

BDASC

**49TH ANNUAL
MEETING AND
H.E.L.L.O
CONFERENCE**



**RESEARCH: PROVIDING BRIGHTER
TOMORROWS**

PROGRAM AGENDA

**June 10-11, 2022
Embassy Suites
Greenville, South Carolina**

Friday, June 10



Grand Pinehurst Ballroom

4:00 p.m. - Registration Opens (Pre-Function Hallway)

5:30 p.m. - Premier Sponsor Welcomes

6:00 p.m. - Chapter Opening Welcomes

6:30 p.m. - Dinner Buffet Opening

6:45 p.m. - Dinner Keynote Presentation: "Together, We Have Come a Long Way"

The bleeding disorders community has a long history of advocacy that began with the voices of many diverse individuals all coming together to advance access to quality care and treatment.

As we venture into the future and continue to advocate for research in treatment for enhancing the quality of life of all those affected by bleeding disorders, the community voice should be at the forefront, having a seat at the table for conversations and education on what is most important. Hear about the rich history of our community's advocacy with the Hemophilia Federation of America, and how you and your family can help lead the way to advance research, treatment, and equal access to quality healthcare for everyone affected.

Sonji Wilkes, Vice President, Public Affairs, Hemophilia Federation of America

7:30 p.m. - Chapter Recognitions

Scholarship Awards – *Marley Day, Devon Mulligan, Sarah Walden, Regan Weber*

New Board Members – *Samantha Javorka, Susie Maloy, Edna Rabb, Taylor Upton*

Board Retirees - *Eric Dunton, Ursula Sagot, Robert Butler, Cristal Day,*

Patricia Tucker

Board Member of the Year

Legislative Advocate of the Year – *SC State Representative Patricia Henegan*

Coalition Advocate of the Year – *Cristal Day, Coalition Chair*

Coalition Ambassadors of the Year – *The Keith Family*

Making a Difference Award – *Prisma Health*

Appreciation and Partnership Award – *Drew Clawson, Kinard Consulting*

Volunteer of the Year "The Fisher Award" – *Matt Tucker*

The Aaron Eugene Gossett "Pillar of Strength Award" – *James Whitmire*

Saturday, June 11

BDASC

Palmetto Club Ballroom

Childcare Services (Ages 1-12 years)

8:30 a.m. - 4:00 p.m. - Childcare Services, Provided by Corporate Kids Events

Video Truck Tournament Play, 6-12 years

10:00 - 11:00 a.m. - 10-12 year-olds

11:00 a.m. - 12:00 p.m. - 6-9 year-olds

12:00 p.m. - Kids Lunchtime

Charleston and Columbia Ballrooms, and Outside Lawn Terrace

Teen Programming (Ages 13-18 years)

9:00 a.m. - 12:00 p.m. - Teen Programming, GutMonkey's "Leading Edge" Program

Play some classic games, new games, and games with a twist! Teens will spend time getting to know their peers, building community with other teens from their chapter, and having some good fun and laughs along the way.

12:00 - 1:30 p.m. - Lunch (with parents)

1:30 - 4:00 p.m. - Teen Programming, GutMonkey's "Leading Edge" Program (cont.)

Participants will engage in the Leading Edge Scavenger Hunt! Think scavenger hunt meets escape room meets minute-to-win-it. Teens will work together in teams to navigate and complete a challenging and fun activity. Their goal? Find the keys to unlock a top-secret GutMonkey lockbox. Along the way, teens will work together and engage with various challenges related to their lives, like being in the bleeding disorder community and being a teenager. We'll wrap up the day with a mini art project related to their scavenger hunt experience.

Facilitated by *Tom Hamm and Margaret Bridges, GutMonkey*



Tom Hamm, Program Manager, GutMonkey

Tom Hamm began working as an outdoor educator about 10 years ago. He has worked with youth across the country: from the Outward Bound Schools in Baltimore and Florida, running a university outdoor program in California, to now working with the bleeding disorder community with GutMonkey. Tom considers himself to be a fierce youth advocate and committed educator. He is dedicated to providing the community with learning experiences that strive for equity and a greater understanding of self and others.



Margaret Bridges, Program Manager, GutMonkey

Margaret Bridges is a facilitator and creative that believes that holistic healthcare lies at the intersection of a nurturing community, a connection to the outdoors, and a patient-first relationship with providers. She devises programs centered on play, joy, and reflection that offer communities a connection to each other and the world around them. Her curiosity and drive to explore emerging practices in community engagement stems from a decade of experience in civic practice; arts and creative development; and experiential outdoor programming.

MORNING EDUCATIONAL SESSIONS



Doral Ballroom

8:00 - 9:00 a.m. – Open Exhibiting: Premier Sponsors

Pinehurst Ballroom

9:00 – 10:00 a.m. - Opening Keynote Plenary: "The Blue-Sky Vision of NHF"

The National Hemophilia Foundations' (NHF) Chief Scientific Officer, Dr. Kevin Mills, will share about the research collaboration and national Blue-Sky Vision for the future of the Bleeding Disorders Community. Learn about the development of the national vision, how it all began, how the community was involved, and how future research efforts will include the voices of our community. We will also hear about the Community Voices in Research (CVR) initiative and how our members can be involved in the direction of future research.

Kevin Mills, PhD, Chief Scientific Officer, National Hemophilia Foundation

Felix Olaya, MPH, Research Recruitment & Engagement Specialist, National Hemophilia Foundation

Doral Ballroom

10:00 - 10:45 a.m. - Open Exhibits

Pinehurst Ballroom

10:45 a.m. – 12:00 p.m. - "Understanding our Diverse Perspectives: How Individual Experiences Strengthen a Unified Voice"

This session will focus on "sharing our stories" as an avenue for building advocacy awareness. Every person sees the world differently. Diversity leads to better, more informed decision-making by increasing the perspectives being considered. It spurs creativity and innovation, and it bolsters our voices as advocates. This panel discussion will help us explore how things like gender, race, age, socio-economic status, type of healthcare coverage, and distinct disease states inform how we advocate, and how listening to one another makes us stronger and can facilitate changes within our healthcare systems for access to quality care and treatment.

Moderators: *Sonji Wilkes, Vice President, Public Affairs, Hemophilia Federation of America; Sue Martin, Executive Director, BDASC; and Jeremy Williams, Advocacy and Organizational Development Coordinator, BDASC*

Panelists:

New Coalition Ambassador, Mild Hemophilia, B – Seth Morgan

Representing Women with Bleeding Disorders – Kristin Shelton

Representing Von Willebrand Disease – Samantha Javorka

Representing Rare Platelet Disorders/Glanzmann Thrombasthenia - Edna Rabb

Representing Rare Bleeding Disorders, Factor 7 – Ryan Coleman

Representing Mild Hemophilia A – Ward Keith

Representing Hemophilia B with Inhibitors – Meggan and Brian Burton

Doral Ballroom
12:00 – 1:30 p.m. - Lunch and Exhibits



**12:00 p.m. – Members leaving on Saturday
must check out of hotel rooms**

AFTERNOON EDUCATIONAL SESSIONS #1

1:30 - 2:30 p.m. - Breakout Sessions

Pinehurst Ballroom

"Gene Therapy Jeopardy"

Expand your gene therapy research knowledge with this fun new experience from BioMarin to make the science behind gene therapy research memorable and entertaining. Whether you're already a whiz or are just starting to explore, you and your friends can learn together and earn points to win bragging rights. Will you become the next Jeopardy Gene-ius? Join us to find out!

Dr. Kimo Stine, Medical Director, Arkansas Center for Bleeding Disorders

Sponsored by BioMarin

Greenbrier Breakout Room

"VWD for ALL: VWD Wrap"

Join the VWD Community in South Carolina and beyond for a brief overview of Von Willebrand Disease (VWD), when to seek treatment, how to manage the condition, and skills to empower yourself. Discuss what to do when your doctor won't listen to your needs and learn self-advocacy skills. Open discussions will allow participants within the VWD, rare, and platelet bleeding disorders community to learn from shared experiences and support one another.

Sue Geraghty, RN, MBA, Nurse Consultant

Sponsored by the Hemophilia Federation of America

Kings Mill Breakout Room

"Women Who Bleed – Women Carriers"

This session empowers women to know the meaning of their hemophilia and bleeding disorders carrier status and to better understand treatment options. It will explore issues important to women carriers—whether they are symptomatic or not—including genetics, carrier testing, emotional impacts of diagnosis, recognition of symptoms, and treatment options. The program aims to bring moms of hemophilia patients together to gain real-life, practical tools for success while building connections for a lifetime. The session offers participants a space to share their bleeding disorders experiences, shift their mindset, and acknowledge their power.

Jessica Lovercamp, RN, Hematology Nurse Educator, Bayer Healthcare

Sponsored by Bayer

3:00 – 4:00 p.m. – Support Group Breakouts

Pinehurst Ballroom

"The Missing Gene"

Get your magnifying glass and trench coat out as host *Justin Willman* attempts to solve the no-family mystery with some help from the community. Meet *Michelle and Joey*, who are looking for answers as to how a hemophilia A diagnosis came to be in their newborn son, and where they should turn next. In this episode, we dive into the challenges families face without any known history of hemophilia face.

Jennifer Harris, RN, Clinical Education Manager (Georgia & Alabama), Genentech
Sponsored by Genentech

King's Mill Breakout Room

"Mind and Body Skills to Tame and Reframe Pain: 7 Mind-Body Approaches"

Putting into practice seven simple techniques that harness the power of the mind may help relieve chronic pain. Diane teaches core concepts in Mind-Body Medicine and the Gate Theory of Pain: how to close your brain's "pain gates" using perception. Diane will help participants discover how deep breathing, mental imagery, meditation, mindfulness, positive self-talk, and self-love can increase pain-blocking body chemistry. She believes in the transforming power of meditation, mindfulness, and other mind-body techniques, and is dedicated to helping people access the healing power of their minds to experience more peace, health, and genuine happiness.

Diane Diamond, DrRS, Professional Speaker, Common Factors
Sponsored by CSL Behring

Greenbrier Ball Breakout Room

"Spotlight On Siblings"

Families who have a mix of children with and without a diagnosis of a bleeding disorders face unique challenges. These include issues stemming from so much time and attention focused on diagnosed children. In this session, learn new tools to help ensure that each child's needs are met in a family where children have bleeding disorders and others do not.

Xaviette Pointer-Kincy, M.Ed., Community Relations and Education Manager,
Sanofi
Sponsored by Sanofi

Pinehurst Ballroom

4:00 p.m. – Infusion Clinic

"There's No Place Like Home: Self-Infusion at Home"

Objectives for this class will be to understand the impact homecare has on persons with bleeding disorders, review the benefits and risks and when is an appropriate time to start, explore options for alleviating needle phobia, discuss the transition to self-infusion, and discuss options for administration of factor concentrated and novel therapies in the home setting and the education required. Individual one-to-one training will also be available after class discussions.

Sue Geraghty, RN, MBA, Nurse Consultant

Robin Jones, RN, Nurse Coordinator, South Carolina Hemophilia Treatment Center

Sponsored by Hemophilia Federation of America

Doral Ballroom

4:00 – 5:00 p.m. – Exhibits Hall (Last Call)

CLOSING DINNER

Outside Hotel Terrace

5:30 – 7:30 p.m.

Exhibitor Hall Hours: On Saturday, come learn about the current and future treatment therapies in the pipeline and supportive services available to our community from our sponsors in healthcare treatment therapies and services.

8:00 - 9:00 a.m. (Premier Sponsors Only)

10:00 - 10:45 a.m.

12:00 - 1:30 p.m.

4:00 - 5:00 p.m.

Don't forget to take our five-minute online evaluation. Go to the link below or scan the QR code to the right with your phone.

Thank you for your feedback!

<https://tinyurl.com/BDASC22>





Kevin Mill, Ph.D., Chief Research Officer, National Hemophilia Foundation

Kevin Mills, Ph.D., serves as the chief scientific officer for the National Hemophilia Foundation (NHF), where he is responsible for overseeing research strategy, including developing and expanding the foundation's research capabilities, and setting research goals. He brings more than 20 years of experience in biotechnology, hematology, and oncology to the role. In 2005, Dr. Mills joined the faculty at the Jackson Laboratory in Bar Harbor, Maine, and led a laboratory focused on the biology of DNA repair in hematology and oncology. In 2012, he co-founded Cyteir Therapeutics, a biotechnology company developing and commercializing new therapies targeting DNA repair pathways. As Cyteir's chief scientific officer, he led the team that brought a first-in-class RAD51 inhibitor into clinical trials. Dr. Mills subsequently joined Civetta Therapeutics as chief scientific officer. He is a graduate of the University of Colorado Boulder, MIT, and Harvard Medical School.



Dr. Kimo Stine, Medical Director, Arkansas Center for Bleeding Disorders

Kimo Stine, MD, received his medical degree from the University of Kansas Medical School where he also completed his internship and residency in Pediatrics. He then completed a fellowship in pediatric hematology-oncology at Duke University Medical Center, before moving to Tulane University Medical Center in New Orleans. There he was mentored by

Dr. Cindy Lessinger and her team in bleeding disorders. He moved to Arkansas Children's Hospital (ACH) in 1991. Dr. Stine is currently the medical director for the bleeding disorders program at ACH and has been involved in several clinical trials for persons with bleeding disorders, including several gene trials. He has also been a consultant to several pharmaceutical companies involved in developing new therapies for persons with bleeding disorders. He is currently a board member of the Hemophilia Alliance.



Sonji Wilkes, Vice President of Public Affairs, Hemophilia Federation of America

Sonji Wilkes, CAE, graduated Magna Cum Laude with a Bachelor of Arts in Behavioral Science and certificate in Public Administration from the Metropolitan State University of Denver in 2001. She holds an executive certificate in Nonprofit Management from Georgetown University. After a decade of advocacy work that led to her family's insurance struggles being published by multiple national and international media, as well as being recognized by the White House, Sonji joined the Hemophilia Federation of America (HFA) in 2013 and has served as a Program Manager for the HFA Families Program and Communications Manager. She currently leads patient engagement and policy and advocacy efforts as the Vice President of Public Affairs. Sonji is intimately familiar with the challenge of caring for a child with a chronic disorder as her son has hemophilia and an inhibitor, and in 2019 testified before a Congressional committee about some of those challenges.



Sue Geraghty, RN, Nurse Consultant

Sue Geraghty has more than 40 years of experience as a registered nurse, mostly spent in orthopedics and bleeding disorders. She worked as a Nurse Coordinator at the University of Colorado-Denver Hemophilia and Thrombosis Center for 25 years, where she coordinated care in a three-state catchment area. Currently, Sue works as an independent consultant in the areas of hemophilia and health care education. She is a graduate of

Lander University, the University of North Carolina at Charlotte, and has a master's in business administration and management from the University of Colorado-Denver.



Diane Dimon, Dr. RS, Professional Speaker, Common Factors

Diane Dimon is a professional speaker at Matters of the Mind, which conducts seminars, retreats, private coaching sessions, and speaker presentations worldwide. Diane holds a doctorate in religious studies, specializing in the study of consciousness, the mechanics of stress, and

the mind-body connection. Her work focuses on meditation for anxiety and stress reduction, reframing pain through mind-body techniques, and mindful eating.



Xaviette Pointer-Kincy, M.Ed., Community Relations and Education Manager

Xaviette Pointer-Kincy is the community relations and education manager at Sanofi. As a longtime hemophilia community member, she finds this role to be a natural fit, and loves educating patients and their families on healthcare trends and treatments. Xaviette also has a passion for supporting nonprofit leaders and their work.



Jennifer Harris, Clinical Education Manager

Jennifer Harris, BSN, RN, has worked in the hemophilia community for over 10 years. She started her bleeding disorders career as an adult hemophilia nurse coordinator for a hemophilia treatment center in Atlanta, Georgia. Her current role is as a hemophilia nurse education manager with Genentech.



Jessica Lovercamp, RN, Hematology Nurse Educator, Bayer Healthcare

Jessica Lovercamp is a hematology nurse educator with Bayer Healthcare. She is a former nurse coordinator for the Oklahoma Center for Bleeding and Clotting Disorders and the Oklahoma hemophilia nurse coordinator for the University of Oklahoma Health Sciences Center.

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Visit each of our sponsor booths, get all their LOGO boxes stamped, then tear off this sheet and place it in our raffle box at the closing dinner to win our annual meeting grand prize. You must be present when we announce the winners to claim the prize. And don't forget to include your name!

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