

**CAB Conference Call
September 28, 2023
12:00 ET
Meeting Minutes**

Participants:

Andrea	Jacobi Medical Center
Anisa	Harvard T.H. Chan School of Public Health
Antoinette	University of Miami
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
Exzavia	Children's Diagnostic & Treatment Center, Ft. Lauderdale
Falon	University of Colorado, Denver
Gena	University of Miami
Jackie	Westat
Joel	University of Puerto Rico
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
Mona	University at Alabama Birmingham
Raiko	University of Colorado, Denver
Rosalva	University of California San Diego
Samantha	Tulane University

- **APPROVAL OF MINUTES**

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

- **ICEBREAKER**

Mandy led the icebreaker.

- **SELF-CARE SPACE**

Eduardo led the self-care space.

- **SPANISH-SPEAKING NATIONAL CAB UPDATES**

The first Spanish-speaking national CAB meeting is scheduled for October 17 at 12 PM ET. This is an opportunity for Spanish-speaking participants to provide their input on PHACS research. This group aims to ensure that language is not a barrier for receiving feedback from Spanish-speaking participants.

Kim shared a quote for the Spanish-speaking members:

- “You are not alone anymore, and welcome to the PHACS family!!”

Several CAB members expressed their happiness with this new opportunity of community engagement in PHACS in the meeting chat:

- **Claire** said: “We are so, so happy that we’ll be able to hear from our Spanish-speaking participants more directly moving forward, and that we can welcome them into this national community!!”
- **Rosalva** mentioned: “CONGRATULATIONS I’m really happy that monolingual participants are be able to participate in their own language 🇪🇸”

• **FALL FORUM 2023: SCIENTIFIC AIMS BRAINSTORM**

Mandy explained that the PHACS Fall Forum is scheduled for November 1, 2023, at 12PM ET. During the forum, every group in PHACS will have the opportunity to present their priorities. Then, the goal is to determine where all the priorities align to decide PHACS priorities for the coming year. The PHACS leadership is asking community members which scientific aims they would want PHACS prioritizing for next year.

Mandy asked the CAB members what the priorities for PHACS should be:

- **Gena** suggested several topics:
 - Aging with HIV.
 - Comorbidities (cancer, blood pressure, etc.).
 - Providers should focus on the overall health of the patient. **Chitara** agreed on prioritizing whole-body health.
- **Carol** mentioned HIV and depression.
- **Samantha** suggested how COVID has affected transmission rates and how the viruses interact.
- **Kim** talked about the lack of new physicians specializing in HIV research. HIV is not taken seriously anymore.
 - **Claire** agreed that there is a need to get more people specializing in HIV and infectious diseases. It is important to have the next generation of researchers to further knowledge about HIV.
- **Exzavia** mentioned oral health as an important topic for PHACS.
- Several members talked about medication:
 - **Chitara** suggested researching the side effects of medication taken for a long period of time.
 - **Samantha** agreed that research should focus on the effects of long-term medication on body organs.

- **Claire** talked about the different types of medication that have been available over time.
- **Exzavia** agreed that medication and resistance. Sometimes people need to stay with certain medications that have side effects.
- **Samantha** mentioned that people need to advocate for themselves. She explained that patients should ask their doctors for explanations regarding lab results when they are uncertain on what they mean.
 - **Claire** agreed that providers should provide explanations to their patients and be mindful of their patients' whole-body health.
 - **Kim** suggested a small dictionary with explanations of lab results.
 - **Claire** agreed it is a good idea although it could be challenging because some lab results don't mean anything unless they are combined with additional results.
 - **Kim** mentioned that sometimes patients don't understand their provider, there's a disconnection between them.

- **CREATIVE PROJECTS: UPDATES**

Mandy thanked community members for their input in the development of the SMARTT coloring pages. These pages will be provided to SMARTT participants at their 5-, 7- and 9-year-old visits. The first series is "Go with Coco to the Doctor!" All the coloring pages will be available on the PHACS website to download and print. The next installment will be Coco and the tooth fairy. These will focus on the tooth collection of SMARTT participants. The materials include a cover letter, instruction sheet and activity pages of Coco meeting the tooth fairy.

NOTE: The next CAB call will be on October 26, 2023, at 12:00 PM ET.