The News Infusion

The Official Newsletter of Bleeding Disorders Association of South Carolina
VOLUME 14, ISSUE 2 SPRING 2024

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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.

Spring 2024 Calendar of Events

Looking Ahead: Save the Dates!

Community Engagements

May 25—Women Matter in Bleeding Disorders Dinner and Group Activity, Summerville

May 31—Let Us Talk Mental Health Community Engagement Dinner, Greenville

May 31–June 1—South Carolina School Nurse's Conference, Columbia

June 14—The Voices of 46 Outreach, Abbeville

June 21-22—HELLO Conference and Annual Meeting, Greenville

June 23-28—Camp Courage (Greenville HTC) – BDASC Ice Cream Social June 25

July 8 – 13—Camp Burnt Gin BDASC Ice Cream Social July 9

July 18-2—Carolina Crew Teen Retreat, Parkton, NC

July 26—Community Education Dinner, Columbia

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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!

2024 STEP for Bleeding Disorders 5K Run/Walk Saluda Shoals Park, Columbia, SC

On Saturday, May 11, our 11th annual STEP for Bleeding Disorders Walk/5K Run fundraiser was blessed with perfect weather for a day of community spirit and giving. Our volunteers and sponsors arrived bright and early to get everything set up and ready for our participants. Before long, the walk site was transformed into a perfect venue to gather and we knew it would be a fantastic day. In the end we had hundreds of people donate, walk, run, and join in the fun! Participants old and young had fun with our face painting and artistry tattoos provided by Emerald Artistry, a commemorative STEP photo booth, and music throughout the event provided by our favorite DJ, Andre, with Big Time Entertainment. Olly the Otter and Benny the Blood Drop joined in on the dancing fun to get everyone warmed up and excited to take to the course. Before we headed out, we enjoyed a parade lead by Olly and Benny for the teams wishing to participate in the costume contest or to just walk in the parade. Our parade volunteers watched the parade as they decided which costumes would win the awards for the Most Creative Individual and Most Creative Team. This year, Join the Clot Side took the award for Most Creative Team with Martha Breitwieser, with Team Hunters receiving the award for the Most Creative Individual Costume.

Once the parade completed, runners and walkers of all ages headed to the starting line. Participants were counted off by Andre and the walk began. Participants rode bikes, walked their dogs, pushed strollers packed with children excited to participate, and walkers set off to enjoy the 5K or the short—less than a mile—course. At the halfway mark, walkers were greeted by our volunteers, Edna Rabb and Susie Malloy, to provide quick fuel beverages and snacks. Avid runners also took part in the excitement and soon the first runner, Michael Valerio, returned to the starting line. He was quickly followed by Jose Frias and Michael Kim. Our top three runners were presented with medals to commemorate their achievement. Way to go!

As participants began to complete their runs/walks, pizza was delivered for lunch and the food tents were stocked with everything needed

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for the hungry appetites before the awards ceremony would begin. We were grateful to have Marble Slab with us again this year providing ice cream and cookies for dessert! We would like to express our gratitude to *Ryan Griffith*, President of the NBDF board of directors and owner of Marble Slab for his support.

We would like to express our heartfelt gratitude for those involved in this year's STEP for Bleeding Disorders. We are truly grateful for all the volunteers, participants, fundraisers, donors, and sponsors. With your help, we were able to raise **$51,471** – which was **68% of our goal**. These funds you have helped us raise will aid in our mission to provide support, research, education, and advocacy throughout the South Carolina bleeding disorders community.

We are so grateful for everyone's continued support and commitment to raising funds to support our community. Congratulations to our award winners! Please view all our pictures on our Facebook page and save the date to return, **May 10, 2025,** for our 12th Annual STEP for Bleeding Disorders Walk!

Most Creative and Original Costume: Martha Breitwieser

Most Creative and Original Team Costumes: Join the Clot Side

Top Fundraising Individual: Joey Krakowiak

Runner-Up Individual Top Fundraiser: Misty Sturkie

Top Fundraising Team: Team Fleming

Runner-Up Top Fundraising Team: Team Logan

Largest Run/Walk Team: Free Bleeders with 33

Runner-Up Top Run/Walk Team: Team Logan and Team Limitless Tied with 26

Oldest Participant: Bob Young (86 years)

Youngest Participant: Henry Pittman (7 weeks)

Race Finishers:

1st Place: Michael Valerio

2nd Place: Jose Frias

3rd Place: Michael Kim

We are grateful to all our sponsors of the 11th Annual STEP for Bleeding Disorders.

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2024 STEP for Bleeding Disorders

EVENT PHOTOS

To View the Event Photos from the 2024 STEP for Bleeding Disorders Walk scan the QR code or visit https://tinyurl.com/STEP24Photos

STEP
for bleeding disorders
5K WALK/RUN FUNDRAISER

Executive Director's Welcome

By Sue Martin

An Era of Transformational Time for the Bleeding Disorders Community

It is hard to believe that many of you are ending the 2023-2024 school season in just a few weeks; students of all ages are graduating, and we have just awarded fours college academic scholarship which will be awarded at our Annual Meeting, June 21. Speaking of our [Annual Meeting and Hello Conference](), I hope your schedules allow you to attend this once-a-year bleeding disorders educational conference and networking opportunity, complete with updates and information on treatment therapies and support services. We are sold out for travel hotel rooms and have a waiting list for those who may cancel, however day attendance to both Friday night and Saturday are still open. Learn more on page 14 and join the community. We work especially hard to bring in the top national speakers who will be coming from all regions of the country. We believe it is important whether you are new to bleeding disorders, or are seasoned members, that keeping up with what is happening in this community is important to everyone. Many have heard me say lately that we are in transformational times within the bleeding disorders community, and I cannot express this enough. We will need everyone to bond together for our futures as together we advance research, *(you will hear about this at the meeting)*, help our women who bleed advance their access to treatment care, *(we have made progress but are a long way away for where we need to be)*, advance treatment and testing for better diagnosis of vWD and Ultra Rares/Platelet bleeding disorders, and save our healthcare access. YOU are the only one who can make a difference and help us advance these priorities with your involvement, stories, and voices. Treatment therapies are no longer just factor replacements, and gene therapy is here, but access is often complicated for those wishing to advance their treatment. Medicaid expansion for South Carolina may be possible in the coming years, but what will that mean for those on Medicaid now? Will you still have full access to all the current products and services you have now for the most part, or will we have more restrictions? And what about the current healthcare system we have for providing insurance and our state marketplace plans? These are just not sustainable for our community with the extremely high out-of-pocket cost of copays, deductibles, co-insurances, and premiums. We need your help and your voice to advance changes for tomorrow. We have a history of being fierce advocates and we need to continue. It is an exciting time for those within our community, but we are not there yet and still have much to do.

I would also like to note the outstanding work of our STEP for Bleeding Disorders Walk Fundraiser. We had a great turnout, raised a lot of awareness for bleeding disorders, opened our doors to many who we now feel are part of our family, and raised over $50,000 to support the organization. To those involved, thank you! Your efforts paid off. Thank you to our volunteers, our teams, individuals, and to my engagement coordinator, Samantha Javorka, for her dedication to the event and our teams. I appreciated everyone's support including the board of directors who helped volunteer. In one hour, over 30 volunteers helped transform a quiet park into a venue perfect for the spirit of giving, and a lot of fun. If you missed the opportunity to donate, the STEP Walk for

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Volunteers Are Our Lifeline!

Thank you to all who volunteer to support BDASC! We are so grateful for your continued support. Without you, we would not be able to provide quality support, education, and opportunities for our bleeding disorders community within South Carolina. We are especially appreciative at this time to our walk volunteers! Our walk is our large community fundraiser that helps support the bleeding disorders community throughout the year. The success of the event is dependent upon our walk volunteers. Thank you for your continued support! With our Par for the Clot Golf Tournament planning to begin soon, please don't hesitate to reach out to volunteer!

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 at events, helping with the teens 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.

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Bleeding Disorders is still open for donations. Read about the STEP on page 3 and know we appreciated you all, including all our wonderful sponsors.I have been saying for some time now, with the decline nationally in sponsorships and grants from our industry partners which we do not see changing, we MUST as a community do more to raise outside funds. This is critical for us for the future and I hope you will stay involved. Make a commitment to give what you can when we have fundraisers or giving campaigns and remember what our mission is and how you have benefitted. We want to be here for future generations and to continue to be here to fight the good fight for access to treatment care, today and in the future. I thank you on behalf of our membership, board of directors, and my dedicated staff. They work so hard for South Carolina and I am grateful to work among them as we work to advance BDASC each year. Last, let me say thank you to everyone for making an effort to show up at events you have registered for, or to provide enough advance notice to help us cancel in time to not waste our precious funds. I know it is not always easy to keep up with all we have going on today at school, work, church, and within our family and friends and we so appreciate you being with us when time allows. Thank you for being our wonderful extended family and members of BDASC. I wish you a wonderful, safe, and fun summer. I hope to see you soon!

Warm regards,
Sue

Community Engagements

Celebrating Black History Month

What is Healthy Aging with a Bleeding Disorder?

February 23, 2024

What does it really mean to "age gracefully" or, rather, age healthfully? During our February community engagement event designed to embrace our community members during Black History Month, we enjoyed a wonderful dinner at Logan's of Greenville and learned 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. Everyone learned something, and Morgan with Takeda did a great job helping the participants learn how to age healthfully. After the interactive dinner, we enjoyed a mindfulness art activity with Burlap and Ribbons and our friend Toshia Leisten and painted a special wood project to take home. We are grateful to Takeda for this support group activity, number one of a four part series.

Takeda

2024 Adult Connection Symposium

March 22-24, 2024

We are so grateful to have provided an adult weekend symposium to our adult membership 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 brought all adults into the event so couples could take a weekend away from the kids, single men and women can enjoy time with community members for fellowship and support, and everyone

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can enjoy being connected while learning in an atmosphere of beauty and opportunity, such as downtown Greenville. The weekend provided a variety of educational sessions on gene therapy, health, and wellness, vWD and the Ultra-Rare bleeding disorders, sessions for affected men and women, and sessions with updates on our advocacy and national research.

Friday night began with social connections and our keynote presentation with Jim Stroker, followed with a fun night at Group Therapy of Greenville. Attendees had a blast flinging axes, playing Duck Pin Bowling and Wacky Miniature Golf. It was a perfect way for adults to connect and get to know one another before two days

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of educational breakouts. The hotel food was delicious and the session led by Sue Geraghty, Anna Bell, and life coach Jim Stroker during the weekend presented the retreat with the perfect touch. CSL Behring and BioMarin led our morning sessions on gene therapy, bringing the most current treatment therapies to attendees with interest in learning.

Saturday night provided another opportunity for adult connections with an interactive night of golfing at Top Golf of Greenville, including a dinner buffet. Saturday night's event was sponsored by CSL Behring.

Sunday morning provided chapter updates, a look at the forecast in funding, and advocacy updates, provided by the executive director, Sue Martin. The weekend ended with a fun wrap-up advocacy timeline activity, led by Sue Geraghty. We will be heading back to downtown Greenville for a repeat of 2024 next year. Save the date for next year's Adult Connection Symposium on April 4-6, 2025. We look forward to seeing you there!

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World Hemophilia Day – April 17

On April 20 in Columbia, the community gathered to celebrate World Hemophilia Day. Our community shares a connection that spans for generations. The 2024 One Family Program, sponsored by Sanofi, was a celebration of the bonds that come from living with hemophilia: young and old, near and far, where we are now, and where we want to be. We enjoyed a wonderful dinner buffet and presentation along with making a personal time capsule to take home, enjoyed a selfie station and DIY photo frames, and made wish ribbons for the global community. The afternoon event was a wonderful way to celebrate our global community. With appreciation we thank Sanofi for the opportunity to share our voices in celebration of this year's World Hemophilia Day.

Brave Blood Family Camp, Upstate HTC

April 27 Pleasant Ridge Camp & Retreat, Marietta, SC

BDASC traveled to camp again this year to meet and greet families and individuals coming to enjoy a day at camp with the staff at Prisma Health Upstate. The chapter provided coffee, juice, breakfast snacks, resources, and BDASC camp bags with beach towels for the pool. Campers began the day with learning how to draw cartoon caricatures, followed by a group lunch, fishing, gem mining, slingshot fun, golf cart rides through the camp, archery, and the famous climbing tower. The camp day ended with a closing ceremony complete with s'mores.

We love attending camp and are grateful to all our summer camp sponsors. If you are attending summer camp this year, let us know so you can apply for summer camp travel and supplies reimbursement. We want to assure that our members have no barriers to attending summer camps for bleeding disorders.

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Women Matter in Bleeding Disorders

Education and Support Group Activity
May 25, 2024, Summerville

Women with bleeding disorders face unique challenges that are often unrecognized or under-appreciated. During the Memorial weekend, BDASC traveled to Summerville to unite community women and girls who bleed for a brunch and learn at Oscar's, followed by a group activity of painting on wood planks at Painting with a Twist of Summerville. The women shared discussions on understanding some of the special challenges faced by our carrier women and women with bleeding disorders, and identifying options for emotional support within the community. These support group events are appreciated by community members and allow attendees to share experiences and provide support to one another. The event was sponsored by an educational grant from Takeda and is the second event in our four-part series.

Takeda

Upcoming Engagement Opportunities

51st Annual Meeting and HELLO Conference

June 21–June 22 Greenville, SC

We have come a long way in bleeding disorders care and treatment throughout the past 50 years. We have traveled many roads together as a united community. Our past shares times of heartaches and huge successes, paving the way for those who are diagnosed with a bleeding disorder today, not so frightening. We still have a lot to accomplish and discover together as a community. Advocating for the bleeding disorders community remains a high priority today as we face many barriers and threats with access to treatment care. We are living in a transformational era and we are excited, and concerned, all at the same time. On June 21, we will join the South Carolina community with our national partners and come together for the 51st annual meeting of Bleeding Disorders Association of South Carolina.

BDASC's Annual Meeting has taken place for 51 years and provides the South Carolina bleeding disorders community the opportunity to come together and network, learn, and enjoy the empowerment of education and support. The presentation of the Chapter's Annual Awards are provided on Friday night, including our awarding of college scholarships, introducing new board members and celebrating those who have served. Dinner and our keynote speaker presentation are always a highlight for attendees as we search hard to provide the very best and most current information in bleeding disorders. The HELLO Conference allows for attendees to enjoy a learning environment with educational presentations and breakout sessions. Information on current and future treatment therapies and bleeding disorders services are made available during our exhibit hall experience. All meals, sessions and childcare are included with hotel accommodation available for our traveling guests. The event is free of charge for BDASC members. Our Saturday educational sessions are still available to attend with registration. We are excited to have the President and CEO, Phillip Gattone, of the National

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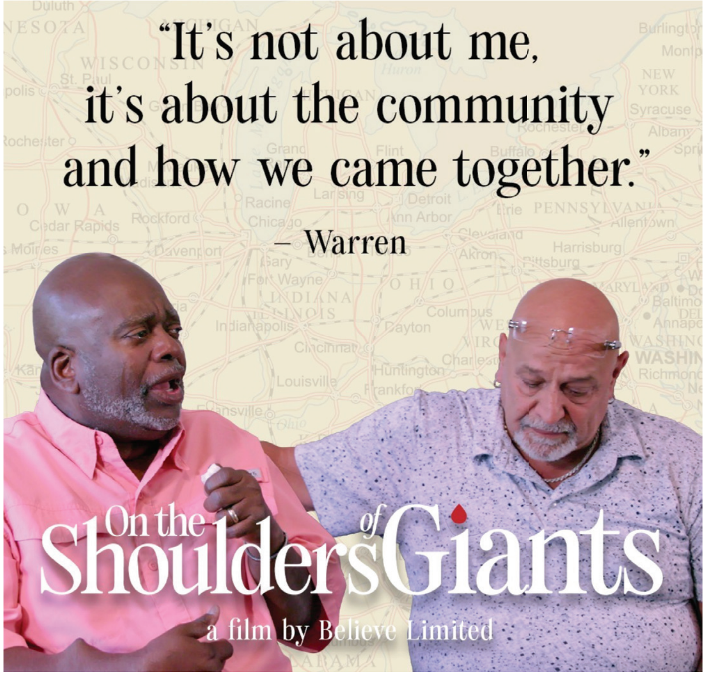
Bleeding Disorders Foundation (NBDF), the director of advocacy and research of NBDF, and many other national speakers who will be with us this year. Visit our HELLO website page and see what the annual event is all about and be sure to join us! Registration is still available for this event. *(Travel rooms are sold out however.)*



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Movie Screening
We are excited to provide a screening of "On The Shoulders of Giants" on Friday night after the award ceremony. For the first time in history, a generation of people with hemophilia are living past 50. This heartwarming road trip around the country reunites the survivors from past generations who share their journey. Join us for this state viewing of this incredible look back in time, and the strength of our community. Let's all honor those who paved the way for our future today!

Childcare Provided by Corporate Kids Events
We have contracted Corporate Kids Events again this year to care for children ages 1-11 years. CKE provides a wealth of experience and the total care you need to enjoy the annual HELLO Conference as your children enjoy activities designed for them. Kids will enjoy a camp day being "Super Spectacular Heroes."

Teen Programming Provided by GutMonkey
GutMonkey is also back again this year to provide their Leading-Edge Program. Teens will tackle topics like building communities, teamwork, getting clued in on current topics in bleeding disorders, and shared decision making. Gut Monkey will have our teens laughing and making new connections in the community. They will explore these ideas using community building activities that will have teens on their feet and interacting with each other in fun and memorable ways.

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2024 Teen Retreat
"The Carolina Crew"
July 18–July 21, 2024, Rockfish Camp & Retreat Center, Raeford, NC

We believe that teens have a lot to offer to the bleeding disorders community and are a wealth of knowledge for the future. We work throughout the year to provide opportunities for teens to gather and build lasting bonds while growing their knowledge of living with a bleeding disorder personally or within their families. Most of our large events will have a teen program tailored just for their needs. Together with the Bleeding Disorders Foundation of North Carolina, BDASC annually provides a joint teen retreat for teens. This event is open to anyone ages 13-18 who has either a bleeding disorder, or a sister, brother, or parent with a bleeding disorder. An educational component is included each year on topics related to independence, job and career preparation, advocacy training, and bleeding disorders education. Fun activities are also planned to engage teens and their friends from across both states. We invite you to come

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Registration Now Open!

Come spend a weekend with friends, new & old! We're planning a terrific weekend full of fun activities and sessions that will challenge you, inform you, and inspire you. Share your interests, passion, and ideas about how you can make a difference for yourself and in our community.

The Bleeding Disorders Foundation of North Carolina and the Bleeding Disorders Association of South Carolina are offering this program to teen members free of charge. This includes lodging, busing, all meals and activities.

CAROLINA CREW

JULY 18TH - JULY 21ST

BDASC
Bleeding Disorders Association of South Carolina

BLEEDING DISORDERS FOUNDATION OF NORTH CAROLINA

Let’s Talk Mental Health

May is National Mental Health Awareness month and it is not surprising that many within the bleeding disorders community may have some stress with their mental health that comes from living with a bleeding disorder and the complexity of our crazy lives in general.

On May 31 during the National Mental Health Month of May, community members will come together for a dinner in Columbia to experience the “Let’s Talk” program, produced by Believe Limited, in partnership with Mental Health Matters Too. The program is an immersive journey through the lives of five members of the U.S. bleeding disorders community, as they open their hearts and lives to show how we can gain strength through struggle, and that perhaps we are not so different after all. The film is intended to spark conversation, increase awareness, and decrease stigma. Following the screening, there will be talk-back facilitated by Patrick James Lynch and Debbie de la Riva.

The time provided to discuss mental health within the bleeding disorders community is so important and we are grateful to Sanofi for the opportunity to gather for these important conversations. Registration closes on May 29, 2024.

For information, services and resources on Mental Health in South Carolina, visit the National Alliance on Mental Health South Carolina.

https://namisc.org/

Par for the Clot Charity Golf Fundraiser

September 27, The Preserve at Verdae, Greenville

Save the date to join us and help raise funds and bleeding disorders awareness to support the South Carolina Bleeding Disorders Community!

Learn more about the Par for the Clot on our Golf Website page!

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spend a weekend with friends — new and old! Share your interests, passion, and ideas about how you can make a difference for yourself and in our community. Our program will include engaging activities including learning self-advocacy, sharing your story, and how to adapt to many other life-skill challenges as you learn to transition into adulthood!

We have a new location this year!

Unfortunately, we were unable to secure Camp Canaan for this summer, but that provided an opportunity to check out a new site! This year we will head to Parkton, North Carolina, to Rockfish Camp and Retreat Center. This camp will provide our campers with similar activities and plenty of fun! Campers will still be able to meet at the HTC in Columbia and be driven to camp on a charter bus provided by the Chapter. Registration is open and closes on June 14 with information on our website page for Teen Programs.

We are grateful to our Teen Camp Sponsors who make this event possible!

"The Voices of 46"

Community Resources and Engagement Program

During our 2022 Advocacy Summit in Charleston, we discussed barriers to support services, engagement opportunities, and health equity within our more rural areas and counties in South Carolina. To take a personal outreach approach to our communities in all 46 counties in South Carolina where we currently have members, we would like to map out access barriers to quality treatment and affordable healthcare, along with other needs, while providing Chapter resources for health equity. We will strive to discover healthcare disparities and lack of education in bleeding disorders care according to zip codes within the counties in South Carolina. We will map our findings with

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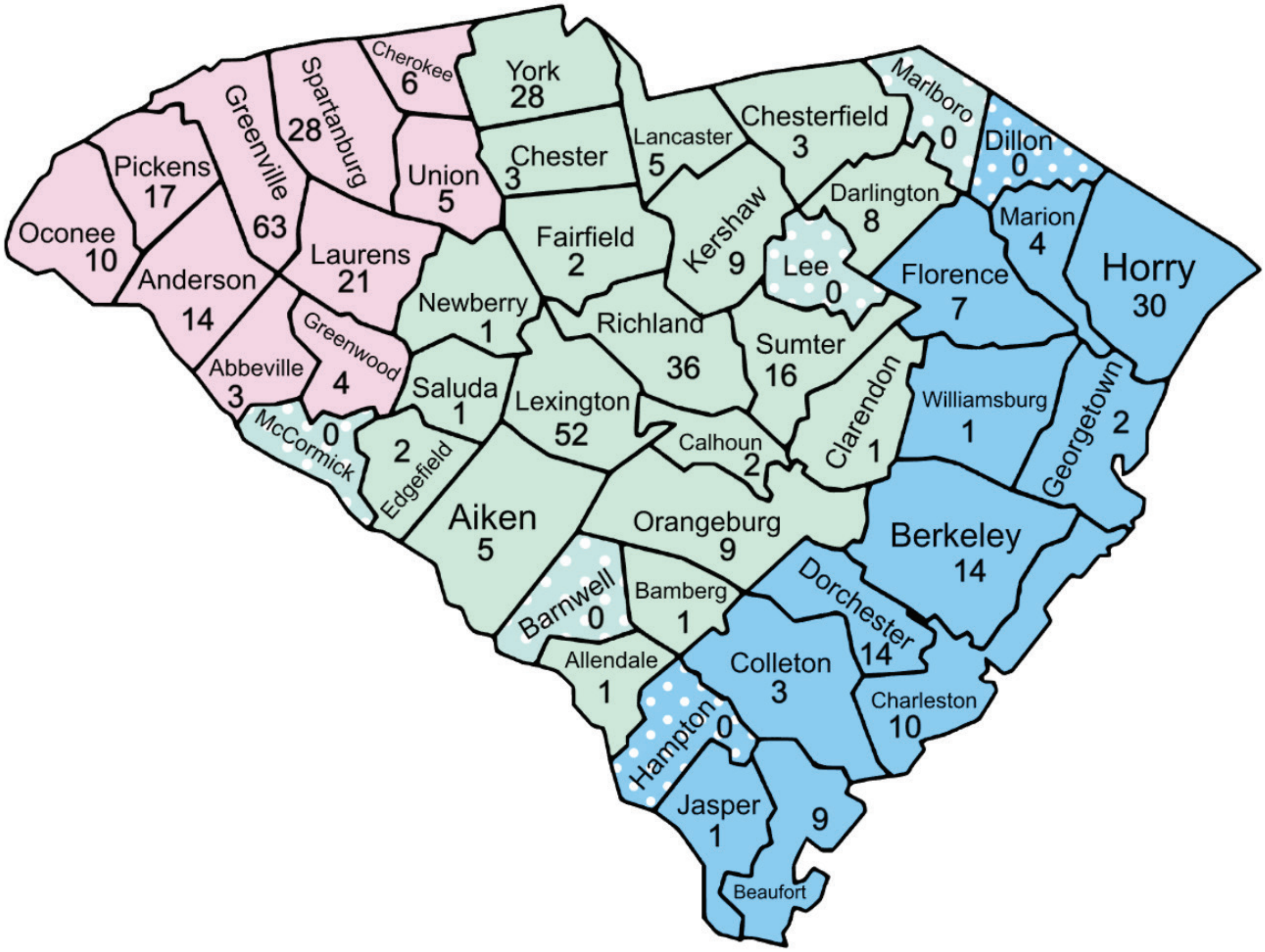
Current Membership By Region and County



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a heat map to show the visualization of our data within areas of the state. We will include as many diverse individuals and their families living with bleeding disorders with our survey outreach. Our goal is to take a broad look at all 46 counties in the state and discover barriers in access to care and treatment, graph all barriers or challenges, while also providing information and resources to community members that we can provide to help with these access challenges.

Throughout the year, we will be traveling to rural counties where our members reside. These meetings will be casual events at local restaurants or facilities to engage in conversations between BDASC and the community. These gatherings, similarl to all BDASC events, will be offered free of charge to all community members in the designated targeted area. We will provide community members the opportunity to provide anonymous information with access to quality healthcare barriers and challenges through our outreach survey taken at each location.

The outcome goal of this project will be to share the dates we discover with our HTCs and healthcare agencies within South Carolina and look at ways to partner to help bridge any gaps we can achieve together. We also hope that by having these small meetings we can introduce community members to other members living in the areas in which they live.

Your Input Is Appreciated

We would like to ask each member family in attendance to take a moment and complete the following survey. This survey is completely anonymous and is designed to help our members have a voice in helping to identify a lack of education in treatment care needs and access barriers in their counties in which they reside. This information may be shared with the community and healthcare agencies within South Carolina including our HTCs and hematologist offices. This is done to share the needs of our community with those who can provide change. There are no questions within the survey asking for identifying personal information. We ask you to be honest and provide as much information as possible about any of your concerns. This information will be used to better serve the different regions of South Carolina.

If you want to take the survey now, feel free, but please only take the survey once.

"The Voices of 46"
Community Resources & Engagement
Program - Rural Communities
Health Equity Outreach
(Greenwood, Abbeville, McCormick, Edgefield)

YOUR VOICE MATTERS

Your invited to join BDASC and our community members in your county for a dinner gathering and conversations.

FRIDAY, JUNE 14, AT 6:30PM.
Venue: REFUEL
100 Vienna St. Abbeville, SC 29620

Our Objective

We are excited to meet up with our members in their local counties and connect them to others. We will take a personal outreach approach to our rural communities and all 46 counties in South Carolina where we currently have members to map out access barriers to quality treatment and affordable healthcare, while providing resources to health equity. We will strive to discover healthcare disparities and lack of education within bleeding disorders care according to zip codes within the various counties in South Carolina. At the end of the year-long program, we will map our findings with a heat map to show the visualization of our data within areas of the state. We will include as many diverse individuals and their families living with Bleeding Disorders with our survey outreach. Our goal is to take a broad look at all 46 counties in the state and discover barriers in access to care and treatment, including education of bleeding disorders, and graft all barriers or challenges. We will also provide Chapter updates and resources currently available to our community members.

BDASC
Green Gate Office Park,
25 Woods Lake Road, Ste. 300
Greenville, SC. 29607
864. 350.9941

RSVP to Sue Martin by June 7th by calling or texting 864-350-9941 or email at sue.martin@bda-sc.org
We look forward to seeing you there!

This survey may be taken by scanning the QR code to the left with your cell phone. This can be done using the Camera all on your phone. Once you get the camera to focus on the QR Code, the link will pop-up and allow you to click on it.

You may also visit this survey by entering the following URL into your browser: **https://tinyurl.com/46VoicesSurvey**

Gettin' In The Game Junior National Championship

September 20-22, 2024, Henderson, Nevada

CSL Behring will once again host the Gettin' in the Game Junior National Championship (JNC) in Henderson, NV. from September 20-22, 2024. It has been 22 years since CSL Behring created the JNC, the first national and currently the only sports competition for children with bleeding disorders.

Participants will have the opportunity to learn the fundamentals of their respective sport, participate in friendly competitions and have a chance to connect with fellow members of the bleeding disorders community from across the country. Additionally, educational seminars focusing on the importance of physical fitness and other related topics will be available on-site.

We will be sending, along with all bleeding disorders chapters throughout the United States, two children from our chapter to participate in this experience of a lifetime. The JNC is for children, ages 7 through 18, to represent BDASC during this national competition. Each participant will have the opportunity to choose either baseball, basketball, golf, or swimming for this year's JNC. BDASC will choose from applications received who will represent us again this year. Be sure to save the date and apply on our website JNC Webpage. https://bda-sc.org/events/recreational-programs/gettin-in-the-game-junior-national-championships-jnc/

Voices of Our Community

Some of the most inspirational voices of our bleeding disorders community come from our scholarship recipients each year which will be awarded this June to our 2024 Scholarship Award Winners. In our application, we asked "how living with a bleeding disorder has affected your life." Whether they are personally affected or live in a household with an affected parent or sibling, everyone has a unique inspiring story to share. We hope you will be with us at our HELLO Awards Ceremony as we congratulate these individuals for all they have accomplished. With permission we are sharing a brief excerpt of their voices.

Aiden Budde

University of South Carolina, Freshman, majoring in Aerospace Engineering, from Goose Creek, SC. The impact of DGSPD extends far beyond the physical challenges it presents; it has also had a profound emotional and psychological impact on both myself and my family. I inherited the disorder and so did my sister, so it's also been there: a constant weight on the family. The vigilance required to prevent and manage bleeding episodes, the fear of injury and the uncertainty of what each day may bring has all contributed to heightened sense of anxiety and apprehension. Yet, amidst the challenges, my family has remained a pillar of strength, and support, providing unwavering encouragement, advocacy and love.

Makayla Keith

University of South Carolina Upstate, Sophomore, majoring in Nursing from Irmo, SC When asked how my life has been influenced by my dad having a bleeding disorder, a couple situations come to mind. The annual meetings with our chapter, state and national advocacy days, the summers spent learning more and more about this specific community of people who have this one thing in common. Not everything was peachy as some people would say. There were many scares that still, to this day, have affected my family and me. Overall, it's taught me a lot about community as well as health education.

Regan Weber

Clemson University, Sophomore, majoring in Modern Language Education, emphasis in French, from Greenville, SC.;Hemophilia has also given me so many connections that I would never have had before. I have connected with so many people because they know about hemophilia or a relative who has it. I have a friend from high school, and one of the significant connections we had early on was that her dad has hemophilia. Hearing about the different treatments for hemophilia and how they impact our lives differently is fascinating.

Ava Newhart

Tri-County Tech, Sophomore, majoring in Political Science, from Awendaw, SC. With this scholarship, I know that I can take the time to do all the good deeds for society and continue to shape my future educating those who are unaware about hemophilia and its effects through my career. The potential of the scholarship is tremendous to me, because I see how research has been able to change my father's life and others.

Von Willebrand and Women Who Bleed Community News

NBDF Emergency Care for Patients with von Willebrand Disease Treatment Manual Now in Spanish

We are pleased to announce that the *Emergency Care for Patients with von Willebrand Disease* treatment manual is now available in a Spanish language version. Funding for the translation, *Cuidado de Emergencia a Pacientes con Enfermedad de von Willebrand*, was provided by Akron Children's Hospital

The manual is meant to be a reference point for Emergency Department staff who are not well versed in the treatment and management of von Willebrand disease (VWD).The stated goals of the manual are to:

- Promote understanding of the complexities of VWD with an emphasis on rapid treatment for correction of the hemostatic abnormality
- Provide a reference for emergency center staff
- Promote a consultative dialogue with the ED, treatment center, and patient/family

This publication is authored by hematology nurses Susan C. Zappa RN, Lucie Lacasse RN, Rose Jacobson RN, Sherry Purcell RN, and Karen Wulff RN. It was produced by Judith Bell, an Adult Nurse Practitioner from Buffalo, NY.

Visit hemophiliabooks.com to order copies of the Spanish language version or additional copies in English. If you wish to pay by check please download this PDF form and submit it completed by email to jbell@clarenceprinting.com or fax to 716.542.6533.

Questions should be directed to Judith Bell at the email noted above or by calling 716.983.0166.

Did You Know?

National Bleeding Disorders Foundation Website Change

Have you heard? We have changed our website name from Hemophilia.org to Bleeding.org.

"This website transition is a bold leap for our community," said Philip Gattone, President and CEO of NBDF. "This new URL allows us to be more inclusive and better represent the full spectrum of bleeding disorders, including hemophilia, von Willebrand disease, and other rare conditions. By using a more inclusive domain, we hope to reach a wider audience

Continued on page 23

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and provide more comprehensive resources and support to all who need it." Learn more at https://bit.ly/4aBRFL4.

The Importance of an Annual HTC Visit

Hemophilia and other bleeding disorders are complex disorders that require specialized care and treatment. Good quality medical care from a team of specialists who know a lot about bleeding disorders can help prevent many serious problems. It is often the best choice for patients to visit Federally Funded Hemophilia Treatment Centers. Federally Funded Hemophilia Treatment Centers are comprehensive care clinics designed to treat the whole patient. These treatment centers specialize in a wide range of bleeding disorders, not just hemophilia. The staff and physician(s) are experienced in treating all bleeding disorders. A CDC study of 3,000 people living with hemophilia, showed that those who visited an HTC were 40% less likely to die of a hemophilia-related complication. Similarly, people who visited an HTC were 40% less likely to be hospitalized for bleeding complications.

The Comprehensive Care Model

Hemophilia Treatment Centers encourage treatment of the whole patient, rather than the bleeding disorder. In this vein, the HTC provides access to multidisciplinary heath care professionals. Some of these professionals may include (but are not limited to):

- Lab technicians or pathologists
- Hematologists
- Physical therapists
- Nurses
- Social workers
- Other specialists (eg. dentist, gynecologist, nutritionist, genetic counselor)

These healthcare professionals work together to provide patient care and support. They specialize in working with bleeding disorders patients. Your HTC will also be able to work with other healthcare professionals — such as dentists, orthodontists, surgeons, etc. — to ensure that your bleeding disorder is managed during any medical situation.

Ensuring That South Carolina Receives Adequate Funding for HTCs

Working together with the CDC, federally funded HTCs throughout the country can participate in a program called "Community Counts." This program collects a consistent set of data to monitor the health of people living with bleeding disorders. This data consists of census data for those living with all types of bleeding disorders. Funding for HTCs is determined based on the number of people living within a region or state. **Being counted** can help the HTC to receive more funding and be able to provide additional care.

Advancing Knowledge and Impacting Care for the Future

Along with the "Community Counts" program, federally funded HTCs can participate in a variety of studies throughout the Bleeding Disorders Community. A study may be used to ensure that the community's blood supply remains free of contamination — such as the CDC's study for patients who receive human based medication. Or patients may have new treatment options available to them sooner — such as the new Gene Therapies which are currently accessible at South Carolina HTCs.

Are you connected to a South Carolina Hemophilia Treatment Center?

If you are currently not being seen at an HTC, but are being seen by another local hematologist, you can still see your local hematologist but also see an HTC annually. Your hematologist can work with the HTC team to ensure that you are receiving the best, most up-to-date treatment care.

Within the State of South Carolina, there are two federally supported HTCs. **Both HTCs see and**

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treat adults and children — even if labeled as Pediatric Hematology. The location and contact information for these HTCs (and the satellite locations) are below:

SC Hemophilia Treatment Center Prisma Health – Midlands
14 Richland Medical Park Ste 410
Columbia, SC 29203

Hemophilia Treatment Center Prisma Health – Orangeburg
1724 Village Park Drive
Orangeburg, SC 29118

Hemophilia Treatment Center Prisma Health – Florence
101 William H Johnson St., Suite 400
Florence, SC 29506
Phone: 803-434-1028
Fax: 803-434-2515
Email: schemophilia@prismahealth.org

Stephanie Ambrose, MD, Medical Director
803-434-3533

Robin Jones, MSN, MHA, RN, CPN, CPHON
Nurse Navigator/ SC Hemophilia Treatment Center Nurse Coordinator
803-434-1028 or robin.jones@prismahealth.org

Shonequa Smith, LMSW
SC Hemophilia Treatment Center Social Worker
803-434-4255 or
Shonequa.Smith@PrismaHealth.org

SC Hemophilia Treatment Center Prisma Health – Upstate
900 West Faris Road, 2nd Floor
Greenville, SC 29605
Phone: 864-455-8898
Fax 864-455-5164

Leslie Gilbert, MD, Lead Hematologist – Greenville

Diana Moreno, RN, Hematology Nurse

Pamela Broughton, LISW, SC Hemophilia Treatment Center Social Worker

Source: https://www.cdc.gov/ncbddd/hemophilia/htc.html

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

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

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Above 40% for most of the week (near-normal to normal range).[*][†]

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In a Phase 3 study,[†] ALTUVIIIO 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 ALTUVIIIO 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 ALTUVIIIO prophylaxis from prior prophylaxis therapy. Efficacy of prophylaxis was evaluated in 128 of these patients.
[‡] Data based on treated bleeds.

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

IMPORTANT SAFETY INFORMATION

What is the most important information I need to know about ALTUVIIIO?
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 ALTUVIIIO so that your treatment will work best for you.

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

What should I tell my healthcare provider before using ALTUVIIIO?
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 ALTUVIIIO?
You can have an allergic reaction to ALTUVIIIO. 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 ALTUVIIIO. This can stop ALTUVIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

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

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

Please see full Prescribing Information.

sanofi

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Copayment Accumulator Legislation: Victory is in Sight

By James Romano, BDASC Legislative Coordinator

The Bleeding Disorders Association of South Carolina membership worked extremely hard this winter and spring to pass H.3618, the Copayment Accumulator Ban. The community was up against long odds to advance the legislation as far as we did due to the hard work of the community. The excellent news is we have made considerable progress and paved the way for passage in the next legislative session beginning in 2025. However, passage of this important legislation is not guaranteed so that is why we will always need assistance from the community. Passing legislation is always difficult because the system is designed to make people work hard to obtain their objectives. The process sometimes takes several legislative sessions. With legislation involving insurance issues, the process becomes even more difficult because health insurance providers want less regulation and pass more costs onto patients. Health insurance providers provide campaign contributions to every member of the legislature guaranteeing more access. The only way around this is for advocates to share their stories making the Capitol Advocacy Days so important. It is also notable that in South Carolina, the legislation introduces around 3,000 bills each year with only around 300 becoming law. This is why working together as a community is imperative.

The BDASC kicked off the year with our 2nd Annual Legislative Breakfast which made it possible for members of the chapter to speak with Representatives and Senators about bleeding disorders and the copayment

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accumulator legislation. Many members attended because of their past association with the community members and their respect for the organization and its leadership. The BDASC engineered the introduction of a Senate Companion bill (S. 1024) introduced by Senator Mike Fanning (D-SC).

In February, the House Labor Commerce and Industry Committee, Subcommittee on Insurance hosted a hearing on the bill, allowing the community to testify on the need for the legislation. That same month, the BDASC community stormed the Capitol in Columbia obtaining an additional 22 cosponsors. Representative Stewart Jones (R-SC-14th) and Senator Larry Grooms (R-SC-37th) honored our community by recognizing the chapter from the floor of the House of Representatives and the Senate. Many Representatives and Senators surrounded them in support and respect for the community. Representative Jones gathered cosponsors on the House floor. Together we have built and maintained a respect in the legislature that keeps growing year after year.

In March, we reached a majority of the House of Representatives as cosponsors for the bill, so if a vote was held the bill would pass. One of our patient advocates worked with Representative Carla Schuessler (R-SC-61st) to gather the ten more cosponsors to attain the majority. We are currently up to 64 members of the House of Representatives as cosponsors.

At the start of the next legislative session in January, we will introduce compromise language that our leadership has worked with other advocacy organizations to develop. This language has initial support from the committees of jurisdiction. Our champion, Representative Pat Henegan (D-SC-54th) announced she is retiring. We will be working this summer to secure a new sponsor. BDASC hosts our Legislative Breakfast in January 2025. The chapter will need your assistance and support more than ever.

Moving forward, if your representative has not signed on, please contact Sue Martin or myself so we can reach out and schedule a virtual meeting to discuss the bill. Thank you for your hard work, we could not have come so far without you. Your voice does matter!

National News

Leading bleeding disorders advocacy organizations celebrate new federal rule strengthening protections against disability discrimination

May 10, 2024—The Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC), National Bleeding Disorder Foundation (NBDF), and Hemophilia Federation of America (HFA), are pleased to share that after advocacy from the bleeding disorders community, the U.S. Department of Health and Human Services (HHS), through its Office for Civil Rights (OCR), **finalized a new rule that will increase equity and access to behavioral health facilities for people with bleeding disorders.**

The new rule, entitled Discrimination on the Basis of Disability in Health and Human Service Programs or Activities, clarifies that the protections afforded to people with disabilities (including people with bleeding disorders) under Section 504 of the Rehabilitation Act of 1973 (Section 504) apply to medical settings. Importantly for the bleeding disorders community, it clarifies that **medical providers (including behavioral health facilities) must conduct an individualized inquiry** in order to make the determination whether the facility can meet the person's needs, and that they cannot deny access based solely on the presence of a diagnosis, such as a bleeding disorder.

BD SUMHAC, which includes HFA and NBDF as key coalition members, is pleased that HHS responded to their public comments and included strong language in the final rule that will increase equity and access for the bleeding disorders community. The rule states, "In the vast majority of circumstances, where medically indicated care depends on the specific clinical circumstances of the patient seeking treatment, [medical providers] must engage in an individualized inquiry when determining eligibility for treatment." In other words, a facility must conduct an individualized inquiry and talk with the individual's care team (and learn about the bleeding disorder and person's needs) to determine whether they could accommodate that specific individual.

According to a national survey conducted in 2022, **people with bleeding disorders are often denied access to inpatient and residential mental health and substance use treatment** because of their bleeding disorder. BD SUMHAC's mission is to address this issue and increase equity and access to inpatient and residential treatment facilities for all people with bleeding disorders. In talking with providers whose patients had been denied access to appropriate treatment because of their condition, BD SUMHAC found that facilities are often uneducated about bleeding disorders and have significant misconceptions, bias, and stereotypes about the needs of people with bleeding disorders. Yet, rather than taking the time to learn more about the needs of the specific individual requesting access, facilities often deny people with bleeding disorders on the basis that the condition is too "medically complex." BD SUMHAC looks forward to working with OCR to ensure the appropriate enforcement of this newly released clarification of Section 504.

We are honored to financially support the work of the BD SUMHAC along with many other national chapters. Your funding and donations are being put to good use. Thank you!

Read the **press release** from HHS announcing the new rule.

View or download the **final rule**.

View or download the **fact sheet** on the rule.

National Bleeding Disorders Conference 2024

September 12-14, 2024, Atlanta, GA

BDASC has always been a firm believer in helping our members attend national events and conferences. The education you can receive is broader than we can provide. In our 2023 Member Survey, our community indicated that the best way to save funding was to eliminate our national travel grants. We would still love to be able to provide this opportunity to our community if funding allows. We encourage any community member to apply for a travel grant to attend the conference in Atlanta, and we will see if our funding will allow some flexibility in granting requests. Refer to the BDC website at bleeding.org for available grants through NBDF. For more information on our travel grants, visit our website at https://bda-sc.org/national-education-and-conferences-travel-scholarships/

The National Bleeding Disorders Foundation's 76th Annual Bleeding Disorders Conference (BDC) will take place September 12-14, 2024 in Atlanta. The conference will bring the bleeding disorders community together for three incredible days of educational sessions, valuable networking opportunities, and exciting exhibits at the Georgia World Congress Center. For more information and to register, visit the website at https://na.eventscloud.com/website/64934/home/.

Ultra Rare Bleeding Disorders News: Researchers Look at Impact of Factor X Deficiency on Patients/Caregivers

Hereditary factor X deficiency is an ultra-rare bleeding disorder that occurs in approximately 1 in 500,000 to 1 in a million people across the globe. A new study published in the journal *Blood Coagulation and Fibrinolysis*, looked at the impact of hereditary factor X deficiency (HFXD) on patients and caregivers in the United States. HFXD is an ultra-rare bleeding disorder that occurs in approximately 1 in 500,000 to 1 in a million people globally. People with this condition can experience a wide range of bleeding symptoms that range from mild to severe. Symptoms can include nose bleeds, easy bruising, bleeding after trauma or surgery. joint bleeds, excessive umbilical cord bleeding, and intramuscular bleeds can also occur. HFXD is also linked to a high risk for intracranial hemorrhaging in infants. Females often experience additional symptoms and complications including heavy menstrual bleeding, first trimester miscarriage, and postpartum hemorrhaging.

The online survey was open to patients with HFXD and/or their caregivers in the United States from October 2021 through June 2022. Survey questions were designed to shed light on patient/caregiver experiences with diagnosis, bleeding episodes, treatment, and the effect of the disease on their quality of life (QOL). A total of 30 and 38 people completed the patient and caregiver surveys respectively. 76% of patient responders indicated that they were either diagnosed at birth or in early childhood after a bleeding episode. The majority were diagnosed within three months of the initial symptoms, while a minority (7%) received a diagnosis 12 months or more after the first symptoms. Overall, 23% of patients and 26% of caregivers reported that the path to diagnosis was somewhat/very difficult.

“Often, manifestations of severe HFXD are observed in early childhood and patients may present with spontaneous life-threatening hemorrhage during the first month of life, explained the authors. “Patients with milder deficiencies may experience a delay in diagnosis. Perhaps attributable to these delays, one in four patients surveyed found the diagnostic process somewhat/very difficult.” The majority of patients (77%) indicated that they receive care at a hemophilia treatment center. The most often used therapies were single factor replacement (53%), fresh frozen plasma (27%), and oral contraceptives (13%). These therapies were used either as stand-alone treatments or in combination. Bleeding episodes were less frequent in patients using single factor replacement vs an alternative therapy.

Bleeding episodes were prevalent with 63% of patients experiencing one-to-three bleeds within just four weeks of survey completion. Easy bruising/hematomas, along with bleeding into muscles and joints were the most commonly reported symptoms. While some of these bleeds were caused by trauma others were spontaneous bleeding events. All patients indicated some degree of satisfaction with their current treatments to control bleeding and improve their quality of life. However, patient respondents perceived a relatively poorer well-being overall relative to the general population. Caregivers reported that they were satisfied at least some of the time with how treatments helped control bleeding in the patients under their care, while 58% reported satisfaction all of the time.

“Even with the advances in treatment options, management of HFXD could be improved through earlier diagnosis, earlier initiation of treatment, and optimization of medical management, which may lead to better QOL and wellbeing for both patients and caregivers,” explained the authors.

The lead author of the paper is Brian Branchford, MD. Dr. Branchford is a former recipient of the NHF (now NBDF)-Takeda Clinical Fellowship. Branchford and his co-authors empathized the value of a patient-reported outcome (PRO) focus in such a rare condition. “Overall, the HFXD in America Survey provides the first PRO-focused glimpse of disease burden and insight into significant diagnosis and treatment gaps that negatively impact the HFXD community, concluded the authors. **"Opportunities to collect data over the course of several years may add further to our understanding of this rare coagulation disorder."**

Access this link to read the full article and learn more about the study design, results, and limitations.

Supplemental Resources:

Learn more about the **resources and educational opportunities** available to individuals affected by rare and ultra-rare bleeding disorders

Read **Factor X (FX) Deficiency: You Are Not Alone**

Learn more about the **NBDF-Takeda Clinical Fellowship Program**

Citation: Reprinted from NBDF Website - *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.*

Study Suggests Prophylaxis Can Mitigate Intracranial Hemorrhage Risk

Results of a new study published in the Journal of Blood Medicine, indicate that people with hemophilia A who have been on a prophylactic treatment regimen have a reduced risk for intracranial hemorrhage (ICH).

Often referred to as a "brain bleed," ICH is a very serious event whereby blood accumulates within parts of the skull, including the brain itself. This can result in built up pressure which can block critical oxygen and nutrients from reaching brain cells and tissues. ICH events that are not treated expeditiously can result in major disability and even death. These type bleeds can occur spontaneously or triggered by something specific such as trauma. While people with hemophilia are at some risk for ICH, any given patients' risk level will vary and depend on a variety of factors.

Authors of the JBM paper used retrospective data from the ATHNdataset to inform their research, eventually identifying 7,837 hemophilia A patients between two and 75 years of age. Included in the study were moderate and severe HA males (assigned at birth) who had hemophilia treatment center visit information from January 1, 2010, through September 30, 2020.

Their investigation showed that 135 of 7837 of the subjects experienced an ICH. A review of the data pointed to several factors associated with a higher risk including being in the 2–12-year age range; being covered by Medicaid; having had HIV, hepatitis C, or hypertension; and never having received factor VIII replacement therapy or prophylactic treatment. The authors also conveyed that these results align with earlier studies which demonstrated that prophylaxis provides a "protective effect" against ICH.

Because emicizumab became available at the tail end of the study period, data relevant to its use and findings relevant to its use, along with opportunities for comprehensive analysis, were limited. "As of 2018, the standard of care for congenital hemophilia A has evolved to include emicizumab, a humanized antibody that mimics activated FVIII to allow continuation of the coagulation cascade. This study's period includes data from before and after emicizumab approval in 2018. The ICH rate significantly decreased across the study period, but data from the periods before and after emicizumab approval cannot be conclusively analyzed because of the limited sample size after emicizumab approval and the inability to account for all possible confounders," explained the investigators.

"This study, using data from the ATHNdataset, identified the following risk factors for ICH in PWHA: being aged between 2 and 12 years, having ever received Medicaid coverage, having had certain comorbidities (HIV and HTN), never having received factor treatment, and never having received prophylactic treatment.

The study, "Risk of Intracranial Hemorrhage in Persons with Hemophilia A in the United States: Real-World Retrospective Cohort Study Using the ATHNdataset," was published in the Journal of Blood Medicine. Read the full paper to learn more.

Source: docsirenews, May 21, 2024

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: 2024 Major Community Engagement Opportunities — Save the Dates!

June 14: Voices Outreach Dinner: (Abbeville, SC)

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

June 25: BDASC Ice Cream Social, Camp Courage (Mariette, SC)

July 9: BDASC Ice Cream Social, Camp Burnt Gin (Wedgefield, SC)

July 18-21: BDASC Teen Retreat with (North Carolina)

July 26: Community Engagement and Connections Dinner (Columbia, SC)

August 1: Community Engagement and Connections Dinner (Greenville, SC)

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

August 24: Community Engagement and Connections Event (Charleston, SC)

September 20-22: Gettin' in the Game (Henderson, Nevada)

September 27: Par for the Clot Charity Golf Fundraiser (Greenville, SC)

October 18-20: Fall Gathering (TBD)

November 6-8: HTC Southeast Regional Meeting

November 9: Advocacy Coalition Stakeholders Meeting and Training (TBD)

November 18-22: NBDF Chapter Leadership Conference

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

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!

United Way

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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