



# Annual Meeting

June 12, 2024

Keynote Speaker: Dr. M. Elaine Eyster, MD, FACP



The  
Winning  
Spirit  
Newsletter

Spring 2024



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## Eastern PA Hemophilia Treatment Centers



## DE Hemophilia Treatment Center



## UPCOMING EVENTS

11-14 APRIL  
THURSDAY - SUNDAY  
HFA ANNUAL SYMPOSIUM

6 MAY  
MONDAY  
ADVOCACY AMBASSADOR  
EDUCATION & TRAINING

7 MAY  
TUESDAY  
HARRISBURG DAY

18 MAY  
SATURDAY  
WOMEN'S WELLNESS DAY

1 JUNE  
SATURDAY  
SPRING FLING FAMILY DAY

12 JUNE  
WEDNESDAY  
EPBDF ANNUAL MEETING

28-30 JUNE  
FRIDAY - SUNDAY  
COUPLES RETREAT (WITH WPBDF)

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

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# Letter from Executive Director

**Sarah Ross Pilacik**

Dear Community Members,

As we race to the end of March, I wish to highlight the significance of Bleeding Disorders Awareness Month and the forthcoming World Hemophilia Day on April 17th. These observances offer us opportunities to amplify our voices, raise awareness, and advocate for those affected by bleeding disorders. It's a time to come together as a community, share our stories, and educate others about these conditions. Throughout the state, several counties have issued Proclamations, and buildings have been lit up red. We thank our Western PA Bleeding Disorders Foundation (WPBDF) partners, led by Kara Dornish, for their leadership and friendship as we work together for the good of this community!

Several community and board members attended The National Bleeding Disorders Foundation Washington Days from March 6-8. One day was spent training for our meetings on Capitol Hill. Our focus was to request support for H.R. 830/S. 1375 bills, the Help Ensure Lower Patient (HELP) Copays, and to ask for support on policies to protect individuals with bleeding disorders from narrow formularies. We met with Senator Fetterman and Senator Casey's offices, among others! Our advocacy day in Harrisburg will be May 7 with training provided the day before. If you are interested in attending, please go to our events page.

Speaking of events, our calendar is brimming with numerous programs and fundraisers aimed at furthering our mission. I encourage you to visit and register on our events page for more details and to stay updated. Your involvement in these initiatives is invaluable and contributes significantly to our collective efforts.

I am also proud to share an update on our collaboration with WPBDF on the Innovation Grant, which was awarded to us in late 2023 by Hemophilia Alliance. The focus on this Women's Bleeding Disorder Initiative is to spread awareness with hopes to increase early diagnosis for girls and women with bleeding disorders. Thank you to our community and board members who have been supporting us with this effort by hitting the pavement and delivering educational material and period packs to schools, colleges, health fairs, etc. In addition, we were able to exhibit and spread awareness at the Pennsylvania Association of School Nurses' and Practitioners conference in Hershey. This was a great opportunity to meet with school district health care workers from all over the state! We will be presenting in Atlanta at The National Bleeding Disorders Foundation Bleeding Disorders Conference (BDC) in September. I hope to see many of you there!

We are honored to announce that Dr. Elaine Eyster has accepted our invitation to be the Keynote Speaker at our Annual Meeting on June 12. **This is a big deal.** We look forward to seeing you there to welcome and honor her.

None of this would be possible without the unwavering support of our Board of Directors, community, national foundations, Hemophilia Treatment Centers (HTCs), and industry partners. Your dedication and partnership fuel our mission and drive our progress forward. Together, we are making a tangible difference in the lives of those affected by bleeding disorders.

As we continue our journey, let us reaffirm our commitment to advocacy, education, and support. Together, we can create a world where individuals with bleeding disorders receive the care, understanding, access and opportunities they deserve.

Thank you for your continued support and dedication.

With Kindness,



Sarah Ross Pilacik | Executive Director  
Eastern Pennsylvania Bleeding Disorders Foundation | EIN 23-1567876

# Washington Days

MARCH 6-8



# Bowling for Bleeding Disorders

MARCH 16



# 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



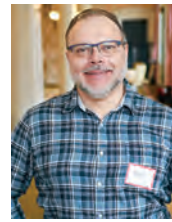
**Nora Bullock**  
ARDMORE,  
MONTGOMERY  
COUNTY



**Joseph Butler**  
RED LION,  
YORK COUNTY



**Marisa Ferger**  
STATE COLLEGE,  
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**Chris Templin**  
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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>

### 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).

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

# ADVOCACY UPDATE

MG LEGISLATIVE UPDATE: PENNSYLVANIA BLEEDING DISORDERS FOUNDATION



## HARRISBURG OVERVIEW

### Budget

While the 2023-24 budget was just recently completed, Governor Josh Shapiro delivered the 2024-25 budget proposal in February. This officially started the next budget season.

The Governor's 2024-25 budget proposal is a \$48.3 billion plan, a 7.5% increase over last year's budget. For some highlights, Governor Shapiro called for:

- \$1.5 billion in new funding for K-12 basic education;
- \$3 million to support a new student meal program for the summer months; and
- An increase of the minimum wage to \$15/hour beginning on July 1, 2024.

To support this plan (in part), Governor Shapiro proposes to utilize \$3 billion from the state's rainy-day fund, legalize and tax recreational marijuana (20%) and tax skill games (42%).

For the past few weeks, the House and Senate Appropriations Committees hosted budget hearings with the state agencies. Budget hearings allow each state agency the public opportunity to promote their successes over the past year, discuss upcoming projects and costs, and pending legislation with legislators. Legislators will incorporate this feedback into the ongoing budget negotiations.

### House of Representatives

The House continues to operate with slim margins between Democrats and Republicans. Without a clear majority, it's difficult for either caucus to successfully pass controversial bills through the chamber. So far this session, whenever a split ratio occurred, voting session was put on hold in the House.

House Democrats recently picked up a vacant seat (Galloway, D-Bucks) and brought their number back up to 102.

Shortly after that special election, Representative Joe Adams (R-Pike) announced his resignation. The election to fill that seat is scheduled for April 23rd (Primary Day). Republicans currently hold 100 seats.

### Senate

Senate Republicans continue to hold the majority with 28 seats. Senate Democrats have 22 seats.

All bills have until November 30th, 2024 to be signed into law, otherwise they are effectively dead and have to restart the legislative process in the next session. So far, less than 3% of introduced bills have made it across the Governor's desk and signed into law.

### BUDGET LINE ITEM

As pictured on page 8, Governor Shapiro is proposing level-funding for the hemophilia line item in the 2024-25 budget.

While a great starting point, BDF is requesting an increase up to \$1,250,000 and has already made this request with the House and Senate Appropriations Committees as well as all legislators representing the seven treatment centers.

The legislature has until June 30th to pass a balanced budget. The Milliron Goodman team will continue to advocate for this increase.

### LEGISLATION

#### Medical Screenings for Women with Suspected BD

The Milliron Goodman team is coordinating a conversation with the PA Chapter of the American College of Obstetricians and Gynecologists (ACOG) and the leaders of BDF. There are concerns that OBGYN patients are underdiagnosed for potential bleeding disorders. There might be an opportunity to address these concerns with some educational components through the Department of Health. Stay tuned.

*Continue on page 8*

# HARRISBURG OVERVIEW

28	For diagnosis and treatment	
29	for Cooley's anemia.	
30	State appropriation.....	106,000
	2024D07682	- 81 -
<hr/>		
1	For hemophilia services.	
2	State appropriation.....	1,017,000
3	For lupus programs.	
4	State appropriation.....	106,000
5	For sickle cell anemia	
6	services, including camps for	
7	children with sickle cell anemia.	

## Prohibiting Health Insurers from Altering Coverage or Premiums

Representative Joe Hogan (R-Bucks) recently circulated a co-sponsorship memo indicating his intent to introduce legislation re: non-medical switching. His legislation would amend the Unfair Insurance Practices Act to prohibit health insurers from altering the coverage or premiums included in an insured person's health insurance policy during the policy term when an insured person has already received a specific treatment, service or prescription drug. We anticipate bill introduction soon.

Please continue to share your experiences with the BDF team so we can help advance this bill.

## Co-Pay Accumulator

Senator Judy Ward's SB 372 amends the Insurance Company Law of 1921 by requiring insurers or pharmacy benefit managers to count any amounts paid, by the enrollee or paid on behalf of the enrollee by another party, towards the deductible or out-of-pocket limit. SB 372 is waiting for consideration by the Senate Banking and Insurance Committee.

Representative Bridget Kosierowski (D-Lackawanna) is planning to introduce a companion bill in the House.

The Milliron Goodman team is continuing to stay engaged on this issue. Please continue to share your

personal experiences with co-pay accumulators with the BDF team.

## ADVOCACY DAY

We are excited to announce that the 2024 BDF Advocacy Day is scheduled for Tuesday, May 7th in the Pennsylvania State Capitol.

This is another great and timely opportunity for the hemophilia community to meet directly with their legislators/staff and share their personal experience with hemophilia as well as the benefits of the treatment centers. We want to continue to educate legislators about this disease and request their support of our budget line-item requests.

Milliron Goodman is currently scheduling meetings with local legislators/staff. Please sign-up ASAP so we can add you to the calendar!

## WORLD HEMOPHILIA DAY

In recognition of World Hemophilia Day, Milliron Goodman was able to secure the Pennsylvania State Capitol lights from April 16th-17th. The Capitol lights will be red on those days.

## THANK YOU

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



# CARBON DECLARES BLEEDING DISORDERS MONTH

By Amy Miller [amiller@tnonline.com](mailto:amiller@tnonline.com)

Published by Times News tnonline.com March 01, 2024 01:45PM

Joey Smiles has lived his whole life with the realization that if he gets a cut, the bleeding may not stop. The Pittston man was born with severe hemophilia, a blood clotting disorder, and takes an injectable medicine weekly in order for normal clotting to occur.

The problem, he said, is the expense of these medications, which for those facing bleeding disorders, is a lifeline that comes with a very steep price tag.

On Thursday, the Carbon County Commissioners recognized this disorder that affects approximately 3,500 in Pennsylvania, naming March as Bleeding Disorders Awareness Month in Carbon County. The awareness month coincides with the federal awareness month that was designated in 2016.

The proclamation that was adopted stated that “bleeding disorders, which share the inability to form proper blood clot, are characterized by extended bleeding after injury, surgery, trauma or menstruation and can lead to significant morbidity and can be fatal if not treated effectively.”

There is no cure for the disorder, however therapies, such as the injectable medication Smiles is on, helps replace the missing proteins and help clotting to occur if an injury happens.

In Pennsylvania, there are seven hemophilia treatment centers, including Lehigh Valley Hospital.



Joey Smiles, second from left, accepts the proclamation naming March as Bleeding Disorders Awareness Month from Carbon County Commissioners Rocky Ahner, left; Chairman Michael Sofranko, second from right; and Wayne Nothstein. AMY MILLER/TIMES NEWS

Smiles, representing the Eastern Pennsylvania Bleeding Disorders Foundation, thanked the board for recognizing this very significant issue for some residents. He spoke about his own experiences, traveling to Penn State Hershey Medical Center every three months for medical care.

He also pointed out that most doctors won't treat patients with this disorder unless they are in one of these treatment centers.

“Just getting a skin tag removed, which is a minor dermatological procedures. Most doctors don't want to touch you and you have to go to an affiliate treatment center where they have comprehensive care,” Smiles said.

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## “THE LAW”

J.Palumbo, 12 12 23

It has been fifty years since the Pennsylvania Hemophilia Comprehensive Care Centers opened their doors. Most of the patients who utilize those same centers today were born decades after-the-fact. The story of the hard effort that built the network is lost to many. As we come to the end of this anniversary year, we must bear in mind that the work never ends. If a law is to remain a law, its beneficiaries must continue to voice their support for its maintenance. We put ourselves at risk by simply taking the gifts of the past for granted.

What follows is the foundational legislation that started it all.

*\*Authors Note: There have been multiple publications listing what appears to be erroneous dates for both the state and federal support for hemophilia treatment. When researching legislation, it is important to verify its full history and beyond being introduced if it was actually signed into law.*

Continued on page 10

THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE BILL

No. 1789 Session of 1971

INTRODUCED BY MR. McCLATCHY, MRS. ANDERSON, MESSRS. M. P. MULLEN, MEBUS, SELTZER, BERKES, MRS. CRAWFORD, MESSRS. BERSON, WOJDAK, KATZ, SPENCER, R. K. HAMILTON, J. H. HAMILTON, MRS. KELLY, MESSRS. BARBER, KAUFMAN, BITTLE, SMITH, GELFAND, MRS. TOLL, MESSRS. SEMANOFF, HILL, MRS. FAWCETT, MESSRS. SCIRICA, MASTRANGELO, COPPOLINO, O'CONNELL, WELLS, CESSAR, KNEPPER, RUSH AND RIEGER, DECEMBER 8, 1971

REFERRED TO COMMITTEE ON APPROPRIATIONS, DECEMBER 8, 1971

AN ACT

1 Making appropriations to the Department of Health for the
2 establishment in of a pilot comprehensive program relating to
3 and the treatment of persons with hemophilia.
4 The General Assembly of the Commonwealth of Pennsylvania
5 hereby enacts as follows:
6 Section 1. The sum of eighty-six thousand dollars (\$86,000)
7 is hereby appropriated to the Department of Health for the
8 fiscal year July 1, 1972 to June 30, 1973, for the establishment
9 of a pilot comprehensive program relating to persons with
10 hemophilia and for the expansion of the program of treatment of
11 persons with hemophilia at hospitals having a program of
12 treatment of persons with hemophilia, and which the Secretary of
13 Health shall designate. The pilot program shall include the
14 detection of hemophilia in the community, counseling of
15 individuals and families, education of the public, and

1 institution and coordination of research into the treatment and

2 control for hemophilia.
3 Section 2. The Department of Health shall ascertain that the
4 funds appropriated by this act are used by the hospitals
5 designated to receive the funds for the purpose set forth in
6 this act.
7 Section 3. This act shall take effect immediately.

L3L3RLC/19710H1789B2241

- 2 -

HB 1789 By Representatives McCLATCHY, S. A. ANDERSON, M. P. MULLEN, MEBUS, SELTZER, BERKES, CRAWFORD, BERSON, WOJDAK, KATZ, SPENCER, R. K. HAMILTON, A. P. KELLY, BARBER, KAUFMAN, BITTLE, SMITH, GELFAND, TOLL, SEMANOFF, HILL, FAWCETT, SCIRICA, MASTRANGELO, COPPOLINO, O'CONNELL, WELLS, CESSAR, KNEPPER, RUSH, RIEGER and J. H. HAMILTON.

Printer's No. 2241.

An Act making appropriations to the Department of Health for the establishment of a pilot comprehensive program relating to and the treatment of persons with hemophilia.

Referred to APPROPRIATIONS, Dec. 8, 1971
Reported as committed, May 9, 1972
First consideration, May 9, 1972
Second consideration, May 15, 1972
Third consideration and final passage, May 30, 1972 (172-2)
In the Senate
Referred to APPROPRIATIONS, May 31, 1972
Reported as committed, Sept. 13, 1972
First consideration, Sept. 13, 1972
Second consideration, Sept. 19, 1972
Third consideration and final passage, Sept. 20, 1972 (47-0)
Signed in House, Sept. 25, 1972
Signed in Senate, Sept. 26, 1972
In hands of the Governor, Oct. 19, 1972
Last day for action, Oct. 30, 1972
Approved by the Governor, Oct. 26, 1972
Act No. 50A

THE GENERAL ASSEMBLY OF PENNSYLVANIA

SENATE BILL

No. 1708 Session of 1972

INTRODUCED BY MCCREESH, MURRAY, R. D. FLEMING, DONOLOW, CIANFRANI, MELLOW, STAUFFER, SMITH AND HILL, NOVEMBER 13, 1972

REFERRED TO APPROPRIATIONS, NOVEMBER 13, 1972

AN ACT

1 Making appropriations to the Department of Health for the
2 treatment of persons with Hemophilia.
3 The General Assembly of the Commonwealth of Pennsylvania
4 hereby enacts as follows:
5 Section 1. The sum of two hundred fifty thousand dollars
6 (\$250,000), or as much thereof as may be necessary is hereby
7 specifically appropriated to the Department of Health for the
8 fiscal period ending June 30, 1973 for the purposes of
9 establishing a State-wide comprehensive program for the medical
10 care of persons with Hemophilia, which shall include but not be
11 limited to the development of centers for the comprehensive care
12 of Hemophilia patients, provision of blood products for patients
13 enrolled in such centers and establishment of blood donor
14 recruitment programs.
15 Section 2. The funds herein provided shall not be used to
16 supplement or replace funds being made available by the
17 Department of Public Welfare to persons who qualify under the

1 public assistance program.
2 Section 3. This act shall take effect immediately.

# MARCH IS BLEEDING DISORDERS AWARENESS MONTH AND AMERICAN RED CROSS MONTH IN CENTRE COUNTY

By Danielle Blake - March 15, 2024

Centre County Gazette | Community | Local News

BELLEFONTE — The Centre County Board of Commissioners approved two proclamations at the Tuesday, March 12, meeting, declaring March as both Bleeding Disorders Awareness Month and American Red Cross Month in Centre County.

Marisa Ferger spoke on behalf of both the Eastern and Western Pennsylvania chapters of the Bleeding Disorders Foundation to shed light on issues surrounding bleeding disorders.

“Bleeding disorders are inheritable; they don’t discriminate. It affects both men and women, all races and all religions; they’re expensive diseases to deal with and it’s traumatic for families,” Ferger explained.

Ferger is a board member for the Eastern Pennsylvania Chapter of the Bleeding Disorders Foundation, and both she and her 19-year-old son live with hemophilia A, which, according to the Centers for Disease Control and Prevention, is a bleeding disorder where the blood does not clot properly, often manifesting in spontaneous bleeding and in bleeding following injuries or surgeries.

During the meeting, Ferger emphasized the importance of community support and legislative policy in addressing challenges people with bleeding disorders regularly face.

“The big thing is paying attention to legislation. There are obstacles in place for people who have to pay for medications that are non-generic and that cost a lot of money,” Ferger said.

She noted that policies such as the Affordable Care Act benefited people with bleeding disorders in many ways.

Ferger’s remarks also underscored the need for increased awareness and early diagnosis of bleeding disorders, dispelling misconceptions and promoting timely medical intervention. While disorders such as hemophilia A are considered rare, Ferger explained that only in the last 20 years have experts begun to understand how prevalent the disorders are and how they appear in women.

“For years I was dismissed and I was just told, ‘Your bleeding is normal,’ even when I was hospitalized



From left, Commissioner Vice Chair Amber Concepcion, Commissioner Chair Mark Higgins, Marisa Ferger of the Eastern and Western chapters of the Blood Disorders Foundation and Commissioner Steve Dershem with the proclamation declaring March 2024 as Bleeding Disorders Awareness Month in Centre County. Courtesy of the Centre County Board of Commissioners office

after having a child,” Ferger said. “Both chapters of the Bleeding Disorder Foundation are currently going out to universities and schools to try and find more women to get diagnosed because there are so many women going undiagnosed since many medical professionals were trained that only men could have these diseases.”

The second proclamation the commissioners approved was to declare March 2024 as American Red Cross Month.

During the meeting, Megan Switzer and Gary Langsdale, community members and board members of the Central Pennsylvania Chapter of the American Red Cross, spoke about the organization and its impact on the community. Switzer explained that since July 2023, the Red Cross has responded to 11 disaster events that impacted 38 individuals in Centre County.

“We have about 134 volunteers that are part of our mission here in the county. We also responded or provided services to 14 disaster, health and mental health events,” Switzer explained. “We’ve collected over 4,000 units of blood across 133 blood drives, we have served 98 people through our home fire campaign and we provide services for 40 different cases of the Armed Forces branch of Red Cross.”

*Continued on page 12*

SENATE BILL 1708 P.N. 2166 10/25/06 1:14 PM

K9L3JW/19720S1708B2166 - 2 -

<http://www.legis.state.pa.us/WU01/LI/DB/DT/1971/0/5B/1708P2166.HTM>

Page 2 of 2

Senate Bill 1708 History 10/25/06 1:12 PM

SB 1708 By Senators MCCREESH, MURRAY, R. D. FLEMING, DONOLOW, CIANFRANI, MELLOW, STAUFFER, SMITH and HILL.

Printer's No. 2166.

An Act amending the act of July 7, 1972 (Act No. 17-A), entitled "An act to provide for the expenses of the Executive, Legislative and Judicial Departments of the Commonwealth, the public debt and for the public schools for the fiscal year July 1, 1972 to June 30, 1973, and for the payment of bills incurred and remaining unpaid at the close of the fiscal period ending June 30, 1972," increasing and clarifying certain appropriations to the Department of Property and Supplies and the Department of State.

Referred to APPROPRIATIONS, Nov. 13, 1972  
 Reported as committed, Nov. 13, 1972  
 First consideration, Nov. 13, 1972  
 Second consideration, Nov. 14, 1972  
 Third consideration and final passage, Nov. 15, 1972 (49-0)  
 In the House  
 Referred to HEALTH AND WELFARE, Nov. 15, 1972  
 Reported as committed, Nov. 20, 1972  
 First consideration, Nov. 20, 1972  
 Second consideration, Nov. 21, 1972  
 Third consideration and final passage, Nov. 22, 1972 (144-0)  
 Signed in Senate, Nov. 29, 1972  
 Signed in House, Nov. 30, 1972  
 In hands of the Governor, Dec. 4, 1972  
 Last day for action, Dec. 30, 1972  
 Approved by the Governor, Dec. 4, 1972  
 Act No. 59A

(\$250,000)

<http://www.legis.state.pa.us/WU01/LI/DB/DT/1971/0/5B/1708.HTM>

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# MARCH IS BLEEDING DISORDERS AWARENESS MONTH AND AMERICAN RED CROSS MONTH IN CENTRE COUNTY

Switzer noted numerous projects conducted by the Red Cross, all of which aim to impact individuals and communities experiencing unfortunate events and disasters.

Langsdale highlighted the Red Cross's role in supporting families during times of crisis, including providing essential resources and assistance with recovery efforts. He also emphasized the importance of community engagement and preparedness.

"Many of the people and families that we serve are renters who don't have insurance or homeowners who don't have enough money to have insurance, and they find themselves without clothes and food and that sort of thing. Everything from their eyeglasses to their car keys may be lost in a fire, and we help them to get replacements," Langsdale said.

StateCollege.com March 18, 2024

**ADVOCACY AMBASSADOR**

**WPIED**

**Have you experienced non-medical switching?**

**HEALTH INSURANCE**

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>

**ADVOCACY AMBASSADOR**

**WPIED**

**URGE SENATOR FETTERMAN TO ENSURE ALL CO-PAYS COUNT!**

**We need YOUR help!**

Senators Kane and Marshall have introduced a Senate companion bill, S 1376, with the goal of having it included in the upcoming HCUA Committee mark-up on PRBA. 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 1376, 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/BBMIZUF](https://p2a.co/bbmizuf)  
 Scan me to email Senator Fetterman's office

Support SB 1376!

ALL CO-PAYS COUNT!

# Counties with Proclamations

BERKS BRADFORD CARBON CHESTER CUMBERLAND DAUPHIN LACKAWANNA  
LANCASTER MONTGOMERY NORTHAMPTON NORTHUMBERLAND

## County Of Chester



## Proclamation

**WHEREAS:** We, the Chester County Commissioners, commemorate March 2024 as *Bleeding Disorders Awareness Month* in Chester County, a recognition that formalizes and expands upon *Hemophilia Awareness Month*, which was federally designated in March 1986 and expanded in 2016 to include the entirety of all bleeding disorders; and

**WHEREAS:** Bleeding disorders share the inability to form proper blood clots and are characterized by extended bleeding after injury, surgery, trauma, or menstruation that can lead to significant morbidity and death if not treated effectively; and

**WHEREAS:** *Bleeding Disorders Awareness Month* is an opportunity to generate greater awareness and understanding of not only hemophilia but all inheritable bleeding disorders, and to shine a light on scientific achievements in treating bleeding disorders – for which there is no cure – and encourage the pursuit of advanced therapies and cures; and

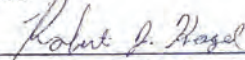
**WHEREAS:** *Bleeding Disorders Awareness Month* fosters a sense of community among individuals with inheritable bleeding disorders and elevates engagement with the public, preventing illness, unnecessary procedures, and disability.

**NOW, THEREFORE,** be it resolved that the Board of Commissioners, County of Chester, Commonwealth of Pennsylvania, hereby proclaims March 2024 as

## Bleeding Disorders Awareness Month

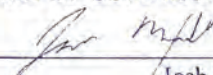
in Chester County and encourages the citizens of Chester County to become aware of the disease's impact on others.

Attest:

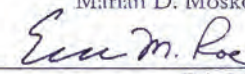
  
Robert J. Kagel, Chief Clerk



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March 6, 2024

# LAWMAKERS SHOULD PROTECT PEOPLE BEING HURT BY THE PRACTICES OF HEALTH INSURANCE COMPANIES

Chris Templin



As someone who has had hemophilia B since I was born, and who has a daughter who has it, too, I'm pretty savvy at navigating the healthcare system. And, from my experience it's clear that health insurers and their pharmacy benefit managers (PBMs) have figured out various ways to discriminate against those who cost them a lot.

Hemophilia B is a rare genetic blood clotting disease that only 6000 other people in the country have. It can be fatal without immediate treatment of replacement factor 9 therapy. A simple bleed can cause permanent injuries or death. Because of that I have to do infusions three times a week on a prophylactic basis.

## **While expensive, there are no alternatives for orphan drugs, like those used to treat our condition.**

The tactics the insurance industry and their PBMs have taken to keep folks like me from following the doctor's orders to treat one's bleeding disorders, span claims denials to an exorbitant amount of paperwork to prove you still have a rare genetic orphan condition that you were born with and will still have until you take your dying breath. Insurance representatives even came into my house to inspect the premises for ostensibly huge stockpiles of clotting factor. They didn't find any.

Every month when I go to the pharmacy it requires a multi-step process to pick up my medicine. The pharmacist ends up having to give it to me "on loan" because the insurance approval takes a long time. That means I have to take the medicine on good faith because if the insurer says no, it's too late for me. I've already had to take it and have run the risk of

having to pay for it out of pocket. I feel like a puppet sometimes with people who aren't even qualified, yanking me this way and that, making life and death decisions for me. They are bean counters who don't know the various medical conditions and who follow formularies established by insurers and PBMs that don't always act in the patient's favor.

I live in constant fear because I know my health insurer would do anything to get me off their books. I think about it every day. At night I have nightmares. It's mentally and emotionally exhausting. Instead of this disease killing me, I'll more likely die due an overdose of pain medication and/or suicide from the stress my insurer puts me through.

As the governor said in his State of the State address, PBMs have made record profits on the backs of Pennsylvanians like me. And I'm hardly alone. The way PBMs operate needs to be reformed. There's a bill pending at the capitol that would do just that. SB1000 seeks to shine a light on PBMs, hold them accountable and make their practices more transparent.

Among other things, the bill would also prohibit something called "patient steering" where a PBM directs the patient to use a preferred pharmacy, over which the PBM has financial controls.

The nefarious practices don't end there. I know patients who have been victimized by something called a co-pay accumulator program. This is when the insurer and PBM take financial assistance, given to the patient, for themselves.

## **What do I mean?**

Patients are often given copay assistance from drug manufacturers, patient groups or other third parties. That copay assistance is meant to offset the high out-of-pocket cost burden that insurers place on patients. This financial assistance used to count towards a patient's deductible or maximum out-of-pocket costs. But now insurers and PBMs aren't doing that. They're taking the assistance and still forcing the patient to meet their deductibles and maximum costs. If that sounds like the insurers and their PBMs are getting paid twice, you're right. They are. And that's immoral.

*Continued on page 15*

## LAWMAKERS SHOULD PROTECT PEOPLE BEING HURT BY THE PRACTICES OF HEALTH INSURANCE COMPANIES

Luckily, here too, there's a bill at the capitol that will come to the rescue. SB 372 would ban insurers from using copay accumulator programs, something that 19 other states, Washington D.C., and Puerto Rico have already done.

The Constitution and Bill of Rights of the United States of America grant the citizens of the United States certain rights. Every citizen has the right to pursue life, liberty, and happiness. Unfortunately for me, and the many folks living with bleeding disorders, our rights are being stolen by the health insurance companies, and our state and federal elected lawmakers need to work together to end it once and for all.

These two bills are pro-patient and have the potential to help thousands of people across the state. It's my hope that legislators do the right thing and pass them.

My medicine is the be alive and smell the coffee drug, be a husband to my wife drug, be a father to my son drug, a protector of my daughter drug.

It's time to stop insurers and PBMs from playing games with people's lives.

*Chris Templin is a patient living with Hemophilia B and a caregiver in Birdsboro, Pa. Printed in the PennLive Patriot-News*

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# Community Spirit

## "GOOD MORNING"

Written and arranged by Bryant E. Culpepper Sr.

Good morning to this day, as I opened up my eyes.  
I peeped through my blinds, and what a wonderful surprise.  
It's the beginning of January, but the sun is standing up.  
I stretched and I yawn, thinking coffee in my cup.  
I slid my feet into my slippers, as I proceeded to stand myself.  
I turned and I looked, upon the elf that was on my shelf.  
I headed for the washroom, to wash the face of last night's sleep.  
Thinking more and more of the coffee, along with something to eat.  
Then I headed to the kitchen, as I peered at last night's dishes.  
Thinking all up in my head, of a Jeanie with three awesome wishes.  
But coming back to reality, I cleaned those dishes in my sink.  
And now a breakfast and some coffee, my mind is clear to think.  
As I finished eating I took a shower, cleaned up oh so fine.  
Got dressed and sprayed the smell good, and sipped just a little wine.  
Got my keys and I headed, straight to the front door.  
Another day at the grinding mills, another day to explore.  
The sky is clear the sun is shining, a slight breeze that I'm adorning.  
I'm on my way to a beautiful day, and to all I bid you good morning.

END



EPBDF

## *Period Product Support for Women with Bleeding Disorders*

Feminine hygiene products, sanitary products, menstrual products, period products, whatever you call them, they're all the same--expensive! These products are a necessity, not a luxury, and they can put a strain on personal finances, causing many people to have to choose between purchasing products for their periods and purchasing food or other necessities. Having heavy or prolonged periods increases the need for these products, creating an even greater impact on personal and family budgets. This fund will provide gift cards for period products.



### *Eligibility:*

1. The applicant is a member of the Eastern Pennsylvania Bleeding Disorders Foundation with a diagnosed bleeding disorder.
2. The cost of period products is making it difficult to afford essential household bills.

To apply, please fill out the application by scanning the QR code above or visiting: <https://forms.gle/qwVuyLxCpiJhvWpd8>

Questions? Contact Sarah Pilacik (sarah@epbdf.org/ 610-770-5215) or Lisa Lee (lisa@epbdf.org/ 610-883-3266)

### **How to Help**

If you are in a position to help and would like to contribute, we welcome you to bring new, unopened packages of tampons, pads, period underwear, menstrual cups, etc., to EPBDF events, to donate. These items will be available for others to take home with them at no cost.



# WOMEN'S WELLNESS DAY

**Saturday, May 18, 2024**

**11 AM - 3:00 PM**

*Women With Hemophilia, Now Is Your Time*

Lunch, henna tattoos, chair massages and more!

**Crossing Vineyards & Winery**

**1853 Wrightstown Road,**

**Newtown, PA 18940**



**scan code  
to register**





# SPRING FLING FAMILY DAY

A DAY OF  
FUN FOR  
EVERYONE!



SATURDAY  
JUNE 1

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ELMWOOD  
PARK ZOO

---

10 AM - 1:00 PM

LUNCH WILL BE  
PROVIDED





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# Annual Meeting

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**June 12, 2024**  
**5:00 PM**

Sheraton Valley Forge Hotel  
480 North Gulph Road,  
King of Prussia, PA 19406



SCAN CODE  
TO REGISTER

We are honored that Dr. M. Elaine Eyster, MD, FACP has accepted our invitation to serve as the Keynote Speaker at our 2024 Annual Meeting.



Dr. Eyster received her medical degree from Duke University, School of Medicine in 1960 and completed a residency in Internal Medicine at New York Hospital-Cornell Medical Center (currently known as New York-Presbyterian/Weill Cornell Medical Center) in 1963. She remained at New York Hospital-Cornell Medical Center, where she completed a fellowship in hematology in 1966.

Dr. Eyster joined the medical staff at Penn State Hershey Medical Center in 1970. She served as Chief of the Division of Hematology from 1973-1995, and has been the Director of the Hemophilia Program and Medical Director of the Special Hematology/Coagulation laboratory since 1973. In 2022, she was appointed interim chief of the newly established Division of Blood and Vascular Disorders. Her clinical and laboratory interests are disorders of bleeding and clotting, and the anemias.



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## Supporting our community is the foundation of what we do



That's why Novo Nordisk goes beyond offering a broad range of treatments and is dedicated to providing educational resources and one-on-one support!

We have **resources** for people living with:

- Hemophilia A
- Hemophilia B
- Hemophilia A with inhibitors
- Hemophilia B with inhibitors
- Glanzmann's thrombasthenia when platelets don't work
- Factor VII deficiency
- Factor XIII A-subunit deficiency

Get connected locally with one of our Hemophilia Community Liaisons (HCL) to see how they can help you!



Scan to connect



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antihemophilic factor (recombinant),  
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Denville, NJ 07834  
973-513-9031 t 973-513-9032 f  
Mon-Fri: 9am to 5pm Toll Free: 888-692-3761



By working together with consumers, treatment professionals, and insurers we can help give you peace of mind and better control over your bleeding disorder.



- Pharmacy Services
- Insurance & Reimbursement Services
- Customized Hands On Approach
- Patient Services

### HIV Update Recap

BDRN, LLC hosted a virtual "HIV Update" on Saturday, 1/20/24 for individuals living with HIV in the bleeding disorders community. HIV/HCV specialist, Dr. Diana Finkel, DO of Rutgers Health Medical School, presented on several topics that included long acting injectables, benefits of taking a statin medication and ongoing "functional cure" clinical trials. Her talk was followed by a Q & A session with the group. BDRN, LLC is a specialty pharmacy that supports patient education and advocacy for better healthcare in the bleeding disorders community.

## 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!

## 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>

## 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!





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



# Save the Date

## **Pennsylvania Bleeding Disorders Conference**

May 16 - 18, 2025

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

More information coming soon!  
To stay up-to-date on all upcoming  
EPBDF events, visit [epbdf.org](http://epbdf.org).

**NEVER MISS  
AN UPDATE!**

