

**CAB Conference Call  
September 22, 2011  
12:00 EDT  
Meeting Minutes**

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**Participants:**

<b>Deangelo</b>	University of Jacksonville
<b>Delia</b>	University of Miami
<b>Dorothy</b>	University of Alabama at Birmingham
<b>Gloria</b>	University of Florida – Jacksonville
<b>Grace</b>	Westat
<b>Jennifer</b>	University of Colorado
<b>Julie</b>	Harvard
<b>Julie</b>	Westat
<b>Kimbrae</b>	Texas Children’s Hospital
<b>Lori</b>	FSTRF
<b>Leslie</b>	Texas Children’s Hospital
<b>Marilyn</b>	Bronx - Lebanon
<b>Megan</b>	Westat
<b>Melanie</b>	UMD – New Jersey Medical School
<b>Sherry</b>	St. Jude
<b>Susie</b>	University of Alabama at Birmingham
<b>Theresa</b>	Texas Children’s Hospital
<b>Yuri</b>	University of Miami
<b>Virginia</b>	Children’s Hospital Boston

• **APPROVAL OF MINUTES**

The minutes from the August 25, 2011 call were approved with no changes.

• **PHACS CAB EVALUATION SURVEY RESULTS**

Megan talked about the PHACS CAB Evaluation Survey results. Many people responded that they enjoy being on the call. People also responded that they like to hear about other local CABs. Some suggested topics for upcoming calls are retention, new HIV medications, adherence, children’s mental health after the passing of a parent, substudy updates, and talking to children about safe sex. Thanks to everyone who participated. The survey will be sent out in an email after every call.

• **CAB NETWORK MEETING DISCUSSION**

The PHACS Fall Network Meeting is November 3-4, 2011 in Bethesda, Maryland at the Bethesda Hyatt Regency. The deadline for registration at the government room rate is September 30, 2011. Westat is still working with the Study Coordinators (SC) to find one CAB member from each site to come to the meeting. Megan sent out the latest draft of the network meeting agenda.

Julie from Westat talked about the agenda. Registration is on Wednesday, November 2 from 6:00 pm-8:00 pm. Registration will also be on Thursday morning. There will be a plenary session with a speaker talking about early life experience and neurodevelopmental topics. Another speaker will talk about oral health in HIV positive people. The meeting will break out into different working groups talking about different topics of interest—adolescents, hearing/language, maternal exposure, nutrition. On Thursday morning there will be a CAB-specific session with an orientation to PHACS. On Friday there will be a retention and disclosure panel discussion. This will include Study Coordinators and CAB leadership.

Julie from Westat suggested a meet and greet. The CAB decided to meet at the registration table on Wednesday night around 7:00 pm. The CAB representatives will meet and have dinner together.

- **SUBSTUDY UPDATES**

Julie from Westat talked about the substudies. There were many updates to the enrollment numbers. The dynamic cohort of SMARTT has 1230 enrolled participants. The SMARTT reference cohort has 178/200 enrolled participants. The Maternal nutrition substudy has 206/265 enrolled participants. The SMARTT Tenofovir substudy, has 36/174 enrolled participants. These participants are newborn babies. In the AMP Mitochondrial Determinant Component, there are 147/210 enrolled participants. The AMP Memory substudy has 210/275 enrolled participants.

There are two letters of amendment coming out soon. One is for AMP and one is for SMARTT. For AMP, a letter is being written to address some changes about kids reaching the age of majority. The changes to the protocol will say that those kids will complete two assessments that their caregivers used to complete. These assessments are the adaptive behavior assessment (ABAS), and another assessment about demographic information. The informed consent will also be revised to show these changes. There will also be another data collected from another resistance test. It is very important to collect information for HIV resistance, and make sure that participants are not becoming resistant to their medication.

The letter of amendment to SMARTT will make minor changes. They will add a Tanner stage assessment to the body mass index for the growth trigger. This will help to assess that measure better. It shows where the participants are in pubertal development. There will also be updates to the hearing/language trigger. They will also collect a small dried blood spot at the dynamic entry visit. For the reference cohort, they will try to enroll more echo-only reference cohort participants.

Two new substudies have been approved by the PHACS leadership. One is the Neuroimaging pilot study. This will only be done at Site 24. It is a one visit study. They will do an MRI on 40 AMP participants to look at brain development. Right now the protocol is being reviewed at the Chicago IRB. That project should take about one year to complete. The second study is called "Oral Health in AMP Subjects". This looks at the dental health in HIV infected and uninfected children. It is expected to be conducted at 9 AMP sites.

- **TALKING WITH CHILDREN ABOUT SAFE SEX**

Yuri talked about talking to kids about safe sex. It is important for caretakers to know the types of prevention. The best way to prevent STDs is abstinence. It is difficult for teenagers to find the right information on the internet because there is lots of misinformation. Caretakers need to be able to explain the nature of sex to their children. Yuri recommended that caretakers try to figure out what their child's idea of sex is. Caretakers should focus on the age and the maturity level. Always refer to the child's doctor or social worker if you are uncomfortable talking about this topic.

Yuri mentioned that both male and female condoms exist. There are diaphragms, implantable rods, and IUDs. Always be aware of what they know and how much they know. Learn from your child as he/she learns from you.

Leslie brought up talking about safe sex and HIV disclosure. Yuri talked about how kids might have contemplated the thought of sex before knowing he/she was HIV positive. He suggested seeking out doctors and social workers to help talk to your child about disclosure. The CDC also has recommendations about disclosure before sex.

Delia asked about how to show children how to use condoms. Yuri pointed out that if a child asks about it, tell them what it is and what it is used for. If the child wants a demonstration, and you are uncomfortable, go to the clinic and ask them to help.

Kim asked about how to make your children comfortable talking about sex. Yuri recommended not pushing the topic. It is important to let the child come to you. Start the conversation with questions. The best thing is to make resources available to them.

**NOTE: The next CAB call will be on Thursday, October 27, 2011 at 12:00 pm EDT.**