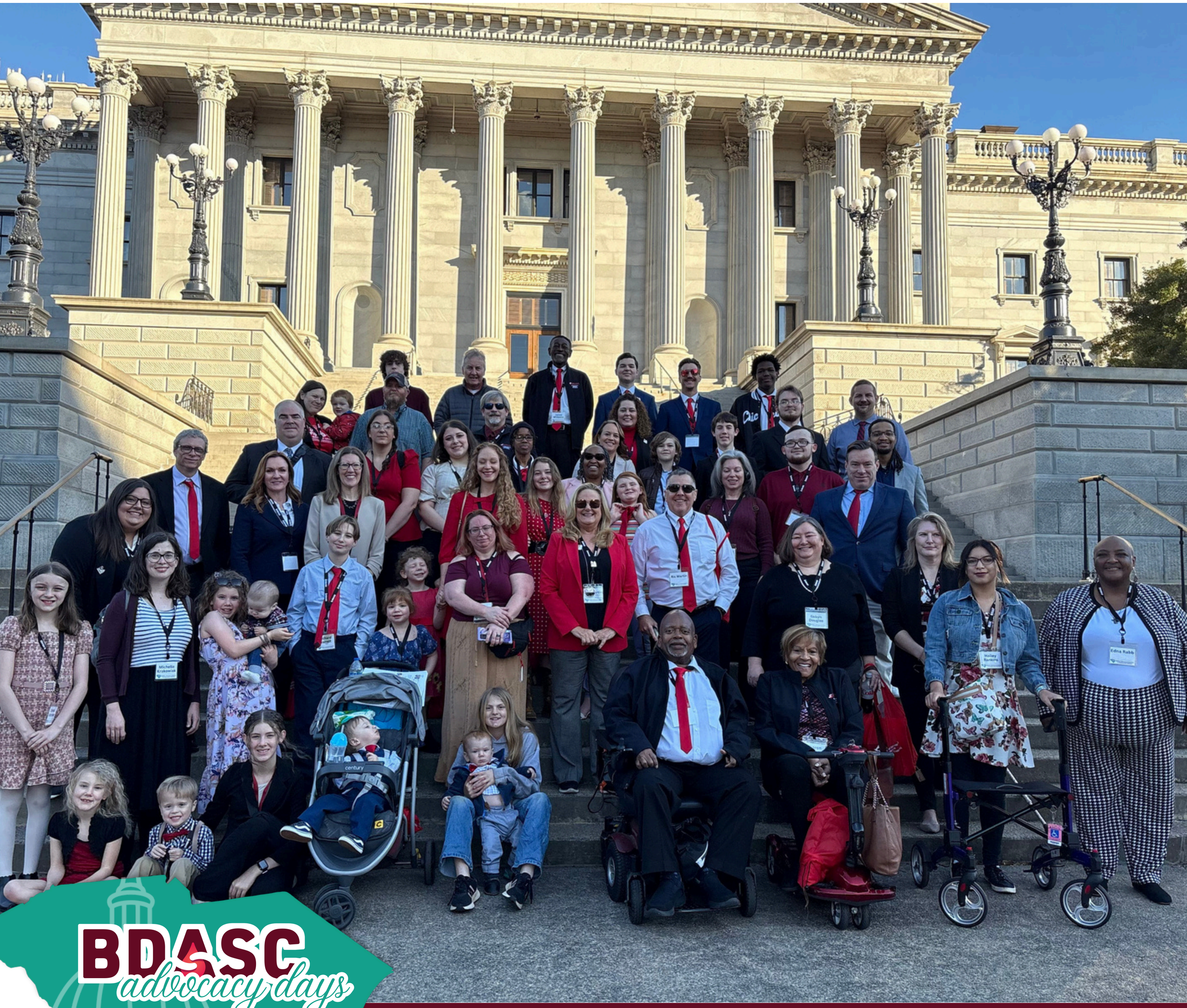
The News Infusion

The Official Newsletter of Bleeding Disorders Association of South Carolina

Volume 15, Issue 2 Spring 2025



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About BDASC & The News Infusion

Inside this Issue:

- A Chapter of the National Bleeding Disorders Foundation
- A Chapter Member of the Hemophilia Federation of America
- A Registered Greenville County Charitable Organization
- A Member of the Greenville Chamber of Commerce
- A Member of the South Carolina Associations of Non Profit Organizations - Together SC
- A Member of the SC Palmetto Health Collective

BDASC Mission: Our mission is 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: Our vision 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.

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Shelley Crisp
Sue Martin, *Ex-Officio Board Member*

Looking Ahead: Save the Dates!
Summer 2025 Calendar of Events

June 6-7: *Annual Meeting & HELLO Conference, Greenville, SC*
June 17: *Community Engagement Dinner Connections*
June 24: *Chapter Day at Camp Courage, Greenville, SC*
June 25: *Community Engagement Dinner Connections*
June 28: *Support Group Community Connections Event*
July 8: *Chapter Day at Camp Burnt Gin, Wedgefield, SC*
July 22: *Virtual Reach & Teach – Platelets, VWD & Ultra Rare, Zoom*
July 31- August 3: *Teen Camp, Parkton, NC*
August 30*: Community Engagement Event, Myrtle Beach, SC*
September 26: *Par Fore the Clot, Greenville, SC*

About this Publication

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The News Infusion's mission is to provide communication, connections, education and advocacy awareness. It is published quarterly by the Bleeding Disorders Association of South Carolina as an informational service to it's 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 healthcare 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 centers and 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!

2025 Advocacy Days - Columbia, SC & Washington, DC

February 28, 2025 - April 17, 2025

Each year, we kick off our Bleeding Disorders Awareness Month campaign with an impactful advocacy event in Columbia. Our State Advocacy days is an annual event to gather together to raise our voices and make meaningful change. We start off our advocacy days events on the evening before our day at the Capitol. We gather together to share a meal, listen to stories, receive national and local presentations on our policy issues, and receive guidance for the following day. This year, 70 community members and attendees from around the state and nation were involved.

We kicked off our beautiful day in the Capitol bright and early with a quick walk over to the Capitol building. Our community members gather on the steps of the Capitol building for one big group photo to start off our day. Then everyone was off to their meetings. Community members met with their representatives and senators throughout the day. These meetings consisted of groups of community members from their representative's or senator's districts. Everyone took turns sharing their stories and sharing the importance of our bills – H. 3934 & S.330*.

Community members were greeted again by the South Carolina Lieutenant Governor, Pamela Evette. The Bleeding Disorders Community has had an outstanding relationship with the Lieutenant Governor, even presenting her with our community's Appreciation and Partnership Award during our 2024 Annual Meeting. It's great to see our photos with her throughout the years as it shows how our community grows and changes. This year again, we were fortunate enough to be recognized on the floor of both the house and the senate. Senator Larry Grooms recognized our young advocates in attendance this year on the senate floor. This is always a highlight of the day as each community member is invited to stand and be recognized. The entire chamber claps and it is a fantastic way to spread awareness for those living with bleeding disorders.

After an amazing event in South Carolina there was no time for rest! The following week, fourteen community members hopped aboard flights and headed to Washington, DC to join with over 400 advocates from the bleeding disorders community for NBDF's 2025 Washington Days. Advocates participated in 248 Congressional meetings and represented 49 states and Puerto Rico. We were proud to see our community member, and amazing advocate, Candi Mitchum speak at the start of Washington Days. Candi was provided with the opportunity to share her story and to encourage each participant to raise their voice for change. Our community returned safely to South Carolina energized to continue to advocate.

As our Bleeding Disorders Awareness Campaign continued throughout the month of March and into April, our advocates remain steadfast in their determination. Our Executive Director, Sue Martin, along with our Legislative Coordinator, James Romano, have taken many meetings with state representatives as well as representatives of our state insurance companies. These meetings were productive and educational. We look forward to continuing our commitment to advocacy by providing opportunities for community members to learn what role they can play within our state and our nation. Keep an eye out for our advocacy sessions at our Annual Meeting & HELLO Conference, advocacy sessions at Teen Camp and into the fall.

** For more information on our current state House (H.3934) and Senate (S.330) bills, please turn to page 24, Advocacy In Action.*

Thank You To Our Advocacy Sponsors

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Executive Director's Welcome

By Sue Martin

I hope this message finds you well and as excited as I am for the summer session and all it has to offer. This is such a vibrant time for our community, and I'm especially looking forward to our HELLO Annual Meeting and Conference happening this week. If you're joining us, we can't wait to connect with you! And if you aren't able to attend this year, please know you'll be missed—we hope to welcome you at next year's gathering.

As we look ahead to the rest of the year, I'm filled with both hope and deep gratitude. There will be many opportunities to come together through our programs and services, and I'm truly looking forward to each and every one. Our forecast may feel uncertain at times, with so many changes happening around us, but I believe that when we move forward together—with compassion, determination, and community—we can meet any challenge head-on.

Advocacy will remain our number one initiative as we work to ensure you and your families have continued access to the treatment, care, and health services you deserve. With policy shifts on the horizon, it's never been more important to stay engaged. I know many of you have seen my messages encouraging you to write to your representatives and senators—and I want to thank you for stepping up. Your voice truly matters.

To meet the growing needs of our community, we must also be successful in all of our fundraising efforts. Our revenue outlook remains uncertain, and your support is more critical than ever. Whether through participation, donations, or spreading the word, every bit helps sustain the programs and services we all rely on.

If you're able to assist through volunteer service or have other ways you'd like to support our mission, please don't hesitate to reach out. I would truly love to connect and explore new opportunities with you.

These may be uncharted waters, but we've navigated tough times before, and we'll do it again. Together, we are resilient. Together, we are powerful. And together, we will continue building a stronger future for all.

With heartfelt appreciation,
Sue Martin, Executive Director

Thank You for Your Dedication Aaron Smith;
Welcome to our Returning Board President, Shelley Crisp

We are excited to announce that Shelley Crisp will be returning as Board President starting this June as our current President, Aaron Smith, will be stepping down as his term expires. We are truly grateful to Aaron for his hard work and continued dedication while being a member of the board and moving up to be President. We are certain he will enjoy his time off with his family – especially with their new addition. Thank you, Aaron!

"Becoming President of the South Carolina Bleeding Disorders Association is incredibly meaningful to me. I've been involved with this chapter for 10 years, ever since my son, Lucas, was diagnosed with severe Hemophilia A at just a year old. He'll be 12 this July, and watching him grow into a strong, compassionate, and resilient young advocate has been one of the greatest joys of my life. He's learning about the importance of speaking up and is already beginning to participate in advocacy himself. This organization has been a lifeline for our family, and I'm so grateful for the people we've met and the strength we've found through this community. Taking on this role feels like a full-circle moment, and I'm excited—and deeply committed—to giving back and helping other families feel seen, supported, and empowered." - *Shelley Crisp*

Volunteers Always Needed, Forever Appreciated

Our BDASC programs are such a success because of our amazing volunteers. We would like to thank each and every one of you for your continued support and contributions. We are grateful that our volunteers return year after year to assist in events that they are passionate about.

We are especially appreciative of our Walk and Golf volunteers! Our annual walk is our largest community fundraiser that helps support the bleeding disorders community throughout the year. Our volunteers are committed to helping raise awareness and funds for our community walk.

Our Par For The Clot Charity Golf Tournament brings in funds from outside corporations and business throughout both South Carolina and the nation. It is critical for BDASC to bring in additional funds to be able to support our community as industry funds and support continue to decrease while costs continue to rise. This event is hosted by volunteers and committee members who work half the year to ensure it is successful and raises funds to support our robust advocacy work, operations and services we provide, such as camp support, travel grants, financial assistance, and scholarships. Speaking of advocacy, we are equally appreciative of our advocacy volunteers who work hard to voice our needs for access to treatment.

You too can become involved in the BDASC community and become a volunteer! Everyone is welcome to volunteer, you do not need a bleeding disorder to become involved and make a difference. If you have a passion for making an impact, we have an opportunity for you! Volunteers are welcomed in the office, along with events working with kids and teens, setting up or handing out items and information. If you would like to volunteer, or would like additional information, please contact Sue at the Chapter office, or register on our volunteer page on our website.

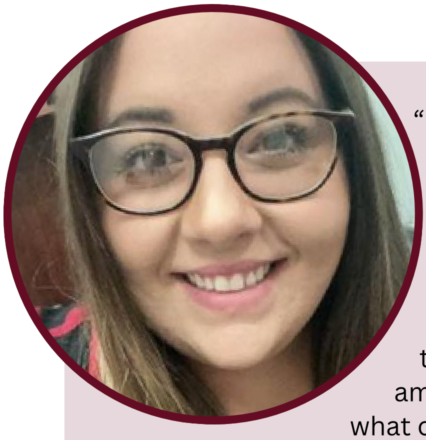
scan for more info

> *"The heart of a volunteer is not measured in size, but by the depth of the commitment to make a difference in the lives of others."*

Help Shape BDASC - Join the Board!

BDASC's mission is to raise awareness for and advocate on behalf of people with bleeding disorders and their families; provide education and supportive services; and promote ongoing research to improve the quality of life for those affected. In order to support this mission, BDASC is comprised of staff, consultants and a Board of Directors. Our Board of Directors are responsible for the governance of the organization and work closely with our staff. The board members and executive director meet monthly to discuss the direction, governance, programs, services, and support for the organization and its members. We accept applications at any time and review as new board positions become available.

This year, we have several members from our Board of Directors that will be leaving the board. We are on the lookout for new members to join our team of dedicated individuals to help guide and shape the organization to meet the needs of our community. If you know of someone who is interested in joining our board, or if you, yourself, are interested, we invite you to learn more at our website, bda-sc.org, or reach out to our Executive Director, Sue Martin, or any of our dedicated board members for more information.



"Being a part of this community and knowing I have people to lean on when even my own family doesn't understand what I'm going through. It's so amazing to have people what completely understand what it feels like to be in the hospital on Christmas, or to have a port in your chest. I have met people here that have become like family to me and I'm so grateful for them all! I am so thankful Lincoln was born into this community because I never even met anyone with a blood disorder until I was in my 20s and that was really hard. He won't have to experience that, thank goodness, he will always have a place in the Bleeding Disorders Association of South Carolina community." - Taylor Upton

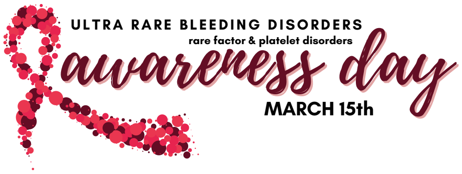
Community Engagements

von Willebrand Disease Awareness Day Virtual Event - *March 1, 2025 - Via Zoom*

In 2024, we made it our mission to lift up those in our community who are living with von Willebrand Disease and Ultra Rare Bleeding Disorders. We introduced the idea of "VWD Awareness Day" and "Ultra Rare Bleeding Disorders Awareness Day." We added language to our Proclamations; we created graphics to spread the word, and we used social media to spread awareness of these days. This year, we also added the "Women Who Bleed Awareness Day" to increase awareness for those women living with bleeding disorders that have been previously underrecognized.

The first event to kick off our Bleeding Disorders Awareness Month this year was von Willebrand Disease Awareness Day. Throughout the day on March 1st, we posted several social media graphics sharing information on von Willebrand Disease. We capped off the day with a virtual gathering to celebrate those living with von Willebrand Disease. We were fortunate to have Morgan Cook, with Takeda, speak with us on the importance of resilience. She not only shared why we in the bleeding disorders community must have resilience, but also how we can boost our resilience. The participants took turns sharing their stories and explained why recognition of VWD is important. It was a fantastic way to start our month of awareness and support!

Ultra Rare Bleeding Disorders Awareness Day Virtual Event - *March 15, 2025 - Via Zoom*



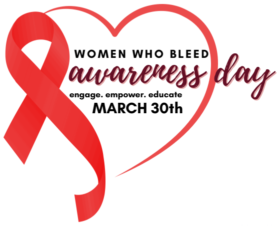
Following up after an amazing few weeks of Awareness celebrations and Advocacy, we hosted our virtual Ultra Rare Bleeding Disorders Awareness Day Celebration! Our community again gathered, but this time in recognition of those living with Ultra Rare Bleeding Disorders, such as rare factor deficiencies (Factor I, II, V, VII, X, XI, XII, XIII) and Glanzmann's Thrombasthenia. We were a small but mighty group. We shared our experiences with each other and learned new information and ways we can all support one another.

"Go Red" for St. Patrick's Day Event - *March 17, 2025 - Columbia, SC*

We had a fantastic time "Going Red" on St. Patrick's Day at Braza Do Sul Brazilian Steakhouse in Columbia on March 17th. Our community came together wearing both red and green in honor of Bleeding Disorders Awareness Day and St. Patrick's Day. We wear red on a day where people typically wear green to spark a conversation and to help spread awareness.

We were provided with a delicious dinner and an evening centered around Positive Self-Talk with Shelby Smoak, from Sanofi. We explored behavioral insights that may help you discuss your bleeding disorders management with your loved ones and healthcare team.

Women Who Bleed Awareness Day Virtual Event - *March 30, 2025 - Via Zoom*



Our final virtual gathering for Bleeding Disorders Awareness Month celebrated the women who bleed in our community. We had a large gathering of community members come together and hear about the unique ways women within our community bleed. Brittany Savage, sponsored by Novo Nordisk, provided us with a story about a women living with hemophilia and the community shared how they have experienced similar situations. This presentation provided advice and tips to ensure that all women who are experiencing bleeding receive proper care and treatment. Thank you to those who attended our virtual awareness day celebrations! We look forward to continuing to spread awareness and understanding throughout the year!

Adult Connections Retreat

April 4- 6, 2025, Greenville, SC

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 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 bleeding disorders, health and wellness, vWD and Ultra Rare bleeding disorders, sessions for affected men and women, and sessions with updates on our advocacy and national research.

GUT MONKEY

Friday night began with social connections followed by a fun night at Group Therapy of Greenville. Attendees had a blast flinging axes, playing digital darts and Wacky Miniature Golf. It was a perfect way for adults to connect and get to know one another before two days of educational breakouts.

Saturday morning started off with Caregiver's Compass provided by GutMonkey. This session was an interactive workshop about meeting our young family members where they are developmentally. Determining what responsibilities are appropriate by age and understanding the challenges associated with living with a bleeding disorder as a child.

The afternoon breakout sessions were led by Sue Geraghty, Morgan Cook, Dr. Angie Forsyth and Shelby Smoak. Each group, VWD, Women & Men were provided with education and support through these educational sessions on living with VWD, utilizing K-Tape, learning about women with bleeding disorders and joint management.

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 started with a relaxing yoga session followed by a quick look at our advocacy program and what's a head for the year, provided by the executive director, Sue Martin.

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Community Engagements

World Hemophilia Day Celebration

April 17, 2025 - Grand Bohemian Lodge, 44 E Camperdown Way, Greenville, SC

World Hemophilia Day was celebrated with immense joy and we were united with the spirit of family and community in South Carolina and in Washington as community members gathered in recognition of this special day. We were fortunate to be supported by Sanofi in recognition of World Hemophilia Day – recognizing all bleeding disorders. Community members were treated to a fantastic evening at the Grand Bohemian Lodge in Greenville, SC. We kicked off the evening with fun activities for the entire family, such as a Selfie Station and making milestone bracelets celebrating our unbreakable bond. Our community members engaged in education and meaningful conversations throughout the evening and capped off the night with a photo of the group outside.

While most of our community was celebrating World Hemophilia Day in Greenville, Candi Mitchum was in Washington DC with the National Bleeding Disorders Foundation and the Hemophilia Federation of America for a special event on the Hill. The "Women and Girls Bleed Too" theme prevailed on the Hill this World Hemophilia Day. Select advocates from across the country joined together to shed a spotlight on an often-overlooked part of our community. Advocates met with lawmakers throughout the day to advocate for women and girls living with bleeding disorders and to spread awareness for all bleeding disorders.

We will continue to empower our community and advocate for access to treatment care and programs and more support for our women. Thank you all for coming out and sharing your time with us. A huge thank you to Shelby and Sanofi for the opportunity to participate in this day of recognition!

World Hemophilia Day
April 17
Recognizing all bleeding disorders

sanofi

Y.E.S. Support Group @ the Zoo

April 19, 2025 - Wallys Tacos & The Greenville Zoo, Greenville, SC

We had an amazing day to come together in support of our Young Family's Empowerment Support Group for young and new families. We united to share our journeys and to learn valuable lessons from each other. We started the afternoon off at Willy's Taco's in Greenville. We had a powerful presentation provided by Morgan Cook with Takeda about preparing for the unexpected, and were provided with an emergency tool kit packet to take home while eating a delicious taco lunch. After our educational lunch, everyone headed over to the Greenville Zoo where we had an amazing time enjoying seeing the animals!

Takeda

2025 STEP for Bleeding Disorders 5K Walk/Run Fundraiser

May 10, 2025, Columbia, SC

On Saturday, May 10th, our 12th annual STEP for Bleeding Disorders Walk/5K Run fundraiser was a little bit overcast and drizzly, but it didn't stop our community from showing up strong! 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, young and old, had fun with our face painting and artistry tattoos provided by Masquerade Designs, a commemorative STEP photo booth, and music throughout the event provided by our favorite DJ, Andre, with iPartyology. Cocky, the Gamecock, 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 Cocky 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, **Thomas and the Yabba Dabba Dashers** took the award for Most Creative Team with **Tim Freeman, of Thomas and the Yabba Dabba Dashers**, receiving the award for the Most Creative Individual Costume.

Once the parade was 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 Keith**, returned to the starting line. He was quickly followed by **Noah Mitchum and Bryce Martin**. 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 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 for dessert! We would like to express our gratitude to Ryan Griffith, Chair of 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 to all the volunteers, participants, fundraisers, donors, and sponsors. With your help, we were able to raise **$45,109. – which was 75% 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 16, 2026, for our 13th Annual STEP for Bleeding Disorders Walk!**

2025 STEP for Bleeding Disorders 5K Walk/Run Fundraiser (continued)

Most Creative and Original Costume: Tim Freeman
Most Creative and Original Team Costumes: Thomas and the Yabba Dabba Dashers
Top Fundraising Individual: Jakavius Watkins
Runner-Up Individual Top Fundraiser: Joey Krakowiak
Top Fundraising Team: Team Limitless
Runner-Up Top Fundraising Team: Team Logan
Largest Run/Walk Team: Team Limitless with 22
Runner-Up Top Run/Walk Team: Team Logan with 19
Oldest Participant: Jeff Lumnell
Youngest Participant: Emery Smith (1 month)

Race Finishers:
1st Place: Michael Keith
2nd Place: Noah Mitchum
3rd Place: Bryce Martin

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Community Engagements

Virtual Reach & Teach: VWD, Platelet Disorders & Ultra Rare Community Support Group

May 20, 2025 - via Zoom

During our annual Fall Family Advocacy Camp, it was requested by the VWD and Rare communities to have virtual events dedicated to the unique challenges these two communities face. We heard your request and made it happen with our Virtual Reach & Teaches! We have scheduled quarterly zoom meetings for our VWD, Platelet Disorders and Ultra Rare communities to gather together virtually to share updates on the VWD, Platelet & Ultra Rare communities and to support each other while sharing stories and lived expert experiences. Our first meeting was held on January 21st and was a success. While we did not have a large attendance for this first meeting, what we lacked in numbers we made up for in support. We had community members from all over the state join us and connect.

Community Connection & Engagement Dinner in Spartanburg

May 29, 2025 - CityRange, Spartanburg, SC

Continuing with the Voices of 46 outreach program, we headed to Spartanburg on May 29th! We concluded Mental Health Awareness month by hosting a community connections educational dinner centered around Mental Wellness. Bradley Odac presented an impactful presentation with useful information for addressing mental health, anxiety and checking in on your mental wellness. This dinner was sponsored by Novo Nordisk.

novo nordisk

Connect With Us!

Did you miss one of these amazing events? Learn more about our past and upcoming events by visiting our website at bda-sc.org or by subscribing to our e-newsletter.

Sign Up for Our E-Newsletter

Visit our Website

Visit our Facebook Page

Visit our Instagram Page

Upcoming Community Engagements

Helping embrace life's learning opportunities

H.E.L.L.O Annual Meeting & Bleeding Disorders Conference

June 6-7, 2025 - Embassy Suites Golf and Conference Center by Hilton 670 Verdae Blvd., Greenville, SC

We are excited to come together in unity and EMBRACE the opportunities of learning, connecting, sharing, and networking within the bleeding disorders community. We will hear from experts in the field of bleeding disorders care and treatment. There is no other event like this one in the state.

Participants will leave feeling empowered with support and knowledge. Please join us and see what it is all about.

Friday Night Opening Annual Meeting

Friday night we will start out with interactive and engaging opening session, "Connect & Celebrate", provided by BDASC, that will have you up, moving, and connecting with community members. We will have dinner together and connect with each other. BDASC will provide with the community a look at the past year and what is coming up for the rest of 2025.

Friday Night Chapter Awards

We love celebrating our Chapter Awards Recipients! Annually, BDASC chooses a selecting of outstanding individuals who embody the mission of the chapter. Chapter awards include Board Member of the Year, Legislative Advocate of the Year, Junior Advocacy Ambassador of the Year, the Volunteer of the Year and more. Academic scholarships are awarded to those members who are attending or plan on attending institutes of higher education in the fall. These scholarship recipients have applied through BDASC's Academic Scholarship program.

2024 Award Recipient, Warren Ingram

Saturday Education

Saturday will feature multiple sessions for you to explore and learn. We will kick off the morning with our general sessions for the entire community. We will hear about the Innovations in Treatment Therapies and what is in the development from Dr Bryant, sponsored by NHDF. From there we will break off into different tracks. Breakout sessions will be provided for men, women, caregivers, people with rare bleeding disorders, VWD and so much more.

But we cannot forget the teens and kids! Corporate Kids Events will be back with an amazing "Kids Camp" to keep our littlest community members entertained and safe! This year's theme is Super Spectacular Hero Day! Our Teens will also have their own programing, provided by the Leading Edge with GutMonkey! Teens will tackle important topics regarding bleeding disorders and their shared decision making, and learning independence skills. There is truly something for everyone!

More information can be found about our 2025 Annual Meeting & HELLO Conference by visiting our website at bda-sc.org.

The Following Pages Contain an Except from the 2024 Gratitude Report that will be shared at the Annual Meeting. To read the full report, please scan the QR Code or visit bda-sc.org.

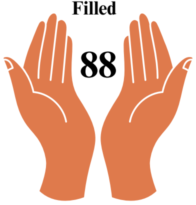
Excerpt From the 2024 Gratitude Report

2024 By the Numbers

2024 Major Events
Memberships Outreach

Advocacy Program: (year - round - 700 attendee outreach)
Adult Connections Retreat: 76 attendees
STEP for Bleeding Disorders Fundraiser and Awareness Campaign: 155 attendees
Annual Meeting & HELLO Conference: 162 attendees
Community Connection Outreach Programs & Support Groups: over 500 attendees
Teen Camp and Kids Camp Support: 250-300
Par For The Clot Charity Golf and Awareness Campaign: 175 attendees
Fall Family Advocacy Camp and Medical Symposium: 80 attendees
Winterfest Statewide Meeting: 80 attendees

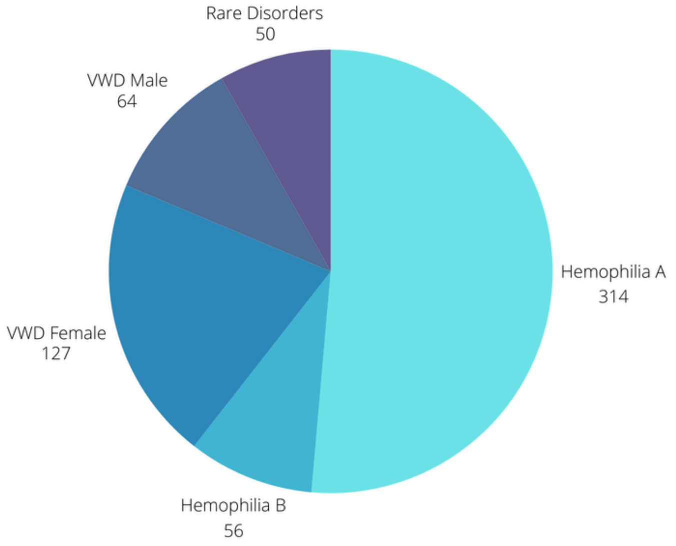
Financial Requests Filled



Financial Assistance and Scholarships Total: $26,006.00

Membership Served

(2025 Data by Disease State)



Social Media

Hours Uploaded: 28:05

Posts: 1,049
Reached: 15,419

Posts: 987
Reached: 5,700
New Followers: 47

Tweets: 110

Virtual Innovation Program Managed Devices: 82

Website Pages: 74

Communications Blast Recipients: 17,436

Hundreds of Volunteer Hours

Volunteers are the heart of this work. You are the reason we can offer hope, connection, and care to so many. From the bottom of our hearts, thank you—for showing up, for giving your time, and for believing in our mission. You make a difference, and we are deeply grateful for all that YOU do.

Financial Report

2024 Expenses

Programs - $265,810
Services - $73,120
Operations - $54,667
Fundraisers - $63,780
Camps - $58,225
Total Expenses - $515,602

Program Expenses

National & Local Education: $147,626
Advocacy: $74,699
Medical Symposium: $21,098
Community Outreach Support: $22,388

Services Expenses

Outreach and Communications: $44,059
Financial Assistance: $26,006
Research: $1,000
Global and National Support: $2,055

Operational Expenses

Management: $23,660
Facilities and IT: $20,329
Legal, Bookkeeping: $8,439
Organizational Development: $2,239

Fundraising Expenses

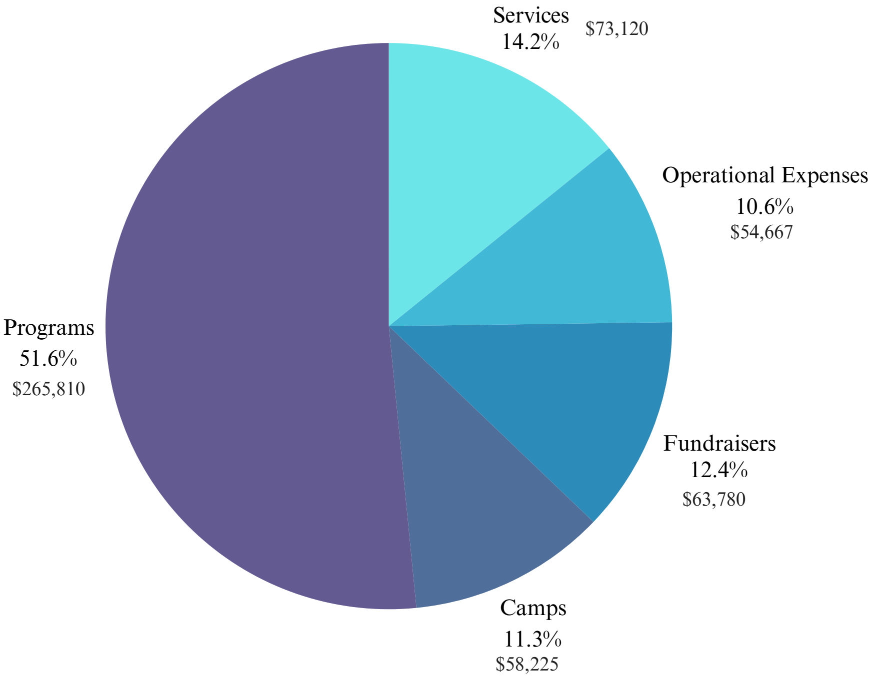
Step for Bleeding Disorders: $22,409
Par for the Clot: $41,372
Total: $63,780

2024 Revenue

Individual Donations - $12,624
Fundraisers -$116,706
Foundation, Corporate, and Grant Support - $356,961
Legacy Investments - $205,108
Total Revenue - $691,399

Our expenses outpaced our general revenue by $13,820 this year. With our growing membership and the costs of events and overhead rising, we have had to utilize our investment savings to cover these additional expenses. We need to increase our revenue to avoid pulling funds from our future legacy investments savings.

2024 Expenses $515,602



Excerpt From the 2024 Gratitude Report

Financial Report

2024 Revenue

Individual Donations - $12,624
Fundraisers -$116,706
Foundation, Corporate, and Grant Support - $356,961
Legacy Investments - $205,108

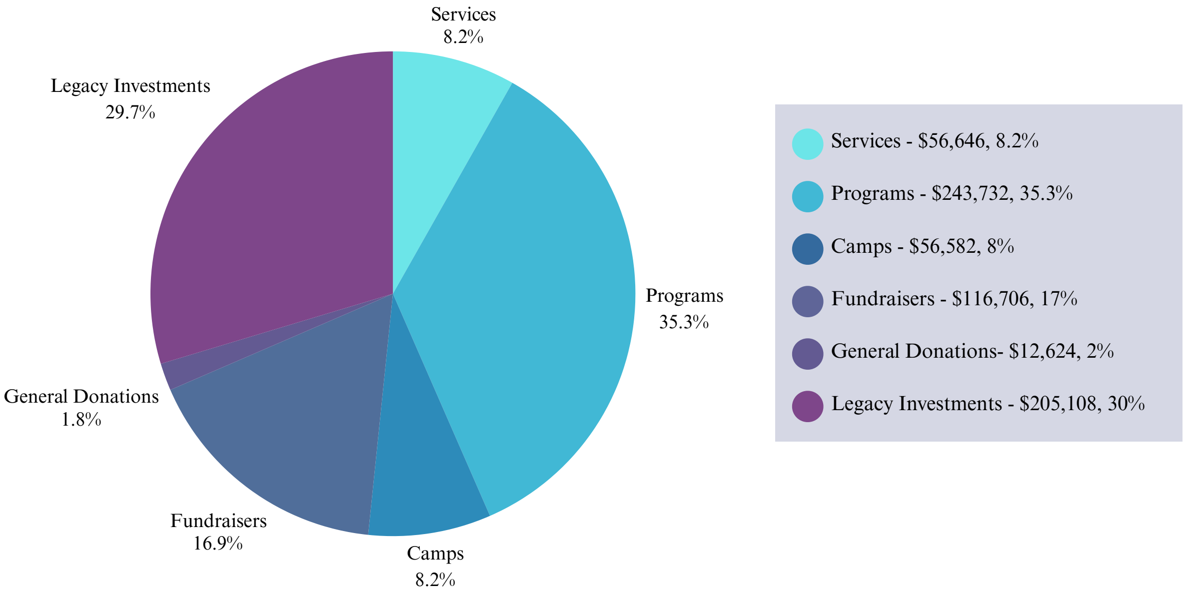
Total Revenue - $691,399

Fundraising Revenue

Par for the Clot Golf Tournament: $64,937
STEP 5K Walk: $51,749
Bleeding Disorders Awareness Month: $20
Annual Appeals (Giving Tuesday): $0

Total: $116,706

2024 Net Revenue & Legacy Investments - $691,399
General Revenue Funds - $501,782



Excerpt From the 2024 Gratitude Report

BDASC

About Us

Bleeding Disorders of South Carolina (BDASC) is a 501 (C) 3 Non-Profit organization and is a Chapter of the National Hemophilia Foundation (NHF) and a Chapter Member of Hemophilia Federation of America (HFA). BDASC was founded in 1973 by a group of parents interested in promoting awareness, providing group support, and assisting other national hemophilia organizations. The organization for 42 years existed as all-volunteer; providing programs and education, support and advocacy for access to care at the states capitol. Today, BDASC serves all 46 counties in the state, currently providing education and support services to over 1700 members and their families in 42 counties. BDASC provides the most current information and education in topics related to bleeding disorders, treatment therapies, insurance and advocacy. Today, BDASC has one full time Executive Director, a full time Engagement & Development Manager, and an advocacy consultant but relies on a strong volunteer base of its board of directors and members. Without our volunteers, we could not serve our mission.

What Are Bleeding Disorders?

Approximately 3.2 million Americans live with Hemophilia, von Willebrand's disease, and other rare factor deficiencies that prevent their blood from clotting normally. This can lead to extended bleeding from injuries, traumas, and even surgery, all of which can be fatal if not treated effectively.

Our History

1720 A woman in Plymouth, New Hampshire, is identified as one of the first people in America to be a carrier of hemophilia.

1803 First recognized that hemorrhagic bleeding disorder primarily affected men, and ran in certain families.

1948 The National Hemophilia Foundation is formed.

1965 Dr. Judith Graham Pool discovers thawing plasma was rich in factor VIII. Freeze-dried powdered concentrates containing factor VIII and IX soon became available for home infusions.

1973 Hemophilia of South Carolina is established.

Late 1970s to Mid-1980s Nearly half of all people with hemophilia became infected with HIV after using contaminated blood products.

1986 President Ronald Reagan proclaims March as "National Hemophilia Month."

1992 First recombinant factor VIII product approved by the Food and Drug Administration. The first factor IX would be approved five years later.

2010 Hemophilia of South Carolina holds its first legislative days and Gov. Mark Sanford proclaims March as Hemophilia Awareness Month.

2016 NHF and the U.S. Department of Health and Human Services worked together to designate March as an official U.S. health observance month Bleeding Disorders Awareness Month.

2018 The first subcutaneous treatment for hemophilia introduced to the market.

2020 HSC secures 30 proclamations throughout South Carolina commemorating March as Bleeding Disorders Awareness Month and the FDA gives Priority Review to the first gene therapy for Hemophilia A.

2021 Hemophilia of South Carolina becomes Bleeding Disorders Association of South Carolina to reflect all the Bleeding Disorders the organization serves.

2024 Bleeding Disorders Association of South Carolina creates the first nationally recognized von Willebrand's Disease Awareness Day.

2025 Bleeding Disorders Association of South Carolina creates the first nationally recognized Ultra Rare Bleeding Disorders Awareness Day.

2025 Bleeding Disorders Association of South Carolina creates the first nationally recognized Women Who Bleed Awareness Day.

Upcoming Community Engagements

Community Engagement & Educational Dinner: Building Your Advocacy Toolkit

June 17, 2025, Fort Mill, SC

Join us for an evening of connections and conversations in York County! Enjoy dinner while you get the tools you need to confidently advocate for yourself and others in the bleeding disorders community. Registration is available on our website.

Community Connection & Engagement Dinner in Anderson

June 25, 2025 - Earle Street Kitchen & Bar, Anderson, SC

It's always wonderful to come together in Anderson, serving the Oconee, Pickens and Anderson counties! We are delighted to host a community connections educational dinner centered around Gratitude. We will learn how practicing gratitude may be good for people living with chronic conditions. This dinner is sponsored by Sanofi.

Thank you for your understanding with our postponement of this event. If you have already registered, there is no need to re-register. If you would like to join us, registration is available on our website.

Sharing Your Story and Advocacy: Day at the Ballpark

June 28, 2025, Columbia, SC

Take me out to the Ballgame! Join us for an evening at the ballpark. We will meet up for an educational late lunch at Politico – Bull Street at 2:30pm. Our educational lunch topic will center around "Sharing your Story and Advocacy." Our educational lunch is being provided by Morgan Cook with Takeda. After lunch, we will head over to Segra Park for an evening ball game featuring the Columbia Fireflies VS. the Myrtle Beach Pelicans. It's also GLOW NIGHT featuring an LED wristband giveaway at the gates. This event is targeted toward gathering our VWD community but all members are welcome until the event is full. Lunch will begin promptly at 2:30 so we have enough time to head over to the park to catch the first pitch at 6:05pm. Registration is available on our website.

Virtual Reach & Teach - Platelets, VWD & Ultra Rare

July 22, 2025, Virtual via Zoom

During our annual Fall Family Advocacy Camp, it was requested by the VWD and Rare communities to have virtual events dedicated to the unique challenges these two communities face. We heard your request and made it happen with our Virtual Reach & Teaches! We have scheduled quarterly zoom meetings for our VWD, Platelet Disorders, and Ultra Rare communities to gather together virtually to share updates on VWD, Platelet & Ultra Rare bleeding disorders and to support each other, while sharing stories and lived expert experiences. Be sure to join us for our next Virtual Reach & Teach on July 22 , 2025 at 7PM.

Upcoming Community Engagements

Carolina Crew: Teen Retreat

July 31-3, 2025, Parkton, NC

We believe that teens have a lot to provide 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. All of our large events will have a teen program tailored just for their needs.

The Carolina Crew

BDASC and BDFNC annually provide a joint teen retreat for teens ages 13-18 years. 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 our teens to spend a weekend with friends – new & 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! Registration is currently available on our website. We have limited attendance so register today!

NBDF Bleeding Disorders Conference

August 21-23, 2025, Denver, CO

The National Bleeding Disorders Foundation's 77th annual Bleeding Disorders Conference will take place from August 21-23, 2025. Join NBDF for their premiere three-day event designed to connect, educate, and empower those in the Bleeding Disorders community.

BDC offers a program full of rich educational sessions, engaging networking opportunities, and a vibrant exhibit hall showcasing the latest advancements in research and patient care. Aurora's stunning scenery and the family-friendly venue will make this an unforgettable experience for both professional development and relaxation.

Par Fore the Clot Charity Golf Tournament

September 26, 2025,The Preserve at Verdae, Greenville, SC

We look forward to hosting our annual golf tournament fundraiser, the Par Fore The Clot on September 26, 2025. Players will enjoy a wonderful day of golf, food, fun, and competition. In 2024, the Par Fore The Clot gathered 36 teams and 144 participants who competed for great prizes and enjoyed a wonderful awards banquet immediately following the tournament in the Embassy Suites Hotel Terrace. We are grateful to all our 2024 tournament players for helping us raise over $64,000 and invite everyone back to compete again in 2025!

Learn More by Scanning the QR Code or visiting our website at bda-sc.org.

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Want to hear from someone who has received HEMGENIX?

Watch Michael's Story here:

Visit HEMGENIX.com to learn more

— Michael, 23-year-old treated with HEMGENIX

Actual HEMGENIX patient. Patient experiences may vary.

CSL Behring

Voices of Our Community

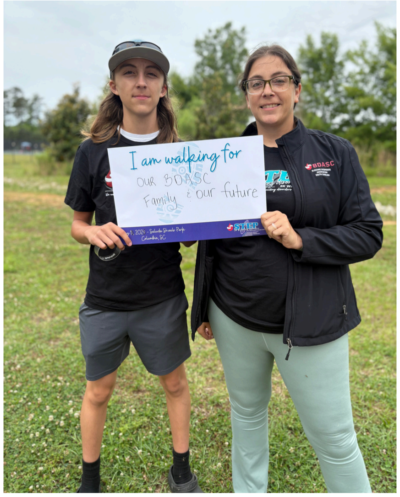
your voice matters

This issue of The News Infusion includes a new version of the Voices of our Community. We have enjoyed reaching out to community members asking them to share their voices. We have been on a mission to ensure that every member of the bleeding disorders community is represented and heard. With the implementation of the Voices of 46 and providing our community members a microphone in which to share their stories, we hope to encourage every BDASC member to advocate for themselves and share their experiences. To learn more about our Voices of 46 program, visit our website at www.bda-sc.org or attend one of our outreach program events.

Would you like to be featured in our “Voices of Our Community” section of our newsletter? We would love to share your voice. Please reach out to the Chapter Office at 864-350-9941 or email Sue Martin at sue.martin@bda-sc.org.

My Reasons to Advocate

by Candi Mitchum



I hear the phrase "you don’t know till you know " a lot in our bleeding disorder community and it really hits home for me. I went through my childhood, teenage years and part of adulthood without realizing I had a bleeding disorder. Now that’s not to say that my VWD wasn’t making itself known because it definitely was.

By the time I was in high school, I had been seen several times by my doctors for issues with my bleeding. I was sent home from school for bleeding through my clothing so many times. The doctors dismissed me and told my mom it was in head and that I should use better hygiene. I was left feeling ashamed and confused as to why no one else was bleeding like me.

When my husband joined the Marines, we moved to North Carolina at his first duty station. Our family grew and as it did my bleeding issues did as well. I had seen so many doctors and tried every form of birth control to help slow down my bleeding. You name it pills, rings, IUDs, patches, they placed me on it. And of course nothing helped like I had hoped. Every doctor that treated me assured me that the problem was my uterus.

By the time my third baby, little Emma, arrived, my bleeding was so out of control that I was having two 7-day periods a month. Which when you do the math, that I was bleeding 6 months in a year. It was so bad that even if I wasn’t bleeding if I even got my heartrate too high, I would start bleeding again. Desperate to fix the problem I kept going to the doctors, eventually that is when they left me with only one option to have a hysterectomy. So, at 27 years old I agreed to have a hysterectomy as I was told it was the only way to stop my suffering.

However, my doctors unknowingly opened pandoras box. By day two, I noticed when I went to the restroom I was spotting. By the next day, I had to be taken to the doctor’s office who performed my surgery. My spotting from the day before was now a non-stop trickle. I was treated with silver nitrate as much as he could to stop bleeding. I was told that I must have torn a stitch, so I was placed on bed rest, and I thought the worst was over. However, a week post op I was playing cards with my family while still on bedrest when I sneezed. That sneeze was the scariest sneeze of my life.

I felt a gush and I knew something was wrong. My mother and husband helped me to the bathroom. By the time we got to the bathroom I was passing large tennis ball size clots. I will NEVER forget the looks on my husband and mother’s faces, the complete looks of fear and shock. I don’t remember much of how I got to the hospital, I can’t tell you which car or where I sat. However, I do remember the ER staff confused and not understanding why I am passing so much blood and clots. They treated me like post-partum moms. They for some reason began to roughly massage my abdomen trying to get more clots to come. I remember crying and begging for them to call my doctor so he could explain I had just had a hysterectomy.

After waking from my second surgery my doctor told me that I had never ripped a stitch like he had originally thought. In fact, He had no idea where I was even bleeding from. He said when he went back in, he just double stitched back over all the original stitches. He said that he then prayed over me for the bleeding to stop. I was never treated at any time during this with Factor. After that I was referred to my first Hematologist/Oncologist. After some tests I was told I was fine and nothing was wrong.

Continued On Page 21

Continued from Page 20

During this time, I was also working in the Veterinary field and believe it or not, but we had been treating a Doberman for Von Willebrand's. It was the first time I had ever heard of VWD. So not too long later when I first heard that they were testing me for VWD, I knew that it was genetic. So, with that knowledge, I went to my kids' pediatrician and told her everything. She sent the kids to Prisma Hospital for testing which of course is now our HTC. That's when my son Noah's bloodwork came back as also having VWD.

That entire process led us to the wonderful Robin Jones and Dr. Ambrose. When they took on Noah as a patient, they immediately opened their arms and accepted me as a patient. So, I could finally receive care for my VWD. Noah and I now have yearly family appts together in the same room. My wonderful care team also helped me get active in the Bleeding Disorders Association of South Carolina. Noah and I are both thankful for our Hemophilia treatment center and our care team. We both have had unnecessary procedures due to our VWD and the lack of knowledge that we had a bleeding disorder.

This is where I lead you back to the saying I told you before that "You don't know till you know". I often think back about my story and think "Heck, dozens of doctors treating me didn't know until they knew" and some still don't to this day. That is why I will advocate and use my voice as much as I can. No patient should have to go through what I did to receive their diagnosis, and I hope to use my story to prevent it.

Bleeding Disorders Summer Camp - An Opportunity for Fun and Growth

by Samantha Javorka

Each summer provides an opportunity for relaxation and fun! Many children look forward to time by the pool or heading to summer camp. But when it comes to living with a bleeding disorder going to many typical summer camps can be a challenge, never mind sleep-away summer camps. This is why many chapters and states offer a camp experience for those with chronic illnesses and bleeding disorders.

> "My favorite thing about bleeding disorder camp is having fun and meeting new people. The counselors were a lot of fun." - Rylee

The first bleeding disorder summer camp was created almost 50 years ago in Michigan as a way to serve the upper-Midwest bleeding disorders community. The camp was created as a way to provide a safe, but fun environment for children and teens with bleeding disorders. It's a place where they can learn valuable skills in order to become independent teens and adults. It's a place where they can meet other children living with bleeding disorders as well. Often these camps are staffed with your HTC physicians, nurses and trained staff, that make sending your child to camp easier!

Here in South Carolina, there are 2 major camp opportunities for sleep-away camp for children. Camp Courage is held in the Upstate and is available to those children who seek care at the Prisma Hemostasis and Thrombosis Center of the Upstate in Greenville. Camp Burnt Gin is offered to every child living with a bleeding disorder in the state of South Carolina. Camp Burnt Gin is located in Wedgefield, SC and offers a weeklong camp for children living with sickle cell and bleeding disorders.

Both camps offer the opportunity for children to experience a traditional camp with a few extra safety precautions. Campers are allowed to practice their self-infusion skills and to watch other kids practice their infusions. This helps campers to gain the confidence to take on the responsibility for their own treatment.

BDASC *ice cream social*

BDASC will be at camp to provide an Ice Cream Social to campers & staff!

Chapter Day at Camp Courage: Ice Cream Social
June 24, 2025, Greenville, SC

Chapter Day at Camp Burnt Gin: Ice Cream Social
July 8, 2025, Wedgefield, SC

"I scream, you scream, we all scream for ice cream!" One of our favorite ways to support our bleeding disorders camps is to provide an Ice Cream Social for all the kids in attendance. We are excited to be attending Camp Courage and Camp Burnt Gin. We are grateful to partner with Marble Slab again to bring ice cream and everyone's favorite toppings to camp. Our staff and volunteers will be dishing out ice cream during the day after the kids have lunch. Check out the dates to see when BDASC will be at your child's camp this summer! Thank you to our sponsors for our charitable grants in support of our camp program!

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First von Willebrand Disease Patient Dosed with Investigational Sub-Q Therapy

March 5, 2025

Hemab Therapeutics recently announced that the first patient has been dosed in their phase 1/2 clinical trial of HMB-002, an investigational subcutaneous therapy for patients with von Willebrand disease (VWD). It is developed with a monovalent antibody to increase levels of both von Willebrand factor and factor VIII. HMB-002 is a prophylactic therapy to prevent bleeding in people will all types of VWD.

The trial, known as Velora Pioneer, is designed to evaluate the safety, tolerability, pharmacokinetics, pharmacodynamics, and efficacy of HMB-002 in individuals with VWD.

According to a Hemab press release, this first patient was administered HMB-002 at Richmond Pharmacology in London under the supervision of Principal Investigator, Dr. Ulrike Lorch. The study is currently enrolling additional participants. The company also presented preclinical data on HMB-002 at the recent 18th Annual Congress of the European Association for Haemophilia and Allied Disorders (EAHAD).

“Von Willebrand Disease is characterized by a deficiency in VWF activity and sometimes associated with lowered levels of FVIII – both essential to control severe bleeding,” said Dr. Priyanka Raheja, the Royal London Hospital, Barts Health NHS Trust. “HMB-002 functions by increasing VWF and FVIII and could offer a complete disease correction for some and substantial modification for bleeding tendency for others. I am excited to be a contributing investigator on the Phase 1/2 trial.”

Source: Hemab Therapeutics press release dated February 27, 2025
https://www.bleeding.org/news/first-patient-dosed-with-investigational-sub-q-therapy-for-von-willebrand-disease

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Be sure to keep up-to-date with what is happening within the von Willebrand Disease, Ultra Rare Bleeding Disorders and Platelet Disorders communities by attending our Virtual Reach & Teach events. These virtual meetings happen throughout the year and are a great opportunity to meet with others in the community facing similar challenges. We provide the opportunity to hear about new therapies and resources as they become available, as well as a chance to connect with others.

Upcoming Dates:
July 22 @ 7pm
September 2 @7pm
November 18 @ 7pm

Register Here

vWD Support Group Webpage

Ultra Rare Support Group Webpage

Visit our von Willebrand Disease and Ultra Rare Bleeding Disorders Support Group Webpages at our website at bda-sc.org or by scanning the QR Codes. These pages are updated with resources and events as available. Please be sure to check out these pages for more information.

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

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Neal Lourie / Law Firm
New Laurel St. Missionary Baptist Church
North Edisto Logging Co. - Dedra Rush
Palmetto Smiles - Heather Danley
Rick Anthony - State Farm
Roof Hardware
Worthys Florist

Thank you South Carolina Legislators for your support in protecting South Carolinians who rely on third party patient assistance to afford their high cost treatment medication. Enact legislation and ensure all copays count towards a enrollee's maximum out of pocket cost share.

Pass H.3934 & S.330

House of Representatives

Rep. Kevin Hardee (R-105th)
Rep. Carla Schuessler (R-61st)
Rep. Terry Alexander (D-59th)
Rep. Carl Anderson (D-103rd)
Rep. Frank Atkinson (D-57th)
Rep. William Bailey (R-104th)
Rep. Nathan Ballentine (R-71st)
Rep. Justin T. Bamberg (D-90th)
Rep. Bruce Bannister (R-24th)
Rep. Heather Bauer (D-75th)
Rep. Thomas Beach (R-10th)
Rep. Beth E. Bernstein (D-78th)
Rep. Phillip Bowers (R-3rd)
Rep. Jeff Bradley (R-123rd)
Rep. Gary Brewer (R-114th)
Rep. Case Brittain (R-107th)
Rep. James Burns (R-17th)
Rep. Joseph Bustos (R-112th)
Rep. Michah Caskey (R-89)
Rep. Don Chapman (R-8th)
Rep. William Chumley (R-35th)
Rep. William Clyburn (D-82nd)
Rep. Gilda Cobb-Hunter (D-95th)
Rep. Neal Collins (R-5th)
Rep. Bobby Cox (R-89th)
Rep. Brandon Cox (R-92nd)
Rep. Heather Crawford (R-68th)
Rep. Sylleste Davis (R-100th)
Rep. Chandra Dillard (D-23rd)
Rep. Adam Duncan (R-2nd)
Rep. Sarita Edgerton (R-34th)
Rep. Shannon Erickson (R-124th)
Rep. Cal Forrest, Jr. (R-39th)
Rep. Craig Gagnon (R-11th)
Rep. Kambrell Garvin (D-77th)
Rep. Gil Gatch (R-94th)
Rep. Daniel Gibson (R-12th)
Rep. Doug Gilliam (R-42nd)
Rep. Wendell G. Gilliard (D-111th)
Rep. Lee Gilreath (R-7th)
Rep. Jerry N. Govan, Jr (D-93rd)
Rep. Hamilton Grant (D-79th)
Rep. Val Guest (R-106th)
Rep. Brandon Guffey (R-48th)
Rep. Patrick Haddon (R-19)
Rep. Bill Hager (R-122nd)
Rep. Christopher Hart (D-73)
Rep. Tom Hartnett (R-110th)
Rep. Charles Hartz (R-81st)
Rep. Jackie Hayes (D-55th)
Rep. Rosalyn D. Henderson-Myers, Ph.D. (D-31st)
Rep. William Herbkersman (R-118th)
Rep. William Hewitt (R-108th)
Rep. Davey Hiott (R-4th)
Rep. William Hixon (R-83rd)
Rep. Harriet Holman (R-102nd)
Rep. Lonnie Hosey (D-91st)
Rep. Chris Huff (R-28th)
Rep. Jay Jordan (R-63rd)
Rep. Jeffrey Johnson (R-58th)
Rep. Jermaine Johnson (D-52nd)
Rep. Wendell Jones (D-25th)
Rep. Jay Kilmartin (R-85th)
Rep. John King (D-49th)
Rep. Roger Kirby (D-101st)
Rep. Kathy Landing (R-80th)
Rep. Brian Lawson (R-30th)
Rep. Randy Ligon (R-43rd)
Rep. Steven Wayne Long (R-37th)
Rep. Phillip Lowe (R-60th)
Rep. Jason Luck (D-54th)
Rep. David Martin (R- 26th)
Rep. John Mccravy (R-13th)
Rep. Annie McDaniel (D-41st)
Rep. Timothy McGinnis (R -56th)
Rep. Cody Mitchell (R-65th)
Rep. W. Scott Montgomery (R-32nd)
Rep. Travis A. Moore (R-33rd)
Rep. Dennis C. Moss (R-29th)
Rep. Mike Neese (R-44th)
Rep. Brandon Newton (R-45th)
Rep. Weston Newton (R-120th)
Rep. Melissa Oremus (R-84th)
Rep. Jordan Pace (R-117th)
Rep. Fawn Pedalino (R-64th)
Rep. Thomas Pope (R-47th)
Rep. Paula Rawl Calhoon (R-87th)
Rep. Robert Reese (D-70th)
Rep. Michael Rivers (D-121st)
Rep. Robby Robbins (R-97th)
Rep. Seth Rose (D-72nd)
Rep. Todd Rutherford (D-74th)
Rep. Blake Sanders (R-9th)
Rep. Heath Sessions (R-46th)
Rep. Tiffany Spann-Wilder (D-109th)
Rep. Leonidas Stavrinakis (D-119th)
Rep. Bill Taylor (R-86th)
Rep. James Teeple (R-116th)
Rep. Jackie R. Terribile (R-66th)
Rep. David Vaughan (R-27th)
Rep. Courtney Waters (D-113th)
Rep. David Weeks (D-51st)
Rep. Elizabeth Wetmore (D-115th)
Rep. Joe White (R-40th)
Rep. William Whitmire (R-1st)
Rep. Paul Wickensimer (R-22nd)
Rep. Robert Williams (D-62nd)
Rep. Mark Willis (R-16th)
Rep. Christopher Wooten (R-69th)
Rep. Richard Yow (R-53rd)

Senate

Sen. Michael Gambrell (R-2nd)
Sen. Jason Elliott (R-6th)
Sen. Karl Allen (D-7th)
Sen. Allen Blackmon (R-27th)
Sen. Greg Hembree (R-28th)
Sen. Everett Stubbs (R-17th)
Sen. Ross Turner (R-8th)
Sen. Tom Young (R-24th)
Sen. Russell Ott (D-26th)
Sen. Billy Garrett (R-10th)
Sen. Larry Grooms (R-37th)
Sen. Carlisle Kennedy (R-23rd)

On Wednesday, May 7th, advocates from BDASC, the National Bleeding Disorders Foundation, the National MS Society and the American Cancer society came together in Columbia to present their testimonies with the Labor, Commerce & Insurance Sub-Committee that will decide the fate of our bill, H.3934. Advocates testified on the effects of co-pay accumulators and the importance of passing H.3934. Representative Carla Schuessler (R-61st), as a co-sponsor presented the bill to the committee and shared the following in support of this legislation:

- There are **110 Co-Sponsors** in the House of Representatives
- 7 of the 8 members on the LCI Sub Committee are in support of the bill.
- 16 of the 17 members on the LCI Committee are in support of the bill.
- All 7 members on the 3M LCI Pharmacy Benefits Manager Ad-Hoc Committee are in support of the bill.
- All 12 on the Insurance Rate Review Ad-Hoc Committee are in support of the bill.

Supporters are Members from:

- Majority Caucus
- Minority Caucus
- Freedom Caucus
- Women's Caucus
- Black Caucus
- Family Caucus

Watch the full hearing by scanning the QR Code.

Received 7 Letters of Support from the following Organizations:

- Hypertrophic Cardio Myopathy Association
- SC Pharmacy Association
- Oncology Nursing Society
- Association of Clinical Oncology
- Cystic Fibrosis United
- Cystic Fibrosis Foundation
- National Multiple Sclerosis Foundation

SINE DIE

By James Romano

The first year of the two-year legislative session of the South Carolina Legislative Session has come to an end. The Legislature adjourned Sine Die on May 8th, 2025. Sine Die is a Latin legal term for ending for an unspecified length of time. The Legislature will definitely reconvene in January but has adjourned Sine Die to allow the Governor to reconvene in special session if he chooses or the need arises. Where does our legislation stand at the end of the first session? The House bill, H. 3934, has accumulated 110 sponsors & cosponsors out of 123 Members of the South Carolina House of Representatives. This is remarkable work that the community has undertaken. The Insurance Subcommittee of the House Labor, Commerce and Industry Committee held a hearing where the Bleeding Disorders Association of South Carolina (BDASC) testified for over 1 hour. We have strong headwinds, and we need your help to see this to the end. The bill in the Senate, S. 330, currently has 12 cosponsors which represents a major advancement over the last session. To overcome opposition in the Senate we need to continue pushing Senators for support. We have made herculean strides this year, and our success is because of our advocates voices, hard work and support.

Recapping, the legislation would ban the health insurance industry practice of copayment accumulators. Copayment accumulators are used to pass more costs onto patients and families by accepting patient assistance then not counting that assistance towards the policy out-of-pocket maximum. This policy affects patients with rare diseases and chronic illnesses who receive copayment assistance from pharmaceutical manufacturers, patient assistance organizations and other entities such as places of worship. The legislation would mandate that health insurance policies, regulated by the State of South Carolina, accept patient assistance and count it towards the deductible and out-of-pocket maximum.

We will have limited time to pass this bill next year. We have to work all summer and fall meeting Members of the House and Senate to keep this bill at the forefront of their focus. BDASC will host its legislative breakfast on January 14th, the first breakfast of the new session, and we will need our advocates and members to attend and talk with legislators who are wavering on their support. We will need to push for a hearing/mark up of the bill in January and a smooth trajectory to a House vote. At the same time, we will need to have solid support in the Senate to get the bill moving in that Chamber. Next year is an election year in South Carolina, all of the seats in the House of Representatives are up for election as well as Governor.

What Can You Do to Help?

1. Ask your family members and friends to reach out to offices voicing their support for this legislation, this is critical for offices to hear from multiple constituents. Have your children reach out and ask to speak to legislators, BDASC can facilitate all of this.
2. Reach out to your Representative and ask for their continued support for the legislation entering the next session of the legislature. Offices are being bombarded by the insurance companies to change their support for the bill. We need you to make sure your Representatives continues to stand with the Community.
3. Representative Mark Smith (R-99th) has pulled off as a cosponsor. If you are interested in reaching out to Representative Smith and asking him for his reasoning, BDASC can provide you with his email and cell phone number.
4. Work with Sue Martin and Jim Romano to schedule a virtual meeting with your Senator and ask them to cosponsor the Senate bill. Please, if your Senator has not cosponsored this is critical moving forward.

Learn More About H.3934 & S.330 on the Palmetto Health Collective Website

Find our who your state Legislators are at scstatehouse.gov

Pfizer Halts Hemophilia B Gene Therapy

February 25 , 2025

Pfizer, Inc. has announced that they are ceasing global development and commercialization of Beqvez™, the company's hemophilia B gene therapy product.

Beqvez was designed with bioengineered adeno-associated virus (AAVs) vectors to introduce a working copy of the factor IX (FIX) gene to generate therapeutic levels of clotting FIX. It received approval from the U.S. Food and Drug Administration less than a year ago, in the spring of 2024.

According to a recent Fierce Pharma news post, several reasons led to the discontinuation, including "limited interest" from patients and doctors toward hemophilia gene therapies to date, a Pfizer spokesperson told Fierce Pharma in a statement.

People with hemophilia, their families, and healthcare providers must weigh several considerations and unknowns when deciding on whether to embark on a one-time treatment such as gene therapy. These include questions about long-term safety and efficacy, cost, and the potential promise of other advanced therapies.

Supplemental NBDF Resources
Gene Therapy Resource Guide: https://www.bleeding.org/bleeding-disorders-a-z/treatment/future-therapies/resource-guide
Shared Decision Making: https://www.bleeding.org/bleeding-disorders-a-z/treatment/shared-decision-making

Printed with permission from the National Bleeding Disorders Foundation
Source: https://www.bleeding.org/news/pfizer-discontinues-beqvez-hemophilia-b-gene-therapy

Massive Layoffs and Restructuring at the Department of Health and Human Services

On March 27, the Department of Health and Human Services (HHS) announced a significant restructuring, including a drastic reduction in the number of employees as well as organizational changes. The organizational changes include the creation of a new agency, the Administration for a Healthy America, which will combine multiple agencies, including the Health Resources and Services Administration (HRSA), which houses hemophilia programs.

In response to the reduction in force, on April 1, thousands of employees throughout HHS, including at the CDC, NIH, FDA, and CMS received termination emails. It has been reported that all but two people within the CDC's Division of Blood Disorders and Public Health Genomics were laid off. It is still unclear what the impact of this restructuring will have on existing programs, but it is certain that layoffs of this size will affect the operations of many federal programs. NBDF is working closely with community and coalition partners and Congressional champions to understand what is happening and will continue to advocate to protect all federal bleeding disorders programs.

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Source: https://www.bleeding.org/news/government-relations-update-march-2025


BLEED PROTECTION
YOU CAN MEASURE

Paper Finds Bone Health Screening Rates at HTCs Represent Clinical Care Gap

The topic of bone health in people with bleeding disorders has received more attention and study in recent years, with reports suggesting that people with hemophilia (PwH) and people with von Willebrand disease (PwVWD) experience higher rates of osteoporosis and bone fractures. That said, screening for bone health is not consistent across federally funded hemophilia treatment centers. A lack of clear, uniform screening guidelines is a major contributing factor to this disparity.

A new paper published in the journal Haemophilia looked to shed light on current practices of HTCs for assessing bone health. The authors created a survey focused on HTC's utilization of two common methods for assessment: bone density scanning through Dual-energy X-ray Absorptiometry (DEXA) and blood serum tests of vitamin D levels.

The electronic survey was disseminated to all federally funded HTCs in the U.S. from June 2023 to August 2023. It included nine multiple choice questions relevant to the demographics of HTC participants, overall HTC profiles, plus current practices for DEXA scanning and measurements of vitamin D levels. A total of 147 HTCs received the survey, with 66 responding.

Only nine of the 66 (13.6%) indicated that they use DEXA scans to assess bone health. Of these three were adult HTCs and six were "lifespan" HTCs; meaning they serve both pediatric and adult patients. DEXA scans were ordered by HTC physicians in five of the centers (55.5%), while at the other four (44.4%), patients were referred to primary care doctors, endocrinologists or other specialists for bone health evaluation and performance of DEXA scans. In terms of types of patients scanned, the majority were individuals with hemophilia A or B. Four HTCs performed screening exclusively in males, while five HTCs conducted screening in both males and females.

Among the 66 centres, 21 HTCs (31.9%) indicated that they routinely conducted screening for vitamin D deficiency during comprehensive visits, while the remaining 45 (68.1%) did not conduct any vitamin D deficiency screening. Of the 21 centers that screened for vitamin D deficiency, there were seven were exclusively pediatric centres, three wereadult centers and 11 lifespan centers. Lastly, only five HTCs – all lifespan centers, conducted both DEXA scans and vitamin D deficiency screening.

It should be noted that a foremost limitation on this study was the modest overall response rate of 44.8% representing less than half of federally funded HTCs in the U.S. Therefore, the authors caution against drawing sweeping conclusions, emphasizing that the data does not necessarily reflect the practices of all or even the majority of HTCs.

The authors also offer some explanations for why bone health assessments are not more widely recommended at HTCs.

"While this finding was rather surprising, there are several reasons why providers are not recommending bone health assessment. First, there is a lack of consistency in expert recommendations regarding bone health assessment," explained the authors. "The World Federation of Hemophilia (WFH) guidelines recommend that screening may be appropriate for those with haemophilia who are at high risk or have multiple clinical risk factors for osteoporosis but acknowledge the uncertainty whether routine osteoporosis screening is necessary for all individuals with haemophilia or not. Furthermore, the criteria for 'high risk' are not clearly elaborated."

Paper Finds Bone Health Screening Rates at HTCs Represent Clinical Care Gap (Cont.)

The paper goes on to lay out examples of the somewhat disparate guidelines for bone health assessment amongst various international health organizations. In addition, guidance from U.S. based entities such as The United States Preventive Services Task Force and the National Osteoporosis (NOF) include clear recommendations for health screening in women 65 years or older, and potentially younger women as well depending on other risk factors. However, there seems to be a lack of consensus relevant to screening in other subgroups such as for osteoporosis in men. And while a multispecialty council of bone health experts convened by the NOF has identified hemophilia as a condition that can be linked to increased risk for osteoporosis, von Willebrand disease was not mentioned.

The authors suggest several ways that bone health assessments could be enhanced including the integration of standardized osteoporosis screening guidelines into national hemophilia care protocols. Accredited healthcare provider education and resources to support clinical decisions may also improve awareness and lead to enhanced screening practices. Better interdisciplinary collaboration between HTC providers, primary care physicians, and endocrinologists could also foster more prompt assessments of bone health.

In addition, patient advocacy organizations could complement these efforts by fostering awareness, monitoring bone health outcomes, and promoting/supporting screening initiatives. Lastly, significant barriers associated with insurance and reimbursement would also need to be addressed if broad enhancements in bone health screening may be achieved.

“In summary, our study identified a clinical care gap in the evaluation of bone health in PwH and PwVWD at HTCs across the United States. Considering the growing burden of an aging population with haemophilia and VWD (and the broad scope of bleeding disorders), future efforts should focus on gaining a deeper understanding of barriers to bone health in PwH and PwVWD and developing guidelines for bone health assessment, with a specific focus on measuring vitamin D levels and performing DEXA scans,” concluded the authors.

Citation
Citla-Sridhar D, Ahuja S, Sidonio R, Chitlur M, Sharathkumar A, Tobase P, Acharya S, Isaac D, Kulkarni R, Johnson MM. Bone Health Screening in Persons with Bleeding Disorders: A Survey of United States Haemophilia Treatment Centres. Haemophilia. 2025 Mar 7. doi: 10.1111/hae.70027. Epub ahead of print. PMID: 40052405.

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 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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Resources and Contact Information

Medical Facilities

Prisma Health Hemostasis and Thrombosis Center of SC - Midstate

For all new and previously scheduled appointments, factor refills, school needs, general questions or general concerns: Contact Robin Jones, MSN, MHA, RN, CPN, CPHON, Nurse Navigator, SC Hemophilia Treatment Center at 803-434-1028 or email: schemophilia@prismahealth.org.

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

Florence
101 William H Johnson Street, Suite 400
Florence, SC 29506

Orangeburg
1724 Village Park Drive
Orangeburg, SC 29118

Prisma Health Hemostasis and Thrombosis Center of SC - Upstate

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

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

Resource Information

SC Dept. of Public Health Children with Special Health Care Needs Hemophilia Program
2100 Bull Street
Columbia, SC 29201
Phone: 803-898-0784
Website: dph.sc.gov/health-wellness/child-teen-health/services-children-and-youth-special-health-care-needs/hemophilia

American Pain Foundation (APF)
Phone: 888-615-PAIN (7246)
Hemophilia Chronic Pain Support Group
Website: painaid.painfoundation.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

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: panfoundation.org
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.

Accessia Health
Financial assistance to people who are diagnosed with chronic medical conditions.
P.O. Box 5930
Midlothian, VA 23112
Phone: 800-366-7741
Website: www.accessiahealth.org/

The Assistance Fund - TAF
8427 Southpark Circle, Suite 100
Orlando, FL 32819
Phone: 855-845-3663
Website: www.tafcares.org

Resource Information

Patient Notification System
The Patient Notification System is a free, confidential, 24-hour communication system providing information on therapy withdrawals and recalls.
Phone: 888-UPDATE U (873-2838)
Website: www.patientnotificationsystem.org

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

The South Carolina Rare Disease Advisory Council
Website: www.rarediseasesc.org/

SC Healthcare Marketplace
Phone: 800-318-2596
Website: www.healthcare.gov

National Organizations

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@Bleeding.org
Website: www.Bleeding.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: 514-875-7944
Fax: 514-875-8916
Email: wfh@wfh.org
Website: www.wfh.org

Bleeding Disorders Association of SC
Green Gate Office Park
25 Woods Lake Road, Ste. 300
Greenville, SC. 29607
Phone: 864-350-9941
Website: www.bda-sc.org

Mark Your Calendar!

Looking Ahead: 2025 Major Community Engagement Opportunities - Save the Dates!

June 6 - 7: HELLO Bleeding Disorders Conference, Greenville, SC
July 31 - August 3: Teen Retreat, Rockfish Camp and Retreat, NC
August 21 - 23: NBDF's Bleeding Disorders Conference, Denver, CO
September 26: BDASC's Par for the Clot Charity Golf Tournament, Greenville, SC
October 17-19: (TBD) - Fall Advocacy Family Camp and Medical Symposium, SC
December 13: Winterfest, Columbia, SC

Be sure to check out our website, e-blast newsletters and social media for registrations and updated information on upcoming events.

Additional Ways to Support BDASC

BDASC

Visit our website at bda-sc.org (or scan the QR code) and click "Make a Donation" to learn more about how you can support BDASC!

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

United Way

Donate through United Way! Go to Donate through the United Way. Visit their website at www.unitedway.org. Be sure to ask to have BDASC as your planned giving or workplace campaign.

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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ROCKFISH CAMP AND RETREAT CENTER

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