

PHACS COMMUNITY CONCERNS AND PRIORITIES

PURPOSE OF THE CAB'S ATTENDANCE AT THE NETWORK MEETINGS:

- Represent the PHACS community and local site community
- Learn about PHACS studies
- Give feedback about current PHACS studies from the unique community perspective
- Share information from the meeting with the local site CAB and community

"...the inclusion of community has not only helped to identify specific issues but also to help resolve particular problems that can help in understanding and working with the clients/patients within the PHACS clinical trials. **Who better to relate to the PHACS study participants than the PHACS CAB?"**

--CAB Attendee

ADHERENCE

- How does HIV stigma affect adherence? Does this have an impact on whether people want to be in research?
- Helping young adults become increasingly involved in their own care without risking them becoming non adherent.
- **Adherence-** importance of providing young adults with information that helps them understand why taking their meds is so important (this is why adolescent CABs are so important).
- Is there a difference in adherence in adoptive homes or children with biological parents?
- Is there a difference in adherence between males and females?
- Does the evidence show that the young adults with strong support systems tend to adhere to their HIV treatment?

COMMUNITY

- **With so many research updates coming out of PHACS in recent years, how does that information get back to the community? What is the CAB's role in disseminating that information? How might dissemination of study-related information play a role in retention?**
- **What are the challenges you face steering the PHACS study and how can the CAB help?**
- How might the CAB contribute to PHACS publications?
- Establishing bi-directional feedback between the researchers and the community.
- Recruitment & retention in CABs.
- CAB funding.

COMPLICATIONS

- How are researchers following up on developmental delays in HEU youth? Are we seeing more acute or chronic problems?
- Cognitive impairments relating to HIV.
- What is the effect of HIV exposure or infection on school performance?
- Developmental delay, hearing loss, language delay, and memory loss in children infected with HIV.
- How is obesity related to HIV exposure?

CONFIDENTIALITY

- There may be a need for education in regards to confidentiality. Many mothers do not want to be in the study because they don't fully understand the confidentiality practices in research. We need to approach mothers with information about research in general, in addition to the information about the study.
- Children not getting primary care because the mothers do not want to sign the confidentiality form. The mothers do not trust the privacy laws. They feel that their child's information is not private, and they do not trust the system.
- Need to have more respect for privacy when attending a doctor's visit for both adults and children.
- Gain the trust of the clients and their children by providing more detailed education on confidentiality for parents to feel at ease.

DISCLOSURE

- Does disclosure have an impact on whether parents allow children to participate in research?
- **Emphasis on disclosure as a personal decision. There is a need to incorporate all views on disclosure including families who choose not to disclose.**
- Inadvertent disclosure. We need to continue to take precaution to ensure that HIV-information is only shared with people that the mother appoints.
- Keeping HEU in the study as they age up; even if the mother doesn't disclose. Could there be a consent for participants to sign that does not mention HIV?
- **Disclosure of HIV status.**
- Importance of providing education to parent and providing support for both parent and child during the disclosure process.

MENTAL HEALTH

- Stress and violence in the home.
- Depression and anxiety.
- **Mental health and HIV-** many HEU children have learning delays, asthma, ADHD, or autism. Is this a result of the ARV's?
- Focus and working memory in young adults and adolescents living with HIV or exposed to HIV
- Access to mental health services and treatment and identification of mental health disorders such as depression, anxiety, PTSD, and bipolar disorders.

STIGMA

- HIV-stigma is a barrier to treatment, and research-related stigma is a barrier to participation in a research study. We need to continue to make combatting HIV-related and research-related stigma a priority to recruit and retain participants.
- What strategies or approaches can we utilize to empower people who are experiencing stigma or

prejudice within in their own families, friends or workplace. Are there some legal ramifications that can be pursued when considering defamation of character or threatening situations just on the basis of their HIV diagnosis? Unfortunately, in some communities in the USA there is still a significant amount of ignorance, prejudice, discrimination and stigma. So how can we take steps to start overcoming these concerns.

- How can we help the stigmatized?
- Does stigma affect HIV-infected adolescents and their participation in sports? Can this lead into greater issues of physical health, social isolation, and/or obesity?
- Shame and how it affects overall quality of life and HIV
- Communication interventions for reducing HIV-stigma
- Provider and peer led communication on reducing stigma and empowering Moms
- Stigma and discrimination against HIV positive people.
- HIV stigma- still a huge problem in the Bronx and elsewhere, education is important!

TREATMENT

- Difficulties communicating adverse effects of medication.
- Complications with medications and over the counter vitamins/medications.
- **Continued study of the safety and effectiveness of ARV's in newborns, children, and adolescents.**
- Complications resulting from HIV and/or ARV's.
- Treatment improvement – less pills, safer medications, more regimen options.
- New ARV medications.
- **Identifying long-term effects of ARV's and/or exposure to HIV.**
- ARV medication and nutrition – weight gain and body image.
- Is pill/liquid for once a day dosing available for children? Do once a day medications increase adherence in teens?
- Review the interactions of HIV medications with illicit drugs

OTHER

- Spanish-interpretation
- **How can we make clinic visits better for our participants and caregivers?**
- Mutation, reinfection, and resistance
- Sero-discordant couples
- ADHD
- Obesity in children
- Cancer and HIV
- **Substance use** and neurocognition among youth
- Abuse
- Oral health – what is the effect of ARVs on the teeth on children and adolescents? Does the liquid medication cause teeth to decay? What can stop the decay in baby teeth? Does tooth eruption occur later in HIV infected children?
- HIV prevention strategies for youth/adolescents.
- Are the needs of young adults being met the same as they were being met in pediatric practices?
- Mothers do not want to bring their child to clinic because they don't think that it is necessary for their child to go through pain having their blood drawn since the child does not have HIV.