

September 15th meeting, 2018

Attendance:

Not in attendance

Meagan Murray

Katherine (Katie) Rosevear

Terri Laliberte

Rebecca (Becca) Smith

Jennifer Banks

Nemo Delgado

Dennis Mackey

Janine Achury

Maryann May

Sharon Liss

Meghan Canedy by phone

Open at 5:15

President: Dennis: Bylaws. We made a couple changes and edits. To be reviewed at BOD retreat 9/16

Financials. Will need new treasurer, Sharon stepping down to become paid book keeper. Meagan stepping in if she's voted in in. Tabled to future date.

\$250,00 moved to a saving account from Checking. Financial advisor will move us to investments. This will help on income, 4% return. No charges to move \$, advisor will make 1% of investments. Market value. He gets paid quarterly. We will have visibility to account. Discussion ensued, as to whether to leave with advisor to move funds or if we're moving it ourselves. Explanations to board on money markets.

- What is he investing in?
- Is he taking his cut each quarter?
- Is it 1% of earnings?
- Den will find out if he is reinvesting or just sitting on it?

In the future we will have a P&L available.

Fraud protection policy (internal controls) Done in August 2018

Financial committee: Dennis, Sharon, Meagan.

Treasurer: Sharon:

Current \$52,162.27 Checking

\$250,60.01 Savings (\$60.01 interest since moving to savings)

Advocacy: Jennifer:

Jennifer and Maryann: Meeting with Sen Murphy for information around pre-existing conditions. Listened to our stories and those with other rare disorders.

CT Rare Action Network (RAN) is looking for youth to advocate for NORD. After speaking with them Jennifer feels we in BDs are very far ahead of other rares in our knowledge of legislation and advocacy.

- CT Rare Task force meetings on Oct 10 and Nov 14th. * I am out of town. CT RAN is asking for patient testimony.

MM DUR BOD meeting. Drug Utilization Review boards

- Made up of pharmacists and docs
- set up in each state to review medications
- List of 50 most expensive meds
- Recommend dosing form each of those meds

Their board meets quarterly to review medications listed. As far as MM can tell they receive the lists in advance but only review certain meds at meetings. Nathan from NHF is investigating how we find out what their recommendations are for factor products.

November 1 is when their recommendations go to legislature for review. We may need testimony from patients at that time. Jennifer has offered to go. As NHF gives more detail MM will update.

Spanish Language: Janine, Nemo: From Janine's email in August;

******"We are talking with 4 families from CT. I sent the info a year ago. Sasha Marie and Edwin (with one kid with hemophilia) were members with us but I just find out that they are not continuing because it was a courtesy. *we gave them a membership in 2017.

We invited 2 more families; Larry Drumwright and his wife Elena Machado (her daughter has Factor VII deficiency) to the Annual Meeting and I remember it was another family who went that day but I don't have any record about them. I just met them that day like 1 or 2 years ago and 2 others to Spring Social, one we gave the annual membership as a courtesy and the other family, Jose M. Lopez y Jessica Figueroa went to Spring Social but we don't know if you are in communication with them to try to engage them with us.

We sent information from 2 more families. I will look it up for the info tonight.

They wish to have a place where they can talk in Spanish and hear sessions in Spanish. They are afraid to participate in something that is new for them and they are more reserved about their health issues.

Some of the families of course speak both languages but is important to have a session or information in Spanish.

If we can have a little corner in the website or Facebook page and the newsletter that could be awesome.

Nemo and I are continuing speaking with them and see how they can be CHS members.”

Can we have a Latin language section on our website? Will work out with Website committee.

DO we create a pamphlet in both English and Spanish at HTC's. Will cover in outreach portion of meeting.

Website: Meagan:

- New website managers, Ujjwall and Sunita.
- Committee going through website to look for changes.
- Setting up access for CHS BOD to see minutes, correspondences etc. on website.

ED: Maryann

Paint night in October. Co-sponsored by CSI and Diplomat. Will be posted on FB and emailed when details are set. Can also be added to website.

newsletter is in the works. So far there are roughly 14 articles, lots of pictures, three advertisers (total of 4 ½ pages) and something about HFAs Project Calls.

Discussion on much lower ad rates by industry. As far as MM can tell it's simply because it's the end of the year and industry budgets have run out. Questions as to whether partners notified at the beginning of the year, which they are. Mention of three chapters and many events so budgets are spread thin by fall.

Janine to write section to ad.

Yesu Babu: our sponsee from India through SOL. They have now new information from him currently. TSOL has set up a page on the site for sponsors to follow their sponsee's progress.

**** Accredo client dinners** I have been talking with Dave from Accredo, we are going to work on a series of dinners, we sponsor, he brings clients, we meet clients and get new people involved.

**** Letter to school nurses,** Meghan C. Meghan wrote, we revamped, NHF has the letter to review for edits and accuracy. We will need a list of the middle and high schools in CT to send them to their nursing departments.

**** will address in strategic planning as part of outreach**

OLD BUSINESS

- What oversight does MM need? Has the executive committee addressed this? If so, we'll find out tomorrow.
- Pampered Chef was cancelled.
- Smug mug. Someone was going to find out how to let people post without giving out our log in, did this ever happen? Still looking into a lock account, main account and sub accounts. Falls into internet /website committee

NEW BUSINESS

Set schedule for 2019 meetings.

- February 9 – Live
- May 3- live
- August 15- phone
- November 14- phone

others to be set as needed

Annual Meeting

Most of the submissions have been made for exhibits for the Annual Meeting. We have eight confirmed so far. Gail from Pfizer is asking if she has a coworker that can go, haven't heard from Ann at Cottrills yet. Tommy/NOVO is a no.

I'm working on sessions. We have Genentech, possibly Octapharma and CSL. Sandy (Octa) won't be there this year, she is asking coworkers if anyone is available. I haven't heard from CSL yet. If they are unavailable I have a list to go down.

Next, I will be contacting several nonprofits since we will have more space this year. If you want to help with the contacting, if you know any insiders, that would be great. NEHA and HAM have an open invitation as part of our New England coordination, just like we have at their events.

- Save One Life * Will be exhibiting*
- CHES
- Daniela
- Yale -MM
- CCMC -MM
- Double HH -Meagan M

My thought is this, they won't all come and if we need space we can do what we did last year and put some in the session room.

Express scripts are doing a program for kids in the morning. I still need to know if:

A: Daniela is doing cupcakes *yes for session after lunch*

B: Game truck - yes

The comment I hear most is “it’s the time of year” for not attending. There are only a couple that won’t be there because of that. I believe we should move it to the spring, have a whole day event with several sessions, dare I say, make it bigger and more centralized. A place with more meeting rooms for us to use. I know it will cost more but again, we’re stagnating, it’s time to get moving. Then if we want to have a small holiday event, we can but not involve exhibitors.

Now that they (industry) is pulling back from having to push products they have become more difficult to get funding from. I have had to put in for December exhibits by July in a couple of cases and of course the ones that have the whole East coast can only be in one place at a time. I realize we had ours before HAM but if you had ever gone to theirs you would see why it’s popular. We will never find a place as cool as the Samoset.

Alpine 2019.

Diane has agreed to work with us again. If we’re going to up our game and change programming I recommend a raise of \$500 this year.

Grant cycles for industry have started, Diane needs to start this month, 2019 is due by the end of October for some of them.

This year we are having everything in the ballroom, where the Saturday dinner is held. We have the room blocked off for the weekend from Friday afternoon through Saturday night.

* I’m just throwing ideas out. We can keep it the way it is but if it’s staying a fund raiser we need to up our game*

- How are we doing it?
- How do we get better attendance?
- Exhibits? If we’re having exhibits I need to know asap to get requests in. I have spoken with some of our industry partners. As we know some of them can no longer sponsor. If we have exhibits, we will at least have that income. Now we set up a sliding scale, the number of trail signs and attendees is based on the amount of the sponsorship. We lost two of our contributors last year because they no longer sponsor for “nothing”, meaning there’s no educational component. The DIA and MIA don’t count.
- Virtual walkers?
- Still have the auction? If so we, as a board, need to work harder on donations.
- Coordinate with all three chapters?

Decide whether to have AW as NHF walk.

MM to talk to Tracie Earl to see if we can do Virtual Walker. MM has invited Tracie Earl to the AW 2019 for her to see how it works.

Motion #1

Meagan M second Stacie

Motions. Make AW NHF walk.

Passed Unanimously

Motion #2

Meagan M, Second Sharon

If we decide to move forward with walk as described, we will increase Diane Bruno's pay by \$500.

Passed unanimously.

Motion #3

Dennis: Second Stacie.

Eliminate membership fees.

Discussion on how to proceed. Draft letter to define membership, benefits. What's our "ask"? How do we ask it? How do we foster relationships?

Passes unanimously

Needs to be defined though bylaws.

****Hemophilia Alliance** <https://hemoalliance.org/overview/>

This is a nonprofit that HTC's belong to, see above link for more information

I talked with Sean Singh from the HA, we discussed the need for better patient understanding of 340b's and how they impact HTC's. With current legislative concerns about funding cuts we need to be vigilant. We are working on a program to coordinate with the HTC's in CT and their patient base to educate (sort of a 340b 101). He is not able to come to our December meeting and we both feel we should do this sooner than later. We are looking at an early November time frame. *they provide \$1000 funding towards educational programs*

****Strategic Planning****

Jennifer to provide documents and facilitate.