

# The News Infusion

The Official Newsletter of Bleeding Disorders Association of South Carolina

VOLUME 11, ISSUE 3

SUMMER 2022

*Summer Camp—a place for teens and kids*



## FEATURED ARTICLES

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**Special Times at Camp Canaan, page 14**

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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.

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

## Fall 2022 Calendar of Events

### Looking Ahead: Save the Dates!

#### Community Engagements

August 20 – October 8: Inspiring Shots, Greenville, SC  
September 17 – YES Support Group Event, Greenville, SC  
October 7 – Par for the Clot Charity Golf Tournament, Greenville, SC  
October 21-23 – Health Equity Advocacy Family Camp, Charleston, SC  
November 3 – Community Dinner Engagement, Columbia, SC  
December 10 – Winter Statewide Meeting, Columbia, SC

## BDASC 2022 Staff & Board of Directors

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Samantha Javorka

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Joey Krakowiak

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Susie Maloy

Samantha Javorka

Taylor Upton

Edan Rabb

Sue Martin, Ex-Officio Board Member

Bleeding Disorders Association  
of South Carolina  
Green Gate Office Park  
25 Woods Lake Road, Ste 300  
Greenville, SC 29607  
Office: 864.236.8663  
Fax: 864.236.8663  
Mobile: 864.350.9941



[info@bda-sc.org](mailto:info@bda-sc.org)

[www.bda-sc.org](http://www.bda-sc.org)



### Editor-in-Chief

Sue Martin

### Publisher

Linda Hastie

### Contributing Writers

Sue Martin

Samantha Javorka

### Grace Church Printers

### 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@bda-sc.org](mailto:sue.martin@bda-sc.org). Mail to: 25 Woods Lake Road, Ste 300, Greenville, SC 29607, Attention: Editor-in-Chief, The News Infusion. We look forward to hearing from you soon!

## Lead Article



## H.E.L.L.O: 49th Annual State-Wide Conference

### **Helping Embrace Life's Learning Opportunities Research: Providing Brighter Tomorrows**

On June 10-11, 2022, more than 150 BDASC members, staff, national policy experts, industry representatives, and state lawmakers met for the 49th Annual Meeting and H.E.L.L.O. Conference in Greenville, South Carolina. The weekend was full of instruction, networking, support, and fellowship.

Friday evening kicked off with a keynote presentation "Together, We Have Come a Long Way" by Sonji Wilkes, Vice President of Public Affairs at the Hemophilia Federation of America. Her talk addressed the long history of advocacy in the bleeding disorders community that began with the voices of many diverse individuals all coming together to advance access to quality care and treatment. She emphasized that, as we continue to advocate for research to enhance the quality of life of all those affected by bleeding disorders, the community voice should be at the forefront, involved in conversations and education on what is most important. She challenged the audience to help lead the way to advance research, treatment, and equal access to quality healthcare for everyone affected. The annual Awards Ceremony followed her talk, starting with recognition of college scholarships.

The following were granted to our college-age members this year:

*Marley Day* – the Roy Clifford Sperry Memorial Scholarship

*Devon Mulligan* – Bleeding Disorders Association of South Carolina Scholarship

*Sarah Walden* – the Mark Asbury Eichelberger Memorial Scholarship

*Regan Weber* – the Alba Myers Lewis Memorial Scholarship



Next, BDASC recognized departing Board members—*Robert Butler, Cristal Day, Eric Dunton, Ursula Sagot, and Patricia Tucker*—and thanked them for their service. We then welcomed new board members: *Samantha Javorka, Susie Maloy, Edna Rabb, and Taylor Upton*. BDASC then an-

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nounced the Board Member of the Year, which went to *Shelley Crisp*, the current Board president.



We then turned to other awards and recipients, including:

- Legislative Advocate of the Year - *SC State Representative Patricia Henegan*
- Coalition Advocate of the Year - *Cristal Day*, Coalition Chair
- Coalition Ambassadors of the Year - *The Keith Family*
- Making a Difference Award - *Prisma Health*
- Appreciation and Partnership Award - *Drew Clawson*, Kinard Consulting
- Volunteer of the Year "The Fisher Award" - *Matthew Tucker*
- The Aaron Eugene Gossett "Pillar of Strength Award" - *James Whitmire*



The evening was a wonderful time to reconnect for the community after many years of restrictions due to COVID-19, and to bring back long-



time members like the *Wentzky Family*. *Joyce* and her blankets of love she provides in partnership with her group of volunteers are a special treat for the children each year. On Saturday, childcare services were provided by Corporate Kids Events for all children under 12 years old, including a video truck tournament. Teen events were provided by *Margaret Bridges*

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and Tom Hamm, program managers at GutMonkey. They ran the “Leading Edge” program that focused on leadership and teamwork skills and is specific to populations affected by chronic health conditions.

The opening plenary on Saturday morning featured a presentation by the National Hemophilia Foundation’s (NHF) Chief Scientific Officer, *Dr. Kevin Mills*, and their Research Recruitment and Engagement Specialist, Felix Olaya, who talked about the development of the national vision, how it all began, how the community was involved, and how future research efforts will include the voices of our community. He opened his talk by emphasizing that “Research requires all of us” and that “research needs to be about people—not patients, people.” He also addressed the Community Voices in Research (CVR) initiative and how BDASC members can be involved in the direction of future research. He focused especially on global themes of “people centricity,” “collaboration,” health equity and diversity,” and “inclusion.” He spoke at length about the different ways that community members can become involved in research initiatives. *Felix Olaya*, Research Recruitment and Engagement Specialist with NHF, followed the talk and reiterated the need to synchronize research with community, and encouraged members to share their experiences for the benefit of the entire bleeding disorder

community.

The late morning featured a discussion “Understanding our Diverse Perspectives: How Individual Experiences Strengthen a Unified Voice,” sponsored by the Hemophilia Federation of America and led by *Sonji Wilkes*. This session



focused on “sharing our stories” as an avenue for building advocacy awareness and how things like gender, race, age, socio-economic status, type of healthcare coverage, and distinct disease states inform how we advocate, and how listening to one another makes us stronger and can facilitate changes within our healthcare systems for access to quality care and treatment. Panelists included community members: *Meggan Burton*, *Dana Gurley*, *Samantha Javorka*, *Ward Keith*, *Edna Rabb*, and *Kristin Shelton*. They all gave heartfelt accounts of their own experiences—including challenges and triumphs—and encouraged members to “stick together” even if healthcare threats do not affect them directly.

Two rounds of breakout sessions occupied the

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afternoon. The first round included a “Gene Therapy Jeopardy,” sponsored by BioMarin and led by *Dr. Kimo Stine*, Medical Director at the Arkansas Center for Bleeding Disorders, that tested audience members’ expertise on gene therapy and provided some updates on current trends as well. Another session, “VWD for ALL,” sponsored by Bayer, involved a presentation by *Sue Geraghty*, Nurse Consultant, and gave an overview of Von Willebrand Disease (VWD), advice on when to seek treatment, how to manage the condition, and skills to empower yourself. A final session, “Women Who Bleed,” sponsored by Bayer and led by their hematology nurse educator, *Jessica Lovercamp*, encouraged women to know the meaning of their bleeding disorders carrier status and understand treatment options. It explored issues important to women carriers, including genetics, carrier testing, emotional impacts of diagnosis, recognition of symptoms, and treatment options. Afternoon breakout sessions included one on “The Missing Gene,” led by clinical education manager *Jennifer Harris* and sponsored by Ge-

nentech, featured BDASC community members *Michelle and Joey Krakowiak*. They led a discussion on exploring issues around a new diagnosis and challenges families without any known history of hemophilia face. Another session, “Mind and Body Skills to Tame and Reframe



Pain” was sponsored by CSL Behring and led by *Dian Dimon*, professional speaker and founder of Common Factors. She went over seven simple techniques that harness the power of the mind and could help relieve chronic pain. A final session, “Spotlight on Siblings,” was sponsored by Sanofi and led by their community relations and education manager, *Xaviette Pointer-Kincy*.

*Continued on page 7*

## With Heartfelt Appreciation to All Our 2022 Annual Meeting Sponsors

### PREMIER SPONSORS



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## Board's **BLOG**

### Executive's Welcome

By Sue Martin, Executive Director

## Looking Forward

As we look forward to the fall season, I find it hard to believe our spring and summer days are over. Kids are back in school, teens are off to college, and we are starting to now think about the holiday season. I want to reflect for a minute on our spring and summer season and the exciting times we have had. I welcome you to read about our [summer camp](#) experiences, our May, [STEP for Bleeding Disorders Walk](#), the June, [H.E.L.L.O. Annual Meeting](#), and the many accomplishments we all have had as a community. Thank you for being our devoted members and extended family of BDASC. I ask you to continue to stay connected and engaged throughout the coming years so together we can accomplish so much more in meeting the needs of our bleeding disorders community.

I am waiting for the time in treatment care when we all can achieve “zero bleeds” through the advancements in treatment therapies for all rare bleeding disorders; including our VWD, platelet disorders, and Ultra- Rare's. But until that day comes, we must continue to keep in mind what our mission is, and what remains important collectively to our community.

ACCESS TO CARE, health equity for all, and removing the barriers that create inequities in our health outcomes will remain at the top of our priorities. After all, if we are not doing the work to advance those priorities, who will do it for us? Additionally, taking on the role of being

an ambassador in advancing RESEARCH is almost equally important. In order for us all to live a life of zero bleeds in our futures, we must make advances in testing, receiving proper diagnoses, and having the ability to treat the most difficult and complicated disorders. We must all do our part, as we are able, to partner with our national organizations until treatment therapies are available for all and they become readily available, including the potentials of Gene Therapy. Those working in the fields of research can't accomplish this without our clinical data and our partnership support.

Last, we will continue to keep COMMUNITY ENGAGEMENT strong, providing as much as we can in bleeding disorders education, programs, and support services. Staying informed of all we do is important to access these engagement opportunities. I encourage you to stay informed and join us by reading our e-mail news blasts and printed news brief, newsletters, mailing, and our social media community engagements such as our [Facebook](#), [Instagram](#), and other platforms. I wish we had all the resources, financial wealth, staff, and time to mail everything we do to all our members. However, as we continue to grow, that is just not a sustainable goal. Log in often to [www.bda-sc.org](http://www.bda-sc.org) and join us at our community engagements. I welcome you to reach out at any time and give me a call. My door is always open and I am honored to work beside you all.

Have a wonderful fall season and I hope to see you soon!

Warm regards,  
Sue

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It looked at families that have a mix of children with and without a bleeding disorders diagnosis and the unique challenges they face. It offered some tools to help ensure that each child's needs are met in a family where children have bleeding disorders and others do not.

The event included a self-infusion clinic, led by *Sue Geraghty* and *Robin Jones*, nurse coordina-

tor at the South Carolina Hemophilia Treatment Center. A closing dinner sponsored by the Hemophilia Federation of America concluded the event. The exhibitor hall was available throughout the event to support members and offer up-to-date information on the latest trends in treatment therapies and support services. We cannot thank our sponsors enough for helping make this event possible.

## Dedicated to Service

Please help us welcome our newest Board of Directors of BDASC. They began a two-year term this past July 1, 2022!

### We Welcome Samantha Javorka



Samantha resides in Summerville, South Carolina, with her husband and three kids. Samantha's youngest daughter was diagnosed with severe Von Willebrand disease (vWD) when she was a year old. Her diagnosis was a surprise to everyone since no one in her family has

the disorder. Samantha and her family recently moved to South Carolina from Michigan and became involved with BDASC immediately. Samantha looks forward to advocating for those diagnosed with bleeding disorders and VWD. Samantha has a background in graphic design and is enjoying exploring South Carolina and all it has to offer with her family. Samantha looks forward to connecting more with the BDASC family.

### We Welcome Taylor Upton



Taylor resides in the Upstate in the quaint town of Belton, SC. At the age of eight, Taylor was diagnosed with Von Willebrand disease. She has spent most of her life proving she can live life without letting her disorder hold her back.

As a teenager she watched her sister advocate for her while learning about her disorder which has given her the ambition to fight hard for those affected. Having the desire to start a family of her own is what has really driven Taylor to want to help people understand Von Willebrand disease and expand the research. Taylor has recently been diagnosed as Type 1C

after being diagnosed with Type 3 for over ten years. She is excited to be a part of BDASC to share her story, encourage others to advocate for themselves by sharing the tools she has, and continue to grow her own knowledge. Taylor attended Tri-County Technical College in general studies and is currently a Territory Manager for Southland Consultants/Owl Music Company. She lives with her husband Jonathan and her stepdaughter Sadie.

### We Welcome Edna Rabb



Edna lives in Winnsboro, South Carolina. She has a daughter and an adult son who lives with Glanzmann's Thrombasthenia. Edna worked in manufacturing for over 30 years and then worked in home health care and for the board of disabilities for South Carolina

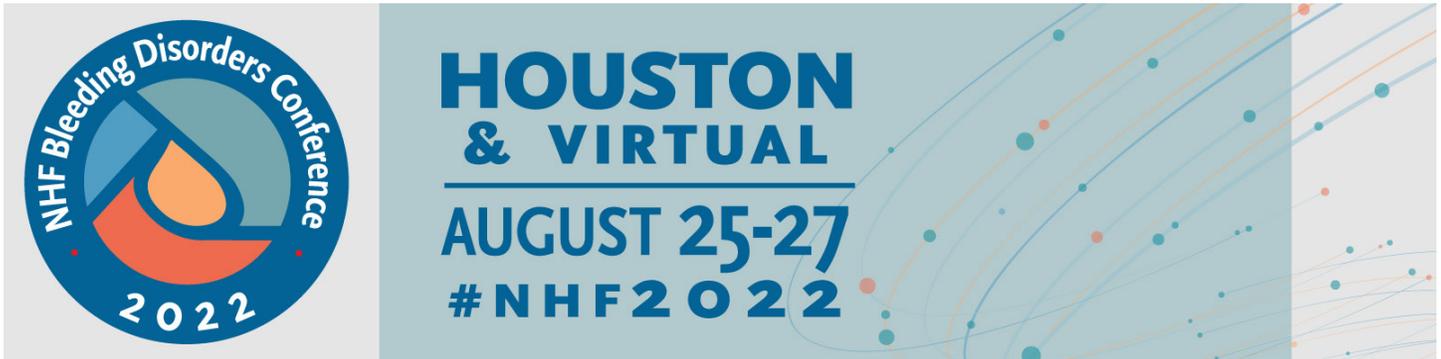
for another eleven years. She is now retired and loves assisting the Bleeding Disorders Association of South Carolina Chapter and their members. Edna loves listening to music and dancing in her spare time.

### We Welcome Sherlene Maloy



Sherlene Maloy lives in Summerville, SC, and has been a lifetime member of the organization. She has a family history of hemophilia and a son affected. Susie, as she calls herself, has a strong passion for educating

others about bleeding disorders and advocating. She is the recipient of the 2021 Ambassador of the Year Award of BDASC and its Advocacy Coalition. Susie loves volunteering for the Chapter and helping make a difference in the lives of community members affected by bleeding disorders in South Carolina.



## National Meeting and Opportunities for Support

The Chapter will head to Houston next week to attend the National Hemophilia Foundation's Annual Bleeding Disorders Conference where individuals and their families from across the nation and around the world will receive the best in education and support from leaders and experts in bleeding disorders. It is the first time the community will be together for this national conference in three years, and we are all excited! We congratulate Matthew Tucker for applying for

the [\*Joe Caronna Memorial Scholarship\*](#) of BDASC and the Gurley and Smith family who were awarded travel grants to attend.

We are equally excited to announce the winner of the BDASC participant who will attend and represent South Carolina at the Junior National Championships in Arizona this late fall. Mykell Raysor will be competing in Baseball and we wish him all the best.

## Community Engagements

### MENS Zoom Event

Thursday, May 12, 2022 — MENS Group Event. The MENS Group met for a Zoom call featuring a special presentation by Dr. Claudio Sandoval, director of scientific and medical affairs at Octapharma, about bone health for people affected by bleeding disorders. He shared about research and studies looking at how people with severe hemophilia have a higher incidence of bone fractures than mild or moderate hemophilia, and how those with mild or moderate hemophilia have a higher incidence than the general public. Dr. Sandoval gave a great overview of bone mineralization and the biological processes involved in building and maintaining good bone health. We had a great group, with lots of follow-up questions and discussions. A special thanks to Dr. Sandoval and Octapharma for putting this together and to all of our members who participated.

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### 9th Annual STEP For Bleeding Disorders

On Saturday, May 14, the sun was shining brightly over Saluda Shoals Park in Columbia for our 9th Annual STEP for Bleeding Disorders 5K Run/Walk. With volunteers arriving early before the sun rose to set up, we were ready for participants as they began to arrive for registration. With our sponsor booths and friendly faces welcoming the walkers, followed by some warmup dancing with the USC Mascot "Cocky", our friends "Olly Otter" and "Benny", our Blood Drop, all were ready to hit the 5K to show solidarity for those who are living with bleeding disorders. The walk also provided entertainment from our friends at *Big Time Entertainment*, a photo booth, face painting, t-shirts, ice cream and cookies from Marble Slab, and plenty of beverages and snacks, complete with pizza for all. The walk had over 150 participants and raised \$53,208.82, or 88 percent of our goal, which will go to educational, advocacy, and support programs at BDASC. A

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special thanks to our volunteers and to everyone who created teams and helped fundraise. And a huge “thank you” to our sponsors who helped make this event possible.

Congratulations to all our award winners, both at the event and on the fundraising front. We are grateful for your commitment to raising funds for the South Carolina Community! Please view all the walk pictures on our [FaceBook Page!](#) Save the date on your calendar of May 6, 2023, as we return to Saluda Shoals for another great time of community spirit!

Top Fundraising Individual: Michelle Krakowiak - \$2,606.00

Runner-Up Top Fundraising Individual: Cole Dean - \$1,922.50

Top Fundraising Team: Team Krakowiak Attack! - \$4,284.50

Runner-Up Top Fundraising Team: Team Logan - \$3,703.50

Largest Team (Walking/Running): Team Logan - 20 Members

Runner-Up Largest Team (Walking/Running): Team May the Factor be with You! - 18 Members

Best Creative Costume (Individual): May the Factor be with You - Jackson

Best Creative Team Costumes: The Hunters

Oldest Registered Walker: From Team Logan - Jeff Lummel - 78 Yrs.

Youngest Registered Walker: Team Limitless - Mac Martin - 7 months

**Race Finishers**

First Place: Brandon Pittman and his daughter in her stroller, Maggie

Second Place: Joe Segars

Third Place: Hunter Prest with Grady Smith





## 2022 STEP Sponsors

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### Y.E.S. Event - EdVenture Museum Columbia, May 28, 2022

Our Y.E.S. (Young Families Empowerment and Support) Program met at EdVenture

Museum in Columbia on Saturday, May 28, for a program on summer camp readiness. Sanofi sponsored the event, including a lunch-and-learn discussion for children and teens with bleeding disorders. Participants—families of young or newly-diagnosed families—enjoyed discussions, activities, sharing time together, as well as exploring the museum. A special thanks to

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Sanofi for the opportunity and to our community for joining us.



### Ladies' Night Out in Mt. Pleasant

On June 24, the Chapter traveled to the Lowcountry to support the ladies of CARE: BDASC's Women and Girls Support Program. The dinner program was sponsored by Sanofi and discussed *Factor Fiction: Women and Hemophilia*. The ladies learned about how women are affected by hemophilia and bleeding disorders and explored strategies to have productive discussions with doctors about their healthcare needs. It was great to visit the group in this region and everyone enjoyed robust conversations and a supportive time.



### MENS Zoom Event

Thursday, July 14, 2022 - MENS Group Event. The MENS Group met for a Zoom call featuring a special presentation by Dr. Joey Krakowiak, Board Treasurer, community member, and father

of a son with hemophilia. Joey shared important information about what men of all ages should consider about their health and that having a primary care physician could help to address aging and other health care needs that can come up throughout your life and will need to be addressed. The group asked plenty of questions and received great information for keeping their bodies healthy.

### MENS Support Group Activity

In honor of our men and fathers, the August 6 gathering of men, boys, and their families was held at the Segra Field in Columbia for a special group recognition ball game. Over 45 participants attended and after a rainy start, they enjoyed a buffet dinner, a commemorative ball cap, and a fireworks show at the end of the game. The Chapter was recognized on the Jumbotron and the families enjoyed the time to connect and network while enjoying America's favorite pastime. The event was provided in partnership with Octapharma and we are grateful for the opportunity to connect our men.



# Soaring Through Life

## The Carolina Crew 2022 Teen Retreat

The busses rolled into Camp Canaan in Rock Hill, SC, on August 11-14, coming from as far as the coastlines of North and South Carolina for a four-day teen retreat, finally held back in person. The camp was ready for the teens, complete with a new lake and covered basketball court. As quickly as the busses rolled in, the teens began to bond and have fun. We were excited to welcome Gut Monkey and The Leading-Edge Program, sponsored by Pfizer, which provided 6 hours of leadership and team building skills over the first two days of programming. North and South Carolina come together each year to host this event and always provide an advocacy program. This year it was in the form of a robust educational game of Advocacy Kahoot!

The following days provided swimming, basketball, volleyball, fishing, ziplining, a high ropes course, and of course kayaking on the Catawba River. Camp fires with s'mores and a three-hour Rube Goldberg team competition, ice cream socials, chess games, and late-night talks and games filled the evening hours. Our camp counselors, staff, volunteers, and nurse Robin Jones from the Hemophilia Treatment Center helped to keep everyone safe and having fun.

*"Being a counselor at the teen camp was an*

*amazing experience. I had the opportunity to witness the next generation interact and bond with each other. There were no social barriers, no fears, and they all united to support one another during the four-day event. Watching the teens and witnessing how they handle each day reminded me of how upbeat, resilient, and oblivious we are at that age to any idea that you live with a bleeding disorder. It was very inspiring to me personally. As someone who lives with severe hemophilia, I would strive to be more like them."*—Robert Butler

The annual teen retreat is a wonderful opportunity for our teens with bleeding disorders to come together and wouldn't be available without the support of our sponsors and grants. We wish to express our sincere appreciation to the Colburn Keenan Foundation for granting us the 2022 Marcy Shulman Memorial Organization Grant Program. The Colburn-Keenan Foundation is committed to providing assistance and support to community, local, and national organizations that offer programs and services to individuals and families with chronic illnesses in the United States, with priority on those within bleeding disorders community. We also wish to thank our Industry Sponsors for their commitment to camp support!

*CK Colburn  Keenan Foundation, Inc.*

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# BLEEDING DISORDERS SUMMER CAMPS



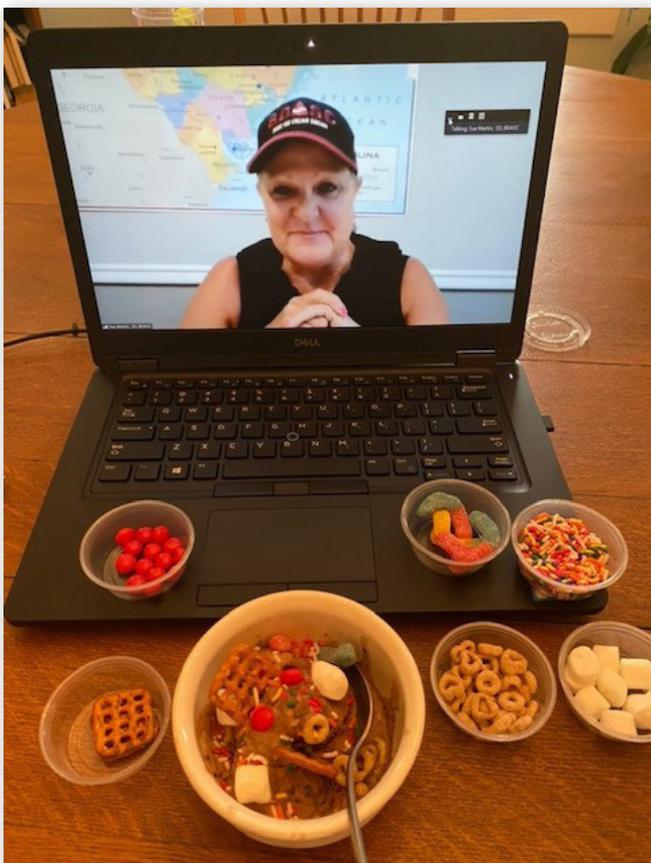
## Summer Camp and Our Famous Ice Cream Sundaes

### June 29 Camp Courage

### July 26 Virtual Camp Burnt Gin

Our famous BDASC Ice Cream Sundae Social is a hit at camp each year and this year was no different. While camps are slowly easing back to normal, we didn't miss a beat this year. We were excited to be invited back to provide the

yummy treat for *Camp Courage*, which is held at the Pleasant Ridge Camp and Retreat Center in Marietta, SC, and to provide a virtual Ice Cream Social for *Camp Burnt Gin* and the Department of Health and Environment Control. Campers zoomed in safely from home and together we learned how to make a "Blood Sundae" and enjoyed learning about the different components within our blood and understanding how the blood clots. BDASC provided (by mail and in person) all the treat supplies for the campers and each participant received an Ice Cream Sundae Cap! We are grateful to our sponsors and Marble Slab for being our partners for Camp!



## Voices of Our Community

## Parents in the Bleeding Disorders Community Share Their Best Advice

By Samantha Javorka  
Summerville, South Carolina

**Daughter Daphne, 8, diagnosed with von Willebrand disease type 2B and thrombocytopenia at the age of 2.**

Learning to treat with prophylaxis at home was the best piece of advice we got. At the time (of diagnosis), that was uncommon for people with von Willebrand disease. We had a really open-minded doctor in Michigan, where we moved from, who was up on all the current treatments and who supported our decision. In the past six months, NHF has released [new guidelines for people with von Willebrand disease](#) saying that there are positive results with prophylactic treatment.

Get advice from someone who lives with the condition every day—a parent or a child. When my daughter had pain from the car seat strap over her port, parents who experienced similar situations gave us different suggestions.

Showing our daughter videos of other kids getting infused took the fear out of it for her. We've also learned that sucking on a lemon wedge helps. There's something about the connection in your brain that focusing on the sour takes priority over focusing on the pain. To handle the unknowns of emergency room visits, ask to set up a tour of the ER. We took our daughter when she was not having a bleed, so she could meet the nurses, see the facility and feel comfortable if she ever needed to go in. The lead nurse updated my daughter's online chart



so now it flashes red with information to call our hematologist. Before that, if we went to the ER, I would have to call my doctor and hand over my cellphone to make sure they called. I'd overheard nurses joking before, "It's just a bloody nose. Who comes to the ER for a bloody nose?" But the flashing screen validates us.

*(Reprinted from the NHF HemAware with Permission)*

## Upcoming Engagement Opportunities

### YES Program: Young Families Empowerment & Support



**SEPTEMBER 17 10:00am - 2:00pm**

[Register today!](#)

We are excited to invite our young and new families to join us on September 17 in Greenville for another exciting support group activity for making connections and providing support.

Join us for lunch, networking, education, and tickets to the museum afterwards with your BDASC friends! We will host in partnership with Sanofi a conversation discussion on how best to manage heading back to school, **Setting Educational Expectations:** What does it mean to be truly “School Savvy”? This program reviews the unique assistance a child with a bleeding disorder may need in school and what options may exist for academic support. We will explore the world of education for a child with a bleeding disorder, the impact of setting expectations at home, and steps you can take to form a proactive relationship with your child’s school. Share your knowledge with the group of your own experience! **RSVP by September 12.**

### Par for the Clot Charity Golf: More than a Fundraiser

In the setting of the beautiful Preserve at Verdae Golf Course, for the second year in a row, 144 golfers and over 35 volunteers will hit the course for fun and competition, hoping to bring home

trophies and cash! This important event, which is so much more than a fundraiser, will take place on October 7 with registration at 8:30 a.m. Many tournament play activities will be part of the completion, including the Charity Gun Hole Contest, a Spin to Win hole, Men and Women’s Longest Drive Competition, Closest to the Pin Wins, a Putting Contest, Charity Golf International Donation Hole Competition, and the Poker Holes, a 50/50 split the pot. While the tournament is a lot of fun (and hard work), it really is so much more than that.



The partnerships we build each year with many local and national companies outside our bleeding disorders community help us spread awareness of the BDASC mission and vision, and awareness education of bleeding disorder to the general public. It also allows companies to come together and network, getting their names exposed and their company marketed. We always want our partners to make new relationships and network with the hope to increase their businesses. More the this, the funds raised help us to directly support the research of national organizations, like funding the researcher asking the questions “why” with the [Judith Graham Pool Post-doctoral Research Fellowship](#) . For eight years we have been a funding partner. In addition to research support, the funds raised provide direct support to

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our robust advocacy programming. Being known nationally as an advocacy powerhouse raising our voice for quality treatment care and access for all, the fundraiser equally benefits those outside the bleeding disorders community in healthcare access. The volunteer members are so grateful to the players for their support during their time on the course and show their appreciation in kindness and in words of thanks.

We look forward to another wonderful time together this October and with the Par for The Clot being a full eight weeks before the tournament date, we feel blessed to have so much support. So many people make this event happen and we are appreciative of everyone's time, talents, and financial support. A full write up will be provided in the Fall Newsletter. We do wish to express our appreciation to our major sponsors!



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\* Hemophilia FIX Market Assessment. Third-Party Market Research.

† The average AsBR for people who started and stayed on 7- or 14-day prophylaxis was 0. For people who switched to prophylaxis from on-demand, the average AsBR was 0.7. AsBR-annualized spontaneous bleed rate.

‡ Once well-controlled (1 month without spontaneous bleeding or requiring dose adjustments on a weekly dose of ≤40 IU/kg), people 12 years and older can be transitioned to 14-day dosing.

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Tell your healthcare provider of any medical condition you might have, including allergies and pregnancy, as well as all medications

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**Please see additional Important Safety Information and brief summary of prescribing information on adjacent page and full prescribing information including patient product information at IDELVION.com.**

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call **1-800-FDA-1088**.

You can also report side effects to CSL Behring's Pharmacovigilance Department at **1-866-915-6958**.

# Alternatives to Recalled Desmopressin Nasal Spray

With Stimate Nasal Spray not expected to be available until at least mid-2024, here are some other treatment options, including a new DDAVP nasal spray.

## What alternatives are there for **Stimate Nasal Spray**?

That's a question many people in the bleeding disorders community have been asking since summer 2020, when Ferring Pharmaceuticals issued a voluntary recall of the nasal spray version of desmopressin (DDAVP). The nasal spray is commonly used to treat von Willebrand disease (vWD) and mild hemophilia A and is sold under the brand name Stimate.

Desmopressin is a synthetic analog of vasopressin, which boosts plasma levels of von Willebrand factor and factor VIII and helps stop bleeding. The nasal spray is often prescribed for people with frequent nosebleeds, serious bruising, or heavy menstrual periods (menorrhagia). DDAVP is also sometimes given to people before procedures that involve the mucous membranes, such as dental work, as well as for home treatment of minor injuries and before minor surgeries.

Stimate, which is owned and manufactured by Ferring, was recalled due to superpotency, meaning that some products contained higher-than-specified amounts of the medication. In June 2022, the company announced that the nasal spray will not be available until mid-2024 at the earliest.

Here are some other medication options that are available as alternatives to the recalled nasal spray:

### **DDAVP Nasal Spray from STAQ**

In September 2021, a DDAVP nasal spray manufactured by STAQ Pharma Inc. (DDAVP NS) began distribution. As of April 4, 2022, the product had been fully licensed in 44 states, and the National Hemophilia Foundation (NHF), the Hemophilia Federation of America (HFA), and the Hemophilia Alliance were working with the manufacturer to get licenses in the remaining states. "The Hemophilia Alliance and its members were delighted to fund the development of DDAVP

NS for the bleeding disorders community," says Joe Pugliese, president and CEO of the Hemophilia Alliance. "We have been working closely with NHF and HFA to help ensure coverage for and access to the product. If you have questions about how to obtain DDAVP NS and you are a patient, please contact your health care provider. If you are a health care provider with questions, please [contact me](#)."

### **Antifibrinolytics**

Oral medications such as tranexamic acid (Lysteda) and aminocaproic acid (Amicar) help promote blood clotting by preventing the breakdown of fibrin, which is the main protein involved in a blood clot.

Robert Sidonio Jr., M.D., director of hemostasis and thrombosis clinical operations at the Aflac Cancer and Blood Disorders Center of Children's Healthcare of Atlanta, says he often prescribes high doses of an antifibrinolytic instead of DDAVP for patients with mildly reduced levels of von Willebrand factor or mild hemophilia A or B who are having minor mucosal surgeries. "We have been following this strategy for a while now, and we also apply it to non-mucosal procedures, such as skin biopsies, ear tube placement, colonoscopies, and tattoos," Sidonio says.

### **IV or Subcutaneous DDAVP**

Before the nasal spray version was introduced, DDAVP was primarily given as an injection, either intravenously or subcutaneously. Both of these options are still available.

"If DDAVP is working well for someone and they want to be maintained on the same medication, then subcutaneous injections of DDAVP, which patients can be taught to do at home, are an option that's worth considering," says Alexis Koon, PharmD, a hematology/oncology pharmacy resident at Atrium Health Carolinas Medical Center in Charlotte, North Carolina, who co-authored a 2021 paper outlining alternatives to the recalled nasal spray. Sidonio notes, however, that subcutaneous DDAVP is less practical for obese and overweight people because of the high volume

*Continued on page 29*

# Females with Bleeding Disorders

The Hemophilia Treatment Centers (HTCs) Network Investigators, a group of researchers from several U.S. HTCs, recently published a study on disparities associated with bleeding symptoms, age at diagnosis and provider interventions for females with bleeding disorders. Females living with an undiagnosed bleeding disorder are unwittingly foregoing the care and resources that can have real world implication for their quality of life, including appropriate treatment, education and psychosocial support.

The article “Differences in Bleeding Phenotype and Provider Interventions in Postmenarchal Adolescents when Compared to Adult Women with Bleeding Disorders and Heavy Menstrual Bleeding,” was published in the January issue of the journal *Haemophilia*. The lead author was Lakshmi V. Srivaths, department of pediatrics, section of hematology/oncology at Baylor College of Medicine in Houston, Texas.

Investigators focused, in part, on the differences in phenotype of adolescent vs adult women with heavy menstrual bleeding (HMB) and a bleeding disorder (BD). Study data was drawn from the U.S. Centers for Disease Control and Prevention’s Universal Data Collection (UDC) surveillance project, which culled information annually on enrolled patients at 135 federally funded HTCs. The project included annual data from 1998-2011. In 2009 a female component was added to the UDC which was implemented in 23 HTCs. The module was designed to capture data related to diagnoses, menstrual bleeding, other bleeding symptoms, obstetrical-gynecological symptoms, treatment and gynecological/reproductive history.

The UDC data encompassed 269 females with HMB/BD, including von Willebrand disease (vWD), other factor deficiencies and platelet disorders. Of these, 79 were adolescents (median age 16) and 190 were adults (median age 27). The majority enrolled

were diagnosed with vWD (223; 83%) with the remaining diagnosis encompassing other factor deficiencies, platelet function disorders and unspecified BDs.

The median age at diagnosis was 12 for adolescents vs 16 for adults. Forty-five adolescents (57%) and 138 adults (73%) experienced a delay in diagnosis, defined by the number of years passed since a patient’s first bleed. Srivaths and her co-authors observed that there was a reduction in long delays in diagnosis for adolescents vs adults and that this could be an indicator of a positive trend. “We suspect the difference in delay in diagnosis in adults vs adolescents is because of improved earlier diagnosis due to greater awareness in the past decade through national advocacy organizations such as the National Hemophilia Foundation and the Foundation for Women and Girls with Blood Disorders.”

Differences were also seen in bleeding phenotypes of adolescent vs adult females with HMB/BD. Adults experienced more frequent bleeding complications, anemia, gynecologic procedures and surgeries. While both groups were treated with hormonal therapy and antifibrinolytic agents equally, the synthetic hormone desmopressin acetate was utilized more often by adolescents due in part to its ease of administration via nasal spray. Adults more often opted for hormonal therapy and surgeries. The authors suggested that this was due to the additional contraceptive benefits of hormonal therapy and a preference for the type of “definitive outcome” associated with surgical interventions.

The authors cited several study limitations, including those associated with a small patient sample size and the use of retrospective, self-reported study data based on patient recall. Data were also limited to patients enrolled at HTCs, which may not be representative of the

*Continued on page 23*

## Von Willebrand and Women Who Bleed Community News

# The NOW Conference is Open for Registration!

**November 18-20, 2022**

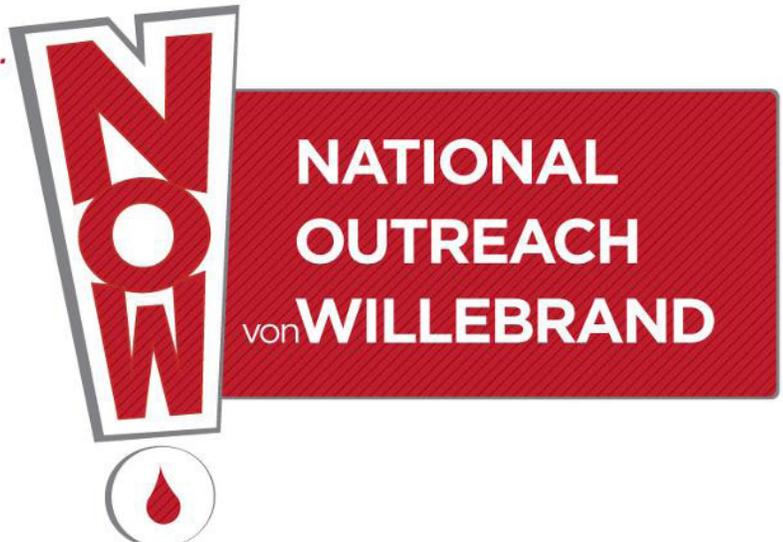
**Phoenix, AZ**

Don't miss out on this exciting opportunity to be part of the November 2022 NOW Conference, being held in Phoenix, AZ, at the Hilton Phoenix Resort at the Peak.

### What is NOW?

NOW stands for National Outreach for von Willebrand. Over the years, von Willebrand Disease (vWD) has always been "lumped in" with hemophilia. Well, NOW is the time to focus exclusively on von Willebrand Disease! NOW is a national educational symposium for individuals and families who are living with this chronic disease. It is a forum to learn about new medical advances, gain tools that can help you manage vWD and to share with others facing the same or similar challenges. We will bring in expert healthcare professionals who can best address the issues unique to vWD. Funded through a grant by CSL Behring, the Arizona Bleeding Disorders is excited to host this

*The time is...*



national conference focused specifically on von Willebrand Disease.

### Who is Eligible?

Attendees must have von Willebrand Disease and/or be a caretaker of someone who has it. The conference is funded to accept a limited number of participants. Families are welcome and there will be educational activities and daycare for children.

[Learn more and register today!](#)

*Continued from page 22*

broader U.S. population. Despite the limitations, Srivaths and fellow investigators note that this study is important as it represents the first concerted effort to compare the bleeding phenotype, diagnosis and management of females with HMB/BD. They acknowledge that while public awareness related to women affected with bleeding disorders has been

enhanced in recent years, additional studies are necessary to establish definitively whether better patient/healthcare provider education translates to better outcomes. The results of such studies could inform future efforts to reduce hematologic/gynecologic complications for females with BD/HMB.

*Reference: NHF Website*



# JOURNEY TO KNOW



NATIONAL HEMOPHILIA FOUNDATION  
for all bleeding disorders

## What is The Journey to Know Program?

The Journey to Know program was created as part of the National Hemophilia Foundation's *Better You Know* campaign to better support women and individuals with the potential to menstruate who may be experiencing symptoms of a bleeding disorder but haven't been diagnosed yet.

Over the course of three months, this program provides a series of informational videos to help women navigate next steps and communication with healthcare providers, as well as detailing the resources available to you. We also provide automated check-ins (email and/or text) with information and resources to encourage women to continue to seek your diagnosis as well as virtual opportunities for

community support. Through this program, we hope to empower women with knowledge on the basics of bleeding disorders and equip them with the proper skills to confidently advocate for their health needs.

This program is supported by the Centers for Disease Control and Prevention (CDC) of the U.S. Department of Health and Human Services (HHS) as part of a financial award with 100% funded by CDC/HHS. [Learn more here!](#)



SCAN ME

## Did You Know?

# TOOLKIT FOR YOU

## Health Equity Through HTCs



NHF is forming a Health Equity Working Group to make recommendations on a definition of what health equity means for NHF, examine the social determinants of health that impact people with bleeding disorders and their support network, and prioritize strategies for programs to address these disparities. For more information, please contact Kate Nammacher, Vice President of Education at: [knammacher@hemophilia.org](mailto:knammacher@hemophilia.org). NHF is also now presenting the Health Equity Through HTC pilot project! The materials are now ready to share with all HCPs and community members.

Learn more about the [Consumer Tool Kit](#) and [Health Care Provider Toolkit](#)

## 2022 Health Equity Summit

In June 2022, NHF hosted its first-ever Health Equity Summit in Atlanta, Georgia. BDASC's Executive Director Sue Martin was a featured guest speaker along with the executive directors of San Diego and New England. "Lessons from the Hemophilia Community" was moderated by Nick Kallinicou and panelists discussed how they address health equity within their state or chapter, the challenges of addressing health equity, how they engage hard to reach populations, and getting stakeholder buy in. The goal of this invite-only conference was to identify barriers to care and access,

and thusly outline actionable strategies to address the most important needs within the IBD community. The conference will deliver a white paper featuring outcomes in late 2022, specifically looking at opportunities of coordinated collaboration. [Click here to learn about the Summit](#), and its keynote speaker, [Dr. Italo M. Brown](#). The next Summit is being planned for 2024, with community roundtables set to occur in 2023. [Contact Dr. Keri Norris](#) if interested in learning more. Plans for another Summit will be released in early 2023.

## Advocacy Action

### Family Camp Becomes a Time for Advocacy

#### Health Equity Advocacy Family Camp

This year on October 21 through October 23, BDASC's annual recreational and educational family camp will be held in Charleston, SC. The event is available to individuals and families who either have a bleeding disorder, are carriers of a bleeding disorder, or have an immediate family member living in the same household diagnosed with a bleeding disorder. This year's event is going to be centered around addressing South Carolina's bleeding disorders health equity, inclusion, and diversity (HEDI), all wrapped within a three-day summit. With members throughout the state, the summit is being held in the Lowcountry to provide advocacy education and support to our community members who live in the region, while also providing our advocate members a coastal venue experience. Members will enjoy an extended opportunity to connect with others who may be experiencing some of the same bleeding disorders health care journeys and challenges, while advocating for solutions to address the barriers we still face as a community today. Participants will learn how to best advocate for themselves and their families and learn what we can do as a community to help make change. We have invited our local and national speakers and educators who are among the best in the nation to join us. We will



**RAISE YOUR SHIELDS**  
BECAUSE WE ALL HAVE A HAND



concentrate on access to care and treatment, health equity, inclusion and diversity with members leading the conversations. We will also prepare for our next SC legislative session and address threats with barriers to treatment access. You will leave engaged on how you can make a difference. You and your family will also have time to visit and explore Charleston with all its history and coastal experiences. There will be fun and community connections for the whole family, including our teens and children. Educational exhibit opportunities will be offered for participants throughout the weekend to provide informational materials and one-on-one conversation opportunities on the most up to date treatment therapies and support services.

*Continued on page 27*

## National News

## The Patient Advocacy Organization Has Formally Submitted a Citizen's Petition to the Food and Drug Administration

On July 1, the National Hemophilia Foundation (NHF) submitted a citizen's petition to the Food and Drug Administration (FDA) in relation to the pending approval of two gene therapy treatments. The intent of the requests in this petition are to ensure the health and well-being of people with hemophilia who receive a gene therapy product. In the document, NHF requested a risk evaluation and mitigation strategy (REMS) for both valoctocogene roxaparvovec, a BioMarin investigational gene therapy under regulatory review for the treatment of severe hemophilia A, and etranacogene dezaparvovec, a CSL Behring investigational gene therapy currently under review for the treatment of hemophilia B. NHF places the safety of the community first and foremost, which is why the request has been made. According to Leonard Valentino, MD, NHF's President and CEO, "We at the National Hemophilia Foundation look forward to the innovation and improved outcomes that gene therapy may offer to people with hemophilia. Many uncertainties with these products still remain, which we may not fully appreciate for

years to come. We must ensure that the FDA implements a rigorous safety program in an effort to protect our community." Gene therapy, while highly promising, is a treatment decision that members of the community should make in close consultation with their medical team and families to address the long-term risks and benefits. Before being heralded as a potentially life-changing treatment, gene therapy should be evaluated with safety outcomes in mind by the regulatory authorities.

NHF is thrilled by the possibility of the benefits that gene therapy may bring but moves forward with cautious optimism with the community in mind. NHF will continue to partner with the bio-pharmaceutical companies, as well as researchers, health care providers, and others as gene therapy continues to emerge as a treatment option. NHF will work with all partners to encourage truthful, timely, transparent communication about all safety concerns.

[Read NHF's citizen petition here.](#) The FDA is expected to respond to NHF's request within the next 200 days. To learn more about submitting your own citizen petition, [click here.](#)

*Continued from page 26*

The weekend is free of charge to our BDASC members. All meals, lodging, and activities are included. Come join us, [register today](#), and "Raise

*Your Shields" in advocacy. Every voice counts!* We are grateful to all our sponsors who make this time together possible!

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## Research & Development

### Paper Features Q&A Resource on Shared Decision Making and Gene Therapy

As investigational hemophilia gene therapies move closer to regulatory authorization, community stakeholders have recognized the acute need for people with hemophilia (PWH) and health-care professionals (HCPs) to be fully engaged in shared decision making (SDM). While the [concept of SDM](#) whereby patient and provider collaborate to reach informed treatment decisions has gained support in recent years, the arrival of such a paradigm-shifting will present unique challenges and opportunities.

Disparities in health literacy, the proliferation of inaccurate and contradictory content on social media, direct-to-patient marketing, plus the sheer complexity of gene therapy, may prevent a PWH from fully engaging in SDM. While some HCPs may also lack a thorough enough understanding of gene therapy, hindering their full participation in the SDM model. In addition, an HCP's perception of their patient's comprehension of this therapy may not align with their patient's actual understanding, a discordance that further compromises SDM, increasing the potential for delayed treatment decisions and other negative outcomes. In light of these anticipated obstacles, an international and multidisciplinary group known as the Council of the Hemophilia Community (CHC) was convened. Composed of independent advisors, HCPs, industry and patient representatives, the goal of the CHC was to fill these information gaps through the development of a resource that would help generate an ongoing dialogue between PWH/HCP, with patient-centricity as its guiding principle.

The CHC held three roundtable meetings between November 2020 and May 2021 wherein they fleshed out a series of questions and answers that would best foster a genuine SDM process amongst PWHs/HCPs. The majority of the decided-upon questions fell under several over-arching categories including treatment regimen/adherence requirements, treatment predictability and

variability, treatment durability, and the risk/benefit profile.

Each of the questions were subsequently assigned to the five stages of the patient "decision making journey." These included 1) Pre-gene therapy information seeking 2) Pre-gene therapy decision making 3) Treat initiation 4) Short-term post-gene therapy follow up (less than one year since receiving gene therapy) 5) Long-term gene therapy follow up (more than one year after receiving gene therapy).

A recent paper published online in the journal *Patient Preference and Adherence (PPA)*, describes in greater detail the process of developing the resource and context in which it was created. [Read the open-access PPA article.](#)

The authors highlight the value of this tool to enhance SDM relevant to hemophilia gene therapy, while also hinting at its potential utility in other disease groups.

"The educational and decision support resources described herein recognize that each patient's decision journey will evolve throughout their lifetime with their individual preferences at different life stages, and with the emergence of new therapies and a growing evidence base," explain the authors. "The Q&A resource provides HCPs and PWH with timely, relevant information, facilitates discussions, and empowers PWH to engage in shared decision-making. As gene therapy products enter the market, the themes and questions mapped here should stimulate discussion and aid interactions among HCPs, PWH, and family members, to ensure that they are fully informed and realize the clinical potential of this treatment. While the issues discussed here pertain to hemophilia, they could also be applied to other hereditary diseases with multiple treatment options."

*Disclaimer: NHF provides periodic [synopses of articles published in peer reviewed journals](#), the purpose of which is to highlight papers that cover a wide range of topics and speak to a broad*

*Continued on page 29*

*Continued from page 28*

spectrum of the inherited blood disorders community. Topics include shared decision making, gene therapy, health equity, and more. NHF hopes you find this content to be informative and engaging. Any questions about the articles featured here should be directed to the publishing journal and/or the study authors. This content is for general

information only. NHF does not give medical advice or engage in the practice of medicine. NHF under no circumstances recommends particular treatment for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

*(Reprinted with permission of NHF)*

*Continued from page 21*

of injections needed in addition to the higher rate of side effects such as facial flushing, headaches, and nausea.

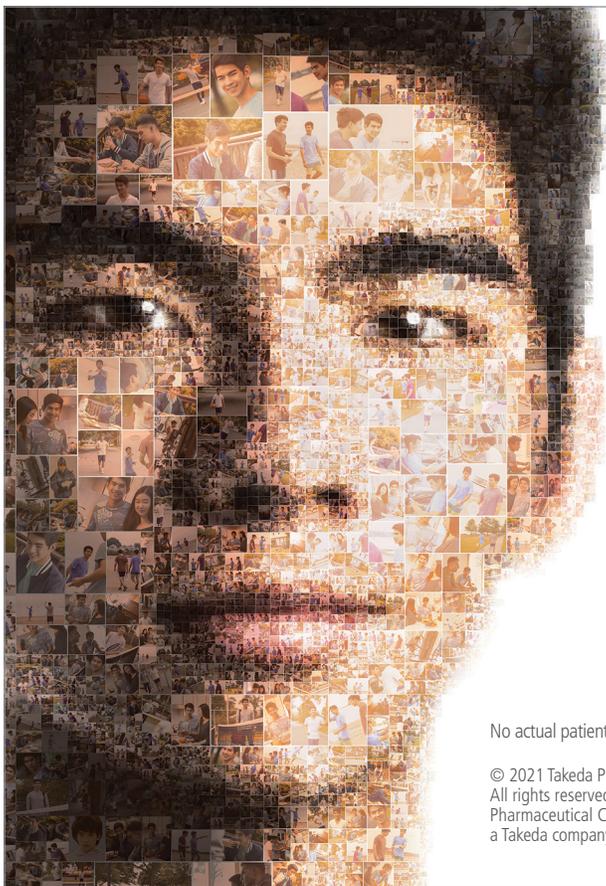
### **Factor Replacement Products**

People who have more severe vWD or who don't respond to DDAVP are often prescribed factor replacement therapy, which is injected into a vein in the arm to replace the missing factor in the blood.

"If the patient has a clinically severe phenotype

of vWD and it isn't clear how invasive the procedure is, then we will need to rely on factor replacement, typically one dose prior to the procedure, followed by a prolonged course of an antifibrinolytic with possible additional factor doses," Sidonio says. "For persons with mild hemophilia A and B, we have definitely been using more single-dose factor replacement, particularly if their levels are below 30%."

*(Reprinted, NHF Website)*



  
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## Resources & Contact Information

### Medical Facilities

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

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

Prisma Health's Upstate Children's Hospital  
MAIN CAMPUS:  
BI-LO Charities Children's Cancer Center Serving Hematology/Oncology Patients  
900 W. Faris Road  
Greenville, SC 29605  
Phone: 864-455-8898  
Fax: 864-455-5164  
Hours: Mon, Wed., Thurs. 8:00-4:30;  
Tues & Fri. 8:00-12:00

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

Hours: Wednesday - alternating mornings and afternoons

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

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

### Local and National Orgs

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

National Hemophilia Foundation  
7 Penn Plaza, Suite 1204  
New York, NY 10001  
Phone: 212-328-3700  
Fax: 212-328-3777  
Phone: 800- 42-HANDI (4-2634)  
Fax: 212- 328-3799  
Email: [handi@hemophilia.org](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)

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

Medic Alert Foundation  
2323 Colorado Avenue  
Turlock, CA 95382  
Phone: 800-432-5378  
Website: [www.medicalert.org](http://www.medicalert.org)

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

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

## Upcoming BDASC Community Events

# **Mark Your Calendar!**

## Looking Ahead: Major Community Engagement Opportunities – Save the Dates!

August 20 – October 8: Inspiring Shots, Greenville, SC

September 17: YES: Young Families Support Group Event, Greenville, SC

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

October 21-23: Health Equity Advocacy Family Camp, Charleston, SC

November 3: Community Dinner Engagement, Columbia, SC

December 10: Winter Statewide Meeting, Columbia, SC

January 12, 2023: Legislative Breakfast at the State Capitol

February 28, 2023: Rare Disease Day at the State Capitol

### **March 1-31, 2023: Bleeding Disorders Awareness Month**

March 1, 2023: Advocacy Days at the State Capitol

March 8-10, 2023: NHF Washington Days

April 13-16, 2023: Hemophilic Federation of America Symposium, Orlando

May 6, 2023: STEP for Bleeding Disorders

June 9-10, 2023: 50<sup>th</sup> Annual Meeting and HELLO Conference

August 10-13, 2023: Teen Retreat

August 17-19, 2023: NHF BDC

## Additional ways to support BDASC



Go to [www.bda-sc.org](http://www.bda-sc.org) and click “Make a Donation” to learn more about how you can support BDASC!



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



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



With MakeMeSmile extension enabled in Google Chrome, you will be redirected to a corresponding AmazonSmile page when you shop on Amazon and 0.5% of all applicable purchases will be donated to Bleeding Disorders Association of South Carolina. Visit our MakeMeSmile page to learn more: <http://www.couponchief.com/makemesmile#23-7400632>



Shop, sell, and donate for a good cause! Go to [www.charity.ebay.com](http://www.charity.ebay.com)



Bleeding Disorders Association  
of South Carolina  
Green Gate Office Park  
25 Woods Lake Road, Ste 300  
Greenville, SC 29607  
[www.bda-sc.org](http://www.bda-sc.org)



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**Thank you to everyone for helping us raise over \$53,000.00 in our STEP for Bleeding Disorders Walk!**



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