CAB Conference Call December 11, 2008 12:00 EST Meeting Minutes

Participants:

Theresa Texas Children's Hospital
Courtney Boston Medical Center
University of Miami
Merilyn Bronx Lebanon

Shatara UMDNJ

Sharan University of Alabama Birmingham

Tanisha Westat Laura Denver Shirley Westat Marsha Westat

MEETING MINUTES

The October 23, 2008, minutes were approved. **Tanisha** will post them on the CAB website.

PHACS UPDATES

There are three new AMP sites: San Juan City Hospital, the University of Colorado and Bronx Lebanon. The hope is that the new sites will enroll 100 more kids in AMP.

There are updates to the CAB website. When you click on the CAB Toolbox, three new links appear, Documents, HIV/AIDS News, and Resources:

- The Documents page has all the handouts from past CAB calls.
- The HIV/AIDS News page will have links to news articles that are interesting to CAB members.
- The Resources page will list online resources/websites for CAB members.

Tanisha asked that CAB members send their suggestions for the website to her at: tanishasavage@westat.com

On past calls, CAB members suggested creating a CAB glossary. The glossary has been added to the CAB webpage. The glossary is an ongoing project. If you have word ideas for the glossary, send them to Tanisha.

Action Item: Tanisha will send CAB members a reminder to go online and view the updates.

The first PHACS CAB newsletter was sent with the meeting reminder. The newsletter is another way that CAB members can get the latest information on PHACS . CAB members gave positive feedback on the newsletter. **Tanisha** stated that CAB members should send her ideas for the newsletter. If a CAB member does not feel comfortable putting their name on an article, they do not have to.

Shirley told the group that she will be retiring from Westat at the end of January 2009. Mercy Swatson will take over as the Westat Project Director for PHACS. **Shirley** wished the PHACS CAB continued success.

LOCAL CAB SPOTLIGHT

Theresa talked about the CAB at Texas Children's Hospital. Her CAB started meeting in 1991. At first, the CAB was large and made up of parents, caregivers and community members. The CAB is now split into two groups. The bigger CAB meets 4 times a year. This CAB is made up of agency reps, parents and caregivers. At least once a year, staff members from the clinic meet with the large CAB. During this get-together, they discuss issues about HIV/AIDS research. CAB members are able to voice their concerns and ask questions about AIDS research. This meeting also gives everyone a chance to talk to the other agencies, community members and staff.

The smaller CAB is made up of dedicated caregivers. The smaller CAB has a lunch meeting once a month. Transportation is always available to CAB members so that they can attend. Volunteers help with babysitting during the meetings. Theresa organizes each meeting. She sets up parking, transportation and food. She also calls CAB members to make sure that they are coming. When she can, she tries to provide small gifts to CAB members who come to the meetings. **Theresa** stated that most research sites have some money set aside for their CAB. Be sure to ask the PI or study coordinator at your site about available money. **Theresa** said that one of the biggest challenges is finding new people to join the CAB.

PHACS NETWORK MEETING

Tanisha said that the Westat site monitors gave a talk on legal guardianship. There were also several talks about enrollment and early findings from the studies. These talks from the network meeting are on the PHACS project website.

Action Item: Tanisha will send CAB members an email with the website login and the link to network meeting materials this afternoon.

The CAB conference call is expected to go back to its normal schedule in 2009. Tanisha will send CAB members information about the date and time of the next conference call.