

South Carolina Hemophilia and Bleeding Disorders Advocacy Coalition Bleeding Disorders Association of South Carolina

With Appreciation to our 2022 Coalition and SBAC Advocacy Sponsors!



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders



2022 STAKEHOLDERS MEETING

South Carolina Hemophilia and Bleeding Disorders Advocacy Coalition November 12, 2022 ~ Bleeding Disorders Association of South Carolina

- ❖ Welcomes and Introductions; Sponsors Recognition
- ❖ Strategic Advocacy Objectives (2020-2023)
 - ❖ NHF SBAC Matrix Outcomes
- ❖ SCHBDAC Members and Ambassadors
- ❖ 2022 Coalition Wrap-up
 - ❖ Successes and Challenges
- ❖ 2023 Focus and Advocacy Priorities
 - Health Equity & Legislative Agenda
- ❖ HEDI Report
 - ❖ Moving Forward 2023
 - ❖ VWD Awareness and Support
 - ❖ Mental Health State Bleeding Disorders Survey (HTC Partnerships)
 - ❖ Teen Transitioning and Young Adult Advocacy
 - ❖ Women With Bleeding Disorders Awareness and Support
- ❖ 2022 State and National Forecast, Trends, Barriers



BDASC

46 COUNTIES – 7 CONGRESSIONAL DISTRICTS YOUR VOICE MATTERS!

The South Carolina Hemophilia and Bleeding Disorders Coalition and Ambassadors

20 Counties Represented to Date

55 Members Strong

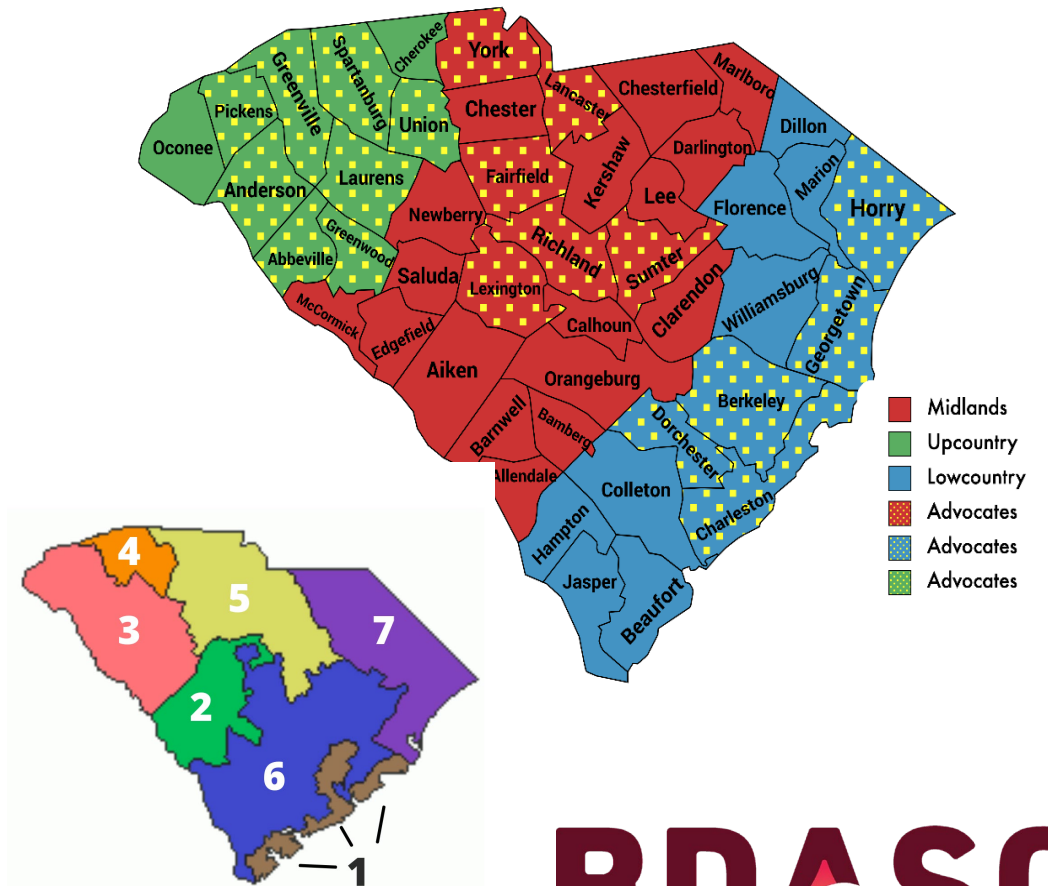
16 Stakeholder Partnerships

Several Advocacy Coalition Partnerships

Goal – one advocacy representative in every county!

All (7) Congressional Districts are NOW represented

Ambassador Program: To help drive the efforts of Hemophilia of South Carolina's Advocacy Coalition, we have **Advocacy Ambassadors who are volunteers in a leadership position** responsible for helping to establish and build a strong grassroots network of bleeding disorders advocates within South Carolina. The goal is to help increase awareness of Hemophilia, Von Willebrand Disease, and other rare bleeding disorders and the challenges persons affected and their families face. Ambassadors increase awareness and support of Hemophilia of South Carolina and the Advocacy Coalition's mission. Ambassadors serve as liaisons between the Coalition and the public, state agencies, and officials working towards improving the quality of life of individuals and their families who are affected by bleeding disorders. The Coalition team is committed to our volunteer's engagement and contributions to the bleeding disorders community.



BDASC

2020-2023 Strategic Advocacy Plan

Advocacy Priority: Relationship Partnerships (Legislative and Agency)

Objective #1 Continue to nurture relationships with key state officials and payers. Build upon current and new relationships.

Advocacy Priority: Grassroots Capacity Maintaining and Expanding

Objective #2 Advance growth, and maintain our grassroots capacity building to maintain ~~our~~ Advocacy and Ambassador Program.

Advocacy Priority: Identify State Access to Care Issues and Threats in South Carolina

Objective #3 Continue to identify state access to care issues and threats, make action plans to be taken.

Advocacy Priority: Nurture and Grow Partnerships with Allied Healthcare Organizations

Objective #4 Continue to build and nurture strong relationships with healthcare organizations while focusing on policy ~~issues~~ ~~as~~ strong emphasis on the hospital and emergency room standards.

Advocacy Priority: Continue to Build Strong Communications, Relationships with Stakeholders

Objective #5 Maintain Advocacy Communications and Education Strategies

Advocacy Priority: Strong Consumer Education on Patient Advocacy

Objective #6 Continue with ongoing advocacy education for Chapter members

Advocacy Priority: Fundraising for Advocacy Initiatives

Objective #7 Continue to increase advocacy funds by fundraising to support advocacy programs, Coalition work, and Ambassador ~~program~~ ~~ing~~.

NHF 2022 SBAC MATRIX OUTCOMES

- 21 advocacy meetings, calls, touch points in advocacy with community and stakeholders
- 516 total members / stakeholders in attendance over the year
- 559 received (above) received some type of advocacy education
- 36 state legislative meeting this year, Advocacy Days
- 13 Proclamations / Resolutions this year, Recognized on the House Floor
- 4 calls to action with 90 members participating, including 126 in Phone 2Action
- 2 in district meetings with legislators (Howard / Henegan)
- 2 state agencies meetings (DHEC)
- 1 Testifying (RDAC)
- Multiple Social Media Posts
- 12 new Ambassador members (2 Teens)

2022 Success Stories & Challenges

Successes Stories

- ❑ **Continue to have an overall strong advocacy and Ambassador Program**
 - ❑ **Recognized at the state and national level**
 - ❑ **Leader in access to care for Chronic and Rare Conditions**
- ❑ **HEDI Summit / BCBS Relationship / Gov. and Lt Governor Engagement / HAP/ RDAC/ Accum Bill**
- ❑ **No Significant Changes in Medicaid Benefits that directly affect us! – NO PREFERRED DRUG LISTS (PDL'S) FOR CLOTTING FACTORS**
- ❑ **Promoting to Implement Chronic and Rare Disease State Coalition**

Challenges:

- ❑ **Time to concentrate on advocacy work**
- ❑ **Reduced Relationships: Changes in Staff-Medicaid, Governor's staff, DHHS Staff**
- ❑ **Staffing, consulting, admin advocacy work**
- ❑ **Keeping Advocates and Ambassador Engagement**
 - ❑ **Gathering of new members to the team**
 - ❑ **Engaging one advocate for every county and congressional district**
- ❑ **Gathering of relevant stories with impact**
- ❑ **Public Awareness Videos**

SCHBDAC SWOT

Strengths

Advocacy Coalition, partnerships, and Grass Roots Advocates
Ambassadors – Utilizing the voices of many
Passion and Perseverance
Dedicated Diverse Team
HEDI Commitment- HEDI Outcomes

Weaknesses

Time Dedication
Funding limitations
Burnout of Advocates
Currently, no statewide Patient Advocacy Coalition / Alliance

Opportunity

Partnering with Rare Disease Coalitions and like organizations
Corporate partnerships outside bleeding disorders
Ultra Rare and Chronic Disorders
Expand our membership and reach
Statewide Patient Alliance
Health Equity for all
Strong HTC Alliance and Support

Threats

Insurance Barriers / no Medicaid expansions
Insurance Health Policies; Accumulators, Step, Prior Auth, High out of pocket costs
Economy
Physicians retiring or leaving the field: Experts in Care and Treatment of BD patients
Political Climate

2023 Focus - Looking Ahead

Legislative Breakfast January 12, 2023- State Capitol, 9am – in need of strong advocates and children

Virtual and Hybrid Legislative Days- February 28 and March 1, 2023 (Virtual Trainings: Jan & Feb for new members / legislative priorities)

- State Legislative Training on the 28th, Meetings on the 1st
- Many Phone 2 Action
- Media Expansion / Stories / Videos
- Renewed Relationships / DHHS/ Medicaid / New Educational Opportunities

Legislative Priorities

General Education on bleeding disorders & **patient stories**

Support for our State Hemophilia Assistance Program (HAP)

Support Anti - Accumulator Education / Legislation (Federal and State)

Support Rare Disease Council Bill – Permanent Statute (if desired)

Other bills of interest

State Patient Advocacy Alliance / Coalition

Health Equity: Mental Health, VWD, Teen and Young Adults Transitioning and Advocacy Engagement, Women Who Bleed

THANK YOU ALL!

With your support, together we can accomplish anything!

