

What's Inside

Page 1

Flight for Tomorrow Golf
Tournament

Page 2

Executive Directors Column

Page 3

Flight for Tomorrow Cont'd.

Page 4

Research Update

Page 5

Research Update Cont'd.

Page 6

Orlando Creepy Crawl

Page 7

Jacksonville Creepy Crawl

Flight for Tomorrow Golf Tournament a Win for HFGF!

The 25th annual Flight for Tomorrow Golf Tournament was held Monday October 25, 2021, at East Woodlands Gold Club in Oldsmar on what started as a rainy day but cleared up as the golfers teed off. Followed by dinner and accompanied by an all-day silent auction, there was a lot of fun besides the golf itself. A great success, the tournament raised more than \$50,000 to support the programs of the HFGF including providing Medic Alert bracelets and helmets, supporting the Emergency Assistance Fund Camp Programs, and informational programs among others. Plans for the 2022 tournament are underway and a date will be announced soon.

First place went to the Norris foursome. Second was captured by Hegseth, Sharts, Martell and Fletcher and third place went to O'Connor, O'Conner, Yonker and Brissenden. Men's Long Drive was Butch Martel on the 13th hole. Women's long drive was Sherri Rojhani on the 2nd.

Continued on page 3



HFGF Connections is 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
Katie Hawkins
Patrice Bravo

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.

HFGF Connections



Executive Director's Column

Dear Friends,

It has been absolutely wonderful to see everyone this fall at events. I have missed everyone very much. Nothing beats seeing folks in person. Believe it or not, we have had a very busy fall. We have hosted three walks and a golf tournament, and they were so much fun.

As you know, this has been a tough year for the chapter. Because of the support of those who supported and participated in the walks and golf tournament, we were able to raise much needed donations for the bleeding disorders community.

Special thanks to our Golf Co-Chairs Rhonda and Brian McDonald for their time and dedication. They co-founded the HFGF, have hosted the Golf Tournament for 25 years, and also been honorary walk chairs.

We have a lot of programs and fun celebrations scheduled for the next few months. We hope you will join us.

Don't forget to check out our calendar at <https://www.hemophiliaflorida.org/events/list/>.

Also, we are celebrating our 25th anniversary this year, and we are asking our supporters to donate \$25 in celebration of this great milestone.

I hope you have a happy and healthy holiday season.

Take care,

Fran

Calendar of Events



December 2 – Product Update – Rusty Pelican, Tampa
December 4 – Youth Retreat – Tampa Zoo, Tampa
December 15 – Family Dinner – Winter Park (Orlando)
December 18 – Gainesville Holiday Party
December 19 – Jacksonville Holiday Party

More Information:

<https://www.hemophiliaflorida.org/events/list/>

HFGF Connections

Continued from page 1

A very special thank-you to all our sponsors for making the event possible:

Title Sponsor

Rhonda and Brian McDonald

Silver Sponsors



CSL Behring
Biotherapies for Life™

Bronze Sponsor



Copper Sponsor



The HFGF would also like to thank the silent auction donors:

Atlantis Paradise Island Bahamas, Countryside Country Club, Crayola Experience Orlando, The Don Cesar, East Lake Woodlands, The Florida Aquarium, Florida Strawberry Festival, Hunter's Green, Hyatt Jacksonville, Innisbrook Golf Resort, Jacksonville Jaguars football, Kennedy Space Center, Rhonda and Brian McDonald, Rays Baseball, Spirit Airlines, Tampa Palms, Total Wine, Universal Orlando, Walt Disney World – Golf, Zoo Tampa at Lowry Park

19th Annual Evening on Broadway Theatre Event

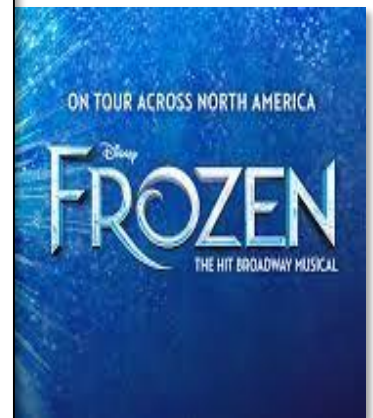
Featuring the Broadway production of

“FROZEN”

March 4, 2022 – 6:00PM

Dr. Phillips Performing Arts Center

Orlando, Florida



Tickets Available Now - \$130 each

Sponsorships Available Now

Follow us on:



HFGF Connections



Notice to Parents: This Research Update, while presenting Important information to the Bleeding Disorders Community, contains some frank language about sexuality and may not be appropriate for children.

Patient-Reported Data Informs New Study on Sexual Health and Hemophilia

An understanding of sexual health in people living with hemophilia (PWH), including difficulties with sexual activity and intimacy, has been historically lacking. To help fill this knowledge gap, a new study was conducted to establish the prevalence of sexual difficulty in this population, compare it with that of people with no bleeding disorder (PWNoBD), and to uncover contributing factors to those difficulties.

The resulting paper, “Evaluation of the Sexual Health in People living with Hemophilia,” was published in the journal *Haemophilia*. Investigators performed a retrospective analysis of data generated from the Patient Reported Outcomes Burdens and Experiences (PROBE) initiative, an international data collection network and a questionnaire tool created to learn more about the impact of hemophilia specifically on patient reported outcomes.

The PROBE questionnaire includes questions related to difficulties with sexual intimacy and is designed to be anonymous, can be administered by paper, through the myPROBE app, or via the PROBE website. It takes approximately 7–15 minutes to complete. Participants were recruited by National Member Organizations of the World Federation of Hemophilia and matched control groups in 48 countries. Those recruited included individuals with hemophilia A or B and PWNoBD who were 18 years old or older.

Because the questionnaire gleans data on demographics, co-morbid diseases, general health problems, and hemophilia-related health problems, it allowed investigators the opportunity to draw several significant associations with sexual difficulties.

There were ultimately 2,007 PWH and 1,972 PWNoBD included in the analysis. Mean age was 41 years in PWH and 42 years in PWNoBD. Sexual difficulty was reported in 302 (15.1%) PWH and 79 (4.0%) PWNoBD, with the odds of sexual difficulty significantly higher in PWH.

While investigators found that general health problems and various conditions affected the sexual health of both PWH and PWNoBD, the association between self-reported co-morbid diseases and sexual health was greater in the former group.

Hepatitis B, hepatitis C, hypertension, arthritis, and gingivitis were each associated with higher negative impact on the sexual health of PWH.

HFGF Connections

Continued from page 4

Further, certain types of bleeds experienced by PWH had greater adverse effects on sexual activity, including those in the psoas, a pair of large muscles which run from the lumbar spine through the groin area and attaching to the femur. Collectively, these muscles are known as the iliopsoas and help to flex the hip joint.

“We observed that PWH who reported recent psoas bleeding had more frequent sexual difficulty than those who did not. Iliopsoas muscle bleeding can limit sexual intercourse because this muscle functions in the thrusting movement during sexual intercourse,” explained the authors.

Investigators also observed that were a series of independent contributors to sexual difficulty in PWH including older age, experiencing acute pain or chronic pain in the past 12 months, having bleeds within the past two weeks, reduced range of motion of any joints, having more than three spontaneous joint bleeds in the previous six months, and having life- or limb-threatening bleeds in the past 12 months. Any combination of these factors can lead to increased pain, hindered mobility, with subsequent limitations to sexual positioning and intercourse.

In light of the knowledge generated by this study, investigators see an opportunity to ensure that sexual health becomes a key part of the conversations that will, going forward, inform hemophilia care and quality of life for PWH.

“Sexual difficulty is more prevalent in PWH. Health problems and comorbidities resulted in more frequent sexual health difficulty in PWH than PWNoBD. Healthcare providers, researchers, and policy makers should incorporate sexual health discussions in comprehensive hemophilia care, future research, and health policy,” concluded the authors.

Germini F, Chai-Adisaksopha C, Pete D, et al. Evaluation of the sexual health in people living with hemophilia. *Haemophilia*. 2021;1-9.

<https://doi.org/10.1111/hae.14410>



**Save
the
Date!**

2022 Annual Walk/Run Fundraising Events

11th Gainesville Gator Clot Trot – April 9, 2022
14th Super Hero Fun Walk – September 24, 2022
14th Jacksonville Creepy Crawl – October 15, 2022
16th Orlando Creepy Crawl – October 29, 2022



HFGF Connections

2021 Orlando Creepy Crawl Is a Success!

Approximately 200 costume-clad people gathered Saturday Oct. 30th to walk to raise funds to support the work of the HFGF. A total of just over \$45,000 was raised at Harbor Park in Orlando. There were some special Halloween guests: The Orange County Ghostbusters of Florida and the 501st Legion Vader's Fist Storm Troopers were there to urge on the walkers.

The competition for most funds raised was won by Team INFOPIPE. Second was La Mar Jackson's Memorium and third place went to Team Hunter. Team Josiah received a trophy for winning the costume contest. Team Hunter won the Spirit Award.

After the walk, a Halloween Party was held featuring chicken and fries, caramel apples, chips and candy.

A good SPOOKY time was had by all!



Thank you to the following sponsors for making this event possible!

CHAMPION SPONSORS

Bayer HealthCare, City National Bank, CSL Behring, Genentech, novo Nordisk, Orlando Health, Pfizer, Takeda

GOLD MEDAL SPONSORS:

Accredo, BIOMARIN

SPRINT SPONSOR

SpecialtyCareR

STROLL SPONSOR

MEDEXUS PHARMA

IN-KIND SPONSORS

Cabot, decibel DJ, LET'S ROAM, PDQ, Ria & Dream, Orange County Ghostbusters, 501st Storm Troopers

HFGF would also like to thank the members of the walk committee for all their hard work making the event a success.

Barbie Arrebola, Tyron Benoit, Christina Buth, Marcy Foertsch, Peggy Klingman, Rene Lebron, David Lau, Alex Monica, Samantha Navario, Dawn Solomon, Jose Versace

HFGF Connections

More Creepy Crawl Action from Jacksonville

More than 100 people participated in this year's walk, held October 23, 2021, at Nocatee Station Field in Ponte Vedra. A total of just over \$29,000 was raised for the programs of the HFGF, benefitting the bleeding disorders community of Florida. There was a special appearance by the 501st legion Storm Troopers.

First place for team fundraising went to Nemours. The second-place team was Missy's Mob and third place was team Flash.



The HFGF wants to give a very special thank-you to all the event sponsors for making the walk possible.

CHAMPION SPONSORS

Bayer HealthCare, CSL Behring, Genentech, Nemours Children's Health, novo nordisk, Pfizer, SANOFI Genzyme, Takeda

GOLD MEDAL SPONSORS:

Accredo, BIOMARIN

SPRINT SPONSOR

SpecialtyCareR

STROLL SPONSOR

MEDEXUS PHARMA

In-Kind Sponsors

Dunkin Donuts, Garden Produce, Starbucks, Treylor Park Restaurant, 501st Storm Troopers

Also, thanks to our volunteer committee members: Susan Durbin , Rene Lebron , Alex Monica, Kristin Saunders, Missy Zippel