CAB Conference Call April 23, 2009 12:00 EST Meeting Minutes

Participants:

MarilynBronx LebanonJulieHarvard UniversityLindaSt. Christopher's

Sharan University of Alabama, Birmingham **Sheila** University of Florida, Jacksonville

Tanisha Westat

Samantha Children's Diagnostic and Treatment Center

Delia University of Miami

Gloria University of Florida, Jacksonville **Chas** University of Florida, Jacksonville

Stephanie University of Miami

Theresa Texas Children's Hospital

Monica University of Miami

Mariam University of Southern California

MEETING MINUTES

The group approved the minutes for March 26, 2009.

PHACS NETWORK MEETING

Tanisha stated that the PHACS network meeting took place in New Orleans on April 6-7, 2009. **Theresa** attended in place of **Samantha**, who could not attend. **Carlos**, the vice chair, also attended the meeting. This meeting focused on how to best analyze PHACS data. **Julie** stated that the attendees talked about important research questions that will need to be answered in the future.

Abstracts are being turned into manuscripts. Manuscripts are detailed explanations of the research background. They also give details about what the data shows. New ideas, about future research topics, were talked about during the meeting. One of those topics was having additional genetics research for PHACS.

Theresa talked about the network meeting. She left the meeting with the sense that there is still a lot to learn about HIV infected and exposed kids. **Theresa** said that there were concerns from sites about how to start a CAB at their sites. Renee Smith, a pediatric psychologist at the University of Illinois, Chicago, said that she and other people on PHACS would like to see more input from the

PHACS CAB at future network meetings. She hoped that they would think about putting a presentation together.

ND BATTERY AND PRELIMINARY FINDINGS

Renee Smith introduced herself. She works with various working groups listed below:

- Hearing and language
- Adolescent focus is risk behaviors (substance use, sexual risk behavior, mental health, and adherence
- ND behavioral working group focus is cognitive functioning, adaptive behaviors and mental health

Renee reviewed the goals of each study for the area of neurodevelopment. The aims of AMP are to see if HIV is related to problems in cognitive functioning, adaptive functioning, behavior, mental health, and adherence.

- Cognitive function refers to verbal skills and perception
 - Problem-solving skills
 - How your brain sees the world
 - What you understand about culture and society
- Adaptive functioning refers to how you apply what you know in the world.
 - o How well a child adapts to different settings or situations

We want to know if having HIV causes problems in expected development for children. If so, we want to know when those problems start. We also want to know how often those problems happen, and if there are patterns. We want to find out if those problems are due to the virus or to other factors. Other factors may include family, environment and genetics. AMP takes children from similar backgrounds, and compares those children with HIV to those children without HIV.

AMP data is collected in different ways. Children are asked questions about how they understand things, like vocabulary and other information about our culture. They are asked about their feelings. They are also asked to do tasks, like pick out patterns from picture books. Parents/guardians are asked questions about their children also, like how they would rate their child's behavior and emotions. They are also asked about their relationship with them. The older kids also do the ACASI. The ACASI is a computer interview that the kids do alone. It asks questions about drug use and sex.

The goal of the Behavioral Group for SMARTT is to see if exposure to antiretrovirals in the womb has an effect on long-term cognitive, language, motor skills, and behavior development. SMARTT also looks at adolescent drug use and achievement. In SMARTT, when a child does not score a certain level on a test, researchers do more in depth tests called "triggered evaluations".

Researchers want to find out if a low score is due to exposure to medications in the womb or something else.

Researchers are using the PHACS data to focus on certain areas for writing papers. One paper will look at behavioral and emotional risk in children with HIV exposure and infection. Here is what some of the data shows:

- Took data from 229 infected and 70 exposed, but not infected children between the ages of 7 and 15
- Almost half of those participants (children and caregivers) reported a high-level of behavioral and emotional problems in the children
- The caregivers of pre-adolescents (7-11) reported higher rates of problems such as being sad than adolescents
- The research also shows higher rates of behavior problems in HIV exposed, but not infected kids than infected kids
- Both groups of adolescents (exposed/infected) show high rates of reported problems

This data shows that we need to focus resources and interventions for children living with HIV themselves, as well as those who are not HIV infected, but are living with a family member who has HIV.

Another paper is looking at immune response and cognitive/behavioral outcomes. When your body has an infection, it gives off an immune response to protect the body against harmful things. This immune response sometimes causes the cells in the body to become inflamed. When cells become inflamed, they release toxins. Medications can stop some of this inflammation. Researchers are looking at the children with healthy immune systems. They want to see if they think better and behave better than kids who do not have healthy immune systems.

Two analyses are looking at the effects of ARV exposure in the womb. The aim of the first paper is to see if specific medications or certain times of exposure (in other words, takings ARVs *early* in the pregnancy or *late* in the pregnancy) make a difference in early development, and the other is looking at whether those in utero exposures have an effect on development later in life.

The team is also working on a paper that looks at cognitive development in older children. This paper will look at whether those children who get very sick (an AIDS-defining illness) early in life, develop poorly later in life.

These papers will eventually be submitted to journals to share with others in the field of HIV care and research.

NOTE: CAB calls take place every 4th Thursday of the month. The next CAB call is scheduled for May 28, 2009.