

**CAB Conference Call  
May 24, 2012  
12:00 EST  
Meeting Minutes**

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**Participants:**

<b>Carrie</b>	University of Colorado
<b>De`Angelo</b>	University of Florida – Jacksonville
<b>Delia</b>	University of Miami
<b>Jennifer</b>	University of Colorado
<b>Julie</b>	Harvard University
<b>Kimbrae</b>	Texas Children’s Hospital
<b>Laurie</b>	FSTRF
<b>Leslie</b>	Texas Children’s Hospital
<b>Linda</b>	St. Christopher’s Hospital for Children
<b>Megan</b>	Westat
<b>Rosetta</b>	Bronx - Lebanon
<b>Theresa</b>	Texas Children’s Hospital
<b>Yuri</b>	University of Miami

• **APPROVAL OF MINUTES**

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

• **PHACS CAB EVALUATION SURVEY RESULTS**

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

- Cure research updates,
- sero discordant couple studies,
- treatment as prevention,
- medications,
- drug use by parents,
- children born positive,
- children having adherence issues,
- natural methods for treatment,
- food and drink that affect treatment,
- weight/protein/whey shakes and how they affect us,
- exercising or yoga,
- eating healthier, and
- safe sex.

• **CAB VICE CHAIR NOMINATIONS**

Megan talked about the PHACS CAB Vice-Chair nominations. Jennifer Whitehill, the PHACS CAB Chair, will be stepping down after serving for the past two years. Delia has been serving as Vice-Chair for 2 years. Delia is now the incoming CAB Chair effective June 2012. Therefore, the Vice-Chair position is open. We will be taking nominations by email or through the PHACS CAB evaluation survey.

The CAB Vice-Chair position is a two-year commitment. The Vice-Chair attends the monthly CAB calls and helps to set the agenda for those calls. The Vice-Chair also attends the PHACS Network meetings in the spring and fall each year. PHACS pays for all travel, room and board during those meetings. The Vice-Chair participates as a non-voting member on the monthly EC call. Megan reminded the CAB

that the last day for nominations is May 31, 2012. Megan will send out the list of the nominees as well as the brief summaries of the nominee's qualifications to the CAB for a vote.

Jennifer talked about the Vice-Chair and Chair positions. Jennifer shared that as the Chair, she learned a lot about HIV and about the PHACS study. Jennifer was able to stay connected with PHACS on a personal level. Being the Chair allowed Jennifer to learn more about the results of the study. She also enjoyed traveling to the meetings. The CAB thanked Jennifer for her time serving as the PHACS CAB Chair.

Delia talked about the Vice-Chair position. Delia shared that as the Vice-Chair, she learned a lot about HIV. She also has learned a lot of information that she has shared with her daughter.

Theresa wondered about babysitters for the CAB Chair and Vice-Chair at the network meetings. Julie from Harvard explained that babysitters at home would not be covered by PHACS. Julie will find out if it would be possible to provide a babysitter at the network meetings.

**Action Items:**

- 1. Please nominate yourself or another CAB member for the Vice-Chair position. To nominate someone, submit a brief summary why you or your nominee would be a good candidate. Once names have been collected, a list of the nominees and the brief summaries will be sent to the CAB for a vote.**
- 2. Julie from Harvard will find out if it would be possible to provide a babysitter at the network meetings.**

• **NEWSLETTER, JUNE 2012 EDITION**

Megan asked the CAB to consider submitting articles to the June 2012 edition of the PHACS CAB Newsletter. The theme for the newsletter is Living Healthy with HIV. Please consider submitting an anonymous (your name will not be included) testimonial to the newsletter about living healthy with HIV. This can also be about children living with HIV. The deadline to submit personal testimonials is June 8, 2012.

The newsletter will also include a section for "My Favorite Thing About Summer" by CAB kids. CAB kids can submit anything having to do with their favorite thing about summer including (but not limited to):

- pictures,
- drawings,
- descriptions of 1-3 sentences,
- poems, and
- recipes.

The deadline for CAB kids submissions is also June 8, 2012.

• **FUTURE CALL – HELPING CHILDREN AND TEENS COPE WITH LOSS**

Megan talked about a future call with the PHACS neuropsychologists. The PHACS CAB leadership has been working with the PHACS neuropsychologists on the topic of helping children and teens cope with the loss of a parent. The PHACS neuropsychologists are professionals who specialize in mental health. Megan sent out articles that highlight the main issues. Megan asked the CAB to look over the articles and share them with their local CABs. If you are interested in participating in a discussion with the PHACS neuropsychologists regarding this topic, please let us know. We are planning to hold a separate conference call with them in the next couple months to talk about this topic. This call will be voluntary.

## • PHACS WEBSITE USER GUIDE REVIEW

Megan reviewed the PHACS website user guide. Megan reminded the CAB that a username and password is required to enter the website. The username is "phacs" and the password is "westat@06". The "Quick Links" page shows direct links to the all pages on the PHACS website. The calendar can be found on the left sidebar of the home page. The calendar is updated monthly. The most recent PHACS news can be found on the left sidebar. The "Overview" page on the left sidebar shows a summary of the PHACS project. The "Documents" page on the left sidebar has protocol-specific documents. The "Study Administration" page shows PHACS policies and general information.

CAB members can locate participant summaries by clicking on the "Participant Summaries" page. The participant summaries are written to be easier to understand. Minutes from all the PHACS committee and Working Group (WG) calls can be found under the "Minutes" tab. The "Network Meetings" page is on the left sidebar. This page has handouts and presentations from the PHACS meetings.

The "Community Advisory Board (CAB)" page on the left sidebar has all the CAB materials. The CAB page has the CAB overview, CAB meeting documents, Newsletters, CAB glossary, resources, and other HIV/AIDS news and events. The "CAB Meeting Documents" page has the CAB call minutes and the CAB call schedule. CAB minutes from every CAB call are available in English and Spanish.

The "Analyses" page is on the left sidebar. The "Analyses" page shows the PHACS accepted abstracts, conference presentations and posters, published manuscripts, capsules, and concept sheets. All PHACS members' contact information is listed under the "Contact List" page on the left side bar. The "Alphabetical Listing" page shows PHACS members alphabetically by last name. CAB members can also perform a directory search to find PHACS members.

## • PHACS DISCLOSURE FACT SHEET

Megan talked about disclosure. There are still parents struggling with telling their children about their own HIV infection. Some PHACS Study Coordinators (SC) thought it might be helpful to develop a fact sheet about disclosure. The fact sheet would talk about the issue of disclosure from the CAB member perspective.

Megan sent an article to the CAB on disclosing HIV diagnosis to children. The article talks about the difficulty of disclosure of HIV infection. It can be helpful for parents to attend support groups that talk about HIV infection disclosure. Parents may struggle with fear that their children will abandon them after they learn about the HIV infection of their parents. Friends or family may urge parents not to disclose to their children. Disclosure is a process. Disclosure is not just a one-time event. It helps to prepare before disclosing. There isn't necessarily a right time or a right age to disclose.

Megan asked the CAB about their experiences with disclosure. Rosetta talked about disclosing to younger children. It may be helpful to wait to disclose until the children can understand the information. It helps for children to understand that the information is private.

Jennifer talked about disclosing more information about HIV to children as they get older. Disclosure of HIV infection is a continual conversation. Jennifer pointed out that it may be helpful to pick out a safe person for the children to talk to if they do not want to talk to their parents. Jennifer talked about learning more about HIV before you disclose to your children. This can help the parent be more comfortable with the information. This can help the parent better communicate with the child about HIV.

Delia and Yuri talked about support groups for children. Support groups exist for newly diagnosed and/or newly disclosed children. Yuri encouraged the CAB to ask their site staff about support groups for children. De`Angelo recommended involving children in peer groups. There is a peer group at De`Angelo's site. The children react well to learning information from other children.

Theresa talked about developmental stages of children. Children think differently in the various developmental stages. It may be helpful to include a sentence about the stages in the disclosure fact sheet. Parents can get a sense of how to approach their children about HIV. It might be helpful to talk to children about health before talking to them about HIV. Theresa reminded the CAB that physicians and nurses can help talk to children. It may help to include the child's religious leader (pastor, priest, rabbi, etc.) in the conversation.

The CAB decided to include the following facts in the disclosure fact sheet:

- disclosure is a process, not a one-time event,
- prepare to talk about disclosure with children by having little conversations about health and HIV that the child can understand at his/her age,
- designate a safe person that the child can talk to about HIV if the child does not want to talk with his/her parents,
- it helps to get involved with a local support group,
- encourage children to get involved with a local support group, and
- keep learning about HIV before and after disclosing to children to be able to be comfortable with the information.

Megan encouraged the CAB to talk about the disclosure fact sheet with their local CABs.

**NOTE: The next CAB call will be on Thursday, June 21, 2012 at 12:00 pm EST.**