



The Quarterly Newsletter of the BDFB Spring 2025 Volume 47 Issue 73

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TOLL FREE 800-293-6527  
[www.bleedingdisordersfl.org](http://www.bleedingdisordersfl.org)

## Success Roars at Jacksonville Safari Walk!

We had a "wild" time at the 15th Annual Jacksonville Safari Walk! Held at the Jacksonville Zoo and Gardens, the event kicked off Bleeding Disorders Awareness Month on March 1, 2025, with participants arriving bright and early for registration at 7:30 AM.

Families, friends, and animal lovers enjoyed a delightful stroll through the zoo, complete with light refreshments, engaging activities, and the chance to meet special guests.

We're thrilled to report that we surpassed our fundraising goal of \$30,000, and we're so thankful for everyone's support! Special shoutout to **Team Ashi, our Sky High Top Fundraiser, who raised an amazing \$1,291.25!**

The funds raised will go towards vital programs like emergency financial assistance and educational resources, making a real difference in the bleeding disorders community.

**A special **THANK YOU** to our incredible sponsors:**

**Bayer HealthCare  
CSL Behring  
DrugCo Health  
Genentech  
HEMA Biologics  
Hemophilia of Georgia  
Kedrion Biopharma  
Nemours Children's Health  
Novo Nordisk,  
Sanofi  
Takeda**

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## BDF Connections

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The Bleeding Disorders Foundation  
of Florida

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### Staff

Fran Haynes - Executive Director  
Samantha Alenius - Marketing and  
Events Coordinator  
Kevin Free - Office Assistant

### Physical and Mailing Address The Bleeding Disorders Foundation of Florida:

1350 Orange Ave. Suite 227 Winter  
Park, Florida, 32789

**TEL:** 407-629-0000

**TOLL FREE:** 800-293-6527

**FAX:** 407-629-9600

### EMAIL:

info@bleedingdisordersfl.org **WEB:**  
www.bleedingdisordersfl.org

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

YAY—spring has arrived, and we've got fun for everyone! From dinners and walks to programs and the beloved Camp Spirit, the season is packed with excitement. Check out our calendar of events [here](#) and jump in on the fun!

March was a whirlwind, kicking off Bleeding Disorders Month with the Jacksonville Safari Walk—a huge success thanks to our amazing planning committee.

Another highlight was the Flight for Tomorrow Golf Tournament—hats off to Rhonda and Brian McDonald for their generosity and dedication to our community.

Don't miss the 14th Annual Gator Clot Trot on April 19th! Join us for a fun walk, 5k run, Easter egg hunt, and a visit from the Easter Bunny—perfect for the whole family. Get all the details and sign up at [www.bleedingdisordersfl.org](http://www.bleedingdisordersfl.org).

Looking ahead, we're thrilled about our World Hemophilia Day Celebration on April 26th at Leu Gardens. It'll be a day filled with connection and awareness. For info, reach us at [info@bleedingdisordersfl.org](mailto:info@bleedingdisordersfl.org) or 800-293-6527.

Wishing you a spring full of sunshine, smiles, and great memories—see you soon!

*Fran Haynes*



**Gator Clot Trot - Gainesville**

**April 19, 2025**

**World Hemophilia Celebration - Orlando**

**April 24, 2025**

**Annual Theater Event - Orlando**

**May 3, 2025**

**Woman's Tea Program - Tampa**

**May 10, 2025**

**BDF Board of Directors Meeting**

**May 18, 2025**

**Annual Family Program - Orlando**

**June 7, 2025**

**Woman's Retreat - St. Augustine**

**June 20-21, 2025**

**Camp Spirit Summer Camp**

**July 15-19, 2025**



We also want to extend our gratitude to our in-kind sponsors, the 501st Legion Star Wars Characters, Polar Flame Performances, and DJ Aairius for volunteering their time to make the event so much more fun! Your support truly made this event special. We appreciate everyone who came out, donated, and volunteered, and we can't wait to see you again next year, **March 14, 2026!**



**HIGH SCHOOL STUDENTS EARN  
COMMUNITY SERVICE HOURS**

**VOLUNTEER FOR THE BDIFF**

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



The 28th annual Flight for Tomorrow Golf Tournament took place on Monday, April 7, 2025, at the Ardea Golf and Country Club in Oldsmar.

Despite the slightly windy weather, the day was sunny, the food was delightful, and the company was exceptional. This incredible event successfully raised over \$50,000 to support the bleeding disorders community.

A heartfelt thank-you goes to Co-Chairs and BDFF Founders, Brian and Rhonda McDonald, for their unwavering dedication and hard work that made the tournament not only possible but also thoroughly enjoyable. Remarkably, Rhonda and Brian not only organize the event but personally fund it, ensuring that all proceeds directly benefit the BDFF and the bleeding disorders community.

Special thanks are also extended to the tournament's volunteers, sponsors, and auction donors, whose contributions played a vital role in making this event a success.

## SPECIAL THANK YOU TO OUR SPONSORS

### Tournament Sponsor

**RHONDA AND BRIAN MCDONALD**



### Gold Sponsor



### Silver Sponsor

**CSL Behring**

Biotherapies for Life™



### Display Sponsor

**Novo Nordisk**



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**Our heartfelt gratitude goes to the generous raffle and auction donors who made this event a reality**



Ardea Country Club  
Beef O'Grady's  
Bobbie Brown  
Coopers Hawk Landing  
Countryside Country Club  
Dawn Solomon  
Doris Goldman



Ethical Factor  
Gino's Pizza  
Hooters  
Hunters Green Golf  
Innisbrook Golf Resort  
Legoland



Tampa Bay Rowdies  
Mendy Hood  
Nathan Hood  
Rhonda and Brian McDonald  
Top Golf  
Barbara & David Burgeson  
Song of Solomon  
(Sprouted Spelt Sourdough)







## Bleeding Disorders Foundation of Florida Scholarships

The Bleeding Disorders Foundation of Florida offers two scholarship opportunities to support individuals with bleeding disorders in their educational endeavors.

The **Calvin Dawson Memorial Scholarship** awards a varying number of scholarships and amounts to Florida residents with hemophilia, von Willebrand disease, or other related hereditary bleeding disorders who are attending a college, university, or trade school. **The application deadline is April 30, 2025.**

Additionally, the **Founders Medical Scholarship** provides a varying number of scholarships and amounts as well, targeting Florida residents with similar conditions who have completed a bachelor's degree and are enrolled in a post-baccalaureate program in areas such as medicine, nurse practitioner, pharmacy, psychiatry, physician assistant, physical therapy, or medical social work. There is no application deadline for the Founders Medical Scholarship.

For more information or to request an application, please contact the Bleeding Disorders Foundation of Florida at 1350 Orange Ave, Suite 227, Winter Park, FL 32789, or call (800) 293-6527 or (407) 629-0000. You can also reach us via fax at (407) 629-9600 or email at [Info@bleedingdisordersfl.org](mailto:Info@bleedingdisordersfl.org) or <https://bleedingdisordersfl.org/> We encourage all eligible candidates to apply.

## 23rd Annual Evening on Broadway

FEATURING THE HIT BROADWAY PRODUCTION OF

### **THE LION KING**

Join us at the Dr.  
Phillips Center for  
the Performing Arts  
for a night of  
Theater Magic!

**The Evening Includes:**

A Private Reception  
Reserved Orchestra Seating  
Silent Auction & Raffle



**TICKETS ARE ON  
SALE NOW!**

**Tickets are \$200 each**

**Saturday, May 3, 2025  
6:00PM**

**CORPORATE SPONSORSHIPS ARE AVAILABLE**

**800-293-6527**  
[info@bleedingdisordersfl.org](mailto:info@bleedingdisordersfl.org)

Evening on Broadway event buy your tickets today!



### **Follow/Like the BDFF on social media**

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The topic of bone health in people with bleeding disorders has received more attention and study in recent years, with reports suggesting that people with hemophilia (PwH) and people with von Willebrand disease (PwVWD) experience higher rates of osteoporosis and bone fractures. That said, screening for bone health is not consistent across federally funded hemophilia treatment centers. A lack of clear, uniform screening guidelines is a major contributing factor to this disparity.

A new paper published in the journal *Haemophilia* looked to shed light on current practices of HTCs for assessing bone health. The authors created a survey focused on HTC's utilization of two common methods for assessment: bone density scanning through Dual-energy X-ray Absorptiometry (DEXA) and blood serum tests of vitamin D levels.

The electronic survey was disseminated to all federally funded HTCs in the U.S. from June 2023 to August 2023. It included nine multiple choice questions relevant to the demographics of HTC participants, overall HTC profiles, plus current practices for DEXA scanning and measurements of vitamin D levels. A total of 147 HTCs received the survey, with 66 responding.

Only nine of the 66 (13.6%) indicated that they use DEXA scans to assess bone health. Of these three were adult HTCs and six were "lifespan" HTCs; meaning they serve both pediatric and adult patients. DEXA scans were ordered by HTC physicians in five of the centers (55.5%), while at the other four (44.4%), patients were referred to primary care doctors, endocrinologists or other specialists for bone health evaluation and performance of DEXA scans. In terms of types of patients scanned, the majority were individuals with hemophilia A or B. Four HTCs performed screening exclusively in males, while five HTCs conducted screening in both males and females.

Among the 66 centres, 21 HTCs (31.9%) indicated that they routinely conducted screening for vitamin D deficiency during comprehensive visits, while the remaining 45 (68.1%) did not conduct any vitamin D deficiency screening. Of the 21 centers that screened for vitamin D deficiency, there were seven exclusively pediatric centres, three were adult centers and 11 lifespan centers. Lastly, only five HTCs – all lifespan centers, conducted both DEXA scans and vitamin D deficiency screening.

It should be noted that a foremost limitation on this study was the modest overall response rate of 44.8% representing less than half of federally funded HTCs in the U.S. Therefore, the authors caution against drawing sweeping conclusions, emphasizing that the data does not necessarily reflect the practices of all or even the majority of HTCs.

The authors also offer some explanations for why bone health assessments are not more widely recommended at HTCs.

"While this finding was rather surprising, there are several reasons why providers are not recommending bone health assessment. First, there is a lack of consistency in expert recommendations regarding bone health assessment," explained the authors. "The World Federation of Hemophilia (WFH) guidelines recommend that screening may be appropriate for those with haemophilia who are at high risk or have multiple clinical risk factors for osteoporosis but acknowledge the uncertainty whether routine osteoporosis screening is necessary for all individuals with haemophilia or not. Furthermore, the criteria for 'high risk' are not clearly elaborated."



The paper goes on to lay out examples of the somewhat disparate guidelines for bone health assessment amongst various international health organizations. In addition, guidance from U.S. based entities such as The United States Preventive Services Task Force and the National Osteoporosis (NOF) include clear recommendations for health screening in women 65 years or older, and potentially younger women as well depending on other risk factors. However, there seems to be a lack of consensus relevant to screening in other subgroups such as for osteoporosis in men. And while a multispecialty council of bone health experts convened by the NOF has identified hemophilia as a condition that can be linked to increased risk for osteoporosis, von Willebrand disease was not mentioned.

The authors suggest several ways that bone health assessments could be enhanced including the integration of standardized osteoporosis screening guidelines into national hemophilia care protocols. Accredited healthcare provider education and resources to support clinical decisions may also improve awareness and lead to enhanced screening practices. Better interdisciplinary collaboration between HTC providers, primary care physicians, and endocrinologists could also foster more prompt assessments of bone health.

In addition, patient advocacy organizations could complement these efforts by fostering awareness, monitoring bone health outcomes, and promoting/supporting screening initiatives. Lastly, significant barriers associated with insurance and reimbursement would also need to be addressed if broad enhancements in bone health screening may be achieved.

“In summary, our study identified a clinical care gap in the evaluation of bone health in PwH and PwVWD at HTCs across the United States. Considering the growing burden of an aging population with haemophilia and VWD (and the broad scope of bleeding disorders), future efforts should focus on gaining a deeper understanding of barriers to bone health in PwH and PwVWD and developing guidelines for bone health assessment, with a specific focus on measuring vitamin D levels and performing DEXA scans,” concluded the authors.

#### Citation

Citla-Sridhar D, Ahuja S, Sidonio R, Chitlur M, Sharathkumar A, Tobase P, Acharya S, Isaac D, Kulkarni R, Johnson MM. Bone Health Screening in Persons with Bleeding Disorders: A Survey of United States Haemophilia Treatment Centres. *Haemophilia*. 2025 Mar 7. doi: 10.1111/hae.70027. Epub ahead of print. PMID: 40052405.

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