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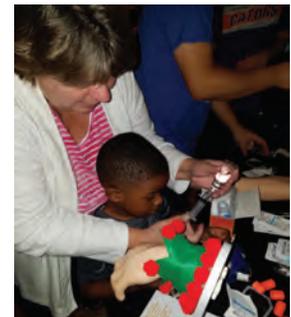
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2018 was a very productive year for the HFGF. Thanks to your generosity in supporting our fundraising efforts and your donations, we were able to provide the following services:

Partnering with Hemophilia Treatment Centers (HTCs) throughout the state of Florida, we produced 26 informational programs serving 1700 people. These included a Women's Tea, Smart Games, HTC Information, Volunteer Reception, Jacksonville Program, Family Fun Day, Getting in the Game, Advocacy Program, Special Family Programs Dinners, Bleeding Disorders Trivia, Resilience Dinner, Holiday Gatherings, Step It Up, HTC and Me, PEP, Camping Programs, Bleeding Disorder Coalition of Florida (BDCF) Advocacy in Tallahassee. HFGF paid for 78 children to attend a week-long Camp Spirit at Camp Bogy Creek. We handed out 596 gift cards to make the holidays a little brighter for those with bleeding disorders and their families.



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The Hemophilia Foundation of
Greater Florida
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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 Con-
nections is for your general informa-
tion only. HFGF does not give medi-
cal 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,

I hope everyone is doing well. We are so excited that spring is here, although we do not have cold weather, it is so nice when the sun sets after 8:00 P.M.

This year has already been very busy. We have held our annual theater event featuring the Broadway production of Hamilton, our Annual Gator Clot Trot walk and 5K, and the Tampa Superhero Walk. What a great 2019!!!

On June 1, we have a special family program at the Ports of Call: READY –SET... TRANSITION," an interactive program for the entire family.

This year, we will be introducing Summer Family Fun Nights, an opportunity for families to get together, play games, eat and have fun. Check out our website at www.hemophiliaflorida.org for details.

Speaking of our website, we have a new one. Check it out and let us know what you think.

Camp Spirit is around the corner (June 19-24, 2019) at Camp Boggy Creek. if you have not registered for camp yet, please go to <http://www.boggycreek.org/campers/camper-application/> and complete the camp application.

Have a great spring!

Warmest Regards,
Fran



June 1, 2019

June 19-24, 2019

July 19-20, 2019

July 21, 2019

August 10, 2019

August 17, 2019

August 25-26, 2019

September 7, 2019

September 20-21, 2019

October 12, 2019

October 26, 2019

October 28, 2019

Annual Family Program at SeaWorld

Camp Spirit

Teen Retreat

Board of Directors Meeting

Orlando Pride Soccer Event/Walk Kick off

Adventure Island Program

Florida State Meeting

Gainesville Program

Family Retreat Weekend

Jacksonville Creepy Crawl

Orlando Creepy Crawl

Flight for Tomorrow Golf Tournament

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



Speak Up For Bleeding Disorders

By Leah Nash

If someone is treating you unfairly or poorly, do you believe that it is your right to stick up for yourself? If so, you are an advocate. This is something that we all have the right and privilege to do.

In terms of politics, there are instances when you may feel powerless. That is not the case. When you are an advocate, you are empowering yourself and the community that you represent. In the case of bleeding disorders, the Bleeding Disorders Coalition of Florida (BDCF) is available to guide you in your advocacy efforts. BDCF is the combined efforts of the Hemophilia Foundation of Greater Florida and the Florida Hemophilia Association to create a stronger voice for bleeding disorders legislatively.

Tallahassee 2019

On World Hemophilia Day of this year, bleeding disorders advocates from all over the state travelled to the great state of Florida's Capitol to train about storytelling and state issues affecting our community.

Seventeen advocates came together and spoke to their legislators about issues affecting health insurance such as step therapy and short term health insurance plans.

BDCF is in support of step therapy (also known as fail first) protective legislation. Step therapy occurs when a doctor prescribes a treatment and the insurance company requires the patient to try one or several other drugs first usually based on financial rather than medical considerations. As your health advocate, the BDCF stands firmly in support of legislation that establishes important protections around the use of step therapy protocols, safeguarding patient health and returning the power of

practicing medicine back to the treating physician.

BDCF is in opposition of short-term and association health plans (STPs and AHPs) that don't meet important ACA standards for coverage, availability, and/or protection against out-of-pocket spending. STPs and AHPs often seem more affordable but the proliferation of these types of plans jeopardize coverage for people with bleeding disorders, destabilizing the individual insurance market. Expansion of STPs and AHPs lead to underinsurance and increases the cost of comprehensive insurance plans that are needed by people with pre-existing conditions such as hemophilia and other bleeding disorders.

Be An Advocate All Year Long

BDCF advocates made their voices heard in Tallahassee this year, as they have done in previous years. But advocacy efforts must continue beyond an annual visit to Tallahassee. Advocacy must continue throughout the year. Most importantly, we encourage advocates to make appointments while their legislators are back in their home

districts to educate them about bleeding disorders issues. Creating a relationship with your legislator is the most important thing you can do to have your voice heard.

Don't worry! BDCF will provide you the resources you need to create these relationships and speak intelligently about bleeding disorders issues, as well as upcoming legislation. Please visit hemophiliaflorida.org/advocacy or email leahnash@hemophiliaflorida.org for more information.



**CHANGE THEIR WORLD. CHANGE YOURS.
THIS CHANGES EVERYTHING.**

[BECOME A VOLUNTEER](#)

OR

[DONATE](#)



Named Funds Available To Honor Bleeding Disorders

By Leah Nash

The Hemophilia Foundation of Greater Florida (HFGF) is offering a wonderful opportunity to honor someone you love with a named fund. For example, HFGF has established the Ron Sachs Camp Spirit endowment fund in honor of our previous Board of Directors Chairperson, who passed away in December 2018. As a way to honor Ron and his passion for Camp Spirit, the HFGF Board of Directors decided to start a fund to support Camp Spirit tuition in his name.

What is an endowment fund? It is an investment fund established by a foundation that makes consistent withdrawals from invested capital. The capital in endowment funds is utilized for specific needs or to further a company's operating process.

HFGF invites you to start an endowment fund in the name of someone you would like to honor as well. When you open an endowment fund with HFGF, you may select where you would like the proceeds to go to. For example, any interest generated from donations made to the Ron Sachs endowment fund will go towards sending HFGF youth to Camp Spirit. If you open an endowment fund in the name of someone, you may select where you would like that interest to go to as well. Examples of HFGF services are Camp Spirit, scholarships, and emergency financial assistance. An endowment fund can be opened with any dollar amount even as low as \$10

If you do create a HFGF endowment fund, we recommend that you tell others about it and encourage them to donate to it as well. Instead of receiving birthday gifts, you may ask your loved ones to donate to the endowment fund that you have created.

Endowment funds are the perfect way to honor someone special in your life, as well as support your bleeding disorders community. If you are interested in starting a named HFGF endowment fund, please contact Leah Nash at leahnash@hemophiliaflorida.org or 407.629.0000.

Follow the HFGF on



Like our page on Facebook:
Hemophilia Foundation of Greater Florida or
follow us on Twitter @HemophiliaFL or
follow us on Instagram
[Instagram@hemophiliaflorida](https://www.instagram.com/hemophiliaflorida)

**HIGH SCHOOL STUDENTS
EARN COMMUNITY SERVICE HOURS**

VOLUNTEER FOR THE HFGF

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

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they'll donate to

**The Hemophilia Foundation of
Greater Florida**



Clot Trotters and Superheroes Galore

By Leah Nash

HFGF walks breezed by this spring and brought out Clot Trotters in Gainesville and Superheroes in Tampa.

will be back at Al Lopez Park on April 18th... just after World Hemophilia Day!



The Gainesville Clot Trot occurred on March 23rd on a cool morning that turned out to be a gorgeous day for runners, walkers, and fundraisers.

Need help fundraising or have a fundraising idea? Contact leahnash@hemophiliaflorida.org. Registrations for both the Jacksonville and Orlando Creepy Crawls are now open at hemophiliaflorida.org. Hover over "Walks and 5Ks" on the menu and click on the location you'd like register for.

Over \$40,000 was raised at this year's Gator Clot Trot and approximately 150 people came out to support HFGF and bleeding disorders awareness at beautiful Depot Park. Please mark your calendar for March 14th in 2020 for the Gator Clot Trot, again at Depot Park. Be on the lookout for registration opens. The Gator Clot Trot is the perfect tribute to Bleeding Disorders Awareness Month, which occurs annually in March.



Congrats to BioTest Plasma for being awarded both the Spirit and Corporate awards, UF HTC for being awarded the team with the most kids, Team E-Man for being top fundraising team, and Alex Wyrick for being top individual fundraiser.

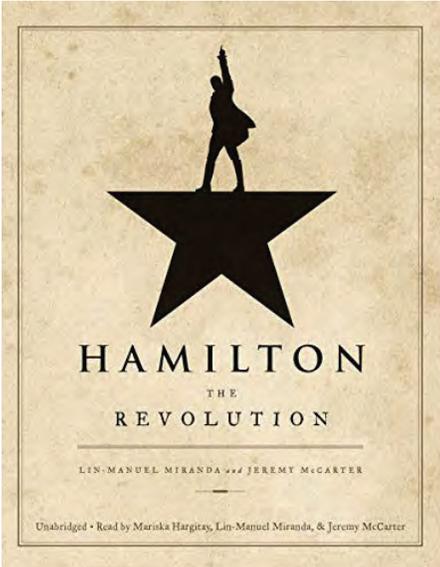


The Tampa Superhero Fun Walk occurred on April 7th at Al Lopez Park. Congrats to our award winners: Layne Strong as top individual fundraiser, Layne's Superheroes as top team fundraiser, Incredible Liam as Best Dressed Superhero Squad, and St. Joseph's Children's Hospital Hemophilia Treatment Center (HTC) as Champions in Action Corporate Award. Over \$45,000 has been raised from the Tampa walk and we are still fundraising. Save the date now for 2020, we





The Hamilton Revolution



The HFGF joined the Hamilton Revolution, February 6, 2019 at the Dr. Phillips Center of Performing Arts Center. Our patrons and sponsors experienced a great evening seeing the show of a lifetime, Hamilton. The evening included orchestra seating, a reception, silent auction/raffle and the opportunity to support the Bleeding Disorders Community raising more than \$72,000 to support HFGF programs and services.

Thank you patrons and sponsors for supporting this amazing event. Your support helped send kids to Camp Spirit, (at \$825 a camper) which is our special medically supervised overnight camping experience. You supported our Emergency Financial Assistance Program which includes Medic Alerts, medical care for uninsured patients, dental care and many other HFGF services .

THANK YOU SPONSORS AND EVENT SPONSORS

Best Musical Sponsor **Best Play Sponsor** **Best Actor Sponsor**



CSL Behring
Rare Patient Voice

Novo Nordisk

Program Sponsor



Thank You Event Donors

- Alex and Ani
- Blue Man Group at Universal
- JoAnn Brownrigg
- EO Inn
- 4RSmokehouse
- Hampton Inn Suites
- Hemophilia Foundation of Greater Florida
- LegoLand
- Lizzy McCormack's Irish Pub
- Morse Museum in Winter Park
- Orlando Magic
- Orlando Solar Bears
- Rifle Paper Company
- TooJay's
- Spirit Airlines
- Ventura Country Club
- Vistana Signature Experiences
- Walt Disney World



2018

YEAR IN REVIEW *cont'd*

The HFGF hosted a Family Retreat Weekend at Camp Boggy Creek, where 32 families participated.

The HFGF was also the host for the 3rd Annual Florida State Meeting, in which 45 medical professionals specializing in treating bleeding disorders participated.

The HFGF also provided 223 Medic Alert Memberships and helmets to members of the bleeding disorders community. The HFGF provided more than \$65,000 in emergency assistance including dental care, medical labs, medical care for those without insurance, and life support issues





MedicAlert 101

MedicAlert is something everyone with a medical or cognitive diagnosis should have. A MedicAlert is a bracelet or necklace that alerts first responders that there is a medical and/or cognitive diagnosis. When first responders contact MedicAlert they will be provided with the person's name, diagnosis, medication, and dosing. This information is vital for the first responders to be able to properly care for the person wearing the MedicAlert. Additionally, the MedicAlert company will notify your emergency contact listed, expediting the reunification and support to the wearer.

If you have not yet obtained a MedicAlert, you can receive one through your Hemophilia Foundation of Greater Florida (HFGF). We encourage

all of our community member's with Hemophilia to get one and wear it at all times. You can contact your Hemophilia Treatment Center or HFGF directly to submit an application for a MedicAlert. Choose your own MedicAlert and HFGF will cover anything



\$29.99 or under. In order for HFGF to cover the MedicAlert, the application has to be submitted to your HTC or HFGF directly.

Once you receive your MedicAlert, it's crucial to keep the information that you provide to MedicAlert updated as to your diagnosis, medications, and emergency contact. If at any point in the year any of these change, please contact MedicAlert directly at 800.432.5378 to provide the updated information.

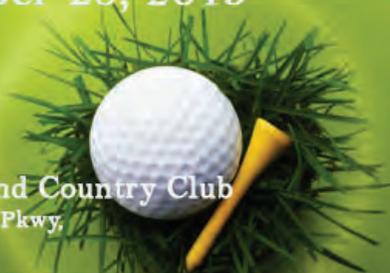
MedicAlert needs to be renewed annually. The only time that you should be receiving mail from them is when they are notifying you that your MedicAlert renewal is approaching. Please do not disregard this notice! If it is not renewed, MedicAlert will not be able to assist in the event of an emergency. Please send your renewals to your Hemophilia Treatment Center or HFGF directly.

If you have any questions, please contact us! 407.629.0000

**SAVE THE DATE
& SIGN UP NOW**

**23rd Annual
Flight for Tomorrow
Invitational Golf Tournament**

October 28, 2019



East Lake Woodland Country Club
1055 E Lake Woodlands Pkwy,
Oldsmar, FL 34677

For More Information Contact
Rhonda McDonald 727-638-8979 rhonda@brmgroup.us
Info@hemophiliaflorida.org

MISSION STATEMENT

Our Mission

The Hemophilia Foundation of Greater Florida, a chapter of the National Hemophilia Foundation, has been serving people with bleeding disorders since 1996. We are helping the bleeding disorders community improve their quality of life by offering programs and services to support healthier.

