

**CAB Conference Call
August 13, 2020
12:00 EST
Meeting Minutes**

Participants:

Anisa	Harvard University
Carrie	University of Colorado, Denver
Claire	Harvard University
Exzavia	Children's Diagnostic and Treatment Center
Ellen	Ann & Robert H. Lurie Children's Hospital of Chicago
Gloria	University of Florida, Jacksonville
Juanita	Tulane University
Julie D.	Westat
Haleigh	FSTRF
Kimbrae	Texas Children's Hospital
Kylie	Texas Children's Hospital
Liz	Harvard University
Megan	Westat
Raiko	University of Colorado, Denver
Sannita	University of Miami
Stephanie M.	University of California, San Diego
Theresa	Texas Children's Hospital
Trinise	Tulane University
Veronica	University of California, San Diego

• **APPROVAL OF MINUTES**

The minutes from the July 23, 2020 call were approved with no changes.

Megan talked to the CAB about the Women's Health Working Group (WG) calls. A high school student will be joining the Women's Health WG calls. She is interested in a career in public health. She has been told not to share any information from CAB members. CAB members can contact **Megan** with any additional guidance for the student.

• **PHACS 2020 TRANSITION**

Dr. Ellen Chadwick talked about the PHACS 2020 transition. **Ellen** explained that two grant applications were submitted to the NIH. One application was for the Health Outcomes around Pregnancy and Exposure to HIV/ARV (HOPE) study. This study will be an extension of the Maternal Health supplement. **Dr. Deb Kacanek** talked to the CAB about HOPE during the June 16, 2020 CAB call. The other application was for PHACS 2020. PHACS 2020 is the next round of funding for all of PHACS. Both applications were reviewed positively. Both applications were approved. The study team hopes to hear about the budget for the studies in the next couple of months.

Due to COVID-19, the reviews of the applications were delayed. Due to this delay, the grant that PHACS is currently using was due to expire before the new PHACS 2020 grant. That means that some budget cuts had to be made to make the transition. The budget cuts are only until the funding for the new grant is received.

Many sites were concerned about how to fund staff. It appears as though PHACS has received some bridge money to make the transition time a bit easier. However, sites have had to cut back study activities until PHACS 2020 is up and running. Sites have been asked to prioritize the study visits for 1, 3, and 5-year-olds in SMARTT. They can also prioritize new SMARTT enrollments. All other study visits

are postponed. PHACS 2020 will include some changes, but those have not yet been finalized. This is because the budget has not yet been received.

Ellen talked about site re-competition. In PHACS 2020, the NIH wants to make sure PHACS runs as smoothly as possible. This means they want confirmation that every site is doing the best work possible. In order to get that confirmation, all sites will have to “compete” to show that they should continue to work on PHACS. There is a possibility that some sites will not be able to continue next year. It is also possible that all sites will be able to continue. The re-competition will not happen until next year.

Kim talked about the re-competition. **Kim** expressed concern that some sites would not be able to continue in PHACS. **Ellen** and **Megan** explained that all CAB members may continue to participate in the CAB even if their sites are no longer part of PHACS.

Trinise talked about the re-competition. **Trinise** was concerned about the research participants that will be affected by sites potentially being closed. This research benefits the world. It seems wrong for sites to compete to contribute to this important research. It does not seem like the right time for competition. The study should be trying to be as unified as ever during this difficult time. **Kim** worried that some participants may be lost to care if their site closes. **Trinise** explained that some people may only visit the clinic to participate in PHACS. If PHACS closes at their site, they might not come to the clinic for care at all.

Ellen talk about the re-competition. **Ellen** confirmed that the re-competition will not happen until next year. **Ellen** encouraged the CAB to consider advocating against re-competition if they are concerned about it. **Megan** and **Claire** will work with the CAB to find the best way to advocate to the NIH.

Claire talked about the re-competition. **Claire** thanked the CAB for sharing their feelings. **Claire** acknowledged that this is a very difficult situation. PHACS wants to support the CAB, however possible. If the CAB wants to advocate for change, they should work together to find ways to advocate in meaningful ways.

Liz thanked the CAB for sharing their feelings. **Liz** agreed that it does not feel like the time for competition. **Liz** supports the CAB’s advocacy efforts.

Megan asked about whether participants would be able to transfer to other nearby sites if their site closed. **Ellen** confirmed that PHACS will make every possible effort to transfer participants, where geographically possible.

Gloria talked about advocacy. **Gloria** suggested that the CAB consider working with their site CABs to organize a letter writing campaign.

Ellen talked about the re-competition. **Ellen** explained that the re-competition was originally proposed to happen right away. The NIH agreed to postpone the re-competition until next year. The NIH wants to support PHACS as much as possible, but funding is very tight at the NIH. This means they have to put limits on budgets. This does not mean that NIH does not support PHACS. The NIH considers PHACS to be very important and valuable.

Theresa thanked **Ellen** for sharing this information. **Theresa** asked whether site staff should call participants to let them know their study visits are on hold. **Ellen** explained that site staff are encouraged to follow up with participants. Site staff are also reaching out to participants to complete a new health survey over the phone. This survey asks participants and their families about how COVID-19 has affected them. Many site staff are using this as an opportunity to check in with their participants.

Liz led the CAB through a mindfulness exercise.

Sannita recommended that the CAB talk about COVID-19 and children’s mental health on a future CAB call. Some children may be experiencing grief.

NOTE: The next CAB call will be on Thursday, August 27, 2020 at 12:00 pm EST.