



Add Your **VOICE!**

We invite you to use your voice
and get involved in HIV/AIDS research.

Opportunities for Community Participation
in HIV/AIDS Research

Division of AIDS

National Institute of Allergy and Infectious Diseases
National Institutes of Health



National Institute of
Allergy and Infectious Diseases

The Division of AIDS at the National Institute of Allergy and Infectious Diseases (NIAID), National Institutes of Health (NIH) has taken a leadership role in involving community representatives in local, national and international research activities. NIAID believes that community members must play an active role in all aspects of research. This facilitates communication and an exchange of ideas, and helps ensure that new HIV/AIDS treatment and prevention strategies address areas of utmost concern to those affected by the disease. Each of NIAID's HIV/AIDS research networks (consisting of multiple study sites) has opportunities for community representatives to participate in the research process through the local, national, and international Community Advisory Boards (CABs).

NIAID supports seven networks that conduct research on the natural history of HIV infection, HIV vaccines, prevention, and treatment. Opportunities for you to get involved are highlighted below. For more information, visit www.niaid.nih.gov/daids.

TREATMENT



The Community Advisory Boards (CABs) of the **Adult AIDS Clinical Trials Group (AACTG)** are

crucial in the development of successful trials. CABs provide an opportunity for members of affected communities, especially clinical trial participants, to help in the design and implementation of clinical studies through ongoing interaction with researchers and study staff. At the local level, CAB members

take research and treatment information to their communities and relay community concerns to the researchers. CAB members also advise researchers in their sites on issues related to volunteer participation and provide peer support for trial participants. Nationally, the AACTG's Community Constituency Group (CCG) actively participates in the network's scientific committees and protocol teams, and have input in setting the research agenda and scientific priorities. For information about the AACTG and local CAB/national CCG membership, visit <http://aactg.s-3.com/>.

Terry Beirn Community Programs for Clinical Research on AIDS (CPCRA) involves

C·P·C·R·A

community
members
through its
local CABs
and national

Community Constituency Group (CCG). At the local level, each CAB plays an active role in protocol development and implementation, community education and training; input into the research agenda and scientific planning; and recruitment and outreach. The National CCG is comprised of one member from each local CAB and serves to represent community issues on the scientific committees and protocol teams within CPCRA. The CCG integrates the participation of HIV-infected people and their advocates into the CPCRA as partners and works to ensure that the needs of traditionally underserved populations in the clinical research process are heard. For more information about the CPCRA and CCG/CAB membership visit, www.cpcra.org.



The Community
Constituency Group
(CCG) of the
**Pediatric AIDS
Clinical Trials
Group (PACTG)**

was established to increase and improve community input in the development and delivery of clinical research in pediatric HIV/AIDS. As a constant reminder of the impact of HIV/AIDS in the minds and hearts of clinicians and researchers, the CCG helps the PACTG focus its research and take into account the challenges faced by children with HIV/AIDS. The CCG plays an active role in all aspects of the research process, including setting the scientific agenda, protocol design and implementation, and information dissemination. At the local level, each site has a Community Advisory Board (CAB) that helps to bring local needs and concerns to the attention of the researchers and staff at the site. For more information about the PACTG and CCG/CAB membership, visit <http://pactg.s-3.com>.

PREVENTION



The **HIV
Prevention
Trials
Network
(HPTN)** is

a global clinical trials research network that evaluates promising non-vaccine interventions to prevent HIV transmission. Community participation occurs locally, nationally and internationally through a variety of processes, including Community Advisory Boards (CABs), the Network's Community Working Group (CWG), and through community member

participation on HPTN committees and protocol teams. A key goal of the HPTN is to foster partnerships between researchers and local communities impacted by HIV/AIDS. An active community participation and advisory process works to meet this goal by strengthening local capacity to respond to prevention research needs while serving as a voice for study participants and the community. As partners in the research process, community advisory members inform researchers of local issues or concerns that can greatly affect the conduct and success of research studies. At the international level, CAB and CWG members have input in all aspects of the research agenda, including study design, implementation, and information dissemination. For more information about the HPTN and the Community Participation Program, visit www.hptn.org.

PREVENTIVE VACCINES



HIV VACCINE
TRIALS NETWORK

The **HIV
Vaccine Trials
Network
(HVTN)** is a
global research
network designed

to develop and test preventive HIV vaccines. The Global Community Advisory Board (GCAB) includes representatives from CABs of research sites located in sub-Saharan Africa, Asia, Latin America, the Caribbean, and the United States. Local CABs help to prepare and educate the community about HIV vaccine trials. Working with community educators and other staff at each site, local CAB members help the community better understand the science of HIV/AIDS and vaccines and

the clinical research process. Opportunities exist for community input and involvement at all levels of the HVTN's research agenda. CAB members have input into study design and local procedures, and assist in planning, developing, and implementing HVTN research, making sure that community concerns and needs are taken into consideration throughout the research process. CAB representatives are involved in HVTN governance and research and serve as liaisons between the general and scientific communities for information exchange. The HVTN also works with other NIAID networks to ensure that vaccine products are evaluated for their therapeutic effect. For more information about the HVTN and CAB membership, visit www.hvtn.org.

NATURAL HISTORY STUDIES



The **Women's Interagency HIV Study (WIHS)** is a collaborative, multi-site longitudinal study designed to

investigate the impact of HIV infection on women in the United States. The study was initiated in 1993, and has enrolled over 2600 HIV-infected and non-infected women at risk of HIV. The WIHS has interacted with the community from the outset, by soliciting the community's input to better identify problems and pursue research opportunities. Community involvement through the individual WIHS sites and the Community Advisory Board (CAB) is encouraged to foster women's participation and understanding of

research scope and results. The mission of the CAB is to provide ongoing community input into the national WIHS agenda. The CAB helps ensure that the study is representative of the community at large, and that participants are well informed and have the support they need during the course of the study. For more information about the WIHS and CAB membership, visit <http://statepi.jhsph.edu/wihs/index.html>.



The **Multicenter AIDS Cohort Study (MACS)** is an

ongoing study of the natural history of HIV infection in homosexual men. The study began in 1984 with sites located in Baltimore, Chicago, Pittsburgh, and Los Angeles. The MACS has made a number of significant contributions to our knowledge and understanding of HIV and the AIDS epidemic, and in doing so has helped to guide public health policy. Each MACS site has a Community Advisory Board (CAB) that was established to provide ongoing input into the scientific agenda and to ensure that the study and its findings were well understood in the community. For more information about the MACS and CAB membership, visit <http://statepi.jhsph.edu/mac/mac.html>.