



fall family advocacy camp & medical symposium

October 19-20, 2024

Hilton Embassy Suites Greystone
200 Stoneridge Dr. Columbia, SC



Share your thoughts with us by taking our event survey. Scan the QR code or visit <https://tinyurl.com/FFACSurvey>

8:30am: BDASC Welcomes and Breakfast Refreshments; Registration – Exhibits

9:30am: It Takes a Village - Greystone Hall

Hear from BDASC's leadership and advocacy members as they welcome participants to engage in community advocacy and learn how together we will advance treatment care, research, and have a seat at the table of conversations when it comes to those living in South Carolina with Bleeding Disorders. We will discuss who is our global Industry and affiliates, how they contribute to our future, and how we must all come together today as one voice for all. It starts with all of us at home and within South Carolina.

10:00 - 11:45am: Industry Forum - Mix and Mingle: Choose your session

Join us for an Industry Forum with companies of your choice and learn about their products and services pipeline and new innovative treatment options to treat bleeding disorders. Sessions begin promptly at 10:00am for the entire family. You will attend 2 different sessions of your choice. (Art activities will be included in each session for the kids and teens)

10:00am - 10:30am: Session 1 (Choose One Session)

- **Bayer: Kovaltry and Jivi - How they are designed to work for people with hemophilia A - Salon E** - Presented by Christine Barnes, Hemophilia Sales Executive
- **Platelet Disorders & Rares: Discussion Group Conversations - Salon F** - Facilitated by James Romano, BDASC Legislative Coordinator and Sue Martin, Executive Director
- **CSL Behring: Understanding Hemgenix Gene Therapy & CSL Behring Products Updates - Salon G** - Presented by Betsy Koval, Patient Resource Navigator

10:30am - 11:00am: Break - Exhibits - Greystone Hall

11:00am - 11:30am: Session 2 (Choose One Session)

- **Pfizer: Emerging Therapies - Salon E** - Presented by Chad Richardson, PharmD, is a Field Medical Director
Hemophilia patients now have multiple therapeutic options, with many new treatments in development. Understanding the science behind these novel therapies can empower patients to better navigate the evolving treatment landscape. This presentation explores the science of innovative approaches to hemophilia treatment, including investigational therapies such as gene therapy for hemophilia A and B, and rebalancing approaches. Collaborative discussions with healthcare providers are crucial for making informed decisions that best meet patient needs. Join us to explore the evolution of hemophilia treatment and the importance of patient engagement in shared decision-making.
- **Platelet Disorders & Rares: Discussion Group Conversations - Salon F** - Facilitated by James Romano, BDASC Legislative Coordinator and Sue Martin, Executive Director
- **Sanofi: Product Updates and Altuviio - Salon G** - Presented by Shelby Smoak, Ph.D, Community Relations & Education Manager

11:35am: Drop off Teens and Children -- Children's Program: Salon F & G -- Teen Program: Salon E

11:45am: Advocacy Is Within All of US (Advocacy Plenary Part 1) - Greystone Hall

This session will take an overarching quick look at today's landscape to health care access and treatment for those living with bleeding disorders in South Carolina, including resource information when access barriers become our reality. How do we collectively move forward in women's diagnosis and treatment care, serve our platelet and rare bleeding disorders community, and advance VWD treatment and early diagnosis. How can members of the bleeding disorders community become better stewards in their own health care needs and together advance patient-centered care and shared decision making to drive positive outcomes while reducing personal health care costs?

11:45am: Advocacy Is Within All of US (Advocacy Plenary Part 1) - Continued

- **South Carolina Treatment Centers Updates:** Listen and learn from our HTC's how they are addressing women who bleed with access to treatment care, access to testing, caring for our VWD community, and providing treatment access for our more rural areas. Who do they treat today and how can you get an appointment? How can we best have shared decision-making responsibilities and cooperation between physicians and patients. *Presented by Robin Jones, MSN, MHA, RN, CPN, CPHON*
- **Are You Good Stewards of Your Bleeding Disorders Health Care?** Scheduling an HTC visit; do you make an annual appointment, are your logs up to date, what happens when we miss an appointment or don't call in? What is the benefit of participating in the Community Counts Registry for Bleeding Disorders Surveillance of the CDC, and the ATHN dataset, NBDF Research and Own Your Own Path Programs and how does that information play a role in our future treatment care? Are we connecting with our specialty pharmacy's and using the resources they have available to us; are you a good partner in your bleeding disorders health care? - *Moderated by Sue Martin, BDASC Executive Director*
- **South Carolina Resources:**
 - **State Hemophilia Assistance Program & BDASC Financial Assistance:** *Presented by Sue Martin, BDASC Executive Director*
 - **Understanding Health Care Access; Open Enrollment in South Carolina; Patient Assistance Programs and Disability in South Carolina:** *Presented by James Romano, Legislative Coordinator, BDASC*
 - **South Carolina Medicaid Updates:** What will Medicaid look like in 2025, are there any changes coming?

1:00pm - 2:00pm: Lunch & Exhibits (be sure to pick up your teens & children) Greystone Hall

2:00pm - 3:30pm: Advocacy Plenary Part 2- Greystone Hall

This session will look at our advocacy accomplishments, challenges, and our movement forward into 2025. We will address what we will need to do together to remove the current health care barriers and future threats and assure we continue to have a voice for quality and affordable health care for the rare community. We will discuss the importance of coalition building with every voice being heard and how it begins with all of us. Share your concerns and barriers within this session of community conversations.

- **2025 Legislative Session Outlook:** *Guest Speaker, Representative Seth Rose, (D) Richland District #72*
- **The National Outlook for Bleeding Disorders and Barriers Today: How You Can Be Involved!** *Presented by Nathan Schaefer, National Bleeding Disorder Foundation*
- **Patient Lived Experiences; Advocacy Stories and Barriers Today:**
Panel Guests
 - **Virginia Maxwell, Coalition for Rare Skin Disease**
 - **Cori Ann Harris, VWD, Are We Being Heard?**
 - **Candi Mitcum, Advancing access for Women with Bleeding Disorders**

3:30pm - 5:00pm: Round Tables Member Conversations / Free Time (pick up children & teens)

- **Support Group Round Tables "Community Talks" Conversations - Greystone Hall**
Leading the discussions are BDASC Members
 - **Men, Women, VWD, Rare Bleeding Disorders, Platelet Disorders**

-- Hotel Check-In @ 4pm --

Children & Teen Programming - Saturday

11:45am - 1:00pm: Morning Session

1:00pm - 2:00pm: Lunch with parents

2:00pm - 3:30pm: Afternoon Session

Children's Program: Salon F & G
Teen Program: Salon E

Children's Programs

Age-appropriate activities including for the younger kids, book reading: "I Love you Smore" and "Brown Bear, Brown Bear" with arts and crafts to match. **Games** include "Camp Bingo" with prizes and our favorite getting to know you activity, "My Favorite and Yours." **Projects** include "3 Stars and a Wish" helping to discover goals and self-achievements and other activities.

Teen Programming

Educational activities that will encourage team building and connections to the community, and will address the following:

- Encouraging the development of social relationships.
- Assist in identifying skills, strengths, interests, and goals.
- Discuss conflict resolution and stress management.
- Discuss the importance of schedules and routines (i.e. sleep, homework, responsibilities,) and learning to maintain these independently.
- Discuss the importance of healthy relationships (i.e. school, clubs, scouts, and religious groups, etc.)

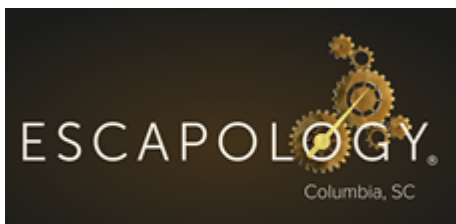
Activities will begin with a twist to our "Fast Friends Mix and Mingle" and the 5 Second Bleeding Disorders Rule. Afternoon activities will include our "Steps to Independence" discussions and project work.

Saturday Evening, October 19th

5:30pm - 7:00pm: Dinner - Greystone Hall

Presentation: Pathfinders Pre-Hike Conversation and Instructions - Getting us hyped up for Sunday's Hike!

7:00pm: Teen Evening Entertainment - Meet in Hotel Lobby for Van Drop Off At Escapology



Teen Entertainment:
Team Building at Escapology Columbia
717 Lady St D, Columbia, SC 29201

Discover how to solve the mysteries of: The Lost City, Budapest Express, Who Stole Mona, and Under Pressure

7:30pm: Community & Family Evening Entertainment - Greystone Hall



BDASC's Got Talent (Camp Activities & Talent Show)

Families, children, and anyone who is willing to join in, will enjoy a family fun Saturday night of BDASC's Got Talent Karaoke Show. Bring your best and show off your skills! All in family fun style.

Sunday, October 20th

7:00am: Hotel Breakfast

9:00am: Hotel Check Out- Pathfinders Group Activities - Meet in Graystone Hall for last announcements and supplies

Environmental Education Center
Harbison State Forest
5600 Broad River Rd.
Columbia, SC 29212

9:30am- 12:00pm: Wellness and Health Track



We are delighted to host the newest national bleeding disorders program during our Family Advocacy Camp provided by GutMonkey- Pathfinders! We will discover the beauty of the outdoors while forging lasting connections with others who understand the journey.

- Become one with Empowering Nature Walks surrounded by the calming presence of nature.
- Discover Educational Insights: Learn to manage bleeding disorders in the great outdoors.
- Supportive Community Connection: connect with others in the community, fostering a sense of camaraderie and understanding; share experiences, stories, and triumphs – discover you are not alone.
- Advocacy Awareness; raise awareness for positive change for access to resources for bleeding disorders
- Celebrate Resilience by commemorating the resilience of this community and the inspiring moments of this event



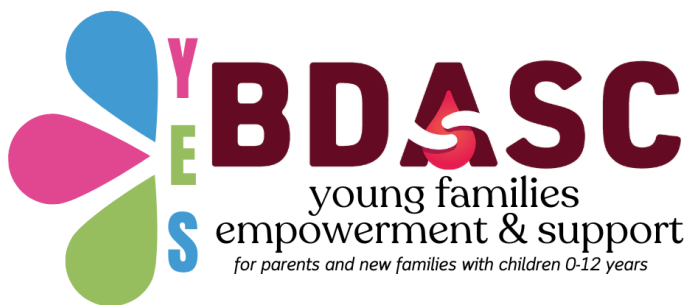
Scan to learn more about the Pathfinders Program

Pathfinders is made possible through a healthcare contribution from



Bloom Davis - GutMonkey Facilitator

Bloom Davis is dedicated to fostering a compassionate world through collective action and meaningful connections. With a liberation-centered approach, Bloom harnesses the power of play, community, and nature to inspire change. An avid long-distance backpacker and wilderness guide, Bloom has hiked the Pacific Crest and John Muir Trails, and thrives on helping others build skills and align their practices with integrity. As an educator and facilitator, Bloom knows how listening and understanding helps build resilient communities. Bloom is also a writer who explores themes of transformation, accessibility, and adventure.



NOTE: Attendees must have participated in all activities and educational sessions on Saturday to receive this opportunity.

For our families with young children, or Family Camp participants are not able to participate physically with the Pathfinders activity on Sunday. You will be provided with tickets to enjoy a Sunday morning visit at the Riverbanks Zoo and Garden.

RIVERBANKS ZOO & GARDEN
columbia south carolina
500 Wildlife Parkway,
Columbia, 29210



James Romano, Care and Cure Partners, CEO & President and BDASC Legislative Coordinator

James Romano is the founder of Care & Cure Partners. Care & Cure Partners works to advance the advocacy, nonprofit, fundraising and government relations needs of our clients. James has over 25 years' experience working with nonprofit organizations in a government relations and advocacy capacity. Throughout his eventful career, James has worked for a Member of Congress, nonprofit organizations and a Washington, DC lobbying firm. James brings this experience to the benefit of the Care & Cure Partners clients.



SC Representative Seth Rose, (D) Richland District #72

Seth Rose, an American lawyer and public servant, has seamlessly intertwined his passion for justice, community service, and leadership, creating a legacy that resonates far beyond his extensive legal and political career.



Betsy Koval, RN BSN Patient Resource Navigator for CSL Behring

Betsy has many years of experience in the bleeding disorders community. She previously worked as a senior clinical specialist, an educator, and in training with the learning and development team. Prior to that she was the lead pediatric and adolescent transition nurse coordinator at the Hemophilia of Georgia Center for Bleeding and Clotting Disorders at Emory University and Children's Healthcare of Atlanta for about 10 years. Empowering patients, families, and providers with knowledge for improving health is Betsy's favorite part of her role and she is honored to work within the bleeding disorders community.



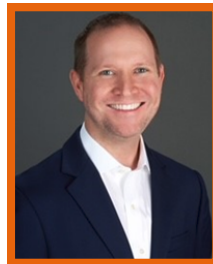
Christine Barnes, Hemophilia Sales Executive Bayer

Christine has many years experience in the bleeding disorders community. She is dedicated to education and patient support.



Nathan Schaefer, MSW, Senior Vice President of Public Policy & Access, NBDF

Nathan is a Senior Nonprofit Executive with 20 years of progressive leadership experience, overseeing political advocacy organizations in supporting Bleeding disorders (i.e. education, advocacy, research, prevention), LGBTQ, and HIV-affected communities across the State of New York and Metropolitan Washington, D.C. geographic areas. Skilled Public Policy leader providing strategic planning and direction on executing nonprofit vision, mission, and objectives, advocating the nonprofit's brand messaging and strategic communication goals.



Chad Richardson, PharmD, Field Medical Director with Pfizer Pharmaceuticals in the Rare Hematology division of US Medical Affairs

Chad Richardson, PharmD, is a Field Medical Director with Pfizer Pharmaceuticals in the Rare Hematology division of US Medical Affairs, where he focuses on hemophilia. Before joining Pfizer, Chad practiced as a Solid Organ Transplant Clinical Pharmacist for over 12 years where he managed complex medication regimens and provided education to patients and their caregivers. Chad has over a decade of teaching experience including lecturing for multiple universities and speaking at scientific conferences. Chad joined Pfizer in 2022, bringing his clinical experience and passion for patient and provider education to the role.



Shelby Smoak, Ph.D, Community Relations Manager for Rare Blood Disorders, Sanofi

As lifelong advocate, drawing on his lived experience and academic approach, Shelby helps people advocate for themselves and understand hemophilia on a deeper level. Growing up, Shelby gravitated towards the arts. He's a former literature professor, memoir author, and musician. Shelby wakes up excited to talk with team members and meet new friends in the community—and see what stories unfold.

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2025 Advocacy Events

Jan. 15, 2025 Legislative Breakfast, *State Capital, Room TBD, Columbia, SC*

Feb. 25th - 26th, 2025 BDASC State Advocacy Days, *Courtyard by Marriott Columbia Down, Columbia, SC*

March 5th - 7th, 2025 NBDF Washington Days, *Washington D.C.*



Have you taken our 46 Voices Survey yet?

We are taking a personal outreach approach to reach our rural community members in all 46 counties in South Carolina where we currently have members. The goal is to map out access barriers to quality treatment and affordable healthcare, while providing resources to health equity. We strive to discover healthcare disparities and lack of education within bleeding disorders care according to zip codes within the various counties in South Carolina.

Your voice is important in meeting our goals. If you haven't already, we ask you to please scan the QR code to the right and take our short survey. By providing your feedback, we will be able to ensure our community's voices are heard by those who can enact change.

