

**CAB Conference Call
January 23, 2014
12:00 EST
Meeting Minutes**

Participants:

Carlos	San Juan Hospital
Carrie	University of Colorado, Denver
Claire	Harvard University
Delia	University of Miami
Dwan	University of Florida, Jacksonville
Jennifer	University of Colorado, Denver
Juan	University of Puerto Rico
Julie	Harvard University
Julie	Westat
Kim	Texas Children's Hospital
Krystal	Harvard University
Laurie	FSTRF
Marilyn	Bronx-Lebanon Hospital Center
Marlene	Jacobi Medical Center
Megan	Westat
Rosetta	Bronx-Lebanon Hospital Center
Stephanie	University of Miami

• **APPROVAL OF MINUTES**

The minutes from the December 19, 2013 call were approved with no changes.

• **PHACS CAB EVALUATION SURVEY RESULTS**

Megan talked about the PHACS CAB Evaluation Survey results. There were 5 responses. Some suggested topics for upcoming calls are:

- Site closure; and
- CABs and support groups.

• **NETWORK MEETINGS AND CAB RETREATS – CAB CALL ATTENDANCE REQUIREMENTS**

Megan talked about CAB call attendance requirements for future PHACS Network Meetings and retreats. Starting with the January conference call today, PHACS CAB attendees must attend 60% of monthly CAB calls in order to be eligible to go to the retreat and meeting. This means CAB attendees must call-in to four monthly calls from January to August 2014. CAB attendees are typically picked in August. CAB attendees must also attend the August and September 2014 calls. This will help attendees prepare for the meeting and retreat.

There will be exceptions made as needed for unavoidable barriers. Exceptions will only be given to active Site CAB members. Exceptions may include barriers such as: language, call availability, and illness.

• AMP UP OVERVIEW

Julie Alperen talked about the Adolescent Master Protocol for Participants 18 Years of Age and Older (AMP Up). Julie is the PHACS Project Director at the Harvard School of Public Health. The protocol was sent to the sites. However, the AMP Up protocol team is making some edits to the protocol before enrolling participants. The edits are about adding laboratory tests for AMP Up participants who are enrolled in AMP substudies. Site will send the final protocol to their local Institutional Review Board (IRB) for approval. Once approved by the IRBs, the protocol may potentially open for enrollment in February 2014.

The objective of AMP Up is to define the impact of HIV and antiretroviral therapy (ART) on young adults with perinatal HIV as they reach adulthood. There will be fewer regular clinic visits. There will be seven study visits. Participants will only need to come to the clinic for the enrollment/entry, year three, and year six study visits. All other visits can be done at home or anywhere outside of the clinic. Participants can choose to come to the clinic for other visits if they want. Site staff will look at participants' medical charts each year.

Laboratory samples will be collected every year. For the years that participants do not have to come to the clinic, the samples will be self-collected. Participants will be able to collect their own laboratory specimens at home using a kit. They will be able to drop their samples off at the clinic. They may also have the option to mail the samples to the clinic. Site staff will collect samples for the storage center (repository) during the in-person visits. This is only for participants that gave consent for specimen storage. These samples are sent to the repository for future testing.

AMP Up participants will take online surveys by themselves every year. There are eight surveys about demographics, health care, quality of life, sex, reproductive history, substance use, adherence, and diet. Surveys will take about one hour to complete. The surveys will be easy to use. The AMP Up protocol team reviewed the surveys with the PHACS Working Groups (WGs), study coordinators, and data managers. The team also reviewed surveys with Young Adult CAB (YACAB) members and adult CAB members.

Researchers will be collecting neurodevelopmental information in AMP Up. Participants will take surveys using the NIH Toolbox during the in-person visits. Each survey in the NIH Toolbox takes about five minutes. The surveys from the NIH Toolbox will be given by clinic staff. The surveys look at cognition, memory, emotions, and hearing.

There will be a few different tools for measuring diet and exercise. Participants will take the Online Automated Self-Administered 24 Hour Recall (ASA24) survey. This survey asks participants about what they ate in the last 24 hours. It takes 20-30 minutes to complete. Participants will also take a survey about physical activity. This survey is called the Block Physical Activity Screener. It has eleven questions. It should take about five minutes. The survey asks about job-related, daily life and leisure activities.

Delia asked about confidentiality. The online surveys use highly protected servers with firewalls. Information is connected to codes, not to participants' names. Participants will be given participant instruction sheets. These sheets have information about how to protect confidentiality while taking the surveys.

AMP Up participation right now is limited to AMP participants who are HIV-infected or HIV-exposed but uninfected. The protocol states that the study may be opened up to other adolescent HIV cohorts in the future.

AMP Up participants will take a language test. The language test is called the Clinical Evaluation of Language Fundamentals (CELF). The CELF will be given once during one of the in-person visits. The CELF looks at many language skills. It will be given by a trained interviewer.

In AMP Up there are a couple tests for depression and symptoms of other psychiatric conditions. The Center for Epidemiologic Studies Short Depression Scale (CES-D 10) test measures self-reported depressive symptoms. This test is done with an interviewer at the site.

The Client Diagnostic Questionnaire (CDQ) is currently done with caregivers in AMP. In AMP Up, participants will take the CDQ. It looks at current symptoms of psychiatric disorders. The CDQ is given by a psychologist. It takes about 20 minutes to complete.

Dwan asked about laboratory sample collection. Participants will use a self-collection kit for STI testing. The AMP Up protocol team made an instruction sheet for AMP UP participants. The instruction sheet will be given to participants with the testing kit. The kit is designed to be able to be sent through the mail. Participants will be given mailing materials. Participants may be able to mail in their samples or drop them off at the clinic. Some clinics may use different kits for local STI testing that may not be able to be sent through the mail.

Participants enrolling in AMP Up will have the opportunity to open an account on a PHACS Young Adult website. Participants must make a website account at the clinic with a study coordinator.

Jennifer asked about disclosure. The AMP Up protocol team got advice from an ethics committee about disclosure. Participants in the control group in AMP Up are not required to know about their HIV exposure status. Based on recommendations from the ethics committee, the AMP Up informed consent form template does not disclose to participants that they were exposed to HIV. Each site's IRB will make final decisions about what to put in the informed consent forms about disclosure. In AMP and SMARTT, site staff members regularly ask caregivers about disclosure. The PHACS protocol teams are continuing to explore the issue of disclosure.

• **CAB HANDBOOK – COMMUNICATION AND SITE CAB MEETINGS**

Megan talked about the CAB Handbook. Megan asked the CAB about how they communicate at their sites about site CAB meetings. Stephanie talked about site CAB communication. The site CAB Chair emails and/or calls CAB members to let them know about upcoming meetings. During the first meeting of the year, the CAB Liaison hands out the meeting schedule for the year. If a meeting is cancelled, the site CAB Chair calls and emails CAB members.

Kim talked about site CAB communication. CAB Leadership and Liaisons call and email CAB members about upcoming meetings. They also mail information for members who don't use email or phone. The CAB Liaison often calls CAB members about transportation needs. Marilyn talked about site CAB communication. The CAB chair texts, calls, and/or emails members about upcoming meetings. Site staff members send meeting-related mailings if needed. Dwan talked about site CAB communication. Peer navigators make phone calls and send out mail invites for upcoming meetings. Most is done by mail and phone. The site CAB Chair comes up with the agenda.

• **ROUNDTABLE DISCUSSION**

Delia talked about the roundtable discussion series. Many CAB members wanted to have more interactive and personal discussions during CAB calls. Roundtable discussions were suggested to be for CAB members only. During the last call, there was some concern voiced about staff participation in roundtable discussions. The CAB Leadership recommended that these discussions happen 30 minutes before the regularly schedule PHACS CAB conference calls. CAB members can comment through the survey about when to hold roundtable discussions.

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

Claire talked about the Health Education and Communication Committee (HECC). Claire talked about the new AMP Up website for young adults. All AMP Up participants will be able to sign up for the

website during their first AMP Up study visit. The new website will have resources for transitioning into adulthood. It will also feature a storytelling feature called a "story map." Young adults will be able to log onto the website and answer questions. The map will show what young adults from different parts of the country and Puerto Rico think about different topics.

Claire talked about the disclosure resource. The resource will be for caregivers living with HIV. It is aimed to help them make a decision about whether and when to disclose to their children. The HECC is working with an intern, Lauren, on the disclosure resource. Lauren will be helping create coloring books and comic strips for the disclosure resource. The resource will hopefully help caregivers talk to their children about HIV. CAB members can volunteer to help give feedback for the disclosure resource.

Another intern, Chinyere, is working with the HECC. Chinyere is helping to make a media strategy for PHACS. The strategy will help us find ways to reach out to people within PHACS. It will also help PHACS members reach out to the public. Chinyere, Megan, and Claire had a call with the Site 13 CAB. The Site 13 CAB shared their ideas about how to talk with the public about PHACS. All other site CABs are welcome to volunteer to give feedback about the media strategy.

NOTE: The next CAB call will be on Thursday, February 27, 2014 at 12:00 pm EST.