

# for men, women and couples impacted by bleeding disorders COUNTY COUNTY

# **Weekend Agenda**

AC Mariott Hotel Greenville Downtown 315 S. Main St. Greenville, SC 29601

### Reedy Hall Ballroom

4:00pm: Registration Check in Hotel/ BDASC

5:00pm - 5:30pm: Chapter Opening Welcome Reception

5:30pm - 6:30pm: Participant Connections & Icebreaker Games

6:30pm - 8:00pm: Dinner Buffet

**6:30pm - 7:30pm:** Dinner Presentations: Premier Sponsors

8:00pm - 10:30pm: Team Building and Networking Activity: Group Therapy of Greenville



## **Group Therapy of Greenville**

We will walk together next door to Group Therapy and have 2 ½ hours of Wacky Mini Golf, Axe Throwing or Digital Darts, and 2 beverage tickets for a fun group activity.

Address: 320 Falls St Suite G, Greenville, SC 29601

## Saturday, April 5, 2025

Open Exhibits (8am-5pm)

7:30am - 9:00am Reedy Hall III - Breakfast

9:00am - 10:30am Reedy Hall I,II - Session 1: Caregiver's Compass

10:30am - 10:45am - Break and Exhibits

10:45am - 12:00pm Reedy Hall I,II - Session 2: Caregiver's Compass



Caregiver's Compass: Where Experiential Education Meets Heartfelt Conversations – Facilitated by Jo Linden, Schaefer Raposa, and Niels Damman with GutMonkey Sponsored by CSL Behring

We'll delve into the intricacies of how children process new information, empowering caregivers to guide youth with confidence through different stages of their development. We will explore decision-making processes tailored to understand children's unique developmental journey and consider the many ways of unlocking their full potential. Participants will learn about "motivator styles," gaining invaluable insights that will shape the way they nurture and support youth in our community as they transition into adulthood. Participants should prepare to step out of their comfort zone as they learn and connect with fellow caregivers and parents in their area who share similar experiences and challenges.

12:00pm - 1:15pm Reedy Hall III - Lunch and Open Exhibits
 1:15pm - 1:30pm Camperdown Plaza - Group Photo
 1:30pm - 4:00pm - Afternoon Breakout Sessions

1:30pm - 2:30pm - Session #1

**Women's Session #1: Women Matter in Bleeding Disorders** *Presented by Takeda & Facilitated by Morgan Cook* – **Reedy Hall I** 

Women with bleeding disorders face unique challenges that are often unrecognized or underappreciated. We will learn to understand some of the special challenges faced by women with bleeding disorders and identify options for emotional support within the community.

Men's Session #1: The Joint Movement Series: Mind Over Matter Presented by Sanofi and Facilitated by Shelby Smoak, Ph.D. - Reedy Hall II

Gather for conversations and enjoy learning about the bond between the Body and the Mind. This session will be an interactive joint health workshop designed to help you keep moving. This program features insights from musician Max.

**VWD Session #1: Advocacy: Choice or Challenge** *Presented by BDASC, Facilitated by Sue Geraghty, RN* – **Reedy Hall III** 

During this session we will discuss ways to advocate for yourself or your loved one in many settings that you might encounter. This will include advocating in the school setting, the Emergency Room, during your HTC visit and other areas.

2:30pm - 3:00pm - Break and Open Exhibits

**3:00pm - 4:00pm -** Session #2

Women's Session #2: Health Equity for Carriers & Women Who Bleed Presented by BDASC and The Hemophilia Treatment Center - Reedy Hall I

Join us for round table discussions of shared stories and lived experiences: Discuss with our HTC how to get an appointment and carrier level testing, learn about the clinics for women who bleed combined with an OBGYN. When do we test our carrier children, or adults, and should they all be followed by an HTC? How do we make that happen? What about insurance challenges, do we need a diagnosis? This session will be facilitated by those in attendance along with our HTC staff and BDASC. This session will be an open discussion on the needs of our women who bleed that do not have a diagnosis of VWD.

Men's Session #2: Stuck on You: K-Tape Basics Presented by Optum & Facilitated by Dr. Angie Forsyth - Reedy Hall II

This workshop will teach our young adults and adults about kinesiology tape (K-tape). Topics explore the makeup and uses for this therapeutic tape. Discussion includes how professionals also may use it. Individuals also learn how to apply and safely remove K-tape. The session includes a demo and hands-on interaction.

VWD Session #2: If You (or a family member) have vWD or a Rare Bleeding Disorder, How Would You Handle... Presented by BDASC, Facilitated by Sue Geraghty - Reedy Hall III

During this session we will work in small groups to solve some day to day issues that may come up when you have a vWD or a Rare Bleeding Disorder. This will be an interactive session, and we can make it what you want it to be.

## Saturday, April 5, 2025 - Afternoon/Evening

Open Exhibits (8am-5pm)

4:00pm - Snack Break - Outside Reedy Hall 4:00pm - 7:00pm - Attendee Free Time

4:15pm - Infusions & Injections: A look at Self- Infusions and Injections for adults - Reedy Hall I,II

- Included: "Tips & Tricks" and Trouble Shooting what do you do when there is scar tissue? How can we make the veins show up more? Are there tips to make it hurt less? What are all the locations we can use if one place does not work? How many times do you try per infusion if we fail? How do we push past the mental barriers?
- What are the ways to increase visibility of veins? Are their exercises that help ones that young kids or adults could safely do? Do vein finders really work (there is an app now)?
- Take-away documents filled with tips and tricks.
- Port information, and injections. Pros and cons of port vs. peripheral. Understanding the challenges of each. Opting for ports in adulthood.



**7:00pm - 10:00pm** - Dinner & Team Building at Top Golf **Address:** 201 Clifton Ct, Greenville, SC 29615

After a day of education, let us all enjoy time to relax and make connections with participants during this Community Engagement Support Group event. Participants will drive on their own or in groups to Top Golf of Greenville (12-minute drive) and enjoy a buffet dinner and bay golfing at the premier entertainment destination in Greenville, Top Golf. We will enjoy the climate-controlled hitting bays with HDTVs in every bay and throughout the sports bar and restaurant. Using their complimentary clubs or your own, we will take aim at the giant outfield targets and let the high-tech balls score themselves.

## Sunday, April 6, 2025

Open Exhibits (8:30am-9:30am)

8:30am - 9:30am - Breakfast and Exhibits - Reedy Hall III

9:30am - 10:30am - Group Wellness Session for All

Yoga where you are: linking mind, body and breath in your everyday life Presented by Optum & Facilitated by Karen Leaming - Reedy Hall I, II

This workshop will teach our families and adults about the link between mind, body and breath. Groups learn the different forms of yoga breathing and the benefits of working with their breath. Participants will explore variations to traditional yoga practice, including using a prop such as a chair or the wall to support yoga poses.

10:30am - 10:45am - Quick Break

10:45am - 11:45am - Round Table Chapter Updates & Attendee Discussions - Reedy Hall I, II

**11:45am - 12:00pm -** Wrapping It Up & Evaluations **12:00pm** - Hotel Checkout - Lunch on your own

Please share your feedback with us by scanning the QR Code



## **Speaker Bios**



Sue Geraghty, RN, MBA, worked as Nurse Coordinator at the University of Colorado Denver Hemophilia and Thrombosis Center for 25 years where she retired in 2013. She has over 45 years of nursing experience and currently she is working as an independent consultant in the areas of hemophilia and health care education. During her time as nurse coordinator at the Hemophilia Treatment Center she sat on several national committees including the Nursing Working Group for the National Hemophilia Foundation. Her areas of interest within the bleeding disorder community include new families affected with a bleeding disorder and adult patient issues, women with bleeding disorders, patients with inhibitors, and orthopaedic issues. She has an associate degree in nursing from Lander College, a Bachelor's degree in nursing from the University of NC Charlotte, and a Master's in Business from the University of Colorado Denver. Sue continues to educate and speak at many bleeding disorders camps, chapter meetings, and national conferences.



**Dr. Angie Forsyth, PT, DPT** is an internationally recognized leader and educator in bleeding disorder physical therapy. She has nearly 30 years of experience specializing in bleeding disorders and orthopedics, including 18 years as a Hemophilia Treatment Center PT in Pennsylvania, Delaware and Illinois. Angie has held leadership positions in WFH and NBDF and has authored more than 25 peer-reviewed journal articles.



**Karen Leaming** is a 500-hour certified yoga teacher with over 13 years teaching experience and owner of Ananda Yoga and Wellness. Trained in the Vinyasa style with an emphasis on therapeutic application, she loves teaching all student levels. Karen is passionate about creating an environment where yoga is accessible to everyone and focuses on creating a safe, non-judgmental and inspiring space where you can truly let go, be yourself, and connect to mind, body and spirit.



Morgan Cook, Community Education Specialist, joined the Takeda team in 2022. Being a part of Takeda's Community Education Specialist (CES) team allows her to continue to give back to the bleeding disorders community, by playing an integral part in educating and supporting patients on their journey and living their best, healthy life. As a person with VWD, as well as marrying into a family of bleeders, Morgan believes this is just as much of a personal journey as it is for her to help others. Outside of work Morgan enjoys spending time with her husband and their fur baby, Cooper. Together they collect vinyl records and can often be found listening to their vastly dynamic collection. Morgan is also an avid reader and loves to repurpose and refinish furniture in her garage workshop!



**Shelby Smoak, Ph.D.**, a North Carolina native, is an advocate, a writer, a musician, and a person with Hemophilia B. His book Bleeder: A Memoir (Michigan State University Press) received praise from sources as diverse as The Minneapolis Star Tribune, Library Journal, and Glamour, and has won several awards, including "Best of the Best" by the American Library Association. He was also featured on local TV and radio, including NPR for his book and music. He has recorded 6 albums, released numerous singles, and performed over 500 shows along the Eastern Seaboard. Awarded a Pen/American grant for writers living with HIV, Smoak holds a Ph.D. in Literature and an M.A. in English. He works as the North and South Carolina Community Relations and Education Manager (CoRe) for Sanofi.

# Notes

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# JOIN US!



Learn more and register at <a href="https://tinyurl.com/2025STEP">https://tinyurl.com/2025STEP</a>

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# **Upcoming BDASC Events**

**April 17:** World Hemophilia Day Event, Greenville SC **April 19:** Young & New Families Event, Greenville, SC

April 24: Couples Night, Charleston, SC

May 10: STEP for Bleeding Disorders Walk/Run, Columbia, SC

May 15: Community Engagement Dinner Connections

May 17: T.E.A.M Teen Transition Event

June 6-7: Annual Meeting & HELLO Conference, Greenville, SC

June 17: Community Engagement Dinner Connections

July 31- August 3: Teen Retreat, Rockfish Camp and Retreat, NC

September 26: Par for the Clot Charity Golf Tournament, Greenville, SC



We would love for you to join us at an upcoming event! Scan the QR code for a complete list of events that we currently have scheduled!