

**CAB Conference Call
October 25, 2012
12:00 EST
Meeting Minutes**

Participants:

| | |
|----------------|-------------------------------------|
| Claire | Harvard University |
| Delia | University of Miami |
| Julie | Harvard University |
| Julie | Westat |
| Julie | University of Alabama at Birmingham |
| Krystal | Harvard |
| Laurie | FSTRF |
| Mariana | University of California San Diego |
| Marilyn | Bronx-Lebanon Hospital Center |
| Megan | Westat |
| Melanie | UMD – New Jersey Medical School |
| Rosetta | Bronx-Lebanon Hospital Center |
| Sherry | St. Jude Children’s Hospital |

• **APPROVAL OF MINUTES**

The minutes from the September 27, 2012 call were approved with no changes.

• **PHACS CAB EVALUATION SURVEY RESULTS**

Megan talked about the PHACS CAB Evaluation Survey results. There were 10 responses. Some suggested topics for upcoming calls are:

- PHACS CAB and local CAB accomplishments,
- disclosure,
- challenges of raising children with HIV and HIV exposure,
- stigma,
- adolescent participation in the CAB,
- CAB activities in future meetings,
- aging and HIV,
- hepatitis C, and
- incidence of birth defects in PHACS participants.

• **INVITATION FROM THE PULMONARY COMPLICATIONS IN PHACS AMP (PCPA) PROTOCOL TEAM**

Julie from Westat talked about the Pulmonary Complications in PHACS AMP (PCPA) protocol. The PCPA study will be looking at lung diseases in the PHACS AMP cohort. Participants will be currently enrolled AMP participants. The protocol team is looking for signs of lung abnormalities of structure and function. Participants will be given a survey about asthma history, degree of asthma, and control and history of exposure to tobacco. Participants will go answer questions, have some blood tests, and other tests to see if participants have signs of lung disease. One objective of the study is to estimate

and compare the prevalence of lung disease in HIV-infected and HIV-exposed but uninfected children. The other objective is to explore the link between lung disease and immune dysfunction.

A CAB representative was invited to join the PCPA protocol team. The CAB representative has to attend conference calls. The CAB representative should give feedback on the protocol. The next PCPA protocol team call is Wednesday, October 31 at 9:00 AM EST. Delia and Sherry volunteered to be on the PCPA protocol team.

Action Item: Megan will add a section to the PHACS CAB Evaluation Survey for CAB members to volunteer to be a CAB representative on the Pulmonary Complications in PHACS AMP (PCPA) protocol team.

• CAB NETWORK MEETING DISCUSSION

The PHACS Fall 2012 Network Meeting is November 8-9, 2012 in Bethesda, Maryland at the Bethesda Hyatt Regency. Megan sent out the meeting agenda. The per diem checks were sent to CAB members. The per diem check is for meals and ground transportation. It covers meals that are not given at the meeting. All travel arrangements have been made for CAB representatives. Hotel rooms have been booked for all CAB representatives.

Megan invited the CAB to come to an informal dinner on Wednesday, November 7. The dinner will be at La Madeleine restaurant. The group will meet at the meeting registration table in the hotel lobby at 7:00 PM. The group will walk to the restaurant together. Megan will send out an email with details about the dinner.

There will not be a third CAB session. Megan talked about the second CAB session. During the second CAB session, CAB members will participate in a story circle. Claire talked about what a story circle is. A story circle is an exercise where people share stories about similar experiences. CAB members will sit in small groups of 6-10 people. Three CAB members are needed to facilitate the story circles. Facilitators will regulate the story circle. CAB members will take turns telling a story about a topic. CAB members do not have to tell a story. Claire invited CAB members to volunteer to be a story circle facilitator.

Action Items:

- 1. Megan will send an email to the PHACS CAB meeting attendees with details about the informal dinner gathering.**
- 2. Megan will add an item to the PHACS CAB Evaluation Survey for CAB members to volunteer to be a story circle facilitator.**

• PHACS CAB COMMUNITY CONCERNS AND PRIORITIES

Megan sent out the PHACS Community Concerns and Priorities list. The CAB finalized the list.

Action Items:

- 1. Megan will include the PHACS Community Concerns and Priorities list in the Fall 2012 Network Meeting packets.**
- 2. Megan will post the PHACS Community Concerns and Priorities list on the PHACS website.**

• PHACS CAB NEWSLETTER, DECEMBER 2012 EDITION

Megan talked about the PHACS CAB Newsletter, December 2012 Edition. CAB members were able to suggest themes for the newsletter through the PHACS CAB Evaluation Survey. Some suggested themes are:

- Stigma reducing efforts,
- PHACS 2012 and beyond,
- PHACS 2013,
- raising a healthy child,
- emotional and developmental aspects of children and adolescents,
- raising children with HIV and HIV exposure,
- stigma and discrimination,
- benefits of participating in a research study,
- prevention,
- community,
- bright stars shine through while dealing with HIV,
- support systems,
- the holidays,
- HIV/AIDS free generation,
- the future of HIV/AIDS, and
- long-term HIV survivors.

The CAB agreed to vote on a theme through the PHACS CAB Evaluation Survey.

Action Item: Megan will add an item to the PHACS CAB Evaluation Survey for CAB members to vote for a theme for the PHACS CAB Newsletter, December 2012 Edition.

• **PHACS CAB DISCLOSURE FACT SHEET**

Megan sent out the PHACS CAB Disclosure Fact Sheets. The PHACS Study Coordinators and Neuropsychologists recommended that the CAB make two separate fact sheets. One fact sheet talks about the issue of disclosing a child's own HIV infection. The other fact sheet talks about the issue of disclosing a parental HIV infection to an HIV-infected but unexposed child. The Spanish version of the PHACS CAB Disclosure Fact Sheets will be sent out soon.

Action Items:

- 1. Megan will distribute the PHACS CAB Disclosure Fact Sheets to the PHACS CAB, Study Coordinators, Neuropsychologists and Clinical Investigators.**
- 2. Megan will post the PHACS CAB Disclosure Fact Sheets on the PHACS website**
- 3. Megan will include the PHACS CAB Disclosure Fact Sheets in the Fall 2012 Network Meeting packets.**

• **INVITATION FROM THE PHACS HEALTH EDUCATION AND COMMUNICATION COMMITTEE (HECC)**

Claire talked about the Health Education and Communication Committee (HECC). The HECC will have members from different areas of PHACS. The HECC is looking to work on health education and communication projects in PHACS. The HECC is also looking to make a website for young adults in PHACS. The HECC will have monthly conference calls. Claire invited CAB members to join the HECC.

Action Items:

- 1. Claire will send out a summary of the Health Education and Communication Committee (HECC) to the CAB.**

2. **Megan will add a section to the PHACS CAB Evaluation Survey for CAB members to volunteer to join the HECC.**

NOTE: The next CAB call will be on Thursday, November 29, 2012 at 12:00 pm EST.