

THE HEMO HERALD

A Newsletter of the Brandywine Valley Hemophilia Foundation

Serving the Bleeding Disorder Community of Pennsylvania, Delaware, & New Jersey

BVHF Mission:

Brandywine Valley Hemophilia Foundation was founded in 1972 and is a totally volunteer organization dedicated to serving the Bleeding Disorder communities of Pennsylvania, Delaware, & New Jersey. We provide:

- Education/Outreach meetings & Events for patients & families
- Funding for local Hemophilia Treatment Centers, Hospitals, & Summer camps
- Education scholarships & Conference Travel Scholarships
- Emotional/Financial support for patients/families in times of hardship
- Advocacy in the political spectrum for the continued needs of the Bleeding Disorder community
- Funding for research for improved treatment & the Hope of a Cure

HEMO HERALD FALL 2024 Newsletter

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Mark Your Calendars

Upcoming Events:

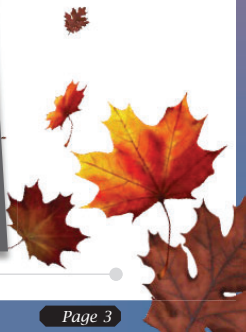
December 8: BVHF End of Year Event

*December 15: Education & Cookie
Decorating*

March 23, 2025: Brandywine Red Run 5K

June 2025: Spring Education Fundraiser

<https://brandywinehemophilia.org/index.html>



BVHF Education Mission:

We at BVHF believe that our job is to help educate, support, & encourage our fellow bleeding disorder patients/families to strive to achieve the greatest degree of physical & mental wellness possible. We never suggest any specific drug company, specialty pharmacy, or product to be the best for anyone. Instead, we hope to provide you with information on ALL available options so that in partnership with your physicians/HTC professionals, you can find the best fit for you and/or your loved one(s).

BVHF would like to Thank our 2024 Sponsoring Product Manufacturers & Specialty HomeCare Companies

Accredo

Axiva

Bayer

BDRN, LLC

BIOMARIN

BioMatrix

*BioTek
ReMEDys*

*CVS
Specialty*

*DrugCo
health*

Genentech

GRIFOLS

*HPC Specialty
Pharmacy*

InfuCare Rx

MEDEXUS

Pharma

NOVO Nordisk

OCTAPHARMA

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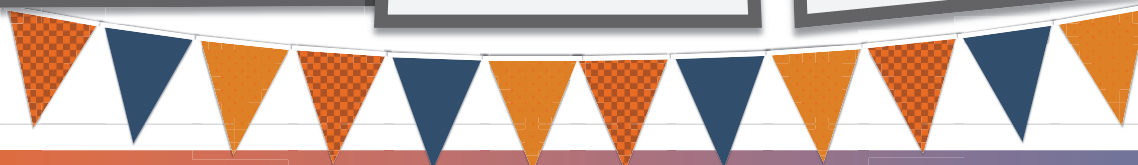
**THANK
YOU!!**

PFIZER

SANOFI

SOLEO Health

Takeda



BVHF HERO Biography: Nancy Olsen

By: Jennifer Davis, MSN, R.N., ATCN, CCTC

As a nurse, I always look to stories of caring and courage that shaped our healthcare landscape. Stories that help encourage me in my own practice. From Florence Nightingale, to Clara Barton, to Dorothea Dix...and our very own Nancy Olsen. Many people do not know the impact that Nancy Olsen has had on the bleeding disorder community over the last 60+ years. I would like to share a few things that made Nancy our own local nursing hero.

Nancy was a Registered Nurse who worked at CHOP (*Children's Hospital of Philadelphia*) in the late 1960's. Both of her young sons (Jeff & Chris) had severe Hemophilia A, as well as her younger sister, Jane (one of the first female Hemophiliacs in the region). Nancy was the one who petitioned the CHOP Nursing Director about starting an IV team/infusion center. She wanted to have a place where patients with bleeding disorders could simply go for needed infusions, without sitting in the Emergency Room or being admitted. Nancy's efforts are what started the first Infusion Center. Nancy was also the first in the region to pilot taking factor product home and infusing her family herself. Her son, Chris, remembers early mornings at the breakfast table, when he was being infused while eating cereal before school. A routine for many now, but Nancy was a pioneer in the late 1960s. Nancy helped train other families regarding the benefit of home infusion and prophylaxis. In fact, her son Chris and others are now a generation of bleeders without joint disability because of this practice.



Nancy(right) with her siblings Paul & Jane

(Cont.) BVHF HERO Biography: Nancy Olsen

- Nancy became a founding member of the Delaware Valley Chapter of the National Hemophilia Foundation to help support patients and families in the region. Over time, Nancy had disagreements regarding paid salaries to administrators running the national and regional foundation chapters. This led to Nancy and others starting our BVHF (*Brandywine Valley Hemophilia Foundation*) in 1972, which was and continues to be a fully volunteer foundation with no salaries paid to administrators/board members.
- Nancy believed that a foundation should be about “people, not bureaucracy”. This was proven in the early 1980’s with the AIDS crisis. While many foundation chapters and hospitals did not want to initially publicly acknowledge there was HIV risks for our patient population due to contamination of product; BVHF became a brave voice in the chaos. This was largely in part because Nancy was seeing it amongst her patients, including her own son, Jeff, who later became one of the over 4,000 Hemophiliacs who died from HIV/AIDS.
- Nancy continued for decades, helping to promote education, teach patients/families how to self-infuse, raise funds to support the community and kid’s camps. Nancy has given an amazing lifetime of care to the bleeding disorder community. I am so honored to know her and be a part of the foundation that is her legacy.

BVHF Education Conference Scholarship Winner 2024

Christine Bond was our 2024 Education Conference Scholarship Winner. Christine attended the NBDF conference in Atlanta, Georgia with her husband, Michael.

Our scholarship grants help cover the costs of conference registration, travel, hotel fees up to an amount of \$2,000.

Check our website for 2025 scholarship applications!



2024 BVHF Scholarship Winner



- **Luc Chapall**

I am so honored to be chosen as one of the Brandywine Hemophilia Foundation Scholarship recipients. I am excited to be attending the University of Tennessee, Haslam School of Business in the fall. My platelet disorder has affected me and my family our whole lives. It was with the help of my speciality care team that I learned how to navigate through life by being careful and making smart choices. They instilled in me that It doesn't have to define me. I've spent a large amount of time around some of the sickest children in the world and I have learned that someone always has it worse and to always be grateful for life. All of my experiences have transcended into an appreciation and given me a sense of community, instilling qualities of compassion and a desire to help others. I couldn't attend college without the support of scholarships. I don't take one dollar for granted or anyone's time and energy that is put into the scholarship process. I am so thankful and my hope is always to give back to our community one day.

2024 BVHF Scholarship Winner

- **Cole M. Hamstead**

I am grateful to be chosen as the recipient of the Brandywine Valley Hemophilia Foundation Scholarship. I will be attending Southern Methodist University Cox School of Business in Dallas, TX in the fall of 2024 and plan to pursue an Accounting Degree. My diagnosis of severe hemophilia A has given me the opportunity to 'Pay it Forward' by giving back to the bleeding disorders community by attending Washington Days Advocacy for 14 years and the PA State Advocacy Days in Harrisburg for 4 years. My cousin Devin and I have led a walk team named Cousins for a Cure to raise funding for hemophilia research and programs. Over the past 10+ years the walk team has raised over \$130,000 for the bleeding disorders community. I have been honored to have my work within the bleeding disorders community recognized by being awarded the Ryan White Youth Award (2017) from the National Bleeding Disorders Foundation and the Leaders of the Future Award (2022) from the Hemophilia Federation of America. Through all my years of giving back to the bleeding disorders community these experiences have given me the chance to grow and develop my skills of leadership, public speaking, a deeper appreciation for the diverse issues facing the community and a better understanding of the legislative process.



Want to Apply for our 2025 Scholarship?

- BVHF is pleased to make available a \$2000.00 scholarship to an individual in our service area (Delaware, Southern Jersey, Brandywine Valley/Pennsylvania) impacted by hemophilia or other significant bleeding disorders. (*Active members of BVH living outside these designated areas are also qualified to apply.)
- Once chosen as the recipient, the scholarship will be renewed each year for four years as long as the individual remains in good academic standing. A check will be made payable to the educational institution and mailed to that institution each year following verification of continuing education and an adequate academic record.
- Any post-secondary educational opportunity will be considered for funding.

• Who Can Apply

- Any individual diagnosed with hemophilia or other significant bleeding disorders within our service area or active within the organization may apply. Evidence of this diagnosis must be provided by your clinician or HTC.
- Any individual whose immediate family member is attached to the hemophilia/bleeding disorder community within our service area or active within the organization may apply. Evidence of this must be provided by your clinician or HTC.
- **DEADLINE FOR APPLICATION: May 16, 2025**
NOTIFICATION OF ACCEPTANCE: June 6, 2025
- <https://brandywinehemophilia.org/scholarships.html>



The Brandywine Red Run 5k was held on March 24, 2024, at Bellevue State Park in Wilmington, Delaware. Over 100 runners/walkers, volunteers and sponsors gathered to make this fundraising event fun and a great success, raising over \$30,000. We had 5 great teams present: Team Little Ladybug, Hemo-Holcombes, Team Dakota, HALO's Heroes and Bolinski Blood Brothers as well as a host of individual runners and walkers.

Thank you to our exhibiting sponsors: *Biomarin, Bayer, Novo Nordisk, Sanofi, Takeda, InfuCareRX, BDRN, BioTek reMEDys and Accredo.*

Participants received a t-shirt, metals for placing 1st, 2nd or 3rd in their age category and there was a great snack table stocked with beverages and goodies ***all generously donated by Starbucks, Wawa, Wegman's, Costco, Trader Joe's and Krispy Kreme.***

Save the date:

March 23, 2025 will be our next Brandywine Red Run. Keep an eye out for more information to be provided later this year through foundation emails and on social media. We will have a team gift card raffle again this year, where each team leader with a team of at least 4 registered participants will be entered for a day of gift card drawing.

Reach out to Race Director Tara Bolinski at tara.bolinski@gmail.com or 717-873-8547 with any question or to sign up to volunteer during the event.

Decision Fatigue or Expanded Menu Choice?

By: Chris Ramsey, Hemophilia A-severe patient, BVHF Board Member

- The new century has seen the product choice landscape explode with new options. There were improvements to the standard recombinant products that increased purity, reducing reconstitution time, and decreasing infusion volumes. In the 2010's new extended half-life products, Factor VIII mimetic bispecific antibodies, additional therapies for vWD patients, and a Factor X product.
- The 2020's have seen the release of an extended half-life product for Hemophilia A that doubles the half-life versus previous products, an additional inhibitor bypassing agent, and after decades of research - three gene therapy products (one for Factor VIII and two for Factor IX.) These new therapies offer the possibility of fewer IV injections, subcutaneous options, and improved bleed protection for a greater portion of the bleeding disorders population, including patients with Factor VIII inhibitors, patients with VWD, and patients with Factor VII or Factor X deficiency.
- The medical research community is not done with us, yet. On October 11, 2024, the FDA approved a first of its kind subcutaneous injectable rebalancing agent that targets tissue factor pathway inhibitor (TFPI), allowing the tissue factor clotting pathway to work longer, bypassing Factor VIII and IX. This is the first approved therapy for both Hemophilia A and B with or without inhibitors.

(Continued) Decision Fatigue or Expanded Menu Choice?

- There are numerous new therapies in Phase 3 clinical trials: another anti-tissue factor pathway inhibitor, another Factor VIII mimetic antibody, and a thrombin/anti-thrombin rebalancing agent (the end point of clotting is thrombin production). All of these will be subcutaneous injections.
 - There are also additional gene therapy products in phase 3 trials. Looking further out to products in Phase 1 trials there are additional anti-TFPI products and a trial of Emicizumab (Hemlibra) in type 3 vWD. In pre-clinical/investigation stages are Crispr/Cas9 gene editing in dogs with vWD and a Factor VIII mimetic that would be taken as a daily oral medication.
- So many choices, and more to come. Wow!

WASHINGTON DAYS MARCH 2024



BVHF Gathered for World Hemophilia Day (April 19, 2024)



Summertime Education Dinner & Movie



BVHF at the Blue Rocks Game!





NATIONAL
BLEEDING DISORDERS
FOUNDATION
Formerly NHF

- National Bleeding Disorders Foundation (NBDF). <https://www.bleeding.org/>

- **NBDF is conducting a “Drug Affordability Survey”**

- **Drug Affordability Survey:** NBDF is a member of the Ensuring Access through Collaborative Health (EACH) Coalition, made up of national patient advocacy organizations addressing the potential impact of state Prescription Drug Affordability Boards on patient access to prescription drugs. [NBDF and the EACH Coalition are seeking patient input on the cost of their drugs](#), rare disease implications, and access challenges. EACH has developed a confidential, patient-designed survey [here](#) to collect patient experiences and help ensure the patient voice is included in PDAB policy discussions.



FOUNDATION FOR
Women & Girls
with Blood Disorders

- The Foundation for Women & Girls⁺ with Blood Disorders works to ensure all women and girls with blood disorders are correctly diagnosed and optimally managed at every life stage.
- **FWGBD:**
 - Raises awareness and educates key healthcare professionals
 - Translates and disseminates information and research
 - Nurtures future healthcare leaders
 - Fosters collaboration and generates knowledge among core disciplines
- *⁺ Includes people who have or had the ability to menstruate.*
- <https://www.fwgbd.org/>

Did You Know?



- The Foundation for Women & Girls with Blood Disorders has a Podcast entitled “**7 2 1**”.
- **7-2-1** Refers to the signs of a heavy period:
 - **7** – cycles lasting longer than **7 days**
 - **2** – changing a pad/tampon every **2 hours** or less
 - **1** – passing blood clots more than **1 inch** or a quarter in size
- This is a discussion podcast hosted by Dr. Sweta Gupta, a board-certified Pediatric Hematologist practicing at the Indiana Hemophilia & Thrombosis Treatment Center.
- <https://www.fwgbd.org/resources/7-2-1-podcast>

HTC Member Spotlight

Our Bleeding Disorder Community has so many great providers. Here's just one of them who has made a difference in our patient's lives.

- CHOP HTC
- Regina B. Butler, RN
- Regina Butler, RN-BC, is the clinical manager for the Division of Hematology, director of the Mid-Atlantic/Region III Hemophilia Treatment Centers and the CHOP Hemostasis and Thrombosis Center nurse coordinator.
- **Areas of expertise:** Care of children and adolescents with hemophilia and other bleeding disorders with an emphasis on patient/family education and education for healthcare providers
- **THANK YOU, REGINA, FOR ALL OF YOUR AMAZING CARE TO CHILDREN WITH BLEEDING DISORDERS!**



HFA Webinar 11/12/2024

<https://www.hemophiliafed.org/events/bleeding-disorders-rural-needs-virtual-summit/>

• Bleeding Disorders Rural Needs Virtual Summit



- Join HFA's **Rural Needs Summit** to connect stakeholders, change makers, and community voices in the bleeding disorder community on issues related to rural health outcomes and communities. This virtual summit is scheduled over half a day, will feature subject matter experts discussing a wide range of issues related to barriers to reaching, receiving, continuing treatment/care for a bleeding disorder, and welcomes participant engagement through questions and comments using the virtual platform engagement features.

World Federation of Hemophilia

World Hemophilia Day 2025 theme revealed



- On April 17, 2025, the global bleeding disorders community will come together to celebrate **World Hemophilia Day**. This year's theme is *"Access for all: Women and girls bleed too"*. Today, women and girls with bleeding disorders (WGBDs) are still underdiagnosed and underserved. The global bleeding disorders community has the power—and the responsibility—to change this. Through recognition, diagnosis, treatment, and care, the quality of life of women and girls will improve, and the bleeding disorders community will become stronger. <https://wfh.org/article/world-hemophilia-day-2025-theme-revealed/>

ChristianaCare HTC

- Are you having difficulty getting a return phone call or struggling to get in to see a Hematologist or HTC provider in your area?
- ChristianaCare HTC wants you to know they offer Telehealth appointments for patients in many states throughout the country. Their HTC NP, Mary Gant, is providing her direct contact phone number for emergent telehealth needs. (302-320-9521).



BVHF is honored to help fund...

- **POSTER CHILD**, a documentary film (in production).
- Directors: [Ryan Gielen](#) [Patrick James Lynch](#)
- In 2007 USA Today's 25th anniversary issue ranked the 25 most influential people on earth since the paper's founding in 1982. Ryan White was listed in the Top 10, between Pope John Paul II and the protestor who stood in front of the tank in Tiananmen Square. Poster Child is the story of how, after contracting HIV/AIDS at age 14 through his tainted hemophilia medication, Ryan White took on his school board, the corporate media complex, and even the president of the United States, Ronald Reagan, in his quest to convince the world to fight the disease, not the person afflicted by it, and in so doing changed the world.



BVHF Board Members & Volunteers

Officers:

*President: Gail
Novak*

*Vice President:
Jennifer Davis*

*Co-Treasurers:
Steve Steinmetz &
Paul Haldeman*

*Treasurer: Tom
Wallace*

Members:

Tara Bolinski,
Michael Gowen,
Kim Hamstead,
Agnesann Mathis,
Chris Ramsey,
Gerry Reed





CHECK OUT OUR WEBSITE UPDATES AT

WWW.BRANDYWINEHEMOPHILIA.ORG

MAKE SURE TO FOLLOW US ON FACEBOOK & TAG

US IN ANY PHOTOS FROM OUR EVENTS!