

**CAB Conference Call  
January 27, 2011  
12:00 EST  
Meeting Minutes**

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**Participants:**

<b>Allison</b>	Bronx-Lebanon
<b>Carrie</b>	Denver Children's Hospital
<b>Dorothy</b>	University of Alabama at Birmingham
<b>Ginny</b>	Boston Children's Hospital
<b>Gloria</b>	University of Florida at Jacksonville
<b>Jennifer</b>	University of Colorado
<b>Julie</b>	Harvard
<b>Julie</b>	Westat
<b>Lennie</b>	St. Jude
<b>Mariana</b>	University of California – San Diego
<b>Megan</b>	Harvard
<b>Rosia</b>	Westat
<b>Sharon</b>	University of California – San Diego
<b>Sherry</b>	St. Jude
<b>Theresa</b>	Texas Children's Hospital
<b>Vikas</b>	Bronx-Lebanon
<b>Yuri</b>	University of Miami

- **MEETING MINUTES**

The minutes for December 02, 2010 were approved with no changes.

- **MEMORY SUBSTUDY CAB PARTICIPATION**

Sharon from the AMP Memory Substudy requested CAB participation. Feedback from CAB members is helpful for this study. It is important for the study to understand the family perspective. The CAB member becomes the liaison between the CAB and the researchers. If you are interested in joining the team, please let Rosia know. This is call that meets once a month on Tuesday at 2pm EST.

The Memory Substudy looks at how kids learn and remember information. The study wants to know about problems with thinking, problem solving, and memory. The study also looks at if these problems relate to issues with taking medicine, school, family, and other areas. Another area that is looked at is executive functioning. Executive functioning is what is in charge of a person's behavior and thinking. It keeps track of what to do, remembering to do tasks, and solving problems.

- **US & International Travel**

Jennifer spoke about online resources for people with HIV when traveling in and outside of the US. AIDS.Gov has a travel database. All countries are listed with information about travel restrictions and regulations for each country. Some CAB members shared on the call about their personal experiences with traveling abroad. The CAB members agreed that the travel problem has lessened in recent years.

- **ADAP EMERGENCY**

Yuri shared about the ADAP waitlist crisis. ADAP is the AIDS Drugs Assistance Program. This federal

and state program helps pay for ARVs. It is Part D of the Ryan White Care Act. If someone with HIV cannot pay for their medications, they enroll in ADAP. There are 165,000 people who receive ADAP services. Because there are many people with HIV who are low-income, ADAP is going through a crisis. Many people have been waitlisted for their services.

Florida is one of twelve states involved in ADAP. In Florida, 15,000 are on ADAP. The health department in Florida recently said that the drug companies could not provide medications for everyone through the end of the fiscal year. The fiscal year ends in April. From February to April, the 3,000 people who have been waitlisted in Florida will not receive their medications. Many more people are waitlisted nationwide. The problem is complicated since there are new HIV diagnoses each day, so the waitlists continues to grow.

Yuri also spoke about political activism. Yuri encouraged CAB members to advocate for their health. Yuri suggested a website called the AIDS Alliance [www.aids-alliance.org](http://www.aids-alliance.org) to find out how contribute politically.

## • PROJECT UPDATES

Julie from Westat updated the group about the study enrollment. The main AMP study is closed to accrual, but the follow-up visits continue. The SMARTT Dynamic cohort has enrolled 1,055 participants. The SMARTT Reference Cohort has enrolled 88 participants. For the nutrition study, there are 42% enrolled with 111 participants. The Memory Study is 53% enrolled with 147 participants. The PHACS Leadership is pleased with how the studies are progressing.

In February, PHACS leadership members are presenting at CROI. CROI is the Conference on Retroviruses and Opportunistic Infections. It is February 27 – March 2 in Boston. Two people on PHACS are presenting their research. The first presentation is called, "Decreased Prevalence of Proteinuria among treatment experienced by children and adolescence with perinatal HIV infections." The second is "Association of in utero ARV exposure with late language emergence in HIV uninfected children born to mothers with HIV." After CROI, the CAB members will have access to the participant summaries to easily understand the research. These summaries will be emailed to the PHACS CAB members and posted to the website.

Julie, the Harvard Project Director, discussed papers that were submitted to scientific journals. Eight papers were submitted to journals. This is impressive since PHACS only had two papers that were submitted and accepted to journals since 2009. Two were SMARTT papers and eight were AMP. They are all under review. Julie will give a brief description of each paper in February.

**NOTE: the next CAB call will be on Thursday, February 24, 2011 at 12:00 pm EST.**