

**CAB Conference Call
September 26, 2024
12:00 ET
Meeting Minutes**

Participants:

Antoinette	University of Miami
Chitara	Ann & Robert H. Lurie Children's Hospital
Claire	Harvard T.H. Chan School of Public Health
Eduardo	Harvard T.H. Chan School of Public Health
Falon	University of Colorado, Denver
Jackie	Westat
Joy	Westat
Karim	Westat
Kim	Texas Children's Hospital
Kylie	Texas Children's Hospital
Liam	FSTRF
Liz	Harvard T.H. Chan School of Public Health
Mandy	Harvard T.H. Chan School of Public Health
Raiko	University of Colorado, Denver
Rosalva	UCSD
Tameka	St. Jude Children Research Hospital

• **APPROVAL OF MINUTES**

The minutes from the August call were approved with no changes.

• **ICEBREAKER**

Mandy led the icebreaker.

• **SPACES FOR SELF-CARE**

Eduardo led the icebreaker.

• **PHACS GRANT CYCLE UPDATES**

Mandy explained that every five years PHACS needs to reapply for funding. The new call for funding that was sent by NIH has many implications on how PHACS could operate in the future. It is important to take into consideration that is a recompetes and not a renewal, so funding is not guaranteed. Since funding is not guaranteed, some sites and the open PHACS studies will need to close. The new call for funding is focused on people living with HIV.

Questions/comments:

- **Kim** asked if there will be a CAB Retreat during the next Spring Network Meeting in June 2025.
 - **Mandy** mentioned that there should be a retreat next year.
 - **Claire** shared that there is a contract with the hotel already.
- **Mandy** explained that there will be more understanding of the new iteration of PHACS in November.

- **Claire** mentioned that PHACS leadership is rethinking their focus and scientific aims for the new iteration of PHACS. After leadership decides their focus and projects, then they will indicate what will be included. She explained that the scientific aims will be shared with the community members, so everyone can provide feedback.
- **Rosalva** mentioned that her site had an NIH visit. They expressed their interest in knowing the feedback from community members. The CAB is an important element in every study/project.
 - **Liz** agreed with Rosalva. The voices of our community members create the heartbeat and moral compass of PHACS, and we deeply need this in an ongoing way -- no matter what shape this next version of PHACS takes.
 - **Rosalva** suggested that CAB members should continue participating in community groups even if their site is not selected.
- **Chitara** suggested a panel with community members, PHACS leadership and NIH representatives to discuss concerns and questions about the new call for funding.
 - **Claire** mentioned that CAB and PUG members asked how they can advocate to PHACS leadership. She and Liz asked PHACS leadership for a town hall.
 - **Rosalva** said she will always be an advocate for the families. One of her concerns is how to communicate the information to the participants.
 - **Kim** shared that community members join the PHACS CAB because of the discrimination that they experienced. The PHACS CAB is a family that has taught community members how to advocate for themselves and for their families. The CAB has evolved over the years, because community members have raised their voice and advocate. She mentioned the importance of the human component in the data. A town hall should be scheduled where the community member voices can be heard.
- **Claire** mentioned that the HECC were tasked with creating materials that sites can use to share this news with their participants.
- **Liz** acknowledged the importance of making sure that the community members' voices are heard. This advocacy effort should be continued to make sure the needs of the communities are shared.
- **Chitara** encouraged everyone to continue to advocate and ask questions, because this is important. This is not people participating in research, this is a family.
 - "You can't use us without including us."
- **Mandy** mentioned that ad hoc meetings with community members will be scheduled when there is more information.

NOTE: The next CAB call will be on October 24, 2024, at 12:00 PM ET.

POST MEETING UPDATE: Next CAB Call was rescheduled to October 31, 2024 at 12 PM ET.