



BDFFF CONNECTION



The Quarterly Newsletter of the BDFFF Spring 2024 -Volume 44-Issue 70

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The BDFFF is offering a **Scholarship** for people with bleeding disorders in Florida in pursuit of a Medical Career

The Founders Medical Scholarship was established to honor Brian and Rhonda McDonald, founders of the Hemophilia Foundation of Greater Florida, now known as the Bleeding Disorders Foundation of Florida. For over 35 years they have worked to improve the quality of life for people with bleeding disorders and



their families through Brian's role as Pharmacist and President and Rhonda serving as a Patient Advocate and Chief Operating Officer of a home infusion company. In their role as co-chairs of the Flight for Tomorrow Invitational Golf Tournament, they have raised 2 million dollars to support the needs of the bleeding disorders community. This scholarship was created in their honor to support individuals with bleeding disorders in their pursuit

of a career in a medical profession.

Florida residents with hemophilia, von Willebrand disease, or other related hereditary bleeding disorders are eligible to apply for the Founders Medical Scholarship. Applicants must have completed a bachelor's degree and be enrolled in a post-baccalaureate program in one of the following areas of study: medicine, nurse practitioner, pharmacist, psychiatrist, physician assistant, physical therapist, or medical social worker.

Scholarships are awarded based on merit, need, record of community service, and the aspirations of the applicant. The monetary award is given directly to the institution that the recipient attends.

Application forms may be downloaded from the BDFFF web site: bleedingdisordersfl.org/what-we-do/scholarships/. If you have any questions regarding the application process, please contact the Bleeding Disorders Foundation of Florida at 1-800-293-6527 or info@bleedingdisordersfl.org.

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

BDFF Connections

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Mission

The mission of the Bleeding Disorders Foundation of 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 BDFF Connections is for your general information only. BDFF does not give medical advice or engage in the practice of medicine. The BDFF does not recommend particular treatments for specific individuals and recommends that you consult your physician or treatment center before pursuing any course of treatment.

Executive Director's Column

Dear Friends

We are swinging into **Spring** we have so many exciting and fun opportunities for everyone! We have dinners, programs, walks, and Camp Spirit scheduled (Check out our calendar of events: bleedingdisordersfl.org/events/list/).

This was another important year for advocacy. We tried to get the accumulator adjuster bill over the finish line, but we were not able to make it happen. We are not giving up! We have a great group of advocacy ambassadors ready to take on the Florida Legislature to get the bill passed in 2025 (see op-ed written by Cindy Meide)

March was Bleeding Disorders Month, we kicked it off with our Annual Theater Event and we received quite a few Proclamations from local government throughout the state. Special shout out to Samantha Nazario for getting proclamations for Bleeding Disorders Awareness Month.

April 17, 2024, is World Hemophilia Day, World Hemophilia Day celebrates the birthday of Frank Schnabel who founded the World Federation of Hemophilia and serves as a platform to increase awareness and provide education about hemophilia and other bleeding disorders. Join us on April 26, 2024, at Leu Gardens for our World Hemophilia Day Celebration. For more information contact the BDFF at info@bleedingdisordersfl.org or 800-293-6527.

I look forward to seeing everyone soon. Have a wonderful spring.

Fran



April 21, 2024

BDFF Board of Directors Meeting

April 26, 2024

**World Hemophilia Day Celebration-
Leu Gardens Orlando Florida**

April 27, 2024

**Women's/Girls Tea Program –
Empress Tea Room, Tampa**

May 8, 2024

Pensacola Dinner Program – Gene Therapy

May 16, 2024

**Jacksonville Dinner Program –
Celebration of Life Missy**

June 1, 2024

Annual Family Program- Orlando, Florida

June 19-24, 2024

**Camp Spirit Summer Camp Program –
Eustis Florida**

The Bleeding Disorders Foundation of Florida (BDFF) kicked off Bleeding Disorders Awareness Month with a fun night of theater, Saturday, March 2, 2024, benefitting the BDFF. Supporters enjoyed orchestra seating for a production of the Broadway hit Moulin Rouge, a private reception, and silent auction and raffle at the Dr. Phillips Performing Arts Center in Orlando. The event raised at least \$31,000 to support BDFF's programs including Camp Spirit, the Emergency Assistance Fund, and bleeding disorders educational programs.

A very special thank-you to our sponsors for helping make the event possible:

Tony Award Winning Sponsor

CSL Behring

Biotherapies for Life®

Corporate Sponsor



**In recognition of Bleeding Disorders Awareness month
We would like to thank the following friends.**



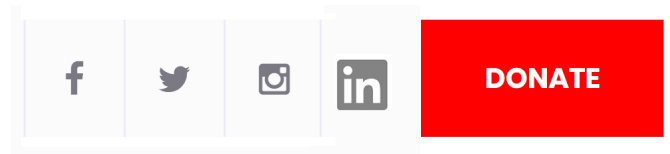
- Bayer**
- CSL Behring**
- CVS**
- HEMA Biologics**
- Octapharma**
- Paragon**
- Sanofi**



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A big thank-you to all the individuals and organizations who contributed goods and services to our silent auction and raffle.

Alfond Inn
Bark Box
Bok Towers
Butterfly World
Dawn Wren
Carson Family
4 Rivers Smokehouse
Dr. Phillips Center for the Performing Arts Lillian and Chip Hearn
Natural Life
Orlando Magic
Orlando Science Center
PRP Wine International
Solar Bears
Solomon Family
The Glass Knife
Texas Roadhouse
TopGolf Orlando
Total Wine & More
Trader Joes
Tyler Nazario
Tyler's Grandmothers
Wine for Humanity
Wonder Works



On Saturday April 6, 2024, 125 people gathered in Gainesville to take part in the 13th annual Gator Clot Trot 5K fun run and walk to raise funds for the BDFF. At the event were the 501st Legion Star Wars characters, UF cheerleaders and dancers, and dogs that play soccer against humans! Not only was the event so much fun, but also it was a successful fundraiser. More than \$25,000 was raised to support the programs of the BDFF.

Congratulations to Jack DeLoach for being the Top Individual Fundraiser, Team Don't Stop 'til You Clot for being the Top Fundraising team, Red Madden for being the Volunteer of the Year, and to UF Health's Hemostasis Treatment Center for winning the Sunshine Spirit Award! And of course, congratulations to our runners and walkers for completing the race!



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

Major Sponsor:
Winsupply of Gainesville

Champion Sponsors:
Bayer HealthCare
CSL Behring
Genentech
Hemophilia of Georgia
DrugCo Health
Takeda
Novo Nordisk
Sanofi
UF Health Hemostasis Treatment Center

Sprint Sponsor:
HEMA Biologics

Stroll Sponsor:
PARAGON Hemophilia

Media Sponsor:
I AM 106.9 COUNTRY



Camp Spirit
Summer Camp
Applications are OPEN!

Join us for a summer filled with friendship,
adventure, and fun!

June 19-23, 2024

Apply now to secure your spot in this
impactful program:

<https://bleedingdisordersfl.org/what-we-do/camp-spirit/>

Camp Spirit Family Retreat Weekend
October 18-20, 2024

Family Retreat Weekend Applications are open! Register Today at

bleedingdisordersfl.org/what-we-do/family-retreat/





Monday, OCTOBER 21, 2024

Ardea Country Club
1055 East Lake Woodlands Pkwy
Oldsmar, FL 34677

bleedingdisordersfl.org/fundraising/golf-tournament/

Golf Tournament

Follow/Like BDFF on Social Media!

[Facebook.com/bleedingdisordersfl](https://www.facebook.com/bleedingdisordersfl)

[Twitter.com/hemophiliafl](https://twitter.com/hemophiliafl)

[Instagram.com/hemophiliaflorida](https://www.instagram.com/hemophiliaflorida)

[Linkedin.com/in/company/bleeding-disorders-foundation-of-florida](https://www.linkedin.com/in/company/bleeding-disorders-foundation-of-florida)



17th Annual Superhero Walk

A blue poster for the 17th Annual Superhero Walk. On the left is a yellow and red comic book-style explosion graphic containing the text "17th ANNUAL SUPERHERO walk" and a white superhero silhouette. To the right, the event details are listed in white and yellow text. At the bottom, the date "Saturday, September 21, 2024" is written in large yellow letters, followed by registration information in white.

Vinoy Park
701 Bayshore Dr. NE
St. Petersburg, FL 33701

Registration - 9:00 AM
Walk Begins - 10:00 AM

Saturday, September 21, 2024

Register at bleedingdisordersfl.org/walks-5ks
More info: info@bleedingdisordersfl.org or 800.293.6527

18th Annual Creepy Crawl Walk and 5k Run

A purple poster for the 18th Annual Creepy Crawl. It features a large full moon, several black bats flying around it, and a mummy character on the right. The text "18th ANNUAL Orlando Creepy Crawl" is written in orange and green. Below that is the date "OCTOBER 26, 2024" in green. The location "Harbor Park at Baldwin Park" is listed in white. At the bottom left is the logo for the Bleeding Disorders Foundation of Florida, which includes a red blood drop icon with a white silhouette of a person.

18th ANNUAL
Orlando
Creepy Crawl

OCTOBER 26, 2024

Harbor Park at Baldwin Park
4990 New Broad Street
Orlando, Florida

Bleeding Disorders
Foundation of Florida

Walk Website: <https://bleedingdisordersfl.org/walks-5ks/>

Jacksonville mom: State must pass life-saving legislation, ban copay accumulator programs.

My child has lived with severe hemophilia since birth. A chronic condition, hemophilia is a disease that prevents blood from clotting properly, resulting in abnormal and spontaneous bleeding. This can result in serious pain, chronic joint disease, large frequent bruises and excessive bleeding from cuts, routine dental procedures and after surgeries.

As a mother, the importance of affordable and timely access to hemophilia treatments cannot be overstated. Unfortunately, hemophilia is one of the most expensive chronic diseases that someone can live with, as average costs add up to roughly \$300,000 per year.

For our family, the preventive treatment to keep my child stable is over \$60,000 per month — more than \$700,000 annually. These costs only refer to hemophilia treatments that prevent bleeding. If bleeding occurs, the cost of treatment is much more expensive.

After multiple lengthy fights with our insurance company for coverage and an adequate supply of medication, my child is finally stabilized on an innovative, breakthrough hemophilia treatment that has led to a decrease in bleeding. Before this medication, my child had to receive multiple infusions a day and was in a wheelchair, unable to walk due to the bleeding.

The quality of life we have now is immeasurably better, but only because of these life-saving medications.

Thankfully, to help families offset the high costs of treatment, some drug manufacturers offer prescription assistance programs. For our family, the assistance program provides up to \$15,000 per year.

However, the money intended to cover the cost of treatment is going directly to our insurance company, which neglects to count the assistance toward our deductible or out-of-pocket maximum. This harmful and discriminatory practice is called a copay accumulator program.

Because of this policy, our health insurance company is pocketing the money from copay assistance programs and continuing to overcharge us our cost-sharing responsibilities. Their strategy rakes in thousands of dollars from us, just from the cost of my child's medicine.

That's in addition to the \$15,000 from the drug manufacturer — an amount that is far above our deductible and out-of-pocket maximum.

Our family faces many challenges when navigating hemophilia, and working overtime to make sure our insurance operates properly shouldn't be one of them. Copay accumulator programs prevent many patients from being able to afford life-saving treatments and medicines.

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The policy decreases patient access to health care, especially for patients living with hemophilia and other chronic conditions.

My advocacy against copay accumulator programs has resulted in difficult conversations with my health insurance company, who defend the policy by saying the payments are a “member responsibility” intended to ensure that members have “skin in the game.”

This defense of an anti-patient policy fails to account for what my family has gone through living with this disease, advocating for my child and shoveling out tens of thousands of dollars in treatment costs. My family is not the only one with “skin in the game,” as families navigating chronic conditions face unique challenges every day.

I urge Florida’s state and federal policymakers to join 19 other states, Washington, D.C., and Puerto Rico to lower patient health care costs and increase patient access to treatments and medicines by passing legislation that bans copay accumulator programs. Congress is currently reviewing the HELP Copays Act (HR 830/S 1375), which includes eight Florida cosponsors.

The Florida Legislature has also reviewed this policy over the past several years. I encourage Gov. Ron DeSantis and Florida lawmakers to prioritize this necessary legislation to continue their effort at reigning in anti-patient pharmacy benefit managers and insurance policies.

There’s a lot of noise around health care costs. I hope our federal and state policymakers in Florida will support simple solutions, like a ban on copay accumulator programs, to immediately drive down out-of-pocket costs for patients.

Cindy Meide, Jacksonville



Thanks to our generous donors, The Bleeding Disorders Foundation of Florida is proud to offer the bleeding disorders community Medic Alerts.

Please email us at info@bleedingdisordersfl.org , you can also fill out a contact form and ask for a Medic Alert or simply download the form, fill it out and email it back.



Download Application