

The News Infusion

The Official Newsletter of Bleeding Disorders Association of South Carolina

VOLUME 15, ISSUE 3

SUMMER 2024



Featured Articles

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2024 Par for the Clot, page 17



June 21-22

Greenville, SC

About BDASC & *The News Infusion*

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

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.

Fall/Winter 2024 Calendar of Events

Looking Ahead: Save the Dates!

Community Engagements

August 24—Charleston Back to School Event, Charleston	September 20-22—Getting' In the Game, JNC, Henderson, NV
August 31—Tailgating and Bowling Community Event, Myrtle Beach	September 27—Par for the Clot Charity Golf Tournament, Greenville
September 8—Celebrating Hispanic Heritage Month, Columbia	October 19-20—Fall Family Advocacy Camp, Columbia, SC
September 12-15—NBDF's Bleeding Disorder Conference, Atlanta, GA	December 14—Winterfest, Columbia, SC

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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!

51st HELLO Conference & Annual Meeting

June 21-22, 2024, 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. At the end of June, our community came together to celebrate achievements and to learn about the current situation within the bleeding disorders community. On Friday evening, we hosted our annual Chapter Awards and Scholarship Presentations. We were delighted to honor, not just

and young adults who are striving to continue their education through higher learning. BDASC provides several scholarship opportunities for its members. We received many amazing applications this year and were proud to present our scholarship recipients. We strive to support those impacted by bleeding disorders in our community in many ways, and we are proud of our scholarship program. After our dinner and award



bleeding disorders community members, but also those who have supported our community over the last year. We were pleased to have Representative Jason Elliot in attendance as we presented him with our Legislative Advocate of the Year award. Representative Elliot has been vital in helping us secure co-sponsors for our current year legislative task—H. 3618. Each year, BDASC proudly supports our teens



ceremony, we were honored to be able to present a showing on "On The Shoulders of Giants." For the first time in history, a generation of people with hemophilia are living past 50. This heartwarming road trip around the country reunited the survivors from past generations and shared their journey. Our South Carolina Bleeding

Continued on page 4



Continued from page 3

Disorders community is fortunate to count Warren & Sharon Ingram amongst its members and it was amazing to see them share their story. On Saturday, during our Annual Meeting, BDASC welcomed the new CEO of the National Bleeding Disorders Foundation, Phillip Gattone, as our keynote speaker to share with the South Carolina community his vision for the future during these transformational times. We were fortunate to have a panel of distinguished national speakers within research, advocacy, access to care and local resources. These panelists shared our struggles and our victories that will impact the entire bleeding disorders community. We were delighted to highlight several of our own members as they shared their stories and provided conversational discussions. Throughout the day, community members were provided the opportunity to choose different sessions and join in the conversation.

Late afternoon sessions focused on the support groups within BDASC. Women were presented with information on the Women, Girls, and People who have or had the Potential to Menstruate (WGPPM) Summit that took place nationally in May of 2023. Everyone had the opportunity to learn with Barbara Castano Arrebola by discussing how to be prepared for an emergency by communicating and



advocating for your needs in emergency and travel situations. The VWD community took some time to learn the basics about VWD and what treatment approaches are

available to them. Finally, our Men had the opportunity to come together in a group “Wrap” session to support each other.

We didn't forget our teens and kids! The kids had a blast with Corporate Kids during the day on Saturday. We were excited to have Critter Keepers come and share their animals with our

young kids. From snakes to turtles, our kids were enthralled. Our Teens spent the day with GutMonkey! The teens were treated to trivia, mystery challenges, and a food/cooking challenge to encourage teamwork and making shared decisions.

We came together at the end of the day for a final closing dinner at the beautiful outside terrace. Gathering as a community is an amazing way to end our Annual Meeting. We concluded the weekend full of gratitude and comforted in the knowledge that we are not alone. The support of this bleeding disorders community in South Carolina is unparalleled.



Chapter Awards and Acknowledgements

Retiring board member, Samantha Javorka.
Thank you for your dedication and service.

Welcome to our new board members, Eric Townsend, Candi Mitchum, and Shelley Crisp.

Scholarship Award Winners

Alba Myers Lewis Academic Memorial

Scholarship - Aiden Budde

John N Tiller Memorial Scholarship—Makayla Keith

BDASA Academic Scholarship—Regan Weber & Ava Newhart

Board Member of the Year—Sherlene Maloy

Legislative Advocate of the Year—
Representative Jason Elliot, District 22 (R),
Greenville County & Representative Kevin
Hardee, District 105 (R), Horry County

Coalition Advocate of the Year—Whitney Galloway

Coalition Ambassador of the Year—Michelle Krakowiak

Junior Advocacy Ambassadors of the Year—
Natalie Mitchum and Adonis Rabb

Appreciation and Partnership Award—Lt.
Governor Pamela Evette

Making a Difference Award—Malerie Hartsel,
Program Manager & Interim Director, DHEC
Hemophilia Assistance Program

Volunteer of the Year “The Fisher Award”—
Patricia Tucker

**Aaron Eugene Gossett Pillar of Strength Award,
“On the Shoulder of Giants”**—Warren Ingram

*“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.”—
Regan Weber, BDASC Academic Scholarships Recipient*

“The impact of DGSPD extends 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 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.”—Aiden Budde, BDASC Alba Meyers Lewis Memorial Scholarship Recipient

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TEEN PROGRAMMING PROVIDED BY




Executive Director's Welcome

By Sue Martin

Where did the summer go? How are we already planning for Fall and Winter events? I guess time just flies when you are having fun, as they say. I hope you and your family are doing well and please reach out if we at the Chapter can help you in your bleeding disorders journey in any way. While we love to support our community members with programs, education, and supportive services, we are always just a phone call away for more.

The Summer events ended nicely and we are now transitioning into our Fall events. I hope you will join me as we provide many supportive and educational community events throughout South Carolina. Some of my favorite programs are when we bring community members together to meet one another, discovering they are

never alone in their bleeding disorders journey. I also love watching everyone grow in their own unique ways, especially in discovering their advocacy voices. Many of you are doing amazing things and congratulations! For those who are struggling, we are here for you.

I will keep my hello short and encourage you to read the entire newsletter to stay engaged in all we have to offer you and your family. Be sure to update your addresses and contact information if they have changed so we can be sure to stay in touch. Things are changing every day, but what will not change is the strength and commitment of the South Carolina's Bleeding Disorders community and us, BDASC! I hope to see you all soon.

Warm regards,
Sue

We Welcome the Newest Member of Our Team! Erin Van Nostrand

We are thrilled to announce the newest addition to the BDASC team — Erin Van Nostrand. Erin is our new part-time contract employee. With



a background as a Certified Child Life Specialist and years of experience working in various medical settings, Erin brings a wealth of knowledge and expertise to her role as Operations and Events Assistant.

She will be focusing on expanding our Volunteer Program, creating opportunities for community involvement and enhancing our fundraisers. She will also take a special emphasis on working within our teen and children's programming. Erin's passion for helping others and her dedication to making a difference in the community makes her an asset to our team. She has a Bachelor of Science Degree, Psychology of Child Life, and is a member of the Association of Child Life Professionals. Erin is a member of the Bleeding Disorders Community and BDASC. She was diagnosed with VWD as a teen. She lives in Chapin with her husband, young son and two dogs. She enjoys helping kids and teens understand their diagnosis and medical needs, and discovering that "aha" moment. We look forward to having Erin at our events.

Volunteers Are Our Lifeline!

By Erin Van Nostrand

I am so excited to work with all our volunteers who make our Chapter special! We are so grateful for your continued support. Without you, BDASC would not be able to provide quality support and opportunities for our bleeding disorders community within South Carolina. Would you like to help support BDASC? Volunteering for events and committees is a fantastic way to help. To continue to support and engage with our community, BDASC requires some help at events—whether it is helping in

the Greenville office, manning the registration booths, helping with the teens and kids during our programs, or helping to assist in the needs of our events and fundraisers, there is something for everyone! Be sure to hop on the volunteer train so we can highlight you in the next newsletter. We will be featuring a new “Volunteer Highlight Spotlight” section, so do not wait to get involved. If you would like to volunteer, please contact Sue at the Chapter office, or register on our [volunteer page on our website](#). You can also email Erin at erin.vannostrand@bda-sc.org!



Community Shoutout!

Thank you to Cori Ann Harris and her family for hosting a local fundraiser in support of the Bleeding Disorders Association of South Carolina. Cori Ann was able to secure BDASC as the beneficiary of the Summerfest Market at Triangle Char + Bar in West Ashley and the event raised over \$500 in donations. If you are interested in hosting a local fundraiser for BDASC, please reach out to the Chapter Office at 864-350-9941 to find out how you can help us continue to raise critical funds to support all we do at BDASC.



Community Engagements

Women Matter in Bleeding Disorders Support Event

May 25, 2024, Summerville, SC

It's always an amazing day when the women of BDASC get together for a fun filled afternoon. The women of our community were treated to a fantastic brunch at Oscars in Summerville to kick off an afternoon of education and support. We had a wonderful time learning more about how bleeding disorders affect women from our presenter, Morgan Cook with Takeda, and from engaging with each other. Coming together as a community allows each of us to share our experiences and help one another with issues

we are facing. The ladies also participated in our Voices of 46 Outreach Program with conversations and by taking our survey. After our brunch at Oscars, we headed over to Painting with a Twist to enjoy a relaxing painting session. Each woman was able to paint their own picture with instruction from the Painting with a Twist team. It's always amazing to see how perfectly unique each painting ends up. Thank you to Takeda for this support group activity.



Let's Talk Mental Health Community Engagement Dinner

May 31, 2024, Columbia, SC

During the National Mental Health Awareness month of March, we were excited to host a community engagement dinner discussion on Mental Health and Wellness. The Let's Talk program, sponsored by Sanofi, facilitated by Debbie De La Riva and Believe Limited with Hanna Beary, brought out a packed dinner venue to learn, have discussions, share experiences, and provide support to the community with resources and conversations around our mental wellness. Keeping our mental health a priority in our bleeding disorders journey is important and we were grateful to have this limited national program brought to South

Carolina. Many thanks to Believe Limited and Sanofi for the opportunity.





South Carolina School Nurses Conference

May 31-June 1, Columbia, SC

Attending the South Carolina School Nurses Conferences each year is a great way to assure our schools and their nurses who care for our children with bleeding disorders have some basic knowledge and support from our organization and the Hemophilia Treatment Centers.

Sue Martin and Robin

Jones, Nurse Coordinator at Prisma Health Midlands HTC, attended the conference this year and were able to supply over 500 pieces of educational materials for nurses throughout the state. We are grateful to Robin Jones for her help in providing treatment support knowledge.





WE'RE IN THIS TOGETHER.

Friday 6:26 pm

Sharing stories by the campfire with friends

Isaac, living with hemophilia B

Not an actual patient

Let's make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world is stronger than ever.

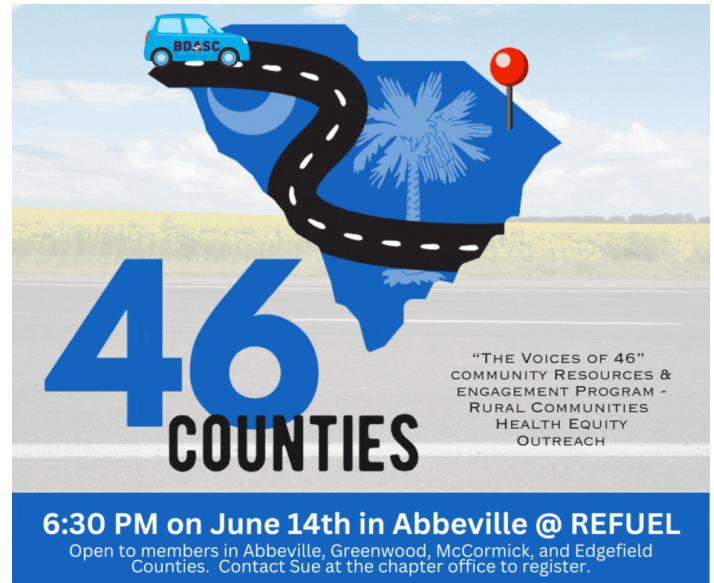
 bleedingdisorders.com | 

The Voices of 46 Outreach: Abbeville, Greenwood, Edgefield Rural Outreach

June 14, 2024, Abbeville, SC

It was a great time in Abbeville, SC, as we enjoyed the historic town gathering our members where they live. We learned a lot about the smaller rural counties in our state and what challenges they can have with treatment for themselves and loved ones living with bleeding disorders. Thank you to Refuel of Abbeville for hosting our community event and your warm hospitality. The food was great and the service superb! Each family also took our Outreach Program Survey which is gathering the information we are discussing and providing us data to talk with our healthcare systems to look for solutions to some of the challenges we are discovering.

It was a nice experience for community members in their own counties to gather over a great meal and share their knowledge and experiences and make new friends. They did not have to travel long distances to meet others with bleeding disorders and were able to receive some educational materials and resources. We look forward to our continuing conversation and resources we provide to our members and what we are learning in this “46



46 COUNTIES

“THE VOICES OF 46”
COMMUNITY RESOURCES &
ENGAGEMENT PROGRAM -
RURAL COMMUNITIES
HEALTH EQUITY
OUTREACH

6:30 PM on June 14th in Abbeville @ REFUEL
Open to members in Abbeville, Greenwood, McCormick, and Edgefield Counties. Contact Sue at the chapter office to register.

Voices” Outreach Program. To learn more about our [“46 Voices” Outreach Program](#) or to see where we are going next, please visit our website. We wish to acknowledge the grant support of Genentech and HFA with their Impact Grant to support our rural community



Summer Camp Ice Cream Socials

Camp Courage: Upstate HTC

June 25-28, 2024, Greenville, SC

Camp Burnt Gin: SC DHEC Camp for Kids with Bleeding Disorders

July 8-13, 2024, Wedgefield, SC

Each year we are excited to bring our famous BDASC Ice Cream Social to our campers at the Bleeding Disorders camps throughout the state. We were



invited to Camp Courage, Prisma Health Upstate HTC Family Camp, and Camp Burnt Gin. We were delighted to bring campers and families welcoming treats and resources, along with our Ice Cream Sundaes, camp towels, bags, and more. We look forward to seeing all the smiling faces of campers enjoying their tasty treats. Staff and counselors love it too, as they are always included!

For children living with bleeding disorders, camp is an opportunity to experience life away from home in a safe environment. Each camp is staffed with medical professionals who can assist with the needs of each child. Children participate in many fun and safe camp activities, such as campfires, fishing, swimming, boating, talent shows, and so much more. Children also can hone their infusion skills during infusion classes. The medical staff works with each child in a group setting to teach infusion skills and allow the child to practice. Infusion classes are intended to encourage independence.

Camp is held during the summer for kids and teens living with bleeding disorders. Within the state of South Carolina, there are three camps hosted that are supported by the Bleeding Disorders Association of South Carolina. Camp Courage is run by Prisma Health Upstate and is open to patients who attend HTC Services at

the Prisma Health Upstate location. Camp Burnt Gin is run by the SC Department of Health and is open to all children and teens living within South Carolina who are diagnosed with a bleeding disorder. The Carolina Crew Teen Retreat is run in partnership with the Bleeding Disorders

Association of South Carolina and the Bleeding Disorders Foundation of North Carolina. You can read more about this year's teen retreat in the following article.

We would like to thank all the staff at Prisma Health Upstate HTC, Camp Burnt Gin, Prisma Health Midlands HTC, all camp counselors, volunteers, and those we partner with each year to make this day happen. We also wish to express our appreciation to Sue and Ric Martin, Samantha Javorka and Erin Van Nostrand for providing our campers this fun activity. Thanks to our camp sponsors and Marble Slab of Greenville and Columbia for their partnership!

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The Carolina Crew: BDASC and NCBDF Teen Retreat July 18-22, 2024, Parkton, NC

The chartered busses rolled into Camp Rockfish within minutes of each other this year as teens from all over North and South Carolina met up again for our exciting 2024 Carolina Crew Teen Retreat! The



retreat provided teens with bleeding disorders, or who have family members affected, the opportunity to enjoy four days and three nights



of camp activities, comradery, friendships, activity challenges, and team building skills. It also created time for learning independence skills and gaining knowledge about bleeding disorders and advocacy awareness. This year's camp was held in a different location but provided time for fishing, archery, paddle boating, kayaking, field games, pool time, basketball, table games, and time to connect just being teens.

Of course there was movie night, campfires and s'mores, arts and crafts, and plenty of food and snacks. One highlight was the high ropes course and zipline which was a challenge many teens enjoyed completing. For thirty teens, our camp counselors and HTC nurse Robin Jones provided the teens with a safe experience and camp memories to last a lifetime. We look forward to



and volunteers who make it all happen. A warm appreciation to **Ric Martin, James Romano, Eric Townsend, Robin Jones, RN, Sue Martin, and North Carolina's Ryle Blair, Charlene Cowel, and Gillian Shultz.**



2025 as we head back to camp for another exciting time together. Camp would not be possible without the support of our charitable donations from our sponsors and the staff

and volunteers who make it all happen. A warm appreciation to **Ric Martin, James Romano, Eric Townsend, Robin Jones, RN, Sue Martin, and North Carolina's Ryle Blair, Charlene Cowel, and Gillian Shultz.**



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Upcoming Engagement Opportunities

Community Engagement Dinner: Product Update with Sanofi July 26, 2024, Columbia, SC

At Ruth's Chris in downtown Columbia, members came together for a dinner presentation brought to us by Sanofi and HTC Nurse Robin Jones, for a limited product update on Altuviiio. Participants enjoy a wonderful dinner, time to connect, receive chapter resources and information, and learn about this treatment option. Participants had plenty of time to ask questions and learn. It

was a good time for all. Thank you to Sanofi for the opportunity to connect!

BDASC does not endorse any product or provider and always recommends patients talk to their healthcare provider for all their treatment needs.



Charleston Community Back to School Event at Patriot's Point August 24, 2024, Mount Pleasant, SC

We hope you have registered to join us in Mount Pleasant on August 24 for the Charleston Community Back to School Event. Each year we like to have a community event to celebrate the school season and provide resources to support a successful school season for those affected by bleeding disorders. Our educational program; Adherence - never easy, always necessary, will focus on the importance of adherence and why it matters in the school setting and later in life and in the professional world. This presentation will be provided by Claudio Sandoval, MD,

Senior Director, Scientific and Medical Affairs - Hematology. We will have plenty of time to connect and engage, have a nice lunch, and enjoy a tour of the USS Yorktown at Patriot's Point. We are thankful to Octapharma and Blue Sky Pharmacy for this opportunity to engage with our members where they live.



Tailgating and Bowling at 810 Billiards & Bowling August 31, 2024, Myrtle Beach, SC

Football tailgating, family fun, and food, oh yeah, and bowling too! We are excited to travel to the coast for another Engaging Community Event for the whole family. On August 31, we will gather for a Tailgating Party bringing members together where they live! We will watch the Clemson Tigers face off against the Georgia Bulldogs and if you are not into football, we have got you covered as we bowl in our private VIP room. We will also be bringing resources from our Chapter's "Voices of 46" Outreach Program,

with our concentration on Horry County. We will discuss the needs of this county and healthcare access while taking our Voices Survey! We hope you will be joining us at 810 Billiards & Bowling in Myrtle Beach. Thanks to DrugCo and CSL Behring for this awesome community event.



Celebrating September's National Hispanic Heritage Month September 8, 2:30pm, Columbia

Join BDASC and our Spanish Community Members for a Community Engagement Event with an educational lunch and ballgame at Segra Park for the last game of the season - Columbia Fireflies Fan Appreciation Day.

We will enjoy lunch at Publico at Bull Street starting at 2:30 where we will hear from our educational speaker. After lunch, we will head over to Segra Park for the Columbia Fireflies season closer at 5:05pm. The game will be followed by fireworks.

Educational Presentation Topic: Expect the Unexpected: Prepare for Anything. Emergency room staff, including physicians, may have little experience in the management of patients with bleeding disorders because they are rare conditions. This presentation will help you avoid and prepare for a possible trip to the ER.

Registration is available online at <https://tinyurl.com/HispanicHeritageEvent> or by contacting Sue Martin at the Chapter Office. Call/Text 864-350-9941 or email at sue.martin@bda-sc.org
~Translated in Spanish

Celebrando el Mes Nacional de la Hispanidad / Celebrating Hispanic Heritage Month
September 8th, 2024, Columbia, SC
Acompañe a BDASC y a nuestros miembros de la comunidad hispana a un evento comunitario

donde tendremos un almuerzo educativo y un juego de beisbol en Segra Park para el último juego de la temporada: el Día de Agradecimiento a los Fanáticos de los Columbia Fireflies.

Disfrutaremos de un almuerzo en Publico en Bull Street a partir de las 14:30h, donde escucharemos a nuestros oradores educativos.

Después del almuerzo, caminaremos hacia el Parque Segra para el cierre de la temporada de las Luciérnagas de Columbia a las 17:05 h. El juego será seguido por fuegos artificiales.

Tema de presentación educativa: Espere lo inesperado: prepárese para cualquier cosa. El personal de la sala de emergencias, incluidos los médicos, puede tener poca experiencia en el manejo de pacientes con trastornos hemorrágicos porque son afecciones poco frecuentes. Esta presentación le ayudará a evitar y prepararse para un posible viaje a la sala de emergencias.

Para obtener más información e inscripción, comuníquese por teléfono o envíe un mensaje de texto a Sue Martin a la Oficina del Capítulo al 864-350-9941 o envíe un correo electrónico a sue.martin@bda-sc.org. También puedes registrarte en el sitio web. Visite nuestro sitio web en <https://tinyurl.com/HispanicHeritageEvent>.



Par for the Clot Charity Golf Tournament The Preserve at Verdae September 27, 2024, Greenville, SC

The Bleeding Disorders Association of South Carolina is excited to host our annual charity golf fundraiser, "Par for the Clot," on September 27, 2024. Players will enjoy a wonderful day of golf, food, fun, and competition. This year again, we will have 36 teams and 144 participants who will compete for some great prizes and enjoy a wonderful awards dinner reception banquet immediately following the tournament at the Embassy Hotel Terrace.

Each year we bring together BDASC community

members, industry sponsors, and the public to raise, not only funds, but awareness as well for BDASC and all the work that we do. Fundraisers for a non-profit organization are crucial not only for their survival, but also for their success. We can provide support, advocacy, and education to our community because of events like the Par for the Clot Charity Golf Tournament. Your continued support is greatly appreciated.

The tournament is full currently but if you like

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to golf or volunteer, give us a call as we usually have a few spots for participants to fill in. The Preserve at Verdae is a beautiful course which offers fantastic greens and many opportunities for players to help support BDASC. Participants have the opportunity to compete in competitions throughout the day; such as the men's and women's long drive competition, try your luck at a poker hand drive, be the winner of the closest to the pin hole, enjoy a putting contest, the Gun Hole contest, the spin to win, visit our professional charity donation hole competition with Kyle Blakley, and back again this year, beat the Pro with PGA community advocate, Perry Parker!

After a day on the course, we will be gathering for dinner on the Terrace. We will present the awards winners with their prizes, share our thanks, and draw our raffle prize winners. Thank you to our Tee-Off Committee members and volunteers who have committed to creating this amazing event. Without our volunteers we would not be able to support this amazing community. Also, we want to share our appreciation for Prisma Health Upstate & Prisma Health Midstate who will be with us throughout the day supporting our community. We can't thank our sponsors enough for making this event possible and appreciate their continued support!



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CSL Behring

Voices of Our Community

von Willebrand and Women Who Bleed Community News

Learn About Clinical Issues in Women with Bleeding Disorders

The National Bleeding Disorders Foundation (NBDF) is pleased to announce a series of educational videos on clinical issues in women, girls, and people with the propensity to menstruate (WGPPM). They were created for physicians, physician assistants, nurse practitioners, and other clinicians who treat patients with bleeding disorders, including von Willebrand disease (vWD), hemophilia A or hemophilia B. We are sharing this information for those individuals who may have missed the earlier announcement.

The series tackles four key areas of diagnostic testing and management concerns of clinicians who encounter heavy menstrual bleeding. They were first presented in live/virtual educational activities in the [Collaborative Learning Exchange](#) (CLE) program.

Featured topics include vWD Diagnostic Testing Challenges for WGPPM; Provider and Patient

Communications for Shared Decision Making when Providing Healthcare for WGPPM; vWD Treatment Across the Lifespan for WGPPM; Clinical Challenges in the Management of Pregnancy and Delivery in WGPPM. Visit the CLE homepage to [watch these easily accessible videos](#) and be sure to leave your invaluable feedback by answering a brief survey. These provider education trainings were supported by Cooperative Agreement Number (NU01DD000006), funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

Printed with permission from the National Bleeding Disorders Foundation

Share Your Voice!

We are on the road again and heading out to Florence. Make your voice heard and join us as we travel around the state this year meeting our members where they live.

46 COUNTIES

"THE VOICES OF 46"
COMMUNITY RESOURCES &
ENGAGEMENT PROGRAM -
RURAL COMMUNITIES
HEALTH EQUITY
OUTREACH

6:30 PM on August 29th in Florence@ Victors
Open to members in (Florence, Marion and Darlington Counties.
Contact Sue at the chapter office to register.

Did You Know?

Own Your Path

Take control of your healthcare with the Own Your Path program! If you are an adult (18+) and on a prophylaxis treatment plan for vWD

or hemophilia A or B, NBDF would love to have you join!



The graphic features a dark blue background with a pattern of light blue and red teardrop shapes on the left. In the center, a circular photo shows five diverse people smiling. To the right of the photo is a teal button that says "JOIN TODAY!" and a URL: <https://www.bleeding.org/OYP>. At the bottom center is the logo for the National Bleeding Disorders Foundation, which consists of a stylized starburst icon followed by the text "NATIONAL BLEEDING DISORDERS FOUNDATION".

What's in it for you?

This app-based program will provide you with information to navigate life with a bleeding disorder. Being able to stay on top of your treatment is easier if you are able to manage your stress, get enough sleep, move your body, and stay on top of your nutrition. It is also helpful to ensure you have access to information to help you build your knowledge and skills about bleeding disorders: from insurance, to relationships, to traveling with a bleeding disorder, we've got you covered!

You will have access to a health coach who will help you throughout the program to set and achieve goals, access resources and tools, and get the most out of the program. You will have the opportunity to attend monthly virtual

meetups where we will dive into topics that are important to you, and where you will meet others in the program. We have participation incentives throughout the program to reward you for being active in the program.

To determine your eligibility, you will need to take a short survey. Once it is determined that you are eligible for the program, you will receive a link from the app partner, NexJ Health, to download the app and create your account. Please note that it may take 2-3 days to receive the email to sign up for the program.

Take the eligibility survey by visiting this website: <https://www.surveymonkey.com/r/22QQCHR>



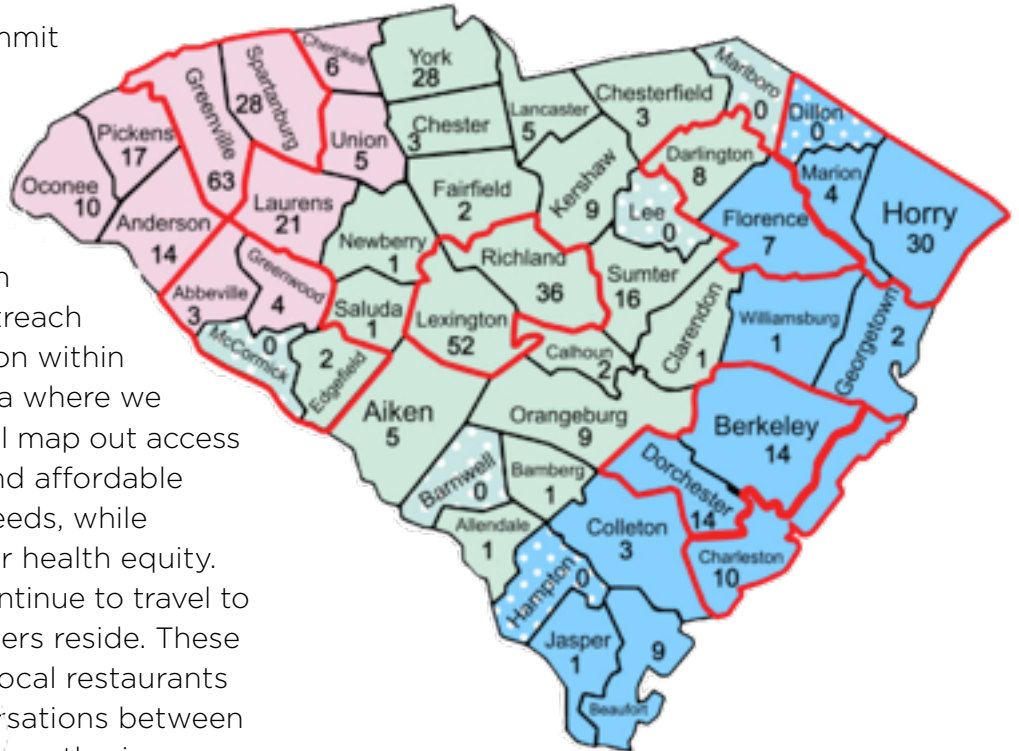
“The Voices of 46” Continues Throughout the State Community Resources and Rural Outreach Program

During our 2022 Advocacy Summit in Charleston, one of the areas we discussed was barriers to support services, engagement opportunities, and healthcare equity within our more rural areas and counties within South Carolina. To take a personal outreach approach and gather information within all 46 counties in South Carolina where we currently have members, we will map out access barriers to quality treatment and affordable health care, along with other needs, while providing Chapter resources for health equity. Throughout the year, we will continue to travel to rural counties where our members reside. These meetings are casual events at local restaurants or facilities to engage in conversations between BDASC and the community. The gatherings, similar to all BDASC events, are offered free of charge to all community members in the designated targeted area. We 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 intended outcome goal of this project will be to share the data we discover with our HTC's, national organizations, and healthcare agencies within South Carolina and look at ways to partner to help bridge any gaps we can achieve together. Sue Martin, our executive director, is currently part of HFA's Rural Working Group and will be presenting this program nationally during their November Rural Summit. We also hope by having these small meetings that we can introduce community members to other members living in the areas in which they live.

Your Input Is Appreciated

For this program to be successful, we 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 the counties in which they reside. 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. Where we will travel next is always on our website and members are invited by phone, mailing and email.

Everyone is encouraged to take the survey now whether you have attended an event we are hosting or have not. We are asking for all voices within all counties of the state. Please only take the survey once. Thanks so much!



FACTOR UP with ALTUVIIIIO™

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

ALTUVIIIIO™
Antihemophilic Factor (Recombinant),
Fc-VWF-XTEN Fusion Protein-ehf1



HIGHER FACTOR LEVELS FOR LONGER

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

48

HOUR HALF-LIFE IN ADULTS

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

0.7

BLEEDS PER YEAR[‡]

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

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

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

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

[‡]Data based on treated bleeds.

CONNECT WITH YOUR CoRe TODAY

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



Xaviette Pointer-Kincy
xaviette.pointer-kincy@sanofi.com
(857) 259-2447
Serving the Carolinas

INDICATION

ALTUVIIIIO™ [antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-ehf1] is an injectable medicine that is used to control and reduce the number of bleeding episodes in people with hemophilia A (congenital Factor VIII deficiency).

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

IMPORTANT SAFETY INFORMATION

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

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

Who should not use ALTUVIIIIO?

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

What should I tell my healthcare provider before using ALTUVIIIIO?

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

What are the possible side effects of ALTUVIIIIO?

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

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

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

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

Please see full [Prescribing Information](#).

sanofi

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

Advocacy Action

2024 Fall Family Advocacy Camp and Medical Symposium October 19-20, 2024 Embassy Suites Greystone, Columbia, SC



We are excited to once again invite our South Carolina members and bleeding disorders community to join us for our annual statewide Fall Advocacy Camp and Medical Symposium. The event this year will have a family camp theme where we hope in the following years to host the event in a camp retreat venue. Learning the skills to advocate for yourself and your family begins at birth and will continue throughout a lifespan. For the Bleeding Disorders Community, advocating for the needs of your health care and daily life seems to never end. We are planning

sessions with advocacy updates and skills for the whole family in a fun and inviting environment. Sessions will take an overarching quick snap shot look at the landscape today of healthcare access to affordable treatment care and services for those living in South Carolina, including resource information when barriers to access become our reality. We will engage our Hemophilia Treatment Centers for updates and how they are addressing barriers and what they are working on for bleeding disorders futures within the HTC

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

General Donors

Blue Cross / Blue Shield
Deltha Snelgrove, Anita Runyan, Keith Runyan
Edward Jones / Janice Hickman
Heather Hill / HFCU
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Industry Donations

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Takeda

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Regional networks. We will begin our Advocacy Camp in the morning with an Industry Forum, learning about current and new innovative treatment options through quick breakout sessions with companies of your choice. We will learn about their product pipelines and newer pipelines today and in the future to treat bleeding disorders.

As we develop this Advocacy Camp, teens and children will also have programs helping them learn to advocate for themselves and making “Stepping Stones” towards daily independence. We also will have plenty of time for fun activities with engagement connections for everyone. Support Group Breakouts for all bleeding disorders sub-types: VWD, Women Carriers, Men, Moms, Dads, Couples, Rares, Platelet Disorders, Teen, Tweens, and mentoring within all will also be included in the Advocacy Camp agenda. Teens will enjoy going as a group to Escapology in Columbia (an escape room experience team building activity) on Saturday night too! Also, a highlight for family camps is talent shows, and BDASC knows how to have fun! Families, children, and anyone who is willing to join in, will enjoy a family fun Saturday night of “BDASC’s Got Talent Karaoke.” Bring your best talents and show off your skills!

On Sunday morning, attendees will enjoy the new Pathfinders program, sponsored by Sanofi with GutMonkey. After a day of learning on Saturday, participants will relax and discover the beauty of the outdoors while forging lasting connections with others who understand the journey. A guided hike, hosted by GutMonkey on the walking trails at the beautiful Harbison State Forest will be the venue. The hike will foster community connections as participants stop along the way for discussions and engagement with the Pathfinders guide. For members who have attended the Fall Family Advocacy Camp and are not able to physically participate in the hike, group tickets to the Riverbank Zoo and Garden will be provided to enjoy and engage together.



Pathfinders Highlights include:

- Become one with **Empowering Nature Walks** surrounded by the calming presence of nature.
- Discover Educational Insights: **Learn to manage bleeding disorders in the great outdoors.**
- **Supportive Community Connection:** connect with others in the community, fostering a sense of camaraderie and understanding; share experiences, stories, and triumphs – discover you are not alone.
- **Advocacy Awareness:** raise awareness for positive change for access to resources for bleeding disorders
- **Celebrate Resilience** by commemorating the resilience of this community and the inspiring moments of this event

The 2024 Advocacy Camp and Medical Symposium will begin on Saturday morning with a light breakfast, snacks, exhibitors, social hour, and registration check in. The Industry Forum begins promptly at 10am. Travel grants for gas assistance, overnight stays for attendees attending the entire event will be provided, but are limited. Participation on Saturday for the educational session only is also available. Registration is open online at <https://tinyurl.com/FallFamilyAdvocacyCamp>. For questions, please call Sue Martin at the Chapter Office. Thanks to our Fall Family Advocacy Camp and Medical Symposium Sponsors who allow us to come together and learn to advocate!



National News

Gettin' In the Game, JNC September 20-22, 2024, Henderson, NV

Developed by CSL Behring, the Gettin' in the Game (GIG) Junior National Championship (JNC) was the first national golf, basketball, swimming, and baseball competition designed specifically for the bleeding disorders community. The program gives children with bleeding disorders an opportunity to compete in golf, basketball, baseball, and swimming and provides education and information-sharing opportunities for participants and their parents/caregivers. Chapters throughout the nation partner each year to provide this opportunity to their members. 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. Each bleeding disorder chapter throughout the United States was given the opportunity to nominate two children (ages 7-18) from their chapter to participate. This year, BDASC is sending Noal Mitchum and Jack Weber to represent BDASC and South Carolina. Noah will be participating in baseball and Jack will be participating in golf. Congratulations!

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

The National Bleeding Disorders Foundation (formally NHF)'s 76th Annual Bleeding Disorders Conference (BDC) will take place from September 12-14, in Atlanta, Georgia! NBDF is excited to bring the bleeding disorders community together once again for three incredible days of educational sessions, valuable networking opportunities, and exciting

exhibits at the Georgia World Congress Center in downtown Atlanta. Information is on [their website](#) and BDASC travel grants may be available for community members who wish to attend. We hope to see you there at the BDC! <https://bda-sc.org/national-education-and-conferences-travel-scholarships/>





National Bleeding Disorders Foundation Re-Launches Steps for Living Website

Since 2011, Steps for Living has served as a go-to online resource for life-stages education. With resources and tools divided by age groups — First Step, for ages 0–8, which focuses on helping parents navigate their child’s condition; Next Step, for ages 9–15, looks at education, independence, and healthy decision-making; and Stepping Out, for ages 16–25, covers high school, college, and early adulthood — there are age-appropriate tips and tools for everyone. Steps for Living was created with financial support from both the CDC and Pfizer, Inc. On July 23, 2024, the National Bleeding Disorders Foundation hosted a virtual launch celebration of the newly redesigned Steps for Living Website. Community members throughout the nation were invited to come

together to explore this comprehensive and user-friendly resource that has been thoughtfully re-envisioned to better serve the bleeding disorders community.

About Steps for Living: Education for All Life Stages

Steps for Living is your NBDF go-to source for up-to-date information, helpful tools, and valuable insights through every stage of life. Whether you are newly diagnosed, a caregiver, a healthcare professional, or someone looking to expand your knowledge, Steps for Living offers tailored content to meet your needs. Visit the newly redesigned Steps For Living website at <https://stepsforliving.bleeding.org/>.

Research & Development

Study Provides New Data on Neurodevelopment in Younger Hemophilia Population

Jun 21, 2024

It has been several decades since the publishing of large U.S. studies of neurodevelopment and other cognitive functions in children and young adults with hemophilia. Results of this earlier research that evaluated hemophilia and neurocognitive development suggested that the disease was associated with poorer outcomes compared with the general U.S. These lesser outcomes were observed specifically in areas such as academic achievement, attention, behaviors, and emotional and adaptive functioning. However, these studies reflected a very different time, when HIV viral infections placed a significant burden on patients and before enhanced, contemporary standards of care were available. Investigators of a newly published observational study set out to capture new data that accounts for advances in care and other factors.

“Evolving Treatment of Hemophilia’s Impact on Neurodevelopment, Intelligence, and Other Cognitive Functions (eTHINK),” was published in *The Journal of Pediatrics*.

“The only large study examining neurodevelopment in hemophilia (HGDS - **H**emophilia **G**rowth and **D**evelopment **S**tudy) was conducted over 30 years ago. Since then, many disease and treatment-related factors have evolved, making the current study an

important update of the existing literature,” explained the authors. HGDS was published in the spring of 1994.

The new study assessed the impacts of hemophilia type and severity, intracerebral hemorrhage (ICH), hemophilia treatment type, socioeconomic status, and neurodevelopmental disorders or symptoms (i.e., ADHD, attention problems) on cognitive, adaptive, and social-emotional functioning compared with the general population. Between September 2018 and October 2019, eTHINK investigators at hemophilia treatment centers enrolled 551 males aged 1-21 years with hemophilia A or B of any severity, with or without inhibitors.

The tools used for assessing things such as intellectual ability, attention, processing speed, adaptive skills, and behavioral function were selected by experts in pediatric neuropsychology and neurology. Further data was collected from HTC chart information and medical history obtained from the parent/child/family. Developmental and cognitive assessment of the affected individuals were completed by patients or guardians/parents via questionnaires.

Investigators found that male children and young adults with hemophilia performed within

Continued on page 29

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or above age expectations on standardized tests of “higher-order” intellectual ability.

This stands in contrast to the earlier HGDS study results showing decreased intellectual functioning associated with HIV presence.

As HIV is not a significant comorbidity for hemophilia patients in developed countries, the authors suggest that this is a contributing factor in higher intellectual performance.

They also observed that while individuals with increased hemophilia severity had a lower IQ in the HGDS, severity-related results of eTHINK show a different picture.

“The current study assessed a broader range of disease severity than did the HGDS, including patients with mild, moderate, and severe hemophilia; however, we did not find that patients with moderate or severe hemophilia performed worse or reported more significant problems than those with mild hemophilia,” explained the authors. “This may be attributable to changes in treatment and improved HTC-led patient/family education that has emerged over the past 3 decades.”

In addition, while ICH is historically associated with a high risk for developmental and cognitive problems, eTHINK did not yield robust data on the subject. This is due to much lower rates of ICH in current pediatric hemophilia populations, as compared to earlier generations. Investigators were therefore unable to analyze the impact of ICH in light of the modest data sample.

The authors were also surprised to find that they did not identify relationships between hemophilia type or severity and early development or cognitive function. They posit one possible explanation - that the regular

use of more effective therapies has helped to mitigate the kinds of developmental risks often associated with severe disease. In addition, the need for moderate/severe patients to carefully monitor activities for injury risk may lessen associations between disease severity and cognitive morbidity.

The authors did observe a higher prevalence of ADHD in some groups, particularly in boys 13-17 years old. Attention deficits and/or ADHD diagnoses were associated with considerably reduced attention, executive function, and adaptive skills, along with more reported behavioral/emotional symptoms and more problems at school. These findings provide greater impetus for screening for ADHD and other neurobehavioral or neurodevelopmental disorders in hemophilia patients to facilitate early intervention and improved outcomes.

Overall, the results of eTHINK suggest that when compared to the general population, boys with hemophilia develop and function within the normal range for their age in several cognitive and behavioral areas. That said, investigators clearly identified specific groups at higher risk for poor outcomes.

“These include individuals with comorbid neurobehavioral disorders, young adults and adolescents transitioning into adulthood, and patients from more disadvantaged socioeconomic backgrounds. Identifying at-risk individuals within the hemophilia population should allow for more individualized monitoring, assessment, and intervention,” concluded the authors. [Read the full paper](#) to read the full results, plus learn more about the study methods, limitations, and further comparisons to the HGDS. *Printed with permission from the National Bleeding Disorders Foundation*

Resources & Contact Information

Medical Facilities

Prisma Health Hemostasis and Thrombosis Center of South Carolina - Midlands

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

Prisma Health Hemostasis and Thrombosis Center of South Carolina-Orangeburg
1724 Village Park Drive, Orangeburg, SC 29118

Prisma Health Hemostasis and Thrombosis Center of South Carolina-Florence
101 William H Johnson Street, Suite 400, Florence, SC 29506

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@Bleeding.org

Website: <http://www.Bleeding.org>

National & BDASC Community Events

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!

September 12-15, 2024: NBDF Bleeding Disorders Conference (Atlanta, Georgia)

September 20 - 22, 2024: Gettin' in the Game, JNC (Henderson, Nevada)

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

October 19-20, 2024: Family Fall Fest (Columbia)

November 22-24, 2024: NOW Conference (Phoenix, Arizona)

November 30, 2024: Community Connections & Engagement Event: Teens

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

Additional ways to support BDASC



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



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

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





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



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Supporting those with bleeding disorders in South Carolina

10th Annual

PAR FOR THE CLOT

September 27, 2024



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