

May 6th CHS board meeting

Meeting opened at 11:20 AM

Attendance:

Joe Liberman

Jennifer Banks Advocacy chair

Stacie Hebert

Nemo Delgado

Janine Achury

Dennis Mackey President

Maryann May executive director

Treasurer: (via email) Report Balance as of 05/04/17 \$256,428.51 *attachment 1

Advocacy: CHS is working with the New England Bleeding Disorders Advocacy coalition (NEBDAC). One of the coalition goals was to get March declared Bleeding Disorders Awareness month in all 6 NE states, which was accomplished. Due to work of the CT ambassadors CT was declared BDAM on Thursday March 30th. A large group of CT residents from CHS met with the Lt. Governor at the capital for the signing.

BA Con; to be discussed in new business

CHS helped in form the CT Rare Disease Task Force.

President: Due to our financial success, it was recommended that we set up a business credit account for the debit card holders (president and ED) to keep excess funds protected in a separate account. It was also recommended that CHS invest. Jennifer recommends Spider Funds. **See motions 1&2 in motion section.

ED: thank you to those that participated in the NEBDAC informational call on May 1st.

*Update on the application for the CSL LEAD grant. If granted \$10,000 to be applied to the NEBDAC.

*NEHA and HAM have used this grant for the same thing so there is only a small chance we'll be granted.

*MM applied and was granted \$1000 from Coburn and Keenen towards lunch at Lake Compounce Family Day.

*MM attended CT Rare Disease Task Force monthly meeting on April 27th. Will continue to attend when possible. Will be looking for someone to take on this role. Nemo expressed interest in volunteering for this.

CHS and NEHA are partnering in a DIA/BB event in June in Windsor. Improv team coming in for team building session followed by HFA session and pizza/wing bar. We should be looking for a DIA and BB lead as well as someone for moms and families sessions sponsored by HFA.

CHS, HAM, NEHA will be cross referencing financial assistance request to avoid over use from "repeat requestors". MM suggests setting up a committee to oversee deidentified requests.

Old business: Survey from Alpine Walk. Lonely 10 respondents. Two suggestions were skiing instead of snowshoeing and to have lunch between DIA and walk. Responses mostly very positive. Need to have better email list of attendees.

New business:

Annual Budget. We as a board must start having them done by midyear annually.

NEHA Family Camp funding. CHS sends several families (8 this year). The cost to NEHA is \$1000+ per family. Reviewed HAM/NEHA camp agreement. [See motion 3](#)

BA Con. Encourage members to go. Mention NEHA 100 for 100 and CHS gas cards to help them attend.

NEBDAC call with HAM and NEHA follow up discussion. Board members have better understanding of NEBDAC and its goals. Jennifer was better able to explain some of the accomplishments of the coalition to date.

Gears for Good. Dennis explained new pledge amounts and ride distances, how sponsorships and the trail signs and bag stuffers for businesses, industry and donors are going to look. *See attachment 2

Advocacy training sponsored by Shire. Decision to include community as well as board members. Board will pick dates to ask presenter about availability.

Infusion class in fall. BOD to pick dates to speak with Emily B about availability.

Strike Out Hemophilia. Dates for park availability to be investigated.

Newsletter update by MM. This issue to focus on advocacy. Jennifer to do WD's and RDD. Dennis - proclamation. Devin B will be this issue's community spotlight due to his advocacy work. Have article from 3 families we sent to HFA Symposium. Diane B doing one for AW. Need something for AM. Daniela going to NYC with NHF gala, Janine will get pictures and see if Daniela will do small write up. Decided to call the spotlight "Kid's Corner".

MM suggested having a cruise raffle. We have someone in our community that is in travel, Dennis will see about getting a package we can raffle, drawing to be done at 2017AM.

MM asks if CHS can sponsor someone from Save One life. [See motion 4](#)

NHF membership. Small discussion with agreement to have conference call with Dawn R from NHF [see motion 5](#)

Janine suggests we do short videos of community describing their BD, association with CHS. Raise awareness and involvement.

Janine recommends board members can have CHS business cards. [See motion 6](#)

FYI: Dawn Vanmayerhausen is leaving CCMC. There is a new social worker coming in. Comedy show from previous evening (May 5) brought in approximately \$1445

Motions:

1: Move to set up business credit account; maximum 20,000.

Intent: separation from larger holdings will protect them from theft and unauthorized use.

Passed 6 yay 0 nay 0 abstention

2: Move to set up brokerage account for long term investments.

Intent: invest monies in account for future use and to keep funds fluid and not just sitting in an account.

Jennifer suggests considering "Spider funds".

Passed 6 yay 0 nay 0 abstention

3: Move for CHS to provide 20% of the total cost of the number of Connecticut families attending NEHA's family camp each year not to exceed \$3000.

Intent: Aid in the cost of sending CT families to NEHA Family Camp

Passed 6 yay 0 nay 0 abstention

4: Move to have CHS to sponsor a person from Save One Life foundation.

Intent: Aid someone with a bleeding disorder from a developing country to access treatment and care.

Passed 6 yay 0 nay 0 abstention

5: Move to set up a conference call with Dawn Rotelini, NHF chapter service coordinator.

Intent: To gain further information on becoming an NHF chapter.

Passed 6 yay 0 nay 0 abstention

6: Move to have CHS business cards made for board members for board members that would like to have them.

Intent: give board members the ability to reach out with contact information at outside events and places outside of the CT region. To help further carry the CHS message.

Passed 6 yay 0 nay 0 abstention

Meeting closed at 1:10 PM

Treasurer's report:

CHS		
Balance 11/30/16:		230,938.48
Deposits:		
Dec	3,225.00	
Jan	15,210.00	
Feb	7,250.00	
Mar	34,967.45	
Apr	-	
May	15,100.00	
	75,752.45	75,752.45
Expenses:		
Dec	18,576.11	
Jan	11,389.71	
Feb	7,836.60	
Mar	11,496.83	
Apr	5,023.37	
May	1,414.80	
	55,737.42	(55,737.42)
Balance 5/5/17		250,953.51
Undeposit funds		5,475.00
Balance today		256,428.51



GEARS FOR GOOD



Farmington Heritage and Farmington River Trails

LOCAL SPONSORSHIP OPPORTUNITIES

BBQ Finish Line Sponsor - \$2,500

- Company logo predominately placed at the BBQ lunch table.
- Company name recognition on Connecticut Hemophilia Society (CHS) website.
- Company logo on **local** sponsor thank you sign.
- 5- minute greeting to riders
- Stuff goodies in a bag to hand out at the BBQ
- Acknowledgment of sponsorship and final thank you with a button on Hemophilia Federation of America's Gears for Good page linking to CHS site for list of local sponsors.
- Acknowledgment of sponsorship in one (1) HFA Gears for Good e-blast (distribution 6,000).

Saturday Dinner Sponsor - \$1,500

- Company name recognition on Connecticut Hemophilia Society (CHS) website.
- Company logo on **local** sponsor thank you sign.
- 5- minute greeting to riders
- Acknowledgment of sponsorship and final thank you with a button on Hemophilia Federation of America's Gears for Good page linking to CHS site for list of local sponsors.
- Acknowledgment of sponsorship in one (1) HFA Gears for Good e-blast (distribution 6,000).

Water and Snack Sponsor - \$1,000 (TWO available)

- Company name recognition on Connecticut Hemophilia Society (CHS) website.
- Company logo on **local** sponsor thank you sign.
- Acknowledgment of sponsorship and final thank you with a button on Hemophilia Federation of America's Gears for Good page linking to CHA site for list of local sponsors.

Industry Bag Stuffer - \$1,500

- Stuff goodies in a bag to hand out at the BBQ

Finish Line Sign Sponsor - \$500

- Company logo on a Finish Line sign.

Mile Marker Route Signs - \$250

Company logo on a Mile Marker sign along the route.

Family Marker Signs - \$100

- Family Sign placed along the route.

Local Business Bag Stuffers - \$100

- Bag stuffer (coupons, etc.)