CAB Conference Call June 28, 2018 12:00 EST Meeting Minutes

Participants:

Andrea Jacobi Medical Center
Camille San Juan Hospital
Claire Harvard University
Delia University of Miami

Exzavia Children's Diagnostic and Treatment Center

Gena University of Miami

Julie Westat

Kimberly Rutgers New Jersey Medical School

KimbraeTexas Children's HospitalLatoniaUniversity of Illinois, ChicagoLesleyTexas Children's HospitalLeslieTexas Children's Hospital

Lourdes San Juan Hospital

Megan Westat

Morten
Paolin
University of Colorado, Denver
Raiko
University of Colorado, Denver
University of Colorado, Denver
Stephanie
University of California, San Diego

StephanieUniversity of MiamiTheresaTexas Children's Hospital

APPROVAL OF MINUTES

The minutes from the May 24, 2018 call were approved with no changes.

PHACS CAB EVALUATION SURVEY

Megan talked about the May PHACS CAB Evaluation Survey. There were 5 responses. It was suggested that future guest speakers present only main concepts. Too many details may be overwhelming. **Megan** reminded the CAB that topics from the May CAB call will also be in the newsletter. Future CAB calls will include more time for questions.

Megan talked about the Fall 2018 CAB Retreat and Network Meeting. The meeting will be September 17-18, 2018. The meeting will be at the Hyatt Regency in Bethesda, Maryland. The half-day CAB Retreat will be September 19, 2018. CAB members will travel to the meeting September 16, 2018. CAB members will travel home September 19, 2018 after the retreat. CAB members must have attended 70% of monthly CAB calls to be eligible to be invited to the retreat/meeting. This means CAB members must have attended 5 calls from December 2017 to June 2018. Invitations will be sent in July 2018.

Megan talked about the Additional Maternal Data Collection for SMARTT Dynamic Cohort Biological Mothers. PHACS was granted a supplement to study the health of biological mothers to children in the SMARTT Dynamic Cohort. The study is enrolling mothers of SMARTT Dynamic Cohort participants before birth and less than 5 years of age. Researchers will be looking at mothers' health in this study. CAB members enrolled in the supplement are invited to give feedback to the study team. CAB members can contact **Megan** to be connected to the study team.

PHACS CAB NEWSLETTER, JULY 2018 EDITION

Stephanie talked about the newsletter. The theme is "the importance of CABs in research." The CAB talked about the theme. **Exzavia** talked about giving back to others. Many people participated in research to help future generations. **Leslie** talked about community feedback. The community gives feedback to researchers to help improve study design.

Morten talked about engaging the community. It may be helpful to target the community. Invite community members to sites to ask questions about the study. **Kimberly** talked about engaging the community. Sites should try to connect with community members where they are. Community members could email study staff members or video chat from their homes. **Stephanie** talked about reaching out to community members who are not currently in research studies. **Megan** encouraged the CAB to brainstorm ideas for future PHACS CAB projects. The CAB will review ideas during the next CAB call.

Stephanie talked about tips and tools for staying engaged as a CAB member. **Lesley** talked about contributing to research. It feels good to give feedback and learn about study results. **Latonia** talked about engaging as a CAB member. CAB members learn helpful information at CAB meetings. It is also helpful to connect with others. **Kim** talked about staying engaged. It is helpful to think about having a voice in research. **Kimberly** talked about staying engaged. CAB members can be motivated by the community.

HEALTH EDUCATION AND COMMUNICATION COMMITTEE (HECC)UPDATE

Claire talked about the HECC. The informed consent whiteboard videos have been completed. The CAB and YACAB gave lot of feedback for the videos. **Claire** thanked the CAB for giving feedback.

The International AIDS Conference is held every two years. This year, the conference is being held in Amsterdam, Netherlands, July 23-27, 2018. The HECC will be presenting two posters at the conference. One poster will be about maternal disclosure. The other poster will focus on data collected from the focus groups with PHACS young adults. The conference also includes the Workshop on HIV Pediatrics. Claire will show the Faces of PHACS youth documentary at the workshop. The Adolescent and Young Adult Working Group (WG) invited **Stephanie** and **Alexis** to participate in a panel discussion at the workshop.

NOTE: The next CAB call will be on Thursday, July 26, 2018 at 12:00 pm EST.