CAB Conference Call April 24, 2014 12:00 EST Meeting Minutes

Participants:

Carlos Claire Delia Dolores Jennifer	San Juan Hospital Harvard University University of Miami St. Christopher's Hospital for Children University of Colorado, Denver
Juan	University of Puerto Rico
Juanita	Tulane University
Julie	University of Alabama, Birmingham
Julie	Westat
Kim	Rutgers New Jersey Medical School
Kim	Texas Children's Hospital
Laurie	FSTRF
Lesley	Texas Children's Hospital
Marilyn	Bronx-Lebanon Hospital Center
Megan	Westat
Ramona	University of Florida, Jacksonville
Rosetta	Bronx-Lebanon Hospital Center
Tatania	Tulane University

• APPROVAL OF MINUTES

The minutes from the March 27, 2014 call were approved with no changes.

• PHACS CAB EVALUATION SURVEY RESULTS

Megan talked about the PHACS CAB Evaluation Survey results. There were 9 responses. Some suggested topics for upcoming calls are:

- Stigma;
- ADHD; and
- Consent Issues.

• PHACS CAB CHAIR AND VICE CHAIR ELECTIONS

Delia talked about the PHACs CAB Chair and Vice Chair nominations. The CAB submitted nominations for Chair and Vice Chair. The Chair and Vice Chair positions require a two year commitment. De'Angelo was nominated for Chair, but is unable to work with the PHACS CAB at this time. Yuri was nominated for Chair. Yuri is not able to serve as the Chair at this time, but he will continue to work with the CAB. Kim was nominated for Vice Chair. Kim will be the new Vice Chair starting in May 2014. The CAB congratulated Kim. Dolores was nominated and will serve as Chair starting in May 2014.

• PHACS CAB NEWSLETTER, JUNE 2014 EDITION

Delia talked about the PHACS CAB Newsletter, June 2014 Edition. The CAB voted on a theme of "disclosure" for the newsletter. Megan will send out a call for submissions after the call. Megan encouraged CAB members to consider submitting anonymous personal testimonials about disclosure for the newsletter. Claire will submit an article about the disclosure comic strips for the newsletter. Site staff members will submit an article about the disclosure workshops.

Kim talked about disclosure. Kim suggested submitting an article having to do with steps to take if a medical professional reveals your status without your permission.

Claire talked about a disclosure storytelling resource. The resource would be for mothers living with HIV who are interested in the possibility of disclosing their status to their children. The Health Education and Communication Committee (HECC) has put together a list of topics for mothers to think about when considering disclosure. The topics will help mothers think about whether they want to disclose, and/or when they'd like to start talking about disclosure with their children. The storytelling resource will be a website for caregivers to share their disclosure stories with each other. CAB members who submit disclosure stories for the newsletter will also have the option to choose whether they would like to share their story with the storytelling resource.

Dolores talked about disclosure. CAB members may submit their stories anonymously. Some people may not feel comfortable disclosing their status. Claire talked about the storytelling resource. Confidentiality is a top priority. The HECC has not yet decided whether the website will be private or open to the public.

Lesley talked about disclosure. Lesley suggested that children of mothers living with HIV be able to participant in the storytelling resource. Claire talked about youth participation. There may be restrictions about youth participation if they are below the age of consent.

• NEW PHACS WEBSITE

Megan and Claire presented a demonstration of the new PHACS website (<u>http://phacsstudy.org</u>). There are three website portals. One portal is for the public. Users do not need a username and password to see the public pages. The other two portals are for researchers and CAB members. CAB members will have access to CAB pages with a username and password. CAB members may register for a username on the register page (<u>https://my.phacsstudy.org/register</u>).

Megan talked about the CAB pages on the new website. There are pages for CAB conference call minutes, resources, activities, structure, and the newsletter. Future CAB newsletters will be available on the public part of the website starting in June 2014. There is also a discussion forum that is for CAB members only.

Megan talked about the research summaries page. The research summaries are categorized by Working Group (WG). The research summaries page shows descriptions of each WG. Within each WG page, there are research summaries that were developed by that WG. Users can click on the research summary titles to see 1-2 sentence descriptions of each summary. Users can also click on a link to the full PDF summary. Finally, users may also click on a link to the full manuscript article.

Claire talked about the HIV/AIDS Newsfeed. The newsfeed is on the member home page. There are also links to events and announcements on the member home page.

Claire talked about the Inspiration Hub. The Inspiration Hub page can be found under the About Us page. Inspiration Hub quotes are scattered throughout the website as well as on the Inspiration Hub page.

Megan talked about the CAB Handbook. The CAB Handbook is posted on the public part of the website. The CAB Handbook has five modules with information about setting up a CAB, CAB structure,

communication, meeting content, and health education. CAB members can view and/or download the entire book or by module in PDF form.

NOTE: The next CAB call will be on Thursday, May 22, 2014 at 12:00 pm EST.