

# PHACS COMMUNITY ADVISORY BOARD

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## THE PURPOSE AND MISSION OF THE PHACS CAB

In the multifaceted world of clinical research, it is essential for research protocols to be as comprehensive and as inclusive as possible. Community Advisory Boards (CABs) help establish partnerships between a clinical research team and the community they serve. CABs give a voice to the community, advocate for research participants' rights, and help research teams successfully implement and conduct research protocols.

The **purpose** of the PHACS CAB is to seek input from community representatives in order to reflect the interests of participants and caregivers in PHACS. The CAB is also a forum for local CAB members to share resources and support. Many CAB members view the CAB as a second family.

The **mission** of the PHACS CAB is to serve as a connection between researchers and community members in order to improve and optimize clinical research studies for children/young adults/families who are participants, and who are most affected by the research.

**"I PARTICIPATE IN THE CAB TO HELP THE COMMUNITY, GIVE INPUT, BE A VOICE, AND MAKE A DIFFERENCE." – CAB MEMBER**

## PHACS CAB LEADERSHIP

By majority vote, the PHACS CAB elects a Chair and a Vice Chair, each to serve a two-year term. The CAB Chair also serves as a non-voting member of the PHACS Executive Committee. Former CAB Chair Delia states that "Our purpose as CAB Leadership has been to take our knowledge and share it with the community, educate about research, get involved in research, and let the community know that there is hope. With the knowledge gained from the PHACS CAB, we can continue to help improve our site CABs."



Since its formation in 2008, eight (8) Chairs have served on the PHACS CAB. PHACS CAB Chairs attend all PHACS in-person meetings, lead PHACS CAB conference calls, contribute to the PHACS CAB Newsletters, and help lead CAB Retreats.

**"[CAB] LEADERSHIP HELPS THE NEW CAB MEMBERS/FAMILY LEARN HOW TO FIND AND USE THEIR VOICES."**  
– KIM, CAB CHAIR

## PHACS CAB ACCOMPLISHMENTS AND COLLABORATIONS

In addition to meeting by conference call each month, the CAB has accomplished the following objectives since its formation in 2008 including (but not limited to):

### COLLABORATION

CAB members actively participate in PHACS committees and give feedback on PHACS protocol teams.

Seven (7) CAB members are active members of the Health Education and Communication Committee (HECC).

TDF  
PCPA

OH

Four (4) CAB members have served as community representatives on PHACS substudy teams including the Newborn Evaluation for Effects of Maternal Tenofovir (TDF) Use During Pregnancy Substudy, Oral Health (OH) Among Participants in PHACS PH200 – Adolescent Master Protocol (AMP), and Pulmonary Complications in PHACS AMP Substudy.

## RESOURCES

Since its inception, the CAB has not only shared helpful resources, but has also worked together to create resources to strengthen the PHACS CAB. The following are four (4) examples of CAB-generated resources:

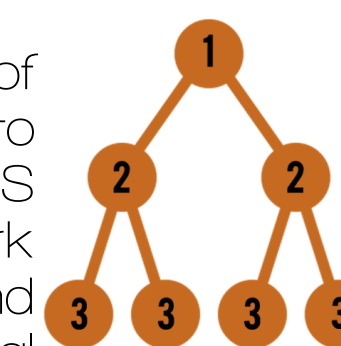
### PHACS CAB Disclosure Fact Sheets

In 2012, along with the PHACS Neuropsychologists, the CAB developed two fact sheets that helped address disclosure of parental HIV infection to an HIV-exposed but uninfected child, and disclosure of a child's own HIV infection.



### Community Concerns and Priorities Lists

In 2012, the CAB put together a list of community concerns and priorities to be distributed to the entire PHACS Network during the Fall Network Meeting. This list is updated and distributed to the team on an annual basis.



### PHACS CAB Role and Responsibilities List

In 2014, the CAB brainstormed a list of CAB member expectations in an effort to help new and current CAB members understand their roles and responsibilities. This list was generated for PHACS CAB members, but can also be used as an example for site CABs.

### PHACS CAB Vice Chair and Chair Roles and Responsibilities List

In 2014, the CAB compiled a list of Chair roles and responsibilities. This list was generated in an effort to prepare and encourage CAB members to consider CAB Leadership roles. New Chairs are encouraged to add to this list as the responsibilities of the Chairs evolve with the group.

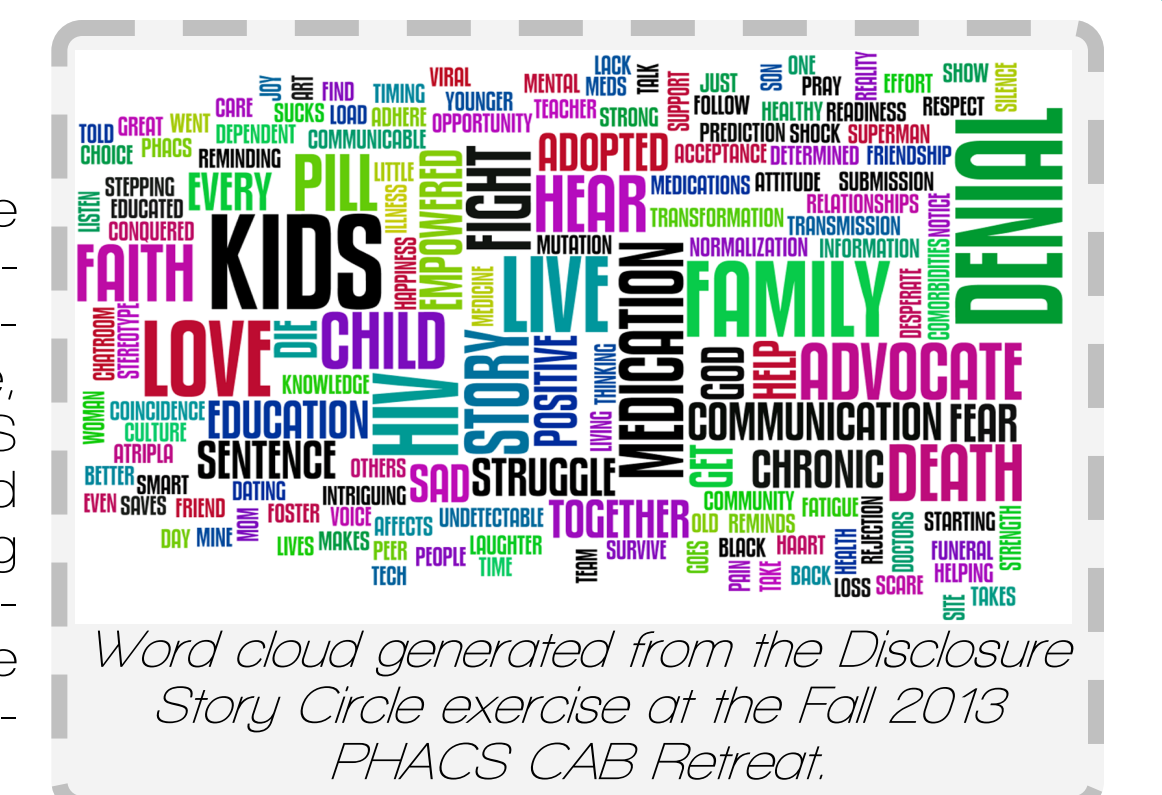
## CAB NEWSLETTERS

CAB members work together to create semi-annual PHACS CAB newsletters. These newsletters are distributed to the entire PHACS network and include artwork, poems, personal testimonials, PHACS member spotlights, recipes, research summaries, and more. To date the CAB has published fourteen (14) newsletters.



## RETREATS

The PHACS CAB held its first CAB Retreat in 2013 in response to a growing need to discuss CAB-specific topics and issues in-person. The retreats are held annually at the Fall Network Meetings and have covered CAB-specific topics such as disclosure, site CABs, community involvement, stigma, survival, PHACS protocol and Working Group (WG) updates, advocacy, and youth community engagement. Because these are working meetings, CAB Retreat sessions are structured to be both engaging and interactive. By soliciting feedback from the CAB, the retreats continue to evolve to help the team focus on and address the important topics within the PHACS community.



Word cloud generated from the Disclosure Story Circle exercise at the Fall 2013 PHACS CAB Retreat.

## SITE CABS AND RESOURCE SHARING

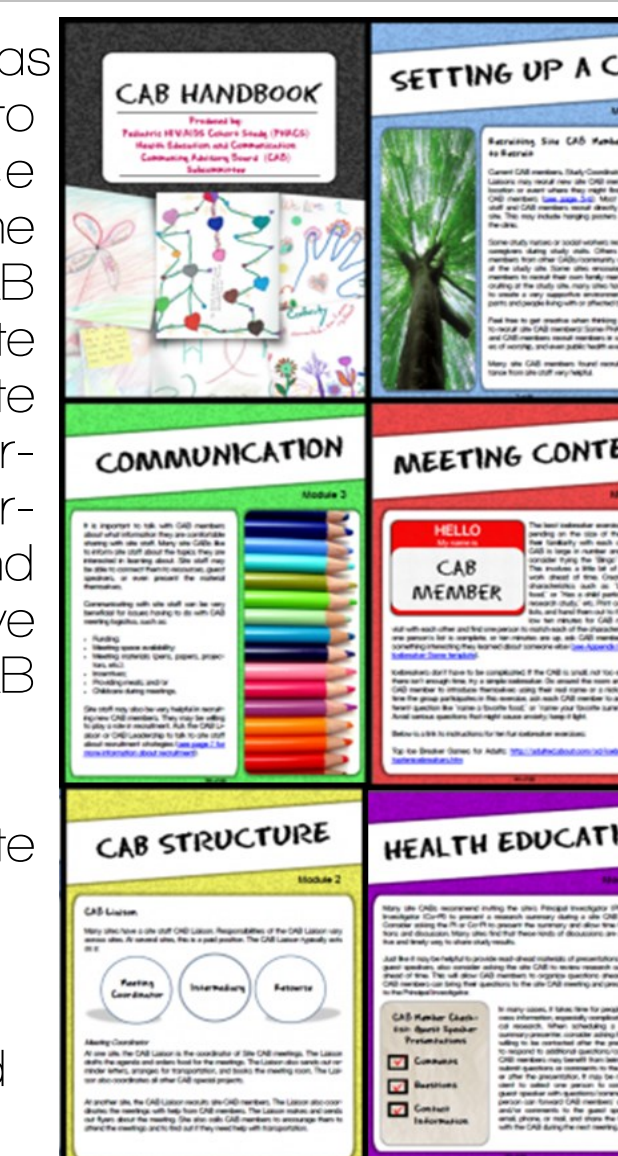
One of the primary functions of the PHACS CAB is to share resources and support across all 21 domestic clinical sites. Through monthly conference calls and implementation of the PHACS CAB Handbook, the CAB effectively disseminates resources and information to each of its 17 site CABs.

17/21 SITES HAVE A SITE CAB

## CAB HANDBOOK

The CAB Handbook was developed in an effort to streamline resource sharing. To compile the content for the CAB handbook, PHACS site CAB members and site staff liaisons were surveyed about their current CAB practices and preferences. The five (5) modules of the CAB Handbook include:

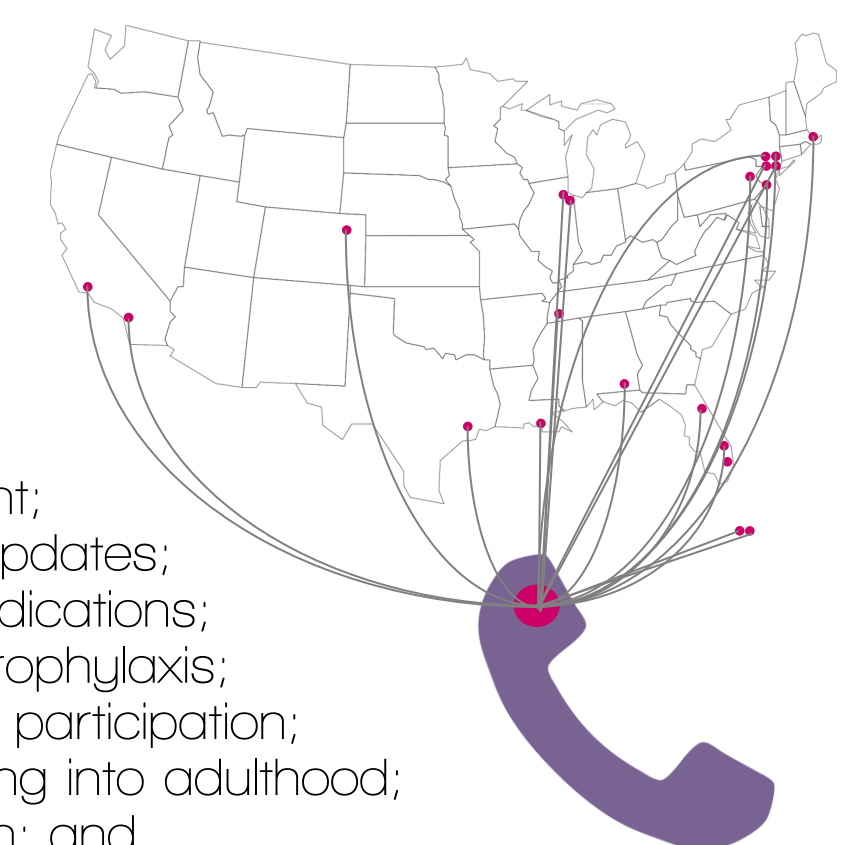
- ⇒ Setting Up a Site CAB;
- ⇒ CAB Structure;
- ⇒ Meeting Content; and
- ⇒ Health Education.



## CONFERENCE CALLS

The CAB meets by conference call on a monthly basis to discuss important topics including (but not limited to):

- ⇒ Disclosure;
- ⇒ Stigma;
- ⇒ Nutrition;
- ⇒ Mental health;
- ⇒ Adherence;
- ⇒ Site CABs;
- ⇒ Violence;
- ⇒ Safe sex;
- ⇒ Informed consent;
- ⇒ PHACS study updates;
- ⇒ Antiretroviral medications;
- ⇒ Pre-exposure prophylaxis;
- ⇒ Research study participation;
- ⇒ Youth transitioning into adulthood;
- ⇒ Health education; and
- ⇒ Living healthy with HIV.



## FUTURE DIRECTIONS

- As the CAB continues to grow, the CAB will continue its efforts to:
- ⇒ Collaborate with PHACS WGs and writing teams to give community input into PHACS publications;
- ⇒ Contribute to all PHACS CAB and Health Education and Communication Committee Projects; and
- ⇒ Support mothers/caregivers enrolled in or considering enrolling in PHACS protocols.

Please contact Megan Reznick ([MeganReznick@westat.com](mailto:MeganReznick@westat.com)) and/or visit the PHACS website (<https://phacsstudy.org/Education-Hub/Adult-Community-Advisory-Board>) for more information about the PHACS CAB.