

## In this Issue

Page 1  
Sign Up For Camp Spirit!

Page 3  
Volunteer for HFGF

Page 4  
Research Update

Page 5  
Gator Trot Springs to Success

Page 6  
Patient Assistant Programs

Page 9  
Register for the Creepy Crawl!

## Camp Spirit



A graphic for Camp Spirit featuring a stylized tree on the left. In the center, a large diamond shape contains the text "SAVE the DATE" with arrows pointing left and right. Below this, the dates "July 6-11, 2017" are written in a cursive font, flanked by double arrows.

### Camp Spirit

is coming up July 6-11, 2017. Some spots are still open so it's not too late to get your application in. Children with bleeding disorders ages 7-16 are eligible. Enjoy a week of medically supervised camping paid for by donations to the HFGF. Applications are available online at <http://www.boggycreek.org/wp-content/uploads/2017/01/Parent-handout-with-hyper-link-updated-1.3.pdf>



toll free 800-293-6527  
[www.HemophiliaFlorida.org](http://www.HemophiliaFlorida.org)

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The Hemophilia Foundation of Greater Florida  
Board of Directors  
President Ron Sachs  
Vice President Mike Berkman  
Secretary/Treasurer  
Pete Vrochopoulos  
Ed Bookbinder  
Hector Cartagena  
Joe Riggs

Staff  
Executive Director, Fran Haynes  
Social Worker, Sandra Davy  
Development Coordinator,  
Caitlyn Beersdorf  
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](mailto:info@hemophiliaflorida.org)  
web [www.hemophiliaflorida.org](http://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 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.

Dear Friends,

Spring is here! And so is the warm weather—congratulations to our high school and college grads... the best is yet to come. We wish you every success with your future endeavors.

On June 10th, we have a special family program at the Ports of Call in Orlando. We have a special program planned for you that day called "Independence Day". It is an interactive program for the entire family.

Camp Spirit is around the corner (July 6-11, 2017) at Camp Boggy Creek—if you have not registered for camp please go to <http://www.boggycreek.org/campers/camper-application/> and complete the camp application (although the deadline has passed –it is never too late).

Have a great spring!  
Warmest Regards,  
*Fran*



- June 10 – Annual Family Program at Ports of Call, Orlando
- June 22-23, 2017 – Social Worker/PT conference
- July 6-11, 2017 – CAMP SPIRIT
- August 23-26 – NHF Annual meeting, Chicago
- October 14 – Jacksonville Creepy Crawl 5k and walk, Nocatee
- October 22, 2017 – Board of Directors Meeting
- October 23, 2017 – Flight For Tomorrow Invitational Golf Tournament
- October 29, 2017 – Orlando Creepy Crawl 5K and Walk, Baldwin Park

## Corporate Matching

Did you know that many companies will match your tax- deductible donation to the Hemophilia Foundation of Greater Florida? [Click here](#) to check out our list to see if your company has a matching program!

# SAVE THE DATE

## Flight for Tomorrow Invitational Golf Tournament

October 23, 2017

Avila Golf & Country Club

[www.hemophiliaflorida.org/golf-tournament.html](http://www.hemophiliaflorida.org/golf-tournament.html)



**VOLUNTEER**

**FOR THE HFGF**

**CONTACT US AT**

**800-293-6527**

[info@hemophiliaflorida.org](mailto:info@hemophiliaflorida.org)

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# Research Update

## BloodCenter of Wisconsin Announces New Test for VWD



The BloodCenter of Wisconsin (BCW) recently announced the launch of a new and more sensitive test for von Willebrand disease (VWD), a genetic disorder characterized by either a qualitative or quantitative flaw in von Willebrand factor (VWF). Milwaukee-based BCW is a not-for-profit organization that specializes in blood services, organ, tissue and marrow donation, diagnostic testing, medical services and research.

Depending on the specific type, individuals with VWD can experience bleeding-related symptoms that range from mild to severe. Despite being the most common bleeding disorder,

VWD is historically a more challenging condition to screen for, often necessitating a battery of tests to pinpoint a diagnosis.

The “VWF GPIbM Activity” test is designed to uncover qualitative VWF defects to reduce variability and provide “more precise, reliable and sensitive test results,” according to a BCW press release. The availability of the test could be a boon to clinicians, particularly hematologists encountering potential cases of VWD.

“As a physician caring for individuals with inherited bleeding disorders, this development is an exciting advancement in von Willebrand disease diagnostics,” said Jonathan Roberts, MD, Associate Medical Director, Bleeding & Clotting Disorders Institute, Peoria, IL. “This assay will reduce some of the diagnostic challenges in caring for individuals with von Willebrand disease.”

Source: BloodCenter of Wisconsin press release dated April 4, 2017

**Beams and Bubbles Deliver Gene Therapy to Mice with Hemophilia B**

Scientists from the Center for Cardiovascular Research at the University of Hawaii (UH) have developed a novel approach to hemophilia gene therapy that employs microbubbles and an ultrasonic beam to deliver the treatment.

The study was led by Dr. Cindy Anderson and Dr. Chad Walton, who were both studying at UH’s John A. Burns School of Medicine (JABSOM) during the breakthrough phase of the research. Anderson at that time was a graduate student in the Cell & Molecular Biology Department at JABSOM and is now an Assistant Professor at Georgetown University. Walton was an Assistant Professor of Medicine at JABSOM and is now an assistant to the Vice-Chancellor for Research at UH Mānoa. Their study was funded by the American Heart Association and the U.S. National Institutes of Health.

The UH team took genetic material that can elicit the production of factor IX (FIX) and placed it within miniscule microbubbles composed of lipid molecules that do not dissolve in water. The therapy was then injected into the bloodstream of mice with hemophilia B. As the microbubbles passed through the bloodstream they were hit by a beam of ultrasound that dispersed the genetic “payload” and deposited it into liver cells targeted for their ability to stimulate the production of FIX. The technique is known as ultrasound-targeted microbubble destruction (UTMD).

The animals subsequently showed both reductions in clotting time and increased FIX levels. An additional set of mice were treated via UTMD and evaluated for long-term effects, the results of which demonstrated a persistent reduction in average clotting time 160 days after one administration of the therapy.

“We were able to improve clotting in mice for months after a single treatment,” said Ralph Shohet, MD, Professor of Medicine and Director of the Center for Cardiovascular Research. Shohet sees unique advantages in UTMD, as it is both non-viral and minimally invasive.

“Hemophilia is a chronic debilitating disease. If we can treat it simply, cheaply, and non-invasively with gene therapy, we will have helped to fulfill the promise of the modern medical era.” added Shohet.

The study, “Ultrasound-Targeted Hepatic Delivery of Factor IX in Hemophiliac Mice,” was published in April, 2016, in the journal *Gene Therapy*

Source: JABSOM news release dated March 10, 2017



# Gator Clot Trot Springs to Success

The 6th annual Gator Clot Trot 5K and Fun Walk was held April 22, 2017 at Depot Park in Gainesville. So far, a total of **\$20, 862** has been raised by the event that included more than 100 runners and walkers.

Top fundraising teams among the walkers were

Team E-Man (winner of the Traveling Walk Trophy),  
Team Peds Clinic  
UHF Adult Heme Dream Team.

Top individual fundraiser was  
Ethan Howick.

Team Landon won the Team Spirit award  
with more than 25 walkers.

Dr. Tung Wynn, and the Team UF Peds Clinic won the Champions in Action award for top fundraising HTC for the 2nd year in a row.

In the 5k, Michael Dougherty finished first among male runners

Robin Potter was the first female finisher.

Members of Vader's Fist, the 501st Legion of Star Wars Storm Troopers, came out to warm up the walkers and runners and take pictures with the crowd.



## A big thank-you to all of our sponsors:

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CSL Behring  
Novo Nordisk  
Octapharma  
Shire

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# Sorting Through Patient Assistance Programs

Dealing with a chronic bleeding disorder can prove to be difficult financially for a family. The makers of factor products sometimes provide co-pay assistance programs to help users of their products offset some of the costs. Below is an overview of the programs.

Factor Assistance Co-Pay Programs			
Company Name	Co-Pay/Co-Insurance Program Name & Contact Information	Limit Total	Program Requirements
Aptevo Therapeutics	IXINITY Savings Program 1-855-494-6489	\$12,000	Must have a valid prescription for IXINITY. Must have commercial insurance. No monthly limits unless limit total is reached. No income requirements. Co-pay program can be used retroactively for up to 12 months.
Bayer	Bayer Access Solutions Kogenate FS Co-Pay/ Co-insurance Program 1-800-288-8374	\$12,000	Must have a diagnosis of hemophilia A. Must have a private health insurance plan. No income requirements. Must first contact Bayer Access Solutions.
Bioverativ	ALPROLIX Co-pay Program 1-855-692-5776 ELOCTATE Co-pay Program 1-855-693-5628	\$12,000	Available to those who use ALPROLIX or ELOCTATE. Must have commercial insurance. US prescriber and pharmacy required. No income requirements or caps. Enrollment forms available via links provided. Not responsible for costs associated with administration of therapy, such as office visits, infusion costs, or other professional services.



# Sorting Through Patient Assistance Programs

cont'd

## Factor Assistance Co-Pay Programs

Company Name	Co-Pay/Co-Insurance Program Name & Contact Information	Limit Total	Program Requirements
CSL Behring	MySource Cost-Share Program 1-800-676-4266	\$12,000 for Afstyla, Idelvion, Hlixate, or Humate	<p>Must take a CSL Behring eligible product (on-label) for the treatment of von Willebrand disease or hemophilia.</p> <p>Must currently have active commercial insurance (federal or state insurance programs are not eligible).</p> <p>Co-pay enrollment requests requires patient consent.</p> <p>Only products purchased from Specialty Pharmacies (SP), Hemophilia Treatment Centers (HTC) and Outpatient Hospital services will be eligible.</p> <p>Co-pay program is not retroactive and cannot be transferred. Exception requests may be submitted for consideration.</p> <p>Must be a US resident.</p> <p>No financial restrictions apply.</p> <p>Program benefit DOES NOT apply toward out-of-pocket costs for:</p> <ul style="list-style-type: none"> <li>Physician office visit co-pays.</li> <li>Infusion-related costs or ancillary supplies.</li> <li>Insurance premiums.</li> </ul>
Grifols	AlphaNine SD Co-pay Card 1-844-693-2286 (844-MY-FACTOR)	\$6,000 (\$500 each month max)	<p>Pay as little as \$0.</p> <p>No monthly or annual maximums.</p> <p>Prescription is covered up to the patient's annual out-of-pocket maximum.</p> <p>No waiting period; patients may use the offer as soon as they enroll.</p> <p>No income requirements.</p> <p>Annual program enrollment is required.</p> <p>Must have commercial insurance.</p> <p>Patients must have a valid AlphaNine SD prescription.</p> <p>Restrictions apply.</p> <p>Helps cover co-pay and co-insurance costs for AlphaNine SD only. It does not cover costs related to physician visits and is not for in-patient use.</p>



# Sorting Through Patient Assistance Programs

cont'd

## Factor Assistance Co-Pay Programs

Company Name	Co-Pay/Co-Insurance Program Name & Contact Information	Limit Total	Program Requirements
Kedrion Biopharma	No co-pay program currently available. 1-855-353-7466	N/A	N/A
Novo Nordisk	Co-pay Assistance Program 1-844-668-6732	\$12,000	Must be using a Novo Nordisk product for an FDA-approved diagnosis. Must have a commercial insurance plan. May apply through web port with link provided (60-day retroactive).
Octapharma	Octapharma Co-Pay Program 1-800-554-4440	Up to \$12,000 for NUWIQ per year Up to \$6,000 for Wilate per year	NUWIQ CoPay Program Wilate CoPay Program No income requirements. Only applies to patients with private commercial insurance. Must have a prescription for NUWIQ and/or Wilate. Other restrictions may apply.
Pfizer	Pfizer Factor Savings Program 1-888-240-9040	\$12,000	Provides a co-pay and co-insurance assistance for a Pfizer factor product. Patient financial responsibility of \$10 per month. No financial eligibility requirements. Must be commercially insured with health insurance that covers factor. Medicare/Medicaid beneficiaries are not eligible.
Shire	Shire's Hemophilia Co-pay Program 1-888-BAX-8379 (1-888-229-8379)	\$12,000	Enrollment can be submitted online or over the phone. Must have commercial insurance. Must use eligible Shire hemophilia products. Eligible patients with private insurance received up to \$12,000 every 12 months for medication-related co-payment/co-insurance with retroactive assistance for a date of service within 120 days prior to their co-pay activation date. No income requirements. Adynovate follows FDA guidelines (approved for 12 years of age or older).





# REGISTER NOW!



Jacksonville Creepy Crawl  
October 14, 2017  
Nocatee  
100 Marketside Ave.  
Ponte Vedra, FL 32081

<http://www.hemophiliaflorida.org/jacksonville.html>

Orlando Creepy Crawl  
Sunday October 29, 2017  
Harbor Park at Lake Baldwin  
4990 New Broad St.  
Orlando, FL 3281

<http://www.hemophiliaflorida.org/orlando.html>

