



HFGF CONNECTION



The Quarterly Newsletter of the HFGF Spring 2023 Volume 40 Issue 66

In this Issue

Page 1
Evening on Broadway Sold Out!

Page 2
Mark Your Calendar

Page 3
Evening on Broadway Sold Out! *cont'd*

Page 4
Research Update

Page 5
Gator Clot Raised Fun and Funds

Page 6
Get in on the Fun With Our Walks and Runs

TOLL FREE 800-293-6527
www.HemophiliaFlorida.org



The 20th annual Evening on Broadway featuring a performance of *Wicked* was sold out. One hundred people gathered on Saturday, February 11, 2023 to enjoy the show, a pre-performance reception, silent auction and raffle. The event raised more than \$30,000 to support the Foundation's programs.

Big Thank-You to our sponsors:

Tony Award Winner
CSL Berhring

Best Musical Sponsor
Octapharma

Other Friends of the HFGF:

Bayer
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Sanofi
Takeda

Special thanks to John Louis and CSI Pharmacy for providing the programs.

cont'd on pg 3

HFGF Connections

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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 bleed-
ing disorders and their families
through education, information and
referral services, advocacy and
research.

Disclaimer

The material provided in HFGF
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information only. HFGF does not
give medical advice or engage
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ular treatments for specific indi-
viduals and recommends that you
consult your physician or treatment
center before pursuing any course
of treatment.

Executive Director's Column

Dear Friends,

Spring is here, and we have so many exciting and fun opportunities for everyone! We have dinners and programs scheduled. What a fun spring we have had.

Our Gator Clot Trot was April 15, 2023, and it was a lot of fun. We chose a new venue, and the weather was perfect. Special shout out to our wonderful volunteers and sponsors who helped make the event a success. We are already thinking about our 2024 event.

Advocacy was again at the forefront as we tried to get the accumulator adjuster bill over the finish line, but we were not able to make it happen. We have a great group of advocacy ambassadors ready to take on the Florida Legislature to get the bill passed in 2024.

What is a copay accumulator adjuster program? Thousands of Floridians with chronic health conditions rely on copay assistance to help them pay out-of-pocket costs for expensive specialty medicines. But many insurers have stopped counting copay assistance toward annual deductibles and the out-of-pocket limit, leaving patients with serious illnesses to foot the bill. These practices harm the most vulnerable Americans—those who need the most help affording their care—and make existing health disparities even worse. When insurers don't count copay assistance toward a patient's deductible or out-of-pocket limit, patients continue to owe that money (even though they've paid it), leaving them facing an enormous bill when they try to refill a prescription or get other health care. That leaves many patients with tough choices between paying for necessities like rent and food or paying for their prescriptions. Too many patients delay care or stop taking their medication, which can lead to serious complications of their illness and even greater health care costs.

We are always looking for great advocacy ambassadors, if you are interested, please email me at Franhaynes@hemophiliaflorida.org.

Fran



mark your Calendar

June 12-16, 2023

July 13, 2023

July 23, 2023

July 29, 2023

August 16-20, 2023

August 26, 2023

Camp Spirit

Gene Therapy Dinner Orlando

Board of Directors Meeting

Youth Retreat

NHF Annual Meeting

Bleeding Disorders Trivia

HIGH SCHOOL STUDENTS
EARN COMMUNITY SERVICE HOURS

VOLUNTEER FOR THE HFGF

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

Thanks also to our auction donors:

4 Rivers Smokehouse
Busch Gardens Tampa Bay
Crayola Experience
Dr. Phillips Center for the Performing Arts
Ethical Factor
Lillian Gomez
Mendy and Nathan Hood
Natural Life
Orlando Science Center
Renaissance Marriott
Rifle Paper Company
Solomon Family
Texas Roadhouse
Trader Joe's
Tyler Nazario
Wonder Works



Flight for Tomorrow Golf Tournament

Monday October 23, 2023

East Lake Woodlands Country Club Oldsmar, FL

To become a sponsor or to register to play, go to:

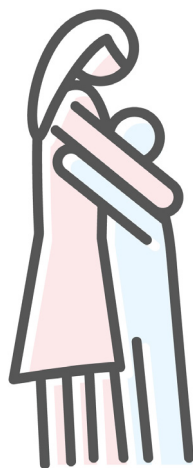
hemophiliaflorida.org/fundraising/golf-tournament/

Guilt in Mothers of Children with Hemophilia Focus of New Study

Researchers from Children's Healthcare of Atlanta and Emory University recently published the results of a small study investigating the subject of guilt in mothers of children with hemophilia (CWH).

Anonymous electronic surveys were distributed to 291 mothers of CWH from May to October 2021, which measured feelings of guilt along with potential contributing factors, subsequent coping strategies, and perception of their child's life satisfaction.

In all, 87 mothers completed the survey. The mean age of respondents was 41.6 years and their CWH was a mean age of 13.3 years. While mothers indicated perceptions of their child's life satisfaction that didn't vary appreciably from the general population, 40% did indicate increased guilt. The most commonly cited reasons associated with this guilt were passing on the X chromosome associated with the condition and putting their child through painful infusions. The most common coping strategies were accessing social support, self-education, and connecting with other mothers of CWH in the inherited bleeding disorders community.



The authors emphasized the need for healthcare providers to “tactfully” provide anticipatory guidance and counseling for these mothers. They also suggested some positive takeaways.

“Community immersion was beneficial, as other mothers in the community served as a source of social and educational support. Most mothers did not report guilt, illustrating the adaptability and resilience of the hemophilia community,” concluded the authors.

The study, “The Emotional Experience of Mothers of Children with Hemophilia: Maternal Guilt, Effective Coping Strategies and Resilience within the Hemophilia Community,” was published online in the journal *Haemophilia*.

Source: Hematology Advisor, February 21, 2023



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Instagram.com/hemophiliaflorida



DONATE

On Saturday April 15, 2023, 175 people, of which 50 were runners, gathered in Gainesville to take part in the 12th annual Gator Clot Trot 5K fun run and walk to raise funds for the HFGF. A total of more than \$30,000 was raised to support the programs of the HFGF.

Individual top fundraisers were Sally Wynn in first with Matthew Barnes in second place and Elna Fletcher in third.

We would like to give a big thank you to the sponsors who made this event possible:

Champion Sponsors

ARJ Infusion
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James Moore
Novo Nordisk
PARAGON Hemophilia
Sanofi
SpecialtyCareRX
UF Health Hemostasis Treatment Center

Media Sponsor

I AM 106.9 COUNTRY

Major Sponsor

Winsupply of Gainesville



Two more opportunities this year!



The poster for the 16th Annual Superhero Walk features a bright yellow starburst shape on a red background. Inside the starburst, the text reads "16th ANNUAL SUPERHERO walk" and "SEPTEMBER 23, 2023". A small logo for the Hemophilia Foundation of Greater Florida is at the top of the starburst. Below the starburst, a white silhouette of a superhero is shown in a running pose. The background is decorated with yellow lightning bolts and stars.

Vinoy Park
701 Bay Shore Dr. NE
St. Petersburg, FL

Registration starts 9:00 AM
Walk starts 10:00 AM

Register at [Hemophiliaflorida.org/walks-5ks](https://hemophiliaflorida.org/walks-5ks)
More info: info@hemophiliaflorida.org or 800.293.6527



The poster for the 17th Annual Orlando Creepy Crawl features a dark blue background with a large, full orange moon on the right. A mummy character, wrapped in white bandages with black stripes, stands in the foreground. In the background, there is a silhouette of a tree and a bat. The text "17th ANNUAL Orlando Creepy Crawl" is written in a stylized font. Below it, it says "FUN WALK OR 5K RUN" and "OCTOBER 28, 2023". The location "Harbor Park at Baldwin Park" and "4990 New Broad Street Orlando, Florida" are listed. At the bottom left, it says "FOOD & FUN, MUSIC & PRIZES", "SPECIAL GUESTS", "COSTUME CONTEST", and "FOR ALL AGES (PETS INCLUDED)". The Hemophilia Foundation of Greater Florida logo is at the bottom left.

17th ANNUAL Orlando Creepy Crawl
FUN WALK OR 5K RUN
OCTOBER 28, 2023
Harbor Park at Baldwin Park
4990 New Broad Street
Orlando, Florida

FOOD & FUN, MUSIC & PRIZES
SPECIAL GUESTS
COSTUME CONTEST
FOR ALL AGES (PETS INCLUDED)

Hemophilia Foundation of Greater Florida

For more information or to sign up, go to:
hemophiliaflorida.org/walks-5ks/