

BDAC August 10, 2021

Meeting Minutes

1) Welcome:

Attendees: Fernando (Bayer)
Virginia (Genentech)
Betsy and Amy (Takeda)
Apryl (Accredo)
Paul (Octapharma)
Michael (Medexus)
Laura and Wayne (CVS Specialty)
Janet (Optum)
Norberto (Novo)
Rachel (Pfizer)
Kelly and Janet (Optum)
Laureen (Spark)
Stormy (Paragon)
Xaviette (Sanofi)
Kerrie (CSL)

2) Name Change Transition Update:

W9's and 501 (c) 3 need to read the same so for now just leave everything as HSC and Sue will alert us after everything is completed.
The new Website is being built and it will take about a year all the transformations to be complete.

3) Calendar Review and Updates for Events:

From the Home Page find Upcoming Community Connections and Events-All Events will link to this- For example- Fundraiser Page for the Walk in the Link and make note of the new name: Step for Bleeding Disorders.

The Major Calendar of Events through Dec 2022 has been sent out- Dates of Importance:

March 8 and 9- Advocacy Days

May 14th- Walk

June 10 and 1- Hello Annual Meeting

August 11-14- Teen Event

Family Camp-Either September 16th or September 23-25

Par for the Clot- October 7

Winter Meeting- Either December 3 or December 16

4) Covid 19- Updates and Discussion-Moving Forward

Board Meeting outcome was the Community all want to be together however we need to follow the State Guidelines

Everyone must sign a liability Waiver for the Chapter Events in regard to Covid-19

The Chapter will require masks for all participants for any Indoor Events like the upcoming Family Education Event. The plan is for families to stay together in Pods and wear masks during meeting sessions. Safety first is the priority.

5) Event Updates

Updates on Myrtle Beach Family Weekend Event:

43 Families are signed up and event is now closed. Families with small kids will have to stay with their parents however they will have activity kits and games programmed into the Chapter provided iPads.

From the Industry Side: Updates are provided to Pfizer, Bayer, and Sanofi as to a Red, Yellow, or Green based on the state or the county that the potential event is in.

Overall input includes that the rest of the companies are following CDC guidelines at the events.

NHF will be at the Family Camp this year providing the Advocacy Q3 Training Session with SCHBDAC and the Chapter.

Mailings for Family Camp Welcome Bags: All items to be included need to be sent to Sue's home address by **no later than September 13th**.

Suzanne Martin- 17 Steadman Way, Greer, SC 29650

Please connect with Sue on any questions on these items.

Agenda firm and on the website page. Virtual live streaming on Saturday 25th from 9-12pm for those who are unable to attend. Exhibiting is 4-7 pm exhibits on Fri September 24th. Set up at 2:00pm on Friday in the main hall of the Nautilus ballroom downstairs from the registration desks.

Saturday Am 7-9 Exhibits, 12-1:30 Exhibits, 4-4:30 Exhibits

Updates to Par for the Clot and Step for Bleeding Disorders Walk:

Volunteer list is full at this time for Golf however alternates are encouraged in case someone becomes ill beforehand- contact Sue with interest. -864-350-9941.

Chapter has need for donations of Water, Gatorade, and Snacks for Golf and the Walk Event

Walk- Please try to get sponsorship commitments in sooner than later due to the need to get tents ordered and logistics for the Walk which is confirmed for November 6th, 9-2pm.

Updates on the Winter Meeting:

On hold at this time.

- 6) South Carolina Hemophilia and Bleeding Disorders Advocacy Coalition/ Ambassador program
Passed in budget at MUSC to start a RARE DISEASE COUNCIL as a proviso which lasts just 1 year.
The goal would be for this to be made into a Bill that is passed with law so it will be ongoing vs just 1 year.
- 7) 2021 BDAC Meeting Dates (confirm/ set the dates)
January 11, May 10th, and September 13th.
- 8) Nothing requested via Industry today.

Thank you everyone for your participation.

Meeting Minutes submitted by Kerri Barnes
August 26, 2021