

**CAB Conference Call
June 27, 2024
12:00 ET
Meeting Minutes**

Participants:

Andrea	Jacobi Medical Center
Antoinette	University of Miami
Chitara	Ann & Robert H. Lurie Children’s Hospital
Claire	Harvard T.H. Chan School of Public Health
Denisse	Harvard T.H. Chan School of Public Health
Eduardo	Harvard T.H. Chan School of Public Health
Exzavia	Children's Diagnostic & Treatment Center, Ft. Lauderdale
Falon	University of Colorado, Denver
Jackie	Westat
Karim	Westat
Kim	Texas Children’s Hospital
Kylie	Texas Children’s Hospital
Liam	FSTRF
Mandy	Harvard T.H. Chan School of Public Health
Raiko	University of Colorado, Denver
Samantha	Tulane University
Tameka	St. Jude Children Research Hospital

• **APPROVAL OF MINUTES**

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

• **ICEBREAKER**

Mandy led the icebreaker.

• **MENTORSHIP PROGRAM**

Denise explained that PHACS created “Walk the Talk” to promote equity, diversity, inclusion and belonging in the network. Everyone is welcome to take part in this group. At one of the network meetings, there was input that PHACS should promote mentorship for people that are not researchers. It is important to recognize that everyone, no matter their role, has something to offer. PHACS wants to set up the mentorship program where there is bidirectional mentorship - learning partnership.

Denise asked the CAB members their feedback on this initiative of learning partnership in PHACS:

- **Samantha** expressed her interest in peer mentorship. Matching should be taking into consideration similar backgrounds and backgrounds of their diagnoses. People with similar backgrounds can support each other because they have similar experiences with mental health and living with a chronic disease.
 - **Kim** talked about providing support to newly diagnosed women that learn of their diagnosis when pregnant. These women have a unique experience because they need to deal with the diagnosis, medications, deciding if they want to take part in research and the baby. Some of these moms will focus only on the baby. **Kim** mentioned that

peers are very important to support these moms, because they have already experienced the same struggles. She added that sites should be doing more with peer mentorship.

- **Eduardo** agreed that there is strength in peer mentorship, there's mutual help and understanding.
- **Antoinette** would like to be mentored to be able to contribute more.
- Several CAB members agreed on the importance of peer mentorship.
- **Samantha** added that counselors and peers are different because peers will have similar experiences that counselors will not have.
 - **Tameka** agreed that having someone that is going through the same experiences is totally different from someone who has read a book and is trying to understand.
- **Claire** mentioned that the priority for the CAB members is peer support. There has been discussion on how to support this initiative. The idea is to have virtual peers (pair community members from different sites). It is important to advocate for peer mentorship at the site level as well. The other aspect of mentorship is to match people with different roles in PHACS (investigator, PHACS leadership, med student, epidemiologist).
- **Chitara** mentioned that CAB members could visit CABs at other PHACS sites. The idea is to share experiences and be mentored on strategies to recruit and keep CAB members.
 - **Kim** added that this has been an idea presented years ago. She mentioned that the struggle of this type of initiative is funding.
- **Mandy** talked about the opportunity that Kim had of talking about community involvement in research studies at Mariam Davtyan's class. This could be a learning opportunity that could be incorporated in the peer mentorship program.
 - **Kim** mentioned that peer mentorship is important, even with people outside of the United States. Some people are not comfortable talking about their experiences in their community but will feel comfortable with peers.
 - At Mariam's class, she talked to new doctors about community involvement and input in research. She reminded them to remember "the human in the data." Their research is changing someone's life.

● **PHACS 2024 NETWORK MEETING + CAB RETREAT RECAP**

Mandy talked about the network meeting and CAB retreat. The CAB retreat was held on June 3. There were several activities: mindfulness, grounding sessions, journaling, open discussions, CAB retention, Project Positive website and a talk with Deb and Kate (HOPE study Co-chairs).

- The website had a soft launch at the network meeting. Anyone can access the website: www.ourprojectpositive.com. It includes a timeline with 40+ years of pediatric HIV research in

the United States. The website is not mobile friendly yet. The website will be available in Spanish.

- The talk with the HOPE co-chairs was focused on women's health in general and some study updates.

The network meeting was held on June 4 and 5. During the meeting, there were presentations about PHACS research studies, a talk about mental well-being of adults with PHIV by Ezra Kang and Whitney Rice's presentation on mixed methods.

Mandy reminded CAB members to fill out the survey about the retreat. The survey is anonymous, and every suggestion and feedback are greatly appreciated.

• **RETREAT DISCUSSIONS – NEXT STEPS**

Based on the discussions at the retreat, one of the new projects that the CAB will be working are resources for doctors or individuals entering the medical field. Resources on providing guidance to doctors to be more patient focused.

- **Samantha** shared that it is important for doctors entering the infectious disease field as well as primary care doctors know how to work with their patients living with HIV.
- **Chitara** suggested that the resource should have both: a video and a manual.
 - **Kim** agreed on having a speaker talk on how to be more patient focused. She mentioned that having a pamphlet with anonymous quotes from people living with HIV from all over the United States will have a great impact.
 - **Exzavia** also agreed on a video with real life experiences.

Mandy mentioned that these resources could be posted on the Project Positive website, so anyone can have access to them. Anyone who wants to contribute in any way can contact Mandy (aflores@hsph.harvard.edu).

NOTE: The next CAB call will be on July 25, 2024, at 12:00 PM ET.