

Meeting opened at 7.

Attendance:

Dennis; President

Sharon; treasurer

Nemo; SL Specialist

Stacie

Jennifer; advo coordinator

Janine; SL Specialist

Maegan

Maryann; ED

Annual Meeting 2017.

Right now it looks like we have 13 exhibit tables, that is fluid at this moment. If we need to have a separate space for the non profits we could try using the small conference room we used for the teens last year. We can fit at least six in there. To be decided closer to event.

Exhibitors have been requested, except Shire, they have a new website and none of us can figure it out yet.

Nonprofit tables;

HFA

Daniela's Little Wish

NEHA

HAM

\*Maryann to contact Laurie Kelley and offer a table for Save One Life.

Meal Sponsors:

Aptevo, breakfast.

Bayer lunch/ partial. We can use the HFA funding for the balance.

No requests for Dinner yet, some of the funding we get for using HFA programming can be put towards dinner.

Sessions:

Shire; Bullying

Pfizer;

Bayer;

Kids; We will tell parents in emails, fliers, on facebook and mention it again when they register that devices are to be left with parents during the activities. **NO DEVICES ALLOWED.**

10-12:30; Morning after drop off will have the HFA presentation, about 45 minute to an hour, then the Improv group, we just need to decide how long to have them. They can do an extra 1/2 hour but there is a fee. It may well be worth it. Improv total will be \$1500-&1750 depending on how long we use them. \$1500 of that will be covered by HFA.\*\*Stacie request we do 1 ½ hours!

Lunch. 12:30- 1:30

1:30 -3:30 Game truck to run alongside of HFA Fear Factor/fiction. Splitting into two groups with one in truck and the other doing session.

Agenda; see attached.

Last session for adults; HFA "Been There Done That" We can have a panel of our own men and women who have a story to tell relating to hemophilia and vWD. Something interactive. \*Possible facilitators Chris Smith, Jim Boutin or Rich Pezzillo.

EX: Until I had a brain bleed I was "just" a symptomatic carrier.

How someone switched to peripheral sticks from a port.

Older guys (Max? Mark Z? ) what it was like for them as opposed to today's treatments. \*Max has volunteered if we use this.

What getting treatment for vWD is like, maybe find someone with a late diagnosis.

Stories of getting diagnosed before knowing you were a carrier.

Meagan will track and list registrations.

Dennis will send out a "save the date card"

Other Points of interest:

Meredith Adler has agreed to become one of our CT State Leads for NEBDAC along with Jennifer.

Upcoming industry dinners;

\*\*Rocky Hill, October 19th. Shire Advocacy dinner at Casa Mia <http://www.casamiact.com/>

\*\* Rocky Hill November 7th Bioverativ Fact-or fiction dinner, location to follow.

Hiring Maryann as full-time director; Dennis checked with a payroll service and found it was inexpensive to set up services for paycheck and to have taxes deducted etc. Probable change to take place January 1, 2018.

Ismeal Castillo and Andre Sweet will be attending this year's CSL "Getting in the Game".

Diane Bruno will be 2018 Alpine Walk coordinator again. She has begun the process of putting in for grants etc. Rooms at Mt Snow are available to reserve.

Katie Rosevear is considering CHS joining the BOD. Maryann has sent information for her to look over.

Maryann to meet with new Kedrion rep at NEHA Fall Fest. Also has submitted to them for AM exhibit.

Next meeting will be by phone to solidify Annual Meeting planning.

Next in person meeting to be held in the morning before the Annual Meeting.

Meeting closed at 7:50

Respectfully submitted;

Maryann May

