



South Carolina Hemophilia and Bleeding Disorders Advocacy Coalition

The Coalition Mission: To Empower the Hemophilia and Bleeding Disorders Community in South Carolina to speak to public and private decision-makers about improving Access to Quality and Affordable Health Care and Treatment.

Monthly Coalition Meeting

January 20, 2022, 7:00 pm

Agenda

Call in number: 1-605-475-3235

Access Code 747583#

I. Welcome and Introductions

Cristal Day, BDASC Advocacy Coalition Chair

Sue Martin, BDASC Executive Director

A. New website page

II. Announcements: next meeting Thursday, February 17, 7:00 pm

III. National Policy Updates from Stakeholders:

National Hemophilia Foundation – Nathen Schaefer, Vice President of Public Policy

Hemophilia Federation of America – Miriam Goldstein, Director of Policy

National Hemophilia Foundation - Kollet Koulianos, Senior Director of Payer Relations

National Organization for Rare Diseases - Annissa Reed, State Policy Manager, Eastern US

SC Rare Action Network – Kerri Nelson, State Ambassador

Pfizer – Melissa Bishop-Murphy, Senior Director of Government Relations

Pfizer - Vitoria Andrade Cunningham, Alliance Development Manager

Takeda – Alison Clifford, Director of Therapeutic Advocacy and Policy

Takeda – Marcus Downs, Director of State Government Affairs

CSL Behring – Karla White, Director of State Government Affairs

Genentech – Gina Marie Dalferro Truslow, Senior Manager of Patient Advocacy Relations

Bleeding Disorders Association of South Carolina, formerly known as Hemophilia of South Carolina is a proud recipient of the NHF Advocacy & Public Policy Chapter of Excellence Award in recognition of our commitment to advocacy and education initiatives both at the state and local level, aimed at improving the lives of those in the bleeding disorders community.

Chronic Disease Coalition – Erin Foote Morgan, Executive Director
Hemophilia Alliance – Sean Singh, Senior Vice President of Marketing and Operations
SC PhRMA Alliance – Drew Clawson, President, Kinard Consulting

IV. State Advocacy Days March 8-9, 2022

Courtyard by Marriott Columbia Downtown at USC
630 Assembly St. Columbia, SC 29201

- A. Schedule of events
- B. Reminder to sign up / Hotel rooms available now
 - 1. <http://events.r20.constantcontact.com/register/event?oeidk=a07eiz2me9ibedaf905&llr=rrgp9woab>
- C. Draft agenda
 - 1. Topics
 - 2. Prospective speakers
- D. Discussion of 2022 priorities
 - 1. Rare Disease Advisory Council
 - a) Sue attendance at upcoming virtual meeting
 - b) Need for legislation? Moving forward
 - 2. Combatting accumulator adjuster policies
 - 3. Continued funding for SC Hemophilia Assistance Plan (HAP)

V. Attendance at NHF Virtual Washington Days- March 1-2, 2022

- A. Commitments; one advocate for each region minimum

VI. 2022 Proclamations

- A. Commitments needed for reaching out

VII. Phone2Action Platform

VIII. Building Connections: South Carolina Healthcare Agency Outreach

IX. Comments and Questions

X. Adjournment

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