

**CAB Conference Call
March 27, 2014
12:00 EST
Meeting Minutes**

Participants:

Claire	Harvard University
De`Angelo	University of Florida, Jacksonville
Delia	University of Miami
Gloria	University of Florida, Jacksonville
Julie	University of Alabama
Julie	Westat
Kim	Texas Children's Hospital
Latrina	University of Alabama
Leslie	Texas Children's Hospital
Marilyn	Bronx-Lebanon Hospital Center
Megan	Westat
Ramona	University of Florida, Jacksonville
Rosetta	Bronx-Lebanon Hospital Center
Stephanie	University of Miami
Yuri	University of Miami

• **APPROVAL OF MINUTES**

The minutes from the February 27, 2014 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:

- Puberty and sexuality in youth living with HIV;
- Toxic love and being positive;
- Study visits;
- Educational needs and children with learning challenges; and
- Outlets for children who live in violent households.

• **SPRING 2014 LEADERSHIP RETREAT**

Delia talked about the PHACS Spring 2014 Leadership Retreat. The retreat was at the Bolger Center in Potomac, Maryland on March 20-21, 2014. Mary-Ann Davies was one of the plenary speakers. Mary-Ann is a public health medicine specialist and epidemiologist at the University of South Africa in Cape Town, South Africa. She talked about pediatric HIV in Southern Africa. She also talked about the International Epidemiologic Databases to Evaluate AIDS (IeDEA) project. She talked about age of consent in South Africa. In some cases, children in South Africa may be able to consent to treatment. De`Angelo talked about Mary-Ann's presentation. As soon as children in South Africa are able to understand, in some cases, they can decide to be in a research study. They may also be able to decide on whether to take medications.

Delia talked about the second plenary speaker, Andrea Ciaranello. She is the Assistant Professor of Medicine at the Medical Practice Evaluation Center and Division of Infectious Diseases at Massachusetts General Hospital and Harvard Medical School. She talked about pediatric HIV policy and clinical care. She talked about computer simulation modeling. She also talked about cost-effectiveness. De`Angelo talked about the computer simulation. The researchers used the model to determine whether a research study would benefit the participants. It considers many different variables.

Delia talked about the Working Group (WG) sessions. The Hearing and Language WG session focused on hearing testing. It also focused on ADHD diagnosis. Researchers noted that ADHD may be linked to poor social outcomes.

De`Angelo talked about ADHD. There is not a diagnostic medical test for ADHD. A doctor can diagnose a child with ADHD through a series of screenings and medical history evaluation. Leslie talked about ADHD. ADHD can be different in girls and boys. Learning may be challenging for children with ADHD. Doctors can prescribe medication to help children with ADHD. Parents can advocate for their children. CAB Members can ask their doctors for more information about ADHD.

Delia talked about the Maternal Exposures WG session. The session focused on pre-term baby delivery. Delia talked about the Complications WG session. The session focused on medication adherence. Researchers also talked about adolescents living with HIV who were born to mothers with HIV. Also at the meeting, Megan and Claire talked about the new PHACS website.

- **NEW PHACS WEBSITE**

Claire stated that the new PHACS website (<http://phacsstudy.org>) will be released on April 4, 2014. The website is currently in a testing phase. 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. CAB members will be able to create their own usernames and passwords. There will be a discussion forum that is for CAB members only.

Megan talked about the CAB pages on the new website. CAB members must have a user name and password to access the CAB pages. 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.

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.

Megan and Claire will present a new website demonstration during the April call.

- **PHACS CAB CHAIR AND VICE CHAIR ELECTIONS**

Delia talked about the PHACS CAB Chair and Vice Chair elections. The Vice Chair has slightly less responsibilities. The Vice Chair position is a good fit for someone who wants to get involved in CAB Leadership but is not quite ready for the Chair role.

The Chair and Vice Chair positions require a time commitment. During a typical month, the CAB Chair will put in about 3 hours of work. The Vice Chair will put in about 1 hour a month. The Chair and the Vice Chair will work more time before June and December to work on the PHACS CAB Newsletters. The Chair and Vice Chair will also work longer during Spring and Fall to prepare for and attend the PHACS meetings. The PHACS CAB Chair and Vice Chair roles are a two year commitment.

Megan talked about the nomination process. CAB members can nominate themselves or other CAB members. CAB members can submit nominations by emailing Megan. They may also nominate someone through the PHACS CAB Evaluation Survey. CAB members must write 3-5 sentences about why their nominee would be a good candidate. The CAB will review nominations during the April call. Kim nominated herself for the Vice Chair position.

- **HEALTH EDUCATION AND COMMUNICATE COMMITTEE (HECC)**

Claire talked about the Health Education and Communication Committee (HECC). Claire talked about the disclosure comics. The comics will be for caregivers living with HIV. The purpose of the disclosure comics is to help caregivers disclosure their HIV status to their children. The HECC is working with an intern, Lauren, on the disclosure comics. Lauren is continuing to work on drafts of the comic strips. She has almost completed the first comic strip about basic information about HIV. She's hoping to create about 3-5 comics. The HECC received feedback about the comic strips during the Spring 2014 Leadership Retreat. All CAB members are welcome to give feedback for the disclosure comics.

NOTE: The next CAB call will be on Thursday, April 24, 2014 at 12:00 pm EST.