

**CAB Conference Call  
July 25, 2019  
12:00 EST  
Meeting Minutes**

---

**Participants:**

<b>Alex</b>	FSTRF
<b>Anisa</b>	Harvard University
<b>Carol</b>	Bronx-Lebanon Hospital Center
<b>Carrie</b>	University of Colorado, Denver
<b>Claire</b>	Harvard University
<b>Exzavia</b>	Children's Diagnostic and Treatment Center
<b>Delia</b>	University of Miami
<b>Fallon</b>	University of Colorado, Denver
<b>Gena</b>	University of Miami
<b>Joel</b>	University of Puerto Rico
<b>Juanita</b>	Tulane University
<b>Julie</b>	University of Alabama
<b>Julie</b>	Westat
<b>Kamil</b>	San Juan Hospital
<b>Kimbrae</b>	Texas Children's Hospital
<b>Latonia</b>	University of Illinois, Chicago
<b>Lesley</b>	Texas Children's Hospital
<b>Megan</b>	Westat
<b>Mildred</b>	Bronx-Lebanon Hospital Center
<b>Morten</b>	Bronx-Lebanon Hospital Center
<b>Raiko</b>	University of Colorado, Denver
<b>Shannon</b>	University of Alabama, Birmingham
<b>Sharry</b>	University of Southern California
<b>Stephanie M.</b>	University of California, San Diego
<b>Stephanie S.</b>	University of Miami
<b>Theresa</b>	Texas Children's Hospital
<b>Tracey</b>	University of Illinois, Chicago
<b>Trinise</b>	Tulane University

• **APPROVAL OF MINUTES**

The minutes from the June 27, 2019 call were approved with no changes.

• **CAB AMBASSADOR INVITATION – CARDIOLPULMONARY WORKING GROUP (WG)**

**Stephanie** talked about the Cardiopulmonary (heart and lung health) WG. The WG leaders reached out to the CAB. The WG reviewed the CAB's ideas for collaboration with PHACS WGs. The WG looks at heart and lung function in children born to mothers living with HIV. A lot of their work looks at evaluating safety of the ARV treatment given to pregnant mothers living with HIV. Specifically, they are looking at how ARV treatment affects the heart and lung health of youth. They're looking for a CAB ambassador to their WG. The WG is interested in inviting someone who has not participated much in other WGs. Interested CAB members should contact **Stephanie** and **Megan**.

## • PHACS CAB EVALUATION SURVEY REVIEW

**Megan** reviewed the May PHACS CAB Evaluation Survey. There were eleven (11) responses.

There were many responses about resilience. These responses will be featured in the PHACS CAB Newsletter, July 2019 Edition. The newsletter is currently being edited. The newsletter will be sent out at the end of July.

**Megan** reviewed the feedback from the June 2019 CAB call. One CAB member stated that the CAB calls are an excellent opportunity for CAB members to voice their thoughts, personal stories, and struggles. CAB members are able to provide support during the calls. Many CAB members are also available after the calls to provide support. Another CAB member felt it was an excellent call. The CAB member was very proud of all CAB members for their hard work. Finally, the CAB member thanked those who shared about their personal struggles.

**Sharry** talked about resilience. This topic is important to many CAB members. Resilience is based on everyone's journey, including their journey involving their diagnosis. Sharry thanked the CAB members for sharing their stories. The CAB is a great support system. Resilience is an ongoing journey. Sharing stories of resilience helps to inspire each other.

**Latonia** talked about resilience. It may be helpful to revisit the topic of resilience. It may be hard for someone to feel comfortable talking about resilience. Finding support in the CAB may be helpful for CAB members.

## • PHACS 2019 FALL CAB RETREAT AND NETWORK MEETING

**Megan** talked about the 2019 Fall CAB Retreat and Networking Meeting. The 2019 Fall CAB Retreat and Network Meeting will take place at the Bethesda Hyatt Regency in Bethesda, Maryland. The CAB Retreat is scheduled for September 18, 2019. The Fall Network Meeting is scheduled for September 19-20, 2019. CAB attendees will arrive on September 17, 2019. CAB members will depart after the meeting on September 20, 2019. 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 seven calls from September 2018 through June 2019. Twenty (20) CAB members were eligible to attend the meeting. CAB members will receive invitations before August 5, 2019. CAB members can contact Megan with any questions.

Once CAB members receive their invitations, they should email Megan with their contact information. CAB members should provide an address where they can receive their per diem check. Per diem is the money provided for the meals not provided by the meeting. Per diem also include money for ground transportation to and from the meeting and airports. Westat Travel will contact CAB members to arrange flights. Per diem will be distributed in late August/early September.

**Megan** talked about the Statement of Commitment. **Megan** reminded CAB members to sign their Statements of Commitments with their site staff members. The Statement of Commitment ensures that CAB members understand their responsibilities at the meeting and retreat.

**Megan** talked about the Fall 2019 CAB Retreat. Many sessions will be included in the retreat. The retreat will include breakfast, a buffet lunch, and afternoon snacks. The retreat will take place from approximately 10:00 AM to 5:00 PM.

One session will focus on the research summaries. The CAB will split up into groups to review select draft research summaries of recent PHACS publications. The CAB will give feedback on the research summaries as well as brainstorm ideas for disseminating study results.

Another session will focus on disclosure. Megan explained that there will be a session during the Network Meeting focused on disclosure. The facilitators of the session will meet with the CAB during the breakout

session. To prepare for that session, the CAB members will talk about disclosure during the retreat. CAB members are encouraged to take notes during the retreat to bring to the breakout session.

**Liz** from the PHACS Data and Operations Center will be leading the CAB through a mindfulness meditation session during the retreat. Additionally, **Liz** and other PHACS Leadership will be presenting a session to the CAB. Megan reviewed suggestions from the CAB for the PHACS Leadership session. It was suggested that the Leadership review current PHACS research and capsules. It was also suggested that the Leadership bring questions to ask the CAB. The CAB is interested in providing feedback directly to the researchers. The Leadership will also meet with the CAB on a CAB call after the meeting to answer any follow up questions. **Gena** suggested that the CAB consider talking with the Study Coordinators about any issues coming up at study visits. There may be issues with adherence or other barriers to study participation that CAB members may be to assist. **Kamil** talked about the importance of the CAB and Study Coordinators working together. **Megan** explained that there may not be time for the CAB and the Study Coordinators to meet during the CAB Retreat because the Study Coordinator Retreat is happening at the same time as the CAB Retreat. However, CAB members are encouraged to submit ideas for Study Coordinator collaboration through the PHACS CAB Evaluation Survey. The CAB will invite Study Coordinator Leadership to attend a future CAB call.

- **CAB REVIEW OF CAPSULES PROPOSAL**

**Megan** talked about the capsule review process. One of the Chairs of the Women's Health WG, Deb, presented to the CAB during the May CAB call about the capsule process. In the Women's Health WG, the capsules are reviewed during the Women's Health WG calls, and then voted on by the WG members. The Women's Health WG was brainstorming ways to better involve CAB members including CAB members who are not available to participate on the Women's Health WG calls. It was suggested that CAB members review Women's Health WG capsules on an ongoing basis on the CAB calls. CAB members could vote on priority for a capsule as it relates to the community (high, medium, or low priority). This feedback would then be given to the WG and the author to consider for this capsule and future capsules. **Sharry** talked about the voting process. It would be helpful for CAB members to vote on priority of a capsule, rather than to approve or disapprove. It can be intimidating to approve or disapprove a capsule. Priority voting allows all CAB members to weigh in on a capsule.

**Megan** encouraged CAB members to comment about voting on capsule priority through the PHACS CAB Evaluation Survey.

- **AUGUST CAB CALL RESCHEDULED**

**Megan** talked about the August CAB call. The call has been rescheduled to August 29, 2019.

**NOTE: The next CAB call will be on Thursday, August 29, 2019 at 12:00 pm EST.**