

# Fall Advocacy Summit

ACCESS TO CARE & TREATMENT

November 10th-11th, Greenville, SC



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## 2023 Fall Advocacy Summit

### Friday, November 10, 2023

**4:00pm:** Hotel Check In

BDASC Registration Begins Pre-Function Hall Birch Ballrooms

- Open Exhibits  
(Throughout the Evening)

**5:00pm:** Cocktails and Social Engagement Pre-Function Hall Birch Ballrooms

**6:00pm:** Opening Welcomes and Sponsor Recognition Welcomes - Birch Ballroom A & B

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

**6:30pm:** Buffet Dinner Opens - Pre-Function Hall Birch Ballrooms

**7:00pm:** *The Patient Voice: Cristal Day*

**7:05pm:** **Setting the Stage for Success: Special Guest Speaker**

Moving A Bill Through Committee to the Governor's Desk; The 2024 Legislative Landscape

- South Carolina House Representative Chandra Dillard, (D) District 23

**Setting Goals for Success; Straight from the Source**

*Words of Encouragement*

- Josie Gamez, NBDF & Former Legislative Staffer
- James Romano, BDASC Legislative Coordinator & President of Cure and Care

**Recapping 2023 Advocacy Successes / Stakeholders Report**

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

**9:00pm:** Social Free Time

## **Saturday, November 11, 2023**

**7:00 – 8:15am:** Breakfast Buffett (*Oak & Honey Restaurant*)

- Open Exhibits

**8:15am:** Teens and Tweens: Teens Leadership Alliance Check in (*Hive-A-Way Room*)  
(*Entrance is next to the Valet Parking- Outside*)

**Morning Sessions** - Birch Ballroom A & B

**8:30am:** *The Patient Voice: Sue Martin*

**8:35am – 10:00am:** South Carolina Hemophilia Treatment Centers; Access to Care and Treatment Updates

- *Hemophilia Treatment Centers, South Carolina*  
*Dr. Shayla Bergmann, Director Pediatric Nonmalignant Hematology, MUSC*  
*Dr. Leslie Gilbert, Lead Hematologist Prisma Health HTC Upstate,*  
*Dr. Stephanie Ambrose, Medical Director & Robin Jones, Nurse Coordinator, Prisma Health HTC Mid-State*

**Understanding Today's Healthcare Environment, Challenges with Access**

- *Kollet Koulianos, Hemophilia Alliance*

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

**10:30am:** *The Patient Voice: Whitney Galloway*

**10:35am – 11:45am:** 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 & Former Legislative Staffer*
    - *Lessons Learned & National Successes*
- Identifying and Building Compelling Stories
- Building Strength with Coalitions
  - Partnerships: Palmetto Health Collective; Industry; Non-Profits; Medical Associations
    - *Sue Martin, Executive Director, BDASC*
    - *Drew Clawson, Kinard Consulting*
    - *Alison Clifford, Director, Therapeutic Policy and Advocacy, Rare Disease US Public Affairs, Takeda*

**11:45 – 1:00pm:** Lunch Buffet and Open Exhibits (*Hotel Check Out*)  
(*Lunch buffet held in the Bee Hive Room*)

**Afternoon Sessions** - Birch Ballroom A & B

**1:00pm:** *The Patient Voice: Kristin Shelton*

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

- 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*

*Josie Gamez, NBDF & Former Legislative Staffer*

- **2024 Timeline: Process to the Governor's Desk**
  - *Drew Clawson & James Romano, BDASC Legislative Coordinator*

**2:00pm:** Break and Open Exhibits

**2:30 – 3:50pm: Direct Targeted Messaging; Marketing and Education Awareness**

- Twitter (X) & Posting (*training*)
- Securing TV Interviews, Opinion Pieces
  - *Social Media Training*
    - *Khadija Butt, Director, Rational 360*

**Wrapping Up: 2024 Priorities: Capital Visits and Meetings**

- January 10, 2024 Legislative Breakfast
  - *James Romano, BDASC Legislative Coordinator*
- February 27-28, 2024 Advocacy Days and Pre-Meeting Training
  - 2024 Registrations on Site
    - *Sue Martin, James Romano, Josie Gamez*
- Legislative Meetings January – May
  - *James Romano*
- Expectations and Advocate Commitments
  - *Sue Martin*

**3:50pm: *The Patient Closing Voice: Warren Ingrum***

**4:00pm:** Tween and Teen Certificate Presentation

**5:00pm:** Dinner Event, Downtown Greenville at the [Ink N Ivy Restaurant](#) third floor private dining space, 21 E Coffee St, Greenville, SC 29601  
*Appetizers begin at 5:00pm with Dinner Buffet at 5:45pm*

**\*\*\* Saturday:** *Teen & Tween Leadership Alliance Programming will be in the Hide – A – Way room running concurrently with the adult programming. Teens and tweens will have all meals with parents. Check in with a parent promptly at 8:15am. They will join you at lunch.*

**Don't forget to take our Fall Advocacy Summit Evaluation! Thank you for attending 😊**



<https://www.surveymonkey.com/r/2023FallAdvocacySummit>

