

**CAB Conference Call
June 22, 2017
12:00 EST
Meeting Minutes**

Participants:

Alexandria	FSTRF
Amy	University of California, San Diego
Andrea	Jacobi Medical Center
Brandon	University of Florida, Jacksonville
Claire	Harvard University
Delia	University of Miami
Exzavia	Children's Diagnostic and Treatment Center
Gena	University of Miami
Jeanie	University of Southern California
Joel	University of Puerto Rico
Julie	University of Alabama, Birmingham
Julie	Westat
Kimbrae	Texas Children's Hospital
Latrina	University of Alabama, Birmingham
Lesley	Texas Children's Hospital
Lourdes	San Juan Hospital
Marilyn	Bronx-Lebanon Hospital Center
Megan	Westat
Raiko	University of Colorado, Denver
Rosetta	Bronx-Lebanon Hospital Center
Stephanie	University of California, San Diego
Stephanie	University of Miami
Theresa	Texas Children's Hospital
Veronica	University of California, San Diego

• **APPROVAL OF MINUTES**

The minutes from the May 25, 2017 call were approved with no changes.

• **PHACS CAB EVALUATION SURVEY RESULTS**

Megan talked about the call attendance requirement. CAB members who attended 60% of the calls from December – June are eligible to attend the meeting and retreat. This means that CAB members who have fulfilled the requirement may be invited to attend. **Megan** will contact the Study Coordinators to let them know which CAB members may attend. **Megan** will email Study Coordinators before the July CAB call.

Megan talked about the survey. There were 8 responses. Topics suggested through the survey included:

- Transitions to adult care;
- Strategies to contact teens and young adults living with HIV;
- Getting local community members involved with the CAB;
- Publicity for PHACS;
- Updates from the Human Longevity Institute;

- Health literacy;
- New medications and side effects;
- HIV and mental health;
- HIV and aging;
- Dating with HIV;
- Living with HIV;
- Lowering stress levels;
- Happiness and HIV; and
- HIV replication.

- **QUESTIONS FOR THE METABOLIC WORKING GROUP ABOUT METABOLISM AND HIV-EXPOSED BUT UNINFECTED YOUTH**

Stephanie talked about questions for the Metabolic Working Group (WG). Many CAB members expressed an interest in learning about metabolism and HIV-exposed but uninfected (HEU) youth. The Metabolic WG will be giving a presentation during the July CAB call. **Stephanie** suggested that the CAB put together some questions for the Metabolic WG. The Metabolic WG may review the questions during their presentation. The following questions were suggested by CAB members:

- What has PHACS learned about children’s metabolism and medications given during pregnancy? Are there any data about specific medications received during pregnancy?
- What has PHACS learned about medications given during pregnancy and other conditions that may affect metabolism? Is there any research about hyperthyroidism?
- Are there any data regarding other non-ARV medications given during pregnancy and metabolism?
- Do genetics play a role in metabolism?
- Tell us more about the metabolic trigger for Body Mass Index (BMI). What is the significance of this trigger? What have we learned so far from the triggered laboratory results for children who met this trigger?

Megan will send the questions to the Metabolic WG. **Megan** reminded the CAB that the Metabolic WG will answer as many of the questions as possible with the data that PHACS has collected.

- **PHACS CAB NEWSLETTER, JULY 2017 EDITION**

Stephanie talked about the PHACS CAB Newsletter, July 2017 edition. The CAB chose a theme of, “Endurance, Strength, and Survival.” **Stephanie** encouraged CAB members to send in articles, for the newsletter. **Stephanie** talked about sources of strength. The CAB also talked about survival. Several CAB members anonymously submitted quotes about strength and survival for the newsletter.

- **SITE CAB SHARING**

Stephanie talked about site CAB meetings. **Stephanie** encouraged CAB members to share about their site CAB meetings.

Stephanie from Miami talked about her site CAB. There are several new members at the University of Miami site CAB. The CAB has not had a recent site CAB meeting. Some of the new site CAB members want to participate in the PHACS CAB.

Veronica talked about the most recent site CAB meeting at the University of California, San Diego. A researchers joined the site CAB meeting to talk about HIV research. A site CAB member helped lead the meeting. Many site CAB members liked having the meeting led by a fellow CAB member. **Veronica** suggested that other site CABs consider encouraging site CAB members to lead site CAB meetings.

Marilyn talked about the most recent site CAB meeting at Bronx-Lebanon Hospital Center. Research staff talked about studies on new HIV medications. Researchers also talked about stigma.

- **HEALTH EDUCATION AND COMMUNICATION COMMITTEE**

Claire talked about the Health Education and Communication Committee (HECC). **Claire** was invited to speak on a panel at a conference. The panel was about HIV health literacy in communities of color. Many of the panel members talked about language barriers in medical clinics. The panel also talked about HIV stigma in medical clinics. The panel talked about the importance of training everyone at a medical clinic on stigmatizing behaviors. **Claire** shared **Mariam Davtyan's** Photovoice project with the panel. Many of the Photovoice participants are now training healthcare workers on stigmatizing behaviors.

The panel talked about respect and peer empowerment. It's important not to assume an understanding of someone's cultural beliefs without getting to know them. It can help to employ peer navigators. Empowerment can help guide others through diagnosis and treatment. **Exzavia** talked about the importance of peer navigation. Many patients may be more open to listening to a peer.

The panel talked about personal goals outside of living with HIV. Many patients go to a medical clinic having their own goals. These goals may or may not be directly related to HIV. One panelist recommended asking patients, "What's the dream, and how can I help you get there?"

- **INTERVIEWS WITH THE CAB CHAIRS**

Stephanie talked about interviews with the CAB Chairs. **Stephanie** and **Brandon** would like to get to know the CAB members better. CAB members can volunteer to meet with **Stephanie** and **Brandon** through the PHACS CAB Evaluation Survey. CAB members can share feedback, propose ideas, or share personal stories with the CAB Chairs.

NOTE: The next CAB call will be on Thursday, July 27, 2017 at 12:00 pm EST.