



**Hemophilia of South Carolina**  
**Bleeding Disorders Advisory Committee (BDAC)**  
**April 13, 2021**  
**Via ZOOM MEETING**  
**10:00am – 11:00pm**

1) Welcome all:

- i. New members welcome and introductions
- ii. Capturing all industry contact information- (*send to Sue and Kerrie asap*)
- iii. Ask Kerrie for anything you wish to discuss at the BDAC meetings
- iv. Quick reminder: HSC policies are on the HSC website-  
<https://www.hemophiliasc.org/advocacy/bleeding-disorders-advisory-committee-bdac/>

Notes on #1: Kerrie will add in those contacts that were not included on the original list.

Policy Guidelines - <https://www.hemophiliasc.org/advocacy/bleeding-disorders-advisory-committee-bdac/>

- 2) Change Name Transition: a. Bleeding Disorders Association of South Carolina  
b. How does that work with your grants / Company?

Notes on #2: As far as the name change some community members are concerned that Hemophilia will no longer be in the Chapter Name. However, everyone should be aware that the Chapter is educating and advocating for Hemophilia, VWD, Platelet Disorders and the name change reflects on broadening the community. Hope is to gather those unaware that HSC serves all bleeding disorders.

The Chapter just put through the request for 501c3 determination for the IRS for the name change so for now for purposes of check requests for exhibits, etc., it will still be Hemophilia of South Carolina.

The Tax ID # will not change and overall the focus is on a goal of inclusion and broadening the name for supporting all of those being served with the Chapter.

The Chapter has also just joined the Greenville Chamber of Commerce.

- 3) HSC Annual Gratitude Report a. Available on our website- great snapshot of 2020

The Gratitude Report is posted for review on the About Us section on the HSC website  
<https://www.hemophiliasc.org/about-us/>

- b. Reminder: HSC Calendar of Events- check our website page often for updates on events -  
<https://www.hemophiliasc.org/programs-and-events/calendar/>

- c. Front Page: <https://www.hemophiliasc.org/>  
<https://www.hemophiliasc.org/>

There are links to the Calendar of Events on the Chapter Website- these events are spaced out over time in order to keep the patients engaged in connecting at the chapter event and providing support and education.

Also, please if there is ever a question on what you in your industry position are welcome to attend just give Sue a call or email her and she will determine if it is an option based on the particular program, or sponsorships.

#### 4) HSC - No in-person events at this time – potential timeframe

Nothing In-person yet.

A question was put out to members at the last community gathering and most people are choosing to get vaccinated either now or plan to eventually, and they would prefer masks if in-person events begin.

We have to consider that the Chapter has a Liability and there are risks involved and when the events go back “live” then if we attend we will need to follow strict guidelines that are given to us as well as the patients.

Also, a key finding in these virtual events includes the fact that some patients would not attend in person however they have easily joined with the virtual option through the Virtual I-Pad Program. This should support consideration for “Hybrid” events long term so that anyone could join remotely to the event if necessary and offers opportunities to community members that perhaps never attended any events previously.

Sue has a goal to start “Live” events with small groups in outside settings in late June. For example the Camp Connections Event at Saluda Shoals Park on July 17<sup>th</sup> will be outside and there may be some exhibit opportunities for industry. Strict Guidelines will need to be followed for participation in the event. Call or email Sue to learn of this opportunity.

Sue intends to go full Live for the September Family Camp at Myrtle Beach.

Each industry member continues to have individual rules that are subject to the local area and those restrictions and/ or State Mandates.

##### a. Industry restrictions? Time frame discussions updates

Each industry member continues to have individual rules that are subject to the local area and those restrictions and/ or State Mandates. A few examples include Apryl (Accredo) who is playing by ear with no overnights, Paul (Octapharma) has no restrictions and just needs to follow the local requirements, and Janet (Optum) has to complete travel requests in order to go in person.

#### 5) Summer Camps:

##### ii. Need support and items for camp bags

a. PRISMA Upstate and DHEC- Camp Burnt Gin

b. Dates TBD, running throughout the summer- Ice Cream Social Mailings / t-shirts

150 giveaway items would be sufficient for these two camp events. Send before the end on May to the HSC office please.

6) HSC Welcome – New patient / members bags: Need more supplies sent to the office  
Items needed will include educational books for the kids, teens, and adults. These items should be non-branded (drug related) but company branding is fine within items. Check with Sue if you have a specific question as to appropriate items.

Sue is receiving referrals to the organization daily from all three HTC's so supplies are running low.

7) Events:

a) HSC 1<sup>st</sup> Medical Symposium April 23-24<sup>th</sup> - HTC's Partnerships

Target Audience- (please let others know, any docs and nurses, ER's, Etc.)

350 Packets with invitations were sent to SC Hematologists and Hospitals state wide with a focus on the ER Departments as well.

This meeting was a success and the links to the recorded sessions are included for your review below on HSC's You Tube with HTC session on the front page of the HSC website for clear visibility for patients:

[https://www.youtube.com/channel/UCJHeH\\_xVpCBH-JqgTtYLjLA](https://www.youtube.com/channel/UCJHeH_xVpCBH-JqgTtYLjLA)

b) Hello: Dates- Extended dates (limited session times)-Great opportunities for community connections.

June 3<sup>rd</sup> – Pre- Conference / Sponsor Greetings

Kahoot meeting with the members and sponsors, fun, relaxed and assuring all members are comfortable with virtual technology and questions can be answered at that time.

June 11<sup>th</sup> – opening night and awards / annual meeting, keynote

June 12<sup>th</sup> – Education Day 9am – 5:00pm

A Premier sponsor will get a session time with 5 minutes opener

The sessions for the exhibit hall (June 12 and 19<sup>th</sup>) will be managed by Jillian and Charlene from NC and (Sue and Greg). Sue is working to provide the best and most effective way for members and exhibitors to connect for information and questions and has taken feedback from many Chapters on both sides. The feedback is positive from Virginia and Stephanie.

June 19<sup>th</sup> – Advocacy / Teen and Kids Day

Family Camp: Planned for in person/ maybe smaller

➤ September 24-26<sup>th</sup> Myrtle Beach

d) Teen Camp: - August 8-10<sup>th</sup>

e) Par for the Clot- October 1<sup>st</sup>-Sponsorships are on the website:

Industry Exclusive for the company that sponsors at that Gold Level. (\$2000.00) - there will be a chance to do a special event with the Chapter later in the year or in 2021.

There will be Hole Sponsors and Exhibit Table opportunities at the reception as well. Please check with Sue for the specifics.

f) Walk- November 6, Columbia

g) Winter Meeting- December 11, Columbia

8) Sponsorship Opportunity Quick Review

a) No Changes: <https://www.hemophiliasc.org/sponsorship-opportunities/>

b) Marketing Project opportunity- Outreach History Cards

[Sponsoring this allows a Company Card within a deck of playing cards which Teaches the History of Hemophilia in SC.](#)

[Company Sponsorship is \\$4000, and 2500 sets of cards will be created](#)

c) VIP Program – Review / Communications and connections,

[As of April 17<sup>th</sup>, there are 70 Tablets spread throughout the SC community.](#)

[There is a study being conducted across 10 treatment centers and 10 chapters and SC is part of it looking into the Telehealth of the Rural Communities.](#)

9) Financial Assistance is fully funded and available for patients and members, please refer to the Chapter those in need.

10) Advocacy- Rare Disease Advisory Bill is making its way into the Senate where it will remain until next year when it is picked up again.

11) 2021 BDAC Meeting Dates (confirm / set the dates)

a) Set dates for 1<sup>st</sup> Tuesday of that month

August 10, 2021

[Meeting at the Library in Columbia](#)

12) Open Discussions

a) Industry Needs / concerns / suggestions

Adjourn meeting- **Next Meeting – August 10, 2021 - 10:00am** (virtual/ in person perhaps)

Minutes respectively submitted by Kerrie Barnes

May 10, 2021