

Photo: Willistown Township: Chester County

EASTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

1 MISSION

STAFF



Sarah Ross Pilacik **Executive Director** sarah@epbdf.org



Lisa Lee Assistant Director lisa@epbdf.org



Keyai Lee Director of Marketing & Communications keyai@epbdf.org

2026 UPCOMING EVENTS

6-8 February FRIDAY – SUNDAY

BLEEDING DISORDERS

WOMEN'S RETREAT

7 March

FOUNDATION Formerly NHF

BOWLING FOR BLEEDING DISORDERS

11 April SATURDAY

SPRING FLING FAMILY DAY

24 June WEDNESDAY

EPBDF ANNUAL FAMILY DINNER

18 July SATURDAY

ADVENTURES IN LEARNING

1 August

UNITE WALK

15 September

GOLF CLASSIC

10 October SATURDAY

FALL FEST FAMILY DAY

7 November SATURDAY

DESIGNER BAG BINGO

5 December SATURDAY

HOLIDAY PARTY

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

BOARD OF DIRECTORS



Marisa Ferger President



Anthony Deni Vice President



Tammy Jones Secretary



Mike Wood Treasurer



Hajar Abusief **Board Member**



Leonard M. Azzarano **Board Member**



Bernadette Fox Board Member



Patricia Mangino Board Member



Larry McHugh **Board Member**

Eastern PA Hemophilia Treatment Centers



🔀 Penn Medicine









DE Hemophilia Treatment Center





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Letter from Our Executive Director

A Year of Impact, Gratitude, and Growth

As we close out a meaningful year at the Eastern Pennsylvania Bleeding Disorders Foundation, I want to extend my heartfelt thanks to every member of our community. Together—our Staff, friends at Western PA Bleeding Disorders Foundation, Board of Directors, dedicated volunteers, Hemophilia Treatment Center partners, families, and friends—we have strengthened the support, education, and advocacy, and financial aid across our 41 counties.

This year, we reached an extraordinary milestone: **over \$50,000 awarded in scholarships to students within our community.** These awards represent more than financial assistance—they symbolize possibility, empowerment, and the bright future of the next generation. We are excited to watch these recipients continue to grow, pursue their dreams, and, as so many past scholars have done, stay connected with and give back to EPBDF in the years ahead.

We are profoundly grateful for the continued support of the annual Matthew Thomas Scholarship Fund. If you or anyone that you know have the means and the heart to contribute to this vital pillar of our Foundation, please reach out—I would be honored to share more about this important initiative.

We are also deeply grateful for our continued partnership with The Foxwynd Foundation, based right here in Chester County. Their generous grant allowed us to directly support our Patient Assistance Fund, providing immediate and meaningful help to families in need. In addition, thanks to an anonymous donor who offered a \$10,000 match, we were able to raise over \$19,000 more to strengthen this vital resource. We look forward to continuing our work with The Foxwynd Foundation in 2026 and beyond.

From community events and family programs to statewide advocacy work and the 2nd Annual Christine M. Carroll Benefit, every effort this year reflects a shared commitment to ensuring that no one living with a bleeding disorder feels alone. Your participation, presence, and partnership make all the difference—and for that, we are truly grateful.

As we look ahead, our **2026 calendar is already taking shape**, filled with meaningful programs, educational opportunities, and cherished gatherings. We look forward to seeing you, reconnecting, and continuing this important work—together.

Thank you for being an essential part of the EPBDF family. Wishing you and your loved ones a joyful holiday season and a healthy, hopeful new year.

With gratitude,

Sarah Pilacik

Executive Director, EPBDF

Letter from Our Board of Directors

As the holiday season approaches, the EPBDF Board of Directors would like to express our heartfelt gratitude to everyone who helps advance our mission to support individuals and families in the bleeding disorders community. Our engaged members, valued partners, and dedicated staff are the foundation of our continued success.

We are especially thankful for our office team—Executive Director Sarah Pilacik, Lisa Lee, and Keyai Lee—whose leadership, innovation, and commitment have guided us through post-pandemic transitions and positioned the Foundation for long-term sustainability and growth. Their efforts to modernize operations, streamline expenses, and pursue new grants and funding opportunities have strengthened EPBDF in meaningful ways.

This past year has been remarkable. From hosting impactful programs like the Women's Retreat and Adventures in Learning to expanding partnerships—most notably with the Western Pennsylvania Bleeding Disorders Foundation—the team's collaboration and initiative have been exceptional. Their hard work culminated in the inaugural Pennsylvania Bleeding Disorders Conference, which brought together more than 400 community members for a weekend of education and connection.

Our community is in excellent hands. Sarah's vision, coupled with Lisa's and Keyai's dedication and professionalism, continues to elevate EPBDF's impact. We are deeply proud of their accomplishments and look forward with excitement and gratitude to our hope-filled future.

As we count our blessings this season, we hope you'll continue supporting our work. Every donation—big or small—helps us provide programs, education, and connection for individuals and families affected by bleeding disorders.

Your generosity truly makes a difference. Thank you for being such an important part of the EPBDF community! With appreciation,

The EPBDF Board of Directors



We are excited to welcome our new Board member,

Patricia (Tricia) Mangino!



Patricia (Tricia) is a Registered Nurse with nearly a decade of clinical experience and holds a master's degree in nursing. She has worked across a range of specialties, including step-down care, cardiology, pediatrics, and currently serves in an intensive care unit. In addition to her clinical

work, Tricia teaches clinical rotations for collegelevel nursing students, supporting the education and development of future nurses.

Diagnosed with hemophilia at the age of seven despite no known family history—Tricia brings a deeply personal perspective to her role on the board

and a strong commitment to advocacy, education, and patient-centered care within the bleeding disorders community.

An avid golfer, Tricia was introduced to the sport through a YWCA Girls Golf program, which provided a safe and empowering athletic outlet. She went on to play competitively for Easton Area High School and Saint Francis University, fostering a lifelong passion for the game.

Tricia lives with her spouse, newborn daughter, and dog. In her free time, she enjoys traveling, golfing, and spending time with her family. Each year, they travel to Hilton Head—her favorite week of the year where she enjoys combining all these passions.

Annual Family Dinner



Adventures in Learning



Unite Walk









Annual Golf Classic













Christine M. Carroll Toast to a legacy



Designer Bag Bingo For Bleeding Disorders
NOVEMBER 22







FAREWELL TO DR. TONYA WRIGHT

We at Eastern Pennsylvania Bleeding Disorders Foundation want to extend our deepest gratitude and heartfelt farewell to Dr. Tonya S. Wright for her years of compassion, dedication, and unwavering support for our community. As Associate Professor and Chief of the Division of Academic Specialists in Obstetrics and Gynecology, she contributed to the collaborative "Women and Girls with Bleeding Disorders" clinic alongside Dr. Peter H. Cygan to provide specialized, sensitive care to women and girls facing bleeding disorders.

Over the years, Dr. Wright also attended many of our women's retreats. After her presentations, attendees would gather around her, drawn by her warmth, openness, and her willingness to listen. You always left conversations with her feeling heard, validated, and supported. Her commitment to providing the very best in patient-centered care made a real difference.

While we are sad to see her go, we celebrate the impact she's had with so many of us. Dr. Wright, your dedication and kindness will be missed, and you will always hold a special impact in our foundation.

ADVOCACY UPDATE

EPBDF OO

MG LEGISLATIVE UPDATE: PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

HARRISBURG UPDATE

2026 is an election year. All 203 members of the House of Representatives and 25 out of 50 Senators are up for re-election (only even-numbered district seats). In addition, Governor Josh Shapiro and Lt. Governor Austin Davis are also up for re-election.

A few members have already announced their plans to resign/retire at the end of session in November 2026 including:

- 1. Rep. Seth Grove (R-York) (State House of Representatives D-196)
- 2. Rep. Mary Jo Daley (D-Montgomery) (State House of Representatives D-148)
- 3. Rep. Anita Kulik (D-Allegheny) (State House of Representatives D-45)

The primary is scheduled for Tuesday, May 19, 2026. Please note that May 12, 2026 is the last day to apply for a mail-in or civilian absentee ballot.

PA GENERAL ASSEMBLY

The legislature continues to operate with slim margins between Democrats and Republicans in both chambers, making strong bipartisan support a necessity for every piece of legislation.

Here is the current breakdown:

House: 102 D - 101 R (2/3 = 136)
Senate: 27 R - 23 D (2/3 = 34)

A handful of representatives will be resigning from the House in January (before the end of the current session):

- 1. State Rep. Torren Ecker (R-193): Elected to Adams County Court of Common Pleas
- 2. State Rep. Dan Miller (D-42): Elected to Allegheny County Court of Common Pleas
- 3. State Rep. Lou Schmitt (R-79): Elected to Blair County Court of Common Pleas
- 4. State Rep. Josh Siegel (D-22): Elected Lehigh County Executive

Special elections will be held in the coming months to fill these four seats. Those elections must be held at least 70 days after each resignation.

REVENUE COLLECTIONS

The Independent Fiscal Office (IFO) recently released their Fiscal Outlook for FY 2025-26 through FY 2030-31. Here's a brief overview:

- General Fund surplus projected to be depleted in FY 26-27;
- Rainy Day Fund (currently \$4.7 B) projected to be depleted by FY 27-28;
- FY 25-26 deficit is currently projected at \$3.7 B and projected to grow to \$7.7 B by FY 30-31; and
- \$1.3 B temporary measures used in FY 25-26 must be back-filled next year.

2025-26 BUDGET

On November 12, 2025, 135 days past the June 30 deadline, the General Assembly passed a budget and the Governor signed it into law.

- The total spend is **\$50.09 Billion**, a 4.6% increase over last year.
- There are no new revenue sources (no new taxes, no increased tax rates, no removal of any tax exemptions) and they didn't utilize the Rainy Day Fund (\$4.7 B).

HEMOPHILIA LINE ITEM

We are pleased to announce that we were able to secure full funding for the hemophilia line item at \$1,017,000 and keep it separated from the other rare disease line items.

In addition, the Fiscal Code clarifies that funding for the hemophilia treatment centers (HTCs) shall be distributed in the same proportion as fiscal year 2019-2020, protecting the HTCs from potentially competing against each other for grant dollars.

2026-27 BUDGET

Given the deficit projections, we expect a more austere budget proposal from Governor Shapiro on February 3rd, and another difficult budget cycle ahead.

After the Governor's Budget Address, the House and Senate Appropriations Committees will hold hearings with each state agency to discuss the details of the proposal. Those hearings are typically scheduled

Advocacy

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throughout February and March. And then the legislature has until June 30 to pass a budget.

In the meantime, our office will continue our engagement and educational outreach with legislators and staff and prepare for upcoming appropriations requests as well as a variety of insurance and healthcare related topics.

2026 SPRING SESSION SCHEDULE

We are halfway through the 2025-26 legislative session. All introduced bills have until November 30, 2026 to pass through the legislative process and get across the Governor's desk. If they don't make it through, they effectively die and must be reintroduced in the following session for future consideration.

The House and Senate released their spring session schedule as follows:

	Senate	House
January	6, 26, 27 & 28	6(NV), 26, 27 & 28
February	2, 3 & 4	2, 3 & 4
March	16, 17, 18, 23, 24 & 25	23, 24 & 25
April	20, 21 & 22	13, 14, 15, 27, 28 & 29
May	4, 5 & 6	4, 5 & 6

2026 ADVOCACY DAY

BDF is planning to host the next advocacy day in Harrisburg on Tuesday, May 5th. Details regarding advocacy training and talking points will be available as we get closer.

Please consider participating and taking the opportunity to meet with your local Representative, Senator and staff. Let your voice be heard!

ADVOCATE (provided by community member)



Being an advocate for your own health or your child's health is an ongoing journey that takes practice and courage. Both my son and I have vonWillebrand's disease, he was diagnosed as an infant. After many years of both being treated in the best hospital systems in the country, I can tell you that you still need to be

advocate for your own care.

When facing a planned procedure you need to be prepared in advance with a hematology treatment plan that is reviewed by you and the treating team at the hospital. In many instances you know more about your disease than the treating speciality outside of hematology.

Teaching your child to be an advocate is something I encourage you to do from the time they are old enough to talk. When my son was about 3, he was going to CHOP for a procedure and he asked me why he had to get his IV in his arm versus his hand like he had seen me get. I explained that I didn't know why, but I encouraged him that he should ask the IV team nurse at the hospital. The day of his procedure, the IV team arrived and started to evaluate where to place the IV, at that time, I said to him, "isn't there something you'd like to ask?" and he replied "yes". He nicely requested if the IV could be placed in his

hand and the nurse said she'd try. She was able to place it in his hand much to his delight and he didn't even flinch! This was his first lesson in being an advocate for your own care.

Recently, he had another surgery at CHOP which is always complicated because he is on two services. We had a hematology plan but not a pain management plan and it became a very difficult situations as patients with hematology needs cannot receive any ibuprofen based drugs. This is outside the normal protocol for post-op pain management as the treating team cannot alternate between ibuprofen based drugs and narcotic drugs. As a parent and as a young man (now 20 years old) it was another lesson learned in needing an advance pain management plan along with a hematology treatment plan.

We are fortunate to live in an area with an incredible array of superior medical facilities and providers for

which we are grateful. However, you still need to be a vocal advocate for your own care.

Allyson McHugh



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.



assistance policy.



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

Advocacy

CANCER ADVISORY (provided by community member)

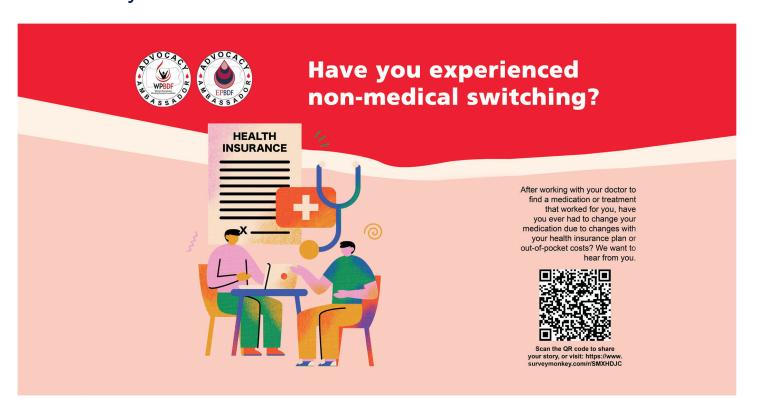
I am 67 years old and I have Factor VIII hemophilia – severe. I received my first dose of Factor VIII concentrates in 1968. At that time the package inserts warned of the risk of "non A non B hepatitis." Given the risks of living with hemophilia at that time and the vast therapeutic improvement that 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

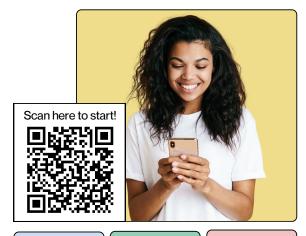




Affordable Online Mental Health Therapy

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

"EYE OF THE MEDIA"

Now Before I get to the crux of my message. Allow me to birdseye my intended scope of a platform that truly holds the power of thought through the masses. I'm talking about the media. And the power of effectiveness it has on mankind. A time ago, I was watching a movie called Armageddon. Now please don't get off track because I'm speaking of a Hollywood motion picture. However, God does work in most mystical ways. Now allow me to caption my point with the landmark notion of, as I quote: "separate church from state". Lo and behold, please let's not make this a political or a religious gender. Because religion is not God HIMSELF, and politics don't truly rule, and almost never lean on the shoulders of the Divine. Because as we see currently in societies of today, neither works out for our current existence of mankind. The world is in total chaos. This is not a local thing, it's a global sorrow. And mankind are the objects of the search. Because both Entities of good and evil use man as the ultimate battling ground for purposes of triumph. That's why each and every individual on earth struggle with the battles of what's good and what's wrong. We just don't actually show it in our everyday of existence each day we live. But Armageddon, the final battle of good versus evil will indeed be the role of existence as we as mankind know it.

And face it. We're in the year, 2025. God just don't do miracles like in Biblical days. But don't be fooled. Miracles do happen today. But in subtle ways that's daily flown over our heads. In the motion picture Armageddon, the plot was a son and his father, in which the son gained pride over in his thoughts, that his outdated father as a figure to rule that day's society. In which the father owned a platform that provided a way of mass communication via mankind to reach the frontier of connection. Yes, through televised, and audio contact throughout the world into the ears of every man.

This was and is an awesome thing for mankind to use as connections to loved ones anywhere on this globe. You see, the father used his invention for good. But the son rebelled, and turned to mutiny against his father, the Godhead figure in order to carry out his diabolical plot to control the masses of mankind in a sense of dictatorship.

This is the very way of the characteristics of the onery that has taken over in the spirit of mankind today, especially through the hallways of our youths. It's not a color thing, it's not an economical thing, it's really not a religious thing. It's the war that's going on in realms we as mankind today truly have no idea of the true battle we face each and every day we awaken on this side of life. And that war is tunneled through the platforms of our current media, and yes, I'll be the one to quote Mr. Trump's favorite quote, "Fake news". Because yes I tell you, it's the fake capitalized stories that these major mediums air on global broadcast to reach the masses to fuel movements like. Woke and their misguided delusions. Because platforms of such, can cause more harm than good. And the whole truth to the matter is, when that old ongoing sideswipe of a slogan, "Separate church from state", is always brought forth and front. It is a relic that mankind has truly lived up to a Divine track to the total truth of a harmonized lifestyle, and truthfully it's not working. No matter the color, race, or creed. Because inside of each living human being, is the anatomy of organs that for the most part was purposed for the existence and longevity of life itself. In a true peaceful state of governing, I for the most part believe that yes, a type of Biblical leadership should govern. Because capitalism wouldn't have a solemn say in ones existence. So yeah, look deep into the eyes of the media. Because really, who wants to be bamboozled???

END

Written and arranged by; Bryant E. Culpepper Sr.

Congratulations 2025-2026 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.



KRISTIAN AZZARANO Senior Rochester Institute of Technology



RIOS Senior Thomas Jefferson University



BRENDA BALVUENA- MEREDITH BROWNHILL Sophmore Elizabethtown College



IORDAN DAVIS Sophmore Weidener University



CALEB DEFRANK Senior Alvernia University



KARISSA DOERR University of Mount Olive



JOCELYN DOERR University of Mount Olive



LOGAN EASTBURN Senior Rider University



NATALIE GARTSIDE Junior Penn State University



COLE HAMSTEAD Sophmore Southern Methodist University



ISAAC HEILMAN Senior Saint Joseph's University



NATALIA HERCHELROATH Freshman Messiah University



STEVEN HUANG Junior Lycoming College



TEIA HUDSON Senior University of Pennsylvania



SAMANTHA KNUDSON Freshman Lancaster Bible College



MARCO MAROZZI Freshman Penn State University



STELLA MCGRAW Freshman University of Vermont



JASPER MCHUGH Junior West Chester University



NICHOLAS MCKEEN Senior Harford County Electrical Contractors Assn



HANNAH MILLER Sophmore Cairn University



CALLIOPE PADILLA Freshman **Duquesne University**



SEBASTIAN PEREZ Junior **Drexel University**



COURTNEY ROWE Junior West Chester University



ELIAS SCHECTMAN Freshman University of Tennessee Knoxville



MATTHEW WINARTO Senior St. Joseph's University



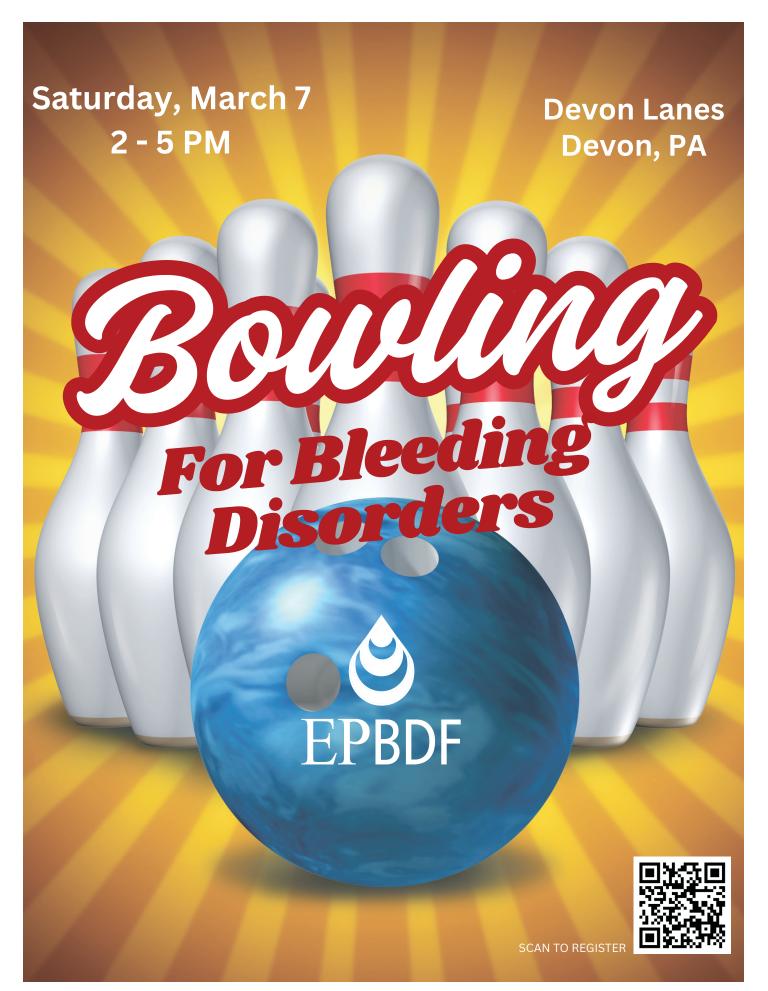
Annual Women's Retreat

Normandy Farm Blue Bell, PA

Feb 6 - 8, 2026



SCAN TO REGISTER





Spring Fling Family Day Is Back!

SAVE THE DATE

April 11, 2026







STAY TUNED FOR MORE DETAILS



Annual Family Dinner

June 24, 2026

Sheraton Valley Forge Hotel King of Prussia, PA.

Scan to register





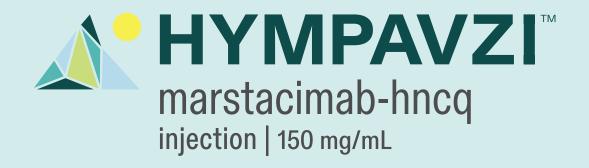
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Michael's
Story here:



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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. PARAGONHEALTHCARE.COM/HEMO





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NEVER MISS AN UPDATE!







