

BDFF



The Quarterly Newsletter of the BDFF Winter 2025 Volume 47 Issue 73

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

2024: A Year in Review

2024 was a remarkable year for the Bleeding Disorders Foundation of Florida. We kicked off with the 2nd Annual Latin Conference held on January 20-21, 2024, at the Renaissance Orlando at SeaWorld. As the year progressed, things only got better



An essential part of the BDFF's mission is to educate the bleeding disorders community and the broader public about bleeding disorders, and to support the work of the Hemophilia Treatment Centers (HTCs). To fulfill this mission, BDFF hosts educational programs across the state, including Jacksonville, Gainesville, Orlando, Tampa-St. Petersburg, and Miami. Over \$85,000 was invested in educational programs on topics such as bleeding disorders trivia games, self-care, self-belief, teen and young adult programs, women and bleeding disorders conferences, and the distribution of 300 Women Wellness Kits.

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BDFF Connections

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The Bleeding Disorders Foundation
of Florida

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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

2025 has been an exciting, fun, and very BUSY year for us. We hosted our 3rd Annual Latin Conference, which was a tremendous success. Our dedicated committee crafted a fantastic agenda, and our wonderful speakers provided invaluable information. It was truly an event we could not have asked to be better.

We are set to kick off Bleeding Disorders Awareness Month on March 1, 2025, as we join our Jacksonville friends for the Annual Jacksonville Safari Walk at the Jacksonville Zoo. We are eagerly anticipating a fun-filled event. You can register today at https://secure.ggiv.com/event/2025safariwalk/.

Thanks to your support, we experienced many great moments in 2024. Although our Flight for Tomorrow Golf Tournament had to be canceled due to the hurricane, Rhonda and Brian McDonald helped us raise more than \$45,000 for the BDFF. Thank you, Rhonda and Brian McDonald, for turning a challenging situation into a triumph. Your dedication and commitment to the BDFF are appreciated beyond words.

Stay tuned! We have many exciting events happening in 2025. Check out our calendar at Events - Bleeding Disorders Foundation of Florida (bleedingdisordersfl.org).

Warmest wishes,

Fran



February 6, 2025 February 10-11, 2025 February 23, 2025 March 1, 2025 February 29, 2024 March 5-7, 2025

April 19, 2025

Dinner on Dental Health – Orlando Florida
Florida State Meeting, Orlando
Board of Directors Meeting
Jacksonville, Safari Walk – Jacksonville Zoo
Orlando Dinner Program
NBDF Washington Days
Gainesville Clot Trot Walk/Run



2024: A Year in Review

cont'd

We had the privilege of hosting 47 kids at Camp Spirit, where they took significant steps towards independence and managing their care by learning to infuse themselves for the first time. The Annual Family Retreat was also a huge success, with over 28 families participating in a weekend full of information, education, and fun.





Furthermore, our Gator Clot Trot, Superhero, Safari, and Creepy Crawl Walks drew more than 650 participants, fostering a sense of community and support for those affected by bleeding disorders. Thanks to supporters like you, we provided opportunities for our clients to connect, which is crucial when living with a rare bleeding disorder.







The 2nd Annual Trailblazer's Holiday Bike Ride and Stroll was an amazing event. Folks gathered at Waterfront Park in Clermont to enjoy a beautiful day of bike riding, walking, and getting into the holiday spirit.





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BDFF CONNECTION

Orlando Creepy Crawl: A SCARY Success

Halloween was extra spooky and a lot more fun at the 18th Annual Orlando Creepy Crawl Walk and Run, held on October 26, 2024, at Harbor Park in Baldwin Park. The event raised over \$35,000 for the BDFF, thanks to the incredible efforts of our participants and supporters.

A special shoutout goes to Creepy Crawl Chair, Jill Viglione, and the amazing committee who helped us make this frightfully fantastic event a success:



Your contributions and dedication have made this year's Creepy Crawl a monstrous success. Thank you for helping us support the bleeding disorders community.

Creepy Crawl Committee:

Alex Monica
David Lau
Dawn Solomon
Ellie Bottey
Mendy & Nathan Hood
Rene Lebron
Samantha Nazario
Tina Bierman

Our Champion Sponsors deserve enormous thanks for their generous support:

Bayer Healthcare
CSL Behring
Drugco
Genentech
Hemophilia of Georgia
Kedrion
Promptcare
Orlando Health Arnold Palmer Hospital
Sanofi
Takeda



We are also grateful to our In-kind Sponsors:

Ethical Factor
Specialty Care Rx
Ghost Busters
BioMatrix
Nothing Bundt Cakes
Song of Solomon









Scholarships

The Bleeding Disorders Foundation of Florida offers scholarship opportunities to Florida residents navigating bleeding disorders.



The Calvin Dawson Memorial Scholarship is available to individuals with hemophilia, von Willebrand disease, or related conditions who are pursuing higher education at a college, university, or trade school; applications are due by April 30, 2025.

The Founders Medical Scholarship supports those who have completed their bachelor's degree and are enrolled in post-baccalaureate programs in healthcare fields such as medicine and nursing, with no set deadline for applications.

Both scholarships aim to empower individuals in their educational pursuits, providing essential financial support for their

journeys. 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 BDFF 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.

2024: A Year in Review

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This year, we impacted the lives of more than 7,000 people in Florida, providing them with essential resources to manage the costly care associated with bleeding disorders. We are incredibly grateful to people like you who make this possible. From medical bills to dental assistance and transportation to medical appointments, we have helped numerous families alleviate financial burdens.

Your donations make a real, lasting impact on people right here in Florida. Thank you for helping us fulfill our mission to educate, support, and advocate for the bleeding disorders community of Greater Florida.

Warmest wishes to you and your family, Your Friends at the BDFF







Trailblazers Holiday Bike Ride & Stroll



The 2nd annual Trailblazers Holiday Bike Ride & Stroll at Waterfront Park in Clermont, Florida was a huge success! We had a great turnout, and it was amazing to see the community come together. Highlights of the event included a hot chocolate station, a fun raffle, tons of delicious treats, arts and crafts (even made our own ornaments!), and a special visit from Santa Claus to add a touch of holiday magic. All proceeds go towards supporting individuals and families affected by bleeding disorders.

THANK YOU to our sponsors, volunteers, donors and amazing community members for making this a wonderful event! See you in 2025!



High Performance Sponsors:

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Ethical Factor RX



First Gear Sponsor: Southlake Wellness & Injury Center







BDFF CONNECTION

3rd Annual Latin Conference a Success!







What a great meeting! The 3rd Annual Latin Conference was held January 25-26, 2025, at the Hotel Landy. The event was attended by more than 145 participants from Florida and Puerto Rico. After the welcome and introductions, the day kicked off with a round of Family bleeding disorders Jeopardy offered by BioMatrix.

Following lunch, the first session "Current and New Trends for the Bleeding Disorders Community in 2025... An Experts' Round tablé Discussion..."

Facilitator Dr. Corrales Medina MD, FAAP
Medical Director, Pediatric Hemophilia Program
Director, Pediatric Hematology and Oncology Fellowship Program
University of Miami Comprehensive Hemophilia Treatment Center

Round Table Presenters were:

Dr. Leslie Soto, Pediatric Hematology/Oncology Specialist Assistant Professor, San Juan University Pediatric Hospital, Puerto Rico





They shared their expertise and knowledge and answered participants' questions.

Cristie Vidal-Strub Certified nurse practitioner with experience in family medicine, emergency medicine, and intensive care. She has volunteered at Camp Boggy Creek for over 25 years

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BDFFCONNECTION

3rd Annual Latin Conference a Success!

The conference then broke into support group sessions: Participants really enjoyed their group experiences.

Men: Andrew Lagomasino, PsyD, ABPP Board Certified Clinical Psychologist, Diplomate in Psychoanalysis

Women: Lisette Sanchez, BSN, RN, Nursing Coordinator at the Coagulation and Clotting Disorders Center of St. Joseph's Hospital

Youth Session for youth 13-21 - Improvised Storytelling Workshop -- The Corner Gallery Improv

The meeting ended with time to visit the booths followed by dinner, dancing, and a raffle.







Special thank you to our committee who helped make this meeting a wonderful, fun success

Co Chairs
Barbie Castano Arrebola
Samantha Nazario
Javier Aguilu
Lourdes Arvelo
Dr. Corrales-Medina
Liliana Gomez
Myriam Lagomasino
Rene Lebron
Anthony Llanes
Will Lopez
Lisette Sanchez
Cristie Vidal-Strub

THANK YOU SPONSORS

PRESENTING SPONSOR

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Safari Walk

Join us as we walk together to raise awareness and funds to support the bleeding disorders community!



HIGH SCHOOL STUDENTS
EARN COMMUNITY SERVICE HOURS

VOLUNTEER FOR THE HFGF

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

23rd Annual Evening On Broadway

This year, the Bleeding Disorders Foundation of Florida is thrilled to be holding the it's 23rd annual Theater event featuring the musical The Lion King.

23rd ANNUAL EVENING ON BROADWAY







DR. PHILLIPS CENTER FOR THE PERFORMING ARTS

445 S Magnolia Ave Orlando, FL

Ticket Packages are \$200 each

(CORPORATE SPONSORS ARE AVAILABLE)

THE EVENING INCLUDES A CATERED RECEPTION, SILENT AUCTION, AND ORCHESTRA SEATING TO THE LION KING

Proceeds benefit people affected by bleeding disorders

FOR MORE INFORMATION, CONTACT THE BLEEDING DISORDERS FOUNDATION OF FLORIDA AT 407-629-0000 OR INFO@BLEEDINGDISORDERSFL.ORG.

WWW.BLEEDINGDISORDERSFL.ORG/FUNDRAISING/EVENING-ON-BROADWAY

May 3, 2025 • 6pm reception





The 29th Annual Flight for Tomorrow Golf Tournament
April 7, 2025

The Bleeding Disorders Foundation of Florida is pleased to be holding the 29th Annual Flight for Tomorrow Golf Tournament on April 7, 2025 at the Ardea Country Club in Oldsmar, Florida. Register at https://bleedingdisordersfl.org/fundraising/golf-Tournament/

JÖIN THE FÜN!



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