

Save the Date!

Patient Education Day

APRIL

29th

*The
Winning
Spirit
Newsletter*



EPBDF

Spring 2023



EASTERN PENNSYLVANIA BLEEDING DISORDERS FOUNDATION

41 COUNTIES

1 MISSION

STAFF



Sarah Ross Pilacik
Executive Director
sarah@epbdf.org



Lisa Lee
Assistant Director
lisa@epbdf.org



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UPCOMING EVENTS

April 29

Patient Education Day

May 6

Spring Fling Family Day

June 21

EPBDF Annual Meeting

July 22

Adventure Sports

September 9

Adventures in Learning

September 12

Annual Golf Classic

September 30

Unite for Bleeding Disorders Walk

November 3-5

Women's Retreat

November 28

Giving Tuesday

December 2023

Holiday Party (TBD)

Hemophilia Treatment Centers



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

MARCH IS BLEEDING DISORDERS AWARENESS MONTH



March is Bleeding Disorders Awareness Month! This is followed by World Hemophilia Day on April 17. The purpose of both these events is to raise awareness for those with bleeding disorders. I would encourage us all to use our platforms - whatever they may be - to tell others about bleeding disorders, about the history, the community, advancements, continued struggles with insurance, resources, Hemophilia Treatment Centers, and the overall word which I would describe this small but mighty community as I enter my second year at EPBDF: RESILIENT. Not sure what to say or how to say it? Please Follow us on Social Media and share what we post!

In this first issue of 2023, please spend some time reading how we are moving our Mission forward and consider how you might support us through participation, volunteering, advocacy efforts, giving, or all!

Advocacy

There is much news to share on the advocacy front!

- February 27th: Western and Eastern PA Bleeding Disorders Foundations participated in a virtual meeting presented by NHF about copay maximizers. Thanks to those who attended!
- March 4th and 5th: in collaboration with Western PA Bleeding Disorders Foundation we held an Advocacy Ambassador Retreat in Bedford, PA. Over fifty community ambassadors attended. Speakers included Kerry Lange, from our lobbyist firm Milliron and Goodman in Harrisburg, who provided an update at the state level and what will be lobbied for on behalf of our community (please see the letter included in this newsletter). Miriam Goldstein from HFA, and Matt Delaney from NHF provided education and training to prepare us for Washington Days, which would be just a few days later. We concluded the retreat on Sunday morning with small groups working on grassroots issues and action items.
- March 8th-10th we traveled to Washington D.C. with several of our community members who have also committed to being our Advocacy Ambassadors. Washington Days is organized by NHF, and I am excited to let you know that this year, there were 52 chapters from 45 states + Puerto Rico, nearly 400 advocates with 250 visits on Capitol Hill. We spoke to aides from Senator Casey's office, Congressman Fitzpatrick's, and U.S. Representative Houlihan's. Our agenda was to ask representatives in the House to co-sponsor HR 830, and to ask the Senate to introduce a companion bill, which would put legislation in place banning copay accumulators and ensuring all copays count. On the western side of PA, Representative DeLuzio agreed to co-sponsor!

Lisa and I had the opportunity to meet and speak in depth with many community members across the state over the course of these two events and we are *thankful* that you have trusted us with your life stories and experiences. We look forward to continuing our mission with you.

“Advocacy is empathy, compassion and community at work.” – Janna Cachola

Warmly,

Sarah

Advocacy Ambassador

MARCH 4-5

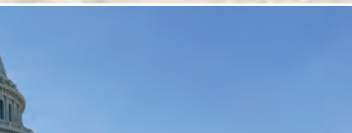
Washington Days

MARCH 8-10



Bowling for Bleeding Disorders

MARCH 11



PA Advocacy Update

LETTER TO APPROPRIATIONS CHAIRS



March 13th, 2023

The Honorable Jordan Harris
Chairman, House Appropriations Committee
428 Main Capitol Building
PO Box 202186
Harrisburg, PA 17120-2094

The Honorable Scott Martin
Chairman, Senate Appropriations Committee
281 Main Capitol
Senate Box 203013
Harrisburg, PA 17120-3016

The Honorable Seth Grove
Chairman, House Appropriations Committee
245 Main Capitol Building
PO Box 202196
Harrisburg, PA 17120-2070

The Honorable Vincent Hughes
Chairman, Senate Appropriations Committee
545 Main Capitol
Senate Box 203007
Harrisburg, PA 17120-3007

RE: PENNSYLVANIA STATE SUPPORT FOR HEMOPHILIA TREATMENT CENTERS

Dear Chairmen:

The Eastern Pennsylvania Bleeding Disorders Foundation supports medical research and provides financial assistance, education, family programming, and advocacy at the state and federal level to benefit patients with hemophilia, von Willebrand disease and other factor deficiencies. We proudly represent 41 counties, which stretch from Philadelphia to Potter, Clinton, Centre, Huntingdon, and Fulton. It is the Foundation's responsibility to serve our community with the highest level of service while always displaying compassion, respect and understanding.

The eastern chapter works closely with six hemophilia treatment centers (HTCs) in Pennsylvania:

1. The Children's Hospital of Philadelphia
2. St. Christopher's Hospital for Children

3. Hospital of the University of Pennsylvania
4. Penn State Hershey Medical Center
5. Thomas Jefferson University Hospital
6. Lehigh Valley Hospital

The seventh HTC, the Hemophilia Center of Western Pennsylvania, services the remainder of the state and partners with our sister chapter, the Western Pennsylvania Bleeding Disorders Foundation.

All seven HTCs provide comprehensive, coordinated care via specially trained multidisciplinary teams that include hematologists, pediatricians, nurses, social workers, physical therapists, orthopedists, and dentists, among others.

We wanted to again express our appreciation for the 6% increase in state support for the HTCs last year. We are greatly appreciative that the General Assembly kept the Hemophilia Program as a separate line item and clarified through the fiscal code that the funding continues to be distributed, as in previous years, to all seven HTCs.

As we begin the FY 2023-24 budget process, we respectfully make the following requests:

- **Increase state support from \$1,017,000 to \$1,250,000;**
- **Maintain the hemophilia line item as a separate line item in the budget bill; and**
- **Include language in the fiscal code to maintain the existing funding distribution to the HTCs.**

It is important to note that 100% of the Hemophilia Program line item goes directly to patient care (i.e., mostly for non-billable nursing and social work services). A portion is also used as an emergency fund to help patients in financial hardship due to their bleeding disorder. This year there has been an unprecedented number of requests and it is anticipated the emergency assistance funds will be depleted by the end of the month.

There are approximately 20,000 patients with hemophilia and thousands more with other inherited bleeding disorders in the U.S. **More than 3,000 patients receive care in Pennsylvania at the HTCs**, all of which have been recognized as centers of excellence by the Commonwealth.

The HTCs are critical to the patients who receive care at these facilities. Without this support, Pennsylvania will incur approximately 5x more costs for these citizens, from emergency and inappropriate care via Medicaid and lost tax revenue from those who become unable to remain gainfully employed. **The Hemophilia Program saves Pennsylvania lives and saves Pennsylvania money.**

Again, on behalf of Pennsylvania's bleeding disorders community, thank you for your continued support and understanding of our issues. If you need any additional information, please feel free to contact me at sarah@epbdf.org.

Very truly yours,



Sarah Ross Pilacik

Executive Director

Eastern Pennsylvania Bleeding Disorders Foundation

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



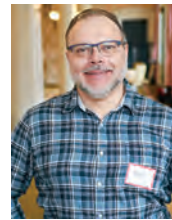
Nora Bullock
ARDMORE,
MONTGOMERY
COUNTY



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

COMMUNITY SPIRIT - New Section!

This section of the newsletter will be reserved each quarter for you - our community! Please send info to info@epbdf.org or to our office address, which can be found on the back of the newsletter. Examples could be accomplishments, brags, births, deaths, upcoming events, memories, history related to Hemophilia/bleeding disorders, "on this date", etc. Please indicate if you would like to remain anonymous. If additional information or clarification would be needed before publication, someone from the Foundation will contact you.

MARCH IS BLEEDING DISORDERS AWARENESS MONTH



www.epbdf.org

Bleeding Disorders: A Primer



A person with a bleeding disorder lacks a clotting protein that stops or prevents excessive bleeding. The most commonly recognized bleeding disorders are hemophilia and von Willebrand Disease.

30,000
people in the
United States
have hemophilia.



400,000 people in the world have
a bleeding disorder. Sadly, **75%** of
those with a bleeding disorder
have no access to treatment.



1-2%

of the population
is thought to have
von Willebrand
Disease and have
not been properly
diagnosed.

Treatment options vary depending
on diagnosis; most patients have to
take intravenous injections to replace
the missing clotting protein their
body lacks. It costs an average of

\$300,000

per year to treat hemophilia.

30%

of Hemophilia A patients
will develop an inhibitor, or
antibodies, to treatment. 1-2%
of Hemophilia B patients will
develop inhibitors. A 2014 CDC
study found that anyone with
hemophilia can form an inhibitor
and that all patients should be
tested yearly.



In 1973, the Hemophilia Act was passed to form a
nationwide network of federally funded Hemophilia Treatment
Centers to provide comprehensive care and medical experts
for bleeding disorders patients.



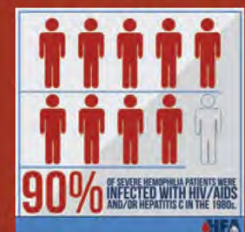
Bleeding disorders are inherited genetic
conditions. However, 30% of new hemophilia
diagnoses happen with no family history.
Women who carry the hemophilia gene have a
50% chance of passing it along to all of their
offspring. Women can and do have bleeding
disorders, including hemophilia.

In 1990, the Patient
Notification System (PNS)
was created to provide a
fast, free, and confidential
program alerting patients
with bleeding disorders of
a withdrawal or recall of
therapy products or
ancillary supplies.

Hemophilia A is the
most common type
of hemophilia.

Hemophilia B (or Christmas
Disease) is another type
of hemophilia.

In the 1980's many members of the
bleeding disorders community contracted
HIV/AIDS and/or Hepatitis C from tainted
blood products. Tragically many of those
infected have since died.



Hemophilia Federation of America (HFA) became an independent entity in 1994 as a place of education and support for hemophilia families. Today, HFA continues to assist, advocate, and serve as the voice of the bleeding disorders community.



Presents:

PATIENT EDUCATION DAY



**SATURDAY
APRIL 29**

9-3 PM

**REGISTER
TODAY!**

Sheraton Valley Forge Hotel
480 North Gulph Road
King of Prussia, PA





A DAY OF FUN
FOR EVERYONE!

SPRING FLING FAMILY DAY

SATURDAY, MAY 6



ELMWOOD PARK ZOO



EPBDF

EASTERN PENNSYLVANIA
BLEEDING DISORDERS FOUNDATION

Annual Meeting

Sheraton Valley Forge
480 N. Gulph Road
King of Prussia, PA 19401

June 21



EASTERN PENNSYLVANIA
BLEEDING DISORDERS FOUNDATION



ANNUAL

GOLF

CLASSIC

SAVE THE DATE!

12 SEPTEMBER
2023

Rivercrest Golf Club
100 Revercrest Drive
Phoenixville, PA 19460

Unite

for Bleeding Disorders



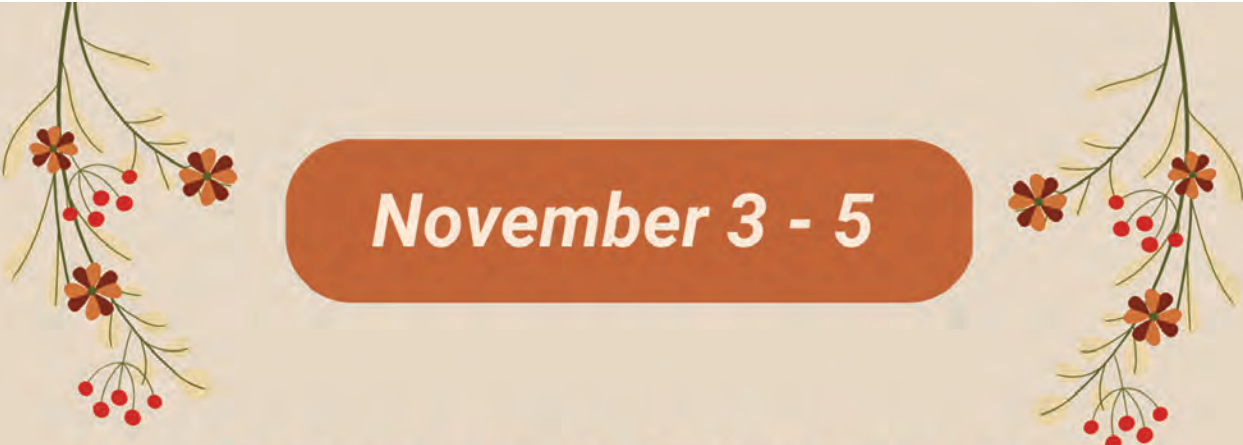
Fundraising Walk



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

Connected to milestones.

Life shouldn't be defined by limits. Through education and resources, we're focused on making more possible for people living with hemophilia.



Let's connect.
rareblooddisorders.com
f @ @HemophiliaCoRes
1-855-SGZHEME

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MAT-US-2019890-v2.0-04/2022

sanofi

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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SEE A DEMO ABOUT THE SCIENCE OF GENE THERAPY.

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HEMOPHILIA
FORWARD.

Spark
THERAPEUTICS



THE WOMEN'S AND MEN'S GROUPS ARE BACK!



EMAIL FOR MORE INFO: FRANK.P.LENTINI@GMAIL.COM

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

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!

New!



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TWITTER

SCAN THE QR CODES TO FOLLOW US