

**CAB Conference Call  
November 17, 2011  
12:00 EST  
Meeting Minutes**

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**Participants:**

<b>Carrie</b>	University of Colorado
<b>Deangelo</b>	University of Jacksonville
<b>Delia</b>	University of Miami
<b>Dorothy</b>	University of Alabama Birmingham
<b>Emily</b>	FSTRF
<b>Jennifer</b>	University of Colorado
<b>Julie</b>	Westat
<b>Lennie</b>	St. Jude Children's Hospital
<b>Linda</b>	St. Christopher's Hospital for Children
<b>Marilyn</b>	Bronx - Lebanon
<b>Megan</b>	Harvard
<b>Megan</b>	Westat
<b>Melanie</b>	UMD – New Jersey Medical School
<b>Sherry</b>	St. Jude Children's Hospital
<b>Susie</b>	University of Alabama Birmingham
<b>Theresa</b>	Texas Children's Hospital

• **APPROVAL OF MINUTES**

The minutes from the October 27, 2011 call were approved with no changes.

• **PHACS CAB EVALUATION SURVEY RESULTS**

Megan from Westat talked about the PHACS CAB Evaluation Survey results. Some asked to slow down the pace of the call. Some suggested topics for upcoming calls are managing emotions in children and adolescents, new ARTs, prevention and secondary prevention, stigma, and ways the CAB will relay this information back to their communities. Megan talked to the researchers who specialize in mental health. They are going to talk about child's mental health after the passing of a parent on a future call.

• **INTERNET USE SURVEY**

Megan from Harvard talked about the Internet Use Survey. The PHACS leadership wants to find the best way to give information to the study participants. This survey will help determine how the participants use the internet. It will also help determine how PHACS kids use the internet. Megan from Westat will send a link to the survey after the call.

Megan from Westat asked the CAB about how often they use the PHACS website. She also asked what the CAB uses the website for. The CAB agreed to have training on the website on the December call. Megan will send out the website user guide with the December call agenda.

• **CAB NETWORK MEETING DISCUSSION**

Megan from Westat talked about the Fall Network Meeting. At the meeting, the CAB came up with two goals for 2012. One of the goals is to have one CAB member on each Working Group (WG) call. The CAB member can report back to the PHACS CAB with updates from each WG. There is an Adolescent

WG, Neurology WG, Maternal Exposures WG, Hearing/Language WG, Cardiopulmonary WG, and Complications WG. The CAB can contact Megan to be placed on a WG. The minutes for the WG can be found on the PHACS website.

Jennifer talked about the Fall Network Meeting. There were two plenary speakers – Ezra Susser and Caroline Shiboski. Ezra Susser talked about Early Life Experiences in Neurodevelopment. This study looked at a medication mothers took during pregnancy and how it affected the children later in life. Jennifer added that this shows how important it is for families to stay on study because some issues from the pregnancy do not show up in children until later in life. Caroline Shiboski talked about Oral Health in HIV-infected children.

There were sessions for each Working Group (WG), and a session for the CAB. The CAB was also invited to attend the Clinical Investigators Group Business Meeting and the joint Study Coordinator session.

Sherry talked about the Network Meeting. Sherry pointed out that the CAB was able to give their opinions about PHACS. Jennifer thought it was encouraging to hear about the CAB's experiences in PHACS. The CAB showed interest in coming to future meetings.

Jennifer asked the CAB to give examples of ways to enable greater participation in PHACS. Jennifer will share this information with the Clinical Investigators Group. The CAB talked about compensation at the study visits. Julie from Westat pointed out that some Institutional Review Boards do not approve monetary compensation. Some sites find other ways to compensate the study participants. Dorothy mentioned that the University of Alabama at Birmingham tries to compensate both the parent and the child.

Jennifer asked the CAB about the importance of a personal relationship with the site staff. Susie pointed out that the site staff at the University of Alabama at Birmingham sends personal cards to her children. The CAB agreed that the personal relationship is important.

The CAB talked about helping the participants to understand the research on a more user-friendly level. Julie from Westat talked about the participant summaries that talk about the study results. Julie suggested that the sites have copies of the participant summaries at the clinics.

Julie asked if the CAB would like sites to provide more materials for parents to enjoy while waiting at study visits. Jennifer recommended that sites provide materials that don't just involve being the parent of a newborn. Jennifer will share these recommendations with the Clinical Investigators Group.

- **NEWSLETTER, DECEMBER 2011 EDITION**

Megan talked about the ribbon coloring contest for CAB Kids. Megan sent out the ribbon coloring page to the CAB. There are 4 different age categories in the contest. One winner will be chosen from each age category.

The theme for the December 2011 newsletter is adherence. Adherence means sticking to HIV medication schedules. Please consider submitting an anonymous (your name will not be included) testimonial to the newsletter about your experience with adherence. This can also be experience with children and adherence. Julie from Westat also asked the CAB to submit recipes, poems, stories, etc. The deadline for submissions to the newsletter is December 9<sup>th</sup>.

- **CAB EVALUATION SURVEY TOPIC – STIGMA**

Megan talked about HIV stigma. HIV/AIDS related stigma refers to prejudice, negative attitudes, abuse, and poor treatment directed at people living with HIV/AIDS. Sherry thought that stigma has gone undercover. HIV stigma is still around, but not as bold. The way an HIV positive person perceives

themselves will determine the effects of the stigma. Lennie mentioned that people pick up on negative self perception.

Melanie talked about HIV stigma and children. Melanie experienced her child face HIV stigma when joining a soccer team. Julie from Westat pointed out there is still a lot of education that needs to be done about HIV. Delia talked about challenges she has faced with HIV stigma with her family. Linda mentioned that she finds support in her site staff and at her church. Melanie talked about support in her family and friends with adopted children. Melanie recommended getting to know other study participants at the site. Other participants may be able to offer support, advice, or resources.

**NOTE: The next CAB call will be on Thursday, December 22, 2011 at 12:00 pm EST.**