



The University of Puerto Rico's 2nd Community Engagement Conference

By Sheyla Garced, Community Educator, Maternal-Infant Studies Center (CEMI), University of Puerto Rico.

The University of Puerto Rico's Clinical Trials Unit (UPR-CTU) is composed of three clinics: the Center for Maternal and Infant Studies (CEMI), the AIDS Clinical Trial Unit (ACTU), and GAMMA, named for an earlier HIV treatment drug. All work on different aspects of HIV research, prevention and treatment, but each clinic is affiliated with different DAIDS



CAB members from UPR's three clinics.

networks (see page 4 for a description of the DAIDS networks). CEMI works with the HVTN; the ACTU works with ACTG, HPTN and INSIGHT; and GAMMA works with ATN and IMPAACT. Each clinic, or Clinical Research Site (CRS), has its own CAB. This June, CAB members from all three sites were invited to attend the UPR-CTU's 2nd Community Engagement Conference: *Learning about the clinical trial process.*

The conference was designed to share new research findings associated with HIV/AIDS, to facilitate a greater understanding of the clinical trials process, and to assess the educational and health care needs of People Living with HIV/AIDS (PLWHA). The event was also part of an initiative to learn more from other networks and share information about UPR's three trial sites. In addition to CAB members, the CTU also welcomed study participants, PLWHA, and clinic staff to attend the event. Throughout the conference, CAB members were able to refresh their knowledge about clinical trials, learn about the other CABs and their networks, and talk about CAB and Educator roles at each of the sites. However, the main goal of the conference was for all three CABs to get to know each other and to talk about future collaborations.

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Chicago's Project Wish CAB Looks Back in Order to Move Forward

By Chicago CAB members Kate Miller and Dave Crawford. Kate is the co-chair of the HVTN's Global CAB and Dave is the chair of the HVTN's CAB Scientific Working Group and is on the HVTN's Concept Working Group.

Last April 7 the CRS at the University of Illinois-Chicago, known locally as Project Wish, held a CAB retreat for its members and several site staff. The CAB decided to organize this retreat because there had been many changes in the CAB and site over the last few years. Our idea was to create common ground to discuss and evaluate our goals as a CAB.

We had many objectives for this retreat. These included assessing the accomplishments of the CAB, using these accomplishments as a basis for developing a vision for our future, developing processes for increased effectiveness, identifying the gaps between where we are and where we want to be, and determining how best to achieve our desired future.

The site hired a professional facilitator, Richard Friend, to lead the retreat. One of the first activities he had us do was to create a physical timeline to mark different historical moments in the history of AIDS and in the CAB. This activity helped us truly understand the progress and impact of our work. Since its inception, our CAB has supported recruitment of women and people of color into various clinical trials even when this wasn't consistently happening across the US. These groups may not be perceived as the face of HIV but are nonetheless impacted disproportionately by the epidemic in the US. The Project Wish CAB continues to work hard to make the voices of women and minorities heard.

This timeline activity also served as a starting point to help us envision where we wanted the CAB to be in 3-5 years. We discussed our main goal of providing support to the research site, and broke down this goal into various activities. These activities included research support, community education and advocacy, and to act as a liaison with the HVTN and other global networks conducting vaccine research.

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What is VISP?

By Genevieve Meyer, HVTN
Community Engagement Unit

We hear this question a lot around the HVTN. VISP is short for Vaccine Induced Seropositivity. Defining VISP is easy, but explaining

how it can impact HIV vaccine study participants can often be a challenge.

Vaccines are designed to teach your body to recognize an invader, such as a virus, and then fight it off. The body fights off invaders with antibodies. Antibodies are like soldiers. An effective vaccine would teach your body to create many of these soldiers who specifically recognize the HIV invaders. This would be great! The challenge is that most common HIV tests do not look for HIV itself; they work by seeing if your body has made antibodies. This HIV testing system works well for most people because it is quick and inexpensive, but it can cause confusion for HIV vaccine study participants.

If you're in an HIV vaccine study, you may have these antibodies to HIV even if you do not have HIV -- or even if you have never been exposed to HIV. One way to talk about this phenomenon is to say VISP, but you can also talk about being HIV antibody positive. Study participants need specific testing to tell the difference between being HIV antibody positive and actually being infected with HIV. The HVTN offers this testing for free to anyone who is in our studies or who has been in a study in the past.



Durbin CAB member Lindiwe Mvubu gave a site perspective on VISP.

To learn more about the types of questions and concerns that staff and CAB members encounter at their sites, the Community Engagement Unit (CEU) facilitated a session during the recent HVTN conference. The session opened with a role-play starring Durban CAB member Lindiwe Mvubu and Nashville Educator Casey Braddy. Lindiwe played a study participant who was having a difficult time getting her fiancé to believe that

she was not actually infected with HIV, just because she was testing antibody positive. Casey played the counselor who talked with her about how she might approach the situation with her partner and family, and offered to talk to them for her. They both could have won acting awards for their amazing performances!

Next, Casey led a discussion on how and when to incorporate the idea of VISP into the informed consent process. Informed consent can begin long before someone enters the clinic. Community education around VISP can happen anytime an HIV vaccine conversation arises; it

can happen with potential participants and with anyone interested in learning about HIV vaccines.

Following this discussion, Katie Brooks, the primary counselor for the HVTN's Testing Service, opened the floor for general questions about VISP. The questions generated will be used to help create a comprehensive Frequently Asked Question (FAQ) document for sites and the HVTN website, www.hvtn.org/visp. More information on the Testing Service can also be found on this website.

Several recurring themes arose during the Question and Answer period. The most common theme was "How long will this last?" Unfortunately, we do not know. For some people the antibodies may disappear quickly, while others have continued to test antibody positive for over 15 years. The HVTN is conducting a new study, HVTN 910 that will gather data on how long the antibodies last. This study will also provide free HIV testing for these study participants for as long as needed.



The new VISP brochure will be available in multiple languages.

The second theme had to do with transmission. For example, there were many questions like "Can I pass the antibodies through sex?" or "What if I cut my finger and the blood drips on my child, will the antibodies be spread this way?" Vaccine antibodies cannot be passed through sex, nor from a cut on your body. There is not enough fluid being passed in either of these situations.

The final broad theme covered issues like travel and visas, immigration, and military service. These are all issues that sites can help a participant navigate. HVTN Core and the Division of AIDS (DAIDS) can also step in if necessary to help a participant resolve a situation.

To wrap up the session, several new resources were shown that help explain VISP, including a new brochure and pages on the HVTN's website. The slides from the presentation are available here: hvtn.org/meeting/nov2011.html

We are constantly looking for new ways to talk about antibody responses to HIV vaccines and new tools to explain these concepts. If you have additional questions or suggestions, please read through our webpages www.hvtn.org/visp, www.hvtn.org/visp/vispcare.html, or email gmeyer@hvtn.org.

Chicago's Project Wish CAB Looks Back in Order to Move Forward



Project Wish CAB members creating priorities for the next year during their April retreat.

As with any CAB, we face challenges in maintaining appropriate participation of members who represent HIV-affected communities. Recently, we nearly doubled the size of our CAB, bringing in many new members with diverse backgrounds and experiences. However, new membership without enough orientation led to chaos and disruption of normal CAB operations. This also led to a dramatic turnover in CAB membership. Thus, one main purpose of the CAB retreat was to reflect on how to best initiate new members and provide them with the tools to be successful, contributing members.

For new and current CAB members, we agreed that certain core competencies were desirable. Some of these competencies included a passion for the site's mission, knowledge of the communities being targeted for

recruitment, interest and concern for HIV issues, knowledge of research basics and health policy, and willingness to learn and achieve results. To this end, the CAB reached consensus on future activities for CAB functions and actions.

The retreat also helped us decide the next steps for our CAB development. We needed to have intentional recruitment and training of new CAB members. We have several potential CAB members and we have already arranged for one-on-one training and meetings for reviewing expectations and sharing background information such as:

- Basic HIV vaccine science
- The history of the CAB and site
- Effective CAB participation and an understanding of the commitments for being a CAB member
- Accountability as a CAB member
- Effective CAB decision making and leadership structure

As a closing activity, each participant in the retreat shared one thing they were committed to do in the upcoming quarter. There was overwhelming support for a yearly CAB retreat and continued quarterly discussions on the progress we are making as a result of this retreat. As of November, we had already recruited several new, committed CAB members and implemented a mentoring and training program.

We encourage other CABs to seriously consider a retreat to take stock of where they've been, where they are, and where they'd like to go!

The University of Puerto Rico's 2nd Community Engagement Conference

During the conference, Dr. Carmen D. Zorrilla, Principal Investigator of the UPR-CTU, spoke about HIV/AIDS Biomedical Strategies for Prevention. Mr. Alessandro Gravina from FHI360's Center on AIDS & Community Health offered an overview of the HIV vaccine research education initiatives that his organization has supported in the United States.

Later in the afternoon, a panel of community leaders talked about the educational and research needs of the community. Among the issues discussed were recruitment and retention of CAB members, dissemination of research study information to the community by CAB members, and the importance of HIV vaccine trials.

This conference provided an important opportunity to integrate the CABs from our sites. Through the years, the UPR-CTU CABs have shared ideas and participated in

community and educational activities such as the Puerto Rican Gay Pride Parade, the first Puerto Rican LGBT health conference, health fairs, and World AIDS Day, among others. This year the CABs collaborated on several community activities including the 30 Years of HIV/AIDS Documentary Series, and a 5K walk that took place October 23, and an event for World AIDS Day. The CTU plans on holding a meeting next year to continue to work on the topics that the CAB members suggested.

All of the sites are in a precarious time of limited resources. Since the Networks have related scientific agendas, it is critical that there is increased collaboration among the three sites. This collaboration has been essential to the success of the UPR-CTU. We know that continued efforts between the CRSs, CABs, and Networks create bonds and friendships that solidify our continued commitment to the community.

Helpful Vocabulary for Understanding the DAIDS HIV Clinical Trial Networks

The HVTN is one of six networks within the Division of AIDS (DAIDS). DAIDS is part of the National Institute of Allergies and Infectious Diseases (NIAID). NIAID is one Institute of the National Institutes of Health (NIH) in the US. Below is a summary of the DAIDS networks and their primary research focus. For more information on the networks, visit: <http://tinyurl.com/daidsnetworks>.

AIDS Clinical Trials Group (ACTG) Conducts studies that seek to improve clinical management of HIV/AIDS, including co-infections and other HIV-related conditions. In addition, the ACTG conducts research on new drug development.

HIV Prevention Trials Network (HPTN) Conducts studies that evaluate non-vaccine HIV prevention strategies.

HIV Vaccine Trials Network (HVTN) Conducts studies focused on developing preventive HIV vaccines.

International Maternal Pediatric Adolescent AIDS Clinical Trials (IMPAACT) Works to prevent mother to child transmission of HIV and to optimize clinical management of HIV, including co-morbidities and other HIV-related conditions in children, adolescents and pregnant women.

International Network for Strategic Initiatives in Global HIV Trials (INSIGHT) Works to improve clinical management of HIV/AIDS, including co-infections and other HIV-related conditions.

Microbicide Trials Network (MTN) Evaluates vaginal and rectal microbicides for HIV prevention.

Adolescent Trials Network (ATN) Works with existing research networks and individual investigators, conducts studies focused on HIV-infected and HIV-at-risk pre-adolescents, adolescents, and young adults up to age 25. www.atnonline.org.

Clinical Trials Unit (CTU). A CTU can have multiple Clinical Research Sites that it oversees, and can participate in the work of one or more of the networks.

Clinical Research Site (CRS). Locations where DAIDS' clinical studies, including HVTN vaccine studies, are conducted. Some CRSs are part of large universities, some are part of hospitals, and some are small, private clinics.

For more information: <http://tinyurl.com/daidslocations>.

Send suggestions, questions, and article submissions for the CAB Bulletin to:

Genevieve Meyer, Editor
gmeyer@hvtvn.org
Tel: 206 667-5300

Layout: Lisa Donohue

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www.infinitytranslations.com

Missed an Issue?

View past issues of the CAB Bulletin at www.hvtvn.org/community/bulletin.html.
No password required!

ABOUT CABS

Community Advisory Boards (CABs) are one way that the HVTN involves community members in the research process. CABs consist of volunteers from diverse backgrounds who work with local research units and advise the site from a community perspective. Community input is invaluable to community education efforts, as well as to the development of this bulletin.

CAB CONFERENCE CALLS

If you are interested in joining one of these calls, email Genevieve Meyer (gmeyer@hvtvn.org)

GLOBAL GCAB CALL*

Second Thursday of every month

Thurs., January 12th: 8 a.m. PT/11 a.m. ET

Thurs., February 9th: 8 a.m. PT/11 a.m. ET

SPANISH LANGUAGE CAB CALL

Third Thursday of odd months

Thurs., January 19th: 9 a.m. PT/12 p.m. ET

Thurs., March 15th: 9 a.m. PT/12 p.m. ET

ETHICS WORKING GROUP CALL

First Wednesday of every month

Wed., January 4th: 11 a.m. PT/2 p.m. ET

Wed., February 1st: 11 a.m. PT/2 p.m. ET

AFRICAN REGIONAL CAB CALL

Third Thursday of even months

Thurs., February 16th: 9 a.m. PT/7 p.m. RSA

Thurs., April 19th: 9 a.m. PT/7 p.m. RSA

SCIENTIFIC WORKING GROUP CALL

First Friday of every month

Fri., January 6th: 8 a.m. PT/11 a.m. ET

Fri., February 3rd: 8 a.m. PT/11 a.m. ET

**Please note that the GCAB call is only open to GCAB representatives and alternates at each site. All other CAB calls are open to any and all CAB members.*