

**CAB Conference Call
February 26, 2009
12:00 EST
Meeting Minutes**

Participants:

Marilyn	Bronx Lebanon
Theresa	Texas Children's Hospital
Julie	Harvard University
Kathy	Harvard University
Linda	St. Christopher's
Carlos	San Juan City Hospital
Sharan	University of Alabama, Birmingham
Tanisha	Westat
Samantha	Children's Diagnostic and Treatment Center
Mercy	Westat
Delia	University of Miami
Gloria	University of Florida, Jacksonville
Chas	University of Florida, Jacksonville
Gail	Texas Children's Hospital

• **MEETING MINUTES**

The group accepted the minutes for January 22, 2009. **Tanisha** will post the minutes on the website.

• **PROJECT UPDATES**

The patient information sheets for AMP and SMARTT have been sent to sites. These handout explains the how, what and why of the PHACS study. Sites must get IRB approval before they can give them out.

The next PHACS newsletter will come out spring 2009. It is important that CAB members be involved in the newsletter. If any CAB member would like to write for the newsletter, please contact Tanisha.

Tanisha stated that the next PHACS network meeting is April 6-7, 2009 in New Orleans. One cab member asked if each site would have a CAB member go to the meeting. The PHACS budget only supports the chair and vice chair coming to the meeting.

Julie stated that nine abstracts from PHACS have been accepted at various conferences. An abstract is a research summary.

Three new AMP sites have opened. One of the IRBs did not want the ACASI given to younger kids. We were able to tell the IRBs that parents and caregivers think that the ACASI questions are vital. This shows the power of the community in research. The most explicit ACASI questions are only asked of patients who answer yes when asked if they are taking drugs or are sexually active. Some younger subjects have answered yes when asked these questions. **Linda** stated it is important to ask these questions.

Samantha added that it is good to have this information so that we can share it with other parents and caregivers at local CABs.

• CROI ABSTRACTS

CROI stands for the Conference on Retrovirus and Opportunistic Infections. CROI focuses on understanding, treating, and preventing HIV and AIDS. The conference is science focused. PHACS had 5 posters at this year's conference. The nutrition/metabolism working group had 2 posters. The hearing and language group had 1 poster. The complications working group had 2 posters. All of the posters focused on AMP.

Julie briefly reviewed two of the complications working group posters.

Title: Discontinuation of Antiretroviral Therapy (ART) among Children with Perinatally Acquired HIV infection.

- Looks at children who stop taking ARTs for at least 6 month who remained healthy
- 4 % of all subjects on study were not taking ARTs at the time that they enrolled in the study; these patients were healthy even though they were not taking ARTs.
- The most common reason that these children were taken off ARTs was because their doctor did not think they were necessary.
- This information might help us to create a study that looks at ways for safely stopping ARTs in children who are having a hard time with their ARTs.
- The researchers are going to look into the ART histories of these subjects from before they start AMP and write a paper.

Title: Antiretroviral Therapy (ART) among Children with Perinatally Acquired HIV infection: Temporal Changes in Therapy Virologic and Immunologic Outcomes.

- Looks at the history of important factors such as: health, healthcare and treatment of kids on our study with HIV. This abstract focuses on ARTs, CD4 and viral load counts, and demographic factors.
 - Median age 12 years old
 - 54% female
 - 76% African American and 16% Hispanic
 - Median CD4 count: 718
 - Median viral load <400 (65%), greater than 50,000 (6%)
 - 28% of subjects at CDC clinical stage 3
 - At beginning of study 93% of subjects getting ARTs, all had taken ARTs at some point.
 - Average age of starting ARTs is less than 1 year old. Average time on ARTs is 11.2 years. The number of regimes that subjects have been on range 1- 19 (average number of regimes is 5).
 - Despite different standards of care and multiple regimes, children have normal CD4 counts and viral suppression.

Julie and Tanisha will try to get some of the people who worked on the posters to join future CAB calls.

• **ADDITIONAL ITEMS**

Tanisha asked if there was any news or feedback about study visits or local CABs. **Linda** stated that the visits are going smoother. **Theresa** told the group about her recent large CAB meeting with site staff. Her large CAB is made up of agency reps, parents and caregivers. Staff members from the clinic meet with the large CAB at least once a year. The main topic of the meeting with the staff members is the state of HIV/AIDS research. CAB members voiced their concerns and ask questions about AIDS research. This meeting also gave everyone a chance to network with other agencies, community members and staff.

NOTE: CAB calls take place every 4th Thursday of the month. The next CAB call is scheduled for March 26, 2009.