



BDFF CONNECTION

The Quarterly Newsletter of the BDFF Summer 2024 Volume 45 Issue 71



Bleeding Disorders
Foundation of Florida

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

Tidal Wave of Fun:

Annual Family Program at SeaWorld Makes a Big Splash!



On June 1st, over 500 individuals gathered for a memorable day, combining education and entertainment with family members who have a bleeding disorder. The event featured engaging arts and crafts activities, allowing participants to reflect on their current journey and set aspirations for the future.

A special thank you to our presenter, Michael Rosenthal, for his inspiring and enjoyable presentation. Michael has over 33 years of leadership experience in the bleeding disorder community and has developed a range of innovative initiatives and programs. He has served as the Executive Director of the Arizona Hemophilia Association and National Director of the World Federation of Hemophilia US and has made significant contributions to the field through his work.

After the event, attendees were free to enjoy the SeaWorld experience. BDFF wants to especially thank our volunteers and sponsors for making the day possible:



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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,

Happy Summer! I hope everyone is having a wonderful SUMMER! YAY! My favorite time of the year, I love the hot, humid weather and sunset at 8:00 pm. We have a lot of fun and educational summer programs scheduled (view our updated calendar on our website <https://bleedingdisordersfl.org/events/list/>).

Our annual family program: *What has changed and what is the same?* at SeaWorld was a blast. Folks enjoyed a fun family program testing your bleeding disorders skills and knowledge. Special thank you to SeaWorld for their generosity and wonderful support. They are the best!

Camp Spirit was June 19-23, and it was a lot of fun. Campers enjoyed swimming, archery, theater and so many more activities. We love camp and we have been camp partners for more than 28 years. Thank you to our camp supporters we could not do it without you!

It is time to register for the Superhero Walk, we are looking forward to a stellar event with lots of guest appearances, face painting and superhero fun.

I hope everyone has an amazing summer, and I look forward to seeing you soon.

Take care,

Fran



July 14, 2024

July 19, 2024

July 27, 2024

August 10, 2024

September 11-14, 2024

September 21, 2024

October 21, 2024

October 26, 2024

BDFF Board of Directors Meeting

Youth Retreat -Orlando

Woman's Tea – Orlando

Bleeding Disorders Trivia – Tampa

**National Bleeding Disorders Foundation
Conference**

**17th Annual Superhero Walk –
St. Petersburg**

**28th Annual Flight for Tomorrow Invitational
Golf Tournament**

18th Annual Orlando Creepy Crawl

Thank you, Display Sponsors!

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 TAKEDA



VOLUNTEERS NEEDED

WE DESPRATELY NEED VOLUNTEERS FOR WALKS AND EVENTS, IF YOU ARE INTERESTED IN LENDING US A HAND PLEASE REACH OUT TO US AT INFO@BLEEDINGDISORDERSFL.ORG. COMMUNITY SERVICE HOURS ARE AVAILABLE. WE CANNOT DO OUR MISSION TO IMPROVE THE QUALITY OF LIFE FOR PEOPLE WITH BLEEDING DISORDERS WITHOUT YOUR SUPPORT AND HELP!

THANK YOU!



Camp Spirit Celebrates Another Year of Fun and Friendship



Camp Spirit, our annual summer camp for children with bleeding disorders, wrapped up its successful run at Camp Boggy Creek last week. Campers enjoyed a fun-filled week of adventure and friendship, participating in activities such as arts and crafts, team sports, and outdoor games.

Our campers also learned important skills for managing their bleeding disorders and connected with others who understand their experiences. With the support of our dedicated staff and volunteers, the campers left with memories to last a lifetime and a sense of belonging to a community that gets them. We're grateful for another year of providing a safe and inclusive environment for our campers to thrive.

THANK YOU, CAMP SPIRIT SUPPORTERS

- CVS
- COMMUNITY FOUNDATION OF SARASOTA COUNTY
- GENENTECH
- PFIZER
- SANOVI
- TAKEDA



Join us as we run and walk together to raise funds and awareness for the bleeding disorders community. From dressing up as your favorite superhero to wearing your Halloween costume, these are events you will not want to miss. Join us September 21st for the Superhero Fun Walk, and/or October 26th for the Creepy Crawl 5K Run & Walk. Gather friends, family, neighbors, and co-workers to join the fun.

Don't delay, register today!

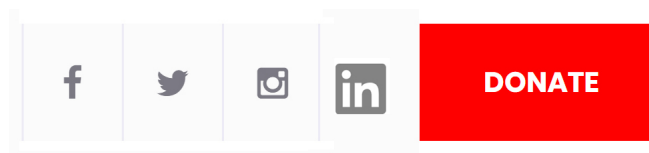
17th Annual Superhero Walk



18th Annual Creepy Crawl Walk and 5k Run



Walk Website: bleedingdisordersfl.org/walks-5ks/





Monday, OCTOBER 21, 2024

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



CHECK OUT THE LINK BELOW FOR MORE INFORMATION AND TO REGISTER

bleedingdisordersfl.org/fundraising/golf-tournament/

Join us for a fun Bike Ride or Walk (you determine your distance) on the beautiful Clermont Trail!

Trailblazers Holiday Bike Ride & Fun Walk

Fun, Friends and Refreshments!

 December 14, 2024
Clermont Bike Trail
Clermont Florida, 34711

REGISTRATION IS AT 10:00 AM
Event begins at 11:00 AM



Waterfront Park 300
3rd Street
Clermont, FL 34711



Results of a new study published in the Journal of Blood Medicine (JBM), indicate that people with hemophilia A (HA) who have been on a prophylactic treatment regimen have a reduced risk for intracranial hemorrhage (ICH).

Often referred to as a “brain bleed,” ICH is a very serious event whereby blood accumulates within parts of the skull, including the brain itself. This can result in built up pressure which can block critical oxygen and nutrients from reaching brain cells and tissues. ICH events that are not treated expeditiously can result in major disability and even death. These type bleeds can occur spontaneously or triggered by something specific such as trauma. While people with hemophilia are at some risk for ICH, any given patients’ risk level will vary and depend on a variety of factors.

Authors of the JBM paper used retrospective data from the ATHNdataset to inform their research, eventually identifying 7,837 hemophilia A patients between two and 75 years of age. Included in the study were moderate and severe HA males (assigned at birth) who had hemophilia treatment center visit information from January 1, 2010, through September 30, 2020. The median follow-up period was 10.7 years.

Their investigation showed that 135 of 7837 of the subjects (1.7%) experienced an ICH. A review of the data pointed to several factors associated with a higher risk including being in the 2–12-year age range; being covered by Medicaid; having had HIV, hepatitis C, or hypertension; and never having received factor VIII replacement therapy or prophylactic treatment. The authors also conveyed that these results align with earlier studies which demonstrated that prophylaxis provides a “protective effect” against ICH.

Because emicizumab became available at the tail end of the study period, data relevant to its use and findings relevant to its use, along with opportunities for comprehensive analysis, were limited. “As of 2018, the standard of care for congenital hemophilia A has evolved to include emicizumab, a humanized antibody that mimics activated FVIII to allow continuation of the coagulation cascade. This study’s period includes data from before and after emicizumab approval in 2018. The ICH rate significantly decreased across the study period, but data from the periods before and after emicizumab approval cannot be conclusively analyzed because of the limited sample size after emicizumab approval and the inability to account for all possible confounders,” explained the investigators.

However, the authors urge continued investigation into ICH risk factors, especially as the availability and use of newer novel therapies continue to rise.

“This study, using data from the ATHNdataset, identified the following risk factors for ICH in PWHA: being aged between 2 and 12 years, having ever received Medicaid coverage, having had certain comorbidities (HIV and HTN), never having received factor treatment, and never having received prophylactic treatment. These risk factors will need to be continually reevaluated as the treatment landscape for hemophilia evolves to include increased use of non-factor products and gene therapy.

The study, “Risk of Intracranial Hemorrhage in Persons with Hemophilia A in the United States: Real-World Retrospective Cohort Study Using the ATHNdataset,” was published April 25th in the Journal of Blood Medicine. Read the full paper to learn more.

Source: docsirenews, May 21, 2024