

**CAB Conference Call
October 31, 2013
12:00 EST
Meeting Minutes**

Participants:

Claire	Harvard
Delia	University of Miami
Jennifer	University
Julie	University of Alabama, Birmingham
Julie	Westat
Kim	Texas Children's Hospital
Laurie	FSTRF
Mariana	University of California, San Diego
Marilyn	Bronx-Lebanon Hospital Center
Megan	Westat
Olivetta	University of Florida, Jacksonville
Rosetta	Bronx-Lebanon Hospital Center
Theresa	Texas Children's Hospital
Veronica	University of California, San Diego
Yuri	University of Miami

• **APPROVAL OF MINUTES**

The minutes from the September 26, 2013 call were approved with no changes.

• **PHACS CAB EVALUATION SURVEY RESULTS**

Megan talked about the PHACS CAB Evaluation Survey results. There were 6 responses. Some suggested topics for upcoming calls are:

- Local CAB updates;
- Complications with Combivir and breast mass; and
- Updates from Working Groups.

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

Delia talked about the Fall 2013 CAB Retreat. Delia talked about goals for the retreat. The goals for the CAB Retreat were:

- Learn new strategies on how to assist other families at our site;
- Learn about research and support opportunities for families living with HIV;
- Continue to provide insight as to the issues related to community;
- Network; and
- Learn about the PHACS team.

The Welcome and Bingo session helped CAB members get to know each other. There was a clinical trials Game. There was a community panel discussion. Five CAB members were on the panel. The community discussion was very engaging. The group skipped the PHACS overview presentation to

have an extra hour for the community session. The group held story circles at the end of the retreat. The story circles focused on disclosure.

Delia talked about the Network Meeting. Dr. Peter Hunt and Dr. Kendall Marcus were the plenary speakers. Dr. Hunt talked about immune activation during antiretroviral therapy (ART). Dr. Marcus talked about evaluation of drug safety in pediatrics. She also talked about drug labeling.

At the meeting, there were Working Group (WG) sessions. The Complications WG focused on topics like ART resistance in perinatally HIV-infected children. Speakers presented about CCR5 activity in perinatally HIV-infected children. The group also talked about HIV-1 remission with early HAART.

The Maternal Exposures WG focused on topics like ARV analysis in hair in newborns. Speakers also presented about birth defects in perinatally HIV-exposed children. The Metabolic WG focused on metabolism. The Adolescent WG session talked about the focus groups. Speakers also presented about structural equation modeling. Megan and Claire showed a preview of the new PHACS website.

Delia talked about the CAB session at the Network Meeting. The CAB learned about how to take information from the meeting back to site CABs. The CAB brainstormed some activities for the coming year.

• **PHACS FALL 2013 CAB RETREAT EVALUATIONS**

Megan talked about the Fall 2013 CAB Retreat evaluations. The story circle session was the highest rated session. Some CAB members asked to have more detailed summaries from each story circle. Megan and Claire will send out a survey about the Story Circle session soon.

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

Delia talked about the PHACS CAB Newsletter, December 2013 Edition. CAB meeting attendees may submit quotes about the retreat and meeting for the newsletter. Megan encouraged the CAB to submit materials to the newsletter. Submissions are due by December 6th, 2013. CAB members can vote for a theme for the newsletter through the PHACS CAB Evaluation Survey. Votes are due by Friday, November 8th, 2013. Some suggested themes are:

- Stigma and stigma-reducing efforts;
- Mothers/Caregivers of HIV-infected or HIV-exposed children;
- Participation in a research study;
- Mental health and HIV; and
- Adolescents and young adults in PHACS.

Delia suggested that parents send photos of their children in their Halloween costumes. Yuri suggested that CAB members submit photos of their fall decorations. Megan reminded the CAB that CAB kids may submit articles to the newsletter. Claire talked about the community session at the retreat. Claire suggested that the community panelists submit quotes about community involvement. Theresa and Yuri suggested that the Young Adult CAB write an article for the newsletter.

- **PHACS OVERVIEW PRESENTATION**

Julie from Westat gave the PHACS overview presentation. The presentation can be found on the PHACS website (<https://phacs.nichdclinicalstudies.org>).

NOTE: The next CAB call will be on Thursday, November 21, 2013 at 12:00 pm EST.