

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

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**Participants:**

<b>Alexandria</b>	FSTRF
<b>Andrea</b>	Jacobi Medical Center
<b>Claire</b>	Harvard University
<b>D'Andra</b>	University of Colorado, Denver
<b>Ellen</b>	Ann & Robert Lurie Children's Hospital of Chicago
<b>Exzavia</b>	Children's Diagnostic and Treatment Center
<b>Gloria</b>	University of Florida, Jacksonville
<b>Jeanie</b>	University of Southern California
<b>Joel</b>	University of Puerto Rico
<b>Julie</b>	Westat
<b>Julie</b>	University of Alabama, Birmingham
<b>Kimbrae</b>	Texas Children's Hospital
<b>Kylie</b>	Texas Children's Hospital
<b>Lesley</b>	Texas Children's Hospital
<b>Marilyn</b>	Bronx-Lebanon Hospital Center
<b>Megan</b>	Westat
<b>Raiko</b>	University of Colorado, Denver
<b>Rosetta</b>	Bronx-Lebanon Hospital
<b>Stephanie</b>	University of California, San Diego
<b>Stephanie</b>	University of Miami
<b>Theresa</b>	Texas Children's Hospital
<b>Veronica</b>	University of California, San Diego

• **NEW SMARTT RESEARCH PRIORITIES**

**Dr. Ellen Chadwick** talked about new SMARTT research priorities. The SMARTT protocol team is finalizing SMARTT Version 5.0. In this version, there will be a Young Adult cohort. SMARTT participants who turn 18 will be invited to participate in the (YA) cohort.

**Dr. Chadwick** summarized the Spring 2016 Leadership Retreat. 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.

**Dr. Chadwick** reviewed the new SMARTT research priorities. The first priority is to look at pregnancy outcomes in mothers born with HIV. High priorities within this group include looking at outcomes of pregnancy. Outcomes may include preterm birth, baby's growth in the womb, and pregnancy complications. The team has already analyzed moms born with HIV. The next step is to compare pregnancy outcomes between moms who got HIV during their life and moms born with HIV. The team will also look at outcomes for babies born to moms born with HIV. They will look at things like growth, brain development, and weight. They will then be able to compare babies born to moms who got HIV during their life and moms born with HIV.

The second priority is to create a PHACS women's cohort. The team will be looking to get a blood sample from moms of babies in the dynamic cohort. The blood sample will be taken at enrollment and at the Year 1 visit. The team will also get pregnancy data from moms. This will help the team to look

at factors that may influence outcomes of the babies. For example, they may look at whether there were infections during pregnancy that may impact the baby. Cytomegalovirus (CMV) is another infection that can possibly impact the health of a baby. CMV can cause a slight fever and throat pain. CMV may also have no symptoms at all. Moms may not know that they have CMV. CMV can affect a baby's growth or hearing. CMV can be found in a blood test. Understanding these infections during pregnancy will help doctors to figure out what can influence a baby's development besides HIV and/or antiretroviral drugs.

Also with the women's cohort, the PHACS research team will look at inflammation during pregnancy and study how it can contribute to baby outcomes and/or pregnancy outcomes. Inflammation is an important area to study. It can be hard to study because some inflammation happens in a person's cells. A participant might not feel any symptoms. PHACS may need to get additional funding to look further at inflammation.

**Joel** talked about socioeconomic status in participants in PHACS. **Dr. Chadwick** stated that PHACS collects socioeconomic data and will continue to collect it, especially in the new women's cohort.

The last priority is to look at neurodevelopmental outcomes. The PHACS team will look at different tests for all children in PHACS. Tests focus on domains like hearing, language, and behaviors. This will help the team gain a better understanding of the brain issues across all children in PHACS. **Veronica** talked about outcomes in bilingual babies. **Dr. Chadwick** talked about outcomes. The team will likely look at families who are bilingual in English and Spanish.

The SMARTT protocol team will bring the priorities back to the Working Groups (WGs). The WGs will help figure out the best ways to study the priorities. Research will begin soon. The team plans to talk about the progress during the Spring 2017 Leadership Retreat.

**Dr. Chadwick** thanked the CAB for their input and support.

## • **APPROVAL OF MINUTES**

The minutes from the March 24, 2016 call were approved with no changes.

## • **SPOTLIGHT ON PHACS CAB MEMBER SKILLS**

**Exzavia** shared about her skills. Communication is very important to keeping participants engaged. It may help to get to know a participant's family. Families help support participants. Families may help participants get to their study visits. Caregivers are participants, too. It's helpful for staff to get to know participants on a personal level. The team at the Children's Diagnostic and Treatment Center is very supportive. The site also has a living facility. The facility has couches, kitchen, televisions, and a washer/dryer.

## • **PHACS CAB NEWSLETTER, JULY 2016 EDITION**

**Megan** talked about the PHACS CAB Newsletter, July 2016 Edition. Suggested themes included:

- Children in school;
- Community service and outreach;
- Co-morbidities in HIV;
- Coping with HIV;
- Transitioning to adult care;

- Drug interactions;
- Socioeconomic status of people living with HIV; and
- Community reaching out to the community.

The CAB decided on a theme of "Community Involvement." It was suggested that the newsletter include community resources by site.

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

**Claire** gave the HECC update. **Claire** will present the HIV Disclosure Comics at ComicCon 2016. The HECC is looking into making a whiteboard video about online informed consent.

**NOTE: The next CAB call will be on Thursday, May 19, 2016 at 12:00 pm EST.**