

HFGF Connections

The Quarterly Newsletter of the HFGF Spring 2021

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Our first ever fundraising event was held 25 years ago, the year that the HFGF was founded. Fittingly, on October 25, 2021, the 25th annual Flight for Tomorrow Golf Tournament will be held at the East Woodlands Country Club in Oldsmar, Florida. HFGF founders and longtime supporters Brian and Rhonda McDonald are co-chairing the event. Throughout the history of the HFGF, the yearly tournament has raised more than a million dollars to help support Florida's bleeding disorders community.

To register for the tournament, go to https://www.hemophiliaflorida.org/fundraising/ golf-tournament/. Sponsorships are also available for the tournament, and the HFGF is looking for silent auction donations in the areas of entertainment (events, sporting events, sports memorabilia), travel (airline flights, hotels) experiences (golf games, restaurants, museums, theme parks).

Join us to tee off for a lot of fun and a great cause.



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HFGF Connections Executive Director's Column

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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.

Dear Friends.

Happy Pring I really miss everyone and look forward to seeing everyone in person soon. We have a our first in-person program June 5, 2021 at SeaWorld (Space is limited due to Covid.). We are looking forward to a wonderful program, "Coming Out of Our Shell, Life After the Pandemic". We will be following CDC guidelines so we can have a safe, fun opportunity.

We are looking forward to hosting other in-person programs as the CDC guidelines dictate. We will transition to in-person programs while we are still offering virtual programs. If there are any topics you would like us to address, please reach out to us at info@hemophiliaflorida.org or 407-629-0000.

We are so excited about having our first in-person walk, August 7, 2021 at Veterans Park in Gainesville, Florida. It will be a fun day for everyone.

I hope everyone stays healthy, and I look forward to seeing you on June 5, 2021.

Take Care,

Fran



Being Prepared for an Emergency (virtual) Annual Family Program (in-person) Florida State Meeting (in-person) Summer Family Weekend **Gator Clot Trot**

May 27, 2021 June 5, 2021 June 14-15, 2021 July 23-24,2021 August 7, 2021

HIGH SCHOOL STUDENTS EARN COMMUNITY SERVICE HOURS

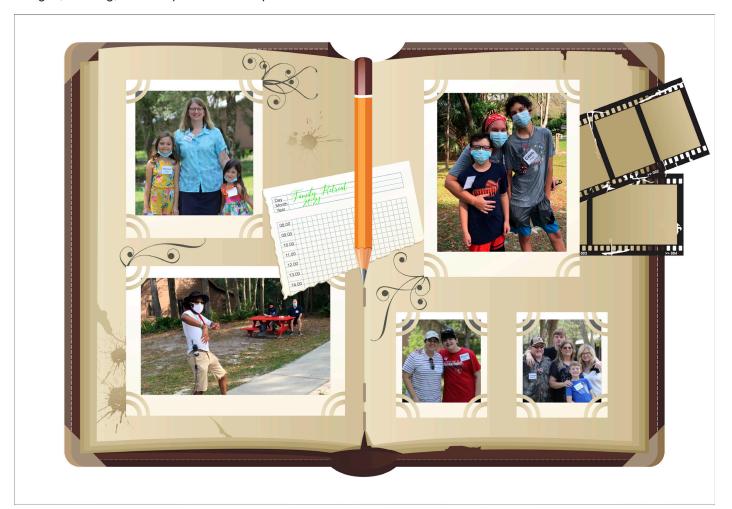
VOLUNTEER FOR THE HFGF

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



Family Retreat Weekend

April 23-24 was the first family retreat weekend held at Camp Boggy Creek in more than a year. Eleven families participated in a safe camping experience following CDC guidelines. Along with just hanging out, the campers enjoyed miniature golf, dancing, and campfires. See the photos below for some of the fun.



25th HFGF Anniversary Tidbit

Did you know that the HFGF was the first non-profit to partner with Camp Boggy Creek for a medically supervised camping experience?

CHANGE THEIR WORLD. CHANGE YOURS.
THIS CHANGES EVERYTHING.

BECOME A VOLUNTEER OR DONATE



Walk with Us in Real Life!

The walks are back and in 2021 will be in-person once again. So come join us for the fun and fundraising for the HFGF. Choose the walk that works best for you. Captain a team of walkers. To register or get information on successfully raising funds, go to https://www.hemophiliaflorida.org/walks-5ks/.

Gator Clot Trot - August 7, 2021

Registration starts at 8 A.M. Veterans Memorial Park, 7400 SW 41st Pl Gainesville, FL 32608



Super Hero Walk- September 25, 2021

Registration starts at 8 A.M.
Vinoy Park
701 Bayshore Dr NE
St. Petersburg, FL 33701



Jacksonville Creepy Crawl- October 23, 2021

Registration starts at 8 A.M. Nocatee Station Field 400 Nocatee Center Way Ponte Vedra, FL 32081



Orlando Creepy Crawl - October 30, 2021

Registration starts at 4 P.M. Harbor Park at Baldwin Park 4990 New Broad St Orlando, FL 32814





Study Looks at Neuraxial Anesthesia and Postpartum Complications in Hemophilia

Findings from a recently published study in the Journal of Anesthesia suggest that pregnant patients with hemophilia whose factor VIII or IX levels drop below 50% at the time of receiving neuraxial anesthesia are more likely to experience postpartum complications. Neuraxial anesthesia refers to the administration of local anesthetics and analgesia to targeted locations in the spinal

area. Epidurals are a commonly utilized form of neuraxial anesthesia, often used as a method of pain relief during labor.

Investigators were led by Brandon Togioka, MD, Associate Professor, Department of Anesthesiology and Perioperative Medicine at the Oregon Health & Science University in Portland. Togioka and his colleagues conducted two sets of literature reviews in October 2019. The first review, which included 13 articles, encompassed individual case reports and case series that described neuraxial techniques in patients with hemophilia—regardless of sex, age, or pregnancy status.

The second review, which included 19 articles, looked for case reports and series that outlined bleeding outcomes among pregnant patients.

Findings from the first review showed that three of 134 patients had neuraxial hematoma with paraplegia (paralysis of the legs and lower body). All three of these patients presented with a factor level of 1%. The second review showed that out of 2,712 deliveries, postpartum hemorrhage occurred in 193 patients (7.1%), which necessitated blood transfusion in 60% of these patients. Overall, postpartum bleeding complications were nearly "twice as likely" where factor levels were below 50%.

"In summary, we found low-level evidence (Level 4) that factor VIII and IX levels should be greater than 50% for delivery and neuraxial techniques. In our review of 134 neuraxial placements and 2,712 deliveries, neuraxial hematomas were found with a factor level of 1% and hemorrhagic complications were higher when factor

activity was <50%," explained Togioka and his fellow authors. "Therefore, factor levels should be assessed and increased above 50% prior to neuraxial technique and delivery."

The review, "Delivery and Neuraxial Technique Outcomes in Patients with Hemophilia and in Hemophilia Carriers: A Systematic Review," was published March 2021 in the Journal of Anesthesia.

Please note that earlier this year, NHF's Medical and Scientific Advisory Council (MASAC) issued MASAC Document #265 which provides recommendations for the diagnosis and management of women with bleeding

disorders during pregnancy, labor, and delivery. It also addresses the critical postpartum period with specific treatment recommendations designed to both mitigate the risk of bleeding-related complications in women and to enable the early diagnosis of affected infants. The document also does include recommendations on the appropriate use of neuraxial anesthesia.

Source: Hematology Advisor, April 6, 2021

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