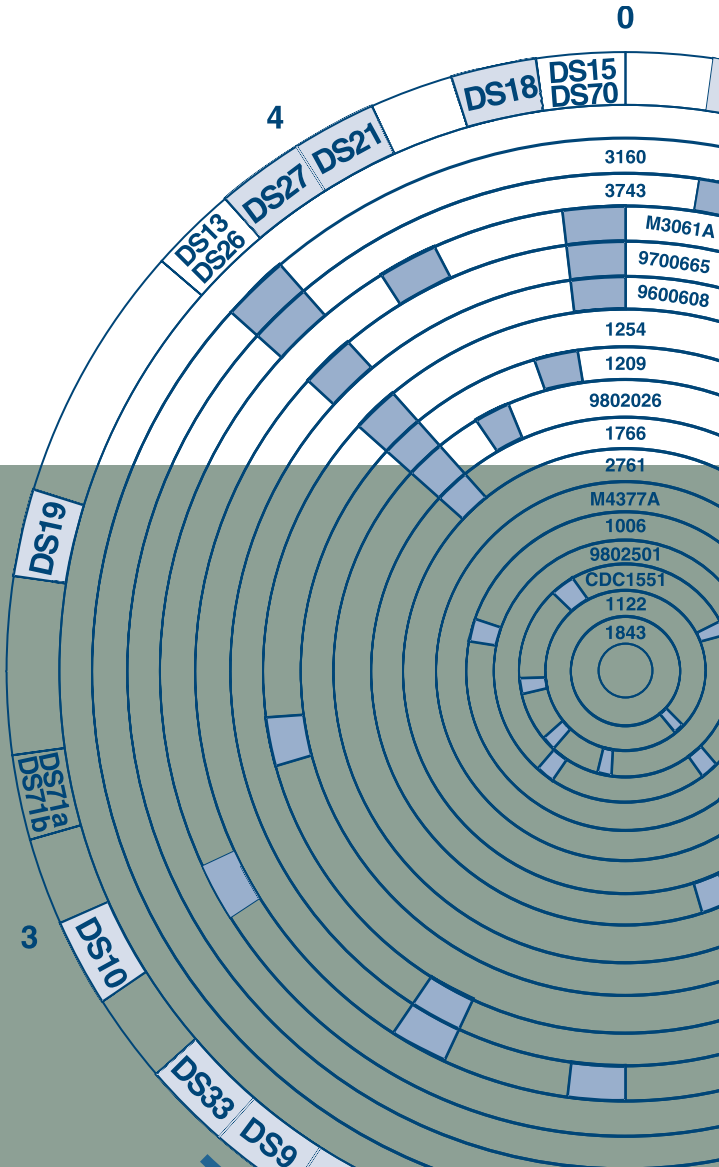
Report from the 3rd International TB/HIV Community Workshop

26–29 October 2004
Paris, France



Acknowledgments

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Bob Huff, editor of Gay Men's Health Crisis (GMHC)'s Treatment Issues, interviewed participants and documented the first two days of the workshop.

Mark Harrington, Executive Director of Treatment Action Group (TAG), edited this report.

Javid Syed, TAG's TB/HIV Project Director, provided useful comments.

The Treatment Action Group (TAG) works to accelerate and intensify research to improve treatment and 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. TAG meets with researchers, pharmaceutical companies, and government officials to encourage exploration of understudied areas in AIDS research and speed up drug development, approval, and access. TAG works 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.

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"I've seen HIV/AIDS tear up my own family. I can tell you that within the last eight years, I have lost 8 members of my family to HIV/AIDS. And I lost my own sister to TB. At that time they could not diagnose the TB because the smear was negative. They didn't treat her, so gradually, she died. Now that I see the signs, I realize that this was TB. Had they treated her she would have lived."

—Elizabeth Anyango, Kenya

"In 2003 I got TB and it was at a time when I was failing HIV therapy. I know what it means to treat both diseases and how hard it is. If I had been dependent on the public health care system in Brazil, I would be dead."

—Ezio Távora dos Santos Filho, Brazil

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Introduction

The 3rd International Community TB/HIV Workshop was held in Paris from October 26-29, 2004. Participants were nominated by organizations and networks from all regions. From 229 applicants the Advisory Committee — Beverley Figaji (Namibia), Ezio Santos Filho (Brazil), Pervaiz Tufail (Pakistan) and Wan Yanhai (China) — selected 40 persons to attend the Workshop. Additional participants came from AIDES, the Bill & Melinda Gates Foundation, the European AIDS Treatment Group (EATG)/European Community Advisory Board (ECAB), Gay Men's Health Crisis (GMHC), Open Society Institute (OSI), the Stop TB Partnership Secretariat, TAG, UNAIDS and WHO.

Workshop participants came from Argentina, Belarus, Bolivia, Brazil, Cambodia, Cameroon, China, Ecuador, Estonia, Ethiopia, France, Georgia, Greece, India, Kenya, Kyrgyzstan, Malawi, Mexico, Namibia, Nepal, Nigeria, Pakistan, the Philippines, Romania, Russia, Switzerland, Tanzania, Uganda, Ukraine, the United States, Zambia, and Zimbabwe.

The main goal of the meeting was to develop ideas for national, regional and global advocacy responses to the TB/HIV epidemics. Half the participants had submitted letters of intent to Open Society Institute (OSI) for the first round of TB/HIV advocacy grants prior to the Paris workshop. Subsequently, they developed revised proposals for country-level TB/HIV advocacy and submitted them to OSI for Advisory Committee review in mid-December. Successful applicants were notified in January 2005, when OSI also announced a second round of TB/HIV advocacy grants.

African, Asian, Eastern European, and Latin American regional breakout groups discussed national, regional, and global TB/HIV advocacy strategies and reported back on them in full-group strategy sessions.

<u>Strategies proposed by all groups</u>

- Advocate aggressively with respect to TB/HIV at all levels
- Base activities on WHO guidelines for collaborative TB/HIV activities
- Create linkages with collaborative TB/HIV activities
- Implement GIPA – greater involvement of people living with HIV/AIDS Stress the advantage of partnerships
- Involve the media
- Use list-serves to build networks

Mark Harrington, USA: This is an advocacy meeting: it is about creating change and mobilizing resources. At past meetings we had formal presentations with experts, but we will be doing less of that at this meeting. Here we will interact, get to know each other and hear about activism going on around the world. We're here to create an advocacy agenda. We're not here to discuss services. We need to think of strategies for change at the global, national and community level. We are driven by a different process this year: What practical things can you do that you can get funded when you get home? We assume you are all leaders. We want to bring TB into the mainstream of AIDS treatment advocacy and activism.

WHO Policy on HIV/TB Activities

Dr. Haileyesus Getahun, Switzerland, Stop TB Department, World Health Organization (WHO): I want to present the Interim Global Policy on Collaborative HIV/TB activities. It is an interim policy because it is not yet complete [some elements may be revised], but it is meant to address the emergency of TB and HIV. We need to introduce new methods of confronting the TB epidemic and the interaction of TB with HIV. This policy is a set of recommendations for what is to be done. Here are the principles behind the policy: First, we say that we are dealing with two diseases, but one patient. In some places the TB and HIV service programs have already been integrated. But in other places the TB patient is considered an independent entity regardless of HIV status. We don't want to ask a patient to come on Tuesdays for his HIV services and then come back on Thursdays for his TB services. So we have to try to put all of the care into single patient centers. This policy does not call for the institution of a new specialist or independent disease control program. Rather, it promotes enhanced collaboration between tuberculosis and HIV/AIDS programs in the provision of a continuum of quality care at service-delivery level for people with, or at risk of, tuberculosis and people living with HIV/AIDS. In other words, TB programs should be open to take up HIV services (which is not really happening yet). Likewise, HIV programs should carry TB services, and there should be a strong system of referral and linkages between the two. All countries should be aware of TB and HIV and all countries should implement these activities in one way or another.

We need HIV and TB advocacy groups to help mainstream these TB/HIV activities. At the meeting in Addis it was stated, "There is no longer any excuse for any country not to implement collaborative HIV/TB activities." We have the minimum package of policy guidelines we need to get started. But the future lies in having country-specific TB/HIV policies and implementation

plans that will assure that governments, political authorities and NGOs are committed to scaling up TB/HIV activities. We need accelerated implementation of collaboration activities, particularly at the country level, and for this we need HIV and TB advocacy groups to help mainstream these TB/HIV activities.

WHO Interim Policy on Collaborative TB/HIV Activities

The goal of the policy is to reduce the burden of HIV and TB in dually affected populations. There are three specific objectives and twelve recommended collaborative TB/HIV activities:

A. Establish the mechanisms for collaboration.

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

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

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

C. Decrease the burden of HIV in tuberculosis patients.

1. Provide HIV testing and counseling.
2. Introduce HIV prevention methods.
3. Introduce cotrimoxazole preventive therapy.
4. Ensure HIV/AIDS care and support.
5. Provide antiretroviral therapy (ART).

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

These activities should be implemented with collaboration between HIV and TB programs, with the programs minimizing differences, building on strengths and avoiding weaknesses.

Discussion: The Need for Advocacy

Lucy Chesire, Kenya: For a long time the NGO world has been doing a lot in relation to TB and HIV. But it has been more or less at a global perspective, and there has been no involvement of the PLWHA community. Because, when we are talking about TB and HIV integration, at the end of the day, who is it that it is affecting? It is us. We are the ones who are on the ground; we know what is going on and we have the statistics. So, now they have brought the PLWHA community on board, and that's a major change. But if we had been involved from the very beginning, integrating the two programs together would not be an issue now. The PLWHA community has to be more aggressive in undertaking the TB/HIV activities. We have a lot of work to do in terms of advocacy and in terms of health care training. I've realized there are quite a number of NGOs that are willing to sponsor the TB and HIV activities in the country and that is really good news, because they've realized that there is something we can do there.

Mohammad Farouk Auwalu, Nigeria: We, the activists, need to understand the relationship between HIV and TB. We need to integrate TB into the HIV treatment preparedness movement so that activists broaden their knowledge and begin asking for the same thing everywhere in the world. We need to mobilize critical mass at the national level. We need to include TB when we organize our regional treatment literacy sessions. We need to embrace the phrase, "Two diseases; one patient." We are fighting for the same person, whether for ARVs or for TB treatment.

Haileyesus Getahun, Switzerland: Normally, policies such as this one are dispatched to the health ministries and then we wait. But we can't wait. So we use the strong PWA networks in these countries to influence the governments. But since the governments often change their policies slowly, we try to get the service providers to integrate their services so they can provide optimal patient care. The question is: How can we accelerate the implementation of policies?

Lillian Kyomuhangi Mworkeo, Uganda: When you are defining an advocacy agenda, you have to have the facts. You have to be knowledgeable. Our role as advocates is to engage the decision makers with these facts to make sure the problems are addressed.

Haileyesus Getahun, Switzerland: We are trying to develop an HIV/TB advocacy manual similar to what we have for HIV. PLWHA networks have developed action plans and we have provided them with small grants to get

them started.

Beverley Figaji, Namibia: Before I came here, I was trying to obtain the Namibian guidelines on TB, but it was so difficult. We need to change things on our level instead of waiting for policies to come down from the top. We are very active on our district level. A number of us realized we were seeing the same faces at our various weekly meetings for HIV and TB and other things. So we said, why not combine our resources and have one day for one meeting and bring everything together?

Mohammed Farouk Auwalu, Nigeria: The professionals in these fields doing their own thing but they are not talking to each other. We need to crash the meetings that we are not invited to. We know it will be difficult in the beginning, but if we push and push we can close the gaps.

Nina Schwalbe, USA: When you go to the International Union against Tuberculosis and Lung Disease (IUATLD) meeting later this week, it will be like the 1940s. You will see zero activism. There are only three NGO seats – and one is the U.S. CDC! They are not used to hearing criticism. They believe that a target of 70% coverage and 85% cure rate is acceptable. They say that will reverse the global epidemic but they have forgotten about the individuals. TB is preventable and treatable and curable. But there have been no new drugs in last 40 years; no vaccines. This is unacceptable. I don't know why so few NGOs are involved in TB, but we need your help.

Elie Bertrand Gaston Kampoer Pfouminzhouer, Cameroon: Before coming here I had a meeting with the national health minister, but I am not sure he will still be there when I get home. On paper our program on HIV is the best in the world. It is headed by the minister of health and there is also a provincial coordinator for the program in each of the 10 provinces. Our NGO is involved in implementing the 2000-2005 program and we estimate that a third of the villages in the country have some kind of HIV program. The TB program is also fairly well structured. But there is a problem because we have little coordination between the HIV and TB centers. There is free access to TB treatment but people don't know about it.

Ezio Távora dos Santos Filho, Brazil: Every country has its difficulties and we try to do what we can for our societies. In the 1950s, Brazil was a world model for dealing with TB. But this program was abandoned in 1990 because they said TB was no longer a problem for Brazil. This was just as HIV was rising. Now we have a horrible problem.

Haileyesus Getahun, Switzerland: We have to drop the policies down to the grassroots level. It is better to have adaptation of these policies at the national level, but it is up to the countries; WHO can't push them. One suggestion is to use advocacy and activists – to have activists and community representatives get onto these dormant national coordinating bodies.

Anjan Amatya, Nepal: We are the best ones to deal with this [bringing HIV and TB programs together] because we are living with and fighting this epidemic.

Participant's Voices: The Issues

Mark Harrington, USA: These are some of the issues that the community members sent to the STOP TB Partnership [see Appendix II]. We had ten AIDS activists out of 200 participants at Addis. Yet there is a sense among some that we can't expose these issues because it will undermine DOTS[1] expansion. I think the Partnership needs to wake up and discuss these problems.

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1. Confusingly, DOTS refers to the entire WHO-recommended strategy for TB control, as well as the TB treatment course recommended. Countries adopting the DOTS Strategy are supposedly committed to detecting 70% of infectious (sputum-smear positive) TB cases and curing 85% of those thus detected. It is a public health approach rather than a patient-centered one. The five elements of the DOTS Strategy are:

- Strong political will and commitment [usually lacking in spite of a full decade of multilateral statements].
- Passive case finding and diagnosis by sputum-smear microscopy to determine presence of acid-fast bacilli (AFB) after examining at least three sputum samples. [This omits people who do not present with couth for diagnosis at a clinic or TB center. It lacks a focus on smear-negative or extra-pulmonary TB, which together may make up as much as 70% of TB cases among people with HIV.]
- Treatment with directly-observed therapy, short course (DOTS) – currently it usually comprises two months of daily treatment with four drugs followed by four to six months of daily or thrice weekly treatment with two drugs. Most commonly the four-drug regimen includes isoniazid (INH, H), rifampin (rifampicin, R), pyrazinamide (Z) and ethambutol (E). The two-drug regimen is either isoniazid-rifampin (HR) or ethambutol-isoniazid (EH) [In practice many programs do not actually involve daily direct observation, particularly during the continuation phase of therapy, but discussion of alternative methods of assuring treatment adherence are often regarded as dangerous and heretical in TB circles.]
- A constant supply of high-quality drugs. [Use of fixed dose combinations (FDCs is another means of enhancing adherence. Continuing reports of stock-outs or critical TB drugs in places such as Lusaka, Zambia, demonstrate ongoing lack of real political commitment to TB control.]
- Accurate reporting of treatment outcomes – cured (smear-negative at 2 and 6-8 months), treatment completed, defaulted, transferred out, or died. [Recording and reporting of TB case detection, treatment and outcome takes place at district, central/national, regional and global levels. The quality of the data reported by countries may vary significantly.]

Rethinking DOTS

DOTS = Directly Observed Therapy, Short-course. DOTS programs traditionally rely on diagnosis by a positive acid-fast bacilli (AFB) stain on a series of three sputum smear microscopy tests – a diagnostic approach which has remained unchanged since its discovery by Robert Koch in 1888. While every TB clinic needs a functioning microscope to diagnose sputum-smear positive TB, among people infected with HIV as many as two-thirds of TB cases may be sputum-smear negative (SSN) or extrapulmonary TB (ETB). Mortality during the first phase of TB treatment is as over 30% in some African and south-east Asian countries, largely due to late diagnosis of SSN and ETB, leading to treatment failure, or to AIDS complications among those co-infected with HIV.

Mark Harrington, USA: I want to question DOTS. The experts say it is different things depending on the context. They assume people are too stupid to follow treatment on their own without direct observation. But it would not have been possible for me to take my antiretrovirals [ARVs] if I had to go someplace to be directly observed. How do South African ARV programs achieve 95% adherence rates? Not with DOTS. They have community support. I think the approach to TB needs to change. It needs to empower the community. People are not given an explanation of why they take their medications. Isoniazid [INH] prophylaxis is not explained to patients, yet six to nine months of INH prophylaxis can cut TB rates in half. Cotrimoxazole cuts death rates from some opportunistic infections in half among TB patients. Why are there still questions about implementing this? Even before ARV comes, people could have access to TB treatment. So I'm not going to use the term DOTS; I'm going to say "good TB treatment." It is a scandal that they do not have these prophylaxis treatments [cotrimoxazole, isoniazid] in place.

Rajiv Kafle, Nepal: DOTS has to be rethought. Why are we not advocating for 100% detections and cure? There is a limitation to DOTS that I don't like. In Nepal, DOTS is supposed to be a successful program. But people are dying around us because we don't have basic resources. So there is a gap between having the policies and the implementation.

Mohammed Farouk Auwalu, Nigeria: Are the drugs available in the DOTS centers? Because you go to some of these centers and you find that the drugs are not there. What do you do? You have to end up going back to the

open market and buying the drugs. Like myself, when I was treated for TB three years ago. I can tell you that I was at a drug center, but I had to buy the drugs myself. So I know how expensive they are. And if you don't have the money to buy the drugs, what happens? You just die. So that's it.

Lucy Chesire, Kenya: When we look at the Kenyan set up, if you talk about DOTS, they say it is 100% and when you tell them about integration and collaboration they ask if it is really necessary. They don't see a need, because they are addressing the TB issue. So I think we need treatment literacy so that both the community living with HIV/AIDS and the caregivers are aware of TB and HIV.

Access: Limited Resources / Limited Progress

Julia Vinckler, Estonia: At the moment, those who are visiting the infectious diseases hospital and need ARVs get the treatment, if they need it. It is 77 persons, at the moment on ARV treatment. If they need TB treatment, it is a different department at the hospital. But that is at a very low level because a few years ago our special hospital for tuberculosis closed. I think it was mostly a political decision, because we do need it. I think it will be a big problem.

Rajiv Kafle, Nepal: In Nepal, TB programs are established and have been running for some time. Although the diagnostics and treatments are not of high quality, these TB programs are better established than programs for HIV or programs for drug users.

Sunil Pant, Nepal: There is a government health system but it is very poor. There are 25 people in the whole country taking ARVs through the government health system. We don't know how many people need treatment; we don't have statistics; maybe 5,000?

Tesfalidet Debesay, Ethiopia: Antiretroviral treatment in Ethiopia only started 10 or 11 months ago. There has been a government program but it was a service for those who could pay; people from the affluent society. Those who were poor or marginalized did not get treatment. So far, there is no government program for the poor, but it is said that the Global Fund, the Bush Initiative (PEPFAR) and others are to start soon with free treatment for the poor.

Francisco Rosas, Mexico: In Mexico City there are 4,000 people living with HIV/AIDS and there are 10 physicians to attend these people. It is impossible.

I live 10 minutes outside Mexico City, and in my community's hospital there are 300 people living with HIV/AIDS and there is one doctor. It is incredible. These people get little attention, their quality of life is low and their quality of health is low. TB is one of the most important opportunistic infections in Mexico, but the linkage between HIV and TB care is nonexistent.

Access: Rural / Urban Disparities

Eid Muhammad Shamas, Pakistan: There is more TB in Pakistan than HIV. The main problem is poverty. People don't have access to medicines. They are uneducated and lack resources to buy medicines. There are also so many quacks in Pakistan who treat patients the wrong way. If somebody can afford to go to a specialist doctor he may be sent to a government hospital where they will treat TB. But that is very rare and facilities are lacking. The public health hospitals provide whatever TB treatment there is, but the system is not good. If anyone has a relationship with a doctor, they can be treated, but others can't. And this is the situation in the cities… when you go to the villages, it is much worse. There they are not even getting attention from a qualified doctor, because qualified doctors don't want to work in the villages where there are not proper facilities.

Elizabeth Anyango, Kenya: I work in the poorest part of Kenya. Given that it is a rural center also, issues like education, healthcare, transportation are not adequate. So we realize that, even for people who are sick, sometimes reaching a hospital is not easy. Any specialists that are available, lack facilities. Many of the basic drugs are missing, so when you go to a hospital you are given a list of drugs and you have to provide them, but you don't have the money. So that discourages people from seeking healthcare. Also, facilities are few, for example, X-rays are only available at the district hospital, which is about 35km away from our center. So that too discourages people from seeking care.

René Roa-Flores, Argentina: TB treatment and HIV treatment can be obtained in an integrated setting, but only in the cities. At the community level there are doctors specialized in infections who can work with TB and HIV together. But outside of the city we have a problem with patient compliance with their medications. And these problems are due to geographic distance – hundreds of kilometers, up to 400 km. People run out of medication and can't get re-supplied. As a typical example, a person has been diagnosed as HIV-positive and also diagnosed with tuberculosis. This person goes into hospital, is given treatment and once he is stabilized and out of danger he leaves the hospital and is given drugs for the TB and

the HIV. But after he leaves the hospital, that treatment soon comes to an end because he is no longer able to get a hold of the medication.

Siddhi Aryal, Nepal: In Nepal we are challenged geographically. We go from Mt. Everest to sea level. We are also going through a difficult political period with an insurgency. So just doing the normal work of development is challenging.

Integration of TB and HIV Care

Elie Bertrand Gaston Kampoer Pfouminzhouer, Cameroon: The big problem in Cameroon is there is one program to fight AIDS and another program to fight TB. They don't work together. On paper there is a program for them to work together in the future, but now they don't. People are treated separately. If you have TB you have one path to follow; if you have HIV it's different. The TB clinics are not prepared to have people who have both illnesses. Making this happen is what motivates me today.

Tesfalidet Debesay, Ethiopia: There is a separate system for treating tuberculosis – I say separate because people with tuberculosis can get free treatment. There is DOTS treatment for free and there is a TB specialist hospital in Addis. Now they are planning to integrate the HIV treatment with the TB program. But so far, they are only treating TB for free and not HIV.

Wan Yanhai, China: Our government has taken action on AIDS and on tuberculosis, but I think it is very important to work together on these. For many years the office of STDs did not work together with the office of AIDS, even though they were both in the same small building. Eventually they were combined. Now, there are seven people who are in charge of TB, but they don't work with anyone from sexually transmitted diseases.

Lydia Mungherera, Uganda: In TASO (The AIDS Support Organisation), where I work, we treat HIV and TB together in an integrated system. So if a person comes for TB they can have VCT (voluntary testing and counseling) and have treatment for any infection done in the same place. And this is happening in Uganda in most of the hospitals which are accredited for antiviral therapy. These are government hospitals primarily and also a few private hospitals. But not all hospitals are accredited.

Kasem Kolnary, Cambodia: In Cambodia we have a national HIV center and a national TB center, they link their programs but they refer for TB diagnosis if one is HIV positive. If they are TB active then they are sent to

the TB treatment center. They have a continuum of care for people with HIV at the district level. The TB and HIV policy is on the national level. They refer to each other.

Mohammed Farouk Auwalu, Nigeria: In the past, the resources going to HIV/AIDS were minimal. But today, a lot of donor focus has shifted to the issue of HIV/AIDS, placing the issue of TB into lesser priority. Bringing the two programs together has been practically very difficult, particularly in a country like Nigeria, because everybody wants to hold their own program; nobody wants to give and take. As activists and as people living with HIV/AIDS, we continue to advocate with the program managers that it is two diseases, yet in one patient.

Tamara Gvaramadze, Georgia: The next step is to start connecting TB with HIV, because this is at zero level – there are no NGOs working on this; there is no information about co-infection. Next year we will start on this task; talking about it to the general public.

Community Education: Awareness and Literacy

Fatima Koshokova, Kyrgyzstan: People in my country don't treat AIDS or TB as a big problem and they don't think they can be at risk. For example, injecting drug users – they do not treat TB as a serious disease. They don't realize that getting TB can have consequences. During the Soviet Union it was an affair of the state medical structures to test the whole population for TB and to provide treatment; it was not a problem in my country. Now, it's a widespread disease but people think that TB is treated very well, very quickly. Many people think this. They do not treat this seriously. We are educating people about what connection there is between TB and HIV; what risks people can have; and those who have TB, what risks they have of getting HIV and vice versa.

Elizabeth Anyango, Kenya: We've seen an improvement in the acceptance in the past year. The peer educators who have accepted their condition have been influencing the others to seek medical care. People see that, people who were very sick, now walk. Because, some people are sick with TB and after the TB has been sorted out, they're able to work and they're able to walk. So, the other people feel that, since so-and-so is able to come back and work, I too can seek healthcare.

MacBain Mkandawire, Malawi: When they find someone at the TB clinic with HIV they don't always refer them back to the HIV program. They do

provide the TB medication. But the challenge is for the people to be open and go to have the TB examined and then get to know their HIV status. The other key challenge is that within the hospital structure, it becomes difficult sometimes to provide on-site counseling and testing. And therefore, while we are doing the TB advocacy program; we should also do HIV advocacy.

Julia Vinckler, Estonia: Right now we don't have any program for developing knowledge about TB and HIV. We have a lot of HIV-positive persons in the prisons and we have to start from there.

MacBain Mkandawire, Malawi: If someone has TB, they go to the TB clinic. But people know that TB is associated with HIV. This is where the challenge comes in. Because of HIV and because of the stigma that is associated with HIV there is a danger that people may not go to the TB clinic because they think that "if I go, then people will think I have HIV." Therefore, there is a high need for educating the community that TB is treatable, inasmuch as HIV is not curable at this moment. They also need to know that even if they have TB and they have HIV, there are opportunities for them by going for treatment for TB. Therefore you also open an opportunity for them to know their status and encourage them to either go on ARV or whatever sort of care and support they need from other people. Because the critical component is destigmatization, which we have to work on; to get across the knowledge that, if one has TB, it doesn't necessarily mean he has HIV. But even if he has HIV, there are still opportunities that one has.

Community Education: Stigma

Marvelous Muchenje, Zimbabwe: There is so much discrimination that people don't even go to the hospitals, even for TB.

Elie Bertrand Gaston Kampoer Pfouminzhouer, Cameroon: Discrimination still exists for HIV, so if you have both HIV and TB, you are in greater danger. One of the directors of our organization had HIV and received good care for three years until he found out he had TB. He obtained good care because he was well known and was part of our group. But because the systems are not connected—the TB was in a private service in the hospital and you had to go there to get a proper diagnosis—it became very difficult for him—and he had every advantage, so for a common person it is very dangerous.

Elizabeth Anyango, Kenya: At the community level, the stigma is still great. I can give a case in my family: five members have had TB. Most of them have come to seek treatment in my house. They come and stay with me

because other people are afraid they will give their children TB. So the stigma discourages people from coming out and seeking healthcare. Some people have died because of the stigma. Some people seek medical care, but they still hide. So the stigma is there. But there is now a small percentage of people who have accepted their situation and are working with us. But we are still far from reaching our goal.

Yuliya Chorna, Ukraine: In our city of 200,000 people, more than 2,000 are ill with TB. The chief doctor of the TB clinic in our city revealed this statistic but treated it like it was a secret because he thought that if the people know there will be panic.

Fatima Koshokova, Kyrgyzstan: If you compare HIV/AIDS stigma and TB stigma, HIV/AIDS is stronger. At the moment, only one person in my country has come out with his HIV-positive status. As for TB stigma, it depends on the community where the person lives. For example, injecting drug users are not afraid of TB stigma; if they have TB, it's not a big deal. But, for example, if a person works at the university, it will be a stigma. People don't want other people to know they have TB. They will try not to avoid contact with the person so they won't get TB.

MacBain Mkandawire, Malawi: In the context of Malawi, if someone has TB, then the next thing people think is that, well, he's or she is positive. So in trying to de-stigmatize the situation, we wanted to merge the prevention component with the care and support program so that we were able to work with them together and do a continuum of prevention and care.

Provider Education: Equitable Care & Human Rights Protections

Thankiah Selva Ramkumar, India: The government hospitals offer TB treatment, but they have also tested people for HIV without them knowing it and if found positive they were thrown out of the TB program.

Arjun Rajendra (Romy) Shirke, India: A situation I have seen in the past few years is that an HIV-positive person who comes to an admitting hospital is sent to the TB ward – even though he doesn't have TB. So here is a person with HIV who is in the TB ward and naturally he is soon going to get TB. But nobody cares! It is insensitivity to HIV. They think he has HIV and he is going to die, so they just shift him somewhere else.

Mohammed Farouk Auwalu, Nigeria: In some of the hospitals, and at some sites in Nigeria, I think it has become a kind of policy that once you are

diagnosed with TB, and without seeking your consent, they test you for HIV. And once they test you for HIV and find you positive, sometimes you don't even get treatment for TB; they refer you to the AIDS clinic. There was a case where a patient was diagnosed with TB and they tested him positive for HIV and the TB clinic refused that person treatment and sent him to the MSF clinic at the general hospital. The MSF clinic sent that person back to where he was tested and asked that doctor, "What right do you have not to treat him because he has HIV?" And still the doctor refused. So you can imagine, that for those who are not aware; who don't know where to go to; you can imagine the number of patients that are turned down who have gone to their villages and died from things that they are supposed to get treatment for.

Dário Abarca Runruil, Ecuador: The government gives people with HIV/AIDS tuberculosis treatment first. But when people go to the hospital and they are very sick, the hospital doesn't always give it to them and they die. It is very bad. They do not get proper TB treatment and they have to wait to get ARVs.

Mikhail Victorovich Rukavishnikov, Russia: There is an unusual diagnosis in Russia that can be used to deny a patient treatment. A doctor can decide that a patient lacks "social perspective".

Provider Education: Quality of Care

Sunil Pant, Nepal: There are separate TB clinics in government hospitals and some also run by NGOs. TB programs have been in Nepal for a long time. TB drugs are still free. But with TB compounded with HIV, I don't think we have a mechanism or clinical facility to cope with both. If you go to one of the big hospitals in Kathmandu there are only 2 or 3 HIV experts, but if you go to an ordinary doctor they wouldn't even think about HIV if you had TB. If they are treating TB and it is not doing well, then maybe the doctor would suspect or think towards HIV; but usually not. Out of the valley so many people have TB that if they are not HIV, then maybe they get well; but if they are, then they just die.

Lydia Mungherera, Uganda: Most of the doctors that now see patients with symptoms will send a person for VCT – especially if they have TB, because, of course, "their immune system must be down." Even if it's malaria or pneumonia with coughing, most of the health workers in Uganda now think of HIV and send the person for counseling and testing. Even in the community, if someone is not feeling very well, people say, "Maybe you should go for a

test." But VCT is very accessible and very easy to get, and more are being opened by the Ministry of Health.

Francisco Rosas, Mexico: People can get care at government hospitals, especially people who don't have social security, poor people and marginal populations. You have a different system if you are working and have social security. But in my opinion, these programs are big pharmacies, where people with HIV/AIDS go for their treatment each month, but they don't receive palliative care, prophylactic medicines, and they get much less information and counseling. They simply pass through month-to-month for their medicines.

Beverley Figaji, Namibia: We have national guidelines on DOTS, but again, the ministry just cannot keep up with the numbers of people. We currently have just under 1,000 people on DOTS. So we've got all these different clinics where people go – a health clinic, a TB clinic, a HIV clinic, and ours, which is a VCT center. What we're seeing now is that people going to the ARV clinic – because we don't have enough qualified doctors, we have to bring them from other countries now, and they're doing a wonderful job: the pharmacists, the nurses and the doctors – because we don't have our own people in our country. And so what they are looking at very quickly is if the person if co-infected with TB, then they start the TB treatment first. So it's actually the other way around, not going to the TB clinic and first going to the ARV clinic and noticing it.

Rajiv Kafle, Nepal: We have access to a lot of experience and knowledge about ARVs; we have list-serves where we can ask a question and get a huge number of responses from global activists about side effects, benefits, and food management. But if we go to the TB clinics and ask these questions they say, "We don't know anything." The availability of the drugs is expanding but they have very little knowledge about them. A few weeks ago a guy was dying so I went to the TB clinic and they told me they don't have a second line therapy for him. They do not have that community of expertise to consult with; they are isolated, with one or two people in one TB DOTS center.

Joshua Formentera, Philippines: There are a number of people who are on the ARV treatment but then after two years they develop tuberculosis. That was a surprise to us because we were not prepared to handle this. We use a peer support mechanism and those who are caregivers are mostly people with HIV, so when there is TB there are cross-infections. Now our doctors do not allow us to use our peers. So that's one of the problems at the moment.

Medical Complications: Diagnosis, Drug Interactions & Resistance

Greg Manning, India: I've seen TB killing people for more than a decade in our region. We've had a lot of trouble diagnosing it. And only recently, when we've come in contact with the Treatment Action Group and the Treatment Action Campaign, who have been providing information about the relationship between HIV and TB, we've been able to increase our rates of diagnoses and encourage people to stay in the diagnostic process until they find out what they have and get good treatment. It's made a massive difference in our work. We're treating many more people. We've had a small DOTS program double in the time that we've been doing this, which is less than a year. Before that we were just telling people to stop smoking.

Joshua Formentera, Philippines: The majority of our HIV patients are not tested for tuberculosis. And they might have been infected with tuberculosis, but it is not manifested in the body. I've tried to talk to the doctors about it, but there are few answers at that level. We would recommend that those who have HIV, before they begin treatment, they should be tested for tuberculosis.

Rajiv Kafle, Nepal: Only this year I have lost five people… and all to TB. So, I am living the epidemic. It's not like TB is something over there. There are very real-life consequences of HIV/TB going on. There are people who are not diagnosed; there are people who are misdiagnosed. We had someone who went for TB treatment for 13 months then suddenly the doctors said it was not TB but something else he had.

Mark Harrington, USA: We still don't know how to use nevirapine with rifampin. No one has taken responsibility to do the drug interaction studies. The TB clinics are worried about how to do HIV testing… but they should be doing it because then they can save lives. If people with HIV don't have TB, then they can get INH to prevent it. If they do, then they can get cotrimoxazole and TB treatment. MDR TB (multi-drug resistant TB) is also treatable and curable and should not be a death sentence.

Greg Manning, India: In India INH prophylaxis is viewed with suspicion. There are conflicting guidelines on this. Some recommend it and at least one doesn't. Since the diagnostics are so poor, how do you confirm someone doesn't have TB and should receive INH? What are the consequences of not adhering to INH? These questions cause doctors to shy away from using it. A lot of people have HCV. We need some guidelines on INH and liver impairment. People start to put age limits on who should have INH. These

ambiguities cause doctors to back away.

Juan Carlos Rejas Rivero, Bolivia: The annual operational plan for HIV includes prophylactic treatment. The TB program asks for INH, but not especially for people with HIV. We need to integrate these two programs so people understand how these two diseases are linked.

Tamara Gvaramadze, Georgia: If someone has TB, they go to the government TB hospital for treatment, but we don't have a DOTS program. And often the drugs that they are using are not effective anymore; the microbe changed and the drugs don't work the way they used to work.

Mohammed Farouk Auwalu, Nigeria: They are doing some research to try to find out about MDR in Nigeria. At the last working group meeting we had, the TB program manager assured us that they have a plan to carry out research on the MDR tuberculosis in Nigeria. But I can't pass any comment because there's not enough evidence to prove that.

Wan Yanhai, China: In some areas in China we have a high incidence of tuberculosis, and a high incidence of HIV infection, and a high incidence of hepatitis C and hepatitis B. And in some rural areas of Henan province there is multi-drug resistant TB.

Dário Abarca Runruil, Ecuador: Kaletra (lopinavir/ritonavir) was accepted by the government as an ARV to give to people with TB and HIV because it doesn't affect the TB treatment. But only about 10 people have gotten Kaletra. So, people with TB and HIV who need treatment are dying.

Joshua Formentera, Philippines: In the Philippines, if there is TB and the patient is in care, usually they will be treated with tuberculosis medications. But, when you take TB treatment, then they have no option but to stop the ARV medication.

Ezio Távora dos Santos Filho, Brazil: In 2003 I got TB and it was at a time when I was failing HIV therapy. I know what it means to treat both diseases and how hard it is. It was really tough. I had hepatitis from taking both the HAART and the TB medication. The TB therapy was unbearable, so I had to suspend the ARVs and just have the TB treatment, and I had to change the TB treatment four times because I was allergic to three different regimens. And now I have developed asthma because of the medications. The recommended period of TB treatment for a person with AIDS is one year, but I only went through eight months, so I don't know if I fully controlled it. But it

seems to be gone. I had a CT scan a few weeks ago and it looks fine. I had access to the best care and all the top physicians in private clinics. If I had been dependent on the public health care system in Brazil, I would be dead.

Discussion with Mario Raviglione, Director, Stop TB Department, WHO, October 29, 2004

Mario Raviglione, Director, Stop TB Department, World Health Organization, Switzerland: We never previously had the fortune to have activists pushing and going to governments and complaining about TB. In Addis I saw the activists in action: participating, influencing the discussion, giving the public health people the correct direction. I can say that we strongly support this opening-up by the communities affected by TB and TB/HIV.

There was a question about participating more in the bodies that make decisions. From my perspective on our supreme guiding body, having the perspective from the community is important, particularly with respect to the Guidelines. With respect to the Partnership, there has been a discussion about having representatives of affected communities on the Board. It's quite important that someone puts his or her name to the Board to say we want to represent affected communities. I also want to say that's quite important that WHO and the Partnership should present a united front for the effort confront, control, and eliminate TB, and we want to consider the affected communities an integral part of the effort.

There are many opportunities for advocacy at the national level: South Africa for example isn't doing enough on TB – nor is Zimbabwe, Nigeria, or Ethiopia. In Ethiopia we went to the Prime Minister and the Minister of Health. They said, "We have to deal with ARVs. We're doing fine with TB." Not so. They're far from reaching the targets. I hope that the new Advocacy & Communications Working Group of the Stop TB Partnership takes this on seriously.

I wanted to show the slide I presented on the first day of the DOTS Expansion Working Group "DOTS Redefined" or "DOTS II". It's not the DOTS of 1994. There's been an evolution:

1. Government commitment needs to move to political commitment on all fronts to implement the MDGs [millennium development goals] to cut incidence and mortality.
2. We need to move from the limitations of smear microscopy to culture technology. We are going to the Diagnostic Working Group that is meeting here to accelerate the transfer of technology available in the North to the South – accelerate culture proce dures, which may be essential for identifying TB among HIV-positive sputum-smear negative TB patients.
3. We need to get out of the trap that direct observation must be so rigid; it should mean treatment support to get through six months of treatment.
4. We need strengthening of laboratories, drug supply system, and surveillance.
5. We need engagement of all care providers – not just the public health approach, but also a care approach.
6. We need partnerships with communities.
7. And finally, we need the mainstreaming of TB/HIV and DOTS-Plus/MDR-TB (multi-drug resistant tuberculosis) into country plans – at the present they limit themselves to pilot projects and operational research. We must go beyond this and get money not just for DOTS Expansion but also for TB/HIV and DOTS-Plus. This will require the active participation of the community.

Lillian Mworkeo, Uganda: Thank you very much, Dr. Mario. In TASO in Uganda, when we introduce ARVs, we also introduce the treatment companion and household VCT. I hope this is something that we're going to talk about with TB. Another issue is that the second-line TB drugs are lacking in Uganda. Dr. Aduatu [head of the Uganda TB program] says it is so expensive they can't afford it. The third question is when to start ARVs after you start TB treatment.

Mario Raviglione, Switzerland: We have had community care projects in Uganda, Malawi, and Zambia. There is the GLC [Green Light Committee] through which second-line drugs can be bought at 95% less – they were unaffordable three-to-four years ago when they were $15-20,000 for 18 months of treatment. Now with the GLC, the prices have gone down consistently. So, Dr. Aduatu needs to do a drug resistance survey to understand the situation and simply implement appropriate treatment. But if there are MDR-TB patients, they should be treated regardless of the drug resistance survey.

Lucy Chesire, Kenya: Is Stop TB interested in TB/HIV research?

Mario Raviglione, Switzerland: I believe the Addis Ababa meeting changed that. It created a concept at WHO headquarters of a Task Force between our department, with seven TB/HIV people full-time, and the HIV/AIDS Department. They have designated one full-time person from the HIV Department – Gilles Poumerol – and Jim Kim has said that he's going to invest money into TB/HIV work from their side. Every year we put $2-3 million into TB/HIV at global level.

Ezio Távora dos Santos Filho, Brazil: Latin America is a region where TB is reasonably under control ... except in a few cases: there has been a big deterioration in Peru in the past few years, with constant changes of ministers of health and policies. Latin America needs to be activated. In PAHO TB is not considered a priority. The vice-minister of health of Mexico, Robert Tapie, who sits on the Stop TB Coordinating Board, has requested formally to consider TB a priority and make it a special project in PAHO (Pan American Health Organization). Brazil, which is considered a model for AIDS, could do much better in TB.

Nina Schwalbe, USA: It would help if you would invite people from the communities when you arrange high-level meetings with ministries.

Mohammed Farouk Auwalu, Nigeria: I want to thank WHO for finding it important to get activists and community people involved, particularly in the last Working Group meeting in Addis. Can we have a commitment from you that you will get activists and community people involved in the different Working Groups?

Ezio Távora dos Santos Filho, Brazil: The Latin American group is going to ask to have seats on the Stop TB Coordinating Board for representatives from all regions; at least two individuals per region; to divide Asia into two to have better representation for Asia; to have at least two from Latin America/Caribbean, and have all regions represented by at least two people. I reinforce what Nina raised to have community participation at all levels.

Lillian Mworkeo, Uganda: It's not asking a favor; we are fighting a war; affected communities are critical; unless we're there the war will be lost; history is going to judge us.

Joshua Formentera, Philippines: In Asia we're going to make a commitment to work at the national level. But the WHO's national level staff treat

us like ping-pong balls. We need assurance that there's a commitment from WHO to meet with us at the national level.

Mario Raviglione, Switzerland: Last night we meet with all WHO staff [present in Paris]. We discussed the modernization of the DOTS strategy at country level, including partnership. We have country level WHO people who say you are creating more things for them to do and that they don't have the time. The process has to evolve. If it doesn't succeed let me know. Be aware that you may encounter this type of thing.

Plans for Action: Advocacy and Education

Ezio Távora dos Santos Filho, Brazil: How can we can go home and create strategies to put community and government to work together to get programs working effectively – not just theoretically? We have a lack of communication between the programs in my country. I'm afraid that we come out with a beautiful global suggestion but we have strong obstacles within the countries that resist change. How can we overcome obstacles?

Mohammed Farouk Auwalu, Nigeria: One of the major problems we have in sub-Saharan Africa is that most of the doctors who are working in TB don't have knowledge of HIV and people working in HIV don't have knowledge of TB. It is our responsibility as activists and as community people, to try and see how we can bridge this gap for the overall interest and benefit of the patient.

Yuliya Chorna, Ukraine: In our country we have legislation for a national TB program, but the legislation is not absorbed on the local level. For example, the legislation says there should be free pills for people ill with TB, but on the local level there is no money in the budget so there are no pills for the ill people. There is also a policy that socially vulnerable groups, like people living with HIV, injection drug users, and prisoners must have assistance. But we asked our clients when they last had an X-ray and most of them couldn't remember. That's why we developed our project to make policy complaints on the local level about the denial of TB services in these vulnerable populations. We are planning to influence local policy and to ask our city's mayor to decree free testing for our clients. When we organize this campaign we will see how many are ill and we will teach about how TB is treated, prevented, and disseminated among their communities. And I think we can better the situation.

Ivan Vodnev, Belarus: Even if there is legislation, a public officer can't implement policy because it is not within his competency. We have to do the public officer's work.

Rajiv Kafle, Nepal: I see the TB/HIV collaborative effort and wonder how we can benefit from existing TB services. We are scaling up ARV treatment but we don't have infrastructure, so we want to see if we can benefit from existing TB programs. So for the next year we will be advocating on how we can make our voices heard in the TB community. We can also help the TB community because we in HIV have more experience advocating for drug and diagnostic development. So we are in a position where we can bargain and not just go and do whatever the TB community says. For example, we have been promoting a human rights approach to VCT and I can not support the opt-out stuff that is being recommended by WHO. We have been doing human rights based advocacy and we could not just change our philosophy because WHO thinks so. So there are certain things that we would not agree on with the TB community.

Tamara Gvaramadze, Georgia: There is no information at all on HIV and TB in the Georgian language, so we decided the first step we can do is publish materials specifically designed for a general audience; a booklet for people infected with HIV; a booklet for their family members on how to take care of them. We are planning to deliver a series of lectures in Georgian prisons and to prison personnel. Those were our general ideas and we hope to get more specific materials translated. The Georgian Plus Group has quite a lot of experience in advocacy and doing things designed to raise the awareness of the general public regarding HIV/AIDS. But they also advocate at all levels, including the government.

Olayide Akanni, Nigeria: We try to highlight what TB is all about. If the people don't know that TB is treatable, then they don't push for it. So alongside holding policy makers accountable we are tying to increase awareness of TB. Our primary focus is building the capacity of the media. If the media doesn't understand the policy issues, they can't challenge the government. Advocacy is an ongoing process and you need to constantly challenge them to hold them accountable.

Fatima Koshokova, Kyrgyzstan: The health system has broken down; people's awareness about these diseases is very low; and my organization decided to start this TB program, promotion of TB education – first with injecting drug users. And then we will go on to the population of young people, and the whole population, of course. It will be basic knowledge

about TB. And we also want to promote those who have TB to seek treatment. Because, some people know they have TB, but they do not get treatment. And maybe after our educational sessions they will think, "Oh, I have a very serious disease, I have to get treatment." Right now most of them don't think they have a serious disease.

Mikhail Victorovich Rukavishnikov, Russia: Maybe you heard that twelve HIV-positive people chained themselves together in Kaliningrad saying, "Our deaths are your shame." In that region about 950 of 5,000 infected people have died. The city authorities then took measures to help the people.

Problems and Strategies: Reports from Group Discussions

Discussions on national, regional and global TB/HIV advocacy strategies were held by the African, Asian, Eastern European, and Latin American breakout groups:

Strategies proposed by all groups

- Advocate aggressively with respect to TB/HIV at all levels
- Base activities on WHO guidelines for collaborative TB/HIV activities
- Create linkages with collaborative TB/HIV activities
- Implement GIPA – greater involvement of people living with HIV/AIDS
  Stress the advantage of partnerships
- Involve the media
- Use list-serves to build networks

AFRICAN GROUP

Agnes Akinyi Adala, Kenya; Ailed Akanni, Nigeria; Mohammed Farouk Auwalu, Nigeria; Lucy Chesire, Kenya; Tesfalidet Debesay, Ethiopia; Elizabeth Anyango Owiti, Kenya; Beverley Jane Figaji, Namibia; Elie Bertrand Gaston Kampoer Pfouminzhouer, Cameroon; MacBain Mkandawire, Malawi; Marvelous Muchenje, Zimbabwe; Lydia Mungherera, Uganda; Lillian Kyomuhangi Mworeko, Uganda

Problems

- Lack of TB/HIV research
- Inadequate resource mobilization
- Macro-economic policy issues – e.g. limits on recruitment of staff
- Translating implementation of GIPA at all levels
- Co-ordination and networking among advocates and decision makers
- Access to treatment for migrants
- Transparency and accountability of leadership at all levels
- Organizational change impeded by founder syndrome
- Lack of youth participation in TB/HIV advocacy

Strategies

- Form global alliances to serve as watchdogs
- Invest in the organizational development of existing networks
- Promote GIPA [greater involvement of people with HIV/AIDS] in the TB/HIV working groups
- Champion the TB/HIV agenda at G77, G8, AU, etc.
- Advocate for increased government spending/investment in TB/HIV research
- Encourage aggressive activism by local and regional networks
- Advocate for debt relief/reduction; change health care worker recruitment policies

ASIAN GROUP

Anjan Amatya, Nepal; Siddhi Aryal, Nepal; Joshua Calixto T. Formentera, Jr., Philippines; Dominic L. Garcia, Philippines; Rajiv Kafle, Nepal; Kasem Kolnary, Cambodia; Greg Manning, India; Sunil B. Pant, Nepal; Rajendra Arjun Shirke, India; T.S. Ramkumar, India; Eid Muhammad Shamas, Pakistan; Wan Yanhai, China

Strategies

- Gain representation on all advisory committees related to TB programs
- Organize an Asian ministers meeting
- Organize satellite meetings at ICAAP, etc.
- Produce regional and national reports based on the TAG workshop
- Detail commitments for advocacy with each country showing the work they have done, e.g., Cambodia; lessons learned.
- Tap regional and funding agencies for support; document

the expenses involved.
- Start/expand list serve groups for TB/HIV.
- Establish or strengthen existing networks within the region.

EASTERN EUROPEAN GROUP

Julia Chorna, Ukraine; Tamara Gvaramadze, Georgia; Fatima Koshokova, Kyrgyzstan; Florentin Logigan, Romania; Mikhail Rukavishnikov, Russia; Nina Schwalbe, USA; Julia Vinckler, Estonia; Ivan Vodnev, Belarus.

Problems

- HIV & TB problems/programs are not linked;
- National programs (if any) function poorly;
- No standards for diagnosis, prevention and treatment of HIV/TB co-infection;
- No or unreliable statistics;
- No political will, i.e. government authorities deny the problem

Strategies

- Develop and implement national standards for diagnosis, prevention, and treatment of dual infection based on WHO recommendations. Emphasize necessity of HIV+ community inclusion in this process.
- Develop national programs on TB/HIV; include training on diagnosis and treatment issues with the special attention on treatment adherence.
- Develop and implement similar standards and programs for prison settings.

How to implement strategies

National Level

- Convince decision-makers of the necessity of adopting the standards through the media; personal meetings; round table discussions; direct actions (demonstrations and the like); public talks; press conferences; and presentations by people with disclosed HIV/TB status.
- Compile an informational packet for advocates in order to arm them for the successful dialogue with the authorities. Include

specific HIV/TB information as well as documentation of any legal basis for action and documents concerned with the specific issue of interest.
- Raise awareness of people living with TB/HIV about issues affecting them;
- Invite specialists (medical doctors working in TB & HIV), leaders, both country-wide and world-wide known people, and interna tional organizations (UNAIDS, WHO etc.) to participate in advocacy activities. Ask the organizations to include TB issues in HIV forums and vice versa.
- Create informational campaigns aimed at the general public and at medical workers to raise awareness and tolerance towards people living with HIV, TB, and HIV/TB

Regional/Global Level

- Organize so-called best-practice meetings and seminars.
- Organize regional seminars involving countries not represented here at this meeting.
- Develop online newsgroups and mailing lists to expand our networks.

LATIN AMERICAN GROUP

Dário Abarca, Ecuador; Juan Carlos Rejas Rivero, Bolivia; René Roa-Flores, Argentina; Francisco Rosas, México; Ezio Santos Filho, Brazil

The Latin American group was careful to be humble about its limitations. From (roughly) 30 countries in the Latin American region; "we bring only four perspectives for a regional perspective." They particularly noted the absence of Caribbean representatives and the consequent limited inclusion of their priorities. Therefore, the strategies and suggestions mostly have regional relevance, although they are the product of the national discussions and comparisons.

Strategies

- First use existing community structures in the HIV/AIDS field to implement initiatives for TB/HIV social mobilization; existing forums, networks and associations should be the means for sensitizing and raising community consciousness on the TB/HIV problem.

- Promote seminars and workshops to help create community leadership on TB/HIV.
- Identify key decision makers within the governmental sectors who understand the need for community participation in the fight against TB/HIV. Advocate for community participation in decision making.
- With governmental support, establish and increase the participa tion of community members in the formulation of TB/HIV public policies. Increase opportunities to achieve larger budgets and other funds, and to improve human resources in the field.
- Use media and different means of social mobilization (e.g., demonstrations) to raise public awareness of the problem and to push for implementation of good policies.
- Introduce TB/HIV into the educational curriculum at all levels. Invest in widely distributed basic information for general or targeted populations as well as handbooks for trainers, social workers and health agents.
- Country or regional representation at international meetings is limited therefore the cost-effectiveness of such meetings and impact in the regions is low. To enhance regional representation:
  – Promote regional meetings with a greater impact and lower cost;
  – Give priority to community-based organizations (particularly those linked to forums and networks) in planning these regional meetings, in order to widen the impact of mobilization;
  – Focus these regional meetings on the creation and empowerment of new TB/HIV leadership.

Demands:

- Establish and rapidly increase regular participation of community representatives in the TB/HIV public health forums. This will help spread information and raise awareness about the context of the diseases (the epidemiological situation) and will also foster accountability for the TB programs via community participation in policy and budget formulation processes and reports.
- Participate in the decision making of global programs and multilateral institutions such as the WHO, PAHO, Stop TB and GFATM. This should help build internal and national legitimacy. There will likely be areas of conflict as these forums are opened to participation by critics and to suggestions and negotiation between community and its international partners. Examples of critical

issues for these bodies: the need for decentralization; need for decreasing bureaucracy; need for increased transparency on inter national transfer of funds and tax/interest payments; language barriers; the impact of national policies on the regional level (e.g., access to antiretroviral treatment in Brazil used by WHO to imply high access for the entire region; trade limits on medicines due to fears of international trade retaliation).

Meeting with Stop TB Partnership, 30 October 2004

Gregg Gonsalves, USA: Does the STOP TB partnership have representation from the communities?

Petra Heitkamp, Stop TB Partnership, Switzerland: An NGO from the North — the Red Cross — was added.

Gregg Gonsalves, USA: That's not acceptable.

TB/HIV workshop participants, along with members of TBTV.org and LHL (the Norwegian Heart & Lung Patients Association) and OSI met with Marcos Espinal, director of the Stop TB Partnership, and other Partnership staff, to discuss HIV community involvement in the Stop TB Partnership and its governing and policy bodies, including the Partnership Coordinating Board, its seven Working Groups (DOTS Expansion, TB/HIV, DOTS-Plus, New Diagnostics, New Drugs, New Vaccines, and Advocacy & Communications).

Participants told the Partnership that they want broad community involvement in all the activities of the Partnership including at least two seats on the Partnership Coordinating Board and each of its Working Group Core Groups. The Partnership committed to an open process for selecting a representative of affected communities (from the TB and HIV communities) as well as a strong recommendation to all Core Groups to include at least two community representatives on each Core. Working Group membership is said to be open to anyone willing to sign up. Dr. Espinal asked the community participants present to select a focal point to disseminate information on the Partnership and Core Group community participation and representation process. The group suggested that TAG take on this role. Subsequently, information on the Stop TB Partnership Coordinating Board duties and terms of reference were distributed to members of the ITP Coalition, the TB/HIV list-serve and other interested individuals and networks. http://www.aidsinfonyc.org/tag/tbhiv/workshop3ltr3.htmlhttp://www.aidsinfonyc.org/tag/tbhiv/manualICB.htmlhttp://www.aidsinfonyc.org/tag/tbhiv/workshop3ltr2.html
In a subsequent letter to the Stop TB Partnership Coordinating Board meeting held in Beijing in October 2004, Dr. Espinal wrote:

> Specifically, I would like to highlight [at the recent Union meeting] the visual presence of Communities affected by TB and HIV. I am very encouraged to hear their voice of wanting to be involved in the Stop TB Partnership and its governing and policy bodies, including the Partnership Coordinating Board, its seven Working Groups

(DOTS Expansion, TB/HIV, DOTS-Plus, New Diagnostics, New Drugs, New Vaccines, and Advocacy & Communications). I had a productive meeting with a group of TB/HIV patients in Paris who requested active participation on the Core Groups and the Working Groups in order to help moving the TB agenda forward. I will contact separately the Chairs and Secretariat of the Working Groups with more information on this meeting and suggestions to engage the TB patients and the HIV community. In this regard, I would also like to draw your attention and opinions on the attached letter sent by HIV community participants who attended the 4th TBHIV Working Group meeting in Addis Ababa, Ethiopia on 20-21 September 2004. (After Addis 101404.pdf)

Meeting with IUATLD [International Union Against Tuberculosis and Lung Diseases], 31 October 2004

On 31 October 2004 participants from the 3rd TB/HIV Community Workshop along with members of TBTV.org and representatives of LHL met with Dr. Nils Billo, Executive Director, and Wendy Atkinson, Communications Director, of the International Union Against TB and Lung Diseases (IUATLD). The meeting was facilitated by Ailed Akanni from Journalists Against AIDS, Nigeria, and Kasem Kolnary, Cambodia HIV/AIDS Education Project (CHEC). Participants introduced themselves and their organizations and requested the following:

- Continued free registration for international TB/HIV community workshop participants in the Union World Congress on Lung Health;
- Integration of the Workshop into the formal programme of the Union conference;
- Participation of representatives in the planning and implementation of the Union conference including input into the programme and identification of topics and speakers relevant to affected communities;
- Integration of community representatives into the Union's upcoming regional meetings

Dr. Billo explained that the Union is not pharmaceutically-funded. Its annual conference runs a deficit. However, he offered to let workshop representatives work on planning the subsequent conference, and stated firmly for the record that registration to the conference for workshop participants next year will be free.

3rd International TB/HIV Community Workshop Participants

Agnes Akinyi Adala, Women Fighting AIDS in Kenya (WOFAK), Kenya
Ailed Akanni, Journalists Against AIDS (JAAIDS), Nigeria
Anjan Amatya, National Association of PLWHA in Nepal (NAP+N), Nepal
Siddhi Aryal, Oxygen Research and Development Forum, Nepal
Mohammed Farouk Auwalu, AIDS Alliance in Nigeria, Nigeria
Lucy Chesire, MOI Teaching and Referral Hospital, Kenya
Yuliya Chorna, Salvation, Ukraine
Tesfalidet Debesay, Panos Ethiopia, Ethiopia
Nikos Dedes, European Community Advisory Board (ECAB), Greece
Ezio Távora dos Santos Filho, Grupo Pela Vidda, RJ, Brazil
Beverley Jane Figaji, Walvis Bay Multi-Purpose Centre Trust (WB MPC), Namibia
Joshua Calixto T. Formentera, Jr., Positive Action Foundation Philippines, Inc., Philippines
Dominic L. Garcia, AIDS Society of the Philippines, Philippines
Haileyesus Getahun, Stop TB Department, World Health Organization (WHO), Switzerland
Gregg Gonsalves, Gay Men's Health Crisis (GMHC), USA
Tamara Gvaramadze, Union Georgian Plus Group, Georgia
Mark Harrington, Treatment Action Group, USA
Petra Heitkamp, Stop TB Partnership Secretariat, Switzerland
Robert Huff, Gay Men's Health Crisis (GMHC), USA
Eleonora Jimenez, Open Society Institute (OSI), USA
Rajiv Kafle, Nava Kiran Plus, Nepal
Elie Bertrand Gaston Kampoer, Pfouminzhouer, FISS- MST/SIDA, Cameroon
Kasem Kolnary, Cambodian HIV/AIDS Education and Care (CHEC), Cambodia
Fatima Koshokova, Info Center Rainbow, Kyrgystan
Lillian Kyomuhangi Mworkeo, The National Forum of PLHA Networks in Uganda, Uganda
Florentin Logigan, UNOPA, Romania
Greg Manning, Sharan, India
MacBain Mkandawire, Youth Net and Counselling (YONECO), Malawi
Marvelous Muchenje, The Centre, Zimbabwe
Lydia Mungherera, National Forum of PLWHA Networks in Uganda, Uganda
Elizabeth Anyango Owiti, HealthPartners, Kenya
Sunil B. Pant, Blue Diamond Society, Nepal
Shirke Rajendra Arjun, Network of Maharashtra by People Living with HIV/AIDS, India
Mario Raviglione, Stop TB Department, WHO, Switzerland
Ramkumar Thankiah Selva, Centre for Social Reconstruction, India
Juan Carlos Rejas Rivero, REDBOL (Bolivian Network of PLWHA), MAS VIDA NGO, Bolivia
Rene Roa-Flores, de Sida por la Vida, Argentina
Francisco Rosas, Fundación Mexicana para la lucha contra el SIDA, A.C., México
Máximo Dário Abarca Runruil, Ecuadorian Coalition of PLWHA, Ecuador
Nina Schwalbe, Open Society Institute (OSI), USA
Eid Muhammad Shamas, AIDS Prevention & Education Society, Pakistan
Mikhail Victorovich, Rukavishnikov, Regional Public Organization, Community of PLWHA, Russia
Julia Vinckler, Convictus Estonia, Estonia
Ivan Vodnev, InterSocAid/Social Aid, Belarus
Wan Yanhai, Beijing Aizhixing Institute of Health Education, China

3rd International TB/HIV Community Workshop Schedule

Tuesday 26 October 2004 – TB/HIV Workshop Day One

9:00 – 10:30 Welcome & Overview
- HélPne Rossert, AIDES
- Mark Harrington, Treatment Action Group
- Nina Schwalbe, Open Society Institute (OSI)

Introductions – Workshop Participants

11:00 – 13:00 Update on TB/HIV Policy & Advocacy

11:00 Policy on Collaborative TB/HIV Activities
- Haileyesus Getahun, WHO

11:30 Report from the 4th TB/HIV Working Group Meeting: Strengthening HIV Community Involvement in TB/HIV Advocacy
- Mark Harrington, TAG

12:00 TB/HIV Advocacy since the 2003 Workshop – Panel Discussion
- Jane Agnes Akinyi Adala, Women Fighting AIDS in Kenya (WOFAK), Kenya
- Ailed Akanni, Journalists Against AIDS (JAAIDS), Nigeria
- Kasem Kolnary, Cambodian HIV/AIDS Education & Care (CHEC), Cambodia
- Eid Muhammed Shamas, AIDS Prevention & Education Society, Pakistan
- Juan Carlos Rejas Rivero, REDBOL, Bolivia

Discussion

14:30 – 18:00 Defining the TB/HIV Advocacy Agenda

14:30 – 16:30 Panel discussion
- Mohammed Farouk Auwalu, AIDS Alliance in Nigeria
- Lucy Chesire, MOI Teaching & Referral Hospital, Kenya
- Beverley Jane Figaji, Multi-Purpose Centre, Namibia
- Haileyesus Getahun, Stop TB, WHO, Switzerland
- Tamara Gvaramadze, Georgian Plus Group, Georgia
- Elie Bertrand Gaston Kampoer Pfouminzhouer, FISS-MST/SIDA, Cameroon
- Lillian Kyomuhangi Mworeko, National Forum of PLHA Networks, Uganda
- Sunil B. Pant, Blue Diamond Society, Nepal
- Máximo Dário Abarca Runruil, Ecuadorian Coalition of

PLWHA, Ecuador
- Mikhail Rukavishnikov, Community of PLWHA, Russia
- Ezio Távora dos Santos Filho, Grupo Pela Vidda, Brazil
- Wan Yanhai, Beijing Aizhixing Institute of Health Education, China

16:30 – 18:00 Full group discussion

Wednesday 27 October 2004 – TB/HIV Workshop Day 2

Advocacy Strategy Brainstorming Sessions

8:30 Full Group Discussion & Assignment to Break-Out Groups

9:00 – 13:00 Break-Out Sessions I
- Defining National TB/HIV Advocacy Strategies

14:30 – 18:00 Break-Out Sessions II
- Defining Regional & Global Advocacy Strategies

Thursday 28 October 2004

7:30 Registration and welcome desk for 35th Union Conference on Lung Health opens. All workshop participants are registered for the Conference – Palais des CongrPs de Paris.

8:30 – 17:30 5th STB DOTS Expansion Working Group meeting. All workshop participants registered for this all-day meeting of the Stop TB Partnership DOTS Expansion Working Group.

Friday 29 October 2004

8:30 – 17:00 TB/HIV Workshop Day 3

8:30 – 10:30 Update and Discussion on OSI TB/HIV Advocacy Grants
– Nina Schwalbe, OSI

Perspectives from the Advisory Committee
– Beverley Figaji, Multi-Purpose Centre, Namibia
– Ezio Távora dos Santos Filho, Grupo Pela Vidda, Brazil

10:30 Coffee Break

11:00 – 13:00 Report-Backs & Discussion of National TB/HIV Advocacy Strategies

14:30 – 16:00 Report-Backs & Discussion of Regional & Global TB/HIV Advocacy Strategies

16:30 – 18:80 Next Steps & Way Forward: Concluding Discussion

Saturday 30 October 2004 – IUATLD Conference – Day 1

8:00 – 10:15 TB/HIV MDGs in children / TB in prisons/closed institutions / Impact of new drug access mechanisms / Measuring drug resistance

14:30 – 16:45 DOTS implementation QA, labs, NTPs / TB prevalence surveys / DR and MDR-TB treatment

Afternoon: Workshop participants meet with Dr. Marcos Espinal, Director, Stop TB Partnership

Sunday 31 October 2004 – IUATLD Conference – Day 2

8:00 – 9:00 HIV/TB scaling up ARV links to TB control / Advances in new TB diagnostics

12:00 – 14:00 Advocacy & Communications Working Group discussion

16:00 – 16:15 TB in children / DOTS performance incentives / TB in mobile populations / Operational research to improve NTPs / TB virulence & genetic susceptibility

Afternoon: Workshop participants meet with Dr. Nils Billo, Director, IUATLD (Union)

19:30 – 22:00 TB/HIV Workshop Closing Group Dinner

Monday 1 November 2004 – IUATLD Conference – Day 3

9:00 – 11:15 TB late-breakers / TB treatment adherence in resource-poor settings / Human resource development for TB control

14:00 – 16:00 TB contact investigation/active case finding / Sustaining achievements in TB control / HIV/TB: two diseases, one patient

Appendix I: Frequently asked questions about TB and HIV

How can TB and HIV/AIDS work be better coordinated?

The World Health Organization's interim policy on collaborative TB/HIV activities* gives guidance on what should be done to address the dual TB and HIV epidemic. This includes the identification of collaborative TB/HIV activities and the establishment of TB/HIV coordinating bodies to promote and coordinate the response of the two programmes at all levels.

Avoid missed opportunities

HIV-positive people can easily be screened for TB; if they are infected they can be given prophylactic treatment to prevent development of the disease or curative drugs if they already have the disease. TB patients can be offered an HIV test; indeed, research shows that TB patients are more likely to accept HIV testing than the general population. This means TB programmes can make a major contribution to identifying eligible candidates for ARV treatment.

What is TB?

Tuberculosis is a disease that usually attacks the lungs but can affect almost any part of the body. A person infected with TB does not necessarily feel ill – and such cases are known as silent or "latent" infections. When the lung disease becomes "active", the symptoms include cough that last for more than two or three weeks, weight loss, loss of appetite, fever, night sweats and coughing up blood.

What causes TB?

TB is caused by the bacterium Mycobacterium tuberculosis. The bacterium can cause disease in any part of the body, but it normally enters the body though the lungs and resides there.

How is TB spread?

TB is spread from an infectious person to a vulnerable person through the air. Like the common cold, TB is spread through aerosolized droplets after infected people cough, sneeze or even speak. People nearby, if exposed long enough, may breathe in bacteria in the droplets and become infected. People with TB of the lungs are most likely to spread bacteria to those with

whom they spend time every day – including family members, friends and colleagues.

When a person breathes in TB bacteria, the bacteria settle in the lungs. If that person's immune system is compromised, or becomes compromised, the bacteria begin to multiply. From the lungs, they can move through the blood to other parts of the body, such as the kidney, spine and brain. TB in these other parts of the body is usually not infectious.

Is TB treatable?

Yes. TB can be cured, even in people living with HIV. DOTS is the internationally recommended strategy for TB control.

DOTS treatment uses a variety of powerful antibiotics in different ways over a long period to attack bacteria and ensure their eradication. Treatment with anti-TB drugs has been shown to prolong the life of people living with HIV by at least two years. It is important that people who have the disease are identified at the earliest possible stage, so that they can receive treatment, contacts can be traced for investigation of TB, and measures can be taken to minimize the risk to others.

However, some strains of bacteria have now acquired resistance to one or more of the antibiotics commonly used to treat them; these are known as drug-resistant strains.

So TB is a growing concern for people working in the AIDS field?

Yes. It is estimated that one-third of the 40 million people living with HIV/AIDS worldwide are co-infected with TB. People with HIV are up to 50 times more likely to develop TB in a given year than HIV-negative people.

Another aspect of the resurgence of TB is the development of drug-resistant strains. These strains can be created by inconsistent and inadequate treatment practices that encourage bacteria to become tougher. The multidrug-resistant strains are much more difficult and costly to treat and multidrug-resistant TB (MDR-TB) is often fatal. Mortality rates of MDR-TB are comparable with those for TB in the days before the development of antibiotics.

What are the links between HIV and TB?

HIV/AIDS and TB are so closely connected that the term "co-epidemic" or

"dual epidemic" is often used to describe their relationship. The intersecting epidemic is often denoted as TB/HIV or HIV/TB. HIV affects the immune system and increases the likelihood of people acquiring new TB infection. It also promotes both the progression of latent TB infection to active disease and relapse of the disease in previously treated patients. TB is one of the leading causes of death in HIV-infected people.

How many people are co-infected with TB and HIV?

An estimate one-third of the 40 million people living with HIV/AIDS worldwide are co-infected with TB. Furthermore, without proper treatment, approximately 90% of those living with HIV die within months of contracting TB. The majority of people who are co-infected with both diseases live in sub-Saharan Africa.

What is the impact of co-infection with TB and HIV?

Each disease speeds up the progress of the other, and TB considerably shortens the survival of people with HIV/AIDS. TB kills up to half of all AIDS patients worldwide. People who are HIV-positive and infected with TB are up to 50 times more likely to develop active TB in a given year than people who are HIV-negative.

HIV infection is the most potent risk factor for converting latent TB into active TB, while TB bacteria accelerate the progress of AIDS infection in the patient.

Many people infected with HIV in developing countries develop TB as the first manifestation of AIDS. The two diseases represent a deadly combination, since they more destructive together than either disease alone.

- TB is harder to diagnose in HIV-positive people.
- TB progresses faster in HIV-infected people.
- TB in HIV-positive people is almost certain to be fatal if undiagnosed or left untreated.
- TB occurs earlier in the course of HIV infection than many other opportunistic infections.

How much of a threat is TB?

According to WHO, TB infection is currently spreading at the rate of one person per second. It kills more young people and adults than any other

infectious disease and is the world's biggest killer of women. In 1993, WHO declared TB to be "a global health emergency". Every year 8–10 million people catch the disease and 2 million die from it. About a third of the world's population, or around 2 billion people, carry the TB bacteria but most never develop the active disease. Around 10% of people infected with TB actually develop the disease in their lifetimes, but this proportion is changing as HIV severely weakens the human immune system and makes people much more vulnerable.

What is the impact of TB/HIV on women?

Worldwide, women bear a disproportionate burden of poverty, ill-health, malnutrition and disease. TB causes more deaths among women than all causes of maternal mortality combined, and more than 900 million women are infected with TB worldwide. This year, 1 million women will die and 2.5 million, mainly between the ages of 15 and 44, will become sick from the disease.

Once infected with TB, women of reproductive age are more susceptible to developing TB disease than men of the same age. Women in this age group are also at greater risk of becoming infected with HIV. As a result, in certain regions, young women aged 15–24 with TB outnumber young men of the same age with the disease.

While poverty is the underlying cause of much infection in rural areas, poverty is also aggravated by the impact of TB. In 1996, a study by the World Bank, WHO and Harvard University reported TB as a leading cause of “healthy years lost” among women of reproductive age.

What can be done to combat the spread of TB?

The internationally recommended strategy to control TB, known as DOTS, has five components:

- Political commitment to sustained TB control;
- Access to quality-assured TB sputum microscopy;
- Standardized short-course chemotherapy, including direct observation of treatment;
- An uninterrupted supply of drugs;
- A standardized recording and reporting system, enabling assessment of outcome in all patients.

The Global Partnership to Stop TB is a global movement to accelerate social and political action to stop the spread of tuberculosis around the world. The Stop TB mission is to increase access, security and support in order to:

- Ensure that every TB patient has access to TB treatment and cure, and protect vulnerable populations from TB;
- Reduce the social and economic toll that TB exacts from families, communities, and nations.

The Partnership's approach is a coordinated, multinational, multisectoral global effort to control TB.

Why is more collaborative action on TB and HIV important?

HIV/AIDS is dramatically fueling the TB epidemic in sub-Saharan Africa, where up to 70% of TB patients are co-infected with HIV in some countries. For many years efforts to tackle TB and HIV have been largely separate, despite the overlapping epidemiology. Improved collaboration between TB and HIV/AIDS programmes will lead to more effective control of TB among HIV-infected people and to significant public health gains.

– http://www.who.int/tb/hiv/faq/en

Appendix II: Letter from AIDS Activists to WHO/Stop TB Partnership and Response

14 October 2004

Dr. Gijs Elzinga
Chair, TB/HIV Working Group
Stop TB Partnership

Dr. Jim Kim
Director, HIV Department
World Health Organization

Dr. Mario Raviglione
Director, Stop TB Department
World Health Organization

Re: Strengthening HIV Community Involvement in the Fight Against TB and HIV

The 4th Global Stop TB Partnership TB/HIV Working Group meeting held in Addis Ababa on 20-21 September 2004 and followed by a three-day CDC-sponsored workshop on integrating HIV testing into TB programs was the first such meeting attended by significant numbers of representatives from HIV/AIDS treatment activist organizations. Activists attended from India, Kenya, Nigeria, South Africa, the United States, Uganda and Zambia. They were invited based on attendance at a TB/HIV advocacy workshop held in Nairobi, Kenya, by WHO in July 2004, or on submission of an accepted poster on TB/HIV advocacy for the marketplace session at the Working Group meeting.

Most of the activists present met during a breakout session on the afternoon of September 21 – some were presenting present posters in the marketplace time – to discuss working together.

This letter to the TB/HIV Working Group and the directors of the WHO HIV and Stop TB Departments reflects the discussions held by us in Addis Ababa and by e-mail afterwards. Here we raise some issues which we think are critical to expanding the fight against HIV-related TB.

1. HIV community participation in the Stop TB movement is essential and must be expanded.

> *"Adherence is higher with antiretroviral therapy than it is with TB treatment – we've had less than 5% loss to follow-up at 36 months [in the Khayelitsha MSF ARV program] versus 76% one-year completion rate for TB."*
>
> —Eric Goemaere, MSF/Khayelitsha, South Africa [all quotes are from the 4th TB/HIV Working Group meeting]

The HIV treatment activist community welcomes the first steps toward our inclusion within the Stop TB Partnership and its TB/HIV Working Group. This inclusion needs to be expanded into all activities of the Working Group as well as into the other six Working Groups of the Partnership – DOTS Expansion, MDR-TB, Diagnostics, New Drugs, Vaccines, and particularly the new Advocacy & Communications Working Group.

Representatives of HIV community and treatment activist organizations and networks need to be involved in these working groups. Each region will need significant representation on the Advocacy and Communications Working Group in particular. We look forward to hearing the results of the Stop TB Partnership Coordinating Board meeting and its discussion of these issues.

The WHO is still learning how to work more effectively with broadly-based civil society organizations, including HIV community and treatment activist groups. However, we believe that such intensified involvement will be a critical part of doing better in meeting the global targets for TB control. This requires community involvement at all levels in global, regional, country-level and local/district level TB and HIV programs. We call upon the Partnership and the WHO to move rapidly forward to increase such community involvement.

2. TB/HIV needs to be incorporated into HIV community treatment activist and treatment literacy efforts and programs.

> *"There is an emerging people with HIV/AIDS-led TB/HIV advocacy movement in Uganda. We need to translate what is learned into action."*
>
> —Lillian Kyomuhangi Mworeko, National Forum for PLHA Networks, Uganda

Everywhere, TB is a major killer of people with HIV/AIDS. Activist groups and treatment literacy programs need to incorporate TB/HIV as a core activity in their advocacy and education activities. Some successful examples of this already exist, such as with Treatment Action Campaign (TAC) in South Africa. Such examples need to be documented, adapted, and emulated elsewhere. We salute the WHO for the recent $1 million award to the Collaborative Fund for Treatment Preparedness as a step forward in supporting strengthened treatment literacy activities, which should include TB/HIV as an integral part of their programs. Other mechanisms such as Global Fund to Fight AIDS, TB and Malaria (GFATM) grants and the President's Emergency Plan for AIDS Relief (PEPFAR), as well as other bilateral donor programs and national AIDS and TB programs should also support community-led treatment literacy as a core activity.

3. Political commitment to TB control needs to move from words to action.

> *"WHO is one of the most important instruments which we must reclaim to rebuild decent public health care systems in developing systems."*
>
> *"Our work will be measured by how many people we put on anti-retroviral therapy through our TB programs – how many you put on ART, IPT, etc., in each country."*
>
> —Zackie Achmat, Treatment Action Campaign, South Africa

All world governments have endorsed TB control since 1993, when the World Health Assembly (WHA) declared TB a global health emergency. Yet worldwide over 31% of people lack access to functioning TB control programs. Where DOTS is available, it is often not of acceptable quality, or accessible. In too many places even the poorest TB patients must pay to attend a clinic, be tested, see a doctor, and be treated. In Africa, 70% of people with AIDS lack access to a functioning TB program. TB care and treatment must be universal and free. Governments everywhere must meet their commitments made in the Amsterdam Declaration, the Millennium Summit, the UNGASS, the Abuja Summit, and the World Health Assembly. Access to TB prevention, diagnosis, treatment, and cure is an essential human right.

4. The DOTS strategy must be expanded and adapted to the challenges of TB-HIV.

> *"DOTS alone is insufficient to control TB where HIV rates are high."*
> —Peter Godfrey-Faussett, London School of Hygiene & Tropical Medicine

Since 1993 the world has broadly increased implementation of the five-point framework of DOTS, the WHO-recommended TB control strategy. However, DOTS must be expanded and adapted to the challenges posed by the HIV pandemic, which require new ways of doing things.

a. TB detection in people with HIV/AIDS must from passive to active case finding.

The DOTS strategy relies on passive case finding, in which patients report to TB centers with a chronic cough. Passive case finding must be replaced by active case-finding among populations and settings where HIV infection is endemic or expanding. This means seeking out people with TB symptoms where they live and work and encouraging them to be tested for TB.

b. Develop more aggressive diagnostic techniques for sputum-smear negative and extra-pulmonary TB.

> *"Two-thirds of HIV+ TB patients are not diagnosed properly because sputum smear microscopy misses it. We can catch another third with culture systems. TB culture should be available from coinfected patients from the first sputum smear."*
> —Eric Goemaere, MSF/Khayelitsha

DOTS traditionally relies on diagnosis by a positive acid-fast bacilli (AFB) stain on a series of three sputum smear microscopy tests – an approach which has remained unchanged since its discovery by Robert Koch in 1888. While every TB clinic needs a functioning microscope to diagnose sputum-smear positive TB, among people infected with HIV as many as two-thirds of TB cases may be sputum-smear negative (SSN) or extrapulmonary TB (ETB). Mortality during the first phase of TB treatment is as over 30% in some African countries, largely due to late diagnosis of SSN and ETB, leading to treatment failure, or to AIDS complications among those coinfected with HIV.

TB programs need to be much more aggressive in diagnosing SSN and ETB

earlier. New WHO diagnostic guidelines are needed to assure faster diagnosis using existing tools. Access to chest X-ray facilities and bacterial culture technologies should be expanded to provide better surveillance of drug-resistant TB and where possible to speed diagnosis of SSN and ETB.

Accelerated research efforts are needed to develop new, low-cost diagnostics for TB, including SSN, ETB and MDR-TB, which can be used with high accuracy in field settings.

c. Deepen understanding about use of TB and ARV drugs together.

"We need randomized controlled trials and observational studies in well-run programs."

—Anthony D. Harries, Malawi TB/HIV Programme

We need better information on how best to use TB drugs, particularly rifampicin (rifampin) concurrently with antiretroviral (ARV) drugs such as the non-nucleoside nevirapine and the protease inhibitors. This information will help assure those with HIV-TB coinfection of early, effective treatment for both conditions. Pharmacokinetic, safety and effectiveness studies of these combinations are an urgent priority.

d. Provide universal access to isoniazid and cotrimoxazole preventive therapy.

"INH [isoniazid prophylaxis therapy] reduces TB rates 40-60%... CPT [cotrimoxazole prophylaxis therapy] is available, easy, safe, requires no labs, cheap – $6-12/year – and is effective for at least two years."

—Anthony D. Harries, Malawi TB/HIV Programme

Shockingly, according to WHO, in 2002 just 1% of eligible people with HIV and latent tuberculosis infection (LTBI) worldwide received isoniazid prophylaxis therapy (IPT) – despite WHO recommendations for its use since the 1990s, backed by evidence from over ten randomized clinical trials proving its effectiveness. All people with HIV and latent tuberculosis infection (LTBI) should receive six to nine months of isoniazid preventive therapy (IPT). We are particularly concerned that many countries have failed to implement IPT in spite of the overwhelming evidence of its efficacy, based on concerns about adherence and the emergence of resistance. With strong community treatment literacy programs, these problems can be addressed and mitigated. We are encouraged that Botswana and Malawi are implementing IPT in their national HIV/AIDS treatment programs.

In 1998 two clinical trials from Abidjan, Côte d'Ivoire were published in The Lancet proving that cotrimoxazole preventive therapy (CPT) reduced hospitalization and death by 50% among TB patients coinfected with HIV. Shockingly, however, by 2002 fewer than 1% of eligible individuals worldwide were receiving CPT. Universal access to CPT should be implemented immediately for all HIV-infected persons with TB.

e. Scale-up of HIV testing, prevention and treatment needs to occur in all TB programs in countries where the two epidemics interact.

"Non-delivery of HIV services increases stigma for TB in high HIV incidence areas."

—Jeroen von Gorkom, KNCV, Namibia

Evidence presented at the 4th TB/HIV Working Group showed that many countries are making progress in harmonizing their TB and HIV programs, and some are already implementing the WHO-recommended collaborative TB/HIV activities. Universal implementation of these activities as appropriate for different country settings needs to be an immediate priority for all AIDS and TB programs.

f. Alternatives to fully directly-observed therapy (DOT) need to be investigated and, where successful, expanded.

"Do we need to modify the DOTS paradigm in high HIV burden areas? There are no labs to diagnose sputum-smear negative TB... Where do HIV+ TB patients go after TB treatment?"

—Charlie Gilks, WHO

Requiring fully directly-observed therapy (DOT) for the entire six- to eight-month TB treatment course imposes heavy burdens on TB program staff and on TB patients. Many programs have successfully introduced self-administered therapy (SAT), particularly during the continuation (two-drug) phase of therapy. Moreover, much experience from HIV demonstrates that with proper treatment literacy interventions and community-based treatment support, people can achieve very high adherence rates even where DOT is not the preferred model of care. This underlines the importance of expanding treatment literacy about TB care in communities affected by TB and in patients undergoing TB treatment. Alternatives to DOT can help to widen access to effective TB treatment in places where traditional DOT is infeasible or too resource-intensive.

Another issue which needs to be addressed is continuity of TB treatment in mobile populations. Examples include long-distance truck drivers, miners, prisoners, and economic and political refugees. Systems must be developed and strengthened to assure continuity of TB treatment for individuals who do not stay in the same location over the six to eight months of treatment.

g. TB programs need to phase out continuation therapy with six months of ethambutol-isoniazid (EH) for the more effective four month regimen of isoniazid-rifampicin (HR) in line with the results of IUATLD study A.

On 2 October 2004 The Lancet published the results of IUATLD study A, a large international study which enrolled 1,355 patients with TB, which included a comparison of four months of continuation therapy with INH-rifampicin (HR) to six months with ethambutol-isoniazid (EH). The results clearly showed that EH was "significantly inferior" to HR with successful outcomes in 83-84% (EH) versus 91% (HR) 12 months after treatment completion. Unfavorable responses to EH continuation therapy were even more pronounced among those with baseline resistance to INH – just 4% failed treatment on HR versus 27-38% in the two arms including EH. Among 68 HIV-coinfected Africans in the study, 5% failed HR versus 27% who failed EH (A Jindani, AJ Nunn, DA Enarson, "Two 8-month regimens of chemotherapy for treatment of newly diagnosed pulmonary tuberculosis: international multicentre randomised trial," The Lancet 2004; 364:1244-51, 2 October). Thus, switching continuation-phase regimens from EH to HR should be a priority, especially in areas – such as the former Soviet states – with high rates of baseline resistance to INH – and in others – such as sub-Saharan Africa – with high rates of TB/HIV coinfection. In June, the Strategic & Technical Advisory Group for Tuberculosis (STAG-TB) recommended that WHO release updated TB treatment guidelines incorporating the new findings, but these have yet to be released, and some country TB programs are resisting the change due to program inertia and the reluctance to implement six months of directly-observed RH therapy. (As noted in 4f above stronger treatment literacy and support be used to address this issue.)

h. Multi-drug resistant (MDR) TB must no longer be a death sentence.

In most places, infection with multi-drug resistant (MDR) TB can be a death sentence because of inadequate diagnosis, insufficient drug supply, and an antiquated public health philosophy that emphasizes cost-effectiveness over the basic human right to health and life. As part of expanding and improving DOTS worldwide, universal access to diagnosis and treatment for MDR-TB

must become a routine part of effective TB control programs.

5. The Stop TB Partnership needs to add its voices to those calling for macro-economic reforms to improve health systems worldwide.

> *"We need a global emergency human resources plan; debt reduction targeted towards health, education and social security; and removal of trade barriers against developing countries."*
>
> —Zackie Achmat, TAC

> "In Malawi 50% of Ministry of Health posts are unfilled. Ninety percent of public health clinic sites are unable to deliver the essential health package."
>
> —Rony Zachariah, MSF

The Stop TB Partnership needs to add its voices to those calling for macro-economic reforms to improve health systems worldwide, including continuing reductions in the price of essential drugs and diagnostics, long-term efforts to address the crisis in human resources for health (HRH) and debt relief for developing and middle-income countries.

6. Ultimately the battle against TB will only be won with new diagnostics, drugs and vaccines. Intensified, expanded basic, applied, clinical and operational research on TB and TB/HIV is urgently needed.

> "There is no advocacy movement in the TB community to push for discovery of new drugs and diagnostics."
>
> —Eric Goemaere, MSF/Khayelitsha

Just as AIDS activists played a key role in speeding the discovery, development, approval, and distribution of safe, effective antiretroviral drugs, so TB/HIV activists and the Partnership need to put new emphasis on efforts to optimize the use of existing tools through well-designed operational research and, most importantly, to stimulate the development of new diagnostics which can be used in field settings, new more potent and shorter-acting regimens for treatment of LTBI, TB disease and MDR-TB, and a safe, effective TB vaccine. Both developed and developing countries need to support strengthened research efforts to bring us to a world without TB. We thank you for attending to our input and look forward to your response to our concerns, and to further interaction and integration into the world-wide movement against TB and HIV/AIDS.

Yours truly,

Abdurrazack (Zackie) Achmat
Chairperson, Treatment Action Campaign (TAC)
Muizenberg, South Africa

Mohammed Farouk Auwalu
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Lillian Kyomuhangi Mworeko
National Forum for PLHA Networks
Kampala, Uganda

Amos Nota
Homecare Services / ZAMBART
Lusaka, Zambia

and on behalf of

Agnes Adala
Women Fighting AIDS in Kenya (WOFAK)
Nairobi, Kenya

Linda Cynthia Ahor
Coordinator, Policy Project Nigeria/Organisation for Positive
Abuja, Nigeria

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Kim Nichols
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cc: Dr. Nils Billo, IUATLD
Joanne Carter, RESULTS
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Dr. Marcos Espinal, Director, Stop TB Partnership
Dr. Anthony S. Fauci, Director, NIAID, NIH
Dr. Richard Feachem, Director, GFATM
Drs. Helene Gayle, Peter Small, Renée Ridzon,
Bill & Melinda Gates Foundation
Dr. Julie Gerberding, CDC
Dr. Haileyesus Getahun, TB/HIV WHO
Dr. Charlie Gilks, HIV Dept., WHO
Dr. Cate Hankins, UNAIDS
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Open letter to representatives from HIV/AIDS treatment activist organisation[s:]

This open letter is a response to the communication of October 14, 2004 from representatives of HIV/AIDS treatment activist organisations who attended the Fourth Meeting of the Global TB/HIV Working Group in Addis Ababa, Ethiopia on September 20-21, 2004, addressed to us, the Chair of the TB/HIV Working Group, and Directors of the HIV and Stop TB Departments of WHO. The letter by the activists reflected on how best to strengthen the involvement of treatment activists in the worldwide movement against TB/HIV, and included several suggestions for improvement of the current TB control strategy. First of all, in this joint response by the three of us, we salute this timely and appropriate involvement of activist and community groups, which we consider essential if TB and TB/HIV are to be fought effectively. Our response is organised around the key issues raised by the letter.

Expansion of HIV community participation in the Stop TB movement and incorporation of TB/HIV needs into HIV community treatment activist and literacy efforts

Under the umbrella of the Stop TB Partnership, the TB/HIV Working Group has developed a 12-point policy package to address TB/HIV, which includes the involvement of patient support groups and their communities in the planning, implementation and advocacy of collaborative TB/HIV activities. In fact this is already happening through WHO's work with the Futures Group in Ethiopia, Uganda, Tanzania, Nigeria, and Kenya. Malawi, Zambia, South Africa, Mozambique and Ukraine (provided the situation stabilizes) will start shortly. We all need HIV/AIDS activist and community groups to join the Stop TB Partnership, if we are to achieve the global control targets and ultimately obtain a world free of TB. The TB/HIV Working Group has warmly welcomed patient support groups and activists in its policy development and partnership activities, as demonstrated, for example, in its recent meeting in Addis Ababa, Ethiopia. Representation of activists and community groups in its Core Group will shortly be doubled. We expect, and will push for, increased involvement of the HIV community in country missions and training programmes at national and district levels in support of TB and TB/HIV activities. We will assist the inclusion of TB/HIV treatment literacy programmes in GFATM proposals for HIV and TB as well as in national and bilateral programmes.

Increased political commitment to TB control

You can be assured that WHO will continue to fight for TB control for all, whether HIV infected or uninfected. DOTS is now implemented in 180 (out of 210) countries and territories of the world and, through it, over 16 million patients with TB have been diagnosed and treated properly by the end of 2003. It is highly cost-effective, and has resulted in incidence decline in many low HIV settings such as Cuba, Malaysia, Nicaragua and Peru, which have already reached the 2005 TB targets of 70% case detection and 85% cure rate. Prevalence rates fell 37% in response to DOTS in China. Improvements to the treatment regimen have recently been made - rifampicin throughout the 6 month regimen is now the recommended first line treatment (http://wwwstage.who.int/gtb/publications/ttgnp/index.html). We agree that TB diagnosis and treatment should be free. We will continue to press for governments to honour their commitments made at Amsterdam, Abuja and the World Health Assemblies.

Expanding and adapting the DOTS strategy

The DOTS strategy has successfully involved, and will continue involving, community members, families, neighbours, lay health workers, patients, teachers etc. in TB treatment support, including direct observation. We agree that the TB community needs to learn the lessons of the HIV community in promoting evidence-based treatment literacy in order to promote adherence to TB treatment. We welcome any practical suggestions from the community and HIV groups to reinforce treatment support for TB patients.

The HIV epidemic and a surge in drug resistant forms of TB have adversely impacted the implementation of DOTS and the control of TB. In view of these challenges, the Stop TB Partnership and WHO have expanded the scope of DOTS and joined forces to address these emerging issues focusing on a patient-centred approach. We are working with countries affected by MDR-TB to mainstream MDR diagnosis and treatment into the routine programme. We recognize that further work is required to ensure the DOTS strategy remains effective in delivering cures to all people with TB, including those with smear negative and extrapulmonary disease. In addition, however, the joint work on TB/HIV has really only just begun. We look to you, as representatives of the HIV community, to take your share of the responsibility to ensure that TB issues are fully integrated into HIV control efforts.

WHO policy on TB/HIV recommends isoniazid and co-trimoxazole preventive therapies to reduce morbidity and mortality in people living with

HIV. Intensified TB case finding in people living with HIV is recommended in health institutions as well as household contacts, populations at high risk of HIV and congregate settings. HIV testing among TB patients is set to expand, and open the way to far more access to anti-retroviral treatment for such patients. This should build on increased population awareness of the interaction of TB and HIV. However, we are aware that these recommendations are not yet generally followed in countries affected by the dual epidemic. Country level advocacy by activists and community groups to stimulate demand and encourage implementation is overdue. Louder voices from communities demanding realistic solutions to outstanding problems of the health system, such as the health workforce crisis through improved remuneration and working conditions along with positive macroeconomic reforms, are essential. WHO and the TB/HIV Working Group look forward to working in partnership with activist and community groups to add their voices to positive macro-economic reforms that will eventually accelerate country level implementation.

New drugs and tools

Most likely the ultimate control and elimination of TB will be possible only with new diagnostics, new drugs and a vaccine. The Stop TB Partnership has been coordinating efforts to deliver these new tools through its Working Groups. However, more political commitment, scientific interest and resources are needed to hasten this development. We in the TB community look to learn from HIV/AIDS activism, which accelerated production of simple HIV tests and antiretroviral drugs, and apply the same motivation and assertiveness to TB. In the meantime, we will continue supporting operational research with meetings on this topic in December (HIV) and next February (TB/HIV). The latter will address particularly the diagnosis of smear negative pulmonary TB and studies of anti-TB and ARV drug interactions aimed at expanding the evidence available and modifying existing policy.

Finally, we would like to reiterate our personal commitment, and that of our institutions, to work in partnership with HIV/AIDS activist groups for a TB-free world, and to be jointly responsible and jointly held accountable for success or failure. We see the annual TB/HIV Working group meetings as the essential forum for all of us to report on progress.

Dr Gijs Elzinga
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Stop TB Partnership

Dr Jim Kim
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Dr Mario Raviglione
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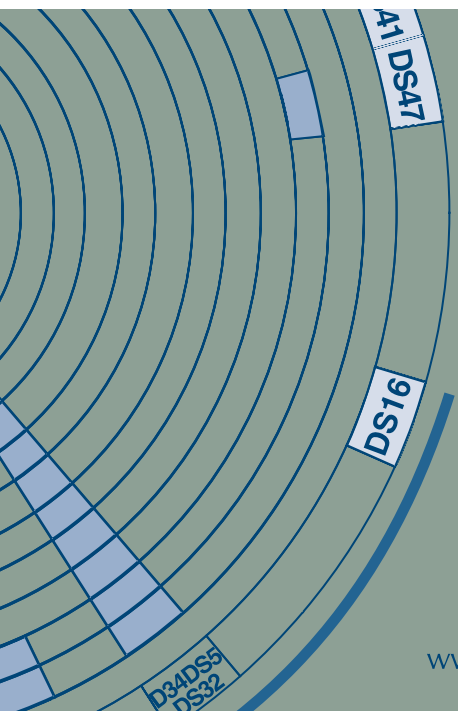
Geneva, 29 November 2004



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