

The News Infusion

The Official Newsletter of Bleeding Disorders Association of South Carolina

VOLUME 12, ISSUE 4

FALL 2023



50th Legacy Annual Meeting; Behind Every Mask Lies a Story, Page 5

NHT's 75th Annual Bleeding Disorders Conference, Page 19

South Carolina Summer Camps Highlights, Page 10

50th anniversary
1973-2023

HELLO Conference
June 9th - 10th in Greenville, SC

About BDASC & The News Infusion

Inside this issue:

About Us	2
Lead Article: Celebrating 50th Legacy Annual Meeting	3-5
Community Engagements	8
Voices of the Community	19
Von Willebrand Community	21
Advocacy	26
National News	28
Research & Development	29
Resources & Contact Information	30
Calendar of Events	31

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

Fall-Winter 2023 Calendar of Events

Looking Ahead: Save the Dates!

Community Engagements

August 24, Community Engagement Dinner: Spanish Presentation & Support Group

August 28, HEDI Working Group Committee Virtual Meeting

August 31, VWD Community Virtual Support Group Meeting

September 22, Par for the Clot Charity Golf Fundraiser

October 7, VWD Community Support & Education Event

October 27, Community Engagement Dinner

November 10-11, Fall Advocacy Summit; Access to Care and Treatment

November 30, Community Engagement Dinner

December 9, Statewide Winter Gathering

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About This Publication

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

Celebrating 50th Legacy Annual Meeting; Behind Every Mask Lies a Story

June 9-10, 2023, Greenville, SC

In 1973, Hemophilia of South Carolina was founded by a group of parents interested in promoting awareness, providing group support, and assisting other national hemophilia organizations to support their children and other families in South Carolina who had hemophilia. Together as a community of past and present members, we celebrated our 50th Annual Meeting Anniversary with a Masquerade Gala in Greenville at the HELLO Conference.



Friday night kicked off the weekend with a buffet dinner and the annual awards ceremonies. Each year, BDASC is honored to present a variety of awards and scholarships to our community members. This year, we were fortunate to award four scholarships. Our scholarship recipients were **Regan Kayleigh Weber, Makayla Carrie Keith, Sarah Beth Walden, and Ava Elizabeth Newhart**. Each of these recipients shows qualities that exemplify our community, and we wish them all the best in their education and futures.

We also took some time to share our appreciation with our retiring board members. At the end of June, both Shelley Crisp and Wendy LeGrand would be leaving the board of directors. Both completed their three, 2-year terms, a maximum for consecutive board membership. Wendy and Shelley have spent the last six years serving our community well—with Shelley being the President of the

Board of Directors these past two years. As we thanked them, we are also excited to welcome back April Baird and Cristal Day to the board.

Both ladies would be returning as members of the board starting in July!

BDASC relies strongly on its community members, donors, sponsors, and volunteers. Providing supportive services, education, and advocacy for those impacted with bleeding disorders is our mission

and we are grateful to all who support our organization with gifts of time, talents, and funding. We were honored to present the 2023 Chapter Awards to community members and our community partners that go above and beyond for our South Carolina Bleeding Disorders Community.

Board Member of the Year: Edna Rabb
Appreciation and Partnership Award: Ryan Griffith with Marble Slab, Camp Ice Cream Socials

Making a Difference: John H. Tiller, Philanthropy

Volunteer of the Year: Joyce Wentzky, Children's Blankets of Love

Legislative Advocate of the Year: SC House Representative Stewart Jones, (R), District 14; Supporting Bill H.3618

Jr. Advocacy Ambassador of the Year: Danny Shelton

Continued on page 4

Continued from page 3

Advocacy Coalition Advocate of the Year:

Taylor Upton

Advocacy Coalition Ambassadors of the Year:

April Baird and Ginger Snead

After dinner and the awards presentations, the community was invited to dance the night away. Entertainment was provided by Big Time Entertainment and our DJ, Andre Bell, who has provided music for our walk fundraisers for many years. We also had a commemorative photo booth with fun props for great pictures to remember this special evening. Remembrance boards for those who have lost loved ones and a board to share special memories of belonging to the Chapter were provided and now hang in the Chapter's office. There was also a "Time Capsule" now sealed and filled with dreams for the future which awaits opening at the Chapter's 75th annual meeting. A fantastic evening was enjoyed by all.

On Saturday, attendees participated in eight different educational and supportive sessions throughout the day. Starting the day off was Our Past, Present, and the Future of Bleeding Disorders Treatment & Care, by our keynote speaker, Dr. "Bobby" Duc Tran. Dr. Tran provided a look back through the decades which included an interactive Kahoot quiz game with attendee participation. Between each decade, community members shared their experiences during these eras. Community members representing the past 50 years in Bleeding Disorders history shared their experience, life without treatment, the HIV epidemic, those who were introduced to prophylaxis treatments later in life, those who never lived without prophylaxis, those who have experienced the changes in VWD treatment, and those who now have experienced the new innovative treatment of today. Dr. Tran then also provided the community with a small look into where treatment is going in the near future. Along with Robin Jones, Prisma Health Midlands HTC Nurse Coordinator, the advancement of

gene therapy and South Carolina were also discussed.

Following Dr. Tran's presentation, BDASC's Advocacy Coalition (SCHBDAC) along with our executive director, Sue Martin, and Legislative Coordinator, James Romano, provided the Past, Present & Future Advocacy of the Chapter, and the bleeding disorder's community's rich history of successful advocacy throughout the past 50 years. Sue and James provided information on the barriers to care that we are currently facing and the importance of continuing to strengthen our advocacy efforts over the next few years. After hearing about what we are doing in South Carolina, Brendan Hayes, and Heather Hicks with NHF, shared a new initiative program for young adults that was created in partnership with the CDC and NHF called "Own Your Path." Brendan and Heather spoke of the resources available to the young adults in our community.

Following lunch, attendees chose from several breakouts providing the opportunity to learn about; Kinesiology Taping with Dr. Zolotnitsky, sponsored by Octapharma, how to ensure Shared Decision Making and Person-Centered Care with Brendan Hayes, and discussing Women with Bleeding Disorders and the needs of women carriers with Linda Casto, sponsored by Bayer. Breakouts in the last hours of education included; How to Advocate in the ER with Heather Hicks, a support group discussion around VWD, moderated by Sue Martin and Samantha Javorka and our HTC staff, and a session on the resources available to the chapter members provided by BDASC Board Members. Upon completing these sessions, members also had the opportunity to sit down with Robin Jones, Prisma Health Midstate HTC Nurse Coordinator to discuss and learn about self-infusion. Throughout the day, attendees were able to meet with manufacturers and health care support services in the exhibit hall to discover and discuss treatments and services available to the bleeding disorders community.

Continued on page 5

Continued from page 4

Do not think that we forgot about our kids and teens! The teens had a day of The Leading-Edge Program led by Gut Monkey, sponsored by Pfizer. The program allowed teens to learn about the small ways in which we live our lives and what it says about who we are and

our goals. Our kids had a blast as well. The kids were treated to a “Wacky Olympics” with Corporate Kids. The kids had the opportunity to play games—such as potato sack races and parachutes, do crafts and have loads of fun keeping busy. They were also provided with fun and educational activities from Optum, facilitated by Jordan Martin, and CVS Specialty and Factor Man. We were so fortunate to have had Corporate Kids to keep our kids safe and entertained.

Concluding a fantastic day of community and education, members were treated to another phenomenal meal on the terrace of the hotel. Over the past 50 years, the Annual Meeting has provided the community the opportunity to come together, learn something new, and meet up with old friends, and perhaps meet someone new. We look forward to continuing to support our community for the next 50 years and beyond. We are very grateful to all our community partners, providers, and sponsors who helped make this opportunity available to our community! Save the date for next year’s HELLO Conference beginning on June 21, 2024.

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Volunteers Are a Welcome Gift!

We would like to invite you to volunteer your time and talents when you are able to 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 manning the registration booth, keeping an eye on the kids in childcare, helping to work and support our fundraisers, and advocating as needed by sharing your stories and voices. There is something for everyone! If you would like to volunteer, please contact Sue at the chapter office. We do not have a large staff, and can use your help. Administrative help and other opportunities are available. Thanks!

Executive Director's Welcome

By Sue Martin

I hope everyone is excited to return to school or perhaps new adventures, and that you all had a wonderful summer. It is hard to believe we are now heading into the fall season which will be very busy for us at BDASC.

We truly enjoyed celebrating our 50th Anniversary in June and having with us for the evening some of the original founders' fathers and our members, the old and the new. It was a wonderful celebration of the many years of love and hard work. (Please read on page 3). We rolled immediately into our South Carolina summer camps for kids with bleeding disorders and provided our special "Ice Cream Social," something the campers and staff look forward to each year. And just recently at the end of summer, we were hanging out with our teens from North and South Carolina at our joint Teen Retreat while they bonded high in the tree tops of Camp Canaan. Check out the Summer Camp wrap-ups on page 10 and be sure to send your kids and teens to camp next year. As we traveled the state this summer with community engagement events, including a baseball game preparing participants to head back to school, which included providing backpacks filled with supplies and gift cards, we enjoyed meeting our newer members and connecting members to others in their home towns. We even developed together some new ideas for community connections. We will begin soon to have regional virtual meetings, and we will call them, Monday Meet-Ups. They will be provided on Monday nights at 7PM, connecting our three regions in the state: the Upstate, the Midstate, and the Low Country. Thank you to our Myrtle Beach members who helped us come up with this new idea. Stay tuned for more information



to come soon. We provided our first Spanish support group event late August to help connect our non-English-speaking members and Hispanic community, and we will have events and virtual meetings for our VWD community beginning again in October and beyond. We have plans to implement additional

support group connections for our ultra rare and platelet disorders community, our African American community members, and those living in our rural areas.

In lieu of family camp this year, (I know we are all disappointed) we will be having a Fall Advocacy Summit (read more page 17) for our community advocates to prepare for an aggressive legislative session in 2024 as we battle to pass H3618 and remove the Accumulator Adjustment Programs in our healthcare plans that are creating access to treatment difficulties for our community. We will need everyone's help and our success will depend on you. Please learn more about the issue by reading our Advocacy Action posts and e-blasts. As we continue to search for a new venue for family camp to return, we will look forward to bringing our families back together again with adventures, education, and community support.

I hope you have heard by now that our national organization, the National Hemophilia Foundation is now The National Bleeding Disorders Foundation (NBDF)! This new name is reflective of the members they serve. It is so exciting to see their name reflect our global community. Rest assured, our hemophilia community is just as important and remembered as it has always been, for the fights they have led, and their many accomplishments. We

Continued on page 7

Message from the New President

Aaron Smith, Board of Directors, President

Hey there everyone! I hope you had a wonderful summer and are ready for a busy second half of the year. After having a great 50th Annual Meeting & HELLO Conference and celebration, I am honored to take on the position of Chapter President. During our presentations we covered experiences, treatments, and advocacy in the past, present, and future of bleeding disorders and the role our chapter has held. As President, I hope to help provide leadership that prepares us for an ever-changing future.

Looking back, we have come a long way in 50 years, and I am very grateful for everyone's sacrifices. As I heard stories from our chapter family's success and sadness, it was a reminder of the struggles we have gone through and how fragile our present is. Our Chapter provides many services for our community. I recognized this shortly after the first phone



call I got from Sue telling me "It is going to be ok and welcome to the family." Since being on the Board of Directors and being involved, I have come to realize how dependent we are on one another. To continue providing services tomorrow and the next 50 years, the Chapter needs us. The Chapter needs us to participate in events, share our talents, tell our stories, fundraise, and continue to build and grow our connections within and outside our community. Again, I am deeply thankful for everyone's involvement over the years. Let's keep the momentum going to make a better tomorrow for our families and for new families that don't know how much

they need us. Everyone can help lead us into the future, even in the smallest, most simple ways. I will do my best, but I know that I will need your involvement to continue our success.

Continued from page 6

are assuring as we all have grown throughout the years to open our arms to more bleeding disorders, our names are inclusive to reflect us all. Please read about the NBDF BDC in the National News Section and all the happenings from those who were present this year on behalf of South Carolina.

I hope you will continue to be actively involved with Bleeding Disorders Association of South Carolina and help support and join us at our many community engagements, fundraisers, and advocacy events. I look forward to seeing you

all soon and feel free to give me a call anytime to connect. I love hearing from everyone. I have some exciting ideas I would like to achieve in 2024 so stay tuned. Let us take South Carolina to its highest potential. Together, we can do so much to help our families and those in the future to live high quality lives without boundaries. A life without bleeds will take a global community to achieve. I ask you to do what you can to help us achieve this goal.

Warm regards,
Sue

Community Engagements

Back to School Night with the Greenville Drive

July 23, Greenville, SC

It was a fun day in July as community members prepared for heading back to school with the Greenville Drive at Fluor Field. In partnership with Takeda, this community engagement event provided an interactive presentation facilitated by John Martinez, the Community Education Specialist with Takeda. “Navigating School with a Bleeding Disorder” discussed how students, parents, family members, and school staff can work together to provide a positive environment for students with bleeding disorders—from pre-school through college. Attendees engaged in sharing their personal experiences with the group, which brought



some potential solutions to situations that community members often face. The attendees enjoyed lunch, drinks, and snacks throughout the game and a visit from Reedy Rip’it, the Greenville Drive’s mascot. This annual event was enjoyable and informative for all. The children and teens even went home with a loaded backpack of school supplies and a gift card to purchase a little more. We would like to extend a very special thank you to Takeda for our support group grant which helps provide us this opportunity of community engagement.



On the Road with BDASC: Myrtle Beach

August 3, 2023

Taking support and education on the road to towns across the state where community members reside is one of our favorite things to do. We love meeting members where they live and providing them the opportunity to meet up

with others in their local cities and towns making it easier for future gatherings among members. In August, we visited with our community members in Myrtle Beach and the surrounding counties, some coming from as far as Charleston

Continued on page 9

Continued from page 8

for a community engagement dinner, which was in partnership with Sanofi at Ruth's Chris Steakhouse. It was such a beautiful setting and the food was great. Over 40 attendees gathered to connect and learn about "Understanding Hemostasis & The Clotting Cascade". After our presentation was over and dinner had concluded, Sue shared all the chapter has going on for the

remainder of the year. Participants shared their interest to stay connected and asked how we could help make that happen. We decided to have virtual meetings for now until they can get better connected and we can provide another group activity. We wish to thank Sanofi for this community gathering opportunity.



Hispanic Community Support Group



On August 24 in Columbia, the Chapter invited their non-English, Hispanic community members to come together for an educational engagement presentation,

sponsored by Takeda, at Rios Brazilian Grill. The group enjoyed an all-Spanish presentation on transition and living with bleeding disorders and it was great to see them connect in their native

language. Sue Martin, executive director, invited community member Ursula Sagot and her daughters to translate her words into Spanish throughout the night as she welcomed the members and shared Chapter information. We were delighted to have additional non-Hispanic members there in attendance to support the Hispanic community. We would like to continue to bring our community together to socialize, support each other, and to meet the individual needs of this community. Stay tuned for more events to come in the future. A special thanks to John and Takeda for this support group



South Carolina Summer Camps for Children and Teens with Bleeding Disorders

We are grateful for the opportunity to partner each year with the staff and camp directors at Camp Burnt Gin, Camp Courage, and DHEC to provide each camper and the camp staff with our famous Ice Cream Social. Executive Director, Sue Martin, attended camp along with her volunteers and our partner Ryan Griffith, owner of Marble Slab of Greenville and Columbia, for this year's annual events. Hats and commemorative bags and other items were provided and were made possible from the support of our 2023 camp sponsors. Bringing campers together to share ice cream and enjoy spending time together at camp is such a joy. We cannot say thank you enough to our partners at Marble Slab for supporting our Ice Cream Socials this year at camp. Enjoy reading below the wrap

up of our camper's experiences. Do you have a young child that you would like to send to camp next year? We would love to help! Check out our website at www.bda-sc.org for details on each camp and keep an eye on our social media channels, e-blasts, and newsletters for dates and applications as they become available. We want to see each of our eligible children attend a bleeding disorders summer camp. Do not forget, travel grants are available for those traveling to and from camp. Camp is a fantastic experience for kids with bleeding disorders with the extra support of our medical staff from our local HTCs. Should you have any questions or concerns, please reach out to your HTC and the Chapter for any questions you may have about attending.

Camp Brave Blood—Prisma Health Upstate HTC Family Camp

Pleasant Ridge Camp & Retreat Center, Mariette, SC



While it is true, we are not having family camp this fall for many reasons, it was great to see the Upstate Prisma Health HTC in Greenville host their first ever bleeding disorders family camp day. Sue was able to host a welcome greeting table with BDASC information, coffee, juice, and doughnuts while hanging out as campers and their families enjoyed several activities throughout the day, including fishing, a sling shot challenge, the Challenge by Choice Course, making tie-dye shirts and potted plants, eating lunch, enjoying ice cream, and so much more. The activities did not stop until the campers packed up and went home. Could this be the start of something new and grow bigger each year? Stay tuned and connected....



*Rylee, "I can't wait to go back"
BDASC Community Member and
Rylee's Mom, Coree Snider—"I enjoyed
watching them being active in a safe
environment and watching them meet
other kids with different disorders"*





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Camp Burnt Gin—A Week of Summer Camp for Kids and Teens with Bleeding Disorders Wedgefield, SC

Camp Burnt Gin and the staff from the Midstate Prisma Health HTC welcomed kids from around South Carolina to enjoy a week of Summer



Camp. After a brief hiatus due to COVID, Camp Burnt Gin opened back up in June 2023. Kids from the Bleeding Disorders and the Sickle Cell communities shared a week of fun, interaction, and incredible camp activities. Campers and

staff remembered the famous Ice Cream Social provided by BDASC as we pulled up to camp and made some awesome sundaes. Throughout the week they also enjoyed a talent show, a dance, crafts, an inflatable water slide, water balloon fights, and so much more! Kids were also guided by Robin Jones, Prisma Health Midstate HTC Nurse Coordinator with education and practice on their infusions. Robin provided

the opportunity for our kids to learn how to self-infuse and gain more independence in their treatment.

All children with bleeding disorders no matter where they receive treatment are welcomed to attend CBG Summer Camp which is funded by the state legislature. BDASC is working to provide funding for a new basketball court for the camp, a longtime dream and project wish of both the Chapter and Marie Armonie, the camp director. Stay tuned as plans begin to be discussed soon!



"It's a lot of fun and you get to meet a lot of people that have been through the same situations as you. I can't wait to go back next year!" – Daphne Javorka, BDASC Community Member, Age 9 VWD

Camp Courage – Prisma Health Upstate HTC Summer Camp

Pleasant Ridge Camp & Retreat Center, Mariette, SC

If you receive treatment at the BI-LO Cancer Center in Greenville and the HTC at Prisma Health Upstate, you may have received an application to attend summer camp, intended for kids beginning at the age of six years. BDASC again provided its famous Ice Cream Social to kids with Bleeding and Blood Disorders, and all the staff. Fun camp activities



were also provided along with BDASC t-shirts and camp mess bags! The summer day campers enjoyed many of the same activities that the family camp provided, including a talent show, pool time, the Challenge course, fishing, and so much more. Be sure to keep your eyes out for next year's registration and join the Upstate Summer Camp for kids diagnosed with bleeding disorders!



The Carolina Crew, Together Again Teen Retreat—A Partnership between BDASC AND BDFNC

For over 10 years, North and South Carolina have hosted a joint retreat for teens ages 13 through 18 years who have a diagnosis of bleeding disorders, are a sibling of a family member affected, or they have a parent with a bleeding disorder. At times, the retreat allowed the teens to bring a friend to feel more comfortable in the new surroundings. From all counties of each state, they joined together at



Camp Canaan in Rock Hill, SC, on August 10-13 for three nights and four days to learn about advocating for themselves and their families, discover their strengths within themselves, learning to be challenged and having positive outcomes with the guidance and support from others, and to simply hang out with teens all with a common bond of being connected to the bleeding disorders community. They also



discovered the different challenges some teens face living with bleeding disorders, and additional information about the different bleeding disorders the teens had, from some of the most

common, to the rarest. However, for most of the time at camp, they were just teens, doing what they love to do, each in their own unique way. We were appreciative to have Joe Torrey at GutMonkey with us again this year all the way from Oregon, sponsored by Pfizer, who provided 8 hours of thought-provoking educational activities as they explored “systems”, or the small ways in which we live our lives, and what it says about who we are and our future goals. During



Continued on page 18

Upcoming Engagement Opportunities

Par for the Clot 9th Annual Charity Golf Fundraiser

The Preserve at Verde & Embassy Suites Hotel Terrace, Greenville, SC



BDASC will host its 9th annual charity golf tournament fundraiser, the Par for the Clot, on September

22, 2023. Players will enjoy a wonderful day of golf, food, fun, competition, and a community reception following the tournament. This sold-out event will host 144 participants and close to 40 volunteers, special guests, and community members.

This year we are excited to welcome back our Professionals: Perry Parker, PGA Professional and community advocate with CSL Behring, our title Sponsor, who will meet our players on Hole #11 in the Beat the Pro Challenge and Kyle Blakely, long



drive professional with Charity Golf International on our Donation Hole. Our fun and challenging tournament course play will include again this year the Charity Golf Gun

Hole, Spin to Win, our Poker Challenge, Putting Contest, and much more. We will also have the opportunity for all attendees to participate in our Silent Auction and Raffles during the banquet reception. Check out our website at tinyurl.com/2023ParForTheClot to see the awesome raffle items available.

We are excited to welcome this year our new lunch Sponsor. We are thrilled that Logan's Roadhouse will be providing our golfers with their lunch on the course this year. This tournament is so important to the success of our organization, and for over six months, the

T-Off Committee has been planning and working to execute the **"Best Charity Golf of the Upstate."**

Proceeds from this tournament will help continue funding the strong advocacy work BDASC

does throughout the state and in Washington to remove barriers to access to treatment care our community needs. Affording the high cost of healthcare

treatment is not easy for anyone today, especially those diagnosed with rare medical conditions like hemophilia, von Willebrands disease, and all our other ultra rare and platelet bleeding disorders. Attendees will hear from our

physicians who treat our patients, professionals like Perry Parker who lives with hemophilia, and community members such as the Javorka family, our featured members. Daphne Javorka, age 9, was diagnosed with Severe VWD Type 2B and Thrombocytopenia when she was one year old. She will be sharing her experience with VWD and why BDASC is so important to her.

It is with great appreciation we thank all our sponsors, our in-kind donors, our community donor partners, and everyone involved in this very special fundraiser and community awareness campaign. Thank you to all who help make this event possible!



With our Admiration and Gratitude, we wish to thank our 2023 T-Off Committee Members

Event Manager—Sue Martin, BDASC Executive Director

Event Chairman—Ric Martin and Co- Chair Brian Burton

BDASC Board Members—Aaron Smith, Joey Krakowiak, Cristal Day, Samantha Javorka, Edna Rabb, Taylor Upton, Susie Maloy

BDASC Community Members—Corbin, Bryce and Jordan Martin, Felicia Alexander, Hunter Day, Mandy Weber, Mike Walden

Industry Partners—Kerrie Barnes, Laura Benton, Apryl Tilert

Fall Advocacy Summit: Access to Care and Treatment

November 10-11, 2023, Greenville, SC

We are thankful to the Advocacy Coalition Committee Members who came together from all regions throughout the state and nationally, to form the South Carolina Hemophilia and Bleeding Disorders Advocacy Coalition (SCHBDAC). Our commitment to the Bleeding Disorders Association of South Carolina and all South Carolinians affected by bleeding disorders is to improve access to Quality Care and Treatment. Improving lives is our mission.



This November, BDASC will be hosting an All-Coalition Advocates State Meeting and Fall Training along with our annual Stakeholders Meeting in Greenville. The Coalition Stakeholders include members of our national bleeding disorders organizations, our Government Relations Industry partners, and other rare and chronic conditions advocacy organizations supporting our state. This important meeting and training will be held in downtown Greenville at the Spring Hill Marriott for two days of informational healthcare access sessions, and it will also be a celebration of the advocacy work accomplished so far. The Summit is free to our advocacy members, and members who would like to join in our efforts for policy changes. More information will be available soon. We hope you will attend.

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Wine Xpress, Coca Cola, Krispy Kream, Palmetto State Armory

Continued from page 15

the retreat, teens also had pool and lake time, kayaking, zip-lining over the Catawba River, and walking on ropes tethered high in the trees on the high ropes course. Of course, we could not provide this event without the staff of North and South Carolina, and our many volunteer counselors who shared in the experience and assured our teens were safe and provided for. We wish to thank from South Carolina: Sue Martin, Ric Martin, James Romano, and our Nurse for the weekend, Robin Jones, nurse coordinator from the HTC at Prisma Health Midstate, and from North Carolina: Charlene Cowell, Gillian Schultz, JerDan Smith, and Benjamin Grubbs. We cannot wait to return to our Teen Retreat next year! Stay tuned and connected, and be sure to register to join us all next year.

“The people I met and the relationships I made are what makes this camp so important. To make bonds with people like me.”—Danny Shelton

“I had a wonderful time at Camp Canaan. It was my first time coming to camp and I loved it because I was able to learn about other teenagers with bleeding disorders and about



them in general. The activities were very fun to me. It was my first time kayaking and zip lining and I think others would love the experience, and feel this love and joy I had. Thank you for allowing me to come to camp, it was a fun experience!”—Adonis Rabb

“We especially loved that you had good food and plenty of it.”—Laithan Lundy and Calvin Rocheleau

“I didn’t know there were so many types of bleeding disorders.”—Calvin

We wish to thank our South Carolina Sponsors for making all the summer camps we support available for our members.



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Voices of Our Community

The National Bleeding Disorders Conference was held just a few weeks ago and BDASC is proud to have provided national meeting grants to eight community members and families to attend. This annual conference is such a great opportunity to connect with the global bleeding disorders community and to gain knowledge from the sessions and attendees. Be sure to apply next year as we head to Atlanta, just a short drive across our border!



*"We are so thankful for the financial assistance provided to us so that we could attend NHF. It was an enjoyable time to reconnect with old friends from the community and make new ones. I must admit, a lot has changed since we were last at an NHF conference which was in 2016. I found some of the sessions very encouraging and helpful. I attended the Blood and Product Safety session which was very informative and is special to me because my friend Dana Kuhn was one of the original Board members and was created because of the work of the Hemophilia Community on the Hill in the 90's. I also attended the SilverStorm: Aging Men and Comorbidities. This was my favorite session because it is where I live with my hemophilia now. I was able to see the trailer for the documentary: On the Shoulders of Giants and a private showing at an off-site venue. The private showing was for the older members of the community. This was very much needed and embraced by all that were there. We have made a commitment to come along beside generations coming behind us to share and support them, and help them to preserve the history of this community long after we are gone." — **Warren P. Ingram***

"I absolutely reconnected to the bleeding disorder conference at such a pivotal time. To me it is like, wow, how were we blind to not have been inclusive across the boards with other bleeding groups. Then I thought, this had to be solidified with our hemophilia community, looking how hard



*our community was hit, yet we are still standing. I attended, How Do You Keep the Love Going session. I was comforted by the camaraderie and love that enveloped us from the community and especially from you, Sue. I am looking forward to becoming an active member again and to help be an extension of whatever you need. We are grateful to BDCSC, for investing in us. I am excited to encourage the youth and teens that they are not their diagnosis. I want to share with wives and partners regarding living creatively with someone with a chronic illness and I want to be a support to the community where I am needed."—**Sharon Ingram***

*"It is thrilling to see the entire bleeding disorders community being represented. It might seem like an unnecessary change to some, but it has a huge impact on those of us living with VWD or rare bleeding disorders. It helps us feel included and in turn allows us to feel as though we can seek help and resources from the organization."— **Samantha Javorka***

"Every opportunity we can get to learn more about bleeding disorders and how to support this



Aaron Smith, Sue Martin, Dana Gurley, Shelley Crisp, Caleb Gurley, Samantha Javorka

community is a grateful experience. To be able to attend the conference in Maryland was a blessing. Caleb and I have met new families, learned

Continued on page 20

HEDI Conclusion & Updates

August 28, 2023 - Virtual Meeting

On August 28 the Health, Equity, Diversity, and Inclusion working group reconvened virtually to recap our two-year long program and



to engage in continued conversations on our HEDI initiative. We are extremely grateful to the community members who have been committed to providing their insight and help in creating the BDASC HEDI working group. While the initial grant requirements provided to us by NHF are coming to an end, BDASC will continue to move forward with the knowledge gained over the past two years. The conversations that have taken place have been invaluable. BDASC is here to support the entire bleeding disorders community and it is hard to guess what the needs are. Within these conversations, we have learned not only which groups need additional support, but how we can support them.

Some of the HEDI Working Group's Tangible Accomplishments are:

- Holding the first ever HEDI Summit for Bleeding Disorders in South Carolina
- Identified and created an outcome Summary Statement on the HEDI needs for our community in SC
- Putting together web pages to ensure access

to resources for both the VWD and the Ultra Rare Communities

- Creating and distributing new tri-fold brochures for VWD and Women Who Bleed. This also prompted a revamp of our existing BDASC Brochure and CARE Brochure.
- Updating and improving our South Carolina Resource Guide.
- Providing a community survey for Women Who Bleed to learn more about their needs.
- Creating the "VWD Connections" community support quarterly zoom meetings, events, and newsletter section to focus on the needs of our women and the VWD community.
- Held an Ultra Rare and Spanish Community Engagement Event to celebrate our community members

We will continue to strive to ensure that everyone has access to quality care and treatment and a voice. If you would like to learn more about our HEDI Working Group, join and continue the work of the HEDI, or read our HEDI report, please visit our website at bda-sc.org. We would like to express our gratitude to the National Bleeding Disorders Foundation for aiding this initiative. NBDF granted the Bleeding Disorders Association of South Carolina a Chapter Capacity Building Grant to create our HEDI Working Group initiative and to host our Health Equity Summit last October in Charleston.

Continued from page 19

some amazing new information on gene therapy and the newest treatment options available for us in this community. There was importance this year on inclusiveness which is so important in the bleeding disorder community so each person feels truly connected and supported. Several of our sessions focused on mental health issues within our community which is so important to address to encourage and support each other on this road we travel, because it is not an easy

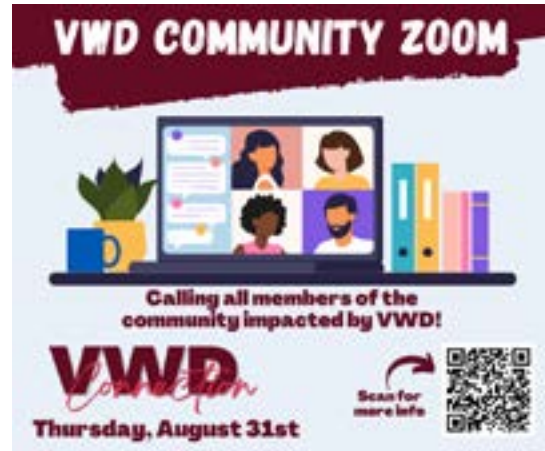
one. There were several sessions on self-care, care for the caregiver, and supporting our teens and children as they navigate their bleeding disorder in life. Caleb was able to meet people from all over and even experience a session in Spanish to learn how to communicate and support the Hispanic families in our community better. This trip to the conference has been something we will always remember and treasure!" —**Dana and Caleb Gurley**

Von Willebrand and Women Who Bleed Community News

Upcoming VWD Community Connections Virtual Meeting August 31, 2023 @ 7pm - Virtual

Due to the overwhelmingly positive response to our VWD Roundtable session at the 2023 HELLO Conference, we have put together a series of events focusing on community members with VWD. We will be hosting quarterly virtual meetings to get together to continue the great conversations that were started at the HELLO Conference. What we took from the HELLO Conference session was that there is a large need for discussion and community gathering amongst our members impacted by VWD. This meeting will be subsequently followed up by in-person events throughout the state. Our next

VWD Community gathering will be in Columbia on October 7.



VWD Community Connections Event October 7 2023, 1pm-7pm, Columbia, SC

1:00 pm at the Liberty Tap Room & Grill

828 Gervais St., Columbia, SC

4:00 pm at The Plant House

702 Cross Hill Rd. 400B, Columbia, SC

Register to join the SC VWD Community Members for a fun day in Columbia. We will begin with a "Lunch and Learn" with an educational session and conversations on "Women's Empowerment: Bleeding Disorders and Advocacy." Our speaker will be John

Martinez, Takeda's Educational Specialist. After our late lunch, we will travel over to The Plant House for a fun activity as together we make our own Jellyfish Terrarium. With assistance from the Plant House crew, our members will learn how to create a unique, ocean-inspired terrarium. We will choose from an array of decor to make your new terrarium uniquely yours. Information and registration is on our VWD Connections website page at www.bda-sc.org.

National Outreach von Willebrand (NOW) Conference

November 17-19, 2023, Phoenix, AZ

Don't miss out on this exciting opportunity to be part of the November 2023 NOW Conference, being held in Phoenix, AZ, at the Hilton Phoenix Resort at the Peak.

What is NOW? NOW stands for National Outreach for von Willebrand. Over the years, von Willebrand Disease (VWD) has always been "lumped" in with hemophilia. Well, NOW is the time to focus exclusively on von Willebrand Disease! NOW is a national educational symposium for individuals and families who are living with this chronic disease. It is a forum to learn about new medical advances, gain tools that can help you manage VWD and to share with others facing the same or similar challenges. We will bring in expert healthcare professionals who

can best address the issues unique to VWD. Funded through a grant by CSL Behring, Arizona Bleeding Disorders is excited to host this national conference focused specifically on von Willebrand Disease.

Who is Eligible? Applicants must have von Willebrand Disease and/or be a caretaker of someone who is diagnosed. The conference is funded to accept a limited number of participants. Families are welcome and there will be educational activities and daycare for children. Information to attend is available on our VWD Connections website page.



Did You Know?

South Carolina Sends Three to the JNC!

October 6-8 2023, 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 and caregivers. BDASC and chapters throughout the nation partner each year to provide this opportunity to our members. We are excited to announce and congratulate **Lucas Crisp (baseball), Harley Lubic (baseball), and Rylee Copeland (basketball)** for being selected to participate in the Gettin'in the Game's Junior National Championship and to represent South Carolina and BDASC! This is a fantastic opportunity for kids with bleeding disorders to learn about baseball, basketball, swimming, or golf and for community members to meet other



families from around the nation. If you missed the deadline to apply for this year's Junior National Championship, do not fret! Keep an eye out on our website, eblasts, and social media pages to know when to apply for next year! Good luck Lucas, Harley, and Rylee and have fun.

Financial Assistance Program Available

Did you know that BDASC provides financial assistance to its members? It is quick and easy to make a request on our website. You can either submit the online application or print and send over the application form (via fax, email, or mail). Once the application is submitted, the Executive Director will follow up with the applicant. **Please note that these applications are confidential.** No personal information will ever be disclosed, not even to the committee which decides approvals and denials of requests. Only the Executive Director will have the personal information application to verify organizational membership within BDASC's database.

The Bleeding Disorders of South Carolina Emergency and Financial Assistance Fund is intended to improve the quality of life of individuals and families affected by bleeding disorders. The assistance fund provides funds to eligible individuals and families who need emergency financial assistance and non-emergency aid for basic living expense emergencies, medical and living expenses incurred due to the medical care associated with a bleeding disorder, transportation and lodging to HTC clinics, hospitals, medical equipment needs and supplies, Medical Alert ID, medical testing and bills, labs, health care insurance assistance, **dental expenses** (orthodontics are not covered), **and mental health services.** Other assistance requests may be available upon an individual basis and funding revenue, such as school needs, work training, college tuition assistance, and national meetings support. Because of the timeline in processing these requests, we will make every attempt to process the requests in the timeliest matter. Efforts should also be made to utilize other community resources such as Social Services, food banks, and other organizations that supply these types of needs.

Financial Assistance is available for the following:

- Basic living expense emergencies—Utilities, Electric, Housing, Water, Car, etc.

- Medical and living expenses incurred due to medical care associated with a bleeding disorder
- Transportation and lodging expenses to attend HTC Clinics or hospitals
- Medical equipment or supplies
- Medical Alert IDs
- Medical testing/labs
- Healthcare insurance assistance
- Dental Expenses (except for orthodontic care)
- Mental health expenses
- Travel to and from educational and support BDASC and National Events
- Travel to and from bleeding disorders summer camps and teen retreat

To be eligible for assistance you must be:

- A registered member of BDASC (or register at the time of request), a current patient under the care of a SC Hemophilia Treatment Center, or medical facility and physician treating bleeding disorders patients in South Carolina.
- A person with a clinical diagnosis of a bleeding disorder, caregiver of a dependent person clinically diagnosed with a bleeding disorder or a confirmed carrier of a bleeding disorder.
- A resident of the state of South Carolina.

How does the applicant receive the funding?

If the applicant has already paid the bill, reimbursements for the approved amount will be made directly to the applicant upon the Chapter receiving receipts providing proof of payment. All other payment for an approved request will be made directly to the creditor.

Continued on page 24



Continued from page 23

Where can I find the application? The application can be found on our website at <http://www.bda-sc.org/>. Visit the “Member Services” section (see image above). Once on the “Member Services” page, click on the “Financial Assistance Program” link on the top banner. From there you will find all the necessary forms on the right side of the page. For the direct link you can go to <https://bda-sc.org/financial-assistance-program/>. The application can also be found on the BDASC VIP iPad. (See image below)



The funds for our financial assistance are provided by a generous grant from the Hemophilia Alliance Foundation in partnership with BDASC and the Prisma Health Hemophilia Treatment Centers. We do our best to aid everyone who needs it within our South Carolina Bleeding Disorders community, but please know that we are limited in the amount of money available. Because of these limitations, it is necessary for BDASC to place limitations on financial assistance. The maximum request per year is \$500, unless under special circumstances that the financial assistance committee approves. For more information on the Policies and

Procedures for Financial Assistance please visit: <https://bda-sc.org/financial-assistance-program/>.

Additional resources are available to our community members:

HFA's Helping Hands (Disaster Relief Only): This program provides financial assistance for disaster relief for those living with or caring for a person with a bleeding disorder. For more information visit: <https://www.hemophiliafed.org/resource/disaster-relief/>.

PAN Foundation: This program provides copay and premium assistance funds for applicants. Applicants must have hemophilia A, B or von Willebrand Disease and the medication must be covered in PAN's list of covered medications. For more information visit: <https://www.panfoundation.org/find-disease-fund/>.

Accessia Health: This program provides financial support for copays, health insurance premiums, travel costs and other medical expenses at no cost to the patient. For more information visit: <https://accessiahealth.org/financial-assistance/>.

The Assistance Fund/Hemophilia Financial Assistance Program (currently enrolling):

This program is for those living with bleeding disorders, but only covers a specific medication list. This program provides assistance for prescription drugs, health insurance premiums, therapy administrative costs, treatment-related ground travel, and genetic testing. For more information visit: <https://enroll.tafcares.org/>.

Co-Pay Relief Fund from Patient Advocate

Foundation (currently enrolling): This program provides assistance for those living with Hemophilia. This program includes co-pays, co-insurance, deductibles, and medical insurance premiums. For more information visit: <https://copays.org/funds/hemophilia/>.

Please note: At the time of printing, the CK Colburn Keenan Program and HFA's Helping Hands Emergency Assistance and Inhibitor Support are not currently accepting applications due to not having funds available to provide.



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

**Industry Sponsorships
and Donations**

Bayer
Blue Sky Pharmacy
Compas, Inc-Genentech
CSL Behring
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DrugCo
Genentech
Hemophilia Federation of
America
Kedrion Biopharma Inc.
Medexus Pharma Inc.
Novo Nordisk
Optum
Paragon
PhRMA
Sanofi
SCRX Specialty Pharmacy
Sparks Therapeutics
Takeda
The Hemophilia Alliance
Foudation

**Friends and Family,
Community Partners
Donations**

**Donation in Memory of
Gene Wilson**

Jan and Dexter Covington

**In Memorial of John
Lucas, Jr**

Anna Miller
Barry and William Lide
Charles and Elizabeth
Lorick
Christie Walters
Connie and Bob Warren
David and Betzy Moxley
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Kathryn Harvey
Kay Johnston
Leslie McFall
Lewis and Arlene Milligan
Lori Fleming
Patricia and James
Watson
Robert Mancini
Stephen Hirsch
Tim Wilson
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Church / John Rowland
Sunday School Class
W.Q and Julia Long

General Donations

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Jim Kick
Edward Jones / Janice
Hickman
Grayson Smith
Gwendolyn Furcron /
Tangela Rease
Hemophilia Federation of
America
HT Johnson
Joey Krakowiak
Joseph Carrero /
McKesson Corporation
Joseph Chandri
Kevin Lucas
Keystone Instructors, Inc.
Matthew Weber
The National Bleeding
Disorders Foundation
Network for Good
Phillip Ross
Rarity Health
Ric Martin
Rick S. Anthony
Ross Phillip
Specialty Care Rx LLC
Sue Martin
Thomas Tilert

Advocacy Action

The Path Forward, Falling into Fall Advocacy

By James Romano, BDASC Legislative Coordinator



Bleeding Disorders Association of South Carolina is gearing up for a great fall. The fall will see the community preparing for a huge advocacy push that will be sustained through the end of the Legislative session in the summer of 2024. Beginning this summer, the Chapter gained an advocacy champion through Representative Stewart Jones (R-Laurens). As many know, the Chapter named Representative Jones as our Legislator of the Year and he joined us at our 50th Anniversary Gala. Representative Jones committed to work with the community to obtain more Republican cosponsors for H3618, the Copayment Accumulator Legislation. The Chapter hosted a fantastic advocacy workshop during the 50th Annual Meeting bringing together many voices and stressing the importance of state advocacy. I attended the National Conference of State Legislators meeting in Indiana this past August and met with some of our state legislators asking the

Representatives to cosponsor the legislation while asking the Senators to be initial sponsors of a Senate companion legislation. Following the NBDF BDC Annual meeting, we will be holding virtual meetings with all the South Carolina Congressional Delegation advocating for co-sponsorship of HR830, the HELP Copays Act, the federal copayment accumulator legislation. During the fall the chapter will be meeting with Members of the Legislature to push the state legislation.

This November BDASC will host a Fall Advocacy and Stakeholders Summit in Greenville. The focus of the Summit will be continued training for 2024 in advocating with legislators, education on the major issues facing the bleeding disorders community, social media advocacy training and meeting with legislative leaders, preparing for testimonials, and Chapter leadership will speak about best practices and working together to advance the priorities for

Continued from page 26

the community. Prior to our advocacy summit, Sue will be hosting community public policy expert, Kollet Koulianos, with the purpose to meet with the House Committee on Labor Commerce and Industry to discuss their concerns for advancing the legislation. We will also be taking a larger leadership role in advancing the Palmetto Health Initiative by reaching out and expanding membership to other SC based nonprofit organizations. Sue will be participating and helping to host an advocacy summit day event in Columbia with the leadership of the many Palmetto Health Collaborative state organizations. The goal of the summit is to lay out a strategy for other organizations to follow and to engage on the copayment accumulator legislation and move to passage. Advocacy partners are very important! The first half of 2024 will be a very busy time in our advocacy efforts and your participation is key. On January 10, 2024, we will be hosting our Legislative Breakfast in the Blatt House

Office Building. This is a fantastic opportunity to meet legislators and staff and discuss the legislative agenda of the chapter including H3618 copayment accumulator legislation. We ask for all community members to please join us to greet and speak with legislators and staff. This will be the first legislative breakfast of the year, and we anticipate a well-attended event. We will ask you to reach out to your legislators to invite them to breakfast. Finally, our state advocacy days will be on February 27 and 28 with the opportunity to push H3618 through and we will need every advocate to participate. Please mark your calendars now. If you have any questions, please contact Sue Martin (Sue.Martin@bda-sc.org) or James Romano (james.romano@bda-sc.org) for additional information.

Save the Dates!

Legislative Breakfast is January 10, 2024

BDASC State Advocacy Days are February 27-28, 2024

NHF Washington Days are March 6-8, 2024



Saturday 1:22 pm
Swinging in the
backyard with mom
Evan, living with
hemophilia A

Not an actual patient

WE'RE IN THIS TOGETHER.

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



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National News

The National Bleeding Disorders Foundation, formerly NHF Celebrates 75 years with a Rebranding!

The 75th Anniversary Bleeding Disorders Conference (BDC) kicked off on Thursday, August 17, with an exciting presentation and unveiling of NHF's long anticipated rebranding. NHF has officially become the National Bleeding Disorders Foundation (NBDF)! To be more inclusive of those living with a wide variety of bleeding disorders, the National Hemophilia Foundation is ushering in a new season of inclusivity with this name change. The National Bleeding Disorders Foundation will continue with their existing mission and vision—finding cures for inheritable blood disorders and addressing and preventing the complications of these disorders through research, education, and advocacy.

This name change was made to better reflect their mission as well as our bleeding disorders community.

We had a fantastic group of community members representing South Carolina at this year's BDC in National Harbor, MD. Representing our Board & Staff, Sue Martin, Aaron Smith, and Samantha Javorka were present to learn from the Chapter Track—sessions provided to support Chapter



leadership and staff. Shelley and Lucas Crisp, Dana and Caleb Gurley, and Warren and Sharon Ingram were this year's BDASC Travel Grant recipients. BDC provided the opportunity for community members to learn about different aspects of living with a bleeding disorder. From updates on therapies, to learning how to provide mental health support to teens, to dealing with bleeding disorders as we age, there was something for everyone. But it wasn't all education—there was plenty of fun as well! Industry provided education and interactive meals as well as an engaging exhibit hall (with tons of SWAG!). The final night of the conference

concluded with an awards ceremony and a fun closing event. Next year's BDC date and location were also announced. We hope you save the date for next year in Atlanta, GA on September 12-14, 2024. You can read from our attendees on what they thought of this exciting national meeting in the Community Voices Section.

Research & Development

Gene Therapies Now Available for Hemophilia A & B

As of June 29 this year, the second gene therapy for Hemophilia—this time Hemophilia A—was approved by the U.S. Federal Drug Administration. In a statement released on June 29 pharmaceutical company, BioMarin, announced the FDA's decision to approve their gene therapy treatment for adults with severe hemophilia A. This one-time, single-dose infusion was first approved by the European Medicines Agency in August of 2022. BioMarin has begun working with HTC's around the U.S. to ensure that HTC's are prepared to administer the treatment. Along with this news comes another

significant step forward in gene therapy. On June 20, CSL Behring announced that two patients have received their gene therapy for Hemophilia B. Discussions continue throughout the US between manufacturers, national bleeding disorders organizations, chapters, HTC's, and insurance. The cost of these therapies and access to them remain at the forefront of gene therapy discussion. In South Carolina, our Columbia HTC—Prisma Health Midlands—prepares for the day they will infuse their first patient with one of these treatment options.

Stay Connected with BDASC

BDASC is always looking for ways to keep you informed and up-to-date with all the resources available to the South Carolina bleeding disorders community. We want to ensure that everyone in our community is aware of upcoming events. Check out up-to-date information on our social media pages, website, and do not forget to look for our E-Newsletter Blasts in your email inbox. Not seeing the e-news, check your spam! If you are not seeing our social media content in your news feed, we can help you with that. The way Facebook and Instagram work is that they try to predict what you want to see based on what you comment, like and share. Sometimes it works great, and you see everything you want to, but other times it doesn't work out so well. To

help ensure that you are seeing our content, you can do a few things. The first thing is to ensure that you are a follower of our pages. Once you are following our pages, like, comment on, and share our content. Over a short period of time, Facebook and Instagram will catch up and start showing you our content in your newsfeed. We share tons of information on our social media pages! Anything from upcoming events (with registration links) to informational tidbits. After events, we share photos that we take (or, with their permission, photos from others). We would love for you to share photos, quotes, thoughts, etc. with us to share on our social media pages, after all, the community is about raising your voices and sharing your story!

Stay Connected With
BDASC



Facebook



Instagram



Newsletter



bda-sc.org

Resources & Contact Information

Medical Facilities

The Hemophilia Treatment Center of South Carolina
Children's Cancer & Blood Disorders Clinic at Prisma Health Children's Hospital-Midlands
7 Richland Medical Park Rd., Suite 7215
Columbia, SC 29203-6872
Phone: 803-434-3533

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

Prisma Health's Upstate Children's Hospital
MAIN CAMPUS:
BI-LO Charities Children's Cancer Center Serving Hematology/Oncology Patients
900 W. Faris Road
Greenville, SC 29605
Phone: 864-455-8898
Fax: 864-455-5164

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

SATELLITE OFFICE:
Spartanburg- Children's Hospital Outpatient Specialties
1700 Skylyn Drive, Suite 200
Spartanburg, SC 29307
Phone: 864-716-6490
Fax: 864-596-5164

Hours: Wednesday - alternating mornings and afternoons

SATELLITE OFFICE:
Anderson - Pediatric Specialties of the Upstate
2000 E. Greenville Street, Suite 3500
Anderson, SC 29621
Phone: 864-716-6490
Fax: 864-716-6492

Medical University of South Carolina
Shawn Jenkins Children's Hospital
10 McClennan Banks Dr.
Charleston, South Carolina 29425
Shayla Bergmann, MD, Assistant Professor
Director, Pediatric Hemophilia Clinic
Phone: 843-876-1980
Mobile: 843-812-5682
Fax: 843-792-7562

Local and National Orgs

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

National Bleeding Disorders Foundation
7 Penn Plaza, Suite 1204
New York, NY 10001
Phone: 212-328-3700
Fax: 212-328-3777
Phone: 800- 42-HANDI (4-2634)
Fax: 212- 328-3799
Email: handi@hemophilia.org
Website: <http://www.hemophilia.org/>

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

World Federation of Hemophilia
1425, boul. René-Lévesque O.

Bureau 1010
Montréal, Québec

H3G 1T7 Canada
Phone: +1 (514) 875-7944
Fax: +1 (514) 875-8916
Email: wfh@wfh.org
Website: www.wfh.org

Resource Information

SC Dept. of Health & Environmental Control (DHEC)
Children with Special Health Care Needs Hemophilia Program
2100 Bull Street
Columbia, SC 29201
Phone: 803-898-0784
Website: <https://www.scdhec.gov/health/child-teen-health/services-children-special-health-care-needs/hemophilia-assistance-plan>

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

American Society of Pediatric Hematology/Oncology
Phone: 847-275-4716
Website: www.aspho.org

The Coalition for Hemophilia B, Inc.
Phone: 212-520-8272
E-Mail: hemob@ix.netcom.com
Website: www.hemob.org

Bleeding Disorders Legal Hotline
Phone: 800-520-6154

Centers for Disease Control & Prevention
Phone: 1-800-311-3435
Website: www.cdc.gov

Committee of Ten Thousand (COTT)
Phone: 800-488-2688
Website: www.cott1.org

LA Kelley Communications, Inc.
Phone: 978-352-7657
Website: www.kelleycom.com

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

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

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

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

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

South Carolina Healthcare Market Place
Call 800-318-2596
Website: www.HealthCare.gov

The South Carolina Rare Disease Advisory Council
Website: <http://rarediseasesc.org/>

Upcoming BDASC Community Events



Mark Your Calendar!

Looking Ahead: Major Community Engagement Opportunity – Save the Dates!

September 22: Par for the Clot Charity Golf Fundraiser - Greenville
 October 7: VWD Community Support & Education Event - Columbia
 October 27: Summerville Community Engagement Dinner
 November 10-11: Fall Advocacy Summit: Access to Care and Treatment - Greenville
 November 30: Community Engagement Dinner - TBD
 December 9: Statewide Winter Gathering - Columbia

2024 Major Events

January 10, 2024: Legislative Breakfast in Columbia
 February 27-28, 2024: BDASC State Advocacy Days in Columbia
 March 6-8, 2024: NHF Washington Days
 March 22-24: Adult Retreat Greenville
 April 11-14: HFA Symposium
 May 11: STEP for Bleeding Disorders Walk Run 5k Columbia
 June 21-23: Annual Meeting & HELLO Conference Greenville
 July 18-21: Tentative Teen Retreat
 August 12-15: NBDF Conference Atlanta, GA
 September 27: Par for the Clot Greenville

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/>



Shop, sell, and donate for a good cause! Go to www.charity.ebay.com



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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