

**CAB Conference Call
October 27, 2011
12:00 EDT
Meeting Minutes**

Participants:

Carrie	University of Colorado
Carlos	San Juan Hospital
Deangelo	University of Jacksonville
Delia	University of Miami
Gloria	University of Florida – Jacksonville
Jennifer	University of Colorado
Julie	Alabama
Julie	Harvard
Julie	Westat
Leslie	Texas Children’s Hospital
Lori	FSTRF
Linda	St. Christopher’s Hospital for Children
Mariana	University of California San Diego Hospital Center
Marilyn	Bronx - Lebanon
Megan	Westat
Samantha	Children’s Diagnostic & Treatment Center
Theresa	Texas Children’s Hospital
Yuri	University of Miami

• **APPROVAL OF MINUTES**

The minutes from the September 22, 2011 call were approved with no changes.

• **PHACS CAB EVALUATION SURVEY RESULTS**

Megan talked about the PHACS CAB Evaluation Survey results. Some suggested topics for upcoming calls are how caregivers are going to keep up with extra study visits for new substudies, new publications on studies that are closed to accrual, recruitment and retention, youths speaking out about HIV, and cure research. Thanks to everyone who participated. Megan writes down each topic suggestion.

• **CAB NETWORK MEETING DISCUSSION**

The PHACS Fall Network Meeting is November 3-4, 2011 in Bethesda, Maryland at the Bethesda Hyatt Regency. Megan sent out the latest draft of the Network Meeting agenda. There will be an informal dinner with the CAB at BD’s Mongolian grill. Interested CAB members should meet at the registration table in the hotel at 7:00 pm. The CAB will walk to the restaurant. Fourteen people have said they will attend the dinner.

On the Executive Committee call, the CAB was invited to the Clinical Investigators Group Business Meeting at the Network Meeting. This session is from 7:30 am to 8:30 am on Friday, November 4. The CAB was also invited to the Study Coordinator session on Thursday, November 3 from 3:30 pm – 4:15 pm. Both sessions will be on ways to keep kids staying on the PHACS studies.

The CAB specific session is from 10:30 am – 12:00 pm on Thursday, November 3. Megan sent out the CAB session agenda. At the end of the session there will be an open forum discussion. Some potential topics are how to recruit and keep local CAB members, 2012 goals for the PHACS CAB based on the

mission statement, ways to spread out and better understand the research findings within the community, ideas for ways the CAB can contribute more input on PHACS, forming an Education Committee, and ways to improve the PHACS CAB calls.

Delia talked about what to expect at the Network Meeting. Delia mentioned that some sessions are at the same time. The doctors and researchers talk about ongoing research, what has happened in the past year, and future directions. There are many speakers. Delia added that she takes notes on the presentations that interest her.

Megan talked about the presentation, PHACS 101: An Introduction to the PHACS Network. This presentation will also describe the PHACS working groups.

Megan talked about the CAB packet. This packet will include the session agendas, CAB-specific hand outs, and other meeting materials.

Jennifer reminded that CAB that Russ Van Dyke and George Seage will be welcoming the CAB at the CAB session. Russ Van Dyke is the AMP Protocol Chair. George Seage is the Principal Investigator from Harvard. They will briefly take questions about PHACS. Julie from Westat added that additional questions can be emailed to Megan. CAB members can also bring their questions up on the call.

Linda asked about inviting youth to the Network Meeting. Julie from Westat pointed out that this is the first year that PHACS has invited CAB representatives from each site. Currently, youth are not invited to the meetings. Julie added that the PHACS leadership has considered starting an adolescent CAB.

- **NEWSLETTER, DECEMBER 2011 EDITION**

Megan asked the CAB to consider submitting articles to the newsletter. The theme for the December 2011 newsletter is adherence. Adherence means sticking to HIV medication schedules. Please consider submitting an anonymous (your name will not be included) testimonial to the newsletter about your experience with adherence. This can also be experience with children and adherence. Julie from Westat added that the project will add some information on how the project is measuring adherence. There will also be a participant summary of a poster presentation and abstract. This presentation was presented at a scientific meeting.

- **CAB EVALUATION SURVEY QUESTION – HOW ARE CAREGIVERS GOING TO KEEP UP WITH THE EXTRA STUDY VISITS FOR NEW SUBSTUDIES**

Megan talked about the survey question. One of the CAB members who completed the survey asked how caregivers are going to keep up with extra study visits for new substudies. Long study visits can be a burden for working families. Maybe sites could get an increase in funds for compensation. Leslie wondered if the leadership has information about working families involved in PHACS. Julie from Harvard mentioned that data on working families is available. They will look at it soon. Julie also added that compensation is decided by the site's institutional review board. The leadership is aware of the time requirements for the substudies. Site staff is welcome to be on the protocol teams.

Julie from Harvard talked about the new Oral Health substudy for AMP. The protocol has not yet been written. Jennifer added that participation in PHACS gives people access to medical exams. This includes dental exams. Theresa mentioned that participants have noted that the site staff pays more attention to their kids needs than their individual pediatricians.

- **ARTICLE ON CONTRACEPTIVE USED IN AFRICA MAY DOUBLE THE RISK OF HIV**

Megan talked about the article on contraceptive use in Africa. This study involved couples. The study looked at women using injectable hormones for contraception. This means women using hormone shots every three months to prevent pregnancy. In each couple either the man or the woman already had HIV. They found that it appeared that using the hormonal shots doubled the risk of HIV infection.

The hormone, progestin, is in injectable contraceptives. The researchers noted that it appeared to cause immunologic changes in the vagina and cervix. They found that there was more HIV in the genital fluid of those using hormonal contraception than those who are not. They also found that pregnancy doubled the risk of women's contracting HIV. It also doubled the risk of HIV infected women transmitting it to men.

There is much more research to be done. The researchers promote condom use along with hormonal methods.

Julie from Westat added that the World Health Organization is going to have a meeting in January about this study. They will look to see if the evidence is strong enough to advise women that this hormonal contraception method may increase their risk of getting or transmitting HIV.

- **ARTICLE ON US DOCTOR CAUTIOUS ABOUT HIV VACCINE**

Megan discussed the article on the HIV vaccine. The vaccine was developed in Spain. The study used a trial of 30 healthy volunteers. They found that 90% of those who got the vaccine developed immunity against HIV. They also found that 85% of those people maintained the immunity for one year. The researchers described the vaccine as showing the body a picture of HIV. The body could then recognize it and fight it if it sees it in the future. With the vaccine, the immune system could then inactivate the virus and destroy the infected cell.

If the vaccine is a success than HIV would no longer cause AIDS. It would also make HIV less contagious. The researchers are still trying to find how long the vaccine works for. This study was very small. There are many more trials needed to involve more people to make any good conclusions. Jennifer wondered how they exposed the healthy volunteers to HIV.

NOTE: The next CAB call will be on Thursday, November 17, 2011 at 12:00 pm EDT.