



*The
Winning
Spirit
Newsletter*

Winter 2023



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Proud Member



UPCOMING EVENTS

TBD FEBRUARY
MEN'S GROUP EVENT

6-8 MARCH
WEDNESDAY - FRIDAY
WASHINGTON DAYS

16 MARCH
SATURDAY
BOWLING FOR BLEEDING DISORDERS

11-14 APRIL
THURSDAY - SUNDAY
HFA ANNUAL SYMPOSIUM

27 APRIL
SATURDAY
BINGO FOR BLEEDING DISORDERS

6 MAY
MONDAY
ADVOCACY AMBASSADOR
EDUCATION & TRAINING

7 MAY
TUESDAY
HARRISBURG DAY

1 JUNE
SATURDAY
SPRING FLING FAMILY DAY

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

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Manager
GlazoSmithKline



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Eastern PA Hemophilia Treatment Centers



DE Hemophilia Treatment Center



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Letter from Executive Director

Sarah Ross Pilacik

Dear EPBDF Community/Stakeholders,

As we approach the end of another impactful year, we are excited to reach out to you, our valued members, with a special message about the 2023 Eastern Pennsylvania Bleeding Disorders Foundation (EPBDF) Annual Campaign.

Our mission at EPBDF is to unite those affected by bleeding disorders in our 41-county coverage area, fostering a sense of connection and support through Education, Programming, Advocacy, and Financial Assistance. This year, our goal is to raise \$30,000 to further empower our community and enhance the resources and services we provide.

Education & Programming:

Knowledge is power, and at EPBDF, we are committed to providing informative resources and educational opportunities. From workshops and seminars to online resources, we strive to empower our community with the knowledge needed to confidently navigate the challenges of bleeding disorders. Building a strong sense of community is at the heart of what we do. Our diverse range of programs, events, and support groups create spaces where individuals and families facing bleeding disorders can connect, share experiences, and build lasting relationships. This year, we provided over forty (40) educational events and programs, including, with volunteers from the community, our Men's & Women's groups.

Advocacy:

EPBDF is dedicated to being a strong voice for our community. We advocate for policies that ensure access to quality healthcare, affordable treatment options, and improved overall well-being for those affected by bleeding disorders. Your support enables us to continue advocating for positive change on behalf of our community. This year, we held or participated in five advocacy events including Washington D.C. and Harrisburg.

Financial Assistance:

We understand that the financial burden of bleeding disorders can be overwhelming. That's why we offer financial assistance programs, including our annual scholarships, to help alleviate some of the challenges which our community members may face. Your contribution to our Annual Campaign directly supports these crucial initiatives. By the end of this year, we will have provided over \$82,000 in financial aid and scholarships to the community.

Your generous support is instrumental in helping us achieve our mission and strengthen the bonds within our community. Here's how you can contribute to the success of the EPBDF Annual Campaign:

1. Make a Donation:

Every contribution, no matter the size, makes a significant impact. Visit this link <https://givebutter.com/EUjP2g> to make your secure online donation today, send your enclosed check in the provided envelope, or scan here:



2. Spread the Word:

Share our mission and the Annual Campaign with your friends, family, and social networks. Help us reach a broader audience and raise awareness about bleeding disorders and the support we provide.

3. Volunteer:

Your time and skills are invaluable. Consider volunteering with EPBDF to actively contribute to the success of our programs and events.

Together, we can make a difference in the lives of those affected by bleeding disorders. Your support is not just a donation; it's an investment in the strength and resilience of our community.

Thank you for being a vital part of the EPBDF family. We look forward to your continued support and the positive impact we can create together.

With Kindness,

A handwritten signature in black ink that reads "Sarah Pilacik".

Sarah Ross Pilacik | Executive Director

Eastern Pennsylvania Bleeding Disorders Foundation | EIN 23-1567876

Community Spirit

Joe Pugliese Retires

Dear Eastern Pennsylvania Bleeding Disorders Foundation:

It has been a real pleasure and honor for Karen and me to have been part of your community since moving here in 1989. Our involvement with the community started in 1977 when I joined Armour Pharmaceutical (today known as CSL Behring) in Chicago as a sales representative. Factor concentrates had just been introduced and the promise for the bleeding disorders community was unlimited. Obviously, the AIDs crisis had a profound and lasting impact on everyone it touched. What Karen and I remember so well was the great humanity, courage and compassion the community showed.

When we arrived here in 1989, we were quickly adopted by Ann and John Rogers and the board of the Delaware Valley Hemophilia Foundation. We had walks in Valley Forge National Park, casino night fund raisers, golf outings, wine tasting, annual dinners and always our favorite family weekend getaway weekend. Karen organized all the craft projects. I was the only 'industry guy' allowed to attend. I was in charge of mixing concrete and removing the trash. One of the little girls who attended my steppingstone craft station came back the next day and gave me a hand painted rock. It was so sweet. I still have the rock.

All of those early tragedies and struggles have led to the remarkable products we have today with even more remarkable therapies to come. While I am retiring, I will certainly keep my finger on the community, and it is our hope that in our time there will be a cure for hemophilia. Thanks so much for making us part of the journey.

Living with Hemophilia

Things you Really Need to Know

BILL JAMISON

Living with hemophilia or any chronic condition requires you to learn as much as you possibly can about your condition to make sure you have the best healthy outcome to live a long and healthy life.

So, what qualifies me to speak on this topic? Well, I have Severe Hemophilia Type "A," Factor VIII Deficiency and have been living with hemophilia for almost 70 years.

Growing up in the 1950's and 1960's, the available treatments for hemophilia were extremely limited and did not work very well. Factor concentrates were decades away and bleeds involving joints and muscles were serious business at that time as they are now. For the most part, the treatments available were whole blood, fresh frozen plasma, lyophilized plasma and in the early 1960's, cryoprecipitates. None of them worked very well, but that is all we had at that time.

Resolving bleeds was often a long and painful process requiring multiple hospitalizations, sometimes for months on end, to resolve the bleed. Joint and muscle damage was common, often leading to joint replacements later in life. I am a living example of that.

Treating a bleeding disorder today is 180 degrees different than what people of my generation experienced. Today we have factor concentrates, gene therapy and other treatment options that can usually resolve a bleed quickly with one or two doses or prevent you from bleeding all together in some cases.

I was very fortunate to be in some of the first clinical trials back in 1968 to test this new "Miracle Drug" called factor VIII concentrate. No longer did it take thousands and thousands of cc's of plasma to resolve a bleed. No longer did my treatment require months long

hospitalizations to stop me from bleeding. Treatment now consisted of injecting 50-60 cc's of this Miracle Juice - as I called it - to resolve a bleeding episode.

I was 14 years old when I got my first infusion of factor VIII concentrate and even at that young age, I knew this was going to be the "Hot Ticket" to treat my hemophilia and would change my life for the better. It did just that!

Back in 1971, I had a very forward-thinking hematologist that had some groundbreaking thoughts on treating my hemophilia. He decided to have me infuse factor VIII three times a week to see how much it reduced my spontaneous bleeding. He did not have to twist my arm to agree with this treatment option. After being in the clinical trial, I absolutely knew this would be a positive life changing treatment for me and it worked! As far as I know, prophylactic treatment was not the treatment of choice until many years later, but it was my choice and that is exactly what I did.

Prophylactic infusion of factor VIII three times a week enabled me to lead a full and productive life. I was married for 47 years until my wife passed. I have two wonderful adult kids, a boy, and a girl and four grandchildren including a set of twin boys! So, for me, prophylactic treatment and adhering to my treatment protocol made a positive difference in my life.

I attribute my positive outcome to a few things. Living with a bleeding disorder has not been easy at times. Worrying about your job, your insurance, your family and all the crazy things that challenge us that we all face every day have an influence on your overall health. I am sure all of you would know that.

I made it my goal to learn as much as I could about my hemophilia to have the best healthy outcome as I go through life's journey.

Here is a list that I have used over the years that might be of some help to you to navigate this sometimes-confusing maze of living with a bleeding disorder. These are in no particular order:

- **What** is the name of your factor product or medication?
- **What** is your usual dose?
- **What** is the name of your insurance company?

- **If you** use a Specialty Pharmacy, what is their name and phone number? Who is the contact person if you need meds or services? Is there an after-hours number?
- **Know** your HTC (Hemophilia Treatment Center)! Who is your contact person? What is their phone number? Is there an emergency number to call after hours? Do you know your HTC doctors and nurses' names?
- **Get** some kind of Medic-Alert
- **Get** a copy of your treatment protocol. Keep a copy in your vehicle, wallet, or purse.
- **Pennsylvania** has the Yellow Dot program. Use it!
- **Know** who your legislators are for your area.
- **Get** involved with your Bleeding Disorders Chapter
- **Volunteer** if you are able
- **Advocate** for yourself and others with bleeding disorders

I hope this information is useful to you. By no means is this a complete list of all the things you can do to help yourself navigate through the challenges we face every day living with a bleeding disorder.

The future of treating bleeding disorders is very bright and getting better all the time. The choices that are available today are something I could only dream of as a child. You CAN do "this" thing of living with a bleeding disorder! Just be smart about it. Sometimes it is hard and sometimes it is easy. Just stay ever vigilant of what is going on in the Bleeding Disorders Community and Never Forget what happened to our community in the 1980's. Over 10,000 men were infected with HIV, and most have died because the focus was lost on what was moral and correct. Never let this happen again! Advocate, initiate, participate.

In closing, the Most Important thing you can do is educate yourself on your condition. This is a life-long process. There is always something new to learn. New medications, new procedures, new treatment protocols and much more to help you have a better health outcome.

...Just some thoughts from some old guy that has been around the track a few times.

Be kind, be safe, be well!

Bill

Advocacy Ambassador MARCH 4-5



Patient Education Day 4/29/2023



Washington Days MARCH 8-10



Spring Fling Family Day 5/6/2023



Bowling for Bleeding Disorders MARCH 11



REVIEW

Summer Kickoff

6/3/2023



Adventure Sports

7/22/2023



Harrisburg Day

6/7/2023



Adventures in Learning

9/9/2023



Annual Meeting

6/21/2023



Annual Golf Classic

9/12/2023



Women's Retreat

11/3-5/2023



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



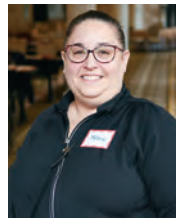
Frank Lentini
ANNVILLE,
LEBANON COUNTY



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](#).¹

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.

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

ADVOCACY UPDATE

MG LEGISLATIVE UPDATE: PENNSYLVANIA BLEEDING DISORDERS FOUNDATION



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 Senate amended the general appropriations budget bill, HB 611. Senate Republican leadership claimed that they had a deal with Governor Josh Shapiro. They would support a significant portion of the Democrat's requested line items, so long as he would support the inclusion of a \$100 million dollar line item for a school voucher program.

Shortly after the Senate passed the bill and sent it over to the House, Governor Shapiro reneged on his agreement and promised the Democratic-led House that he would line-item veto the school voucher program. To Senate Republicans, he argued that there wasn't enough support for the voucher program. He argued that to pass an on-time budget, they would have to disregard the school voucher program. With 86 Republicans in opposition, the House passed HB 611.

As part of normal operating procedure, 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 to sign the 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.

The Governor quickly signed HB 611 into law, allowing state departments to start distributing some of the funding and prevent various disruptions in schools and human services programs. **But the budget package is not quite 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 separate 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 sent over to the House. On October 4th, the House amended HB 1300 and sent it back to the Senate, where it currently waits for a concurrence vote.

We are about half-way through the two-year legislative cycle. There are 3 session days remaining this year.

BUDGET LINE ITEM

We are very 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 finalized, the current version of HB 1300 includes our requested language. It clarifies that there shall be no changes to the hemophilia funding distribution formula. Again, HB 1300 passed the Senate, was amended by the House, and is waiting for a concurrence vote in the Senate.

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

When pressed over whether the fiscal code language was mandatory for the state to start distributing the funding to the HTCs, we received the below response from Capitol staff: *"The language had been to prevent the prior Administration from opening their RFA/new contract entirely (state and federal funding streams). Therefore, language may or may not be necessary depending on the viewpoint/intentions of this Administration. Even so, most non-program payments are not being distributed until a budget package is viewed as final."*

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

We are hopeful that the 2023-24 budget will be finalized in December. Shortly after, we will begin our meetings and advocacy for the 2024-25 budget line item.

CO-PAY ACCUMULATORS

SB 372 (Ward, R-Blair): Amends the Insurance Company Law by requiring insurers to count the drug manufacturers' assistance program towards the deductible and out-of-pocket costs.

The bill was introduced and referred to the Senate Banking & Insurance Committee, where it currently waits for consideration. BDF circulated a letter of support.

Please note that the previous Executive Director for the Senate Banking & Insurance Committee recently resigned, and we are anticipating a new Executive Director shortly. Once that position is filled, we will coordinate

a meeting with BDF. This will allow BDF to bring the new person up-to-speed and directly advocate for committee consideration.

We are currently collaborating with the Immune Deficiency Foundation and their government relations team. We've agreed to divert from Representative Mary Isaacson (D-Philadelphia) to Representative Bridget Kosierowski (D-Lackawanna) for the introduction of companion bill in the House. Representative Kosierowski is a Registered Nurse and a member of the House Insurance Committee. We are prepared to circulate a letter of support once the bill is introduced.

OTHER LEGISLATION

Legislators have introduced several bills relating to menstrual education (HB 354) and menstrual product access (HB 850) and we plan to engage on a few of them.

- **HB 354** (Isaacson, D-Philadelphia): Amends the Public School Code by requiring the Pennsylvania Department of Education to develop a curriculum for menstrual education that school districts can implement into their instruction for students. This curriculum would include topics related to the menstrual cycle, menstrual hygiene management, menstrual disorders, and more. This legislation will expand access to menstrual education for all students in Pennsylvania, regardless of gender, and ensure that students who menstruate are better equipped to manage their periods.
 - Introduced and referred to the House Health Committee on 3.13.23.
- **HB 850** (Parker, D-Philadelphia): Amends the Human Services Code by requiring our Department of Human Services to apply to the federal government if a waiver is made available to states to allow those receiving Supplemental Nutrition Assistance Program (SNAP) and Women, Infants, and Children (WIC) to use the two programs for menstrual hygiene products. Currently, these programs do not allow for the purchase of menstrual hygiene products, despite being a necessity.
 - Introduced and referred to the House Health and Human Services Committee on 7.13.23.

Senator Judy Schwank (D-Berks) has also announced her intent to introduce a Senate companion bill to HB 850 and recently circulated a co-sponsorship memo.

2024 STATE ADVOCACY DAY

Milliron Goodman is excited to host the BDF community for a revitalized advocacy day in Harrisburg, Pennsylvania. We are planning on Spring 2024.

Advocacy days are critical opportunities for the community. Attendees are guaranteed to have facetime with legislators and staff. This allows legislators (the decision makers!) to become more attuned to the current issues impacting the community, their voting constituents. Please stay tuned for more details!

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.

**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!

ADVOCACY AMBASSADOR WPBDF

ADVOCACY AMBASSADOR EPBDF



★ ★ ★ ★ ★

WASHINGTON DAYS 2024



Scan this QR code with your phone to apply for the Washington Days Scholarship or visit: <https://www.surveymonkey.com/r/PNSTB7R>

The National Bleeding Disorders Foundation's Washington Days is an opportunity for people affected by inherited blood disorders to advocate for issues important to them. Washington Days will take place in person March 6-8, 2024

The Pennsylvania Bleeding Disorders Foundations are thrilled to be able to provide scholarships for individuals and families to attend Washington Days. Funds are limited and awards will be granted based on eligibility, advocacy experience, and district location. We will notify and announce scholarship recipients the week of January 8, 2024.


In order to be eligible for a scholarship to attend NBDF's Washington Days you must:

- 1.) Be an active Advocacy Ambassador and/or have attended our Advocacy Ambassador Retreat in 2023.
- 2.) Agree to attend and stay for the entire duration of Washington Days, March 6-8, 2024.
- 3.) Agree to attend the virtual training webinar on February 26, 2024.
- 4.) Submit the form to apply by Friday, January 5, 2024.


Scholarships include a 2 night hotel stay at the Hyatt Regency Washington on Capitol Hill and a gas card for transportation costs from your home to Washington, DC. You will be responsible for meals and off site parking.

NBDF will provide the following meals at the hotel:
Wednesday, March 6 – Reception/Dinner
Thursday, March 7 – Breakfast, AM/PM Snacks, and Dinner
Friday, March 8 – Breakfast






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!

IN LOVING MEMORY

"A Mom"

This year marked the passing of Barbara Jamison. She was born in Harrisburg and spent her life there. In the nineteen fifties she was the young mother of a hemophiliac child. A time when there were no factor concentrates, no treatment center, no homecare company, no local advocacy group and no state or federal dollars. Hemophilia meant wheelchairs, leg braces, endless hospital stays and bleeds that wouldn't stop. Like many hemophilia mothers of her generation she faced all of it without a guidebook. Barbara was direct, fearless and honest. She was a founding officer of the Central Pennsylvania Hemophilia Chapter, a longtime guest lecturer for nursing students, an advocate for Hemophilia legislation and most of all a trusted friend. She was a source of comfort and humor for other women who faced the unwelcome reality of hemophilia. She will be dearly missed.

J. Palumbo



Maria Shoemaker: A mother asks: Are we too expensive to keep alive?

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 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?

Sadness and pain

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 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 stockholders' 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?

Too expensive to keep alive

Persons with serious health conditions in our country no longer carry value of simply being a human life. We are now a matter of cost-benefit analysis.

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 to the GDP.

His life means nothing

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 is clear our government will not do anything to help us.

Maria Shoemaker, a resident of Vandergrift, is an accounting student and mother of five children.

First Published Pittsburgh Post-Gazette November 9, 2023, 5:30am

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



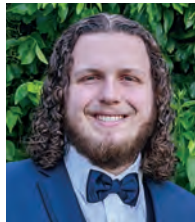
Jocelyn Doerr
Freshman
Univeristy of Mount Olive



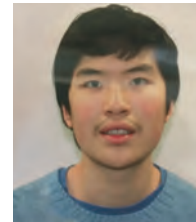
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Freshman
Univeristy of Mount Olive



Zachary Glavin
Freshman
University of Pittsburgh



Isaac Heilman
Sophomore
Saint Joseph's University



Steven Huang
Freshman
Lycoming College



Teia Hudson
Sophomore
University of Pennsylvania



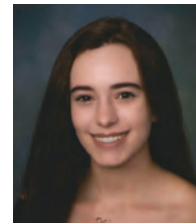
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Senior
Rowan College at
Burlington County



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



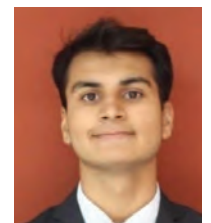
Noah Penica
Sophomore
Penn State University



Jose Perez
Sophomore
Community College of
Philadelphia



Courtney Rowe
Freshman
Shippensburg University



Tejas Sharma
Senior
Villanova University



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.

Special Considerations for Girls

The Onset of Menstruation May Be a Time to Focus on a Hemophilia Care Plan



For more information, visit b2byourvoice.com to download *Hemophilia B: Her Voice, Her Life*.

This content is brought to you by Pfizer.

Puberty on its own can be a difficult experience, but it can become even more complicated with a hemophilia diagnosis. The start of menstruation is one of the many aspects of a girl's life that may be affected by a bleeding disorder. For girls who are showing symptoms of hemophilia, puberty may be a good time to identify a health care team and develop a care plan.

Identifying a Health Care Team

The lack of knowledge about how hemophilia impacts girls can affect the level of medical care and emotional support received by a girl with this condition.¹ It may be recommended that a girl who is diagnosed with hemophilia wear a medical identifier at all times so that medical personnel are aware of her bleeding disorder in an emergency. It is important for every female with hemophilia to enlist a team that includes a primary care physician, a gynecologist, and a hematologist who can coordinate care and needs.²

Tools that can help girls manage symptoms include³:

- Care plans designed for patients by their team of health care providers to help facilitate care coordination
- Apps that allow patients to track their hemophilia symptoms and care
- Self-monitoring assistance for better symptom accuracy

Heavy Menstrual Bleeding

Periods with heavy blood loss (called *menorrhagia*) can lead to anemia and have a negative effect on quality of life. Girls with bleeding disorders who are experiencing symptoms of menorrhagia should have a discussion with their health care team in order to coordinate management and care.⁴

References: 1. Aldridge S. The carrier barrier: women push for mild hemophilia diagnosis. HemAware.org Web site. www.hemaware.org/story/carrier-barrier. Published July 19, 2012. Accessed February 20, 2019. 2. Canadian Hemophilia Society (CHS). Precautions for pregnant women with a bleeding disorder. Hemophilia.ca Web site. www.hemophilia.ca/en/women/precautions-for-pregnant-women/. Accessed February 20, 2019. 3. Carr S. A new look at patient communications in outcomes-driven healthcare. Pharmaphorum.com Web site. http://pharmaphorum.com/views-and-analysis/a_new_look_at_patient_communications_in_outcomes-driven_healthcare/. Published November 5, 2012. Accessed February 20, 2019. 4. National Hemophilia Foundation (NHF). Effects of puberty on girls with a bleeding disorder. StepsforLiving.Hemophilia.org Web site. <https://stepsforliving.hemophilia.org/next-step/maintaining-a-healthy-body/growing-up-puberty/effects-of-puberty-on-girls-with-a-bleeding-disorder>. Accessed February 20, 2019.

The signs and symptoms of menorrhagia include⁴:

- Having a menstrual period that lasts longer than 7 days
- Needing to change pads or tampons at least every 2 hours
- Passing blood clots larger than a quarter
- Bleeding that affects daily activities

"I am a true testament to the fact that factor replacement therapies can help when it comes to being a woman with hemophilia. Not only do we have to deal with the joint bleeds that men do, but we also have specific issues as women."

- ELIZABETH
Has hemophilia B

Tips for Parents⁴

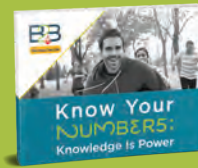
Parents of a girl with a bleeding disorder can ease their daughter's transition into puberty by preparing her for the experience of having periods and helping her learn how to manage them. It can also be helpful for parents to ensure that a supply of feminine products is available and provide a way for their daughter to carry the products discreetly if needed. Parents can also help by providing honest, accurate information about menstruation and the impact hemophilia may have.

The beginning of menstruation, which can already be a confusing and demanding time in the life of any girl, brings special concerns for those showing symptoms of hemophilia. It's important for girls to talk with health care providers and caregivers about their periods, especially if bleeding becomes heavy.



Patient Affairs Liaisons are Pfizer hemophilia employees who are dedicated solely to providing support to the community. Your Pfizer Patient Affairs Liaison is available to help you access the support and information you need. To find your Patient Affairs Liaison, go to hemophiliavillage.com/support/patient-affairs-liaison-finder or call Pfizer Hemophilia Connect® at 1.844.989.HEMO (4366).

The Power In Knowing Your Numbers



For more information, scan the QR code with your smartphone camera to access *Know Your Numbers: Knowledge Is Power.*



This content is brought to you by Pfizer.

This information is provided for educational purposes only and is not intended to replace discussions with a health care provider. Speak to your treatment team if you have any questions about your/your child's care.

For those who live with hemophilia and their caregivers and families, it's important to understand how specific sets of numbers, test values, and data about the condition can impact patients throughout their lifetimes. It's important for all people with hemophilia to understand their numbers in order to communicate effectively with their health care professionals (HCPs).

Replacement Factor

One important number to know is how the dose of replacement factor is calculated and how that number may vary from person to person:

- For treating hemophilia A, the factor VIII dosage = body weight (kg) × desired factor VIII level increase (%) × 0.5¹
- For treating hemophilia B, the number of factor IX units required = body weight (kg) × desired factor IX increase (%) × product-specific multiplier (varies by factor IX replacement product)^{2,3}
- For severe bleeding associated with both hemophilia A and B, an appropriate dose of factor should yield a factor level of 80% to 100%¹⁻³
- Because of the wide variation in recovery time, further adjustments may be needed. Talk to your treatment team to determine the right treatment³

"I have encouraged my patients with hemophilia to communicate with the hemophilia treatment team about all aspects of their condition. When it comes to test results and what they mean, patients should never hesitate to seek a discussion with the health care team."

-PATRICK F. FOGARTY, MD

Drug Half-life

The half-life of a drug is important because it can help guide the appropriate drug dosage.³ The drug half-life is helpful for HCPs when recommending a particular dose regimen.

- The half-life is the length of time it takes for the body to eliminate 50% of the amount of drug in the bloodstream⁴
- The half-life measures how quickly or slowly the factor breaks down in the body
- The amount of factor in the bloodstream is highest right after an infusion and then subsequently decreases

Keep a Log

As part of a total self-management program, keep a log that includes all your health information such as dates of bleeds, types of bleeds, how bleeds were treated, factor levels when known, and the dosage of any other medications you are taking. Tracking day-to-day information may help your health care professional or treatment team develop a treatment plan. Knowing how many bleeds you have had or your child has had will provide important information to your health care professional or HTC treatment team.

Know Your Numbers—Know Yourself

Being an active advocate for your health care can be part of living with hemophilia. Part of effective communication with your treatment team is knowing and understanding your numbers. Finally, making sure family members and caregivers also understand your numbers can be part of a comprehensive plan for living with hemophilia.

References: 1. Hemophilia A. ClinLab Navigator website. <http://www.clinlabnavigator.com/hemophilia-a.html>. Accessed April 8, 2020. 2. Hemophilia B. ClinLab Navigator website. <http://www.clinlabnavigator.com/hemophilia-b.html>. Accessed April 5, 2020. 3. Srivastava A, Brewer AK, Mauer-Bunschoten EP, et al. Guidelines for the management of hemophilia. *Haemophilia*. 2013;19:e1-e47. doi:10.1111/j.1365-2516.2012.02909.x 4. Half-life definition. Beltina.org Encyclopedia of Health website. <https://www.beltina.org/half-life-definition>. Accessed April 5, 2020.



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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)



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WOMEN'S GROUP



FOR MORE INFO EMAIL THE FOLLOWING COMMUNITY MEMBERS:

NORABBULLOCK@GMAIL.COM

ROSENPHOTO@AOL.COM

FRANK.P.LENTINI@GMAIL.COM



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.



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<https://forms.gle/nhcvrQjrSWzzwdfX8>

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