

In this Issue

- Page 1
8th Annual Gator Clot Trot
- Page 2
Calendar of Events
- Page 3
Planned Giving
- Page 3
Bombardier Blood
- Page 4
Social Work Resources
- Page 5
HFGF Volunteer Resources
- Page 6
Hemophilia Treatment
Centers
- Page 8
Your Year to Fundraise!



Schedule of Events

- 7:00 a.m. Check-in and registration opens
7:50 a.m. registration closes (our volunteers want to run/walk, too!)
8:00 a.m. Line up at starting line
8:05 a.m. 5K and Walk starts!
10:00 a.m. Awards ceremony

Register at:

<http://www.hemophiliaflorida.org/Gainesville>

**AWARDS FOR TOP RUNNERS, FUNDRAISERS, AND TEAM WITH THE BEST
GATOR GEAR!**

**5K
AND
FUN WALK**



**• FOOD
• FUN
• GAMES**

toll free 800-293-6527
www.HemophiliaFlorida.org

Published quarterly by
The Hemophilia Foundation of
Greater Florida
Board of Directors
President Pete Vrochopoulos
Vice President Mike Berkman
Secretary/Treasurer
Eileen Gregory
Ed Bookbinder
Hector Cartagena
Joe Riggs
Jose Villarreal Charris LCSW

Staff
Executive Director, Fran Haynes
Development Manager
Leah Nash
Social Worker, Dina Richardson
Outreach Nurse, Missy Zippel
Office Administrator,
Shannon Baidenmann
Volunteer Coordinator,
JoAnn Brownrigg

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
The mission of the Hemophilia
Foundation of Greater Florida is
dedicated to improving the quality of
life for people with related bleeding
disorders and their families through
education, information and referral
services, advocacy and research.

Disclaimer
The material provided in HFGF Con-
nections is for your general informa-
tion only. HFGF does not give medi-
cal 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.

Dear Friends,

Happy New Year! I hope everyone has a healthy and happy 2019. We have some great programs and services this year.

Keep an eye out for our new website—we will be unveiling it soon—it promises to be easier to navigate, and we will have the most updated information for you.

We have a very special program March 16, 2019 “Bombardier Blood.” Experienced mountaineer Chris Bombardier has never let severe hemophilia B stop him from summiting some of the world’s tallest mountains. In 2017, Chris partnered with the WEBBY-Award winning production team at Believe Limited to film his journey through Nepal to summit the world’s tallest peak, Mount Everest. We will be showing “Bombardier Blood” at the AMC theater at Westshore, Tampa Florida.

Our Gainesville walk is around the corner. Register—we need your support. Did you know that our walks help us provide programs and services to the community? Ninety-one cents of every dollar raised goes back into the community.

We have so many exciting things planned for you...camp, family retreat weekend, teen programs. Check out our calendar for dates, times, and locations.

I hope to see everyone soon.

Warmest Regards,

Fran



February 22, 2019 – Tattoos & Piercings , Orlando, Florida

March 16, 2019 – Bombardier Blood film, Tampa, Florida

March 23, 2019 – Gainesville Clot Trot, Depot Park, Gainesville, Florida

March 27-28, 2019 – Washington Days, Washington, DC

April 7, 2019 – Tampa Super Hero Walk, Al Lopez Park, Tampa, Florida

June 19-24, 2019 – Camp Spirit, Camp Boggy Creek, Eustis, Florida

April 17-18, 2019 – Bleeding Disorders Coalition of Florida Legislative Day

[CLICK HERE](#) to subscribe to our email to receive notices and updates of all our upcoming programs and events



Planned Giving, the HFGF, and You

The Hemophilia Foundation of Greater Florida (HFGF) uses the planned gifts of donors to strengthen its financial position and provide continued benefits to the bleeding disorders community in the future.

Planned giving involves giving a charitable donation during your lifetime or after death. It is best done as part of your overall financial and estate planning. Since there are legal and tax implications, planned giving may require the help of professionals.

But there are some simple ways to set up a planned gift that anyone can do:

Bequests, gifts made through a will, can be set up easily by your attorney in your will, sometimes with only a couple of sentences.

Another way to remember the HFGF quickly and easily is to make the foundation the beneficiary of all or part of the proceeds from a life insurance policy.

A third way to remember the HFGF in your estate is to designate the organization as the beneficiary of all or part of the remaining balance in a retirement account (IRAs, 401Ks, 403Bs, or pension plans). Simply notify the plan administrator of your intentions.



A fourth method for easily remembering the foundation is make a financial service products, such as a certificate of deposit or a bank account, payable upon death to the HFGF.

Your planned gift now will go a long way to ensuring continuing benefits to Florida's bleeding disorders community.

Contact Leah Nash at Leahnash@hemophiliaflorida.org to discuss your planned giving options

See the Film Bombardier Blood

Mountaineer Chris Bombardier, the first Hemophiliac to have conquered the Seven Summits, was filmed as he summited Mount Everest in Nepal. The documentary records his six months of training for the ascent and follows him to Base Camp, where Chris launched his successful effort to reach the summit, filming the final ascent himself. The film also depicts the shameful plight of Hemophiliacs living in Nepal, and their struggles in the wake of the country's devastation after a major earthquake.

You can see this breathtaking and inspiring film on Saturday March 16 at the Westshore AMC theater in Tampa, Florida. Call the HFGF at 800-293-6527 to RSVP or info@hemophiliaflorida.org Seats are limited.





Social Work Resources





By Dina Richardson, MSW






you know that there are potential funding sources available? We are now at the mid-point of the school year, a perfect time to really assess the financial needs of the graduating high school students continuing their education. When trying to find out what scholarships are available for a person, it's always a great idea to start with the student's high school guidance counselor. If the person has bleeding disorders, there are specific scholarships that they can apply for, starting right here at HFGF!! We have a scholarship program that is available ,and you can find the information at: www.hemophiliaflorida.org/scholarships.html. On top of that, the Hemophilia Federation of America has a list of scholarships. Their list can be found at hemophiliafed.org. It is important to start this process, if you haven't already, as each scholarship has its own deadline, and you don't want to miss out.

Nowadays, there are so many options available for kids as they decide what lies in their future. Work? Trade school? College or university? Travel? And many more. If further education is the decision, did

Requirements for HFGF Scholarship:

-  Florida Resident
-  Must have hemophilia, vWD, or other related inherited bleeding disorders.
-  High school graduate pursuing post-secondary education at college, university, technical school, or trade school.
-  Applicant must have volunteered with HFGF or another program/foundation/treatment center within the bleeding disorders community in the past year.

Application must include:

-  Completed application.
-  Three references by either an employer or teacher (reference from family and/or friends will not be allowed).
-  Current transcripts.

Application deadline is April 30, 2019.



Meet Your Legislators

The fall elections are over and new federal and state legislators have taken their seats. Now is a great time to say hello and congratulate them on their election victory (regardless of party). Introduce yourself, talk about your or a family member's bleeding disorder, and how the disorder affects your lives.

To find out who your government representatives are, go to:

<http://www.leg.state.fl.us/>.



HFGF Volunteer Spotlight

When your father is the local high school football coach, and you are his only son with Hemophilia, growing up can be a bit disconcerting. “When I was 10 years old, I taught myself to kick field goals and punt,” recalls Brett Sherman, 2019 Gator Clot Trot Committee Chair. It was his attempt to somehow fit in and play the sport his father loved so much. “But then dad sat me down and told me that I was never going to play football.”

So, Brett took up golf, swimming and baseball. Still, classmates teased him about not playing football.

“Kids are mean,” he says. “It used to bother me a lot in middle school. But then, I got so good at golf, no one bothered me about it anymore. Things got easier.”

Taking up golf proved to be the answer for young Brett. The sport kept him active growing up, and he traveled the world playing in tournaments. He decided to make the sport his career and enrolled at Florida State University and earned a degree in Golf Course Management. Now 36, Brett has managed a 63-hole facility in The Villages for the past 14 years.

Diagnosed at birth with Severe Hemophilia A in Kentucky, the family moved to Central Florida when Brett was three months old. That trek south proved to be a moment in time he may not remember but set a course for treatment still with him today.

“We were on the road moving from Kentucky, and we

had a car accident,” he says. “No one was hurt, but my father told the paramedics that his son had Hemophilia. He was shocked they knew what it was. I was taken to Shands [Hospital in Gainesville] as a precaution.”

Brett received his first infusion that day and has remained a Shands patient ever since.

Brett, who lives in Bushnell with his wife Landi, son Landen, and daughter Delani, has been involved with the Foundation on some level or another since arriving in Florida.

“I think we got involved when the Foundation began,” he says. “I remember going to golf outings and dinners.” This is Brett’s first foray into chairing a Foundation Walk, scheduled for March 23 at Depot Park in Gainesville.

While Brett was never able to play football for his dad, the story does have a happy ending. Brett’s son, who is the same age Brett was when he was told that football was not in the cards, plays Pop Warner football and Brett and his dad, Inman, coach the team. Inman retired after coaching more than three decades at South Sumter High School.

“Before a big rivalry game, I tell him my son, ‘I never got to play these guys so you have to beat them for me,’” he laughs. “And while I never did get to play, I can still make field goals to this day.”



Brett Sherman
Resides: Bushnell
Hometown: Bushnell

Involvement with HFGF: 36 years

When you shop with
amazon.com
Smile
they'll donate to
The Hemophilia Foundation of
Greater Florida

HIGH SCHOOL STUDENTS
EARN COMMUNITY SERVICE HOURS

VOLUNTEER FOR THE HFGF

CONTACT US AT 800-293-6527 or
info@hemophiliaflorida.org



Hemophilia Treatment Centers: Lifelines of Care

There is no place like home. And that is exactly how Heather Frederick feels when she and her five-year-old son Hunter Miller visit the Hemophilia Treatment Center (HTC) at Orlando Health's Arnold Palmer Hospital.



"They are amazing," she says. "They know our names and make us feel like family."

Hunter, who was diagnosed with severe Hemophilia A one week after birth, visits the center every six months with his mom for checkups and lab work. With regular comprehensive care at the HTC and factor infusions twice a week, Hunter has avoided any complications or episodes.

Born out of an idea in the 1970s to create a network for men, women and children with bleeding disorders, federally-funded HTCs are designed to care for and treat the whole person and their families throughout the patient's life. The concept is so revered, advocates of other chronic conditions have opened similar centers.

"The idea is to provide for patients and their families dealing with this lifelong condition," says Dr. Joanna A. Davis, MD, Associate Professor, Medical Director of Pediatric Comprehensive Hemophilia Treatment Center at the University of Miami. "By belonging to this network of HTCs, they have access and the ability to participate in programs and initiatives."

Dr. Davis, who launched the Miami HTC 35 years ago, says HTCs act as both a referral source for community physicians and a primary hematology provider for patients. Following guidelines of the National Hemophilia Foundation (NHF), HTCs provide core services and staff including physical therapists, nurse practitioners, hematologists, social workers and orthopedists.

Not all HTCs are the same, however, giving them the autonomy to support patients who in turn support their respective HTC. All offer comprehensive care. Some provide in-house

dental care, while others utilize a referral network for dentistry. Others provide more extensive education, research and outreach. The Orlando HTC provides a dietician.

Moreover, HTCs that are part of the federal government's 340B program are allowed to access and sell factor to patients at a discount and use proceeds to support HTC services.

"The money goes back into the bleeding disorders community," says Dr. Shveta Gupta, a physician with the Haley Center for Children's Cancer and Blood Disorders at Arnold Palmer Hospital for Children and director of the Orlando HTC, which is in its infancy and on the verge of joining the 340B program.

"The 340B program is a win-win," adds Dr. Davis, who depends on factor-sale proceeds for payroll assistance, including the entire salary of her physical therapist. "The insurance company is happy not to pay so much, and we are happy because we can increase our offerings by retuning money to the hemophilia program."

In Gainesville, those funds pay for half of the nurse coordinator's salary, but the goal is to use 340B funds to further support the HTC and continue to serve both children and adults.

"We are a whole life center," says Dr. Tung Wynn, Assistant Professor Pediatric Hematology/Oncology and Director of the Pediatric Hemophilia Treatment Center at UF Health Shands Children's Hospital for past seven years. "From birth to death, we care for the entire person."





Hemophilia Treatment Centers: Lifelines of Care *cont'd*

Dr. Wynn, whose center serves 250-300 patients annually, believes there are misconceptions about HTC causing some eligible patients to bypass available care. One is that HTCs are only for those with Hemophilia. Not true, he says, noting HTCs care for anyone with Thrombosis and other clotting disorders as well. And while there are certain insurance providers who may not cover HTC visits, a member of the bleeding disorders community is always welcome in Gainesville.

“Everyone is eligible for care,” he says. “We won’t turn anyone away.”

Beyond insurance coverage acting as a deterrent not to frequent an HTC, distance is also an issue, says Dr. Wynn. Of the 141 centers and programs in the country, Florida is home to nine HTCs spread out across the state. Patients in rural areas may need to drive three to five hours to visit the closest center.

Dr. Davis adds that she sees a lack of awareness and recognition of HTCs that prevents more patients from coming through her doors.

“Bleeding disorders are not sexy and not a money maker,” she explains. “Our HTC is the best kept secret at the University of Miami. Beyond our tight, little circles the awareness, support and excitement is not there.”

Odessa resident Joe Riggs, a former regular patient at the Gainesville HTC before switching to the closer-to-home University of South Florida Adult Comprehensive HTC, is a firm believer of the care and services provided by HTCs. He takes full advantage of annual checkups, spending time with his hematologist, discussing mobility issues with a physical therapist and receiving insurance updates.

“It really has been a great experience,” says Joe who is in touch with his HTC once a month to report in and order fac-

tor. “They are the quarterback for my care and treatment.” When it was time for a colonoscopy, the HTC found Joe a gastroenterologist familiar with Hemophilia. When his dentist retired, HTC personnel located a new dentist. With help from the HTC, Joe is now infusing with long-lasting factor, which has changed his life.

“While I was on vacation, I only had to infuse three times in two weeks and remained physically active,” says Joe, 55, who was featured on a panel titled “Live Long and Prosper” at the 70th Annual NHF Bleeding Disorders Conference this fall. “I am more active now than I was in my twenties.”

Unlike Joe, though, Dr. Gupta finds that some patients and families do not understand the concept of an HTC, such as who can make an appointment and what services are included with those visits. Most are not aware that HTC care is proven to be highly beneficial, especially for Hemophiliacs.

“There may be certain disorders for which you can go to a Hematologist, but for Hemophilia, they should come to us,” she says. “We can offer 100 percent better care and support services.”

“Patients who receive care at HTCs have a better quality of life,” adds Dr. Wynn, citing a CDC study. “Those with Hemophilia who accessed an HTC were 40 percent less likely to die of a Hemophilia-related complication and 40 percent less likely to be hospitalized due to complications.”

That, and the feeling of being treated like family. Indeed, there is no place like home.

Johns Hopkins All Children’s Pediatric HTC, Tampa, Fort Myers, St. Petersburg, and Lakeland: 727.767.4931

Arnold Palmer Pediatric Orlando: 321.841.8588

Nemours Children’s Clinic Jacksonville: 904.697.3789

St. Josephs Adult/Pediatric HTC in Tampa: 813.554.8294

University of Florida Adult HTC Gainesville: 352.265.0725

University of Florida Pediatric HTC Gainesville: 352.265.8250

Kidz Medical Services at Nicklaus Children’s Hospital 305.662.8360

University of Miami HTC: 305.243.0834

USF Adult HTC Tampa: 813.974.3725



Make 2019 Your Year to Fundraise

By Leah Nash

We here at HFGF are so proud to say that 91% of all fundraising dollars go back to serving the Florida bleeding disorders community. These dollars pay for Camp Spirit tuitions, secondary education scholarships, emergency financial assistance, services such as helmets and MedicAlert memberships; fund educational programming and advocacy initiatives, and more. In 2018, HFGF was able to send 78 kids to Camp Spirit, fund almost \$40,000 in scholarships, and help more than 100 people in our bleeding disorders community when they needed it most through the Emergency Fund!

Throughout the year, HFGF produces fundraising events like our four walks, Evening on Broadway event, and golf tournament. These events are important on so many different levels. First and foremost, these events are how HFGF is able to provide the important products and services listed above. We are so grateful for everyone who attends these events and, more importantly, fundraises. Literally, every dollar counts. I would like to encourage all of you to take a look at the HFGF calendar and select at least one of our fundraising events to get truly involved in and make a commitment to that event for the year of 2019. Here is our calendar of fundraising events:



March 23rd – Gainesville Clot Trot 5K and Fun Walk

April 7th - Tampa Superhero Fun Walk

October 12th – Jacksonville Creepy Crawl 5K and Vampire Mile

October 26th – Orlando Creepy Crawl 5K and Vampire Mile

October 28th – Flight For Tomorrow Golf Tournament

As you can see, HFGF offers fundraising events throughout the year. Please visit hemophiliaflorida.org/walks—5ks to register for any of the walks now. Even if your walk is not

until October, you can register and start fundraising now!



HFGF fundraising events not only raise dollars for important programs and services, they offer a safe place for members of our bleeding disorders community to congregate, meet, and support each other. I encourage you to attend the event you choose to support in person as well. If you have not attended an HFGF event, you will be pleasantly surprised at the joy, and general happy disposition of those in attendance. It will warm your heart, I promise.

Another function of HFGF fundraising events is to raise awareness of bleeding disorders in the general public. Here at HFGF, we are constantly working to educate the general public about what it's like to live with a bleeding disorder through our media relations, social media, and public relations tactics. Our very best tool, believe it or not, is YOU! Please visit hemophiliaflorida.org/voicesofhfgf to read the stories of those from your bleeding disorders community and share!

Thank you again for fundraising for HFGF and we hope that you will consider fundraising throughout the year. If you cannot make one of these events, there is also the option to participate in a virtual walk (starting a team and fundraising without attending) or investing in our planned giving efforts. Be on the lookout for more information on planned giving and endowment funds elsewhere in this issue!

