

# 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:**

**Brandywine Red Run 5K: Sunday, 5/2/21 at Bellevue State Park**

**More info To Be Announced Soon on:**

**Annual Blue Rocks Family Night: Friday 6/4/21**

**Spring Wine Tasting/Education Fundraiser: Saturday, 6/12/21**

<http://brandywinehemophilia.org>



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# BRANDYWINE **RED** RUN 5K Run/Walk

8:00AM Registration Opens

9:00AM 5K begins

And the fun continues

**Bellevue State Park, 800 Carr Road, Wilmington, DE 19809**

Medals for overall female and male winners 5year age groups will be awarded 1st, 2nd, and 3rd place medals. A virtual 5k has been added as well. If registering for virtual 5k, requested t-shirt and/or medal will be forwarded to you after you submit a photo and/or time of completed miles.

Sign up at:

<https://runsignup.com/Race/DE/Wilmington/BrandywineRedRun>

- 5k Preregistration by January 31st, 2021: \$25
- 5k Registration after February 1st, 2021: \$30
- 5k Registration day of event –cash only: \$35
- 5k Registration –Virtual \$30

Due to COVID, the state of DELAWARE currently encourages outdoor gatherings up to 250 people since they pose a lower risk of infection and are encouraged as alternatives to indoor events. If this mandate changes, the race will move to an all virtual event and t-shirts and medals will be delivered to registered participants.

Want grant PRIZE help to attend National Hemophilia Conference in Denver, CO 2021, or next live conference?  
Team Captain raising the most \$ for Foundation at BRR 2021 receives \$1500 PRIZE \$

For more information, email Gail Novak, Race Director at [gvannicola@verizon.net](mailto:gvannicola@verizon.net)

# BVHF 2021 Student Scholarship



All of us at Brandywine Valley Hemophilia Foundation know these past months have been enormously difficult for students trying to complete courses and create an academic path forward. We recognize your steadfastness and hope the availability of this scholarship makes your road forward easier.

BVHF is pleased to make available a \$2000.00 scholarship to an individual within our service area whose life is impacted by hemophilia or other significant bleeding disorder. Once chosen as the recipient, the scholarship will be renewed for a maximum of four years providing 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 who has been diagnosed with hemophilia or other significant bleeding disorder. 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. Evidence of this must be provided by your clinician or HTC.

**DEADLINE FOR APPLICATION: June 30, 2021**

**NOTIFICATION OF ACCEPTANCE: July 9, 2021**

**An application must be submitted that includes the following:**

1. Application form
2. Essay
3. Two Personal References (one must be from an individual who can identify you in relation to hemophilia or other bleeding disorder and its impact on your life)
4. Evidence of diagnosis through clinician or HTC
5. Record of academic transcript if applicable

To Download the application form & instructions for submission:

<http://brandywinehemophilia.org/scholarships.html>

# COVID-19 Vaccination Guidance for People with Bleeding Disorders

Guidance from the World Federation of Hemophilia (WFH), European Association for Haemophilia and Allied Disorders (EAHAD), European Haemophilia Consortium (EHC), and U.S. National Hemophilia Foundation (NHF).



It is important that hemophilia treatment centers, in close collaboration with patient organizations, take action to inform people with bleeding disorders about the COVID-19 vaccines and contribute to an effective vaccination program.

1. People with bleeding disorders are not at greater risk of contracting COVID-19 or developing a severe form of the disease, so they are not considered a priority group for vaccination.
2. The vaccine should be administered intramuscularly. The smallest gauge needle available (25-27 gauge) should be used, if possible. Some vaccines must be administered using the accompanying needle–syringe combination, and so the use of an alternative needle may not be possible or desirable. Pressure should be

applied to the site for at least 10 minutes post-injection to reduce bleeding and swelling. Additionally, self-inspection/palpation of the injection area several minutes and 2-4 hours later is recommended to ensure that there is no delayed hematoma. Discomfort in the arm felt for 1-2 days after injection should not be alarming unless it worsens and is accompanied by swelling. Any adverse events (e.g., hematoma, allergic reaction) should be reported to a hemophilia treatment center.

3. Patients should contact their physician immediately or go to the nearest hospital emergency room right away if they experience an allergic reaction (fever, warmth, redness, itchy skin rash, shortness of breath, or swelling of the face or tongue) as it can be life-threatening. Patients with a history of allergic reactions to extended half-life clotting factor concentrates containing polyethylene glycol (PEG) should discuss vaccine choice with their physician because some vaccines contain PEG as an excipient.
4. Many individuals with bleeding disorders may not have ready access to hemostatic therapies prior to vaccination. In these cases, make efforts to access other clotting factors if possible. Alternatively, follow the instructions above making sure the smallest possible needle is used and maintain pressure for more than 10 minutes.
5. For patients with severe/moderate hemophilia, the injection should be given after a factor VIII (FVIII) or factor IX (FIX) injection. For patients with a basal FVIII or FIX level above 10%, no hemostatic precautions are required.
6. Patients on emicizumab (with or without an inhibitor) can be vaccinated by intramuscular injection at any time without hemostatic precautions and without receiving a dose of FVIII.
7. Patients with Type 1 or 2 Willebrand disease (VWD), depending on their baseline von Willebrand factor (VWF) ristocetin cofactor (RiCof) activity levels, should use therapies (i.e., DDAVP if available, tranexamic acid), in consultation with their hemophilia treatment centre. Patients with Type 3 VWD should be given a VWF-containing injection.
8. All rare bleeding disorder patients (including those with thrombocytopenia and/or platelet function disorders) should be vaccinated. Patients on anticoagulants should have prothrombin time testing performed within 72 hours prior to injection to determine international normalized ratio (INR); if results are stable and within the therapeutic range, they can be vaccinated intramuscularly.

9. There are no specific contraindications to vaccination related to complications of hemophilia and other bleeding disorders or their therapies. Immune tolerance, treatment of hepatitis C and HIV, and other conditions do not contraindicate vaccination.
10. Vaccination is not contraindicated for patients on immunosuppressive agents (cortisone, other immunosuppressive drugs).
11. Potential contraindications should be discussed individually with the physician because recommendations vary in different jurisdictions due to lack of data in special populations (e.g., pregnant or breastfeeding women).
12. The U.K. Medicines and Healthcare Products Regulatory Agency and the U.S. Centers for Disease Control and Prevention have advised caution in using the Pfizer/BioNTech vaccine in people with a history of significant allergic reactions. Specific recommendations for people with a history of allergic/anaphylactoid reactions can be found in the advisory published by each agency.
13. For patients in a clinical study, vaccination should be reported to the study investigators.

Information will be updated on the [WFH](#), [EAHAD](#), [EHC](#), and [NHF](#) websites as needed.

<https://news.wfh.org/covid-19-vaccination-guidance-for-people-with-bleeding-disorders/>



**Saturday June 12, 2021**  
**Spring Wine Tasting/Education Celebration**



Please join the Brandywine Valley Hemophilia Foundation for a late afternoon gathering including Raw Bar and Hors D'oeuvres, Educational Exhibits and speeches, raffle tickets for prizes. \$100/per person.

*A discount is available for patients with a bleeding disorder or their caregivers: \$60 per person*

**Fieldstone Golf Club  
1000 Dean Road  
Greenville, DE 19807**

\*This event is for age 21 or older

RSVP to Board Member and Chairman of this event: Stephen Steinmetz 610-235-1229.

# Want to help the BVHF Spring Raffle Fundraiser?



Contact Jennifer Davis if you would like to donate: [Jenny2Davis@gmail.com](mailto:Jenny2Davis@gmail.com) or 302-312-6244

**It is with great pleasure that the entire Brandywine Valley Hemophilia Foundation welcomes Tara Bolinski as our newest BVHF Board member!**



Tara Bolinski is a newer member of the bleeding disorder community. She is the mother of one toddler, with a new baby on the way. Her son Walter has severe hemophilia A. Walter was diagnosed when he was circumcised shortly after birth. Since this diagnosis, Tara has also learned that she is a hemophilia carrier. Upon learning about Walter's diagnosis, Tara and her husband Rob felt it was extremely important to gain the education needed to advocate for their son. Tara became involved with the local Foundation as a way to connect with those in the bleeding disorder community and has enjoyed being a part of the fundraising, including forming Team Walter for the annual 5k. Welcome Tara!



# HFA NEWS

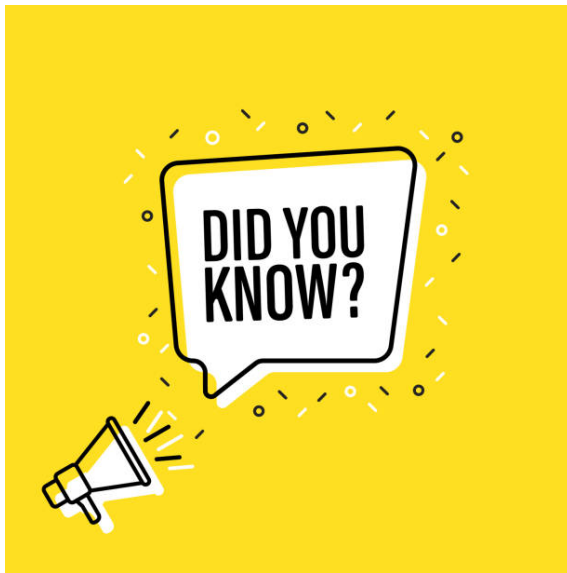
## Hemophilia Federation of America Offers \$1000 Grants to Learn New Skills and Help Land Your Dream Job!

**Deadline to Apply: Friday, April 30**

Could you use \$1000 to gain a skill or certification to help you get a job? Are you an adult (age 18 – 64) with a [bleeding disorder](#)? You may be eligible for an HFA Job Readiness Grant! From bookkeeping to blogging, Scrum Master to Salesforce Administrator, coder to Certified Property Manager, we're here to support your goals. Not sure where to start? The Career Planning course on HFA's own [Learning Central](#) will set you up for success!

<https://www.hemophiliafed.org/news-stories/2021/04/hemophilia-federation-of-america-offers-grants-for-patients-to-learn-job-skills-gain-certification/>





## National Hemophilia

### Foundation:

2021 Bleeding Disorder Conference is Virtual!

August 25, 2021 at 1:00 PM - August 28,  
2021 at 5:15 PM





**amazon**smile  
You shop. Amazon gives.

Do you shop on **Amazon**? Did you know that your shopping on Amazon can help support BVHF without costing you any extra money? Simply register on **Amazon Smile** and choose ***Brandywine Valley Hemophilia Foundation*** as the organization you want your shopping proceeds to go towards.

Check out our Website updates at [www.Brandywinehemophilia.org](http://www.Brandywinehemophilia.org)

**Make sure to follow us on Facebook & tag us in any photos from our events!**

\*If you are interested in having advertising space to sponsor our next Newsletter, contact [GVannicola@verizon.net](mailto:GVannicola@verizon.net)

Do you have recommendations/requests of what you would like to see in our next Newsletter? Contact

[Jenny2Davis@gmail.com](mailto:Jenny2Davis@gmail.com)