

Patient advocacy is an area of lay specialization in health care concerned with promoting the healthcare needs of patients, family members, survivors, and caretakers. This comprises direct service to the individual or family as well as activities that promote health access to health care in and communities and throughout a region. Advocates support and promote the rights of the patients in the healthcare arena, help build capacity to improve community health, and support health policy initiatives focused on safe, affordable, and quality care.

START THE CONVERSATION

March is National Bleeding Disorders Awareness Month "Light it up Red"

# Advocac

BDASC

Bleeding Disorders Association of South Carolia

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### **Our Advocacy Coalition**

All BDASC advocacy efforts are coordinated through the South Carolina Hemophilia and Bleeding Disorders Advocacy Coalition (SCHBDAC). This is a group of staff, members, and stakeholders who set strategic goals and formulate plans to achieve them through regular meetings and trainings. It also includes our Ambassadors, who are grassroots organizers at the county level. SCHBAC is a proud member of the State Based Advocacy Coalition of the National Hemophilia Foundation

#### **State Advocacy Days**

During advocacy days, BDASC staff and members travel to the state capital, Columbia, where we advocate for the needs of people with bleeding disorders living in South Carolina. Participants meet the evening before for a training session where they receive all of the necessary information for meeting with state lawmakers. The following day is filled with legislative meetings at the state capitol complex. We often are introduced on the floor of either the House of Representatives or Senate. In addition to being a lot of fun, it is a direct way to have an impact on the policies made in our state regarding healthcare and other issues that affect people with bleeding disorders.

#### Accomplishments

The Bleeding Disorders Association of South Carolina (BDASC) has a robust Advocacy Coalition, comprising 47 Ambassadors and members representing 17 counties across the state.

- Held annual Advocacy Days at the state capitol for the last 13 years, totaling over 500 meetings with state lawmakers.
- Advocate for support of the state Hemophilia Assistance Plan.
- In 2021, worked to help create a Rare Disease Advisory Council in the state.
- Participate in National Hemophilia Foundation's "Washington Days" each year, meeting with the state's nine members of Congress and their staff.
- Secure dozens of proclamations recognizing March as "Bleeding Disorders Awareness Month" from cities and counties across the state, and a proclamation from the governor each year.
- Engage with executive branch members and staff, including three separate meetings with the lieutenant governor.
- Regularly meet with staff from state health insurance agencies, including DHEC and DHHS, as well as local chambers of commerce.
- Hold policy forums for individuals from myriad aspects of bleeding disorders, including advocates, physicians, policy experts, and government officials.
- Participate in various coalitions locally and nationally, such as the All Copay Counts Coalition and the National Organization for Rare Diseases.

## How You Can Make a Difference

Consider joining our efforts to make South Carolina a better place for people and their families affected by bleeding disorders. You can get involved in any of these regular projects and initiatives:

• Join our Advocacy Coalition or Ambassadors Program - Help us have Ambassadors in every county of the state.

**Current Ambassadors Representation:** 



- State Advocacy Days Held each March in Columbia, SC.
- Proclamations State, county, and city proclamations recognizing March as "Bleeding Disorders Awareness Month," which helps spread awareness about living with bleeding disorders.
- County Council and Legislative Delegation Outreach – Help organize letter-writing campaigns and attend delegation meetings.
- Let us help you "Tell Your Story" Education opens doors to improved healthcare access and patient-centered treatment care for positive outcomes.