

**CAB Conference Call
May 25, 2023
12:00 ET
Meeting Minutes**

Participants:

Andrea	Jacobi Medical Center
Carol	Bronx-Lebanon Hospital Center
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
Gena	University of Miami
Jackie	Westat
Kim	Texas Children's Hospital
Kylie	Texas Children's Hospital
Liz	Harvard T.H. Chan School of Public Health
Mandy	Harvard T.H. Chan School of Public Health
Morganne	FSTRF
Raiko	University of Colorado, Denver
Robert	University of Miami
Rosalva	University of California San Diego
Theresa	Texas Children's Hospital

• **APPROVAL OF MINUTES**

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

• **ICEBREAKER**

Mandy led the icebreaker.

• **SELF-CARE SPACE**

Eduardo led the self-care space.

• **SPRING 2023 NETWORK MEETING + CAB RETREAT: UPDATES AND HIGHLIGHTS**

Mandy presented a recap of the CAB Retreat at the PHACS Network Meeting. The retreat was held on Monday, May 8. The retreat theme was "Self-Trust".

The CAB retreat included sessions on:

- Journaling and Discussion on What is Self-Trust
- Mindfulness sessions
- Meet and Greet with PIs
- Creative Project: Mosaic of Research, including researchers and PUG members
 - The PHACS network is composed of people with different perspectives and experiences working together.

- Coco comes to the CAB
 - CAB and PUG members had the opportunity to color pictures of Coco.

Self-trust recap:

- Definition
 - Trust that what I'm feeling and experiencing in my body signals a legitimate illness or change in my disease status.
 - Trust that actions I'm taking and decisions I'm making to care for myself make sense.
- Insights from the discussion about self-trust:
 - Self-trust is something that:
 - We can have from the beginning,
 - We can build, and
 - We have to continue to work on.
 - What's the feeling around self-trust in this supportive community (CAB)?
 - Joy, no more pain.
 - Remedy for self-doubt.
 - Feels like success.
 - Trusting that I know what I know.
 - Positive vibes.
 - Maintaining connections that support self-trust
 - Allow time to nurture connections: time at the end of Zoom call
 - Extra 30 minutes after the CAB call
 - **Rosalva** agreed that it will be a great time to share ideas about things that have been successful at site CABs.
 - **Chitara** will like to know how to get participants involved and interested in the site CAB.
 - Support exchange of contact info so we can support each other outside of the Zoom meetings
 - Assign peer CAB members to meet and welcome new CAB members
 - Offer funding for peer advocacy and CAB meetings

Research Topics of Interest: Topics to see PHACS prioritize or continue to prioritize in the future

- Sleep study
 - Effects of ARVs on sleep
- Effects of ARV on hormones, menopause, and offspring reproductive systems
- Effects of ARV classes on weight gain
- Negative effects of ARVs on health
- Long-acting ARVs
- HPV
- Breastfeeding

Feedback from the CAB on the network meeting:

- Several members congratulated Kim for her Lagniappe Award "A little something extra."
- **Kim** and **Mandy** mentioned the great job that Chitara did on the HECC panel.
- **Rosalva** expressed that the meeting was an eye-opening experience for her. She loved that the participants get the opportunity to be involved in every step of the research studies.
- **Eduardo** acknowledged the participation of community members during the meeting. It was demonstrated that the community member's voice is needed.

Mandy will send a survey asking for feedback about the CAB retreat.

• **CAB NEWSLETTER JULY 2023: THEME BRAINSTORM**

Ideas for the theme:

- **Kim** suggested "The Site is Hot!" to feature several sites and the studies they are working. Also, adding summer time activities with Coco and recipes.
- **Rosalva** suggested "Building Bridges" recognizing that everyone in PHACS is connected no matter how far we are.

Mandy will send a survey with additional ideas for the CAB Newsletter theme.

NOTE: The next CAB call will be on June 22, 2023 at 12:00 PM ET.