

February 4, 2018 BOD Meeting
Meeting opened at 2:15

Attendance:

Present

Dennis – President
Sharon – Treasurer
Nemo - Spanish Specialist
Jennifer – Advocacy
Rebecca
Quorum met
Maryann- ED

Absent

Katie
Janine
Meagan

Reports:

Diane- Alpine Walk update

- *Jim is not going to do the kids program. Eric from HFA is going to do it. They have a new program to do with them before they do tubing. It is kind of like Fear Factor.*
- *We talked about getting Pizza and Diane was going to check if we are allowed to do that.*
- Auction items:
 - Dennis got a trip to Cozumel (4 days, all inclusive).
 - Dennis and Chris will do the dinner again.
 - We will have to be prudent this year since industry rules for sponsorships are changing. They are no longer donating to as much or anything without an educational piece.
 - We will probably not be able to provide the free clothing item as in past years.

Treasurer – Sharon

- Balance \$268,114.49

President - Dennis; investments

- Will work on in next couple months

Advocacy – Jennifer

- Hill days/ Proclamation/ RDD February 28, 2018.
 - Will attend RDD with NORD in the morning. 8:30-9:00 meet, 9:00 RDD with NORD
 - Should hear within the week if we get the proclamation signed. *Discussion ensued and Dennis stated that it took about a month last year to get the proclamation.*
 - 8 families to attend RDD/Hill days.
 - Working on appointments with legislators. *Hoping to have each family meet with their legislator representative.*
 - Webinar on Monday February 26th for participants. *Jennifer has a WebEx password and will set it up.*
 - Swag - scarves. Have CHS logo. Get NHF red tie pins. *Discussion ensued. Jennifer stated that we have not gotten a consensus from NEBDEC. She asked what it would take to order it, and if CHS pay for the scarves or does NEBDEC? Maryann stated that CHS would pay for the scarves since we are making them. Dennis suggested*

putting CHS on the scarves. Maryann suggested that we could do the NHF red tie pins instead. It was discussed that the scarves were a better idea. Dennis stated he would order them. Jennifer estimates about 60, but she needs to check.

- *Lunch at the legislative office building. Jennifer stated that the easiest thing to do would be the Cafeteria for lunch. Discussion ensued on how to pay for meals. We decided to have Dennis and Maryann at the registers to pay as people come though. Maryann brought up a concern on seating within the cafeteria, so everyone can sit together to go over what is happening during the meetings.*
- *Jennifer trying to set up a call this week with Joe to finalize things. They would like to get more information out as well as to let everyone know about the WebEx. Dennis asked if Mark has gotten back to her and Jennifer stated no. She was going to reach out to him.*
- *Maryann asked if we are spread out with different legislators. Jennifer stated that she feels that we have a good group.*

- Washington Days, Maryann update on who applied/got NHF scholarship (March 7th – 9th)
 - Used WD scholarship for 2 families. Banks and Camarros. *With the Camarros, we are paying their hotel and they are paying their travel.*
 - Need to discuss how to encourage more participation.
 - Third family will pay their travel, we cover the hotel.
 - Update: one family had to cancel. We had set aside monies for them.

**ED: *Maryann - put in for a grant from The Hemophilia Alliance Foundation for \$1500 for travel and hotel for Washington Days. (Questions on who Hemophilia Alliance is? They are an organization for HTC's. Maryann gave info for BOD to look them up.)

- Joining the CT Nonprofit Alliance. Maryann gave Sharon information to pay 2018 dues. *Ctnonprofitalliance.org (CT based organization that is connected to worldwide organizations, they can tell us when grants are coming up, it allows us to rent a room in Hartford for meetings, etc.),* BOD also given information to look up services and data.
- Point of information: There is a Factor 7 retreat offered by CHES coming up, Maryann has given information to our FVII patient in hopes they can attend.

Where we stand with NHF.

- Maryann has been “attending “informational webinars to gain information on services and history.
- Are we going to commit to BOD training? We are not following some of our requirements as a board. *Discussion ensued. There are two dates that were good on the poll. Neither date had enough people. We have to have 8 BOD members present and Maryann does not count within the 90%. If we do not have enough response we cannot apply for it. Jennifer asked what the issue is. MaryAnn reported that we need 8 people and NHF needs 3 dates. Discussion ensued about dates. Dennis asked about doing another Doodle Poll with dates further out. MaryAnn stated that she did put other dates out there but they were not good for members. The two that were most popular were April 22. Becca and Katie cannot do June 3. Jennifer asked if there were other*

alternatives. Discussion ensued about what NHF will teach us within the retreat. It has to be a day – 6 hours. Maryann printed out and shared the Board Development Team training. Jennifer asked if this is a requirement for NHF. MaryAnn reported that there are things that we have to do, though board training is not one of them. Discussion ensued about what was within the printout and how NHF will do the training. Further discussion ensued.

- *Maryann reported that fundraising will be important since industry is no longer funding. Discussion ensued.*
- Brainstorming how to approach this. Check with board development team to see if we can meet for a minute at WD for further information.

Spanish Language – Nemo

- Will we be planning a dinner? Meeting? We can get HFA funding if we do a session of theirs.
- Need to find more participants. *Maryann stated that per HFA there needs to be 10 people to hold the dinner.*
- Rebecca has given CHS information to vWD family to get them involved.

Old Business

Spring Social planning committee, *which currently is Jennifer*

- Jim will still do DIA. *Jennifer asked how this falls within the day.*
- Exhibit time 2:00 – 6:00
- One session, then DIA (*event TBD*). *Discussion ensued of when dinner will be served. It was decided that Pizza would be served after the DIA and before everyone goes and climbs.*
- RSVP need for those that will climb.
- Make a note on registration 5 and older to climb so we know how many to expect.
- Try to get families to sign release online if possible.
- Push to HTCs. Maryann will talk with Yale, Dennis will talk with CCMC

Website committee

- Not available.

New Business:

Cupcakes with Daniela – Janine

- Do it at the Annual Meeting and just have the kids. May need to be the morning session if we have the game truck. Will look into closer to Annual Meeting.
 - We are doing a joint MIA / BSH in April with NEHA. Looking for facility in northern CT to hold event. Up to so women/ girls. Will talk with committee about opening it up to girls as young as 6 years old.

Separate place to have BOD emails. Meaghan investigating, for now is it worth it to have each BOD member set up an account on Gmail or Yahoo specifically for BOD mails? We need to have a way to expedite voting and memos to insure we do things in a timely manner.

What oversight does Maryann need? How much autonomy does she have? BOD will set up call to define without Maryann.

Update bylaws to include committees/ role/responsibilities (see attached bylaws)

Dennis made a Motion to change bylaws, remove Scientific research from bylaws Line Article 1, section 3.

Passed 5-0-0

Will address other changes at a later date.

*Update mission statement-Done by email vote in Feb. Changed on website also.

Maryann:

How to do Lake Compounce?

This is our biggest out of pocket event. Although the idea of giving people a free play day is great we may need to look at changing it up.

Should I look for industry help? It will mean having a session that people will be asked to attend. The past couple of years I have gotten small grant from Colburn and Keenan towards lunch. I will apply for that again, it'll be around \$1000, which is a very small portion of the cost of the day. If we do a sponsored talk at the lunch thing, we can ask for someone to sponsor.

Can we limit arrival times? Make it clear arrival is between 10 and 12. ** if unable to arrive by 12 make PRIOR arrangements to get tickets. As it is whomever is at the gate is stuck there for the stragglers. Which means myself and whoever else that is we get the cols stuff at the lunch because we get there after 1. This may also limit attendees.

Suggestions:

Do we lower the number to 4 from 5? Most people bring less than 5 anyway.

What to do about families that come each year but don't attend anything else? See suggested guidelines below. Is this something we need to add to the bylaws? Section III members. *Does not belong in bylaws, to be put on website and Facebook page.

Option, subsidized instead of paying full amount.

Option give tickets to LK at SS if you come to SS your ticket is free, if not you pay \$10 per person. *with caveat to help folks that can't pay.

Lake Compounce Family Fun Day final suggested Guidelines:

- Lake Compounce Family Fun Day is available to any active Connecticut Hemophilia Society (CHS) member/member family. Up to 5 people.
- To be an active member one must attend or volunteer for other CHS events throughout the year.
- Active members will be responsible for \$10 per person, up to 5 people.
- Dues should be paid in January of each year.
- Members can bring up to 5 participants for their annual family membership dues of \$50.
- We are unable to accept member dues payment the day of the event.
- CHS is a nonprofit organization that strives to empower and educate members of the bleeding disorder community. The Lake Compounce Family Fun Day is one of the benefits of active membership in CHS. Due to the nature and expense of the event CHS is unable to provide this event to inactive members.

*Mailing list updates-Mailings get returned, we have no way to know how to contact these people. Best option is to remove them from mailing list but keep the names in case we find someone who knows them, or they contact us.

Dennis made a motion to close at 4:10 pm
Pass 5-0-0