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HFGF Year In Review

March Is Bleeding Disorders Awareness Month

In 1986 President Ronald Reagan designated the month of March as Bleeding Disorders Awareness Month to bring awareness and attention to those living with a bleeding disorder. Although the official name only mentions hemophilia, it is intended to bring attention and awareness to all those living with bleeding disorders.

HELP SPREAD AWARENESS About Bleeding Disorders!



National and International Hemophilia Organizations Meet in Orlando in 2016

This year's annual meetings of the National Hemophilia Foundation (July 21-23) and the World Federation of Hemophilia (July 24-28) will take place back-to-back in Orlando. The annual meeting of the NHF is an opportunity to learn about the latest advances in treatment and meet others who live with bleeding disorders. Come, attend sessions and see the exhibit space. Some Connections for Learning travel grants are available to help with expenses. See <https://events.hemophilia.org/ehome/annualmeeting/AnnualMeeting/?&> for more information about the event and registration information.

For the first time in 20 years, the world congress on hemophilia will take place in the USA. The medical track and a multi-disciplinary track offer the latest updates on research and treatments. There will also be an exhibit hall and several social events. Come and join experts from around the world in discussing the latest information available on bleeding disorders. See <http://www.wfh.org/congress/en/> for detailed information on the program and how to register. See you in Orlando in July!

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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.

Executive Director's Column

Hi Everyone,

2016 is already a great year. The HFGF is celebrating its 20th anniversary. For the past 20 years, the HFGF has touched the lives of many in the bleeding disorders community: we have sent more than 1,200 children to camp and been host to more than 500 families in the family retreat weekend. We have helped thousands of people with Emergency Financial Assistance, and we have offered many educational programs regarding living with bleeding disorders with the most updated information.

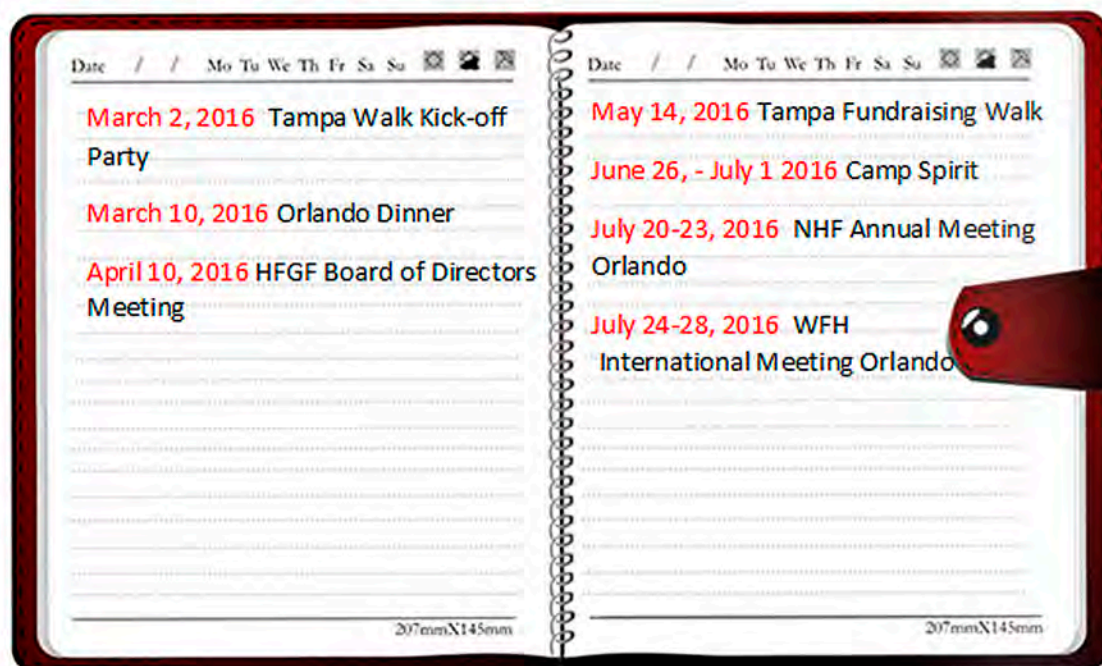
The HFGF has had the privilege of witnessing many changes in the bleeding disorders community—new, safe longer-acting factor therapy, a cure for Hep C, innovative genetic research and many new opportunities. The best is yet to come...we strive to achieve our mission to improve the quality of life for people with bleeding disorders.

We have had a great 20 years, and we invite you to join us as we continue our journey together, we can make a difference for the bleeding disorders community.

Warmest Regards,

Fran

2016 CALENDAR OF EVENTS





Choose the Walk That Best Fits Your Schedule & Save the Date

HFGF has a number of walks scheduled this spring and fall all over the state. Some have 5k run components. So pick the one that best fits your schedule, gather a team to walk or participate as an individual to raise awareness and funds for the bleeding disorders community. **Come join us; it's a lot of fun!**

First up is the 9th annual Tampa Walk, renamed this year as the Woodstock Walk for Bleeding Disorders. Get your groove on as well as your best hippie gear (for the Best Dressed Hippie Contest that will be taking place), move to the beat of music from the 60s and 70s, have your photo taken with a vintage VW minibus and other far out happenings! The walk takes place Saturday May 14th at Al Lopez Park in Tampa. Register for free at

www.hemophiliaflorida.org/tampa

Raise \$25

by April 22, 2016 to receive a free walk t-shirt.

Next up on the schedule is the 5th annual Gator Clot Trot (and 5k fun run) to be held Saturday, September 24th at Tioga Town Center, 25455 S.W. 2nd Ave., Newberry, FL. Wear your best Gator gear and walk or run to raise funds for the HFGF to help support the bleeding disorders community.

**Gainesville
GATOR
CLOT TROT**



Registration for either the race or the walk is cheaper the earlier you sign up! So go online to

www.hemophiliaflorida.org/gainesville

and register for yourself or a whole team of walkers.

If Halloween is more your thing, you might want to wait for one of two opportunities to walk or run and raise funds for the bleeding disorders community that are coming up in October. Choose either the 8th Annual Jacksonville Creepy Crawl 5k and Fun Walk to be held Saturday, Oct. 22nd, at Nocatee, 100 Marketside Ave., Ponte Vedra, FL 32081 or the 10th annual Orlando Creepy Crawl 5k and Fun Walk to be held Sunday, Oct. 30th at Harbor Park at Lake Baldwin, 4990 New Broad St., Orlando, FL 32814.

Whether you choose to walk or run, registration is cheaper if you sign up earlier.

www.hemophiliaflorida.org/jacksonville

www.hemophiliaflorida.org/orlando.



HEMO STRONG FOR 20 YEARS!



**Hemophilia
Foundation**
of Greater Florida

The HFGF was founded on December 20th, 1996 by the late Calvin Dawson, Brian and Rhonda McDonald, and Wanda Bedell. This year will be the organization's 20th year of supporting the bleeding disorders community by providing financial assistance, education, and advocacy for research and beneficial healthcare policies and legislation.

To honor our 20th year, we invite you to participate in one or more of the ways listed here. Join us in the fight to stay Hemo Strong for 20 (more) Years!

1

Join Our Tampa Walk

May 14 is the Woodstock Walk for Bleeding disorders. Put on your best hippie attire and groove to the best of 60's and 70's music as you walk to raise funds for the HFGF.



2

Like Us On Facebook

Go to our page Hemophilia Foundation of Greater Florida and like us.

3

Support a Camper

HFGF fully funds Camp Spirit, a week of medically supervised camp for children with bleeding disorders ages 7-16 every summer. For only \$800, you can sponsor a child's camp experience.



10

Run or Walk in Gainesville

Participate in raising funds for the HFGF by signing up as an individual or a team for our Gator Clot Trot on September 24th.

11

Balloons, Tents and Granola Bars...

What do they have in common? You can find them and more on our Needs List at our website.



15

Donate an Auction Item

Do you have a business or a contact at a business that provides travel, entertainment or sports services? If so, consider having them donate something to our Flight for Tomorrow Golf Tournament.

16

Jacksonville Creepy Crawl

Put on your Halloween costume and run or walk to raise funds for the HFGF October 22nd at Nocatee.



14



Consider Planned Giving

Designate a gift in your will or estate plan to ensure that the HFGF remains strong for years to come.

20 WAYS TO GET INVOLVED DURING OUR 20TH ANNIVERSARY

4

Use Amazon Smiles

When you use Amazon Smiles for your Amazon purchases a portion of your purchase price (at no cost to you) goes to the HFGF.

5

Support the Scholarship Fund

The Calvin Dawson Memorial Scholarship Fund assists Florida residents with bleeding disorders pursue post-secondary education.



6

Add to Our Advocacy Efforts

HFGF acts as an advocate for healthcare issues that benefit the Bleeding Disorders community. Sign up today to be our eyes, ears, and voice.

9

Give a Medic Alert Bracelet

The HFGF provides, at no cost, medic alerts bracelets and helmets to the bleeding disorders community. You can sponsor one or more of them. Call us at 407-629-0000.



7

Donate

Help our efforts today and for years to come, emergency financial assistance program education, infusion, research support and advocacy.

8

Volunteer

Interested in volunteering? Contact our Volunteer Coordinator JoAnn by email at

joannbrownrigg@hemophiliaflorida.org

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Sponsor an Event

Sponsorships provide a unique opportunity to bond with the community and build brand awareness while demonstrating your company's support for our mission.

12



Host a Fundraising Event

Come up with your own or call Caitlyn in our office for ideas on how you can keep the HFGF Hemo Strong!

17



Tweet About the HFGF

Use Twitter to let your friends know about fundraising events, educational opportunities and more about the HFGF and its efforts.

19

Provide In-Kind Services

Got a food business? DJ service? Photography? Face painting? Exercise Facility Consider donating.



18

Play in our annual Flight for Tomorrow Golf Tournament in Tampa in October.



20

Orlando Creepy Crawl

Put on your scariest Halloween costume and join the walk or run to raise funds for the HFGF on October 30th at Harbor Park on Lake Baldwin.



Social Work Corner

by Sandra Davy, MSW

Greetings, everyone!

Ushering in 2016 gives us the opportunity to re-dedicate ourselves to our families and friends, to make positive self-improvement changes, and to commit some of our time to making a difference in the lives of the bleeding disorders community. No one else can be a better advocate for the bleeding disorders community than us!

Make 2016 be the year that you educate the public, educate your Florida Legislature Representatives, and become a bleeding disorder advocate.

Getting the Florida Senate & House Representatives to know and understand our need for health insurance coverage (especially after the age of 18 yrs. old), access to Factor, and access to above standard medical & mental health care services regardless of our income levels, where we live, or where we are from depends on our willingness, either individually or collectively, to voice our needs.

We have a shared commitment to the equality, freedom, and dignity of all individuals affected with or by bleeding disorders. Whether your time and skills are given for one or two hours on a selected weekday, or in between running errands, attending school, taking care of loved ones, or after work, they are highly valuable and always appreciated.

Want to become an advocate for the bleeding disorders community? Looking forward to meeting others who share your commitment and need to become involved in the community? Interested in finding ways you can utilize your skills/talents to make a difference? HFGF can help you.

Throughout 2016, HFGF will conduct advocacy programs in various cities to guide you through the advocacy process step-by-step.

Look for upcoming dates and locations to be announced in the near future.

We can make 2016 a great year of change!

****Remember, change begins with us****



Like our page on Facebook: Hemophilia Foundation of Greater Florida or follow us on Twitter @HemophiliaFL or check us out on Instagram.



Research Update

Researchers Learn More about FVIII Origins
In breakthrough research, Rice University (RU) scientists have uncovered more about the cellular origins of factor VIII (FVIII), a protein that plays a critical role in the blood clotting process. The study paper was co-authored by research biochemist Nancy A. Turner, BA, and hematologist Joel L. Moake, MD, at RU's Department of Bioengineering.

Earlier studies established that FVIII is produced in endothelial cells that line the walls of blood vessels in organs such as the heart, liver and intestines. RU investigators have delved further by looking for the specific source of FVIII generation and deployment from within different types of endothelial cells.

Turner and Moake's experiments focused on human umbilical vein endothelial cells (HUVECs), which are found in large veins, and glomerular microvascular endothelial cells (GMVECs), which are located in the smallest capillaries of the kidneys. Although the presence of FVIII in these types of cells had not been previously confirmed, investigators had recognized them, particularly HUVECs, as a viable focus of research for several reasons.

"HUVECs are the generic human endothelial cells that (biological researchers) use the first time they do anything," Turner said. "They're cheap. They're easy to work with, and they've been the model for endothelial cells for, I don't know, at least 50 years."

With her expertise in biochemistry, Turner first conducted a series of lab tests to verify the presence of FVIII in HUVECs and GMVECs. Follow-up research confirmed that FVIII is not only synthesized in HUVECs and GMVECs, but is also stored in and secreted from Weibel-Palade bodies (WPBs) within these cells. WPBs are specialized organelles (part of a cell with a specific function) that also contain von Willebrand factor (VWF), another critical protein that binds to FVIII during the clotting cascade. VWF works as a carrier for FVIII as it circulates in the bloodstream.

This discovery has future potential therapeutic significance for people with bleeding disorders. "Now that we recognize that factor VIII is normally synthesized in endothelial cells and stored in Weibel-Palade bodies, those become the precise, most effective physiological targets for gene delivery," concluded Moake.

The article, "Factor VIII Is Synthesized in Human Endothelial Cells, Packaged in Weibel-Palade Bodies and Secreted Bound to ULVWF Strings," was published online October 16, 2015, in the journal PLOS ONE.

Source: Rice University news release dated November 2, 2015

When you shop with
amazon.com
Smile
they'll donate to

**The Hemophilia Foundation of
Greater Florida**



14th

Annual Evening on Broadway a Smashing Success

A glorious evening was enjoyed by 130 attendees, who saw the classic, Sound of Music, performed at the Dr. Phillips Center for the Performing Arts in Orlando on Saturday, January 9th.

In addition to seeing the show, guests were treated to a reception with a charity sale and auction. The event raised \$30,000 for the bleeding disorders community.

We want to thank all of our sponsors for making the evening the big success that it was:

Tony Award Winning Sponsor

Baxalta
Bayer

Best Play Sponsors

Biogen
CSL Behring
Novo Nordisk

Reception Sponsor

Pfizer Hemophilia

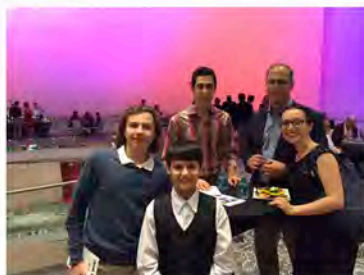
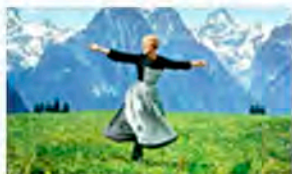
Program Sponsor

BioRx

We'd also like to thank our hardworking volunteer theater committee for organizing this successful event.

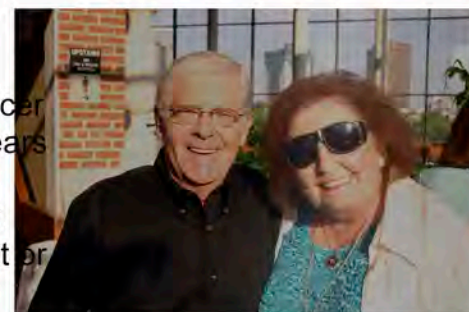
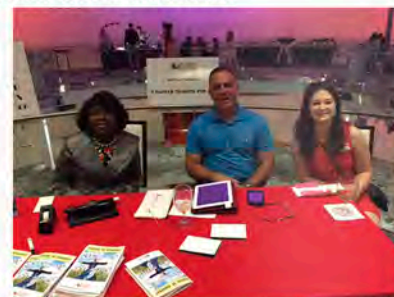
Dawn Solomon, Committee Chair

Chad Brown
Joe Burke
Mendy Hood
Shannon Porter



Finally, our sincere thanks go to all of the businesses and individuals who donated items for tonight's charity raffle.

- Alfond Inn
- Arthurs Catering
- Bok Towers
- Busch Gardens
- Champions Gate Golf International
- Colonial Lanes
- Dawn Solomon
- Elie Tahari
- Enzian Theater
- EO Inn, Orlando
- Euro Day Spa
- Florida Aquarium
- J. McLaughlin, Co
- Macy's University Town Center
- Maggiano's
- Mendy Hood
- Orlando Magic
- Orlando City Soccer
- Orlando Solar Bears
- Peterbrooke
- Prato Restaurant
- Ripley's Believe It or Not
- Rogers
- Shake Shack
- Trader Joes
- Vinoy Renaissance Resorts & Golf Club St. Petersburg
- Westchase Golf
- World Golf Hall of Fame – St. Augustine



THE SOUND OF MUSIC

2015 HFGF's Year in Review

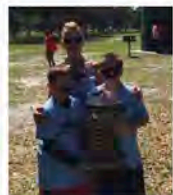


This was a very active year for the HFGF. Our work in the bleeding disorders community included:

Patient Assistance—
Serving more than 500 individuals with \$81,000 in emergency financial assistance, such as

- Counseling (by phone and in office)
- Dental assistance (cleanings, x-rays, extractions, root canals)
- Durable medical equipment
- Food cards
- Gas cards for HTC and medical visits
- General assistance and referrals
- Holiday gift cards, distributed through the Hemophilia Treatment Centers (HTCs)
- Insurance assistance (premiums)
- Medical assistance (office visits, labs)
- Pharmacy product referrals
- Medic alert registration and renewals

Camp Spirit—Underwriting the cost of attending a week long, overnight camping experience for 70 children with bleeding disorders at a cost of \$52,759.



Family Retreat Weekend
Providing a weekend of fun, fellowship and respite for **33 families** with a member who has a bleeding disorder, comprised of **120 individuals**, at a cost of **\$12,000**

Patient and Provider Education—

This year, \$78,479 was spent on education programs, including workshops and support groups provided in conjunction with the HTCs, which served more than 850 people across the state.

Patient Education topics included

- Back-to-School (two programs)
- Bleeding Disorders Trivia
- Bullying Program
- Dental Care
- Healthy Eating and Physical Activity (two workshops)
- Immigration and Health Care
- Infusion Programs
- Jeopardy (bleeding disorders)
- Lunch and Learn (three programs)
- Pain Management
- Traveling with a Bleeding Disorder
- Women's Tea

Professional Education events included

- Hemophilia training at medical schools such as Cambridge Nursing School, South Florida State College and Lincoln Technical College, reaching more than 250 students
- Nurses' Education Dinner
- Social Workers/Nursing Professional Workshop attended by more than 30 professionals.

