

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



UPCOMING EVENTS:

Sunday, 12/8/19—BVHF Annual Family Meeting! Lunch & Learn at Mendenhall Inn followed by an outing to Longwood Gardens to tour their Holiday exhibit. Contact Kim Hamstead at kim.hamstead@bofa.com or call 484-508-8262 to reserve your spot!

Next **Big Red Run/Walk** will be May 3, 2020!



National Hemophilia Foundation's 71st Annual Conference, Diary Journal

By: Gail Novak, BVHF Board President & Hemophilia Mom

I was excited to travel across the country to California, a state I had never had the opportunity to visit. BVHF fellow board members Jill and Kim and their families also made the trip, all of us eager to learn what was new in the last year from Manufacturers and Specialty Pharmacies in order to share with our bleeding community upon our return. Three additional families from our community were able to attend the conference sponsored by our foundation grants, which made this year's conference even more exciting.

The conference's education sessions, speakers, and events were split between three beautiful venues in Anaheim in the Convention Center, Hilton, and Marriott. The weather and mountain views and the California sunshine made the location perfect. I chose education sessions about gene therapy, subcutaneous treatment options, and joint health and ultrasounds. I really feel like I learned a lot. New products and services showcased in the Exhibit Hall were also very informative. The Networking and Social events of The Welcome Reception, Final Formation Family Night, and Final Night were fun with games, live music, and food and cocktails.

Our Brandywine Hemophilia Foundation families that attended met for an off- site lunch in Huntington Beach, California which was sponsored by a specialty pharmacy. Afterwards our families spent the day together playing on the beach and catching the All-American Pacific Air show flying over the ocean. California and NHF 2019 did not disappoint this Hemophilia A Carrier, Mom, Advocate, and Foundation Board Member and President.

NHF 2019 PHOTOS:

BVHF Board Members Jill & Gail



BVHF families attending NHF conference 2019





AI Dupont Children's Hospital & Christiana Care Health Systems joint HTC

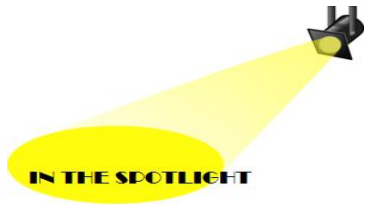
By: *Mary Jones Gant, APRN- BC, RN, RRT, CCM*

In 2018, Christiana Care Health System and Nemours duPont Hospital for children began the process of applying for Hemophilia Treatment Center (HTC) status through the Region III Federally Funded Hemophilia Treatment Centers. The two health centers submitted a combined application since Nemours has the availability to provide care to pediatric patients up to age 21 and Christiana Care primarily had been caring for adults.

Our joint application was approved, and we had a site visit from the Region III leadership to both locations in December of 2018. We were notified in January of 2019 that we were approved for HTC status and could not have been happier. We are now officially known as the ***Delaware Hemophilia Treatment Center***.

This partnership makes us the first of its kind in the Nation! Nowhere else are there two different health systems partnering to provide comprehensive treatment to people with bleeding disorders and we are very proud of that fact. Through this partnership, we will be able to provide care across the lifespan and make transition from pediatric care to adult care seamless. Our teams are working together to establish shared treatment plans as well as transition plans so that our patients are cared for in the best way possible regardless of age or location. Both locations have a dedicated hematologist as well as on call hematologists, nurse coordinators, social workers and physical therapists. We meet as a team quarterly to discuss protocols as well as patients who will be transitioning and records are shared so that the patient does not have to worry about taking care of that process.

We look forward to serving the bleeding disorder community for years to come!



Research Spotlight: CHOP Hemophilia A Gene Therapy

CHOP (Children's Hospital of Philadelphia) Hemophilia and Bleeding Disorders Program was established in 1973 to provide families with a comprehensive, family-centered approach to care. CHOP not only treats bleeding disorder patients but is actively involved in research to improve the care of patients.

Gene therapy for Hemophilia A holds the promise of providing lifelong protection from bleeding after a single administration of the medicine. Recent clinical trial success for gene therapy for hemophilia B has demonstrated the potential of gene therapy for inherited bleeding disorders. However, hemophilia B gene therapy has dramatically benefited from the use of a naturally occurring factor IX variant (factor IX Padua), which dramatically enhances the potency of the gene therapy product. There is currently no analogous factor VIII variant to factor IX Padua that could similarly supercharge hemophilia A gene therapy. The goal of CHOP's research project is to make such a factor VIII variant.

Brandywine Valley Hemophilia Foundation is a proud sponsor of this very important research!



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If you would like to send a End of Year Giving gift to support Brandywine Valley Hemophilia Foundation, please mail to: **BVHF, P.O. Box 56, Pocopson, PA 19366.**

Check out our Website updates at www.Brandywinehemophilia.org

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