

**CAB Conference Call
April 28, 2011
12:00 EST
Meeting Minutes**

Participants:

Carlos	San Juan Hospital
Delia	University of Miami
Gloria	University of Florida - Jacksonville
Grace	Westat
Jaime	San Juan Hospital
Jennifer	University of Colorado
Julie	Harvard
Julie	Westat
Lennie	St. Jude's Children's Hospital
Linda	St. Christopher's Hospital for Children
Mariana	University of California San Diego Hospital Center
Marilyn	Bronx Lebanon Hospital Center
Megan	Harvard
Miriam	Harvard
Raul	University of Puerto Rico
Rosia	Westat
Samantha	Children's Diagnostic & Treatment Center
Sheila	University of Florida - Jacksonville
Sherry	St. Jude's Hospital
Theresa	Texas Children's Hospital
Vikas	Bronx Lebanon Hospital Center
Yuri	University of Miami

- **MEETING MINUTES**

The minutes for the March 24, 2011 call were approved with no changes.

- **LOCAL CAB UPDATES**

CAB members discussed the activities that have taken place at their local CAB.

- **NEWSLETTER**

The deadline for submissions is Friday, May 27, 2011. Please email rosiawarner@westat.com if you have items for the newsletter.

- **DISCLOSURE DISCUSSION**

The topic of HIV disclosure was discussed. Personal experiences were described, including discussing how to reveal HIV status to families and children. Being involved in the research is one of the many useful ways to disclose HIV status. Participating in research also allows for discussion about privacy with children, family, and friends. Researchers and nurses can also help with the process since they have a lot of literature about how to share about HIV status with others. There are useful websites that can help people with disclosure. These website will be presented to the CAB members on the call in May.

- **DESCRIPTION OF STUDY PARTICIPANTS – QUARTERLY ADMIN REPORTS**

Julie from Harvard discussed the AMP Quarterly Administrative Report (QAR). This report was emailed to the CAB members and it can be found on the PHACS website. Julie focused on the demographic information in this report. The report included the following information: 678 teens are enrolled in AMP. OF the 678 in AMP, 451 are HIV infected. The report also lists information by site. For example, Boston Children’s Hospital (BCH) has 6% of the total enrollments. BCH has 39 kids enrolled, out of the 678 participants. Of those enrolled at BCH, 35 are infected with HIV. The QAR also discusses age at enrollment, when the participants start the study. The median age is 11 years old for AMP. The median age of 11 years old means that half of the enrollees are older than 11, and the other half is younger than 11 years old. Infected kids in AMP are a little older, at 12 years of age. The uninfected age at enrollment is 12 years of age.

The QAR also looks at race, ethnicity, percentage that gave consent to store specimens in the repository, and genetic study consent. Furthermore, the report lists the percentage of people who are still in the study. For AMP, of the 678 enrollees, 589 are still on the study. The report also lists the reasons why the participants leave the study.

- **FALL NETWORK MEETING**

The Fall Network Meeting will be in Bethesda, Maryland on November 3-4, 2011. Each site can send one CAB member. The PHACS CAB would like to have a CAB Orientation at the meeting. The CAB wants to go over their roles, responsibilities, and objectives. This time might be a good opportunity for a PHACS researcher to talk about study participant summaries. Several CAB members on the call added that they would like to discuss the topic of retention at the PHACS Network Meeting.

NOTE: The next CAB call will be on Thursday, May 26, 2011 at 12:00 pm EST.