CAB Conference Call September 27, 2012 12:00 EST Meeting Minutes

Participants:

Claire De`Angelo Dorothy Julie Julie Julie	Harvard University University of Florida – Jacksonville University of Alabama at Birmingham Harvard University Westat University of Alabama at Birmingham
Kimbrae	Texas Children's Hospital
Laurie	FSTRF
Leslie	Texas Children's Hospital
Linda	St. Christopher's Hospital for Children
Marilyn	Bronx-Lebanon Hospital Center
Megan	Westat
Rosetta	Bronx-Lebanon Hospital Center
Samantha	Children's Diagnostic and Treatment Center
Sherry	St. Jude's Children's Hospital
Theresa	Texas Children's Hospital
Veronica	University of Florida – Jacksonville
Yuri	University of Miami

• APPROVAL OF MINUTES

The minutes from the August 23, 2012 call were approved with no changes.

• POSTER DISCUSSION – JULIE ALPEREN

Julie from Harvard talked about the poster that was presented at the 4th International Workshop on HIV Pediatrics in Washington, D.C. The study looked at rates and predictors of starting substance use among the HIV-infected and HIV-exposed but uninfected youth in AMP. Substance use is common for youth. Substance use among HIV+ youth can affect their medication adherence. It can also lead to risky sex.

The study had two objectives. The first was to look at prevalence, incidence and predictors of substance use. Prevalence is the general rate. Incidence is the rate over a period of time. The second was to compare rates in the study with rates from national samples.

The study population was youth in AMP. The youth were 10 years old and older. Youth in AMP are asked about using substances starting at age 10. The researchers looked for information on substance use. They collected the information using the ACASI. They looked at HIV-specific traits like CD4 counts, classification of HIV, viral load, and adherence. They also looked at behavioral and psychosocial variables. This includes emotional and behavioral health and academic achievement. It also includes stressful life events, substance use in the home, and caregiver physical and mental health.

The researchers compared the two groups in AMP. The HIV-infected youth came from homes that had a higher average income than the HIV-exposed but uninfected youth. The HIV-infected youth were more likely to be living with a non-relative. There was no difference between the groups in gender and caregiver education. The researchers looked at the lifetime prevalence of substance use. The study asked about alcohol, marijuana, and cigarette use. The study compared the youth in AMP to national samples of the same age. Youth affected by HIV had similar rates of substance use as those in the national samples.

The researchers looked at incidence of substance use. There was not a significant difference in substance use incidence between the HIV-infected youth and the HIV-exposed but uninfected youth.

The study showed factors that have to do with starting to use substances. Girls were less likely than boys to start using marijuana. Youth with a caregiver who was not related to them were less likely to start using alcohol than youth living with a biological parent or relative. This might be because some youth were living at a foster care home. The rules in foster care about using substances are very strict. These adolescents might not have used substances so that they could stay in the foster home.

The study shows predictors of past three months alcohol and marijuana use. Youth who lived at homes where alcohol was used were more likely to have used alcohol in the past three months. Youth who lived in homes where marijuana was used were 10 times more likely to have used marijuana in the past three months. They were also 6 times more likely to have used alcohol in the past three months.

The study found that HIV infection had no influence on whether youth have used substances in the last three months. Youth who had higher academic achievement were more likely to start using substances. Youth with higher viral loads were more likely to use substances in the last three months.

The study showed that youth affected by HIV have rates of alcohol, marijuana and tobacco use that are similar to the nationally representative samples. Rates of starting substance use between the HIV-infected and HIV-exposed but uninfected youth were similar.

• CAB NETWORK MEETING DISCUSSION

The PHACS Fall 2012 Network Meeting is November 8-9, 2012 in Bethesda, Maryland at the Bethesda Hyatt Regency. The PHACS Leadership invited one local CAB member from each site. There are 20 CAB representatives who will be coming to the meeting. The CAB Chair and Vice Chair will also be coming the meeting. The Study Coordinators at each site will contact CAB members to set up travel to the meeting. Harvard will pay for the airplane fees.

Megan talked about the CAB sessions at the meeting. The CAB had previously decided to have a session at the meeting on the topic of helping children and teens cope with the loss of a parent. The PHACS neuropsychologists will hold this session with the CAB. The PHACS neuropsychologists are the professionals who specialize in mental health. The session will be on Thursday, November 8 from 1:15 – 2:45 PM. Last month, the CAB voted to keep the session open to everyone at the meeting.

Megan talked about a second CAB session at the meeting. The second CAB session will be on Friday, November 9, from 10:45 AM- 12:15 PM. CAB Members were able to vote on an agenda for this session through the PHACS CAB Evaluation Survey. Some suggested agenda topics for the second CAB session are:

- Local CAB accomplishments and challenges,
- disclosure,
- raising children with HIV and/or HIV exposure,
- stigma/discrimination and their effect of research participation,
- research updates,
- research priorities,
- networking,
- adolescent participation in the PHACS CAB,
- CAB activities at future meetings,
- orientation processes for new CAB members, and
- neuropsychological issues and development.

Megan talked about the suggestions. Megan reminded the CAB that research updates will be given throughout the entire meeting. The PHACS Leadership is looking into starting a youth CAB.

Megan introduced the new PHACS Health Education Director, Claire Berman. Claire talked about story circle. Story circle is an exercise where people share stories about similar experiences. Every person would have a couple of minutes to talk. This could also be a way to learn this model and bring it back to local CABs.

Julie from Westat asked the CAB about having a third CAB session.

Action Items:

- **1.** Megan will add a question to the PHACS CAB Evaluation Survey about whether to add a third CAB session during the Network Meeting.
- 2. Megan will add an item to the PHACS CAB Evaluation Survey for CAB members to vote on an agenda for the Network Meeting second CAB session.

• PHACS CAB COMMUNITY CONCERNS AND PRIORITIES

Megan urged the CAB to talk about community concerns and priorities with their local CABs. CAB members can email Megan with community concerns and priorities. The CAB decided to add an item to the PHACS CAB Evaluation Survey about community concerns and priorities. Community Concerns and priorities must be submitted by Friday, October 19. The CAB will finalize the list on the October PHACS CAB conference call.

Action Item: Megan will add a section to the PHACS CAB Evaluation Survey for CAB members to suggest community concerns and priorities.

• PHACS CAB DISCLOSURE FACT SHEET

Megan talked about the PHACS CAB Disclosure Fact Sheet. Megan has gotten feedback from the PHACS Study Coordinators and Neuropsychologists. The CAB will finalize the fact sheet on the October PHACS CAB conference call.

• NOVEMBER CALL

Megan talked about the November PHACS CAB call. The fourth Thursday in November is Thanksgiving. Megan suggested moving the call to Thursday, November 15, or Thursday November 29.

Action Item: Megan will add a question to the PHACS CAB Evaluation Survey about rescheduling the November PHACS CAB call.

NOTE: The next CAB call will be on Thursday, October 25, 2012 at 12:00 pm EST.