

**CAB Conference Call  
December 10 2015  
12:00 EST  
Meeting Minutes**

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**Participants:**

<b>Claire</b>	Harvard University
<b>Delia</b>	University of Miami
<b>Exzavia</b>	Children's Diagnostic and Treatment Center
<b>George</b>	Harvard University
<b>Lesley</b>	Texas Children's Hospital
<b>Jennifer</b>	University of Colorado
<b>Joel</b>	University of Puerto Rico
<b>Julie</b>	Westat
<b>Julie</b>	University of Alabama
<b>Kimberly</b>	Rutgers New Jersey Medical School
<b>Kimbrae</b>	Texas Children's Hospital
<b>Kylie</b>	Texas Children's Hospital
<b>Laurie</b>	FSTRF
<b>Lesley</b>	Texas Children's Hospital
<b>Mary Anne</b>	Westat
<b>Megan</b>	Westat
<b>Ramona</b>	University of Florida, Jacksonville
<b>Russ</b>	Tulane University
<b>Stephanie</b>	San Diego
<b>Stephanie</b>	University of Miami
<b>Susie</b>	University of Alabama
<b>Theresa</b>	Texas Children's Hospital
<b>Veronica</b>	University of California, San Diego

• **APPROVAL OF MINUTES**

The minutes from the September 24, 2015 call were approved with no changes.

• **PHACS FALL NETWORK MEETING Q & A**

**Dr. Russ Van Dyke** talked about the role of PHACS Leadership. PHACS Leadership is involved in the scientific leadership of PHACS. The Scientific Leadership Group (SLG) is made up of scientific experts. The SLG is responsible for helping come up with scientific questions. The SLG is also responsible for designing research studies to answer these questions. All Chairs of the Working Groups (WGs) represent one member of the SLG and one member from Harvard University. **Dr. George Seage** explained that Harvard is the PHACS Data and Operations Center (DOC). The DOC is responsible for study design and data analysis. The WGs help keep the scientific agenda moving. They also help get studies published.

**Dr. Russ Van Dyke** talked about the Fall 2015 Network Meeting. The meeting reviewed a lot about the SMARTT study. SMARTT looks at uninfected babies born to mothers living with HIV. The goal of SMARTT is to study the long-term safety of HIV drugs for babies who were exposed to them in the womb or after birth.

Some previous studies have looked at mitochondrial problems in babies who were exposed to HIV drugs. Mitochondria are the powerhouses of cells. They create energy in cells. Mitochondria are very important in tissues and organs that use lots of energy. These include the heart and the brain. Some HIV drugs affect mitochondria. Researchers want to learn the long-term effects of HIV drugs on

mitochondria. The researchers in PHACS have continued to look at birth defects, changes in growth, heart function, and metabolic changes. Throughout the study, researchers have found some issues in these areas, but none have been clinically significant. Researchers want to see if these issues will change over time. Some issues might only be a problem for some children. Researchers want to find out whether certain children are more susceptible to having a problem with their mitochondria when exposed to HIV drugs. The PHACS team is trying to find the best way to move forward with the research findings.

**Kim** asked about follow-up in PHACS. **Dr. Russ Van Dyke** explained that there are new HIV drugs being introduced all the time. Some of these drugs are just starting to be used by pregnant mothers. The PHACS research team wants to continue to study the effect of current and new HIV drugs on babies. The researchers also want to continue to follow currently enrolled participants to study long-term effects. This includes any effects on the participants' children.

**Kim** asked about funding for the PHACS project. **Dr. Russ Van Dyke** explained that the study has just been re-funded for another five years. PHACS has great Medical Officers at the National Institutes of Health (NIH). The NIH and PHACS Leadership have been very impressed by the input from the CAB. **Dr. Russ Van Dyke** encouraged the CAB to continue to give input to support PHACS.

**Dr. George Seage** talked about PHACS. Researchers want to continue to explore long-term effects of exposure to HIV drugs. Researchers are particularly interested in how the young adults in PHACS transition into adulthood.

**Lesley** suggested that the PHACS team consider having future meetings over a weekend. It might make it easier for young adults in school to attend the meetings.

**Kim** talked about **Dr. Fatima Kakkar's** presentation at the meeting. **Dr. Russ Van Dyke** explained that PHACS is interested in working with **Dr. Fatima Kakkar's** study. In her study in Canada and in other studies in Europe, there appears to be higher rates of pneumonia. The PHACS team continues to collaborate with **Dr. Fatima Kakkar** and other studies similar to PHACS. PHACS also works with a large international study, Collaborative Initiative for Pediatric HIV Education and Research (CIPHER). CIPHER has many studies across the world. These studies look at uninfected children born to mothers living with HIV. CIPHER pools information from all these studies to help answer scientific questions.

**Theresa** talked about supportive services for PHACS families. **Dr. Russ Van Dyke** explained that PHACS aims to provide support to infected and affected families involved in the study.

**Veronica** suggested that the team consider providing Spanish interpretation services again at future meetings. **Veronica** stated that it would be interesting to analyze the ND testing that has been conducted in Spanish.

**Lesley** asked about neurological (brain) problems in PHACS participants and cancers. **Dr. Russ Van Dyke** explained that PHACS is tracking cancers in participants. So far there have not been significant findings related to cancer. Researchers continue to look at brain problems in PHACS participants. The team wants to know whether there are any long-term brain issues as PHACS participants age into adulthood.

**Stephanie** recommended that the team reach out to participants and caregivers who may be interested in volunteering for additional studies. **Dr. Russ Van Dyke** encouraged CAB members to join PHACS WGs and writing teams.

- **PHACS CAB NEWSLETTER**

**Megan** talked about the schedule of PHACS CAB Newsletters. Due to holiday timing concerns, future newsletters will be released in January and July instead of December and June. The next newsletter will be released at the end of January 2016.

**Megan** talked about the Newsletter, January 2016 Edition. The theme for the newsletter is Mental Health and HIV. CAB members were encouraged to submit articles to the newsletter. All newsletter submissions are due by January 14, 2016.

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