# CAB Conference Call June 25, 2009 12:00 EST Meeting Minutes

### **Participants:**

**Christina** Westat

DeliaUniversity of MiamiGloriaUniversity of FloridaJulieHarvard University

Mercy Westat

**Monica** University of Miami

Samantha Children's Diagnostic and Treatment Center

**Sharan** University of Alabama

#### MEETING MINUTES

The group approved the minutes for May 28, 2009 CAB. CAB members can send changes to **Christina Garber.** 

### • PHACS PROJECT UPDATES

The Scientific Leadership Group (SLG) is responsible for giving scientific input on PHACS. The group added a new member. **Elizabeth Sowell** is a medical doctor. She is an expert in neurology from the University of California.

The PHACS leadership reviewed three proposals recently. The first is from **Jay Wilkinson**, a heart doctor. He wants to use repository samples to study cardiac biomarkers in SMARTT kids. The repository samples are collected at the AMP and SMARTT visits. These samples are gathered so researchers can conduct future studies. The SLG is reviewing his proposal.

The SLG approved two proposals this week. The first is to look at neurodevelopmental comorbidities. Co-morbidities are two or more conditions that happen at the same time. This study will look at sexual activity, drug use and emotional/behavioral function. The second study will examine the severity of HIV disease and its link to behavioral/emotional function and IQ. **Renee Smith** presented this study to the CAB earlier.

**Julie** gave an overview of the PHACS proposals to get more funding from the National Institutes of Health (NIH). Harvard University and Tulane University are the two governing organizations for PHACS. Harvard sent two proposals to NIH. The first one would enhance the work already being done. For example, some sites are getting lead data from looking at the medical records. Not all states do lead testing. The extra money, if granted, would cover lead testing at the sites where it is not being done. The second proposal is to add five substudies. These substudies support the goals of PHACS, but propose different tests than are currently done. For example, it will add a neurodevelopmental test to the newborn visit, which is not done now. Tulane sent one proposal, which focused on lab assessments to run on repository samples. PHACS leaders expect an answer in the summer or fall.

**Julie** gave an accrual update. The dynamic group has 100 % caregiver enrollment because caregiver enrollment is required for the entry visit. The other three groups have high rates of caregiver involvement as well. Those three groups are getting close to their accrual goals.

<u>SMARTT</u>			
Static children	1168	Caregivers	1148
Dynamic children	609	Caregivers	609
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AMP			
Infected children	394	Caregivers	371
Uninfected children	181	Caregivers	172

#### CAB INVOLVEMENT

The study coordinators have asked for input from the CAB. They would like ideas to increase CAB membership and participation. The CAB chair and vice chair will join the next coordinator call. The group leaders suggested that the CAB chair speak on this topic and then answer questions. Other CAB members are welcome to join that call. **Samantha** asked that the CAB members send in ideas if they cannot join the call. She also shared some of her ideas:

- Training on retention,
- Revolving the leadership,
- Commitment to CAB, and
- Educating CAB members.

Action Items: CAB members should send ideas to Christina Garber. She will send them out before the next CAB and Study Coordinator calls.

## COMMITTEE REPORTS

**Julie** included the committee reports in the project updates. This format will continue in the future. **Samantha** added that CAB participation in other groups is important for visibility. It gives CAB members greater input. **Samantha** participates in the Adolescent Working Group (WG). She reported on their last call. The WG is exploring ideas for looking at some of the data. **Julie** added that this WG uses a lot of caregiver data, and the CAB input is very helpful.

### • OTHER ITEMS

**Christina Garber** will serve as the interim CAB Liaison at Westat. She will lead the calls, send out reminders and write the meeting minutes until a permanent CAB Liaison is identified.

NOTE: The CAB call takes place the fourth Thursday of each month. The next CAB call is July 23, 2009.