



South Carolina Health Equity Family Advocacy Summit

Charleston, SC October 21-23, 2022

Agenda

Convention Center Ballroom C3-C4

Date and Time	Session Title	Speaker / Facilitator	Content
Friday 4:00 p.m.	Registration & Opening Exhibits	Conference Center Ballroom C Foyer	Register with BDASC, pick up your name badges, programs, and meet our sponsors! Meet one-on-one with our manufactures and health care services providers and explore what they have to offer. Member social hours.
Friday 6:00 p.m.	Opening Welcome Remarks Sharing our Stories	<i>Sue Martin</i> , Executive Director, Advocacy Coalition Lead, HEDI Member <i>Samantha Javorka</i> , BDASC Engagement Coordinator, Advocacy ambassador, HEDI member ❖ SME Voices <i>Robert Butler</i> , Advocacy ambassador, HEDI member	Weekend agenda review, sponsor recognitions, social media engagement, and Ice-breakers.
Friday 6:30 p.m.	Dinner Buffet Opens	<i>Shelley Crisp</i> , BDASC President, Advocacy Coalition member	Welcome from the President of BDASC!

<p>Friday 7:00 p. m.</p>	<p>South Carolina Health Equity Diversity and Inclusion Leadership (HEDI)</p>	<p><i>Sue Martin</i>, Executive Director, Advocacy Coalition Lead, HEDI Member</p> <ul style="list-style-type: none"> ❖ SME Voices <i>Cristal Day</i>, Advocacy Coalition, Chair, HEDI member ❖ <i>Renita Johnson</i>, Advocacy Coalition Member, HEDI member 	<p>Meet our HEDI Working Group Team ~Overview</p> <p>The SCHEILD is made up of SME’s (Subject Matter Experts) who are tasked to bare light on the patient voices in South Carolina and address the needs of the underserved bleeding disorders community. To promote health equity, diversity, and inclusion, they are working to address inequities, challenges, and the struggles present today with the goal to raise awareness and promote treatment access to help achieve quality health care outcomes for the SC Bleeding Disorders Community. They are also tasked with the goal of bringing all groups of the membership together from different backgrounds and disease states to feel accepted, welcomed, and to be heard.</p>
<p>Friday 7:30 p.m.</p>	<p>Positive Healthcare Outcomes Begins with Access to Treatment Care</p>	<p>Moderator - <i>Sue Martin</i>, Executive Director, Advocacy Coalition Lead, HEDI Member</p> <p><i>Stephanie Ambrose</i>, DO, Medical Director, Hemophilia Treatment Center of South Carolina - Midlands</p> <p><i>Robin Jones</i>, RN, MSM, CPN, CPHON, Nurse Navigator, Hemophilia Treatment Center of South Carolina - Midlands</p> <p><i>Shonequa Smith</i>, Social Worker, HTC - Midlands</p>	<p>Hear from our Hemophilia Treatment Center, Prisma Health Upstate; learn what the HTC Comprehensive Model of Care provides, meet the team, discover how they are addressing health equity for all and the struggles the HTC’s may face locally and nationally. Learn how we can all play a part in achieving positive health outcomes. Ask your questions in our interactive Q and A.</p>

Date and Time	Session Title	Speaker / Facilitator	Content
Saturday - 7:00 a.m. – 8:45 a.m.	Open Exhibits / Breakfast in the hotel	Ballroom C Foyer	Meet one-on-one with our manufactures and healthcare services providers and explore what they have to offer.
Saturday 9:00 a.m. - 10:30 a.m.	<p>Meeting The Needs of All – What Keeps Payers & Advocates Up at Night</p> <p>❖ SME Voices <i>Samantha Javorka</i>, BDASC Engagement Coordinator, Advocacy ambassador, HEDI member</p>	<p><i>Michelle Rice</i>, Healthcare Advocate –Michelle Rice & Associates, LLC</p> <p><i>Anna Bleasdale</i>, Director, Children and Youth with Special Health Care Needs, S.C. Department of Health and Environment Control (DHEC)</p> <p><i>Malerie Hartsell</i>, Manager, Hemophilia Bleeding Disorders Program, DHEC</p> <p><i>James Romano</i>, MPS, MBA, Principal, Care & Cures Partners, LLC</p> <p><i>Dr. Nathan Henderson</i>, VP Clinical Quality Care, Blue Cross / Blue Shield</p>	<p>Discover and engage in learning about our healthcare access and barriers to care; what insurance companies think about; hear about our state programs and Medicaid access; and understand how together we can strive to build payer relationships improving our access to care and treatment. You will learn how payers and advocates share many of the same concerns and that our healthcare system is about serving the population at large, not one specific disease, ethnicity, or gender group.</p> <p>This panel discussion will be a time for conversations and understanding with an interactive Q & A.</p>
10:30 a.m. – 11:00 a.m. Quick Break / Exhibits			
Saturday 11:00 a.m. - 12:00 p.m.	<p>Health Equity, Diversity, and Inclusion (HEDI) Overview</p> <p>❖ SME Voices <i>Edna Rabb</i>, Advocacy ambassador, HEDI member</p>	<p><i>Keri Norris</i>, Vice President of Health Equity, Diversity & Inclusion, National Hemophilia Foundation</p>	<p>What is Health Equity, Diversity, and Inclusion and why is it import to address? What does HEDI have to do with quality healthcare outcome for those in the bleeding disorders community? Join Keri in a conversation.</p>

12:00 p.m. to 1:00 p.m. Lunch Break and Exhibits
Lunch Served in Ballroom B

Date and Time	Session Title	Speaker / Facilitator	Content
<p>Saturday 1:00 p.m. – 2:15 p.m.</p>	<p>Access to Care and Treatment: The South Carolina Hemophilia Treatment Centers – Part 2 - Health Disparities and Engagement within Treatment Care</p> <p>❖ SME Voices <i>Tim Swanburg</i>, Advocacy Coalition member, HEDI member</p>	<p><i>Adrián Palau-Tejeda</i>, Senior Manager for Health Disparities, Hemophilia Federation of America</p> <p><i>Leslie Gilbert, MD</i>, Director, Hemophilia Treatment Center of South Carolina - Upstate</p> <p><i>Shayla Bergmann, MD</i>, Associate Professor, Director Pediatric Nonmalignant Hematology, MUSC (Virtually)</p>	<p>Join Adrian and the South Carolina Treatment Center’s physicians and staff as they engage in a conversation on access to care and treatment in South Carolina and how health disparities can affect persons with bleeding disorders achieve quality health care outcomes. Join us in conversation with this panel discussion and let us know what challenges you have and what you feel could help to bridge the gaps in your health care.</p>
2:15 p.m. – 2:45 p.m. Quick Break / Exhibits			
<p>Saturday 2:45 p.m. – 4:00 p.m.</p>	<p>National and Local Policy, preparing for the South Carolina Legislative Session: Addressing Health Equity, Diversity, Inclusion and Assess to Care and treatment</p>	<p>Industry Stakeholders Partners: represented by <i>Alison Clifford</i>, Director, Therapeutic Policy and Advocacy, Rare Disease U.S. Public Affairs, Takeda</p>	<p>How is our Industry Partners addressing Health Equity, Diversity, and Inclusion, and what role do they play in accessing quality health care. Learn from one of our community partners stakeholders, Takeda. Then hear from one of our national stakeholders, The National Hemophilia Foundation, and how they are addressing health equity and the barriers we still face today as a community. Learn about the continued concerns we have on the Accumulator Adjuster programs in our</p>

	<ul style="list-style-type: none"> ❖ SME Voices <i>Kristen Shelton</i>, Advocacy Ambassador, HEDI member 	<p><i>Josie Gamez</i>, Manager, Government Relations, National Hemophilia Foundation</p> <p><i>James Romano</i>, MPS, MBA, Principal, Care & Cures Partners, LLC</p> <p><i>Sue Martin</i>, Executive Director, Advocacy Coalition Lead, HEDI Member</p>	<p>insurance policies and the barriers this causes for bleeding disorders patients treatment care. Hear what they are doing nationally and locally throughout the nation, including South Carolina.</p> <ul style="list-style-type: none"> ○ Federal Help Ensure Lower Patient (HELP) Copays Act – H.R. 5801 <p>We will finish this session with hearing stories of success with grass root legislation efforts by the bleeding disorders community and the best practices for effectively passing legislation. Hear what is on the legislative agenda for BDASC in 2023 and how your voices will be needed. Learn what the Rare Disease Advisory Council has been up to.</p>
4:00 p.m. – 7:00 p.m. (Pretzel Snack Break) Free Time for Charleston Explorations			
7:00 p.m. – 8:30 p.m. Dinner Presentation	<p>Protecting Our Mental Health: Handling the Mental Stress of a Chronic Condition</p> <ul style="list-style-type: none"> ❖ SME Voices <i>Mattie Watkins</i>, Coalition Ambassador, HEDI member 	<p><i>Debbie De La Riva</i>, Mental Health Matters, Too, Sponsored by Hemophilia Federation of America</p>	<p>After a long day of learning about healthcare access and feeling some of the stress it may cause individuals and their families, let us come together over a dinner conversation with our expert in the field of Mental Health. You will discover how the body holds on to stress, how the physical stress of a chronic condition compounds mental stress, and learn about some strategies to help you cope and relieve stress.</p>
Date and Time	Session Title	Speaker / Facilitator	Session Content
Sunday - 7:00 a.m. – 11:00 a.m.	Breakfast in the hotel, sign up to share your story with Samantha!	<i>Samantha Javorka</i> / BDASC Engagement Coordinator	Share your story by making a quick video with our Engagement Coordinator, Samantha Javorka throughout the morning on Sunday and help us to educate the public on what bleeding disorders, who we are at BDASC, and some of the challenges we face as a community.
Sunday 9:00 a.m. – 10:00 a.m.	<p>The Power of Story Telling</p> <ul style="list-style-type: none"> ❖ SME Voices <i>Taylor Upton</i>, Coalition ambassador, HEDI member 	<i>Keri Norris</i> , Vice President of Health Equity, Diversity & Inclusion, National Hemophilia Foundation	Learn from Keri how story telling helps to get your message across to legislators, the general public, state agencies, our healthcare system, and others, and how you can learn to share your unique bleeding disorder story to affect change.

10:00 a.m. – 11:00 a.m.		Quick Break / Exhibits	
Sunday - 10:15 a.m. – 11:00 a.m.	Wrapping it up! HEDI Working Group Breakouts	BDASC SME's Leadership and HEDI members	We will break out into smaller table groups with additional time for group discussions of the unique challenges each group may face in access to quality treatment care, rate them as a group of importance, make suggestion for solutions, and then we will share our discussions with the participants in the conference. Group discussions will be led by the SME's.
Sunday - 11:00 a.m.	Hotel Check-Out / Evaluations	BDASC Thank you' s	Pick up your lunch box in the Foyer

➤ **Suggested Charleston Activities:**

- Market street open until 6:00pm daily, then 6:00 p.m. -10:30 p.m. Saturday / Sunday's (less than 10 miles)
- Charleston Battery (10 miles, 21 minutes)
- Sunday SC Aquarium (less than 10 miles) Open daily until 9:00 a.m. - 5:00 p.m.

➤ **Evaluation:** Please take our conference survey so we can improve upon our events.

- https://www.surveymonkey.com/r/HEDI_2022



➤ **Women With Bleeding Disorders:** Please take our SC discovery survey on women's access to care and treatment care.

- <https://www.surveymonkey.com/r/HEDI-WomenWhoBleed>



➤ **Resources:**

- [NHF Health Equity](#)
- [NHF Personal Health Insurance Toolkit](#)
- [Bleeding Disorders Association of South Carolina](#)
- [HFA Health Disparity Council](#)
- [Mental Health Matters Too](#)