CAB Conference Call
May 28, 2009
12:00 EST
Meeting Minutes

Participants:

Marilyn	Bronx-Lebanon Hospital Center
Samantha	Children's Diagnostic and Treatment Center
Carol	Children's Hospital of Philadelphia
Julie	Harvard University
Ashley	Harvard University
Linda	St. Christopher's
Theresa	Texas Children's Hospital
Sharan	University of Alabama
Mariana	University of California
Sheila	University of Florida
Gloria	University of Florida
Chas	University of Florida
Monica	University of Miami
Gail	Texas Children's Hospital
Tanisha	Westat
Mercy	Westat

- ## MEETING MINUTES

The group approved the April 23, 2009 CAB call minutes.

- ## PHACS PROJECT UPDATES

Julie reported that there has been progress in getting summaries written for abstracts. Instructions were sent to authors to help them write their summaries. Once summaries are complete, they will be posted on the PHACS website. Four new abstracts were recently presented at the American Pediatric Society. Most likely, those new abstracts will be presented on a future CAB call.

Julie said the study coordinators asked if a CAB member would give tips on how to make the CAB stronger on the next Study Coordinator's call. This will be discussed in more detail on the next CAB call.

- ## HEARING AND LANGUAGE BATTERY

Ashley Buchanan introduced herself. She is a statistician at Harvard University. Ashley works on hearing and language issues in PHACS. Ashley reviewed all of the information that is collection in PHACS on hearing and language with the CAB.

In **AMP,** we are interested in finding out what hearing and language problems HIV-infected youth have. This will help us understand how to best help them. It may also help us to figure out how to prevent hearing and language problems in these youth.

In AMP, we look at children who have lost hearing and/or language skills. We look at changes in their hearing and language skills during the study. We want to see if they have new problems like hearing loss. We compare hearing loss between children with HIV and similar children without HIV.

For AMP, there are four ways we get information on hearing and language. We give children language tests that ask children what they understand words and sentences. Caregivers are asked if the child has a hearing problem. Caregivers are also asked if the child has had an abnormal hearing screen during a doctor's visit. The doctor can also decide that the child has medical issues related to the cells that produce energy in the body, which are called mitochondria. Damage to mitochondria can also affect hearing and language. After any of these screenings, the child may be sent for a more detailed audiology exam. The tests are done by a doctor specializing in hearing called an audiologist.

For the AMP study, researchers are working on a paper on loss of language skill. This paper looks at how many kids *with* HIV have a loss of language. The paper will also look at how loss of language skills is related to how bad the HIV is.

For this paper, loss of a language skill is decided based on the child's score on the language tests described above. Kids can either have primary or secondary language problems. Primary language problems means a loss of language skills. It means a loss of speaking and listening skills (English only). In addition, the child has no loss of mental skills or hearing loss.

Secondary language problems are language losses with a loss of mental skills or hearing loss. It can also mean speaking and listening to non-English speaking people.

This paper looks at just HIV-positive children. The average age of these children is 13 years. Their ages range from 7-16. Half of them are male. Seventy percent are African American. Eighteen percent are Hispanic. Seventy-six percent are on HAART (a combination of at least three different types of HIV drugs).

Of these 178 HIV-positive children:

- Thirty-five percent (63 children) have some loss of language skills.
- Thirteen percent (23 children) had primary loss of language skill
- Twenty-two percent had secondary loss of language skill (40 children)
- In the entire population, we expect around 16 percent to have a loss of language skills.

Ashley said that children with secondary language loss were more likely to start HIV treatment within the first six months of life. This is compared to children who started later in life. Children who had HIV treatment in utero were not included here.
Researchers also looked at how bad the HIV is in relation to the loss of language skills. Children with secondary language problems tended to have worse HIV disease.

There are additional AMP papers in progress. Researchers are looking at loss of language skills in children with HIV and similar children without HIV. The goal is to evaluate how many kids have primary versus secondary language loss. Researchers will look at the factors that contribute to the loss of language skills and compare them.

For **SMARTT**, we want to see how exposure to HIV treatment during pregnancy and after birth affects children's hearing and language development. We want to find out if hearing and language:

- Are affected by early HIV treatment;
- If the body systems that send messages to the brain are affected by HIV treatment;
- If there are other problems caused by other factors;
- If HIV treatment causes long-term problems; and
- How HIV treatment affects children at different ages.

In SMARTT, the child's age determines the tests that are given:

- Newborns have a newborn hearing screen;
- For one year olds, the caregiver reports on the child's ability to speak and express themselves;
- For two year olds, the caregiver reports on the child's ability to express themselves, speak, solve problems, and interact with others;
- If the child is three or five years old, the child answers questions on speaking and expressing by themselves; and
- For children of any age, a parent, caregiver or doctor can report if a child has a hearing problem based on their experience with the child.

Except for newborns, if a test result is not normal the child gets a hearing screen. If the hearing screen is not normal, then the child gets a more detailed audiology exam.

For SMARTT, researchers will look at the relationship between HIV treatments in the womb and the skills to learn language. The goal will be to see if HIV treatment early in life affects the child's skills to learn language at a young age. The analysis will also look at early language skills, IQ, hearing loss, mother's education and environment. It will also see if language skills change or do not change in the first to second year of life.

Theresa asked if the hearing and language group is using any of the ND data for their analysis. **Ashley** said that some data overlaps for both the hearing and language group and the ND group. **Theresa** asked if researchers are thinking about how non-biological caregivers affect hearing and language. **Ashley** stated that the main caregivers are included in the research. The other caregivers have not been included in the research, but they are an important factor.

NOTE: The CAB call takes place the fourth Thursday of each month. The next CAB call is June 25, 2009.