

Fall Advocacy Summit

ACCESS TO CARE & TREATMENT

November 10th-11th, Greenville, SC



2023 Advocacy Summit and Stakeholders Meeting

Friday, November 10, 2023

4:00pm: Hotel Check In / Registration

- Open Exhibits
(Throughout the Evening)

5:00pm: Cocktails and Social Engagement

6:00pm: Opening Welcomes

- *Sue Martin, BDASC Executive Director, State Coalition Lead, Cristal Day, Coalition Chair, James Romano, BDASC Legislative Coordinator, Aaron Smith, BDASC President*

6:30pm: Buffett Dinner Opens

7:00pm: *The Patient Voice*

7:15pm: Dinner Presentation: **Setting the Stage for Success**

- Moving A Bill to Committee and Beyond; Securing Bipartisan Support
Guest Legislator

Recapping 2023 Advocacy Successes / Stakeholders Report

- *Sue Martin, BDASC Executive Director, State Coalition Lead*

Preparing for 2024, Setting Goals for Success

- *Josie Gamez, NBDF*
- *James Romano, BDASC Legislative Coordinator*

9:00pm: Social Free Time

Saturday, November 11, 2023

7:00am: Breakfast Buffett (*Oak & Honey Restaurant*)

- Open Exhibits

Morning Sessions

8:30am: *The Patient Voice*

8:35am – 10:00am: ***Understanding Today's Health Care Environment, Challenges with Access, and Medical Spend***

- *Kollet Koulianos, Hemophilia Alliance*
- *Hemophilia Treatment Centers, South Carolina*
 - *Dr. Leslie Gilbert, Dr. Stephanie Ambrose, Dr. Shalya Bergmann*
 - *Robin Jones, Nurse Coordinator, HTC*

10:00am – 10:30: Meeting Break and Open Exhibits

10:30am – 12:00pm: **Understand Accumulator Adjustments: What is Needed for Successful Policy Change**

Accumulator Adjustment Programs / Deep Dive / Lessons Learned

- H. 3618
 - *Kollet Koulianos, Hemophilia Alliance*
 - *Josie Gamez, NBDF*
- A Need to Share Stories: Identifying Compelling Stories
- Senate Companion Bill
- Building Large Coalitions
 - Palmetto Health Collective: Voices Needed
 - Building Partnerships / HTC Networks / Medical Associations
 - *Sue Martin, Executive Director, BDASC*
 - *Drew Clawson, Kinard Consulting*
 - *Alison Clifford, Director, Therapeutic Policy and Advocacy, Rare Disease US Public Affairs, Takeda*

12:00 – 1:00pm: Meeting Lunch Buffet Break and Open Exhibits (*Hotel Check Out*)
(*Lunch buffet held in the Bee Hive Room*)

Afternoon Sessions

1:00pm: *The Patient Voice*

1:05 – 2:00pm: **Next Steps; Passing a Bill in SC**

- Process and 2024 Timeline: Getting to the Governor's Desk
 - *Drew Clawson & James Romano, BDASC Legislative Coordinator*
- We have a Hearing, Now What?
 - Voices From Texas: Successes and Lessons Learned
 - Melissa Compton, Executive Director, Lone Star Bleeding Disorders Foundation*
 - Julie Fredericksen Jones, Executive Director, Texas Central Bleeding Disorders*

2:00pm: Meeting Break and Open Exhibits

2:30 – 4:00pm: Direct Targeted Marketing and Education Awareness

- Twitter (X) & Posting (*training*)
 - Securing TV Interview, Opinion Pieces
- Wrapping Up: 2024 Priorities: Capital Visits and Meetings
 - January 10, 2024 Legislative Breakfast
 - February 27-28, 2024 Advocacy Days and Pre-Meeting Training
 - Legislative Meetings January – May
 - Expectations and Advocate Commitments

(Social Media Training – TBD)

Sue Martin, BDASC Executive Director, State Coalition Lead

James Romano, BDASC Legislative Coordinator

4:00pm: *The Patient Closing Voice*

5:00pm: Dinner Event, Downtown Greenville at the [Ink N Ivy Restaurant](#) third floor private dining space, 21 E Coffee St, Greenville, SC 29601

*TBD ***Possible Teen, Tween Programming will be in the Hide – A – Way room running concurrently with the adult programming. Teens and tweens will have all meals with parents.*