

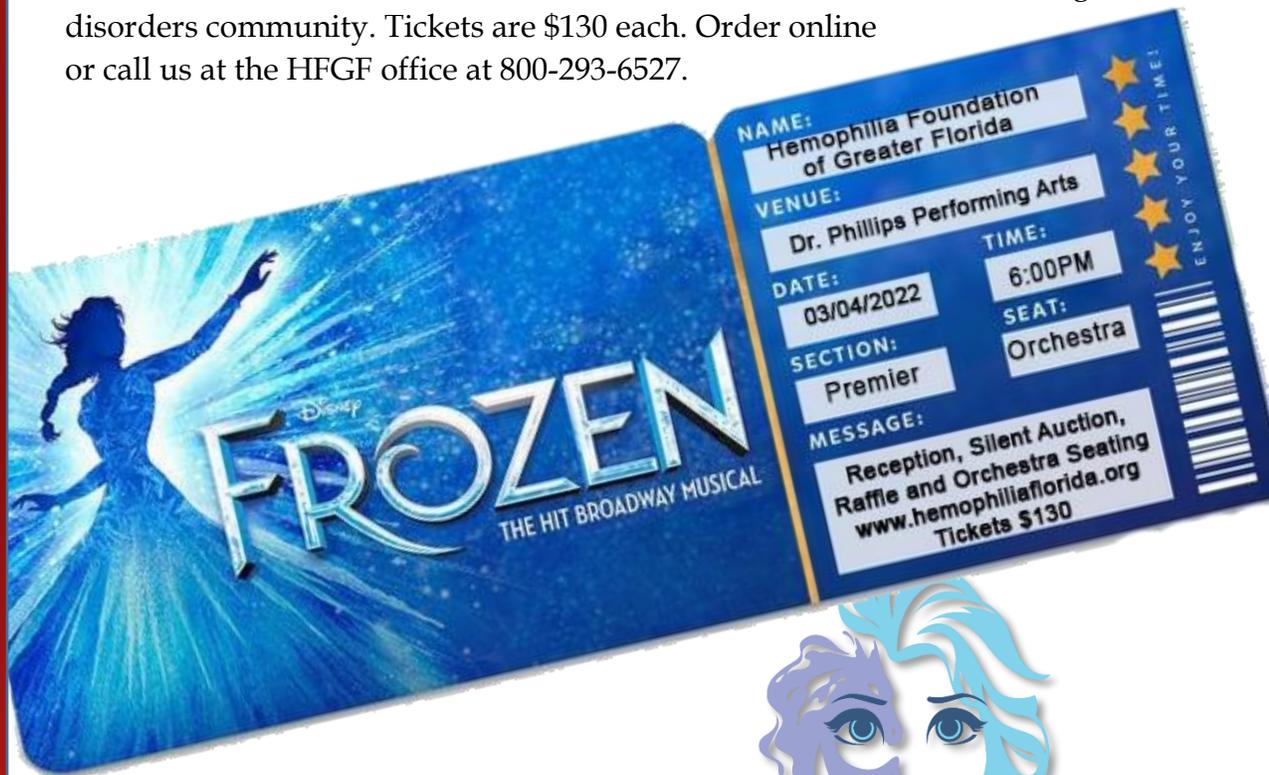
What's Inside

- [Page 1](#)
19th annual Evening on Broadway
- [Page 2](#)
Executive Directors Column
- [Page 3](#)
Calendar of Events
- [Page 4](#)
Research Update
- [Page 5](#)
Women with Bleeding Disorders
- [Page 6](#)
2021 in Review
- [Page 7](#)
Meet Sarah Deason
- [Page 8](#)
Meet Sarah Deason Contd.

Get Your Tickets Now or Risk Being Frozen Out

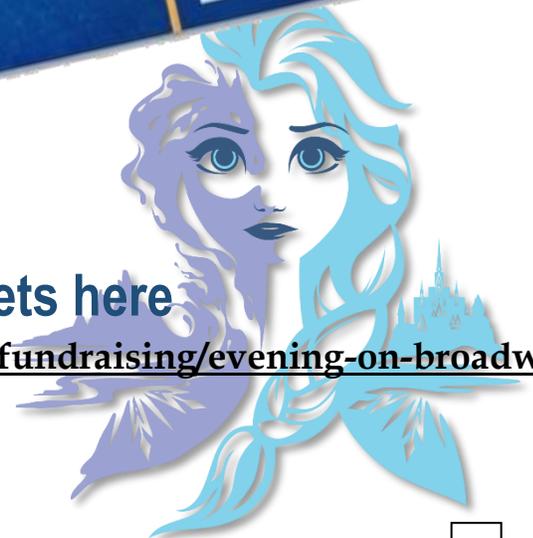
It's time for the 19th annual Evening on Broadway. Join us Friday, March 4 for an evening of magic at the Dr. Phillips Center of Performing Arts for a performance of the touring Broadway show Frozen, which has gotten rave reviews.

The evening includes a private reception, orchestra seating, and a silent auction and raffle to raise funds to further the work of the HFGF for the bleeding disorders community. Tickets are \$130 each. Order online or call us at the HFGF office at 800-293-6527.



Order tickets here

<https://www.hemophiliaflorida.org/fundraising/evening-on-broadway>



The Hemophilia Foundation of Greater Florida publishes HFGF Connections quarterly

Board of Directors

President Pete Vrochopoulos
Vice President Mike Berkman
Secretary/Treasurer Eileen Gregory
Alan Apte
Patrice Bravo
Hector Cartagena
Joe Riggs
Jose Villarreal Charis
Katie Hawkins

Staff

Executive Director, Fran Haynes
Outreach and Education Nurse,
Missy Zippel
Development & Marketing Specialist,
Bonnie Schwartz

Physical and Mailing Address

The Hemophilia Foundation of Greater Florida
1350 Orange Ave. Suite 227
Winter Park, Florida, 32789
Tel. 407-629-0000
Toll-Free 800-293-6527
Fax 407-629-9600
Email: info@hemophiliaflorida.org
Web: www.hemophiliaflorida.org

Mission

Our mission is to improve the quality of life for people with bleeding disorders and their families through education, information and referral services, advocacy and research.

Disclaimer

The material provided in HFGF Connections is for your general information only. HFGF does not give medical advice or engage in the practice of medicine. The HFGF does not recommend particular treatments for specific individuals and recommends that you consult your physician or treatment center before pursuing any course of treatment.

Executive Director's Column



Dear Friends,

Happy New Year! I hope everyone is having a happy and healthy 2022 so far.

"Volunteering is at the very core of being a human. No one has made it through life without someone else's help." – Heather French Henry

We are so happy to be able to offer quality programs and services, but we need your help. Therefore, I am asking everyone today to please share some of your time in 2022.

Here are some of the available volunteer opportunities:

- Office Volunteer to help with data entry and other tasks.
- Committee Volunteers to assist with the walks and programs.
- Camp Volunteers.
- Day of Event Volunteers: We sure can use about 25 or more volunteers at our walks to help with registration, food booth and the raffle table just to name a few of the opportunities.
- Walkers: All walkers are volunteers.
- In-kind donation Volunteers: Help us obtain donated items for our auctions and events.
- Program Volunteers: to assist with registration.
- Advocacy Volunteers: Reach out to our legislators and help us get important legislation through the government maze.
- Volunteers to assist us in getting proclamations for Bleeding Disorders Awareness Month.

We have so many great opportunities, and we offer community service hours to our high school and college volunteers. Please reach out to us at info@hemophiliaflorida.org, and if we do not get back to you right away, do not give up on us – we really need your help.

We look forward to working with you for an amazing 2022.

Warmest Regards,

Fran

DID YOU KNOW?



**March is
Bleeding
Disorders
Awareness
Month**

HFGF Connections

Calendar of Events



February 25-26, 2022- Stakeholders Meeting, Winter Park
March 4, 2022 - 19th Annual Theater Event, Orlando
March 11, 2022 - Family Dinner Columbia Restaurant, Tampa
March 14-15, 2022 HTC Florida State Meeting, Winter Park
April 9, 2022 - Gainesville Clot Trot Walk/Run
More Information:
<https://www.hemophiliaflorida.org/events/list/>

REMEMBER THIS DEADLINE

Applications for 2022 Calvin Dawson Memorial Scholarships are due by:
April 30, 2022

Candidates must be Florida residents with a bleeding disorder pursuing education at a college, university or trade school. For more information and a link to the Application form, go to <https://www.hemophiliaflorida.org/what-we-do/scholarships/>

Walk – or Run – to Raise Funds to Support the Work of the HFGF

Join one of our walks or runs and help raise awareness about bleeding disorders. The funds raised support the community through the programs and work of the HFGF including Camp Spirit, a week-long camp for children with bleeding disorders; the Scholarship program; the Emergency Assistance Fund for help with rent, medical insurance and dental care; Medic Alert bracelets and helmets; Education Programs for the bleeding disorders community; and legislative advocacy for bleeding disorders.

Choose a location – register online – fundraise - make a difference.

For fundraising help at <https://www.hemophiliaflorida.org/walks-5ks/>.



Follow us on:



HFGF Connections



Clinical Study and New Website to Focus on von Willebrand Disease and Pregnancy

The onset of childbirth and the postpartum period are times when women with von Willebrand disease (VWD) are at an increased risk for excessive bleeding, exposing them to further, and in some instances, serious complications. While there exist therapies with VWD-specific indications, it is not uncommon for these patients to still experience excessive bleeding while receiving treatment. These scenarios are challenging, as there is sparse clinical data and a subsequent lack of clear guidance on the optimal management of bleeding in these particular settings.

The von Willebrand factor in pregnancy (VIP) study was therefore developed to enhance understanding of how best to manage bleeding during delivery and the postpartum period in women with VWD. Investigators for this prospective, multicenter trial will focus on maintaining von Willebrand factor (VWF) levels at a specific target level using VWF replacement therapy, and assessing the impact on bleeding rates during and after childbirth.

The VIP study is being stewarded by a trio of experienced principal investigators including Drs. Jill Johnsen (Bloodworks and University of Washington), Barbara Konkle (University of Washington), and Dr. Peter Kouides (Mary M. Gooley Hemophilia Center and University of Rochester). The VIP Study is currently recruiting pregnant women in the U.S. above 18 years of age with VWD of any type.

An exciting component of the VIP is a new companion website, created to keep patients and healthcare professionals informed about the study. It will provide information on VIP's design, patient eligibility, and locations of participating centers. The site was officially launched on December 10th during an educational webinar that preceded the American Society of Hematology Annual Meeting.

Source: PR Newswire/The VIP Study, November 28, 2021

HFGF Connections

Period Kits Program for Women and Teenage Girls with Bleeding Disorders

The HFGF collaborated with the Arnold Palmer Hemophilia Treatment Center (HTC) to develop Period Kits to help teens and women with Bleeding Disorders manage their disorders. According to the Medical and Scientific Advisory Council (MASC) of the National Hemophilia Foundation, it is important that the national outreach and education initiative regarding the role of inherited bleeding disorders in bleeding among women and teenage girls be continued.

Several hundred Period Kits will be distributed through all Florida pediatric and adult HTCs. Including Arnold Palmer Children Nemours Children's Clinic (Jacksonville), St. Joseph's Pediatric and Adult HTC (Tampa), University of Florida Adult and Pediatric HTC (Gainesville), University of Miami Pediatric and Adult HTC, Miami Children's HTC, University of South Florida Adult HTC (Tampa), All Children Hospital Pediatric HTC (St. Petersburg), as well as at HFGF programs and events for women.

The contents of the Period Kits include but are not limited to the following: sanitary pads, ice pack, water wipes, hand sanitizer, educational information, treatment options and miscellaneous items. The use of the kits and managing a bleeding disorder are discussed with the recipient. This has encouraged the patient the opportunity to ask questions and discuss all aspects of their bleeding disorder. The success of the Period Kits has been overwhelmingly positive.

HFGF would like to take this opportunity to thank our sponsors for helping make the Period Kits program possible:

CSL Behring
Biotherapies for Life™

Pfizer


novo nordisk®

octapharma®



HFGF Connections



Our 25th anniversary year was a full one with the return to in-person events and a continuation of our programs benefitting the bleeding disorders community. The Coronavirus pandemic did have an impact on some of our fundraising efforts and curtailed some events. We are looking forward to 2022: hoping for a healthier year for all, and with a renewed sense of mission.

Emergency Financial Assistance

In 2021, HFGF distributed \$91,000 in emergency assistance funds, due to increased need caused by the pandemic, for such uses as:

- Medic Alert bracelets and renewals
- Comfy Cap helmets
- Rent/Mortgage assistance
- Utility bills
- Medical services assistance
- HTC transportation assistance
- Holiday cards for groceries and gifts for children

Camp

Due to the Coronavirus, Camp Spirit was not held this year. Instead, HFGF hosted three Family Retreat Weekends at Camp Boggy Creek for 10 families each, in April, July and October.

Education Programs

- Holiday programs - Advocacy - Bleeding Disorder Trivia - Dinners
- Teen Programs - Family Programs - Women's Programs - Virtual Programs

Scholarships

Fourteen scholarships totaling \$25,700 were bestowed on Florida residents with bleeding disorders pursuing college, university or trade school.

Advocacy

In 2021, HFGF focused its advocacy efforts with the Florida legislature on the topic of Co-Pay Accumulators, an issue that affects the entire bleeding disorders community. Right now, co-pay assistance programs from pharmaceutical manufacturers do not count toward a patient's cost-sharing requirements. A recent study showed that when patient costs hit \$250 or more, 70% of new patients leave the pharmacy without their medication. While the profile of this issue was raised with legislators during 2021, a bill was not passed. HFGF plans to continue its work on this vital issue of equal access to medication in 2022.

HFGF Connections

Meet Social Worker, Sarah Deason

My name is Sarah Deason, and I serve as a social worker for the HTC at The University of Florida. I want to take this time not only to introduce myself but also to introduce (or further explain) the role of social work in the bleeding disorders community. I work with both pediatric and adult patients with bleeding disorders.

I came to my current role with eight years of experience in social work and case management in various clinical and non-clinical settings. My greatest joy in this field is building relationships with my patients in addition, advocating for them in every way that I can.

For patients with hemophilia, von Willebrand disease or other bleeding disorders, effective, comprehensive care includes a visit to a Hemophilia Treatment Center (HTC). Patients who visit the University of Florida Hemophilia and Hemostasis Treatment Center will be evaluated by a multidisciplinary team of hemophilia experts including a hematologist, nurse coordinator, social worker, and, when appropriate, a physical therapist.

I want to thank you for taking the time to read this information. I am excited to be here to support the bleeding disorders community, and I look forward to getting to know many of you at upcoming events. Please feel free to reach out to me with any questions.

Sarah Deason, MBA | **Clinical Case Manager II**

Hemophilia Treatment Center 340B Program | *Division of Hematology/Oncology*

Department of Medicine | **College of Medicine** | **University of Florida**

sarah.deason@medicine.ufl.edu

1600 SW Archer Road

PO Box 100278

Gainesville, FL 32610- 0278

(352) 273-7833

