

SUMMER 2022  
THE WINNING SPIRIT NEWSLETTER

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## STAFF

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## HEMOPHILIA TREATMENT CENTERS

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**C**  
The Children's Hospital of Philadelphia  
DIVISION OF HEMATOLOGY



**L**  
Lehigh Valley Health Network  
A PASSION FOR BETTER MEDICINE



**P**  
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# REFLECTIONS

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

As I reflect on the last five months in this role, there is a part of me that can't quite believe how much has been accomplished, and another equal part that is wondering how behind I am! It is exciting and nerve-racking all at the same time. What I know for certain is that there is no place that I would rather be than serving this amazing community - truly. I look forward to seeing you at our Annual Dinner on October 6th, where you will be hearing in more detail about each of the following:

- Community
- Advocacy
- Building Capacity
- Travel and Learning
- Fiduciary Responsibility
- Hemophilia Treatment Centers
- Social Media & Communication
- Board Relations and Strategic Planning

Thank you to our community members who have reached out to me to introduce yourself, tell your story, and let me know how you want to support. I encourage anyone to do this. Please email me at [sarahp@hemophiliasupport.org](mailto:sarahp@hemophiliasupport.org), or call me at 610-770-5215.

Ask of You - please come to the events in the Fall! We have some really good content planned, or just some good old fashioned fun (like golf.) Please share our Annual Golf Classic with your friends and family so that we can ensure we have as much community representation as possible. See flyer in the newsletter, on Facebook, and in your email.

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## Upcoming Events:

- August 20 Adventure Sports with Hershey HTC  
September 13 CSL Behring Golf Outing  
September 23-25 Camp Kweebec  
October 1 Save One Life's Wheels for the World Event at Blue Marsh Lake in Leesport, PA.  
October 6 Annual Meeting at the Valley Forge Sheraton  
October 8 1Walk at Elmwood Park Zoo  
November 4-6 Women's Retreat at Hershey Lodge  
November 22 10AM (Virtual) Annual Stakeholder Meeting  
November 29 Giving Tuesday  
December (TBD) Holiday Party

## Save the Dates 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

# 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

**O:** 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

HemMobile is a registered trademark of Pfizer Inc.

HemMobile is not intended for curing, treating, seeking treatment for, managing, or diagnosing a specific disease, disorder, or any specific health condition. Pfizer will not have access to any personal information you enter into HemMobile.

# 2022 FAMILY CAMP

**Weekend Program  
Indoor & Outdoor Activities**

**COME JOIN THE FUN**

September  
**23rd-25th**

Come all  
Weekend OR  
just all day  
Saturday!



Once registered, please complete this T-Shirt form

## Our Activities

- Movie night
- Color Wars
- Fishing
- Sports
- Dance Party
- Carnival

[T-Shirt Form](#)

**Register Here for all weekend**

[Family Camp Registration](#)

**Register Here for just Saturday**

[1 Day Family Camp](#)

## Registration Deadline

August 31st

## Camp

Camp Kweebec

More info: Phone 610-770-5215 Email: [sarahp@hemophiliasupport.org](mailto:sarahp@hemophiliasupport.org)

# SPOTLIGHT

## Meet Our New Staff



### Lisa Lee

I am thrilled to introduce you to our Assistant Director, Lisa Lee. Lisa started with us on July 1st and is currently drinking from a firehouse, as I have been! She was able to travel with me to Pittsburgh at the end of July where we met the team at Western PA Bleeding Disorders Foundation, as well as Dawn Rotellini, COO for NHF, and attended Western PA's Annual Dinner where she was able to meet the community. On a personal note, Lisa and I have worked together for many years in our previous career, and it is a true honor and privilege to be able to work alongside her again. We are both excited to know and grow this Foundation for the benefit of our community members.

**Birthplace:** Ridley Park, PA

**Colleges:** Oberlin College

**How many states I have lived in/countries:**  
4; Pennsylvania, Ohio, Vermont, California

**Three words that describe me best:**  
Insightful, Nurturing, Dependable

**Pets:** 2 dogs, Shelby and Ruby (terrier mix)

**Favorite book:** currently my favorite book is  
The Nightingale by Kristin Hannah

**Favorite movie:** Terms of Endearment

**Dream vacation:** currently it is a "staycation"

**Family facts:** I have been married for 28 years to an amazing man with whom I have two college-age sons (and of course two doggie daughters)

**How long have you been involved in the bleeding disorders community:**

This is my introduction to the bleeding disorder community. I am excited to learn and I look forward to being part of such a dynamic and compassionate community.

### Greta Pless

Our Foundation is excited to introduce Greta Pless! We applied for an intern through NHF to help us with event planning, specifically Family Camp, and GRETA PICKED US! It has been such a joy to work with Greta so far in July and it is difficult to believe a month has already passed. Also, if you are coming to Family Camp in September you will meet her in person! She has some really great things planned. Thank you to Greta and NHF for this opportunity. Greta will be with us through September.

**Birthplace:** Palm Beach, Florida

**Colleges:** Juniata College for undergrad and University of Texas Rio Grande Valley for master's

**How many states I have lived in/countries:**  
7; Florida, Massachusetts, Virginia, Pennsylvania, Texas, South Africa, and Australia

**Three words that describe me best:**  
Goofy, Stubborn, and Exuberant

**Pets:** 1 Dog, Fin (chiweenie)

**Favorite book:** The Complete World of Greek Mythology by Richard Buxton

**Favorite movie:** Lake Placid

**Dream vacation:** Going to Guadalupe to dive with the white sharks

**Family facts:** I am the youngest of 4, with two sisters and one brother.

**How long have you been involved in the bleeding disorders community:**

I have been involved for 10 years so far. I was diagnosed with VWD at the age of 16 and got involved in my local chapter which evolved in time with getting involved with The National Hemophilia Foundation through the National Youth Leadership Institute (NYLI) and eventually interning with NHF currently.

# SAVE THE DATE

*10th annual* **WHEELS**  
**for the** **WORLD**



Presented By



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 CVS specialty®

## October 1



We look forward to  
riding with you!

**Register Today**

Use code **PADay** for  
25% off registration.

Registration includes a  
Wheels for the World "Bike Box"  
with items to support your ride.

[www.saveonelife.org](http://www.saveonelife.org)

All proceeds of the PA ride benefit Save One Life and the  
Eastern & Western Pennsylvania Bleeding Disorders Foundations.



# ADVOCACY

## Advocacy Ambassadors

As you might know, 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.**

**We are looking for patient stories to illustrate why it's important for doctors and their patients to have access to the full range of FDA approved products for treating bleeding disorders.**

The most powerful stories are about siblings who have the same bleeding disorder and also have the same biological mother AND the same biological father, in other words, the same DNA, but respond differently to different medications and require different medications to treat or prevent their bleeds.

In addition, stories from individuals who had responded well to a product for a long period of time and then had to switch products because the medication they used to treat or prevent their bleeds stopped being effective.

Real stories from Pennsylvanians are needed to help advance our advocacy efforts. If you or anyone in your family is or has been in either of these situations we would be grateful, if you would share your story with us. Please contact us at [info@hemophiliasupport.org](mailto:info@hemophiliasupport.org) or call the Foundation office at 610-770-5215.



## PA Advocacy Update



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)

## Find Your Legislator



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!

# 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.



**REGISTER HERE:**

**<https://givebutter.com/TFtqi7>**

*Eastern PA Bleeding Disorders Foundation*

2022

# GOLF CLASSIC

RIVERCREST GOLF CLUB & PRESERVE

13  
SEPT

100 GOLF CLUB DRIVE  
PHOENIXVILLE, PA 19460

## **SCHEDULE:**

**Registration at 10:00 AM | Lunch at 10:45 AM**

**Shotgun Start at Noon**

**Cocktail and buffet dinner to follow**

**Contests throughout the day**

The logo features the letters 'CSL' in a bold, red, sans-serif font, with a small 'TM' symbol to the top right.

# CONGRATULATIONS

To our Grads



Ainsley McFarland  
Coatesville Area Senior High School  
Class of 2022 Honor Graduate  
Loyola University Maryland  
Major - Forensic Psychology

Stay tuned, our 2022-2023 scholarship recipients will be featured in our fall issue of *The Winning Spirit*.

## 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

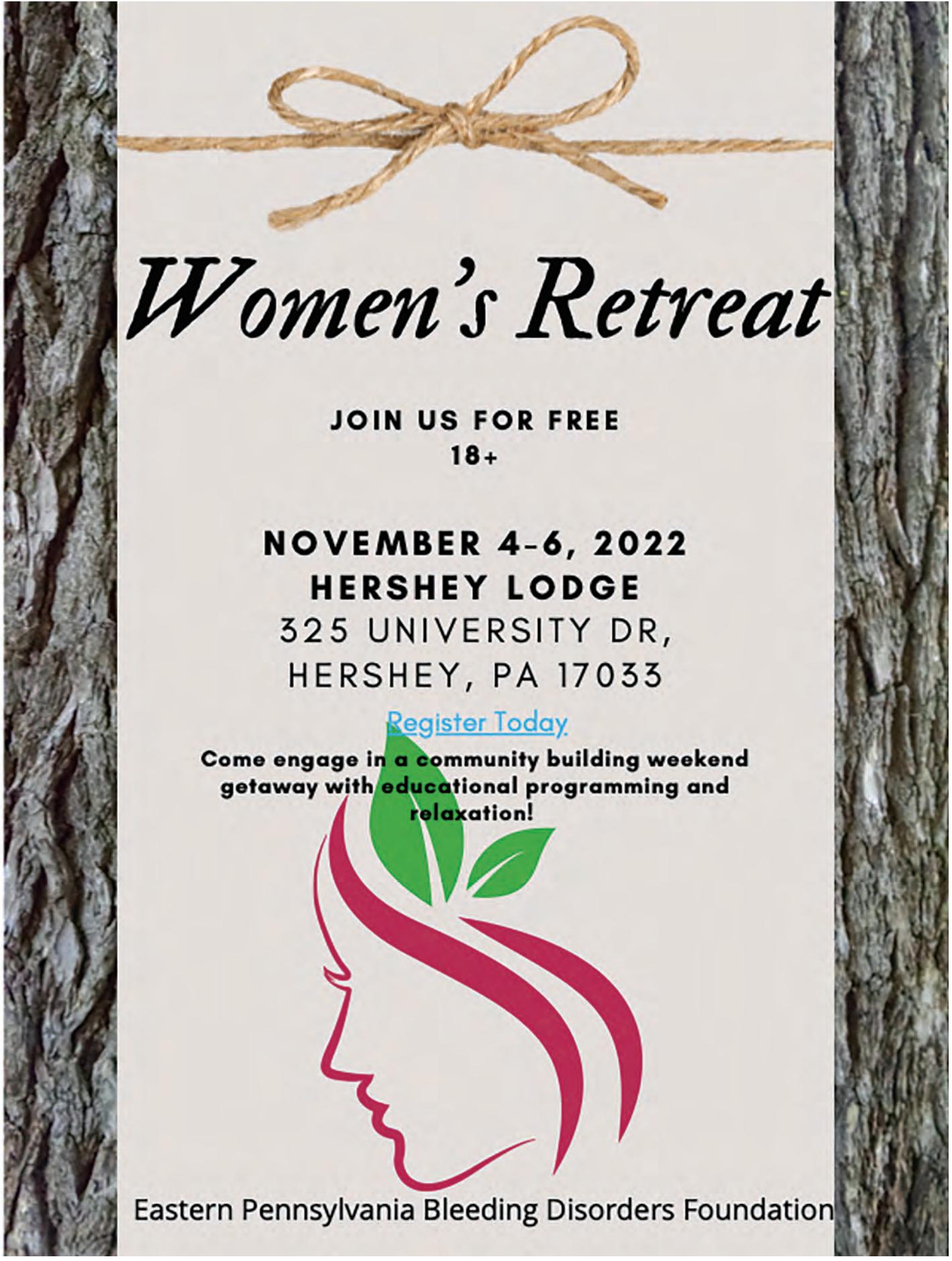
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# *Women's Retreat*

**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**

# 2022 BLEEDING DISORDERS CONFERENCE

## Houston, TX + Online Aug. 25-27

Join the fun at the 74th Annual Bleeding Disorders Conference (BDC) this summer in Houston, Texas!

From August 25-27, you'll be able to reconnect with your community, learn in sessions designed just for you, and more!

For those unable to travel, the conference also features a virtual registration option. However you choose to attend, you don't want to miss this year's event!

Register the whole family at [hemophilia.org/bdc](http://hemophilia.org/bdc).



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3. Select Eastern PA Bleeding Disorders Foundation
4. Spread the word!



### CONTACT

### INFORMATION?

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

EASTERN PA BLEEDING  
DISORDERS FOUNDATION

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# ANNUAL DINNER

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OCTOBER 6 | 5 PM  
SHERATON VALLEY  
FORGE HOTEL

REGISTRATION TO FOLLOW

## FIND US ON SOCIAL MEDIA



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