

**CAB Conference Call
November 29, 2012
12:00 EST
Meeting Minutes**

Participants:

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| Claire | Harvard University |
| De`Angelo | University of Florida, Jacksonville |
| Delia | University of Miami |
| Jennifer | University of Colorado |
| Juan | University of Puerto Rico |
| Julie | Westat |
| Julie | University of Alabama at Birmingham |
| Laurie | FSTRF |
| Leslie | Texas Children's Hospital |
| Marilyn | Bronx-Lebanon Hospital Center |
| Megan | Westat |
| Rosetta | Bronx-Lebanon Hospital Center |
| Theresa | Texas Children's Hospital |

• **APPROVAL OF MINUTES**

The minutes from the October 25, 2012 call were approved with no changes.

• **PHACS CAB EVALUATION SURVEY RESULTS**

Megan talked about the PHACS CAB Evaluation Survey results. There were 8 responses. Some suggested topics for upcoming calls are:

- Hearing and memory loss,
- infected teens coming of age and going away to college, and
- postpartum depression.

• **CAB NETWORK MEETING DISCUSSION**

The PHACS Fall 2012 Network Meeting was November 8-9, 2012 in Bethesda, Maryland at the Bethesda Hyatt Regency. There were 21 CAB members at the meeting.

Delia talked about the meeting. The plenary speakers came from Thailand, Canada, France, and the United Kingdom. The plenary speakers talked about their studies.

There were updates from each PHACS Working Group (WG). During the Complications WG session, researchers gave updates about Measles, Mumps and Rubella (MMR) vaccines among perinatally HIV-infected children. Researchers talked about studies having to do with hearing and balance during the Hearing/Language WG session. The Adolescent WG session featured topics such as pregnancy, long-term effects of HIV, and mental health. The Adolescent WG session also covered topics such as transitioning to adult care, viral resistance, and behavioral health outcomes. There was a project update on sexual risk behavior among youth with perinatal HIV in the US. The presentations from the meeting are posted on the PHACS website.

The first CAB session was about helping children and teens cope with loss. The PHACS neuropsychologists presented information and answered questions. CAB members talked about

resources and support for coping with loss. During the second CAB session, CAB members participated in story circle exercises.

Delia talked about the "Retention Strategies" session. During the session, Jean Twomey talked about a tracking system to get in touch with people who have left the study. She talked about strategies like giving gift certificates and sending birthday cards. She also talked about ways to keep study participants. Jean talked about a booklet called "You and This Very Important Project." Claire emailed the booklet to all PHACS members.

Leslie talked about the meeting. She liked the "Retention Strategies" session. Leslie thought Jean Twomey had a fresh perspective on recruitment and retention. Jean talked about the significance of making the participants feel important.

Claire talked about a resource about transitioning to adult care. The resource was made by a group called "Next Step." It was created by health care providers, youth and caregivers. Claire will send the resource to the CAB.

Action Item: Claire will send the "Moving on Positively" resource to the CAB.

• **STORY CIRCLE**

Claire talked about the story circle exercises that took place at the meeting. Claire thanked Yuri and Delia for facilitating a story circle. Stories help people learn from and connect with each other. At the meeting, the CAB chose three topics to talk about. The topics were HIV disclosure, raising HIV-exposed or HIV-infected children, and HIV medication adherence. Each CAB member told a short story about that topic. CAB members listened to stories without giving feedback. CAB members wrote their reactions to the stories on post-it notes.

De`Angelo talked about the story circle exercise. It was empowering for CAB members to share their experiences. De`Angelo has used story circle exercises in support groups. Marilyn and Rosetta talked about the story circle exercises. Rosetta liked talking with other CAB members about similar experiences.

Delia suggested that the CAB participate in story circle exercises at the next network meeting. Claire suggested that the CAB participate in story circle on a conference call.

• **PHACS CAB NEWSLETTER, DECEMBER 2012 EDITION**

Megan talked about the PHACS CAB Newsletter, December 2012 Edition. The theme for the newsletter is "Emotional and Developmental Aspects of Children and Adolescents." Megan encouraged the CAB to submit articles to the newsletter. There is a section for CAB kids to submit colored snowflakes. There is a section for CAB members to talk about how they celebrate the holidays. There is also a section for CAB members to talk about the network meeting.

Claire talked about health narratives. Health narratives showcase a person's experience with health. Health narratives can be written anonymously. CAB members can contact Claire to write a health narrative for the newsletter.

NOTE: The next CAB call will be on Thursday, December 27, 2012 at 12:00 pm EST.