

**CAB Conference Call
December 27, 2012
12:00 EST
Meeting Minutes**

Participants:

Claire	Harvard University
De`Angelo	University of Florida, Jacksonville
Julie	Westat
Laurie	FSTRF
Marilyn	Bronx-Lebanon Hospital Center
Mary Anne	Westat
Megan	Westat
Rosetta	Bronx-Lebanon Hospital Center
Theresa	Texas Children's Hospital
Yuri	University of Miami

• **APPROVAL OF MINUTES**

The minutes from the November 29, 2012 call were approved with no changes.

• **PHACS CAB EVALUATION SURVEY RESULTS**

Megan talked about the PHACS CAB Evaluation Survey results. There were 3 responses. Some suggested topics for upcoming calls are:

- Vitamins and medication levels,
- HIV+ adoption,
- Vitamin D deficiency in youth transitioning from pediatric to adult care,
- Women's health, and
- The IMPAACT PROMISE study.

• **PHACS CAB NEWSLETTER, DECEMBER 2012 EDITION**

Megan talked about the PHACS CAB Newsletter, December 2012 Edition. The theme for the newsletter is "Emotional and Developmental Aspects of Children and Adolescents." Mega will send the newsletter to the PHACS Broadcast email group by the end of the month. Some newsletter pieces include PHACS member profiles, an article on postpartum depression, CAB kids' snowflake submissions, a poem, recipes and a quiz. Megan thanked the CAB for their newsletter submissions.

Action Item: Megan will send the PHACS CAB Newsletter, December 2012 Edition to the PHACS Broadcast email group.

• **HEALTH EDUCATION AND COMMUNICATION COMMITTEE (HECC) UPDATE**

Claire talked about the Health Education and Communication Committee (HECC). The HECC has members from all different areas of PHACS. The HECC had its first call on December 6, 2012. During this call, the group agreed on the overall goals of the HECC. They also decided on target audiences. The target audiences will include the CAB, PHACs study participants, general public, and researchers.

The HECC is looking to work on health education and communication projects in PHACS. The HECC is also looking to make a website for young adults in PHACS. Claire will be serving as the Chair. The HECC elected Megan to serve as Vice Chair. There will be four subcommittees in the HECC. There will be a Retention Subcommittee and a CAB Subcommittee. There will also be a Publicity Subcommittee. The fourth subcommittee will work on a website for young adults in PHACS. HECC calls will typically be on the first Thursday of every month at 1:00 PM EST. The next HECC will be on January 10 at 1:00 PM EST. The CAB can email Megan or Claire to join the HECC. CAB Members can also ask to be on the HECC through the PHACS CAB Evaluation Survey.

Action Item: Megan will add a section to the PHACS CAB Evaluation Survey for CAB members to volunteer to join the HECC.

• CAB NETWORK MEETING DISCUSSION

The PHACS Fall 2013 Network Meeting is October 2-3, 2013 in Baltimore, MD. The PHACS leadership may extend the meeting to have time for a CAB retreat. The CAB retreat would have CAB-specific sessions. The CAB retreat would be before or after the Network Meeting. CAB members would still attend all sessions at the Network Meeting. Megan asked the CAB about adding a CAB retreat.

DeAngelo thought a CAB retreat would give the CAB more time to process the meeting information. It would also mean that the CAB sessions wouldn't overlap with the Network Meeting sessions. Julie suggested that Megan send an email to the entire PHACS CAB about the CAB retreat. The hotel has meeting space for a CAB retreat during the afternoon before the meeting. Theresa suggested that Megan add an item to the survey about agenda topics for the CAB retreat.

Action Items:

- 1. Megan will email the CAB about adding a CAB retreat before the PHACS Fall 2013 Network Meeting.**
- 2. Megan will add an item to the PHACS CAB Evaluation Survey for CAB members to suggest agenda topics for the possible CAB retreat.**

• PARTICIPANT SUMMARIES – NEW FORMAT

Claire talked about the new format of the participant summaries. Claire got feedback from several CAB members about the new format. Most of those CAB members thought it was easier to read. The new format has less text. It also has a shorter title and more color. There is a short summary at the top to explain what the study was about.

Yuri thought the new format is easier to read. Yuri suggested that Claire include a footnote that includes the full title of the study. Theresa recommended adding a glossary at the end of the summary. Mary Anne suggested adding a glossary on the side of the page. Theresa suggested that Claire confirm that the summary prints clearly in black and white.

Claire will continue to use the new format of the participant summaries. Claire will talk about the new format of the participant summaries on the January CAB call.

Action Items:

- 1. Claire will talk about the new format of the participant summaries on the January CAB call.**
- 2. Megan will add an item to the PHACS CAB Evaluation Survey for CAB members to comment on the new format of the participant summaries.**

- **YOUTH ADHERENCE WEBINAR DISCUSSION**

Megan talked about a webinar called "Youth Adherence: Why Can't They Just Do as I Say!" The webinar was presented by Dr. Marvin Belzer. Dr. Belzer is a Professor of Clinical Pediatrics and Medicine at the Keck School of Medicine. He is also the Director of the Division of Adolescent Medicine at the Children's Hospital Los Angeles.

Adherence means taking medications as they are prescribed. There are direct and indirect ways to measure adherence. Direct measuring means to measure the amount of medication in the body. Indirect measuring can include counting pills or self-report. A doctor can also estimate a young adult's adherence.

There are many types of pill counting. There is a system that can record how many times a pill bottle is opened. It can also count how many pills are left. The easiest way to measure adhere is to ask young adults if they are taking their medications. This is called self-report.

There are many barriers to adherence. Barriers include how difficult the regimen is. This can refer to how many pills to take a day. It can also refer to the size of the pill or the taste of the pill. Unwanted side effects of medications can be a barrier to adherence. Another barrier to adherence is disease severity. This means how bad the disease affects a person. Stigma can be a barrier to taking medication. Other barriers to adherence include personal beliefs, understanding of medication, and doctor-patient relationship. Adherence is better when a patient is given clear instructions about his/her medication.

There are ways to improve adherence. Doctors can prescribe a treatment schedule that works specifically into a young adult's lifestyle. This can include not having to take multiple pills a day or taking pills with fewer side effects. It may also help to educate young adults about their medication. It may help to keep a pill schedule. It may also help to have a daily pill box. Putting an alarm on a young adult's cell phone can help remind them to take their medication.

Teens who were allowed to be more independent and take control of their medication schedules were reported to have better adherence. Megan encouraged the CAB to share the presentation with their local CABS

NOTE: The next CAB call will be on Thursday, January 24, 2013 at 12:00 pm EST.