CAB Conference Call October 27, 2016 12:00 EST Meeting Minutes

Participants:

Alexandria FSTRF

Brandon University of Florida, Jacksonville

Claire Harvard University
Delia University of Miami

Exzavia Children's Diagnostic and Treatment Center

Jeanie University of Southern California
Jennifer University of Colorado, Denver
Joel University of Puerto Rico

Juanita Tulane University

Julie University of Alabama, Birmingham

Julie Westat

Kimberly Rutgers New Jersey Medical School

Kimbrae Texas Children's Hospital
Lesley Texas Children's Hospital
Marilyn Bronx-Lebanon Hospital Center

Megan Westat

RaikoUniversity of Colorado, DenverRosettaBronx-Lebanon Hospital CenterStephanieUniversity of California, San Diego

Stephanie University of Miami Theresa Texas Children's Hospital

Veronica University of California, San Diego

• APPROVAL OF MINUTES

The minutes from the September 22, 2016 call were approved with no changes.

PHACS CAB EVALUATION SURVEY RESULTS

Megan talked about the survey. There were 8 responses. Most CAB members liked the Fall 2016 Network Meeting Q & A with Drs. Russ Van Dyke and Ellen Chadwick. Topics suggested through the survey included:

- HIV and how it affects memory, hearing, and heart issues;
- · Becoming an icon in your community; and
- Supporting CABs.

Megan talked about the suggestion to send out recordings of the CAB calls. **Megan** explained that due to confidentiality concerns, recordings of the CAB calls may not be shared.

FALL 2016 CAB RETREAT REVIEW

Megan reviewed comments from the Fall 2016 CAB Retreat survey. There was mixed feedback about scheduling future CAB Retreats. Several CAB members liked having the retreat the day after the meeting. Having the CAB Retreat the day after the meeting allowed the CAB to come up with

questions for the researchers together. Other CAB members like having the retreat the day before the meeting. It can be helpful to hold the CAB Retreat the day before the meeting so that the CAB can go over general topics that may be covered at the meeting. It may also help to review some of the glossary terms before the meeting.

Many CAB members liked the filming session with **Staffan**. Several CAB members suggested spending more time on community involvement. It was also suggested that there be more discussion about the future of the PHACS CAB.

It was suggested that future sessions focus on how the CAB impacts others in the study. Sessions could also focus on the results of PHACS research. It was suggested that the CAB review the PHACS website. CAB members may also spend time reviewing the CAB's progress and the work of HIV/AIDS advocates.

ANNUAL SITE CAB TRAINING PROJECT

Megan talked about the Annual Site CAB Training project. The CAB had previously decided to put together an annual training for site CABs. The training would be a presentation and resource that site CABs would review once a year. It could also be reviewed with new CAB members. The training would serve as a means for site CABs to refocus on the purpose of the CAB's involvement in PHACS. It would also help site CABs to learn about PHACS' progress within the last year. This project may also help other studies think about this training as a way to disseminate study information to the community.

The training would have about 30% of basic information about PHACS and the PHACS CAB. The majority of the training (about 70%) would focus on PHACS research updates within the past year. **Megan** asked the CAB about what basic information about PHACS should be included in the training. **Kim** suggested that the training include information about language and cultural barriers in PHACS. **Theresa** suggested that the training include information on diversity in PHACS. There should be information on how to work with people from all backgrounds. It was suggested that the training include information about why certain tests are done. For example it could be helpful to explain why researchers are looking at moms' and babies' hair.

It was suggested that the presentation include some information on how to maintain site CABs. Some information from the CAB Handbook could be included in the training. **Brandon** suggested including information about efforts to retain CAB members.

Stephanie talked about childcare during site CAB meetings. It may be difficult for CAB members with children to attend site CAB meetings. **Kimberly** talked about mental health issues. Mental health issues can make it difficult for some CAB members to attend site CAB meetings. **Theresa** stated that it can help for CAB members to develop relationships with site staff. It was suggested that CAB members reach out to other CAB members to keep them engaged in the CAB. The CAB will continue to discuss barriers during the next CAB call.

Megan talked about information to include in the training. It was suggested that the training include information from the informed consent or about general rights of study participants. It may also be helpful to include information about available PHACS resources (i.e., HECC projects, protocols, PHACS website, research summaries, etc.).

PHACS CAB NEWSLETTER, JANUARY 2017 EDITION

Kim talked about the PHACS CAB Newsletter, January 2017 Edition. **Kim** suggested that the theme focus on new beginnings or breaking barriers. **Megan** encouraged CAB members to submit theme suggestions through the PHACS CAB Evaluation Survey.

• HEALTH EDUCATION AND COMMUNICATION COMMITTEE (HECC) UPDATE

Claire talked about the HECC. **Claire** thanked the CAB members for supporting the filmmaking process at the Fall 2016 Network Meeting. **Claire** and **Megan** are working with **Staffan** to edit the scripts for the films. There will be several films. One film will focus on the adult CAB's stories. The CAB film may focus on several CAB members telling their stories and then transitioning to stories about why CAB members chose to be involved in PHACS and the CAB. **Claire** and **Megan** will work with the CAB to develop the videos.

• RESCHEDULING THE NOVEMBER/DECEMBER CAB CALLS

Megan talked about rescheduling the November and December CAB calls due to the fall and winter holidays. The CAB decided to have one call between November and December on December 8th.

NOTE: The next CAB call will be on Thursday, December 8, 2016 at 12:00 pm EST.