

The News Infusion

The Official Newsletter of Bleeding Disorders Association of South Carolina

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SPRING 2022



FEATURED ARTICLES

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

Spring 2022 Calendar of Events

Please visit our website calendar page link to see the most current information on potential scheduled events at <https://bda-sc.org/events/>

May 10 — Bleeding Disorders Advisory Committee (Industry) Meeting

May 12 — M.E.N.S. Program Meeting (Virtual)

May 14 — STEP for Bleeding Disorders (Saluda Shoals Park, Irmo)

May 28 — Y.E.S. New and Young Families Empowerment & Support (Columbia)

June 10–11 — BDASC Annual Meeting & HELLO Conference (Greenville)

June 24 — C.A.R.E. Ladies Night Out (Mt. Pleasant)

July 2 — Y.E.S. New and Young Families Empowerment & Support Group (Columbia)

July 14 — M.E.N.S. Program Meeting

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About This Publication

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Lead Article



Inaugural Women's Bleeding Disorders Retreat & Conference

MARCH 25-27, 2022

SpringHill Suites Greenville Downtown
200 E. Washington Street, Greenville, SC 29601

The inaugural C.A.R.E. Women's Bleeding Disorders Conference and Retreat on March 24 and 25 went off without a hitch. More than 50 participants gathered at the Westin in downtown Greenville to participate in discussions around women who are affected by hemophilia, von Willebrand Disease (VWD), or other rare bleeding and platelet disorders. Participants included women who are carriers of genetic bleeding disorders, as well as those who are caretakers, mothers, daughters, and siblings of someone with a bleeding disorder. The opening discussion on "Women Who Bleed" (sponsored by Bayer) focused on empowering women to know the meaning of their hemophilia and bleeding disorders carrier status and understand all available treatment options. This was led by registered nurse Jessica Lovercamp, who encouraged women to know the meaning of their hemophilia and bleeding disorders carrier status and to investigate bleeding and treatment options. The program focused on going beyond that carrier status, getting tested, and understanding they may need to treat depending on their factor levels. The evening concluded with a session "Connecting Our Women Voices," with a creative spring/Easter art project led by Ribbon

and Burlap.

The next morning began with an opening session on "Mind, Body, Heart, Connection: Women's Mental Health," sponsored by the Hemophilia Federation of America (HFA) and led by Anna Maria Bell of HFA. It concentrated on taking a holistic approach to wellbeing, with a discussion on building coping strategies for leading a healthy lifestyle. Another session, sponsored by the National Hemophilia Foundation (NHF) focused, on "Reproductive Health, Menstruation, and Menopause" as vital topics in the lives of girls and women. This workshop, facilitated by NHF's Natalia Winberry, provided a deeper dive into the physiological components of these issues and highlighted the implications for those with bleeding disorders. The afternoon offered separate tracks: one focusing on carriers and rare disorders and another for those affected by VWD. The first track featured a session on "Carrier Guilt," also sponsored by HFA and led by Ms. Bell, and focused on some of the psychological "baggage" some women carry related to passing a bleeding disorder along to their children. It provided a frank conversation where women were able to share, connect, and support one another. Another session, "Laughing Through Stress," sponsored by CSL Behring, featured Lori Kunkle, who led a discussion on how laughter can

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naturally help with life’s daily stress, as it relates to living with a bleeding disorder (and otherwise).

The first VWD breakout session, sponsored by Grifols and led by Virginia A. Kraus, provided an overview of VWD, including a brief history of testing, classification of subtypes, and current research trends regarding reproductive issues. Another session, “What They Mean For You—New VWD Guidelines and Management,” sponsored by NHF and led by Ms. Winberry, gave an overview of new guidelines on the diagnosis and treatment of VWD. Participants learned how to use these foundations for decision-making about their own healthcare.

At the end of the day, attendees participated in a group yoga activity, led by Hope Brooks. They learned some basic yoga moves and received a yoga mat to take home and continue exploring the benefits of yoga on women’s health. The evening concluded with a dinner at Smoke on the Water, with

a presentation, “Women Matter in Bleeding Disorders” by Ms. Cardarelli of Takeda, who also sponsored the event. It focused on the unique

challenges women with bleeding disorders face and what options they have for finding emotional support within

the community. Sunday morning brought the opportunity for participants to further connect, discuss and explore how to move women’s health initiatives forward and provide feedback and evaluations on the event. It was shared that 100% of the women enjoyed the conference and would like to see a repeat again in 2023. We are grateful to our sponsors for their support of this important conference to address women’s health equity and raising awareness for Women Who Bleed!



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Board's **BLOG**

Dedicated and Committed to the Bleeding Disorders Community

The Bleeding Disorders Association of South Carolina Board of Directors is responsible for the governance of the organization and works closely with the executive director and staff. The team meets monthly to discuss the direction of, programs, services, and support for the membership. With some members ending their terms this June, new board positions will be available. We are actively searching for committed members to serve in this leadership role. If you or anyone you know, including someone outside the bleeding disorder community, would be a great addition to our team, please send them our way! Additional information is on our website [About Us](#) page including the new board member application, or you can contact the office at info@bda-sc.org or 864-350-9941. We would love to

share the visions we have for our future with new board members.



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Not an actual patient.

Executive's Welcome

By Sue Martin, Executive Director

A World Without Bleeds



Spring is one of my favorite times of the year. The sun begins to shine, allowing the growth of new plants and flowers, providing beauty and simplicity all around us. It is especially comforting during these challenging times with the rising costs in healthcare, groceries,

gas, COVID concerns, and the many divisions within the nation. For those who may not be aware, I am just a few days post-op of a total hip joint replacement and have learned many things about staying positive, expressing gratitude, and being appreciative for all I have within my life.

The need for the surgery and the experience have also provided me with an in-depth personal look at what many in our community suffer from today, and makes my resolve to find solutions even stronger. Pain, debilitating joint disease, lack of movement, financial worries, healthcare access, all come into play when our joints or bodies fail us. We have much work to do to assure those who suffer today, have what they need for a high quality of life, and to ensure our younger individuals diagnosed today will not experience joint disease in their future. *A world without bleeds* will be our greatest accomplishment.

Having said this, our Chapter's alignment for future research initiatives where patient-centric treatment care is at the forefront, and where we are present at the table of conversations, providing our input on what is important to us, is extremely strong. In our 2022 [Member Feedback Survey](#), our members expressed that our advocacy work to assure access to care and treatment, and progressing research on what is still needed for those within the

bleeding disorders community, was high on their priorities. While we all want research for developing innovative and enhanced treatment therapies and, of course, a cure one day, we need to continue to look at research within the areas that we are not exploring, or still do not have the answers to. Why can't women who bleed easily get treatment plans that provide them emotional support and relief from bleeding? Why is it easier for our men? Why can't testing be better, less sensitive, and more readily available to all who need it? What about gene therapy which is just around the corner for the U.S.? Who will pay for it and why, who will have access to it, and where is it going to be available for South Carolinians with the desire to give it a chance? What about our long-term bone health within the bleeding disorders community? How do we gracefully age, handle heart disease and concerns—after all, for the longest time, those with hemophilia were not expected to live long enough for heart disease damage. There are so many unanswered questions and I am excited that we are working side by side with those doing the research for our futures, and I hope you will walk with us, providing your voice for the future, such as with the [Community Voices in Research](#), “Research Ambassadors”, and “Subject Matter Experts” (SMEs) will be future initiatives we will be working on to support research for brighter tomorrows.

As we continue to look at the future, we must also build our future leaders in South Carolina, those who will take us into the future, and it begins with our teens and young adults. Our 2022 goal is to build upon these individuals and I hope you will support us and encourage your teens and young adults to get involved. Just as our adult hematologists specializing in bleeding disorders treatment care are retiring and we are in need to replace them nationally, so are our older bleeding disorders community, many retiring and now leaving the work up to the younger generation. How awesome for South Carolina to shape the future leaders of tomorrow! We have so much still

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Community Engagements

STEP for Bleeding Disorders

5K Walk for Hemophilia and Bleeding Disorders

May 14 at Saluda Shoals Park

BDASC's STEP for Bleeding Disorders 5k run/walk fundraising event is scheduled for Saturday, May 14, 10:00 a.m. walk time kick-off, at Saluda Shoals Park in Columbia.

The event is open to the public—anyone can register, raise funds, and attend. You can even participate virtually. You can join a team or participate individually. There will be food—including coffee, snacks, drinks, and a pizza lunch—and many free festivities, including a photo booth, face painting, cookie cart, Big Time Entertainment and our favorite DJ Andre, t-shirts, swag bags, and sponsor booths! Raffle items are also going to be made available for some nice gifts. The University of South Carolina's Cockey the Gamecock will be there, along with Benny the Blood Drop and our great walk friend, Olly Otter. We'll have a costume contest and give out awards

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left to do as a community and it will take all of us together to make progress.

In closing, I hope you will be joining us for our Annual [STEP for Bleeding Disorders](#) Awareness Fundraiser, May 14 in Columbia, and our 49th [Annual Meeting](#) and HELLO Conference in Greenville on June 10-11. These two very important events are vital to our mission work and assuring we are serving the bleeding disorders community in South Carolina to the

best of our ability. I also invite you to review our [2021 Annual Gratitude Report](#) now available for reading online on our website. Thank you all for the time, talents, and financial gifts you provide to the Chapter and to me personally. It is the greatest gift to be able to represent South Carolina and I am grateful for your support. Congratulations to the upcoming graduates of 2022 and may your futures be bright! Warmest regards,
Sue

Continued from page 7 for the best costumes, top fundraising teams, largest teams walking, oldest and youngest participants, and the top three runners. “STEP” encompasses everything the Bleeding Disorders Association of South Carolina holds to its core. “S” is for “Sharing Stories,” “T” for “Transforming Tomorrows,” “E” for “Empowering People,” and “P” is for “Promoting Research.” The funds we raise go to support the bleeding disorders community in South Carolina and our global bleeding disorders family. This includes education, financial assistance, and support for our many programs, including advocacy initiatives. Come help us make a difference in South



Carolina and beyond! We would like to give a special thanks to all our sponsors, teams, donors, and participants. We couldn't do it without you!

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Annual Meeting and H.E.L.L.O. Conference

Registration is open now!

June 10-11, 2022

Friday 5:00 p.m. to Saturday 8:00 p.m.

VENUE: Embassy Suites by Hilton Greenville Golf Resort & Conference Center

670 Verdae Blvd, Greenville, SC 29607

Childcare Onsite Services Will Be Provided By: [Corporate Kids Events](#)

Teen Programming with the Leading Edge and Gut Monkey

The 2022 Annual Meeting and H.E.L.L.O. Conference, set for June 10-11 in Greenville, is taking registrations now and is filling up fast. This will be the chapter's 49th Annual Meeting. It provides the South Carolina bleeding disorders community the opportunity to come together, network, learn, and enjoy the empowerment of education and support. As always, we will be holding the presentation of the Chapter's Annual Awards on Friday night, including the announcement of college scholarships. We will be introducing our new board members and celebrating those who have served and are now stepping down. This



dinner also is a chance for us to give certain recognitions, such as the Legislative Advocate of the Year Award, which will

go to Rep. Patricia Henegan for her sponsorship of H4987, the "anti-accumulator adjuster" bill, and her continued support of the South Carolina Bleeding Disorders Community. Other recognitions include the Board Member of the Year, Volunteer of the Year "Fisher Award", Coalition Advocate of the Year, Coalition Ambassador of the Year, Pillar of Strength Award, Appreciation and Partnership Award, and the Making a Difference Award.

Our keynote speaker for this year is, Kevin Mills, Ph.D., Chief Scientific Officer at the National He-

mophilia Foundation (NHF). Dr. Mills is a graduate of the University of Colorado Boulder, MIT, and Harvard Medical School, and is responsible for overseeing NHF's research strategy, including developing and expanding the foundation's research capabilities and setting research goals. We have been working side by side with NHF on advancing research and are so honored Dr. Mills has accepted our invitation to meet the South Carolina Community and share his visions for research advancing patient treatment.

Dr. Mills brings more than 20 years of experience in biotechnology, hematology, and oncology to the role. In 2005, Dr. Mills joined the faculty at the Jackson Laboratory in Bar Harbor, Maine, and led a laboratory focused on the biology of DNA repair in hematology and oncology. In 2012, he co-founded Cyteir Therapeutics, a biotechnology company developing and commercializing new therapies targeting DNA repair pathways. As Cyteir's chief scientific officer, he led the team that brought a first-in-class RAD51 inhibitor into clinical trials. Dr. Mills subsequently joined Civetta Therapeutics as chief scientific officer.

The following morning, the BDASC Advocacy Coalition will host a panel discussion titled "Diverse Perspectives: How Individual Experiences Strengthen a Unified Voice." The session will explore how things like gender, race, age, socioeconomic status, type of healthcare coverage, and distinct disease states inform how we advocate, and how listening to one another makes us stronger." Sonji Wilkes, Vice President of Public Affairs at the Hemophilia Federation of America (HFA), will kick things off with an overview of our national voices and where we are heading as a community. Then, we will turn to member panelists who will facilitate discussions on the nuances of living with and accessing healthcare for those affected by hemophilia A and B, von Willebrand Disease (VWD), platelet disorders, rare clotting factor deficiencies, and those living with inhibi-

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tors. BDASC strives for diversity in our discussions because we are a diverse community, and we know that this leads to better, more informed decision-making as advocates.

The afternoon will feature breakout sessions available to everyone. These will include a “Gene Therapy Jeopardy,” sponsored by BioMarin. Alternatives include a session on VWD, sponsored by HFA and led by registered nurse Sue Geraghty, and one on “Women Who Bleed,” sponsored by

Bayer—a “part two,” if you will, of our women with bleeding disorders series.

A second round of afternoon breakout sessions will feature programs on “Mind and Body Skills to Tame and Reframe Pain,” sponsored by CSL Behring and presented by Dr. Diane Diamond, will be geared towards men. Another session, “Missing Gene,” for young families and sponsored by Genentech, will have discussions about the challenges new diagnoses present to young families. A final session, “Spotlight On Siblings,” sponsored



by Sanofi, will focus on tools parents can employ to ensure all of their children’s needs are met, not just the ones directly affected by bleeding disorders. Information on current and future treatment therapies and bleeding disorders services will be made available during our exhibit hall experience. An infusion clinic, sponsored by HFA and facilitated by Sue Geraghty, will be available to anyone who wishes to participate and learn more about self-infusion. Our HTC Nurse Robin Jones will be joining Sue during this session. We are planning a teen track that will run concurrently with our adult programming, led by GutMonkey, so there will be something for everyone. Their “Leading Edge Program” is designed to provide foundational, life-changing experiences for people with chronic health conditions and to help improve health outcomes, build communities, dismantle stigma, and increase awareness. Their experienced designers and programmers use best-practice experiential education techniques to help teens make real changes in their lives. This

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teen track has been made possible through exclusive support provided by Pfizer. We also have contracted with Corporate Kids events this year to care for our children ages 1-12 years. They provide a wealth of experience and the total care you need to participate in the meeting as your children enjoy activities designed for them. Also, we're going to squeeze in some gaming among all the learning: a video game truck will be available for the kids during the morning to have some fun.

All meals, sessions, and childcare are included with hotel accommodation available for our traveling guests. The event is free of charge for BDASC members. Registration is required for attendance and is now open on our [website](#). Hotel rooms are almost full so don't wait, register today. **Registration Deadline: May 19.** We hope you will plan to join us!

Our Quick Look Agenda Schedule:

- 5:30 p.m.—Friday Night Chapter Annual Meeting
- 9:00 a.m.—4:00 p.m.—Saturday Sessions and Breakouts
- 5:30 p.m.—Dinner Wrap-up, Hotel Terrace

We are grateful to all our sponsors for their support in making this event possible.

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Community Connections Support Group Activities



February 10—M.E.N.S. Program Meeting

On the second Thursday of the month, the M.E.N.S. Group met virtually for a presentation by James Whitmire, a certified public accountant and BDASC board member, to discuss tax return strategies, with a specific focus on available deductions and how Advance Child Tax Credit payments could impact your return. The presentation was well-received by all, especially as tax season was near!



February 19—C.A.R.E. Ladies Night Out

On February 19, the C.A.R.E. Women’s Group had a social event sponsored by CSL Behring at Nailed It! in Fort Mill where they made vision boards. They also heard from Kristy, a Common Factor Advocate from CSL Behring, who shared her story of a mother’s persistence in obtaining an accurate diagnosis for her son. It was a reminder of the importance of raising awareness about bleeding disorders.



February 26—M.E.N.S. Day Out

On Saturday, February 26, the M.E.N.S. Group met in Greenville for a social event at Board and Brush, sponsored by CSL Behring. The men enjoyed getting to know one another, sharing experiences and support as they hammered, nailed, sanded, and painted projects to take home. Great food was also enjoyed by all.



February 28—Rare Disease Day

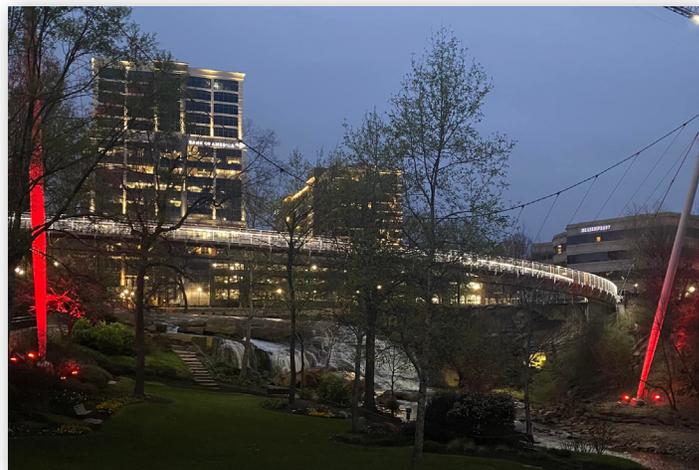
February 28 was “Rare Disease Day,” which recognizes the more than 7,000 rare diseases in existence that impact 300 million people globally. BDASC raised awareness in downtown Greenville by setting up signage in Falls Park recognizing March as “Bleeding Disorders Awareness Month” and explaining the significance of red lighting on the Liberty Bridge.

April 15-16—World Hemophilia Day Celebrations

Since World Hemophilia Day, which is April 17, fell on Easter this year, BDASC held two celebrations on the two days leading up to commemorate the event. See the full article in the Advocacy Section.

April 29—C.A.R.E. Ladies Night Out

On April 29, the C.A.R.E. Women’s Group met for a social and educational event in Columbia at Ruth’s Chris steakhouse. The program, sponsored by Sanofi Genzyme, focused on “Cognitive Conversations: Positive Self-Talk,” in which



discussions provided by Gretchen Hover revolved around behavioral insights that could aid in discussing issues related to bleeding disorders with healthcare professionals, friends, and family. The women enjoyed the time together to learn, support one another, and just have some time away and out on the town! We thank Sanofi for the opportunity to connect our women within the bleeding disorders community!



Upcoming Support Group Activities



**Young Families
Empowerment and
Support**
for parents with children 0-12 years

May 28—YES Program Event

On Saturday, May 28, BDASC families with young children and new members of the organization will meet at EdVenture Museum in Columbia for a Y.E.S. Support Group event sponsored by Sanofi. The program will focus on “Camp Readiness,” and will include lunch and tickets to the children’s museum. The Y.E.S. program is provided for families with children 12 years of age and under affected by bleeding disorders. [Registration](#) is now open on our website!

June 24—C.A.R.E. Ladies Night Out

The C.A.R.E. Support Group Program will be heading to Mt. Pleasant for another “Ladies Night Out,” sponsored by Sanofi. Look for details to come soon!

July 2—Y.E.S. New and Young Families Support Group, Columbia

On July 2, our Y.E.S. Program will hold an event in Columbia for new and young families affected by bleeding disorders. This event is sponsored by Sanofi. More details are forthcoming.

July 14—M.E.N.S. Program Meeting

On July 14, the M.E.N.S. Group will meet for a social gathering. Additional details to come.

sanofi

Voices of Our Community

Meet Cristal Day, BDASC Board Member and Advocacy Coalition Chair



I have been an active member of BDASC for many, many years. I truly feel as though this community is my second family. I love attending all the different types of events we have in order to learn and grow with others

who share my struggles AND my triumphs. Advocacy is such a huge part of my life as well. It is something I am very passionate about. I was honored to have joined our Advocacy Coalition at its creation six years ago. I have been the Chairperson for the last five years. I am overwhelmed with gratitude for all the hard work, dedication, and commitment our Advocacy Coalition has shown all these years. We have definitely come a long way! When I was growing up, I had no idea what bleeding disorders were or how they would impact my

life. No one talked about it in my family or in the community. However, once I became a mother of a hemophiliac, I learned (out of necessity) to speak up and use my own voice! My son’s life depended on everyone knowing what a bleeding disorder was and what to do when a bleeding episode happens. If I wanted the best quality of life for my son, then educating my community, city, county, state, and country was a MUST! I learned how to find my voice and then how to use it through BDASC events. I became very active in our chapter. I even joined the Board of Directors where I will rotate off in June of this year. I have grown so much as a mother, daughter, sister, and citizen through my time with BDASC. There are so many ways to get involved and be proactive. We always need volunteers for events like the STEP walk or even joining our Board of Directors. Whatever your talents are, we can find a great place for you. Just reach out and get involved!



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Bonnie Hawley

Von Willebrand Community News

BDASC Continues to Focus on VWD Research and Engagement

At our recent C.A.R.E. Women's Retreat (see "Inaugural Women's Bleeding Disorders Retreat & Conference" above) there were a series of programs dedicated to issues related to von Willebrand disease (VWD). The first was an overview of the disorder and the different ways it can manifest in women. The program included a history of testing for VWD, the different subtypes that exist, and an overview of ongoing research trends. Another session focused on the new Medical and Scientific Advisory Council (MASAC) guidelines regarding the diagnosis and treatment of VWD.

We know that there are many BDASC members affected by VWD, and we want to do our best to keep you connected and informed. At our upcoming Annual Meeting and H.E.L.L.O. Conference, we will have a session that focuses on the diversity of experiences in our community, including distinct disease states, including ultra-rare disorders like the combination of VWD and

other factor deficiencies. We encourage you to join us for the event and to help make your voice for the South Carolina VWD (and broader bleeding disorders) community heard.

In terms of resources, we of course always want you to keep the chapter in mind as your go-to source of information and education. We see a big part of this role as being able to point you in the right direction, especially when we don't have the answers at our fingertips. Hemophilia Federation of America (www.hemophiliafed.org) and The National Hemophilia Foundation (www.hemophilia.org) are preeminent sources of information and advice for the VWD community, and they are always willing to help community members when they can. VWD Connect (www.vwd-connect.org) is a fairly new non-profit that works to serve the bleeding disorders community, with a focus on VWD. They provide education and connection for patients and families, in addition to supporting VWD research efforts. Do not hesitate to get involved with these organizations and make the most of the resources and services they offer.

Did You Know?

Exploring the New BDASC Website

As most of you are already aware, "Hemophilia of South Carolina" officially became the "Bleeding Disorders Association of South Carolina" this year. That warranted new branding and a new website (www.bda-sc.org/). This gave us the opportunity to reorganize where and how users navigate to relevant information on our page. Note that the main page has a *lot* of information for you, but it also is the place where you can navigate to details about any program or event associated with BDASC. Here is a quick run-down on where to find the information you are looking for.

On the main page, there is a box that scrolls through the most important upcoming events

and news. As you move down the page, you will find a link to the most recent *News Infusion* newsletter. Scroll down and you will see a set of boxes with links to a calendar of events, our advocacy page, and how to join BDASC. Also, the first box, "About Bleeding Disorders," links to information on specific disease states, including hemophilia, von Willebrand disease, rare factor deficiencies, platelet disorders, and info specific to women with bleeding disorders. There also is physician contact info categorized by each region of the state.

Back on the main web page, keep scrolling down and you will find lists of upcoming community connections, fundraisers, support groups, and

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other events and meetings, as well as links for registering for them. At the very top of the page, there is a link to chapter contact information, one on how to join BDASC, and a newsletter link. Here also is a “Member Services” tab.

This contains a link to different resources the chapter helps provide to our community. These include:

- Academic scholarships — downloadable forms and information on how to apply
- Financial assistance — for emergency and compassionate care
- Available infusion clinics
- Travel scholarships — to national and other conferences
- Summer camp assistance
- Virtual Innovations Program — This is an iPad program, for personal use and for keeping connected with what is going on at BDASC
- Medical alert ID

Back on the main page, you will find another menu of options just to the right of the main BDASC logo. These include an “About” section that links to the history and main goals and functions of BDASC. Next to it is a link to “News,” which contains local, regional, and national updates on everything from research to new healthcare policies that may impact the bleeding disorders community. Next to it is a “Programs and Events” tab. This links to a calendar of upcoming BDASC happenings, but links to specific program pages. These include:

- Fundraiser Events — Such as Par for the Clot, STEP for Bleeding Disorders 5k, and Red Tie Campaign
- Education Programs — Including the Annual Meeting and Medical Symposium
- Support Programs — The M.E.N.’s Program, the C.A.R.E. Program, and teen and children’s programs
- Recreational Programs — These include Family Camp, the Holiday Meeting, and World Hemophilia Day events

- Volunteer Programs — Information on volunteer opportunities and awards associated with outstanding volunteers

Next to the “Programs and Events” tab, you will also find a “Resources” tab. This links to information on myriad organizations and programs—like the National Hemophilia Foundation, Hemophilia Federation of America, and the state Hemophilia Assistance Plan—that can be resources for the South Carolina bleeding disorders community.

Finally, you will find an “Advocacy” tab, which

links to all of the information you will need about BDASC’s advocacy initiatives. This includes details about the South Carolina Bleeding Disorders Advo-

cacy Coalition and Ambassadors program, how you can join, and what upcoming activities you might participate in.

We hope you find the new website as useful as we do. If you have any questions about the website or are unable to locate the information you need, please contact our office at 864-236-8663 or info@bda-sc.org.



Accumulator Adjusters: What Are They and How Might They Impact Your Health Plan?

A very important issue facing South Carolinians (and people across the nation) right now, one that disproportionately impacts those with high-cost medications like clotting factors for bleeding disorders, is that of “accumulator adjusters.” These are policies put in place by health insurance plans that do *not* count copay

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assistance cards towards deductibles and out-of-pocket maximums. With the guidance of our national organizations, BDASC has been tracking such policies for years now, and currently, 100 percent of marketplace plans in the state have them. This means that people who have monthly medications that are more than their yearly deductible, who are utilizing co-pay cards to purchase their medication during the first few months of the year, are being faced with the requirement to meet their full deductible once the card runs out. Often, they are surprised that this is the case since they assume their deductible was being met, which only exacerbates the challenge of pulling together a large amount of money in order to buy the medication they or their children need to live healthy lives. Even more insidious is that these programs are often named things like “Out-of-Pocket Protection Program” or “Benefit Plan Protection Program,” which further confuses beneficiaries and, at the outset, conceals the reality of how these policies will impact them once implemented.

If you are unfamiliar with this issue, the National Hemophilia Foundation put together a handy video a few years ago that explains accumulators in layman’s terms. <https://tinyurl.com/accumulatoradjuster>

We are currently working to discern how many of our members this may be affecting, especially since this is the time of year when these policies start having an impact. We have no doubt that this is driving people to emergency rooms as the only means of accessing medication, which is both unnecessarily inconvenient and more expensive than the alternative.

We also supported a bill (H4987) this legislative session that would require “insurers to include cost-sharing amounts paid when calculating an enrollee’s contribution.” In short, it would have prohibited South Carolina healthcare plans

from implementing accumulator adjustment policies. We met with the lead sponsor of the bill, Representative Pat Henegan, who is our 2022 Legislative Advocate of the Year, as well as other sponsors and members of the House Ways and Means Committee, where the bill was assigned. Although the measure did not pass, it was an opportunity to raise awareness about this issue among state lawmakers. We gained a lot of bipartisan support during the 2022 session. We plan to have an identical bill filed in 2023 and are optimistic it will gain traction very quickly, based on the groundwork laid this year and in sessions past. We also are working to build a coalition of other chronic-disease organizations to join us in these efforts.

While it would have a positive impact in South Carolina, H4987 would only regulate state healthcare plans, and not private sector policies, which are covered by the federal Employee Retirement Security Act of 1974 (ERISA). That is why we also are supporting HR5801, the “Help Ensure Lower Patient (HELP) Copays Act,” a federal bill currently before Congress. It has bipartisan support in the House of Representatives, and our federal organizations are working feverishly to find sponsors for a companion bill in the Senate.

In the meantime, what can you do? The first thing is to investigate whether you have an accumulator on your health insurance policy. If you have been using a copay card or some other type of assistance and that does not seem to be reflected in what you owe on your deductible, this may be the result of an accumulator adjuster plan. If you happen to be in this situation, please let the chapter know. In addition to providing you with any assistance and advice we can, we would like to know how many of our members this may be impacting, so that we can relay that to our elected officials. Finally, please consider joining in our advocacy efforts to help affect change in Washington and Columbia. Your voice helps make us stronger.

Advocacy Action

2022 State Advocacy Days



For the first time since 2020, on March 8-9, BDASC held in-person state Advocacy Days in Columbia. We had over 50 individuals participate this year for 36 contacts with legislators or their staff. We were very pleased with the turnout and the results of the engagement with lawmakers. The event kicked off with a training for participants on Tuesday evening. State Senator Danny Verdin spoke to the group about his role as the chair of the Medical Affairs Committee. He had clearly “done his homework,” as he also was able to address BDASC’s main 2022 legislative priorities. These include continued funding for the Hemophilia Assistance Plan, run by the state

Department of Health and Environmental Control (DHEC), which offers premium assistance for people purchasing marketplace plans. The second main priority is continued support for the Rare Disease Advisory Council, which was created last year by proviso, but we are interested in it becoming a permanent entity in the state through legislation. The final issue deals with “accumulator adjuster” programs, which allow health insurance plans to not count copay assistance cards towards deductibles and out-of-pocket maximums. Senator Verdin expressed his support for our legislative efforts and vowed to assist where he could.

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A special thanks to April Baird, Patricia Tucker, Ginger Snead, and their families, for cultivating this relationship with Senator Verdin over the years. It's a great example of how tenacious advocacy pays off by creating allies in the statehouse.

The program then turned to a deeper dive into the legislative priorities. Anna Bleasdale, Director of the Children with Special Health Care Needs program at DHEC, gave an update on the status of that program. Jeremy Williams, Advocacy and Organizational Development Coordinator at BDASC, talked about the Rare Disease Advisory Council and the status of the existing bill (which was assigned to Senator Verdin's committee).

Zachary Poss, Director of State Policy at PhRMA explained accumulator adjuster legislation and gave an overview of bills that had passed in other states.

The program also included a national update by Nathan Shaefer, Vice President of Public Policy at the National Hemophilia Foundation. It provided members with "best practices" on having impactful meetings, a discussion led by Alison Clifford, Director of Therapeutic Advocacy and Policy at Takeda, and Drew Clawson, President of Kinard Consulting.

One of our teen members, Makayla Keith, helped lead a breakout advocacy discussion for our children and teens. The evening concluded with inspiring words from three advocates, Aaron Smith, Jameelah Malcolm, and 11-year-old Danny

Shelton, on why they advocate. It was a great way to wrap up the night and get ready for the following day.

On Wednesday, the group made their way to the state capitol complex for the yearly group picture on the capitol steps, then dispersed for meetings. In addition to various rank-and-file members, BDASC members and staff met with leadership, including chairs of the House Judiciary; Labor, Commerce and Industry; Medical, Military, Public and Municipal Affairs; Regulations and Administration; and Rules Committees; as well as the Speaker Pro Tem's office. They met with chairs of the Senate Banking and Insurance; Ethics; Finance; Medical Affairs; and Rules Committees.



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Also, BDASC Staff met with the lead sponsor of H4987 (the anti-accumulator adjuster bill), Representative Pat Henegan, as well as co-sponsor Representative Bill Sandifer. Constituent members met with another co-sponsor, Representative Ivory Thigpen. They also met with two members—Representative Nathan Ballentine and Representative Chip Huggins—of the Ways and Means Committee, where H4987 is currently assigned. Representative Neal Collins introduced the group on the House floor. (A special thanks to Cristal Day, a constituent of Rep. Collins, for establishing a solid relationship with him and his staff over the years—all your work has paid off.) The entire group met with Lieutenant Governor Pamela Evette in the rotunda of the capitol. She presented the state proclamation recognizing March as “Bleeding Disorders Awareness Month,” and spoke to BDASC Executive Director Sue Martin about the accumulator adjuster issue. The Lt. Governor promised to reach out to pharmacy benefits managers about this issue in order to learn more about it and hopefully formulate a solution.

Following the event, BDASC also held one virtual meeting with longtime supporter Representative Jason Elliott and a member/constituent. It was a productive meeting, and we hope to continue leveraging virtual tools in the future to engage as many lawmakers as possible.

Overall, the 2022 Advocacy Days event was a huge success. Thanks to each of our members who took time out of their busy schedules—taking off work and missing school—to participate. We appreciate your time and dedication; we couldn’t do it without you. A special thanks to all our sponsors in advocacy!

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BDASC Participates in NHF Washington Days

On March 1-2, eight BDASC members and staff participated in the National Hemophilia Foundation's (NHF) annual Washington Days. It was a completely virtual event but allowed some lengthy and poignant policy discussions with members of Congress. Cristal Day, Renita Johnson, the Keith family (Marilyn, Ward, and Makayla), Sue Martin, Tim Swanburg, and Jeremy Williams participated in NHF's training, which involved a thorough discussion of legislative priorities, schedule, and etiquette for meetings. The group met with seven of the nine members of the South Carolina Congressional

delegation, including the offices of Senators Tim Scott and Lindsey Graham. The group also met with the offices of Representatives Jeff Duncan, Ralph Norman, Nancey Mace, William Timmons, and Joe Wilson. During the meetings, advocates discussed the need for continued funding for federal agencies that are vital to the bleeding disorders community. These include the Centers for Disease Control and Prevention's "Community Counts" program, which does data collection

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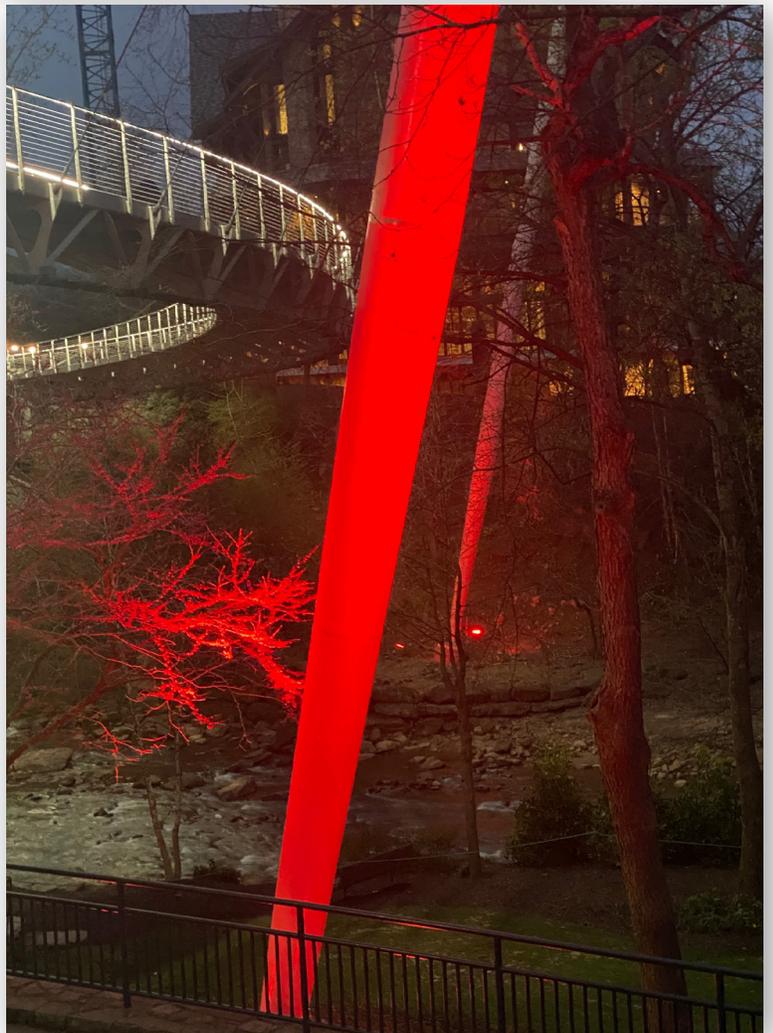


Bleeding Disorders Awareness Month: “Red Tie Campaign” and Proclamations



The red tie was introduced as a symbol for the bleeding disorders community in 2016, when the National Hemophilia Foundation and the U.S. Department of Health and Human Services worked together to designate March as an official U.S. health observance: “Bleeding Disorders Awareness Month.” The Red Tie reflects the fact that blood “ties” are what bind the community together.

This year, BDASC secured six proclamations recognizing March as “Bleeding Disorders Awareness Month.” These included recognitions and presentations by the City of Cowpens, the City of Greer, the City of Greenville, Greenville County, and Summerville County. Also, in recognition of this designation, the City of Greenville turned the lights on Liberty Bridge and the fountains in Falls Park red. BDASC placed a sign at the entrance of the bridge, explaining the significance of the lighting. A special thanks to Passerelle Bistro for allowing us to use their space for the signage.



World Hemophilia Day Festivities

Every year since 1989, World Hemophilia Day is celebrated on April 17. It is a day of raising awareness and encouraging reflection on the

individuals throughout every country in the world who are affected by bleeding disorders.

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and research—including on inhibitors—as well as patient education programs; the Health Resources and Services Administration (HRSA), which provides grants and programs to improve health outcomes for people in geographically isolated areas, or economically or medically vulnerable populations, and supports the 340B drug-purchasing program that Hemophilia Treatment Centers rely on; and the National Institutes of Health (NIH), the nation's preeminent research institution. The group also urged members of Congress to support the "Help Ensure Lower Patient" (HELP) Copays Act (HR5801), which would

prohibit health plans from implementing "accumulator adjustment" programs, which do not count copay assistance cards towards deductibles and out-of-pocket maximums and disproportionately impact anyone with high-priced medications like clotting factor. Our members were great at telling their stories and making their voices heard in the most important policy forum in our nation. We appreciate their dedication to this important event. As always, NHF did a fantastic job coordinating this momentous event, setting up meetings, and conducting trainings that ensured everyone was all prepared.

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Since this year the date fell on Easter, BDASC chose to hold two celebrations in recognition of this event, both sponsored by Sanofi, on the Friday and Saturday prior. On April 15, members met for a dinner and program in downtown Greenville. The theme was “One Family” with a focus on joint health, including an overview of hemophilia care around the world, global hemophilia community support, and a discussion of the challenges of living with damaged joints. It also included an activity that simulated limitations associated with damaged joints.

The next day, BDASC held a dinner and program in Columbia, with a presentation by Laith Elkhurd, a CoRe Manager with Sanofi. He led a discussion on advocating for oneself in different situations, including with healthcare providers, employers, colleagues, friends, and loved ones, and offered advice on crafting meaningful and compelling personal messages as a way of telling your story as someone affected by a bleeding disorder. The event was open to everyone but was held in honor of BDASC’s M.E.N.S. Group.



National News

Hemophilia Federation of America Symposium 2022



Hemophilia Federation of America (HFA) held its annual Symposium in San Antonio on April 20-23, 2022. This was the first time in two years that the Symposium was held in person. The event included sessions on: mental health; balancing family issues after diagnosis; mild bleeding disorders; gene therapy; coping with grief and loss; joint health; and issues specific to women, the LGBTQIA+ community, and other groups. The meeting also had a special program for members of HFA's "Blood

Brotherhood" men's group.

BDASC was represented this year by board member and treasurer, Patricia Tucker. Patricia also participated in a special training class to bring the knowledge of Mental Health Awareness back to the board. We express a special thanks to Patricia for taking this specialized training course during your time in Houston and thanks to HFA for the opportunity to grow our mental health awareness!

NHF 74th Annual Bleeding Disorders Conference



The National Hemophilia Foundation (NHF) will hold its 74th Annual Bleeding Disorders Conference (BDC) in Houston, Texas, on August 25-27, 2022. With three full days of educational sessions,

workshops, industry

symposia, networking, and social events, this will be one of the largest and most comprehensive bleeding disorders events in the nation. There will be more than 90 hours of programming,

with tracks specific to consumers, teens, and chapter staff available. Programs will explore important treatment and research developments in hemophilia, von Willebrand disease, and other inheritable bleeding disorders. This will also include discussions on gene therapy.

BDASC has scholarship opportunities for members to receive grant funding to attend. Information is located on our website at <https://bda-sc.org/national-education-and-conferences-travel-scholarships/>

Please contact the Chapter for additional information if you would like to attend this national conference.

Research & Development

BDASC Participates in National Blueprint Workshop in Washington, D.C.

On April 7-9, BDASC Executive Director, Sue Martin, and two longtime community members, Christine Evans and Jameelah Malcolm, joined



chapter staff and members from around the country in Washington, D.C., for a National Hemophilia Foundation (NHF) forum, “Nothing About Us Without Us: Developing Future Research Champions.” The workshop was part of NHF’s National Research Blueprint (NRB) initiative, which focuses on persistent gaps in care for the bleeding disorders community, especially for those with rare disorders as well as underserved populations, such as women with bleeding disorders.

NHF has taken the lead on a community-driven journey to shape the future of research for bleeding disorders. The goal is to establish a clear understanding of the most pressing issues challenging people and families and bring these experiences to the forefront of transformational research, so that we can better discern where research can have the

greatest community impact.

Sue has been involved with NRB since its inception, including the initial “State of the Science” research summit. This recent workshop was a chance for participants to continue discussions on health equity, diversity, and inclusion as they relate to healthcare policy and community engagement. NHF did a fantastic job of putting together a full two days of programs that both allowed our South Carolina delegation to have input on this initiative and to learn a great deal that we can take back to our members, so that we can all be better catalysts for change. Look for information to come on our future to build our Research Ambassador Program where members of our South Carolina community can help drive the conversations on future research.

NHLBI Grant Supports Scientific Research to Enhance Hemophilia A Gene Therapies

A group of investigators are embarking on a new research program designed to unpack some of the outstanding fundamental questions associated with current approaches to gene therapy for hemophilia A. While multiple gene therapies are currently in various stages of preclinical or clinical studies there remain concerns relevant to the biological nuances affecting long term safety and efficacy.

The new program, which is being supported by a \$12 million grant from the National Heart Lung and Blood Institute (NHLBI), represents a multi-institutional effort to ultimately help improve these therapies. It will be led by Roland Herzog, PhD, at the Indiana University (IU) School of Medicine.

Herzog is the Director of IU’s Gene and Cell Therapy Program. He was also a recipient of NHF’s Career Development Award from 2000-2003, for his funded project “Immunology of Liver-Derived Expression of Factor IX from AAV Vectors.”

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“Several companies have taken this forward into clinical trials, and in some of these trials, the patients initially looked like they were cured,” said Herzog, who is the Riley Children’s Foundation Professor of Immunology. “But what they all have in common is that they need to deliver a lot of the virus in order to get the desired results, and over time clotting factor levels started to decline. So, it’s clear that we need to further study the biology of this phenomenon.”

According to an IU School of Medicine press release this program will include three major projects, with investigators conducting molecular-level analysis of key components in liver-directed gene therapy, including human liver cells and factor VIII (FVIII) viral vectors. Herzog and his colleagues hope to garner new insights that can ultimately lead to lower levels of cellular toxicity and “improved longevity of FVIII production” in individuals who are treated with gene therapy for hemophilia A.

“This is an incredibly significant and urgent medical question, and it requires the synergy of multiple groups with different expertise to come together and solve a problem that they wouldn’t be able to solve on their own,” said Herzog. “My hope is that our studies will help the field as a whole move toward curing hemophilia A.”

Source: Indiana University School of Medicine news release dated March 8, 2022

Freeline Announces First Patient Dosed in Hemophilia B Trial

March 11, 2022

LONDON, March 9, 2022 (GLOBE NEWSWIRE) — [Freeline Therapeutics](#) Holdings plc announced that the first patient was dosed in its Phase 1/2 B-LIEVE dose-confirmation clinical trial of FLT180a for the treatment of hemophilia B, a debilitating genetic bleeding disorder caused by a deficiency in the clotting factor IX protein. FLT180a uses a potent and proprietary adeno-associated virus vector capsid (AAVS3) to deliver the functioning gene of a variant of

human factor IX and restore normal blood clot formation.

Pamela Foulds, MD, Chief Medical Officer of Freeline, said, “We are optimistic that the combination of a low dose (7.7e11 vg/kg) of our high-expression AAVS3 capsid with a short prophylactic immune management regimen can get and keep hemophilia B patients in the normal range of Factor IX expression. This is a meaningful step towards realizing the potential of FLT180a to provide a functional cure through sustained, normalized FIX activity.”

Michael Parini, Chief Executive Officer of Freeline, said “We are very excited about this progress in our hemophilia B program as our enhanced focus on execution is starting to pay dividends to unlock the value of our clinical programs. In addition, this is the first patient Freeline has dosed in the U.S., which affirms our commitment to diversify our clinical trial footprint and build resiliency into our programs.”

“Looking ahead, we believe we have already identified enough patients to fully enroll the B-LIEVE trial via the ECLIPSE run-in study, and expect to complete the dosing of the first cohort and share initial results by the end of the first half of this year. We continue to progress against these key milestones as we chart the path toward a pivotal Phase 3 study of FLT180a, and currently plan to initiate start-up activities for that study in the first half of 2023,” Michael Parini continued.

The Company expects to report initial safety and biomarker data from the first dose cohort of the B-LIEVE trial in the first half of 2022. Should dosing of additional patients in the first dose cohort or dosing of the second cohort be necessary, Freeline expects those to be completed by the end of the third quarter of 2022. The Company expects to report further updated safety and biomarker data in both the second half of 2022 and the first half of 2023 and to initiate Phase 3 pivotal trial start-up activities in the first half of 2023.

Source: Hemophilia Federation of America

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 Hemophilia 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/>

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Patient Services Incorporated (PSI)
Assists persons with chronic medical illnesses in accessing health insurance and pharmacy co-payment assistance.
Phone: 800-366-7741
Website: <https://www.patientservicesinc.org/>

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

Upcoming BDASC Community Events

Mark Your Calendar!

Looking Ahead: Save the Dates!

2022 Major Event Dates

June 10-11: Annual Hello Conference and Annual Meeting, Greenville, SC

August 11-14: Teen Retreat, Camp Canaan, Rock Hill, SC

October 7: Par for the Clot Charity Golf Tournament, Greenville, SC

December 11: Winter Statewide Meeting, Columbia, SC

Additional ways to help BDASC



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



Register with Amazon Smiles. BDASC receives 5% of the sale! Go to <https://smile.amazon.com/>



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



Use Goodsearch.com for all your shopping needs. Go to <http://www.goodsearch.com/nonprofit/hemophilia-of-south-carolina.aspx>



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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