

January 22, 2024

**Bleeding Disorders Association of South Carolina
Bleeding Disorders Advisory Committee (BDAC)**

BDASC BDAC Notes for 1/22/2024.

Attendees- In person: Jordan Martin (Optum) and Kerrie

Attendees -In Zoom: Xaviette Pointer-Kincy (Sanofi), Paul Brayshaw (Octapharma), Cynthia Delay (Genentech), Johanna Robertson (SCRX), Morgan Cook (Takeda), Evan Haskins (Kedrion), Norberto (Novo Nordisk), Wayne Cook (CVS Health), Laura Benton (CVS Health), Apryl Tilert (Accredo), Michael McElhaney (Medexus), Alex Lighthouse (Hema-biologics), Lesley Milner (Spark), Stormy Johnson (Paragon), Cheryl Steep (BioMarin), Chris Barnes (Bayer), Janet Rivera (Optum)

1) Sponsorships and Opportunities:

Many great opportunities for all Industry to sponsor and it's a very important time for fundraising due to the state of the Chapter with being down in funding this past year about 50,0000.

Chapter would prefer to raise more money vs cutting back on community offerings or charging fees to the community for different events.

So please encourage your organizations to bring something to the table for the fundraiser events-like exhibit fees, pay for the pizza, or the water or whatever could help the chapter have a great day for the patients.

****Specialty Pharmacy folks are welcome to attend a manufacturer's dinner however you must have a patient on service in attendance and best-case scenario is to bring a patient or encourage your patient to register and come to the dinner event****

Please be kind when approaching patients at events-Sue prefers that you offer your card and contact information to the patient as opposed to getting the contact information from the patient.

Please look at [Website for BDASC policies](#) as well to review information.

****Note that the Chapter conducts Surveys for the community. Serving multiple disease states within the Bleeding Disorders Community including tracking Women who are diagnosed with Hemophilia. Take a look at all these things the Chapter does for the community.**

Please refer to the Calendar with the Community Connections section.

Trying to host events that reach all 46 counties. Sue is discussing with patients on a regular basis and there were 16 counties within the Surveys.

*****Events that are being held outside the Scope of the Chapter please do check in with Sue to make sure there are no conflicts of dates with Chapter events being planned.**

The Chapter is open to hear ideas that you all have from other areas if you have seen success on some so, please share ideas and experiences and Sue will consider if those events could work here in SC.

2) **Events:** Please have open discussions for planning for future events for the community with Sue.

3) **Advertising:** Please advertise and support the printed Newsletter.

News blast: \$1000 for company Ad for a Banner. Another option is a Weekly Chapter Blast.

Keep in mind there are 85 iPad out in the community for use. What that means is all the Updates and Events are right on the iPad. Please review the package for the VIP Page. It has a Link on the iPad VIP for the big event.

If you have a specific page or link that you would like to provide for your advertisement, please open a discussion with Sue at the Chapter.

The iPad are so useful that patients can even use them for Virtual Doctor Visits.

Sue does monitor and make sure the patients that have the iPad do use them.

4) **Great News!** The BDASC Community is growing in numbers however the funding is going down overall.

Sue has helped in the search for a new CEO for NHF that should be announced soon.

HFA- has no financial assistance to offer for patients right now.

HFA is restructuring with decisions being made the with CEO and the Board.

In the past they provided extra financial assistance but not this year.

Patients can come to Sue for a grant for patient assistance for \$750 from the Colburn Keenan Foundation.

Sue writes a grant at the end of January to obtain this funding to help patients.

*****The Hemophilia Community is the one watching over the Blood Supply for everyone.**

- 5) Please keep in mind that March is Bleeding Disorders Awareness Month
March 1st VWD Awareness Day
March 15th Ultra Rare BD Awareness Day

For Big Events Please Book Early for your Hotel Rooms due to a busy tourist season in SC.

6) Advocacy

Hemophilia Assistance Program: if patients don't have insurance the state will help to get the patients enrolled in an insurance plan.

There is an ongoing challenge with United Healthcare and the Prisma System.

North Carolina will be in a similar situation with United Healthcare starting April 1.

Hopefully they can work this all out for the Patient's Sake.

February 27 and 28th is Advocacy Days. Ask Sue about Sponsorship Levels.

March 22-24th- Make sure you are signed up to sponsor the Adult Symposium.

May 11th- the Walk and Basic Exhibit Level starts at 2500, ask Sue for the additional options like sponsoring pizza, water, etc if you cannot exhibit this year.

Sue needs help since she is having surgery.

Create a walk team (Samantha will be the team leader this year) , sponsor the pizza, soda, snacks, etc.

7) HELLO Annual Conference

June 21st and 22nd Annual Meeting.

The goal is high this year, but we can hit it. Very important to turn out for the Chapter this day.

Annual Meeting- High level sponsorship may offer a chance for educational speakers and the cost is on the website.

- 8) **Teen Camps** July 18th-July 21st. Perhaps you can sponsor an activity on a specific day. Sue will be writing grants for funding for the camp.

Next meeting plan for May 14th and September date is TBD.

Minutes Submitted by Kerrie Barnes, Chair