



**THE  
WINNING  
SPIRIT  
NEWSLETTER**

FALL 2022

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## Upcoming Events:

**November 4-6**  
 Women's Retreat at Hershey Lodge

**November 22 10am**  
 (Virtual) Annual Stakeholder  
 Meeting

**November 29**  
 Giving Tuesday

## 2023:

**March 4-5**  
 Advocacy Ambassador Retreat with  
 Western PA Bleeding Disorders  
 Foundation (WPBDF) Bedford  
 Springs

**March 8-10**  
 Washington Days

**Spring/Summer**  
 National Conferences 2023

## Hemophilia Treatment Centers



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# REFLECTIONS

## From the Desk of the Executive Director Sarah Ross Pilacik

I love this time of year: beautiful days, cool nights, leaves changing and falling, football, pumpkins. I hope that you all are enjoying the change of season and everything that comes with it. Try to steal some time away each day to sit in the sunshine and feel the warmth. It really does feed the soul.

I cannot believe how much has happened at the Foundation since our last newsletter in August. We have held five events, and they have all been a success! How is that measured? To me, it is measured by community, and community has **come out**. It has been such a pleasure to meet so many new people and what I have been eagerly awaiting. Now that we have met you, we are really looking forward to getting to know you better. We appreciate your support, feedback, and encouragement.

We hope to see many of you at our Women's Retreat which is the first weekend of November at The Hershey Lodge. All women and teenage girls starting at age 13 and up are welcome to come. If you don't have a bleeding disorder but directly care for someone who does, we hope that you will consider coming.

We have several mini educational programming events between now and December. These can be found on our events page at [www.hemophiliasupport.org](http://www.hemophiliasupport.org). Other ways to follow our events and RSVP:

1. Social Media: Facebook, Instagram, LinkedIn
2. Through our email database: we will send one email about these mini events
3. Please RSVP on the Google form provided on each flyer;
4. Or email [info@hemophiliasupport.org](mailto:info@hemophiliasupport.org).
5. Or call 610-770-5215

Some exciting news is that we hired Greta, our expert intern from NHF, to work part-time with us through December of this year. We are thrilled she chose to continue working with us for the remainder of the year and want to shout a HUGE THANKS to her for all of the planning, organization, and energy she brought to Family Camp this year. We are so blessed to have her on our team as she continues to help us plan for events and oversee our social media platforms

We are working hard on our 2023 calendar of programs for next year. If you have any suggestions or ideas, please email us! Sarah Pilacik at [sarahp@hemophiliasupport.org](mailto:sarahp@hemophiliasupport.org), Lisa Lee at [lisal@hemophiliasupport.org](mailto:lisal@hemophiliasupport.org), or Greta Hayden-Pless at [gretap@hemophiliasupport.org](mailto:gretap@hemophiliasupport.org).

Our last quarter newsletter will be out in December! Blink and we will be there already! Enjoy these last months of 2022.

Warmly,

Sarah

# WHAT'S NEXT? YOU DECIDE.

At Genentech, we're committed to creating programs for you, with you. From a web series focused on finding the *magic* in life, to a tournament for gamers, to workshops designed to help you think well, do well, and be well, we're here to help you take on what comes next.



VISIT [GENENTECHHEMOPHILIA.COM](https://www.genentechhemophilia.com)  
TO SEE HOW WE'RE CREATING  
WHAT'S NEXT, TOGETHER.

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**GENENTECH IN  
HEMOPHILIA**

**Genentech**  
*A Member of the Roche Group*

# CONGRATULATIONS

## Melanie Bove

Congratulations to Melanie Bove, who is attending CSL Behring's Getting in the Game, Junior National Championship (JNC)! Melanie will be traveling this October to Scottsdale, Arizona where she will be participating in a weekend of fitness and learning. As described on the CSL Behring website:



"Participants will have the opportunity to learn the fundamentals of their respective sport, participate in friendly competition, and have a chance to connect with fellow members of the bleeding disorders community from across the country. Additionally, educational seminars focusing on the importance of physical fitness and other related topics will be available on site."

-Home | JNC ([csljnc.com](http://csljnc.com))

Please be on the lookout to apply for this opportunity in 2023. All children with bleeding disorders ages 7-18 may apply.

# ADVENTURE SPORTS

## August 20th



# Dedication and Personal Support

**Your Pfizer Patient Affairs Liaison** is a professional dedicated to serving you and the hemophilia community by connecting patients and caregivers with Pfizer Hemophilia tools and resources. These Pfizer colleagues are committed to continuing Pfizer's more-than-20-year history of listening to the hemophilia community and working to meet its needs.



## Annie Sukhnandan

NY Metro, NJ, E. PA

[annie.sukhnandan@pfizer.com](mailto:annie.sukhnandan@pfizer.com)

📞: 347-757-0922

*"I've been a passionate and dedicated advocate for the rare disease community for over 16 years."*

### My work is guided by:

#### Compassion

Listening to your needs and addressing questions and concerns that you may have

#### Commitment

Educating you about Pfizer's tools and resources, including the Pfizer Community Connections Program, the HemMobile® app for logging bleeds and infusions, B2B materials, and more

#### Connection

Connecting you with hemophilia advocacy groups and programs like Leading Edge, the National Hemophilia Foundation, The Coalition for Hemophilia B, and others

# THANK YOU!

## Mona Almaala

EPBDF would like to extend our gratitude to one of our community members, Mona Almaala, for providing social media content during the month of September! We are working to grow our Facebook presence and during the time Mona was writing for us, we increased our followers from 95-130! Thank you, Mona, for your time and professionalism!

\*If you would like to provide any content for social media or the newsletter, please contact us at [info@hemophiliasupport.org](mailto:info@hemophiliasupport.org).

# ANNUAL CAMPAIGN

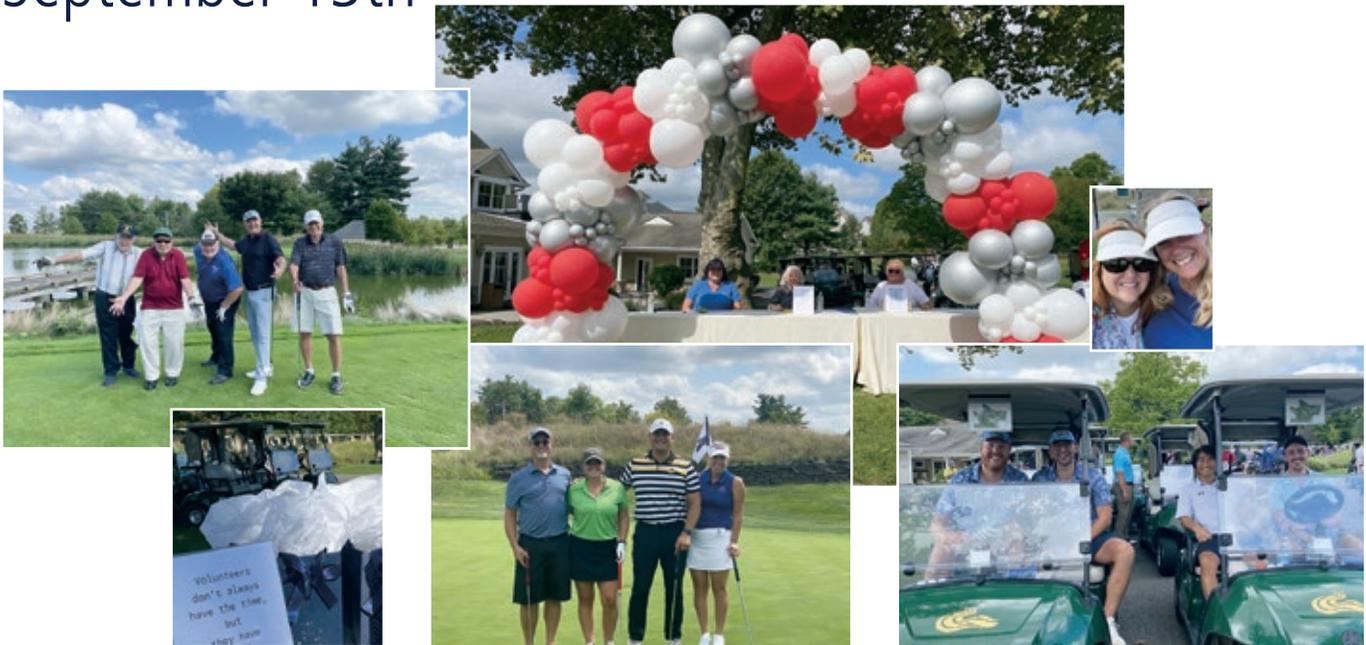
Our Annual Campaign in advance of Giving Tuesday will be formally announced on November 1.

Donations will go towards patient assistance including scholarships. Information will be shared via mail, email and social media. Please make checks out to "Eastern PA Bleeding Disorders Foundation" and mailed to the address below. Thank you for anything you are able to give.

Eastern PA Bleeding Disorders Foundation  
Liberty Place at Kennett Square  
148 W. State Street, Suite 305  
Kennett Square, PA 19348

# ANNUAL GOLF CLASSIC

## September 13th



# ADVOCACY

## Advocacy Ambassadors

Pennsylvania's Medicaid program has a Preferred Drug List. Not all products used to treat bleeding disorders are on the preferred drug list. If a doctor wants to prescribe a medication that is on the non-preferred list, they need to seek authorization and may or may not receive approval from the insurance company. We advocate for open access or for every FDA Approved product for treating bleeding disorders to be placed on the preferred drug list.

On September 14th and 15th, Pennsylvania Medicaid's Pharmaceuticals & Therapeutics (P&T) committee reviewed a variety of hemophilia agents. The Western PA Bleeding Disorders Foundation along with the Eastern Pennsylvania Bleeding Disorders Foundation, the National Hemophilia Foundation, and the Hemophilia Federation of America submitted a joint written testimony urging the P&T Committee to allow patients access to all FDA-approved therapies available to treat hemophilia and related bleeding disorders. You can view the PA Preferred Drug List at: [https:// papdl.com/preferred-drug-list](https://papdl.com/preferred-drug-list). If you or anyone in your family is experiencing access issues, please contact us at 724-741-6160.

### State Senate Bill 225

On June 19, 2022 State Senate Bill 225 passed the Senate unanimously, bringing patients one step closer to having better access to care. Now, we're racing toward the finish line, and the House has a limited number of session days to schedule a vote and pass the bill.

This legislation will create a quicker, more efficient prior authorization process. The bill also provides a clearer route to request an override from the step therapy process. Health insurance practices such as prior authorization and step therapy allow insurers to deny a prescribed medication or treatment, requiring patients to try and fail different treatment(s) before approving

the original. Additionally, these practices undermine the patient-provider relationship and delay access to needed treatment which may result in worsened symptoms and associated higher healthcare costs.

On Tuesday, September 20, 2022 SB 225 passed the House Insurance committee unanimously. We are now working towards a floor vote. Be sure to stay up to date on issues affecting the bleeding disorders community and what you can do to take action by signing up for our Advocacy Action Alerts here: Sign up to receive our action alerts here: <https://p2a.co/udfkjur>

### HELP Copays Act HR 5801

We continue to look for additional co-sponsors for H.R.5801 (HELP Copays Act), addressing co-pay accumulator adjuster programs on the federal level. NHF has an action alert to directly send a request to your Representative to support this legislation. Please use the following link to urge your Representative to support for H.R. 5801 today: <https://p2a.co/7jWIBtF>

### NHF responds to potential contraception bans

Following the June 24th Supreme Court decision overturning Roe v. Wade, NHF has reiterated our mission to ensure that the bleeding disorders community has access to the healthcare that they need. For the bleeding disorders community, safe and effective medical contraceptive tools can serve as a crucial aid to control bleeding and is one of many communities that may use these tools for medical purposes beyond reproductive rights. Read NHF's statement at: <https://www.hemophilia.org/news/nhf-addresses-potential-contraception-bans>

Thank you to Western PA Bleeding Disorders Foundation for providing and allowing us to use this update!

# PA Advocacy Update

# Find Your Legislator



On August 3rd the Western PA Bleeding Disorders Foundation Advocacy Ambassadors and the Eastern PA Bleeding Disorders Advocacy Ambassadors met via a Zoom. To read the minutes use the QR Code or go to our website: [hemophiliasupport.org/advocacy](http://hemophiliasupport.org/advocacy)

Please use this QR Code to Find Your Legislator AND to thank them for their work on the increase in our line item for the state budget!

## FAMILY CAMP September 23-25th





# *Women's Retreat*

**JOIN US FOR FREE  
18+**

**NOVEMBER 4-6, 2022  
HERSHEY LODGE  
325 UNIVERSITY DR,  
HERSHEY, PA 17033**

[Register Today.](#)

**Come engage in a community building weekend  
getaway with educational programming and  
relaxation!**



**Eastern Pennsylvania Bleeding Disorders Foundation**

# ANNUAL MEETING

October 6th



## 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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# COVID-19 and Hemophilia

## Preparedness and Self-Care in a Pandemic

*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.*

This content is brought to you by Pfizer.

**The COVID-19 pandemic brought with it many lessons that can be carried into the future, including ones on preparedness, health care provider (HCP) communication, and self-care.**

### HCP Communication

Good communication with your hemophilia treatment center or care team can be an important part of living with hemophilia. During a pandemic, your team can help you understand possible risks based on your condition, as well as advise on treatment and vaccination.

### Being prepared and proactive in hemophilia care<sup>1</sup>

One of the lessons of the COVID-19 pandemic is that it is important to be prepared, and that also applies to the hemophilia community. National Hemophilia Foundation's (NHF's) Medical and Scientific Advisory Council recommends:

- Having a 14-day supply of factor products available during crisis for those who treat at home
- If an ER visit is required, call in advance so staff knows you are coming and why; this will help them prepare
- Staying in contact with your doctor's office or hemophilia treatment center (HTC). They can explain what to do if you need to visit in person or can help get you connected with telehealth appointments, if available

### Caring for yourself<sup>2</sup>

Events such as the COVID-19 pandemic can create uncertainty for many, which can stir up emotions such as anxiety, fear, anger, sadness, discouragement, or a sense of being out of control. Self-care is important to help you

address these feelings. Here are a few tips you can use to take care of your mental health:

- Set and maintain a routine
- Focus on things you can control
- Use technology to maintain social connections with your loved ones
- Focus on reasons to be grateful
- Read books or listen to music
- Take a break from news and social media if it makes you anxious
- Look for ways to help your community
- Acknowledge and appreciate what others are doing to help

### Further information

Many of the larger advocacy groups have sites to keep you in the know, see below:

- **The Coalition for Hemophilia B**  
hemob.org
- **Hemophilia Federation of America**  
hemophiliafed.org
- **Hope for Hemophilia**  
hopeforhemophilia.org
- **National Hemophilia Foundation**  
hemophilia.org
- **World Federation of Hemophilia**  
wfh.org

These websites are neither owned nor controlled by Pfizer. Pfizer does not endorse and is not responsible for the content or services of these sites.

Be sure to also inquire of your local chapter/advocacy organization and speak to your HTC's social worker for more information about available assistance programs.

**References:** 1. Supplemental MASAC statement regarding home delivery and refill under state of emergency declaration. National Hemophilia Foundation website. Published March 30, 2020. Accessed July 27, 2021. <https://www.hemophilia.org/news/supplemental-masac-statement-regarding-home-delivery-and-refill-under-state-of-emergency-declaration> 2. Reichert S. Self-care tips during the COVID-19 pandemic. Mayo Clinic Health System website. Published April 7, 2020. Accessed March 30, 2021. <https://www.mayoclinichealthsystem.org/hometown-health/speaking-of-health/self-care-tips-during-the-covid-19-pandemic>



Patient Affairs Liaisons are a team of non-sales, non-promotional field-based professionals. Pfizer's Patient Affairs Liaisons are dedicated to serving the rare disease community by connecting patients and caregivers with Pfizer Rare Disease tools, including educational resources, access support, and community events in your area.

**Visit [www.pfizerpal.com](http://www.pfizerpal.com) to connect with your Patient Affairs Liaison.**

# CONGRATULATIONS

## 2022-2023 Scholarship Recipients

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



**Kristian Azzarano**  
Sophomore  
Rochester Institute of  
Technology



**Nickolas Azzarano**  
Junior  
Rochester Institute of  
Technology



**Matthew Bayer**  
Junior  
Thomas Jefferson  
University



**Caleb DeFrank**  
Freshman  
Alvernia University



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



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



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



**Rylee Knepper**  
Junior  
Lancaster Bible College



**Justine Lampe**  
Sophomore  
Indiana University



**Nadine Lampe**  
Senior  
University of Southern  
California



**Elisa Macera**  
Senior  
University of Delaware



**Ainsely McFarland**  
Freshman  
Loyola University



**Noah Penica**  
Freshman  
Penn State University



**Jose Perez**  
Freshman  
Community College of  
Philadelphia



**Tori Robbins**  
Senior  
Stockton University



**Dylan Rooney**  
Senior  
The Catholic University of  
America



**Victoria Selinsky**  
Senior  
YTI Career Institute  
Lancaster



**Tejas Sharma**  
Junior  
Villanova University

# HEY KIDS!



Check out our Pumpkin Carving Contest!

Send photos of your carved pumpkins to [info@hemophiliasupport.org](mailto:info@hemophiliasupport.org) by **October 28!** All photos will be posted on Facebook and Instagram and ONE winner will be announced on Halloween! The winner's pumpkin will be featured on the cover of the Fall 2023 issue of The Winning Spirit! We can't wait to see how creative you are!

## 1 WALK October 8th



# COMMUNITY SPIRIT

## - New Section!

This section of the newsletter will be reserved each quarter for you - our community! Our next deadline for this will be December 1. Please send info to [info@hemophiliasupport.org](mailto:info@hemophiliasupport.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.



### DID YOU KNOW?

.5% of each Amazon Smile purchase can go towards our foundation.

Here's how:

1. Visit [smile.amazon.com](https://smile.amazon.com)
2. Sign in with the same account you use for Amazon.com
3. Select Eastern PA Bleeding Disorders Foundation
4. Spread the word!

### NEW CONTACT INFORMATION?



If you have an updated address, email address or phone number, please send to [info@hemophiliasupport.org](mailto:info@hemophiliasupport.org).

## FIND US ON SOCIAL MEDIA



[www.facebook.com/EasternPennsylvaniaBleedingDisordersFoundation/](https://www.facebook.com/EasternPennsylvaniaBleedingDisordersFoundation/)



[@epbdf\\_hemophilia](https://www.instagram.com/epbdf_hemophilia)



[www.linkedin.com/company/eastern-pennsylvania-bleeding-disorders-foundation/](https://www.linkedin.com/company/eastern-pennsylvania-bleeding-disorders-foundation/)



[@eastern\\_pabdf](https://twitter.com/eastern_pabdf)



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