
HIV VACCINES AND THE COMMUNITY

The Community Advisory Board Bulletin

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HVTN October Conference in San Francisco

Conference highlights and summaries from the community education meetings

By Steve Wakefield & Siobhan Malone

Three jam-packed days of vaccine science and vaccine trial information made the HVTN meeting in San Francisco October 3rd through 5th a busy but productive time. All of the network's sites were represented and most sites sent their Community Educators/Recruiters and one or two CAB members. The Community Educators/Recruiters and CAB members met together on both Tuesday and Wednesday, and then separately on Wednesday evening to discuss everything from Participant's Bill of Rights to the CAB orientation manual. Steve Wakefield, Director of the HVTN's Community Education Program, addressed the entire network Tuesday morning and spoke about the role of Principal Investigators in Community Education and what is expected of the HVTU's. Steve asked the PIs to provide leadership in developing site specific community education plans which will prepare each locale for multiple large trials to find a vaccine.

Later in the day on Tuesday the CAB members and Community Educators/Recruiters came together to get to know one another and discuss some of the business of the new network. A few brave CAB members joined some of the protocol teams that needed community representation. (Although all of the protocols have at least one rep now, there are several that still need another CAB member, so be sure to take a look at last month's Bulletin and let us know if you are interested in joining one.) During this meeting, a CAB orientation manual, developed by the HVTN Community Education Program, was passed out so that each site had two or three manuals from which they could copy resource materials, add or remove pieces, and distribute as they like.

In the Wednesday afternoon CAB/Community Educators/Recruiter's meeting, the CAB orientation manual was reviewed at length and it was decided that other pieces, such as material more specific to CAB development for new sites, and a skills building resource book for community educators should be developed as well. CAB members decided to further review the

documents in the manual and make changes by the end of November.

Steve and Siobhan emphasized that their role as staff is to support all of the community education activities, ensure that logistical support and resources are available, and to facilitate CAB and staff in gathering information needed to ensure that the local activity is coordinated with the national and international activity of the network. The HVTN Community Education Program is also responsible for developing the CAB retreat plan and creating regional training opportunities.

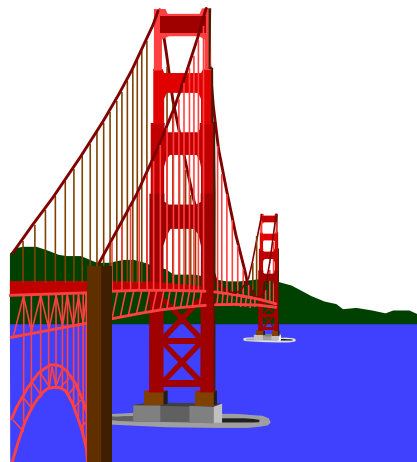
Following that discussion/activity, Bill Snow gave an update from the Scientific Steering Committee. He discussed the network's future and its need to get more products to test into the pipeline. It was noted that CAB members and treatment advocates need to build alliances and send a clear message to pharmaceutical companies to do more for vaccine research while improving current therapies so they are less toxic. He also discussed the development of a Site Evaluation Group and challenged the CAB to identify some members for the team.

After Bill, Tom LaSalvia spoke to the group about the National Steering Committee. Tom highlighted that the group is working to inform those individuals, organizations and institutions who influence and act as gatekeepers of higher risk audiences about HIV vaccine research and the hope a vaccine brings for the future using positive, proactive, culturally-sensitive messages and strategies. In response, CAB members and Community Educators noted the need for more interaction with the network's sites. Specifically, persons suggested a more bottom-up approach to getting accrued knowledge and accumulated experience from

the sites into this national agenda. All noted that the VAXGEN trial will provide information which will have an impact on attitudes and beliefs about trial site activities.

For the last hour of this meeting, Dr. Larry Corey, Chair of the Scientific Steering Committee,

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Thoughts from a Virgin Trial Networker

Understanding the similarities and differences between the HPTN and the HVTN

By Wayne L. Wilson, Family Health International

I started working with the HIV Prevention Trial Network (HPTN) in August of this year after being out of the HIV working arena for almost 3 years, hence the virgin reference in the title. My role with the HPTN is similar to Steve Wakefield's, only there are two of us heading the Community Program of the HPTN – Stella Kirkendale and me. As if starting with one network was not enough, I was fortunate to be able to attend the HIV Vaccine Trial Network (HVTN) Full Group Meeting (October 3-5) and be pushed to the limit on vaccine science while meeting all the wonderful people in the HVTN. And I survived!

As I was meeting everyone and soaking up the science, Siobhan Malone mentioned it would be interesting to have an article on the similarities and differences between the two Networks. Little did I realize what I was getting into when I agreed! First a little background.

Whereas the HVTN is working with vaccine trials, the HPTN is working with other HIV prevention science strategies. There are six main science areas where the trials will be concentrating: perinatal transmission, sexually transmitted diseases, substance use interventions, behavioral interventions, microbicide use, and antiretroviral therapies. Each of these science areas has a Science Working Group that is presently working to identify study concepts to be developed into study protocols.

There is another working group, the Community Working Group (CWG), which is assigned to be the liaison for and representative of community issues in the HPTN. The CWG is charged to identify community representatives, site Community Advisory Board members, site community health educators, and ex-officio experts in the field of community development and behavioral sciences to be in the group. The CWG is where Stella and I spend our time supporting efforts and developing materials to ensure that community participation is reflected throughout the HPTN's activities.

Now that you know a little more about what the HPTN is, we can talk about the similarities and the differences. Please keep in mind this in my perspective as a Networker virgin!

Here are some key similarities I observed at the HVTN meeting. Both the HVTN and HPTN are networks of interested researchers, site staff and community people working together to push the envelope to get something done about stopping and pre-

venting HIV in the world. Both have committed to concepts supporting community participation at all levels of the research process. It also seems both Networks have a collaborative feel to getting the work done in teams rather than in a hierarchical structure. We also both seem to share an underlying feeling that there may be some polarization between “the science” and “the community” which needs to be discussed openly. Another similarity is that we both are faced with truly integrating our processes on a global level and this is presenting some important challenges.

It is interesting that I found somewhat fewer differences. The HVTN has the good fortune to focus on one prevention method (vaccines), whereas the HPTN has six science working groups developing protocols that cover a broader spectrum of implementation methods. Many of the historical resources have migrated to the HVTN while the HPTN has the challenge of creating a new structure. And that is really about the extent of it, as I see it.

Our numerous similarities offer some interesting opportunities to work together, specifically in supporting the community programs. Sharing how we will overcome challenges to communicating internationally is one way. Specifically, we need to identify effective ways to include community representatives (particularly those from outside the U.S.) so they can stay informed and have a truly representative voice. Sharing resources and information about strategies we develop that work (or lessons on why they did

not!) for community education and recruitment. Some examples for this are: CAB training, community education and awareness campaigns, and the Participant's Bill of Rights. Of course, there are many, many more! We just need to remember to ask our Network siblings what's happening in their

yard to see if there might be a way to support each other!

One final observation about the HVTN and HPTN comparison: I heard a number of times from HVTN participants, “Oh, the HPTN is so far ahead of us.” I found this to be interesting because, before I left for the HVTN meeting, I had talked with some folks about how we thought the HVTN was light years ahead of the HPTN. What I found is that the truth is somewhere in between. Both Networks are ahead of the other in some areas and behind in others. In fact, some areas I have observed are totally different and will probably never be able to be compared. But the great thing is, we are all working on this tremendous effort together. We have some opportunities to work together on important issues, so let's make sure we keep the communication lines open. That way we can reach out every once in awhile and make sure we are on track.

I want to thank everyone that spent time with me at the HVTN meeting – you helped me formulate this article. For the rest of you, I look forward to meeting you the next time! I may have to relinquish my virgin status, and I think it will be worth it! ♦

**** Visit the HPTN website at www.hptn.org ****



Profile du CAB-HAITI

Par **Dr. Mireille L.S. Peck** (Coordinatrice CAB –HAITI et Directeur des activités communautaires) & **Dr. Sonia S. Jean** (Coordinatrice des recherches et Coordinatrice des activités communautaires)

L'épidémie du VIH/SIDA prend de l'ampleur partout dans le monde, et la communauté haïtienne doit amplifier également ses stratégies de lutte. Dans cette optique, les Conseils Consultatifs Communautaires (aussi connu comme le 'CAB') jouent un grand rôle. Le CAB-HAITI contribue à limiter la propagation du virus et, à enrayer les préjugés qui l'entourent en:

- diffusant les moyens de prévention
- accompagnant la recherche vaccinale
- accueillant des infectés comme membres à part entière du Conseil Consultatif Haïtien, qui compte 13 membres venant de différents secteurs de la société haïtienne, tels que: l'Éducation, la Religion, la Jeunesse, les Groupes de Femmes, les Infectés et les Affectés, les Étudiants, et la Presse.

Conscient de sa mission, le CAB-HAITI s'est fixé les objectifs suivants dans le processus de la recherche vaccinale. Il veut aider à:

1. diffuser des moyens de prévention de la maladie.

2. faire comprendre à la communauté toutes les phases de la recherche.
3. informer la communauté des travaux des centres nationaux GHEKIO.
4. établir une bonne communication entre la communauté et les centres GHEKIO
5. diffuser la prise en charge des malades infectés au VIH des centres GHEKIO
6. rendre disponibles certains publics pour la diffusion de l'information
7. faire comprendre l'ampleur de la maladie
8. faire connaître la prévalence de la maladie
9. identifier certains problèmes
10. rendre la recherche plus éthique
11. faire respecter les droits des volontaires
12. passer les messages des responsables GHEKIO de la recherche

Avec nos faibles moyens économiques, la prévention représente pour nous en Haïti le moyen le plus efficace de lutte. La recherche vaccinale nous intéresse au premier plan. Le vaccin symbolise la plus grande arme de prévention.

Le Conseil Consultatif Haïtien est prêt à fournir tout son support aux centres GHEKIO. Le centre utilisera le CAB comme canal de diffusion en approchant chaque secteur du CAB. Le Conseil Consultatif atteindra le plus possible des membres de la communauté haïtienne. Il sensibilisera le public haïtien du problème national et mondial que constitue le SIDA. Beaucoup de citoyens haïtiens seront touchés à travers le Conseil. Ainsi les centres GHEKIO ne seront plus seuls dans la lutte contre le SIDA. ♦

HAITI- CAB Profile

By **Dr. Mireille L.S. Peck** (CAB Coordinator & Director of Community Activities) & **Dr. Sonia S. Jean** (Study Coordinator & Coordinator of Community Activities)

The HIV/AIDS epidemic is continuing to grow in strength and numbers throughout the world, and the Haitian community must continue to intensify its fight against the disease. In this way, the Community Advisory Board of Haiti plays an important role. The CAB-Haiti contributes to limiting the propagation of the virus, and to stemming the prejudices that surround it by:

- spreading the word concerning means of prevention
- supporting vaccine research
- recruiting infected individuals as members of the CAB-Haiti, which, to date, includes 13 members from the different sectors of Haitian society, such as: Educators, the Religious, Youth, Women's Groups, the Infected and the Affected, Students, and the Media.

Conscious of its mission, the CAB-Haiti has developed the following objectives with regards to vaccine research. The CAB's priorities include:

1. spreading the word concerning methods of prevention
2. helping the community to understand all of the phases of the research
3. informing the community about the work at the national centers of GHEKIO (The Haitian Group of Studies of Kaposi Sarcoma and other Opportunistic Infections)
4. establishing a good rapport between the community and the centers of GHEKIO
5. expanding the long term care of HIV positive people at GHEKIO centers.
6. making available certain people for the distribution of information
7. helping communities understand the extent of the epidemic
8. helping communities know the prevalence of the disease
9. identifying certain problems
10. ensuring that the ethical standards of research involving human subjects are met
11. ensuring that the rights of volunteers are respected
12. passing on to the community important information revealed by research investigators at GHEKIO



With our economic struggles, prevention represents, for us in Haïti, the most promising method in our fight against HIV/AIDS. Vaccine research is in the foreground of our plan of attack. The vaccine symbolizes one of the biggest weapons in prevention. The CAB-Haiti is ready to give all of its support to the centers of GHEKIO. The center will be able to use the CAB, with its representatives from the various sectors of society, as a channel for spreading information. The CAB will work to reach out to as many members of the Haitian community as possible to inform them of the national and global HIV/AIDS problem. Many Haitian citizens will be contacted by the CAB. As such, the GHEKIO centers will not be alone in their fight against the AIDS epidemic in Haïti. ♦

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joined the group to discuss, in more straightforward terms, the scientific presentations from the conference. He also touched on the Participant's Bill of Rights and some of the reasons why it has been a difficult issue, such as the fact that the *network*, as such, cannot be held liable, and that therefore individual institutional liability must be looked at. In closing, he stressed that what the network does is research, and that we must be prepared with the fact that not everything will work, but that the experiments need to be done in order to learn about the possibilities and the best process for achieving the goals of the network- to develop an effective HIV vaccine as soon as possible.

Wednesday evening, the group split up and the CAB members held their own meeting in which they elected Danny Pickett co-chair of the Global CAB, and discussed other business, while a few of the Community Educators/Recruiters got together to get to know one another better and to discuss site-specific topics and some of the issues regarding the creation of a Global Community Education Plan for the network. ♦



The group of Community Educators/Recruiters/CAB members who earned the most frequent flyer miles at the conference: Janet Fröhlich (South Africa), Patrice Sévère (Haiti), Monica Barbosa De Souza (Brazil) & Victor Coombs (Trinidad & Tobago)

CALENDAR OF EVENTS

PROTOCOL WORKING GROUP CAB CONFERENCE CALL:

November 7, 2000 7 p.m. EST, 4 p.m. PST. (non-staff)

GLOBAL CAB CONFERENCE CALL:

November 9, 2000 7 p.m. EST, 4 p.m. PST (non-staff)

COMMUNITY EDUCATION/RECRUITMENT COORDINATION CALL:

November 21, 2000 2:30 p.m. EST, 11:30 p.m. PST (staff)

December 1 is...



Each site should be working on its plan for participation in this year's World AIDS Day (WAD). This is an opportunity to build collaborations and focus attention on HIV vaccines as a prevention strategy. Several sites found it difficult to execute public information campaigns on May 18th last year because of the transition. You may want to consider past HIV Vaccine Day activities such as an open house or volunteer information brown bag.

Important steps to take in planning include:

- Review of past WAD activities
- Survey other organizations for local plans and events
- Brainstorm with CAB, PI and other staff regarding plan.
- Update media contact list and send reminder notes that site is part of the HVTN and willing to be a resource on HIV vaccines.
- Let public know that a vaccine is possible and that your HVTU is providing leadership in the search.

Note: A CAB working group will convene on October 19th for a conference call to continue discussions regarding the Participant's Bill of Rights and Responsibilities. Any resolutions/discussion items will be taken back to the Global CAB for review.

Please send suggestion, questions and article submissions to:
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