

**CAB Conference Call
May 27, 2010
12:00 EST
Meeting Minutes**

Participants:

Allison	Bronx-Lebanon Hospital Center
Carrie	Denver Children's Hospital
Dorothy	University of Alabama at Birmingham
Ginny	Boston Children's Hospital
Gloria	University of Florida- Jacksonville
Julie	Westat
Lori	FSTRF
Mariana	University of California
Marilyn	Bronx-Lebanon Hospital Center
Megan	Harvard
Miriam	Harvard
Rosia	Westat
Samantha	Children's Diagnostic & Treatment Center
Stephanie	University of Miami
Theresa	Texas Children's Hospital
Yuri	University of Miami

- **WELCOME**

The group welcomed its new members.

- **MEETING MINUTES**

The minutes for March 25, 2010 were approved.

- **APRIL PHACS MEETING**

Samantha updated the CAB about the April PHACS Meeting in Washington, DC. Samantha said the meeting very interesting, and the committees are doing fantastic work, including coming up with new protocols. Samantha affirmed that community is very valuable for our studies and that the researchers value community too. An example of this was observed at the Adolescent Working Group, which was a meeting that Samantha attended. The group talked about a study they are conducting. They discussed how they are getting caregiver and community input for that study and all their other studies.

Samantha also attended the Executive Committee Meeting. At that meeting, it was suggested that more community members be invited to participate in the PHACS Meeting. Members of PHACS are going to look into how to support more CAB members to attend the meeting.

- **CHAIR AND VICE CHAIR POSITIONS**

The May CAB Call is **Samantha's** last call as the Chair of CAB for PHACS. Samantha has been the Chair for the past two years. Samantha has been very humbled by being Chair. Samantha spoke words of gratitude for being able to be a leader in this community of research and to have access to the breadth of information and research results. Samantha said being the CAB Chair has been a wonderful journey for her.

Jennifer has been serving as Vice Chair since October 2009. Jennifer is now the incoming CAB Chair, effective June 2010. Jennifer will speak on the June CAB call about the Network Meeting and her role as the incoming CAB Chair. Therefore, the Vice Chair position is open. We will be taking nominations for the next month. This will give everyone a chance to think about the position and to give others who are not on the call this month the opportunity to join the call in June.

The CAB Vice Chair position is a two-year commitment. The Vice Chair attends the monthly CAB calls and helps to set the agenda for those calls. The Vice Chair also attends the PHACS Network meetings in the spring and fall each year. PHACS pays for all travel, room and board during those meetings. The Vice Chair participates as a non-voting member on the monthly Executive Committee call.

Action Item: Please nominate yourself or another CAB member for the position. To nominate someone, submit a brief summary why you or your nominee would be a good candidate. Once names have been collected, a list of the nominees and the brief summaries will be sent to the CAB for a vote.

• CAB SPOTLIGHT

Every month on the CAB Call, two CAB members are going to share about their local CAB experiences. Please let Rosia at rosiawarner@westat.com know if you are interested in sharing.

Marilyn described the CAB at her site at the Bronx-Lebanon Hospital in New York. They have a new pediatric CAB for IMPAACT and PHACS. This CAB includes adolescent members. Some of the members of the CAB are HIV-positive. They meet once a month. The site doctor recommended who should be on the CAB. Right now, they have four members. They are looking for eight members.

At the CAB meetings, they do trainings every two months. The last training was about the importance of consent forms and what to expect from study visits. They are also learning about how to retain and attract members to the CAB. The CAB also provides input for the PHACS protocols. The CAB also provides childcare and lunch.

Marilyn stated that in order to retain members, the CAB meeting has to be convenient for the members to attend.

Yuri spoke about the difficulty of retention, especially in the adolescent population. At the Miami site, PHACS and IMPAACT share a CAB, but the Adolescent Medicine Division has their own adolescent CAB, with members between 18-27 years old. There are infected males and infected mothers with children who participate on the CAB. They have seven loyal CAB members with a 100% attendance rates. This is achieved because their meetings are every six weeks, and dinner is provided because the meeting time is 4-6pm. The CAB also provides transportation to and from the meeting. Also for retention, Yuri emphasized the importance of members feeling acknowledged and that their opinions are valued. It is important to make sure that everyone's voice is heard and that their concerns are being addressed. PHACS wants the CAB feedback about research, so retention on the CAB is important. CAB commentary is a great benefit for the HIV and research community.

Action Item: In June, Sherri and Yuri will speak to the CAB about their local CAB experiences.

PROJECT UPDATES

ENROLLMENT ACCRUAL

Julie updated the CAB about enrollment accrual. The SMARTT study enrollment accrual into the static cohort is closed. They have enrolled 1240 participants. For the Dynamic Cohort, they have 874 participants. The Dynamic Cohort continues to enroll participants. The AMP study protocol is closed

to enrollment. However, the study participants continue to come to their study visits. The Memory Sub Study has 18 children enrolled.

Julie spoke about the retention rates for the studies. A retention rate is the percentage of participants who stay on the study versus the total that are enrolled. For the SMARTT Static Cohort, they have enrolled 1175 people on the study. However, 53 went off study. They now have 1122 participants enrolled. This means that they have a 95.5% retention rate.

Participants who went off study because of an "unavoidable loss" are also included in the data. Unavoidable loss includes death, moving away, incarceration, or withdrawing consent from the study. The percentage increases, if we do not include those that left for unavoidable loss reasons. For the above example, the percent changes from 95.5% to 98.5%. For the SMARTT Dynamic Cohort, out of the 794 total enrolled, there are 751 remaining on study. This is a 94.6% retention rate. If we do not include the unavoidable losses, it is 98.6%.

For AMP HIV-positive cohort, there were 428 people enrolled. Twenty-five participants went off study, which means that 403 remained, which is a 94.2% retention rate. Sixteen participants left due to unavoidable loss, so the retention is now 97.9%. For the AMP Control Cohort that is HIV-negative, they enrolled 219 people. Five have gone off study, with a retention rate of 97.7%. One participant was an unavoidable loss, which changes the retention rate to 98.2%.

Year 6 of PHACS

Year 6 of PHACS begins on August 1. There are government budget cuts. The study team has been making changes to the protocols. We will have another version of the protocols for Year 6. The PHACS Leadership has been working hard to determine where to make changes and cuts. They are also ensuring that they will meet their scientific objectives.

The frequency of visits for both studies is going to change. For AMP, the study visits will be once a year instead of twice a year. For SMARTT, the study visits will be once a year until age six. After age six, the visits will be every other year. The study staff will contact the caregivers in the year that there is no study visit. The study staff will call to check in, make sure the participant's address and phone numbers are up to date, and to see if there has been any change in the health of the children since the previous visit.

Dorothy wanted to know if the CAB was asked for input into these changes. Dorothy has concerns about the impact on retention. **Julie** responded that it was discussed at the Network Meeting. Jennifer and Samantha were able to provide feedback.

Retention is an issue that was discussed by the study team. They know it is important to stay in contact with the caregivers and study participants. Participants will be contacted with study updates to keep the motivation and retention levels up. A frequent study newsletter is being considered to keep people informed the study results. CAB members are encouraged to share information they are learning at this CAB call to their local CAB meetings.

Abstracts and Publications

Four abstracts were presented at the February 2010 Conferences on Retroviruses and Opportunistic Infections meeting. In March and May, there were two more abstracts presented at scientific conferences. Three abstracts will also be presented at the International AIDS conference in July 2010. We have two papers that are in the process of being published in some scientific AIDS journals. All of these abstracts and publications have participant summaries. They will be posted to the website soon. Please share the participant summaries with your local CAB.

• NEWSLETTER

Please also consider submitting to the newsletter. You may write about special events that your local CAB has participated in, your own experience as a CAB member, upcoming events, HIV events, or anything else that you would like to share. Your input is needed.

- **OTHER ITEMS**

NOTE: the next CAB call will be on Thursday, June 24, 2010 at 12:00 pm EST.