

**CAB Conference Call
August 28, 2014
12:00 EST
Meeting Minutes**

Participants:

Andrea	Jacobi Medical Center
Carrie	University of Colorado, Denver
Claire	Harvard University
Delia	University of Miami
Dolores	St. Christopher's Hospital for Children
Exzavia	Children's Diagnostic and Treatment Center
Jeanie	University of Southern California, Los Angeles
Jennifer	University of Colorado, Denver
Juan	University of Puerto Rico
Juanita	Tulane University
Julie	Harvard 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
Marlene	Jacobi Medical Center
Megan	Westat
Ramona	University of Florida, Jacksonville
Rosetta	Bronx-Lebanon Hospital Center
Stephanie	University of Miami
Susie	University of Alabama, Birmingham
Tatania	Tulane University
Theresa	Texas Children's Hospital
Veronica	University of California, San Diego
Yuri	University of Miami

• **APPROVAL OF MINUTES**

The minutes from the July 24, 2014 call were approved with no changes.

• **PHACS CAB EVALUATION SURVEY RESULTS**

Megan talked about the PHACS CAB Evaluation Survey results. There were 8 responses. Comments about the SMARTT Hair Collection Handout were sent to Monica Gandhi. Many CAB members enjoyed the stigma discussion. Some suggested topics for upcoming calls are:

- Pre-exposure prophylaxis (PrEP);
- Site CAB meetings;
- Disclosure;
- Response to protocols;
- Vasectomies for prevention;
- Re-infection;

- Stem cells and HIV;
- Depression; and
- Antiretroviral options.

• **PREP OVERVIEW**

Yuri talked about Pre-Exposure Prophylaxis (PrEP). Prophylaxis is something you do to prevent an infection. For PrEP, HIV-negative people take an anti-HIV medication daily, such as Truvada, to prevent HIV infection. Truvada was approved by the FDA for use by HIV-negative people as PrEP in June 2012.

The first biomedical HIV prevention success was the Prevention of Mother to Child Transmission (PMTCT). In PMTCT, HIV-medication is taken by HIV-infected mothers during pregnancy. This helps to stop the baby from getting HIV. Yuri talked about the "Comprehensive HIV Prevention Toolbox." The toolbox includes condom use, PrEP, and PMTCT. It also includes education, and circumcision.

There have been many PrEP research studies. One study enrolled 2,500 HIV-negative men-who-have-sex-with-men (MSM) and transgender women. This study took place in six countries from 2007-2010. Half of the participants took Truvada daily. The other half took a sugar pill daily. Results showed an average 44% reduction in HIV transmission for the participants who took Truvada. This was compared to the group who took the sugar pills.

Another research study enrolled about 5,000 heterosexual couples. In these couples, one partner had HIV. One partner did not have HIV. This study took place in Kenya and Uganda. This study looked at using Truvada or Viread to prevent HIV. Results showed 67% reduction in HIV transmission for the participants who took Viread. There was a 75% reduction in HIV transmission for the participants who took Truvada.

A third study looked at 2,000 HIV-negative women who had an increased risk for getting HIV. They had an increased risk for getting HIV because they engaged in high-risk sexual behavior. Women were enrolled in three countries in Africa. Half of the women took Truvada daily. The other half took a sugar pill daily. Results showed that there was no difference in the rate of HIV transmission between the two groups. Less than 40% of the women who took Truvada used it daily.

The Centers for Disease Control (CDC) made several recommendations because of the research studies. Truvada should only be taken for HIV-prevention by people who are confirmed to not have HIV. It is shown to be partially effective for prevention of HIV transmission when used in combination with other methods. Truvada does not protect against other STIs. People taking Truvada for HIV prevention should be closely followed by health care providers. There are some people who shouldn't take Truvada due to other medical conditions. There are more research studies in progress looking at the efficacy of PrEP.

Theresa talked about PrEP. There are some studies in Houston looking at the efficacy of PrEP. Truvada can be very expensive. Women may be looking to use Truvada to prevent HIV transmission if they have an HIV-infected partner.

Megan talked about PrEP. Some people have worried that people taking Truvada will engage in high-risk sexual behavior. Yuri also said that the CDC recommends that HIV-negative people taking Truvada talk with their doctors and get tested for HIV and STIs regularly.

Jennifer talked about the cost of Truvada. It may be difficult for HIV-negative people to afford Truvada. It might also be difficult for HIV-negative people to remember to take Truvada every day.

- **PHACS FALL 2014 CAB RETREAT AND NETWORK MEETING**

Megan talked about the PHACS Fall 2014 CAB Retreat and Network Meeting. The CAB Retreat is on October 21, 2014 from 1:00 PM – 6:00 PM EST at the Bethesda Hyatt Regency in Bethesda, MD. The Fall Network Meeting will take place at the same place on October 22-23, 2014. Megan sent invitations to CAB members who met the call attendance requirement last week. Westat Travel representatives have started calling CAB members to make their travel and hotel arrangements. CAB attendees must sign their "Statement of Commitment" forms by Friday, September 19, 2014.

Westat will send CAB attendees a check for the full per diem amount before the start of the meeting. Per diem is the money given to attendees to pay for meals not provided by the meetings and ground transportation. Ground transportation includes travel to and from the meeting and airport. Westat will send a letter with the per diem check that shows the breakdown of expenses. The letter will show how much money has been given for each meal not provided by the meeting. It will also show money given for ground transportation. CAB attendees should cash the check before the meeting. CAB attendees can keep any money they don't use. Megan is working with Study Coordinators to figure out the best place to send the per diem checks for the CAB members.

The HECC CAB Subcommittee put together the agenda for the CAB Retreat. Megan reviewed the agenda. Kim and Dolores will present the welcome/icebreaker session. Claire will run the disclosure workshop. Julie from Westat will present the AMP Up jeopardy game. Yuri will lead a panel discussion about working with young adults. Several CAB members will participate on the panel. Julie will present the Working Group (WG) updates from each PHACS WG. Claire will present a Young Adult CAB (YACAB) overview. Finally, there will be a joint Study Coordinator/CAB session. Megan encouraged CAB members to suggest questions to ask the Study Coordinators.

Megan talked about an invitation from the Hearing/Language WG. The Hearing/Language WG has invited CAB members to share their experiences with hearing, language, and speech disorders. The WG is looking to share these anonymous CAB testimonials during their WG session at the meeting. CAB members can contact Megan for more information.

Megan talked about the informal CAB dinner. CAB members are invited to attend an optional informal dinner after the CAB Retreat. CAB attendees will use their per diem money for the dinner. Megan sent out website links to two restaurant menus, La Madeleine, and Tommy Joe's. Megan encouraged CAB members to vote for a restaurant. Megan will share the results of the vote before the next CAB conference call.

Claire talked about the disclosure workshop. During the workshop, the CAB will review disclosure scenarios. The CAB will talk about comfort levels with each of the disclosure scenarios. The CAB will talk about the differences in reactions to real-life disclosure scenarios. Kim talked about the disclosure workshop. At the end of the workshop, the CAB will pop balloons with the word, "stigma," written on them.

NOTE: The next CAB call will be on Thursday, September 25, 2014 at 12:00 pm EST.