

# Friends of NCBDDD

## Minutes of Executive Committee Call: January 16, 2013

**In Attendance:** Adriane Griffen, Sarah Yates, Pat Johnson, Angela Blackwell, Barbara Kornblau, Erica Reott (filing in for Melody Stevens), Gaylon Morris, Ursula Phoenix Weir (CDC representative), Annie Acosta

**Absent:** Emil Wigode, Craig Mason, Jeff Cohen, Mary Andrus, Sara Struwe, Roberta Carlin, Joe Isaacs

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**Convene: 2:00pm**

**Welcome and Intros:** Adriane Griffen

- Adriane welcomed the new members to the Friends of NCBDDD Executive Committee.

**Review of New Meeting Format:** Adriane Griffen

- Adriane asked everyone what they thought of using AdobeConnect for future Friends of NCBDDD Executive Committee meetings. All members attending the meeting were able to connect and were receptive to using the format in upcoming meetings.

**Update from NCBDDD:** Gaylon Morris

- Gaylon Morris summarized the final FY 2014 appropriations for NCBDDD.
- The Center took significant cuts, with the elimination of the craniofacial malformation line and cuts to the blood disorders program.
- Dr. Colleen Boyle and NCBDDD staff are looking through the appropriations bill to determine how the Center will react moving forward.
- Adriane asked if the position of the director for human development and disability division is on hold, and Gaylon said he was not sure, but would try to find out.

**Update from Friends of NCBDDD Chair:** Adriane Griffen

- Adriane pilot-tested the new meeting format with Adobe Connect with the orientation of the new Executive Committee members, where she went through the roles and responsibilities for each member of the committee.
- Adriane said she had no specifics yet to share regarding the first in-person meeting of the year. She said she was hoping for a First Quarter or early Second Quarter meeting. She also mentioned a possible trip down to Atlanta to meet with the leadership of the NCBDDD.
- Gaylon reported that Dr. Boyle is enthusiastic about the idea of the Executive Committee making a visit to the Atlanta office, although she is trying to determine what the format of

the meeting would be and which Executive Committee members should attend. Dr. Boyle is also trying to determine which topic areas should be discussed during the meeting.

- Adriane reminded everyone on the call that there is a listserve that all members can use, hopefully to share information and updates from each member's organizations. She also mentioned the twitter handle #friendsofncbddd and said all members are welcome to participate in tweets.
- Adriane also reminded the Executive Committee that members are expected to attend the majority of meetings throughout the year.

**Update from Friends of NCBDDD Advocacy Coalition: none**

- Due to the Annual Meeting of the Consortium of Citizens with Disabilities, a number of Executive Committee members from the Advocacy Coalition were not able to attend this meeting.
- Annie Acosta mentioned that her office is conducting preliminary outreach to set up a Friends of NCBDDD with the Office of Management and Budget.

**Committee Reports: Member/Communications Committee:**

- Sarah Yates reported that she had no updates, but was looking forward to getting more involved in her role.

**New Business: Soliciting Stories of Budget Cuts Impact**

- Adriane noted that the discussion of collecting stories of budget cut impacts is a carry-over item from the December meeting. She wondered if using a survey monkey could work to collect stories, asking members for their thoughts.
- Gaylon reported that NCBDDD would appreciate stories to help shine a light on the impact on individuals or NCBDDD programs.
- Angela Blackwell said she thought it was a good idea to help demonstrate how people or organizations reacted to the change in budgets – how did they overcome the changes?
- There was a discussion amongst members on what type of stories to collect and how to collect the information.
- Adriane said she would check in with Emil and Craig and report back next month.

**Next Meeting: February 19, 2pm ET**

**Adjourn: 3:15pm**