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

Participants:

Chas University of Florida, Jacksonville

Elizabeth St. Christopher Hospital

Gloria University of Florida, Jacksonville

Julie Harvard University

Latanya University of Alabama, Birmingham

Laurie FSTRF

Linda St. Christopher Hospital Renee University of Illinois

Samantha Children's Diagnostic and Treatment Ctn.
Sharan University of Alabama, Birmingham
Sheila University of Florida, Jacksonville

Shirley Westat Tanisha Westat

Theresa Texas Children's Hospital

WELCOME

Tanisha Savage welcomed everyone to the call; introductions were made.

MEETING MINUTES

The group reviewed and approved the minutes for June 26, 2008. **Tanisha** will post the minutes on the website.

NUTRITION PRESENTATION

Tanisha inquired if any CAB members had feedback about the nutrition presentation. During the previous CAB call, Daniela Neri Almeida RD, University of Miami, talked about nutrition and HIV. The handout that Daniela created for her presentation is available online at: https://phacs.nichdclinicalstudies.org/viewDoc.asp?id=4

Any suggestions or questions regarding the nutrition presentation should be sent to Tanisha at: TanishaSavage@westat.com.

NOVEMBER PHACS MEETING

The PHACS CAB Chair and Vice Chair will attend the November PHACS network meeting. **Julie Alperen** discussed that the PHACS leadership is interested in having a CAB session during the meeting. The leadership would like feedback from CAB members on possible topics. **Samantha Kuryla** submitted the following list of possible topics for the fall meeting:

- Disclosure
- Adolescents
- Protocol development
- Adherence issues
- Treatment resistance

Samantha asked if the purpose of the CAB session is to educate the CAB or to receive input from the CAB. **Julie** noted that both education and feedback are important for PHACS.

CAB members offered several points/questions that they think the leadership should cover during the CAB session:

- How is PHACS organized?
- What is the difference between AMP and SMARTT?
- What makes PHACS different from IMPAACT, ATN, or other studies?
- What are the benefits of participating in PHACS?
- What are the outcomes or trends?
- Where does the community go from here?
- Why do consents change? / Why is re-consenting necessary?
- Can a PHACS glossary be developed?
- Are there other mediums of educating the community?

PHACS CAB NEWSLETTER

A CAB Newsletter is in the planning stage. This newsletter will be another way to keep members informed about PHACS. CAB members were asked to think about what they would like to include in the newsletter. Tanisha sent out the following list of suggestions with the meeting agenda:

- Lay Summaries,
- CAB Member Profiles,
- Local CAB Spotlight,
- HIV Knowledge Quiz, and
- Upcoming Events.

CAB members offered several suggestions for the newsletter:

- A welcome from the PHACS leadership
- Enrollment Data
- Study Trends
- Study Status/Brief Updates
- PHACS Organization Chart

Samantha suggested sending the IMPAACT CAB newsletter to the PHACS CAB. This will provide CAB members with a visual example of a newsletter.

ACTION ITEM: Tanisha will send PHACS CAB members the IMPAACT CAB newsletter.

ADDITIONAL ITEMS

Theresa Aldape discussed that consenting subjects continues to be challenging. Extended family members, who sometimes serve as primary caregivers, often bring subjects in for appointments. The individual who brings the child to clinic may not be the "legal" guardian. This presents a challenge of getting the legal guardian into clinic to give consent for the child.

Samantha asked if the PHACS project was open to networking with other HIV/AIDS CABs. **Julie** replied that PHACS is open to sharing resources that are beneficial to community members.

NOTE: CAB calls take place every 4^{th} Thursday of the month. The next CAB call will be August 28th, at Noon.