

# The News Infusion



The Official Newsletter of Bleeding Disorder Association of South Carolina

VOLUME 10, ISSUE 4

FALL 2021



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State of the Science, page 28

Keeping It Coastal—Educational Family  
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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.

### 2021 Calendar of Events

Please visit our website calendar page link to see the most current information on scheduled events <http://hemophiliasc.org/programs-and-events/calendar/>

**November 11 — Blood Brothers Meeting**

**November 13 — Advocacy Coalition Stakeholder Meeting**

**November 18 — Advocacy Coalition Call**

**November 29 — Virtual Community Connections—Advocacy and Insurance**

**November 30 — Insurance Educational Dinner**

**December 9 — Adults and Couples Holiday Night Out**

**December 11 — Holiday Winter State Meeting in Columbia (Canceled due to COVID)**

**December 11 — Virtual Holiday Events TBD**

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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 Hemophilia 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@hemophiliasc.org](mailto:sue.martin@hemophiliasc.org). Mail to: 439 Congaree Road, Suite 5, SC 29607, Attention: Editor-in-Chief, *The News Infusion*. We look forward to hearing from you soon!

## Lead Article



### **“Keeping It Coastal” Educational Family Camp and Adult Retreat**

From September 24th to the 26th the Bleeding Disorders Association of South Carolina family took over Myrtle Beach’s Marina Inn at Grande Dunes for the 2021 “Keeping It Coastal” Educational Family Camp & Adult Retreat. With over 150 registrants, the members of the BDASC took part in learning new skills, sharpening their advocacy techniques, and having some fun, all while staying in sync with the COVID and masking policies.



The retreat started the evening of Friday the 24th with the presentation, *Do What Moves You: Staying Active* by Dr. Jeffery Kallberg and Pete E., and sponsored by Takeda. Dr. Jeffrey, a Physical Therapist at South Texas Hemophilia Treatment Center with over 26 years of experience, went back and forth with Peter about how staying true to his treatment plan allowed him to live the active life he wanted. Doctor Kallberg also used his experience as a person living with hemophilia to express the importance of working with your treatment team to help in trying to reach each

individual's physical activity goals.

Day two officially kicked off with the opening of the Infusion Clinic at 7 a.m. Our very own Robin Jones, MSN, MHA, RN, CPN, CPHON and Sue Geraghty, RN, MBA trained a half dozen members on how to properly prep, find a vein, and infuse Factor. Each student was recognized on the morning of day three with an “Independence Award”.

The first session of Saturday was Advocacy: *Access to Care with Treatment for All*, led by BDASC Executive Director Suzanne Martin. Nathan Schaefer, Vice President of Public Policy for the National Hemophilia Foundation, and Jeremy Williams, BDASC’s Advocacy and Public Policy Consultant, provided status updates, policy news, and emphasized the importance of advocacy by the members. They also addressed the evolution of the State Based Advocacy Coalition, and talked about the importance of developing partnerships, and how these relationships are vital to health care access. Many community members also spoke about their advocacy experiences. Thank you to Cristal Day, Susie Maloy, April Baird, Ward Keith, Ursula Sagot,



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and Christine Evans for your advocacy voice. The kids had fun too while remaining in their family PODS as they took to the Logo Master



Challenge with an exciting “Get Your Brick On” start hosted by Lucas Crisp and Logan and Grady Smith.

For the teens, there was *Kahoot It* and *BELCH* (*Bringing Elevated Learning with Competitive Humor*) and the Bingo Mat Challenge. The BELCH program was a game of Kahoot with bleeding disorder and life skills questions mixed in. “Should you have a professional looking email when applying for a job?”, “Is drinking a gallon of spoiled milk Part of the 5s?”, and “Is a Cheese head proper work attire for an office

job?” were questions our teens got universally correct. Cole, Gracie, and Jayden took the top prizes in the extremely tight competition, while Kennedy and Caleb earned honorable mentions.

The Bingo Mat Challenge was classic Bingo, but with some interesting challenges thrown in for some of the squares. The challenges ranged from “Pronounce your name backwards” to “Take a socially distant selfie.” The bingo winners had an additional opportunity to double their winnings by taking on a mega challenge.

The two best were “while standing on your head, tell us why it’s important to be a good advocate for bleeding disorders, in under a minute” and “hopping on one foot around the group, name five events the Chapter holds every year in under a minute.” Both are viewable here on our YouTube channel, within the Family Camp Wrap-up video. [tinyurl.com/BDASCKICTEENS](http://tinyurl.com/BDASCKICTEENS) The last three sessions of the day were *Emergency Room Care and Treatment* with Sue Geraghty, *M-POWERED: Giving Voice to Your Strength* with Jennifer Laughlin of Bayer and

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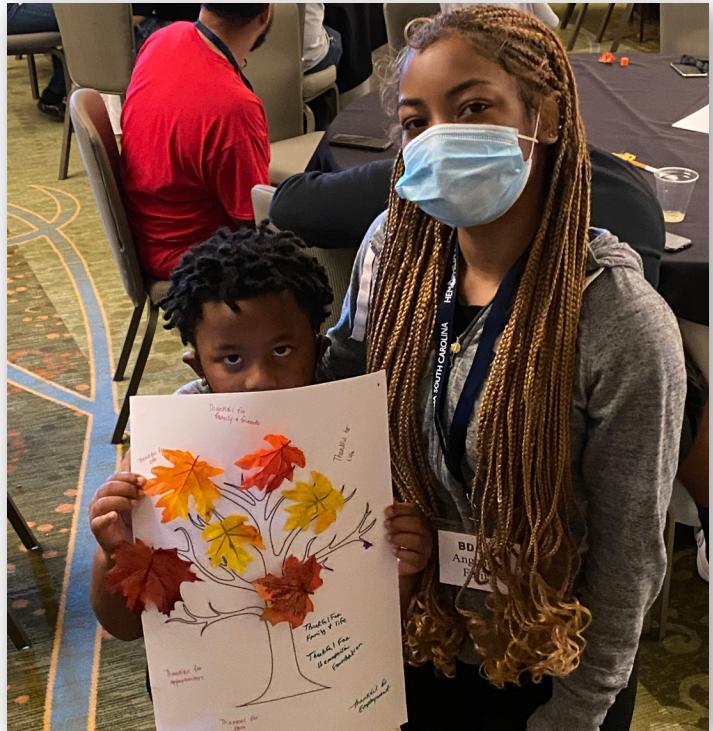
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*Heart Health, Strokes, and the Importance of Nutrition* by CVS Specialty's Linda Stepien. In *Emergency Room Care*, Ms. Geraghty explained how to best navigate an emergency room visit for patients with bleeding disorders. She gave a primer on what they should know going in, what they can expect, and how to advocate for their needs in an often-stressful situation. One closing piece of advice she delivered was to ask the ER staff if you could leave some information about bleeding disorders with them, to review at their leisure, or to file away for the next time they encounter a patient with a bleeding disorder. During her *M-POWERED* talk sponsored by Bayer, Jennifer brought the moms of hemophilia patients together to gain real-life, practical tools for success while building connections for a lifetime. The emotional session offered a space for the moms to share their care giver experiences, address their fears, explain their mindset, and acknowledge their strength. While at *Heart Health* by CVS, Linda spoke about heart attacks and strokes while living with a bleeding disorder. She covered learning how to identify risk factors, from inherited ones to those that can pose serious threats. She also covered prevention steps individuals can take to help address risks and special treatment options for individuals living with bleeding disorders.

The rest of day two was spent on relaxing, recreation, and reconnecting. On the beach, the annual BDASC Sand Castle Contest was held with the BDASC Castle by the Baird family coming in first, B-Boy City by Rylee and KJ in second, and the Volcano Castle by the Teen Crew placing third. In the evening, the BDASC family gathered together for a Hawaiian Luau and the "BDASC's Got Talent Show". With a lot of tough competition, from a soulful rendition of Carrie Underwood's "Before He Cheats" by Gracie Baird, to a highly coordinated dance routine, it would be the dancing duo of James Whitmire and Kaylee Branham who would take home the top prize.

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The last day of the affair began with the exercise Gratitude Nation by Sanofi Genzyme's Xaviette Pointer-Kincy. During the session, Ms. Pointer-Kincy taught why practicing gratitude may be good for people living with a chronic condition and spoke about leverage gratitude in one own's life. This was complimented with a craft where members added leaves of gratitude to their life trees.

The final events for the 2021 "Keeping It Coastal" Educational Family Camp & Adult Retreat were the official launch of the STEP for Bleeding Disorders 5K Walk / Run Fundraiser followed by the Community Connections Roundtables. The roundtable groups were broken down to YES: New Families and Parents, Teens and Young Adults, Blood Brothers Men's Group, CARE

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Women Group and VWD, Rare's, and Platelet Disorders Education and Conversations. The day ended at noon with everyone grabbing a to-go lunch and spreading back across the state as they headed home.

We would like to acknowledge our sponsors who made this event possible! A sincere thanks to our Moby Dick Sponsors: Bayer, CSL Behring, CVS Specialty, Genentech, Takeda, and Pfizer, as well as Great White Sponsors: Spark Therapeutics, Sanofi Genzyme, Paragon Healthcare, Novo Nordisk, Medexus, BioMarin, DrugCo, BioMatrix and Accredo. We also would like to recognize the educational support of the National Hemophilia Foundation and the Hemophilia Federation of America. Last, we can't thank the Colburn Keenan Foundation (CKF) enough for their generous grant support of this event. CKF has been a long-

time sponsor of many of our events. The CKF is a charitable organization dedicated to improving the health and well-being of individuals and families living with chronic illnesses, with priority placed on those living with bleeding disorders. Their Mission is to create a perpetual source of grant funding that will support charitable organizations whose programs and activities benefit the bleeding disorders and chronic illness communities, assist families with bleeding disorders and other chronic illnesses to meet their socio-economic needs, support research to find a cure for hemophilia, and support students with bleeding disorders through a designated program for scholarships for higher education. (Pictures can be found on our Facebook page at <https://www.facebook.com/HemophiliaofSouthCarolina>

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## Executive Director Welcome

By Sue Martin

# A Year to Remember!



As we begin to see the signs that we are counting down toward the end of the year with holiday decorations coming out in the stores, who would have thought that at the end of the 2021 my conversations on events and services

would still begin with, "How do we do this in the pandemic era of COVID-19?" Keeping our organization and those we serve safe as we provide programs and services, is and always will be, number one. I am saddened that this year we will not all be together in our large winter year-end event, but with many things in mind, including the cost to the Chapter of reservation cancellations due to exposures of COVID and the funds lost, it was just the correct thing to do this year. I know next year will be so exciting when we gather for the holidays, as I hope we will have this all behind us.

If you will bear with me, I thought I would provide our readers with a quick wrap-up of the year and what I see for our future here at BDASC. Yes, we have completed the necessary work to change over to our new inclusive name, but unfortunately, we are still waiting for the IRS final designation. Once that is received, we will move forward complete with a new website and much more. Hemophilia of South Carolina will always be in our blood, as it is part of our history and the soul of the organization's makeup, and rest assured, HSC is always within us. We are excited that HSC will take on a new and more inclusive name, fitting for the individuals and families we truly serve. HSC will become BDASC soon.

Wrapping Up the Year- Highlights!

Our Fundraisers: I can't say enough about how appreciative we are at BDASC for all who have supported our fundraisers this year—The Red Tie Campaign in March, commemorating the National Bleeding Disorders Awareness Month, Our Par for the Clot Charity Golf last October, the newly named STEP for Bleeding Disorders 5K Walk/Run a few weeks back (formerly the Turkey Trot), and coming soon, Giving Tuesday, a Global Day of Generosity. Your efforts, donations, and participation help keep our Chapter available to our members with operational overhead support such as staffing, insurance, office supplies, website, and communications; you help provide services that are not funded with any other means of revenue. These include, but are not limited to, our Academic Scholarship program, support group activities, camps and retreats for kids and teens, national educational member meetings and travel, local outreach programs and awareness campaigns, research and global initiatives support, and portions of our advocacy work, which now consumes the second highest revenue spend behind educational programming. Access to affordable and quality treatment care is very high on our priority initiatives. The announcements of gene therapy making strides is exciting, but this too has many unanswered questions that won't be solved for many years to come. Can you imagine if all our guys with severe hemophilia became mild hemophiliacs suddenly for the rest of their lives? Wow, that would be a miracle in the first steps to achieving a higher quality of life, but as I said, that day is just not here yet but we are working together towards dreaming of that possibility someday. And what about a true cure! Well, that is going to take a much longer time. I do hope that in my lifetime, I will see the day when the genetic disorder is not passed on from mom to son or daughters, or from an affected male to his daughter. Then we would still need to cure everyone affected too. But until then, we still have a lot to accomplish to achieve quality and

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affordable care.

About Advocacy: On this advocacy note, we did accomplish and complete a few key highlights this year, and in this direction, I am very proud of us. First, working with many patient advocacy groups for over three years on creating a space for the voice of rare disease patients in South Carolina, a Rare Disease Advisory Council (RDAC) was finally established and will be meeting in January as they begin the important priority work of the council. We hope to be a resource and voice for the Council and are very excited. We thank the hard work of all our advocates in our Advocacy Program, approximately 53 members strong, and invite everyone to join our program.

Second, for many years we have been working closely with our HTCs, state agencies, nurses and physicians, and the clinics that serve our community within the healthcare space. Bringing many key individuals together through our Bleeding Disorders Forums in 2018-2019, a Medical Symposium this year, and our yearly stakeholders' meetings, and by helping to create a space where they can all collaborate with us, and with each other, learn what each agency or organization has to offer and provide, through discussions and reaching out, has proven to be very beneficial. Working hard to expand our Hemophilia Treatment Centers, which are Centers Of Excellence in Comprehensive Treatment Care according to the National Hemophilia Foundation (NHF), the Centers for Disease Control and Prevention (CDC) and the Medical and Scientific Advisory Council (MASAC), we are excited to share the new Hemophilia Treatment Center for patients in the upstate at Prisma Health, led by the efforts of Dr. Leslie Gilbert and Dr. Stephanie Ambrose at Midlands Hemophilia Treatment Center. (Please read the press release on page 24.)

It is also exciting to hear that MUSC Shawn Jenkins Children's Hospital, under the leadership of Dr. Shayla Bergmann is also striving in

support of this designation. On behalf of BDASC, I express my sincere appreciation to all parties involved. It was an incredible amount of dedication and work to make this happen and a joint collaboration by so many. I am grateful to be privileged to attend monthly clinics visits and witness first-hand the excellent work the teams provide and how deeply they care about their patients. Yes, they do treat adults with adult clinic dates and this is exciting. Would I still like to see an adult facility and adult bleeding disorders hematologist dedicated to adult bleeding disorders patients only, (for those reluctant to see a pediatric doctor in a pediatric facility)? Of course, but we do have this covered for now and invite any adults not yet seen at the HTCs to give it a try. They have taken on many complex medical situations that have been challenging, and for that I am grateful. Perhaps in time, an adult HTC can be established but for now, the new expansions are exciting. Additional satellite clinics are also in future plans.

What Is My Ask? What if the HTCs were gone? What would we do? How do we assure that this never happens? I can tell you that working closely within the rare disease space, others would love to have what we have within bleeding disorders and the comprehensive care model. So why am I bringing this up now? Funding a treatment center is not easy and some states don't have them. Without going into all the details at this time, what is important is that we all work hard to make our appointments, show up on time, and IF YOU HAVE to cancel, please do so in a timely manner (at least a week) so that the HTC can give your time to someone else on a waiting list. Also important is that the treatment center professional staff (the physical therapist, social worker, psychosocial team, and others) scheduled to see you that day at the clinic are not waiting for a patient who becomes a no-show or is extremely late. Be sure to make your scheduled time as someday this model of care could be gone if we are not careful.

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## Looking Ahead in 2022

The Board of Directors and I will get together in January for our annual organizational strategic planning retreat. We will look at all programs and services and reevaluate the past year and see what is best for 2022 and beyond. We will look at how to increase our revenue sources so we can provide additional programs and services that are of interest to our members and as always, we value your input, suggestions, and any concerns. When we send out our annual member survey in December, please take the time to complete it so your voice can be part of our planning. We are here for you, and your voice matters.

I hope you will embrace any changes we feel are necessary for our growth and to assure our Chapter continues well into the future. We are growing leaps and bounds with referrals from our HTCs and other state agencies, our website, social media platforms, and those moving into our state. With fixed revenue and a growth in members, you can see that limited resources are not what we want. We will have to look at ways

to cut back to continue to provide our member services. One way to do this will be in our mailing services. Not only is this expensive, time consuming (with nearing 500 families served), and with the rise in paper products, stamps, ink, and envelopes, we will need to ask you to rely more on online communications. Our new website, our social media platforms, and our VIP technology will keep everyone connected and served if utilized as it is intended. Of course, for those without the ability to use online technology, mailing will still be provided. In closing, it has been such an honor and a blessing to be your Executive Director, a face of the organization, and the one who speaks on BDASC's behalf. Thank you for the trust in my ability, my passion and visions, alongside the Board of Directors and our members. You all drive and inspire me each and every day, and I love walking this journey with you at my side. Thank you for all you do for BDASC and those we serve!

Have a safe and enjoyable holiday season,  
Sue



A man with a beard and glasses, wearing a grey vest over a plaid shirt, is using a black leaf blower to clear fallen leaves from a lawn. He is wearing red and yellow work gloves. The background shows a garden with trees and a house. A large, stylized swoosh graphic in shades of blue and green sweeps across the bottom of the image, containing the IDELVION logo and promotional text.

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## Community Engagements

# Par for the Clot Charity Golf: A Huge Success!

After almost a year of planning, the 2021 Par for the Clot went off without a hitch on October 1st. With beautiful weather, a full course of 144 players drove, chipped, and putted their way to glory at the Preserve at Verdae Golf Course in Greenville, SC. Ensuring they had an enjoyable time were 22 volunteers checking them in, selling raffle tickets, dealing cards for the poker hole, hawking red tees and mulligans,

refilling coffee, serving up donuts, handing out mini-Chick-Fil-A chicken sandwiches, and manning selected holes around the course. A new fun challenge added this year was a Putting Contest, with a long and short putt. This year's notable tees were the Spin-to-Win Hole where players had the chance to get a bonus—like moving to a closer tee or a drop on the green—or a whammy such as an exploding ball, move back a tee, or



having to use a really short club. Another popular hole, sponsored by CVS Specialty, was the charity gun hole where players got to fire off a modified AR-15 loaded with a golf ball for a competition closest to the target, and then play the rest of the hole from where it

landed. Making his triumph return to Par after a one-year hiatus was friend and community advocate spokesman of title sponsor CSL Behring, Perry Parker. Eight skilled players were able to Beat the Pro getting their ball closer to the hole than Perry. Of those eight, Amy Graessle's name was pulled from a hat and she took home an

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Evenroll putter donated by Perry. As they have in the past, the on-course boxed lunch was provided by Greenville's own Quaker Steak & Lube, while the morning breakfast buffet was sponsored by Tac Custom Homes and filled with donations from the Starbucks at Hendrix and Woodruff, the Saralee Bakery of Summerville, and the Krispy Kreme on Woodruff. As the players finished their rounds, the teams made their way to the Embassy Suites Pavilion and enjoyed a dinner of fried chicken, steak, salads and potatoes, and a selection of desserts. While everyone ate, host Sue Martin introduced this year's BDASC family of the tournament, the Krakowiak's, who gave those present a glimpse of what it's like to suddenly have a child with a bleeding disorder. They also highlighted how the funds raised from the event help support the work of the Chapter. This year's champions were team Quaker Steak & Lube with Josh Johnson, John Taylor, Randall Cushman, Zack Dennis, who also took home the championship last year. Coming in second this year was a team from Metromont



consisting of Jason Woodard, Johnny Fleming, Derrick Hiott and Ryan Homer. The Poker Hole winner was Todd Daniel who came in holding a spade flush. The player that was Closest to the Pin was Charlie Lee who was only 3'1" off of the hole. The Longest Drive prize was taken home by Zack Hancock in the men's category and reigning women's champion Megan Comen of Metromont once again made the best ladies' drive.

After the talks and tournament winners, the day concluded with a silent auction and raffle. With many donations that included a Sportsclub Fitness Membership, a private tasting session from Total Wine & More, a silver necklace by Solid Gold Ltd, and a Health and Skincare Gift Basket, bidding was secured on these and other silent auction items. For the raffle, an autographed photo of Clemson Tigers Coach Dabo Swinney, gas cards from SpinX, two hours of the Indoor Golf Simulator at Carolina Indoor Golf, a day at Highlands Aerial Park, and many others, all proved

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to be popular. When all was said and done, the tournament raised \$47,695 and we can't express enough our gratitude to everyone for helping us to continue to support the bleeding disorder community.

The tournament could not be so successful without the hard work of the 2021 T-Off Committee and our devoted volunteers who dedicate their time during the event. With our deepest appreciation we would like to recognize and thank the following individuals: **2021 Tee Off Committee:** Ric Martin, Chairman and BDASC Member; Brian Burton and Mike Walden, BDASC Members and Co-Chairs; Sue Martin, BDASC Executive Director, Gregory Witul, BDASC Chapter Development and Communications Coordinator; Felicia Alexander, BDASC Member; Cristal Day, BDASC Board Member; Aaron Smith, BDASC Board Member; Joey Krakowiak, BDASC Board Member; Corbin and Bryce Martin, BDASC Members; Hunter Day, BDASC Member; Karrie Barnes, CSL Behring; Laura Benton, CVS Specialty; Norberto Liriano, Novo Nordisk and Apryl Tilert, Accredo. **2021 Golf Day Volunteers:** Ric Martin, Brian Burton, Mike Walden, Sue Martin, Greg Witul, Felicia Alexander, Donald Dominique, Cristal Day, Aaron Smith, Joey Krakowiak, Corbin Martin, Hunter Day, Karrie Barnes, Apryl Tilert, Virginia Chandler, Laura Benton, Janet Rivera, Kelly Hoots, Matt Igelman, Jacorie Lyons, Mandy Weber, Martha Breitweiser, Kristen Smith, Vanessa Bright, Tiffany Diaz, and Kim Cato.

We want to also thank all who played and supported our Tournament this year. Special thanks go to title and reception sponsor **CSL Behring**, Crystal Cup sponsors **Genentech and Thermo Fisher Scientific**, Gold Cup sponsors **G.A. West, Novo Nordisk, Metromont, Jacobs, HKA Enterprises and Bayer**, as well as **Optum, McKesson Plasma and Biologics, CVS Specialty, Fuyao North America Inc., Century Contractors, Keystone Constructors, Inc., and Wolseley Industrial Group** who were Corporate Sponsors. Special appreciation to **Blue Sky Pharmacy** our beverage sponsor, and **HKA and DrugCo**, our golf cart sponsors. With our deep

appreciation to our tournament teams and their captains: **aeSolutions** - Jim Garrison, **Advanced Auto Parts** - Robert Eunice, **Appalachian Specialty Pharmacy** - Jay Worthington, **Bayer** - Fernando Andrzejewski, **Carolina Holdings Inc.** - Michael McNicholas, **Century Contractors** - Jim Kick, **CSL Behring** - Kerrie Barnes, **CVS Specialty** - Rob Williamson, **Dearybury Oil & Gas, Inc.** - Eric Dunton, **Flowserve** - Dackery Patterson, **Fuyao North America Inc.** - Joseph Chandrl, **G.A. West & Co., Inc.** - Josh Black, **Genentech** - Virginia Chandler, **HKA Enterprises** - Walt Chandler, **Industrial Supply Inc.** - Bill Newhouse, **Jacobs Engineering** - Kent Smith, **Keystone Constructors, Inc.** - David Shehan, **McKesson Plasma and Biologics** - Joseph Carrero, **Metromont** - Harry Gleich and Jason Woodard, **Novo Nordisk** - Norberto Liriano, **Optum** - Chris Barns, **Quaker Steak and Lube** - Josh Johnson and, Jennifer Harnage GM., **TaylorMade** - Matt Fouchey, **Team HT Johnson** - J.T. Johnson, **Team Krakowiak** - Dr. Joey Krakowiak, **Team Ric** - Ric Martin, **Team Ross** - Philip Ross, **Retail Business Services** - Thomas Tilert, **The Bohemian Cafe** - Kevin Lucas, **Thermo Fisher Scientific** - Maranda Weber, **Wolseley Industrial Group and Ferguson Waterworks** - Karl Horn and Keith Vandergrift. We invite all to join us in 2022 as we return to the Preserve on October 7, 2022. For additional photos and videos, please visit our [Facebook](#) and [YouTube page](#).



## Inspiring Shots: A Catalyst for Building Bonds Among Community

When the opportunity presented itself for the Chapter to engage with other chapters across the nation in a fun-filled competition, of course we had to see what it was all about. Better yet, with free golf lessons, community friendship building, and a chance to travel and meet other community members from around the nation, not to mention a possible prize donation of \$2500, it was game on! This opportunity was hosted by the [Wingmen Foundation](#) whose mission is to offer individuals, families, and groups a platform to be inspired through fitness, activities, camp, advocacy, education, and financial assistance. The Inspiring Shot program of the Wingman Foundation, sponsored by CSL Behring, offers people with bleeding disorders and caregivers 18 years and up to learn how to golf or improve their game. The 4-8-week course is for everyone from beginners to advanced with hands-on golf instruction and a great experience to connect with others. Pro Golfer Perry Parker joins the

group during one of the clinics in each area. Under the guidance of Director of Golf and PGA Paul Albert from the Preserve at Verdae in Greenville, twelve members of BDASC joined the Inspiring Shot Program for private golf lessons. For five weekends from August 7 to October 2, members learned to drive, hit, chip, and putt to a better game. On the day following the Par for the Clot Tournament a master class was given to the members by PGA and community advocate Perry Parker. Perry had five pillars for the Inspiring Shots program:

**Participation**—The first step to success is participation! You have to be in it to win it!

**Attitude**—A good attitude is essential.

**Enthusiasm**—“Nothing is as contagious as enthusiasm!”

**Teamwork**—The program promotes and encourages teamwork. We believe that we are all blood brothers and sisters and we should support each other. When we work together, we can accomplish great things.

**Have Fun**—The most important thing to remember about this program is that we all have fun. The pros at the Preserve had a very difficult time picking just two winners as the group had a blast and, as members of BDASC, they hope to get together occasionally and

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continue to play. Two participants from the clinic, Hunter Day and Joey Krakowiak, were selected to represent BDASC at an upcoming tournament planned for December in Florida where they have the chance to compete with the other regional chapters (Minnesota, New England, and Utah) and could win a \$2,500 Chapter donation. Good luck Hunter and Joey, do us proud! Members who participated included: Aaron Smith, Kristen Smith, Bryce Martin, Joey Krakowiak, Ric Martin, Hunter Day, David Rodriguez, Jeff Breitwieser, Brian Burton, Corbin Martin, Ross Philip, Matt Weber, and James Whitmire.



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## Support Groups Outreach and Community Connections

**August 9—Blood Brothers Meeting:** In an agenda-free meeting, a handful of Brothers discussed the future of the group and what they wanted to accomplish. They had discussions on speaker topics, group gatherings that would be of interest, and how often the group should or could meet. The program has been very beneficial to the men who have been meeting, and they invite others to join them. Additional information is on our website [Men's Support Group page](#). The next meeting is set for November 11 at 7 p.m.

### August 11—On the Road with Community—

**Myrtle Beach:** In a triumphant return to in-person events, about 30 COVID-compliant community members descended on Ruth's Chris Steak House to hear Takeda's *A Joint Effort: Teaming Up for Joint Protection*. The theme of the talk



was that "You're not alone in this!" and that access to a team—the patient, caregivers, and clinicians—can help you stay on top of your joint health. Members also learned how to maintain healthy joints,

help prevent joint damage, and how to treat joint issues. This was also our first hybrid event with a number of community members taking part in the talk via Zoom. It was good to see everyone and the community members were very appreciative to be together again. Thanks to Takeda for this opportunity to learn and connect!



**August 16—On the Road with Community—Summerville:** At Oscar's of Summerville, over 25 community members heard a talk about the different types of bleeds one can suffer. This was



highlighted by the ramifications of these bleeds and some of their impacts. Most importantly,

different ways of recognizing and responding to them were covered as well as other ways to stay healthy. New members attended for the first time and felt BDASC's connection to the community. We thank Takeda for partnering with us for this COVID-compliant event.



### October 12—On the Road with Community—

**Greenville:** In Greenville, over 30 socially-distanced members learned about Emotional Health and Wellbeing -Exploring the Mind-Body while dining at the CityRange Steakhouse Grill. Betsy Koval a Senior Clinical Specialist with Takeda talked about how the mind and body are connected and how taking care of your emotional health is imperative to bettering your physical and overall wellness. Her talk also explored how living with a bleeding disorder can affect one's general mental health and well-being, and how emotional health can affect someone's quality of life. During the presentation Betsy gave opportunities for self-reflection, as well as exercises to practice reducing stress and increase mindfulness. Members from the upstate traveled as far as 90 miles to attend. The event was again sponsored in partnership with Takeda.

*Continued on page 24*





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# A Cold Day at the STEP!

In the heart of autumn, on a very windy and blustery day, BDASC held their 8th Annual Walk/Run and inaugural STEP For Bleeding Disorders on November 6. With the morning chill in the air, community members, families, and friends from across the state and around the country still gathered at Saluda Shoals Park to have fun, raise money for, and spread awareness of bleeding disorders.

Being the first in-person walk in two years, the community made an amazing showing with over 186 registered runners/walkers. Officially starting at 8:30AM for registration, there was already a gaggle of members who had been setting up the day since sunrise. The day began with a Welcoming Address to all gathered explaining that the word "STEP" is an acronym of everything the Bleeding Disorder Association of South Carolina holds to its core, Sharing Stories, Transforming Tomorrows, Empowering People, and Promoting Research.

Following the opening talk, Olly Otter, Benny the Blood Drop, and M.C. Andre of Big Time Entertainment got everybody moving. Participants danced and partied down to the music and to mark the special occasion, Olly debuted his new BDASC outfit sponsored by the Chapter. Dressed to handle both the cold



weather and for the costume contest, it was a sight to behold as members paraded around for the 9:30 a.m. contest.

This year's team winners were Cole and the Clotting Factory who were dressed as Willy Wonka & the Chocolate Factory, while Thomas Krakowiak in an Animal Crossing costume took

home best individual. At 9:45 runners began gathering behind the Run Arch and CLS Behring starting tape and at ten sharp took off to see who would have the fastest time. With COVID in mind, those who were walking the track had staggered starts after the runners to keep a level of socially distant safety for the participants. The fastest runner taking home the 1st place medal for 2021 was Jason Cole (25:00), followed by Dillon Snead (28:51), and Kenny Shelton (29:55).

The Top Fundraiser Individual for 2021 was Cole Dean who raised an impressive \$2,143. Finnegan Javorka was the Runner-up with an amount of \$401.50. For teams, (pic #Team Limitless) Team Limitless raised a total of \$3,026 securing the prize for Top Fundraising Team while Cole and the Clotting Factory was the Runner-up. The team with the Most Walkers this year was a tie Team Limitless and Cole and the Clotting Factory both having 17 walkers, followed closely behind with a three-way tie for second between Team Clinton Team, Crispy Clotters and Team Logan with 15 walkers. Our Oldest Walker was Barbara Kraft at 75 years young and still looks amazing, with the wee baby Mac Martin being the youngest stroller at 5 weeks. In total \$49,668.37 or 82% of our \$60,000 goal was raised over the campaign! STEP participants also enjoyed the holiday tree and crafts, the photo booth, the balloon artistry

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of Christavan Kroy, ate pizza and munched on all the food and drink they desired. Each participant received a race medal, swag bag, and commemorative t-shirt as well. They visited our sponsor booths which provided information and services for the bleeding disorder community, their families and friends, and enjoyed catching up with fellow members while showing off their extended family, BDASC!

With Family Camp and now the Par for the Clot Tournament being held in the Fall, we'll be moving the STEP for Bleeding Disorders Walk Run to the Spring. Our first Spring Walk will be in six months on May 14, 2022, so start getting ready for it now! We would like to thank all our walkers, donors and sponsors. A special Thank You to our Ultra-Marathon Title Sponsor **CSL Behring**, as well as our Marathon Sponsor **Bayer HealthCare**, Half-Marathon Sponsors **Genentech, Novo Nordisk, Sanofi Genzyme, Octapharma, Takeda, and Drug Co.** We also want to recognize Quarter-Marathon Sponsor the **Houston Federal Credit Union** and **Accredo**, Mile Sponsor **Optum**, Pizza Sponsor **Paragon Healthcare**, Entertainment Sponsor the **Colburn-Keenan Foundation, Inc.**, as well as our

Community Donor & Partners the **Starbucks** Coffee on Harbison Blvd, in Columbia and the local branches of **Marble Slab Creamery**. Of course, we couldn't do this event without the support of our volunteers who come from all around the state to set up early in the brisk fall morning and work the event throughout the day! We owe you all a debt of gratitude: BDASC Event Manager and Executive Director, Sue Martin and her husband Ric; BDASC Communications and Development Coordinator, Greg Witul; Shelley Crisp, BDASC President; Aaron Smith, BDASC Vice President; Patricia Tucker, BDASC Treasurer; Mathew Tucker; Anna Gossett and Patricia Patterson; Wendy Legrand, BDASC Board member; Joey Krakowiak, BDASC Board Member; Eric Dunton, BDASC Board Member; James Whitmire, BDASC Board Member; Ursula Sagot, BDASC Board Member; Christine Evans, BDASC Members, Felicia Alexander; April Baird and family—Gracie, Mason, Clayton and Tammy; Ginger Snead and family—Elizabeth, Dillon and Justin; Makayla Keith; Edna Rabb; Renita Johnson; Kelly Hoots and Janet Rivera; and Stormy Johnson. We also would like to recognize the volunteer students from USC in Columbia.



The image is a promotional flyer for the STEP for Bleeding Disorders event. At the top, the title "STEP FOR BLEEDING DISORDERS" is displayed in large red letters, with "NOVEMBER 6, 2021" below it. To the right, four red letters (P, E, T, S) each have a word associated with them: P - PROMOTING RESEARCH, E - EMPOWERING PEOPLE, T - TRANSFORMING TOMORROWS, and S - SHARING STORIES. Below the main title, there are several sponsor logos and descriptions. On the left, "ULTRA MARATHON SPONSOR" is listed with "CSL Behring" and "Biotherapies for Life". In the center, "TITLE MARATHON SPONSORS" is listed with "BAYER" (in a circular logo) and "OPTUM". To the right, "HALF MARATHON SPONSORS" is listed with "SANOFI GENZYME", "Genentech" (with the note "A Member of the Roche Group"), "DrugCo", "Takeda", "novo nordisk", and "octapharma". At the bottom, "QUARTER MARATHON SPONSOR" is listed with "HFCU" (Houston Federal Credit Union) and "accredo". The background of the flyer shows a group of people participating in a walk or run.

## Voices of The Community

# Meet Our New Members: the Javorka Family!

By Samantha Javorka



Hello! We are the Javorka family and our Step for Bleeding Disorders team was Team Daphne! We've recently moved to Summerville from SW Michigan with our three children—Preston (11), Finn (9) and Daphne (7). We needed a break from the cold weather, and we are enjoying exploring all that South Carolina has to offer. The first thing we did before moving here was to find our local Bleeding Disorder Chapter. We were involved in our chapter in Michigan and knew how important the bleeding disorder community is to us. Each year, we walk in honor of our youngest child—Daphne. When Daphne was an infant, she developed odd bruises. I would bring these up at our doctor visits but was told it was normal. Just before her one-year appointment I was picking up Daphne out of her crib and left a handprint. This time, I took a picture of it to show the doctor right away. At this next

appointment she decided to run some tests. After a failed blood draw (her blood clotted before they could run the tests) and another successful blood draw, she was given the general diagnosis of Von Willebrand Disease.

A few tests and about a year later she was officially diagnosed as type 2B severe and it was determined that she has thrombocytopenia (low platelet counts) as well. A lot of people with VWD have a type that causes their body to not produce enough VWD protein—which is necessary for your blood to clot, but Daphne's body doesn't produce enough and the protein she does produce doesn't work properly. We typically say that her VWD protein is extra sticky. Her body acts as if she is always bleeding so that when she is actually bleeding there isn't enough VWD protein (factor), factor 8 and platelets to do their jobs. This causes extended bleeding. She does not bleed more, but she bleeds for longer periods of time.

When injury happens sometimes it looks like a big purple bruise and sometimes it's visual bleeding, but other times it's bleeding we do not see. What makes Daphne somewhat unusual is that she tends to have muscle bleeding. We typically don't see this bleeding by looking at her, but boy can she feel it. When she had her flu shot this year, she had a two-day muscle bleed that required ice, an infusion and relaxation! She says it feels bubbly and painful inside.

When Daphne receives medication, it's not just a pill. She receives intravenous medications. At this point we do prophylactic treatment twice a week to prevent spontaneous bleeding (as well as to get her to a more normal level in case of injury). And we treat on demand as needed (injuries, bloody noses, vaccines, surgery, etc.). She currently has a port-a-cath to help us with the infusions. When she first started treatment, she was tiny, and her veins were difficult to get (they

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had to call pediatric nurses and NICU nurses to get her veins) so we opted for the port. Her port provides us a freedom that we didn't have before. There are plenty of downsides to the port, but the good heavily outweigh the bad. We are currently in the process of learning how to use her veins to infuse—she's even learning to infuse herself! We hope that within the next two years to be ready to remove the port completely! On top of her having VWD she also has thrombocytopenia. Low platelets are typical for someone with type 2B VWD, especially if they are considered severe. A typical person has approximately 150,000–400,000 platelets at any given time. It fluctuates a lot, but typically people stay in that normal range, though it isn't unusual for a typical person to drop to the lower 100s during active bleeding, but their body will make more platelets to replenish. Most type 2B patients have levels between 75,000–100,000. This level typically doesn't require any treatment but is watched closely. Daphne has a baseline of

about 50,000 which puts her in the more severe range. Before surgery she gets platelet infusions. She has dipped well below the 50K mark on several occasions, but only during active bleeding and it does eventually go back up. We don't treat prophylactically for low platelets because there have been cases where people's bodies reject the infused platelets when given too many times. We only treat in emergency situations. Phew, that's a lot, but I hope that helps people to understand Daphne a little bit and to help understand why this cause is near and dear to us. We walk every year for hope. Hope that we will eventually see a cure. Hope that we will have better treatment options available to us. Hope that Daphne will grow up feeling confident and secure, even though she has something different about her. Hope that everyone with a bleeding disorder has access to care, education and advocacy. This is a hard road we walk every day, knowing that there is an organization out there to support us makes it a little easier.



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## Von Willebrand Community

# Women Who Bleed Conference and Awareness Campaign

Our fundamental goal in changing our name to the Bleeding Disorders Association of South Carolina is to better reflect all the different bleeding disorders patients we serve. In that spirit, we are looking at hosting a Women Who Bleed Conference and Awareness Campaign in Greenville in March of 2022 during the National Bleeding Disorders Awareness Month! Fitting for sure: raising awareness about women and girls who bleed and von Willebrand Disease. This event will be for women who are living with Von Willebrand Disease, have or are symptomatic carriers of hemophilia, and all those who are living with any of a number

of other platelet disorders and rare bleeding disorders that fall under our umbrella. We will also be trying to reach the undiagnosed or misdiagnosed women throughout the state that are living with a bleeding disorder and don't even know it!

Some of what we need from you for this event is, what do you struggle with most? How can we better reach the undiagnosed women living with VWD? What would you like to learn more about? How can we reach out to the general community? Let us know what you think at [info@hemophiliasc.org](mailto:info@hemophiliasc.org) and stay tuned as we explore this possibility for our women and girls.

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## Have You Heard?

# Prisma Health expands Hemophilia Treatment Center to Greenville

**Prisma Health Media Relations**

**Wednesday, August 25, 2021**

Prisma Health has expanded its Hemophilia Treatment Center to include an office in Greenville as well as Columbia. Prisma Health has South Carolina's only federally supported comprehensive hemophilia treatment center, serving a growing number of both children and adults across the state.

"Our mission is to provide access of care to all residents of South Carolina with hemophilia or other types of bleeding disorders," said Leslie Gilbert, MD, director of the new location in the Upstate. "It is important that we educate the community about hemophilia and other bleeding disorders because they are so rare, and the lack of awareness can be detrimental to an individual's health by leading to delayed

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### **October 14—On the Road with Community—**

**Columbia:** At the Blue Marlin in Columbia, members of the BDASC learned about pharmacokinetics and bleeding disorders from Bayer speaker Linda Peacock. Pharmacokinetics (PK) is the study of the bodily absorption, distribution, metabolism, and elimination of drugs. The importance of PK testing was highlighted as it allows your doctor to understand your unique PK profile and create a treatment plan that matches your needs. The subject matter sparked many conversations among attendees and was well received. This Chapter community partnership event was sponsored by Bayer.



or missed diagnoses," said Gilbert, a pediatric hematologist oncologist at Prisma Health in the Upstate.

"Though bleeding disorders can be inherited, patients with bleeding disorders do not always have a family history of bleeding," she cautioned. "It is important that even people without a family history of a bleeding disorder, immediately notify their doctor if they are suddenly experiencing prolonged bleeding from minor cuts, easy bruising or spontaneous joint pain and swelling as those can be signs of a bleeding disorder."

While hemophilia most often occurs in males, it can affect women, too. Hemophilia is usually detected soon after birth whereas other bleeding disorders may remain undiagnosed until later in childhood or adolescence.

Treatment is available that allows affected individuals to lead relatively normal lives. The most common form of treatment—clotting-factor replacement therapy—is given intravenously and can be completed at home two to three times a week. As a result of recent advancements in treatment, some patients with hemophilia can give a subcutaneous shot once a week, but this is not available to all patients with hemophilia.

Two-to-three comprehensive clinics are offered each month. Comprehensive clinics use an integrated, team-based approach to improve health and quality of life. During comprehensive clinics, patients meet with a hematologist, nurse coordinator, pharmacist, physical therapist, psychologist, program associate and social worker.

"Our patients play a role in impacting the future of hemophilia through participation in the broader hemophilia research and advocacy

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community," said Gilbert. "Federally supported Hemophilia Treatment Centers work closely with the Centers for Disease Control and Prevention, which collects data to monitor the health of people with hemophilia and uses data to advance knowledge and health practices for hemophilia and other related disorders." Gilbert said collaboration across Prisma Health was key to developing the full accredited

program in Greenville, which helps bring leading-edge research and treatment closer to families in the Upstate.

The Hemophilia Treatment Center also has close partnerships with and access to resources from educational and advocacy community organizations, such as the [Bleeding Disorders Association of South Carolina \(BDASC\)](#). For more information, visit Hemophilia Treatment Center in Greenville or in the Midlands, visit Hemophilia Treatment Center.



Dr. Stephanie Ambrose



Dr. Leslie Gilbert

## Winter Year-End Meeting Postponed to 2022

It is with deep sadness we will be postponing our Annual Holiday Winter meeting this year. Because of the ongoing COVID-19 pandemic, funding, large group activity in closed space, and supply chain issues, and for the safety of our members, we felt this was the best decision to make at this time. We will return to

Cooperative Conference Center in Columbia on December 10, 2022. In the meantime, we will be looking at what we can provide to celebrate the holidays with the community virtually. Be sure to stay tuned to our social media, website, and eblasts for any tentative Virtual Holiday events.

## Marketplace is Opening!

The 2022 Health Insurance Marketplace is already open for enrollment! Started on November 1, 2021, you can purchase new insurance plans from now until Saturday, January 15, 2022, but you need to enroll by December 15, 2021, for coverage that starts January 1, 2022. Living with a rare disease or a bleeding disorder can make shopping for

insurance exceedingly difficult. That is why we are partnering with Takeda for an Insurance Educational Event in Columbia on November 30. Insurance is not the most exciting subject, but it is one of the most important! Check our social media and website as details become available and we hope to see you there.

## Advocacy Action

### 2021 Year in Advocacy

#### By Jeremy Williams

The Bleeding Disorders Association of South Carolina (BDASC) has been a proud recipient of the National Hemophilia Foundation's (NHF) State-Based Advocacy Coalition (SBAC) partnership grant for the last six years. In that capacity, we strive to meet the highest standards of advocacy expectations, mainly through the work of our South Carolina Hemophilia and Bleeding Disorders Advocacy Coalition (SCHBDAC), including our Ambassador Program, which is the grass-roots component of the Coalition. Despite the persistence of the COVID-19 pandemic, we managed to achieve all of the goals laid out in our 2021 Strategic Plan year. We have had to employ new tactics (e.g., the use of virtual conferencing platforms like Zoom to engage state lawmakers) to further the important advocacy work we do in our state. Below is a brief summary of the activities of SCHBDAC members and BDASC staff throughout 2021.

**Monthly Coalition Calls:** On the third Thursday of every month, Advocacy Coalition members, Ambassadors, and stakeholders, met for a regular call on ongoing BDASC advocacy and policy initiatives.

**Ambassadors 2021 Legislative Briefing:** On January 26, the Ambassadors and Advocacy Coalition members held their first training of the year. It was virtual and featured a national update by *Nathan Shaefer*, Vice President of Public Policy at the National Hemophilia Foundation, and *Kimberly Ramseur*, Senior Manager of Policy and Advocacy at the Hemophilia Federation of America. The group also heard from stakeholder *Alison Clifford*, Director of Therapeutic Advocacy and Policy with Takeda, as well as from several members (*Shelley Crisp*, *Renita Johnson*, *Jameelah Malcolm*, *Susie Maloy*, and *Renita Johnson*) directly about their advocacy experiences. The program focused on the logistics of virtual meetings; NHF's new Phone2Action campaign; the proclamations request process; and the Red Tie Campaign. The remainder of the program drilled down on BDASC's 2021 legislative agenda, which included pushing for continued funding of the state Hemophilia Assistance Plan; a bill to create a Rare Disease Advisory Council in the state; and efforts to combat accumulator adjustor

programs. This portion of the program featured insights from *Fernando Andrzejewski*, Executive Director of the West Virginia hemophilia chapter, about their successes in getting an RDAC passed in the state.

**Advocacy Days Trainings:** On February 16, Ambassadors and Coalition members held another training to focus on "How to talk to your state legislator." *Tony Mitchell*, Senior Manager of State Government Affairs (Southeast) with CSL Behring, offered some advice on communicating your message to lawmakers in a concise and impactful way. A final Advocacy Days training was conducted on the evening of March 8, to ensure all members were prepared for legislative meetings. The program included an overview of the schedule and individual assignments; a discussion of Zoom logistics and virtual meeting etiquette; and BDASC's 2021 policy and advocacy legislative priorities.

#### National Hemophilia Foundation's Washington

**Days:** During the week of March 1-5, several BDASC members (*Renita Johnson* and *Susie Maloy*) and staff (*Sue Martin*, *Jeremy Williams*, and *Greg Witul*) participated in the National Hemophilia Foundation's (NHF) annual Washington Days. There were several trainings leading up to the meeting, where NHF staff prepared the group regarding schedule, etiquette, and policy talking points. During the week, the South Carolina delegation met with staff from the offices of: *Representative Jeff Duncan*, *Representatives Nancy Mace*, *Representative Ralph Norman*, *Representatives William Timmons*, *Senator Lindsey Graham*, and *Senator Tim Scott*. The group asked for continued funding for federal organizations vital to bleeding disorders research and education, namely the Health Resources and Services Administration; the Centers for Disease Control and Prevention; and the National Institutes of Health. They also asked for members of Congress to sign a letter to *President Joe Biden* to roll back rules that make it possible for health insurance companies to implement "accumulator adjustment" programs, which disallow counting co-pay assistance cards toward deductibles and out-of-pocket maximums. The hope was that executive action would eliminate

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the need for legislation to address these policies that stand in the way of people with chronic health conditions like hemophilia from accessing their medications. The collective advocacy efforts generated 33 additional members of Congress to sign on to the Biden letter.

**BDASC Advocacy Days:** During the week of March 9, BDASC began holding virtual meetings with members and their state elected officials. When possible, Zoom meetings were conducted, with some phone calls with legislators. Members asked lawmakers to support policies and programs important to people with bleeding disorders living in South Carolina, like the state Hemophilia Assistance Plan. They also urged passage of H3956, which would create a Rare Disease Advisory Council in the state. They talked to legislators about the rise in accumulator adjuster plans in private health insurance policies, which do not count co-pay assistance towards deductibles and out-of-pocket maximums—these are particularly detrimental to people who have expensive medications and are faced with exorbitant deductibles and who are often blindsided by such plans. In total, BDASC facilitated 22 legislative meetings with over 30 advocates and their families.

**Rare Disease Advisory Council Bill:** On March 23, Sue Martin, Executive Director of BDASC, along with representatives from the National Organization for Rare Diseases, gave testimony to the Health and Environmental Affairs Subcommittee of the House Medical, Military, Public and Municipal Affairs (3M) Committee, on H3956 to create a Rare Disease Advisory Council (RDAC) in the state. After the testimony, the Subcommittee voted favorably to pass the bill. The next week, the 3M Committee passed the bill to the full House, which approved it on April 22. (Since this date was after “crossover day,” the Senate will not be able to take it up until the 2022 regular session. The measure has been assigned to the Senate Medical Affairs Committee.) Throughout this process, BDASC utilized the Phone2Action platform, which was provided by the National Hemophilia Foundation. This program allows targeted email campaigns that send individualized messages to elected officials. BDASC also used it to urge approval of seed money in a proviso signed by Governor Henry McMaster for one year of funding for an RDAC at the Medical University of South Carolina.

**Proclamations:** Despite challenges related to the COVID pandemic, this year our members still managed to pass at least eight county and municipal proclamations recognizing March as “Bleeding Disorders Awareness Month.” These included Anderson, Greenville, and Richland Counties, as well as the cities of Greenville, Greenwood, Greer, and Irmo. It also included a statewide resolution issued by the governor’s office. We also lit the City of Greenville, Liberty Bridge, red and held a kick off awareness luncheon during the month of March in commemoration of the national awareness month.

**Annual Meeting and June Training:** In June, at its Annual Meeting, BDASC recognized state Representative Adam Morgan as the 2021 Legislative Advocate of the Year; Jameelah Malcolm as Advocate of the Year; and Susie Maloy as Ambassador of the Year. Also, at the meeting, on June 19, Advocacy Coalition members and Ambassadors held a virtual training to go over 2021 legislative accomplishments; the status of the Rare Disease Advisory Council bill and current organization efforts (per the 2021 proviso); and an update on national healthcare policy trends. Speakers included Nathan Shaefer, Vice President of Public Policy at NHF; Annissa Reed, Regional State Policy Manager (East Coast); the National Organization for Rare Diseases; and BDASC staff: Sue Martin, Jeremy Williams, and Greg Witul.

**September Training:** At BDASC’s annual “Keeping It Coastal” Educational Family Camp, Coalition members and Ambassadors held an in-person (with virtual option) training to discuss 2022 advocacy and policy goals. The training kicked off with a federal update and overview of the importance of advocacy and what other states are working on by Nathan Shaefer, Vice President of Public Policy at NHF. Jeremy Williams, Advocacy and Policy Consultant at BDASC, gave an overview of the 2021 legislative accomplishments. The program concluded with inspiring talks by several members (current Advocacy Coalition President Cristal Day, April Baird, Christine Evans, Ward Keith, Susie Maloy, and Ursula Sagot) on the many challenges they have overcome in advocating for themselves and their families. During the meeting, 12 new Ambassadors and two new Junior Ambassadors (under 18 years of age) signed up for the program. Currently, the Advocacy Coali-

*Continued on page 29*

## National News

### **Our African American Voices at the State of the Science National Hemophilia Federation Conference September 12-16**

The National Hemophilia Federation held their State of the Science Research Summit virtually on September 12-15, 2021. This community-driven dialogue aimed to come up with actionable research priorities that can create real and lasting impact for people with inherited bleeding disorders. The Summit brought together multi-disciplinary experts from a wide range of fields that shape bleeding disorders research, clinical care, and patient support, as well as patients, caregivers, and allied community members, for discussions on critical themes for research. The sessions featured testimonials on pressing unmet needs in care, plenary presentations summarizing research opportunities and panel discussions, during which the greater community had participated.

For BDASC's part, Executive Director Sue Martin was one of several members of the national community who participated in the research project as a Subject Matter Expert (SME) and offered to host the African-American voice for a remote viewing of the Summit. A small gathering of 12 community members met at the Spring Hill Suites Marriott/The Vista in downtown Columbia on Sunday, the opening day of the SOS, with our moderator Dr. Paullette Bryant, National Hemophilia Federation Board Member and Hemophilia Treatment Center Medical Director in North Carolina. The speaker in the first session the group participated in was one Professor Emeritus Norman Fost from the University of Wisconsin School of Medicine and Public Health, who addressed common misconceptions about ethical issues in research on bleeding disorders, including the distinction between legally and morally valid consent; equal access to novel therapies; the use of democratic principles in developing policy; and efficiency vs fairness in allocating scarce resources. The second part was by Annette Von Drygalski, MD, PharmD, RMSK Professor of Clinical Medicine and Director of the Hemophilia and Thrombosis Treatment Center, University of California, San Diego and "Bobby" Duc Tran, MD, MSc Assistant Professor, Emory University School of Medicine, who talked about how the current research priorities for Hemophilia A and B were derived.

After a quick lunch break provided by the Chapter, our group submitted a number of precise questions

that were relayed by Dr. Bryant to the committee. The key outcomes from all the groups across the nation will be organized into a National Research Blueprint, which will define specific research priorities and opportunities for community collaboration and how to achieve their desired impact. The Blueprint is still being worked on and a final publication date has yet to be determined.



### **NHF's COVID-19 Vaccines and Bleeding Disorders: Frequently Asked Questions (FAQs)**

(This is a condensed version of an NHF article first published on August 24, 2021, with some questions removed for space. To read the article in its entirety, please visit: [tinyurl.com/NHFCOVID](https://tinyurl.com/NHFCOVID))

NHF recognizes that people with bleeding disorders may have questions and concerns related to the variant coronavirus' causing COVID-19 and the new COVID-19 vaccines, including any implications specific to their conditions. The following FAQs are therefore meant to address some of the most common questions from our community members. Please note that these answers were created for broad purposes and that affected individuals should engage closely with their healthcare provider to discuss the possibilities of disease signs and symptoms and vaccination, including potential contraindications (if any), and specific questions related to safety and efficacy. Given the nature of this virus, rapid developments in vaccines, and the ongoing transitions in our federal government, this continues to be a very fluid situation. If you have additional questions or need more information, please consult with your healthcare professional.

#### **Preparing for your COVID-19 vaccine**

To learn more about vaccines including those to prevent COVID-19, you may want to visit [www.vaccines.gov](https://www.vaccines.gov) for more information and to receive email updates on the vaccines. This website is available in

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Spanish and has a vaccine finder to help you locate sites in your state or territory.

Before receiving a COVID-19 vaccine, you may be asked questions about your history of bleeding and your bleeding disorder. Below are some of the questions you may be asked, and an explanation as to why the people administering the vaccine might ask them. These questions should not deter anyone from receiving a vaccine. If you have a question about your specific situation, be sure to discuss it with your hematologist.

### **SCREENING QUESTIONS**

#### ***Do you have a bleeding disorder or have any issues with bleeding?***

A bleeding disorder neither increases the risk for getting coronavirus infection nor having a serious infection, being hospitalized, or dying if you are infected. Likewise, having a bleeding disorder is not a reason to avoid getting the vaccine. Following precautions such as infusing with a factor replacement product prior to or right after the vaccination and applying pressure for 10 minutes after the vaccination should be considered. Contact your hematologist or healthcare professional to plan to safely receive the vaccine. Patients receiving emicizumab may be vaccinated by intra-muscular injection at any time without receiving an additional dose of FVIII. Patients with von Willebrand disease or a rare bleeding disorders should consult with their hematologist regarding special precautions prior to receiving the vaccination. All rare bleeding disorder patients (including those with thrombocytopenia and/or platelet function disorders) should be vaccinated. Patients on warfarin should have prothrombin time testing performed within 72 hours prior to

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tion has representation in all seven South Carolina Congressional districts and 18 counties in the state.

**Outlook for Remainder of 2021:** For the remainder of 2021, BDASC plans to finalize its 2022 legislative agenda and advocacy priority goals for 2022 with a year-end Stakeholders Forum to be held virtually on November 13. Some of the priorities will include (but may not be limited to) the final push for passage of H3956 through the state Senate, and approval by the governor, to create a permanent RDAC in the state of South Carolina. We also plan to pursue legislation to address issues pertaining to accumulator adjusters in health insurance plans offered in

injection to determine international normalized ratio (INR); if results are stable and within the therapeutic range, they can be vaccinated intramuscularly.

#### ***Have you or are you currently receiving any monoclonal antibody treatments?***

You may be asked this question before you receive the vaccine. Receiving emicizumab is not a reason not to receive a vaccine to prevent COVID-19 infection. Emicizumab is a monoclonal antibody that is used to prevent bleeding in people with hemophilia A. Other monoclonal antibodies have been and are being developed as treatments for COVID-19 infections. You can and should receive a vaccine even if you are taking emicizumab to prevent bleeding.

#### ***Are you taking any medications with one of the following ingredients.....one of those ingredients being a PEG?***

Polyethylene glycol (PEG) is a stabilizer that is used in many medications including plasma derived and recombinant factor products. Factor products that use PEG to extend the half-life of the factor product or any factor products are not a reason to not take a vaccine unless you have had a reaction to PEG. If you have a question about this please talk with your hematologist or healthcare professional.

### **FREQUENTLY ASKED QUESTIONS**

#### ***These vaccines were developed very fast. Are they safe?***

It is true that the Pfizer/BioNTech, Moderna and Janssen Biotech vaccines have been developed very quickly. But the technology behind the Pfizer/BioNTech and Moderna vaccines is not new. They both are what are called mRNA vaccines, which function very differently than the types of vaccines used in the past. mRNA vaccines, rather than

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our state. BDASC will continue to work to improve access to treatment for people with bleeding disorders, including support of the Hemophilia Treatment Centers at Prisma Health, as well clinics and satellite offices at the Medical University of South Carolina and other locations throughout the state. We also will continue to ask for support for the Hemophilia Assistance Program operated by the Division of Children and Youth with Special Health Care Needs within the South Carolina Department of Health and Environmental Control. We wish to thank all our Coalition members and Ambassador and our Advocacy Sponsor which all can be viewed on our [Advocacy Coalition](#) Page.

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using a weak or ineffective sample of the virus to trigger antibodies—like in a flu shot—mRNA vaccines instruct your cells to create a harmless protein (called “spike” protein) that your body recognizes as foreign, creating an immune system response. Scientific papers describing this mRNA technology, discovered by Hungarian scientist Katalin Karikó (who oversees mRNA work for BioNTech) were first published in 2005. The Janssen Biotech vaccine uses a different mechanism of action, a recombinant, replication-incompetent human adenovirus serotype 26 (Ad26) vector, encoding the SARS-CoV-2 viral spike (S) glycoprotein. All three vaccines are designed to tell your body how to make the Spike protein, part of the SARS-CoV-2 virus.

### **Is it safe for a person with a bleeding disorder to receive the COVID vaccine?**

If you have a bleeding disorder, there are no contraindications to being vaccinated with any of the three vaccines now available via EUA status for intramuscular administration. It should be noted that, immune tolerance therapy, treatment for hepatitis C, and HIV and other conditions including the use of immunosuppressive agents do not preclude a person from receiving the available vaccines. For patients in a clinical study, vaccination should be reported to the study investigators.

### **Is it safe for people with low platelets or ITP, or platelet function disorders to receive the COVID vaccine?**

For those with pre-existing ITP (even if you don't take medicine for your ITP and even if your platelet count is normal), consult your hematologist and obtain a platelet count prior to vaccination. Your hematologist may advise you as to whether and when your platelet count should be checked after the first and/or second vaccination in addition to the baseline value. Patients with low platelet disorders like ITP should take extra precautions when receiving the vaccine to prevent hematoma formation. A fine gauge needle (25 or 27 gauge) should be used for the vaccination, followed by pressure on the site, without rubbing, for at 10 minutes.

For persons with other low platelet disorders or platelet function disorders (like Glanzmann thrombasthenia, Hermansky Pudlak syndrome, Grey Platelet syndrome), the recommendations for preparing for the vaccine may be similar or identical as those for persons with ITP. Persons with other platelet disorders should also consult with their hematologist

prior to receiving the COVID-19 vaccine.

For persons with platelet disorders caused by medications (such as aspirin, clopidogrel, ticagrelor), follow the recommendations for persons with platelet function disorders (above). Always consult your hematologist or cardiologist for advice on how best to prepare for the COVID-19 vaccine.

**Patients with ITP or other low platelet disorders should not hesitate to be vaccinated based on available information. Patients that are unsure about getting the vaccine should consult with their hematologist or another physician before proceeding.**

### **Will I have a bleed if I receive the vaccination?**

The vaccination is administered intra-muscularly but the smallest gauge needle should be used (25-27 gauge), if possible. Some vaccines must be administered using the accompanying needle-syringe combination, and so the use of an alternative needle may not be possible or desirable.

It would be preferable for you to infuse with a factor replacement product prior to or right after the vaccination and applying pressure for 10 minutes after the vaccination. Patients receiving emicizumab may be vaccinated by intra-muscular injection at any time without receiving an additional dose of FVIII. Patients with von Willebrand disease or a rare bleeding disorder should consult with their hematologist regarding special precautions prior to receiving the vaccination. All rare bleeding disorder patients (including those with thrombocytopenia and/or platelet function disorders) should be vaccinated. Patients on warfarin should have prothrombin time testing performed within 72 hours prior to injection to determine international normalized ratio (INR); if results are stable and within the therapeutic range, they can be vaccinated intramuscularly. Patients receiving other anticoagulants, such as enoxaparin, apixaban, dabigatran, rivaroxaban should consult their prescribing doctor or practitioner for advice on how to safely prepare for the COVID-19 vaccine. Following the vaccination, the area should be monitored for hematoma formation immediately for 10 minutes to reduce bleeding and swelling and by self-inspection 2-4 hours later at home to ensure that there is no delayed hematoma. Discomfort at the injection site is to be expected. Discomfort in the arm felt for 1-2 days after injection should not be alarming unless it worsens and is accompanied by swelling. Any adverse events should be reported to the physician and any aller-

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gic reactions need to be reported immediately to your physician or you need to go to the emergency room. To read more about vaccinations in general see NHF's Medical and Scientific Advisory Council's recommendation, Recommendations on Administration of Vaccines to Individuals with Bleeding Disorders, available here: [tinyurl.com/MASAC221](https://tinyurl.com/MASAC221)

### **Will the vaccines change my DNA?**

mRNA vaccines do not interact with a person's DNA or cause genetic changes because the mRNA does not enter the nucleus of the cell, which is where our DNA is kept. The Janssen Biotech COVID-19 Vaccine is a viral vector vaccine, meaning it uses a modified version of a different virus (the vector) to deliver important instructions to our cells. Viral vector technology has been used by Janssen for other vaccine development programs. Vaccines that use the same viral vector have been given to pregnant people in all trimesters of pregnancy, including in a large-scale Ebola vaccination trial. No adverse pregnancy-related outcomes, including adverse outcomes that affected the infant, were associated with vaccination in these trials.

### **Are the vaccines effective against the new variants of COVID-19?**

All three vaccines currently having EUA in the US target the Spike protein and are designed to produce an immune response against the Spike protein in the SARS-CoV-2 virus. As the virus mutates or changes, these changes may be in the Spike protein causing the vaccines to be less effective against these mutated strains of the virus. A recent study from the New York Blood Center published in Science Magazine examined the efficacy of the Pfizer, Janssen Biotech and Moderna vaccines to combat variants of the virus. The data suggest that the three vaccines are probably effective against COVID-19 variants, however, the efficacy of the vaccines will need to be reexamined as new strains emerge.

### **NHF Conference Review**

From August 25 to 28 the National Hemophilia Foundation virtually held their 73rd Annual Bleeding Disorders Conference.

Highlights included *Gene Therapy: Where Do We Go From Here?* by Dr. Tami Chrisentery-Singleton the Chief of Pediatric Hematology, and Director of the Hemophilia Treatment Center at the Mississippi Center for Advanced Medicine and the Louisiana Center for Advanced Medicine. The session covered how the pace of innovation is not slowing down and

how it seems like we are "tapping the brakes" on gene therapy. This session helped demystify what we are hearing about the latest results of clinical trials around durability, efficacy, safety and what the future holds for the treatment of hemophilia.

In *Public Health: Aging* The speakers discussed a range of topics including new international guidelines for the diagnosis and management of hereditary hemorrhagic telangiectasia (HHT), mental and emotional health challenges in aging thalassemia patients, aging with a bleeding disorder, basics of Medicare, and skilled nursing facilities.

Finally, the Teen Impact Awards were a proud moment for all the members of the BDASC as Awards were given to members Marques Johnson for Arts and Athletics, Logan Cobb for Service and Volunteering, Elizabeth Snead for Service and Volunteering, Makayla Keith for Advocacy, and Miranda Salas, who even made an appearance during the opening ceremony, for Volunteer and Service! Coagulations to all our teens!

Everything is all set for next summer's Conference which will be held August 25-27, 2022 in Houston, TX.



### **HFA 2021 Symposium Highlights**

With a desire to keep the community safe from COVID and opening the event to as many people as possible the Hemophilia Federation of America kept their 2021 Symposium a virtual event during the weeks of October 18 to 28.

The keynote speaker for this year's symposium was Zander Masser, the son of professional photographer Randy Jay Masser. In his presentation Zander explains how his father, born with hemophilia in the late 1940s, contracted AIDS in the heart of the Bad Blood era. A photographer for the Alvin Ailey

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Dance Company between 1975–1979, Randy captured timeless photos of dance legends such as Judith Jamison and Mikhail Baryshnikov, as well as artfully capturing every-day scenes of life. Following his father's death in 2000, Zander rediscovered old slides which prompted him to dig deeper into his father's story, as well as face his own experience of living through loss. The product of that effort is the book *Unburying My Father*, which he is hoping will serve as a tool for preserving and honoring the memory of the thousands of victims of the tainted blood tragedy.

On the lighter side, a fun highlight for kids was the launch of BelieveLimited's Stop The Bleeding!—Season 11: The *Clotting Cascade Adventure*. In the vein of *Teen Titans Go!* and *Star Trek: Lower Decks* the *Clotting Cascade Adventure* is a five-episode, animated adventure series that follows the journey of a new Factor Eight and Factor Nine protein, as they graduate factor training from Liver Academy and head out into the bloodstream. There they encoun-

ter a major bleed and work together as part of the coagulation cascade to form a clot! The humor is fun for the whole family.

Other highpoints included the annual Celebration of Life, the session *Women with Hemophilia, Insurance Barriers to Care*, and the Awards Ceremony. In a nice addition, many of the sessions this year were presented in both English and Spanish.

In the poster section, Caylynn Carls MS, CGC presented *Genetic Counselors Within U.S. Hemophilia Treatment Centers* while Claudio Sandoval, MD showed *Therapeutic Options During Intranasal DDAVP Recall*. Both presentations will be on the symposium website for the time being, and many of the other sessions are available on YouTube.

While Symposium 2021 is in the books, planning is already underway for 2022 with San Antonio as the destination for what is shaping up to be the biggest and best Symposium yet. Mark your calendars for April 20–23, 2022.

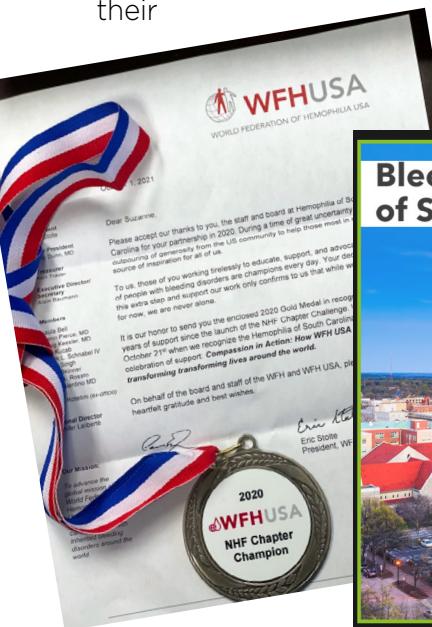


## World News

### BDASC recognized for WFH's Compassion to Action Campaign

In June of 2021 the World Federation of Hemophilia launched the Compassion to Action campaign to ensure the community's needs are being met, both in terms of dealing with the pandemic and in terms of continuing to work towards long-term sustainability. Many have risen to the challenge to show solidarity, including the Bleeding Disorder Association of South

Carolina. For supporting CompWorldtion campaign and the BDASC's previous five years of support of NHF's Chapter Challenge, we were recognized as the 2020 WFHUSA National Chapter Champion with a Gold Medal. The Chapter was recognized at the "Compassion to Action: How WFH USA Supporters Are Transforming Lives Around the World" on October 21 for this achievement at a special ceremony. We are proud to support the work of the WFH and will continue to support treatment access around the world.



**Bleeding Disorders Association of South Carolina**

**BDASC**

**Gold Medalist Five-Time Chapter Champion**

Cesar Garrido	Gregory Witul
Gregory Le Cleir	Joe Pugliese
Jennifer Laliberte	Roddy
Bob Robinson	chavez edg... chavez edgecombe
Eric Strode	Tahira Zafar
Suzanne Martin	Jessica Jaschek

## Research & Development

### Vector Biology and Hemophilia Gene Therapy the Focus of Review

A new review article, “The Intersection of Vector Biology, Gene Therapy, and Hemophilia,” was published recently in the journal *Research Practice in Thrombosis & Haemostasis* (RPTH). It provides a comprehensive overview of the scientific underpinnings of several hemophilia gene therapy platforms, with particular focus on the delivery of genetic payloads at the heart of these technologies.

This review covers both the setbacks and breakthroughs of preclinical and clinical hemophilia A and B gene therapy research that characterize the mass effort to reach a functional cure for hemophilia. The authors examine the unique biology of viral vectors, including aspects of their inherent design that make them especially effective at transduction, the process by which genetic material (transgene) is introduced into a cell by a virus or viral vector. Over recent decades, researchers have leveraged viral vectors’ evolutionary biology and adeptness at transduction to develop and hone investigational gene therapies for hemophilia and other chronic conditions.

The authors describe two primary vector-types at the heart of these advances, including repurposed retroviruses known as lentiviral vectors, and to a greater extent, adeno-associated viruses (AAVs). Engineered recombinant AAVs (rAAVs) have been designed to deliver the genetic messaging that prompt the production of the factor VIII or factor IX in people with hemophilia A and B, respectively. Ideally, rAAVs deliver this genetic material into living cells to achieve a therapeutic effect that is free of unintended adverse reactions in the short and long term.

“rAAV vectors have emerged as the preferred tools for *in vivo* gene therapy due to their relative safety and ability to transduce a variety of tissue cell types,” explain the authors. Liver cells are a particular target for hemophilia gene therapy for their ability to facilitate production factor proteins such as FVIII and FIX.

While rAAVs remain at the forefront of hemophilia gene therapy, their utilization is not without challenges, including the potential for innate and adaptive immune responses to not only the transgene it-

self but to the capsid—the protein shell of the rAAV. Such immune responses, like the existence of naturally occurring pre-existing neutralizing antibodies (NAbs), could have safety and efficacy implications, inflammatory effects on the liver being one example. The authors explain the various strategies being investigated and considered to mitigate the possible impacts of NAbs, including procedures designed to remove the circulating antibodies in a patient prior to administration of a gene therapy, and the employment of diagnostic tests to prescreen for these antibodies.

The review also emphasizes concerns over integration of rAAVs into the genome of patients who have received the therapy, such events could have negative safety implications such as the alteration of cell functionality and subsequent development of tumors or malignancies. While random rAAV integration into a host’s genome is a rare occurrence, the risks warrant further investigation and proven mitigation strategies, as even proportionally low rates of integration could have harmful, unintended consequences.

In sum, the authors envision a path forward for hemophilia gene therapy, albeit with challenges left to overcome.

“Gene therapy represents a potential functional cure for patients with hemophilia and has the goal of providing safe, durable, and effective factor expression. *In vivo* investigational rAAV gene therapy has been demonstrated to ameliorate the bleeding phenotype in adults, but long-term safety and effectiveness remain to be established,” conclude the authors. “Current research seeks to improve vector and other gene therapy attributes to achieve treatment success with simpler and more cost-effective protocols and to expand access to patients not currently candidates due to comorbidities, medical history, age, or other factors.”

The paper, which was published online in RPTH on September 1, 2021, is open access. Follow this link to read the full review: [tinyurl.com/BDASCVB1](https://tinyurl.com/BDASCVB1)

Lisowski L, Staber JM, Wright JF, Valentino LA. *The intersection of vector biology, gene therapy, and hemophilia. Res Pract Thromb Haemost. 2021 Sep 1;5(6):e12586. doi: 10.1002/rth2.12586. PMID: 34485808; PMCID: PMC8410952.*

## 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 [@schemophelia@prismahealth.org](mailto:@schemophelia@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 McClellan 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**  
 439 Congaree Road, Suite #5  
 Greenville, SC 29607  
 Phone: 1-864-350-9941  
 Fax: 864-244-8287  
 Email: [info@hemophiliasc.org](mailto:info@hemophiliasc.org)  
 Web site: [www.hemophiliasc.org](http://www.hemophiliasc.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](mailto: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](mailto:info@hemophiliafed.org)  
 Website: [www.hemophiliafed.org](http://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](mailto:wfh@wfh.org)  
 Website: [www.wfh.org](http://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](http://www.aspho.org)

### The Coalition for Hemophilia B, Inc.

Phone: 212-520-8272  
 E-Mail: [hemob@ix.netcom.com](mailto:hemob@ix.netcom.com)  
 Website: [www.hemob.org](http://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](http://www.cdc.gov)

**Committee of Ten Thousand (COTT)**  
 Phone: 800-488-2688  
 Website: [www.cott1.org](http://www.cott1.org)

**LA Kelley Communications, Inc.**  
 Phone: 978-352-7657  
 Website: [www.kelleycom.com](http://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](http://www.patientnotificationsystem.org)

### 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](http://www.medicalert.org)

**South Carolina Healthcare Market Place**  
 Call 800-318-2596  
 Website: [www.HealthCare.gov](http://www.HealthCare.gov)

## Upcoming BDASC Community Events



# Mark Your Calendar!

**November 11**—Blood Brothers Meeting

**November 13**—Advocacy Coalition Stakeholder Meeting

**November 18**—Advocacy Coalition Call

**November 29**—Virtual Community Connections—Advocacy and Insurance

**November 30**—Insurance Educational Dinner Event

**December 9**—Holiday Adults and Couples Night Out

**December 11**—Holiday Winter State Meeting in Columbia (*Canceled due to COVID*)

**December 11**—Possible Virtual Holiday Event TBD

### 2022 Major Event Dates

**March 1 & 2**—NHF Washington Days

**March 8 & 9**—BDASC State Days

**March 25**—(Potential) VWD/Women's Retreat

**April 20-23**—HFA Symposium

**May 14**—STEP for Bleeding Disorders Walk Run

**June 10 & 11**—HELLO

**August 11-14**—Teen Camp

**August 24-28**—NHF Bleeding Disorders Conference

**September 23-25**—“Keeping It Coastal” Educational Family Camp

**October 7**—Par for the Clot

**November 12**—Advocacy Coalition Stakeholder Meeting

**December 10**—Winter State Meeting



### Additional ways to help BDASC



Go to [www.hemophiliasc.org](http://www.hemophiliasc.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](http://www.charity.ebay.com)



Bleeding Disorder Association  
of South Carolina  
439 Congaree Road, Suite #5  
Greenville, SC 29607  
[www.hemophiliasc.org](http://www.hemophiliasc.org)



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