

**CAB Conference Call
January 26, 2011
12:00 EST
Meeting Minutes**

Participants:

Carlos	San Juan Hospital
Delia	University of Miami
Dorothy	University of Alabama at Birmingham
Ginny	Children's Hospital Boston
Jennifer	University of Colorado
Julie	Westat
Kimbrae	Texas Children's Hospital
Lori	FSTRF
Marilyn	Bronx - Lebanon
Megan	Westat
Melanie	UMD - New Jersey Medical School
Rosetta	Bronx - Lebanon
Theresa	Texas Children's Hospital

• **APPROVAL OF MINUTES**

The minutes from the December 22, 2011 call were approved with no changes.

• **PHACS CAB EVALUATION SURVEY RESULTS**

Megan talked about the PHACS CAB Evaluation Survey results. A suggested topic for upcoming calls is finding ways the CAB will bring this information back to their communities. Megan reminded the CAB that the researchers who specialize in mental health are planning to talk about child's mental health after the passing of a parent on a future call. A speaker will also come on a future call to talk about new antiretroviral medications.

• **NEWSLETTER, DECEMBER 2011 EDITION**

Megan talked about the December 2011 edition of the PHACS CAB Newsletter. All PHACS CAB Newsletters can be found on the PHACS website. The theme for this newsletter was adherence. Megan reminded the CAB that they are accepting submissions for the June 2012 edition of the PHACS CAB Newsletter. Julie from Westat encouraged the CAB to think about possible themes for the upcoming newsletter.

• **PHACS WORKING GROUPS**

Megan from Westat 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. The CAB can contact Megan to be placed on a WG.

Megan talked about the Adolescent WG call. The call had topics about retention and follow-up in PHACS, and how to measure adherence. Jennifer talked about her involvement with the Tenofovir Substudy team. Jennifer is also on the Complications WG and the ND/Neurology WG email list. Participating on a WG lets CAB members hear about the research first hand. The information can be easier to understand after listening to a few calls.

Julie from Westat asked the CAB about reasons for not wanting to participate on a WG. Theresa wondered if the information on the WG calls is hard to understand. Megan will add a question to the PHACS CAB Evaluation Survey about reasons for not wanting to participate on a WG.

- **AMP ORAL HEALTH SUBSTUDY UPDATE**

Julie from Westat thanked Rosetta for joining the AMP Oral Health Substudy Protocol Team as the CAB representative. The study is looking at oral diseases in perinatally HIV-infected and in HIV-exposed but infected children who are currently participating in the AMP protocol. They are looking at whether there are connections between poor oral health and general HIV health. They are also looking at whether oral health has anything to do with HIV medications and quality of life. Participation in the Oral Health Substudy will include one study visit. There will be an oral exam by a dentist. These exams will include saliva collection and a throat wash. Some of the throat wash will be tested for HPV antibodies. If they find a lot of data on HPV they might do a more complete HPV study in the future. Blood specimens will be collected from HIV-infected participants without a current CD4 or viral load count. One blood specimen will be used for CD4 and viral load testing. The other will be put in the PHACS repository.

There are 10 AMP sites that will participate in the substudy. There are two other sites that would like to participate, but are still looking for a dentist. The goal is to enroll about 80% of the AMP participants at these 10 sites. They hope to enroll about 240 HIV-infected and 145 HIV-exposed but infected children. The study will last 3 years. They have completed the fourth draft version of the protocol. The study might begin by March or April.

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

Delia talked about taking the information from the PHACS CAB calls back to her local CAB. She takes notes and shares them at her monthly local CAB meetings. Jennifer forwards the information from the calls to the CAB Coordinator at her site. Theresa's local CAB talks about the issues brought up on the calls and information from new studies. Megan will add a question to the PHACS CAB Evaluation Survey about how the CAB relays information from the calls back to their communities.

- **JOURNAL ARTICLE - TRANSITION FROM PEDIATRIC TO ADULT HEALTHCARE SERVICES**

Megan talked about an article on transitioning from pediatric to adult healthcare services. Healthcare transition means the planned movement of youth with chronic medical conditions such as HIV from pediatric care to adult healthcare systems. Transitioning to adult care changes the center of communication from the parent to the young adult. There are challenges to caring for youth living with HIV like adherence to medication. Transitioning youth to adult care can be hard because of a youth's lack of independence. It can also be hard to leave their lifelong pediatric caregivers.

Other chronic diseases of childhood, like diabetes, have benefited from specific guidelines for transition to adult care. Case management services can be helpful. Case managers can act as liaisons among patients and their families, friends, and schools.

Many health care providers have asked for help with transitioning patients to adult care. Different organizations have made plans for the transition. Youth living with chronic illness should learn skills on how to manage health care needs.

It will take time to make guidelines for the transition of youth living with HIV to adult care. Planned transition programs can help the specific needs of youth living with HIV transition to adult care.

Julie from Westat asked the CAB about transition services at their sites. Ginny has had experience transitioning a chronically ill child to adult care. In her experience, there were no programs in place for the transition. Jennifer agreed that it could be hard to leave lifelong pediatric caregivers.

Theresa talked about finding the resources that are available before transitioning. Melanie talked about problems getting children to take responsibility of their health. Clinicians could help encourage youth to have more responsibility.

- **OTHER**

Rosetta talked about participating in local workshops to learn more about HIV. She is getting a better understanding of HIV from her doctors and nurses.

NOTE: The next CAB call will be on Thursday, February 23, 2011 at 12:00 pm EST.