

**CAB Conference Call
August 22, 2024
12:00 ET
Meeting Minutes**

Participants:

Antoinette	University of Miami
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, Florida
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
Rosalva	UCSD
Sannita	

• **APPROVAL OF MINUTES**

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

• **ICEBREAKER**

Mandy led the icebreaker.

• **SPACES FOR SELF-CARE**

Eduardo led the icebreaker.

• **AIDS 2024 CONFERENCE – UPDATES WITH CLAIRE**

Claire Berman talked about her experience in Munich, Germany at the AIDS 2024 Conference. The conference was held from July 20th – 26th. The conference theme was “Putting people first.” At the conference, **Claire** presented a poster describing the HECC model in PHACS. Title of the poster: “The Health Education and Community Core (HECC): A model of community engagement in the U.S.-based Pediatric HIV/AIDS Cohort Study (PHACS) Network”. The poster was presented on July 23rd. Visitors to the poster included clinicians from the US, Argentina, Zimbabwe, Zambia, South Africa and others.

The poster included several sections:

- Background: Summary of what led to the creation of the HECC model.
- Setting: PHACS/HOPE sites in US and Puerto Rico
- Membership: Staff and participants in HECC

- Community Engagement: Description of what is community engagement in the HECC model. It focuses on the community voices, bi-directional partnership, trust, value of community voices, flexible and dynamic model of participation.
- Model: HECC as a bridge between community and research. Community Engagement structure including all community groups in PHACS.
 - PHACS CAB
 - HOPE CAB
 - Spanish CAB
 - Peers United Group (PUG)
 - Community Task Force
- Research support: Describes HECC input throughout the research process
- Resources for dissemination of findings: Emphasizing on the community priorities. The poster included QR codes with links to animated plain language summaries in English and Spanish.
- Key Lessons learned: Strategies to implement the community engagement model.
- Conclusions
- Additional work: includes QR codes to different HECC resources.

Link to the poster:

https://phacsstudy.org/cms_uploads/Health%20Education%20and%20Communication%20Documents/Berman_HECC_Model_Poster_AIDS_2024.pdf

Claire had the opportunity to attend several sessions:

- On July 20, she attended a pre-conference session on kids that were perinatally exposed to HIV, but not infected.
- The main conference was held from July 21st – 26th.
- Opening and closing sessions
 - Olaf Scholz, Chancellor of Germany, talked about the renewed commitment to fight HIV stigma.
 - Barbara Lee, legislator from US, talked about the AIDS meeting in Durban, South Africa.
 - James Mulucha: First trans man to speak at an AIDS conference. He talked about the anti LGBT legislation in Uganda.
 - Andre Klepikov (Ukraine), Alliance for Public Health, talked about his experience as a drug user.
- Big news of the meeting: Results of the PURPOSE Study
 - Infographic:

https://presentations.gilead.com/files/2017/2181/2794/Bekker_Summary_AIDS2024_PURPOSE1_24Jul24.pdf

- Long acting Lenacapavir (a twice-yearly ARV injection) was 100% effective at preventing new HIV infections in sexually active young women in South Africa compared to two types of oral PrEP (one smaller pill and one “standard” pill).
- The team is testing this long-acting injection in different populations (e.g. LGBTQ, men).
- I once had HIV – The story of a cure: Mark Franke, the Düsseldorf patient, the personal story behind the cure
 - Mark Franke had acute myeloid leukemia and needed a stem cell transplant. Doctors used stem cell donations from people with a specific genetic makeup (CCR5); these people are essentially immune to HIV. The stem cell transplant was done 10 years ago. Mark Franke was able to stop taking his ARVs in 2018. From that time on, he is considered in remission for HIV.
 - **Claire** explained that Mark’s doctors have been looking for HIV reservoirs in different organs. She mentioned that even when someone’s viral load is low, HIV reservoirs have copies of the virus. Doctors have studied his large intestine and lymph nodes and only found fragments of HIV, not a viable virus.

Other major themes during the conference:

- Artificial intelligence (In HIV response, for patient care)
- Language matters (How we talk about HIV in journalism and with stigma)
- Generation of advocacy (Inter-generational conversation between advocates)
 - How do you work together?
 - What can each generation learn from each other?
- Monoclonal antibodies (In treatment of HIV)
- Don’t forget about the kids (Pediatric HIV is important too)
- Gene editing (CRISPR) for cure
- Radical honesty

Book “The viral underclass: The Human Toll when Inequality and Disease Collide” by Steven Thrasher: Social differences depending on someone’s access to healthcare, safe housing, money, among others.

- “As the virus traveled through the streets and the subway, and then through cities and communities, their suffering stretched across layers of disparity. It quickly became clear that sickness and death reflected the existing system... of discriminatory housing, education, employment, income, health care, and justice.”

Advocacy disrupted several sessions:

- Lives over profit: Protest Gilead - manufacturer of long acting antiretrovirals that are not allowing generics to be made.
- Trans rights now: Rights for trans people.

- Sex work is work: Rights for sex workers.
- Communities are experts

Rosalva suggested that the CAB should develop an abstract in English and Spanish.

- **Kim** supported this suggestion. She talked about the importance of including CABs in these conferences. She said: “having the right CAB, the right foundation to getting the people into participation in the research, eventually it will spark a cure”; “the Spark of CAB.”

• **POTENTIAL SPEAKER**

Mandy asked the CAB members if they would like to invite a potential speaker to a CAB call. Mandy and Claire attended a presentation on Tuesday (8/20) where the focus was the importance of CABs. One of the speakers, Christopher Tunstall, talked about the ACTG CAB. ACTG stands for AIDS Clinical Trials Group. It is one of the largest HIV clinical trials networks in the world. Its research is to improve the management of HIV and its comorbidities; develop a cure for HIV; and innovate treatments for tuberculosis, hepatitis B, and emerging infectious diseases.

- CAB members agreed to invite him to a future CAB call.

• **HECC PROJECTS UPDATES**

Mandy talked about the HECC updates

- Coco Series
 - Go with Coco to get an MRI: **Mandy** explained that the TERBO team is helping in the development of these activity pages. The team mentioned that some of the challenges that the participants face during the scan are the sounds and tightness of the machine itself. She presented draft drawings of Coco having an MRI. In the drawings, Coco is imagining being in a spaceship as an astronaut. Other activity pages include:
 - participant selects which items can be taken to the MRI visit
 - fill in the blanks with constellations
- CAB Newsletter: next edition is coming out soon!

NOTE: The next CAB call will be on September 26, 2024, at 12:00 PM ET.