

**CAB Conference Call
August 27, 2009
12:00 EST
Meeting Minutes**

Participants:

Carol	Children's Hospital of Philadelphia
Chas	University of Florida
Christina	Westat
Delia	University of Miami
Gail	Texas Children's Hospital
Gloria	University of Florida
Jennifer	University of Colorado
Julie	Harvard University
Linda	St. Christopher's Hospital for Children
Lisa	Chicago Children's Memorial Hospital
Mariam	University of Southern California
Mariana	University of California
Marilyn	Bronx Lebanon
Marsha	Westat
Mercy	Westat
Monica	University of Miami
Rosia	Westat
Samantha	Children's Diagnostic and Treatment Center
Sharan	University of Alabama
Sheila	University of Florida
Sherry	St. Jude's Children Hospital
Stephanie	University of Miami
Theresa	Texas Children's Hospital

• **MEETING MINUTES**

The group approved the minutes for June 25, 2009. CAB members can send changes to **Christina Garber**.

• **CAB NEWSLETTER**

The newsletter was released about two weeks ago. **Theresa** gave an update on Camp Hope, which has been offered by the AIDS Foundation, Houston to HIV-infected children for the last 15 years. It is free of charge to the children. The camp has doctors, nurses and counselors on staff. Roughly, 130 campers, ages 7-16 years old, attended from all over Texas and Florida. One CAB member expressed pleasure that their child really enjoyed preteen talk and started learning more about HIV. Counseling is also available. **Julie** asked how children from Florida were able to attend the camp. Dr. Puga heard of Camp Home through the website and started attending with children from her site about ten years ago. Five staff members from the site travel to camp with 40 kids. Many children go every year, and they establish friends over time. **Marc Cohen** is the Camp For All contact (www.afhouseton.org).

- **CAB INVOLVEMENT**

Christina clarified that the PowerPoint slides were provided to show how CABs in other networks are operating and to generate ideas about how to develop the PHACS CAB. **Jennifer** found the origins of community involvement interesting. In the beginning of HIV/AIDS research, community involvement drove the research. Now the research brings community into the process. **Carol** added that community members were very vocal in the early days. Some CAB members have been involved a long time and have seen fluctuations in CAB involvement over the years. The disease has also progressed from a very small, specialized population to affecting people in all groups. She added that she really appreciates her CAB. Without the local CAB, the clinic would have less people involved in research.

Christina asked if anyone would share how their local CAB operates. **Marilyn** shared how her local CAB operates. Her group focuses on the children and parents. They discuss medications and how they deal with other areas in their lives. They have different groups that meet and discuss different topics. The parents talk about how to handle children of different ages. The uninfected children deal with having family members who are infected. The infected children discuss taking their medications and how they feel about it.

The group discussed the future direction of the PHACS CAB; how the group can be more involved; and the topics of importance to CAB members. **Marilyn** would like to see more members and more safe sex education for the teenagers. Education is important for everyone. People who are not infected or personally affected are scared of this disease because they do not understand it. **Samantha** challenged everyone to try to get one more person involved in CAB. **Jennifer** suggested that the group discuss ways to enhance the research, ways to provide input from the daily lives of infected people and families. **Theresa** emphasized the importance of hearing from the researchers. A lot of time passes between study visits, which are long and tiresome. The CAB meets more often and offers a great forum to keep subjects and their families engaged. The IMPAACT data summaries are shared with the community, and the community found them informative and helpful. **Samantha** suggested that representatives from other HIV networks, such as ATN, HPTN, or PACTG for example, could share information with the CAB.

Action Items: Christina will find people to give input on sexual education for the teenagers.

- **CAB VICE CHAIR**

Carlos resigned as CAB Vice Chair. The Chair and Vice Chair lead the PHACS CAB and give input to the PHACS leadership by attending the Executive Committee call. The Chair and Vice Chair attend the network meetings every spring and fall in Washington DC. They will be asked to give a brief talk at future meetings as well.

Action Items: CAB members should send nominations to Christina Garber at Westat.

- **PHACS PROJECT UPDATES**

Julie gave an update on the PHACS accrual. The studies will continue, but the SMARTT Static and AMP control cohort have closed to new subjects. The AMP infected cohort is still open to new subjects, but only at the sites that joined the AMP study this year.

<u>SMARTT</u>		<u>AMP</u>	
Static children	1240	Infected children	425 (450)
Dynamic children	659	Uninfected children	225

The PHACS leadership will amend both studies soon. In SMARTT, the amendment will include uninfected children born to uninfected mothers for comparison purposes. This cohort will open at a smaller group of sites. Mothers will be asked if PHACS can access their repository specimens from other studies. This will not happen in all cases and is not required of all subjects.

In AMP, the chart review will be expanded to include kidney and liver function. The growth hormone stimulation test is for children that don't seem to be growing as they should be. This test is difficult for the sites to complete and is being revised.

The first PHACS paper is about to be submitted for publication. This paper talks about substance use during pregnancy. Other researchers are writing papers as well, and those should be submitted soon as well. A PHACS abstract on the echocardiograms was just accepted for a talk at the American Heart Association conference, which is the largest national cardiology conference.

• COMMITTEE REPORTS

Julie gave an update on the Site Evaluation Subcommittee, which reviews each site twice per year. The group just finished their second round of reviews. They review subject enrollment and retention; visit completion; data quality, completeness, and timeliness; regulatory documents; and site monitoring reports. The group reviewed seven sites on their last call. Six sites scored 'excellent', and one site scored 'very good'.

PHACS is now in the last year of a five-year contract. The Executive Committee is anticipating the re-application process soon. It was delayed due to the stimulus funding package. Harvard and Tulane will reapply to be funded again by NIH. The Harvard application includes all of the clinical sites, FSTRF, and Westat.

NOTE: The CAB call takes place the fourth Thursday of each month. The next CAB call is September 24, 2009.