



Gateway Hemophilia Association Board Meeting –Minutes September 10, 2019

PRESENT: Bridget Tyrey, Judy Bagato, Stephanie Bauman, Maria Mohler, Kari Moellenhoff, Kristina Klein, Benjamin Moramarco, Brian Rodgers, Chris Schneider and Nikole Schroeder. ABSENT: Lori Moore

MEETING CALLED TO ORDER by Chris Schneider at 6:00 pm

WELCOME 2019-2020 BOARD MEMBERS

- Chris Schneider, President
- Lori Moore, Vice President
- Stephanie Bauman, Secretary
- Benjamin Moramarco, Treasurer
 - Mike Miller (New)
 - Maria Mohler (Re-elected 7.14.19)
 - Kari Moellenhoff
 - Kristina Klein
 - Nikole Schroeder
 - Judy Bagato, Industry Representative
 - Brian Rodgers, Industry Representative

CONSENT AGENDA- Motion to approve reports by Benjamin Moramarco and 2nd by Stephanie Bauman. Consisted of the 7/12 & 7/14 minutes, the July and August Treasurer's Report.

COMMITTEE REPORTS

- A. Governance Committee** – GHA's governance committee uses a board tracking tool. Also reviewed was the role of a board member. Each board member is asked to be on a committee. A list of committees was presented. Two new chairs were selected: Mike Miller will act as chair for the Men's Group and Nikole Schroeder as the FEW chair.
- B. Advocacy Committee** - The Missouri Bleeding Disorders Coalition (MOBDC), which consist of Chapter staff from GHA and MHA, members from MO HTCs, NHF, HFA, Industry Government Relation representatives and community advocacy experts for the Missouri Bleeding Disorders Coalition will meet to identify advocacy issues for 2020 at their annual stakeholder meeting on Wednesday, November 13 at 9:00 a.m. There is a focus on Skilled Nursing Facilities (SNF).
- a. SNF's per diem reimbursement policies do not allow for separate billing for costly bleeding disorders treatments, most SNFs will not accept these patients. NHF expressed their desire to work with CMS to address this access issue and are submitting comments. Senate Bill is forthcoming; looking for a Republican to sponsor.
- C. Fundraising Committee** -
- Wine –160 pre-registered, 26 walk-ins, 12 volunteers - 12 no shows, total attendees = 186 (+24 from 2018), profit \$8,000.
 - Golf – 27 teams, hopefully 108 players (only 70 names so far) and 18 volunteers
 - Trivia – November 2, please share the flyer at your work or anywhere you think would be beneficial.
 - Auction – Judy needs lotto tickets from the board for trivia night.
- D. Programs Committee-**
- Regional Women's Retreat – a regional Midwest women's retreat is scheduled for March 20-22 at Honey Creek Resort in southern Iowa. This retreat is between four chapters GHA, MHA, Iowa, and Nebraska, covering 5 states.
 - Adult Retreat – was a success, 52 total attendees. Strong speakers.

Helping Hands Update – 4 financial assistance applications, total \$1,541.95. GHA has also assisted with 7 Medic Alert applications.

NEW BUSINESS

- Adopt a policy to include notification for major events that indicates acceptance of participation. Must elect into sign-ups. Ben to draft disclaimers. The aim is to minimize attendees that do not actively engage in major events.
- GHA is pleased to offer an educational participant grant to NHF's 21st Bleeding Disorders Conference in Anaheim, CA October 3-5, 2019 to Steven Kreher. The grant is a reimbursement scholarship with a maximum reimbursement rate up to \$1,000 for an individual or \$2,000 for a family.
- NHF and HFA are slowly responding to request by CSO letter requesting calls for enhanced collaboration and integration. Chapters vote for board of directors for NHF & HFA. CSO sent a second letter pointing out an issue with 3 of 4 executive members work for industry which creates conflicts of interest support. HFA board voted not to allow more industry but current members can term out, which can be up to 6 years. HFA will post a response on 9/13/19 and subsequent board meeting 9/24/19 to discuss. Requested CSO member to be on hiring committee for NHF and HFA. Chapter Staff Organization (CSO) will create a website and keep people updated.

ADJOURN Motion by Kari Moellenhoff and 2nd by Nikole Schroeder at 7:09 pm.