

**CAB Conference Call
March 24, 2016
12:00 EST
Meeting Minutes**

Participants:

Alexandria	FSTRF
Andrea	Jacobi Medical Center
Claire	Harvard University
D'Andra	University of Colorado, Denver
Delia	University of Miami
Exzavia	Children's Diagnostic and Treatment Center
Jennifer	University of Colorado, Denver
Joel	University of Puerto Rico
Juanita	Tulane University
Julie	Westat
Julie	University of Alabama, Birmingham
Kimbrae	Texas Children's Hospital
Marilyn	Bronx-Lebanon Hospital Center
Megan	Westat
Stephanie	University of California, San Diego
Tatania	Tulane University
Trenise	Tulane University
Yuri	Department of Health, Miami

• **APPROVAL OF MINUTES**

The minutes from the February 25, 2016 call were approved with no changes.

• **PHACS CAB EVALUATION SURVEY**

Megan talked about the survey. There were 7 responses. Topics suggested through the survey included:

- Engaging CAB members;
- Sexual abuse and HIV;
- AMP Up; and
- SMARTT Dynamic Cohort.

• **PHACS STUDY VISITS**

Megan talked about study visits. **Megan** talked about the "Engaging PHACS Families" presentation. This was created with CAB and site staff feedback and explored some of the challenges and successes of recruiting and retaining families in SMARTT. The goal of the presentation was to figure out what makes families want to join PHACS. The presentation also talked about what PHACS can do to make the study better for PHACS families.

Claire talked about the "Engaging PHACS Families" presentation. In the presentation, many CAB members expressed that the relationship between families and the clinic was a benefit to being part of the study. It was also a motivation to stay involved in the study. Other benefits included learning about HIV and better access to health services. CAB members also talked about ways PHACS can make the study better. Ways included better explaining the research and research tests. It was also

suggested that sites consider compensation, childcare and transportation. Finally, the presentation outlined the role that stigma and disclosure play in study participation.

Stephanie talked about study visits. Site staff is always friendly and helpful. They explain tests to both parents and children. The site also provides snacks. After any blood draws, children get to pick a toy from a toy box. The site staff treats participants like family. Older children are compensated with gift cards.

Kim talked about study visits. The site staff treat families well and does not make them feel like test subjects. There are playrooms for children at the site. There are also lounges for adults to entertain themselves while children participate in the long study visits. Some of the study questionnaires ask repeat questions. It would be helpful to know why the same questions are asked.

Marilyn talked about study visits. The site staff is very friendly. Many site staff members have known the young participants since birth. This helps the children to trust the doctors. When visits are long, children are given vouchers for food and other snacks. It would help to make the visits shorter.

Exzavia talked about study visits. The site staff is very helpful. The site staff will take the time to explain tests to both parents and children. The site staff may even come with parents to the hospital if needed. The site has a waiting lounge for parents with televisions and reading material.

• **SPRING 2016 LEADERSHIP RETREAT**

Kim talked about the Spring 2016 Leadership Retreat. The retreat was at the Embassy Suites in Baltimore, Maryland from March 15-16, 2016. There were two plenary speakers, **Kate Powis** and **Paige Williams**. **Dr. Powis'** presentation talked about opportunities to make pregnancy outcomes and health of HIV-exposed uninfected children better. **Dr. Williams'** presentation talked about issues in looking at safety of antiretroviral (ARV) exposures in HIV-exposed uninfected children.

The retreat was different than past years. Instead of splitting Working Group (WG) presentations up across two days, each day focused on the different protocols. The PHACS team reviewed SMARTT on the first day and AMP/AMP Up on the second day. WG leaders first presented their thoughts about the future of PHACS from their WG's point of view. The team then broke out into small groups to talk about topics related to each WG. The small groups brainstormed ideas about future PHACS research priorities. After the brainstorm, the team met to vote on the top research priorities for PHACS. Some groups talked about growth and obesity. Some groups also talked about retention and transitioning to adulthood.

Ellen Chadwick and **Russ Van Dyke** will present the new PHACS priorities on the April and May CAB conference calls. Meeting presentations may be found on the PHACS website:
<https://my.phacsstudy.org/document/210/2016>.

• **HEALTH EDUCATION AND COMMUNICATION COMMITTEE (HECC) UPDATE**

Claire gave the HECC update. The HECC met during the Spring 2016 Leadership Retreat. The HECC talked about a potential project about informed consent. The HECC brainstormed the possibilities of creating another whiteboard video that would explain informed consent to young adult participants. It would potentially help young adults sign the informed consent forms online. The HECC also talked about stigma projects. The HECC is trying to find funding for a project that will focus on stigma. The project will look at whether being in a CAB makes a difference in different health outcomes. Health outcomes include adherence and sense of empowerment. The HECC talked about how stigma can affect health literacy. Health literacy is a person's ability to find health information, process it, and act on it. The team talked about how stigma might affect a person's ability to access health information. The HECC is also continuing to talk about transitioning to adult care. Finally, **Megan** and **Claire** are continuing to work on the PHACS participant summaries.

- **PHACS CAB NEWSLETTER, JULY 2016 EDITION**

Kim talked about the PHACS CAB Newsletter, July 2016 Edition. **Kim** invited CAB members to suggest themes for the newsletter through the PHACS CAB Evaluation Survey.

- **RESCHEDULE MAY CALL**

The CAB agreed to reschedule the May CAB conference call to Thursday, May 19, 2016 at 12:00 pm EST.

NOTE: The next CAB call will be on Thursday, April 28, 2016 at 12:00 pm EST.