

**CAB Conference Call
March 22, 2018
12:00 EST
Meeting Minutes**

Participants:

Andrea	Jacobi Medical Center
Brandon	University of Florida, Jacksonville
Claire	Harvard University
Delia	University of Miami
Gena	University of Miami
Jennifer	San Juan Hospital
Jennifer	University of Colorado, Denver
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
Martin	Bronx-Lebanon Hospital Center
Megan	Westat
Raiko	University of Colorado, Denver
Stephanie	University of California, San Diego
Theresa	Texas Children's Hospital
Trinise	Tulane University
Veronica	University of California, San Diego

• **APPROVAL OF MINUTES**

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

• **PHACS CAB EVALUATION SURVEY**

Megan talked about the February PHACS CAB Evaluation Survey. There were 8 responses. Topics suggested through the survey included:

- Mental health and disclosure;
- Oral Health Substudy;
- Toxic relationships;
- Self-love;
- Communication with children;
- Genetic findings in mental health;
- Depression;
- Side effects of medications;
- Mental health as a family issue;

- Gum health;
- Self-care techniques; and
- Coping mechanisms for parents.

Megan, Claire, and **Julie** will be meeting with the PHACS neuropsychologist leadership during the Spring 2018 Leadership Retreat. The group will talk about ways to help the CAB achieve its goals.

• **SPRING 2018 LEADERSHIP RETREAT – BRAINSTORMING QUESTIONS**

Stephanie talked about the Spring 2018 Leadership Retreat. The retreat will be held on April 9-10, 2018 in Potomac, Maryland. Cab Chairs, **Stephanie** and **Brandon** will attend the retreat with other PHACS Leadership.

Megan reviewed the meeting agenda with the CAB. **Kylie** talked about the agenda. **Kylie** suggested that the CAB Chairs takes notes on the echocardiogram presentations. **Kim** suggested that the CAB Chairs take notes about studies involving the lungs and heart. The lungs and heart often work together. **Megan** explained that the Cardiopulmonary Working Group (WG) focuses on heart and lung health. **Leslie** wondered whether any of the new studies will be open to participants not previously enrolled in PHACS. **Leslie** suggested that the CAB Chairs ask about ethics in regards to the genetics studies.

• **HEALTH EDUCATION AND COMMUNICATION COMMITTEE (HECC) UPDATE**

Claire talked about the HECC. The HECC is thinking about making infographics to describe PHACS results. Infographics use pictures and words to help explain a topic. The new infographics would show many PHACS findings in one document. This would help connect some of the publications in PHACS. It will hopefully help better explain important findings. The infographics would focus on overall results.

Several CAB members like the infographic idea. **Veronica** suggested that the HECC create an example infographic. The example could show the difference between the new infographics and the old participant summaries. **Julie** talked about the infographics. It can be difficult to read many participant summaries at once. Combing the information into one infographic might be easier to read.

Claire talked about how the infographics would be shared with the community. **Kim** suggested that the HECC share the infographics using QR codes (barcodes). Participants could scan the QR code with their phones. The code would take them to the infographic online. This would allow participants to see the infographics quickly and privately. **Theresa** suggested that the infographics be printable. It may also be helpful to post them on the PHACS website.

• **SITE CAB SHARING**

Theresa talked about the CAB at Texas Children’s Hospital. During the last CAB meeting, a CAB member talked about getting mental health services for herself and her children. Next week, a mental health professional will talk to the CAB. The following week, a psychiatrist will talk to the CAB about mental health resources available at Texas Children’s Hospital.

- **PHACS CAB NEWSLETTER, JANUARY 2018 EDITION**

Stephanie talked about the PHACS CAB Newsletter, January 2018 Edition. The newsletter followed a theme of "Above and Beyond." **Stephanie** and **Megan** thanked the CAB for submitting articles for the newsletter.

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