



Advocacy and the PHACS CAB

Fall 2015 CAB Retreat

What is Advocacy?

- Advocacy is the support for or recommendation of a particular cause or policy.

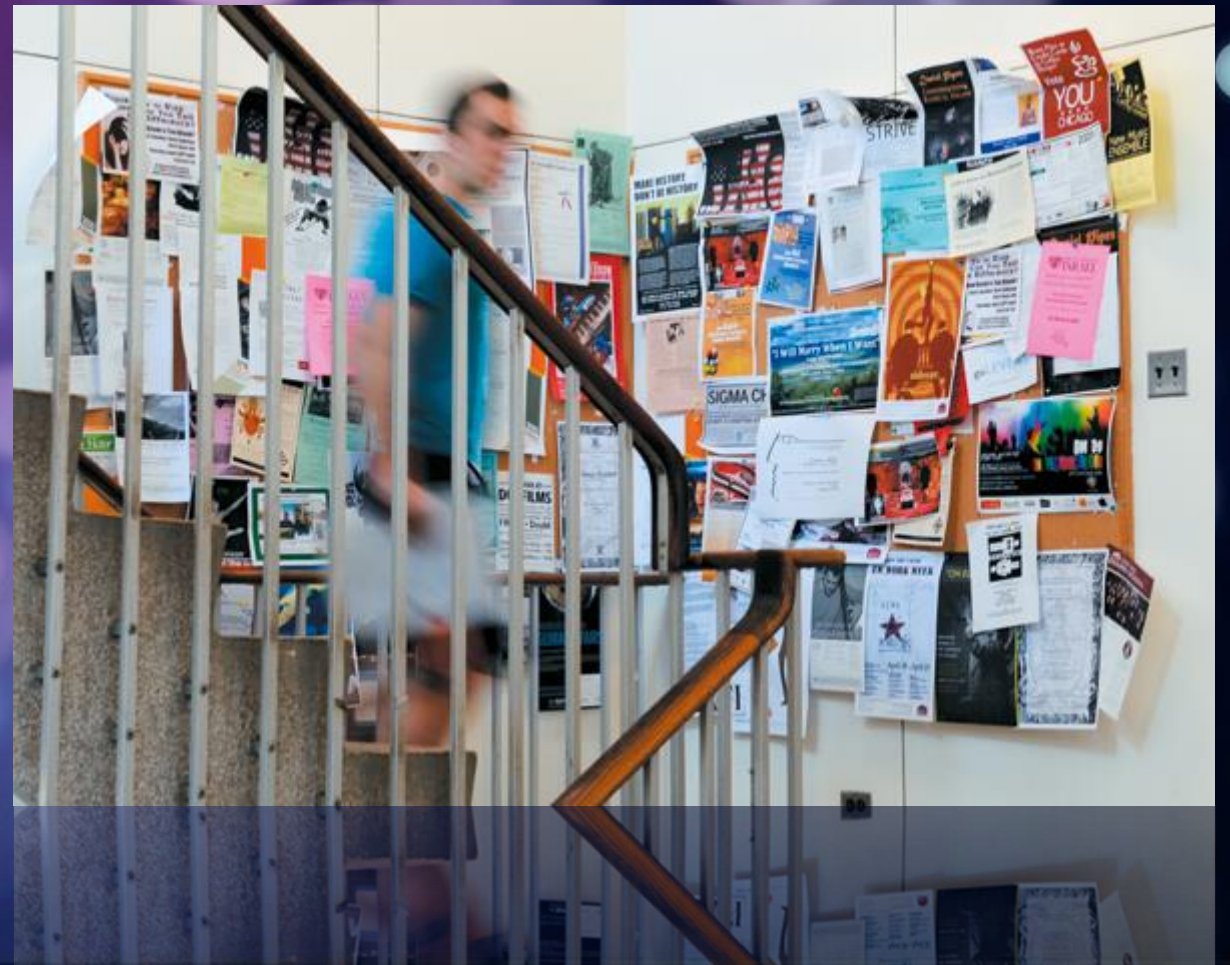


Types of Advocacy

- “Behind-the-Scenes”
 - AIDS Walk
- Sharing your Story Anonymously
 - Newspapers, Blogs, Television, etc.
- Public Speaking
 - Speaking Openly to an Audience
 - National Campaigns

Where to Find Opportunities

- Peers
- Local Organizations
- Non-Profit Groups
- National Campaigns



Advocacy in PHACS



- Mothers and Caregivers
- PHACS CAB
 - Purpose
 - Mission

Team

JEOPARDY!

- Each team will choose a buzzer sound (Beep! Buzz! Ding!, etc).
- Anyone on the team can make the buzzer sound when he/she knows the answer.
- Whichever team “buzzes” first will get 15 seconds to decide on the answer.

- **Each team will have 1 team leader.**
- **The team leader the only person who can say the answer for the team after 15 seconds of team discussion.**
- **If the team answers incorrectly, the other team gets a chance to steal.**

**1 minute to choose team
names, a team leader, and
a team buzzer sound!**

PHACS BASICS	PHACS CAB	CAB HANDBOOK/ SITE CABS	MIXED BAG
<u>100</u>	<u>100</u>	<u>100</u>	<u>100</u>
<u>200</u>	<u>200</u>	<u>200</u>	<u>200</u>
<u>300</u>	<u>300</u>	<u>300</u>	<u>300</u>
<u>400</u>	<u>400</u>	<u>400</u>	<u>400</u>
<u>500</u>	<u>500</u>	<u>500</u>	<u>500</u>

FINAL

**These are the three main
PHACS protocols.**

The goal of SMARTT is to study the long-term safety of _____ for babies who were exposed to them in the womb or after birth.

This PHACS group includes HIV-affected community members, health educators, study nurses, psychologists, epidemiologists, biostatisticians, researchers, and representatives from the National Institutes of Health.

After a study is approved as a capsule, but before it is finalized as a published manuscript, what is the second phase of the manuscript writing process.

DAILY DOUBLE!

Name all seven PHACS
Working Groups.

**The CAB produces two of
these a year.**

**Name the specific titles of
the two CAB leaders.**

**The CAB Chair serves as a
non-voting member on
which other PHACS
committee?**

**Name a PHACS production
or project to which CAB
members contributed.**

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

When setting up a site CAB, it's important to develop this kind of statement which answers the question, "Why do we exist?"

**Some site CABs ask site
CAB members to sign
these types of agreements.**

If the CAB is planning to review study updates or research summaries during a CAB meeting, it is recommended that the CAB invite this type of site staff member to present the research.

**Give an example of where
a site CAB could recruit
new CAB members.**

The CAB Handbook can be located in this section of the PHACS website.



**This term means the
public support for or
recommendation of a
particular cause or policy.**

**Give an example of a way
to keep CAB members
involved in the site CAB.**

**Give an example of
“Behind-the-Scenes”
advocacy.**

**This HECC resource is a
tool for caregivers who
have decided they want to
disclose to their child.**

**This PHACS protocol currently
does not have a component for
participants ages 18 and up.**

**Currently, PHACS has had
this many manuscripts
published in scientific
journals.**

55

Thank you!