

**Bleeding Disorders Association of SC**  
**Bleeding Disorders Advisory Committee**  
**September 12, 2023**

**Welcome All- Attendees In- Person:**

- Jecorei Lyons and Matt Igelman (Drugco)
- Jordan Martin (Optum)
- Apryl Purnell (Accredo)
- Laura Benton (CVS Health)
- Kerrie Barnes (CSL Behring)
  
- Virtual Attendees: Paul Brayshaw (Octapharma)
  - Wayne Cook (CVS Health)
  - Yinell Nunez (Takeda)
  - Cheryl Steep (Biomarin)
  - Janet Rivera (Optum)
  - Norberto Liriano (Novo Nordisk)
  - Johanna Robertson (Specialty Care RX)
  - Alex Lightbourne (Hemabiologics)

ii. and iii. If there are any changes just send them to Sue and/ or Kerrie to be changed or added.

iii. Chapter continues to need educational supplies for Welcome Bags for new members, school nurses, dental informational pieces and unbranded for emergency room conference exhibiting. Also, Treatment Center Visits may offer a chance for educational item distribution. There is no maximum amount that you can send due to Storage Capabilities. Kid focused education and unbranded preferred items.

**2) BDASC Major Calendar of Event Opportunities-**

i. Refer to the calendar of events on the Website:

Fall Advocacy Summit- Nov 10-11 in Greenville at Springhill Suites Downtown- Room can hold 75 attendees. This is important because we only have this season to get the Bill Passed.

- Fri night will be a more Casual setting to cover the discussion of the Bill by Community Members.
- Sponsorship at 3k and 5k level for Exhibits
- Breakfast Sessions focused on Stopping the Accumulator Adjuster. So very important because it causes issues for any person with high-cost medication.
- Sue is participating in the Palmetto Health Collective on October 17<sup>th</sup> to gather information on the landscape.

- BCBS is the largest employer in SC so they have a lot of pull and power over the legislators.
- Winter Statewide Meeting- December 9<sup>th</sup> in Columbia- 200 Community Members are expected.
- Sponsor at \$1,500 and can sponsor craft at 1000.

## ii. Serving the African American Community- Engagement Opportunity

The Spanish Dinner went awesome so Chapter would like to replicate this and offer support to the African American Community as well. A great example is to discuss overcoming healthcare disparities. Inclusion is important for our Community Members.

### b. Discussion of Major Calendar items:

All of the Major Dates are already contracted.

- January 10<sup>th</sup>- All the Legislators for Breakfast on first day of session
- Feb 27-28<sup>th</sup> - BDASC State Advocacy Days- Ask about exhibits/ sponsorships.
- March 6-8 - NHF Washington Days
- March 22-24 - Adult Retreat Greenville- Same place and same sponsorship cost.
- VWD Track and Platelet disorders and Hemophilia-Men and Women will be in some sessions together and some sessions they will be separated.
- May 11<sup>th</sup> - Step for Bleeding Disorders
- June 21<sup>st</sup>-23<sup>rd</sup> - Annual Meeting- "Hello"
- July 18<sup>th</sup> -July 21<sup>st</sup> is combined usually with NC Teen Camp is (TBD)
- For NBDF Conference in ATL August 12-15 - lots of people from SC will attend and there were 5 families who went from 2023 to the conference.
- September 27<sup>th</sup> Par for the Clot
- December 14<sup>th</sup> Winter Statewide Gathering, Columbia

Sue's 2024 Vision- **"The Voices of 46"** - Sue is wanting to do a statewide outreach to all 46 counties in the state, providing education and resources where they live. Let's do dinners, events, lunches for 46 Counties for the Community Members. Lots of opportunity, so just ask Sue.

## 3) Overall Concerns of all state Chapters in 2023

Challenges are that Chapters are frustrated with partnerships outside of Chapter Events. Has caused some issues due to liability for outside events and concerns that the patients may be put in a bad position from Industry, are being confused with whose event is this, having to choose

between chapter and outside events, some people may not be invited, feeling ae hurt. The Chapter serves ALL in SC with Bleeding Disorders equally.

BDASC not doing branded dinners due to a past issue with local HTC provider that stemmed from the dinner.

Industry needs to be a good partner and be respectful of the HTC Provider and Patient relationship. Industry needs to focus on maintaining patients by doing a good job for them.

Sue is looking for some folks interested in part time work for the Chapter to work in the office on mailings, welcome bags, etc.

**Next Meeting: January 18<sup>th</sup>, 2024-** See you all there!