

Volume 16, Issue 1  
Winter 2026

# NEWS

the news



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# About BDASC & The News Infusion

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

**BDASC Mission:** Our mission is 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:** Our vision 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.

## Looking Ahead: Save the Dates! Calendar of Events

February 27, 2026: Rare Disease Day Celebration, Columbia, SC

March 1– 31, 2026: Bleeding Disorders Awareness Month

March 1, 2026: VWD Awareness Day, Greenville, SC

March 15, 2026: Rare & Platelet Disorder Awareness Day, Columbia, SC

March 31, 2026: Women Who Bleed Awareness Day

April 2, 2026: World Hemophilia Day Celebration, Greenville, SC

April 17, 2026: World Hemophilia Day

April 17-19, 2026: Adult Retreat, Greenville, SC

May 16, 2026: STEP for Bleeding Disorders, Columbia, SC

June 12-13, 2026: HELLO Conference & Annual Meeting, Greenville, SC

June 29-July 2, 2026: Camp CoAg, Eastover, SC

## BDASC 2025 Staff & Board of Directors

### Executive Director

Sue Martin

### Engagement & Development Manager

Samantha Javorka

### Legislative Consultant & Coordinator

James Romano

### President

Shelley Crisp

### Vice President

Taylor Upton

### Secretary

Virginia Maxwell

### Treasurer

Cristal Day

### Members

Susie Maloy

Christine Evans

James Whitmire

Eric Townsend

Candi Mitchum

Sue Martin, *Ex-Officio Board Member*

## About this Publication

### 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  
www.bda-sc.org



Editor-In-Chief  
Sue Martin

Editor and Publisher  
Samantha Javorka

Contributing Writers  
Sue Martin  
Samantha Javorka

*The News Infusion's* mission is to provide communication, connections, education and advocacy awareness. It is published quarterly by the Bleeding Disorders Association of South Carolina as an informational service to it's 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 healthcare 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 centers and the National Bleeding Disorders Foundation. We encourage your feedback and communications as a forum for exchange of information, ideas and opinions. We welcome your letters, articles, questions and pictures. All articles may be published or distributed in print, electronic online or in other forms. All submissions will be verified and subject to editing. Please send to the editor-in-chief at sue.martin@bda-sc.org. Mail to: 25 Woods Lake Road, Ste. 300, Greenville, SC 29607, Attention: Editor-in-Chief, The News Infusion. We look forward to hearing from you soon!

**Introducing Camp CoAg – A Summer of Friendship, Growth, and Fun!**  
**June 29 - July 2, 2026, Eastover, SC**



**SUMMER CAMP**  
For Kids and Teens With Bleeding Disorders and their siblings

**VISIT OUR WEBSITE TO LEARN MORE!**

**WHERE CLOTTING ISN'T A FACTOR**

June 29 - July 2

We're thrilled to unveil Camp CoAg, the first summer camp in South Carolina designed specifically for children and teens diagnosed with bleeding disorders – and their siblings! This exciting new 4-day overnight camp will take place at Camp Cole in Eastover, SC, and is open to campers ages 5–18 years. At Camp CoAg, young people will enjoy fun activities, build lifelong friendships, and grow in confidence while connecting with peers who truly understand their journey.

**A Partnership for Community and Care**

Camp CoAg is made possible through a meaningful collaboration between the Bleeding Disorders Association of South Carolina (BDASC) and the Hemostasis & Thrombosis Centers of South Carolina at Prisma Health. Together, these organizations are dedicated to providing a safe, supportive, and empowering environment for campers living with hemophilia, von Willebrand disease, platelet disorders, and other rare bleeding conditions.

**Camp Experiences That Matter**

This immersive camp experience goes beyond traditional summer fun – it offers structured opportunities for social connection, confidence building, and peer mentoring. Teens will have the option to serve as Leaders in Training (LITs), gaining leadership skills and supporting younger campers. Every camper must be either a BDASC member or receive care through a Prisma Health Hemostasis & Thrombosis Center to participate.

**No Cost to Families**

Thanks to the partnership between BDASC and Prisma Health, Camp CoAg is provided free of charge, ensuring that every eligible child and teen can participate regardless of financial need. Through travel assistance and camp resources, we're committed to making this experience accessible to all families across the state.

**Join the Adventure**

Registration opened in mid-January, and space is limited – so mark your calendar and get ready for a summer filled with connection, joy, and growth at Camp CoAg!



**SCAN TO LEARN MORE**

### Executive Director's Welcome 2026

*by Sue Martin, Executive Director*

As we step into February, I find myself reflecting with deep gratitude on all that we have accomplished together over the years. As my own journey toward retirement comes closer with each passing year, I am reminded how truly blessed I have been to serve this incredible community. The impact, the relationships, and the shared purpose are things I can never fully put into words.

The Bleeding Disorders Association of South Carolina is strong because of you—our families, advocates, volunteers, donors, partners, and community members from the past, the present, and those we are working to support well into the future. Every program we offer, every connection we foster, and every voice we elevate is inspired by the resilience, compassion, and strength of this remarkable community.

In this welcome, you will see below a snapshot of where we are today—our growing membership, our expanding reach across South Carolina and beyond, and the meaningful impact we continue to make together. Our growth is something to celebrate, but it also brings responsibility. With a small staff and limited budget, we continually ask ourselves how we can do more, reach further, and serve better—while remaining sustainable.

At the same time, innovation in treatment care continues to advance at an incredible pace. Yet access to those innovations becomes more complex and challenging with each passing year. I remain deeply concerned about affordable access to care and treatment for individuals living with bleeding disorders, which is why advocacy remains at the heart of our mission. I am profoundly grateful to our advocates who continue to speak up, show up, and fight for policies that protect patients and families.

None of this work is possible without sustained community support. Our fundraisers, donors, and sponsors make it possible for BDASC to keep programs accessible, inclusive, and free to our members. As we closed 2025, we did face a financial shortfall of nearly \$35,000, requiring us to once again draw from our reserves. Serving the entire state of South Carolina is not easy, but together we continue to do our very best. I encourage our members and supporters to give as they are able, knowing that every contribution helps honor our past and secure a future for the babies, children, and families yet to come.

We have exciting events ahead this year, meaningful opportunities to connect, and innovative programming designed to meet the evolving needs of our community. I invite each of you to get involved—attend an event, support a fundraiser, and help strengthen BDASC for the years ahead. One mission I have always held close is to have an exclusive bleeding disorders summer camp right here in South Carolina—a place where children and teens affected by bleeding disorders can come together, build confidence, and create lifelong memories within their own community. While there are wonderful summer camps across South Carolina that welcome children and teens with bleeding disorders to attend camp with other campers, these opportunities are not being utilized as fully as they could be. Through surveys and conversations exploring why participation has been low through the years, one message rose to the top: the idea for a camp created specifically for youth and teens living with bleeding disorders only, and including their siblings. From that shared vision, Camp CoAg was born in partnership with our HTC's.

Camp CoAg will take place June 29 – July 2, 2026, and we are thrilled to welcome children and teens from across the state. Campers must be members of BDASC or seek treatment at one of Prisma Health's HTC's. We continue to encourage families to take advantage of all available camp opportunities, but we especially invite those who have never attended a summer camp to join us this year and experience what Camp CoAg is all about. I often share that one of the reasons my own children living with hemophilia did well throughout their youth was in part because of their



# Board's Blog - Executive Director Welcome

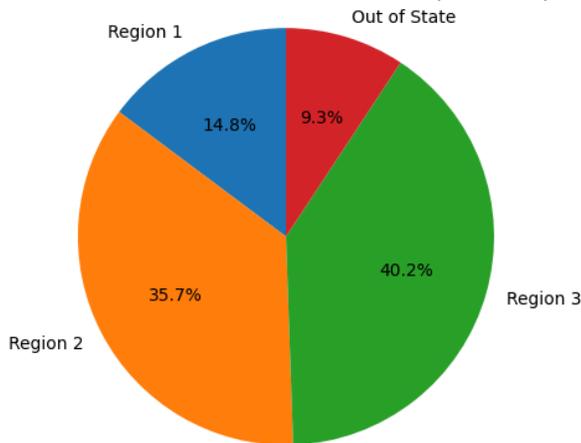
summer camp experience—learning independence, building confidence, and simply being kids among others who understood their journey. That is the gift Camp CoAg offers, and it is only possible because of the generosity of our donors and sponsors and the dedication of volunteers. Your support directly creates these life-changing moments. Whether by donating, sponsoring a camper, volunteering your time, or helping spread the word, you play a vital role in making Camp CoAg a reality. Registration is now open, and I encourage you to visit our website or reach out to our office or the HTC's to get involved. Together, we are building something truly special—for today's children and for generations to come.

We are also seeking passionate individuals ready to step into leadership by joining our Board of Directors. If you feel called to make a deeper impact, I would love to have a conversation with you and share the deep satisfaction that comes from helping guide this organization forward. I am deeply grateful to those who serve today and to those who have served in years past—your leadership has helped shape who we are. Our current Board of Directors will meet in March for our annual Strategic Planning Retreat. If there are needs, ideas, or concerns you would like to bring into that conversation, please feel free to pick up the phone and give me a call. We truly welcome and value all conversations. I am inspired by you every single day. Thank you for believing in this community, for standing together through challenges, and for continuing to move us forward with hope and determination. I ask for your continued support, engagement, and advocacy as we work—together—to ensure a stronger, more equitable future for everyone affected by bleeding disorders in South Carolina.

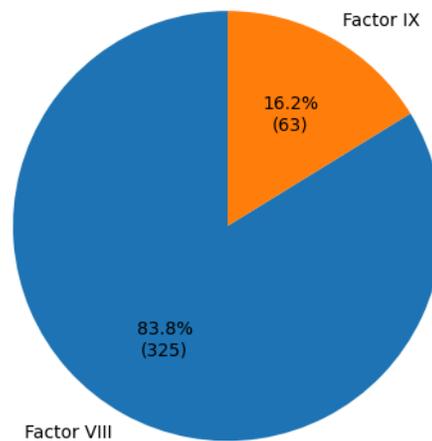
With gratitude, love and appreciation,  
*Sue*

## Our Members Drive Us In All We Do - Thank You! Engage, Empower and Educate

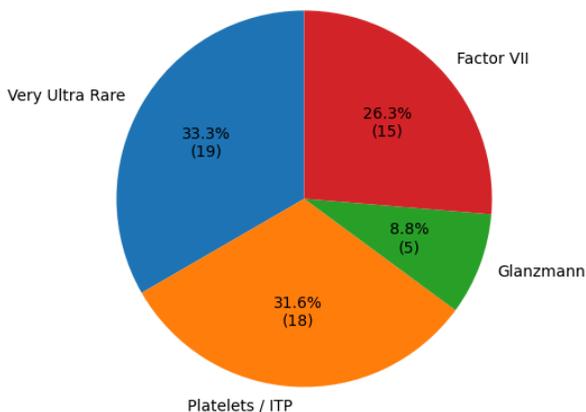
Distribution of BDASC Member Families (Total: 635)



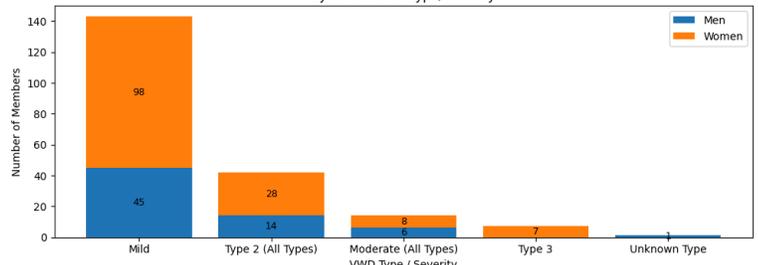
Distribution of Members with Hemophilia (Total: 388)



Distribution of Ultra Rare Bleeding Disorders (Total: 57)



Members Living with von Willebrand Disease (VWD) by Gender and Type/Severity



BDASC supports over 200 members living with von Willebrand disease. The majority are women, many with mild to moderate disease that is frequently underdiagnosed and undertreated—underscoring the need for education, access to specialized care, and ongoing advocacy.

## Behind Every Strong Community Is a Team of Volunteers—Here's Why That Matters

At BDASC, we are deeply grateful for the volunteers who give their time, energy, and heart to our mission—especially those who return year after year. With just two full-time staff, our work would not be possible without your dedication. From planning to final applause, our events succeed because of you. You truly are the heart of BDASC.



**Thinking About Volunteering?** If you're looking to support a meaningful cause, connect with compassionate people, and have fun along the way, we'd love to have you. Whether you're part of the bleeding disorders community or a supportive ally, there's a role for everyone. From assembling welcome packets to helping at fundraisers, every contribution matters.

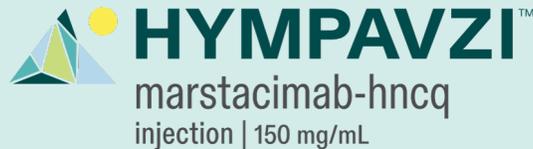
No special skills are required—just a willingness to help and a few hours of your time.

**Ready to Get Involved?** To learn more or sign up, contact Executive Director Sue Martin at [sue.martin@bda-sc.org](mailto:sue.martin@bda-sc.org), call the Chapter office, or register on our volunteer page.

**A Special Thank You!** To our 2025 Volunteers—thank you for your energy, compassion, and teamwork. From volunteering as part of our board of directors, to volunteering for our events, your efforts support our staff and uplift the entire community. We are grateful to have you as part of the BDASC family.



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## Guiding Our Mission. Strengthening Our Community

At BDASC, our mission is more than words—it's a commitment to raising awareness, advocating for individuals and families affected by bleeding disorders, providing education and support, and promoting research for a better future. This work is driven by dedicated staff, consultants, and a committed Board of Directors. Our board helps guide BDASC's vision, ensuring our programs and services reflect the needs of our community. Board members meet monthly with our Executive Director to help shape the organization's direction and impact.



We are seeking new leaders to join our mission. We're looking for individuals who are passionate about making a difference, committed to advocacy and service, and ready to help shape BDASC's future. To learn more about board service or apply, visit [bda-sc.org](http://bda-sc.org) or contact Executive Director Sue Martin or Board President Shelley Crisp.

**Together, we can continue building a stronger, more supported, and empowered community—now and for generations to come.**



“The best part of being on the BDASC board is helping turn awareness into real support for individuals and families living with bleeding disorders. It's incredibly meaningful to work alongside passionate advocates and know our efforts create connection, education, and hope in the community.”

**Shelley Crisp**  
Board President

“Serving on the board is super fulfilling. It makes you feel part of something so much bigger than yourself.”

**Taylor Upton**  
Board Vice President



“Serving on the board is such an honor and blessing. It is very fulfilling to work with my community family as a united front for access to lifesaving healthcare for us all.”

**Cristal Day**  
Board Treasurer

## Board's Blog



“ I am honored to serve on the board for the Bleeding Disorders Association of South Carolina. I feel like I am able to provide helpful insight due to the similar struggles I have had with trying to access medications while having a rare disorder. I volunteer in hope I may ease another patients struggles. ”

**Virginia Maxwell**  
Board Secretary

“ Serving on the board is an honor that allows me to give back to the community that continues to shape and inspire me. As one of the youngest members and the video editor, I'm proud to bring a fresh perspective while using storytelling to amplify our mission and the people we serve. ”

**Eric Townsend**  
Board Member



“ Serving on the board is an uplifting and amazing experience of getting to help and support others in the community while learning just how much goes into making everything possible. Just being able to share and help those who need it, and ensure the community's future, means more to me than anything else. ”

**Candi Mitchum**  
Board Member

“ Serving on the Board of Directors for the bleeding disorders community is an absolute honor. Helping guide the future for those we love and cherish and lending a voice to advance this community forward is both meaningful and necessary. What you receive in return for your service is something that cannot be captured in just a few words. It is a heart forever full and the knowledge that a day of service can truly change someone's life. ”

**Sue Martin**  
Ex Officio Board Member



“ As a member of the board, I am honored to be a voice of persons with bleeding disorders and humbled as part of a great team that holds our community together. ”

**Christian Evans**  
Board Member

“ When I first got my son with Hemophilia of South Carolina, he enjoyed it so much and it helped me a lot to cope with what I was going on with him. I felt like I wanted to give back to them and that's why I decided I wanted to get on the board. I didn't have any extra money to give, but I had my time. I really enjoy being on the board to help others. ”

**Edna Rabb**  
Board Member



“ I have felt honored to be on this board. It gave me the opportunity to help the community with all the issues we face and help whoever needs it. To be on this board at first may seem scary, but everyone makes you feel welcome. There is no opinion discarded. I felt being on this board I was contributing not only my time but actively helping where I could. It really gives you a sense of accomplishment that your input is valued. We need your voices and opinions. ”



**Susie Maloy**  
Board Member

“ As an older board member of BDASC, I am proud of the accomplishments that our organization has made in bringing awareness to the issues facing individuals in the bleeding disorders community. I want my purpose on the board to be to encourage participation from a very diverse community to further the efforts of increasing awareness and gaining greater access to medication treatment. It is an honor to serve with dedicated individuals that understand the significance of Advocacy and fighting for the underserved families of Bleeding Disorders of South Carolina. ”

**James Whitmire**  
Board Member



## Academic Scholarships Now Available for BDASC Members!

We're excited to share that the Bleeding Disorders Association of South Carolina (BDASC) is now accepting applications for our **2026 Academic Scholarship Program!** These scholarships support members of the bleeding disorders community who are pursuing higher education.

### Who can apply?

This opportunity is open to **BDASC members** who:

- Are South Carolina residents,
- Are enrolled in or accepted to an accredited college, university, technical, vocational, or trade school, and
- Have a bleeding disorder themselves or are an immediate family member (dependent child, sibling, parent, or spouse) of someone with a diagnosed bleeding disorder.

Scholarship awards typically range from **\$500 – \$1,000**, with the final amount based on available funds and the number of strong applicants. Don't miss your chance to apply! Be sure to submit your completed application by the **April 20, 2026** deadline.



# Community Engagements

## Winterfest 2025: A Joyful Year-End Celebration December 13, 2025, Riverbanks Zoo, Columbia, SC

BDASC closed out the year with Winterfest, our annual state holiday gathering that brought families and individuals from across South Carolina together to celebrate the season and our community. The event provided a meaningful opportunity to connect, reflect, and enjoy time together in a festive and welcoming setting.



Attendees enjoyed a shared lunch, an educational presentation, and time to explore the zoo and make memories with one another. A special thank you to Bradley Odac with Novo Nordisk for delivering an informative and engaging lunch presentation—we are grateful for his support and partnership.

Winterfest was a wonderful way to end the year with joy, connection, and gratitude, reminding us of the strength and warmth of the BDASC community.



Lunch/Premier Sponsor

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specialty™

**sanofi**



## Supporting our community is the foundation of what we do



**That's why Novo Nordisk goes beyond offering a broad range of treatments and is dedicated to providing educational resources and one-on-one support!**

We have **resources** for people living with:

- Hemophilia A
- Hemophilia B
- Hemophilia A with inhibitors
- Hemophilia B with inhibitors
- Glanzmann's thrombasthenia when platelets don't work
- Factor VII deficiency
- Factor XIII A-subunit deficiency

**Get connected locally with one of our Hemophilia Community Liaisons (HCL) to see how they can help you!**

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# Upcoming Community Engagements

## BDASC Kicked Off the 2026 Legislative Session with Advocacy and Awareness

January 14, 2026, Columbia, SC

BDASC proudly hosted a legislative breakfast to kick off the 2026 legislative session, welcoming legislators for their first breakfast event of the year. With the support of 33 advocates from the bleeding disorders community, the gathering created a warm and impactful opportunity to welcome legislators, share personal stories, and raise awareness about bleeding disorders across South Carolina.

Hosted with support from our national partner the National Bleeding Disorders Foundation (NBDF), the breakfast encouraged meaningful dialogue around current legislation affecting individuals and families living with bleeding disorders. Advocates and legislators alike engaged in conversations that highlighted both the challenges and the importance of continued advocacy at the state level.

Breakfast was provided by Lizards Thicket, adding a local and welcoming touch to the morning. Overall, the event was a successful way to begin the legislative session, ensuring bleeding disorders were part of the conversation from day one.

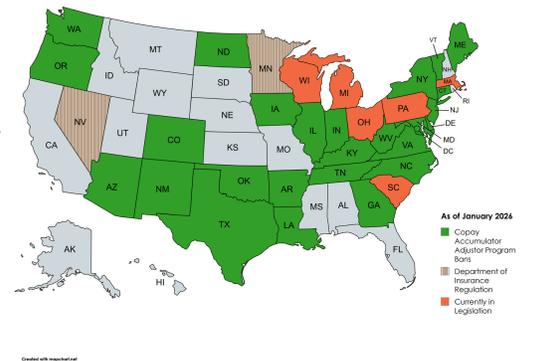


## State Advocacy Days

February 24-25, 2026, Columbia, SC

In February 2026, advocates from across South Carolina will gather in Columbia for the Bleeding Disorders Association of South Carolina's Annual State Capitol Advocacy Days. The event will begin with an educational dinner and advocacy training to prepare participants to confidently share their stories and discuss key policy priorities with lawmakers. Advocates will then convene at the State House to educate legislators and advocate for policies that protect access to life-saving care, including advancing House Bill H.3934 and Senate Bill S.330, which aim to address harmful insurance practices by prohibiting copay accumulator adjustment programs and ensuring copay assistance counts toward patients' out-of-pocket maximums.

Participants will also emphasize the importance of preserving funding for the Hemophilia Assistance Program and supporting South Carolina's Hemophilia Treatment Centers. Through education, engagement, and lived experiences, the 2026 Advocacy Days will strengthen relationships with policymakers and reinforce the shared goal of equitable, affordable, and uninterrupted care for all South Carolinians living with bleeding disorders.



<p><b>Year-Round Advocacy Sponsor</b></p>	<p><b>Advocacy Coalition Sponsor</b></p>	<p><b>Platinum Lunch Sponsor</b></p>	<p><b>Premier Dinner Sponsor</b></p>
<p><b>Platinum Sponsors</b></p>		<p><b>Advocacy Community Partner</b></p>	

# bleeding disorders awareness campaign

**SUPPORTING THOSE LIVING WITH BLEEDING DISORDERS  
FEBRUARY 28TH - APRIL 17TH**

## Bleeding Disorders Awareness Month Campaign

*March 1 - April 17, 2026, Various*

Each March, during Bleeding Disorders Awareness Month, BDASC launches its Annual Giving Drive — a vital campaign that strengthens our mission and supports those living with bleeding disorders across South Carolina.

Funds raised during this campaign help BDASC advance research, global initiatives, community advocacy, education, and access to quality treatment and care. Every dollar donated stays right here in South Carolina, directly benefiting individuals and families within our community. This year’s Bleeding Disorders Awareness Month Campaign runs from Rare Disease Day (February 28) through World Hemophilia Day (April 17). Together, we can continue making a lasting difference — one gift at a time.

We look forward to hosting events in celebration of Bleeding Disorders Awareness Month.



### Lighting it Up Red for Bleeding Disorders Awareness Month

In honor of National Bleeding Disorders Awareness Month two of Greenville’s most iconic landmarks—the **Falls Park Liberty Bridge** and the **Aurora Bridge at Unity Park**—will be illuminated red from March 1–15. These powerful displays help shine a light on the bleeding disorders community and raise awareness across our city

Be sure to stop by and help us spread the word! We’d love for you to snap a photo and share it with us as Greenville goes red in support of our community.

# Thank You!

A Special Thank You to Those Who Purchased our Bleeding Disorders Awareness T-Shirts or made a donation through the campaign. Because of your generosity, we raised **\$171.80** in support of those living with bleeding disorders in South Carolina!

## SC RDAC Rare Disease Symposium

*February 27, 2026, Segra Park, Columbia, SC*

The SC RDAC invites you to join them in honor of Rare Disease Day to learn about innovative and impactful research going on across the state, hear personal stories from those affected by rare disease and discover some of the important advocacy work that’s grown out of both necessity and hope. The symposium is free and open to the public, but registration is strongly encouraged regardless of whether you are attending in-person or virtually. A confirmation email including symposium details (and a Zoom link for those attending virtually) will be sent to all registrants before the scheduled date.

### RARE DISEASE SYMPOSIUM

OPEN TO THE PUBLIC



Attend in-person or virtually to learn about innovative and impactful research going on across the state, hear personal stories from those affected by rare disease and discover some of the important advocacy work that’s grown out of both necessity and hope.

The symposium is free but registration is strongly encouraged. Lunch and parking validation will be provided to anyone attending in-person who registers by February 15.

SCAN TO REGISTER



FEBRUARY 27, 2026

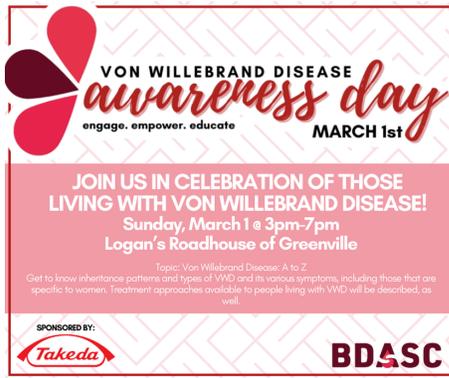
10 AM - 2 PM

IN-PERSON AT SEGRA PARK  
1640 FREED STREET  
COLUMBIA, SC 29201



rarediseaseSC.org

# Upcoming Community Engagements



**VON WILLEBRAND DISEASE**  
*awareness day*  
engage. empower. educate  
**MARCH 1st**

**JOIN US IN CELEBRATION OF THOSE LIVING WITH VON WILLEBRAND DISEASE!**  
Sunday, March 1 @ 3pm-7pm  
Logan's Roadhouse of Greenville

Topic: Von Willebrand Disease: A to Z. Get to know inheritance patterns and types of VWD and its various symptoms, including those that are specific to women. Treatment approaches available to people living with VWD will be described, as well.

SPONSORED BY:  
 **BDASC**

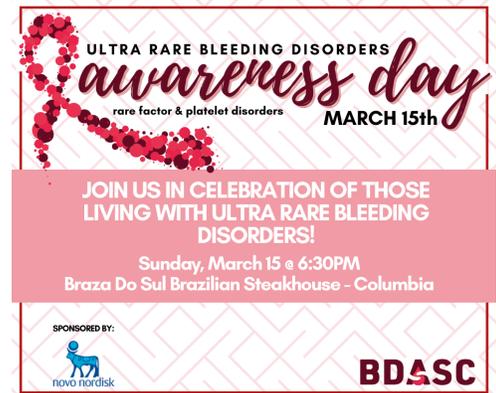
## VWD Awareness Day Celebration Event March 1, 2026, Logan's Roadhouse, Greenville, SC

Join us on Saturday, March 1 at 3:00 PM for our VWD Awareness Day event in Greenville! We'll gather at Logan's Roadhouse for celebrations, attendees will enjoy a fun and creative painting project with Ribbons and Burlap, and then conclude the afternoon with an educational dinner sponsored by Takeda. The featured presentation "VWD: A to Z," will provide a clear, comprehensive overview of von Willebrand disease. This free event is a great opportunity to learn, connect, and celebrate our community—don't miss it!



## Ultra Rare Bleeding Disorders Awareness Day Celebration Event March 15, 2026, Braza Do Sul, Columbia, SC

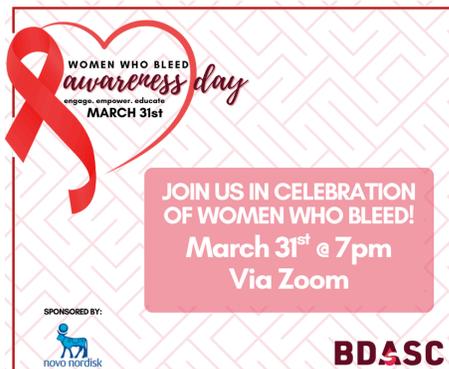
Join us on March 15 at Braza Do Sul in Columbia, SC for our Ultra Rare Awareness Day Celebration—an evening dedicated to education, connection, and community. Beginning at 6:30 PM, this educational dinner will highlight the importance of spreading awareness and amplifying the voices of individuals and families affected by Ultra Rare Bleeding Disorders. Together, we'll learn, share, and stand in support of this often-overlooked community while enjoying a meaningful night of conversation and fellowship. This free event is brought to us by Novo Nordisk.



**ULTRA RARE BLEEDING DISORDERS**  
*awareness day*  
rare factor & platelet disorders  
**MARCH 15th**

**JOIN US IN CELEBRATION OF THOSE LIVING WITH ULTRA RARE BLEEDING DISORDERS!**  
Sunday, March 15 @ 6:30PM  
Braza Do Sul Brazilian Steakhouse - Columbia

SPONSORED BY:  
 **BDASC**



**WOMEN WHO BLEED**  
*awareness day*  
engage. empower. educate  
**MARCH 31st**

**JOIN US IN CELEBRATION OF WOMEN WHO BLEED!**  
March 31st @ 7pm  
Via Zoom

SPONSORED BY:  
 **BDASC**

## Women Who Bleed Awareness Day Celebration Event March 31, 2026, Via Zoom

Join us on March 31 at 7:00 PM for our Women Who Bleed Awareness Day Event, held virtually via Zoom. This educational and supportive session will focus on uplifting and empowering women who bleed, whether they have a formal diagnosis or are still seeking answers. Together, we'll create a welcoming space to learn, share experiences, and raise awareness around the unique challenges women face in the bleeding disorders community—because every story matters, diagnosed or not.



## World Hemophilia Day Celebration Event April 2, 2026, Grand Bohemian Lodge, Greenville, SC

Join us on April 2 at the Grand Bohemian Lodge in Greenville, SC for our World Hemophilia Day Celebration Event, beginning at 6:30 PM. This special evening will honor and uplift all those living with bleeding disorders while highlighting this year's theme, "Diagnosis: First Step to Care." Through education, awareness, and community connection, we'll emphasize the critical role an accurate diagnosis plays in accessing timely, life-changing care. We are grateful to Sanofi for sponsoring this meaningful free event as we come together in support of our bleeding disorders community.



**World Hemophilia Day**  
April 17  
recognizing all bleeding disorders

**JOIN US IN CELEBRATION OF WORLD HEMOPHILIA DAY!**  
April 2, 2026 @ 6:30PM  
Grand Bohemian Lodge Greenville  
44 E. Camperdown Way  
Greenville, SC

SPONSORED BY:  
 **BDASC**

# Upcoming Community Engagements

## Adult Connections Symposium

April 17-19, 2026, Greenville, SC

BDASC's Adult Connections Symposium is a signature weekend designed to bring adults impacted by bleeding disorders together for an enriching experience centered on education, connection, and shared understanding. Created specifically for adults and couples within the bleeding disorders community, this symposium offers a welcoming space to learn, reflect, and grow alongside others who truly understand the realities of navigating life with a bleeding disorder. Through interactive workshops, participants will explore topics such as self-advocacy, wellness, communication, and balancing personal, professional, and health-related priorities.

We are excited to welcome back Jim Stroker, who will lead a dynamic and engaging session filled with practical tools, actionable strategies, and inspiring insights. His presentation will empower participants to better manage challenges, advocate for themselves with confidence, and strengthen skills that support success in both personal relationships and professional settings. Educational programming will be complemented by meaningful opportunities for discussion, peer connection, and shared learning throughout the weekend. Attendees will enjoy a special showing of *Dismissed*, sparking conversation around shared experiences and perspectives within our community. Couples will also have the opportunity to participate in a fun and interactive "Newlywed Game," offering a lighthearted way to connect, laugh, and see just how well partners know each other. Social outings are also included on Friday night at Group Therapy of Greenville and Saturday night at Topgolf.

Space is limited and registration is required. A \$25 registration fee secures your attendance for this memorable and impactful weekend. Don't miss this opportunity to learn, connect, and build lasting relationships with others who share your journey. **The final day to register is March 20th.**



### Dismissed: A Documentary About Women with Hemophilia

*Dismissed* tells the stories of women with hemophilia who have been ignored, misdiagnosed, or left untreated for generations. At its center is 15-year-old Isabelle, a rare case who received early care and now advocates for others. Alongside her are a pregnant mother without a treatment plan, a woman confronting symptoms she's long hidden, and another left partially paralyzed after being dismissed by doctors. The film is a call to action for recognition, advocacy, and change.



Learn more about *Dismissed*



After our welcome and dinner, we'll head next door to Group Therapy for a fun and interactive night of unwinding and connection. Located in the heart of Greenville, this unique venue offers great food, cocktails, and exciting activities—including duckpin bowling and axe throwing. It's the perfect chance to relax, have fun, and connect with other adults in the community.



TOPGOLF

On Saturday evening, we'll head to Topgolf Greenville for a relaxed night of great food, friendly competition, and lots of laughs. Whether you're a seasoned golfer or picking up a club for the first time, it's the perfect opportunity to swing, socialize, and enjoy a memorable evening together.

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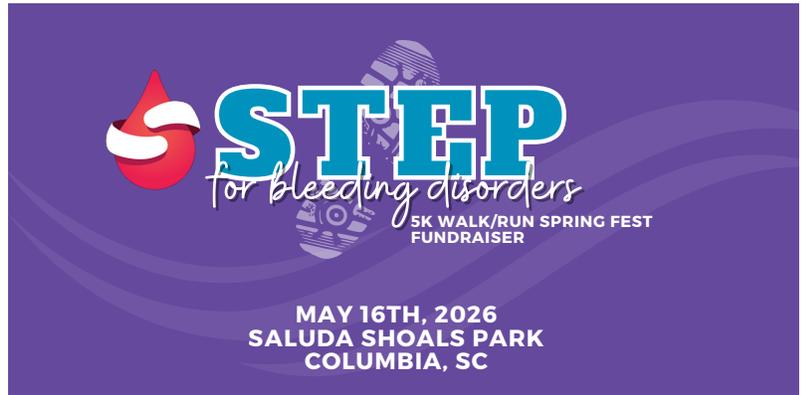
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## Upcoming Community Engagements

### 2026 STEP For Bleeding Disorders - SpringFest! May 16, 2026, Saluda Shoals Park, Columbia, SC

Spring into action with us on May 16, 2026 for the 2026 STEP for Bleeding Disorders 5K Run/Walk & Spring Fest – a family-friendly fundraiser and awareness event hosted by the Bleeding Disorders Association of South Carolina! This annual event brings together our community and allies to raise vital funds that help support people living with bleeding disorders across South Carolina.



Whether you're an avid runner or a casual walker, everyone is welcome to register as a participant or form a team! This event is more than a race – it's a celebration of community, courage, and hope. You can walk or run in person, enjoy entertainment, connect with others, and help drive awareness of bleeding disorders. All proceeds stay right here in South Carolina to fund education, support services, advocacy efforts, camps, scholarships, and more for individuals and families affected by bleeding disorders.

#### Why Your Support Matters

With limited funding this year, STEP for Bleeding Disorders is more important than ever. Your registration and fundraising help ensure we can continue offering essential programs – from advocacy initiatives that protect access to care, to educational resources, financial assistance, and community connections across the state.

#### How You Can Help

- **Register as a participant** – Walk or run the course and be part of something meaningful.
- **Start or join a team** – Teams are a fun way to rally support and raise more funds together!
- **Spread the word** – Share the event with friends, family, coworkers, and your community network.
- **Fundraise** – Every dollar raised brings us closer to serving more families and expanding our impact.



Let's make this year's STEP for Bleeding Disorders our most successful yet – together, we can raise awareness, build community, and bring needed resources to the families who depend on them. Visit the official STEP for Bleeding Disorders page to register and learn more today! This is a wonderful opportunity to invite friends, family, neighbors, and business partners to experience a BDASC event firsthand. By coming together, you'll help raise awareness, spark meaningful conversations, and strengthen community support for individuals and families affected by bleeding disorders.



## Upcoming Community Engagements

### 2026 Annual Meeting & HELLO Conference

*June 12-13, 2026, Greenville, SC*

Join Us for the Annual Meeting & HELLO Conference! BDASC is excited to bring our community together for the Annual Meeting & HELLO Conference, a weekend dedicated to education, connection, and empowerment. This statewide gathering offers dynamic educational sessions, expert speakers, and meaningful opportunities to connect with others in the bleeding disorders community.

The free conference includes interactive workshops, inspiring presentations, and time to build relationships with peers, caregivers, and healthcare partners. Whether you're seeking practical tools, fresh insights, or community support, this event is designed to help you learn, grow, and feel encouraged.

In addition to rich educational content, the conference brings joy and fellowship through shared meals, lively conversation, and moments that strengthen our community bonds.

Space is limited, and registration is required to attend. We encourage you to register early to secure your spot at this impactful annual gathering. Final day to register is May 15<sup>th</sup>! Don't miss this opportunity to connect, learn, and be part of a vibrant community committed to advocacy, education, and mutual support. We hope to see you there!



#### Conference Highlights

Our plenary session offers a patient-centered overview of the current and future landscape of bleeding disorders care, led by Dr. Bobby Duc Tran, MD, MSc, Chief Medical Officer. Attendees will receive clear, practical education on approved and emerging therapies, clinical trials—including ongoing research in von Willebrand disease—and how new treatments work in the body, with attention to safety, benefits, and limitations. Dr. Tran will also address common questions and concerns while sharing insights into how regional Hemophilia Treatment Centers are preparing for an evolving treatment environment. Designed to empower patients, caregivers, and families, the session equips participants with the knowledge needed to engage in informed, meaningful conversations with their healthcare teams now and in the years ahead.

We're excited to share that free childcare will be available during the event, made possible with the support of Corporate Kids Events, so parents and caregivers can fully participate with peace of mind. In addition, we will offer dedicated teen programming designed to engage and inspire older youth, including a special experience with GutMonkey. These activities ensure that children and teens are supported, entertained, and included while families take part in the day's programming.

Additional breakout sessions may also be offered. Proposed topics include education for individuals with mild bleeding conditions—such as VWD, carriers, and women with bleeding disorders—focused on recognizing bleeds, timely treatment, and self-advocacy; an empowered goal-setting session to help individuals and families thrive across health, work or school, relationships, and community life; a mental wellness session exploring stress, its impact, and practical coping strategies; and an advocacy-focused discussion highlighting current issues and ways participants can get involved and make a difference. Afternoon sessions may also include a support and wellness workshop on aging with a bleeding disorder, offering shared experiences, resources, and tools to help navigate the challenges that can come with growing older.





# Want to hear from someone who has received HEMGENIX?

Watch  
Michael's  
Story here:



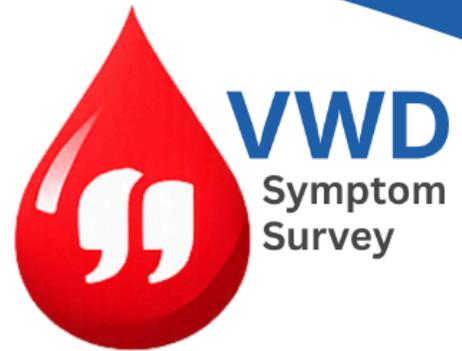
— Michael, 23-year-old  
treated with HEMGENIX

**Actual HEMGENIX patient.**  
Patient experiences may vary.

**Visit [HEMGENIX.com](https://www.hemgenix.com)  
to learn more**

**Study Title:** The Von Willebrand Disease-Health Index (VWD-HI): Development of a Patient-Reported Outcome Measure for Von Willebrand Disease

**Principal Investigator:** Chad Heatwole, MD, MS-CI



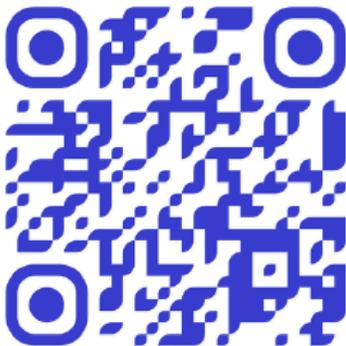
**Study Details:**

Researchers at the University of Rochester are interested in creating a patient-reported outcome measure that will assess the health, symptoms, and disease burden of individuals with Von Willebrand disease. This study is being completed by Dr. Chad Heatwole from the University of Rochester’s Department of Neurology.

This study aims to identify the symptoms that have the greatest impact on quality-of-life for individuals with Von Willebrand disease. This will help guide future research involving individuals with Von Willebrand disease.

**How to participate:**

Interested participants can scan the QR code or navigate to the website address below.



<https://redcap.link/VWDsurvey>

**Who can participate:**

- Be 18 years old or older
- Be diagnosed with Von Willebrand disease
- Reside in the United States, Canada, United Kingdom, European Union, or Australia
- Speak, read, and understand English

**What’s Involved:**

The study involves completing demographic questions and completing an online survey asking about the symptoms of Von Willebrand disease you experience. The survey will take approximately 10 minutes to complete, and you may skip any questions that you do not wish to answer. All responses will be anonymous and strictly confidential.

## Star Therapeutics Presents Interim Data from Phase 1/2 Multidose Study of VGA039 in Von Willebrand Disease, Demonstrating Substantial Bleed Reductions in All Patients, at ASH Annual Meeting

SOUTH SAN FRANCISCO, Calif.--(BUSINESS WIRE)--Star Therapeutics, a late clinical-stage biotechnology company discovering and developing best-in-class antibodies for bleeding disorders and other diseases, today announced interim data from its ongoing Phase 1/2 multidose study of VGA039 in von Willebrand disease (VWD). The data are being presented in an oral session at the 67<sup>th</sup> American Society of Hematology (ASH) Annual Meeting and Exposition in Orlando, Florida. VGA039 is a first-in-class monoclonal antibody therapy that targets Protein S, with dual actions promoting platelet attachment and enhancing fibrin deposition to restore hemostasis.

In the Phase 1/2 multidose study, treatment with VGA039 administered subcutaneously once monthly resulted in a substantial reduction in annual bleeding rate (ABR) across all types of VWD and all types of bleeds, including meaningful improvement in bleed control for patients switching from prior von Willebrand factor (VWF)-containing intravenous (IV) prophylaxis. The study population includes patients with Types 1, 2, and 3 VWD who have high disease burden, including patients with serious gastrointestinal (GI) and hemophilia-like joint and muscle bleeds.

“The data presented at ASH indicate that VGA039 could be transformative for people living with VWD, a condition with more than 130,000 diagnosed patients in the U.S. alone,” said Allison Wheeler, M.D., MSCI, Associate Professor of Pediatrics at the University of Washington. “VWD can have a significant impact on quality of life, with patients experiencing frequent and severe bleeds that can require hospitalization. Current treatment options remain limited, with VWF-containing prophylaxis requiring multiple IV infusions per week. Data from the multidose trial support a once monthly subcutaneous dosing regimen for VGA039, which could meaningfully alleviate the current treatment burden with the potential for even better bleed control over the standard of care.”

### Key highlights from the presentation include:

- As of November 14, 2025, interim data from all 16 patients enrolled in the Phase 1/2 multidose study were available, including safety data on all 16 patients and efficacy data on all 8 patients who had completed treatment with VGA039.
- VGA039 once monthly subcutaneous prophylaxis was safe and well tolerated.
- VGA039 demonstrated substantial reductions in ABR across all patients, with all types of VWD and all types of bleeds (including serious GI and hemophilia-like joint and muscle bleeds).
  - Bleed reductions were 73%-87% for all the participants enrolled who have the same ABR as the population being recruited into the Phase 3 trial (ABR  $\geq$  12, no prior IV prophylaxis).
  - In patients switching from prior VWF-containing prophylaxis (IV infusions multiple times per week), bleed reductions were 75%-100%, indicating potential efficacy and dosing improvement over standard-of-care.
- All participants to date who have completed the multidose study have transitioned to the open-label extension (OLE) study.

“This dataset is compelling, encompassing a diverse patient population across multiple VWD types, a full spectrum of bleed profiles, and individuals transitioning from prior prophylaxis regimens. VGA039’s ability to consistently reduce bleeding across these groups along with its favorable safety and tolerability profile indicate that VGA039 has the potential to improve outcomes for all patients with VWD,” said Steven Pipe, M.D., Professor of Pediatrics and Pathology at the University of Michigan. “Importantly, patients who transitioned from IV prophylaxis multiple times per week to once monthly subcutaneous VGA039 experienced marked improvements in bleed control, highlighting the potential to establish a new standard of care for people living with VWD.”

“These interim data provide further validation of VGA039 as a potential once monthly subcutaneous treatment for multiple bleeding disorders, starting with VWD. All patients to date have opted to continue treatment as part of our open-label extension study after finishing the multidose trial,” said Gary Patou, M.D., Chief Medical Officer of Star Therapeutics. “These data, along with the recent initiation of our pivotal Phase 3 study, VIVID-6, continue to add to the momentum surrounding this program, bringing us another step closer to achieving our mission of creating life-changing therapies for patients with bleeding disorders.”



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

We are deeply grateful for the incredible generosity of our supporters and sponsors. Your contributions make it possible for us to continue our mission of serving and uplifting the bleeding disorders community. Because of you, we are able to reach further, dream bigger, and provide life-changing programs, resources, and opportunities for those who need them most. Thank you for believing in our work and standing beside us—your support is the true driving force behind all that we do.

## **INDIVIDUAL DONORS & SUPPORTERS**

Blackbaud Giving Campaign / Ken  
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Sue Martin  
Tray Causey

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National Bleeding Disorders Foundation



# South Carolina Hemophilia and Bleeding Disorders Advocacy Coalition Hosts 2026 Legislative Breakfast at the State Capitol

by James Romano and Sue Martin

On Wednesday, January 14, the Bleeding Disorders Association of South Carolina (BDASC) proudly hosted its fourth annual Legislative Breakfast at the South Carolina State Capitol in Columbia, bringing together patient advocates, chapter leadership, and state lawmakers for a meaningful morning of education and connection.

This annual event provides a vital opportunity for individuals and families affected by bleeding disorders to meet directly with members of the South Carolina House of Representatives and Senate to discuss healthcare access and policy priorities. Widely attended throughout the Capitol complex, the 2026 breakfast welcomed more than 250 legislators and staff members. BDASC was especially grateful to have 33 patient advocates and community members from across South Carolina join us to share their voices and lived experiences.

This year, the bleeding disorders community continued its focused advocacy for H.3934 and S.330, legislation that would ban the use of copayment accumulator adjustment programs. These programs allow insurance companies to accept copay assistance from manufacturers or nonprofit organizations while refusing to count that assistance toward a patient's out-of-pocket maximum. As a result, patients can be forced to pay thousands of additional dollars for medically necessary, often life-sustaining treatments—while insurers effectively “double dip.” This legislation would ensure that all payments made on a patient's behalf are counted toward their required out-of-pocket costs, restoring fairness and transparency to the system.

BDASC was honored to welcome long-standing legislative champions and friends, including Senator Thomas Alexander (R-1st), Representative Gilda Cobb Hunter (D-9th), Senator Jason Elliot (R-6th), Representative Lucas Atkinson (D-57th), Representative Chandra Dillard (D-23rd), and Representative Paul Wickensimer (R-22nd). We were also pleased to build new relationships with lawmakers such as Representative Greg Ford (R-98th) and Senator Jeffrey Graham (D-35th). The program featured a legislative briefing led by our bill champions, Representative Carla Schuessler (R-61st) and Senator Mike Gambrell (R-4th), who each spoke passionately about the importance of passing this legislation to protect South Carolina families living with chronic and rare conditions.

Attendees also heard powerful personal testimonies from patient advocates Candi Mitchum, Kristen Shelton, and Ginny Maxwell, whose stories underscored the real-life consequences of insurance practices that limit access to care.

The 2026 Legislative Breakfast marked a strong and hopeful start to the year. Passing copayment accumulator reform remains a top priority for our community,

and your voice matters. If you have not yet contacted your Representative or Senator, please reach out to BDASC Executive Director, Sue Martin, and the Chapter will gladly help you connect with your elected officials and share your story.

Together, we can ensure fair access to care for all South Carolinians living with bleeding disorders.

Sue.martin@bda-sc.org / 864-350-9941

Learn More: <https://bda-sc.org/advocacy/state-capitol-days/>



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**ONLY IDELVION DELIVERS**

**7<sup>and</sup> 14** DAY DOSING\*  
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WITH 7-DAY PROPHYLACTIC USE<sup>†</sup>

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**KNOW YOUR FACTOR LEVEL. PROTECT YOUR FUTURE.**

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

† The average dose for adolescents and adults receiving prophylaxis every 7 days was 37 IU/kg.

‡ The median AsBR for people who started on 7- or 14-day prophylaxis was 0. For people who switched to prophylaxis from on-demand, the median AsBR was 0.7.

AsBR=annualized spontaneous bleed rate.

**IMPORTANT SAFETY INFORMATION**

IDELVION<sup>®</sup>, Coagulation Factor IX (Recombinant), Albumin Fusion Protein (rFIX-FP), is used to control and prevent bleeding episodes in children and adults with hemophilia B. Your doctor might also give you IDELVION before surgical procedures. IDELVION can reduce the number of bleeding episodes when used regularly as prophylaxis.

IDELVION is administered by intravenous injection into the bloodstream and can be self-administered or administered by a caregiver. Do not inject IDELVION without training and approval from your healthcare provider or hemophilia treatment center.

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

you are taking. Do not use IDELVION if you know you are allergic to any of its ingredients, including hamster proteins. Tell your doctor if you previously had an allergic reaction to any FIX product.

Stop treatment and immediately contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing, lightheadedness, dizziness, nausea, or a decrease in blood pressure. **Please see continuation of Important Safety Information and brief summary of prescribing information on adjacent page and full prescribing information, including patient product information, at IDELVION.com.**

TO LEARN MORE, GO TO [WWW.IDELVION.COM](http://WWW.IDELVION.COM)



**CSL Behring**

## BDASC at National Bleeding Disorders Foundation Washington Days

From March 4–6, 2026, members of the Bleeding Disorders Association of South Carolina will travel to Washington, D.C. to participate in the National Bleeding Disorders Foundation’s Washington Days, a national advocacy event that brings the bleeding disorders community together to engage directly with federal lawmakers.

We’re proud to share that 5 of South Carolina’s 7 congressional districts will be represented during this year’s event. Advocates attending include Sue Martin, Candi & Noah Mitchum, Whitney Galloway, Taylor Upton, Dustin & Jessica Howells/Jackson and their children, who will meet with members of Congress and their staff to share personal stories and advocate on behalf of our community.

A key priority for Washington Days will be supporting the Federal Copay Accumulator Adjustor (CAAP) bills, which are critical to protecting access to affordable medications and ensuring patients’ financial assistance works as intended.

We are grateful to our advocates for lending their voices and ensuring South Carolina is strongly represented on Capitol Hill. Stay tuned for updates from Washington as they help move this important work forward!



MARCH 4-6, 2026



## Registration Now Open for NBDF’s 78th Annual Bleeding Disorders Conference!

We’re excited to announce that registration is officially open for the National Bleeding Disorders Foundation’s (NBDF) 78th Annual Bleeding Disorders Conference taking place August 13–15, 2026 in Orlando, Florida! This premier three-day event brings together individuals, families, caregivers, and healthcare professionals from across the bleeding disorders community for educational sessions, networking opportunities, and a vibrant exhibit hall showcasing the latest in research, care, and support. Don’t miss your chance to learn, connect, and be inspired—register today and make plans to join NBDF in Orlando this summer!



BDASC is pleased to offer a limited number of travel grants to help support members who wish to attend NBDF’s Bleeding Disorders Conference. These grants are intended to reduce financial barriers and increase access to this important educational and community-building opportunity. Grant availability is subject to the funds available, and applications are not guaranteed. Members interested must complete the travel grant application form available on our website at <https://bda-sc.org/members/national-education-and-conferences-travel-scholarships/>.



# BLEEDING DISORDERS CONFERENCE

Orlando, Florida • August 13-15, 2026

### Hemophilia B gene therapy demonstrates long-term success

*A 13-year follow-up by St. Jude Children's Research Hospital and University College London highlights the safety and longevity of gene therapy.*

A gene transfer approach to treating the bleeding disorder hemophilia B remains safe and effective long-term, as scientists from St. Jude Children's Research Hospital and University College London today report thirteen years of follow-up data. Hemophilia B is a rare genetic disorder caused by insufficient levels of a circulating protein called factor IX, which promotes blood clotting. The researchers used a one-time gene therapy intervention to address the disorder. Published in *The New England Journal of Medicine*, the 13-year follow-up study is the longest reported for any gene therapy for hemophilia B. The results, including an almost tenfold reduction in annualized bleeding rate, support the long-term viability of gene therapy for the disease's treatment.

Hemophilia B is an X-linked genetic disorder affecting one in approximately 25,000 male births. While the disorder can range in severity, frequent spontaneous bleeding and life-threatening hemorrhages occur due to insufficient blood-clotting factor IX. Treatment for hemophilia B has traditionally been expensive for lifelong supplementation of the clotting factor, but gene therapy offers a potentially transformative means to address the disorder.

"The key benefit is that gene therapy is a one-time, simple intravenous infusion that's very straightforward to do and potentially has positive effects for a lifetime," said co-investigator on the study [Andrew Davidoff](#), MD, St. Jude Department of [Surgery](#) chair.

#### Safety, efficacy and long-term viability

The study included 10 adults with severe hemophilia B who received the gene therapy drug between March 2010 and November 2012, with initial safety and efficacy successes reported in 2014 in [The New England Journal of Medicine](#). Now, over a decade later, the new 13-year follow-up report furthers these findings. The patients were followed over 10 additional years and have all maintained a steady level of factor IX and an excellent benefit in terms of freedom from bleeding.

In the field of gene therapy, questions remain regarding the enduring viability of these treatments, with key stakeholders, including patients and families, waiting to see what the long-term outcomes will be, such as durability and stability of expression. "For these 10 patients, the factor levels are stable and have been at the same level across these 13 years," said principal investigator [Ulrike Reiss](#), MD, St. Jude Department of [Hematology](#). "Further, we have not seen any side effects or toxic events in the long-term follow-up."

The lack of toxic events is noteworthy. Upon administering the gene therapy, over 90% ends up in the liver. The researchers kept a careful eye on this to ensure no issues arose, and while a small degree of liver inflammation was noted shortly after vector administration, it was curbed by steroid administration and did not return after initially resolving.

The results point to a significant quality-of-life improvement for the treated individuals. Their annualized bleeding rate (how much someone bleeds over the course of a year) decreased from 14.0 episodes to 1.5 episodes. Additionally, even though patients did not get within the normal range of factor IX expression, their case was still significantly improved with less dependency on factor IX supplements.

"It's incredibly rewarding to see the sustained safety and efficacy, which truly validates the potential of gene therapy as a one-time treatment for this condition," said the study's chief investigator, Amit Nathwani, PhD, from UCL Cancer Institute and the Royal Free Hospital. "Our findings answer critical questions about the long-term durability of gene therapy, offering profound hope and a significantly improved quality of life for patients."

Scan the QR code of visit <https://www.stjude.org/media-resources/news-releases/2025-medicine-science-news/hemophilia-b-gene-therapy-demonstrates-long-term-success.html> to read the full article.



# Resources and Contact Information

## Medical Facilities

### Prisma Health Hemostasis and Thrombosis Center of SC - Midstate

*For all new and previously scheduled appointments, factor refills, school needs, general questions or general concerns: Contact Robin Jones, MSN, MHA, RN, CPN, CPHON, Nurse Navigator, SC Hemophilia Treatment Center at 803-434-1028 or email: [schemophilia@prismahealth.org](mailto:schemophilia@prismahealth.org).*

#### Midlands

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

#### Florence

101 William H Johnson Street, Suite 400  
Florence, SC 29506

#### Orangeburg

1724 Village Park Drive  
Orangeburg, SC 29118

### Prisma Health Hemostasis and Thrombosis Center of SC - Upstate

#### 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

Shayla Bergmann, MD, Assistant Professor Director,

Pediatric Hemophilia Clinic

10 McClennan Banks Dr.

Charleston, SC 29425

Phone: 843-876-1980

Mobile: 843-812-5682

Fax: 843-792-7562

## Resource Information

### SC Dept. of Public Health Children with Special Health Care Needs Hemophilia Program

2100 Bull Street

Columbia, SC 29201

Phone: 803-898-0784

Website: [dph.sc.gov/health-wellness/child-teen-health/services-children-and-youth-special-health-care-needs/hemophilia](http://dph.sc.gov/health-wellness/child-teen-health/services-children-and-youth-special-health-care-needs/hemophilia)

### American Pain Foundation (APF)

Phone: 888-615-PAIN (7246)

Hemophilia Chronic Pain Support Group

Website: [painaid.painfoundation.org](http://painaid.painfoundation.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)

### 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: [panfoundation.org](http://panfoundation.org)

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.

### Accessia Health

Financial assistance to people who are diagnosed with chronic medical conditions.

P.O. Box 5930

Midlothian, VA 23112

Phone: 800-366-7741

Website: [www.accessiahealth.org/](http://www.accessiahealth.org/)

### The Assistance Fund - TAF

8427 Southpark Circle, Suite 100

Orlando, FL 32819

Phone: 855-845-3663

Website: [www.tafcares.org](http://www.tafcares.org)

## Resource Information

### Patient Notification System

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

Phone: 888-UPDATE U (873-2838)

Website:

[www.patientnotificationsystem.org](http://www.patientnotificationsystem.org)

### Medic Alert Foundation

2323 Colorado Avenue

Turlock, CA 95382

Phone: 800-432-5378

Website: [www.medicalert.org](http://www.medicalert.org)

### The South Carolina Rare Disease Advisory Council

Website: [www.rarediseasesc.org/](http://www.rarediseasesc.org/)

### SC Healthcare Marketplace

Phone: 800-318-2596

Website: [www.healthcare.gov](http://www.healthcare.gov)

## National Organizations

### National Bleeding Disorders Foundation

7 Penn Plaza, Suite 1204

New York, NY 10001

Phone: 212-328-3700

Fax: 212-328-3777

Phone: 800-42-HANDI (4-2634)

Fax: 212-328-3799

Email: [handi@Bleeding.org](mailto:handi@Bleeding.org)

Website: [www.Bleeding.org](http://www.Bleeding.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: 514-875-7944

Fax: 514-875-8916

Email: [wfh@wfh.org](mailto:wfh@wfh.org)

Website: [www.wfh.org](http://www.wfh.org)

### Bleeding Disorders Association of SC

Green Gate Office Park

25 Woods Lake Road, Ste. 300

Greenville, SC. 29607

Phone: 864-350-9941

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





*I go red for*

**BLEEDING  
DISORDERS  
AWARENESS**

BLEEDING DISORDERS  
AWARENESS CAMPAIGN

**BDASC**





# Mark Your Calendar!

## Looking Ahead: 2026 Major BDASC Community Engagement Opportunities - Save the Dates!

**March 1 – April 17, 2026:** Bleeding Disorders Awareness Month

**March 4 – 6, 2026:** NBDF Washington Days, Washington DC

**April 17 – 19, 2026:** Adult Retreat, Greenville, SC

**May 16, 2026:** STEP For Bleeding Disorders, Columbia, SC

**June 12 – 13, 2026:** HELLO Annual Meeting, Greenville, SC

**June 29 - July 2, 2026:** Camp CoAG, Eastover, SC

**September 25, 2026:** Par Fore The Clot Charity Golf, Greenville, SC

**October 9 – 11, 2026:** FAMS, Myrtle Beach, SC

*Be sure to check out our website, e-blast newsletters and social media for registrations and updated information on upcoming events.*

## Additional Ways to Support BDASC



### BDASC

Visit our website at [bda-sc.org](http://bda-sc.org) (or scan the QR code) and click “Make a Donation” to learn more about how you can support BDASC!



Purchase an Official BDASC Jacket and help us raise funds for financial assistance. Order online from the BDASC Apparel Store.



Donate through United Way! Go to Donate through the United Way. Visit their website at [www.unitedway.org](http://www.unitedway.org). Be sure to ask to have BDASC as your planned giving or workplace campaign.



We're excited to share that BDASC is now a registered charity on eBay. Visit and favorite the BDASC ebay store <https://charity.ebay.com/charity/i/Bleeding-Disorders-Association-of-South-Carolina/289930> to browse donated items. Proceeds from every sale go directly to support our mission.



Bleeding Disorders Association of South Carolina  
Green Gate Office Park  
25 Woods Lake Road, Ste. 300  
Greenville, SC 29607  
www.bda-sc.org

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WHERE CLOTTING ISN'T A FACTOR

*This new camp experience is being brought to the bleeding disorders community in partnership with the **Bleeding Disorders Association of South Carolina** and the **Prisma Health Hemostasis and Thrombosis Center of South Carolina** – Midstate & Upstate.*

**PRISMA**  
HEALTH<sup>SM</sup>

 **BLEEDING DISORDERS  
ASSOCIATION  
OF SOUTH CAROLINA**