



Weekend Agenda

March 22- March 24th, Greenville, SC

AC Marriott Hotel Greenville Downtown

315 S. Main St.

Greenville, SC 29601



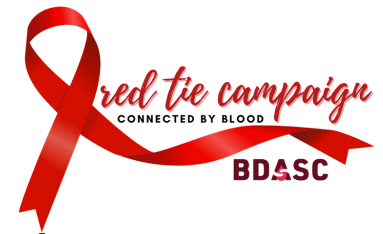
Please complete our Survey on our Adult Connection Symposium.
Your feedback is greatly appreciated.

<http://tinyurl.com/2024AdultSymposiumSurvey>

Friday, March 22, 2024

Open Exhibits (4pm-8pm)

4:00pm: Registration - Reedy Hall Ballroom, Open Exhibit Hallway
5:00pm: Opening Welcomes, Participant Connections & Ice Breakers
6:15 - 7:45pm: Dinner Buffet
6:30pm: Keynote Presentation
8:00pm: Group Activity at "Group Therapy of Greenville"



Keynote Dinner Presentation, E + R = O, Events + your Response = the Outcome
Presented by Jim Stocker, Life Coach

The events in your life do not dictate the outcomes, your response does! Learn how the power is with you. How are you going to choose calm over chaos and reset? Will you just continue down a path filled with anxiety and feeling overwhelmed? Or will you decide to reset your mindset with the power of awareness, optimism, and gratitude? You can either decide to allow your growing anxiety to steal your dreams or you can choose that despite the hardships, you have the power to control what happens in the space between your ears. Your mind. To develop this growth mindset which will allow you to manage your emotions and live your life despite the challenges you face, you need a formula. That is exactly what you will get when you learn the powerful equation $E+R=O$.



Social engagement activities at no cost to attendees:
Let's have fun with some 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 Duckpin Bowling, and 2 beverage tickets for a fun group activity.

Engagement Activity provided by BDASC. Free for BDASC Members and Speakers, HTC staff.



Scan to Learn More About Group Therapy

Saturday, March 23, 2024

Open Exhibits (7:30am-5pm)

7:30am - 8:45am: Breakfast in Reedy Hall III
9:00am - 4:00pm: Educational Sessions
4:00pm - 6:00pm: Free time to explore Greenville
6:30pm - 9:30pm: Group Event & Dinner, TopGolf of Greenville



Social engagement activities at no cost to attendees:
Let's have fun with some at TopGolf of Greenville. Topgolf, there's no pressure to have a good golf swing or score a lot of points. It's all about everyone having fun.

Offsite Activity: Top Golf of Greenville: 201 Clifton Ct., Greenville, SC 29615

Engagement Activity provided by CSL Behring and BDASC. Closed event to BDASC member guests, HTC staff, and speakers only due to the large group.



Scan to Learn More About TopGolf

9:00am - 10:00am: Morning Breakout Session

Gene Therapy in Hemophilia - Hemophilia A & B

We invite you to gene therapy presentations you won't want to miss! Hear how gene therapy is designed to work and why eligibility testing is the first step on the gene therapy journey. We will share the findings from clinical trials and what they could mean for you. Hear a patient's experience - learn how to get started, and what questions to ask your doctor.

Hemophilia A: Reedy Hall I

Hemophilia B: Reedy Hall II

Presentation Provided & Sponsored By:

CSL Behring
Biotherapies for Life™

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Novice to Experienced: Let Us Look at VWD and Rares

Presented by Sue Geraghty

We will start with the basics and advance to a deeper understanding of VWD and Ultra Rare Bleeding Disorders. We will enjoy a level of understanding for those new to VWD or Ultra Rares, and those who have been living with them for three or more years. We will split into groups and have conversations around your burning questions and hear practical solutions by those who have lived experience.

Reedy Hall III

10:00am - 10:30am: Break - Exhibits Open

10:30am - 12:00pm: Group Breakout Session

Women's Session: Reedy Hall I

Managing Multiple Priorities and Taking Care of You!

Presented by Anna Bell

We all live in a very busy world. Finding a work - life balance can be difficult and finding the time to take care of yourself is often put off and sometimes never happens. Managing multiple priorities is tricky. Come share and engage in this informative session.

Men's Session: Reedy Hall II

Uncovering Our Treasures Workshop

Presented by Jim Stocker, Life Coach

Every discussion you make needs to become a value clarifying exercise. We all need to stop and pause and reassess who we are, what are our principles, how do we want to be remembered. Coach Stoker will guide you through a dynamic exercise to uncover these treasures.

12:00 - 1:30pm: Lunch and Group Photo Reedy Hall III - Exhibits Open

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

Choose one session to attend.

Couples and Relationships While Living with Bleeding Disorders

Presented by Anna Bell

Being a spouse of someone with a bleeding disorder or chronic condition can sometimes be challenging for both partners. Starting a new relationship, or keeping the laughter during stressful times. Enjoy this session for engaging conversations and activities to enhance your relationships.

Reedy Hall I

Part 2: VWD and Rares: Now for Practical Information

Presented by Sue Geraghty

Let's discuss schools, work, heading to college, having relationships, Emergency Rooms, HTC Visits, Securing a dentist, and more. Nothing is off the table to discuss.

Reedy Hall II

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

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

A Focus on Fitness (For Everyone)

Presented by Jim Session

Breathing and Meditation; How applying just a little bit, can go a long way to finding your happiness. What are the benefits? Jim will show us some of his ways he keeps his mind and body healthy in this interactive session.

Reedy Hall I & II

4:00pm: Infusions & Injections

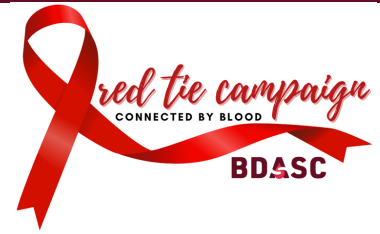
A look at Self- Infusions and Injections for adults

Infusion Session

- 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.

Reedy Hall I & II

8:00am- 9:15am: Breakfast in Reedy Hall III
9:15am - 12:00pm: Morning Sessions
12:00pm: Hotel Checkout & Lunch on your own



9:15am - 10:15am: Reedy Hall I & II

Chapter Updates: Embracing Change in our Ever-Changing Landscape

- Advocacy updates: What are the concerns today? How much do you know about our past history? Engage in a group timeline challenge
- State of the Chapters: Fundraising Challenges - **Make a donation today** during the National Bleeding Disorders Awareness Month!!!
- National Research Blueprint: What is next in research? How you can be involved

10:15am - 11:45am: Reedy Hall I & II

Ask The Experts!

What you always wanted to know but were afraid to ask. What is on your mind? A moderated conversation with you leading the conversation.

(Question cards that were filled out by participants throughout the weekend will be answered by our healthcare providers and Lived Experienced Experts (LEE).

Disclaimer: You should always check with your healthcare providers and others you trust most and make your own opinions on things that matter the most to you and your families. The opinions of our guests who offered to share their knowledge and insights to the questions you may have. BDASC makes no claim to the accuracy or has an opinion on what is shared.)

Panel Guests:

Robin Jones, SCHTC Nurse Coordinator and Bleeding Disorders

Shoniqua Smith, SCHTC Social Worker and Bleeding Disorders

Sue Geraghty - National and International Speaker on Bleeding Disorders

Sue Martin - Chapter and State Advocacy Lead

Members - LEEs on VWD

Members - LEEs on Hemophilia

Members - LEEs on Ultra Rare Bleeding Disorders

11:45am - 12:00pm: Reedy Hall I & II

Wrapping It Up and Evaluations

Please take a moment to complete a survey on your experiences this weekend. We utilize these surveys to ensure that we are providing quality events and education and to mold future events. Scan the QR code to the right with your phone before leaving, or visit the link below:

<http://tinyurl.com/2024AdultSymposiumSurvey>



Meet Our Speakers



Anna Maria Bell, LICSW, LCSW-C, LISW

Anna is a graduate of The Catholic University of America Master's Program in Social Work with a concentration in Gerontology, a graduate of Capella University with a Master's Degree in Public Service Leadership, and a graduate of Walden University with a Master's Degree in Philosophy. She is currently ABD at Walden University where she is pursuing a PhD in Human Services. She is Clinically Licensed to Practice in the District of Columbia, Maryland, Virginia and the State of Ohio. She has worked in a variety of Social Work Settings and provided counseling to various populations including couples, children and adolescents, women, and geriatric populations. For the last twenty-five years she has been employed at the District of Columbia Child Welfare Agency where she has worked in various areas mainly Training, Licensing, Policy, and Clinical Case Management. Anna was promoted to Program Manager of the Foster Parent Training and Licensing Division in 2012. Anna is an active part of the management team at CFSA and heads several committees involving policy creation, program administration and supportive services. Anna joined the Hemophilia Foundation of America consultancy staff in 2015 as a facilitator/speaker, conducting trainings, seminars and facilitations throughout the 50-member organizations. Anna conducts life/professional coaching sessions as well as various workshops throughout the Washington DC Metropolitan Area through her company Bell-ievable, Inc., where she focuses on Development of Leadership, Self Esteem and Self Determination, through group processes and facilitation. Anna is a 26 year member of Delta Sigma Theta Sorority Inc.



Jim Stroker

Coach Jim Stroker is a Life Coach, Leadership Trainer, and Keynote Speaker. Jim carefully crafts each speech to cover topics such as leadership, teamwork, growth mindset and his famous E +R =O formula. His passion for transformation is based on his incredible life experiences and his ability to thrive through one of his greatest life challenges. Coach Stroker's unique gift to craft and deliver motivational and educational keynote seminars resonates with audiences ranging from Fortune 500 CEO's to thousands of high school students throughout the country, as well as Nonprofits, Military, Gaming Associations, Healthcare Practitioners, and Native Americans.

Coach Stroker's wellness program has been cited as one of the nation's best and he is also the creator of "Inspirational Hotline", a morning message delivered to 700 students. He has over 30 years of experience within the New Jersey Public School System as a sports coach as well as a wellness educator. Coach Stroker is an inductee to the New Jersey Coaches Hall of Fame and a recipient of the prestigious Distinguished Alumni Award at Ridgewood High School.

Meet Our Speakers



Sue Geraghty, RN, MBA

Sue Geraghty 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 committee 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. Her passion for bleeding disorders and patients is spoken in every talk she provides. We are grateful to have her back with us again! She will lead our VWD sessions and help with our infusion clinic.

Robin Jones MSN, MHA, RN, CPN, CPHON

Nurse Navigator, Hemophilia Treatment Center of South Carolina

Robin Jones is the nurse coordinator for the South Carolina Hemophilia Treatment Center - Midlands and nurse navigator for the Children's Cancer and Blood Disorder Clinic. She earned her associate's degree in nursing from Orangeburg-Calhoun Technical College in 2001, bachelor's degree in nursing from the University of South Carolina - Upstate in 2004, and a dual master's degree in nursing and health administration from the University of Phoenix in 2015. She began her career as a pediatric hematology/oncology staff nurse in 2001. Robin transitioned to assistant nurse manager and finally nurse navigator/nurse coordinator. She has been the hemophilia camp nurse for the last 16 years. She is a certified pediatric nurse and certified pediatric hematology oncology nurse. Robin enjoys being a part of the bleeding disorder community, offering her assistance when needed. She has taught intravenous infusions to many patients and families over the years and continues to offer this service even in this world of medication administration changes. When she is not working, she enjoys spending time with her family. Robin lives in Gaston, SC, with 2 of her 3 children, 2 dogs and 3 cats.

Shonequa Smith, LMSW

Social Worker, Hemophilia Treatment Center of South Carolina

Shonequa is a licensed social worker in the Pediatric Hematology/Oncology Outpatient Clinic at the Prisma Health-Midlands Children's Center for Cancer and Blood Disorders. She joined the Peds Hem/Onc team in 2022 as the social worker for bleeding disorders and sickle cell disease. As an essential member of the multidisciplinary care team at the HTC, her role as a social worker is to provide psychosocial and case management services for patients and their families with bleeding disorders, including von Willebrand disease and rare bleeding disorders, and patients with sickle cell disease navigate a wide range of issues, including health insurance decisions, financial assistance, school-related matters, mental health challenges, and connecting to community and vocational resources. She earned her Bachelors degree in Psychology from Temple University (Philadelphia, PA), and Master of Social Work degree with a specialization in Health/Mental Health from the University of South Carolina.

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