CAB Conference Call November 19, 2009 12:00 EST Meeting Minutes

Participants:

Cheryl Westat
Christina Westat
Edwin San Juan

Gail Texas Children's Hospital

Jennifer University of Colorado at Boulder

Joanne Westat

Joseph University of Florida Health Sciences Center

JulieHarvardLennieSt. JudeLindaSt. Jude

Marianna University of California - San Diego

Marilyn Bronx Mercy Westat

Naimah University of Medicine and Dentistry of New Jersey

Samantha Children's Diagnostic and Treatment Center
Sharan University of Alabama – Birmingham

Sharan University of Alabama – B **Theresa** University of Alabama – B Texas Children's Hospital

Rosia Westat

MEETING MINUTES

The group approved the minutes for October 24, 2009.

WELCOME NEW CAB MEMBERS

The team welcomed Joseph, Edwin, Linda, and Naimah.

PHACS NETWORK MEETING

Jennifer, the CAB Vice Chair, and **Sharan**, a CAB member, attended the PHACS network meeting. The meeting was November 9-10, 2009 in Washington, DC. **Sharan** attended the meeting for **Samantha**, the CAB Chair.

Jennifer and **Sharan** described the workshops, presentations, and plenary sessions. The first talk was about the Protocol updates to Versions 3.0. SMARTT is being updated to include a new group of study participants. The name of the new group is the reference cohort. The reference cohort will enroll participants who are not HIV positive and whose mothers were not HIV positive when they were born. Participants may be people who get their care at the general pediatric clinic at the study site. They may also be friends or family of current SMARTT participants. The subjects must have similar demographics to the current SMARTT children. There will only be one visit for this study and no triggered assessments. A parent/caregiver of each reference participant will also be enrolled.

The AMP study is being changed to collect more information on renal dysfunction, gynecological, and HPV infection. For both AMP and SMARTT, a new consent form was created for mothers of AMP and

SMARTT children. The form asks to use repository samples that were collected during other studies the mothers were on.

Subject retention was discussed. Subject retention refers to how many enrolled participants are still on the study. PHACS has kept 95-99% of participants in the study. Site staff shared their methods for keeping participants in the study. Money incentives, birthday cards, and training sessions were some approaches used. Similar ideas can also be used to keep CAB members involved. It was suggested that CAB meetings be after work or on the weekend. Sessions on psychosocial support services, housing assistance, Medicaid, and GED services could be offered.

The nutrition arm of the Dynamic cohort was discussed. This study will look at how babies are affected by the mother's food intake during pregnancy. The mothers will be from the Dynamic cohort, and in their third trimester. Another arm, neurobehavioral skills, is a study to test newborns at SMARTT sites. It tests newborns' attention, arousal, stress, and quality of movement. (This study is still in the early planning stages.) The Memory Function arm looks at memory and executive function in adolescents. It was noted that problems with memory and executive function have not been looked at in children with HIV. PHACS wants to study this area because loss of executive functioning and memory can create problems with drug adherence and independent living.

The network meeting had three main science talks. They focused on how HIV affects the brain. They talked about the effects of prenatal exposure to drug abuse and neurological AIDS research in the age of antiretroviral drugs. Working groups also met to discuss their research. On the final day, each working group presented what they had collaboratively worked on during the conference.

Sharan and **Jennifer** thanked PHACS for giving them the opportunity to participate in the Network meeting. They felt very welcomed as CAB members. The Network Meeting slides will be posted on the PHACS website.

SUBSTUDY MEMBERSHIP

The Memory function substudy is looking for a CAB member to serve on their protocol team. It will be important to find a CAB member to provide input for the study.

CAB ACTIVITIES

Information about the Bahamas CAB is available on the PHACS website. The information is posted to help CABs build interest. The CAB is thinking about putting together a cookbook or a gift card raffle to send kids to Camp Hope.

CAB NEWSLETTER

The newsletter will be finalized in December 2009.

PROJECT UPDATES / COMMITTEE REPORTS

Enrollment in the reference cohort will take place at select sites. 200 children are needed. We should know by December which sites will enroll reference children.

Seven PHACS abstracts were submitted to the Conference on Retroviruses and Opportunistic Infections (CROI). Five abstracts were accepted. In the upcoming months, authors of CROI abstracts will speak to our group. PHACS research was also selected for one of the main talks at the American Heart Association Conference.

The group was informed that the PHACS II funding application was submitted. **Julie** will let the group know what the outcome of that application is. The application is for five more years of PHACS.

NEW CAB LIAISON

Christina will not be serving as the CAB liaison anymore. **Christina's** position on the CAB call was temporary. We thank Christina for her dedication to CAB. Her replacement is **Rosia Warner**, who currently works on the PHACS team at Westat.

ADDITIONAL ITEMS

Someone from the Adolescent Trials Network will speak on the December call. In January 2010, a researcher will speak to the group about IMPAACT.

NOTE: the next CAB call will be on Thursday, December 17, 2009 at 12:00 pm EST