

**CAB Conference Call
August 25, 2011
12:00 EDT
Meeting Minutes**

Participants:

Deangelo	University of Jacksonville
Delia	University of Miami
Dorothy	University of Alabama at Birmingham
Gloria	University of Florida - Jacksonville
Jennifer	University of Colorado
Julie	Harvard
Julie	Westat
Lori	FSTRF
Lennie	St. Jude
Mariana	University of California San Diego Hospital Center
Megan	Harvard
Megan	Westat
Rosetta	Bronx-Lebanon Hospital
Sherry	St. Jude
Theresa	Texas Children's Hospital
Yuri	University of Miami

• **APPROVAL OF MINUTES**

The minutes from the July 28, 2011 call were approved with no changes.

• **CAB NETWORK MEETING DISCUSSION**

The PHACS Fall Network Meeting is November 3-4, 2011 in Bethesda, Maryland at the Bethesda Hyatt Regency. The deadline for registration at the government room rate is September 28, 2011. The PHACS Leadership would like to invite one local CAB member from each site. The PHACS Study Coordinators (SC) will help decide who will attend from each site. The representative will be given registration information.

The PHACS Study Coordinators (SC) have seen retention issues in the SMARTT cohort. This cohort has HIV-uninfected children. As the children get older, parents may be taking them out of the study. This could be because they do not want to tell their HIV status to the children. The SC wants to set up a session with the CAB members and the Psychologists to discuss this issue. The PHACS leadership has discussed this too and suggested including issues of HIV disclosure in the session. The PHACS leadership would also like to hear about other reasons why people might be leaving the study and how to prevent it.

Yuri thought CAB members should talk with the social workers and psychologists at their sites. Members should get key points about disclosure to bring up at the session. Dorothy added that people who have experience with disclosure should talk during the session.

Lennie spoke about the Child Life Council (CLC) representative that works at their clinic. The CLC representative helps families with disclosure.

Delia advised CAB members to meet in their local CABS to find questions to ask the researchers. Julie from Westat said there will be ongoing researcher sessions and separate CAB meetings. There will most likely also be a session with the SC group to talk about retention and/or disclosure issues.

- **HIV PAIN MANAGEMENT**

Megan talked about two articles on HIV-related pain. There can be different causes. It can be a symptom of HIV, or a side effect of HIV drugs. It can also be illness or infections because of HIV. There are different types of pain. This includes neuropathy or pain in hands and feet, stomach pain, headache, muscle pain, and bone pain. These can be treated if they can be identified.

If someone is having HIV-related pain, they should talk with a doctor. Pain can be looked at by a doctor based on how bad the pain hurts and on the details of the pain. Once the patient and the doctor find the cause of the pain, the doctor can give therapy. Doctors can recommend over-the-counter medication like aspirin. Stronger pain medication can be prescribed by a doctor if the pain continues. There are also non-medicinal therapies. These include massage, physical therapy, acupuncture, heat and cold therapy, hypnosis, and mental imagery.

Yuri has noticed that more people are coming forward with neuropathy. He thinks people are more comfortable talking about it. There could also be more cases. DeAngelo also said that more people are bringing up neuropathy with their doctors. HIV-related pain could become a barrier to adherence. If a patient relates pain with taking medicine, they might not take their medication.

Delia reminded the CAB to check with their doctors before using over-the-counter medications. Doctors can recommend medications that will not interfere with HIV drugs.

- **PHACS CAB CALL EVALUATION SURVEY**

Megan created a PHACS CAB Call Evaluation Survey. It is voluntary, anonymous, and done by an online company. It has multiple choice questions about the helpfulness of the call topics. It also has a section for CAB members to suggest topics for upcoming calls. There is a section at the end for other comments about the calls. This can get everyone more involved in the CAB. Megan will email a link to the survey after the call.

- **PHACS PRESENTATION AT THE JULY 2011 INTERNATIONAL AIDS SOCIETY MEETING**

Julie from Harvard talked about Kathy Tassiopoulos' presentation at the July 2011 International AIDS Society Meeting. The paper is titled, "Sexual Risk Behavior among Perinatally HIV-Infected Youth in the US: Predictors and Implications for Intervention Development. The objectives were to estimate the prevalence and incidence of sexual activity of perinatally infected youth in the US. Prevalence looks at the issue at a point in time. Incidence is looking at it over time. In addition, they wanted to find out about factors that have to do with starting sexual activity and unprotected sex. They also wanted to find out about youth disclosure of HIV to sexual partners. They also wanted to describe the prevalence of viral resistance with kids who are sexually active. They found perinatally infected youth are becoming sexually active. Over half of the sexually active kids also were having unprotected vaginal and anal sex. There was also a lack of disclosure to their first sexual partners. These youth may be hurting their health and putting their partners at risk for HIV. Help is needed to support youth with adherence, safe sex practices, and disclosure of HIV status. This poster came out of the Adolescent Working Group. After they publish the paper, there will be a participant summary. In addition, Kathy will be at the Network Meeting.

- **OTHER RECENT LOCAL CAB NEWS**

Gloria's local CAB voted in new officers. She became chair, and Deangelo became Vice Chair. DeAngelo will now be the PHACS CAB representative for their site.

NOTE: The next CAB call will be on Thursday, September 22, 2011 at 12:00 pm EDT.