

**CAB Conference Call  
December 02, 2010  
12:00 EST  
Meeting Minutes**

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**Participants:**

<b>Carrie</b>	Denver Children's Hospital
<b>Delia</b>	University of Miami
<b>Dorothy</b>	University of Alabama at Birmingham
<b>Gloria</b>	University of Florida at Jacksonville
<b>Grace</b>	Westat
<b>Jennifer</b>	University of Colorado
<b>Julie</b>	Westat
<b>Kathy</b>	Harvard
<b>Lori</b>	FSTRF
<b>Mariana</b>	University of California – San Diego
<b>Marilyn</b>	Bronx-Lebanon
<b>Rosia</b>	Westat
<b>Theresa</b>	Texas Children's Hospital
<b>Vikas</b>	Bronx-Lebanon
<b>Yuri</b>	University of Miami

• **MEETING MINUTES**

The minutes for October 20, 2010 were accepted with minor changes.

• **ADOLESCENT BEHAVIOR WORKING GROUP**

Kathy spoke about the Adolescent Working Group. She is the Co-Chair of this working group (WG). Kathy spoke to the CAB to encourage CAB member participation on the WGs. This WG looks at how being exposed to HIV or exposed to HIV medications affects how children develop into teens. The children may have HIV, or they were exposed to HIV when they were born. The WG wants to know how the teens take care of their health. The WG also wants to know how they handle their feelings, school friends, family, and other relationships. They also want to find out about how teens are making life decisions. These life decisions include if they are going to take drugs and alcohol and if they are having unprotected sex. The researchers want to know if the teens are putting themselves at risk for being pregnant or for having sexually transmitted infections. The researchers are also interested in how the teens handle their HIV medications. They want to know what helps teens adhere to their medications, and difficulties teens face while taking their medications on a regular basis.

The Adolescent Behaviors WG is trying to get several papers published right now. One paper looks at the percent of AMP kids who have reported behavioral problems, such as having trouble taking their ARV medications. This paper is also looking at the percentage of kids who are sexually active and using substances (cigarettes, alcohol, or illegal drugs). The paper was submitted to be published but was not accepted, so the WG team is resubmitting the paper again.

Another paper looks at the questionnaires given to the caregivers and the kids about adherence to medications. The paper analyzes how well the answers to the questions agree with the kids' viral load. The study found very good agreement with how the teens and caregivers each responded to whether their viral load was detectable or not and their HIV infection management. This paper will be submitted in early 2011.

Another paper looks at what predicts whether someone will use drugs and alcohol and what factors predict if an adolescent will become sexually active. This information comes from the ACASI. The

ACASI is an interview where the child sits in the room by themselves and answers questions on a computer. The first ACASI interview is at the six-month visit for 10 year-olds. The questions are repeated every year. It was found that the average age for being sexually active is 13 years old, which is not different from the rest of the US. It was also found that of those who said they were sexually active, 50% said they have not used a condom at least one time. The researchers are not seeing differences in infected and uninfected children. For the infected children and teens, however, this has implications for transmitting HIV.

Marilyn expressed her interest in becoming more involved with the WGs. The WGs meet on a conference call once per month. The WGs are looking for people to participate on the calls, and to ask questions, listen, and know that there are researchers out there who can talk and ask questions about the studies, and to give the community perspective. Julie said that the WGs would be pleased to have anyone participate. The researchers are interested in any feedback the CAB members might have about the studies.

## • PARTICIPANT SUMMARIES

Jennifer reminded the group that the CAB members have access to Participant Summaries on the PHACS Website. If you would like to find them, go to the PHACS website at <https://phacs.nichdclinicalstudies.org>

Username: phacs  
Password: westat@06

Go to "Community Advisory Board," which you will find on the left of the main screen, and then go to "Resources," to find the Participant Summaries. There are 15 Participant Summaries in English and 12 in Spanish.

## • WORLD AIDS DAY 2010

December 1 was World AIDS Day 2010. Marilyn shared that she went to her first World AIDS Day event. Marilyn really enjoyed it and said it was very moving. The event was at the Bronx-Lebanon site, and 100 people attended.

Delia attended a celebration with the South Florida AIDS Network. It was called "Many Hearts One Beat." Delia's event photos are in the CAB Newsletter.

Gloria attended a World AIDS Day Kickoff event at the University of Florida. There was a big turnout. Gloria read her testimonial in front of the large crowd. Gloria's testimonial is in the December 2010 CAB Newsletter.

Theresa attended an event at her site in Texas. They set up a table with HIV literature, and they gave out red ribbons. There was also information about HIV testing sites. Theresa said there was a good turnout, and people were glad to accept the ribbon to heighten HIV/AIDS awareness.

Rosia went to the International Conference on Stigma in Washington, DC for World AIDS Day. DC has the highest rate of HIV in the country. There were several hundred people at the conference, including Miss America. The conference was about people who had been discriminated against because of their HIV status. There were many senior citizens at the conference that had contracted HIV after they retired, from unprotected sex. Also present was a 23-year-old male who was born with HIV. He was not told he had HIV until six years ago when he was tested for HIV in college. His parents died of HIV, but he was told they died in a car accident. There was another woman who spoke about how her family disowned her because they thought she was contagious. There were also many people at the conference that contracted HIV in the 1980s; they outlived all of their doctors' predictions. Miss America's platform is HIV/AIDS, so she spoke at the conference because her uncle died of AIDS. She also has an adopted sister who was born with HIV.

There was a workshop about how some people with HIV have a hard time traveling internationally. There are still about 30 countries that do not allow people who HIV to come into their country. In the US, the ban for people with HIV to travel to the US was recently lifted, but people still face problems with US travel. Travel issues for people who are HIV positive will be further discussed on the January 2011 conference call.

- **FALL 2011 PHACS MEETING**

It has been decided that one CAB member from each PHACS site will be invited to the PHACS meeting on November 2-4, 2011. All expenses for hotel, food, and travel (airplane and taxis) will be paid. This will make a difference for the CAB members everyone will be together, face-to-face. This is also an opportunity to get a sense of the whole PHACS project.

- **NEWSLETTER**

The newsletter was finalized. It was sent out to the whole PHACS network in English and Spanish in December 2010.

**NOTE: the next CAB call will be on Thursday, January 27, 2011 at 12:00 pm EST.**