

**CAB Conference Call
August 23, 2012
12:00 EST
Meeting Minutes**

Participants:

Carrie	University of Colorado
De`Angelo	University of Florida – Jacksonville
Dorothy	University of Alabama at Birmingham
Jennifer	University of Colorado
Juan	University of Puerto Rico
Julie	Westat
Kimbrae	Texas Children’s Hospital
Krystal	Harvard University
Laurie	FSTRF
Leslie	Texas Children’s Hospital
Linda	St. Christopher’s Hospital for Children
Mariana	University of California San Diego Hospital Center
Mary	Bronx Lebanon Hospital
Megan	Westat
Miriam	Harvard University
Peter	San Diego State University
Theresa	Texas Children’s Hospital

• **APPROVAL OF MINUTES**

The minutes from the July 26, 2012 call were approved with no changes.

• **PARTICIPANT SUMMARY DISCUSSION – DR. PETER TORRE**

Peter talked about the participant summary of his publication “Hearing loss in perinatally human immunodeficiency virus-infected and human immunodeficiency virus-exposed but uninfected children and adolescents.” Data were collected in over 225 children. Most of the children in the study were HIV-infected. Some children in the study were HIV-exposed but uninfected.

The study showed hearing data on children who met a trigger. The trigger led them to have their hearing tested. The researchers looked at the data and made a definition of hearing loss. The HIV-infected group had a higher percentage of hearing loss as compared to the HIV-exposed but uninfected group. Both of those groups had higher percentages of hearing loss as compared to the control group. The control group is the comparison group for when the data is studied. The children in the study were ages 7-16.

The children in the study met a trigger that made them come into the clinic and get their hearing tested. There were three triggers; 1) a score below 85 on the clinical evaluation of language function, 2) parent/caregiver report of their assumption of the child having a hearing problem, or 3) the child met a trigger for abnormal hearing from a regular doctor visit.

The study suggests that something about HIV exposure and HIV infection may have an impact on hearing. Hearing loss could be caused by HIV infection and/or exposure to mothers’ medication during pregnancy. Hearing loss could also be because of other variables.

The research talks about the rates of hearing loss. The HIV-infected group had a 20% rate of hearing loss. The HIV-exposed group had a 10.5% rate of hearing loss. There weren’t many children with

large amounts of hearing loss. The child may not have even noticed that he/she had a hearing problem.

Hearing loss is an unseen problem. Children with hearing loss may have learning problems because of their hearing loss. This problem should be looked at early. This can help to not impact the child's learning development.

Linda wondered if children grow out of having hearing loss. Peter is looking to research how hearing impacts children in later ages. The hearing losses in this study were permanent.

The sicker HIV-infected children with a class C diagnosis of HIV were more at risk for hearing loss. There may be an opportunity to assess this risk with the PHACS data from the 5-year-old group and the control group.

Leslie talked about children who have a history of ear infections, fluid in the ear, and other chronic ear problems. The researchers in the study looked at all middle ear data. They ruled out chronic hearing problems as a reason for permanent hearing loss. They looked at the hearing test and compared it to the most recent middle ear data in each child.

• **PHACS CAB EVALUATION SURVEY RESULTS**

Megan talked about the PHACS CAB Evaluation Survey results. Some suggested topics for upcoming calls are:

- Doctors with knowledge of alternative medicine,
- update from the International AIDS Conference,
- alternative medicine and HIV,
- current alternative medicine studies in the US, and
- HIV self-testing kits.

There was an item on the survey for CAB members to suggest a theme for the newsletter. Some suggested themes are:

- survival,
- alternative foods and drinks, and
- overcoming the holiday blues.

Megan reminded the CAB to think about themes that are related to PHACS.

• **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 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. Fourteen CAB representatives and the CAB chair & vice chair went to the meeting last year. Julie reminded the CAB that all expenses for CAB members to come to the meeting will be paid up front. Westat will send a check for food and transportation costs. Westat will also pay for the hotel stays. Harvard will pay for the airplane fares.

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. This session could be open to everyone at the meeting. This session could also be closed to only include the neuropsychologists and the CAB. The CAB decided to vote on this issue through the PHACS CAB Evaluation Survey.

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. The CAB had a second session during the 2011 meeting. The CAB discussed goals for the CAB for the upcoming year. Megan talked about making an agenda for the second CAB session at the 2012 meeting. Dorothy suggested that CAB members talk about local CAB activities. CAB members can share the challenges and successes of their local CABs. The CAB decided to vote on an agenda for this session through the PHACS CAB Evaluation Survey.

Action Items:

- 1. Megan will add a question to the PHACS CAB Evaluation Survey about whether to allow the Network Meeting CAB session on helping children and teens cope with loss to be open or closed.**
- 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 talked about the IMPAACT meeting. Each person at the meeting had a folder with handouts. The IMPAACT CAB made a handout about community concerns and priorities to put in the folders. Each person at the PHACS Fall Meeting will receive a meeting packet. The packets will have agendas, publications, and general meeting information. Megan wondered if the PHACS CAB would be interested in making a similar handout for the meeting packets. Everyone at the PHACS meeting would have a copy of the list to keep. They would be able to think about the issues that are most important to the PHACS community members. Last month, the CAB decided to make a handout about community concerns and priorities.

Kimbrae suggested having priorities about adolescents. Theresa suggested adding a priority about the cause of complications in the PHACS children. She talked about the need to figure out if it is the exposure to HIV, HIV infection, and/or medications that causes complications.

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.

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. Theresa thought that the group should give examples of places to find support for children. Dorothy suggested including the fact that there are different pieces to disclosure. Mary suggested creating a separate booklet of CAB members' personal stories about disclosure. Megan will send the draft of the PHACS CAB Disclosure Fact Sheet to the PHACS clinical staff for their input. The CAB will then finalize the sheet for posting to the PHACS website.

Action Item: Megan will send the PHACS CAB Disclosure Fact Sheet to the PHACS clinical staff.

NOTE: The next CAB call will be on Thursday, September 27, 2012 at 12:00 pm EST.