

Connecticut Hemophilia Society

January 15, 2017

Meeting opened at 7pm

Attendance

- Katie - Secretary
- Rebecca
- Janine – SL Specialist
- Nemo – SL Specialist
- Dennis – President
- Maryann -ED
- Sharon – Treasurer
- Meghan
- Jennifer – Advocacy
- Diane Bruno -Alpine Walk coordinator

Not in Attendance

- Stacie

Diane Alpine Walk Report

- See report and notes:

Nominations and Volunteers

- None; Rebecca is willing to help Dennis with stuff.
- Rob R would like to hear more about VP position. Maryann will meet with him in the future to define.

Live Meetings

- Sunday Feb 4 Windsor Library 2:30- 4. We can also have call ins.

Advocacy



14th Annual CHS Alpine Walk

Board Update January 15, 2018

Financial

- Industry sponsor requests submitted to:

Diplomat	Bayer	Caremark	Shire	
Grifols	Octapharma	Pfizer	Option Care	Matrix
	Genentech			

- Industry sponsor requests Approved Amounts to date:

Express Scripts - \$2000 (finalized)	Option Care- Water donation (tentative)
CSL Behring- \$5000 (finalized)	Aptevo- \$2000 (finalized)
Novo Nordisk- \$5000 (finalized)	

Bioverativ not sponsoring. They are only sponsoring programs with educational content.

***Was a check received from CSL Behring? They would like a confirmation on the website.*

I had acknowledged receipt. Went on to do it again and it says "Can not update this request. Request is not in the Payment Issued state. Have you already approved this request?"

Other

- Registration and Donation Info are in the process of being sent out
- Facebook event page is set up. Please invite anyone you think would be interested.
- Entertainment- Professional DJ's are around \$1000-\$1500. What exactly are we looking for in a DJ? Do we need lights/credentials? What are we willing to spend for a DJ?
- Diane looking into DJ, dancefloor and if MT Snow will provide a bar service.
- Budget of \$500
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Auction

Requests sent to:

- American Airlines (Waiting)
- Southwest Airlines (Waiting)
- Canobie Lake Park (Waiting)
- Red Sox (Waiting)
- Patriots (Waiting)
- Celtics (Waiting)
- Bruins (Waiting)
- Attitash Mountain Village (waiting)

- Anyone willing to ask local companies for an auction donation can email me and I can send them the donation packet to give to the companies
- I have the updated auction item request letter which I believe I sent to the BOD. Letter attached
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Questions for the Board

- What does everyone think about starting a Facebook Group for people interested in attaining auction items?
 - I think it could be a good way to keep people motivated and get some ideas on how/who to ask. Board agreed Diane to set up page.
 - Who do you all think would be good members to add to the group who are frequent contributors to the auction? Suggestions were made as who to add.

- What do we currently have for auction items?
 - Stacey-silver bracelet
 - Banks-Camo sports jersey
 - Katie/Becca Basket
 -

- Dennis is working on clothing item?
 - Nothing from Octa yet
 - Item logos will depend on who donates

- What is everyone's opinions on seeing if we can get Pizza donated for Lunch?
 - I know we have had some feedback that its hard for people to fit in getting their own lunch. I would still need to check on a whole array of things in order for this to work- Will Mt. Snow allow it? Is there anyone willing to donate? Delivery or Pickup? Timeframe? Etc. BUT first and foremost do we think it is a good idea to investigate?
 - Diane to check with Mt Snow to see if we can bring in pizzas. If approved, she will contact local pizza places to see if any will donate.

Next Steps

- Follow up on sponsorship requests
- Continue the hunt for a DJ in the budget
- Secure additional auction items
- Contact industry reps for goody bag items
- Work out menus with Mount Snow
- Programs We have two HFA sessions like last year. This year Eric Burgess will come out to do the one before tubing, I discussed it with Jim and he said it would be good to have a break and not have to facilitate although he is willing. Carrie and I are developing a casual rap for the mom's session.
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- Assign Volunteers for Event

Jennifer: Kid's programs Projector and movies for Friday and Saturday, prizes purchased for bingo.

- FYI-NEBDAC call on Wednesday January 17th.
- Proclamation/ Hill Days/ RDD Feb 28th
- Combined with NORD for RDD at 9-11 then group lunch then meets with legislators. Save the date to go out soon. NEBDAC call on Wednesday the 17.
- Washington Days March 7-9 let us know if you want to go. Looking for new families.
- CT Rare Task force January 19th.

Upcoming Events

- Spring Social- Will make this the focus of the February meeting.

Meeting Adjourned at 7:50



Connecticut Hemophilia Society, Inc.

December 2017

To Whom It May Concern,

On March 17, 2018, members of the New England bleeding disorders community along with family, friends, and corporate supporters will arrive to the Mount Snow Resort in West Dover VT for an afternoon of active fun while raising money to support the mission of the Connecticut Hemophilia Society (CHS).

The **14th Annual CHS Alpine Walk** is our largest fundraiser and one of the key reasons we've been able to grow so quickly since forming just six short years ago! This event has become one of the premier annual events for the New England community and draws attendees from throughout the region who find the friendship, guidance and support offered by our close-knit group to be invaluable. Many prominent members of the Fairfield and Hartford counties business, medical, sports and political communities will also be attending this year's event.

People who have an inherited bleeding disorder do not naturally produce one or more of the proteins needed to clot blood properly. The result of this is internal bleeding episodes that can cause intense pain, permanent joint damage, and, in some cases, life-threatening emergencies. This is a rare and costly disorder, which can add a sense of isolation as well as emotional and financial stress. CHS aims to break through that isolation by creating educational and support programs that create long-lasting connections and, in turn, an active and aware community. CHS serves affected people throughout the arcs of their lives.

We would like to invite you to become a part of this event by either donating an item to our auction or making a charitable donation. Auction items will be prominently displayed throughout the evening during the cocktail reception and dinner. Donors will receive recognition in the event's auction and program books and the opportunity to provide promotional brochures and literature for display.

We hope that you will join us in our mission to improve the lives of families living with the daily challenges of a bleeding disorder. We need your help to make the 2018 CHS Alpine Walk a huge success. Thank you for considering this request. If you have any questions, please feel free to contact me at 978 241 2414.

Best wishes,

Diane Bruno
Event Coordinator

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www.cthemophilia.org

CHS is a Non-Profit 501(c)(3) organization registered with the State of Connecticut
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