

**CAB Conference Call
April 25, 2013
12:00 EST
Meeting Minutes**

Participants:

Carlos	San Juan Research Hospital
Claire	Harvard University
De`Angelo	University of Florida, Jacksonville
Deborah	Harvard University
Delia	University of Miami
Juan	University of Puerto Rico
Julie	University of Alabama, Birmingham
Julie	Westat
Kim	Texas Children's Hospital
Krystal	Harvard University
Laurie	FSTRF
Leslie	Texas Children's Hospital
Linda	St. Christopher's Hospital for Children
Marilyn	Bronx-Lebanon Hospital Center
Megan	Westat
Monica	University of California, San Francisco Medical Center
Rosetta	Bronx-Lebanon Hospital Center
Theresa	Texas Children's Hospital
Veronica	University of California, San Diego
Yuri	University of Miami

- **APPROVAL OF MINUTES**

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

- **CAPSULE FEEDBACK**

Monica talked about the capsule, "Assessing Mother and Infant Antiretroviral Exposure Using Hair Measures in the Dynamic Surveillance Cohort of SMARTT." Moms in SMARTT take HIV medications while they are pregnant. Researchers are looking to measure how much of the HIV medications are passed from mom to baby. The researchers can measure the amount of HIV medications in the baby by testing their hair. Some studies have collected blood to measure these levels. Blood draws may be painful for babies. Other studies have collected breast milk to measure HIV medication levels. Blood and breast milk only show a snapshot of levels of HIV medications in the baby. Hair can show average medication levels in a baby for up to a month. Hair is easy to store because it is not hazardous. Hair can be stored at room temperature and cannot transmit HIV.

In this study, researchers will collect ~50-100 strands of hair from mom and baby at delivery. Hair collection is painless. There is no need for blood draw. Researchers will be trained on how to collect hair from participants. Researchers will cut participants' hair from under the top layer of hair. Scissors will be cleaned and wiped before hair is cut. Researchers will cut hair as close to the scalp as possible. The researchers will tape and wrap hair in aluminum foil. The foil packet will be sealed in a plastic bag. Once hair is collected, researchers will measure the levels of HIV medications in the mom and baby's hair.

Delia asked if dyed or treated hair is able to be measured. Hair that is dyed or treated may not be collected. It may show distorted HIV medication levels.

Megan asked if hair samples are kept in a repository. Hair collected in this study will be destroyed after it has been tested. Monica explained that the hair gets broken down in the laboratory. It is discarded after testing.

DeAngelo wondered whether additional tests will be done on the hair samples from this study. Monica explained that the hair will only be used to test levels of HIV medications.

• **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:

- Presentations about neurologic issues related to HIV; and
- Study participant vs. guinea pig.

Megan reminded the CAB that participant summaries and network meeting presentations are on the PHACS website. Megan reminded the CAB that Dr. Nichols and the Memory Substudy team will talk about their baseline data at the Fall 2013 Network Meeting.

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

Megan talked about the PHACS CAB Newsletter, June 2013 Edition. The theme is support systems. Megan encouraged the CAB to submit personal testimonials about support. CAB members can send testimonials to Megan. They can also submit testimonials through the survey. Megan sent out coloring pages for CAB kids. Megan encouraged the CAB to ask their children to submit a coloring page to the newsletter.

Theresa talked about the newsletter. Theresa suggested that the newsletter feature articles about getting ready for camp.

Delia reminded the CAB that the deadline for newsletter submissions is June 12, 2013.

• **RESOURCES FOR ADOPTIVE PARENTS OF POSITIVE CHILDREN**

Megan sent out links to websites for adoptive parents of positive children. Megan talked about the Project Hopeful and Positively Adopted websites. The websites have helpful resources. These resources can be used by any parents of positive children. Many resources may even be helpful for family members of positive children.

Megan talked about the Positively Adopted website. The website has a list of basic facts about HIV. It also has a list of questions and answers about disclosure, medical insurance, and parenting a positive child.

Megan talked about the Project Hopeful website. Project Hopeful encourages people to advocate for children with HIV. It also encourages people to adopt children with HIV. The website has resources for parents of positive children. It has information about HIV. It also has information about how to talk to friends and family about parenting a positive child. Leslie helped make some of the brochures and materials for Project Hopeful. CAB members can contact Leslie with any questions about adopting positive children.

Megan asked the CAB to share the websites with their local CAB members.

- **CAB SPOTLIGHTS**

Megan talked about CAB Spotlights. The CAB has repeatedly asked to learn about local CAB activities. Megan encouraged the CAB to volunteer to present a CAB Spotlight about their local CAB. CAB members may present CAB Spotlights during the CAB conference calls. CAB members can talk about events, presentations, or workshops taking place in their local CAB.

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

Claire talked about the HECC. The HECC Publicity Subcommittee is making a list of ways that sites are distributing PHACS study results to participants. This list will help site staff learn helpful ways to distribute study findings to participants.

Claire talked about the Young Adult CAB (YA CAB). The YA CAB had their first conference call in March. Four young adults participated on the call. Megan and Claire talked to the YA CAB about advocacy, purpose of CABs, and YA CAB structure. The next YA CAB call is on April 27, 2013 at 1:00 PM EST. The YA CAB will talk about stories and community during the call.

Claire and Megan will be working with an intern, Kimona, to make Disclosure Storybooks. These books will help parents disclose to their children. Claire, Kimona, and Megan will create a plan for the Disclosure Storybooks soon. Claire invited the CAB to review materials for the Disclosure Storybooks.

The next HECC conference call is May 2, 2013 at 1:00 PM EST.

Megan talked about the HECC CAB Subcommittee. The HECC CAB Subcommittee is working on the CAB Handbook. The CAB Handbook will be a resource for CAB members and site staff. It will talk about how to create a site CAB and recruit and retain site CAB members. It will also talk about ideas for meetings and fundraisers. Yuri encouraged the CAB to volunteer to give feedback about their site CABs for the CAB Handbook. The HECC CAB subcommittee will send a survey to Study Coordinators and CAB members soon.

NOTE: The next CAB call will be on Thursday, May 23, 2013 at 12:00 pm EST.