



Bleeding Disorders Association of South Carolina

South Carolina Hemophilia and Bleeding Disorders Advocacy Coalition 2022 Annual Stakeholders Meeting

[Virtual Registration](#)

Meeting ID: 889 4778 4002

Passcode: 456732

Agenda

- 1) Bleeding Disorders Association of South Carolina Strategic Advocacy Plan 2020– 2023 Review
- 2) Quick Report – NHF SBAC Matrix Outcomes Report – South Carolina
- 3) 2022 Advocacy - Successes and Challenges

Successes:

- Advocacy Days
 - Introduced Accumulator Adjuster Bill (H4987)
 - Continue Funding for South Carolina’s HAP
 - Education and Awareness
- Proclamations / Resolutions
- Rare Disease Advisory Council (RDAC) Update
- Expansion of Advocacy Support / Education Programs
 - C.A.R.E. Program
 - Inaugural Women’s Conference and Retreat Addressing Women with Bleeding Disorders
 - Teen Advocacy
- HTC’s Expansions and Relationships
 - Adult Treatment Care
- Health Equity, Diversity, and Inclusion Advocacy Family Summit
 - Report / Barriers to Care and Treatment
 - Relationship Building
- S C Patient Advocacy Alliance - Collaborative / Coalition for Rare and Chronic Conditions Patients Advocacy Groups

Challenges:

- Staffing
- Relationship building
 - Medicaid
 - Governor’s Staff

4) 2023 Focus- Looking Ahead

- Advocacy Days – Feb. 28 & March 1, 2023- Courtyard Marriot USC Downtown Columbia
- Renewed Relationships and Bleeding Disorders Education / New Members of the SC Legislation
 - January 12th 9:00am - Breakfast – All State and General Assembly Invited
 - Relationship Building, Awareness & Education on BD, Accumulator Bill Education
 - Key Relationships for 2023 Legislation Priorities
 - Medicaid Reconnections
 - Gene Therapy Education

5) Accumulator Adjuster Legislation – Best Approach?

- Reintroduction of State Bill?
- Insurance Regulation?
- Keep Strong Partnership with BCBS / Others
- Other Bills of Interest

6) Additional Advocacy Priorities:

- General Advancing our Presence at the Capitol
- Addressing the Health Disparities in SC – HEDI Outcomes
- Looking at our Membership and Zip Codes with Disparities
- Advancing the Creation of the SC Patient Advocacy Alliance / Collaborative Coalition
- Working with the RDAC team to advance the needs of the Rare Community
- Supporting our Ultra Rare Bleeding Disorders Community / Platelet Disorders / Rural Community Members