

Friends of NCBDDD

Minutes of Executive Committee Call: September 17, 2014

In Attendance: Adriane Griffen, Craig Mason, Beverly Robertson, Barbara Kornblau, Sara Struwe, Roberta Carlin, Melody Stevens, Emil Wigode, Annie Acosta, Lynda Honberg, Caryn Steinman, Pat Johnson

Absent: Sara Yates, Mary Andrus, Angela Blackwell, Jeff Cohen, Gaylon Morris, Katie Verb, Ursula Phoenix-Wear

Convene: 2:00pm

Update from Friends of NCBDDD Chair: Adriane Griffen

Election Update

- Adriane thanked people for volunteering on the elections committee.
- Adriane reviewed where we were in the process and who would be rolling off the executive committee.
- She also reported that she has already received four nominations.

In-Person Meeting

- Adriane gave an update on developments for the In-Person Friends of NCBDDD meeting.
- After acknowledging people who have helped plan the meeting, Adriane noted that the meeting will take place on November 12 in conjunction with the AUCD meeting.
- It was noted that this will be a working meeting with highlights from personnel from the CDC.
- Adriane also said that the people working on the meeting were going to talk the next day with the Communication Committee to flush out more ideas.
- There would also be further discussion on the role of champions and advocacy coordination.
- Adriane acknowledged that November is a tough time for a meeting and appreciates everyone who can make it.

Champions Update

- Adriane went through the current list of champions and announced that Randy Fenninger of the National Blood Clot Alliance will serve as a champion for the blood clot area.
- Adriane thanked Roberta Carlin who participated on a champions call.

- Emil Wigode and Pat Johnson were thanked for their efforts to help distribute the children's clinical preventive services MMWR information.
- Adriane also shared a rough draft of the Communications strategy, which will be reflective of each thematic area and take advantage of the champions work in the areas.
- Lynda Honberg noted that advocacy and family outreach can overlap.

Committee Reports: Membership/Communications Committees: Beverly Robertson

- Beverly thanked Adriane for pulling together the communications call the previous week.
- Beverly asked about the empty boxes that still need to be filled – she wanted to know how to do that and what type of information and activities should be noted?
- It was pointed out that October is Disability Awareness Month and it was questioned whether we wanted to tie some events to that.
- Melody Stevens noted that next year is the 25th anniversary of the ADA.

Update from NCBDDD: Melody Stevens

- Melody noted the release of the children's clinical preventive services MMWR and thanked all involved in those efforts, including AAP's Dr. Perrin who participated in the briefing.
- Melody reminded everyone that they are still accepting feedback on the annual report – she would love to hear from us.
- She noted that they have an aggressive timeline for the next report, as they want to use next year's report to really collaborate with the Friends of NCBDDD.
- Pat asked Melody whether she wanted to focus on stories from the individual champions or the organizations they were with – Melody replied that she was interested in both types of stories.
- It was also clarified that the champion stories are just the next step up from patients' stories, and are not meant to replace the patient stories.

Update from the Advocacy Committee: Annie Acosta

- Annie noted that there was not much to report on rescheduling the meeting with OMB.
- Annie noted that the CR text was released, with mostly level funding until Dec. 11, but that it also provides \$30 million for CDC use to preventing the ebola virus outbreak.
- Annie said that she received a response from Dr. Frieden (in response to disability and health partners). Dr. Frieden replied to each area and described what CDC is doing in each area.
- Adriane asked about the appointment of a CDC disability officer – will it be back filled or split up? Annie did not have much information on this and Adriane said her preference was to have the position back-filled.
- Annie also brought up the possibility of a Hill briefing in early 2015.

Next Meeting: October 15 – 2:00pm

Adjourn: 2:45pm