

**CAB Conference Call
November 19, 2020
12:00 ET
Meeting Minutes**

Participants:

Alejandra	Texas Children’s Hospital
Carol	Bronx-Lebanon Hospital Center
Carrie	University of Colorado, Denver
Claire	Harvard University
Deontay	University of Miami
Exzavia	Children’s Diagnostic and Treatment Center
Falon	University of Colorado, Denver
Gena	University of Miami
Gloria	University of Florida, Jacksonville
Haleigh	FSTRF
Jennifer	University of Colorado, Denver
Julie D.	Westat
Julie H.	University of Alabama, Birmingham
Kylie	Texas Children’s Hospital
Megan	Westat
Morten	Bronx-Lebanon Hospital Center
Nataly	Westat
Raiko	University of Colorado, Denver
Rosetta	Bronx-Lebanon Hospital Center
Shary	University of Southern California
Stephanie M.	University of California, San Diego

• **APPROVAL OF MINUTES**

The minutes from the October 22, 2020 call were approved with no changes.

• **PHACS FALL 2020 VIRTUAL CAB RETREAT**

Megan talked about the PHACS Fall 2020 Virtual CAB Retreat. Due to the COVID-19 pandemic, the in-person Fall Network Meeting was cancelled. Several CAB members met to finalize the schedule of the Virtual CAB retreat based on CAB feedback. The CAB previously talked about structuring the retreat differently than the CAB calls. The goal is for the retreat to feel more like the in-person retreats than a virtual CAB call.. The retreat will focus on bonding and getting to know each other better. The retreat is scheduled for the following dates/times:

- Tuesday, December 8th from 2:00 – 6:00 PM ET
- Thursday, December 10th from 2:00 – 6:00 PM ET

CAB members had previously suggested splitting the retreat into two days. This gives more people opportunity to join. The retreat is optional.

The RSVP email was sent out on Monday with the retreat information. CAB attendees should respond to the RSVP with their mailing addresses. This is because all attendees will receive a package with supplies. **Megan** can help participants fill out the RSVP by email. The RSVP is due by December 27th.

Megan reminded the CAB that they may experience some negative emotions attending the retreat. This is because it may feel sad to be missing the in-person experience. However, the virtual environment

provides a new opportunity to interact with each other at home. The retreat is a safe space. There is no dress code. CAB members can come and go as needed. The agenda was created by the retreat planning committee, however, it can change according to how many people RSVP. Megan will follow up with those who may want to lead sessions.

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

Megan talked about the HECC. The former HECC will become the Health Education and Community Core. It is one of the new cores in PHACS 2020. The new HECC as a core will expand the work of the former HECC. The expansion of the HECC includes creating a Community Task Force. The Community Task Force members would be paid consultants. There will be a time commitment of five hours per month for a term of two years. The compensation would be \$150 per month and the 2-year term can be adjusted if there are any issues. The task force would be involved in providing input to researchers, helping to publish research results in scientific journals, answering questions about how to improve participant-facing materials, brainstorming how to report the findings to the community, and working on creative health education projects. There will be different ways in which to participate. Based on the feedback provided by the CAB, the task force will be formed by 5 AMP Up, 4 SMARTT Caregivers, and a PHACS CAB member. The CAB member can be a current or former PHACS participant or caregiver.

Claire talked about the HECC. A Digital Health Communications Specialist will be hired to help with multimedia products. The Digital Health Communications Specialist may be bilingual in English and Spanish so Spanish-speaking participants can be more involved. The interviewing team for this position will include a PUG and/or a CAB member.

• **PHACS MISSION STATEMENT**

Claire talked about the PHACS mission statement. The mission statement is being created with the input from the different PHACS groups.

The CAB brainstormed about the mission statement and values. Feedback from the group included:

• **Mission Statement**

- Include meaningful environment for people living with HIV
- Use person-first language – be mindful of language when working with people living with HIV to not drive them away
- Hear, see, respond to people living with HIV
- Note that the research is being done for the future of children being exposed to medications and HIV. The study is researching different aspects of health
- Be sure to focus on the future of other children and families
- Note that we are bridging the gap for children who are not coming to doctor's appointments, but are coming to research visits
- Note that we are constantly exploring ways to connect with participants such as Zoom, telehealth, and online surveys
- Mentioned that PHACS will keep participants updated on study progress
- Note that we are supportive of participants and people living with HIV
- It should be communicated that being involved in CAB is a form of support; the CAB is a safe space
- Mention resilience
- Mention empowerment in being part of the ongoing fight against HIV

• **Values**

- Keep CAB members involved
- Include and respect different perspectives
- Inclusion and diversity
- Look out for each other as a family – be supportive of others who are going through a lot

- Build community within so we can be stronger and united
- Show genuine care for each other and the community
- Recognize the difference between what people say to us on research panels and what is really going on inside of people and their experiences
- Empathy
- Recognizing that people are dealing with a lot that is going on in regular life outside of research participation
- Empowerment
- Support
- Trauma-informed approach
- Holistic approach to health and retention in care
- Self-care for people supporting others/peer navigation

- **PHACS CAB NEWSLETTER, JANUARY 2021 EDITION - THEME**

Megan asked the CAB member to send their ideas for the PHACS CAB Newsletter theme. The theme will be discussed during the retreat and will be announced by email.

- **UPCOMING CAB CALL SCHEDULE**

Megan reminded the CAB members that the December CAB call is cancelled due to the virtual CAB retreat taking place in December

NOTE: The next CAB call will be on Thursday, January 28, 2021 at 12:00 pm ET.