

CHS BOD meeting December 9, 2017

Attendance:

Dennis Mackey President

Sharon Liss Treasurer

Jennifer Banks Advocacy

Stacie Hebert

Meagan Murray

Nemo Delgado Spanish Language

Rebecca Smith

Maryann May ED

Unable to attend Janine Achury and Katie Rosevear

[Nominations/ volunteers:](#)

Secretary

Katie Rosevear volunteers.

Passed 8-0

Vice president

Becca Smith inquired about duties, will reread CHS Bylaws

[*ED report- Maryann](#)

NOW conference

Talked with Dr Bernstein in AZ. He would like to do programming with us.

PACT grant conference

Lots of good information that has been given or forwarded to Jennifer and Meredith. Speakers included Dr High talking about SPARK's new gene therapy treatments for Hem B, Speakers on Public affairs, Advocacy, Health plans in NJ and how to use them in each state.

NHF update-

Member org papers signed. We won't know what steps come next until closer to 2018. At the time we can apply for staffing grants and learn about other available training.

HFA programming call 2018. How many?

**Had programming call on 12/13/17. Asked for 7 sessions in 2018; Alpine Walk, 1 or 2 to be determined. Spring Social, 1. Annual Meeting, 2. One Latin language, one girls/ women with BD. Dates and programming to be determined. This does not include sessions combined with NEHA, these will be discussed on a call 12/20/17

*President- Dennis

Financials- Investments. Unable to work on this due to timing.

*Advocacy- Jennifer

NEBDAC- Stakeholder meeting Nov 5

Jennifer and Meredith planning NORD Rare Disease Day (RDD), CT Hill Day and March BDAM signing for Feb 28th. Maryann is still trying to connect with Lesley Bennet from CT Rare to coordinate RDD.

*Treasurer- Sharon

Current balance \$269,646.06 ^ approximately \$30,000 over 2016 *this doesn't include salary and travel expenses for Maryann, actual closer to \$50,000 6 2016.

When ED position becomes full time salary payments will be taken over by outside company at the cost of approximately \$150 annually.

*Raffle tickets- Meagan

At the time of the meeting 155 had been sold. The cut off is 200. Expected to cover cost of gift cards and make small profit after Annual Meeting attendees purchase tickets.

*Programs; Latin and Women- Janine, Nemo and Meagan

Committee has found a small Latin speaking community to begin programming in 2018.

*Alpine Walk-Report from Diane Bruno

Maryann read report from Diane Bruno.
Sponsor requests sent, working on auction items.

BOD discussed having an auction item challenge with prizes to get more people to donate items.

****Is this being worked on? I can bring it to Diane but will need more structure behind it****

New Business:

Formation of:

Financial Assistance committee

Sharon, Dennis, Meagan to form committee to review assistance requests and make recommendations to BOD.

Website committee

Becca, Megan, Janine to form committee to review changes to website. Recommended that we ask Sunita Dhungana to assist since she has web background.

Have you been able to connect with each other and start this? I need to email web person changes asap because next year's events, new board members need to be added and the cruise needs to come off.

I will send a FB message linking everyone with Sunita to ask her assistance, unless someone has her email address.

Membership levels; paid/unpaid

Meagan recommends we hold off and discuss in 2018 once we get current memberships straight: I have a form in English and Spanish will forward to when I can. I started a letter. We are only going to send renewal to those whose membership have expired, or we don't a date listed. We are doing through q1 of 2018. Anyone after that will be good till 2019. (per Dennis suggestion)

Meagan:

I would like to add events or places in CT. For example, we just had hemophilia weekend at hole in the wall and it was awesome. But it was NEHA that partnered with them and my thought is that while fun, should have been us. Do any of you know of a list of places of fun things to do in CT that we can get involved with?

**Board ran out of time to discuss.

Terri laliberte interested in board membership. Maryann to contact with bylaws and other info. She is also willing to set up auction for 2018 Annual Meeting.

Do we have contracts for Lake Compounce and Spring Social 2018?

Yes

There is one industry educational dinner being planned so far for 2018, Bioverativ on May 16 or 17.

Diplomat and CSL are partnering to hold a woman's paint and sip on January 18th in West Hartford. Details with invitation and back up date to follow.

*Next meeting planned for February in Windsor. Details being worked out. We will need to set up full meeting schedule for 2018 by the end of January.

*Has this been looked into yet?

Respectfully submitted; Maryann May

