CAB Conference Call January 23, 2025 12:00 ET Meeting Minutes

Participants:

Antoinette University of Miami

Claire Harvard T.H. Chan School of Public Health Harvard T.H. Chan School of Public Health

Falon University of Colorado, Denver

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

Lorena University of Miami

Mandy Harvard T.H. Chan School of Public Health

Raiko University of Colorado, Denver

Rosalva UCSD

Tameka St. Jude Children Research Hospital

APPROVAL OF MINUTES

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

ICEBREAKER

Mandy led the icebreaker.

SPACES FOR SELF-CARE

Eduardo led the spaces for self-care.

• CAB NEWSLETTER

Mandy explained that the last edition of the CAB Newsletter will be released between March and April. It will be the last version because PHACS P01 grant is ending. Since this is the last edition, the theme could focus on celebrating all the accomplishments that the community groups have achieve for the last 15+ years. Some of the articles could be: community member stories, resources to support community members and sites, positive affirmations during this period of transition.

CAB member comments/feedback:

• **Tameka** agreed with the topic. She agreed that sharing the stories of community members is a great idea. Focusing on the importance of how community members felt when joining the CAB. How community members felt when their voice is heard, when their ideas and feedback were

embraced and implemented in the studies. Also, highlighting the impact of the CAB and how the CAB have impacted the local communities.

- Mandy mentioned focusing on the legacy of the CAB.
- Kim talked about the importance of CAB leadership in providing a safe space and providing support to community members. It has allowed community members to transform into "phoenixes with butterfly wings". Community members have found their voice to be able to advocate at their local CABs. The national CAB has been a birthplace of advocates. Kim suggested including images about multicolored eggs hatching into little phoenixes to represent the diversity among community members.
- Liz loved Kim's and Tameka's ideas. She mentioned that PHACS has worked with many participants and parents since their "hatching" and throughout their growing up. She agreed that the stories and metaphors about eggs and phoenixes rising would be meaningful to many parents and caregivers reading the newsletter.
- **Antoinette** mentioned the importance of the information that has been shared with community members such as the new medications. It has allowed members to be empowered. In addition, the work done in PHACS with children and their families has been great.
- Claire suggested a theme to connect the CAB newsletter with the CAB Retreat such as "Transitions." Transitions can be a time of celebration but also of grief, of hope and of difficulty.
 - Mandy added that transitions can include changes in the HECC with the creation of the Spanish CAB, closing of the P01 and clinical sites, children living with HIV and their transition to adulthood. The CAB newsletter could include stories from the PUG, as well. Mandy also shared that the CAB newsletter could include e a section on self-care and how support everyone in times of transition.
 - Kim agreed that transitions could be a theme for the CAB retreat. The retreat should have a time for talking about the expectations of CAB members had when they started and all the CAB accomplishments throughout the years.
- **Gena** agreed that the theme transitions is a good idea for the newsletter, especially with everything going on with people's lives. She mentioned the importance of seeking mental health services when life gets difficult.
- Mandy added that all the community groups will be invited to submit articles for the newsletter. She will send a Qualtrics survey for the CAB newsletter submissions.

PHACS RISE UPDATE

Mandy explained that the PHACS RISE application was submitted, and the score could be received in the spring. There is no specific date when Harvard will be informed if PHACS RISE will be funded. Also, a no cost extension was submitted to continue PHACS work with funds that were already approved.

NOTE: The next CAB call will be on February 27, 2025, at 12:00 PM ET.