

BDASC



South Carolina Hemophilia Bleeding Disorders Advocacy Coalition 2021 Stakeholders Forum

Maintaining Continued Healthcare Access Through Collaboration

10:00am – 11:30pm, November 13, 2021

Agenda

[View our 2021 Coalition Advocacy Sponsors](#)

This forum will provide the opportunity for national and state policy experts, state leaders, healthcare professionals, and the bleeding disorders community to come together virtually to share information and discuss current healthcare access issues relevant to the bleeding disorders community. This also is an opportunity to consider long-term advocacy priorities and develop strategies for ensuring quality, patient-centered treatment in 2022. Finally, this is a chance for state and national stakeholders to share updates on healthcare trends we can anticipate in 2022.

10:00am: Welcome and Introductions

Sue Martin, Executive Director, BDASC, Advocacy Coalition

- The South Carolina Bleeding Disorders Advocacy Coalition
 - Welcome New Coalition and Ambassador Members
 - Advocacy Coalition Voices
 - Shelley Crisp, President BDASC
 - Aaron Smith, Vice President BDASC

BDASC's 2021 Advocacy Coalition Recap & 2022 Core Values

This discussion will include a brief look back at all of the major advocacy programs and projects carried out by BDASC and the Advocacy Coalition in 2021. This will include a discussion of major successes and challenges faced in achieving our goals. Specifically, we will consider these accomplishments as they relate to our current three-year strategic plan and begin identifying key goals and priorities for 2022.

2022 Advocacy Priority Goals

- The Rare Disease Advisory Council (RDAC)
- Exploring Women's Health Equity & Outreach
- Exploring Standards of Care for Bleeding Disorders Patients
- Individualize, Patient Centric Healthcare & Treatment Plans
- HTC Expansions: Eliminating Barriers to Treatment Care; Satellite Offices
- Mental Healthcare and Healthcare Equity

Brief Outlook: Legislative Agenda

- Legislative Advocacy Day March 8-9, 2022

Sue Martin, Executive Director, BDASC, Advocacy Coalition

South Carolina Hemophilia Assistance Program (HAP) Updates

10:15am: Meet the “new” Director

Anna Bleasdale, MSN, RN, Director, Division of Children & Youth with Special Health Care Needs, S.C. Department of Health and Environmental Control (DHEC)

10:20am: Hemophilia Treatment Center’s Stability and Continuity in Expert Treatment

Here an overview of current federal policies affecting the Hemophilia Treatment Centers and what the Alliance is addressing and the efforts to affect sustainability and the 340B program. Hear updates on South Carolina’s Hemophilia Treatment Centers.

Jeff Blake, Senior Vice President, Payer Relations, Hemophilia Alliance

Stephanie P. Ambrose, DO, SC Hemophilia Treatment Center (SCHTC), Prisma Health Midstate

Shayla M. Bergmann, MD, MUSC Hemophilia Treatment Clinic, MUSC Shawn Jenkins Children's Hospital

10:50am - Quick Break (10 minutes)

11:00am: Looking Ahead: 2022 SC Legislative Outlook

Understanding working within our republican state legislature, the importance of legislative relationships, and the need for developing collaborations and partnerships within South Carolina’s health advocacy organizations and rare disease populations.

Drew Clawson, Consultant PhRMA

11:10am: 2022 State and National Access, Government Relations, Trends, Barriers, and Forecasts

Alison Clifford, Director, Therapeutic Advocacy and Policy, Takeda

Nathan Schaefer, Vice President of Public Policy, National Hemophilia Foundation

Miriam Goldstein, Hemophilia Federation of America, Director, Policy & Principal Legal Counsel

Thank you to our 2021 Advocacy Coalition, and NHF SBAC Sponsors!

Novo Nordisk (Founding Sponsor), Bayer, Genentech, Takeda, Sanofi Genzyme, CSL Behring, The Hemophilia Alliance, PhRMA, National Hemophilia Foundation, Hemophilia Federation of America