



**BLEEDING DISORDERS ASSOCIATION OF SOUTH CAROLINA
15th ANNUAL
STATE ADVOCACY DAYS**

**COURTYARD BY MARRIOTT
COLUMBIA DOWNTOWN AT UNIVERSITY OF SOUTH CAROLINA
630 Assembly Street
Columbia, South Carolina 29201**

TUESDAY, FEBRUARY 27, 2024 and WEDNESDAY, FEBRUARY 28, 2024

Tuesday, February 27, 2024

4:00 pm: **Hotel Check-in**

4:30 pm: **BDASC Registration / Social Hour** (*Richland Ballroom Upstairs*)
~ Please locate your last name on our tables and sit accordingly. You are being assigned seating with your legislative meeting teams ~

5:30 pm: **Welcomes and Introductions**
Sue Martin, Executive Director, BDASC
James Romano, Legislative Coordinator, BDASC

5:45 pm: **National and Local Advocacy**
Josie Gamez, National Bleeding Disorders Foundation
Introduction to our NBDF 2024 Washington Days Team
Sue Martin

6:00 pm: **2024 Legislative Priorities**

Hemophilia Assistance Program (HAP) Updates
Anna Bleasdale, Director, Children with Special Health Care Needs, Department of Health and Environmental Control (DHEC)
Malerie Hartsell, Hemophilia Assistance Program Manager, DHEC

House Bill H.3618 Copay Accumulator Adjuster Program Ban
Representative Patricia Henegan, (D), District 54, South Carolina General Assembly
H.3618 Sponsor

**Senate Bill S.1024 Copay Accumulator Adjuster Program Ban,
Companion Bill**
Senator Michael Fanning, [D] District 17, South Carolina General Assembly
S.1024 Sponsor

(OVER)

- 6:20 pm: **Welcoming Our Legislative Guests**
- 6:45 pm: Dinner Buffet
Put Yourself Out There: Sharing and Advocating for Bleeding Disorders
Presented by Morgan Cook, Community Education Specialist, Sponsored by Takeda
Everyone has a story to tell. It is important that real people share their experiences to help advocate for those within the bleeding disorder community and themselves. Learn how to gain confidence, improve communication skills, and make connections.
- *(During Dinner) Teen and Tween Advocacy Training (Designated area)*
Josie Gamez & Sue Martin
- 7:45: pm: **Why Your Story Matters – Voices of our Advocates**
 ➤ *Advocate: Teen Leadership Alliance*
 ➤ *Advocate:*
- 8:00 pm: **Understanding Your Advocacy Packet and Leave-Behind Folders**
Best Practices for Impactful Meetings
James Romano, Legislative Coordinator, BDASC
Sue Martin, Executive Director, BDASC
 ➤ *Teen Roll-Play – Having a Successful Meeting*
- Meeting Schedule & Navigating the State Capitol (map)**
James Romano, Legislative Coordinator, BDASC
Sue Martin, Executive Director, BDASC

Wednesday, February 28, 2024

- 6:30 am: **Breakfast** *(Richland Ballroom)*
- 7:30am: **Hotel Checkout**
- 8:00 am: **Assemble in the Lobby - Group Photo**
- 8:20 am: **Travel to Capitol Grounds Walk & Hotel Shuttle**
- 8:30 am: ***Photo on the Capitol Steps*** - *(Side Capitol steps facing Pendleton Street, near the Blatt and Gressette buildings - Everyone is invited!)*
- 9:00am – 12:00pm: **Legislative Meetings**
- Proclamation Meet and Greet with Lt. Governor Pamela Evette (front of her Capitol office– Rotunda) TBD
- 10:00am: SC House Recognition, Representative Stewart Jones
(House Balcony)
- 12:00am: SC Senate Recognition, Senator Mike Fanning
(Senate Balcony)
- 1:00 - **Lunch and Debriefing** *(Marriott Richland Ballroom)*

2:30pm: *Sanofi and Xaviette Pointer-Kinsey, Community Relations & Education Manager*

All Participants and Guests can wear their **Red Ties** to support our **Going RED for Bleeding Disorders Campaign** to recognize our community's support of **March, National Bleeding Disorders Awareness Month**. *Please ask your legislators if they will support our Going Red Campaign and pose for a picture with you. Post on your Facebook page and be sure to send it to Sue (sue.martin@bda-sc.org, text to 864-350-9941) so we can post on social media.*

Press and social media sharing: #BDASC2024Advocacy

With Appreciation to the South Carolina Hemophilia and Bleeding Disorders Advocacy Coalition members, Ambassadors, National Organizations, and our SPONSORS!

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Advocacy Lunch Sponsor



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