



BDFF CONNECTION



The Quarterly Newsletter of the BDFF Summer 2025 Volume 49 Issue 74

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Get ready to lace up your sneakers, don your capes, or channel your inner goblin—because our two most spirited events of the year are just around the corner! On September 20, join us at Vinoy Park in St. Petersburg for the Superhero Fun Walk—where you can dress as your favorite crime-fighter and support the bleeding disorders community in heroic style. Capes, masks, and bold poses encouraged!

Then, on October 25, we're getting spooky (but still sporty!) with the Creepy Crawl 5K Run & Walk at Harbor Park in Baldwin Park. Costumes welcome—think witches, werewolves, or whatever Halloween magic inspires you.

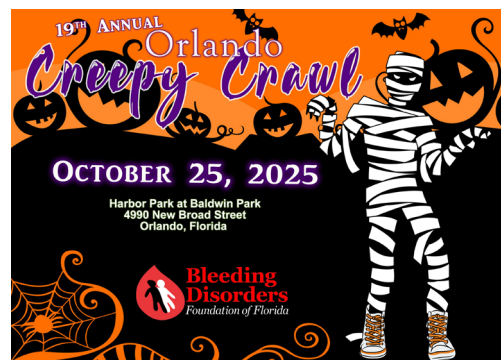
Both events are packed with fun, fitness, and fundraising, all while building awareness and community. So, rally your family, friends, coworkers, and neighbors, and let's make some unforgettable memories together.

Don't wait—register today and join the fun! <https://bleedingdisordersfl.org/walks-5ks/>

18TH ANNUAL SUPERHERO WALK



19TH ANNUAL CREEPY CRAWL



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

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 Summer! I hope everyone is soaking up the sunshine and enjoying this vibrant season, my absolute favorite time of year! There's something fun about the hot, sticky days and those long, glowing sunsets that stretch well past 8 PM.

We have a fantastic lineup of fun and educational summer programs coming your way. Be sure to check out our updated calendar on the website: bleedingdisordersfl.org/events/list.

Our annual family program, Smart Adventures: Learn, Laugh, and Play at SeaWorld, was a total blast! Families came together to test their bleeding disorder skills and enjoy a day full of fun. A huge thank you to SeaWorld for their incredible generosity and support—they truly are the best partners we could ask for.

Camp Spirit is just around the corner, happening July 15–19, 2025! Our campers will dive into swimming, archery, theater, and so much more. We've been proud camp partners for over 29 years, and none of it would be possible without the amazing support from our community. Thank you for making it all happen!

And don't forget—it's time to register for the Superhero Walk! Get ready for a stellar event packed with exciting guest appearances, face painting, and all the superhero fun you can imagine.

Wishing you an amazing summer full of laughter, sunshine, and great memories. I can't wait to see you soon!

Fran

MARK YOUR CALENDAR



Youth Retreat

Camp Spirit

NBDF Meeting, Aurora Colorado

Superhero Walk Vinoy Park, St. Petersburg

Orlando Creepy Crawl Walk and 5k

Trailblazer Bike Ride, Stroll and Holiday Event

Jacksonville Holiday Event

3rd Annual Latin Conference

July 11, 2025

July 15-19, 2025

August 20-22, 2025

September 20, 2025

October 25, 2025

December 13, 2025

December 14, 2025

January 24-25, 2026

On Saturday, April 19, 2025, the Gainesville community came together for the 14th Annual Gator Clot Trot 5K Fun Run and Walk, raising over \$30,000 to support the Bleeding Disorders Foundation of Florida (BDF)!

This year's event was filled with excitement—a 5K run, a walk, and a lively Easter Egg Hunt. The Easter Bunny delighted children, and the incredible 501st Legion Star Wars characters added extra magic and fun for all ages.

Adding to the spirit, Jason Smith gave a moving performance of the Star-Spangled Banner, setting the perfect tone for the day. Thanks to Red Madden and Winsupply, 106.9 I Am Country kept the energy high as our enthusiastic MC.

Congratulations to Our 2025 Award Winners!

- **Top Fundraiser: Johnny Perales – G-Unit**
- **Super Hopping Recruiter: Hemostasis Heroes**
- **Team Spirit Award: Supreme Kai**
- **A big congratulations to all runners, walkers, and teams who made this event a huge success!**



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Special Thanks to Our Committee & Volunteers

This event wouldn't have been possible without the passion and dedication of our outstanding committee and volunteers. Special thanks to our Co-Chairs, Will Lopez and Joshua Wyrick, for their leadership. We're also grateful to Alex Monica, Dave & Barbara Burgeson, Dawn Solomon, Eric Burgeson, Red Madden, Travis Perry, Tung Wynn, and Ashley Clemons for their incredible efforts.

We also extend a heartfelt thank you to the volunteers, UF Physician Assistants, registration volunteers, and everyone who helped make this walk such a great success. Your time, energy, and smiles truly made a difference!

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**Thank you to all our sponsors for your generous support
your contributions make every step possible!**



BDFF's 23rd Evening on Broadway Shines with The Lion King

The Bleeding Disorders Foundation of Florida (BDFF) had a spectacular night of theater on Saturday, May 3, 2025. Supporters gathered at the Dr. Phillips Center for the Performing Arts in Orlando to enjoy orchestra seating for the Broadway hit *The Lion King*, guests enjoyed a pre-show private reception, silent auction, and raffle.



Thanks to the incredible generosity of our community, the event raised more than \$31,000 to support BDFF's vital programs, including Camp Spirit, the Emergency Assistance Fund, and bleeding disorders educational initiatives.



Very Special Thank You to Our Sponsors

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Thank You to Our In-Kind Donors

We are deeply grateful to the following individuals and organizations for their generous in-kind contributions, which helped make our events and programs possible:

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Ethical Factor
4 Rivers
Kennedy Space Center
Mendy Hood
Nathan Hood
Natural Life
Orlando Magic
Rocco Taco
The Glass Knife
Trader Joe's
Solomon Family
Song of Solomon Sourdough
4 Rivers Smokehouse**



This unforgettable evening celebrated the arts and strengthened our community's commitment to improving the lives of people with bleeding disorders. Thank you to everyone who joined us in making it a night to remember!

**Christmas in July!
Register Today!**

<https://secure.qgiv.com/event/trailblazers2025/>



Our Annual Family Program on June 7, 2025, was a tremendous success! More than 500 attendees came together for a fun and meaningful day that blended education, entertainment, and community for families affected by bleeding disorders.

Guests enjoyed a variety of hands-on arts and crafts activities, which offered a thoughtful way to reflect on their personal journeys and set hopes for the future.

It was a beautiful opportunity for connection, creativity, and support.



We extend a heartfelt thank you to our guest speaker, Michael Rosenthal, for his inspiring and engaging presentation. With more than 34 years of leadership in the bleeding disorders community, Michael has developed numerous innovative programs and initiatives. His work as Executive Director of the Arizona Hemophilia Association and National Director of the World Federation of Hemophilia – USA has left a lasting impact on countless families and professionals across the country.

Following the program, families were invited to enjoy a full day exploring SeaWorld—adding even more fun and memories to an already special event.

We are deeply grateful to our dedicated volunteers and generous sponsors, whose support made this unforgettable day possible. Thank you for being part of the Bdff family!

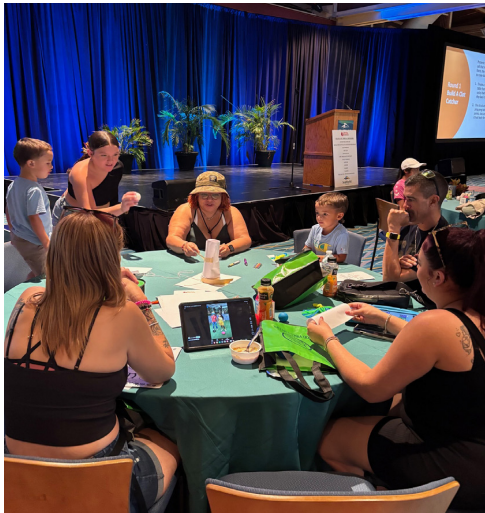


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THANK YOU RAFFLE DONORS

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DAWN SOLOMON
DAWN WREN



DONATE

Historically, women and girls affected by hemophilia have experienced protracted delays in securing an accurate diagnosis and care that takes bleeding disorders into full account. A newly published paper takes a 200+ year view of this history and provides a better understanding of just how this underserved population has slowly but surely garnered greater visibility and awareness – if not equitable care – over the decades.

The paper, “The History of Women and Hemophilia: A Narrative Review of Evolving Beliefs and Testing Practices,” appears in *The Journal of Thrombosis and Haemostasis*. The authors conducted a broad and narrative literature review focused on women and hemophilia from 1800 to 2023, including but not limited to case reports, larger studies, and review articles. Papers about the history of hemophilia were also included in their search.

Their findings helped to identify and characterize nine distinct time periods of hemophilia history that represented fundamental shifts in beliefs and/or testing practices spurred on by scientific breakthroughs in genetics, screening methods, and other technologies. The period encompassed in the review begins in the early 19th century with early descriptions of the possible role of women in disease transmission, then takes the reader through the 20th and into the 21st century – these latter decades saw great leaps in carrier detection techniques and enhanced awareness of the considerable challenges facing affected women and girls. That said, while strides have been made, many women continue to experience significant diagnostic delays, untreated bleeding symptoms, and barriers to appropriate care.

The authors suggest that systemic sexism in bleeding disorders management could be a root cause of these challenges. This factor could explain, at least in part, the persistent and widely held belief that aside from a woman’s carrier status, hemophilia only affects men in a substantive way. It could also explain why some healthcare providers tend to dismiss female-specific symptoms as heavy menstrual bleeding only, without consideration for underlying causes.

“Clear progress has been achieved yet recent publications document many ongoing issues such as delayed diagnosis, untreated symptoms, and barriers to care,”

Concluded the authors. “We owe these patients continued focus, targeted research with patient partnership, reparative knowledge translation efforts focused on unlearning discriminatory principles and learning equity/ social justice focused health care principles, concerted consideration of the female patient’s lived experiences from consideration of her childbearing capacity, and monitoring of progress until the knowledge learned is fully translated into practice with real-world outcomes in screening, diagnosis, treatment, and prevention of bleeding.”

This is a fascinating article, recommended for anyone interested in this important if less understood period of hemophilia history. It could also be a useful resource for advocacy and outreach efforts as it encompasses key context to help explain how far we have come and how much farther we still need to go to ensure that these women receive equitable care.

Read the full open access article [here](#) to learn more.

Citation

Chaigneau M, Bowman M, Wilton P, Card R, Poon MC, Lillicrap D, Sholzberg M, James P. *The history of women and hemophilia: a narrative review of evolving beliefs and testing practices*. *J Thromb Haemost*. 2025 Mar;23(3):928-936. doi: 10.1016/j.jth.2024.12.004. Epub 2024 Dec 13. PMID: 39675566.

Disclaimer: NBDF, through its Neil Frick Resource Center, provides periodic synopses of articles published in peer reviewed journals, the purpose of which is to highlight papers that cover a wide range of topics and relate to a broad spectrum of the inherited blood disorders community. Prior summaries have focused on topics such as shared decision making, gene therapy, health equity, and more. NBDF hopes you find this content to be informative and engaging.

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