



The Quarterly Newsletter of the BDF Fall 2023 Volume 42 Issue 68

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2023 Calvin Dawson Memorial Scholarship Recipients

Meet the 2023 recipients of the Calvin Dawson Memorial Scholarships, available to Florida residents with bleeding disorders pursuing post-secondary education.



Michael Berkman is attending Graduate School at Crummer Graduate School at Rollins College. He would one day like to start his own business. He enjoys spending time outdoors with friends and family and enjoys nature.

Andrew Farren is a Junior at St. Petersburg College majoring in Biology and Education. He is passionate about science, enjoys hiking, researching anatomy and art.

Kevin Free is a Junior at the University of Central Florida majoring in Environmental Studies. He would one day like to do research in the environmental field. He enjoys volunteering and participating in weekly trivia with his friends.



Latosha Gibson is receiving her massage therapy certification from the Institute for Corporate and Continuing Education at Hillsborough Community College. Latosha likes to play the piano, travel, create workshops and events for youth and spend time with her family and friends.

Francis Rivera Pacheco is a Senior majoring in Business Administration at Florida State College in Jacksonville. She would like one day use her entrepreneurial skills to create a product that focuses in on self-growth and education. She enjoys singing, dancing, podcasting, filming, creating and producing events.



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BDDF 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 BDDF Connections is for your general information only. BDDF does not give medical advice or engage in the practice of medicine. The BDDF 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,

Happy Fall, I hope everyone is doing well. So excited for the Holiday Season to begin! The BDDF has had a very busy fall. We have hosted the 16th Annual Superhero walk, our 27th Annual Flight For Tomorrow Invitational Golf Tournament and 17th Annual Orlando Creepy Crawl. There was plenty of fun for everyone! Special thanks to all of our co-chairs and volunteers, Superhero Co -Chairs Lisette Sanchez and Alex Monica, Golf Co- Chairs Rhonda and Brian McDonald. Creepy Crawl Co- Chairs, Rene Lebron and Samantha Nazario, and our amazing committees and volunteers. We are so grateful for your support you have been such a blessing.

We have a lot of programs and fun celebrations scheduled in the next few months we hope you will join us.

Keep in touch with the BDDF by checking out our Calendar <https://bleedingdisordersfl.org/events/list/>

I hope you have a happy and healthy holiday season

Take care,
Fran



Pat Solomon Memorial Bike Ride- Clermont

December 9, 2023

Jacksonville- Holiday Trivia

December 17, 2023

Latin Conference

January 20-21, 2024

Jacksonville Safari Walk

February 24, 2024

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Tyler Nazario is a Junior at Eastern Florida State College in Cocoa majoring in Arts and Science. Art is his passion and he would like to use his talents to have a positive impact on communities. He enjoys drawing, concept design and singing, Comic Cons, and movies with his family.

William Solomon is a Sophomore at Lake Sumter State College majoring in Psychology and hopes to be a Mental Health Counselor. His pastimes include spending time with family and friends, enjoying nature walks, working out, and playing video games.



Yohance De Souza is a Sophomore at the University of Florida in Gainesville majoring in English with a minor in Computer Science. He would like to be an English Teacher. He enjoys creative writing, tennis, reading, video gaming and playing the piano.



John Waters is a Junior at Florida State University majoring in Political Science. John is planning a career in public service and one day serve in Congress.

Applications for next year's Calvin Dawson Memorial Scholarships are due April 30, 2024. To get an application, go to Scholarships - Bleeding Disorders Foundation of Florida (bleedingdisordersfl.org).

If you would like to donate to the Scholarship Fund, go to: www.bleedingdisordersfl.org/donate/



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

September 23rd, 2023 was the 16th annual Superhero Fun Walk in St. Petersburg with over 200 participants. This year's Walk raised more than \$50,000 for the work of the BDFF in the bleeding disorders community.

Participants enjoyed getting photos of themselves in their superhero costumes. A fun raffle offered prizes including a Nintendo Switch Lite, a special BDFF Yeti cooler (donated so generously by the Carson family), Legos, tickets to the Glazer Children's Museum, and more!

Kathy Desgrosiellier, Chris Carson, and Alicia Norris shared their stories and delivered their incredibly impactful Mission Moments. Participants also had a chance to meet Foundation founders Brian and Rhonda McDonald, as well as folks such as the Tampa Bay Lightning's ThunderBug, the Tampa Bay Ray's Raymond, Star Wars characters, and the St. Petersburg Fire Department.

There was fun, food, games and more!

Awards:

Top Fundraiser: Noah Strong

Biggest Team Spirit Award: Wyatt's Warriors

Super Volunteer: Rene Lebron



Thanks to our walk committee members and volunteers for helping to make the event a success:

Alex Monica, Co-Chair
Lisette Sanchez, Co-Chair
Andrew Farren
Kathy Desgrosiellier
Patsie Gibson
Barbara Castano Arrebola
Rene Lebron
Christina Martinez



A very special thank you to our sponsors who helped make the event possible:

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St. Joseph's Children's Hospital
University of South Florida
HTC

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IN-KIND SPONSORS

Special shout out to our DJ: Aairuis,
DJ Entertainment, Joe Sena
CVS Caremark
W-3 Insurance
501st Legion Star Wars Characters
St. Petersburg Fire Department



Flight For Tomorrow Golf Tournament Scored Big for the BDF

The 27th annual Flight for Tomorrow Golf Tournament was held on Monday October 23, 2023, at the Ardea Golf and Country Club in Oldsmar.

The weather was perfect, the food was delicious and the company was the best. This amazing event raised more than \$55,000 for the bleeding disorders community.

A special thank you to Co-chairs Brian and Rhonda McDonald for all their hard work and dedication that made the tournament possible and fun! Also, a big thank-you to the tournament volunteers, sponsors, and auction donors.

Congratulations to our Tournament Winners

1st Place

David Lau
Ed Burke
Tony Farren
Bobby Williams

2nd Place

Jon Mines
Kurt Lotspeich
Raz Taybert
Chris Muhlesisen

3rd Place

Pete Elgo
Hans Schwartz
Dino Romito
Kevin Sheridan

Longest Drive, Men – Mike Coney
Longest Drive Women- Raz Taylert

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Halloween was a little bit spookier and a lot more fun for the participants at the 17th Annual Orlando Creepy Crawl Walk and 5k Run on October 28, 2023 at Harbor Park in Baldwin Park. The event reached its \$40,000 fundraising goal! The top individual fundraiser was Mike Berkman, and the top fundraising team was Lili-ana's Platelet Party. Team Tyler got the Team Spirit Award for forming the largest team!

The event also featured a costume contest, food, music, raffle, face painting, and a special visit from the Orange County Ghostbusters of Florida, 501st Legion Star Wars Characters, and the Guardians of Justice!

A special thank-you to our sponsors who helped make the event possible:

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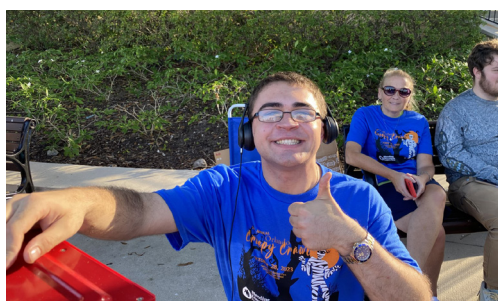
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501st Legion
Orange County Ghost-
busters of Florida
Nothing Bundt Cakes





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Results of a new study published in the journal *Haemophilia* are illustrative of persistent health disparities existing within the U.S. hemophilia population.

The data that informed the study was drawn from National Vital Statistics System (NVSS), which generates comprehensive statistics on births and deaths in the United States. The authors looked at the NVSS' 1999–2020 Multiple Cause-of-Death data set to learn more about rates of hemophilia-related death (rHD).

Investigators ultimately identified 3,115 males associated with a rHD. Data showed that approximately 76.1% of deaths occurred in White men (2370), 13.3% in Black men (413), 7.4% in Hispanic men (233), 2.2% in Asian men (69), and 0.9% in American Indian/Alaska Native men (28), while race and ethnicity data were missing in two cases. A review of the data revealed a noteworthy reduction in overall age-adjusted rHD rates for all race and ethnic groups, with a decrease from 1.37 per 1 million males in 1999-2004 to 0.76 per 1 million males in 2015-2020.

This improvement in rHD rates, driven in part by the evolution of treatment and access to better therapies, represents a positive overall trend. However, the most recent decade's worth of data (2010-2020) also revealed a troublesome disparity as Blacks and Hispanics showed a median rHD of 56 years, putting them significantly behind their white counterparts who experienced a mean age of 68 years.

"Our observation that Black men had a lower median age at death and that HIV continues to be a leading cause of death among Black males with hemophilia listed in their death certificate in both earlier and recent years could signal ongoing survival disparities among Black people with hemophilia and an HIV infection,"

While the data suggest that HIV has a major impact on rHD in Black males, further research is necessary to identify additional inequities contributing to poorer health outcomes in underserved populations.

"Reported haemophilia-death rates improved in males across all race/ethnicities, but rates were higher Black versus White males. Given the inherent limitations of the current study's data source, further investigation of survival rates and disparities in haemophilia are needed," the authors concluded.

The study, "Racial and ethnic differences in reported haemophilia death rates in the United States," was published online in *Haemophilia* on September 23, 2023.

Source: The American Journal of Managed Care, September 23, 2023



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SATURDAY, JANUARY 20 – 21, 2024
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