

The News Infusion

The Official Newsletter of Bleeding Disorders Association of South Carolina

VOLUME 14, ISSUE 1

WINTER 2024



red tie campaign
CONNECTED BY BLOOD



celebrating bleeding disorders awareness month 2024

Featured Articles

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About BDASC & The News Infusion

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A Chapter Member of the Hemophilia Federation of America
A Registered Greenville County Charitable Organization
Member of the Greenville Chamber of Commerce
A Proud Member of the South Carolina Associations
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BDASC MISSION: To raise awareness for and advocate on behalf of persons with bleeding disorders and their families; provide education and supportive services; and promote ongoing research to improve the quality of life for those affected. **BDASC VISION:** The Bleeding Disorder Association of South Carolina is to be recognized as a leading organization providing valued services; as ambassadors of public outreach to enlighten and foster an understanding of what matters most to those affected by hemophilia and bleeding disorders; and to be our community's first choice in partnership to achieve their highest potential through empowerment, connection to their community and being part of the solutions that affect them the most, until a cure is achieved.

Winter 2024 Calendar of Events

Looking Ahead: Save the Dates!

Community Engagements

February 1: Are you Camp Ready? Educational Dinner in Columbia	Platelet Disorders Awareness Day
February 16: Gene Therapy Conversations in Myrtle Beach	March 22 - 24: Adult Connections Symposium in Greenville
February 23: Healthy Aging Educational Dinner and activity in Greenville	April 17: World Hemophilia Day
February 27-28: State Advocacy Days in Columbia	April 20: World Hemophilia Day Celebration in Columbia
March 1-April 17: Red Tie Campaign celebrating Bleeding Disorders Awareness Month	May 11: STEP for Bleeding Disorders Walk/5K
March 1: von Willebrand Disease Awareness Day	May 25: Women Matter in Bleeding Disorders Dinner and Activity
March 6-8: NBDF Washington Days in Washington D.C	May 31: Let Us Talk Mental Health Community Engagement Dinner
March 15: Ultra Rare Bleeding Disorders and	June 21-22: HELLO Conference and Annual Meeting in Greenville

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About This Publication

The News Infusion's mission is to provide communication, connections, education and advocacy awareness. It is published quarterly by the Bleeding Disorder Association of South Carolina as an informational service to its members, friends, and affiliates of South Carolina's bleeding disorders community. *The News Infusion* does not endorse any provider, company or product, and further recommends that its readers always consult with their physicians and health care providers. *The News Infusion* is for educational and communication purposes only and makes no claim to its accuracy. *The News Infusion* is endorsed by the South Carolina Hemophilia Treatment Center and the The National Bleeding Disorders Foundation. We encourage your feedback and communications as a forum for exchange of information, ideas, and opinions. We welcome your letters, articles, questions and pictures. All articles may be published or distributed in print, electronic, online or in other forms. All submissions will be verified and subject to editing. Please send to the editor-in-chief at: sue.martin@bda-sc.org. Mail to: 25 Woods Lake Road, Ste 300, Greenville, SC 29607, Attention: Editor-in-Chief, The News Infusion. We look forward to hearing from you soon!

Celebrating Bleeding Disorders Awareness Month

Two New Awareness Days in 2024

Each March our national bleeding disorders community comes together to spread

awareness for all those living with and affected by bleeding disorders. This tradition started back in 1986, when President Ronald Reagan designated March as Hemophilia Awareness Month. Since the 1980's this month has evolved into so much more.

Each year, the bleeding disorders community becomes more inclusive of all those living with bleeding disorders. In 2016, NBDF and the U.S. Department of Health and Human Services worked together to designate March as Bleeding Disorders Awareness Month and introduced the Red Tie as the symbol for the bleeding disorders

community. The Red Tie signifies the fact the blood ties — embodied in the color red and the tie — are what bind the community together. Our Chapter's Annual Giving drive is held every year during this special month of March as part of the Bleeding Disorders Awareness Month. Funds raised during the campaign help the Bleeding Disorders Association of South Carolina to support research, global initiatives,

community advocacy training and awareness, education, and access to quality treatment care.

All donations to our Red Tie Campaign stay within South Carolina to serve our community. BDASC's Red Tie Campaign runs from Rare Disease Day, February 28 through World Hemophilia Day on April 17.

Throughout this campaign, we not only raise funds to support our community, but we also raise our voices to spread awareness for those living with and affected by bleeding disorders.

How can you participate in Bleeding Disorders Awareness Month?

- We provide many opportunities for our community to share their stories

throughout the month. This year we are running a **"Raise Your Voice"** social media campaign. We are looking for community members who are willing to share a short (one minute or less) video of themselves sharing the importance of bleeding disorders awareness month! Just record your video on your phone or iPad and text it to the chapter at 864-350-9941.

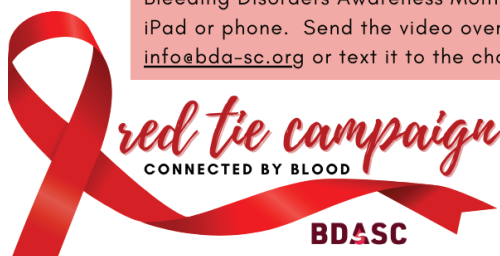


looking for voices!

This year during the month of March we will be celebrating Bleeding Disorders Awareness Month. We will be looking for community members to **SHARE THEIR VOICES** throughout the month!

HOW TO PARTICIPATE

Create a short (no longer than 1 minute) video about what Bleeding Disorders Awareness Month means to you on your iPad or phone. Send the video over to BDASC via email at info@bda-sc.org or text it to the chapter at 864-350-9941!



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- **Share on social media.** You can share any of our social media posts to your account or utilize the Red Tie Campaign website – there is a button to share on Facebook and X.
- Secure a **Bleeding Disorders Awareness Month** Proclamation for your city, town or county. You can learn more about securing a proclamation at our Red Tie Campaign website. Be sure to share the date, time, and location when you are receiving your proclamation. We will share this information with our community, so that local community members can be present as well! If you want to participate and do not know how, contact Sue at the Chapter for information where to reach out to first.
- Be sure to watch our social media and eblasts for upcoming events and ways to celebrate Bleeding Disorders Awareness Month. We will cap our celebrations off with a final celebration, sponsored by Sanofi, for **World Hemophilia Day**

on April 20 in Columbia! Everyone is welcome so be sure to register.

- **Go Red for Bleeding Disorders Awareness** on March 17! Don your favorite red outfit to spread the word about bleeding disorders. Don't have a red shirt? Wear one of your BDASC shirts from an event! Share photos with us and tag us on social media and use the hashtag **#GoRedForBDASC**.

New This Year!

This year, we are proclaiming **March 1 von Willebrand Disease Awareness Day** and **March 15 Ultra Rare Bleeding/Platelet Disorders Awareness Day!** Join us as we share information and share stories and videos from our community.

If you would like to share your VWD or Ultra Rare Bleeding/Platelet Disorder story, please send your stories and reach out to the chapter office at 864-350-9941.



Executive Director's Welcome

The State of the Chapter

By Sue Martin



Hello and Happy New Year! It is crazy to realize that we are already heading into March, our National Bleeding Disorders Awareness Month. It seems like yesterday that we had our Winterfest meeting celebrating a great year together. (Read all about it on page 9) I have been extremely busy planning for 2024 and working with the board of directors to plan for our future, near and distant. Thank you to all who helped us with the directional planning by voicing your feedback on the 2024 Member Feedback Survey. Please read the highlights on page 19 and be sure to link to our website for the full report. We are planning to continue our robust strong advocacy programming, working to educate our teens for transitioning to adulthood, providing general

education and support for sub - groups within our bleeding disorders, and providing as much financial assistance and college scholarships as possible, while also trying our best to raise additional revenue through our fundraisers and corporate funders. We asked the question; would you mind if we had to ask for a small fee to attend big events due to the increase in the cost of doing business today during the feedback survey. Most everyone said no, that would be fine. But the truth is, the amount we would ask for really would not make that much of a difference. We decided instead that we would like to **challenge all our community members** to help us raise funds and donate to our walk and

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other fundraisers we have throughout the year

Why does this matter?

We had 62 new families and individuals join our organization from all regions throughout the state last year. Much of this growth is due to our relationships and partnerships with our HTCs. Our mutual referral system and my attendance at clinic visits have aided to this growth. As you can see from the charts below, while we love the ability to serve more families and individuals, we had a short fall in revenue income by a little over \$50,000. We raised the most revenue to date last year, but with the increase in the costs of goods and services, and our growth, we also had expenses at our highest level to date.

So, what does this mean?

We are going to do our best to consolidate programs, cut where we can, like we have for our Adult Connections Retreat this March 22-24 in Greenville. (Learn more on page 12) Please register to join us as we have a terrific symposium planned. With 82% of our revenue coming from corporate grants and sponsorship, and with these opportunities becoming less available to our national Chapters due to many reasons, we will have to make up these funds by raising more general revenue from donations and additional corporate funders.

How can you help?

If we want to sustain the Chapter into the future, it will take every member to invest in our future, from the smallest donations and assistance, to the largest we all can afford. Being present at events also helps immensely, as our sponsors enjoy seeing a large audience when they invest large funding support in events. I do realize we are all extremely busy and that is great that most of our community is doing so well with the new treatment therapies available today. So, we appreciate you doing what you can to help BDASC advance into the future years. We planned well the past ten years since I have been the Executive Director to have a robust rainy day savings, just for this reason, however, those funds will run out if we continue to have a shortfall in total revenue.

Volunteers are our lifeline and always have been. They are needed more than ever now as we have grown to do more, and serve more individuals. In a recent deep dive with Aaron Smith our president, we discovered my work hours over all are that of 2 ¾ full time people. This is not sustainable for anyone indefinitely. I was hoping to hire an assistant, but at this time, we will need to put that on hold so I am asking for your support to help me out as your time allows. Volunteers, especially in the home office and at events, is a huge need.

As the only fulltime employee responsible for all operations and implementations of our programs, services, and advocacy programming, it has been great to have Samantha Javorka working for me parttime for the past year and a half as the Engagement Coordinator. She works primarily on the marketing side of BDASC — working on social media, the graphics for events and documents, helping with our eblasts as well as the newsletter, among other administrative needs. She also helps me call members for confirmations on events. Samantha and her family moved to South Carolina from Michigan in 2021 so if you see a **“Michigan”** number calling you, it is most likely Samantha, calling on behalf of BDASC.

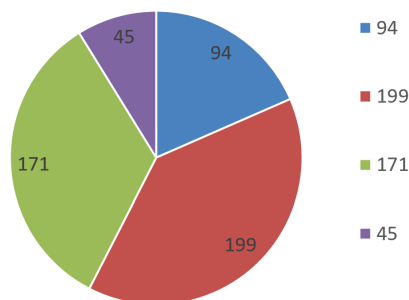
If you have an interest in volunteering for me in the home office of Greenville, let me know. You never know where that could lead! My time is somewhat limited here at BDASC, as I have reached my retirement age a few years ago and my family and mother who is 91 years old, need me too. I have loved every minute doing this job and I do not know when that day will come. However, rest assured, my replacement will be wonderful. I will be sure of that!

Let us all come together for our BDASC family and the families who will need us in the future. Like the advocacy work we do, we are resilient and strong, and can do anything we put our energy in. I hope to see you all soon and thanks for being our wonderful members.

Warm regards always,
Sue

January 2024 BDASC Membership

January 2024 BDASC Membership

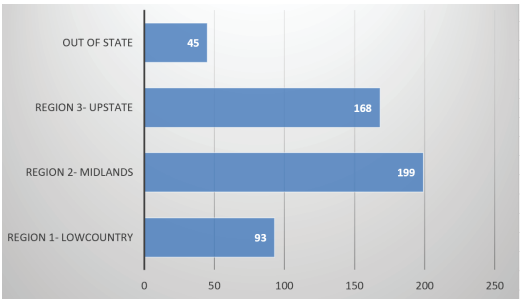


Blue Region 1 Red Region 2 Green Region 3 Purple Out of State

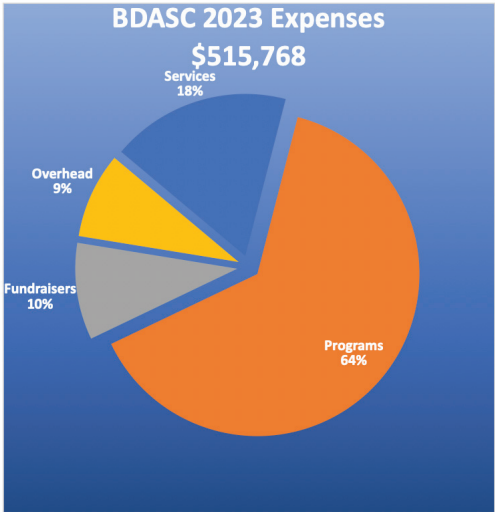
2024 Membership by Disease State



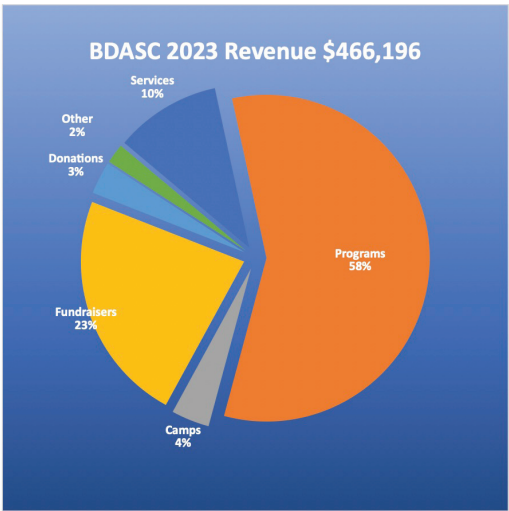
■ Hemophilia A ■ Hemophilia B ■ VWD Female ■ VWD Male ■ Rare Disorder



2024 Membership by Regions



92% of every dollar is given back to the community



82% of our funding revenue is from grants and sponsorships

Board Of Directors Needed!

Each year during our Annual Meeting and HELLO Conference we proudly present to our community the members of the Board of Directors. Our board is currently comprised of diverse members of the South Carolina Bleeding Disorders Community. The board of directors meets monthly to discuss the needs of our Chapter. If you would like to be more

involved and become a member of the Board of Directors, we welcome you to apply! Visit our website at <http://www.bda-sc.org> to learn more about our current board and submit your application. We welcome board members from outside the community too who have board experience and a mission to serve.

Volunteers Greatly Needed!

Thank you to all of our volunteers that made 2023 a successful year. We are so grateful for your continued support. Without you, BDASC would not be able to provide quality support and opportunities for our bleeding disorders community within South Carolina. Thank you! Would you like to help support BDASC? Volunteering for events and committees is a fantastic way to help. To continue to support and engage with our community, BDASC requires some help at events — whether it is

helping in the Greenville office, manning the registration booths, helping with the teen and kids during our programs, or helping to assist in the needs of our events and fundraisers, there is something for everyone! If you would like to volunteer, please contact Sue at the Chapter office, or register on our [volunteer page on our website](#). We are also in need of volunteers in the upcoming [STEP for Bleeding Disorders Walk](#).



Community Engagements

Embracing Our Community

Winterfest Year-End Gathering

Our Annual Statewide Winter Meeting was held on December 9 in Columbia bringing together our bleeding disorders community for one final event of the year. It also allowed special time to celebrate the Winter season festivities. We reported on the progress and mission successes we had during the year, highlighting events, individuals, advocacy initiatives, and the Chapter's programs and services.

The gathering was interactive for the children and our adults. The day included a Candy Cane Adventure, a Teen Leadership Challenge Competition, a search for "Jingles," our Elf on the Shelf, holiday balloon creations with Christovan, the famous balloon artist, holiday arts and crafts festivities, fun exhibit booths provided by our sponsors, reading of "The Night Before Christmas," and a special surprise visit from Santa Claus who brought gifts for all the children to enjoy. Our teens were honored for their involvement and were provided with Amazon gift cards to spend on their own. Adults had fun with "White Elephant Raffles," stealing from one another or picking a gift from the table. Just about everyone had something to take home. We would like to give a shout out to all attendees for donating a gift for this exchange.

During our early dinner, Xaviette with Sanofi,

presented "*Celebrating Connections in Our Bleeding Disorders Community*" and we listened to stories from community members sharing their hopes and dreams for the bleeding disorders community and expressing how to support and empower one another. The Winterfest gathering was enjoyed by all. **We are grateful to all our sponsors who made it possible for us to gather during this special holiday season time!**

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Gene Therapy Across the State

Various Dates throughout December 2023 and February 2024

Gene Therapy is here! We are excited to have provided the opportunity for the entire community to learn more about these novel therapies. Our community members have gained valuable information and a deeper understanding of these new therapies. These events have been hosted by BDASC in partnership with our Hemophilia Treatment Centers and our sponsors

through educational grants. The importance for BDASC was to educate members and assure they had the correct information as there was some confusion whether this was a cure, are they changing my DNA, and more. Gene Therapy is something the community has waited a long time for. It is not available for everyone, and there is still much to learn. Advocating for access is also needed.

We have provided seven opportunities to learn about the new Gene Therapy options with a

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virtual event coming in the Spring. We traveled to all three regions in the state and just recently hosted an event in Myrtle Beach. Please note, while these dinners were specific to the different types of Hemophilia, all BDASC community members were welcome to attend and learn more about what is happening in the bleeding disorders community to advance treatment care. Everyone within our community enjoyed these events and it was amazing to see people representing the different disease states within our community. Our speakers provided an interesting look into the Gene Therapy options available to those living with Hemophilia A and B, and provided information on the studies that took place leading to the FDA approval. It was amazing to hear about their successes and how much of a positive impact on the quality of life that Gene Therapy has made for those in the clinical trials. Whether Gene Therapy is something you are interested in doing or not, there was something for everyone to learn.

IMPORTANT MESSAGE

BDASC does not give medical advice or engage

in the practice of medicine. BDASC under no condition or circumstances recommends treatment for specific individuals and in all cases recommends that our members always consult their physicians or hemophilia treatment centers before pursuing any course of treatment. *BDASC does not endorse or recommend any company or treatment therapy, but as an advocacy organization strives to provide educational information and support to keep our bleeding disorders community informed.*

We are so grateful to our Hemophilia Treatment Center physicians and to CSL Behring and BioMarin for sponsoring and hosting these informational sessions.

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BIOMARIN

HEMOPHILIA B SPONSOR

CSL Behring

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Are You Camp Ready? Summer Camp Info Sessions

January 17, 2024 in Greenville

February 1, 2024 in Columbia

In January and February, our community came together for engagement events in Greenville and in Columbia as we discussed common fears about sending your child to summer camp and got an in-depth look at the camp environment, including socialization, and support resources. The community heard from South Carolina kids (and adults) and their parents who have attended summer camps in the past. The event allowed attendees to ask their questions about what summer camp is all about. Additionally, they learned about SC camps for teens and kids and how to be prepared to send your eligible kids. BDASC shared information on the Chapter's

assistance with miles or needs to attend camp. We write grants and use fundraising revenue to support this assistance. If you are in need of assistance or need more information about camp available, check out our Summer Camp [website page](#). BDASC's and BDFNC's famous Carolina Crew 2024 [TEEN CAMP RETREAT](#) location was revealed and will be held July 18-21, 2024 at [Rockfish Camp & Resort](#) in Raeford, North Carolina. Information will be coming later this spring.

Thanks to Sanofi for the opportunity to assure our members know that summer camps are available for teens and kids with bleeding disorders in South Carolina.

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Upcoming Engagement Opportunities

Celebrating our African American, Black, People of Color Community What is Healthy Aging with a Bleeding Disorder?

February 23, 2024 6:pm-9pm
Logan's Roadhouse of Greenville
53 Beacon Dr., Greenville, SC 29615

What does it really mean to “age gracefully” or, rather, age healthfully? Learn how to reduce the risk of disease and related disabilities, how to preserve and improve physical and mental functioning, and how to actively engage in life and the bleeding disorders community. After a fun and interactive dinner, we will enjoy a

mindfulness art activity with [Burlap and Ribbons](#) and our friend Toshia Leisten and make a special wood project to take home. Different projects are available for all ages. Come and engage with our Black Community for dinner, conversations, and our stress reducing activity. Registration is required and space is limited so do not wait to register.



2024 Adult Connection Symposium

March 22-24, 2024

We are excited to provide this weekend symposium to our membership adults, ages 18-(with an adult 21 or over) 21 and over, who are living with bleeding disorders themselves, are carriers of a genetic bleeding disorder, spouses or are caretakers for someone in their immediate family who is affected. We are excited to bring all adults into the event so couples can take a weekend away from the kids, single men and women can enjoy time with community members for fellowship and support, and everyone can enjoy being connected while learning in an atmosphere of beauty and opportunity, such a downtown Greenville. We will be providing group activities throughout the Symposium, while the time for women and men to have separate sessions related to their unique needs.

Planned Sessions/Tracks:

Keynote: Motivational and Uplifting, with Jim Stroker

- Sessions for affected men: fathers, and caretakers
- Sessions for affected women: mothers and caretakers
- Sessions for our VWD and Rare Community

- Mental Health & Wellness Support
- Advocacy, Research and more!

Session Descriptions:

Keynote Dinner Presentation, E + R = O, Events + your Response = the Outcome

Presented by Jim Stroker, Life Coach

His daughter, Ali, who was paralyzed at the age of two after a car accident, made history by becoming the first performer in a wheelchair to win a Tony Award. Jim will share his story of responding to adversity. The events in your life do not dictate the outcomes, your response does! Learn how the power is with you. How are you going to choose calm over chaos and reset?

Men's Session: Uncovering Our Treasures Workshop

Presented by Jim Stroker, Life Coach

Every discussion you make needs to become a value clarifying exercise. We all need to stop and pause and reassess who we are, what are our principles, how do we want to be remembered.

Women's Session: Managing Multiple Priorities and Taking Care of You!

Presented by Anna Bell

We all live in a very busy world. Finding a work

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– life balance can be difficult and finding the time to take care of yourself is often put off and sometimes never happens. Managing multiple priorities is tricky. Come share and engage in this informative session.

For Men and Women: Couples and Relationships While Living with Bleeding Disorders

Presented by Anna Bell

Being the spouse of someone with a bleeding disorder or chronic condition can sometimes be challenging for both partners. Starting a new relationship or keeping the laughter during stressful times. Enjoy this session for engaging conversations and activities to enhance your relationships.

Men's Session: Breathing and Meditation; Does It Really Work? What is the Benefit?

Presented by Jim Stroker

Coach Stoker's gifts combine skill coaching with the ability to stay calm, focused, and confident. His root message is painted with optimism, gratitude, and kindness. Breathwork, mindfulness, positive self-talk combined with visualization connect his training. Coach Stroker integrates physical movement, exercise, stretching, weight training, cardiovascular, aerobic, yoga, intense HIT training as part of an effective life coaching program.

VWD and Ultra Rares: Novice to Experienced: Let Us Look at VWD and Rares

Presented by Sue Geraghty

We will start with the basics and advance to a deeper understanding of VWD and Ultra Rare Bleeding Disorders. We will enjoy a level of

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adult connection

SYMPOSIUM

for men, women and couples
impacted by bleeding disorders

**March 22-24th, 2024
Greenville, SC**

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understanding for those new to VWD or Ultra Rares, and those who have been living with them for three or more years. We will split into groups and have conversations around your burning questions and hear practical solutions by those who have lived experience.

VWD and Ultra Rares: Part 2: VWD and Rares: Now for Practical Information

Presented by Sue Geraghty

Let's discuss schools, work, heading to college, having relationships, Emergency Rooms, HTC Visits, Securing a dentist, and more. Nothing is off the table to discuss.

Gene Therapy in Hemophilia – Hemophilia A & B Sponsored by CSL Behring and BioMarin

Let's find out what all the buzz is about – from curiosity to eligibility and beyond. A one-hour presentation to hear how gene therapy is designed to work and why eligibility testing is the first step on the gene therapy journey. We will share the findings from clinical trials and what they could mean for you. Learn how to get started, what questions to ask your doctor, and hear one patient's experience.

Chapter Updates: Embracing A New Normal in our Ever-Changing Landscape

- **Advocacy Updates**
- **National Research Blueprint**

Ask The Experts! What Is On Your mind?

A moderated conversation with you leading the conversation. What you always wanted to know but were afraid to ask. What is on your mind? Put your questions into our "Question Jar" throughout the weekend and we all will try to answer your burning questions in the last session on Sunday.

Our Speakers:

Anna Maria Bell, LICSW, LCSW-C, LISW

Anna is a graduate of The Catholic University of America Master's Program in Social Work with a concentration in Gerontology, a graduate of Capella University with a Master's Degree in



Public Service Leadership, and a graduate of Walden University with a Master's Degree in Philosophy. She is currently ABD at Walden University

where she is pursuing a PhD in Human Services. She is Clinically Licensed to Practice in the District of Columbia, Maryland, Virginia and the State of Ohio. She has worked in a variety of Social Work Settings and provided counseling to various populations including couples, children and adolescents, women, and geriatric populations. For the last twenty-five years she has been employed at the District of Columbia Child Welfare Agency where she has worked in various areas mainly Training, Licensing, Policy, and Clinical Case Management. Anna was promoted to Program Manager of the Foster Parent Training and Licensing Division in 2012. Anna is an active part of the management team at CFSA and heads several committees involving policy creation, program administration and supportive services. Anna joined the Hemophilia Foundation of America consultancy staff in 2015 as a facilitator/speaker, conducting trainings, seminars, and facilitations throughout the 50-member organizations. Anna conducts life/professional coaching sessions as well as various workshops throughout the Washington DC Metropolitan Area through her company Bell-ievable, Inc., where she focuses

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on Development of Leadership, Self Esteem and Self Determination, through group processes and facilitation.

Jim Stroker

Coach Jim Stroker is a Life Coach, Leadership Trainer, and Keynote Speaker. Jim carefully crafts each speech to cover topics such as leadership, teamwork, growth mindset and his famous E +R =O formula. His passion for transformation is based on his incredible life experiences and his



ability to thrive through one of his greatest life challenges. Coach Stroker's unique gift to craft and deliver motivational and

educational keynote seminars resonates with audiences ranging from Fortune 500 CEO's to thousands of high school students throughout the country, as well as Nonprofits, Military, Gaming Associations, Healthcare Practitioners, and Native Americans. Coach Stroker's wellness program has been cited as one of the nation's best and he is also the creator of "Inspirational Hotline," a morning message delivered to 700 students. He has over 30 years of experience within the New Jersey Public School System as a sports coach as well as a wellness educator. Coach Stroker is an inductee to the New Jersey Coaches Hall of Fame and a recipient of the prestigious Distinguished Alumni Award at Ridgewood High School.

Sue Geraghty, RN, MBA

Sue Geraghty worked as Nurse Coordinator at the University of Colorado Denver Hemophilia and Thrombosis Center for 25 years where she retired in 2013. She has over 45 years of nursing experience and currently she is working as an independent consultant in the areas of hemophilia and health care education. During her



time as nurse coordinator at the Hemophilia Treatment Center she sat on several national committees including the Nursing Working

Group for the National Hemophilia Foundation. Her areas of interest within the bleeding disorder community include new families affected with a bleeding disorder and adult patient issues, women with bleeding disorders, patients with inhibitors, and orthopaedic issues. She has an associate degree in nursing from Lander College, a bachelor's degree in nursing from the University of NC Charlotte, and a Master's in Business from the University of Colorado Denver. Sue continues to educate and speak at many bleeding disorders camps, chapter meetings, and national conferences. Her passion for bleeding disorders and patients is spoken in every talk she provides. We are grateful to have her back with us again! She will lead our VWD sessions and more.

Virtual Sessions:

We are excited to be able to provide a virtual option to those unable to attend. At the moment, it has not been decided exactly which sessions will be provided virtually, but please look to our website and social media pages for more information as the event draws near. We are planning on providing virtual sessions for the major/large group sessions and the von Willebrand Disease sessions.

Social engagement activities at no cost to attendees:

Let's have fun with some Group Therapy of Greenville, Friday night! We will walk together next door to Group Therapy and have 2 ½ hours of Wacky Mini Golf, Axe Throwing or Duckpin Bowling, and two beverage tickets for

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a fun group activity. Group Activity & Dinner off site at Top Golf of Greenville, Saturday night, sponsored

by CSL Behring and BDASC. At Topgolf, there's no pressure to have a good golf swing or score a lot of points. It's all about everyone having fun. Top Golf features climate-controlled hitting bays for year-round comfort with HDTVs in every bay and throughout our sports bar and restaurant.



REGISTRATION CLOSES: MARCH 7, 2024 or sooner depending on the number of qualified applications received.

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FACTOR **UP** with ALTUVIIIIO™

Higher-for-longer Factor VIII levels in the near-normal to normal range (**over 40%**) for most of the week

ALTUVIIIIO™
Antihemophilic Factor (Recombinant),
Fc-VWF-XTEN Fusion Protein-ehtl



HIGHER FACTOR LEVELS FOR LONGER

Above 40% for most of the week (near-normal to normal range).^{*†}

48

HOUR HALF-LIFE IN ADULTS

In a Phase 3 study,[†] ALTUVIIIIO offered adults the longest half-life of any Factor VIII therapy.

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Mean annual bleed rate observed in 128 people previously treated with prophylaxis therapy.[‡]

In people taking ALTUVIIIIO in the XTEND-1 study, 21% of people had headache, 16% had joint pain, and 6% had back pain

^{*}Average trough levels were 18% for adults 18 years and older, 9% for adolescents aged 12 years to under 18 years, 10% for children aged 6 years to under 12 years, and 7% for children aged 1 year to under 6 years.

[†]159 adults and adolescents with severe hemophilia (aged 12 years and older) were enrolled in the XTEND-1 study; 133 people were in Group 1 and switched to ALTUVIIIIO prophylaxis from prior prophylaxis therapy. Efficacy of prophylaxis was evaluated in 128 of these patients.

[‡]Data based on treated bleeds.

CONNECT WITH YOUR CoRe TODAY

Learn more about ALTUVIIIIO, living with hemophilia, and treatment options from your local CoRe.



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INDICATION

ALTUVIIIIO™ [antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-ehtl] is an injectable medicine that is used to control and reduce the number of bleeding episodes in people with hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ALTUVIIIIO when you have surgery.

IMPORTANT SAFETY INFORMATION

What is the most important information I need to know about ALTUVIIIIO?

Do not attempt to give yourself an injection unless you have been taught how by your healthcare provider or hemophilia center. You must carefully follow your healthcare provider's instructions regarding the dose and schedule for injecting ALTUVIIIIO so that your treatment will work best for you.

Who should not use ALTUVIIIIO?

You should not use ALTUVIIIIO if you have had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ALTUVIIIIO?

Tell your healthcare provider if you have had any medical problems, take any medications, including prescription and non-prescription medicines, supplements, or herbal medicines, are breastfeeding, or are pregnant or planning to become pregnant.

What are the possible side effects of ALTUVIIIIO?

You can have an allergic reaction to ALTUVIIIIO. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called "inhibitors" against ALTUVIIIIO. This can stop ALTUVIIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

The common side effects of ALTUVIIIIO are headache, joint pain, and back pain.

These are not the only possible side effects of ALTUVIIIIO. Tell your healthcare provider about any side effect that bothers you or does not go away.

Please see full [Prescribing Information](#).

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MAT-US-2301368-v1.0-03/2023

2024 STEP For Bleeding Disorders, 5K Walk/Run: Our Goal \$75,000

We invite you to join us on May 11, 2024, for our **11th Annual STEP for Bleeding Disorders 5K**

Walk / Run Fundraiser

and Awareness Campaign.

We encourage you to join us in Columbia or virtually wherever you live! The word STEP encompasses everything the Bleeding Disorder Association of

South Carolina holds to its core. S is for Sharing Stories, T is for Transforming Tomorrows, E is for Empowering People, and P is for Promoting Research. We continue to be determined in our cause to raise awareness and support for our community in South Carolina and our global bleeding disorders family. Please consider forming a team or joining an already existing team or participating as an individual! Come meet our community and help us raise funds too! Any amount you can raise will help make a difference in the lives of our members. So, register today and join us on May 11 at 10 am as we join the community and STEP into action and Walk / Run together! Please enjoy our fundraiser platform website, explore all links, learn what we do as an organization, and check it often as we build together this important event.

All Registrants Receive:

- A Race Bib and Swag
- A Commemorative T-Shirt (*guaranteed if registered by April 12*)
- Refreshments Pre and Post Race
- Race Medal
- Less than a mile short track fun walk / run
- Participation in our Costume Contest Parade Walk
- Free Entertainment / Photo Booth / Face
- Painting
- Visit our Sponsor Booths

Virtual Registrations are Welcome!

Whether you are walking in-person or virtually, we are all in this together! Virtual registrations are welcome and encouraged for those who cannot attend the event in Columbia. Virtual registrants do not need to walk the day of the event but can

walk whenever they choose.

How are the two registrations different? The

only difference is that virtual registrants do not participate in the actual event. We will provide the commemorative T-Shirt to their team captain. Virtual registrants are encouraged to fundraise similarly to

our in-person participants. This is a great way for out-of-state family and friends to be able to participate and support your team! You will be responsible for sending them their shirts, proving they register online.

STEP For Bleeding Disorders FAQ

How is the money Raised Used?

100% of the proceeds from the walk go to supporting our South Carolina Bleeding Disorders Community in several ways. Specifically, BDASC uses this money to support the community's educational events, academic scholarships, financial assistance, research, and advocacy.

How long is the walk?

There are two options for participants: a short track which is less than a mile, and a certified 5K track. Each participant may choose which track they would like to take if they choose to participate. You may also just hang out (as long as you register), you don't have to walk.

What kind of entertainment will be there?

We are excited to welcome back Big Time Entertainment, Face Painting, a Photobooth and more! In previous years we have had such a fantastic response to these activities. Remember, they are all free for you!

Is any food provided?

We provide breakfast snacks before the walk/run and a pizza lunch after the event. There will be plenty of food for all throughout the event!

How do I register?

You can register by visiting our 2024 STEP for Bleeding Disorders website at <http://www.tinyurl.com/2024STEPForBleedingDisorders>



Voices of Our Community

Member Feedback Survey

JANUARY 2024



MEMBER EXPERIENCE & NEEDS ASSESSMENT FEEDBACK SURVEY REPORT

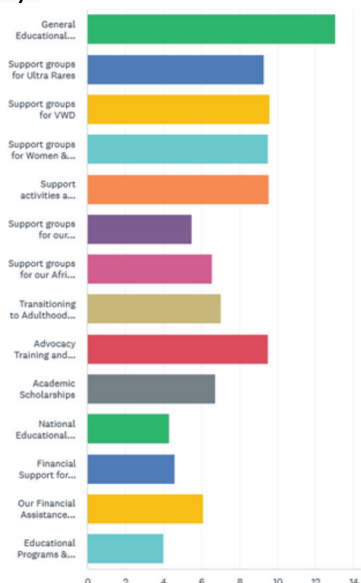


**Bleeding Disorders
Association of South
Carolina**

Serving All Bleeding Disorders
864 - 350 - 9941 | www.bda-sc.org

Did you know that each year, BDASC releases a member feedback survey to the community? The member feedback survey helps us to identify the needs of the community and evaluate any changes we should make or areas you would like us to provide needed support. This is your opportunity to share with us any feedback and what you need in the future. We are committed to ensuring that your voice is heard. This year we heard from 34 community members. The results of this survey were compiled and documented on our website. Scan the QR code or visit our "Member" section of the BDASC website. The BDASC Board of Directors uses this information to make strategic decisions for the next 3-5

Rank what educational and support services you value the most important to you and your family?



years. The board reviews the survey results and all the responses you have provided. This information helps to determine the future direction of the chapter. We truly appreciate your continued feedback.

Please continue to stay connected and engaged throughout 2024. We have many support programs and events to meet everyone's needs. Should you need more information at any time, please reach out to the Chapter or visit the Chapter's website at <http://www.bda-sc.org>. We welcome your volunteer services too! If you missed the survey and would like to provide feedback, we always welcome your thoughts, call, or email us at info@bda-sc.org.



Women Matter in Bleeding Disorders

Education and Support Group Activity

May 25, 2024, Summerville

Ladies, be sure to save the date for our second support group activity and educational engagement in Summerville later this Spring. Women with bleeding disorders face unique challenges that are often unrecognized or underappreciated. We look forward to

understanding some of the special challenges faced by our carrier women and women with bleeding disorders and identify options for emotional support within the community. These support group events are sponsored by an educational grant from Takeda. Registration will open soon.



Von Willebrand and Women Who Bleed Community News

by Samantha Javorka, BDASC Engagement Coordinator

Living with a severe type of von Willebrand Disease presents many challenges to those involved in the care of the patient. That has been my experience at least. I am a caregiver to a young (10 years old) daughter, Daphne, living with von Willebrand Disease Type 2B severe. My daughter was diagnosed at one years old (almost to the day) after months of unexplained bruising. At the time of diagnosis there wasn't a typical path of treatment and there weren't

many guidelines in place for treatment. Within two years of being diagnosed, we realized that Daphne's bleeding disorder was very severe. Spending many more days than I care to count in the ER and the doctor's office. It was decided that something needed to be done. Our physician suggested that we start prophylactic treatment around three years old. We had known about factor replacements by that point having been involved with our Chapter, but we had yet to meet anyone with vWD receiving factor therapy prophylactically.

At this time, the NBDF guidelines weren't created, and we were in a trial-and-error phase with her medication. There were no dosing instructions for prophylactic treatment – especially in children. We started with a low dose and worked our way up to the dosing she needed. It involved lots of blood work and honestly a lot of failure, but we eventually found the right treatment plan.

Along the way, we have been very open about our journey with prophylaxis. We have participated in one study about the quality of life of those living with von Willebrand Disease on prophylaxis. This study lasted approximately three years and involved a blood draw initially, and every year after. They drew a basic vWD panel, did genetic testing, and checked for inhibitors, then yearly they drew the vWD panel. We filled out a survey at



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Did You Know?

Study Suggests Patients Preferences Evolving Along with Treatments

In recent years, the arrival of novel hemophilia treatments that are effective and less burdensome to administer have opened 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.

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the beginning of the study, as well as every six months. The questions were all on quality of life – such as how many bleeds did she have over the last six month period, did she miss school/work, did she have hospital stays, etc.

This study was done to lead the vWD community to a better way of living. It's led to a better understanding of the needs of those living with severe von Willebrand Disease. It's led to new guidelines for care. It's led to the need for approval of long-term prophylactic treatment for all of those living with severe von Willebrand Disease. We are thrilled to see this start to happen, as Wilate (Octapharma) recently became the first FDA approved factor replacement product to be approved for prophylactic use for those living with severe von Willebrand Disease (regardless of type) for adults and children ages six and older.

“Long-term prophylaxis with VWF concentrate, as compared to on-demand treatment for bleeding, is recommended for patients with severe VWD,” according to Shveta Gupta, MD, a specialist in pediatric hematology and oncology with The Haley Center for Children's Cancer and Blood Disorders at Orlando Health Arnold Palmer Hospital for Children. “The approval of

Wilate® for VWD prophylaxis is a welcome new treatment option that can be life-saving for many patients. Increased use of VWF prophylaxis in VWD patients may lead to improved patient care and a reduced burden of disease.”

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I would encourage all those affected by von Willebrand Disease to seek out studies and upcoming research to be a part of. There is still so much work to be done, but if we aren't willing to share our experience as Lived Experience Experts (LEEs), how will anyone know what to study? Our Chapter is fortunate to continue to be involved in research via the National Research Blueprint. The blueprint takes our experiences and our concerns and helps guide research in the right direction. You can read more about this in the Research and Development section of the News Infusion. To read the press release from the National Bleeding Disorders Foundation, please visit their website:

FDA Grants Expanded Approval to Wilate for Prophylaxis in all VWD Types

<https://www.hemophilia.org/news/fda-grants-expanded-approval-to-wilater-for-prophylaxis-in-all-types-of-vwd>

Continued from page 21

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 two 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.

Any questions about the articles featured here should be directed to the publishing journal and/or the study authors. This content is for general information only. NBDF does not give medical advice or engage in the practice of medicine. NBDF under no circumstances recommends any particular treatment for specific individuals and in all cases recommends that you consult your physician or HTC before pursuing any course of treatment.

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● South Carolina Rare Disease Needs Assessment



Are you or someone you care about living with a rare disease? South Carolina's Rare Disease Advisory Council (RDAC) welcomes your feedback on experiences navigating the disease.

We want to hear from you



Your survey responses will be used to help develop and prioritize the SC RDAC's efforts and initiatives.



NEEDS ASSESSMENT

Scan the QR code to go to the Needs Assessment Survey



LEARN MORE

rarediseaseSC.org

● **About the SC RDAC**

The council is composed of fifteen members appointed by statewide leadership with a mission of advising the Governor, the General Assembly, and other stakeholders on research, diagnosis, treatment, and education related to rare diseases.



With Gratitude and Heartfelt Appreciation, We Thank Our Community Partners and Donors

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Winnie Ng

In the memory of Billy
Colin Powers, SR.

Hemophilia Federation of America

Announcement

In response to the ever-evolving landscape and the need to adapt to new challenges, the Hemophilia Federation of America Board of Directors and staff are undertaking an organizational restructure. As part of this process, there will be some necessary staff adjustments, including a reduction in force. While these decisions are never easy, they are essential for the long-term sustainability and effectiveness of our organization. To our former colleagues, we express our deepest thanks and wish them success in their future endeavors. The relationships and bonds formed during their time at HFA will always be cherished, and we are genuinely grateful for the shared journey we undertook to make a difference in our community. Simultaneously, we want to celebrate

the resilience and dedication of our current team members who continue to work tirelessly to advance our mission. In the face of change, they have displayed remarkable adaptability and an exceptional commitment to our cause. The strength of our team lies not only in our collective achievements but also in our ability to come together during challenging times. As we move forward with the restructured organization, we are confident that the passion and expertise of our current team will propel us to new heights and contribute meaningfully to our shared goal of serving our community. Thank you for standing by us as we navigate these changes and work toward a future filled with renewed opportunities and positive impact.

Dan Kelsey, CEO and Luke Runion, Board Chair

Advocacy Action

BDASC Hosts Its Second Annual Legislative Breakfast

January 10, 2024 in Columbia

By James Romano, BDASC Legislative Coordinator

On a crisp January morning, the Bleeding Disorders Association of South Carolina (BDASC) hosted its second annual legislative breakfast. In a large room on the first floor of the Blatt Office Building, advocates from all over South Carolina joined the chapter leadership and

members of the Board of Directors to welcome and speak with all who attended. BDASC is pleased to report that approximately 250 people, including 75 legislators, attended the breakfast. The Legislative Breakfast provides BDASC with an opportunity for the community to meet with legislators in a relaxed and informal atmosphere. Our wonderful advocates spoke with Members

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of the Legislature and their staff on the needed passage of H. 3618, the Copayment Accumulator legislation.

By continuing to host this breakfast, BDASC is building lasting relationships with Members of the Legislature that can be useful in the years to come. The community is becoming increasingly known by Representatives, Senators, and their Staff. BDASC Executive Director, Sue Martin is respected by multiple Representatives and Senators, and many came by to express their support and friendship to the community. During the breakfast, Sue and many advocate members of the bleeding disorders community were so pleased to have in depth conversations with many legislators, such as Representative Jason Elliott, Representative Tommy Pope, Representative Gilda Cobb Hunter, Representative Joe Bustos, Representative Dennis Moss, Senator Thomas Alexander, Senator Mike Fanning and Senator Tom Corbin to name a few. The legislation gained 10 cosponsors in the days since the breakfast. We are excited as to the gains the community has made.

The Chapter urges all our members to join us next January. We will have a brand-new legislature to introduce the bleeding disorders community and our list of important issues—including the importance of health insurance coverage and access to therapies. The 3rd BDASC Legislative Breakfast is set for Wednesday, January 15, 2025. The BDASC is excited for your participation.

Following the breakfast with additional advocacy successes on February 8th, Sue Martin with her husband Ric and our young members, the Shelton girls by her side, Whitney Galloway and her son Colt, and several other rare disease advocacy group leaderships testified in the LCI Subcommittee in support of H3618, our

legislation to ban accumulator adjustment programs in our state insurance plans. While the subcommittee did not vote on the bill, they have requested more time to review this important legislation and have asked for a later date to continue the conversations.



2024 State Legislative Days

On February 27-28, in Columbia, BDASC will be hosting its Annual Advocacy and State Legislative Days on the cusp of the National Bleeding Disorder Awareness Month of March. We will be requesting proclamations throughout the state recognizing this special awareness month and attending event ceremonies as available. BDASC, along with our national partners, will be hosting our advocacy training



session the evening before our state days. This important advocacy event fosters educational awareness with state legislators on the effects living with a bleeding disorder can have on individuals and families. Attendees have the opportunity to have important discussions and to ask for support on key areas of concern for access to affordable treatment care. Since its inception, our State Capitol Advocacy Days have provided for over 600 individual meetings with the SC House of Representatives and our State Senators from districts throughout the state. These meetings are of key importance in helping our elected officials understand our communities' unique needs, how access to medications and treatment are critical, and asking for support of our state programs that provide a safety net to those in need. Health care access is continuously challenging, including the barriers to high-cost medications needed by individuals with bleeding disorders. Only you can help remove these barriers with your advocacy participation! This advocacy event is for the

whole family with teen programming included. Thank you for raising your voice!

Advocacy training is provided in partnership with our national organizations and the South Carolina Hemophilia and Bleeding Disorders Advocacy Coalition and Ambassadors; The National Bleeding Disorders Foundation, Hemophilia Federation of America, our stakeholders, and other local and national advocacy partners. We are grateful to all who will be joining us for this important event this year and to our sponsors who make it possible for us to come together. Learn More about our [Current Legislative Priorities](#) by visiting our website.



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Prisma: United Healthcare – Out of Network

As of January 1, 2024, PRISMA is now out-of-network for patients with bleeding disorders who access coverage through United Healthcare Insurance. Unfortunately, this could mean potential access to the Prisma Hemophilia Treatment Centers in the Upstate and Midstate, and other Satellite offices. PRISMA and United Healthcare have been in protracted negotiations on a contract, the issues revolve around rates and cost increases. United Healthcare members who are in the middle of treatment with a Prisma Health provider or those who have a serious acute or chronic condition may be eligible for continuity of care, which allows them to continue receiving covered services for a specified period after a hospital or physician leaves the network. United Healthcare members should go to the nearest hospital in the event of an emergency. Their care will be covered at the in-network benefit label, regardless of whether the hospital participates in the UCC network. Negotiations will continue, if you have any questions, please contact your United Healthcare representative,

employer, and contact Sue Martin with any barriers to treatment care access. Please contact your HTC's for additional information and coverage care.

Please note we are in contact with our HTC's, National Organizations, and Coalition members to address our concerns. We have already reached out to the Director of Insurance in South Carolina and the CEO at United Health Care and consumer complaints. We unfortunately do not have any positive outcome with what we can do. If you are currently facing problems with United Health Care removing Prisma from In-Network care, please be sure to determine which facilities are In-Network. This includes primary care as well as your HTC. It is advised that you bring your factor products with you when receiving care related to your bleeding disorder. If you have additional questions, please reach out to your care team or to the Chapter office to keep us advised.



National News

Travel Grants for National Conventions

*HFA Symposium
2024-Indianapolis,
IN April 11-13*

This year's HFA Symposium will be held in Indianapolis, Indiana on April 11-13. HFA is offering Hotel Scholarships for those interested in attending the 2024 Symposium. There is one scholarship opportunity available for those in our South



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NBDF Names Phil Gattone, M.Ed., Next Chief Executive Officer

NEW YORK, NY — February 1, 2024 — The National Bleeding Disorders Foundation (NBDF) Board of Directors announced today that Phil Gattone, M.Ed., is the organization's next president and chief executive officer. He will take the helm Feb. 12, 2024, to help advance NBDF's focus of innovative, inclusive research, education, advocacy. Gattone was president and CEO of the Epilepsy Foundation of America (EFA) from 2012-2019.

"Phil is an organizational leader and communicator who understanding the dynamic of a national organization and a chapter network, and he recognizes the importance of a strong collaboration between the two," said Ryan Griffith, NBDF Board of Directors chair. "He's skilled at long-term strategy but also knows the importance of adapting and shifting throughout challenging times."

Under Gattone's leadership and vision, the EFA experienced record growth in community engagement, strategic partnerships, marketing, programming, and fundraising. In less than 10 years during Gattone's time as CEO, the EFA's annual revenues expanded by more than \$15 million. Additionally, Gattone successfully built alliances with multiple community partners,

elevating the EFA's position within the national and global epilepsy community. He introduced new cost-effective solutions that elevated mission impact and united the foundation. For his work, the EFA established the Phil Gattone Award for Exemplary Service to recognize his lifetime of significant achievements.

"This is an era of unprecedented opportunity, and I look forward to continuing to grow NBDF's impact and capacity to serve our community," Gattone said. "Together, we will break down barriers to better health and equity, and create resilient, inclusive communities where everyone can thrive. And I am honored to continue the tremendous work of Dr. Valentino and eager to serve alongside the NBDF team of passionate volunteers, staff, and board leaders to achieve our shared vision and mission."

"As a team, we conducted listening sessions, and committee member and community surveys to find the characteristics needed for our next leader," Griffith said. "The search team vetted more than 100 candidates from inside and outside the community. We are thrilled and confident in Phil as the next NBDF president and CEO."

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Continued from page 28

Carolina Bleeding Disorders Community. This "General Hotel Scholarship" is for all members of the bleeding disorders community that will be attending as a "General Attendee." This scholarship is not available to exhibitors, medical personnel, industry professionals, and non-profit staff. This scholarship includes 1 hotel room (up to 4 people per room) for up to 4 nights. First time attendees will be given priority for this scholarship, but previous attendees will be considered if funds remain. Please note that this scholarship does not include registration fees, parking or travel/flight costs.

To learn more, visit:

<https://hfasymposium.configio.com/content/hotel-scholarships>



NBDF's Bleeding Disorders Conference 2024 - Atlanta, GA on September 12-14

Application Deadline: February 23, 2024

This year's Bleeding Disorders Conference will take place in Atlanta, GA on September 12-14. NBDF is offering a travel grant for individuals/families that wish to attend. This grant is available to families that have not received ANY travel grants from NBDF in the last three years. If you have received a grant from NBDF in the last three years, your application will not be considered. If you receive this travel grant, you

are obligated to attend sessions throughout the conference hours. This grant covers airfare/milage, the children's program (children ages 12 and under), registration fees for up to four people (within your household), and hotel accommodations for a maximum of four nights. To learn more, visit:

<https://na.eventscloud.com/website/64934/connections-for-learning/>

NBDF's National Research Blueprint Summit

NBDF hosted the National Research Blueprint Summit January 25-27 in Arlington, VA to announce the final draft of the Blueprint. Based on the product of the State of the Science, the NRB is defining a comprehensive, collaborative, and community-driven national research strategy that prioritizes patient and caregivers – Lived Experience Experts (LEE) throughout the full spectrum of research. This is called community based

participatory research. Incorporating everyone into the process of research.

At the Summit, each working group: Research & Development, Workforce, Infrastructure, Policy, Community Engagement, Lived Experience Experts, and Health Equity, Diversity, and Inclusion highlighted the priorities on how to coordinate effective collaboration to improve research in the bleeding disorder community. The Steering Committee combined the recommendations into one large structured plan;

incorporating HEDI & LEE principles throughout the entire structure. Historically, LEEs have been participants in clinical trials. Through this initiative, LEEs will be part of the entire process from identifying research priorities through

developing clinical trial design, participant recruitment through a LEE Ambassador program, and sharing the findings in non-scientific language accessible to all. Our executive



director Sue Martin has been involved in the NRB Blue Sky Research Project from its inception, hosting listening session during COVID so our underserved community members could be heard, attended with our members Christine Evens and Jamella Malcome the NRB listening summits for the last several years, and personally worked as an LEE with the research working teams for more than six months as the blueprint was developed for hemophilia and Gene Therapy. Sue was able to also represent BDASC which

she and BDASC are now listed in the published manuscript.

So, what does this mean? NBDF will continue to work with key stakeholders to move forward into the next phases of development. Later this year, NBDF will be announcing the opportunity for people living with bleeding disorders to participate through a LEE Research Ambassador

program. For more information on the National Research Blueprint, please visit the NBDF website or review the below resources: <https://www.hemophilia.org/research/national-research-blueprint/what-is-the->



EXPERT REVIEW	
OF HEMATOLOGY	
SPECIAL ISSUE	The National Hemophilia Foundation's State of the Science Research Summit: Building the foundation for a community-generated national blueprint for future research in inherited bleeding disorders
FOREWORD	The National Hemophilia Foundation's State of the Science Research Summit: the foundation of a national research blueprint for inherited bleeding disorders
EDITORIAL	Lived experience experts: a name created by us for us
	Soliciting international perspectives on an American national research agenda for inherited bleeding disorders
ORIGINAL RESEARCH	Building the foundation for a community-generated national research blueprint for inherited bleeding disorders: research priorities to transform the care of people with hemophilia
	Building the foundation for a community-generated national research blueprint for inherited bleeding disorders: research priorities for mucocutaneous bleeding disorders
	Building the foundation for a community-generated national research blueprint for inherited bleeding disorders: research priorities for ultra-rare inherited bleeding disorders
	Building the foundation for a community-generated national research blueprint for inherited bleeding disorders: research to advance the health of people with inherited bleeding disorders with the potential to menstruate
	Building the foundation for a community-generated national research blueprint for inherited bleeding disorders: research priorities in health services; diversity, equity, and inclusion; and implementation science
	Building the foundation for a community-generated national research blueprint for inherited bleeding disorders: facilitating research through infrastructure, workforce, resources and funding
SPECIAL REPORT	The National Hemophilia Foundation State of the Science Research Summit initiative: executive summary
 Taylor & Francis Taylor & Francis Group	 NATIONAL RESEARCH BLUEPRINT



Research & Development

Patient Receives First Hemophilia A Gene Therapy Outside a Clinical Trial

The first hemophilia A gene therapy infusion to be delivered outside of a clinical trial setting was recently given to a patient in California.

The patient, an adult with severe hemophilia A, received a single infusion of **Roctavian™** (BioMarin) at the Center for Comprehensive Care & Diagnosis of Inherited Blood Disorders (CIBD) in Orange, CA. Roctavian is currently the only hemophilia A gene therapy approved by the U.S. Food and Drug Administration (FDA). It **received**

approval last summer for the treatment of adults with severe hemophilia A without antibodies to adeno-associated virus serotype 5 (AAV5) detected by an FDA-approved diagnostic test. "This is more than a medical breakthrough; it's a game-changer for me and others living with severe hemophilia A, particularly when considering I was able to drive myself to and from the clinic and did not have to stay overnight in a hospital," said the therapy recipient.

"Receiving this treatment is liberating – I am filled with hope and gratitude knowing treatments finally exist that will allow individuals like me to truly break free from the constraints of this disease and embrace life to the fullest."

The care team at CIBD will continue to monitor the patient's response to the therapy.

To read the full story, please visit

<https://www.businesswire.com/news/home/20240111170648/en/Center-for-Inherited-Blood-Disorders-Administers-Countrys-First-Gene-Therapy-Infusion-to-Treat-Hemophilia-A>



Source: Businesswire, January 11, 2024 Reprinted with permission from the National Bleeding Disorders Foundation

Resources & Contact Information

Medical Facilities

The Hemophilia Treatment Center of South Carolina

Children's Cancer & Blood Disorders Clinic at Prisma Health Children's Hospital-Midlands

14 Richland Medical Park Rd., Suite 410
Columbia, SC 29203
Phone: 803-434-3533

For all new and previously scheduled appointments, factor refills, school needs, general questions or general concerns: Contact Robin Jones, MSN, MHA, RN, CPN, CPHON Children's Cancer and Blood Disorders Nurse Navigator/ SC Hemophilia Treatment Center Nurse Coordinator at 803-434-1028 or email @ schemophilia@prismahealth.org. You may leave a message and your call will be returned as soon as possible. Robin may be away from her desk or with a patient in the clinic.

Prisma Health's Upstate Children's Hospital

MAIN CAMPUS:

BI-LO Charities Children's Cancer Center Serving Hematology/Oncology Patients

900 W. Faris Road
Greenville, SC 29605
Phone: 864-455-8898

Fax: 864-455-5164

Hours: Mon, Wed., Thurs. 8:00-4:30; Tues & Fri. 8:00-12:00

SATELLITE OFFICE:

Spartanburg- Children's Hospital Outpatient Specialties

1700 Skylyn Drive, Suite 200
Spartanburg, SC 29307
Phone: 864-716-6490
Fax: 864-596-5164

Hours: Wednesday - alternating mornings and afternoons

SATELLITE OFFICE:

Anderson - Pediatric Specialties of the Upstate

2000 E. Greenville Street, Suite 3500
Anderson, SC 29621
Phone: 864-716-6490
Fax: 864-716-6492

Medical University of South Carolina Shawn Jenkins Children's Hospital

10 McClennan Banks Dr.
Charleston, South Carolina 29425
Shayla Bergmann, MD, Assistant Professor
Director, Pediatric Hemophilia Clinic
Phone: 843-876-1980
Mobile: 843-812-5682
Fax: 843-792-7562

Local and National Orgs

Bleeding Disorders of South Carolina

Green Gate Office Park
25 Woods Lake Road, Ste 300
Greenville, SC 29607
Phone: 864.236.8663
Fax: 864.236.8663
Email: info@bda-sc.org
Web site: www.bda-sc.org

National Bleeding Disorders Foundation 7 Penn Plaza, Suite 1204

New York, NY 10001
Phone: 212-328-3700
Fax: 212-328-3777
Phone: 800- 42-HANDI (4-2634)
Fax: 212- 328-3799
Email: handi@hemophilia.org
Website: http://www.hemophilia.org/

Hemophilia Federation of America

999 North Capitol Street, NE, Suite 201
Washington, DC 20002
Phone: 800-230-9797
Email: info@hemophiliafed.org
Website: www.hemophiliafed.org

World Federation of Hemophilia

1425, boul. René-Lévesque O.
Bureau 1010
Montréal, Québec

H3G 1T7 Canada

Phone: +1 (514) 875-7944
Fax: +1 (514) 875-8916
Email: wfh@wfh.org
Website: www.wfh.org

Resource Information

SC Dept. of Health & Environmental Control (DHEC)

Children with Special Health Care Needs Hemophilia Program

2100 Bull Street
Columbia, SC 29201
Phone: 803-898-0784
Website: https://www.scdhec.gov/health/child-teen-health/services-children-special-health-care-needs/hemophilia-assistance-plan

American Pain Foundation (APF)

Phone: 1-888-615-PAIN (7246)
Hemophilia Chronic Pain Support Group
Website:
http://painaid.painfoundation.org

American Society of Pediatric Hematology/Oncology

Phone: 847-275-4716
Website: www.aspho.org

The Coalition for Hemophilia B, Inc.

Phone: 212-520-8272
E-Mail: hemob@ix.netcom.com
Website: www.hemob.org

Bleeding Disorders Legal Hotline

Phone: 800-520-6154

Centers for Disease Control & Prevention

Phone: 1-800-311-3435
Website: www.cdc.gov

Committee of Ten Thousand (COTT)

Phone: 800-488-2688
Website: www.cott1.org

LA Kelley Communications, Inc.

Phone: 978-352-7657
Website: www.kelleycom.com

Patient Access Network Foundation

805 15th Street, NW, Suite 500
Washington, DC 20005
Phone: 202-347-9272
Website: https://panfoundation.org/index.php/en/

Helps underinsured people with life-threatening, chronic and rare diseases get the medications and treatments they need by assisting with their out-of-pocket costs and advocating for improved access and affordability.

Patient Notification System

The Patient Notification System is a free, confidential, 24-hour communication system providing information on plasma-derived and recombinant analog therapy withdrawals and recalls.

Phone: 888-UPDATE U (873-2838)
Website:
www.patientnotificationsystem.org

Accessia Health

Provides financial assistance to people who are diagnosed with chronic medical conditions.
P.O. Box 5930
Midlothian, VA 23112
https://accessiahealth.org/
1-800-366-7741

Medic Alert Foundation

2323 Colorado Avenue
Turlock, CA 95382
Phone: 800-432-5378
Website: www.medicalert.org

South Carolina Healthcare Market Place

Call 800-318-2596
Website: www.HealthCare.gov

The South Carolina Rare Disease Advisory Council

Website: http://rarediseasesc.org/

Upcoming BDASC Community Events



Mark Your Calendar!

Looking Ahead: Major Community Engagement Opportunities — Save the Dates!

February 27-28, 2024: BDASC State Advocacy Days (Columbia)

March 6-8, 2024: NHBDF Washington Days (Washington, D.C.)

March: Bleeding Disorders Awareness Month

March 1, 2024: 1st Annual VWD Awareness Day

March 15, 2024: 1st Annual Ultra Rare Bleeding/Platelet Disorders Awareness Day

March 22-24, 2024: Adult Retreat (Greenville)

April 11-13, 2024: HFA Symposium (Indianapolis)

April 17, 2024: World Hemophilia Day (Columbia)

May 11, 2024: STEP For Bleeding Disorders Walk/Run (Columbia)

June 21-23, 2024: Annual Meeting & HELLO Conference (Greenville)

July 18 – 21, 2024: BDASC Teen Retreat with (North Carolina)

August 12-15, 2024: NBDF Bleeding Disorders Conference (Atlanta, GA)

October 18-20, 2024: Fall Gathering (TBD)

September 27, 2024: Par for the Clot (Greenville)

December 14, 2024: Winterfest State-Wide Meeting (Columbia)

Additional ways to support BDASC



Go to www.bda-sc.org and click “Make a Donation” to learn more about how you can support BDASC!



Donate through United Way! Go to <http://www.unitedway.org/>

Purchase an Official BDASC Jacket and help us raise funds for financial assistance. Order online from the BDASC Appeal Store





Bleeding Disorders Association
of South Carolina
Green Gate Office Park
25 Woods Lake Road, Ste 300
Greenville, SC 29607
www.bda-sc.org



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STEP

for bleeding disorders

5K WALK/RUN FUNDRAISER

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T TRANSFORMING TOMORROWS
S SHARING STORIES