



# Civil Society Perspectives on TB/HIV

Highlights from a joint initiative to promote community-led advocacy

PUBLIC HEALTH WATCH  
Open Society Institute's Public Health Program

TREATMENT ACTION GROUP



# Civil Society Perspectives on TB/HIV

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This publication is cosponsored by the Open Society Institute, a private operating and grantmaking foundation whose aim is to shape public policy in order to promote democratic governance, human rights, and economic, legal, and social reform, and the Treatment Action Group, the first and only AIDS organization dedicated solely to advocating for larger and more efficient research efforts, both public and private, toward finding a cure for the disease.

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## About this Publication

This publication is a collaborative effort of Public Health Watch, a project of the Network Public Health Program at the Open Society Institute (OSI), and the Treatment Action Group (TAG). It highlights the work of six organizations supported by the TB/HIV Advocacy Grants Project, jointly launched by OSI and TAG in 2004. The six case studies presented in the following pages offer a representative sample of the wide range of community-led advocacy activities funded under this project in 2004 and 2005, all of which were geared toward enhancing the capacity of communities to participate actively in the design, implementation, and evaluation of collaborative TB/HIV services and programs.

## Project Team

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## Open Society Institute

The Open Society Institute works to build vibrant and tolerant democracies whose governments are accountable to their citizens. To achieve its mission, OSI seeks to shape public policies that assure greater fairness in political, legal, and economic systems and safeguard fundamental rights. On a local level, OSI implements a range of initiatives to advance justice, education, public health, and independent media. At the same time, OSI builds alliances across borders and continents on issues such as corruption and freedom of information. OSI places a high priority on protecting and improving the lives of marginalized people and communities.

Investor and philanthropist George Soros in 1993 created OSI as a private operating and grantmaking foundation to support his foundations in Central and Eastern Europe and the former Soviet Union. Those foundations were established, starting in 1984, to help countries make the transition from communism. OSI has expanded the activities of the Soros foundations network to encompass the United States and more than 60 countries in Europe, Asia, Africa, and Latin America. Each Soros foundation relies on the expertise of boards composed of eminent citizens who determine individual agendas based on local priorities.

### Public Health Watch

OSI's Public Health Program established Public Health Watch in 2004 to support and promote independent civil society monitoring of government health vis-à-vis international health commitments such as the United Nations Millennium Declaration, the Amsterdam Declaration to Stop TB, the UNGASS Declaration of Commitment on HIV/AIDS, and the WHO Policy on Collaborative TB/HIV Activities. By actively involving and supporting civil society organizations in monitoring and evaluating governmental and international health policies, Public Health Watch seeks to promote greater public engagement in government efforts to fulfill international health commitments, and in turn to increase national ownership of the response to TB, HIV/AIDS, and other diseases.

### Treatment Action Group

The Treatment Action Group (TAG) fights to find a cure for AIDS and to ensure that all people living with HIV receive the necessary treatment, care, and information they need to save their lives. TAG focuses on the AIDS research effort, both public and private, the drug development process, and health care delivery systems. More specifically, the TAG TB/HIV Project works to combat TB/HIV coinfection through a combination of community-based advocacy, education, and mobilization efforts involving AIDS advocates in developed and developing countries targeted at creating policies, increasing resources, and strengthening research to reduce the impact of TB/HIV coinfection.

## Acknowledgments

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**Wan Yanhai** (China)

We would also like to thank Nina Schwalbe, former director of the Public Health Program at OSI and currently director of policy at the Global Alliance for TB Drug Development, who played a critical role in launching the TB/HIV Advocacy Grants Project.

OSI and TAG are grateful to all TB/HIV grant recipients; their insight and rich experiences made this publication possible. Below is a list of 2004 and 2005 grantees.

## 2004 grantees

Centre for Social Reconstruction (India)  
FISS- MST/SIDA (Cameroon)  
Foundation DELO (Russia)  
Fundación Mexicana para la Lucha contra el Sida (Mexico)  
Georgian Plus Group (Georgia)  
Info Center Rainbow (Kyrgyzstan)  
National Forum of PLWHA Networks in Uganda (Uganda)  
Nava Kiran Plus (Nepal)  
Oxygen Research and Development Forum (Nepal)  
Panos Ethiopia (Ethiopia)  
Regional Public Organization “Community of People Living  
with HIV/AIDS” (Russia)  
Salvation (Ukraine)  
Youth Net and Counseling (Malawi)

## 2005 grantees

Agua Buena Human Rights Association (Costa Rica)  
Armenian National AIDS Foundation (Armenia)  
AVE de Mexico (Mexico)  
CARE Foundation (India)  
Centre for Rural Enlightenment, Salvation for Health and  
Environment (India)  
Convictus Eesti (Estonia)  
Credinta (Moldova)  
Gender AIDS Forum (South Africa)  
Georgian Plus Group (Georgia)  
Grupo de Sida por la Vida (Argentina)  
Horizons Femmes (Cameroon)  
Indian Network for People Living with HIV/AIDS (India)  
International Community of Women Living with HIV/AIDS  
(E. Africa Region) (Uganda)  
Latvian Society for Fight against TB (Latvia)  
Remedios AIDS Foundation, Inc. (Philippines)  
Salvation (Ukraine)  
The Shepherd’s Hospice (Sierra Leone)  
Yayasan Spiritia (Indonesia)



# Introduction

OVER THE PAST TWO DECADES, the HIV epidemic has contributed to a global resurgence of tuberculosis (TB). HIV weakens the immune system, greatly reducing an individual's ability to fight off serious coinfections such as TB, as well as many opportunistic infections. In some high HIV-burden African countries, up to 50 percent of HIV-positive people develop active TB, and TB is now among the most common causes of death by infectious disease among people living with HIV. It makes little sense from any perspective—public health, human rights, social or legal—to confront the two diseases separately. Yet there have been too few collaborative responses from HIV/AIDS and TB programs. In many countries, national TB and HIV/AIDS programs and policies are designed and implemented independently of each other. Lack of coordination greatly reduces access to comprehensive treatment and prevention services for people living with HIV and/or TB.

In recognition of these limitations, the World Health Organization (WHO) adopted its *Interim Policy on Collaborative TB/HIV Activities* in 2004. The *TB/HIV Policy* provides guidelines on measures that can be coordinated jointly by national HIV/AIDS programs and national TB programs to reduce the burden of TB among people with HIV and the burden of HIV among TB patients. It emphasizes the importance of building upon existing programs, systems, and resources, and of involving governments, health care providers, patients, and communities in designing and implementing a collective response to the dual epidemic. The *TB/HIV Policy* explicitly recognizes community-led monitoring and advocacy as an important way to promote and increase public demand for accelerated and improved TB/HIV services.

The Open Society Institute (OSI) and the Treatment Action Group (TAG) jointly launched a TB/HIV Advocacy Grants Project in 2004 to encourage implementation of this important component of the *TB/HIV Policy*. The project aimed to provide funding and technical assistance in support of community-led advocacy for more effective and coordinated TB/HIV programs and services.

With assistance from a Community Advisory Committee of seven TB/HIV activists from around the world, the project awarded 31 grants

to community organizations in 21 countries. Grantmaking focused on promoting more attention to TB by activists and organizations with proven expertise and experience with HIV/AIDS treatment literacy and advocacy. Special priority was given to groups that integrated significant participation from people living with HIV into their project plans. The TB/HIV advocacy grants supported implementation of both “top down” and “bottom up” approaches to advocacy, always prioritizing the direct involvement of people living with HIV and/or TB.

# Case Studies, 2004-2005

THE 31 TB/HIV ADVOCACY GRANTS PROJECT recipients faced a wide range of challenges. Some implemented their projects in countries with barely functioning health care systems; others confronted TB and HIV rates that are among the world's highest; and still others sought to mobilize people living with HIV and/or TB in places where stigmatization and discrimination have long hampered significant advocacy efforts. Many had to deal with all of these challenges simultaneously.

Each grantee designed and implemented project activities in the context of different local and national circumstances and needs. This publication presents six case studies to highlight effective community-based work in a representative sample of these diverse settings and situations. The first case study highlights a regional project that reached several countries in the Caribbean region, which has the world's second highest rate of HIV prevalence after sub-Saharan Africa. Other case studies focus on projects implemented in Indonesia, the world's fourth most populous nation; Sierra Leone, a country of six million people which is just emerging from a devastating civil war; South Africa, which has the most HIV-positive people of any country; and Mexico, where adult HIV prevalence barely reaches 0.3 percent. The final case study presents a project that addressed TB/HIV in Ukraine, where the HIV epidemic is concentrated among injection drug users, as is the case in many countries of the former Soviet Union.

All grantee organizations share a commitment to increasing access to prevention and treatment services for HIV and TB by helping enable people affected by both diseases to advocate for these services on their own behalf. This common thread ultimately makes their individual efforts global in nature.

# T.B. can be Cured!

*Seek Early Treatment  
and take your medicines  
Daily*



NA 10

# Agua Buena Human Rights Association

## **SAN JOSE, COSTA RICA**

**Web:** [www.aguabuena.org](http://www.aguabuena.org)

**Type of grant:** regional network

**Grant amount:** \$10,000

**Year awarded:** 2005

### Latin America and the Caribbean

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**TB incidence by number of individuals, all forms (2004): 363,246**

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**TB prevalence by number of individuals, all forms (2004): 466,232**

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**Estimated number of people living with HIV in Latin America (2004): 1.8 million**

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**Estimated number of people living with HIV in the Caribbean (2004): 300,000**

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**HIV prevalence in adult incident TB cases (2004): 10%**

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### **ABOUT THE ORGANIZATION**

Based on the work of a small group of volunteer advocates in Costa Rica in the late 1990s, Agua Buena Human Rights Association was registered as a nongovernmental organization (NGO) in 2001. Agua Buena subsequently expanded its advocacy work to 12 additional countries in Latin America and the Caribbean region. The organization's primary goals are to increase access to ARVs and to identify, expose, and address human rights abuses experienced by people living with HIV. To achieve these goals, Agua Buena works closely with communities affected by HIV/AIDS to:

- build capacity among members of the HIV/AIDS activist community across the region by holding formal and informal workshops to help them become “experts” on issues that affect them; and
- advocate for commitments from health authorities and changes to health systems to increase access to ARVs.

### **PROJECT OBJECTIVES, ACTIVITIES, AND OUTCOMES**

The overall objective of the association’s TB/HIV project was to integrate advocacy related to TB/HIV coinfection into Agua Buena’s ongoing human rights and empowerment activities. The project dovetails with the organization’s longstanding focus on enhancing the leadership capabilities and engagement in policymaking of people living with HIV.

The main target groups of the nine-month project, which began in August 2005, were people living with HIV and/or TB, health care workers and administrators, health ministries, activists, multilateral and bilateral organizations, and private foundations. During the course of the project, Agua Buena implemented TB/HIV advocacy activities in the Dominican Republic, El Salvador, Guatemala, Honduras, Jamaica, and Nicaragua. Several of the key activities are discussed below.

**WORKSHOPS:** Agua Buena organized six workshops for people living with HIV and/or TB to learn more about local needs as a baseline for developing strategies to improve care for TB/HIV coinfection and access to ARV treatment. One workshop in Managua, Nicaragua, focused on selected issues related to TB/HIV coinfection, including the need for comprehensive HIV testing among all TB patients. Another workshop, for 15 people living with HIV in Guatemala, involved presentation and group discussion of the WHO’s *Interim Policy on Collaborative TB/HIV Activities*. Prior to that workshop, none of the participants had been aware that the policy existed. This is true in other countries as well; few activists are aware that the WHO has adopted such a policy. By disseminating the policy, Agua Buena aims to enhance the ability of the HIV/AIDS activist community to demand better care, treatment, and support for TB/HIV coinfection.

**“Securing access to expensive diagnostics and treatments has proven difficult in La Victoria prison, because the national TB program does not cover these services. International donations were secured to treat these cases, but MDR treatment needs to become a standard and sustainable component of the national TB program.”**

**PRISON VISITS:** Agua Buena staff visited a number of prisons in target countries, including a women’s prison in El Salvador and a men’s prison in the Dominican Republic. Through these visits and interviews with NGOs, activists, HIV-positive inmates, and prison health workers, project staff began the process of assessing and documenting the availability of TB/HIV services in prisons.

Agua Buena published and disseminated a report, *Part of the Punishment? HIV/AIDS and TB in La Victoria Prison*, which presents initial findings and recommendations from two visits to La Victoria prison in the Dominican Republic. According to the report:

- Multidrug-resistant tuberculosis (MDR-TB) poses a threat to the health of prisoners; three cases of MDR-TB have already been confirmed. However, “securing access to expensive diagnostics and treatments has proven difficult in La Victoria prison, because the national TB program does not cover these services. International donations were secured to treat these cases, but MDR treatment needs to become a standard and sustainable component of the national TB program.”

- Overcrowding presents a major challenge to effective service delivery because it greatly limits privacy and confidentiality. For example, the report asserts that prisoners being observed taking ARV medications daily by their peers can lead to stigmatization and discriminatory treatment.
- Access to nutritious food and clean water is practically nonexistent. This makes it very difficult for prisoners to adhere to and complete treatment for either TB or HIV/AIDS.
- Little or no information is available to raise awareness among prisoners about HIV prevention, ARV treatment, TB, TB/HIV coinfection, MDR-TB, or human rights in general. Condoms were largely unavailable in the facility.

Agua Buena will continue to draw attention to important issues affecting HIV-positive prisoners across the region and to advocate for improvements on their behalf. Conditions are such that inmates are at increased risk for both HIV and TB infection, and prisons often lack access to basic health services including HIV and TB care and diagnostics.

**REPORTS:** Agua Buena also produced a series of reports about TB/HIV in target countries, which highlighted the following issues:

- TB treatment issues in Jamaica. Although TB rates are relatively low in Jamaica, HIV poses a significant threat to national TB-control efforts. The main challenges are insufficient training on TB and TB/HIV coinfection for medical personnel and a lack of consistent access to TB diagnostic and treatment services, TB medicines (including treatment for MDR-TB), and ARVs for people living with HIV and/or TB.
- ARV access in Nicaragua. There is an urgent need for improved treatment and testing services for TB/HIV coinfecting individuals. For example, as of February 2006, most of the estimated 2,200 people living with TB had not been tested for HIV.
- TB/HIV coinfection in Honduras. TB and HIV services are not integrated at the clinical and community levels. By empowering and supporting people living with HIV and/or TB, demand for more integrated services would increase.



## RECOMMENDATIONS

Based on Agua Buena's work in Latin America and the Caribbean, project staff recommend that all stakeholders involved in TB/HIV work emphasize the following:

- Further research and reporting on the need for better care and treatment for TB/HIV coinfection in prisons throughout Latin America.
- Targeted efforts to help people living with HIV, AIDS activists, AIDS researchers, and policymakers learn about TB/HIV coinfection and integrate these issues into their existing advocacy agendas.
- Increased involvement from people living with HIV and/or TB in the design and implementation of all projects intended to benefit them. Input from HIV-positive and TB/HIV coinfecting prisoners, drug users, activists, men who have sex with men, transvestites, migrants, and ethnic minorities is vital for ensuring the consistency, intensity, and effectiveness of advocacy efforts.
- Workshops and other outreach efforts for people living with HIV as well as TB patients who do not have HIV to learn more about the interaction between TB and HIV and the need for integrated policies and services. Feedback obtained through these workshops could provide input for governments seeking to develop more effective TB/HIV policies.
- Awareness-raising activities aimed at high-level decision makers in national HIV and TB programs to draw attention to the need for greater coordination of HIV and TB control efforts.

The final recommendation is of particular importance in countries receiving assistance from the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM). Although the GFATM is simultaneously supporting large programs for treatment of HIV and TB in many countries, grant agreements do not always insist upon coordination on issues related to coinfection. The GFATM should consider establishing mechanisms to encourage coordination between HIV and TB projects receiving funding from current and future grants.

## **Charter on TB/HIV Prevention and Care Rights**

**People living with HIV have the right to the highest quality of care for TB/HIV coinfection that can be achieved. The specific rights that must be upheld to obtain this goal include:**

- The right to social organization and mobilization**
- The right to information and education**
- The right to prevention, care, counseling and support**
- The right to be treated for TB coinfection and other opportunistic infections**
- The right to learn about side effects and interactions from both TB and HIV medications**
- The right to be free from stigma, discrimination, and marginalization in health care settings**
- The right to the benefits of scientific progress**

# Fundación Mexicana para la Lucha contra el Sida

## MEXICO CITY, MEXICO

Type of grant: national

Grant amount: \$5,000

Year awarded: 2004

### Mexico

Total population (2006): 107,449,525

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TB incidence by number of individuals, all forms (2004): 33,529

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TB prevalence by number of individuals, all forms (2004): 45,710

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Adult HIV prevalence (end 2003): 0.3%

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HIV prevalence in adult incident TB cases (2004): 1.7%

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### ABOUT THE ORGANIZATION

Fundación Mexicana is a registered NGO that has been focusing on HIV/AIDS issues in Mexico since 1996. The organization has played a critical role in supporting comprehensive health care services for people affected by HIV.

◀ Draft Charter on TB/HIV Prevention and Care Rights, prepared by people living with HIV in consultation with Fundación Mexicana para la Lucha contra el Sida

## PROJECT OBJECTIVES AND ACTIVITIES

According to Fundación Mexicana, most Mexicans lack access to accurate information about TB/HIV. As a result, people living with HIV as well as those at high risk of HIV or TB infection are not well-placed to press for more effective TB/HIV prevention services, diagnostics, treatment, and care.

The six-month TB/HIV project, which began in January 2005, sought to address these issues in Ciudad Nezahualcóyotl, a large city with rising rates of HIV and TB. The project's overall goal was to educate people living with HIV about the linkage between TB and HIV through peer outreach by HIV-positive individuals. Outreach efforts focused on encouraging HIV-positive people in the community to seek treatment and care for TB/HIV coinfection and empowering them to advocate for better integration of TB/HIV services. Organization staff emphasized a rights-based approach in all aspects of the project, including the need to document violations of the rights of people living with HIV and/or TB to appropriate health and legal services.

**“When [the doctors] detected that I had tuberculosis, they did not ask me about the medication I was taking for HIV. I began the TB treatment and noticed right away that instead of getting better, I got worse. No one explained anything to me.”**

Project staff first organized 10 in-depth interviews with people living with HIV to assess their needs; their knowledge, attitudes, and behaviors related to TB and HIV; and their access to quality health services. The interviews revealed that most participants were unaware that TB is an opportunistic disease related to HIV infection and that TB can be treated and cured. Most participants were also unaware of the signs and symptoms of TB and how to prevent infection. Health care personnel regularly failed to give patients important information and assistance regarding their condition. According to one HIV-positive interviewee, “When [the doctors] detected that I had tuberculosis, they did not ask me about the medication I was taking for HIV. I began the TB treatment and noticed right away that instead of getting better, I got worse. No one explained anything to me.”

On the basis of these interviews, project staff organized five workshops for a total of 100 people living with HIV. The workshops had two components: peer education and advocacy. During the peer education sessions, HIV-positive peer educators provided participants with essential information about TB and HIV and the links between the two diseases. The advocacy session was dedicated to identifying key messages and strategies by which participants could advocate for better health services and launch community-driven TB and HIV programs.

Following the workshops, Fundación Mexicana organized a public meeting in June 2005 that was attended by more than 50 government health personnel, including TB program coordinators, nurses from community health centers, the local state HIV/AIDS program coordinator, and the under-secretary of health from the local state government. At the meeting, the project coordinator introduced the TB/HIV project and summarized TB/HIV coinfection issues from the perspective of people living with HIV. This event served as an opportunity to highlight the need for coordinated TB/HIV services among local and national stakeholders. According to the coordinator, there are still significant challenges to provision of TB services to HIV-positive individuals and HIV care to TB patients, especially given the scarcity of resources for care and treatment. Health personnel who participated in the meeting expressed enthusiasm to play a greater role in promoting TB/HIV collaboration in their health facilities.

## **PROJECT OUTCOMES, LESSONS LEARNED, AND NEXT STEPS**

A key outcome of the project was the development of a draft Charter on TB/HIV Prevention and Care Rights. The charter, which was written by people living with HIV, outlines seven specific “rights” related to treatment and care for TB/HIV coinfection (see page 16). The text draws upon perspectives gathered during the public meeting with health policymakers; interviews and workshops with people living with HIV; and human rights instruments, including the UN Universal Declaration of Human Rights. Fundación Mexicana plans to advocate for the Mexican government to adopt the charter; Fundación Mexicana also plans to publicize the charter among people living with HIV and/or TB and civil society in general.

Fundación Mexicana noted that its alliance with key governmental and nongovernmental stakeholders contributed to the project’s success, and that leadership of people living with HIV played a critical role in articulating what would be necessary to achieve more effective and comprehensive TB/HIV policy and programming.

Based on the results of the project, Fundación Mexicana recommends that all stakeholders involved in TB/HIV work in Mexico emphasize the following:

- operational research on DOTS and the interaction between TB drugs and ARVs, in collaboration with local TB/HIV public health officers
- technical support and assistance from donors to support social mobilization and education efforts around TB/HIV coinfection among people living with HIV
- efforts to reduce stigma and address discrimination against people living with HIV and/or TB in public health facilities and more generally
- greater participation of people living with HIV and/or TB in policy planning, implementation, and evaluation as well as in the design and dissemination of clear, accessible, and culturally sensitive information, education, and communication materials
- increased training and sensitization related to TB and HIV for public health personnel

Fundación Mexicana's TB/HIV project has inspired other organizations and funders to take up similar work. For example, one new project has initiated TB/HIV awareness-raising activities in Ciudad Juarez, a city on the Mexican-U.S. border that is a transit area for many Mexican and Central American migrants to the United States. It is headed and coordinated by the United States–Mexico Border Health Association (USMBHA) in El Paso, Texas, in partnership with two Mexican NGOs, SISEX and Programa Compañeros. The initiative has received funding from the U.S. Agency for International Development (USAID).



**POSITIVE**



# Gender AIDS Forum

## **DURBAN, SOUTH AFRICA**

**Web:** [www.gaf.org.za](http://www.gaf.org.za)

**Type of grant:** national

**Grant amount:** \$5,000

**Year awarded:** 2005

### South Africa

**Total population (2006):** 44,187,637

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**TB incidence by number of individuals, all forms (2004):** 339,078

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**TB prevalence by number of individuals, all forms (2004):** 316,260

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**Adult HIV prevalence (end 2003):** 21.5%

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**HIV prevalence in adult incident TB cases (2004):** 60%

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### **ABOUT THE ORGANIZATION**

Gender AIDS Forum (GAF) is an NGO that promotes greater sensitivity, responsiveness, and action on gender issues in the context of HIV/AIDS in South Africa. It was founded in 1998 at the launch of a special edition of *Agenda*, a South African feminist journal. GAF focuses on three main program areas: advocacy, empowerment, and knowledge creation.

## PROJECT OBJECTIVES AND ACTIVITIES

GAF's interest in the TB/HIV project stemmed from widespread acknowledgment throughout South Africa that the links between HIV and TB have not been adequately addressed by either the government or civil society. According to GAF, there has also been inadequate consideration of the special challenges faced by women with TB. With the number of new TB cases increasing by an estimated 7 percent per year in South Africa, it is important to recognize and respond to these challenges as quickly and thoroughly as possible.

The main objective of the GAF project was to develop a “gendered understanding” of TB and its links to HIV in South Africa by examining all factors that may increase the vulnerability of women to these diseases and hinder their access to care, treatment, and support. Through a research process culminating in the publication of a position paper, GAF sought to increase in-house awareness of salient issues related to TB/HIV as a first step in developing a strong advocacy agenda.

GAF initially organized a TB literacy workshop to educate its staff on the technical aspects of TB, including treatment options. GAF staff then conducted a review of existing information and resources on the links between HIV, TB, and gender. This preparatory desktop review helped guide the team charged with designing the research project. One of the team's major objectives was to include fully the most affected individuals—people living with HIV and/or TB and women—in the research process. To that end, the team collected additional information and observations for the report by conducting in-depth interviews with two health care workers and four individuals (two women and two men) who were living with HIV and also have or have had TB. The research team also conducted a focus group meeting with a support group for women living with HIV. The final result was a position paper that analyzes the links between HIV, TB, and gender from the perspective of people living with both diseases and outlines an advocacy agenda for the organization that is informed by this perspective.

## PROJECT OUTCOMES, RECOMMENDATIONS, AND NEXT STEPS

Research findings indicated significant shortfalls in the current South African response to HIV and TB in general, and among women specifically. First, although national TB-control guidelines acknowledge the links between TB and HIV infection, services for the two diseases are rarely coordinated and correlated on the ground—a direct result of the lack of mainstreaming of TB into HIV/AIDS programs. Second, there is little strategic monitoring and evaluation to track the progress of efforts to develop more effectively integrated services for people living with both HIV and TB.

The position paper also noted the following additional obstacles to integrating TB and HIV services in South Africa effectively:

- significant and debilitating stigmatization and discrimination related to both diseases, particularly for women
- limited knowledge about the interaction between HIV and TB among health care workers
- lack of access to basic health care services
- lack of adherence to DOTS TB treatment
- challenges to TB case detection among HIV-positive people

**“The health care workers never wanted to listen when I told them that I had all the symptoms of someone infected with TB. I was examined six times before it was detected.”**

GAF interviews revealed the extent to which these obstacles hinder access to effective treatment and support. According to one woman, “The health care workers never wanted to listen when I told them that I had all the symptoms of someone infected with TB. I was examined six times before it was detected.” Another woman explained: “I tested HIV-positive in 2000, but my partner decided to leave me when I was diagnosed with TB in 2001.”

In February 2006, GAF convened a community experts meeting in Durban to discuss and solicit feedback on the research findings. Thirty women and men from a range of support groups and civil society organizations attended the meeting, as did several municipal officials and staff from government agencies. Participants discussed how to build an effective TB/HIV advocacy agenda that would feed into GAF’s “Claim Back the Right” campaign, which focuses on influencing policy at both the national and community levels and on monitoring at the grassroots level to obtain full access to all HIV prevention and treatment options for women and other marginalized individuals.

GAF’s research helped ensure that TB was written into the “Critical Elements,” a set of demands from civil society organizations to improve the National AIDS Plan. The Critical Elements were presented at a breakfast for influential women on International Women’s Day, March 8, 2006, and were endorsed by the national deputy minister of health.

Based on the research process and findings, as well as the February 2006 community experts meeting, GAF identified the following recommendations for all stakeholders involved in advocacy efforts regarding HIV, TB, and gender:

- Review existing health policies to identify where and how strategies to improve access to integrated HIV and TB services for women could be incorporated.
- Support community-led social research to examine the ways in which women are especially vulnerable to TB/HIV coinfection and the factors that may prevent them from seeking or completing treatment.
- Draw upon research findings to support informed advocacy around the need for integrated TB/HIV services that are responsive to the special needs and vulnerabilities of women.

- Train health care workers to be more responsive to the needs of women in provision of TB diagnostic and treatment services.
- Encourage civil society organizations working on health issues to integrate TB and the specific gender issues related to coinfection into their existing advocacy agendas.

GAF plans to advocate for implementation of these recommendations, particularly around the need for further research and programming to articulate and respond to the vulnerabilities of women with regard to the TB/HIV coepidemic.

аміноміди та тубіцином, відновитися від вживання наркотиків.

- Необхідно щороку проходити флюорографічне обстеження легень, або сучасними методами робити аналіз мокротиння на наявність мікобактерій туберкульозу.

- Якщо Ви є ВІЛ-позитивним людиною, споживаєте наркотичні засоби, зловживаєте алкоголем, не маєте постійного місця проживання, необхідно проходити флюорографічне обстеження легень двічі на рік.

Флюорографічне обстеження можна пройти у кабінетах флюорографії загальної лікувальної мережі за місцем проживання (міських поліклініках). Аналіз мокротиння на наявність мікобактерій туберкульозу можна зробити за направленням дієвочного терапевта у бактеріологічній лабораторії поліклініки. У разі виявлення туберкульозу, збори направляються на стаціонарне лікування у протитуберкульозний заклад. Медичні препарати, лікування і дарування безкоштовно.

### **Вам'ятайте!**

**Туберкульоз можна вилікувати, але тільки в тому разі, якщо Ви своєчасно розпочнете його лікування та будете дотримуватись рекомендацій лікаря.**

Якщо у Вас виникли питання стосовно туберкульозу або ВІЛ/СНІДу, звертайтеся за допомогою до громадської організації «ПОРЯТУНОК» за телефоном (0536) 79-67-14.

Якщо Ви є ВІЛ-позитивною людиною, прийміть антиретровірусну терапію дотримуючись Вашого лікаря, що запобіжить ускладненню на останній туберкульоз. За допомогою звертайтеся до спеціалізованого кабінету лічби з профілактики ВІЛ-інфекції, що діє при обсягах повільності № 3 за телефоном: (05366) 5-36-25 або 5-37-08.

Буклет надруковано в рамках проекту громадської організації «ПОРЯТУНОК» за підтримки гранту фонду інституту відкритого суспільства (Zig).

Зміст буклету є відповідальністю замовника.

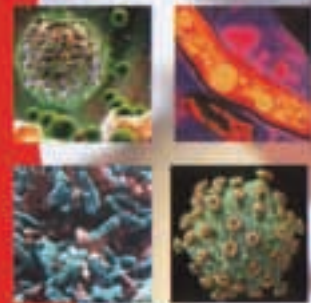
Консультаційному центру у реалізації проекту були в елітні Кременчуцького обласного спеціального управління зрані та Кременчуцьким обласним центром туберкульозним диспансером. Рівнозначність є безплатною.

Зак. № 49-Д, тир. 1000 екз.

### **Виконавець проекту**

Громадська організація «ПОРЯТУНОК»  
адреса: 39617, вул. 40-річчя Жовтня, 15/50,  
м. Кременчук, Полтавська обл., Україна  
тел./факс: + 38 (0536) 79-67-14, 79-67-15

# туберкульоз та ВІЛ/СНІД : ЩО ТРЕБА ЗНАТИ



# Salvation

## KREMENCHUK, UKRAINE

Type of grant: national

Grant amount: \$5,000

Years awarded: 2004 and 2005

### Ukraine

Total population (2006): 46,710,816

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TB incidence by number of individuals, all forms (2004): 47,227

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TB prevalence by number of individuals, all forms (2004): 70,878

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Adult HIV prevalence (end 2003): 1.4%

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HIV prevalence in adult incident TB cases (2004): 8.3%

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### ABOUT THE ORGANIZATION

Salvation was established as an NGO in 1999, just as HIV rates had begun to rise sharply in tandem with a surge in drug use in Ukraine. Injection drug users have comprised the majority of people living with HIV in the country since the beginning of the epidemic. Salvation has worked extensively on HIV prevention activities, such as needle exchange, peer education, and “telephone trust points” where clients can receive confidential and cost-free consultations with Salvation social workers and health specialists.

### PROJECT OBJECTIVES AND ACTIVITIES

TB rates are high in Ukraine, particularly among people living with HIV,

prisoners, injection drug users, and sex workers. In Kremenchuk, for example—a city of about 225,000 people in east-central Ukraine—there were 1,784 officially registered TB cases (and 183 active cases) in early 2006.

However, relatively few individuals living with HIV and/or TB have access to accurate information about treatment and prevention options. Salvation's TB/HIV project—which consisted of two separate grants, one awarded in 2004 and another in 2005—focused on raising awareness of key issues related to TB/HIV coinfection and promoting advocacy activities by coinfecting individuals and people living with HIV. To this end, people living with HIV and/or TB engaged in a variety of project activities, including working closely with Salvation staff during project evaluation meetings and peer education trainings, and in considering potential future TB/HIV initiatives.

#### **2004 GRANT**

With its first grant, implemented over a six-month period ending in August 2005, Salvation aimed to improve local services related to TB/HIV coinfection and TB prevention among people living with or at risk of HIV/AIDS in Kremenchuk. Although TB diagnostic and treatment services are free in Ukraine, accessing these services requires proof of occupation and residency, a requirement that makes it difficult for individuals who do not have steady employment or housing to obtain medical attention. As a result of Salvation's successful advocacy efforts, the local municipal TB ambulatory clinic agreed to grant Salvation clients direct access to free X-ray inspection, sputum analysis, and TB treatment even in the absence of employment or housing records. This agreement has had profound effects for many of the people most at risk of HIV and/or TB infection, including injection drug users and sex workers.

People living with HIV played an active role in this achievement as well as in the development of policy recommendations for inclusion in the municipal HIV/AIDS program for 2005–2008. Several of them also helped organize Salvation's peer education training or were themselves trained as peer educators.

#### **2005 GRANT**

Upon the conclusion of the first grant, Salvation embarked on another



six-month OSI-funded TB/HIV project in September 2005. Its primary goal in this second grant period was to advocate for better coordination of TB and HIV programs at the local level. Salvation sought to achieve this by supporting the implementation and improved coordination of joint TB/HIV planning among government health agencies and other health care facilities and organizations.

Salvation's advocacy activities in pursuit of this objective included:

- capacity building among health care workers (including doctors);
- media outreach to influence public attitudes towards TB/HIV;
- roundtable meetings with local authorities, public health workers, and staff at NGOs to exchange ideas on how to improve coordination of TB and HIV services; and
- awareness-building around TB/HIV through distribution of treatment literacy material.

Over the course of the project, Salvation engaged partners at all levels—from municipal policymakers to intake staff at clinics to HIV-positive individuals with little or no knowledge about either HIV or TB. Project staff provided training to people living with HIV and/or TB as part of an effort to expand community involvement in current and future advocacy efforts.

## **PROJECT OUTCOMES**

One outcome of the second grant deserves special attention because it is likely to have far-ranging implications. Salvation staff succeeded in persuading the chief doctor of Kremenchuk's municipal health care department to issue a decree mandating TB prevention services and TB/HIV coinfection counseling for HIV-positive people at the city's HIV test sites. This means that health care workers will now provide patients with information about the risks of HIV-related TB, how to prevent coinfection, and where to seek services. They will also encourage at-risk patients to get tested for TB at the municipal TB ambulatory clinic.

The decree has marked an important shift in policy: It was the first time the issue of HIV-related TB had been publicly raised by health authorities in Kremenchuk. People living with or at risk of HIV now have greater access to information about the risks of TB/HIV coinfection, methods for preventing TB infection, available tools for TB diagnosis, and treatment

options. The decree may also expand TB services to communities affected by HIV/AIDS and establish or strengthen linkages between the HIV and TB programs. All of this sets the stage for increased TB case detection among HIV-positive individuals. In fact, according to Salvation a total of 62 people with TB received free HIV tests immediately following the decree. Of these, 12 were found to be HIV-positive. In addition, more than 60 individuals considered at risk for TB received X-ray examinations and other health care assistance.

Significant challenges remain despite these advances. For example, most health care workers need additional training before they can provide adequate counseling. There is also a need for expanded information and education campaigns to raise awareness about HIV and TB among people most at risk, thus strengthening their motivation to seek out treatment and care.

While acknowledging the extensive work that still needs to be done, Tetyana Vatulyova, a trainer–psychologist, observed that advocacy conducted through Salvation’s TB/HIV project “gave us a unique chance to organize training sessions for doctors and health care professionals—to teach them how to provide more effective counseling around TB and HIV issues. It made it possible to set a baseline for the establishment of mutual understanding among health workers and patients.”

Salvation’s experience highlights the value for community groups of establishing working relationships with policymakers and health care officials. Forming positive relationships of this sort is not always possible for a variety of reasons, but doing so can have far-reaching policy implications. Salvation’s efforts in Kremenchuk could conceivably serve as an impetus for useful national or regional policy change as well—a possibility the organization hopes to pursue in future advocacy efforts.

**“There is a need for expanded information and education campaigns to raise awareness about HIV and TB among people most at risk.”**

## PERSISTENT OBSTACLES AND RECOMMENDATIONS

During the course of the two grants, Salvation noted several obstacles that could limit or even derail the momentum on improving services for people living with HIV and/or TB. First, there is a lack of statistical information to accurately determine rates of TB/HIV coinfection in Kremenchuk. Second, policy development and implementation are made more difficult by negative public attitudes toward vulnerable groups and people living with HIV as well as by low public awareness of the facts about TB and HIV. Third, many public officials do not recognize the importance of patient involvement in policy development and implementation. Fourth, there is lagging coordination among various municipal agencies involved in TB and/or HIV prevention and treatment services. Finally, case detection efforts around both HIV and TB in Kremenchuk are insufficient, particularly with regard to precisely those groups at highest risk of infection.

Salvation identified and has integrated into its own advocacy agenda the following recommendations for all stakeholders:

- Advocate for the allocation of targeted funds from the local budget to support awareness-raising activities around issues related to TB/HIV coinfection.
- Build and strengthen NGO capacity to engage in policy development and implementation around the need for TB/HIV collaborative activities in Ukraine.
- Develop a training course on TB/HIV issues with the cooperation and participation of public authorities and patients.
- Involve NGOs and community organizations in monitoring and evaluation activities to assess the quality and delivery of collaborative TB/HIV activities and services.
- Design and implement strategies to improve public attitudes toward people living with HIV and/or TB and members of vulnerable groups.
- Strengthen coordination among municipal agencies and programs involved in TB and/or HIV prevention and treatment services.



# The Shepherd's Hospice

## FREETOWN, SIERRA LEONE

Type of grant: national

Grant amount: \$5,000

Year awarded: 2005

### Sierra Leone

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Total population (2006): 6,005,250

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TB incidence by number of individuals, all forms (2004): 45,215

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TB prevalence by number of individuals, all forms (2004): 23,652

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Adult HIV prevalence (2005): 1.5%

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HIV prevalence in adult incident TB cases (2004): 9.9%

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### ABOUT THE ORGANIZATION

The Shepherd's Hospice is the only NGO provider of palliative care in Sierra Leone. Since its founding in 1995, the organization has cared for more than 1,500 people—two-thirds of whom were living with HIV. Many of those individuals have also been treated for TB.

The hospice has been directly involved in addressing HIV/AIDS since its inception, including through the following activities:

- training community volunteers, many of whom are HIV-positive or family members of people living with HIV, in prevention and home-based care

- providing educational, medical, and legal support for AIDS orphans
- training members of the HIV/AIDS Advocacy and Support Association Sierra Leone (HASASL) who are willing to be open about their HIV status to work to reduce stigma and discrimination
- conducting various surveys, including a general HIV/AIDS needs assessment survey in 1997 and one on AIDS orphans and vulnerable children in 2002
- developing a resource center to provide researchers, volunteers, and program managers with the most up-to-date and relevant information about HIV/AIDS prevention, treatment, and care
- training advocates who help promote treatment literacy for HIV and TB patients, including DOTS

### **PROJECT OBJECTIVES AND ACTIVITIES**

Most people in Sierra Leone know little or nothing about HIV and TB. As a result, misconceptions about both diseases are commonplace and create an environment in which stigmatization and discrimination can be severe. The Shepherd's Hospice TB/HIV project was based on the belief that addressing these negative attitudes must be a crucial element of any effective strategy or policy to address the HIV and TB epidemics; and that the most effective way of addressing stigmatization is by increasing knowledge and capacity among all stakeholders—including the government, multilateral and bilateral donors, and people living with HIV and/or TB.

The project focused on advocating for the development of a comprehensive, collaborative policy for HIV/AIDS and TB at the national level. This approach was based on the observation that both the Ministry of Health and the National AIDS Council have structured their responses to the diseases vertically, thus duplicating efforts, reducing effectiveness, and hindering the flow of essential information. At best, patients are inconvenienced by this inefficient use of resources; at worst, it can prove fatal. As noted by a home care nurse, “Some patients suffer from coinfection and need both TB treatment and ARVs. Sadly, these services are found under different roofs, and transportation and diagnostic costs are unaffordable for some patients. How can such patients access treatment and continue adherence?”

**“Some patients suffer from coinfection and need both TB treatment and ARVs. Sadly, these services are found under different roofs, and transportation and diagnostic costs are unaffordable for some patients. How can such patients access treatment and continue adherence?”**

Project staff conducted in-depth interviews and focus group discussions with stakeholders from the National TB Control Program, the WHO, the Ministry of Health, HASASL, and community DOTS centers. The baseline research examined the current situation with regard to the following issues:

- access to TB prevention and treatment services
- access to HIV prevention and treatment services
- national TB/HIV coordination mechanisms
- available resources for TB/HIV responses at the national level
- advocacy related to the development of collaborative policies on TB and HIV

Through these interviews and focus group discussions, the Shepherd’s Hospice staff also explored how to promote greater involvement of people living with HIV and/or TB in the national response to both diseases.

### **PROJECT OUTCOMES AND RECOMMENDATIONS**

The Shepherd’s Hospice prepared a report and used it to conduct targeted advocacy on TB/HIV issues with policymakers and service providers and to influence a positive change in public attitudes toward people affected by

the two diseases. One immediate outcome was a newly formed Partnership Forum on HIV, which includes people living with HIV as well as the manager of the National TB Program. The forum aims to promote a more fully integrated response to TB and HIV. It operates under the guidance of UNAIDS and the WHO, and is chaired by the National AIDS Secretariat.

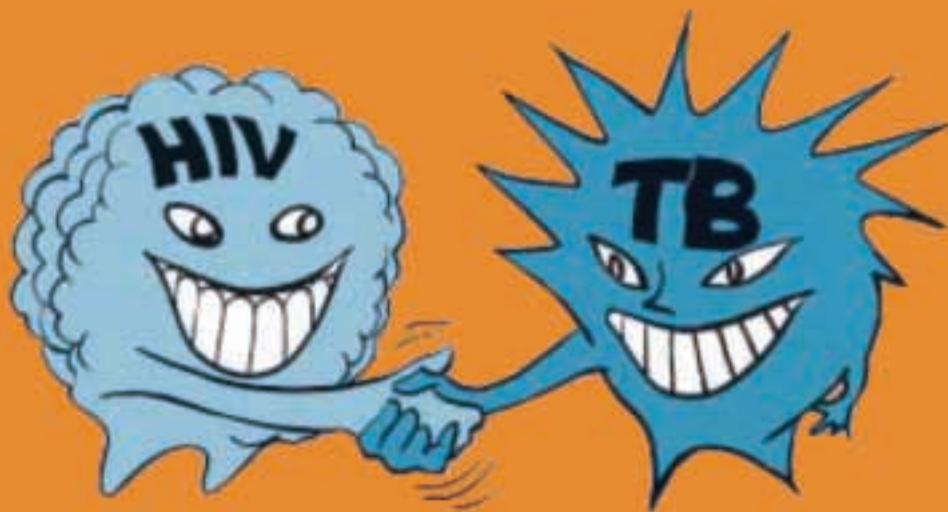
Furthermore, the project laid the groundwork for a proposal to scale up DOTS with the assistance of the Fund for Innovative DOTS Expansion Through Local Initiatives to Stop TB (FIDELIS), which is administered by the International Union Against Tuberculosis and Lung Disease and supported by the Canadian International Development Agency (CIDA). Implemented with the involvement of community volunteers, this DOTS scale-up effort is expected to lead to greater detection and access to treatment for both HIV and TB.

The Shepherd's Hospice TB/HIV project and the subsequent FIDELIS-supported DOTS expansion effort appear strong and sustainable for two key reasons: all major stakeholders recognize and welcome the project's objectives, and the early and direct involvement of the media should broaden public scrutiny of project implementation. In other words, progress will be encouraged both by internal stakeholders who are invested in the success of the project and by external pressure generated by media coverage. Upon conclusion of the project, the Shepherd's Hospice staff offered five general recommendations for all stakeholders engaged in TB/HIV work:

- Make research an integral component of TB/HIV advocacy efforts, because evidence-based advocacy works best in mobilizing a national response to health needs.
- Pay attention to sustainability when designing policy advocacy projects, because policy change does not happen overnight. It is important to mobilize not only resources but the goodwill to ensure that advocacy efforts can be maintained over the long term.
- Rely on community participation to reduce service delivery costs, because universal access to treatment for HIV and TB can only be achieved through partnership between state and nonstate partners.
- Link to poverty-reduction because TB has a devastating impact on the financial well-being of individuals and their families and on the economy as a whole. Advocacy efforts must focus on promoting broader poverty-reduction efforts, rather than a narrow individual and public health approach.



- Adopt a rights-based approach that includes substantive participation by people living with HIV and/or TB. Individuals who are directly affected by the diseases are generally the most committed and passionate advocates for policy change.



▲ Graphic illustration from informational booklet on TB/HIV prepared by Yayasan Spiritia

# Yayasan Spiritia

## JAKARTA, INDONESIA

**Web:** [www.spiritia.or.id](http://www.spiritia.or.id)

**Type of grant:** national

**Grant amount:** \$5,000

**Year awarded:** 2005

### Indonesia

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Total population (2006): 245,452,739

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TB incidence by number of individuals, all forms (2004): 539,189

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TB prevalence by number of individuals, all forms (2004): 605,759

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Adult HIV prevalence (end 2003): 0.1%

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HIV prevalence in adult incident TB cases (2004): 0.9%

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### ABOUT THE ORGANIZATION

Yayasan Spiritia was formed in 1995 as a peer support group for people in the Jakarta region who were infected and affected by HIV. The organization is now national in scope; since 2001, it has served as the secretariat of a countrywide network of peer support groups. The organization's consistent guiding principle has been to empower people living with HIV to play an active and meaningful role in the response to the AIDS epidemic in Indonesia.

## PROJECT OBJECTIVES AND ACTIVITIES

The overall objective of Spiritia's TB/HIV project was to equip members of the national peer support network of people living with HIV with the knowledge and resources to carry out advocacy at a local level in support of integrated responses to HIV and TB. In addition, the project sought to reinforce earlier efforts to advocate for a more comprehensive national policy regarding HIV and TB coinfection.

The project's main output was a 36-page informational booklet on HIV and TB. Written in Bahasa Indonesia, the country's national language, and containing numerous colorful and instructive illustrations, the booklet is intended to provide members of the network—most of whom are living with or affected by HIV and/or TB—the tools and information they need to educate others about both diseases and to advocate successfully for policy change in the areas of prevention and treatment. A key message of the booklet is that TB is preventable and treatable among people living with HIV. Caregivers are among its primary audience, as noted by Yuni, a Spiritia peer support coordinator who has been living with HIV since 1997: “In many parts of the country, doctors treating TB often are not really aware of HIV. This booklet will help to raise their concern, and perhaps identify cases of coinfection earlier.”

The booklet development process began in September 2005, when Spiritia members circulated an initial in-house draft to peer support groups and other stakeholders around Indonesia for comment and feedback. Organizations receiving copies ranged from local NGOs to staff at the TB group in the WHO's Indonesia office. Representatives from some 20 groups, including individuals living with HIV and/or TB, met in November to review the draft and consider revisions based on the feedback. The manager of the Indonesian Ministry of Health's National TB Control Program also attended the meeting.

Spiritia staff members completed a final draft in March 2006. Three thousand copies were printed prior to the official launch, which took place in April 2006 at a half-day meeting in Jakarta attended by some 50 participants from the Ministry of Health, community health centers, AIDS referral hospitals, NGOs working in the field of TB, and the local UNAIDS and WHO offices. They were joined by several journalists and numerous members of the Spiritia-led peer support network.

**“In many parts of the country, doctors treating TB often are not really aware of HIV. This booklet will help to raise their concern, and perhaps identify cases of coinfection earlier.”**

Speakers at the launch included the head of the AIDS sub-directorate in the Communicable Diseases Directorate-General of the Ministry of Health; the manager of the National TB Control Program; a leading Indonesian specialist in pulmonary medicine; and one of the founders of Spiritia (who had previously been treated for extrapulmonary TB). The wide range of interests and expertise among both participants and speakers offers great hope for the further strengthening of partnerships involving the government, civil society, and community groups in the fight against TB and HIV in Indonesia.

### **PROJECT OUTCOMES**

Copies of the booklet were distributed throughout the Spiritia network as well as to other NGOs active on other HIV/AIDS issues, such as prevention and service provision to injection drug users. Wide distribution of the booklet has had the effect of raising awareness around the country of the risks of TB among HIV-positive people and how and when to treat coinfection, among other issues. According to Caroline, a woman who has been living with HIV since 2004, “While I have never experienced TB symptoms, this booklet will be most useful for me because it helps me to better protect myself against TB. I have learned a lot, such as how TB is transmitted, the interaction between HIV and TB, which treatment comes first, immunization, and so on. The booklet is prepared in simple language and with interesting illustrations, which will help other lay people like me to understand HIV and TB.”

Furthermore, the project complemented and strengthened an ongoing TB/HIV advocacy effort that had made slow progress in the previous six years. This effort gained greater prominence during the run up to the

booklet preparation, when the national TB program manager addressed a session on HIV and TB at an inaugural HIV treatment educator training course. Participants at the session raised a number of concerns regarding TB treatment for HIV-positive people, and they urged the manager—successfully, as it turned out—to expand the DOTS program to national AIDS referral hospitals.

This step is expected to provide better and more affordable services to coinfecting people and to lead to greater detection of TB, particularly among people with HIV. The expansion should be especially noteworthy on Java, the nation's most populous island, where patients tend to visit hospitals rather than community health centers. The TB/HIV project also helped spur policymakers to agree that “one-stop” treatment facilities for HIV and TB should be a health care priority at both large hospitals and community clinics.

### **NEXT STEPS**

Support from the Ford Foundation will allow Spiritia to revise and reprint the booklet as needed in the short and long term. Spiritia has also agreed to prepare a pocket-sized version in response to a direct request from the manager of the National TB Control Program for wider distribution through program channels.

Spiritia hopes to help ensure that the agreed-upon national policy changes trickle down to the local level, which is a challenge in a country as large as Indonesia. Among its efforts toward this end will be more intensive engagement with local peer support groups to extend their advocacy to local health services, local AIDS referral hospitals, and community health centers.

The project's initial success may not be easy to maintain, however. Project staff acknowledge that some people involved in TB control and advocacy efforts have been unwilling to work closely with HIV/AIDS organizations, including community groups comprising HIV-positive individuals. Their reluctance apparently stems from a concern that associating closely with HIV will increase TB-related stigma. Spiritia staff are seeking to overcome such opposition by stressing that coinfection is a growing reality that cannot be ignored and that collaborative advocacy efforts based upon the “two diseases, one patient” mantra represent the best opportunity to effectively combat both HIV and TB.

# Future Focus: Expanding Community Involvement and Leadership

**THESE SIX CASE STUDIES** present just a few of the many advocacy activities undertaken over the initial two years of the TB/HIV Advocacy Grants Project and highlight some of the main challenges to the implementation of more collaborative TB/HIV policies and services.

One issue in particular stood out: Most grantees emphasized the need for greater community involvement in the development of TB and HIV strategies and programs. Many expressed frustration with the lack of coordination between national TB and HIV/AIDS programs and felt strongly about getting involved and taking action to demand services that more effectively address the reality of “two diseases, one patient.” But grantees often finished their projects with more questions than answers: Does the health budget include funds to support collaborative TB/HIV activities? Are health care workers and service providers adequately trained to care for patients affected by TB and HIV? Are there sufficient laboratory and human resources to diagnose, manage, and monitor HIV-related TB? Are policymakers aware of the WHO policy on TB/HIV? Are they implementing it? If not, why? Many grantees felt that articulating community and patient perspectives on the answers to these questions would provide a strong basis for informed, community-led advocacy for improved TB/HIV services.

## **TB/HIV MONITORING AND ADVOCACY PROJECT**

In response to these experiences from the first two rounds of grantmaking, Public Health Watch and TAG launched the TB/HIV Monitoring and Advocacy Project in May 2006. The project is awarding grants to support greater participation by those individuals and communities most affected by TB and HIV/AIDS in the design, implementation, and evaluation of collaborative TB/HIV services and programs.

More specifically, the project is supporting a third round of grantees to conduct community-led monitoring of the WHO's 2004 *Policy on Collaborative TB/HIV Activities* and follow-up advocacy around their findings and recommendations. The *TB/HIV Policy* outlines a clear set of recommendations to guide governments in their efforts to reduce the prevalence of TB/HIV coinfection; it therefore provides a sound framework for communities to assess the situation on the ground and point out areas where key services are lacking, outcomes are falling short, or further progress is needed. Grantees will receive support to conduct research on the basis of a monitoring questionnaire structured around the main points of the *TB/HIV Policy*; prepare and publish reports detailing their findings and recommendations; and use their reports as the basis for advocacy efforts to encourage more collaborative TB/HIV policies and to improve access to TB/HIV services in their countries and communities.

#### **TB/HIV COMMUNITY ADVISORY COMMITTEE**

To support project implementation, Public Health Watch and TAG established a new TB/HIV Community Advisory Committee (CAC). The 2006–2007 CAC comprises eight TB and HIV/AIDS advocates from four continents: Africa, Asia, Europe, and Latin America. All CAC members have significant experience in policy and community-led advocacy, and all are actively involved in local, regional, and global TB/HIV advocacy efforts.

**Fogué D. Alain Patric Ledoux**, Positive Generation (Cameroon)  
**Konjengbam Birjit Singh**, Social Awareness Service Organization (India)  
**Lucy Chesire**, KETAM/tbACTION (Kenya)  
**Tamara Gvaramadze**, Georgian Plus Group (Georgia)  
**Nenet L. Ortega**, Pinoy Plus Association (Philippines)  
**Ezio Távora dos Santos Filho**, independent consultant (Brazil)  
**Pervaiz Tufail**, National Group of TB People Pakistan (Pakistan)  
**Jacob Nonmidé Zannou**, Horizon Environment Sante (Benin)



The CAC provides Public Health Watch and TAG with expert advice and support as well as a strong community perspective on monitoring tools, grantee selection, grant implementation, training, evaluation, and project-related advocacy.

Public Health Watch and TAG plan to develop and publish bulletins during the course of the project to present selected monitoring reports and advocacy activities. Additional information about the project is available online at [www.publichealthwatch.info](http://www.publichealthwatch.info).

## Appendix: TB/HIV Web Resources

### TB/HIV Fact Sheet

[www.soros.org/initiatives/health/articles\\_publications/publications/factsheet\\_20040721/tb\\_fact\\_sheet.pdf](http://www.soros.org/initiatives/health/articles_publications/publications/factsheet_20040721/tb_fact_sheet.pdf)

### Interim Policy on Collaborative TB/HIV Activities

[www.who.int/hiv/pub/tb/tbhiv/en/](http://www.who.int/hiv/pub/tb/tbhiv/en/)

### Towards a Revolution in Tuberculosis (TB) Prevention, Care and Treatment: Statement of Individuals from Communities Affected by TB

[www.aidsinfonyc.org/tag/tbhiv/revolutionTB.html](http://www.aidsinfonyc.org/tag/tbhiv/revolutionTB.html)

### Public Health Watch website

[www.publichealthwatch.info](http://www.publichealthwatch.info)

### Treatment Action Group website

[www.treatmentactiongroup.org](http://www.treatmentactiongroup.org)

### World Health Organization TB/HIV website

[www.who.int/tb/hiv/en/](http://www.who.int/tb/hiv/en/)

### Stop TB website

[www.stoptb.org](http://www.stoptb.org)

### Global Alliance for TB Drug Development

[www.tballiance.org](http://www.tballiance.org)

### The Global Fund to Fight AIDS, Tuberculosis and Malaria website

[www.theglobalfund.org](http://www.theglobalfund.org)



**“We cannot win the battle against AIDS if we do not also fight TB. . . . We have known how to cure TB for more than 50 years. . . . What we have lacked is the will and the resources to quickly diagnose people with TB and get them the treatment they need.”**

**—Nelson Mandela,  
at the 15th International AIDS Conference  
in Bangkok, July 2004**



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