

Friends of NCBDDD

Minutes of Executive Committee Call: April 16, 2014

In Attendance: Adriane Griffen, Craig Mason, Pat Johnson, Mary Andrus, Angela Blackwell, Jeff Cohen, Barbara Kornblau, Sara Struwe, Roberta Carlin, Melody Stevens, Ursula Phoenix Weir

Absent: Sarah Yates, Gaylon Morris, Emil Wigode, Annie Acosta, Joe Isaacs

Convene: 2:00pm

Update from Friends of NCBDDD Chair: Adriane Griffen

Atlanta Meeting

- Adriane thanked all who were able to attend the Friends of NCBDDD meeting in Atlanta with CDC in person, and asked those who attended to share their general thoughts and takeaways from the meeting.
- Adriane shared that she thought that there was a lot of value to having a face-to-face meeting with NCBDDD/CDC staff. She also said she thought it was very important to build upon the meeting in Atlanta and increase greater participation of general members of the Friends of NCBDDD – not just limit most activity to the Executive Committee.
- Adriane also reminded people that Melody Stevens is a conduit to the CDC, and that she is a great first point of contact.
- Jeff Cohen said that the most powerful takeaway for him is the need for us to all come together to strategically communicate about the importance of the agency. There are too many critical audiences that do not appreciate the work that the center does and thinks the Friends of NCBDDD can help spread the word about the good work the center does.
- Ursula Phoenix Weir talked about four macro messages that were highlighted in the upcoming annual report: 1) saving babies through the prevention of birth defects; 2) understanding autism; 3) protecting people; and 4) improving the health of people with disabilities.
- Ursula also discussed the possibility of a staff directory, in response to an often asked question of who does what at the NCBDDD.
- Melody Stevens asked if there should be something from her in the Friends of NCBDDD newsletter highlighting the work that a particular division is doing at NCBDDD. People on the call thought this would be a good idea to help spread the word about the work that NCBDDD is doing.
- Adriane said that there were some “a ha” moments with people realizing who to contact while meeting NCBDDD staff in Atlanta. Adriane also thought it would be good for

NCBDDD staff to know that the Friends of NCBDDD group is available to them as a resource as well, so maybe there should also be a directory of members of the Friends of NCBDDD?

- Jeff Cohen thought the idea of a Friends of NCBDDD directory would be good, especially as a way to promote interactive dialogue.

Promotion of Upcoming NCBDDD Events

- Adriane also highlighted two opportunities to promote NCBDDD:
 - April 22 Grand Rounds on Autism Spectrum Disorder
 - May 6 Vital Signs
- Melody said there could be a good opportunity for a twitter chat associated with the Grand Rounds. She also said that CDC was planning to do a partner call on the May 6 Vital Signs event.

Story-Collecting

- Adriane again encouraged story-collecting among member organizations of Friends of NCBDDD as a way of highlighting the impact of budget cuts, but also success stories.
- Barbara Kornblau shared her excitement about this effort and said it would be great to have a website with lots of patient stories.
- Mary Andrus conveyed that Easter Seals talks often about how they can do stories better, but that they do not have anything ongoing right now to collect the stories.
- It was mentioned by several on the call that social media can help amplify any stories collected.

Update from Friends of NCBDDD Advocacy Coalition: Adriane Griffin

- Adriane thanked all on the call for the efforts to promote the FY15 appropriations sign-on letter and that she will send everyone a copy of the final version.

Committee Reports: Member/Communications Committee: Adriane Griffin

- Adriane reported that Sarah Yates is exploring ways to boost membership and outreach and is considering forming a committee to help with these efforts.

Next Meeting: May 21, 2:00-3:30pm

Adjourn: 3:20pm