

**CAB Conference Call
March 27, 2008
12:00 EST
Meeting Minutes**

Participants:

Anna	University of Miami
Carol	Children's Hospital Philadelphia
Celina	New York University
Julie	Harvard University
Latanya	University of Alabama Birmingham
Laura	Denver Children's Hospital
Linda	St. Christopher Hospital
Lori	Harvard University
Samantha	Ft. Lauderdale
Sharan	University of Alabama Birmingham
Renee	University of Illinois Chicago
Shatara	UMDNJ
Shirley	Westat
Tanisha	Westat
Theresa	Texas Children's Hospital

• **WELCOME**

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

Julie Alperen announced that PHACS reached its one-year anniversary of being open to enrollment. **Julie** is making a one-page document that summarizes the progress made in the first year.

• **PHACS PROJECT WEBSITE**

Tanisha Savage gave an overview of the PHACS website. Instructions for how to get to the website were sent with the meeting agenda. **Tanisha** said that it would be good for the CAB to get to know the website. It is the source for PHACS news and information. The website includes:

- Project member information;
- Who the site staff are;
- The kinds of questions sites ask the protocol chairs,
- PHACS committees, and
- All project documents

Tanisha asked CAB members to log on to the website at least once before the next call. The website will be expanded soon to include a CAB webpage. This webpage will contain CAB information, such as:

- Meeting Minutes;
- Meeting schedules;
- Relevant articles submitted by CAB members; and
- Abbreviated abstracts of the PHACS protocols. The PHACS leadership will produce simple summaries of the PHACS protocols. These summaries will outline the objectives, design and purpose of PHACS.

A CAB Newsletter will also be developed. It is in the very early planning stages. This newsletter will be another way to keep members informed about PHACS. The newsletter will be done 4 times a year. It will be posted on the CAB webpage.

Tanisha asked CAB members to make suggestions for the webpage and newsletter (ex. relevant news articles, etc.).

Action Item: CAB member will log into the PHACS website before the next CAB call in April.

• CAB SURVEY

The survey will help PHACS better understand CAB activities at the local sites. It will also help to gather topics and issues important to CAB members. This information will help plan meetings and making future conference calls effective, efficient and relevant.

Action Item: CAB members will fill out the survey. They will return it to Tanisha Savage by April 17, 2008.

• CHAIR AND VICE-CHAIR NOMINATION PROCESS

Tanisha gave a review of the process for the group. The PHACS CAB will have a Chair and Vice Chair. Each will serve for 2 years. They will attend the PHACS network meetings two times each year. The CAB Chair will be a non-voting member of the PHACS Executive Committee. The nomination process is as follows: you can nominate yourself or another CAB member or CAB liaison. To nominate someone, submit a brief summary why you or your nominee would be a good candidate. Once names have been collected, a list of the nominees and the brief summaries will be sent to the CAB for a vote.

The group discussed if it would be possible to list the CAB members on the website. Because of confidentiality concerns, this has not been done. The group was asked if they were okay having their names and the sites they're from on the website.

Action Items: Tanisha will send out an email by March 27, 2008 with the PHACS Chair/Vice Chair nomination process.

Action Items: CAB members will submit their nominations to Tanisha Savage by April 17, 2008.

• CAB INVOLVEMENT

The group discussed how each member became part of the PHACS CAB. Answers included

- family affected by the disease
- personal health reasons (that one should not be defined by their disease)
- interest in the research.

A site asked about PHAC's requirements and expectations of site CABs and how the site's CAB may affect site evaluations. **Julie Alperen** explained that sites are expected to form a local CAB. General guidelines have been distributed describing local CABS. PHACS is very flexible on how the CAB is run and its goals. The suggested goals are education and discussion.

NOTE: CAB Calls will take place every 4th Thursday of the month. The next CAB call will be April 24th at Noon.