

**CAB Conference Call
April 24, 2008
12:00 EST
Meeting Minutes**

Participants:

Carlos	San Juan City Hospital
Celina	New York University
Chas	University of Florida, Jacksonville
Christina	Westat
Elizabeth	St. Christopher Hospital
Elizabeth	University of Puerto Rico
Ginny	Children's Boston
Gloria	University of Florida, Jacksonville
Julie	Harvard University
Latanya	University of Alabama Birmingham
Linda	St. Christopher Hospital
Lisa	New York University
Lourdes	San Juan City Hospital
Mariana	UCSD
Samantha	Ft. Lauderdale
Sharan	University of Alabama Birmingham
Shatara	UMDNJ
Tanisha	Westat
Theresa	Texas Children's Hospital

• **WELCOME**

Tanisha Savage welcomed everyone to the call. Since new people were on, introductions were made again. **Julie Alperen** is the Project Director of the Data and Operations Center at Harvard. **Tanisha Savage** is from Westat. She is the CAB liaison for PHACS. She will support all CAB activities.

• **MEETING MINUTES**

The minutes from the last call were approved.

• **PHACS YEAR-ONE ACHIEVEMENTS**

Julie Alperen created a one-page summary of PHACS first-year achievements. The document is at the Harvard IRB for review. Once approved, it will be sent to sites.

• **PHACS WEBSITE**

Tanisha Savage gave an overview of the PHACS website. She sent login instructions with the meeting agenda. She reminded participants that the website is the best source for information on PHACS. She is also working on the PHACS CAB webpage. It will be part of the larger PHACS website. It will contain:

- An introduction page;
- Meeting schedules;
- Meeting minutes;
- Relevant articles;

- PHACS protocol summaries; and
- The CAB Newsletter (to be developed later).

The CAB webpage will be added to the PHACS website on April 25, 2008. At first it will contain only the CAB introduction and meeting minutes. Other materials will gradually be added. Website suggestions can be sent to TanishaSavage@westat.com.

• CAB CHAIR AND VICE-CHAIR

Tanisha Savage thanked everyone for the CAB Chair and Vice Chair nominations. These positions are for two years. The Chair and Vice Chair will attend the PHACS network meetings. They are held every spring and fall. The next meeting is November 17-18, 2008 in Bethesda, MD at the Hyatt Regency. **Tanisha** will contact the chair and vice-chair to discuss travel arrangements. The CAB Chair will be a non-voting member of the PHACS Executive Committee. The CAB chair is **Lisa Lopes** from New York University. The CAB vice-chair is **Samantha Kuryla** from Fort Lauderdale. Everyone congratulated **Lisa** and **Samantha** on their new positions. **Tanisha** reminded CAB members that there would be opportunities for everyone to contribute to the PHACS CAB.

• CAB SURVEY AND FUTURE DISCUSSION ITEMS

Tanisha Savage thanked members for their survey responses. The PHACS leaders will better understand local CAB activities with this information. The survey results were reviewed. Most CABs include clinical site staff, study participants, their family members and community members. Some sites said their PI or co-PIs attend CAB meetings. Most CAB meetings have a formal agenda. The survey results showed that CABs tend to meet monthly or quarterly. The issues discussed include:

- The research process and the CAB role;
- Community value and input to the CAB;
- Research goals and who benefits;
- Research impact on treatment services;
- Confusion and controversy surrounding human research; and
- Disclosure and stigma.

On future CAB calls, the group would like to discuss:

- Quality of life issues (for example, medications, nutrition, lipodystrophy);
- Disclosure and stigma; and
- Resources, especially for adolescents.

NOTE: The next CAB call will be May 22, 2008 at noon.