

**CAB Conference Call
July 24, 2014
12:00 EST
Meeting Minutes**

Participants:

Carlos	University of Puerto Rico
Delia	University of Miami
Dolores	St. Christopher's Hospital for Children
Exzavia	Children's Diagnostic and Treatment Center
Jeanie	University of Southern California, Los Angeles
Jennifer	University of Colorado, Denver
Juan	University of Puerto Rico
Juanita	Tulane University
Julie	Harvard University
Julie	University of Alabama, Birmingham
Julie	Westat
Kim	Rutgers New Jersey Medical School
Kim	Texas Children's Hospital
Lesley	Texas Children's Hospital
Leslie	Texas Children's Hospital
Marilyn	Bronx-Lebanon Hospital Center
Megan	Westat
Ramona	University of Florida, Jacksonville
Samantha	Children's Diagnostic and Treatment Center
Stephanie	University of Miami
Susie	University of Alabama, Birmingham
Tatania	Tulane University
Theresa	Texas Children's Hospital
Yuri	University of Miami

• **APPROVAL OF MINUTES**

The minutes from the June 26, 2014 call were approved with no changes.

• **PHACS CAB EVALUATION SURVEY RESULTS**

Megan talked about the PHACS CAB Evaluation Survey results. There were 6 responses. Some suggested topics for upcoming calls are:

- Topics covered at last CAB meetings;
- Retention;
- Disclosure;
- Young adults and adults affected by HIV;
- Safe sex in young gay men; and
- Research summaries.

- **SMARTT HAIR COLLECTION HANDOUT**

Julie from Westat talked about the SMARTT hair collection handout. Hair collection was added to the entry visit for babies in the SMARTT Dynamic Cohort. Study staff will ask for permission to collect hair samples from moms and babies. If the hair cannot be collected at the entry visit, it may be taken up until three weeks after the entry visit. The purpose of the hair collection is to measure how much HIV medication was passed to the baby during pregnancy. Monica Gandhi is the researcher who proposed hair collection in PHACS. Hair collection is painless for moms and babies.

Some moms have not felt comfortable allowing their baby's hair to be cut. There may be cultural reasons why moms are uncomfortable. Monica put together a handout for moms. The handout describes the hair collection process. It also explains the purpose. Julie reviewed the handout.

Theresa talked about the handout. Site staff will respect moms' wishes if they do not want to participate in the hair collection. The picture on the flyer is helpful. It shows how much hair is collected. The handout is easy to understand. Some moms might be worried about what researchers are testing for from the hair samples. The flyer needs to make it clear that the researchers are only testing for HIV medication levels, and that they are not allowed to test for anything else without the mom's permission.

Kim talked about the handout. The handout shows moms the purpose of the hair collection. It can help moms understand that they are helping other moms and babies. The handout should stress that there is no pain for the baby or mother.

Juan talked about the handout. It might be more helpful for moms to be able to come back to the clinic for hair collection later. It might be helpful to ask them to come back in six months or a year. The sample could be taken twice in a year. The samples could be compared.

Stephanie talked about the handout. Some African-American families do not cut a baby's hair until the baby's first birthday. The handout should stress that information obtained from the hair analysis will help other moms and babies.

- **STIGMA DISCUSSION**

Megan reviewed a stigma story (<http://medcraveonline.com/JPNC/JPNC-01-00003.php>). Some CAB members shared their personal stories of stigma.

NOTE: The next CAB call will be on Thursday, August 28, 2014 at 12:00 pm EST.