HACA Board Meeting Minutes
SUMMARY
June 13, 2016

Attendees:
Meg Bradbury, Eena Kapoor, Steve Long, Eboni Morris (via phone), Stephanie Phillips, Michelle Stielpfer (via phone), Joe Victor (via phone), Kristen Urbahn, April Owens, Dana Brayshaw, Brenda Bordelon (Staff)
Guests: Grifols Staff (Ed Sotherden, Dave Hill, Virginia Kraus)
Absent: Shelby Smoak, Mark Antell, Krystina Tucker (Staff)

Education Program presented by Grifols – von Willibrand Disease
Virginia Kraus, clinical education manager for Grifols, presented information on von Willebrand disease and treatment. Grifols paid for a portion of the meal, as well as room rental and A/V.

Executive Directors Report/ Treasurers Report
Brenda gave the executive director report

Joe gave the treasurers report. He touched on the possibility of creating a virtual work environment for HACA to eliminate rent payments. Brenda will do some research and report back at the September meeting. HACA’s lease expires in October 2016.

Brenda mentioned that some of the numbers did not match in the treasurers’ report because of some information inadvertently left over from the 2014-2015 budget.

Brenda also applied for the Colburn-Keenan grant and found that they are reopening the grant for applications due to problems with the software.

Brenda discussed donating to the World Federation of Hemophilia. NHF will match the donation. She asked if we would like to make a small donation. Brenda will do some research about how much we have donated in the past. We will have a vote by email.

Brenda also brought up about a visit she had with Kelly Waters, and during their visit, Kelly suggested that HACA schedule a board retreat. This would be good to have our strategic plan updated. Brenda asked if we can get something organized and if everyone was interested in coming. Michelle would like it at the end January.

Future of HACA Walk
A conversation was started about the 2017 walk and whether we want to work with NHF for the walk. The original fund distribution model had NHF sharing all funds with each chapter, both money that was raised nationally and money raised by each chapter. In 2013 it changed, with local money staying with the chapters and NHF keeping national sponsor money. However, as the years have gone by, many of the pharma company sponsors are now only sponsoring nationally, with none of this funding going directly to chapters.
The question also raised about whether to keep the walk at the Lincoln Memorial. We miss out on a lot of opportunities by having it on the National Mall. Brenda will be researching different parks and prices and have more information in September. Eena suggested Clemjontri Park near Great Falls/McLean. Steve also suggested finding a place in Maryland as well. We could also have a floating walk, which would mean a different location each year. This may allow us to get more people involved. Michelle brought up that we could have the walk that also has an educational component as a well.

Joe said that we have to make the decision by December. We should be prepared to vote on the decision. Michelle said we should schedule a conference call to get more information before we have to vote.

**Budget Approval**

A motion was made by Steve, seconded by Dana, and passed unanimously to accept the 2016-2017 budget.

**HFA Update: Dana**

Dana brought up under treatment for people specifically pertaining to Medscape articles release of bad data. Dana also asked if anyone was interested with helping with a committee to get the proper information out there. Michelle said she was interested as well Meg.

**Upcoming Events:**

The family picnic day is August 14th.

**Board Meeting Location**

Brenda also said that we should suggest having another location for our board meetings.

**FOLLOWUP REGARDING ITEMS IN MINUTES:**

1. Brenda found a new office in the Cary Professional Center in Springfield, VA. The board voted to approve the move, and the new lease was signed on August 8. The HACA office will move in late September.
2. Brenda sent out a memo on August 25 with research regarding the 2017 walk. The event will be discussed and voted on at the September meeting.
3. A date has been confirmed for the 2017 Board Retreat. It will take place on Saturday, January 21, and will be facilitated by Dawn Rotellini of NHF. The board will review the strategic plan and update the goals. This was last accomplished in 2013.