

**CAB Conference Call
June 21, 2012
12:00 EST
Meeting Minutes**

Participants:

Carlos	San Juan Hospital
De`Angelo	University of Florida – Jacksonville
Delia	University of Miami
Denise	Harvard University
Dorothy	University of Alabama at Birmingham
Jennifer	University of Colorado
Juan	University of Puerto Rico
Julie	Harvard University
Julie	Westat
Krystal	Harvard University
Laurie	FSTRF
Leslie	Texas Children’s Hospital
Megan	Westat
Miriam	Harvard University
Rosetta	Bronx - Lebanon
Sheila	University of Florida – Jacksonville
Theresa	Texas Children’s Hospital

• **APPROVAL OF MINUTES**

The minutes from the May 24, 2012 call were approved with no changes.

• **NUTRITION SUBSTUDY OVERVIEW**

Denise talked about the PHACS Nutrition Substudy. The researchers in the study get dietary data on women in the dynamic cohort in SMARTT. Women are asked to participate in the study at the site during the third trimester of pregnancy. Site staff draws blood from the participants to look at the micronutrients in their blood. Micronutrients include vitamin D, vitamin A, and vitamin E.

Participants are given a cell phone. The University of Miami dieticians call the participant three times over two weeks. The dieticians write down everything that the participant ate and drank over a 24-hour period. They review the diet many times to make sure they are getting accurate information. This is called the multiple task method.

Three-hundred women have been recruited to participate in the Nutrition Substudy. Denise talked about the data from the study. Denise reported that 66% of the women in the study had a high school education, and 84% had an undetectable viral load. Participants’ average CD4 % was 31. Average Body Mass Index (BMI) was 27. BMIs of 25-30 are considered overweight, and 30+ is considered obese. The weights and head circumferences of the babies born to participants in the study were below average. The participants in the study consumed an average of 2,000 calories.

The scoring system used in the study is called the Healthy Eating Index (HEI). The HEI assigns a score to the items that the participants eat and drink. Healthy diets should include a certain amount of nutrients. The HEI looks at what the participant eats and drinks. The HEI then determines the quality of the diet. HEI also looks at food security. Food security is a household’s ability to access and buy nutritious foods for the family. Of the participants in the study, 32% were food insecure. Tracy Miller, Co-Principal Investigator of the Nutrition Substudy, did an analysis on factors having to do with better eating. The researchers found that women in the study born outside the United States had a higher

HEI. Among women born in the United States, African-American women had a lower HEI. HIV co-variants (high viral loads, drug exposures, etc.) were not associated with the HEI. Denise thought that they should talk with women with lower HEIs to get them to eat better.

Denise is looking at single nutrients and how they affect birth outcomes. Birth outcomes are weight, height, and weight-for-length. She is also looking at characteristics of the children as they age. She will determine if what women eat during pregnancy can have long term outcomes.

Jennifer wondered if the caloric take for the pregnant women in the study was low.

Leslie thought that the use of cell phones to do assessments was a good idea. Participants are able to be reached wherever they are. They do not have to come to the clinic for a study visit.

Theresa thought that the study was successful. The researchers are using patients who are interested in clinical research because most of the women were co-enrolled in other studies. Theresa thought that this may be a biased population. This study minimizes the burden to the participants. The participants are allowed to keep the cell phone. They can buy minutes and use the cell phone for personal use after the study is over.

Denise talked about the feedback for the Nutrition Substudy. Some of the women appreciated getting feedback on what they were eating. Dorothy thought that the participants may also enjoy the personal relationships that they develop with the health care team.

• **PHACS CAB EVALUATION SURVEY RESULTS**

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

- adolescents and pre-adolescents and adherence to medication,
- Drug-on-drug interactions,
- how to cope with the loss of a loved one,
- update on PHACS from each site, and
- invite a Study Coordinator of a successful site and have he/she share experiences in preparation for the PHACS 2012 Fall Network Meeting.

• **HELPING CHILDREN AND TEENS COPE WITH LOSS OF A PARENT**

Megan talked about the topic of helping children and teens cope with loss of a parent. The PHACS CAB leadership had been working with the PHACS neuropsychologists on this topic. Megan emailed the CAB about participating in a separate conference call to talk about this topic. There has been little feedback. The PHACS leadership wondered if the CAB would be interested in having a session at the 2012 Fall Network meeting to talk about this topic. Julie from Westat confirmed that one CAB representative from each PHACS site will be invited to attend the 2012 Fall Network meeting. The CAB agreed to have this session at the meeting.

• **CAB VICE CHAIR NOMINATIONS**

Megan talked about the CAB Vice Chair nominations. Megan thanked Jennifer for her service for the past two years as the CAB Chair. Delia is now the incoming CAB Chair effective June 2012. Rosetta and DeAngelo were both nominated for the CAB Vice Chair. DeAngelo was elected to be the Vice Chair for the next two years.

- **NEWSLETTER, JUNE 2012 EDITION**

Megan talked about the June 2012 edition of the PHACS CAB newsletter. The newsletter follows a theme of living healthy with HIV. Megan will distribute the newsletter to PHACS members soon. The Spanish version of the newsletter will also be sent out as soon as it is available.

Megan talked about the 2012 International AIDS Society (IAS) conference. The IAS conference is on July 22-27, 2012 in Washington, D.C. The National Institute of Health (NIH) will have a booth at the IAS conference. NIH was encouraged to have handouts at their booth. The PHACS leadership wanted to ask the CAB's permission to pass out the PHACS CAB newsletters. The CAB decided to let NIH to distribute the PHACS CAB newsletters at the 2012 IAS conference with minor revisions.

Action Items:

1. **Megan will distribute the PHACS CAB Newsletter, June 2012 Edition to all PHACS members.**
2. **Megan will remove any last names used in the PHACS CAB newsletters.**

- **PHACS DISCLOSURE FACT SHEET**

Megan talked about disclosure. There are still parents struggling with telling their children about their own HIV infection. Some PHACS Study Coordinators (SC) thought it might be helpful to develop a fact sheet about disclosure. The fact sheet would talk about the issue of disclosure from the CAB member perspective. After the CAB finalizes the disclosure fact sheet, Megan will send it to the PHACS clinical staff for their input. Leslie suggested including a fact about providing children with a handout or website about HIV. A handout or website would give the child something to look back on. Rosetta suggested advising parents to have disclosure talks when the child asks questions about medication or trips to the clinic. Theresa talked about the healthcare team as a resource for parents and children dealing with disclosure.

- **CAB SURVEY EVALUATION TOPIC – HOW TO LIVE A NORMAL HEALTHY LIFE WITH HIV**

This topic was suggested in the PHACS CAB Evaluation Survey. Megan sent out two internet articles about living a health normal life with HIV and how to take care of yourself. Megan talked about the articles. The first article talks about general health maintenance strategies. The article talks about a model of health that looks at different areas of health. These areas of health are physical health, mental health, spiritual health, and social health.

The article talked about addressing physical health with healthcare providers. Little changes in diet and exercise can help improve physical health. Healthy sleeping habits and stress reduction can also contribute to good physical health.

Mental health is just as important as physical health. Addiction is a mental health problem that comes in many forms. Addiction is something that people should talk about with their doctor. The article also talked about depression. Some studies suggest that the most common psychiatric diagnosis among people living with HIV is depression. People living with HIV who may be dealing with depression should talk to their doctor.

The article also talked about the importance of spiritual health. Spirituality can mean something different to everyone. Spirituality is not just defined by a religion.

Social health is not necessarily about relationships with others. It is also about a person's relationship with his/her community.

The second article has tips about how to take care of yourself. The article suggests that people living with HIV should refuse to be victims. It can be helpful to be educated about HIV. People should also let out emotions. It can be beneficial to talk with others who are also living with HIV.

Megan talked about the website, www.thebody.com. Jennifer agreed that this website has many good resources about living with HIV.

- **HIV TESTING DAY – JUNE 27**

Megan talked about HIV testing day. HIV testing day is Wednesday, June 27.

NOTE: The next CAB call will be on Thursday, July 26, 2012 at 12:00 pm EST.