CAB Conference Call January 28, 2016 12:00 EST Meeting Minutes

Participants:

Alexandria FSTRF

Allison Bronx-Lebanon
Andrea Jacobi Medical Center

Carrie University of Colorado, Denver

Claire Harvard University
Delia University of Miami

Exzavia Children's Diagnostic and Treatment Center

Jeanie University of Southern California

Jennifer University of Colorado Joel University of Puerto Rico

Julie Westat

Julie University of Alabama

Kimberly Rutgers New Jersey Medical School

Kimbrae Texas Children's Hospital **Kylie** Texas Children's Hospital

Laurie FSTRF

Lesley Texas Children's Hospital

Megan Westat

MichaelUniversity of Florida, JacksonvilleRaikoUniversity of Colorado, DenverRamonaUniversity of Florida, Jacksonville

StephanieUniversity of MiamiTheresaTexas Children's Hospital

Veronica University of California, San Diego

Yuri University of Miami

• APPROVAL OF MINUTES

The minutes from the December 10, 2015 call were approved with no changes.

PHACS CAB EVALUATION SURVEY

Megan talked about the survey. There were 8 responses. Most CAB members liked the Fall 2015 Network Meeting Q & A. CAB members suggested that the Leadership give the Q & A presentation during future network meetings. It was suggested that the CAB ask the Leadership about what they learned from having the CAB at the meeting. Topics suggested through the survey included:

- Social problems and HIV;
- Evidence of toxicities in exposed children;
- Environmental factors;
- How participants and caregivers are feeling about PHACS;
- What's going well at study visits;
- · Disclosure; and
- Community involvement and advocacy.

Megan talked about the February and March CAB calls. **Julie** from Harvard will talk about SMARTT Version 5 during the February CAB call. **Megan** and **Claire** will talk about study visits during the March CAB call. **Theresa** talked about study visits. It was suggested that the Study Coordinators and CAB work together to help make study visits better. **Kim** talked about informed consent. It was suggested that the CAB come up with informed consent resources for new participants. **Raiko** talked about breast-feeding and HIV. It was suggested that the CAB consider talking about breast-feeding during a future CAB call. **Linda** talked about medication adherence. It was suggested that CAB talk about missing medications during a future CAB call. **Veronica** talked about future CAB calls. It was suggested that CAB members share their skills during future CAB calls.

PHACS FALL 2015 CAB RETREAT EVALUATIONS

Megan talked about the PHACS Fall 2015 CAB Retreat evaluations. **Kim** talked about disclosure. The CAB supports all decisions about disclosure. Future CAB Retreat sessions about disclosure will continue to talk about all decisions about disclosure. **Theresa** talked about the retreat. There were some emotional and moving sessions. **Jeanie** talked about the CAB Retreat. **Jeanie** thanked **Claire** for sharing her poem at the retreat.

PARTICIPANT SUMMARY PROCESS

Claire talked about the participant summary process. **Megan** and **Claire** are working with authors to write all new participant summaries using the new participant summary template. At least one CAB member is asked to review every summary. Five CAB members have previously volunteered to review the summaries.

The CAB reviewed the "HIV Drug Resistance in Youth Living with HIV" participant summary. **Theresa** suggested picking another color for the male figure. **Theresa** suggested adding another picture under the "What We Learned" section. **Jennifer** talked about the summary. The text is very clear. The summary is easy to look at and read.

NOTE: The next CAB call will be on Thursday, February 25, 2016 at 12:00 pm EST.