

**CAB Conference Call
April 26, 2018
12:00 EST
Meeting Minutes**

Participants:

Alex	FSTRF
Andrea	Jacobi Medical Center
Brandon	University of Florida, Jacksonville
Carrie	University of Colorado, Denver
Claire	Harvard University
Exzavia	Children's Diagnostic and Treatment Center
Jeanie	University of Southern California
Jennifer	San Juan Hospital
Joel	University of Puerto Rico
Juanita	Tulane University
Julie	University of Alabama, Birmingham
Julie	Westat
Kimbrae	Texas Children's Hospital
Kylie	Texas Children's Hospital
Latonia	University of Chicago, Illinois
Lesley	Texas Children's Hospital
Leslie	Texas Children's Hospital
Lourdes	San Juan Hospital
Marilyn	Bronx-Lebanon Hospital Center
Megan	Westat
Raiko	University of Colorado, Denver
Shannon	University of Alabama, Birmingham
Stephanie	University of California, San Diego
Stephanie	University of Miami
Theresa	Texas Children's Hospital
Trinise	Tulane University
Veronica	University of California, San Diego
Zena	University of Miami

• **APPROVAL OF MINUTES**

The minutes from the March 22, 2018 call were approved with no changes.

• **PHACS CAB EVALUATION SURVEY**

Megan talked about the March PHACS CAB Evaluation Survey. There were 5 responses. Topics suggested through the survey included:

- Domestic violence;
- Coping;
- Bullying; and
- New studies.

• CAB STRUCTURE AND PURPOSE

Megan, Claire, and Julie met with the PHACS neuropsychologist leadership during the Spring 2018 Leadership Retreat. The group talked about ways to help the CAB achieve its goals.

Megan talked about the purpose of the CAB. The purpose of the CAB is to seek input from community representatives in order to reflect the interests of participants and caregivers in PHACS. The CAB is also a space for site CAB members to share resources. The mission of the CAB is to be a connection between researchers and community members in order to improve PHACS for participants and caregivers. The CAB gives feedback about PHACS from the participant/caregiver perspective.

Megan talked about the impact of the CAB. During the meeting, the neuropsychologists gave feedback about the CAB. The CAB has given important feedback over the years. The feedback has shaped many of the PHACS scientific priorities. CAB feedback has also made a difference at the site level. Many sites have made changes to how they carry out study visits based on feedback from the CAB. The neuropsychologists hope to continue to help to CAB continue this important work, and thanked the CAB for their efforts over the years.

Megan talked about the last few CAB calls. Several calls were very emotional. It is important for CAB members to leave the calls on a positive note. In the past, sharing support and stories has been important to CAB members, however the CAB is not a support group. There may be a different space for CAB members to share stories. **Megan, Claire,** and supporting staff members may put together “storyline” calls during the year, as needed. CAB members will be invited to join the call to share stories and support.

It may be helpful for the CAB to set ground rules. Ground rules would be followed during CAB calls and in-person meetings. The CAB suggested the following ground rules:

- Respect each other’s time – limit responses to less than a couple minutes at a time;
- Make sure everyone has a voice – let everyone get a chance to speak. Be mindful of others who haven’t gotten a chance to share. Take turns talking;
- Confidentiality – what is said on the call stays on the call;
- Questions are always welcome at the appropriate time;
- Respect each other’s opinions – allow others to share freely without criticizing or giving advice;
- Mute the phone when not speaking; and
- If joining the call late, wait to announce names until the end of the call.

Many CAB members talked about support. Although the CAB is not a support group, many CAB members may need support after a call. Some topics may remind CAB members of personal experiences. It was suggested that the CAB pay attention to each other during the calls. If someone sounds like they might need additional support, CAB members will work together to contact each other after the calls, when needed.

Megan talked about enforcing the ground rules. The CAB talked about ways to enforce the ground rules during CAB calls. The CAB talked about enforcing time limits. CAB members should time themselves when speaking. **Megan** and the CAB Chairs should go over ground rules including time limits at the start of each call. Additionally, it was suggested that reminders be sent through email. **Megan** will include ground rules on call announcements.

CAB members were encouraged to suggest ground rules and ways to enforce ground rules through the survey. The ground rules are still in development. The CAB will review the ground rules during the May CAB call.

Megan talked about "plus/delta." Plus/delta is an exercise that can be used in groups. The exercise asks groups to talk about the "pluses," or what went well on the call. The exercise also asks groups to talk about "deltas," or what could be done better on future calls. Plus/delta may help the CAB to check in regularly to talk about the calls. It may help to address problems quickly instead of waiting for them to build up over time. The CAB was encouraged to submit plus/delta responses through the survey. The CAB will continue to use the plus/delta exercise during future calls.

NOTE: The next CAB call will be on Thursday, May 24, 2018 at 12:00 pm EST.