

**CAB Conference Call
May 28, 2015
12:00 EST
Meeting Minutes**

Participants:

Andrea	Jacobi Medical Center
Carrie	University of Colorado, Denver
Delia	University of Miami
Denise	Harvard University
Exzavia	Children's Diagnostic and Treatment Center
George	NIH, NICHD
Jeanie	University of Southern California
Jennifer	University of Colorado, Denver
Juanita	Tulane University
Julie	Westat
Kim	Texas Children's Hospital
Kimberly	Rutgers – New Jersey Medical School
Lauren	Ann and Robert Lurie's Hospital for Children
Laurie	FSTRF
Lesley	Texas Children's Hospital
Mary Anne	Westat
Megan	Westat
Raiko	University of Colorado, Denver
Ramona	University of Florida, Jacksonville
Rosetta	Bronx-Lebanon Hospital Center
Stephanie	University of Miami
Tatania	Tulane University
Veronica	University of California, San Diego
William	Texas Children's Hospital

• **PCPA SUBSTUDY UPDATE**

Dr. Shearer talked about the Pulmonary Complications in PHACS AMP (PCPA) Substudy. Dr. Shearer talked about the research that backed the PCPA Substudy. PHACS did a study looking at asthma and eczema in youth living with HIV. This study found that asthma may be more common in youth living with HIV. In addition, youth living with HIV on HAART may have more asthma and eczema.

Researchers can look at how a participant's lungs are working by doing a Pulmonary Function Test (PFT). A PFT looks at how well the lungs take in and exhale air. It also measures how well the lungs transfer oxygen in the blood. PFTs can tell doctors whether a participant has obstructive or restrictive lung problems. People with obstructive lung problems may have shortness of breath. This can be due to difficulty exhaling. Bronchodilators can help people with obstructive lung problems relax their lungs. People with restrictive lung problems may not be able to fully fill their lungs with air.

Denise talked about the PCPA Substudy. The researchers looked at participants who had either self-reported asthma problems or who were diagnosed with asthma by a doctor. The researchers used questionnaires to ask participants and caregivers whether they had asthma or asthma complications in the past. In youth living with HIV, 29% had ever had a diagnosis of asthma. In youth exposed but uninfected, 22% had ever had a diagnosis of asthma. Current rates of asthma were 30% in youth living with HIV and 22% in youth exposed but uninfected. The team is now analyzing all the data.

Dr. Shearer talked about asthma studies. In other research studies, asthma seems to start after youth start taking ARV medications. A study in Thailand suggested that youth who started ARV treatment immediately developed asthma sooner than youth who started ARV treatment later in life. Dr. Siberry talked about other asthma studies. Getting the immune system stronger or starting ARV treatment

may make asthma occur. It has been suggested that part of what causes asthma to occur could be the body's own immune response.

Kim asked about differences in asthma rates by site. The research team has not yet looked at differences by site. The team is still analyzing the data.

- **APPROVAL OF MINUTES**

The minutes from the April 30, 2015 call were approved with no changes.

- **PHACS CAB NEWSLETTER, JUNE 2015 EDITION**

Megan talked about the newsletter. The newsletter will follow a theme of advocacy, empowerment, and self-love. Kim encouraged CAB members to submit articles for the newsletter. The deadline for newsletter submissions is June 8, 2015. Megan encouraged the CAB to submit testimonials/stories, resources, recipes, artwork, and photos. CAB members can call or email Megan with submissions.

Megan talked about empowerment. The newsletter will feature a word cloud with words about empowerment. CAB members suggested several words for the word cloud including: faith, love, hope, unconditional trust, strength, perseverance, endurance, and good.

- **PHACS CAB VICE CHAIR ELECTIONS**

Megan talked about future CAB Chair and Vice Chair elections. The HECC CAB Subcommittee suggested that the CAB create pre-qualifications for Chair and Vice Chair nominees. It was suggested that nominees must have attended 60% of CAB calls in the past year. It was also suggested that nominees must have contributed to CAB productions or participated in other PHACS groups. The CAB agreed with the suggested pre-qualifications. Stephanie talked about the pre-qualifications. Pre-qualifications may minimize the need for time-consuming training. CAB members can suggest additional pre-qualifications through the PHACS CAB Evaluation Survey.

Megan talked about the PHACS CAB Vice Chair elections. Megan thanked all the nominees. Megan introduced Lesley, the newly-elected PHACS CAB Vice Chair. Kim and Megan will work with Lesley to help prepare her for her new role.

- **HEALTH EDUCATION AND COMMUNICATION COMMITTEE**

Megan gave the Health Education and Communication Committee update. Megan talked about the SMARTT videos project. At the Spring 2015 Leadership Retreat, it was suggested that the team make videos for moms who are in SMARTT. The videos could show updates about PHACS. Moms could watch the videos during their child's study visits. The HECC is considering using a whiteboard format for the videos. A whiteboard video is an animation video. In the video, a voice explains something while a hand is drawing to visually show the concept. The whiteboard video could help explain some of the PHACS updates. The CAB agreed with the whiteboard format.

The HECC would like the videos to focus on what happens during a study visit. Megan encouraged CAB members to think about what study visit tests or exams could be explained in the whiteboard videos. CAB members can submit suggestions through the PHACS CAB Evaluation Survey.

- **FUTURE WRITING TEAM INVOLVEMENT**

Megan stated that the CAB had previously expressed interest in getting more involved with PHACS writing teams. There are three steps in the process to writing a paper for PHACS. The writing team must first develop a capsule which is a short description of the proposed study. Once the capsule is approved by several of the PHACS groups, the writing team will be approved to develop a concept sheet. This is a much longer description of what study the team is looking to do. Finally, once the concept sheet is approved by the PHACS groups, it proceeds to a full study. The team can then work to publish papers in scientific journals once approved by all the relevant PHACS groups.

The HECC CAB Subcommittee came up with several suggestions on how the CAB can continue to get involved in the writing process. It was suggested that the CAB continue to invite authors to present their concept sheets during CAB calls. The CAB can start by looking at the current PHACS-approved capsules list during every CAB call. The CAB can choose which capsules are of interest to the group. Megan will contact authors of selected capsules to present on future CAB calls. The CAB agreed with the suggestions and will begin reviewing the PHACS approved capsules lists during the June CAB call.

The HECC CAB Subcommittee also suggested that the CAB put together a training for PHACS staff members at the Fall 2015 Network Meeting. The HECC CAB Subcommittee will work with CAB members and staff members to put together the training. After the meeting, the HECC CAB Subcommittee will put together a list of guidelines for authors about best practices for involving the CAB in writing teams.

- **BIRTHDAYS**

It was suggested that CAB members volunteer to share their birthdays. The CAB would celebrate upcoming birthdays during CAB conference calls. CAB members can share their thoughts on the birthday idea through the PHACS CAB Evaluation Survey.

NOTE: The next CAB call will be on Thursday, June 25, 2015 at 12:00 pm EST.