

JOINING A COMMUNITY ADVISORY BOARD

By David
Mariner

Background Information on CABS

Community involvement is an important way of keeping AIDS research on the right track. There are many ways to get involved. One way is to join a clinical trial. Another way is to become active in the planning and development of research trials.

Many local and national AIDS research networks receive advice from members of HIV-affected communities through Community Advisory Boards (CABs). CABs are patient advisory groups that give the patient's perspective on whether a trial offers ethical, reasonable approaches to the issues that are relevant to that community.

CABs provide input at all levels of the research process, from what will be studied, to the design and running of the trial, to assistance finding and keeping volunteers in the trials.

It was not always like this. Up until the late 1980s, meetings of AIDS research groups did not include patient representatives. This was changed through the hard work of activists.

Today, government-funded clinical trial networks are required to set up CABs. Each local CAB elects members to serve on a nationwide Community Constituency Group (CCG). This system allows the leaders of the national networks to hear the concerns of community members.

One Man's Experience

"I had always wanted to have more involvement and a voice in AIDS research," said Willis Courtney of Washington State. So Willis decided to become a member of the Washington Regional AIDS Program CAB.

"My first meeting was straight forward. Everyone made me feel comfortable by introducing themselves and letting me know about their involvement on the board. When the meeting was over I was overwhelmingly impressed by the involvement of the CAB in clinical trials and studies. It was like a dream come true – I would get my chance to become involved in AIDS research!"

Willis acknowledges that being a CAB member can sometimes be intimidating. There are lots of new terms to learn and understanding the research process can take time. He believes that having a mentor was a key part of his success; "My mentor, Brian Mahoney, got me started by going over information that he had in his archives. I still tell everyone how he sent me home with an armload of research!"

What makes Brian a good mentor? According to Willis: "Brian is very knowledgeable because of his years of experience and involvement in the field of AIDS and he has a lot of patience to teach. He was very willing to work with me until I understood the new concepts."

Willis has come to enjoy his time working at CAB meetings: "When we meet, we greet one another with hugs and smiles. To me it's like a reunion. We come together ready to take on our responsibility as CAB members."


His advice for new CAB members? "Just sit back and be yourself, give your full attention to what's going on and take notes. I found that taking notes in my own words allowed me to understand what was being said. Brian was very good at teaching me how to interpret studies and to break them down to understand what I had read."

Getting Involved

While all HIV+ people are encouraged to become active members of CABs, it is important to be well informed about treatment issues in order to make a valuable contribution.

As well as working with a mentor, you can prepare by attending treatment education workshops and programs at local AIDS organizations, African-American HIV University (www.blackaids.org/university/) and NATAF meetings (www.namc.org, click on conferences and then NATAF). Also consider joining the AIDS Treatment Activists Coalition (ATAC) at www.atac-usa.org.

The following AIDS research networks have opportunities for community representatives:

- Adult AIDS Clinical Trials Group (AACTG): aactg.s-3.com/ccginfo.htm
- Community Programs for Clinical Research on AIDS (CPCRA): www.cpcra.org/index.htm
- Pediatric AIDS Clinical Trials Group (PACTG): pactg.s-3.com/inccg.htm
- HIV Prevention Trials Network (HPTN): www.hptn.org/community_program.htm
- HIV Vaccine Trials Network (HVTN): www.hvtn.org/community/ 

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