CAB Conference Call September 26, 2013 12:00 EST Meeting Minutes

Participants:

Delia University of Miami
Juan University of Puerto Rico
Harvard University

Julie University of Alabama, Birmingham

Julie Westat

Kim Texas Children's Hospital

Laurie FSTRF

Leslie Texas Children's Hospital

Mariana University of California, San Diego

Megan Westat

RamonaUniversity of Florida, Jacksonville **Rosetta**Bronx-Lebanon Hospital Center

StephanieUniversity of MiamiTheresaTexas Children's Hospital

Veronica University of California, San Diego

Yuri University of Miami

APPROVAL OF MINUTES

The minutes from the August 22, 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:

- Nutrition Substudy update;
- New findings;
- Discussion about cure cases;
- Mental health;
- Drugs;
- Alternative medicine;
- Experience taking HAART and side effects;
- Collaboration and resources available through other networks;
- Oral health substudy update; and
- Neuroimaging pilot study follow up.

PHACS FALL 2013 NETWORK MEETING AND CAB RETREAT

Delia talked about the Fall 2013 CAB Retreat. Megan sent out the Working Group descriptions to the CAB. Kim suggested that CAB members talk with their site CABs to come up with questions for the researchers. Kim stated that her CAB is interested in learning about the causes of mastitis. Mastitis is inflammation of breast tissue.

Megan 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. All CAB attendees are registered for the retreat and meeting. Registration at the retreat will start at 11:00 AM. The PHACS registration table will be in the hotel lobby. CAB attendees may check-in and go to their hotel rooms, if the rooms are ready. If not, CAB attendees may leave their luggage in the CAB Retreat meeting room.

Megan talked about per diem. Per diem is money for meals that are not provided by the meeting, and for ground transportation. Westat sent CAB attendees a check for per diem. CAB attendees should cash the check before the meeting and bring the money with them. Westat also sent a letter with the per diem check. The letter explained how to budget the per diem money.

Megan reviewed the CAB Retreat agenda. There will be a welcome session and bingo icebreaker exercise from 1:00-1:45 PM. Delia and Megan will present the welcome session and bingo icebreaker exercise. The second CAB Retreat session will be from 1:45-2:30 PM. Yuri will present a PHACS game.

There will be a panel session about community involvement from 2:30 – 3:00 PM. There will be five CAB members on the panel. Claire will moderate the panel discussion. There will be 15 minutes for creative art work from 3:00 – 3:15 PM. CAB members will be given art supplies. There will also be an art table at the CAB Retreat. At any time, CAB members are welcome to visit the art table and express their feelings about the CAB Retreat sessions through art. CAB attendees may also submit their artwork for the cover of the CAB Handbook. There will be a break with snacks and drinks from 3:15 – 3:30 PM. CAB members who choose not to participate in the creative expression session can take their break starting at 3:00 PM. After the break, Julie from Westat will give a PHACS overview presentation from 3:30 – 4:00 PM.

The last session will feature story circles. This session will take place from 4:00 – 6:00 PM. One or more of the story circles will talk about disclosure. The Health Education and Communication Committee (HECC) is looking to record disclosure stories for the Disclosure Resource. CAB members can choose to record their disclosure stories anonymously during the disclosure story circle exercise. CAB members do not have to record their stories. All other story circles will not be recorded. Yuri volunteered to lead a story circle on youth transitioning into adulthood.

Megan talked about the CAB informal dinner. After the CAB Retreat, CAB members are invited to come to an informal dinner at 6:35 PM. CAB attendees should meet at the registration table in the hotel lobby at 6:35 PM. The group will walk to the restaurant at 6:45 PM. Currently, 16 CAB members have RSVP-ed for the dinner.

Megan talked about goals for the retreat. CAB member suggested goals through the PHACS CAB Evaluation Survey. The goals for the CAB Retreat are:

- 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 Network Meeting is on October 2-3, 2013. There is a final CAB session scheduled on Thursday, October 2, 2013 from 1:30-3:30 PM. During this session, the CAB will review the CAB section of the new website. The CAB will also talk about how to bring the information from the meeting back to site CABs. The CAB will also give feedback for the CAB Handbook and Disclosure Resource. Finally, the CAB will present Site CAB updates.

PHACS 2013 COMMUNITY CONCERNS AND PRIORITIES

Megan sent out the 2013 PHACS CAB Community Concerns and Priorities list. This list will be handed out at the Fall 2013 Network Meeting in the meeting packets. It will also be posted on the website.

• HEALTH EDUCATION AND COMMUNICATION COMMITTEE (HECC) UPDATE

Claire sent out an email about the Inspiration Hub. The HECC will be hosting an Inspiration Hub at the Network Meeting. PHACS Meeting attendees will be able to share brief responses to prompts about what inspires them about their role on PHACS. The HECC will be featuring these submissions on the new PHACS website. The Inspiration Hub will be outside the Network Meeting general session room. There will be a laptop stationed at the Inspiration Hub. Meeting attendees can submit responses on this laptop through a Google Form. Meeting attendees may also send their inspiration submissions to Claire and/or Megan on a paper form.

Megan talked about the CAB Handbook. The HECC CAB Subcommittee drafted the first module of the CAB Handbook. The CAB Handbook will be divided into five separate modules. The final CAB Handbook will be posted on the PHACS website. Users may download the entire CAB Handbook. Users may also download individual modules of the CAB Handbook. The HECC CAB Subcommittee will also be creating PowerPoint presentations of the CAB Handbook modules. CAB members may present the PowerPoint presentations during site CAB meetings. The front cover of the CAB Handbook will be a collage of CAB member artwork. CAB members may submit their artwork to Megan.

NOTE: The next CAB call will be on Thursday, October 31, 2013 at 12:00 pm EST.