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Be a Baller for Bleeding Disorders:

Play March Madness!

You can shoot and score for HFGF with our brand new FUN-draiser, HFGF March Madness... Nothin' But Net! HFGF is offering a basketball bracket that benefits people with bleeding disorders. This is no airball, it's the real deal. Don't PASS up your chance to support your team AND support people with bleeding disorders. Buy-in is only \$30 per entry and funds raised pay for Camp Spirit tuition, emergency financial assistance, educational programming, MedicAlert memberships, comfy caps, scholarships and more... all for the bleeding disorders community in Florida. This is just one easy way to support HFGF... it's digital, interactive, and easy to share. Don't be a ball hog, invite your friends and family to play for the bleeding disorders community.



NOTHIN' BUT NET!



Don't get boxed out, here's a shot clock of important dates:

- 🏀 **March 3 (Tuesday)**, give and go for the HFGF March Madness (Nothin' But Net!) bracket at hemophiliaflorida.org. Be the playmaker and invite your friends and family from all over to get involved. It's only \$30 per entry.
- 🏀 **March 15 (Sunday)**: PICK your teams by 6 p.m. EST, after which the picksheet opens
- 🏀 **March 19 (Thursday)** at 12:15 PM EST: HFGF March Madness Pick Deadline
- 🏀 **March 19 & 20 (Thursday & Friday)**: First Round
- 🏀 **March 21 & 22 (Saturday & Sunday)**: Second Round
- 🏀 **March 26 & 27 (Thursday & Friday)**: Sweet Sixteen
- 🏀 **March 28 & 29 (Saturday & Sunday)**: Elite Eight
- 🏀 **April 4 (Saturday)**: Final Four
- 🏀 **April 6 (Monday)**: Championship Game

Don't be benched, register at hemophiliaflorida.org. There will be prizes for 1st (MVP), 2nd (All-Star) and 3rd (Sixth Man or Woman) for bracket winners. This is no time to foul, get in the zone and register for this slam dunk HFGF FUN-draiser!

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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.

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give medical advice or engage
in the practice of medicine. The
HFGF does not recommend partic-
ular treatments for specific indi-
viduals and recommends that you
consult your physician or treatment
center before pursuing any course
of treatment.

Dear Friends,

Happy New Year! We have so many great programs and events for you in 2020. Please check out our calendar of events at <http://www.hemophiliaflorida.org/event/>. We are always updating the calendar of events.

Special thank you to our founders and Golf Tournament Co-Chairs Rhonda and Brian McDonald for a wonderful golf tournament. It was a great sunny day, and an amazing event, raising more than \$65,000 for the bleeding disorders community.

We have a lot of advocacy activities this year We hope to increase our advocacy volunteers so we can inform our legislators on bleeding disorders issues. Please contact us at info@bleedingdisorderscoalitionflorida.org if you are interested in getting involved.

Thank you very much for supporting the HFGF. We look forward to an amazing 2020.

Warmest Regards,

Fran



February 18-19

Advocacy Days

February 26-28

Washington Days

February 21, 2020

Orlando Magic

March 14, 2020

Gainesville Walk

March 28, 2020

Lightening Hockey Game/Tampa Walk

Registration Party

April 18, 2020

Tampa Walk

April 26, 2020

Board of Directors Meeting

April 30, 2020

Scholarship applications are due

CLICK HERE to subscribe to our email to receive notices and updates of all our upcoming programs and events

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Golf Tournament Raises \$65,000 for the HFGF



The 23rd annual Flight for Tomorrow golf tournament was held on a beautiful, sunny Monday, October 28, 2019 at East Lake Woodlands Country Club in Oldsmar.

The winning foursome comprised Chip Bauder, Ken Fraser, John Balogh and Jay Wiley. In second place were Andrew Norris, Zach Wood, Matt Cote and Ryan Wood. The third-place group consisted of Kevin Slezak, Brian Buck, Bill Lutes and Nick Vaden.

Other winners included Putting Contest: Keith O'Connor, Ryan O'Connor, Mark Brissenden, Adam Heirs;

Men's Long Drive: Jay Wiley;

Ladies' Long Drive: Michelle Froning

Closest to the Pin #6: Jack Dennis

Closest to the Pin #8: Steve Sharts

Closest to the Pin #10: Tyler Hegseth

Closest to the Pin #16: Steve Sharts

Par Three Poker \$700.00: Daniel Hinchee



Thanks to everyone for playing. Join the fun and help raise funds for the Florida bleeding disorders community at next fall's 24th annual Flight for Tomorrow golf tournament to be held Monday October 26, 2020 at East Lake Woodlands Country Club.



A very heartfelt thank you to all our sponsors for making this tournament possible:

Title Sponsor and Co-Chairs

Brian and Rhonda McDonald

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We'd also like to thank the donors of experiences to our auction:

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Hyatt Regency Jacksonville Riverfront
City National Bank Kevin Slezak
Lake Buena Vista, Palm Magnolia or Oak Trail
Legoland Florida Resort

Orlando Solar Bears
Rhonda and Brian McDonald
Ringling Bros Museum
Tampa Bay Buccaneers
Tampa Bay Lightning
Tampa Sports Authority Golf Courses: Babe Zaharias Golf Course, Rocky Point Golf Course or Rogers Park Golf Course
TPC Tampa Bay
Top Golf
Universal Orlando
West Marina





News from the Nurse

By Leanne Buchanan RN



Happy New Year, everyone! As we enter 2020, I wanted to take a moment to remind everyone how to manage their bleeding disorders to live a happy and healthier life. Hemophilia and other bleeding disorders may not have a cure but there are ways to manage the disease and avoid bleeding episodes. Below are some tips to follow for healthier outcomes.

Exercise

Exercise is helpful for maintaining a healthy body weight and improving muscle and bone strength. If making a commitment to start an exercise program, make sure to check with your physician first for any contraindications for you. People with bleeding disorders should avoid sports which are more likely to lead to injury and shouldn't participate in contact sports. Safe exercise options include swimming, walking, and cycling.

Avoid Certain Medications

Hemophilia patients need to avoid taking certain medications that could thin the blood such as warfarin and heparin. They also need to avoid over-the-counter medications such as aspirin and ibuprofen. Acetaminophen is safe for people with Hemophilia to take for pain relief.

Practice Good Dental Hygiene

Thorough cleaning of teeth and gums is essential to help avoid any dental work which may lead to excessive bleeding. Dentists will be able to advise you on how best to keep teeth and gums healthy. Brush and floss your teeth at least once a day.

Keep Children Safe

Safety helmets, along with knee and elbow pads, should be worn by children when cycling. Ensure they always wear their seatbelts in the car and try to discourage too much rough and tumble play. Keep the home as safe as possible by ensuring there are no sharp corners on furniture or tripping hazards.

Get Yearly Checkups and Vaccinations

Yearly checkups at a Hemophilia Treatment Center (HTC) are essential to ensure the best care. Patients should be tested regularly for blood infections and should speak to their doctor about hepatitis A and B vaccinations.

MedicAlert

Make sure that you always have your MedicAlert bracelet or necklace on. If you are in an accident and cannot tell medical help about your bleeding disorder, this can lead to a delay in treatment. Never leave home without your MedicAlert.

My hope is that each of you have a very healthy New Year!

Leanne



Meet the Gainesville Walk Champion

Joseph Burke, Champion Chairperson for the 2020 Gator Clot Trot
Resident: Clermont
Hometown: Whitesburg, Kentucky



Involvement with HFGF: 10+ Years

Joseph Burke has been on quite a journey since being diagnosed at birth with Severe Hemophilia A forty years ago. But through it all, he remains positive, not allowing a bleeding disorder to control his life.

“It’s about turning messes into messages,” says the Clermont resident. “We are not defined by our illnesses.”

Born and raised in Whitesburg, Kentucky, Joseph is a product of a time when information on how to deal with bleeding disorders was sparse. There was little outreach. There were no camps. As a result, he lives with significant joint damage. Some days are better than others, but Joseph is on disability because it can be tough to move around at times.

“If I knew then what I know now, I wouldn’t have played sports,” he laughs, noting that one of his elbows is permanently fused. “And those book bags on my back in high school and college took their toll. A bad situation turned into a worse situation.”

From birth, Joseph’s future appeared ominous. By the time he was 2 years old, he contracted HIV. At 3, Joseph was diagnosed with Hepatitis C. A self-described survivor, he is one of an estimated 12,000 hemophiliacs who contracted

HIV and/or Hepatitis C in the 1980s and early 1990s from the contaminated blood supply that rocked the bleeding disorders community—and the world. Of those infected, less than 1.8% are alive today. Coming from a long history of hemophilia in the family, Joseph had five male cousins who were also born with a bleeding disorder. Three of them have since passed away.

Disheartening as Joseph’s story seems, he has accomplished some really cool things and speaks of his life with much joy and elation despite the trials and tribulations. After receiving his degree in computer science from the University of Kentucky, Joseph, who had developed a passion for the Blue Man Group, created a website from which users could stream Blue Man Group performances. This was before YouTube, or any type of mass streaming existed. His creation was so popular, he was attracting more traffic than the Blue Man Group website. That’s when he received a call from the group’s lawyer.

But instead of asking Joseph to cease and desist, he wanted to help him with his venture and in 2006, Joseph became a Blue Man Group employee. For four years, he toured the United States with the troupe handling social media and marketing.

In 2008, Joseph moved to Central Florida—and life got even better. He met Alexandra, a registered nurse, during a Blue Man Group charity fundraiser. A year later, they were married. And in 2014, he beat Hepatitis C thanks to a new drug called Solvaldi.

He admits, however, that when he first moved here from Kentucky, he was feeling a little lost, so he made his first contact with the Foundation.

“My parents had always been there for me, taking me to school and to the hospital, and now I was on my own,” he recalls. “Fran poured the truth back into my life when I needed it most. What she said was very real and very relevant.”

In March 2020, Joseph will serve as the Champion Chairperson for the Gator Clot Trot held annually in Gainesville. After the Blue Man Group gig ended, Joseph turned his attention to his love of art, and now creates comic books and works as a freelance graphic designer. He also serves as the Ministry Director at Real Life Church helping others who are seemingly lost to find direction. He found his and is glad to be giving back.

“I am so happy where I am right now,” he admits. “I am thankful for the life I have had, or I wouldn’t have the life I have today.”



Federally Funded Florida Hemophilia Treatment Centers

Hemophilia Treatment Centers (HTCs) provide support for those with bleeding disorders. Hemophilia is a complex and rare condition. HTCs give their patients one-stop access to all the multidisciplinary care they need from doctors, nurses, and other health care professionals familiar with bleeding disorders.

HTCs help patients live longer, fuller lives with fewer complications. CDC studies of 3,000 people with hemophilia showed that those who used an HTC were 40% less likely to die of a hemophilia-related complication compared to those who did not receive care at a treatment center.¹ Similarly, people who used a treatment center were 40% less likely to be hospitalized for bleeding complications.²

Arnold Palmer Hospital for Children- The Haley Center for Children's Cancer and Blood Disorders



92 West Miller Street
MP318
Orlando, FL 32806
Phone: (321) 841-8588
Fax: (321) 841-8560
Comments:
For URGENT calls,
please call: (321) 841-
8588, option 2 for Triage
RN

Nurse Coordinator: Stephanie Sharon
Phone: (321) 841-7744
Email: Stephanie.Sharon@orlandohealth.com



**Johns Hopkins All
Children's Hospital
Johns Hopkins All
Children's Outpatient
Care Center
Pediatric Cancer
and Blood Disorders
Center**

601 5th Street South
Third Floor

St. Petersburg, FL 33701
Phone: (727) 767-4176 Fax: (727) 767-4379
Pediatric after hours: (727) 767-4176
Comments: Answering service refers all calls to the on-call hematology/oncology physician after 5 pm weekdays and prior to 8:30 am. Answering service retrieves calls all weekend long.

HTC Director: Irmel Ayala Phone: (727) 767-4176
Email: iayala1@jhmi.edu
Nurse Coordinator: Mary Ann Cardenas
Phone: (727) 767-4931
Email: mcarden4@jhmi.edu



Kidz Medical Services, Inc.

3100 SW 62 Ave.
Miami, FL 33155
Phone: (305) 662-8360
Fax: (305) 666-6387

HTC Director: Dr. Guillermo De Angulo
Phone: (305) 661-1515
Email: Guillermo.DeAngulo@Nicklaushealth.org
Nurse Coordinator: Ms. Sofia Miranda
Phone: (305) 661-1515
Email: Sofia.Miranda@Nicklaushealth.org

Nemours Children's Clinic Division of Pediatric Hematology/Oncology

807 Children's Way
Jacksonville, FL 32207
Phone: (904) 697-3789
Fax: (904) 697-3790
Pediatric after hours: (904) 697-3600
Comments: Please ask for the hematologist on call
HTC Director: Johanna Haneline
Phone: (904) 697-3744
Email: johanna.haneline@nemours.org
Nurse Coordinator: Cindy Gauger
Phone: (904) 697-3793
Email: cgauger@nemours.org
Nurse Coordinator: Sarah Watkins
Phone: (904) 697-3789
Email: Sarah.watkins@nemours.org





Federally Funded Florida Hemophilia Treatment Centers

cont'd



St. Joseph's Hospital Center for Bleeding and Clotting Disorders St. Joseph's Children's Hospital

3001 W. Dr. MLK Jr.
Blvd.
Tampa, FL 33607
Phone: (813) 554-8294
Fax: (813) 554-8937

Adult after hours: (813) 321-6589
Pediatric after hours: (813) 321-6820
Comments: Please call 813-321-6820. Caller will be connected to answering service on nights/weekends to BayCare Medical Group Pediatric Hematology/Oncology
HTC Director: Erin Cockrell
Phone: (813) 554-8294
Email: Erin.Cockrell@baycare.org
Nurse Coordinator: Lisette Sanchez
Phone: (813) 554-8675
Email: Lisette.sanchez@baycare.org

University of Florida Hemophilia Treatment Center Division of Pediatric Hematology/Oncology

1600 SW Archer Road
Gainesville, FL 32610
Phone: (352) 273-9120
Fax: (352) 273-5941

Adult after hours: (352) 961-8802 ext. pager
Comments: Please ask for the hematologist on call
Pediatric after hours: (352) 265-0111
Comments: Please ask for the hematologist on call
HTC Director: Dr. Tung Wynn
Phone: (352) 273-9120
Email: twynn@ufl.edu
HTC Director: Dr. Anita Rajasekhar
Phone: (352) 273-7832
Email: Anita.Rajasekhar@medicine.ufl.edu
Nurse Coordinator: Robert Campbell
Phone: (352) 273-6780
Email: robertcampbell1@ufl.edu



University of Miami Hemophilia Treatment Center Pediatrics and Adults University of Miami Miller School of Medicine Department of Pediatrics Div of Hematology/Oncology

Locator Code D820
1601 NW 12th Ave, Room 5019
Miami, FL 33136
Phone: (305) 243-0834
Fax: (305) 243-0842
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Phone: (305) 243-0834
Email: jdavis3@med.miami.edu
HTC Director: Dr. Thomas Harrington
Phone: (305) 243-6626
Email: tharrington@med.miami.edu
Nurse Coordinator: Maya Bloomberg
Phone: (305) 243-9834
Email: msmith4@med.miami.edu
Nurse Coordinator: Krysten Sargenton
Phone: (305) 243-0831
Email: K.sargenton@miami.edu

University of South Florida - Adult Hematology 4th Floor



13220 Laurel Drive
Tampa, FL 33612
Phone: (813) 974-3725
Fax: (813) 974-9476
Adult after hours:
(813) 974-2201

HTC Director: Dr. Nathan Visweshwar
Phone: (813) 974-3012
Email: nviswesh@health.usf.edu
Nurse Coordinator: Hazina Joseph
Phone: (813) 974-4088
Email: hjoseph1@health.usf.edu

1 Soucie JM, Nuss R, Evatt B, Abdelhak A, Cowan L, Hill H, Kolakoski M, Wilber N, and the Hemophilia Surveillance System Project Investigators. Mortality among males with hemophilia: relations with source of medical care. *Blood* 2000; 96:437-442.

2 Soucie JM, Symons J, Evatt B, Brettler D, Huszti H, Linden J, and the Hemophilia Surveillance System Project Investigators. Home-based factor infusion therapy and hospitalization for bleeding complications among males with hemophilia. *Haemophilia* 2001; 7:198-206



Research Update

Study Shows Higher Postpartum Hemorrhage in FXI Deficiency Patients Post Cesarean

Researchers from the Beth Israel Deaconess Medical Center in Boston, MA conducted a study on the link between postpartum hemorrhage (PPH) and women with mild factor XI (FXI) deficiency. The results were included in a research poster abstract presented on December 9, 2019 during the 61st American Society of Hematology Annual Meeting in Orlando, Florida.

Since direct-to-consumer genetic testing companies now often screen for FXI mutations, more people are learning that they have a mild form of the disease. While many of these individuals have never exhibited symptoms, they may still be vulnerable for excessive bleeding related to surgery. The investigators from Beth Israel looked at a particularly at-risk group, postpartum women with mild FXI deficiency, including those who have undergone a cesarean delivery.

Investigators initiated a retrospective analysis that included two groups, a control group that included 200 women who had undergone deliveries between 2016 and 2018, and a second group which included 40 women with mild FXI deficiency.

The FXI deficiency group included 71 deliveries, of which 45 were vaginal and 26 were cesarean. The control group encompassed 200 deliveries, of which 125 were vaginal and 75 were cesarean. PPH was defined as estimated blood loss of at least 1000 milliliters (mL) or reported symptoms of hypovolemia (a decreased volume of circulating blood in the body) related to blood loss within 24 hours post-delivery.

In both groups, median estimated blood loss for vaginal deliveries was 300 mL and median estimated blood loss for cesarean deliveries was 800 mL. Among patients undergoing vaginal delivery, PPH occurred after no deliveries in the FXI deficiency group and after one delivery in the control group. In contrast, women with mild FXI deficiency undergoing cesarean delivery were approximately twofold more likely to develop PPH when compared to the control group. The overall rates of PPH among those FXI women who underwent cesarean delivery was 38.4% (10 of 26 deliveries) compared with 18.7% (14 of 75 deliveries).

Investigators ultimately found that a prior history of hemorrhage was the best predictor of PPH following cesarean delivery. In fact, most of the women (7 out of 10) who developed PPH following cesarean had a prior history of bleeding. Notably, only two of the women with PPH received some type of prophylactic care prior to delivery. Among the sixteen cesarean deliveries in the FXI group without PPH, significantly fewer had a history of bleeding.

“In this case control study, we did not observe any cases of PPH among women with FXI deficiency who underwent a vaginal delivery but noted a greater than 2-fold increase in PPH among those women who underwent a cesarean delivery,” concluded the study authors. “In those women with a bleeding history, the risk of PPH following cesarean section was nearly 10-fold higher compared to women without a history of hemorrhage supporting the role for prophylactic measures in this high-risk group.”

Source: Hematology Advisor, December 10, 2019



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THIS CHANGES EVERYTHING.**

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Social Work Resources

By Dina Richardson, MSW

This year has flown by! It seems like it wasn't too long ago when the school year started, and now we are already into the second part of the year. If graduation is just around the corner for you and you are looking to further your schooling once graduation concludes, now is the time to explore available scholarships. There are lots of scholarship opportunities out there that can help make it more affordable. Here at HFGF we have scholarships available for those who meet the criteria. Please see the criteria and if you meet the requirements, please apply! We would love to help make this dream into your reality! If you're looking for other scholarships within the bleeding disorders community, check out NHF's scholarship resource guide: <https://www.hemophilia.org/Community-Resources/Scholarships>.

Requirements for HFGF Scholarship:

- Florida Resident.
- Application must be completed by applicant.
- Must have Hemophilia, vWD, or other related inherited bleeding disorders that HFGF serves.
- High school graduate pursuing post-secondary education at a college, university, technical school, or trade school.
- Applicant must have volunteered with HFGF or another program/foundation/treatment center within the bleeding disorders community during 2019/2020.

For volunteer opportunities at HFGF, please contact events@hemophiliaflorida.org

Application must include:

- Completed application.
- 3 references by employers or teachers (references from family and/or friends will not be allowed).
- Current transcripts.

Application deadline is April 30, 2020.

To apply for HFGF's scholarship, please visit our website at: <http://www.hemophiliaflorida.org/what-we-do/scholarships/scholarships>

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