Research networks would falter and stumble without the strength, grace and tireless dedication of community members. We would like to honor one in particular who embodied all of these characteristics: Mama Matilda Mogale, a long time HVTN staff member, then CAB member, at the Perinatal HIV Research Unit (PHRU) in Soweto, who passed away February 9th, 2011.

Matilda Mogale was a career nurse who worked at PHRU. In 1998, she introduced the Prevention of Mother to Child Transmission (PMTCT) program to Soweto health clinics. In 1999, she inaugurated the HIV vaccine CAB. She participated internationally as an HVTN trainer, co-chair of the CERs, attended several conferences and became one of the first members of the Cross Network CAB (later called Community Partners). In 2007, the HVTN presented her with a Network Service Award for her dedication to HIV vaccine community work. In 2008, she retired from the staff and joined the CAB, and was an excellent leader (she served as GCAB co-chair for several years) and helped to spread the model of community engagement around the world.

The staff at HVTN Core thoroughly appreciated the dedication, energy and love Matilda brought to the global fight against HIV/AIDS. Her example is a model for activists and community members. She was, and will continue to be, an inspiration to researchers, staff and community members lucky enough to work with her.

HVTN 914, slated to open in mid-March 2011 at the Lima HVTU Asociacion Civil Impacta Salud y Educacion (Impacta), is the HVTN’s first circumcision study. This study will recruit 30 healthy, 21 to 30 year old, HIV-negative, uncircumcised men who have sex with men (MSM).

The goals of the study are:
1) Assess the feasibility of studies in which safe and tolerable circumcision (removal of skin from the tip of the penis) and rectosigmoid biopsy (removal of skin cells from the colon) are performed.
2) Assess institutional capacities to process mucosal samples, which are more delicate and difficult to process than blood.
3) Identify methods of evaluating foreskin and rectosigmoid mucosal immune responses.

Why this study?
The Step study showed that we need to understand the immune responses in the foreskin if we wish to create a protective vaccine. As a scientific community, we understand little about how HIV enters sites of sexual exposure. We believe that the mucosa of the colon and the foreskin are sites where a vaccine would need to do its job to protect men who are at sexual risk of infection. These sites are not only the first line of defense against the virus, but also a bottleneck for the few viruses that make it through to establish infection. Typically in vaccine studies, we monitor what is happening in blood but we don’t know much about what happens in the mucosa. This study will allow us to look at what happens both in the colon as well as the foreskin and compare these responses to what happens in blood. There are no vaccines given in this study.

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10 years of volunteerism — Selva Amazonica CAB, Iquitos, Peru

By Luis Alberto Chanamé, CAB President

Located in the heart of the Peruvian Amazon is Selva Amazonica, the HIV clinical trials site of Iquitos, Peru. From its inception, CAB members took to heart the responsibility to learn about and raise awareness for HIV vaccine studies, and to represent their community. This was a new experience for the members, but one that was felt to be a privilege, serving as representatives of the people of Iquitos.

This year the CAB at Selva Amazonica will celebrate its tenth straight year. Starting with 15 members, the CAB represents community members of diverse backgrounds including schools of public health, doctors, nurses, people living with HIV, journalists, representatives from the gay and transgender communities, representatives of the education sector, and youth groups. All community members come together to represent these different social and professional sectors. The first CAB president was Ms. Silvia Barbaran. I have been serving as CAB president since December, 2009.

Getting trained as a CAB member has been an interesting process, since hardly anyone was familiar with the work. But thanks to the tremendous support of the Community Education Committee at the site we have now learned about informed consent, the protocols at our site, and the importance of confidentiality for participants. We have also learned many new scientific and medical terms, which have helped us in our heightened understanding of HIV/AIDS and specifically of vaccines. Learning the essentials of HIV prevention has been key in reaching out to the community.

At times there has also been tension with the Selva Amazonica. There have been moments of conflict and even crises during activities that brought together people of diverse social, economic, and cultural sectors. Nonetheless, we have been able to get through this and move forward through ongoing dialogue, discussion and a compromise of ideas and approaches. Sometimes this means giving up one’s own ideas in order to make a protocol a success. With the passing of years, we have learned to be more responsible in how we represent different sectors of our society because we all share the goal of wanting to see a vaccine or a cure for HIV/AIDs in our lifetime.

The CAB has had to hold clandestine meetings; because of the themes we discuss, the people in the room and the ignorance of the society in general, we could be at risk. Sometimes people in the community wonder if some of the CAB members are HIV positive just because of their involvement. But, due to the daily work of the site and CAB, and the periodic trainings in the community, these perceptions are changing. We are also helping overcome this negative outlook by having CAB members and volunteers participate in local activities such as Miss Gay Amazonia or soccer or volleyball games among MSM for HIV Vaccine Awareness day (May 18) or World AIDS day (Dec 1). The CAB has also organized trainings specifically for journalists and other communication professionals to create and discuss appropriate language that is respectful towards the diverse communities.

Sometimes people in the community wonder if some of the CAB members are HIV positive just because of their involvement.
“How far would you go to find a cure for AIDS?”

By John Beal, Atlanta CAB member

Ten years ago I came across this question in a magazine. Behind it was a panoramic photo of an open valley in the Western U.S. with mountains looming tall in the background. I was struck not only by the beauty of the image but also by the challenge it presented: to ride 575 miles across Montana in 7 days and 425 miles through New England over 5 days, raising $3500 for each ride. I remember thinking that if that was all it would take, I would go as far as possible. And I was not alone. Now, in 2011, two small groups of cyclists and volunteers prepare to celebrate their 9th and 10th round of fundraising to support HIV/AIDS vaccine development through these rides. The 9th annual AIDS Vaccine 200 in Georgia is a 2-day, 200-mile ride in May 2011, raising funds for the Emory Vaccine Center and the Hope Clinic (www.aidsvaccine200.com). The 10th anniversary Montreal, Canada to Portland, Maine AIDS Vaccine Bike Trek travels 425 miles over 5 days in August 2011 and raises money for the Emory Vaccine Center and the UCLA AIDS Institute (www.charitytreks.org). This year if the riders meet the goals that have been set for the two rides, we will have raised $2 million since the races began, with 100% going to the beneficiary organizations.

These rides focused attention on the lack of funding for the research and development of HIV/AIDS vaccines and challenged people to make a positive difference in the fight to end HIV. The response was immense both in participation and in dollars raised. I was one of the cyclists to take the fitness and fundraising challenge of this race. This type of personal action gave me a way to participate in a historic struggle to end a pandemic that was, and still is, wiping out millions. In 2002, about 120 riders and crew decided to ride from Montreal to Portland, Maine despite the event being cancelled. This evolved into the Charity Treks ride that is now celebrating its 10th anniversary.

That same year a group of Atlanta cyclists dedicated themselves to continuing to raise funds for vaccine research at Emory with the determination that 100% of the funds raised went to the beneficiaries. This was our response to learning that the European AIDS Vaccine Ride is not often included in the other HIV/AIDS awareness fundraisers. Couldn’t at least a portion of the funds from the other rides go towards HIV vaccine research? I often wonder. Many point to the need for properly funding treatment and care, and I agree. But we can’t lose sight of prevention, especially vaccines, if we really want to find a way to end this epidemic. People are usually amazed to hear that we cycle hundreds of miles and continue to raise funds year after year. But it is the scientists working on the vaccines and the community partners who have dedicated their lives to this work who are truly amazing; they are the long distance warriors in this battle.

Some readers may recognize “How far would you go to find a cure for AIDS?” from advertising for the Pallotta Teamworks AIDS Vaccine Rides (www.pallottateamworks.com).

This has always struck me as a strange divide in the HIV/AIDS field, that support for vaccines is not often included in the other HIV/AIDS awareness fundraisers. Couldn’t at least a portion of the funds from the other rides go towards HIV vaccine research?”

An unofficial pit stop at the end of day three during the 2006 Montreal to Portland AIDS Vaccine Bike Trek.

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The site held a candlelight vigil with support of the Anglican Church Mothers’ Union, led by CAB member Gloria Malindi (right) and welcomed by CAB Coordinator Nomampondo Barnabas (blue shirt).

CAB member Carlos Vélez organized an initiative to celebrate WAD at the Caguas Municipality town square. To commemorate those who passed on, candles were lit and prayers were said by PI Dr. Carmen Zorrilla, Dr. Jorge Santana (ACTU site leader), a priest, William Miranda (Mayor of the Caguas Municipality), and all those who attended the event.

Recruitment staff tabling in the Castro district. They handed out free coffee and recruitment materials like bags, yo-yo’s and chapstick on a cold, gray San Francisco day.

Educator Brooke Willis (center) and volunteers handed out materials for the local AIDS Funding Collaborative along with condoms and postcards for HVTN 505.

Youth were active participants in this WAD mobilization event put on by the Region of Health in the southern part of Lima.

The GHESKIO site staff along with CAB members, conducted two events for World AIDS Day. The first was a meeting with over 150 women and young girls, including those living with HIV (left). The second was an HIV prevention workshop with 70 high school students (right).
Wheelbarrow races were just one of the activities for game day in Nyanga, Cape Town. CBOs partnered with supporters and audience members, then competed against each other, while speakers presented on a variety of topics related to HIV awareness.

Los Angeles Mayor Antonio Villaraigosa (front row center), along with several celebrity attendees, announced December 1st as WAD at LA Live in downtown Los Angeles. The event was organized by AIDS Research Alliance. (Photo courtesy of Evans V. Ward)

Site staff, CAB members, the Regional Health department and Soul City participated in a WAD event to support the multiple orphanages and child-headed homes in the area.

Recruiters tabling in the Fenway lobby during WAD. Shown here (L-R) are Andre Reynoso, Sochet Phoeun, Daniel Tu, and Coco Alinsug.

KOSH CAB members participated by giving WAD messages to the community and by helping make sure the day was a success.

Multiple organizations from the region got together in the plaza “28th of July” to spread awareness about fighting the HIV epidemic.
How far would you go to find a cure for AIDS?

only donated 10% of what they raised to the beneficiaries. This annual ride has become the AIDS Vaccine 200 with the 9th ride happening in May.

In 2003, as I was raising funds for these rides, I began working with Dr. Paula Frew of the Hope Clinic, which was soon to become an HVTN site. Paula and her staff supported me at my community events. This began my particular interest in supporting the Hope Clinic as I learned about their community engagement activities and success at reaching those populations most impacted by HIV around Atlanta. The Hope Clinic was always in need of funds to further their initiatives and I was happy to have found a way that I could help.

Two years later I was elected to the Hope Clinic CAB. My ongoing education since then about the complexities of this virus, developing successful vaccines, and the challenges of inspiring community participation in vaccine trials, has given me an even deeper personal appreciation of the journey we share.

I always come back to that line and how those of us who were inspired by the challenge will not be satisfied until we have both preventive and therapeutic vaccines available for everyone. Until that day, I will not stop. If you or your friends have been looking for a way to make a difference, join us.

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Selva Amazonica CAB, Iquitos, Peru

members of the community who participate in vaccine studies.

One of the goals of the CAB is to provide the institution and the investigators with a broad vision of the impact, consequences and sustainability of the studies they are conducting. As such, they have become a communication channel by sharing information and providing community education about studies and activities of the Selva Amazonica to the public.

Another aspect that has helped us a lot as a group is our personal growth in taking on the responsibility of being representatives of the Selva Amazonica. This group has assumed the volunteer role in a conscientious way to serve our brothers and sisters, to be part of this worldwide movement to find an HIV vaccine, so that one day our children will benefit from our work.

Three riders from the 2009 AIDS Vaccine 200 ride in Atlanta just prior to Day 1.

A brochure about the Iquitos CAB, developed by the CAB.
A Fresh Take on Foreskin: HVTN 914

Why Peru?
Lima, Peru was chosen as the HVTN 914 study site for a number of reasons. First, most men in Peru are not circumcised at birth, so we will be able to study the foreskin of men who are healthy and sexually active. Second, local medical professionals are both experienced and well trained to carry out circumcisions and sigmoidoscopies with ease and safety. Third, Lima was chosen because it was shown in a survey to have a population of MSM with a high willingness to participate in a circumcision trial; only 5.5% of men were circumcised, but 64% of men expressed willingness to be circumcised.

Community Involvement
The Lima CAB reviewed and gave input to the community education and recruitment plan for HVTN 914. With several MSM members, the Lima CAB is particularly sensitive to MSM issues and contributed that perspective to recruitment planning for the study. Some of those plans include using social networks through the institutional website and Facebook page, and partnering with 30 MSM groups, associations, NGOs and community centers. The site is confident that it has strong social networks in the MSM and MSM service provision communities to successfully and sensitively recruit for the study.

Forward Movement
HVTN 914 will help us better understand how and why the foreskin is a target for HIV. If all goes well, we could find whether the kinds of cell activation we see in the foreskin are different from what we see in the rectal tissue. We could find out possible biological explanations for why risk of infection is different between men who are insertive and receptive. This work may lead us to define assays (lab tests) that we can then use to test vaccine responses at the sites of sexual exposure. If safe, tolerable, and feasible, a future vaccine trial could look at these mucosal site responses following vaccination.

HVTN 914 presents new challenges on how to collect, store and sample mucosal surfaces in vaccine studies, for the site and for the HVTN overall. Through the diligent contributions of community members, researchers and participants, HVTN will hopefully be able to inform the global HIV community about what happens in the colon and foreskin sites with the targets of HIV infection.

Together, CAB members, researchers and participants must continue to meet the challenges of designing, implementing and completing new studies to keep moving research forward.

Learning more about HIV in the foreskin and colon will help scientists in developing a vaccine that works in those parts of the body.

How will a circumcision study help vaccine development?
HIV gets into most men’s bodies through the surface of the foreskin or the colon. Studying tissues from these areas will help scientists better understand immune responses there. Understanding what is happening at the cellular level is important because if a vaccine is to prevent HIV infection, it will need to work in both of these parts of the body.

Dominican CAB member Gustav Wiese Santana in an advertisement for the site, "We are committed to preventing HIV."
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 has been invaluable to community education efforts, as well as to the development of this bulletin.

MISSED AN ISSUE?
If you have missed an issue of the CAB Bulletin, all of our past issues are archived on the HVTN website community pages (no password required!). View past issues including featured clinical research sites, scientific updates, CAB experiences and much more. www.hvtn.org/community/bulletin.html

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

GLOBAL GCAB CALL
Second Thursday of every month
Thurs., April 14th, 8 a.m. PT/11 a.m. ET
Thurs., May 12th, 8 a.m. PT/11 a.m. ET

FRENCH LANGUAGE CAB CALL
Second Wednesday of even months
Wed., April 13th, 9 a.m. PT/12 p.m. ET
Wed., June 8th, 9 a.m. PT/12 p.m. ET

GLOBAL ETHICS WORKING GROUP CALL
First Tuesday of every month
Tues., April 5th, 9 a.m. PT/12 p.m. ET
Tues., May 3rd, 9 a.m. PT/12 p.m. ET

SPANISH LANGUAGE CAB CALL
Third Thursday of odd months
Thurs., March 17th, 9 a.m. PT/12 p.m. ET
Thurs., May 19th, 9 a.m. PT/12 p.m. ET

CAB SCIENTIFIC WORKING GROUP CALL
First Friday of every month
Fri., April 1st, 8 a.m. PT/11 a.m. ET
Fri., May 6th, 8 a.m. PT/11 a.m. ET

AFRICAN REGIONAL CAB CALL
Third Thursday of even months
Thurs., April 21th, 9 a.m. PT/6 p.m. RSA
Thurs., June 16th, 9 a.m. PT/6 p.m. RSA