

**CAB Conference Call
July 25, 2013
12:00 EST
Meeting Minutes**

Participants:

Claire	Harvard University
Delia	University of Miami
Jennifer	University of Colorado, Denver
Juan	University of Puerto Rico
Julie	University of Alabama, Birmingham
Julie	Westat
Marilyn	Bronx-Lebanon Hospital Center
Mary Anne	Westat
Megan	Westat
Rosetta	Bronx-Lebanon Hospital Center
Stephanie	University of Miami
Theresa	Texas Children's Hospital
Yuri	University of Miami

• **APPROVAL OF MINUTES**

The minutes from the June 27, 2013 call were approved with no changes.

• **PHACS CAB EVALUATION SURVEY RESULTS**

Megan talked about the PHACS CAB Evaluation Survey results. There were 7 responses. Some suggested topics for upcoming calls are:

- Let every CAB member share about their local CABs;
- Good eating habits and exercise; and
- IQ, memory, attention, organization and planning.

• **PHACS CAB NEWSLETTER, JUNE 2013 EDITION**

Delia talked about the PHACS CAB Newsletter, June 2013 Edition. The theme is support systems. Delia thanked the CAB for submitting articles to the newsletter.

• **PHACS FALL 2013 NETWORK MEETING AND CAB RETREAT**

Delia talked about the Fall 2013 CAB Retreat. The CAB Retreat is from 1:00 PM – 6:00 PM on October 1, 2013 in Baltimore, Maryland. The CAB retreat will have CAB-specific sessions. CAB members will still attend all sessions at the Fall 2013 Network Meeting. CAB members previously gave topics for sessions. Some suggested topics for retreat sessions are:

- Adherence;
- Being a positive teen;
- Youth transitioning into adult care;

- Story circle;
- HIV and dating;
- Youth and HIV;
- New CAB member orientation;
- PHACS refresher;
- Stigma; and
- Age of majority.

Delia talked about networking during the Fall 2013 CAB Retreat and Network Meeting. CAB members can meet and share site CAB experiences. CAB members can suggest topics for the CAB Retreat through the PHACS CAB Evaluation Survey.

Megan talked about the Fall 2013 Network Meeting. The Network Meeting is on October 2-3, 2013 in Baltimore, Maryland. 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. CAB attendees must attend all sessions at the meeting. CAB attendees will sign a "Statement of Commitment" form. This form will help ensure that CAB members understand their roles and requirements at the meeting. Delia suggested that CAB members come up with questions for the researchers before the meeting.

Megan 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 and airplane fares. Delia suggested that CAB members book their flights around the meeting times.

• **CAB HANDBOOK SURVEY RESULTS**

Megan talked about the CAB Handbook. The CAB Handbook will be a resource for CAB members and site staff. It will talk about how to create a CAB and recruit and retain CAB members. CAB members gave feedback about their site CABs through an online survey. The final version of the CAB Handbook will be posted on the PHACS website. CAB members can look at the CAB Handbook online or print it out. The HECC CAB Subcommittee suggested that the CAB Handbook also be posted on the website as a PowerPoint presentation. CAB members can use the PowerPoint presentation in site CAB meetings. The CAB Handbook may be split up into different sections.

Delia talked about activities outside of CAB meetings. Activities outside of site CAB meetings help CAB members get to know each other. Theresa also talked about activities. Activities outside of site CAB meetings help spread awareness about site CABs. They also help spread awareness about research issues.

Megan talked about participant summaries. Many CAB members review participant summaries during site CAB meetings. Julie from Alabama talked about participant summaries. The Principal Investigator reviews the participant summaries during site CAB meetings.

• **HEALTH EDUCATION AND COMMUNICATION COMMITTEE (HECC) UPDATE**

Claire talked about the PHACS focus groups. The focus groups are being held at AMP sites with young adult PHACS participants and CAB members. The aim of the focus groups is to get feedback about the AMP 18+ protocol. The team is also looking to learn about the challenges and strengths of PHACS young adults and CAB members. Young adults are also asked questions about technology. Focus groups were recently held at Site 13 – Bronx-Lebanon Hospital Center. Some young adults feel that

participating in PHACS is a way to help other people. Many young adults are involved in volunteer groups. There will be eight more focus groups.

Claire talked about the Disclosure Resource. The Disclosure Resource will include a workbook for caregivers living with HIV. The workbook will talk about reasons people might decide to disclose their HIV-status to their children. It will also talk about preparation for disclosure, and follow up. The resource will have anonymous personal stories about disclosure. CAB members can also volunteer to share their disclosure stories through art.

The goal of the Disclosure Resource is to provide more information about the disclosure process. It will help caregivers makes a decision about disclosure that is right for their families.

There will be a similar book for children. This book will be in a question/answer format. It will help answer questions children may have after disclosure has taken place. CAB members can help come up with questions for the similar book.

The Disclosure Resource team is looking to finalize a plan for the Disclosure Resource by the end of August. Delia, Rosetta, and Marilyn are working on the Disclosure Resource team.

Claire talked about personal stories about disclosure for the Disclosure Resource. Claire suggested that the CAB consider recording disclosure stories during a disclosure story circle at the Fall 2013 CAB Retreat. CAB members can share their stories anonymously. There will also be story circles that are not recorded.

NOTE: The next CAB call will be on Thursday, August 22, 2013 at 12:00 pm EST.