

# BDASC

*adult retreat and medical symposium*

## Weekend Agenda

AC Marriott Hotel Greenville Downtown

315 S. Main St.

Greenville, SC 29601



Please complete our Survey on  
our Adult Retreat & medical  
symposium. Your feedback is  
greatly appreciated.

<https://tinyurl.com/AdultRetreatSurvey>

*March 21 - April 2, 2023, Greenville, SC*

## Friday, March 31, 2023

## Open Exhibits (4pm-8pm)

**4:00pm:** Registration and Hotel Check-In @ Reedy Hall Ballroom

**5:00pm:** Chapter Opening Welcome Reception & Sponsor Welcome

**5:30pm - 6:00pm:** Participant Connections & Icebreaker

**6:00pm - 7:30pm:** Opening Dinner Presentations

**Gene Therapy in Hemophilia** Presented by Betsy Koval, RN BSN, Sponsored by CSL Behring

Learn about the advances in gene therapy research for hemophilia B in a 30- minute dinner session which dives into gene therapy for hemophilia B, how it works, and the goals of gene therapy.

**Gene Therapy Experience** Presented by Dan Korn, BDASC Guest Member

Dan will share his experience with gene therapy done at the Royal Prince Alfred Hospital in Sydney, Australia. It was on Feb 13, 2018, and he is now 5- years post-dose. The product is now in Phase III trials with final results to be presented to regulators in 2023. Up until his gene therapy treatment, Dan had severe Hemophilia B and was using 60-70 doses of factor each year for prophylaxis.

**7:30pm:** Wrap up and prepare for group activity!

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



**Group Therapy of Greenville, In honor of John H. Tiller**

320 Falls St Suite G, Greenville, SC 29601

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

## Saturday, April 1, 2023

## Open Exhibits (8am-5pm)

**7:30-8:45am:** Breakfast @ Reedy Hall III

**9:00am:** Morning Welcome Session (for all) @ Reedy Hall

**Supporting Health Equity** Presented by Danielle Keisel, Senior National Account Executive, Genentech, Sponsored by Genentech

Learn about what Health Equity is and how it impacts patients now and the potential impact for the future. Understand how health equity can be impacted by social determinants that may present as barriers to accessing and receiving health care services. Learn of some ways health inequities are being addressed and share your thoughts and ideas for reducing health inequities and improving access to care for members of the bleeding disorders community in South Carolina.

**10:00am:** Break/Exhibiting

**10:30am - 11:30am:** Divide into Men's & Women's Tracks (see next page)

**11:30am -12:50pm:** (All) Lunch and Group Photo @ Reedy Hall III

**1:00pm - 2:00pm:** Divide into Men's & Women's Tracks

**2:00pm - 2:30pm:** Break/Exhibiting

**2:30pm - 3:30pm:** Divide into Men's & Women's Tracks (see next page)

**3:30pm – 6:00pm:** Free time, Snack break!

**6:00pm - 10:00pm:** Group Dinner Presentation; Team Building Golf Competition @ Top Golf



**Top Golf of Greenville, Sponsored by CSL Behring**

201 Clifton Ct., Greenville, SC 29615

Let us enjoy a time to relax and network with participants at this all- 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 presentation and bay golfing at the premier entertainment destination in Greenville, Top Golf. 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, you will take aim at the giant outfield targets and let the high-tech balls score themselves. For fun we will have a Men vs. Women Competitions! (You do not have to golf, but we encourage you to try this fun activity)

**Dinner Presentation: Pushing Through with Positivity** Presented by Pete Dyson, *Gettin' in the Game Athlete*

When Pete's coach heard that he had hemophilia, he was almost cut from his college baseball team. He never took "No" as a final answer, and he started in the outfield all four years in college. Pete learned that keeping open communication with his coach and healthcare team to develop an action plan helped keep him in the game. Pete shares his experiences to show others that bleeding disorders do not need to be the end of activity, but rather a different way of moving through everyday life.

**7:30am-8:45am:** Breakfast @ Reedy Hall III

**9:00am – 10:00am:** Divide into Men's & Women's Tracks (see below)

**10:00am:** Break/Exhibiting

**10:30am - 11:45am:** All Group Advocating Activity

**Advocating Activity - What Would You Do?** (Reedy Hall I, 2 & 3) *Presented by Sue Geraghty, Sponsored by BDASC*

Breaking up into small groups, you will be given scenarios to come up with a suggestion on what you would do during times that require you to advocate for yourself or a loved one. Moderated by Sue Geraghty, this group activity will surely be thought provocative – interactive and challenging.

**11:45am - 12:00pm:** Hotel Check Out; Wrapping It Up and Evaluations; Lunch on your own

## **Men's Track**

## **Reedy Hall II**

**Saturday, April 1 - 10:30am-11:30am: Masculine Mental Health** *Presented by Anna Bell, SW, Sponsored by BDASC*

In this workshop we will cover many mental health challenges facing men today. We will discuss general warning signs to lookout for and the different ways mental health presents itself in men versus women. We will address stress related challenges in regards to caregiver stress, depression, and anxiety. We will discuss coping skills and the importance of self-screening and treatment. This workshop will emphasize that getting help is a manly thing to do!

**Saturday, April 1 - 1:00pm – 2:00pm: Tackling Transitions and Embracing Change** *Presented by Pete Dyson, Gettin' in the Game Athlete, Sponsored by CSL Behring*

From athlete to announcer, son to father, and player to coach, Pete has gone through many stages of life and has had to adapt how he manages his bleeding disorder, his lifestyle, and his routines. Pete believes the physical challenges are easier to overcome than the mental ones, so he works to keep his thoughts in balance. Pete discusses how to cope with change through finding small victories and learning to embrace the success of making it through past transitions.

**Saturday, April 1 - 2:30pm – 3:30pm: Wrap Session for Men** *Sponsored by BDASC*

A time for adult men to discuss having children with a bleeding disorder, being affected themselves, or being a caregiver for someone with a bleeding disorder. This session will divide you into groups of your choice and will be a moderated conversation. Thank you to Brian Burton, Robert Butler, Jonathan Garret and Paul Brayshaw for moderating this session.

**Sunday, April 2 - 9:00am – 10:00am: Lifeguards – What Keeps You Afloat?** *Presented by Kevin Harris, Sponsored by Paragon Health*

Learn about the cycle of habits, identifying true fulfillment, and how unconscious behavior affects us daily. This program will encourage you to redirect your habits in a positive direction and leave with a deeper understanding of your day-to-day actions.

## **Women's Track**

## **Reedy Hall I**

**Saturday, April 1 - 10:30am-11:30am: Women's Health - Saving One Uterus at a Time** *Presented by Sandy Puckett, RN, BSN, National Bleeding Disorders Nurse Educator, Sponsored by Optum.* The Optum® Women's Bleeding Disorder Support workshop helps women understand their unique symptoms of bleeding disorders. Often, education and resources are necessary for women to be diagnosed with an inherited bleeding disorder. This workshop helps women receive information that can be helpful when talking to their healthcare provider and empowers them to advocate for themselves throughout their health journey.

**Saturday, April 1 - 1:00pm - 2:00pm: Women and Surgery** *Presented by Sue Geraghty, Sponsored by BDASC*

Women with bleeding disorders will need the same surgeries as other women in their lifetime. Learn what you can do to have a successful outcome for a surgery you may need. Learn who may need a treatment plan and what you can do to advocate for yourself. Whether you are a woman carrier of hemophilia A or B, a woman with VWD, regardless of the type, a woman with other factor deficiencies such as but not limited to, factors II, V, VII, XI, and XIII, women with platelet disorders, and women with a significant bleeding history but no diagnosis, this session is for you!

**Saturday, April 1 - 2:30pm – 3:30pm: Mental Health & Wellness; Caregiver Stress: We Don't Have To Be A Superwomen**

*Presented by Anna Bell, sponsored by BDASC.* In this session we will have an open dialogue regarding life stressors associated with bleeding disorders. We will discuss issues surrounding fear, carrier guilt, and caregiving. We will discuss recognizing stress and anxiety symptoms and way to cope and heal.

**Sunday, April 2 - 9:00am – 10:00am: A Focus on Women's Health- Sunrise Self- Reflection, Safe Movement &**

**Empowerment!** *Presented by Jane Kelley, Sponsored by Optum.* Participants will learn about the connection between mind, body, and breath. In this activity- based workshop, attendees will learn the different forms of Yoga breathing and the benefits of working with the breath. They will explore modifications of traditional Yoga practice, including the use of a "prop".

## Speaker Bios



**Ann Bell, SW**

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 Ohio. She has worked in a variety of social work settings and provided counseling to various populations including couples, children and adolescents, women, men, and geriatric populations. Until August 2022, after serving 28 years in government public service, Anna retired from the D.C. Child Welfare Agency where she had worked in various areas mainly training, policy, program administration and clinical case management. Anna joined the HFA consultancy staff in 2015 as a facilitator/speaker, conducting training, seminars, and curriculum development. Anna conducts life/professional coaching sessions as well as various workshops throughout the Washington D.C. 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 member of Delta Sigma Theta Sorority Inc.



**Sue Geraghty, RN**

Sue 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 orthopedic 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.



**Pete Dyson**

Pete grew up playing basketball in his driveway, commentating his own games. From an early age, he loved playing sports and fought to keep his hemophilia B diagnosis from taking him out of the game. Whenever someone told him he could not do something, it motivated him to get to where he wanted to go. Now a

husband, father, and teacher, Pete's love for sports led him to become a high school basketball and baseball coach, certified basketball official, and got him involved with the CSL Behring Gettin' in the Game<sup>SM</sup> Junior National Championship.



**Sandy Puckett, RN BSN**  
National Bleeding Disorders  
Nurse Educator

Sandy has served as a Bleeding Disorder Nurse Educator for more than 18 years. She develops and presents clinical and program offerings like the 'Optum's Women with Bleeding Disorders Program' to support women with bleeding issues with diagnosis and treatment.

She offers and provides clinical education for healthcare providers, and people affected with inherited bleeding disorders. Sandy earned her Bachelor of Science nursing degree from University of Portland. She worked at Doernbecher Children's Hospital in Portland, Oregon for 17 years on the newborn to four-year-old pediatric unit, served as the Nurse Manager at the Child Development and Rehabilitation Center, and then as Nurse Coordinator at the Oregon Hemophilia Treatment Center covering the State of Oregon and SW Washington. She also served as a School Nurse for 10 years for the Portland public school system. She is published in the Journal of Child and Adolescent Psychiatric Nursing and co-author on an abstract/poster presented at the National Hemophilia Foundation on outcomes related to factor X replacement therapy. Ms. Puckett lives in Portland, Oregon where she enjoys her 2, soon to be 3 grandchildren, gardening, camping in her vintage trailer and traveling with her husband.



**Jane Kelley**

Jane is a Life Coach, Group Fitness Specialist, Yoga Certified Master Trainer, College Professor and Regional Group Fitness Manager. Jane has focused her career on health and wellness training for the last 30+ years and has been certified by the Aerobic and Fitness Association of America (AFAA) for the last 20+ years. She has managed corporate wellness and group fitness programs, and taught ballet and other forms of dance to all ages. Working with groups, families, and businesses to help educate them in health and movement methods is her passion. Jane has worked with the Bleeding Disorders community for over 10 years, offering various educational sessions in the areas of therapeutic art and movement. Jane enjoys spending time with her three granddaughters, and pursuing her hobbies of art, movement, and nature exploration.



**Danielle Kiesel**  
Senior National Account  
Executive, Genentech

Danielle is the Senior National Account Executive leading Genentech's relationship with the Hemophilia Alliance, the Community Oncology Alliance and Amazon. Danielle has

20 years of experience in the Bleeding Disorders Community working in both Specialty Pharmacy and for Pharmaceutical Manufacturers, the last three of which have been with Genentech. Danielle has held roles in Patient Advocacy, Sales, Sales Training, Sales Leadership, Marketing, Reimbursement and Access, Account Management and Health Equity. Danielle has won numerous awards for her contributions to the organizations she has worked for and community she serves but the ones she is the proudest of are being named Volunteer of the Year for the New York City Hemophilia Chapter in 2014 and the 2022 Genentech Breast Network Award for her work on the "What's Your Reason for a Mammogram" campaign centering the experience of and barriers to care for Haitian women.



**Kevin Harris**

Kevin is a Certified Wellness Coach with a focus on nutrition, mobility, and behavior change, a teen program director, and hemophilia B patient. He has a

deep passion for helping people with their journey towards wellness and has recently become a Wilderness First Responder, as he takes on a new passion for first aid training. He has been giving empowerment speeches to the bleeding disorder community for the last eight years while also helping to run camps across the country. Kevin strives to enable individuals with chronic conditions to keep a positive outlook and remember that their choices can improve their overall quality of life.

*Thank you!*

## NOTES



# NOTES

**one family**

World Hemophilia Day 2023



**When:** Monday, April 17, 2023 @ 6:30PM

**Where:** The Westin Poinsett Hotel  
120 South Main Street  
Greenville, SC



## Sharing the power of protection.



Scan Here to Register!

presented by:

**sanofi**

<https://tinyurl.com/WorldHemophiliaDay2023>

# STEP

*for bleeding disorders*

5K WALK/RUN FUNDRAISER

MAY 6, 2023 • SALUDA SHOALS PARK

P - PROMOTING RESEARCH  
E - EMPOWERING PEOPLE  
T - TRANSFORMING TOMORROWS  
S - SHARING STORIES

CHECK-IN BEGINS AT 8:30AM  
WELCOME AT 9AM  
WALK BEGINS AT 10AM



SCAN HERE TO REGISTER!





# HELLO Conference & Annual Meeting

June 9-10th, 2023 ~ 5:30pm Embassy Suites  
670 Verdae Blvd, Greenville, SC 29607

BDASC's Annual Meeting has taken place for 50 years now and provides the South Carolina bleeding disorders community the opportunity to come together and network, learn, and enjoy the empowerment of education and support. The presentation of the Chapter's Annual Awards is provided on Friday night; including our awarding of college scholarships, introducing new board members, and celebrating those who have served. A keynote speaker presentation is always a highlight for attendees as we search hard to bring in the very best and most current information in bleeding disorders. A teen track is provided concurrently with our adult programming. The HELLO Conference allows for attendees to enjoy a learning environment with educational presentations and breakout sessions. Information on current and future treatment therapies and bleeding disorders services are made available during our exhibit hall experience. Registration is required with BDASC for attendance. All meals, sessions and childcare are included with hotel accommodation available for our traveling guests. The event is free of charge for BDASC members.

## Educational Topics to Include:

- Our Past, Present, and Future of Bleeding Disorders Treatment & Care
- BDASC Advocacy Session
- Shared Decision Making and the Shift to Person Centered Care
- Women Who Bleed
- Advocating in the ER
- Learning the Art of Kinesio Taping
- VWD Education & Support Group
- Infusion Class Lessons

## Childcare & Teen Programming

Teen Program *provided by Gut Monkey and the Leading Edge*

Tween (8-12yrs) Programming *provided by Corporate Kids with education provided by Optum*

Child Programming (1-7yrs) Programming *provided by Corporate Kids and education provided by CVS Specialty*



**Registration closes on May 15th, register today**



  
**Scan to Register!**

<https://tinyurl.com/BDASCHELLO2023>

# Thank you sponsors!

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Premier Sponsors

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*adult community event*

**Women and Men's Retreat & Medical Symposium**  
**March 31- April 2, 2023 Greenville, SC**