



The Quarterly Newsletter of the BDF

Winter 2024 Volume 43 Issue 69

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

MARCH IS BLEEDING DISORDERS AWARENESS MONTH

Join the conversation.
Or start the conversation.

For more information about bleeding disorders or
the history of Bleeding Disorders Awareness Month, go to:
Bleeding Disorders Awareness Month | NBDF (hemophilia.org)



BDF's 2023 Year-In-Review

2023 was a year of several firsts.

On January 21, 2023, the Bleeding Disorders Foundation of Florida held its first annual Latin Conference at the Renaissance Orlando at SeaWorld. Additionally, with the highest honor we held the inaugural Patrick Solomon Memorial Bike Ride and Fun Walk on December 9, 2023, to remember a dedicated BDF volunteer and amazing friend, Patrick Solomon.



1st Annual Latin Conference

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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

2024 has been so exciting, fun, and very BUSY, we hosted our 2nd Annual Latin Conference, and it was wonderful. We had an amazing committee who helped us create a great agenda and we had wonderful speakers that shared great information. We could not have asked for a better event.

I can't wait until February 24, 2024, when we get together with our Jacksonville Friends for the Annual Jacksonville Safari Walk at the Jacksonville Zoo. We are looking forward to a fun-filled event. You can register today at 14th Annual Jacksonville Safari Walk, <https://bleedingdisordersfl.org/walks-5ks/>.

Thanks to you we had many great moments in 2023 such as our Flight for Tomorrow Golf Tournament, thank you Rhonda and Brian McDonald for hosting an amazing event, walks and many programs and services. Your dedication and commitment to the BDFF is appreciated beyond Words.

Stay Tuned! we have a lot of great things happening in 2024 (check out our calendar at Events - Bleeding Disorders Foundation of Florida (bleedingdisordersfl.org))

Warmest Regards

Take care,

Fran



February 12-13, 2024

Florida State Meeting, Orlando

February 24, 2024

Jacksonville, Safari Walk – Jacksonville Zoo

February 29, 2024

Orlando Dinner Program

March 2, 2024

Annual Theater Event – Orlando

March-6-8, 2024

NBDF Washington Days

April 6, 2024

Gainesville Clot Trot Walk/Run

HIGH SCHOOL STUDENTS
EARN COMMUNITY SERVICE HOURS

VOLUNTEER FOR THE BDFF

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



DONATE



A very important part of the BDFF's mission is to educate the bleeding disorders community and the broader community about bleeding disorders and to support the work of the Hemophilia Treatment Centers (HTCs). To fulfill that portion of its mission, the BDFF hosts educational programs in settings all around the state including Jacksonville, Gainesville, Orlando, Tampa-St. Petersburg, and Miami. More than \$80,000 was spent on educational programs on topics ranging from bleeding disorders trivia games, self-care, believing in yourself, physical therapy, teen and young adult programs, and women and bleeding disorders including the distribution of more than 300 FemCare kits.

This year the Foundation went through a period of momentous change. Changing its name from the Hemophilia Foundation of Greater Florida to doing business as the Bleeding Disorders Foundation of Florida reflects the Foundation's efforts in creating a more inclusive culture. The Bleeding Disorders Foundation of Florida includes all bleeding disorders such as hemophilia, von Willebrand's Disease, platelet disorders, factor deficiencies, and other rare bleeding disorders.

We had the privilege of hosting 45 kids at Camp Spirit, where they were able to take a big step towards independence and managing their care by learning to infuse themselves for the first time. Our efforts were further amplified by the success of our 27th annual Flight for Tomorrow Golf Tournament, raising over \$50,000 for the Foundation. Furthermore, our Gator Clot Trot, Superhero, Safari, and Creepy Crawl Walks were attended by more than 650 individuals, creating a sense of community and support for those affected by bleeding disorders. Thanks to supporters like you, we offered opportunities for our clients to connect, which is so important when living with a rare bleeding disorder.



Orlando Creepy Crawl



SeaWorld



SuperHero Walk

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We have been able to make an impact in the lives of more than 6,000 people in Florida this year, providing them with necessary resources to manage the expensive cost of bleeding disorders. We are so incredibly grateful to people like you who made that possible. From medical bills to insurance pre-miums and transportation to medical appointments, we have been able to help numerous families alleviate these financial challenges.

When you give, your donation makes a real, lasting impact for people right here in Florida. Thank you for helping us to 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*



Evening on Broadway



Golf Tournament Co-chairs Brian and Rhonda McDonald



Flight For Tomorrow Golf Tournament



Women's Retreat



Gator Clot Trot



SuperHero Walk

What a great meeting!! The 2nd Annual Latin Conference was held January 20-21, 2024, at the Renaissance Marriot Hotel at SeaWorld in Orlando. The event was attended by more than 125 residents of Florida and Puerto Rico. After the welcome and introductions, the day kicked off with a round of Family Jeopardy.

Following lunch, the first session, Conversation - **Round Table: Coagulation Disorders: What Has Changed in Recent Years?**

Facilitated by: **Dr. Corrales Medina MD**,
FAAP Associate Professor of Clinical Pediatrics
Medical Co-Director, Pediatric Hemophilia Program
Director, Pediatric Hematology and Oncology Fellowship Program
University of Miami Comprehensive Hemophilia Treatment Center
Division of Pediatric Hematology-Oncology
University of Miami Miller School of Medicine



Round Table Presenters were:

Dr. Yasmina Abajas, Assistant Professor of Pediatric Hematology/Oncology Clinic
University of North Carolina

Irmel Ayala, Director, Hemophilia and Bleeding Disorders Center Cancer and Blood Disorders
Institute, Johns Hopkins All Children's Hospital St. Petersburg, FL

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

The presenters shared their expertise and knowledge and answered participants' questions.



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The conference then broke into sessions:
Dr. Johary Aybar Cruz- psychologist Women's
Breakout Group Facilitator-

Self-Love, Well-being, and Connection

Fernando Reyes M. ED. Psi. Men's Breakout Group
Facilitator –***How do we stay resilient in the face of
adversity (how do we pick ourselves up when we
feel down).***

Participants really enjoyed their group experiences.

After the breakout sessions everyone got back together
for Comprehensive Care for Patients with Bleeding
Disorder, the University of Miami Hemophilia Treatment
Center team did a great job presenting, led by, Dr.
Corrales Medina MD, FAAP, Kelli Fraga PT, Sasha
Inclan, MSN, APRN, FNP-BC, and Silvia Nicolini, MSW
Social Worker. They gave a great overview of why
comprehensive care is so important for better health
outcomes.

The meeting wound up 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**

Javier Aguilu
Lourdes Arvelo
Barbie Castano- Arrebola
Dr Corrales Medina
Liliana Gomez
Myriam Lagomasino
Rene Lebron
Anthony Llanes
Will Lopez
Barbra Matais
Samantha Nazario
Crisitie Vidal-Strub



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The Bleeding Disorder Coalition of Florida went to Tallahassee January 23-24, 2024, to visit legislators to get support for House Bill 363 Health Insurance Cost Sharing and Senate Bill 228 Health Insurance Cost Sharing:

Copay accumulator adjustment policies are preventing copay assistance from counting toward patients' deductibles and out-of-pocket maximums in Florida. accumulators are putting patients at risk of severe physical complications and financial burden.

These bills require health insurers and their pharmacy benefit managers to provide payments by or behalf of insureds toward total contributions of the insureds' cost-sharing requirements.

We need your help to get these bills passed. Contact your legislator and ask them to support HB 363 and SB 228. If you are not sure who your Legislators are you can search for them on our website at <https://bleedingdisordersfl.org/what-we-do/advocacy/>.

If you are interested in becoming an Advocacy Ambassador for the Bleeding Disorders Coalition of Florida please contact info@bleedingdisordersfl.org or 800-293-6527.



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

February 24, 2024
Jacksonville Safari Walk



April 6, 2024
13th Annual Gator Clot Trot 5K
Run & Walk



Walk Website: <https://bleedingdisordersfl.org/walks-5ks/>



Follow/Like BDFF on Social Media!

[Facebook.com/bleedingdisordersfl](https://facebook.com/bleedingdisordersfl)

<https://twitter.com/hemophiliafl>


[Instagram.com/hemophiliaflorida](https://instagram.com/hemophiliaflorida)

<https://www.linkedin.com/company/bleeding-disorders-foundation-of-florida>

March 2, 2024

21st Annual Evening on Broadway

**21ST ANNUAL
EVENING ON BROADWAY**



**Bleeding
Disorders**
Foundation of Florida

DR. PHILLIPS CENTER FOR THE PERFORMING ARTS
445 S MAGNOLIA AVE ORLANDO, FL

BAZ LUHMAN'S
REVOLUTIONARY FILM COMES TO LIFE

TRUTH BEAUTY FREEDOM LOVE

MOULIN ROUGE!
THE MUSICAL

Ticket Packages are \$150 each
(CORPORATE SPONSORS ARE AVAILABLE)

THE EVENING INCLUDES A CATERED RECEPTION, SILENT AUCTION, AND
ORCHESTRA SEATING TO MOULIN ROUGE

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

March 2, 2024 • 6pm reception

This year, the Bleeding Disorders Foundation of Florida is thrilled to be holding the 2024 Theater event featuring the musical Moulin Rouge. Join us for a private reception, silent auction, and lots of fun!

Theater Website: <https://bleedingdisordersfl.org/fundraising/evening-on-broadway/>

In recent years, the arrival of novel hemophilia treatments that are effective and less burdensome to administer have opened up new possibilities for the consumers of these therapies. This begs the question – How might this evolving landscape be impacting treatment preferences for people with hemophilia?

Investigators sought answers to this question in a new study, “Patient and Caregiver Preferences for Haemophilia Treatments: A Discrete-Choice Experiment,” which was published in the journal *Haemophilia*. The study was informed by a literature review and a survey open to adult males with hemophilia age 18 years and older, and caregivers of teen/adult males with hemophilia age 17 years or younger.



The surveys, which were submitted online from February to April 2022, generated a sample of 151 affected adults and 151 caregiver respondents. Each respondent evaluated hypothetical hemophilia treatment profiles defined by six attributes via a discrete choice experiment (DCE). The DCE was used by the authors to quantify preferences and learn more about trade-offs individuals consider when making decisions about available treatments.

Respondents answered questions based on six attributes: number of annual spontaneous bleeds; ability to live a more active lifestyle; how a medicine is prepared/administered; frequency of administration; risk of an inhibitor; risk of hospitalization due to treatment side-effects.

The burdens of treatment administration (intravenous and subcutaneous) and storage were also explored through a best-worst (BWS) scaling exercise, used to assess an individuals’ priorities. It captures extremes including best and worst items, most and least important factors, biggest and smallest influences.

“In the BWS exercise, adult respondents and caregivers had overall similar preferences regarding the burden of treatment administration features, reported the investigators “Both samples found frequent and longer IV infusions most burdensome and a Sub-Q injection every 2 months least burdensome.” DCE results indicated that both adult patients and caregivers preferred treatments that enabled a

more active lifestyle and are associated with a lower inhibitor risk. Notably, both groups valued an active life more than reducing spontaneous bleeds.

“These findings suggest that adults with haemophilia and caregivers of children with haemophilia are willing to make tradeoffs for potential improvements in lifestyle not offered by clotting factor concentrates, bypass agents or activated factor VIII mimetics,” explained the authors.

The paper also acknowledged limitations. The sample generated from the survey included English speakers exclusively and respondents were predominantly white, highly educated. In addition, the survey was only available online, which would exclude individuals/families who do not have internet.

The authors posit that this study underscores the importance of a shared decision-making (SDM) approach to hemophilia care. Through SDM, healthcare providers and patients/caregivers may arrive at decisions that factor in the current treatment landscape and individual preferences.

Citation

Garcia VC, Mansfield C, Pierce A, Leach C, Smith JC, Afonso M. Patient and caregiver preferences for haemophilia treatments: A discrete-choice experiment. *Haemophilia*. 2024 Jan 10. doi: 10.1111/hae.14928. Epub ahead of print. PMID: 38198352.

Disclaimer: NBDF 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 speak to a broad spectrum of the inherited blood disorders community. Topics include shared decision making, gene therapy, health equity, and more. NBDF hopes you find this content to be informative and engaging.

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