

**CAB Conference Call
October 23, 2008
12:00 EST
Meeting Minutes**

Participants:

Theresa	Texas Children's Hospital
Julie	Harvard University
Gloria	University of Florida, Jacksonville
Mariam	University of Southern California
Linda	St. Christopher Hospital
Chas	University of Florida, Jacksonville
Samantha	Children's Diagnostic and Treatment Ctn.
Delia	University of Miami
Merilyn	Bronx Lebanon
Shatara	UMDNJ
Carlos	San Juan City Hospital
Sharan	University of Alabama Birmingham
Tanisha	Westat
Shirley	Westat

• **MEETING MINUTES**

The September 25, 2008, minutes were approved. **Tanisha** will post them on the website.

• **PHACS UPDATES**

Tanisha reminded the group that the PHACS network meeting is November 17-18, 2008. The CAB chair and vice chair (Samantha and Carlos) will attend.

The first issue of the PHACS CAB newsletter is being put together. The newsletter should be ready before the network meeting.

Tanisha announced three new AMP sites: San Juan City Hospital, University of Colorado and Bronx Lebanon. The PHACS leadership hopes that adding new sites will increase enrollment. These sites will start enrolling when they get IRB approval and register with Westat. When AMP reaches its enrollment goals, all sites will stop signing up subjects. The SMARTT static cohort will also close when it reaches its enrollment goal. The dynamic cohort will continue to enroll subjects.

SMARTT: Over 1,000 children are enrolled in SMARTT. The static cohort (ages 1- less than 12) has 906. The dynamic cohort (newborns) has 286. There are 1,017 caregivers enrolled.

AMP: Amp has enrolled 403 subjects (ages 7- less than 16). There are 313 that are HIV infected, and 90 uninfected. There are 345 caregivers enrolled.

When PHACS began, children had to be in another HIV study before they enrolled in PHACS. Now, as long as a site has the needed information in the patient's medical records, the child can enroll.

At first, enrollment goals were 1600 for SMARTT static and up to 800 a year for SMARTT dynamic. For AMP, the goals were 600 HIV infected teens and 200 uninfected. The goals are now around 1200 for SMARTT static, 450 HIV infected and 150 uninfected subjects.

A CAB member asked about enrolling into PHACS. Julie said CAB members should talk to their local clinic staff about enrolling into PHACS or other studies.

Julie said the PHACS Site Evaluation Committee has a call every month to discuss how sites are doing. They review information about enrollment and data quality. They also review information from site monitoring visits and submission of regulatory documents. Sites get feedback on areas that they are doing well in and others that they need to work on.

- **LOCAL CAB SPOTLIGHT**

Samantha talked about her local CAB at Children's Diagnostic and Treatment Center (CDTC) in Ft. Lauderdale, FL. **Samantha's** CAB is made up of members from ATN, IMPAACT, and PHACS. CDTC has an adult and a teen CAB. When the teen CAB started, just a few HIV-infected teens came. The group has grown to 20-23 teens. They meet once a month. They talk about issues such as research, education, and problems they have. The subjects are not always directly related to HIV-AIDS.

Samantha said it is important to think of creative ways to make research and education interesting for kids. **Linda** stated that her site also has an adolescent CAB. She feels it is important that youth have a place where they can ask questions and talk to other teens.

Theresa's CAB is made up of members from IMPAACT, PHACS and local studies. **Theresa** said that having a babysitter at CAB meetings has helped. Theresa's CAB has two parts. One looks at outreach and education. This part of the CAB is for agencies, caregivers, and other community members. The other part focuses on caregivers, parents and teens. They review patient information sheets and give feedback to the clinical staff.

Shakara said it has been hard to get people to attend CAB meetings at her site. Other CAB members stated that fear of being recognized as HIV+ might be a barrier to people coming. **Shakara** said that getting non-positive community members to come is also hard. One suggestion was to offer small gifts and door prizes at meetings. Pencils and mugs are low-priced and easy to get. Asking private organizations for donations is a way to get extra money to buy supplies. **Theresa** said that her CAB members like events on Saturday between 11am-1pm since they are too busy to come on the weekdays.

- **ADDITIONAL ITEMS**

Samantha told the group that Ailsa Chang of NPR Weekend Edition is working on a story about teens. She wants to talk to teens who did not find out their HIV+ status until they were teens. She is looking for teens that are positive via perinatal transmission. They can be up to age 18, but first found out around age 13-14. Ailsa can keep identities confidential. The show will broadcast on a Sunday in mid-November. Ailsa's contact information was emailed to CAB members.

Tanisha will send CAB members information about the date and time of the next conference call.