



Blue Marsh Lake

*The  
Winning  
Spirit  
Newsletter*

Fall 2023





# EASTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

41 COUNTIES

1 MISSION

## STAFF



Sarah Ross Pilacik  
Executive Director  
sarah@epbdf.org

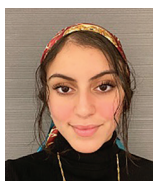


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NATIONAL  
BLEEDING DISORDERS  
FOUNDATION  
Formerly NHF

Proud Member



## UPCOMING EVENTS

30 SEPTEMBER  
SATURDAY  
UNITE WALK

5 OCTOBER  
FRIDAY  
MEN'S/WOMEN'S GROUP EVENT

3-5 NOVEMBER  
FRIDAY-SUNDAY  
WOMEN'S RETREAT

21 NOVEMBER  
TUESDAY  
STAKEHOLDER MEETING

28 NOVEMBER  
TUESDAY  
GIVING TUESDAY

16 DECEMBER  
SATURDAY  
HOLIDAY PARTY

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

## Eastern PA Hemophilia Treatment Centers



## DE Hemophilia Treatment Center



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# Letter from Executive Director

**Sarah Ross Pilacik**

Dear EPBDF Community Members,

I hope this letter finds each of you in good health and high spirits as we approach the 4th quarter of the year. For those of you who do not know me, my name is Sarah Pilacik and I am the Executive Director of the Eastern PA Bleeding Disorders Foundation, a nonprofit organization that is deeply committed to serving the bleeding disorder community in 41 of the 67 counties in Pennsylvania.

Our mission is to bring together those affected by bleeding disorders in our 41-county coverage area so that we can all feel a sense of connection and support through Education, Programming, Advocacy, and Financial Assistance. Community involvement and input are absolutely critical in achieving this goal. It has been my pleasure meeting many of you over the last eighteen months that I have been in this position, and I look forward to meeting more of you as time goes on.

First and foremost, let me provide you with some insight into what a nonprofit organization is and does. Nonprofit organizations, like ours, are driven by a mission to address specific social, environmental, or cultural needs within their communities. Unlike for-profit businesses, nonprofits do not exist to generate profits for their stakeholders but rather to reinvest any surplus revenue into achieving their mission and providing essential services to the community. You may be interested to know that there are over fifty chapters in the United States and Puerto Rico serving those with bleeding disorders. There are two here in Pennsylvania.

Our primary focus is on individuals and families who are grappling with bleeding disorders, such as hemophilia and von Willebrand disease. These conditions are rare but can be life-altering for those affected. Our organization is dedicated to offering support, education, advocacy, and resources to empower those living with bleeding disorders to lead healthier and more fulfilling lives, and to celebrate progress but also remembering the lessons taught from the past.

Community involvement and input are at the heart of what we do. We firmly believe that together, we can make a significant impact. Your input, ideas, and support are invaluable to us. We encourage you to:

- Register and attend our programs and events.
- Share your thoughts, concerns, and suggestions with us. Please visit our website [www.epbdf.org](http://www.epbdf.org) to find our contact information.
- Volunteer your time, skills, or resources to help us further our mission.
- Stay informed about our initiatives and spread awareness in your circles.
- Support our fundraising efforts or consider making a donation to our cause.

The Eastern PA Bleeding Disorders Foundation is deeply committed to serving our community by supporting individuals and families affected by bleeding disorders. We cannot emphasize enough how crucial your involvement and input are in achieving our mission. Together, we can make a difference in the lives of those who need it most.

Thank you for your continued support, and we look forward to working hand in hand with you to continue creating a brighter future for this community.

With Kindness,

Sarah



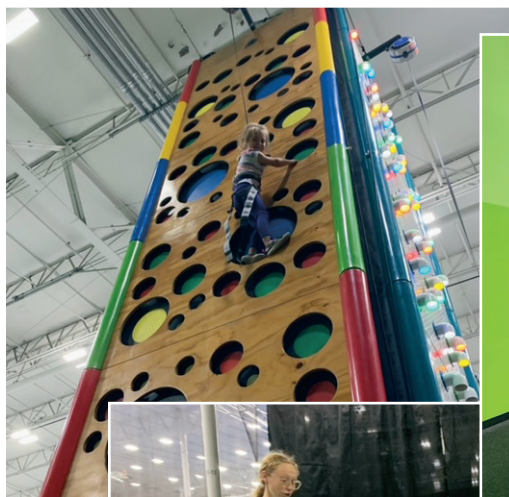
# Adventure Sports

7/22/2023



# Adventures in Learning

9/9/2023





# Annual Golf Classic

9/12/2023





# Maria's letter

## COPAY ACCUMULATORS AND THE HARDSHIPS

Many individuals in the bleeding disorders community rely on copay assistance from drug manufacturers and charities to maintain access to their high-cost treatments. Because blood factor drugs are biological products — in this case, a protein — there are no cheaper copies, called biosimilars, available. The cost of the life saving and life sustaining treatment for a person with a bleeding disorder such as hemophilia, can be several hundred thousand dollars per year and annual treatment costs of \$1 million or more are not unheard of for patients with the most severe forms of the disease.

Copay assistance is often a lifeline to those with bleeding disorders and serious, chronic conditions. However, insurance companies are increasingly utilizing copay accumulator, maximizer, and copay diversion programs, which prevent copay assistance from being counted toward an individual's deductible or out-of-pocket maximum. For example, when an insurer applies a copay accumulator, the insurer collects double (or even more than double) the amount of a patient's required cost-sharing: once from the copay assistance program and then, when the assistance dollars are depleted, the full amount of the cost-sharing (again) from the patient. On the patient's side, all too often, the result is that the patient encounters an unexpected and unaffordable charge for their drug refill. If they are unable to pay, the patient may be forced to abandon their prescription, discontinue therapy, and potentially end up in the emergency room for treatment of an acute (and avoidable) health issue.

It is very important that copay assistance be used to assist patients as was originally intended. Federally, bills have been introduced in the House (H.R. 830) and Senate (S. 1375). If passed, this legislation will 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 and close the essential health benefits loophole. In Pennsylvania, Senator Judy Ward and Senator Maria Collett are the prime sponsors of Senate Bill 372. If passed, this bill will protect Pennsylvanians in state-regulated health plans by ensuring that all payments made by the patient or on behalf of the patient count toward the patient's deductible and out of pocket costs.

Maria Shoemaker, a Pennsylvania resident, and mother of five living with von Willebrand Disease, has written about her own experience with copay accumulators and the hardships she has continually faced as the result of a lack of medication access and affordability.



July 26, 2023

To (the members of Congress),

I overheard my child, on his 16th birthday, tell my husband that he has no hope for a happy life due to his chronic health conditions. He has seen me fight for months just to have the right to pay for his dental work. He has seen me have multiple bleeds that go untreated because of insurance problems. He has seen us struggle to survive financially despite our being above the medium income for the country. He has seen the hours and hours I have spent on emails and phone calls and meetings begging for help. He has seen me come out of my room after those hours with eyes swollen from crying and completely drained. How do I tell my child that he does have a chance at a decent future in a country that is rigged against people with chronic health conditions? I could hear the sadness and pain in his words that night and it broke me.

He is not being judged for his character or his value to the community, as is the same for all Americans with chronic health conditions. He is being judged on a genetic condition, von Willebrand's bleeding disorder, that I had no idea was even present in my family tree before my first child was born. I wish I never had this disease or passed it along to my children. I wish that I did not have to worry about my bleeding or that of my children. I wish I had any other choice but to give myself intravenous medication over and over. I would give almost anything to be fully healthy, and for my children to have that future. That is not our reality.

I have this disease, as do two of my five children. While there are treatments to help us, access is out of reach. The insurance companies are literally middlemen for profit. They make money only when someone is the right kind of sick and wealthy enough to pay for it. So, they create policies to eliminate the high-cost patients that hurt their stockholder's earnings. Most legislators, both federal and in the state of Pennsylvania, are funded by these same insurance companies. Every time we make any progress with laws meant to protect people with chronic health issues, the insurance companies find loopholes to hurt the already disadvantaged even more. Now, when we ask Congress to simply hold the ACA mandates to the intent and stop the insane practices of copay accumulators/maximizers/CAAP policies, the very same protections our federal congressional members already have, we are told the cost to enforce the mandate is too high. How can something be considered too discriminatory for federal employees but not the average American? Why is it that enforcing ACA mandates only impacts the relatively small amount of profit insurance companies would be losing compared to their already record profits? Persons with chronic/serious health conditions in our country no longer carry value of simply being a human life. We are now a cost-benefit analysis. Does the government feel the individual in question, a person with a chronic or serious health condition, is worth the resources spent on them? Individuals like me are simply too expensive to keep alive. My factor replacement therapy is roughly \$14,000 a dose and is very complex to create. I normally use two doses a month but need more for injuries or surgeries. I have more physical limitations due to my disease being undiagnosed for 23 years and the damage done over the years by chronic bleeds. I need to see doctors more frequently. I am currently a college student, so not contributing currently to the GDP. The government does not see the value we add to our community or the work we do. Our lives are now dollar signs and mine is in the red as far as the government is concerned.

Can anyone reading this tell me differently? Can you honestly tell me that my family is not being stripped of the intrinsic value of human life simply because of greed? Can any one of you look my son in the eye and promise him that the reality he is seeing with me is not going to be his life too? That he is not going to spend his life fighting for care and against the stigma that his life means less, or nothing at all, because he carries a genetic defect? These poor children are already facing such an uphill fight in our world. For my son to say he has nothing but fight in his future because he has seen how this country values people with any chronic health condition, it has broken me. I need to focus my efforts on ways to ensure my family's survival and it seems clear our government will not do anything to help us.

Maria Shoemaker  
Vandergrift, Pennsylvania.



# 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



Joey Smiles  
WYOMING,  
LUZERNE COUNTY



Chris Templin  
BIRDSBORO,  
BERKS 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.<sup>1</sup>

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

### 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](mailto:info@hemophiliasupport.org).



# ADVOCACY UPDATE

LEGISLATIVE UPDATE BY MILLIRON & GOODMAN



## HARRISBURG OVERVIEW

With a very divided state government (a one-seat Democratic-Majority in the House, a Republican-controlled Senate, and a Democratic Governor), the 2023 budget season was expected to be less amicable. Below is a brief recap on the most recent developments.

On June 30th, the Constitutional deadline for a balanced budget, the Senate sent the House the general appropriations budget, HB 611. Senate Republicans claimed that they had a deal with Democrat Governor Josh Shapiro. They would support the spending bill, so long as he would support the \$100 million line item for a school voucher program. So, the Senate amended HB 611 to include that voucher program.

Shortly after the Senate passed the bill and sent it over to the House, Governor Shapiro urged House support for the budget and promised that he would line-item veto the voucher program, arguing that there wasn't enough support for it in the House. With 86 Republicans in opposition, the House passed HB 611.

As part of standard operating procedures, each chamber is required to sign the bills that they've passed. Because Governor Shapiro reneged on his agreement with the Senate Republicans, Senate leadership refused to reconvene into session to sign the budget bill and send it to the Governor's desk. However, after mounting pressure from public schools, county human service program providers, and others who depend on state funding, the Senate reconvened on August 3rd, signed the bill and sent it to the Governor's desk.

Although the Governor signed HB 611 into law and many state departments can now start distributing some of the funding and prevent disruptions in schools and human services programs, the budget package is not yet finalized. The general appropriations budget bill is simply the spending portion of the budget package, detailing how much funding shall be allocated to each line item. However, many line items require additional authorization through a supplemental fiscal code bill, detailing *how* the money should be distributed within each line item.

On August 30th, the Senate reconvened to debate two fiscal code bills, HB 1300 and SB 757. HB 1300 directs funding to many non-controversial and bipartisan line items. SB 757 addresses the more controversial priorities, including funding for educational options for students in failing schools. Both bills were passed by the Senate and now await consideration by the House.

We are not anticipating that the House will reconvene before the September 19th special election. The winner of that election will fill former Representative Sara Innamorato's seat in the 21st district. With Representative Innamorato's recent resignation, the House is currently split evenly between 101 Democrats and 101 Republicans.

CONTINUED ON PAGE 10

## 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!



## BUDGET LINE ITEM

We are pleased to report that our advocacy work was successful again this year. We were able to protect the line item in HB 611 PN 1811 (Page 462). The state appropriation for hemophilia services in the 2023-24 state budget is \$1,017,000. As previously noted, HB 611 was signed into law by Governor Shapiro on August 3rd.

7	FOR ADULT CYSTIC FIBROSIS AND	
8	OTHER CHRONIC RESPIRATORY	
9	ILLNESSES.	
10	STATE APPROPRIATION.....	795,000
11	FOR DIAGNOSIS AND TREATMENT	
12	FOR COOLEY'S ANEMIA.	
13	STATE APPROPRIATION.....	106,000
14	FOR HEMOPHILIA SERVICES.	
15	STATE APPROPRIATION.....	1,017,000
16	FOR LUPUS PROGRAMS.	
17	STATE APPROPRIATION.....	106,000
18	FOR SICKLE CELL ANEMIA	
19	SERVICES, INCLUDING CAMPS FOR	
20	CHILDREN WITH SICKLE CELL ANEMIA.	
21	STATE APPROPRIATION.....	1,335,000

While the fiscal code language hasn't been considered by the House yet, the Senate's version, HB 1300, included our requested language, clarifying that there shall be no changes to the hemophilia funding distribution formula. HB 1300 passed the Senate and is waiting for consideration in the House.

12	<u>(7) MONEY APPROPRIATED FOR HEMOPHILIA SERVICES SHALL BE</u>
13	<u>DISTRIBUTED TO GRANTEEES IN THE SAME PROPORTION AS DISTRIBUTED</u>
14	<u>IN FISCAL YEAR 2019-2020.</u>

We'd like to give much deserved credit to all those who were able to come to Harrisburg on June 7th and make a grand finale push for the line item. It was a very productive day where members of the Bleeding Disorders Foundation were able to meet directly with legislators and staff and remind them about the importance of maintaining our line item in the annual budget.

## THANK YOU

On behalf of the Milliron Goodman team, thank you for choosing us to be your advocates in the Capitol. We look forward to continuing to partner with you and will keep you apprised of relevant legislative progress.





**WESTERN AND EASTERN PA BLEEDING  
DISORDERS FOUNDATION**

# **ADVOCACY STAKEHOLDER MEETING**



**TUESDAY, NOVEMBER 21<sup>ST</sup>**



**10:00 AM**



**VIRTUAL ON ZOOM**

We will be discussing national and local issues affecting the bleeding disorders community and planning our advocacy initiatives for the year. We would love your participation at this meeting as we determine actionable steps advocacy ambassadors can take this year.

RSVP by 3pm on Monday, November 20 by emailing [rsvp@wpbdf.org](mailto:rsvp@wpbdf.org). The zoom link to join the meeting will be sent to everyone who registers.

# Editorial: Pa. should ban insurance practice that shifts costs onto vulnerable patients

If there's one constant in the American health care system, it's that the patients never win. And in the case of so-called "copay accumulator" programs, the victims are generally the most vulnerable patients of all: those with rare and chronic diseases who require specialty drugs.

The reason copay accumulators exist, however, is to defend against a drug manufacturer practice that unilaterally, and arguably unfairly, shifts costs onto insurers. It's all part of the shell game that is the American health care system.

A 2020 decision by the Centers for Medicare and Medicaid Services permitted these programs, which moves some of the cost of expensive treatments back onto patients. Since then, 19 states have banned them on state-regulated plans.

Pennsylvania should join them. But copay accumulators didn't arise out of nowhere: They are a response to the complicated and perverse incentives built into American health care. And they shouldn't be understood as an attack by health insurers on their customers, but as those customers getting caught in the crossfire between insurers and drug manufacturers.

Copay accumulators are insurers' response to a drug manufacturer practice called "copay assistance." These assistance programs offer patients, especially those with rare and chronic conditions that require expensive ongoing treatment, discount coupons that defray much of the annual cost of their drugs.

This makes the manufacturers look generous, but those manufacturers then turn around and bill insurers for the full sticker price. A time-consuming negotiation ensues — the kind of tedium that makes American health care so convoluted and expensive —

and insurers often end up on the hook for more than they would have been otherwise, raising their costs and the cost of insurance generally.



Copay accumulators undercut copay assistance by not counting the value of the coupons against a patient's annual deductible or out-of-pocket maximum. Therefore, when the coupons run out for the year, the patient still has, usually, thousands of dollars to pay until coinsurance — the health plan's share of cost-sharing — kicks in. Every organization in the country that advocates for patients with unusual or chronic conditions, from AIDS to cancer to immune deficiency syndromes, strongly opposes copay accumulators, because they shift costs back to those who can least afford them: the patients themselves.

Banning copay accumulators, by requiring that all copay assistance count toward deductibles, essentially rewards drug manufacturers and punishes insurers: It allows the manufacturers the upper hand in the cost-shifting shell game. But it protects vulnerable patients from getting caught in the crossfire, and so is the right thing to do. Of patients in states that have not banned the practice, around 80% are on copay-accumulator plans.


Nearly three years ago, state Sen. Judy Ward, R-Blair, and now-former Sen. John P. Blake, D-Lackawanna, introduced a bill that would bring Pennsylvania in line with the growing number of states banning copay accumulators. We hope Ms. Ward will reintroduce this bipartisan bill this session.

But it's important to remember that arcane practices like copay accumulators are a symptom of a much more extensive condition: a convoluted health care system that lacks all compassion and good sense, and in which patients are always the losers.




# 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

## Summer Fun 2023





# Congratulations

## 2023-2024 Scholarship Recipients

EPBDF is thrilled to award college scholarships to each of the talented students below.



**Kristian Azzarano**  
Junior  
Rochester Institute of  
Technology



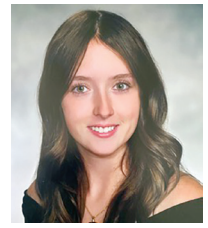
**Nickolas Azzarano**  
Senior  
Rochester Institute of  
Technology



**Matthew Bayer**  
Senior  
Thomas Jefferson  
University



**Caleb DeFrank**  
Sophomore  
Alvernia University



**Jocelyn Doerr**  
Freshman  
Univeristy of Mount Olive



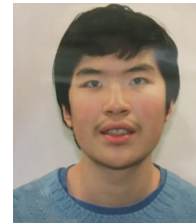
**Karissa Doerr**  
Freshman  
Univeristy of Mount Olive



**Zachary Glavin**  
Freshman  
University of Pittsburgh



**Isaac Heilman**  
Sophomore  
Saint Joseph's University



**Steven Huang**  
Freshman  
Lycoming College



**Teia Hudson**  
Sophomore  
University of Pennsylvania



**Kataryna Iannuzzi**  
Senior  
Rowan College at  
Burlington County



**Michael Iannuzzi**  
Senior  
Rowan College at  
Burlington County



**Rylee Knepper**  
Senior  
Lancaster Bible College



**Justine Lampe**  
Junior  
Indiana University



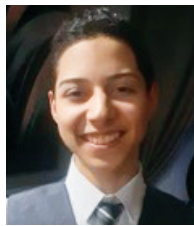
**Jasper McHugh**  
Freshman  
West Chester University



**Nicholas McKeen**  
Sophomore  
Harford County Electrical  
Contractors Assn



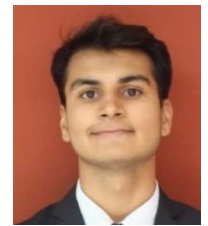
**Noah Penica**  
Sophomore  
Penn State University



**Jose Perez**  
Sophomore  
Community College of  
Philadelphia



**Courtney Rowe**  
Freshman  
Shippensburg University



**Tejas Sharma**  
Senior  
Villanova University





By participating in our various fundraisers, you play a crucial role in supporting our free programs and events that provide education, advocacy, and support to those who depend on our services.

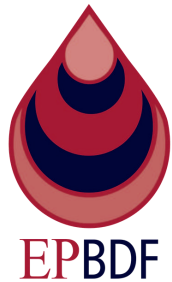
# Thank You

Because of your support, in 2023 we were able to provide \$40,000 in college & trade school scholarships and over \$34,000 in patient aid.



# Unite

for Bleeding Disorders



## Fundraising Walk



## REGISTER TODAY

September 30  
Blue Marsh Lake  
Leesport, PA







***November 3 - 5***



# **WOMEN'S RETREAT**



***Hershey Lodge  
325 University Drive  
Hershey, PA 17033***



***[www.epbdf.org](http://www.epbdf.org)***



**EASTERN PENNSYLVANIA**  
BLEEDING DISORDERS FOUNDATION

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

# Holiday Party

**Saturday, December 16**  
**Starting at 12 PM**

Maggio's The Ballroom at Hampton Square  
400 Second Street Pike, Southampton, PA

Enjoy lunch, crafts,  
prizes, gift cards,  
and a visit from Santa!

Scan to RSVP







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alexis.akins@sanofi.com  
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scanning the QR code

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**sanofi**

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# Lorie Kerstetter

Patient advocate

## About Lorie

Lorie is a Novo Nordisk Hemophilia Community Liaison whose passion for helping people with disorders began years ago when her son was born with severe hemophilia A. She wants to advocate for families in the hemophilia community and is excited to educate them about Novo Nordisk products.

## Connect with Lorie

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

## Hemophilia Community Liaison

NORTHERN APPALACHIA (WV, Western NY, PA)



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

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## OUR VISION: A WORLD WHERE NO LIFE IS LIMITED BY GENETIC DISEASE

At Spark® Therapeutics, we are committed to discovering, developing and delivering gene therapies.

- Learn about gene therapy research for hemophilia.
- Interested in enrolling in a Spark-sponsored hemophilia gene therapy clinical trial?
- Want to know more about gene therapy clinical trials?

Discover more about  
gene therapy research



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## WOMEN'S GROUP



FOR MORE INFO EMAIL THE  
FOLLOWING COMMUNITY MEMBERS:

NORABBULLOCK@GMAIL.COM

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## MEN'S GROUP

## Do you have a great OBGYN?

Please share with us if you have an OBGYN who provides the comprehensive care and understanding which you require for your or your daughters' bleeding disorder! We would like to know the providers in PA who are taking great care of our community.



Scan this QR code

OR

Follow this link to  
complete our form

<https://forms.gle/nhcvrQjrSWzzwdfX8>

## IN SEARCH OF:

PA DENTISTS/ORAL SURGEONS  
WHO KNOW HOW TO TREAT  
PEOPLE WITH BLEEDING  
DISORDERS, AND DO IT WELL.



OR

[bit.ly/padentalsurvey](https://bit.ly/padentalsurvey)

EASTERN AND WESTERN PA BLEEDING  
DISORDERS FOUNDATIONS ARE  
CREATING A LIST OF THESE  
PROVIDERS SO THAT WE CAN HELP  
OTHERS WHO NEED IT.

PLEASE CALL OR EMAIL YOUR  
CHAPTER IF YOU HAVE A REFERRAL,  
CLICK ON THE LINK, OR SCAN THE QR  
CODE. THANK YOU!



**EASTERN PENNSYLVANIA**  
**BLEEDING DISORDERS FOUNDATION**  
Liberty Place at Kennett Square  
148 W. State Street, Suite 305  
Kennett Square, PA 19348

**NEVER MISS AN UPDATE!**



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