. So this decision is hard to make, and it's really so confusing. It's like playing let's make a deal, and lost in all the choosing. I'm scared to choose the left, because the right may be the one. The left is filled with sorrows, and the right is filled with fun. But fun is usually folly, it exhausted all the real. So I must choose the right road, just to seal the deal. I'm still standing at the crossroads, it's really racking my brain. But if I choose the wrong road, it will taint my name. So scared to make a decision, because I just may choose the wrong. It'll take away my honesty, with bad lyrics in my song. So really confused on the crossroads, but I must choose what's right. To give me back my vision, and simply follow the light. So meet me at the crossroads, this day is about to end. But if I choose the right road, I just may find a friend. **FND**

Written and arranged by; Bryant E. Culpepper Sr.

Community Spirit

"Rhyme and Reason"

I'm sharing this scribe with you, because there really is a reason. It will put you in your lane, and place you in your season. But I must put it in a rhyme, to lay the only line. To crux the real story, that's about to blow your mind. Your culture may be different, to make you understand. The concludes of your story, coming from a different man. When the father made his children, he knew of different types. To put us all on one track, so our thoughts won't get all hyped. Like the keys on a piano, one is white and one is black. Just to all harmonize, as we blaze the roaring track. We can't come crashing to an end, it will destroy the major plan. Of why he even made us, to produce the righteous man. So just flow with all the rhymes, and avoid the awful treason. And reach the only truth, that gave us all the reason. Some days I put on your coat, to cover me from the rain. Because that's the love you have for me, to take away my pain. Yes I will lay my crown, and give you all the glory. Just to let you in, to get you to this story. So just understand the reason, and let's share the same mind. To unjade the initial truth, that was brought through from this rhyme.

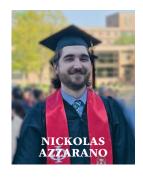
END

Written and arranged by; Bryant E. Culpepper Sr.

Congratulations to the 2025 Graduates









Patient Financial Assistance



SPECIAL CAMPAIGN



Donations to this campaign are dedicated to providing financial relief to families in our community who are in need.

SCAN TO LEARN MORE AND DONATE



THANKS TO AN ANONYMOUS DONOR,
ALL DONATIONS, UP TO \$10,000,
WILL BE MATCHED.

YOUR GIFT HELPS US REACH OUR GOAL.



25 June Wednesday

ANNUAL FAMILY DINNER



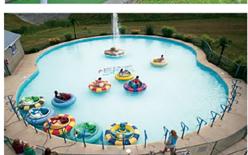
Sheraton Valley Forge, 480 N. Gulph Road, King of Prussia, PA 19406

Adventures in Learning at Adventure Sports

Saturday, July 19th from 11:30am - 3:00pm

Adventure Sports, 3010 Elizabethtown Road, Hershey, PA 17033









Brought to you by the Eastern PA Bleeding Disorders Foundation and the Penn State Health Hemophilia Treatment Center of Central PA



Agenda

11:30am - Check-in opens

12:00pm – Lunch served

12:15pm – HTC welcome

12:15pm-12:45pm – Advocacy and the patient perspective

12:45pm – Adventure Sports rules review

1:00pm-3:00pm – 2-hours for bumper

boats, mini-golf and go-carts

3:00pm - Conclusion

This event is FREE thanks to the Eastern PA Bleeding Disorders Foundation 😂



Join the bleeding disorders community for a day of family fun, networking and advocacy at Adventure Sports!

We can't wait to see you again this summer!

RSVP by calling Meredith Getz at 717-531-1643 or emailing at mgetz1@pennstatehealth.psu.edu by Tuesday, July 1, 2025.

Please include the full names of all attendees and how many wristbands are requested.

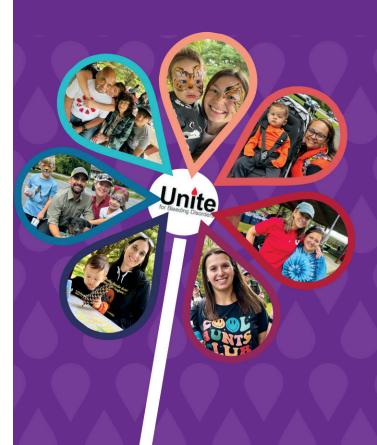


UNITE WALK



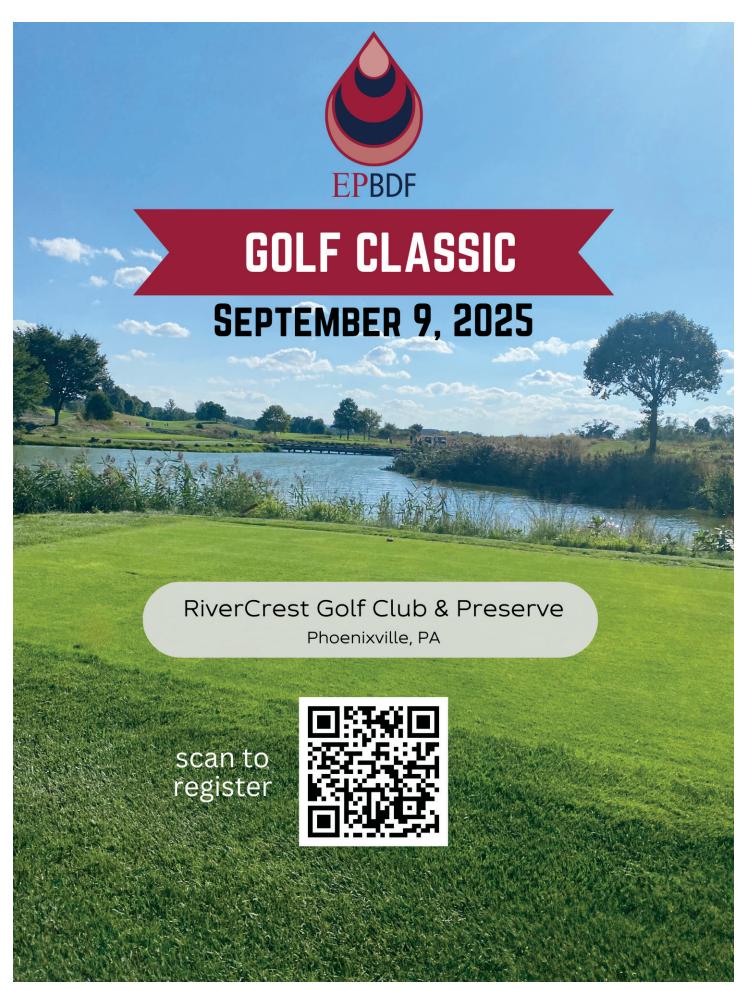
August 9

Elmwood Park Zoo



Fun for the entire family!

REGISTER TODAY!



Toast to a Le



2nd Annual EPBDF Benefit Honoring Christine M. Carroll



November 2, 2025



At Crossing Vineyards Washington Crossing, PA

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

Proceeds to benefit:









DESIGNER BAG

BINGO

FOR BLEEDING DISORDERS



Designer bags from Michael Kors, COACH, Dooney & Bourke, Vera Bradley, and Kate Spade

SATURDAY, NOVEMBER 22

1:00 - 4:00 PM

TYLERSPORT FIRE COMPANY 125 RIDGE ROAD TYLERSPORT, PA 18971



- 15 Games
- Door Prizes
- 50/50 Drawing
- Raffle Baskets
- BYO food and beverages.

FUNDRAISER FOR A GOOD CAUSE

Questions about the event? Email us at info@epbdf.org

\$25 for tickets
purchased prior
to the event.
(\$30 at the door)



Scan or CLICK

QR code

for more info





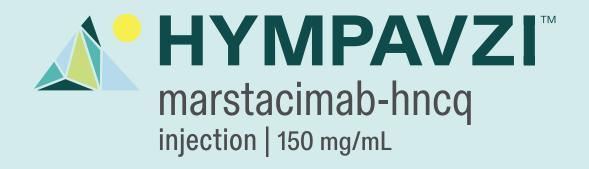
Want to hear from someone who has received HEMGENIX?

Watch
Michael's
Story here:



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*Pfizer Patient Navigators are not measured or awarded based on sales performance nor will they ask you to switch products.

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Empowering you to treat and manage your bleeding disorder

- Dedicated pharmacy transition support
- Timely medication delivery with an overnight shipping option
- In-home nursing support program for patient infusion education
- Assistance with prior authorizations, copay management and more

See how we can help.

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NEVER MISS AN UPDATE!







