



Bleeding Disorders Association of South Carolina

Notes for BDAC on May 14th, 2024

- 1) Welcomes- In Person Attendees: Rachel Cooper-Leal (Pfizer), Alex Lightbourne (HemaBiologics), Apryl Tilert (Accredo), Kerrie Barnes (CSL Behring).
Virtual Attendees: Kelly Hoots (PromptCare), Andrea Bridges (BlueSky), William Black (Specialty Rx), Johanna Robertson (Specialty Rx), Laura Benton (CVS Health), Morgan Cook (Takeda), Wayne Cook (CVS Health), Paul Brayshaw (Octapharma), Jordan Martin (Optum), Chris Barnes (Bayer), Norberto Liriano (Novo Nordisk).

- 2) Review of BDASC Policies- Advocacy is our Job together as BDAC Members supporting the BDASC Community.
Industry Policy- Fairness overall.
Volunteerism is welcome however please have some skin in the game, if possible, in order to market your company. For example, if the industry company is not sponsoring, please do not market your product or services if you are attending as an affected participant.
Based on this policy- if situations come up but you have overstepped them you will be pushed to the bottom of the list when meetings come up and are booked up.

- 3) BDASC Sponsorship and Opportunities for 2024: All 46 Counties Wide
Annual Meeting June 21-23 at the Embassy Suites by Hilton Greenville golf Resort & Conference Center

Address Boxes: HELLO Annual Meeting
Embassy Suites by Hilton Greenville golf Resort & Conference Center
670 Verdae Boulevard
Greenville, SC 29607

Hold For-Attn: Sue Martin/ YOUR NAME, June 21

Summer Camp Shipments to: (Please No Giveaways with Drug Name)

Sue Martin
17 Steadman Way
Greer, SC 29650

Teen Camp: 30-40 attendees
Camp Burnt Gin- 100



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Camp Courage-100

May 31st and June 1st- Nurses Conference-500 Attendees.

Ship items to Sue's Residence.

*Dinners and Community Engagement Programs on Events page- Many events occurring overall that compete with National Events.

*BDASC Community Events are very important, so patients engage in local community and local challenges at the local level.

*Sue works hard to get folks to attend the BDASC Events when an industry partner is sponsoring. Keep this in mind when you partner with BDASC.

Considering a Fall Gathering (Advocacy/ Family Fun Day Fundraiser)

Combining Gut Monkey Sponsored Trail Walk with Campfire for the BD Cause.

Consider a Nature Themed Craft- Stamping painted leaves or create a walking stick to use on the Trail Walk.

Consider- a Product Update we can sponsor in combination with the Advocacy.

Perhaps 2- 3-minute presentations for the industry sponsors for the morning session and maybe catch the zoo after with everyone afterwards.

Let's all email Sue and let her know if we could sponsor an exhibit at a meeting such as this. Considering October 19th and 20th

- 4) Ideas are welcome on Fundraising is so important because there is a need for more funds coming in to cover everything the Chapter is doing at this time.
 - Some thoughts brought to the table include Trivia night, Birthday Fundraisers on FB, etc.
 - Potential Airplane Pull at Greenville Downtown Airport. Exploring the idea.

Par for The Clot- If you would like to be a volunteer, please donate something for the day.

Water, Sponsor Golf Carts, Sponsor a Golf Hole.

-It's time to gather Golf Donations for the Raffles and Prizes.

-Can you help ask for gift cards from frequently visited stores and restaurants?

-There is more room for corporate sponsorship as well



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-Patient Financial Assistance Programs- Currently Open and Funding based on Priority of patient needs.

Examples include this fund helping to cover hospital charges. The continued issue with United Healthcare goes on and funds may need to go to cover expenses such as this.

-SC Medicaid will be expanded in the state in 2025: it's good and can have setbacks for the BD Community since this change may end up limiting treatment options for all of the patients.

-H3618- Banning Accumulator Adjustment Programs Legislation continues

BDAC 2024 Calendar Dates:

Next Meeting Date Confirm- potentially September 10th.

Submitted by Kerrie Barnes 6/18/2024