#### CAB Conference Call March 26, 2015 12:00 EST Meeting Minutes

#### **Participants:**

Andrea Claire Delia	Jacobi Medical Center Harvard University University of Miami
Exzavia	Children's Diagnostic and Treatment Center
Juanita	Tulane University
Julie	Westat
Julie	University of Alabama, Birmingham
Kim	Texas Children's Hospital
Lauren	Ann and Robert Lurie's Children's Hospital
Laurie	FSTRF
Lesley	Texas Children's Hospital
Linda	St. Christopher's Hospital for Children
Megan	Westat
Renee	University of Florida, Jacksonville
Rosetta	Bronx-Lebanon Hospital Center
Tatania	Tulane University
Theresa	Texas Children's Hospital
Tranice	Tulane University
Veronica	University of California, San Diego

#### • APPROVAL OF MINUTES

The minutes from the February 26, 2015 call were approved with no changes.

## • REQUEST TO SHARE PHACS CAB MINUTES

Megan talked about sharing PHACS CAB meeting minutes. The IMPAACT CAB requested that the PHACS CAB share meeting minutes with their group. The CAB suggested that the IMPAACT CAB also share their minutes with the PHACS CAB. Veronica suggested that names be removed from the PHACS CAB minutes before sharing them. Lesley reminded the CAB not to share PHACS CAB minutes without requesting permission from the PHACS CAB.

## • PHACS CAB EVALUATION SURVEY RESULTS

Megan talked about the PHACS CAB Evaluation Survey results. There were 6 responses. Some suggested topics for upcoming calls are:

- Stigma;
- CAB Handbook;
- Pregnancy and HIV;
- Leadership; and
- Improving Focus and Working Memory.

Megan will remind guest speakers to keep presentations to approximately 15 minutes. Megan will remind guest speakers to allow time for questions.

Megan talked about the stigma panel at the PHACS Spring 2015 Leadership Retreat. CAB members suggested questions and topics for the panel discussion through the survey. Megan shared stigma-related resources. Some only stigma-related resources are:

- The Stigma Project: <u>http://stigmaproject.org</u>;
- The Stigma Action Network: <u>http://stigmaactionnetwork.org</u> and
- The Stigma Index: <u>http://stigmaindex.org</u>.

## • SPRING 2015 LEADERSHIP RETREAT

The PHACS Spring 2015 Leadership Retreat took place March 17 – 18, 2015 in Potomac, Maryland. Delia and Kim attended the retreat. Kim talked about the retreat. Kim talked about the Hearing and Language Working Group (WG) session. During the session, presenters talked about a study about children enrolled in speech therapy but not language therapy. Kim, Delia, Megan, Claire, and Dominque met during the retreat to talk about CAB and Young Adult CAB (YACAB) collaboration. Kim talked about the Maternal Exposures WG session. The team talked about HIV-exposed babies with lower birth weights.

Delia talked about the plenary speakers. The first plenary speaker talked about understanding environmental influences on pregnant women and children. Everyday exposures may affect pregnant women and children. There are several research studies looking at effects of exposures in the environment. The second plenary speaker talked about the follow-up of SMARTT participants. The PHACS research team is currently working on a protocol to follow SMARTT participants into adulthood. This protocol may be similar to AMP Up. Delia talked about the stigma panel. The panel discussed many topics. Some of the topics included how stigma affects families and stigma in the healthcare setting.

Megan talked about the retreat. The CAB Leadership brainstormed many ideas for the CAB. The CAB Leadership talked about making a certificate for attendance at network meetings. The CAB may look into inviting Executive Committee members on future CAB calls. The team brainstormed ways to better connect with the WGs. The team also talked about being involved in PHACS writing teams. Finally, the team suggested using a story circle format for some of the CAB calls.

## • PHACS CAB NEWSLETTER, JUNE 2015 EDITION

Megan talked about the newsletter. Delia suggested that the YACAB have their own section of the newsletter. The YACAB expressed an interested in talking about disclosure in the newsletter. Megan reviewed some suggested themes for the newsletter. The suggested themes are:

- Mothers and caregivers of HIV-infected or HIV-exposed children;
- Participation in a research study;
- Mental Health and HIV;
- Bridging the gap of generations in research; and
- Self-love and empowerment.

Megan talked about the CAB Kids section of the newsletter. There were no CAB Kids submissions in the last newsletter. The CAB suggested adding puzzles and games to the CAB Kids section. Delia suggested adding a fun story to the section. The story could continue on every newsletter. Megan suggested that the CAB Kids section be two pages long.

## • HEALTH EDUCATION AND COMMUNICATION COMMITTEE

Claire gave the Health Education and Communication Committee update. Claire talked about the SMARTT videos project. The project had originally been made to create videos for mothers looking to join the SMARTT study. It was suggested by several PHACS members that the videos be aimed at study staff. This would help study staff have a better understanding of why mothers/caregivers may choose to join or not join the SMARTT study.

At the Spring 2015 Leadership Retreat, it was suggested that the team make videos for moms who are in SMARTT. The videos could show updates about PHACS. Moms could watch the videos during their child's study visits. The HECC is considering using a whiteboard format for the videos. A whiteboard video is an animation video. In the video, a voice explains something while a hand is drawing to visually show the concept. The whiteboard video could help explain some of the PHACS updates. The CAB agreed with the whiteboard format.

The videos could have different focuses. One video could talk about results from PHACS research. The videos could be updated every year. Another video could explain study visits. The video could also explain why a test is being performed and what research has come out of the use of a certain test. The CAB approved of both video ideas. The CAB suggested combining the video ideas to make one video with two parts.

# • PHACS CAB VICE CHAIR ELECTIONS

Megan talked about the PHACS CAB Vice Chair elections. CAB members can nominate themselves or other CAB members to run for the position. CAB members can submit nominations through the PHACS CAB Evaluation survey.

NOTE: The next CAB call will be on Thursday, April 30, 2015 at 12:00 pm EST.