# CAB Conference Call March 25, 2010 12:00 EST Meeting Minutes

## **Participants:**

**Carol** FSTRF Data Management Center

DahliaUniversity of MiamiGailTexas Children's Hospital

**Gloria** University of Florida- Jacksonville

**Jennifer** University of Colorado

JulieWestatLennieSt. Jude

**Linda** St. Christopher's Hospital

**Linda** St. Jude

**Lisa** Chicago Children's Memorial Hospital

**Lori** FSTRF

Mariana University of California

Marilyn Bronx-Lebanon Hospital Center

MeganHarvardRosiaWestat

Samantha Children's Diagnostic & Treatment Center

**Sherry** St. Jude

**Sharon** University of California **Theresa** Texas Children's Hospital

## MEETING MINUTES

The group approved the minutes for February 25, 2010.

#### MEMORY SUB STUDY

**Sharon** spoke about the Memory Sub Study for AMP. Kids from AMP, ages 9-19, are being recruited for this study. 200 youth with HIV and 75 uninfected youth will be recruited. The sites participating are Chicago, Boston, St. Jude, Tulane, Florida, Baylor, San Diego, and Jacobi Medical Center.

Memory and Executive Functioning are the focus of this study. Studying memory in kids is important because the learning skills that are involved in learning adult skills are affected. Adult skills include managing life on your own.

There are different types of memory. This study looks at "retrospective memory" and "prospective memory." Retrospective memory looks at learning and memorizing; it is what was learned in the past to see if can be recalled later. This type of memory is useful for remembering what you learned in school to use later in life. Prospective memory is useful for going forward in the future such as remembering to do a task. Teenagers with and without HIV struggle with prospective memory. It is a complicated process. A task that is involved with prospective memory is remembering to take medicine, which is important for people with HIV.

The other area that is being looked at is Executive Functioning (EF). EF manages behavior and function, and helps people to be consistent with their goals. EF is the part of our brain that solves problems, keeps organization, makes decisions, and makes sure goals are achieved. EF comes up with creative ways to achieve tasks. This area of the brain is critical for teens to be successful adults.

The children will do tasks involving memory. The kids will work on word search puzzles. They will also be asked to do a task at a particular time, and they have to remember to do it. The kids will also be asked to write words and draw designs from memory. They will participate in a game similar to "20 Questions," where they will have to figure out what the examiner is thinking. The examiner will then analyze the child's strategies for coming up with yes / no questions.

### CAB UPDATE

Every month on the CAB Call, two CAB members are going to share about their local CAB experiences. Please let **Rosia** at <u>rosiawarner@westat.com</u> know if you are interested in sharing with the CAB. **Samantha** and **Jennifer** shared their local CAB experience with the call.

**Jennifer** shared about the University of Colorado CAB. Jennifer's local CAB meets once a month on Thursday evenings. The last meeting had 12-14 adults in attendance. They also had a room for childcare. Her site provided dinner, which Jennifer thought was helpful. During that CAB meeting, Jennifer shared about the November PHACS Conference in DC. Jennifer updated her CAB on the findings from the studies. Jennifer's CAB also discussed local events, which included "Art Day." A studio provided the CAB members space and materials for Art Day. The CAB members, including children, did artwork on canvas. The program takes the artwork to fundraisers in ski areas to be auctioned off. The money raised goes back to the art program. Jennifer said it was amazing to meet other people on her CAB, to have the creative outlet, and to help another program that has been able to do so much for the community.

**Samantha** discussed her experiences with the Children's Diagnostic and Treatment Center in Fort Lauderdale CAB. At this site, there are multiple CABs. They have an adult CAB for all of the networks, including PHACS and IMPAACT, which do collaborative research with women and other caregivers. Their site provides the local CAB with information including lay summaries, protocols, and study outcomes. For the PHACS CAB, it meets once a month, and there are 20-25 adolescents, many of them are perinatally infected with HIV. The CAB helps with PHACS by giving the researchers insight. At Samantha's CAB, they give the children a stipend to get to and from the CAB meeting if transportation is an issue. The CAB is provided with a meal. The CAB works with the adolescents on empowerment and encouragement, and the adolescents contribute their perspective on the protocols. The last 20-25 minutes is used to educate the adolescents. The CAB also works with the adolescents on empowerment and encouragement, especially since they are adolescents.

Sherry and Marilyn are going to share about their local CAB experiences on the May CAB call.

#### CAB ACTIVITIES

**Rosia** did not receive enough recipes to create a cookbook. The recipes that were intended to be in the CAB cookbook will now be added to the June 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, May 27, 2010 at 12:00 pm EST. The April phone call is cancelled.