

**CAB Conference Call
February 23, 2012
12:00 EST
Meeting Minutes**

Participants:

Carrie	University of Colorado
DeAngelo	University of Florida – Jacksonville
Delia	University of Miami
Dorothy	University of Alabama at Birmingham
Emily	FSTRF
Exzavia	Children’s Diagnostic & Treatment Center
Jennifer	University of Colorado
Juan	University of Puerto Rico
Julie	Harvard University
Julie	Westat
Kimbrae	Texas Children’s Hospital
Laurie	FSTRF
Leslie	Texas Children’s Hospital
Linda	St. Christopher’s Hospital for Children
Mariana	University of California San Diego Hospital Center
Marilyn	Bronx - Lebanon
Megan	Westat
Melanie	UMD – New Jersey Medical School
Rosetta	Bronx - Lebanon
Theresa	Texas Children’s Hospital
Yuri	University of Miami

• **APPROVAL OF MINUTES**

The minutes from the January 26, 2012 call were approved with no changes.

• **PHACS CAB EVALUATION SURVEY RESULTS**

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

- finding ways a team can work together to recruit and retain patients in PHACS
- PHACS Working Groups (WG),
- behavior in HIV-infected teens, and
- the importance of medication.

Megan reported that Dr. Andrew Wiznia will be coming on next month’s call to talk about new antiretroviral medications. Megan reminded the CAB that the researchers who specialize in mental health are planning to talk about children’s mental health after the passing of a parent on a future call.

• **PHACS WORKING GROUPS**

Megan talked about the PHACS Working Groups (WG). At the Fall Network Meeting, the CAB came up with two goals for 2012. One of the goals is to have one CAB member on each WG call. There are no CAB members on the Hearing/Language WG, Nutrition, Growth, & Metabolism WG, Maternal Exposures WG, or Cardiopulmonary WG.

Megan talked about the responses to the PHACS CAB Evaluation Survey question about reasons for not wanting to participate on a PHACS WG. Some CAB members feel intimidated by the calls. Some CAB members said that the calls are not at convenient times. The group decided to keep encouraging CAB members to join a WG, but they will no longer make this a goal for 2012.

Julie from Harvard reminded the CAB that they can listen to a WG call without joining a WG. If CAB members wish to talk with a WG co-leader about the content on a WG call they may contact Julie from Harvard. Jennifer thought it could be intimidating to talk about a WG call on the CAB call. CAB members do not need to talk about a WG call if they are just trying it out.

- **HOW DO CAB MEMBERS RELAY THE INFORMATION FROM THE PHACS CAB CALLS BACK TO THEIR COMMUNITIES?**

Megan talked about the responses to the PHACS CAB Evaluation Survey about how the CAB takes information from the calls back to their communities. Some of the responses included taking notes, giving handouts about the calls to local CAB members, and taking information from the calls to local CAB meetings.

Megan sends out the minutes and newsletters in English and Spanish. The minutes and newsletters can also be found on the PHACS website. Yuri recommended that the CAB share the website with their local CAB.

- **PHACS RETENTION STRATEGIES FROM CAB AND STUDY COORDINATORS**

Megan sent out the "PHACS Retention Strategies from CAB and Study Coordinators (SC)" list. It is a list of ways to keep participants on study that was made based on ideas from the PHACS Fall Network meeting during the joint SC/CAB session. Some of the ideas also came from the last SC call. It is hoped that this can be useful to see how different sites are addressing how to encourage participants to stay on study.

Theresa talked about retention of older children with mothers who have not disclosed their HIV status. When a participant turns 18, they can consent for themselves. The consent form has information about HIV. If a mother has not disclosed to her HIV-exposed but uninfected child, the child may not understand why the consent has information about HIV. Rosetta and Exzavia talked about social workers at their sites that help mothers with disclosure.

Yuri talked about having a family meeting to talk about disclosure. Leslie mentioned that social workers can talk to parents to let them know if a child has questions about what the study visits are for. Theresa pointed out that disclosure is a process.

Melanie talked about incentives for children in PHACS. Leslie thought that it is important to tell the participants about the results of the research. It is helpful to see that the research is showing results that are helpful to children and families living with HIV. Julie from Westat talked about the participant summaries that give the study results. The participant summaries are written to be easier to understand. Julie reminded the CAB that participant summaries are available on the PHACS website. Sites may also be making participant summaries available at study visits.

- **NEWSLETTER, JUNE 2012 EDITION**

Megan talked about the June 2012 edition of the PHACS CAB Newsletter. The theme for the December 2011 edition of the PHACS CAB Newsletter was adherence. Megan will add a question to the evaluation survey about possible newsletter themes for the June 2012 newsletter.

NOTE: The next CAB call will be on Thursday, March 22, 2012 at 12:00 pm EST.