CAB Conference Call January 28, 2010 12:00 EST Meeting Minutes

Participants:

Carlos San Juan Hospital

Dorothy University of Alabama - Birmingham

Ginny Boston Children's Hospital

Gloria University of Florida - Jacksonville

Jennifer University of Colorado

JulieHarvardJulieWestatLennieSt. Jude

Lori Frontier Science& Technology Research Foundation

Mariam University of Southern California

Marilyn Bronx-Lebanon

MercyWestatRosiaWestat

Sharan University of Alabama – Birmingham **Theresa** Texas Children's Hospital - Houston

Travis Bronx-Lebanon Hospital

MEETING MINUTES

The group approved the minutes for December 17, 2009.

WELCOME NEW CAB MEMBERS

The team welcomed **Travis** from the Bronx-Lebanon Hospital to the CAB. **Julie**, the new Westat Program Manager for PHACS, was also welcomed. **Julie** is taking over **Mercy's** position. The group thanked **Mercy** for her dedication to the CAB for the past few years.

INTERNATIONAL MATERNAL PEDIATRIC ADOLESCENT AIDS CLINICAL TRIALS GROUP (IMPAACT)

Doreen Collins, the Project Director for IMPAACT, spoke to the CAB group. Doreen has a background in neurosurgical ICU nursing and a Master's in Public Health. Doreen is currently the Project Director for the Westat contract with National institute of Child Health and Human Development (NICHD) for this network.

Doreen explained that the IMPAACT group used to be Pediatric AIDS Clinical Trials Group (PACTG) for 20 years. The Department of AIDS (DAIDS) originally started PACTG. In the early eighties, DAIDS and NICHD collaborated to increase the scope of the network. PACTG is the network that produced the groundbreaking AZT study that showed AZT given to pregnant women could decrease mother-to-child transmission of HIV. That trial stopped early because it was so effective. At that time, doctors began giving AZT to all pregnant women with HIV. There have been hundreds of studies in the network of pediatric and maternal HIV. Right now, 50 protocols are in various stages of enrollment, follow-up, and development. The network started with many observational protocols. As medications became available, there were more treatment studies. Now, common studies are to measure the effects of treatment on disease and the side effects of medications.

The administrative part of this project operates with NIAID (National Institute of Allergy and Infection Disease) and NICHD (National Institute of Child Health and Human Development). Westat is the gobetween for these organizations.

Westat is the coordinating center for all of the NICHD-funded sites for IMPAACT. Westat does the site monitoring for the NICHD-funded sites, to help them maintain quality at their sites.

ACASI UPDATES

Julie updated the group about the Audio Computer Assisted Survey Instrument (ACASI). ACASI is only for in AMP. AMP is the HIV infected cohort of adolescents. The teens sit at a computer, put headphones on, and the computer will read them the questions that appear on the screen. Computers are used because the questions are sensitive. It was found that the teens are more willing to be honest about the questions if they are on ACASI, rather than being asked by a nurse.

There are questions about HIV and STDs disclosure that are being added to the ACASI. These questions are only for kids who answered that they have had oral, anal, or vaginal sex. Anyone who says "No" to these questions will not have to answer disclosure questions.

It is hard to ask someone, "Do you know you have HIV?" PHACS wanted to use the ACASI to ask in a gentle way so that the teens do not suspect they are being asked the question specifically. The ACASI update now lists medical conditions by asking, "Has anyone ever told you that you have...?" This question could be asking about asthma, a learning disability, and a list of other behavioral and medical conditions, including HIV. The teen would answer "Yes" or "No." If the teen says that they have HIV, then the ACASI asks if and when they have told their sexual partner they have HIV. Contraception use, time of disclosure to their partners about their HIV status, and STDS are also discussed, but the questions are only asked of teens that already indicated that they had oral, anal, or vaginal sex.

PROJECT UPDATES / COMMITTEE REPORTS – JULIE A.

The AMP and SMARTT Protocol Versions 3.0 have been released. SMARTT added prenatal questions, and the Reference Cohort was added. Children who were not born to mothers with HIV (not exposed to HIV and not exposed to ARTs) will be in the Reference Cohort. The Maternal Repository Consent was also added so that we can gain permission to obtain mothers' repository samples from other studies.

Another update in SMARTT was a growth trigger. The PHACS scientists noticed that many very young children were meeting the growth trigger. As a result, they would need to have a blood draw. It was realized that the problem was not growth; it was the way growth was being measured. This measurement was updated, and now fewer infants will meet this trigger.

For AMP, there is also a growth trigger. When the growth trigger is met, a very complicated test needed to be conducted. Now, the growth trigger has been simplified and all that is required is one simple blood draw.

Also in AMP, the maternal repository consent was added. A new form was added to collect data on kidney function. This information will be taken from the medical record. Information on sexually transmitted infections is also now going to be collected for males and females. This information is also already in the medical records.

CAB COOKBOOK

No recipes were received. This cookbook will be a collection of recipes from all of the sites. You can send photos as well. **Jennifer** wants to clarify the goals of the cookbook so that we can get more recipes. She recalled that it was mentioned that the cookbook might serve as a fund-raiser. She

wanted clarification of whether that was the goal. She also asked if we want this cookbook to be shared with our local CABs so that they can see the different communities that are involved in this study.

CAB NEWSLETTER ARTICLES

If you are interested in writing for the next newsletter, please email Rosia Warner. The next newsletter will be released in June 2010. Please let Rosia know if you can write for the upcoming newsletter. **Mariam** will ask one of her CAB members for permission to submit a poem that she wrote.

ADDITIONAL ITEMS

NOTE: the next CAB call will be on Thursday, February 25, 2010 at 12:00 pm EST