



Report from the Second International TB/HIV Community Education & Mobilization Workshop

*at the 34th International Union Against Tuberculosis & Lung
Disease (IUATLD) World Conference on Lung Health*

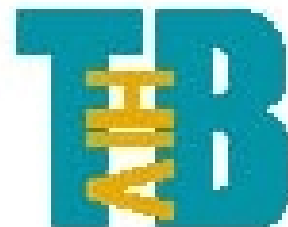
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Paris, France

by Julie Davids

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**Treatment Action Group
New York, NY, USA**



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About AIDES

AIDES was founded in France in 1984 and is now one of the largest European community-based organizations against HIV/AIDS. Our aim is to bring people living with HIV/AIDS, together with their loved ones and peers into an organized entity dedicated to fight HIV/AIDS and to defend the rights of people and communities affected by this disease. In France, 350 staff members and 800 AIDES volunteers are active in 80 cities. Internationally, we have developed strong partnerships with community-based NGOs both in Africa and in Europe to strengthen the role of civil society by sharing best practices and to jointly advocate for global access to care and prevention. AIDES supports people who are infected with or affected by HIV/AIDS. AIDES provides information to the people who remain most vulnerable to HIV/AIDS. AIDES alerts the government when we find shortcomings in the health care system. AIDES mobilizes hundreds of volunteers so that AIDS remains a public health priority.

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About TAG

Founded in January, 1992, the Treatment Action Group, or TAG, is the first and only AIDS organization dedicated solely to advocating for larger and more efficient research efforts, both public and private, towards finding a cure for AIDS. The Treatment Action Group (TAG) fights to find a cure for AIDS and to ensure that all people living with HIV receive the necessary treatment, care, and information they need to save their lives. TAG focuses on the AIDS research effort, both public and private, the drug development process, and health care delivery systems. We meet with researchers, pharmaceutical companies, and government officials to encourage exploration of understudied areas in AIDS research and speed up drug development, approval, and access. We work with the World Health Organization and community organizations globally, and strive to develop the scientific and political expertise needed to transform policy. TAG is committed to working for and with all communities affected by HIV. TAG is a non-profit corporation with 501c(3) status. Contributions are tax deductible to the extent allowed by law.

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Over one million people worldwide die annually of tuberculosis, according to the World Health Organization (WHO). TB, a 100 percent curable disease, is today silently causing more deaths than it has ever done in the history of mankind.

"TB is the biggest killer of People Living with HIV (PLWHA). I know because I watched my brothers die. I would have been dead too. I am alive today because I got access to TB treatment on time," said Winstone Zulu of the Zambian Network of People Living with HIV, during the 2003 IUATLD Conference in Paris. "I never thought TB was a problem until I lost four brothers to the disease within a space of three years," he said.

"Many people don't know they have TB until it's too late," echoed Nomfundo Dubula of the Treatment Action Campaign, South Africa. "I suffered from TB too, and it was difficult staying on medication," she said. "Early detection and prompt treatment saved my life. I couldn't have done it without support. The fear that I might have to start treatment all over again if I didn't complete my doses kept me going."

"The difficulty in diagnosing TB cases has robbed us of the lives of many PLWHA in Brazil," said Ezio Santos-Filho of Gruppo Pela VIDDA, an HIV-positive group in Rio de Janeiro.

"AIDS activism cannot occur without TB activism," said Dr. Fabio Scano of WHO's Stop TB Program. "The social mobilization and community participation that drove the response to HIV/AIDS is needed in the fight against TB."

The case for a closer look at the world's TB epidemic could not have been made more forcefully, as scientists and advocates met for four days in Paris, France in the Fall of 2003 to examine current trends, scientific advances and progress made in controlling the global epidemic.

The scientists met under the aegis of the International Union Against Tuberculosis and Lung Disease (IUATLD). As researchers exchanged data during the conference, treatment advocates attended a TB/HIV co-infection education and community mobilization workshop convened by the US based Treatment Action Group (TAG). The workshop was designed to stimulate discussions about the key issues fueling TB/HIV co-epidemics and strategies for addressing them.

For the many of the over 60 treatment activists from 31 countries who attended the workshop, discussions in the various groups were an eye-opener to the untold havoc TB is wrecking in many communities, its intrinsic linkage with HIV and the need to adopt proactive strategies to stem this 'silent epidemic'.

Various factors were identified as fueling this, such as the rising incidence of new HIV infections, poor diagnostic facilities, low case detection of new TB infections and lack of trained health care professionals. Other factors include brain drain, under funding of national TB programs, lack of political leadership, insufficient drug supply at TB treatment centers and the incidence of multi-drug resistance.

Situation reports presented on the state of TB programs in many countries including Niger, Ukraine, South Africa, Brazil, Zambia Thailand, Kenya and Nigeria revealed that, despite over three decades of existence, national TB programs still remain grossly under-funded, and require stronger political commitment in stemming the tide of the epidemic.

It seemed TB programs have next to nothing, compared to national HIV programs which enjoys huge funding budgets, external donor support, high political will and commitment, civil society and community involvement, established peer support groups, trained human resources, etc.

Dr. Gani Alabi, a WHO staffperson who works on TB in south-western Nigeria, said, "Nigeria has a strong HIV/AIDS committee headed by the President, a multi-sector committee comprised of representatives from many sectors, including numerous civil society groups working on HIV/AIDS. These interventions receive a lot of funding and are well staffed; unfortunately, TB control programs in the country lack this type of support."

He continued, "Although a free TB treatment policy exists, many of the TB treatment centers do not have drugs for their clients when they need them. WHO plans to start the integration of TB/HIV programs in six selected states in the country, but political will and financial commitment is needed in order to make this a reality".

Karyn Kaplan of the Thai AIDS Treatment Action Group (TTAG) also pointed out that while the Global Fund to Fight HIV/AIDS Tuberculosis and Malaria presents a great opportunity to fund proposals for expanding TB interventions, there has been little or no meaningful engagement of PLWHA or those affected by TB in the Country Coordinating Mechanisms (CCM) in countries which ought to push for requests for funding.

At the end of in-depth deliberations, participants recommended the integration of existing HIV and TB programs, and the need to mobilize community support for the Directly Observed Treatment (Short Course) Strategy [DOTS] in reducing the spread of TB.

Activists also proposed various other follow up activities at country levels to support DOTS. High on the recommendations was the need to organize treatment literacy workshops and community education on the signs and symptoms of TB, adherence and drug compliance.

They also agreed to strengthen national coalitions on TB and mobilize for greater political and financial commitment from governments, donors and civil society groups for TB control programs [see "Summary & Recommendations"].

– **Olayide Akanni, Journalists Against AIDS (JAAIDS)
Nigeria, posting to Nigeria AIDS e-forum**

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Even though I had a lot of friends who died from TB, I never realized how important it was to talk about TB... We need to reactivate TB policies in each of our countries. They may be outdated, and they need to be integrated with antiretroviral scale-up. Civil society must pressure the Nigerian Government to deal with TB. There's been so much emphasis on HIV that we have not gotten to hear about TB programs. TB drugs are not always available and [programs] are being starved – they are under-funded and lack the resources they need. The activists must emphasize TB, and we need to get government on board. Over 50% of the money from the Global Fund is going towards ARVs and MTCT – the Fund rejected Nigeria's second round application which ... contained TB projects. We must push the CCM [Country Coordinating Mechanism] to draw up a proposal for expansion of TB programs. DOTS programs are expensive, so some countries have lowered costs by focusing on the community rather than going through the health care system. Health care workers need more hands.

– **Olayinka Jegede-Ekpe, Nigerian Community of Women Living with HIV/AIDS, Nigeria**

I. Overview

a. Objectives

Building on the success of the First International TB/HIV Community Education and Mobilization Workshop, held in conjunction with the 33rd IUATLD Conference on Lung Health in Montreal, Canada, in 2003, the Second International TB/HIV Community Education & Mobilization Workshop had the following objectives:

1. To educate HIV community representatives on the various aspects of TB/HIV coinfection research, prevention, treatment, and policy.
2. To empower HIV community representatives to mobilize and disseminate information about TB/HIV coinfection to their local communities.
3. To give HIV community representatives the skills necessary to help their communities understand, participate in, and provide community input in research and clinical trials.
4. To provide an opportunity for international HIV community representatives to develop working relationships work with WHO, the Stop TB Partnership, the Global Fund, and other stakeholders to more effectively represent affected communities in prevention, research, treatment, and care programs focusing on TB/HIV coinfection.
5. To provide an opportunity for international HIV community representatives to develop working relationships with national and regional public health and TB and HIV/AIDS program officials so that they may work together to implement future TB/HIV initiatives.
6. To provide an opportunity for international HIV community representatives to develop plans and strategies to mobilize communities, policymakers, and resources to better fight TB/HIV at the country and regional levels, and participate in global policy dialogue.

The 2nd workshop incorporated several changes made to address the needs identified by participants in the 1st workshop. Fifty participants took part. The workshop was two-and-a-half days long. There were more opportunities for small group interactions, and longer strategy sessions. As in 2002, participants at the 2nd workshop attended IUATLD conference sessions on TB and TB/HIV coinfection, met with TB program officials, and networked extensively at the Union meeting to develop stronger relationships with national and regional public health, TB and HIV/AIDS program

officers, the World Health Organization (WHO), the Stop TB Partnership, the Global Fund to Fight AIDS, TB and Malaria (GFATM), and others to more effectively represent affected communities.

b. Participants

The Second International TB/HIV Community Education & Mobilization Workshop was designed for TB and/or HIV community representatives with experience or interest in treatment advocacy, community mobilization, and treatment literacy programs, and who work with organizations or networks with an interest in expanding access to TB and HIV care in countries with a high burden of TB and HIV co-infection, or in those where HIV is spreading and TB is highly prevalent.

The application for the Workshop was distributed through a wide range of primarily internet-based international and regional networks on TB and/or HIV/AIDS advocacy, education, and community mobilization. The tremendous response to the call for applicants demonstrates the widespread interest in training and networking opportunities for those on the front lines of the dual epidemics.

Priority was given to applicants from regions with high rates of TB/HIV co-infection. Invitations were extended to activists from 33 nations. Efforts to overcome obstacles to travel visas failed to secure the participation of activists from Peru. Ultimately, 61 individuals from 31 countries participated in the workshop, including residents of 14 African countries, three South American countries, five Eastern European or newly independent states, five south and southeast Asian countries, and four of the United States and Western Europe. Workshop sessions offered French and Spanish translation, and participants collaborated on additional translation into Thai and Russian.

The Workshop was interwoven with the proceedings of the 34th International Union Against Tuberculosis & Lung Diseases (IUATLD) Conference on Lung Health. The IUATLD generously provided all participants with registration for the Union Conference.

In addition to the formal sessions, the workshop provided multiple opportunities for networking and information-sharing during daily breakfasts, report-back sessions, a luncheon where participants sat by region, and a lively closing dinner. An overwhelming majority of participants cited the opportunity to share information with their peers from other countries as a highlight of the workshop that would enhance their community efforts.

c. Program

On the evening of Tuesday 28 October, workshop participants met at an informal welcome reception. The following day, they participated in the "Progress and the Way Ahead" symposium of the Stop TB / DOTS Expansion Working Group.

The first full day of the Community Workshop was Thursday 30 October. Participants were welcomed by H el ene Rossert, Director General of AIDES and northern NGO representative on the board of the Global Fund Against AIDS, Tuberculosis and Malaria as well as Mark Harrington, TAG's Executive Director.

The morning featured an introduction to TB/HIV, with speakers from the World Health Organization (WHO) Stop TB Program, the Malawi National TB Control Program, and the Bill and Melinda Gates Foundation, as well as an overview of the role of community and resource mobilization in the international effort against TB/HIV co-infection from the perspective of staff from the Global Fund to Fight AIDS, TB and Malaria (GFATM), WHO Stop TB, and Treatment Action Group (TAG).

The afternoon was dedicated to reports from 12 workshop participants on local TB/HIV projects and community mobilization. Panelists from Brazil, Cambodia, India, Nepal, Niger, Nigeria, Russia, South Africa, Thailand, Ukraine and Zambia contributed to a dynamic discussion of a range of mobilization strategies. The stirring address of workshop participant Winstone Zulu at that evening's opening ceremony for the Union Conference further highlighted the importance of community-led efforts (see IUATLD website, www.iuatld.org).

On Friday 31 October, workshop participants attended Union Conference sessions on "Ensuring global access to TB drugs," "Globalization & its impact on lung health" and "Advances in the treatment of TB".

Although that evening's Workshop planning meeting (to determine the structure of the next day's small group strategy sessions) was optional, over 80% of workshop participants chose to assist, making for a crowded and productive meeting.

Participants returned to the Union Conference for late-breakers and other sessions on the morning of Saturday 1 November, and sat in regional groupings at our networking lunch. The afternoon featured six small group strategy sessions on key topics identified at the planning meeting:

- o Collaboration at the regional and country level
- o Collaboration between existing programs: patient centered TB and HIV services
- o Community mobilization, treatment literacy and treatment preparedness
- o Continuity of the community mobilization workshop: network resource mobilization
- o Strengthening global TB/HIV collaboration and resources
- o Vulnerable and at-risk populations

Fruitful dialogue and solidarity continued at the Workshop closing dinner. On Sunday 2 November, participants returned to the Union Conference, which included a session on "Integrating patient perspectives into TB policy & practice", at which TAG's Mark Harrington delivered a presentation on community mobilization based on the Workshop proceedings.

d. Outcomes

Over 80% of participants who completed the workshop evaluation said that they will change their work as a result of the Workshop. A similar 80% reported that they made useful contacts at the IUATLD conference among people from their country and region, donors, and scientists.

Everyone agreed that participants from the 2002 and 2003 TB/HIV workshops should strengthen and expand a network to facilitate communication, advocacy, and resource mobilization to strengthen community-based responses to TB/HIV. They agreed that the network would best be developed by

having a single organization coordinate follow-up communication, mobilize resources to retain a network coordinator, and work with participants to identify people and organizations to serve as regional focal points to facilitate communication and information dissemination. Many felt that it would be important to reconvene at the International AIDS Conference in Bangkok, Thailand, in July 2004 in order to continue planning and information sharing.

The workshop challenged participants to identify the role they could play to ensure that the financial resources, international strategies, and lessons learned from pilot projects and best practices be brought to the table to implement care and treatment for persons living with TB and HIV. Workshop participants made it clear that they are well-suited to take on this challenge, and they will seek additional resources to sustain an effective communication and advocacy network to further these vital efforts.

Opportunities

- HIV community groups are eager to promote integration of TB/HIV into HIV work.
- HIV community groups need more information on TB/HIV; TB programs need more information on HIV.
- HIV community groups need resources, information, technical support, networking capacity.

Needs

- Need to strengthen global TB/HIV collaboration & resources.
- Need to strengthen collaboration at regional and country levels.
- TB/HIV needs to be integrated into ongoing and new HIV community mobilization & treatment preparedness efforts.
- TB and HIV services need to be coordinated and integrated from the ground up in order to provide coordinated patient-centered services - "Two diseases, one patient".

Next Steps

- HIV community groups are eager to promote coordination of TB and HIV programs, and integration of TB/HIV issues into HIV work.
- HIV community groups identified the need to strengthen global and country-level TB/HIV collaboration & resources.
- HIV community groups need resources, information, technical support, networking capacity.
- TB/HIV issues need to be integrated into ongoing and new HIV community mobilization & treatment preparedness efforts.
- TB and HIV services need to be coordinated and integrated from the ground up in order to provide coordinated, patient-centered services – "Two diseases, one patient".
- HIV community groups need more information on TB/HIV.
- TB programs need more information on HIV.
- There is an urgent need to strengthen collaboration at regional and country levels.
- Workshop participants will form a TB/HIV network for global, regional, and country level community cooperation.
- The network will develop web-based resources for information exchange.
- Follow-up TB/HIV meetings will take place at global and regional AIDS and TB meetings and at the 2004 IUATLD conference.

II. Workshop Presentations & Discussions

TB & HIV: A Public Health Perspective – Rose Pray, RN, MS, Centers for Disease Control & Prevention (CDC), USA

Pray opened the morning panel with a thorough overview of the scope of the TB/HIV problem, opportunities and challenges in care and prevention, and some examples of the United States Global AIDS Program (GAP) activities on TB/HIV.

TB is the leading cause of death among adults due to a single infectious agent, with more than one-third of the global population infected and at risk of active disease. Two million of the eight million people who develop active TB each year will die from the disease. One-third – or 11 million – of the 42 million people worldwide living with HIV are co-infected with TB, with 71% of co-infected people living in sub-Saharan Africa.

HIV is the most powerful risk factor for the development of TB disease from infection. There is a 10% risk of developing active TB in a HIV-negative person's lifetime, but this risk rises 5-10% per year for those who are co-infected. TB is the cause of an estimated 11–14% of all adult AIDS-related deaths.

Pray identified funding bodies, Ministries of Health, and published strategies and guidelines as three types of opportunities to improve or extend TB/HIV care and prevention. The GAP TB/HIV program recommends DOTS (directly-observed treatment short course) as best practice. DOTS requires:

- o Government commitment
- o TB case detection by sputum smear microscopy
- o Directly observed short course treatment
- o Continuous and reliable drug supply, and
- o Efficient surveillance and monitoring system

Additional elements of the GAP TB/HIV strategy:

- o Screen HIV-infected persons for TB
- o Improve access of TB patients to HIV counseling and testing
- o Include HIV preventive therapy as part of the core package of care offered to people with HIV
- o Refer TB cases for treatment and follow-up
- o Implement community and home-based care for HIV-infected TB patients where possible
- o Promote collaboration between National TB and AIDS Control programs
- o Treat HIV-infected persons with ARV therapy

Isoniazid preventive therapy (IPT) is a core component of care offered to people with HIV, once active disease is ruled out, but adherence can be an issue.

TB can be more difficult to detect among the HIV infected than among uninfected persons. If detected and treated, simultaneous treatment of TB and HIV in one person can mean drug interactions, side effects, and paradoxical reactions, which is when effective HIV therapy in co-infected patients causes immune system recovery that brings with it an aggravation of TB signs and

symptoms such as high fever, worsening chest x-ray findings, or expansion of CNS or TB lesions. Alternatives include deferring antiretroviral therapy (ART) for two months or until TB treatment is completed, or treating TB with rifampin and treating HIV with non-interactive ART (e.g., AZT+ 3TC+ efavirenz, as recommended in the WHO Guidelines).

Operational challenges include access to HIV counseling and testing, staffing HIV services, and establishing good HIV surveillance systems. Increasing demands on health workers, laboratory capacity and the need to nurture collaboration between national TB control and national HIV/AIDS programs pose additional challenges.

Pray concluded with reports from two CDC GAP projects. The Kibera ART program seeks to deliver HIV treatment and care to 300-500 people with HIV in a slum area of Nairobi, Kenya, and includes TB screening, prophylaxis and treatment. To date, 83 persons of 163 screened have begun ARV treatment, and have continued without interruption or discontinuation. The Home-Based Care Project in rural Uganda will evaluate three monitoring strategies for 1000 people with HIV, including field-based monitoring and drug distribution, specimen collection, and supply delivery via motorcycle. Enrollment began in May 2003, and 153 of the 199 persons evaluated as eligible for ARVs were on treatment as of September 2003.

The WHO Interim Policy for Collaborative TB/HIV Activities – *Haileyesus Getahun, Stop TB, World Health Organization (WHO)*

Getahun presented the *Interim Policy on Collaborative TB/HIV Activities*, to be released in January 2004 by WHO on behalf of the Stop TB Partnership. The TB/HIV Working Group met for the first time in 2001, and developed this document in 2003 after broad-based consultation and review by both TB and HIV experts.

HIV fuels the TB epidemic and TB is a leading killer of people with HIV. In high HIV settings, DOTS alone is not sufficient to control TB. Thus, Getahun emphasized, joint TB/HIV interventions are needed to control HIV-associated TB, expand DOTS, and indeed, to control HIV. In this expanding emergency, scale up must happen immediately, subject to revision as the evidence base evolves.

WHO Recommendations for Collaborative TB/HIV activities

A. Establish the mechanism for collaboration

- A.1. Set up a coordinating body for TB/HIV activities effective at all levels
- A.2. Conduct surveillance of HIV prevalence among tuberculosis patients
- A.3. Carry out joint TB/HIV planning
- A.4. Conduct TB/HIV monitoring and evaluation

B. Decrease the burden of tuberculosis in people living with HIV/AIDS

- B.1. Establish intensified tuberculosis case finding
- B.2. Introduce isoniazid preventive therapy
- B.3. Ensure tuberculosis infection control in health care and congregate settings

C. Decrease the burden of HIV in tuberculosis patients

- C.1. Provide HIV testing and counseling
- C.2. Introduce HIV preventive methods
- C.3. Introduce co-trimoxazole preventive therapy
- C.4. Ensure HIV/AIDS care and support
- C.5. Introduce antiretroviral therapy

– *Interim Policy on Collaborative TB/HIV Activities*, WHO/HTM/TB/2004.330
http://whqlibdoc.who.int/hq/2004/WHO_HTM_TB_2004.330.pdf

The Working Group recognizes that different countries are in different positions regarding co-infection and existing levels of cooperation and resources.

Category	Recommendation
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- | | |
|-----|---|
| I | Countries with national adult HIV prevalence rate of at least 1% or
Countries where national HIV prevalence among TB patients is 5% <ul style="list-style-type: none">○ Implement all activities in A, B and C |
| II | Countries with national adult HIV prevalence rate below 1% and
Administrative areas that have adult HIV prevalence rate at least 1% <ul style="list-style-type: none">○ Implement activities as in category III countries, except in administrative areas with at least 1% adult HIV prevalence, where all activities should be implemented. |
| III | Countries with national adult HIV prevalence rate below 1% and
No administrative areas with adult HIV prevalence rate over 1% <ul style="list-style-type: none">○ Implement at a minimum:<ul style="list-style-type: none">A.2. Surveillance of HIV in TB patientsB.1. Intensified TB case finding among PLWHAB.2. Isoniazid preventive therapyB.3. TB infection control |

In conclusion, Getahun emphasized that the crisis of “Two Diseases, One Patient” means that:

- Countries need to develop specific TB/HIV policies and implementation plans,
- Collaborative TB/HIV mechanisms need to be accelerated, and
- HIV and TB advocacy groups need to mainstream TB/HIV in their advocacy activities.

Integrating TB and HIV Services: Experience from Malawi – *Rhehab Chimzizi, TB/HIV Program Officer, Malawi National TB Control Program*

Chimzizi presented a comprehensive analysis of significant success in the integration of TB and HIV services, and his slide presentation should be consulted for significant detail in addition to this summary (INSERT WEBLINK HERE). Malawi, where 65% of the population is impoverished, has been profoundly affected by the HIV epidemic. Among adults, 15% were HIV infected, and among

antenatal mothers, 24% were HIV infected in 1999. Life expectancy has dropped from 46 years in 1996 to 39 in 2000. HIV has fueled an equally severe TB epidemic.

Impact of the HIV Epidemic on TB in Malawi

- o TB notifications have risen five-fold between 1985-2001 (from 5,000 to 27,000 TB cases);
- o In 2000, the HIV seroprevalence rate in TB patients was 77%;
- o HIV infection has led to:
 - Increased number of patients with difficult to diagnose smear negative TB
 - Increased TB case fatality rates
 - Increased rate of recurrent TB disease

However, there is a strong level of political commitment from the Malawi government to fight the HIV/AIDS and TB epidemics. They launched their National Strategic Framework for HIV/AIDS in 1999, have successfully applied for funds from GFATM, and restructured their National AIDS Control Program to initiate a truly multi-sectoral response. They have developed a five-year TB Control Plan, linked to a three-year joint TB/HIV plan, and have nationwide DOTS coverage.

Chimzizi presented the findings of the ProTEST initiative in Malawi (1999-2002) as an example of effective TB/HIV collaboration. ProTEST is a WHO coordinated initiative meaning PROMotion of HIV TESTING as an entry-point into HIV/TB prevention, care and support. Seeking to reduce the burden of the TB/HIV epidemic in Malawi, the initiative established collaboration between TB and HIV service providers and built capacity within current initiatives addressing TB/HIV management in Lilongwe.

ProTEST sought to go beyond AIDS awareness, as over 90% of Malawians in 1990 had accurate knowledge HIV transmission and prevention, but this had had no impact HIV infection rate, partly because knowing one's serostatus had few perceived benefits. AIDS was a stigmatized and feared illness, little medical support was offered to people with HIV, and, at that time, ARVs were too expensive to be considered in this resource limited setting.

Key challenges in the ProTEST initiatives included the donor dependence of Malawi, human resource issues, and the changing health sector environment. Nonetheless, the three-year initiative was successful.

Malawi ProTEST Program TB/HIV Successes

- o Increased collaboration between the TB and HIV/AIDS programs
- o Almost all ProTEST partners registered increases in capacity
- o Capacity to provide clinical care to TB and HIV/AIDS patients in the community
- o Rapid HIV testing increased the number of people accessing voluntary testing and counseling (VCT) services
- o In the pilot district, more than 40,000 clients/patients accessed VCT services during the period of the initiatives)
- o Evaluation of quality of VCT services regularly performed
- o Volunteers able to identify TB suspects in the community and supervise TB patients taking their anti-TB drugs

- o New services introduced and promoted for VCT clients, TB patients and PLWHA:
 - Cotrimoxazole prophylaxis (CPT) for HIV positive TB patients
 - Isoniazid prophylaxis (IPT) for HIV positive clients without active TB
 - TB screening for VCT clients
 - Sputum collection from the stand-alone VCT centre
 - Condom promotion and distribution

Lessons from the ProTEST initiative influenced the three-year (2003-2005) joint TB/HIV services plan, which links TB and HIV efforts in the areas of policy, technical activities, management, and monitoring and evaluation.

The plan was funded by WHO, USAID NORAD, DfID, and KNCV. It seeks to expand the key successes and services of ProTEST, including the expansion of VCT services for TB patients and the general public, the provision of TB prophylaxis and/or treatment to people living with HIV, and nutritional support for TB patients regardless of HIV status. Significantly, it also seeks to provide ARV therapy to HIV positive TB patients.

Implementation began in January 2003, with a countrywide situation analysis as the first activity. The analysis found a clear need for scaling up HIV-TB services, both in quantity and quality, particularly in the areas of counseling and HIV testing. Additional activities being initiated include:

- o A package of VCT and CPT that began on 1 July 2003 and has now reached 15 hospitals in 11 districts;
- o Nutritional support in TB patients, supported by an NGO collaboration, that began in October 2003 in four districts;
- o Intensified TB case finding in one district supported by funds from TB Alert;
- o ARV therapy that is currently offered to eligible TB patients at one district hospital;
- o IPT delivered through programs for prevention of mother-to-child transmission of HIV (PMTCT).

Perspectives on TB/HIV from the Gates Foundation – *Renée Ridzon, MD, The Bill & Melinda Gates Foundation*

Ridzon gave an overview of the Gates Foundation's approach to public health philanthropy and outlined possible mechanisms of assistance in community mobilization on TB/HIV issues. The Foundation strongly supports linking TB and HIV efforts, and are funding a range of programs.

Global Fund Perspective on TB, HIV, and Community Mobilization – *Khaya Matsha, Communications Officer, Global Fund Fighting AIDS, TB and Malaria (GFATM)*

Matsha discussed the role of the Global Fund in financing, dispersing and managing new funds for AIDS, TB and malaria control, including community mobilization efforts. The Fund strives to work from national plans and priorities, while recognizing a country-driven, multi-sectoral approach. She feels it is important to evaluate and understand how the GFATM operates as a power structure, and sees the power of the Fund to be principally located in its Board.

The GFATM seeks to be responsive to Country Coordinating Mechanisms (CCMs), which are

required to include representatives of civil society and affected communities. However, it is important to recognize that, in practice, "the community" has often meant solely people living with HIV (PLWHA), as there have not been parallel movements of people living with TB or with malaria.

How TB Programs can Contribute to 3x5 – Dr. Fabio Scano, Stop TB, World Health Organization (WHO)

Scano presented a comprehensive strategy demonstrating how TB control programs could contribute significantly to the WHO goal of treating 3 million HIV-infected people by 2005. Program collaboration is needed to meet this target. Scano asserted that the TB-related infrastructure is well positioned to assist in developing and implementing innovative approaches, if granted additional financial and human resources.

The model is based on sub-Saharan Africa, but could apply to any setting where TB control programs could help identify HIV infected persons and provide them with or refer them to care. It would require program collaboration that could strengthen the entire health system.

TB Programs as ART Entry Points for up to 536,000 people in Sub-Saharan Africa per year

Objectives

- o HIV testing for all TB patients will be used as an opportunity to provide about 536,000 HIV positive TB patients eligible for antiretroviral therapy (ART).
- o The two programs will collaborate in providing access to ART.

Opportunities

- o Program collaboration would strengthen the entire health system and not just individualized disease programs.
- o ARV drugs can provide significantly better care for HIV positive TB patients.
- o TB programs can provide enormous support for ARV delivery.

Approaches

- o Immediate access to routine HIV testing (opt-out option) for all TB patients.
- o Identification of different models (country specific) for TB program.
- o HIV infected TB patients could receive anti TB-drugs and ARV drugs at the TB centre or at the HIV clinic.

The model includes proposed responses to potential problems, such as issues of ARV delivery through TB-related programs, ARV management and drug security, and widespread lack of knowledge of HIV status. Components such as routine and immediate HIV testing for all TB patients, and fixed-dose ARV combinations that do not interact with rifampicin, are among the suggested resolutions to anticipated problems.

Kenya and Malawi have already developed concept papers about how TB programs can contribute to meeting the 3 x 5 goal. National TB and AIDS program managers will meet in November 2003,

followed by wider consultation in 2004. Scano reminded participants that 2005 is coming up rapidly.

How can AIDS activism contribute to TB control? – *Mark Harrington, Executive Director, Treatment Action Group (TAG)*

AIDS activist movements have developed skills and strategies that can be adapted for use in campaigns against TB and TB/HIV. One of the first key strategies is to increase national spending on research, prevention, treatment and care. Increased funding for the National Institutes of Health (NIH) has been one of TAG's key goals.

The budget for TB research is quite small compared with the disease burden. While the NIH spends \$2.7 billion each year on HIV/AIDS research, it spends just over \$200 million on TB research. More research is needed on shorter TB regimens, better drugs, point-of-use diagnostics, ART and TB drug-drug interactions. Drugs – such as cotrimoxazole and isoniazid – to prevent and treat opportunistic infections are also critical components of TB/HIV care.

There have been different phases of TB advocacy over the past 100 years, from the sanitarium movements to DOTS. There is now a push to link to the strengths of the international AIDS treatment access movement to TB advocacy, but the core strategy of PWAs involvement at all levels is difficult to replicate with TB, which unlike HIV is not a life-long condition.

In the USA, the price of AZT (zidovudine, ZDV; at approval in March 1987 AZT cost \$10,000/year) creating outrage which contributed to the foundation of ACT UP. Drug pricing remains an issue, although continued pressure has brought down the price for generic ART. In less developed countries, ART will need to be free in most settings. Wealthy countries will need to provide the resources to do this. Even if the ART program ultimately cost \$500 per person year for three million people, that is only \$1.5 billion, which is the weekly cost of the US occupation of Iraq.

"Insider" and "outsider" strategies can be useful and complementary: activists identify problems and meet with government policy makers at the same time as they generate pressure via media and social mobilization.

Discussion

Discussion after the morning presentations included:

- Requests for clarification on the implementation of the WHO interim document;
- Challenges to CDC and others to move from pilot programs and research to massive scale-up to meet the need;
- Dialogue on the use of cotrimoxazole prophylaxis therapy [CPT] to prevent opportunistic infections among HIV-infected TB patients
 - One participant asked why the WHO had not been more pro-active in disseminating guidelines on the use of CPT among HIV infected TB patients.
 - While CPT is cheap, easy to administer, and effective in reducing mortality, the WHO has faced opposition from certain countries and professionals who fear that the widespread use of CPT among HIV infected persons might lead to increased sulfa-drug resistance in the

- treatment of malaria and childhood diseases.
- Requests for improved communication between large funders and grassroots community mobilization and care initiatives.
- Discussion on how to guarantee meaningful involvement of community representatives in the CCM [Country Coordinating Mechanism] process.
 - Activists from Thailand and Nigeria expressed frustration on marginalization from decision-making in the GFATM. Thai activists submitted a successful non-CCM application to address the needs of drug users, but not without substantial challenges, and they believe that the GFATM should add a criteria allowing non-CCM applications from vulnerable communities such as drug users and migrant populations.
 - GFATM staff are using their experiences in developing countries to further strategies to ensure that people better understand the GFATM and how it works. They are trying to develop newsletters to distribute to members on the ground.

HIV/AIDS Projects and Community Mobilization

Winstone Zulu – Zambia

Zulu has been an AIDS activist since he tested positive in 1990, but never looked at TB as something to focus on until last year, when he was invited to the first TB/HIV Community Mobilization Workshop in Montreal. Then, he realized that all of his brothers had died of TB, and made a commitment that he would do something about co-infection upon his return. In 1997, he had TB and was cured because he was able to access treatment. Even when you don't have ARVs, you can at least treat TB.

Upon returning to Zambia after the first Workshop, Zulu organized an awareness concert, featuring a band that had eight members. Now there are only five, due to TB deaths that were most likely AIDS-related. After the concert, it was very easy to set up a program for TB testing in a small town. When they said they wanted to do prophylaxis as well as active case finding, they were promised more resources, but none have arrived.

The community around HIV didn't just mobilize by merely bringing people to a conference like this; there were resources involved. In reality, it's not clear if we are talking about 3 x 5 or 3 x 15 [3 million people on ARVs by 2015...], but until then, we have TB treatment. But we need to tell WHO and UNAIDS that to mobilize the community we need resources for the fight.

Mapule Khanye – The AIDS Consortium, South Africa

The AIDS Consortium comprises 800 members, primarily community-based organizations (CBOs), working together to promote human rights, non-discrimination, and rights of people living with HIV/AIDS. The Consortium processes information, works towards an equitable response to the epidemic, and coordinates activities, campaigns, and policy engagement on access on treatment, care and support. They hold monthly meetings with their members to provide a forum for debates, updates and announcements; members also get free internet access and an information database.

CBOs come to the meetings and share the issues are in the township. Then they take coordinated

action. For example, a doctor came with news that the HIV clinic was about to collapse. The Consortium sponsored a march against the hospital and the clinic expanded from one to five days a week. They are now forming a coalition targeting the financial sector to fight discrimination against people with HIV. During the World Summit on Sustainable Development, banks agreed - at least in writing - that HIV infected people should get insurance regardless of their HIV status. This August, they marched against funeral insurance companies and were successful - exclusion clauses for HIV infected people have now been removed.

They also have a capacity-building arm to help organizations develop sustainable skills and resources. They have pilot programs that train people to deliver home based care and to form sewing cooperatives. They strive to protect and nurture community efforts and foster the development of cooperatives as forms of empowerment for their people. They now seek to consolidate members' involvement with the CCM and lobby for greater NGO access to the GFATM.

Ms. Khanye shared methods for ensuring that the campaigns of the Consortium are the priorities of the community people and represent a collective voice, and gave more detail on their income-generating projects.

Dr. Rabiou Sanata Diallo – *Mieux Vivre avec le SIDA, Niger*

Mieux Vivre avec le Sida is the first NGO in Niger to offer psychosocial support for people with HIV "to better live with AIDS", and they have the only program of anonymous, voluntary HIV testing. Working with people with HIV made them realize that TB/HIV co-infection is a big issue, especially for people on ARV treatment. Niger is one of the poorest countries in the world. Ninety-five percent of the population is Muslim. Less than 50% of the population has access to health care; there is one health worker for every 22,013 people, and infant, youth, and maternal mortality rates are high (high?).

In 1999, it was estimated that 22.5% of TB patients were HIV infected, but more and better data are needed. The overall gender ratio of PLWHA is thought to be 1/1.85 male/female, but among those 15-19 years old, there are four HIV infected young women for every young man.

Community-based, local NGOs were the first to provide care and prevention for opportunistic infections, even assisting people with HIV from neighboring countries. They are represented on national committees and initiatives created by the government. The first Strategic Framework to Fight HIV was set up in 2002, and there are detailed plans for multi-sector efforts and a National Antiretroviral Treatment Access Initiative. The government is now following the innovations of the NGOs, but at a slower pace.

Now, there is mobilization against AIDS but very little against TB or against TB/HIV co-infection. There are two completely separate national programs, and people cannot access treatment for AIDS and TB at the same time. This conference provides the opportunity to learn from countries where programs are better integrated.

Dr. Sanata Diallo explained that regional TB centers offered HIV testing to TB patients, who would

be referred to her NGO for care. But now that access to HIV treatment has arrived, they need information and help on treating both diseases at once.

Zhanna Parkhomenko – *Médecins sans Frontières (MSF), Ukraine*

The population of Ukraine has decreased from 47.7 million in 1991 to 40.7 million today because of economic crisis and disease. In 1999, MSF came to the southern region of the country, which is the most affected by HIV and has the fastest growing HIV prevalence in Europe. There are 58,544 officially registered HIV infected adults, although UNAIDS estimates that 400,000, or 1% of the adult population, is infected. Among PLWHA, 65.7% are injection drug users. Fifty percent of AIDS deaths in the Ukraine are attributed to TB [check].

Although the Constitution states that health care must be free, it is estimated that 10-15% of people do not have access to any health care, and people often must pay unofficial fees. The health care system is dramatically centralized, but there is increasing political will in the national government to develop an AIDS program.

The integrated approach is very important. MSF's project had developed a model of medical care that extended mother-to-child-transmission prevention (PMTCT) to include OI prophylaxis and treatment, ARVs, and palliative care. 750 mother-child pairs have been treated, and MSF was able to get the government to commit to continuing health care for the kids. The general transmission rate in the project was reduced from approximately 30% to less than 12%. 450 people are now receiving OI prophylaxis; 18 children are currently on ARVs and 130 will begin soon.

In addition, they have increased laboratory capacity, and administered 1,200 CD4 tests in 2003. They use PCR monitoring for children. They have five peer counselors, and about 60% of their cohort has visited them multiple times for counseling. They have trained doctors, midwives, NGOs and people with HIV; published and distributed general and specific information on TB and HIV, and participated in access to essential drugs and destigmatization campaigns.

Chalermchai Peuan-Buapan – *Thai Network of People Living with HIV/AIDS, Thailand*

Thailand is the home of 700,000 people living with HIV or AIDS. The Thai Government has a famous project of 100% condom use among commercial sex workers, but this definitely does not reflect the practices of the general population. Despite the outside perception of Thailand as an HIV success story, major problems remain, including stigma and discrimination, lack of information, and high drug prices.

The Thai Network of People Living with AIDS includes over 500 groups linked via six regions in a national network. They lobby for equal access within the general health care system, for lower drug prices, and for ARV coverage as part of universal health care.

Changes have started to happen, due to funds from the GFATM. Thailand will scale up to about 50,000 people on ARVs over the next year, 2004. However, TB, although a major issue, has not been a point of discussion. , Peuan-Buapan believes that it will gain more attention when there are

more people being monitored on ARVs.

Manoj Pardeshi – *Indian Network of People Living with HIV/AIDS, India*

Pardeshi chose to present without the use of statistics, explaining that HIV is a statistic for other people, but for himself and his peers, it is reality. Participation in last year's TB/HIV Community Mobilization Workshop gave him the initiative to push for a TB initiative within the HIV initiative sponsored by Indian organizations and CDC on the empowerment of people with HIV. Before that time, stigma and access to ARVs were seen as bigger issues that needed to be addressed first. Now they are screening everyone in the project for HIV. However, out of 50 people working for the project, it is unclear how many themselves are actually living with HIV.

In one case of a successful intervention, a man was so sick that the doctor said there was no hope. Pardeshi took him to the hospital where he had a good personal / professional relationship, and the ill man is now healthy and working, having been cured of his TB. This is an example of a successful public/private partnership.

Participants shared the challenges of providing adequate support, training and staffing for AIDS related NGOs and activist organizations, in order to deal with burnout and illness.

Kasem Kolnary – *Cambodian HIV/AIDS Education and Care (CHEC), Cambodia*

Kolnary shared the experiences of CHEC in village-based HIV/AIDS training. Their basic training focuses on the transmission and prevention of HIV, as well as strategies for community mobilization. Emphasizing that "new diseases demand new responses," they discuss strategies for HIV prevention activities in both literate and non-literate communities. They have trained over 1000 people, and have more than 300 community volunteers who provide counseling, care and support to patients at home. They offer advanced training in:

- o Strategies and planning process of the national AIDS authority
- o The role of a community educator in communities with limited resources
- o Community mapping
- o How to understand, facilitate and sustain behavior change, and
- o Developing capacities to deal with HIV/AIDS

Trainers are doctors, medical assistants or nurses who are experienced in HIV/AIDS training and have worked with an NGO on HIV/AIDS for at least five years. Participants include health center staff, members of health center management committees, traditional birth attendants, villagers, and village health volunteers, Buddhists and Muslims. Health centers report that more people come for condoms after attending trainings, and their workers are more confident about discussing HIV and STIs with their patients.

Lessons they have learned include:

- o Participants need ongoing support if activities are to be sustainable.
- o There must be provisions of the means to act on the training, such as access to low cost condoms.

- o There is a need for more information, education and teaching materials for use at village level.
- o There is a need to mobilize and assist the community in developing home care teams.
- o Locally-developed programs are likely to be the most effective and sustainable.

Thembeke Majali – *Treatment Action Campaign (TAC), South Africa*

South Africa has a large population of more than 43 million people. 5.2 million people are HIV positive, and 50% of TB cases are in people with HIV.

TAC is a movement aiming to end HIV, engaging in HIV prevention, treatment literacy and social mobilization. They are lobbying the government and campaigning to make OI and ARV treatment available in public health centers, especially at the primary health care level. They are pressuring drug companies for access to patented drugs, demanding that they allow generic manufacturing or give compulsory licenses so they can be affordable.

Their campaign also includes demands for MTCT prevention as well as post-exposure prophylaxis for rape survivors. They set up the campaign with assistance from faith-based organizations, labor centers, and many other organizations. They had much support from local and national communities when they embarked on their campaign of civil disobedience for public access to ARVs. Majali stressed the importance of supporting the health care workers' movement and campaigns, as they seek to improve their salaries, and added that TAC's prevention and treatment plan is nurse-driven. On August 8, the government issued a statement that ARVs can be used in the public sector.

Alexey V. Bobrik, MD, PhD, MPH – *Open Health Institute (OHI), Russia*

OHI, the successor to the Public Health Program of OSI/Soros Foundation-Russia, is a charitable grant-giving and operational non-profit specializing in promoting ideas and activities to improve public health, with a staff of 15 and a budget of \$3.5 million. Their major areas of activity include:

- o Strengthening the public health education system
- o Improving the quality of medical care and professional training of health workers
- o Conducting and supporting research
- o Improving the health of at-risk populations

In 1998, they initiated a program of HIV prevention among IDUs. There are currently 50 harm reduction projects conducting informational activities, needle exchanges, and the distribution of condoms and disinfectants. They also offer basic medical care, HIV and STD STI testing, and referrals for medical and social services. Twenty-five projects provide services for commercial sex workers, six address HIV prevention in prisons, and one project focuses on HIV prevention among street children.

Bobrik believes that this spectrum of activities could be a good base for addressing TB issues, such as providing access to TB services for IDUs for harm reduction projects, and using their outreach workers at some stages of TB treatment for direct observation of medication intake and counseling to improve treatment adherence. In addition, he feels that TB treatment for IDUs would prepare both the health service and the clients for the provision of ARV treatment to HIV-infected IDUs. Their first small-scale projects in these areas will start in January 2004

Ezio Távara dos Santos Filho – *Grupo Pela VIDDA-RJ, Brazil*

Santos Filho came to the TB/HIV Community Mobilization Workshop last year, and went back to expand TB/HIV efforts. Brazil has a well-structured HIV/AIDS community but in the past, in the past, organizations had considered TB not relevant – they felt it was a serious problem but they did not have a framework for approaching the situation and were overwhelmed with the AIDS epidemic itself. In September 2002, they distributed a questionnaire throughout the HIV/AIDS community about willingness to engage in TB efforts. Out of 700 questionnaires, 120 responded positively to have training in TB and to mobilizing to do something.

There was an initiative in the state of Rio for local organizations on TB. Rio appears to have the worst TB system in the country because it has the best surveillance. Santos Filho himself developed TB in December 2002, after living with HIV for almost twenty years. His TB took over a month to diagnose, and subsequently combining his TB and ARV treatments was difficult.

They held a needs assessment with the Rio organizations. At their first workshop, 60 people from NGOs agreed to work on the following areas, in order of priority:

1. Monitoring state policies and budget use in TB
2. Empowering and understanding more about co-infection and how to help
3. Implementing DOTS - it was officially adopted in 1999, but was never implemented as a policy for the national program.

Their second workshop, in August, drew 80 people from 56 organizations to craft plans for community mobilization. They created a permanent forum on policies on TB. They are meeting monthly, with a secretariat that meets every week. They monitor TB policies in the state of Rio.

Discussion

The discussion centered around the question, “What level of resources is required to build and sustain community work?”

Mr. Santos-Filho, Brazil: An American NGO received money from USAID to assist them, but their efforts were very low cost - they held meetings, and provided transportation to the meeting and a per diem. Regarding governmental structure, there are two main groups of researchers and specialists. The one in control does not respect DOTS as a program, so it is tough to have money transferred to the program. One of the best resources is the ability to sit together from different countries and discuss what we have in common, how to work together. For example, he has some information that may be useful in comparing the Brazilian and South African situations.

Ms. Majali, South Africa: Their aim is to improve the health care system of the government, so they do not take funds from the South African government or drug companies; instead, they want these sectors to provide services to needy people. TAC's work seeks to influence policies in order to move toward implementation. For this, they need the support of many communities, and need to improve the working conditions of health care workers. Their communities need treatment literacy, which is not just TAC's responsibility but all NGOs as well as the private sector.

Ms. Khanye, South Africa: They have embarked on a process with the community to find resources. Their next step was to collaborate on approaching a private sector bank that acts as a foundation for initiatives like HIV post-exposure prophylaxis. When their cabinet made the statement that ARVs would be available for two programs, they tried to get information about the programs.

Dr. Bobrik, Russian Federation: Right now, most of their resources come from foreign donors. Their application to the Global Fund - which was submitted independently from the CCM and was approved for \$90 million for nine regions of their very large country - includes everything that is needed without exaggeration, including a comprehensive package of treatment and palliative care and support.

Ms. Kolnary, Cambodia: They have achieved remarkable success in the reduction of HIV/AIDS through partnership with the government and foreign organizations. There are many home care, hospital, and other programs, but getting out to the rural areas is a big problem. Only a few programs are operational because of the need for additional support. They have a good mechanism in the country to monitor their Global Fund award, of which \$12 million (out of \$60M) has been received.

Dr. Gani Alabi – *AFRO/WHO, Nigeria*

Alabi relayed that the AIDS office in Nigeria, which began in 1999, met with the TB control office two months ago, and agreed to start collaborations in six cities. There are many HIV NGOs, and a few for TB, but collaboration is a weak point. One of the challenges of bringing the two types of organizations into a network is that the small groups can get swallowed by the larger ones.

Additional challenges include extending the government's political commitment into financial commitment, securing funding from other sources, and dealing with the necessary commodities. But Alabi believes that, by far, the hardest challenge is getting TB and HIV workers together, when one is afraid that he may lose his job to the other. As long as the people who are doing the implementation feel threatened, the process will not work. He believes that WHO should emphasize the need to come together and work together.

Dr. Piryani Rano Mal – *SAARC Tuberculosis Centre, Nepal*

The SAARC region includes the countries of Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka. They have 22% of the global population yet 29% of global TB burden. India, Bangladesh & Pakistan are among the high TB burden countries.

There is a variety in the amount of DOTS coverage in the region; the regional average is 49% but India and Pakistan have very low coverage.

There are about four million people living with HIV in India. Other countries have lower prevalence, but that does not mean they are at low risk. All recognized high-risk groups and risk factors are present in their region, and Rano Mal believes that now is the time to make the choice to intervene, when the epidemic can (hopefully) still be contained.

There has been a positive response of the member countries to the threat of HIV/AIDS, but there are still gaps to fill.

The SAARC declaration came out of the 11th SAARC Summit in Kathmandu in January, 2002 recognized the debilitating and widespread impact of HIV/AIDS, TB and other communicable disease on the region, and emphasized that the SAARC TB Centre should play a coordinating role. They held a meeting in Nepal in October 2003 to develop a regional strategy.

Components of the SAARC Regional TB/HIV Co-infection Strategy include the strengthening of epidemiological surveillance network of the Member Countries, operational research on TB-HIV/AIDS co-infection at pilot project sites, information dissemination, and continuing to expand collaboration between TB and HIV/AIDS programs.

There has been good progress in TB control in the region, and HIV/AIDS prevention activities are gaining momentum. TB/HIV co-infection is an emerging issue, and they must sustain and accelerate the present achievements and efforts in prevention and control of TB and HIV/AIDS, in order to reduce further morbidity and mortality in the Region.

Dr. Antoinette Chileshe-Phiri – *Copperbelt Health Education Project (CHEP), Zambia*

The Copperbelt Health Education Project (CHEP) is an NGO in ten districts in Zambia's copper mining region for the last 14 years.

They have gone through four stages as a health education program working with CBOs in developing information and education, and in providing technical support and communication to respond more effectively to HIV/AIDS.

- First they held public rallies, and spread fear of HIV.
- Then they decided to spread knowledge, not fear. They trained trainers to disseminate correct information and use participant learning techniques and peer learning.
- Next, they added an emphasis on behavior change, prioritizing programs that focused on life-skills and stepping stones to encourage behavior change and behavior formation. They also initiated CBOs themselves, and saw a scaling-up of community responses.
- Finally, they have been working to accelerate the community response to HIV/AIDS through networking, including interaction with a private mining company. They want to further strengthen the community's own response through AIDS programs that are consistent and relevant.

They came to this Workshop because, having been an AIDS activist organization, they agree that TB activism must be taken on as well for AIDS efforts to be successful. They are sponsored by LHL Norway, and hosted a national conference two years ago looking at the dual epidemic. From 1964 - 1884, the TB prevalence rate was about 7000 new cases a year, but by the mid 1990s, it was up to about 40,000. They are here seeking technical support to respond more effectively.

Discussion

Stating that evaluation is the most powerful tool to get more funds, get more people interested, and get more people involved in the process, a participant asked what panelists are building into the system to evaluate the impact they are having. Dr. Chileshe- Phiri explained that they are evaluating change in health-seeking attitudes towards ARVs, and in success in advocacy for access to ARVs through the GFATM. Dr. Alabi added that one of the major reasons they had to tag TB control onto HIV was from a pattern in notification reports that there was a sudden increase in extrapulmonary and smear negative TB in some places; thus, evaluation of treatment indicators and outcome can be helpful for both planning and funding.

Noting that TB control and HIV control seem to work completely apart in the national Ministry of Health, a Nigerian participant added that he is not aware of any WHO partnerships with civil society but wishes to assist with dialogue upon his return. He asked for more information about the selection criteria for the 6 locations of the pilot project, and stressed the importance of VCT as an entry point. Dr. Alabi said that the sites represented areas with high HIV prevalence and political considerations, and stressed that WHO can provide assistance, advice and help get resources, but can not take over the work of the government. He believes that it's only when one hand washes the other that both hands get clean.

A participant from the Democratic Republic of the Congo noted that, on the ground, the people in distinct TB and HIV programs really want to work together. When they have training sessions on HIV, they invite people specializing in TB programs, so they can give us some advice. She suggested moving ahead with informal meetings rather than waiting for the government to bring people together.

With a population of 35 million and nearly 3 million people living with HIV/AIDS, Tanzania is facing an unabated spread of the pandemic... Since the media is a powerful source of information for people, it can also be a powerful tool in the fight against HIV/AIDS. We embarked on a Capacity Building program for journalists because they have a particularly important role to play in providing the public with accurate information and monitoring/pressuring those in high positions - both in government and business circles - to commit to and deal adequately with HIV/AIDS.

My attendance [at the TB/HIV Workshop and the 34th IUATLD conference] marked an important turning point in our future programs by linking/integrating a TB component into these HIV/AIDS Capacity Building trainings/workshops. Journalists (after the trainings/workshops) will generate through writing (newspapers/letters) and speaking (radio/tv programs) a public discussion of the policies of TB/HIV co-infection, which will further encourage public awareness and lead to action by political, financial and other leaders and experts.

However, to accomplish all this, we need resources and funds – remember, we're working in resource poor settings. It's my hope that we will receive useful information on resource mobilization and potential funders.

- **Deogratius B. Kiduduye, Association of Journalists Against AIDS in Tanzania (AJAAT), Tanzania**

III. Strategy Sessions: Summary & Recommendations

A. Strengthening Global TB/HIV Collaboration and Resources – Facilitator: Zhanna Parkhomenko, MSF Ukraine; Rapporteur: Mark Harrington, TAG, USA

Agencies that assist in global TB/HIV collaboration & resources include:

- o Policy and technical agencies such as UNAIDS and the WHO;
- o Funding agencies and countries such as the Global Fund, the United States, the European Union and other members of the G8, and foundations such as the Bill and Melinda Gates Foundation and the Open Society Institute (OSI)

These entities have produced a framework and useful materials for policies related to TB/HIV co-infection, such as the revised WHO guidelines on antiretroviral therapy in resource-poor settings, the Interim WHO TB/HIV policy document, and the CDC TB/HIV operational research plan.

To maximize use of these resources and to enhance collaboration, community-based groups need additional guidance and support including resource guidance information such as:

- o A accurate listing of entities currently providing guidance, technical assistance, funding & other resources, with information on any processes for accessing this support;
- o Project management information, including:
 - Planning
 - Budgeting
 - Fundraising
 - Implementation
 - Monitoring & evaluation
 - Reporting
- o Models of efficient health care systems

- o Models of effective community mobilization & networking

The group recommended taking steps to organize follow-up by creating a framework for:

- o Identifying community information & resource needs
- o Improving information flow;
- o Organizing stronger feedback from the grassroots level to policy, technical, and funding agencies; and
- o Strengthening global support for stronger infection control, public health & primary care.

B. Collaboration at Regional and Country Levels – *Facilitators: Ezio T Santos Filho, Grupo Pela VIDDA-RJ, Brazil; Piryani Rano Mal, SAARC Tuberculosis Centre, Nepal; Rapporteur: Farai Mugweni, SANASO, Zimbabwe*

The group identified four distinct but often interrelated levels of potential collaboration on TB/HIV efforts – regional, national/federal, province/state, and district/community levels.

In order to bridge these spheres, they recommended the use of strategic planning meetings involving stakeholders such as government, national TB and HIV programs, media, the private sector, NGOs, religious leaders and traditional healers. Although meetings can establish a framework for implementation and policy issues, it is likely that NGOs will need to remain as "watchdogs", and be prepared to pressure governments at all levels through lobbying, demonstrations, media and/or the mobilization of public opinion in order to effect lasting, sound policies.

C. Community Mobilization, Treatment Literacy and Treatment Preparedness – *Facilitator: John Wasonga, Kenya Coalition on Access to Essential Medicines; Rapporteur: Nomfundo Dubula, TAC, South Africa*

The group shared experiences and challenges in finding effective ways to:

- o Empower communities with correct knowledge and skills around TB/HIV;
- o Fight against discrimination; and
- o Mainstream TB/HIV messages to prevent new infections

Target groups for their work include a priority on the members of existing support groups for people living with HIV but also include community and political leaders, the general public and families of people living with HIV, and members of vulnerable or hard-to-reach groups such as commercial sex workers, drug users, and gay people.

The environment for these efforts includes the existence of TB and/or HIV programs and some level of financial and human resources in most countries. In all countries represented in this session, there is some degree of community mobilization around issues of health care for TB/HIV prevention and treatment. In addition, political will is increasing in a number of countries, but more leaders need to be brought on board. Ongoing challenges to effective mobilization include:

- o Disparities and gaps between TB and HIV programs;
- o Myths and misconceptions about TB/HIV issues;

- o Continuing stigma and discrimination against TB and/or HIV patients;
- o Widespread "brain drain," particularly in African countries; and
- o The influence of the macroeconomic environment, such as direct or indirect policies limiting government allocations to the health sector

The way forward must include further integration of TB/HIV programs, an emphasis on treatment literacy at all levels, and capacity building of health care workers and community organizations.

Participants also developed country-specific action plans for Nigeria, Zambia, Malawi, Romania, India, Namibia, Thailand, Mozambique, Kenya, Cambodia, South Africa and Zimbabwe. Priorities included:

- o Sensitization of community leaders;
- o Training of support people as treatment assistants;
- o Fundraising towards the cost of document translation into local languages; and
- o Building the capacity of rural health workers in TB/HIV treatment and education.

D. Collaboration between Existing Programs: Patient Centered TB and HIV Services –
Facilitators: Evariste Akpele, African Services Committee, USA; Alexey V. Bobrik, Open Health Institute, Russia; Rapporteur: Tracy Swan, TAG, USA

Strategists agreed that client-centered, integrated TB and HIV services are needed. Provider incentives for collaboration include increased health and survival of patients as well as the opportunity for greater learning.

The WHO *Interim Policy for Collaborative TB/HIV Activities* recommends some of these services, such as HIV testing in TB settings and TB screening among people living with HIV/AIDS. The group identified methods for the development of successful, client-centered TB/HIV programs, including:

- o Providing information to patients about TB and HIV, adherence and side effects of medications;
- o Ensuring that medications, health care and transportation are available at no charge, and offering incentives (food, transportation, child care) when needed;
- o Asking patients what they need and whether they prefer to receive treatment at home, at work, or in the clinic;
- o Working within a broader community to deliver integrated TB/HIV services, including family; traditional healers, support groups/peer educators, NGOs, state/government health services, faith-based and relief organizations, and community health care workers;
- o Providing a wide range of services, such as HIV prevention information, condoms/syringes, TB prophylaxis, clinic-based DOTS, outreach, palliative care.

Some services may be improved and expanded without additional resources, by increasing collaboration and information exchange between patients, providers, NGOs, and community leadership. When additional resources are available, an “umbrella body” or a lead NGO could be entrusted with funds. Joint TB/HIV projects should be developed, such as a national reference laboratory for TB/HIV and a single drug distribution system for TB and HIV medications/prophylaxis.

E. Continuity of Community Workshop / Network Resource Mobilization – *Facilitator: Amos Nota, Zambart Project, Zambia; Rapporteur: Sandie Sempe, AIDES, France*

Strategists agreed that the continuity of the work initiated by the second HIV-TB co-infection community mobilization workshop depends on the creation of an information network and the organization of a 3rd International TB/HIV Community Mobilization Workshop. Such an information would be utilized:

- To update and improve network members' knowledge about HIV-TB co-infection issues.
- To heighten other community activists' awareness of the challenges of HIV-TB co-infection.
- To advocate for better access to treatment for HIV-TB co-infected patients.
- To link with existing TB / HIV networks.

They recommend that this network have a network coordinator as well as regional focal point persons. The coordinator would ensure connectivity with other networks and global initiatives to fight TB and HIV, while the focal points would identify additional participants and disseminate information in the languages of their region. The internet could be utilized to provide an email group for workshop participants and their peers as well as a user-friendly website containing relevant documents such as medical information, research reports, advocacy tools, education materials and news from activists in different countries.

Members of the HIV-TB co-infection network could gather during the existing regional and international conferences on TB or HIV/AIDS. Forthcoming international AIDS meetings could be used to expand the network and to prepare the next community workshop.

F. Vulnerable and At-Risk Populations – *Facilitator: Vlastimil Mayer, MD, DrSc, National Reference Lab /League Against AIDS, Slovakia; Rapporteur: Rob Camp, TAG, USA*

Strategists identified population groups that can be considered at-risk for one or all three of the following categories: HIV, TB, and HIV/TB co-infection (see box below). Effective interventions can be difficult because behavior change takes time and may require access to a range of media and capacity to adapt messages. In addition, there is a need to balance the human rights of the individual as well as the general population, and to identify interventions across a spectrum of prevention and treatment. Cross-border issues can further complicate our efforts. Strategies to address these challenges include:

- Sensitizing and involving leaders in civil society, the state, religious and philanthropic groups;
- Moving beyond the local sphere and prioritizing regional collaboration;
- Identifying NGOs to participate in information dissemination to community partners, and advocacy;
- Creating opportunities to raise issues about the delicate balance of human rights in public health;
- Lobbying international organizations, such as the UN, for support for intensified interventions and better awareness of the special issues of vulnerable and at-risk populations;
- Examining and disseminating information on effective models for behavioral changes that work;
- Continuing dialogue among those involved in these efforts via e-mail and other mechanisms

Vulnerable and At-Risk Populations

Children

Girls & women

Homeless &/or malnourished people

Injection drug users

Internally displaced persons & refugees

Long-route truck drivers

Men who have sex with men

Military personnel

Migrant laborers

Prisoners & ex-prisoners

Sex workers and trafficked populations

Students

Appendix 1**2nd International TB/HIV Community Workshop Participants**

Agnes Adala	Women Fighting AIDS in Kenya (WOFAK)	Kenya
Evariste Akpele	African Services Committee	USA
Olayide Akanni	Journalists Against AIDS (JAAIDS)	Nigeria
Mohammed Farouk Auwalu	AIDS Alliance In Nigeria	Nigeria
Dembele Bintou	CESAC: Centre d'Ecoute, de Soins, d'Animation, et de Conseil pour les personnes vivant avec VIH/SIDA	Mali
Alexey V. Bobrik	Open Health Institute	Russia
Rob Camp	Treatment Action Group (TAG)	USA
Marie de Cenival	INSERM / ACT UP Paris	France
Gilles Cesari	AIDES	France
Dr. Antoinette Chileshe-Phiri	Copperbelt Health Education Project (CHEP)	Zambia
Gladys Chiwome	Women and AIDS Support Network	Zimbabwe
Beatrice Chola	Bwafano Community Home Based Care Organization	Zambia
Veronique Collard	AIDES	France
Julie Davids	Community HIV/AIDS Mobilization Project (CHAMP)	USA
Dr. Rabiou Sanata Diallo	Mieux Vivre avec le SIDA	Niger
Dr. Milan K. Dinda	West Bengal Coalition Against TB/HIV (WBCATH)	India
Nomfundo Dubula	Treatment Action Campaign (TAC)	South Africa
Oleg Eryomin	NGO Vstrecha, Belorussian AIDS Network	Belarus
Mark Harrington	Treatment Action Group (TAG)	USA
Maryrose Baby Ikumi	Associação dos Técnicos Agro-Pecuários (ATAP)	Mozambique
Olayinka Jegede-Ekpe	Nigerian Community of Women Living with HIV/AIDS	Nigeria
Karyn Kaplan	Thai AIDS Treatment Action Group (TTAG)	Thailand
Sunthraporn Kestkaeo	AIDS Access Foundation & Thai Network of PLWHA	Thailand
Mapule Khanye	The AIDS Consortium	South Africa
Deogratius B. Kiduduye	Association of Journalists Against AIDS in Tanzania (AJAAT)	Tanzania
Oleg Kvlivdze	Georgian Plus Group	Georgia
Kasem Kolnary	Cambodian HIV/AIDS Education and Care (CHEC)	Cambodia
Ghislaine Mabeluanga	Ligue Nationale Antituberculeuse du Congo	DR Congo
Thembeke Majali	Treatment Action Campaign (TAC)	South Africa
Dr. Piryani Rano Mal	SAARC Tuberculosis Centre	Nepal
Erick Maville	AIDES	France
Vlastimil Mayer, MD, DrSc.	National Reference Lab /League Against AIDS	Slovakia
Farai Mugweni	Southern African Network of AIDS Service Organisations (SANASO)	Zimbabwe
Isaac Mumba	Copperbelt Health Education Project (CHEP)	Zambia
Ketty Mfune Mumba	Family Health Trust - Home Based Care Project (FHT/HBC)	Zambia
Monica Nganjone	AIDS Law Unit / Legal Assistance Center	Namibia
McBride Nkhalamba	ActionAid	Malawi
Amos Nota	Zambart Project	Zambia
Kwami Eugene Novon	AIDES Medicales & Charite	Togo
Ivy Nomqondiso Ntlangeni	Treatment Action Campaign (TAC)	South Africa
Dorothy Onyango	Women Fighting AIDS in Kenya (WOFAK)	Kenya
Dr Yssouf Ouattara	Renaissance Santé Bouaké	Côte d'Ivoire
Emmanuel Ouedraogo	Centre OASIS de l'Association African Solidarité	Burkina Faso
Manoj Pardeshi	Indian Network of People Living with HIV/AIDS	India
Zhanna Parkhomenko	Médecins sans Frontières (MSF)	Ukraine
Chalermchai Peuan-Buapan	Thai Network of People Living with HIV/AIDS	Thailand

Julien Potet	Ensemble Contre le Sida / Sidaction	France
Juan Carlos Rejas Rivero	Asociacion 'Más Vida'	Bolivia
Ezio T. Santos Filho	Grupo Pela VIDDA-RJ	Brazil
Sandie Sempe	AIDES	France
Eid Mohammed Shamas	AIDS Prevention Association of Pakistan	Pakistan
Lucia Maria Stirbu	National Union of the Organizations of the HIV/AIDS Affected People	Romania
Tracy Swan	Treatment Action Group (TAG)	USA
Boonsanong Thangyudee	Thai AIDS Treatment Action Group (TTAG)	Thailand
Glenn Thomas	World Health Organization (WHO)	Switzerland
Ted Torfoss	Norwegian Association of Heart and Lung Patients (LHL)	Norway
Emmanuel Trenado	AIDES Responsable Lobby Thérapeutique	France
Walter Trejo Urquiola	Universidad de Los Andes Merida	Venezuela
John Wasonga	Kenya Coalition on Access to Essential Medicines	Kenya
Dr. Tokugha Yephthomi	YRG CARE	India

Appendix 2

Second International TB/HIV Community Workshop Program

Tuesday 28 October 2003	Workshop Registration and Reception
8:30 - 18:30	Registration for Community Mobilization Workshop
18:30 - 21:00	Welcome Reception for Workshop Participants
Wednesday 29 October	Stop TB DOTS Expansion Working Group
8:30 - 17:00	Stop TB Partnership DOTS Expansion Working Group
18:00 - 19:00	Informal discussion for Workshop participants
Thursday 30 October	TB/HIV Community Workshop – Day 1
8:30 - 10:00	Welcome, Review of Program & Introductions
10:00 - 11:00	TB/HIV Overview
11:15 - 12:30	Resource Mobilization
14:00 - 17:00	TB/HIV Projects and Community Mobilization
17:30 - 20:00	IAUTLD Opening Ceremony, Guest Lecture, Welcoming Reception
Friday 31 October	IUATLD World Conference on Lung Health
8:15 - 16:15	IAUTLD Sessions, Plenary, Symposia
16:30 - 18:30	HIV/TB Community Mobilization Workshop Planning Session
Saturday 1 November	IUATLD World Conference on Lung Health
9:00 - 11:15	IAUTLD late-breaker session
	TB/HIV Community Workshop – Day 2
12:00 -13:30	Working Luncheon – Regional discussions
14:00 -15:30	Breakout sessions part I
16:00 - 18:00	Breakout sessions part II
19:30 - 23:00	Concluding session and dinner
Sunday 2 November	IUATLD World Conference on Lung Health
9:00 - 16:15	IAUTLD Sessions
17:00 - 18:00	Final report back

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