

The News Infusion

The Official Newsletter of Bleeding Disorders Association of South Carolina

VOLUME 12, ISSUE 4

FALL 2023



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Wake Up. Show Up. Push Up. Advocacy Summit, page 22

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

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

Fall 2023 Calendar of Events

Looking Ahead: Save the Dates!

Community Engagements

November 28—Gene Therapy Community Engagement Dinner, (Hemophilia A), Columbia

November 30—Community Engagement Dinner: Do What Moves You: Staying Active, Greenville

December 9—Winterfest State Meeting: Embracing Our Community, Columbia

December 5—Gene Therapy Community Engagement Dinner, (Hemophilia B), Columbia

December 14—Gene Therapy Community Engagement Dinner, (Hemophilia A), Charleston

December 15—Gene Therapy Community Engagement Dinner, (Hemophilia B), Summerville

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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 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!

Par for the Clot Charity Golf: An Amazing Day on the Course

The 2023 Par For the Clot Charity Golf Tournament held on September 22 had perfect weather for 140 golf participants, competing with 35 teams, and being hosted by over 35 volunteers and guests within the bleeding disorders community. Participants came together at the beautiful Preserve at the Verdae Golf Course for a fun day of competition, hoping to bring home the tournament trophy and cash! Many additional competitions were held throughout the course of the day including the Charity Golf Guns Hole Contest, Spin to Win, Men and Women's Longest Drive Competitions, Closest to the Pin, the Charity Golf International Donation Hole, with Long Drive Champion, Kyle Blakely, the Poker Holes, and Beat the Pro, with Perry Parker, our community advocate who lives with hemophilia and is a PGA International Champion. While this tournament is a lot of fun for many involved, it is so much more than that. It is an opportunity for the bleeding disorders community to come together with the community at large and share our mission and our work.

Together with our community partners, we are able to put on an amazing experience for everyone involved. This event is business friendly and allows for many opportunities to network and to come together for an important cause. We truly enjoy giving back to our community partners by allowing them the opportunity to grow their business networks and to help promote their great services throughout the event.

Changing lives and making a difference, each and every individual at the Par for the Clot and their families have become part of our bleeding disorders community. On behalf of the entire South Carolina membership and its affiliates, we say thank you once more. Proceeds raised will continue our financial aid to those in need of our

Congratulations to the following well deserved teams and individual golfers:

1st Place Team: (Score of 51) **The Bohemian Cafe** in Greenville—Kevin Lucas, Richard Painter, Shane Banks, and Brandon Murgan, The Bear!

2nd Place Team: (Score of 54) **Jacobs of Greenville**—Chris Sorrell, Sam Larsen, Marcus Jackson, and John Campbell.

Closest to the Pin: James Thomas Chiles—(6' 6") Team Octapharma

Charity Golf Guns, Closest to the Target: **Ric Martin**, Team Martin

Beat the Pro, Perry Parker: **Russell Fraizer** from Team HT Johnson, **Joey Krakowiak** from Team Krakowiak & **Joseph Carrero** from Team McKesson (*Congrats to the others who also beat the pro but didn't win the raffle pick for prizes!*)

Longest Men's Drive: **Jason Wood** with Team Octapharma

Longest Women's Drive: No winners this year

Putting Contest: Longest Putt, Split the Pot (\$520 raised by participation, split the pot \$265 donated back)—**Max Buliner** with Team DrugCo

Making the Short Putts—Brian Burton & David Shehan with Team Keystone Constructors

Poker Hole Winner: **Elijah Roberts** of Team Metromont, with a Flush—Ace High, wins \$290 (116 participants raised \$580)

support during difficult times; provide education and support services; allow us to contribute to the research for a cure with our National Bleeding Disorders Foundation, The Judith

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Graham Post Doctoral Research Program; and will **provide the critical funding to advance our advocacy work in removing barriers in access to treatment care with the work of our robust Advocacy State Coalition!**

Thank you to **Perry Parker**, Community Advocate - Beat the Pro, Hole #11, for continuing to support the South Carolina Bleeding Disorders Community! With the community's help, Perry's Beat the Pro Hole was able to raise **\$1,350!** At Hole #17, our Long Drive Professional, **Kyle Blakely**, helped to raise **\$5,407** for our cause! Thank you to Kyle and Charity Golf International!

Thank you to all our teams!

CSL Behring, CVS Specialty, Thermofisher Scientific, Genentech, Novo Nordisk, Team Joey Krakowiak, Specialtycare RX, Team Henry Mac, Team Weber, Team Keystone Constructors, Team Ric Martin, Team Logan's, Team Josh Probst, Team TaylorMade, Team HT Johnson, Team Bayer, Team Bohemian Café, Team DrugCo, Team Tom Tilert, Teams McKesson, Teams Metromont, Team Octapharma, Team Jacobs, Team Century Contractors, Team Blue Sky, Team Fuyao, Team Ross, Team Bushong Industrials, Team Metromont, and Team Griffith!

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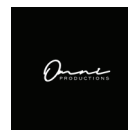
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COMMUNITY PARTNER



IN-KIND



CHARITY GOLF GUN HOLE



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We look forward to next year on September 27, 2024, as we hit the course at the Preserve at Verdae once again. So many people make this event happen and we are appreciative of everyone's time, talents, and financial support. Congratulations again to all our tournament winners! We look forward to seeing you all again next year!

Save the Date
2024 Par for the Clot!



September 27th, 2024 @ The Preserve at Verdae

A very special THANK YOU to our Tee-Off Committee & our Volunteers!

Event Manager: **Sue Martin**, Executive Director, BDASC
Tournament Chairman & Co-Chair: **Ric Martin & Brian Burton**, members BDASC
Committee BDASC Members: **Mike Walden, Aaron Smith, Bryce Martin, Corbin Martin, Cristal Day, Felicia Davenport, Hunter Day, Jordan Martin, Joey Krakowiak, Maranda Weber, Samantha Javorka, Taylor Upton, Edna Rabb, Susie Maloy**
Committee Industry Partners: **Kerrie Barnes, CSL Behring, Laura Benton, CVS Specialty, April Tilert, Accredo**

Tournament Volunteers

All our T-Off Committee Members and Martha Breitwieser, Kristen Smith, Vanessa Martin, Jordan Elise Martin, Tiffany Diaz, Kim Cato, Virginia Chandler, Cynthia Delay, Johanna

Robertson, Robin Jones, Amy Derrick, Norberto Liriano, & Jecorei Lyons

Thank You to our Feature Family & Our HTCs!

Thank you to our feature family, Daphne and Samantha Javorka, and Dr. Leslie Gilbert and Nurse Coordinator, Robin Jones, for their continued support! We appreciate you sharing your stories and experiences during the Par for the Clot Banquet!







Board's **BLOG****Executive Director's Welcome***By Sue Martin***'Embracing Our Community'**

As the year comes to an end in a few short weeks, it is now the time to reflect on 2023 and express gratitude for a year of growth, unity, and determination to push forward and expand on our mission. We have had an incredible year with over 60 programs and services spread throughout the year to our diverse membership in many different geographical areas of the state. We have managed most of the year to keep ahead of the access to care and treatment barriers we are now quickly facing, and have been blessed with new innovations in treatment therapies which allows our bleeding disorders community to thrive. Gene Therapy is finally here and what an exciting time for those who have been waiting!

Because of the close partnerships we have with our HTC's and state health agencies, we have added over 60 new families and individuals to our welcoming organization and have seen a huge upward diagnosis shift in our Von Willebrand Disease population. We have a lot

of work that still needs to be done, but we are happy that our state and treatment centers are receiving referrals for new diagnosis and treatment care. Our work is being recognized on the local and national stages and we have become a welcoming resource to many who call upon us for educational and supportive services. With growing success however, there will be challenges. The ever-shifting higher cost in treatment care access and the overarching inflation in costs for goods and services has made me pause for a moment and ask myself, "what is the most important attributes we can bring to this community to help each and every one of our members thrive to their best selves and abilities"? We will call upon you to let us know as we enter 2024 and beyond. We have our 2024 Member Feedback Survey now out on our website and on all social media platforms and ask that you take a few moments and share your opinions: what is most important to **you and your families?**



Member Feedback Survey (Use your I-phone camera, point and click)

I have many thoughts and ideas I would like to share and implement

for the Chapter in the upcoming months and look forward to working with our membership, board of directors, staff, and volunteers. I will be looking for individuals to work for me in various capacities to help us reach our goals. Please enjoy reading the newsletter and staying up to date with all we have to offer you and your families. I send a heartfelt thank you for each financial contribution you make, ever hour you volunteer, and every inspiring moment you give to me in what you achieve. You continue to amaze me every day and make me proud to be a member of The Bleeding Disorders Association of South Carolina. I wish you and your family a very happy holiday season and new year ahead. Warmest regards to all.

With love,
Sue

Congratulations to Our Board Member Taylor Upton and Family



It is with delight we share the news that our board member, Taylor Upton and Johnathan have welcomed a new baby boy into our bleeding disorders family. He was born 5 weeks early at 35 weeks but is a thriving

sweet boy. ease embrace and welcome Lincoln CarverGarrett, 6lbs 3 oz, 18 inches long into our family. Congratulation!

Volunteers and Board Members: A Welcome Gift!

Would you like to help support BDASC? Volunteering for events and committees, or serving on our board is a fantastic way to help our Chapter grow in programs and services, and for you to get involved. To continue to support and engage with our community, BDASC requires help at events and in governance—whether it is manning

the registration booth, helping with the teens or kids during events and activities, or helping plan and assist with our fundraisers, there is something for everyone to get involved with! If you would like to volunteer or serve on the board of directors, please contact Sue at the chapter office at 864-350-9941.

2024 Member Feedback Survey

Please be sure to provide your opinions and thoughts on our membership survey as we head into a new year and look at what we would like to provide to the community. This is your time to make your needs known and suggest anything you would like to see in the future. Simple and easy, less than five minutes to take, you can help shape the future with your feedback. Thank you!
<https://www.surveymonkey.com/r/2024MemberSurvey>



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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Community Engagements



A Top Golf Community Thank You September 21, 2023

On September 21, the night before the Par for the Clot, the bleeding disorders community was invited to attend a volunteer appreciation dinner and presentation, sponsored by CSL Behring with Perry Parker. Perry presented on his journey of discovering the right fit for what you would like to do while living with a bleeding disorder, and the importance of staying active. His talk also stressed all that can be accomplished. After his presentation, the community engaged in fun competition while swinging golf clubs high on the 3rd floor of the 13 golf bays we took up for the night. Perry walked between the bays giving tips and guidance to participants on how to improve their technique. It was a great time

to reflect on all the work that was done by so many heading into the tournament the next day and bringing the volunteers and community together. With our greatest appreciation, we thank CSL Behring and Perry for the time commitment and sponsorship for this pre-tournament event.

CSL Behring
Biotherapies for Life™

A VWD & Rare Community Support Engagement October 7, 2023

On a beautiful day in October, the women in our community came together to celebrate and embrace those members living with vonWillebrand Disease and Ultra Rare Bleeding Disorders. They were treated to a late lunch and presenta-

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Your Time to Thrive!

On October 26, Logan's in Summerville was the perfect venue to bring old and new members in the Lowcountry together for an active community engagement dinner with a workshop on "Building an Optimistic Mindset". It was a fun night as we ate, thought, and competed to work together with an optimistic mindset. The food was wonderful and it was great to share time with newer members and let them know they are not alone in this new journey.

Thank you to Genentech for the time to connect and learn!



Genentech
A Member of the Roche Group

The Long-Awaited Gene Therapy is Here

November 7 at the City Range Steakhouse in Greenville, we were grateful to host an informational dinner engagement on Gene Therapy, along with the presence of sHTC Prisma Upstate Dr. Leslie Gilbert. The evening event was provided by BioMarin to learn about this new novel therapy for Hemophilia A patients. The attendees were full of great questions which were fielded by our presenters and Dr. Gilbert. The dinner engagement allowed the attendees a better understanding of this new treatment. These are exciting times for the bleeding disorders community and we are grateful to BioMarin for providing this opportunity to BDASC to learn more.

B:OMARIN

Virtual Community Engagement Support

Monday Meetup—Lowcountry: October 16

HEDI Working Group Wrap-Up: October 23

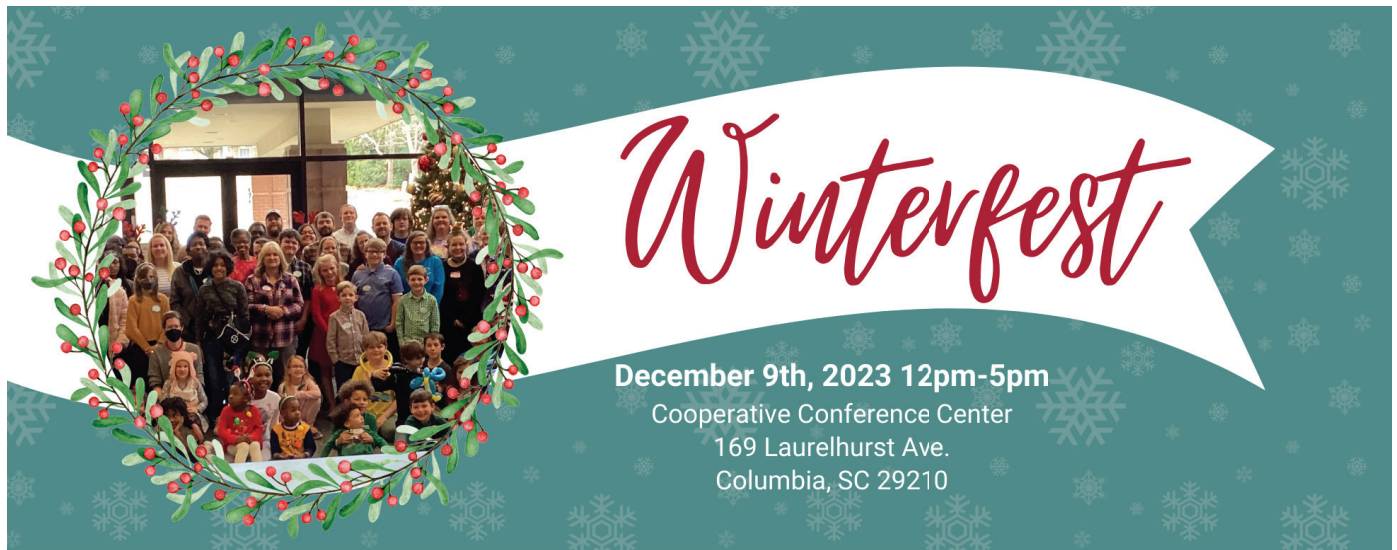
VWD & Ultra Rare Voices: October 25

In an effort to meet people where they live, we have been hosting virtual community gatherings over the month of October. We kicked off our first **"Monday Meet-Ups" Regional Resource** meeting with members from the Lowcountry. We gathered to meet up - no real agenda - and get to know the community members that face some of the same regional challenges. It was fantastic to come together to just talk and get to know each other better.

Additionally, the **Health Equity Diversity and Inclusion** group came together to discuss the progress that the committee has made over the past few months. At each meeting we determine what has been done and what will still need to be done to meet the entire community's needs. Executive Director, Sue Martin, is presenting in November at the National Bleeding Disorders Foundation's Chapter Leadership Summit a review of the great work this committee has accomplished. If you would like to be part of the committee work, just give Sue a call.

During the first **VWD & Ultra Rare Community** get together, it was decided that the group would like to meet more frequently. This meeting was our 2nd and had limited attendance. We discussed any concerns the community has with VWD and ensured that all in attendance knew about camp for kids with bleeding disorders and to keep an eye out for the applications to become available in the beginning of next year. The Chapter's website also has all the information on summer camps available for SC teens and kids so be sure to check in often. We are currently evaluating if we want to continue virtual events. We will be asking additional questions to determine if they are useful or preferred during our yearly survey. We want to ensure that we are using our resources appropriately and effectively.

Upcoming Engagement Opportunities



A Time for Winterfest: ‘Embracing Our Community’

Our Annual Statewide Winterfest Meeting will be held on December 9 in Columbia at the Cooperative Conference Center. The community engagement brings together our bleeding disorders community for one final event of the year. It also allows special time to celebrate the winter season festivities. We report on the progress and mission successes we have had during the year: highlighting events, individuals, advocacy initiatives, and the Chapter’s programs and services. The gathering will provide festive activities for all ages and visits from the North Pole. Our famous “Balloon Artist” will be with us again this year for enjoyment for the kids, a special presentation: “Celebrating Connections in our Bleeding Disorders Community” will be provided by our Premier Dinner Sponsor, Sanofi. Registration is open to all members of the organization who are diagnosed

with a bleeding disorder, or are genetic carriers of a bleeding disorder, and their immediate family members living in their household. We are grateful for our Winterfest Sponsors.



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tion on “Women’s Empowerment” at the Tap House Bar and Grill in Columbia. The lively and engaging conversations discussed advocating for women’s right to treatment care and understanding the complex issues we face today. The group also had discussions on how to raise our voices for change. After the lunch was over, the

ladies headed over to the Plant House to make jellyfish terrariums, supported by BDASC. The day brought the ladies closer together for support and encouragement and was a lot of fun too! We would like to thank Takeda for the Support Grant to provide these opportunities to our diverse community.



Voices of Our Community

Member Feedback Survey

Did you know that each year, BDASC releases a member feedback survey to the community and uses the information you provide to plan for the future? This is your opportunity to share with us what you like or may need from the BDASC organization that we are not currently providing. We are committed to ensuring that your voice is heard. If you would like to submit your feedback, please do so by visiting our

survey website at <https://www.surveymonkey.com/r/2024MemberSurvey> or scan the QR code. Thank you in advance for helping us serve you the best we can.

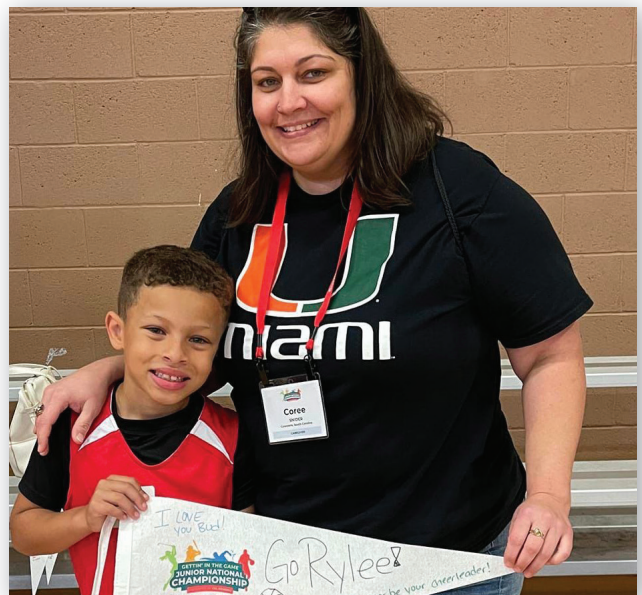


Congratulations to our JNC Participants!

BDASC Sends Three Participants to the Junior National Championship in Nevada!

This year, BDASC was honored to receive three spots to attend the Junior National Championship in Nevada on October 6-8. These three spots were awarded to three young community members living with bleeding disorders: Harley Lubic, Rylee Copeland, and Lucas Crisp. The youths were treated to a weekend of learning new skills and participating in competitions of baseball and basketball. The Junior National Championships are hosted each year by CSL

Behring and provide the opportunity for kids living with bleeding disorders to be active and engage in clinics in their chosen sport. This year, basketball was added to the available sports. Our youths had a blast and we thank CSL Behring for the partnership.



“I met some awesome people and gained another brother, lifelong friends. I can’t wait to go back again.” – Rylee Copeland

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“The JNC was very fun. It meant a lot to me to be able to meet other kids like myself. I was so excited they even like the same sport as myself, baseball. I learned new things about my favorite sport! Thank you JNC and BDASC for the opportunity!” – Harley Lubic



“Lucas and I went on our first ever flight together to Nevada. As soon as we landed, we got registered and headed to the baseball field. We spent two days learning and playing baseball with a bunch of other kids. Lucas got a signed baseball by Evan Greusel who plays professionally with the Marlins and has hemophilia. We met up with a family from Miami who we spent a lot of time with. We were able to share some of our knowledge about copay assistance and how our Chapter has services to help us. Lucas made a lot of new friends and connections all around the U.S.! Thank you for the opportunity to have fun and meet new people.” – Mark Crisp

If you have children with a bleeding disorder that might like to participate in next year’s JNC, keep an eye out for the JNC application next summer on our website JNC page.

How Many Chronically Ill SC Residents Get Caught in Insurance Issues?

The Greenville News

By Sue Martin & Rhonda Young

November 19, 2023

Some South Carolina patients are being forced to choose between affording health care or putting food on the table.

Many patients, especially those living with rare, complex, or chronic diseases, rely upon third-party financial assistance to pay for medications to maintain their health and manage symptoms. However, South Carolina health insurers are blocking this financial assistance from counting toward a patient’s deductible or out-of-pocket costs. Under this practice, patients are unaware their deductible is not being met and thus may be unable to afford their care. It is up to South Carolina legislators to protect patients and ensure South Carolinians can access the medications they need.

Many patients rely on copay assistance programs in the form of coupon cards to afford high-cost medications to manage their health. These discount programs help patients afford their care and provide a critical lifeline for those with rare, chronic, and complex conditions, many of whom do not have access to generic alternatives to treat their medical conditions. More than 99% of copay assistance programs are used for conditions with no generic treatment equivalent. However, some South Carolina insurance companies are increasing their use of “copay accumulator programs,” through which companies can refuse to apply the value of payments made through copay assistance programs to a patient’s annual deductible. Insurance companies will use the copayment assistance funds until the coupon card has met the full contracted maximum deductible and then will reset the patient deductible back to zero. Unaware of the reset, patients may show up at a pharmacy counter

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and are confronted with their full deductible to meet before their medication can be accessed. Copay accumulators increase health care costs and allow health insurers to improve their bottom lines at the expense of patients. Copay assistance can come from drug manufacturers, charities, churches, or other third parties, and is critical for many patients. For many families living in our state with high-cost treatment medications, financial assistance is the only way to afford the out-of-pocket costs needed to stay healthy. Yet, four out of five marketplace insurance plans in South Carolina have copay accumulator policies. Studies indicate that more than two of every three Americans abandon prescription medication when their out-of-pocket costs reach \$250. When a patient's share of prescription costs becomes too high, it increases the likelihood of skipping or abandoning treatments, leading to even higher medical costs down the road through increased emergency room visits or long-term health issues.

Today, patients with blood disorders ranging from hemophilia to sickle cell can live normal and successful lives as long as they can access their medications. As deductibles and out-of-pocket costs continue to rise, South Carolina families should not be punished for using copay assistance programs to help them afford the treatments they need.

Luckily, South Carolina lawmakers in Columbia are considering H3618, which would ban the use of copay accumulator programs and allow patients the use of copay assistance programs to count toward their out-of-pocket costs.

Additionally, at the federal level, Congress is considering similar legislation that would protect

millions of Americans living with chronic conditions through the bipartisan HELP Copays Act HR830, introduced by Rep. Buddy Carter and Rep. Nanette Barragán. This legislation would ban policies that allow pharmacy benefit managers to siphon away co-pay assistance funds from patients, providing much-needed relief. The HELP Copays Act has the potential to make a difference nationally, but our state lawmakers should join the 20 states, including Georgia, North Carolina, Virginia, Tennessee, and Texas, that have already passed similar legislation to count any copay assistance toward a patient's deductible or out-of-pocket costs and protect patients from these predatory tactics.

South Carolina insurance companies should not be allowed to block copay assistance from counting toward a patient's deductible, especially for those living with chronic conditions. H3618 and the HELP Copays Act are critical for helping individuals access essential and lifesaving medical care for those we advocate for within the Bleeding Disorder Association of South Carolina, the L.D. Barksdale Sickle Cell Anemia Foundation, and the many others living with chronic and rare health conditions in South Carolina.

We urge South Carolina legislators to pass H3618 and to support HELP Copays Act to ensure that all copayments made toward a patient's deductible or out-of-pocket costs are accepted. It is time to make all copays count in the Palmetto State.

Sue Martin is the executive director of the Bleeding Disorders Association of South Carolina, which serves all 46 counties in South Carolina. She is the mother of children with hemophilia.

Rhonda Young is the executive director of Louvenia D. Barksdale Sickle Cell Anemia Foundation, which serves 15 counties in Upstate South Carolina.



Von Willebrand and Women Who Bleed Community News

Gynecologists Have Significant Part to Play in Shrinking Diagnostic Gaps

It is fairly well understood, at least *within* the inheritable bleeding disorders (IBDs) community, that people who have the potential or ability to menstruate and an IBD will likely experience especially heavy menstrual bleeding (HMB) in their lifetime. HMB, along with other bleeding symptoms, is associated with negative impacts on physical, social, and emotional well-being, particularly in those who have been suffering year-after-year with an undiagnosed disorder. This scenario is not uncommon as there is often a prolonged period between a first reported bleeding event and a confirmed diagnosis in females with bleeding disorders, when compared to their male counterparts.

These glaring diagnostic gaps, which often stretch well beyond a decade, persist despite the best efforts of the American College of Obstetricians and Gynecologists (ACOG), NBDF, and other organizations to put forth recommendations, educational initiatives, and public awareness campaigns focused on early screening for adolescents and young women with IBDs.

In short, more needs to be done to ensure early diagnosis and interventions to forestall avoidable impacts on quality of life. A new commentary, "Closing the Diagnostic Gap in Adolescents and Young Adult Women with Bleeding Disorders," published in the August issue of the journal *Obstetrics & Gynecology* is a call to maximize the role of gynecologists to achieve early diagnoses in this underserved population.

"This delay from symptom presentation to diagnosis represents the diagnostic gap."

Missing the opportunity for a bleeding

disorder diagnosis early in life can have serious consequences—undue medical procedures and complications, excessive bleeding during procedures and at childbirth, not to mention the effect of excessive menstruation on emotional distress and quality of life, as well as adverse social consequences, explain the authors. "Gynecologists have a tremendous opportunity to improve the lives of so many individuals by closing this diagnostic gap and offering screening to those who need it."

The paper's two authors, a gynecologist and a hematologist, describe the gaps that can be found within several conditions, including hemophilia carriers who will often live with untreated and poorly managed bleeding symptoms.

In many instances, gynecologists and other healthcare providers, still do not recognize the potential for hemophilia carrier status to confer actual risk, including HMB and other types of bleeding. Further, genetic and coagulation testing to confirm carrier status may not even be offered to individuals with a known family history of hemophilia. "This disparity arises from the longstanding and firmly held belief among many in health care that hemophilia affects only males, and that female hemophilia A and B carriership is not associated with a bleeding phenotype. This historic misconception is at the root of dismissive attitudes by health care professionals and results in inappropriate care, delayed diagnosis, and impaired quality of life in affected women and girls."

The authors also cite von Willebrand disease (VWD) as a prime example of enduring

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diagnostic gaps, even as ACOG has for more than 20 years recommended screening for VWD and other bleeding disorders in persons with HMB. The discrepancy between an estimated VWD prevalence of up to 1% of the U.S. population vs. the modest number VWD patients followed at hemophilia treatment centers, potentially reflect this gap. “Indeed, the low estimated prevalence from the hemophilia treatment center population may result primarily from under diagnosis in the primary care setting and inadequate screening of adolescents.”

Fortunately, there exist effective if underutilized screening tools that could help close this gap. “The well-validated and easy-to-use Menorrhagia Specific Screening Tool based on described menstrual bleeding and family and surgical history, can aid in recognizing and diagnosing bleeding disorders, yet it remains underused in the clinical setting,” explain the authors. “Consistent screening in clinical evaluations can help practitioners identify patients most likely to be affected by a bleeding disorder and who require further testing. A subsequent diagnosis would greatly inform treatment strategies.”

The third focus area of the commentary is the under diagnosed connective tissue disorder, Ehlers-Danlos syndrome (EDS), which, depending on the type, is characterized by joint hypermobility, skin extensibility, and/or tissue fragility, and can impact on a variety organ functions. As hypermobile EDS is more often associated to women with HMB it represents an avenue for gynecologists to help forestall peripartum complications such as uterine rupture, preterm delivery, postpartum hemorrhage, and severe lacerations.

“Because many of these individuals may present with heavy menstrual bleeding, increased screening, and referral for confirmation of a hypermobile spectrum disorder diagnosis can potentially improve outcomes over their lifespans.”

The authors conclude by emphasizing the critical part gynecologists can play in this effort, particularly when equipped with greater knowledge and a willingness to work in concert with their counterparts in hematology.

“Given the prevalence of VWD, EDS, and hemophilia-carrier status, gynecologists should expect to encounter patients affected by these conditions in their practices on a frequent basis. Early recognition can have a significant effect on the diagnostic delays that persist from lack of screening, concluded the authors. “When armed with knowledge and increased awareness of the conditions associated with heavy menstrual bleeding, we as gynecologists have an opportunity to close the diagnostic gap and improve outcomes by taking the initiative to screen. We must be prepared to work collaboratively with hematologists to provide interventions directed toward improving quality of life and decreasing rates of complications due to reproductive tract bleeding.”

Citation

Wright TS, Cygan PH. Closing the Diagnostic Gap in Adolescents and Young Adult Women with Bleeding Disorders: Missed Opportunities. *Obstet Gynecol.* 2023 Aug 1;142(2):251-256. doi: 10.1097/AOG.0000000000005262. Epub 2023 Jul 5. PMID: 37411028.

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Did You Know?

South Carolina Midstate Prisma Health HTC's New Location!

Congratulations to the South Carolina Midstate Prisma Health Hemophilia Treatment Center on their new location! Our Executive Director, Sue Martin, was on hand to celebrate this momentous occasion! This office has been moved outside of the Children's hospital to better serve the entire bleeding disorders community, adults, and children. The new facility is larger and better equipped to handle the growing needs and population of the community. The general location of the facility is the same, but in a different building. Be sure to look at your appointment letters for the new location to check in for your next annual HTC

Comprehensive Treatment Care visit.

The "NEW" Columbia Location is:
14 Richland Medical Park Rd. Suite 410
Columbia, SC 29203

Prisma Health HTC has also created two new satellite offices to better serve the Lowcountry. The new offices will be in Orangeburg and Florence.

Orangeburg Location:
1724 Village Park Drive
Orangeburg, SC 29118

Florence Location:
Coming soon!





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Advocacy Action



Wake Up, Show Up, and Push Up: Advocacy Summit

The Spring Hill Marriott in downtown Greenville was the perfect venue to host our Fall Advocacy Summit on November 10-12, which had a mission to provide a high level of advocacy training to our Coalition Advocates and Ambassadors, and to engage new advocacy members. By the time the weekend was over, our advocates had caught the advocacy bug, big time! They were energized and ready to start the new year with the mission to help our legislators realize the importance to pass H3618, the Accumulator Adjustment Copay Adjuster bill (ACAP) currently in the SC State Legislation. To learn more about the ACAP, please read the opinion piece posted in the Greenville News on November 19 in our Community Voices Section, page 15

The Summit began with a social gathering and dinner on Friday night, setting the stage for success with our guest speaker, the *South Carolina House Representative Chandra Dillard, (D) District 23*. Rep. Dillard shared inspiring words of encouragement to help us support this effort and left us all with her inspiring words to practice throughout the event to Wake Up, Show Up, and Push Up our voices to move the bill to the Governor's Desk. We were grateful for her time with us throughout the evening. Following her presentation, *Josie Gamez, NBDF & Former Legislative Staffer*, and our own James

Romano, BDASC Legislative Coordinator & President of Cure and Care sealed the night with their words of encouragement from many years of legislative work that both have done throughout their careers. Ending the evening, *Sue Martin, BDASC Executive Director and the State Advocacy Coalition Lead* recapped a very successful advocacy year and expressed her gratitude to the community members for all their volunteer work.

Saturday began early with the teens heading to the *NEW BDASC Teen Leadership Alliance Programming* as they were engaged throughout the day with the leadership of our presenters from Oregon, Dominic, and Rachel, with our own day staff member, Felicia Davenport, helping the teens stay focused.

The adult sessions all began with our members from the community, keeping the patient voice at the forefront of the weekend. We are grateful to *Cristal Day, Sue Martin, Whitney Galloway, Kristin Shelton, and Warren Ingram* for sharing their stories in advocacy and the need to have everyone involved. We were excited to have with us the South Carolina Hemophilia Treatment Centers who provided their Access to Care and Treatment Updates and were excited to see all the advances in treatment

Continued on page 23

care, new locations, and all they all are working on, especially for women who bleed. We are so grateful to Dr. Shayla Bergmann, Director Pediatric Nonmalignant Hematology, MUSC, Dr. Leslie Gilbert, Lead Hematologist Prisma Health HTC Upstate, & Robin Jones, Nurse Coordinator, Prisma Health HTC Mid-State for joining us. Following the treatment center updates, *Kollet Koulianos from the Hemophilia Alliance*, helped us understand today's healthcare environment, the challenges with access, and understand the Accumulator Adjustment Copays Programs. Next, we looked at identifying and building compelling stories and building strength with coalitions and partnerships, led by *Drew Clawson, Kinard Consulting and Alison Clifford, Director, Therapeutic Policy and Advocacy, Rare Disease US Public Affairs, Takeda*. This session was followed with the delight of listening and speaking with our Texas Colleagues, *Melissa Compton, Executive Director, Lone Star Bleeding Disorders Foundation and Julie Fredericksen Jones, Executive Director, Texas Central Bleeding Disorders* along with *Josie Gamez* to share testifying and how they passed their Texas Bill. We also looked at the strategic timeline we all must recognize to pass this bill this year. Direct targeted messaging, marketing, and social media education including the use of Twitter (X), securing TV interviews and opinion pieces was expertly provided by *Khadija Butt, Director, Rational 360*. We finished the Summit with our legislative agenda and important dates and events to plan for and our teens sharing what they learned in their sessions including testimonials of pride and engagement within one another. They all were presented with Certificates of Achievement for completing the Leadership Alliance Program. The Summit ended with time to relax and socialize, provided by BDASC at the downtown third floor of Ink N Ivy Restaurant for a private dinner event. We are thankful to the South Carolina advocates who

came together from all regions throughout the state and nationally to join our efforts working to improve access to Quality Care and Treatment in South Carolina. **Improving lives is our mission.**

Save the Dates to join us!

2024 Legislative Breakfast, January 10—State Capitol

2024 BDASC State Advocacy Days are February 27-28— Columbia

2024 NBDF Washington Days March 6-8

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National News



Community Voices in Research

National Bleeding Disorders Foundation

Community Voices in Research (CVR) is a community-powered registry that collects, via electronic surveys, the lived experience of people affected by inherited bleeding disorders (BD) and their immediate family members. It is designed to transform experiences into evidence and help researchers understand what it means to live with a bleeding disorder and how current treatments, therapies, and policies affect the community. CVR is open to all adults affected by BDs as well as their parents, spouses, grandparents, siblings, and children.

The information gathered will remain confidential and will always be reported in a grouped and de-identified manner. As a CVR participant, you will have access to this data

via a Personalized Dashboard so that you can see how you compare to others like you, follow trends and patterns over time, and become a more active member of your healthcare team. This information will ultimately be used to identify ways of improving clinical outcomes and quality of life and identify research questions important to the community. Join so that your important perspective is included in this research project. It is the only way to ensure that all findings are relevant and generalizable to you. It will also help you stay up to date on other research opportunities and resources. Scan the QR code for more information.



BDASC Highlighted at National Bleeding Disorders Foundation Leadership Summit

It was an honor for Executive Director, Sue Martin, to present at the BDC Leadership Conference in November on the Chapter's program development in Health Equity, Diversity, and Inclusion. We are grateful for the

Chapter Capacity Grant from NBDF and to our community members who serve on the BDASC HEDI Working Committee. We are proud of the work that has been done so far. Congratulations to all!



Research & Development

Gene Therapy is here! We are excited to be providing the opportunity for the entire community to learn more about these novel therapies. Our community members will gain valuable information and a deeper understanding of Gene Therapy and have the most up-to-date correct information. These events are hosted by BDASC in partnership with our Hemophilia Treatment Centers and our sponsors through educational grants. We are providing several opportunities to learn about the new Gene Therapy options available to our community. With help from our Hemophilia Treatment Centers and our sponsors, we will be traveling the state to provide these educational dinners for all members of the community. Please note that while these dinners are specific to the different types of Hemophilia, all BDASC community members are welcome to attend and learn more about these new treatments.

November 28: Gene Therapy Conversations (Hemophilia A) in Columbia at Blue Marlin @ 6:30pm.

December 5: Gene Therapy Conversations (Hemophilia B) in Columbia at Ruth's Chris Steakhouse, Senate Street @ 6:30pm.

December 14: Gene Therapy Conversations (Hemophilia A) in N. Charleston at MOMO Riverfront Park @ 6:30pm.

December 15: Gene Therapy Conversations (Hemophilia B) in Summerville at Bostonia Public House @ 6:30pm.

IMPORTANT MESSAGE

BDASC does not give medical advice nor engage in the practice of medicine. BDASC under no condition or circumstances recommends treatment for specific individuals and in all cases recommends that our members always consult their physicians or hemophilia treatment centers before pursuing any course of treatment. BDASC does not endorse or recommend any company or treatment therapy, but as an advocacy organization strives to provide educational information and support to keep our bleeding disorders community informed.

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Resources & Contact Information

Medical Facilities

The Hemophilia Treatment Center of South Carolina

Children's Cancer & Blood Disorders Clinic at Prisma Health Children's Hospital-Midlands

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

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

Prisma Health's Upstate Children's Hospital

MAIN CAMPUS:

BI-LO Charities Children's Cancer Center
Serving Hematology/Oncology Patients
900 W. Faris Road

Greenville, SC 29605

Phone: 864-455-8898

Fax: 864-455-5164

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

SATELLITE OFFICE:

Spartanburg- Children's Hospital
Outpatient Specialties

1700 Skylyn Drive, Suite 200

Spartanburg, SC 29307

Phone: 864-716-6490

Fax: 864-596-5164

Hours: Wednesday - alternating
mornings and afternoons

SATELLITE OFFICE:

Anderson - Pediatric Specialties of the
Upstate

2000 E. Greenville Street, Suite 3500

Anderson, SC 29621

Phone: 864-716-6490

Fax: 864-716-6492

Medical University of South Carolina
Shawn Jenkins Children's Hospital
10 McClennan Banks Dr.

Charleston, South Carolina 29425

Shayla Bergmann, MD, Assistant
Professor

Director, Pediatric Hemophilia Clinic

Phone: 843-876-1980

Mobile: 843-812-5682

Fax: 843-792-7562

Orangeburg Location:
1724 Village Park Drive

Orangeburg, SC 29118

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

1230 Avenue of the Americas 16th
Floor, New York, NY 10020, United
States

Phone: 212-328-3700

Toll-free Number: 888.463.6643

Email: info@hemophilia.org

Website: www.hemophilia.org

Hemophilia Federation of America

999 North Capitol Street, NE, Suite 201

Washington, DC 20002

Phone: 800-230-9797

Email: info@hemophilia.org

Website: www.hemophilia.org

World Federation of Hemophilia

1425, boul. René-Lévesque O.

Bureau 1010

Montréal, Québec

H3G 1T7 Canada

Phone: +1 (514) 875-7944

Fax: +1 (514) 875-8916

Email: wfh@wfh.org

Website: www.wfh.org

Resource Information

SC Dept. of Health & Environmental

Control (DHEC)

Children with Special Health Care Needs
Hemophilia Program

2100 Bull Street

Columbia, SC 29201

Phone: 803-898-0784

Website: <https://www.scdhec.gov/health/child-teen-health/services-children-special-health-care-needs/hemophilia-assistance-plan>

American Pain Foundation (APF)

Phone: 1-888-615-PAIN (7246)

Hemophilia Chronic Pain Support Group

Website:

<http://painaid.painfoundation.org>

American Society of Pediatric

Hematology/Oncology

Phone: 847-275-4716

Website: www.aspho.org

The Coalition for Hemophilia B, Inc.

Phone: 212-520-8272

E-Mail: hemob@ix.netcom.com

Website: www.hemob.org

Bleeding Disorders Legal Hotline

Phone: 800-520-6154

Centers for Disease Control & Prevention

Phone: 1-800-311-3435

Website: www.cdc.gov

Committee of Ten Thousand (COTT)

Phone: 800-488-2688

Website: www.cott1.org

LA Kelley Communications, Inc.

Phone: 978-352-7657

Website: www.kelleycom.com

Patient Access Network Foundation

805 15th Street, NW, Suite 500

Washington, DC 20005

Phone: 202-347-9272

Website: <https://panfoundation.org/index.php/en/>

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

Patient Notification System

The Patient Notification System is a free, confidential, 24-hour communication system providing information on plasma-derived and recombinant analog therapy withdrawals and recalls.

Phone: 888-UPDATE U (873-2838)

Website:

www.patientnotificationsystem.org

Accessia Health

Provides financial assistance to people who are diagnosed with chronic medical conditions.

P.O. Box 5930

Midlothian, VA 23112

<https://accessiahealth.org/>

1-800-366-7741

Medic Alert Foundation

2323 Colorado Avenue

Turlock, CA 95382

Phone: 800-432-5378

Website: www.medicalert.org

South Carolina Healthcare Market Place

Call 800-318-2596

Website: www.HealthCare.gov

The South Carolina Rare Disease Advisory
Council

Website: <http://rarediseasesc.org/>

Upcoming BDASC Community Events



Mark Your Calendar!

Looking Ahead: 2024 Major Community Engagement Opportunity – Save the Dates!

January 19, 2024: Advocacy Legislative Breakfast (Columbia State Capitol)

February 27-28, 2024: BDASC State Advocacy Days (Columbia)

March 1, 2024: BDASC Scholarship Applications Open

March 6-8, 2024: NHBDF Washington Days (Washington, D.C.)

March 22-24, 2024: Adult Retreat (Greenville)

April 11-13, 2024: HFA Symposium (Indianapolis, IN)

May 11, 2024: STEP For Bleeding Disorders

Walk/Run (Columbia)

June 21-23, 2024: Annual Meeting & HELLO Conference (Greenville)

August 12-15, 2024: NBDF Bleeding Disorders Conference (Atlanta, GA)

October 18-20, 2024: Potential Family Camp (TBD)

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

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

2024 Summer Camps: SAVE THE DATES:

Camp Dates: July 8–July 13, 2024. Camp Burnt Gin is a summer camp in Wedgefield, South Carolina for children who have physical disabilities and chronic illnesses. **Kids & Teens with Bleeding Disorders** (Hemophilia, VWD, Sickle Cell) ages 7-18 years are eligible. Applications will be available March 1. For more information about Camp Burnt Gin: **Call:** (803) 898-0784 or **Visit:** <https://scdhec.gov/welcome-camp-burnt-gin>. Contact **Camp Director, Marie Aimone at 803-898-0455. Email:** Marie Aimone at aimonemi@dhec.sc.gov.

Prisma Health Upstate Children's Hospital, BI-

LO Charities Children's Cancer Center

2024 Camp Dates: Kids Camp (ages 6-12 yrs)— June 23–28, 2024. **Teen Camp** (ages 13-18 yrs)— July 27–August 1, 2024. Founded in 1994, Camp Courage creates an unforgettable recreational experience for children and teens with cancer or blood disorders from the Upstate of South Carolina. For more information about Camp Courage contact Ericka Turner, Camp Director at: Ericka.Turner4@prismahealth.org or call 716-481-3341. **Visit:** <https://www.choa.org/campcourage>,

BDASC will be at these camps with our famous

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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The South Carolina Hemophilia and Bleeding
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