



Friends of NCBDDD

In Support of the National Center on Birth Defects and Developmental Disabilities

Executive Committee Meeting Minutes

9/20/16

Roll Call: EC Members: Adriane Griffen, AUCD, Sara Struwe, SBA, Jennifer Li, NACCHO, Shannon Haworth, AUCD, Jennifer Bolden Pitre, Family Voices; Members at-Large: Patrick Johnson, AAP, Kate Taft, AMCHP, Annie Acosta, The Arc, Kathy Brill, P2P USA, Roberta Carlin, AAHD The National Center: Melody Stevens, NCBDDD, Ursula Phoenix Weir, NCBDDD, Advocacy Coalition Co-Chairs-Chairs: Becky Slater, MOD, Patrick Johnson AAP, Katie Verb, HFA, April Montgomery, NBDPN

Absent: Barbara Kornblau, Randy Fenninger, NBCA

Updates:

Ursula Phoenix Weir, Acting Associate Director for Health Communications for the Center discussed the Center's annual report. Included in the report are the 4 thematic areas, budget details and a partner's spotlight. The report covers the period October 1, 2015 through September 30, 2016. The report includes stories which spotlight various partners work. The partner's spotlight includes how the partner's work has positively impacted a person and or family. Last year's spotlight focused on work by the March of Dimes, written by James Gelfand and the Autism Society written by Allison Singer, and American Association Health and Disabilities written by Roberta Carlin. Currently working on 2016 report which will include a new section on Zika and the Center's response. It is hoped the Annual report will continue to be a resource to the Friends. The Center is looking to the various divisions to identify organizations that have not been highlighted in the past. The Center is also wondering how the annual report has been used by partners.

Welcome Back Melody Stevens!

Melody Stevens, reported she is happy to be stateside. As soon as she returned she participated in Public Health Ground Rounds with Dr. Shapiro and another. Melody reported that on October 22, a webinar: "Voices of 5,000+ Patients: The First National Survey on Experience of Care at U. S. Hemophilia Treatment Centers" <https://friendsofncbddd.org/voices-of-5000-patients-the-first-national-survey-on-experience-of-care-at-u-s-hemophilia-treatment-centers/> would air, and that 3 representatives from the Center will attend the Sickle cell convention on October 28th. Also, in conjunction with National Disability Awareness Month, a MMWR will be released. And finally, Dr. Peacock will be presenting during a webinar for NCBDDD Family Liaisons & Family Voices on September 27th titled "Zika: What

Family Leaders Working in Public Health Need to Know". Dr. Peacock will discuss transmission and prevention of the Zika Virus and gave updates on the CDC's response.

Updates from the Executive Board:

Nominations: Adriane reminded all to continue to solicit nominations, throughout the month of October. Installations will then be held at our in-person meeting in December. If current officers have questions regarding the term of their office, or the termination date, please contact Adriane Griffen.

Adriane queried the executive committee with regard to Virtual check-ins: To we need to change the model? It was noted: Currently the Friends Virtual Check-ins average 60-70 partners on the calls which take place on Friday afternoons from 2:00-3:00pm. If the call goes over an hour, the call tends to lose callers. There has been engagement from all audiences; NCBDDD Center staff, Partners, families & others. The executive staff discussed moving the calls to another day, perhaps Tuesday or Thursdays and look at ways to condense the agenda to 60 minutes for partners sharing and will draft a 2017 schedule.

Reminder: The in-person meeting of the Friends of NCBDDD will be held on **Wednesday December 7, 2016** at the **AUCD Conference from 12:00-5:00pm** location at **The Renaissance Washington, DC Downtown Hotel Ninth Street, NW, Washington, DC, 20001**. (Becky, Jennifer, and Shannon volunteered). You may register here: <https://www.aucd.org/meetings/register.cfm?id=259>

Adriane solicited volunteers for the meeting: Becky and Jennifer volunteered. This will be an open meeting.

Committee Reports:

- ✓ **Communications** – Shannon Haworth
 - Registration for the AUCD Conference is open.
 - Jennifer Bolden Pitre is assisting with Friends of NCBDDD tweeting.
 - Awareness campaign is on-going
 - Friends Calendar- Will be put in next Friends of NCBDDD Newsletter in order to raise awareness of Friends events and encourage participation. – Calendar is now public

Membership – Jennifer Li

New Member – The *Friends of NCBDDD* welcome our new member; Dr. **Adela Sonaike**. Dr. Sonaike is the National Get Fit Director. <http://www.getfitnj.org/> .

Thematic Area Updates:

- Saving Babies** – Becky Abbot; (Combined & abbreviated report) Excited about upcoming collaborative call. Continued work with advocacy coalition, call advocacy call; anticipated movement in congress. MoD – has a new CEO; Stacey D. Stewart, MBA, and MOD is excited about the change.

- ✓ **Helping Children** – Patrick/Adriane; Working with the Act Early Network and the Ambassadors to monitor and plan Zika response.
- ✓ **Protecting Children** – Katie/Randy; No Champions/Partners on call; Adriane stated they are Collaboration with GA State on some work – some nice policy work may issue - more to follow.
- ✓ **Improving Health** – Sara / Roberta – Adriane commended the Improving Health thematic area on a terrific job on the quarterly call. It was noted that final regulations on the Standards on diagnostic Medical Equipment have been passed and are part of the ACA. Final vote was last week. Ruling was on 14th. Some AAHD projects:
More about Project Accessibility below:
<http://www.aahd.us/initiatives/project-accessibility-usa/>
Self-Assessment Guide for Mammography Facilities below:
http://www.cddlearningportal.org/ProjectAccessibility/Resources/Facility_Assessment.pdf

New Business: Possible partner coordination call around Zika.

Our next Executive Board meeting: October 18, 2016 at 2pm ET