

**CAB Conference Call
March 28, 2013
12:00 EST
Meeting Minutes**

Participants:

Carrie	University of Colorado
Claire	Harvard University
De`Angelo	University of Florida, Jacksonville
Delia	University of Miami
Dorothy	University of Alabama, Birmingham
Jennifer	University of Colorado, Denver
Juan	University of Puerto Rico
Julie	Harvard University
Julie	Westat
Krystal	Harvard University
Laurie	FSTRF
Lennie	St. Jude Children's Hospital
Leslie	Texas Children's Hospital
Linda	St. Christopher's Hospital for Children
Marilyn	Bronx-Lebanon Hospital Center
Megan	Westat
Rosetta	Bronx-Lebanon Hospital Center
Sharon	University of California – San Diego
Theresa	Texas Children's Hospital
Veronica	University of California – San Diego

• **APPROVAL OF MINUTES**

The minutes from the February 28, 2013 call were approved with no changes.

• **MEMORY SUBSTUDY**

Dr. Nichols talked about the Memory Substudy. There are different types of memory. The Memory Substudy is looking at verbal and nonverbal memory. It is also looking at prospective memory and executive functions. Perinatally HIV-infected youth and HIV-exposed but uninfected youth were enrolled in the substudy. There are two study visits. Sites have finished the first visit. Sites have started conducting the second visit. The second study visit helps researchers look at further development of memory and executive functions.

HIV-infected adults may be at risk for problems with memory and executive functions. Prospective memory problems may cause problems with medication management. It is important to look for problems early. Doctors can help youth fix these problems and prepare for adulthood.

Executive functions are skills that control behavior and thinking. Executive functions are skills in planning, problem solving and stopping and starting actions. Other skills include staying focused and having mental flexibility. These skills can help with organization. They can also help people avoid risk behaviors and manage their health.

The parts of the brain that are most likely to show effects of HIV also are related to executive functions. These areas of the brain grow into young adulthood. Problems with learning and executive functions are common in all children. Problems can include learning disabilities and ADHD. Researchers have looked at how to help people manage these problems.

The Memory Substudy is looking at whether perinatally HIV-infected youth have more problems with memory and executive functions than HIV-exposed but uninfected youth.

The Memory Substudy is focusing on whether perinatally HIV-infected youth have problems in their daily lives that are related to memory and executive functions. The substudy is also looking at whether memory and executive functions are related to HIV disease severity.

The Memory Substudy is a substudy of AMP. Eight AMP sites are participating in the study. Participants ages 9-19 were enrolled. There are 173 HIV-infected youth enrolled. There are 85 HIV-exposed but uninfected youth enrolled.

Prospective memory means remembering to do something. An example of prospective memory is remembering to take medication. Study participants took tests to check their learning and prospective memory. They also took tests to measure their executive functions. Participants did word search puzzles to test their prospective memory. Researchers asked participants to keep time while doing the puzzle.

The researchers tested for verbal memory. Participants read a list of words. They were asked to repeat the words. Researchers gave them the same list of words many times to see how they learned the words.

Researchers tested learning and memory of figures to test nonverbal memory. The researchers showed pictures to the participants. Participants were asked to draw the pictures from memory.

Fluency tests were given to test for executive functions. These tests looked at how fast participants can say words in a category. They had to switch between word categories. Participants were also given a survey in AMP. The survey asked about everyday executive functions.

Researchers tested for inhibition by using the Stroop test. This test showed words in different colors. Researchers asked participants to say the color of the word instead of the written word.

Working memory is remembering information while doing something. Researchers tested working memory by asking participants to remember numbers and rearrange them.

Researchers also looked at youth adherence. Researchers counted pharmacy refills to study adherence. They also looked at how fast participants could process information.

The researchers will talk about baseline visit data at the Fall 2013 Network Meeting.

Linda asked about helping youth apply for jobs. Dr. Nichols suggested helping youth learn skills to apply for jobs. Site staff may have information about helping youth get jobs that use their skills the best.

• **PHACS CAB EVALUATION SURVEY RESULTS**

Megan talked about the PHACS CAB Evaluation Survey results. There were 9 responses. Some suggested topics for upcoming calls are:

- Effects of natural herbs, acupuncture, and massage and HIV,
- Disclosure,
- HIV-infected partners and unprotected sex, and
- Pain as a side effect of HIV medications.

- **PHACS SPRING 2013 LEADERSHIP RETREAT REVIEW**

The PHACS Spring 2013 Leadership Retreat was in Potomac, Maryland on March 21-22, 2013. PHACS Leadership were invited to attend. Delia, CAB Chair, and De`Angelo, CAB Vice Chair, went to the retreat.

Delia talked about the retreat. Dr. Wilcox presented about prenatal exposure and long-term health in humans. He talked about a drug called DES. DES was used to help problem pregnancies. De`Angelo talked about the presentation. DES was a drug given to mothers while they were pregnant. The effects of DES did not show up until the DES-exposed children were in their mid-20s. The purpose of the presentation was to show how effects of drugs given during pregnancy may not be known until later in life.

The Hearing and Language Working Group (WG) session talked about risk factors for hearing loss in people living with HIV. HIV infection may increase the risk of hearing loss in children.

Delia talked about the Oral Health Question and Answer session. The Oral Health Substudy team talked about collecting data from participants.

The Complications WG session looked at continental ancestry of PHACS participants.

The Health Education and Communication Committee session talked about redesigning the PHACS website. PHACS Leadership members talked about the current website. They also talked about ideas for the new website.

Megan reminded the CAB that presentations from the Spring 2013 Leadership Retreat are on the PHACS website.

- **PHACS CAB NEWSLETTER, JUNE 2013 EDITION**

Megan talked about the PHACS CAB Newsletter, June 2013 Edition. Last month the CAB voted on a theme for the newsletter. The theme is support systems. Megan encouraged the CAB to submit articles about support.

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

Claire talked about the HECC session at the Spring 2013 Leadership Retreat. The HECC met with a small group to talk about creating a new PHACS website. The new website designer went to the session. The group looked at the PHACS CAB Website Use Survey data during the session. The website designer may join a future CAB call to ask what the CAB thinks about the new website.

NOTE: The next CAB call will be on Thursday, April 25, 2013 at 12:00 pm EST.