

# South Carolina Industry Bleeding Disorders Advisory Committee

## Meeting Minutes

1-12-2021

### Attendees:

#### Introductions- Sue welcomes all and introduces Kerrie Barnes- BDAC Chairwoman

*(Reminder- Greg Witul, Development & Communications Coordinator for Sue at HSC – all industry requests and communications continue to be coordinated directly with Sue only)*

Rachel-Pfizer Patient Advocate NC, SC, GA, AL

Roberto- Novo Patient Advocate

Paul-Octapharma Patient Liaison

Virginia- Genentech Nurse Educator (Cynthia-handles HCP's)

Nick Cady- Biomarin Representative

Amy, Stephanie, and Sean Malone-Account Reps for SC/ GA and Betsy Koval-Nurse Educator

Linda –Bayer Community liaison

Wayne and Laura- CVS Rep and Patient Advocate-NC/ SC

Ryan- Big Sky SP covering 25 states for Bleeding Disorders/ Serves the Medicaid patient contract in SC for DHEC

Apryl-Accredo for SC and GA

Janet Rivera-Optum RX Patient Advocate for SC and NC

#### Company Policies for COVID Restrictions

Octapharma- no restrictions just follow the geographical rules

Bayer- Virtual through June 30

Takeda- Virtual through Mar 31

Accredo- Virtual through April 30

Genentech- Virtual mainly but taken on a case by case basis

CVS- Week by Week decision

Biomarin- Case by case basis decided by high level management approval for travel

## Refer to Agenda:

v. Comments on the Hello Conference; Most likely a virtual event, if it goes live there will no childcare due to pandemic.

vi. Sponsorship Opportunity Quick Review- Sue cannot link anything directly to the drug name due to legal concerns

vii. Attendance for support group member events & activities, (virtual or inperson) must be a sponsor to attend

### 3) South Carolina Hemophilia and Bleeding Disorders Advocacy Coalition Ambassador Program

a) Advocacy Days and Trainings- Opportunities for sponsorship-Check with Sue

Accumulator Adjuster Program concern (stories needed) NHF is working on this so please share if you have any information that could help support this to be addressed on the Advocacy front.

State Hemophilia Assistance Program – needs to continue

Rare Disease Advisory Council Bill- HSC working with NORD and other advocacy groups to pass a bill for implementation in SC. House bill currently in session has this RDAC combined with DHEC's Prenatal screening council. HSC working with NORD to have a stand alone bill.

B) Virtual State Advocacy Days March 9-11-Due to virtual nature of this; Industry is welcome for the evening training but not for the virtual legislative meetings.

### 4) HSC Medical Symposium April 23 and 24

Planned for 2 hours on the Friday evening and 2.5 hours on Saturday including breakout sessions.

Sue will be speaking to the doctors next week about this and would include the overall plan to create a coalition outreach to educate the physicians throughout SC for any provider that may treat a bleeding disorders patient. For example Patients, Hospital staff, ER providers, Nurses, etc.

The planning of the meeting includes Sue, Dr. Gilbert, Dr. Ambrose and Robin, and Dr. Bergmann as well.

The plan is to educate everyone statewide about the HTC and to offer CE on behalf of Dr. Joanna Davis's program in Florida. Dr. Sidonio is also being considered as a speaker.

Topics up for discussion include Orthopedic Education, VWD, Bleeding Disorders 101, (Pain Management for our community in a future meeting).

Industry involvement is up in the air right now and will have limited involvement. Sue will get back on this if allowed to participate or sponsor.

## 5) HSC Services

a) Financial Assistance Program- there are funds available and this program is funded with a partnership between the HTC and grants given by The Hemophilia Alliance Foundation.

B) HAP- (funded by South Carolina budget) A contract with PSI to pay the premiums and case management for the Market Place Plans- (there are many in SC who are not Medicaid eligible and fall into this gap and are not able to afford the Market place or are insured under employer or parents, etc. Must be not Medicaid eligible, low income. Patients often have no choice but to go to the ER and the hospital. Please send these patients to Sue so she can direct them to DHEC for help.

C) For our information-Jim Romano left PSI and opened his own firm.

## VIP Program

So far Sue has funded and provided 70 iPad to the community to use for chapter events. Chapter owns and controls the iPad through a management devise service.

If you are sponsoring a program it shows on the screen: there are icons for each event and lots of advertising for the events and the companies.

Virtual Telehealth is a benefit to the community, HSC does pay for internet access under some circumstances of need by the community.

Company sponsorships are available to expand and continue the program- ask Sue for information.

6) Camps- HSC Camp Connections- Date: July 24<sup>th</sup> at Saluda Shoals Park-expected to be live

Sept Family Education Camp- Myrtle Beach Event-expected to be live

7) Future meetings for BDAC-Next Meeting planned:

May 4<sup>th</sup> at 10 am virtual

September 7<sup>th</sup> at 10:00am (potentially in Colombia).

**Minutes taken by Kerrie Barnes**