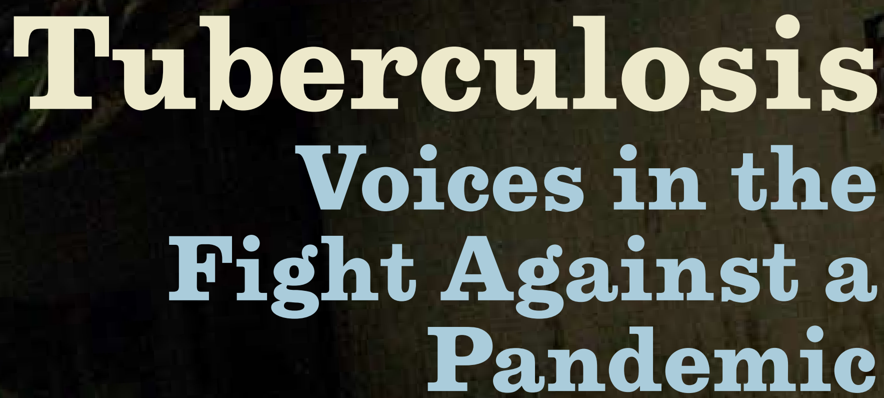


Tuberculosis

Voices in the Fight Against a Pandemic

March 2009

action
Advocacy to Control TB Internationally

The Advocacy to Control Tuberculosis Internationally (ACTION) project is an international partnership of advocates working to mobilise resources to treat and prevent the spread of tuberculosis (TB), a global disease that kills one person every 20 seconds. ACTION's underlying premise is that more rapid progress can be made against the global TB epidemic by building increased support for resources for effective TB control among key policymakers and other opinion leaders in both high TB burden countries (HBCs) and donor countries.

ACTION is a project of:

- AIDES (France)
- Avocats Pour la Santé dans le Monde (France)
- Global Health Advocates
- Indian Network for People Living with HIV / AIDS (INP+)
- Kenya AIDS NGO Consortium (KANCO)
- RESULTS Canada
- RESULTS Educational Fund (US)
- RESULTS Japan
- RESULTS UK

The following case studies were compiled with the assistance of the following organisations, who conducted the interviews, and provided photographs and information:

Bangladesh:	Interviews and photographs by BRAC
India:	Interviews and photographs by the ACTION project in India hosted by INP+
Indonesia:	Interviews by Koalisi untuk Indonesia Sehat/Coalition for Healthy Indonesia (KuIS); photographs by Ramadian Bachtiar
Kenya:	Interviews and photographs by Kenya AIDS NGO Consortium (KANCO)
South Africa:	Interviews by Treatment Action Campaign (TAC); photographs by Yang Zhao

The report was written by Philip Hadley, Louise Holly and Kate Finch of RESULTS UK, with additional editing by ACTION partners.

Printed by Warwick Printing (www.warwickprinting.co.uk)

Designed & typeset by Transform (www.transform.uk.com)

Typeset in Egizio

Contents

Executive Summary	4
Forward	5
Introduction	6
Glossary of Terms and Acronyms	7
Case Studies :	8
Bangladesh	8
India	12
Indonesia	16
Kenya	20
South Africa	24
Conclusion	28
References and Sources of Further Information	31

Executive Summary

Despite being one of the most prevalent infectious diseases worldwide, tuberculosis (TB) is too often a forgotten epidemic. A disease of poverty, the greatest impact of TB is found in low and middle income countries, where limited political will and economic resources hinder the struggle to combat the disease.

As progress is made, new challenges emerge reminding us that the fight against TB requires sustained political will and financial investment if we are to finally eradicate the disease.

Tuberculosis is often reported in figures: the centuries that TB has been prevalent, the millions of people affected, and the billions of dollars needed to eradicate the disease. It is easy to forget that these statistics are made up of individuals, families, and communities who so often lack a voice, but for whom the disease is personally devastating.

This report seeks to tell the human story of TB, from the perspectives of the individuals and communities that feel its greatest effects. In the following pages, patients, advocates, and health care workers from five high TB-burden countries – Bangladesh, India, Indonesia, Kenya, and South Africa – tell of their experiences.

Illustrated through the following case studies, this report identifies the following key themes:

- **TB and local economies are deeply linked**
  Local economies can be devastated by the effects of the disease on the working population. Support initiatives should be incorporated into TB programmes to ensure that the livelihoods of affected patients and their families are not lost and that the cycle of poverty and stigma is not perpetuated;
- **Drug resistance and co-infection require greater investment**
  Collaborative TB-HIV activities are crucial to reducing the spread of both TB and HIV. There is an urgent need for further financial support to scale up these activities and to address the spread of MDR-TB at both the national and community levels;
- **Access to and disbursement of funds**
  Action must be taken to overcome and avoid delays in disbursement and implementation of TB services;
- **Empowerment and community based initiatives**
  Infected and affected communities must have greater participation in TB control programmes. Sufficient resources, both financial and technical, are needed to support and scale up community level interventions and to implement the 'Stop TB Strategy' at the community level;
- **Increasing local capacity**
  Strengthening partnerships between governments, private sector parties, and non-governmental organisations (NGOs) beyond the National TB Programme to provide adequate care and support (including nutrition and transport) is key in the fight against TB.

The following case studies illustrate a number of successful initiatives being used to fight tuberculosis and to respond to emerging challenges. These stories show that we know what works in fighting TB.

A sustained global response to this preventable disease that reaches all TB patients will require greater political will along with increased, long-term funding. The fight against TB must also have at its core a people-centred, rights-based approach taking into account the voices of those most affected by TB.

Forward

Lucy Chesire, TB-HIV advocate, Kenya AIDS NGO Consortium (KANCO)

Fighting the global epidemic of tuberculosis poses one of the greatest challenges of the 21st century. It also poses one of the greatest opportunities; to create a world free of TB, and to consign one of humanity's oldest foes – a foe that is treatable and preventable, yet continues to end the lives and livelihoods of millions – to the dustbin of history.

As a former TB patient myself, I spent seven months in a Kenyan hospital battling TB as it spread from my chest to my lymph nodes and onto my knees. My HIV positive status made me much more susceptible to contracting tuberculosis, and I survived through being given antiretroviral therapy (ART), invasive surgery, and by pure chance.

But what of the nine million people newly infected with TB and the close to two million people killed by this disease every year? In my own country of Kenya, 50 per cent of TB patients are co-infected with HIV – yet efforts to confront these two diseases are seldom co-ordinated or properly funded.

We rarely get the chance to understand, on a human level, what TB actually means for individuals and communities, and how those people primarily affected by the epidemic experience the disease, as well as efforts to confront it. This report seeks to show the human face of TB, and in doing so, to highlight the importance of empowering people and communities affected by TB.

Introduction

Tuberculosis remains one of the world's major causes of illness and death. Every twenty seconds, a person dies from TB somewhere in the world. This needless loss of lives is even more tragic given the fact that TB is a disease that is both treatable and preventable.

TB has been on the rise since the 1980s, with its spread concentrated in Southeast Asia and Africa. Much of TB's resurgence is directly connected to the HIV/AIDS pandemic, especially in Africa, where HIV is the most important factor determining the increased incidence of TB.

Directly Observed Treatment, Short Course, known as DOTS, is the internationally recommended strategy to control TB and a major component of the World Health Organization's (WHO) 'Stop TB Strategy'. DOTS is an inexpensive and highly effective means of detecting and treating patients infected with TB.

Global access to TB treatment is increasing but remains low. DOTS programs have increased the global case detection rate to 61 per cent, but four out of ten patients still do not have access to accurate diagnosis and effective treatment (WHO, 2009).

The success rate for patients on DOTS is also improving, but the emergence of drug-resistant TB (MDR-TB) and extensively drug-resistant TB (XDR-TB), particularly in settings where many TB patients are also infected with HIV, poses a serious threat to TB programmes, re-affirming the need to strengthen prevention and treatment efforts.

A key factor in the progress made to date has been the involvement of patients and communities in the TB response. Partnership between health services and local communities helps to educate people about the basics of TB treatment, prevention, and care, and encourages people to come forward for faster diagnosis and treatment. A community-based approach helps to counter stigma and the negative economic consequences of undergoing TB treatment for the individual and their families.

Although many political and financial commitments to fight TB have been made by governments, multilateral organisations, and corporations, of the US$56 billion that is needed to fully implement the 'Global Plan to Stop TB', there is a current funding gap of US$31 billion. This includes US$3.2 billion to scale-up advocacy, communication, and social mobilisation in donor and endemic countries; US$6.7 billion for TB-HIV integrated services; and US$5.8 billion for MDR-TB (Stop TB Partnership, 2008).

The International Conference on Primary Health Care in Alma-Ata, 1978 declared that "[t]he people have the right and duty to participate individually and collectively in the planning and implementation of their health care" (ICPHC, 1978). Yet the perspectives and voices of those affected by the TB pandemic are often left out of the policy decisions and strategies aimed at fighting the disease. This report aims to tell the human story of TB, to focus on the people behind the statistics, and to understand how people and communities are affected by TB and how they perceive the epidemic as well as efforts to confront it.

This report is built upon stories from TB health care workers, patients, and advocates from five high TB-burden countries: Bangladesh, India, Indonesia, Kenya, and South Africa.

Glossary of Terms and Acronyms

ACTION
Advocacy to Control TB Internationally

ART
Antiretrovirals

ATT
Anti-Tuberculosis Treatment

DOTS
Directly Observed Treatment, Short Course

DST
Drug Susceptibility Screening

HIV
Human Immunodeficiency Virus

ICC TB
Interagency Coordinating Committee for TB (regional)

ICC HIV
Interagency Coordinating Committee for HIV/AIDS (regional)

IDR
Indonesian Rupiahs

INH
Isoniazid

INR
Indian Rupees

IPT
Isoniazid Preventive Therapy

MDR-TB
Multidrug-Resistant Tuberculosis

MDG
Millennium Development Goal

MSF
Médicins Sans Frontières

NGO
Non-Governmental Organisation

PLWHA
People Living With HIV/AIDS

PPM
Public-Private Mix

Shasthya Shebika
Community health volunteer in Bangladesh

Shibani
Local health worker in Bangladesh

TB
Tuberculosis

WHO
World Health Organization

XDR-TB
Extensively Drug-Resistant Tuberculosis

Bangladesh

TB and Local Economies Are Deeply Linked

Communities in Bangladesh know intimately the link between economic livelihoods and TB. The greatest burden of TB falls on economically productive adults, who often must withdraw from the workforce due to sickness. Mean household spending on TB care and treatment can equal 8 to 20 per cent of annual household income (Russell, 2004).

Nargis Akter, a 28-year-old former TB patient works as a 'Shasthya Shebika', a community health volunteer in Bandutia, a village in the Manikgonj district of Bangladesh. Nargis works for BRAC, a Bangladeshi NGO that has been running a community-based TB programme in the district since 1984.

"

Four years ago I developed a serious cough and fever for almost two months, I could not eat at all and began losing a lot of weight.

I was already taking part in BRAC's microcredit activities along with other women in the village, one day a BRAC health worker recognised my symptoms and offered a free sputum test which confirmed that I was TB positive. After six months successful treatment, supervised by another Shasthya Shebika, I was cured of TB.

During my treatment, although my husband and mother-in-law were helpful as they had previously cared for another family member with TB, some of my neighbours were not so helpful. They would not caress my 7 month old son, for fear of infection, as I was breastfeeding him at the time.

I decided to work as a Shasthya Shebika to provide correct messages to the community. As a Shasthya Shebika for two years, I currently supervise two patients in taking their TB medicine.

I know that awareness, early diagnosis and regular treatment are the most important matters to fight tuberculosis.

Involving the community in TB prevention and control means the situation has changed. The community are now counselling other people who have the symptoms of tuberculosis to examine their sputum in the health centres.

"

It is very difficult to earn enough money in villages; I used to work with two other hired co-workers in a very unhygienic room with a poor ventilation system.

Four months ago I started to cough severely, lose my appetite, feel exhausted and feverish. My daughter advised me to go to a BRAC health centre to get a sputum test for TB.

I knew tuberculosis as a killer disease and I thought, if people took me as a TB patient, they would behave weirdly with me and my family. So, I preferred to keep it concealed.

After my condition deteriorated I went to a health centre where my sputum test resulted in a positive TB diagnosis. I started to cry. But the Shibani [local health worker] pacified me saying that tuberculosis is not an incurable disease now. There is modern treatment for it. If I take my medicine regularly for six months in front of a health provider, I would completely regain my health.

After taking the medicine for two months with a Shasthya Shebika in my village, I got my sputum tested again and my result was negative. I thanked God and the community health workers. I am now in the 5th month session and I am very soon going to check my sputum again.

My treatment was completely free. I also did not pay any transportation costs because everything was in my vicinity – the lab, doctor, Shebika and the medicine.

During my first month of treatment my family suffered an economic crisis as I couldn't go to work and had to hire people to continue my business. So it would be a problem if I needed extra money for tuberculosis treatment.

All we need is to be conscious about the disease. I think building consciousness among the uneducated village and slum dwellers is the most important aspect of TB treatment.

Sandyra Roy, 45, lives in a village called West Dashera, in Bangladesh. She has three daughters and a son. Her husband works as a tailor, and Sandyra works with embroidery machines.

Tuberculosis in Bangladesh

Tuberculosis is considered a major public health problem in Bangladesh. With more than 350,000 new cases and 70,000 TB-related deaths occurring annually, the WHO ranks Bangladesh as having the 6th highest burden of TB in the world.

Key TB Statistics

Incidence (all cases/100 000 pop/yr)	223
Of new TB cases, % HIV+	0.3
Of new TB cases, % MDR-TB	3.5
DOTS coverage (%)	100
DOTS case detection rate (new ss+, %)	66 [target 70%]
DOTS treatment success (new ss+, 2005 cohort, %)	92 [target 85%]

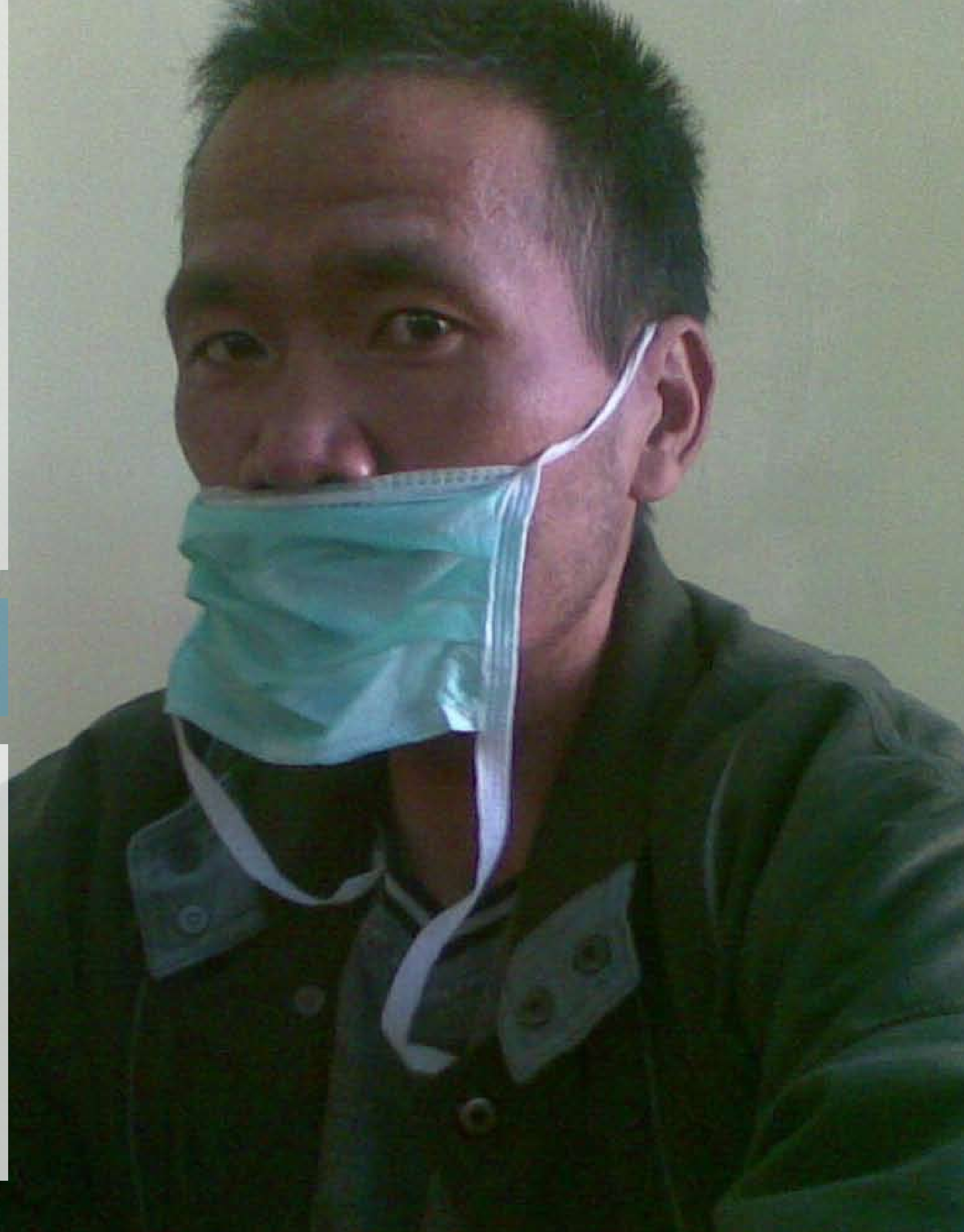
Source: Global Tuberculosis Control, WHO Report 2009

Achievements of Bangladeshi National TB Programme to date	Key challenges
Development and approval of a 5-year strategic plan	Sustaining the quality of DOTS, and expanding community-based DOTS
Development of national guidelines for private-public mix	Involving private providers in TB control
Development of national guidelines for MDR-TB management	Developing human resources, including staffing
Strengthening Community DOTS and participation of patients and communities in TB control	Overcoming delays in disbursement and implementation of Global Fund-funded activities
Initiation of national TB prevalence survey	Management of MDR-TB
Formation of a national TB-HIV co-ordination committee	Sustaining progress made in TB-HIV collaborative activities
Establishment of a National TB Reference Laboratory	Overcoming limited capacity to diagnose smear-negative and extrapulmonary TB

India

Drug Resistance and Co-Infection Require Greater Investment

With the increasing spread of MDR-TB and XDR-TB, it has become ever more urgent that we apply the best tools we have in the fight against TB. Yet across the developing world, few healthcare settings can even detect drug-resistance. We must ensure that new and effective technologies are made available in impoverished communities—especially in those where HIV is prevalent. When we do, as these case studies show us, we can turn this deadly disease around in even its most virulent forms.



Mike Tonsingh, 38, works as a Project Coordinator of a Drop-in-Centre in Delhi. Mike is HIV-positive, on antiretrovirals (ARVs) as well as on MDR-TB treatment, and has a history of injecting drugs.

"*I was put on tuberculosis treatment four times and every time it relapsed. I clung on to hope, and at last I have been lucky enough to undergo DST [drug susceptibility] screening, which detected MDR-TB. I would suggest having DST screening for all TB relapse cases rather than experimenting with them.*

DOTS treatment is good, but people with MDR-TB are ill and find it difficult to go to the DOTS centre. I have to spend 20 to 30 INR [US$0.4 or US$0.6 [Indian Rupees]] daily to travel to a DOTS centre or hospital and then wait for 45 minutes. Because of this every day I am late at the office. I am lucky, there must be many who work in factories, and have to take a day off for this treatment process. Many of them lose their jobs.

The hospitals or the DOTS provider should support by informing the employer about the person on treatment and the reason for his reporting late for work. Proper nutrition should also be given to the patients. With my salary, I cannot afford to supplement with nutrition.

I was not a defaulter, I never missed my medicine. If I am so regular, then I should have been cured, why am I suffering from MDR-TB? I doubt the quality of medicines. The policy-maker or controller should check the quality of medicines.

We have to create awareness about TB in the community. We need to concentrate on MDR-TB. Most MDR-TB patients are depressed, they do not know what medicines to take, they don't even know what MDR-TB is!

I am back at work. People around me know that they should not discriminate or stigmatise me. People are scared that I will infect them. They always try to avoid me, but I know I am sputum negative.

***While the nations and governments are spending millions to bail out bankrupt corporations, I am afraid that the need for expansion of provisions for the health of millions like me not be ignored by the mighty and powerful.*"**

Note:
Currency exchange values as of 24 February 2009.

Rajkumar Sharma is a 33-year-old health care worker in the Ashraya Holistic AIDS Care Centre in Gurgaon, a suburb of New Delhi. Rajkumar tested HIV positive in 1993 and successfully completed TB treatment in 2001.

"The majority of people living with HIV/AIDS [PLWHA] who seek care with us have TB. The risk of transmission of TB to other PLWHA is high, so we keep a special ward for sputum positive TB patients. We come across more patients with extra pulmonary TB than pulmonary.

Our clients often share that if they cover their mouths in the villages, it is like inviting discrimination from people. A severe lack of awareness and a lot of misinformation is out there in the public.

The majority of our clients can afford only to travel by public transport. Buses and trains are overcrowded and so TB transmission is a big possibility.

If a patient does not come to take their medication from the DOTS provider, the providers do not generally follow-up with any of the defaulters, but instead they tear the packets and throw the medicines away to ensure their incentives!

Large numbers of patients are daily-wage labourers and work in the unorganised sector. They sacrifice their work-hour earnings to come to the DOTS centre to take their medicines and generally without a proper diet to support treatment. In such circumstances people often default. People can manage to work without food, but cannot if they have to take medicines without food.

In 2001, I came to Delhi. I was diagnosed with TB by an x-ray, and started ART and ATT [anti TB treatment]. I had to buy ART till 2004. When I was so seriously ill with TB, my sputum was never positive!

We need to "prepare" TB patients before treatment, in the same way as we do for HIV patients. He/she should be informed about TB transmission, TB resistance, the importance of taking medicines regularly, as well as the side effects of medicines.

I think PLWHA can be involved in a TB program. Rigorous awareness is also required on all aspects of TB.

If a government makes a TB program, they should see to it that proper follow-up is made, including whether programs are reaching their goals. Patients should also be supported with a balanced diet."

Tuberculosis in India

Accounting for one-fifth of all global TB cases, tuberculosis is an epidemic of severe proportions in India. Every year close to 2 million people develop active TB in India, about 85 per cent of whom are able to spread the disease to others. Annually, it is estimated that about 325,000 people die due to TB.

Key TB Statistics

Incidence (all cases/100 000 pop/yr)	168
Of new TB cases, % HIV+	5.3
Of new TB cases, % MDR-TB	2.8
DOTS coverage (%)	100
DOTS case detection rate (new ss+, %)	68 [target 70%]
DOTS treatment success (new ss+, 2005 cohort, %)	86 [target 85%]

Source: Global Tuberculosis Control, WHO Report 2009

Achievements of Indian Revised National TB Control Programme (RNTCP)	Key challenges
Expanded DOTS to the entire country in March 2006	Sustaining the quality of DOTS, and expanding community-based DOTS
Public-private mix (PPM) in place in all districts	Strengthening partnerships between Government, Private sector and NGOs beyond the RNTCP
MDR-TB services available in six states, with culture and DST facilities offered in five state-level laboratories and community-based MDR-TB treatment in two states	Developing human resources, including staffing
A coalition of associations of medical professionals launched by the Indian Medical Association to engage the private sector	Establishing formal linkages with HIV programmes for planning and implementing collaborative activities
Implemented TB control with high-risk groups including an action plan for tribal populations and PPM in urban slums.	Strengthening laboratory capacity to scale-up activities to manage MDR-TB
Involved communities in TB control activities in all districts; more than 30,000 community meetings and 40,000 patient-provider meetings	Enhance community involvement in TB control and initiate TB care in the community

Indonesia

Community-Based Programmes Deliver

In Indonesia, as is the case around the world, community-based health workers are often on the front lines in the fight against disease. Too often, however, these workers do not receive the basic training and pay needed to sustain their work as part of a broader health system. Expanded and adequately funded community-based programmes have to be part of the solution to increase rates of TB case detection necessary to eradicate the disease—and Indonesian health workers are showing the way.

Haji Ahmad Insari is 44 years old, he is an "ojek" (motorcycle taxi driver) and a "ngampas" (peddler for various goods) in the west of the island of Lombok, in Indonesia. He has also been a TB community health volunteer in a village called Merbu in the Labuapi Sub-District of West Lombok, since 2003.

"So far, I have brought 10-15 persons to get treatment on my motorcycle. They responded positively. They said, "If pak [honorific for adult male] Haji [title for someone who has made the Islamic pilgrimage] left us, who can we ask for help, because he is the only one who is willing to help". Because this is my principle, whether they have or do not have any money."

I often talk to people who might be infected with TB, I tell them to let me help. I even brought the sputum pots from the community health centre and I'll take their sputum back to the health centre. If the result is negative, I tell others to check their sputum.

Many of the TB patients live below the poverty line. If the head of the family has TB, how can he work? He will be forced to stay at home. Automatically, he will live below the poverty line.

I am very grateful to the government for providing a "free treatment" programme. So the community can set some money aside when the head of a family is sick and they can still have food on the table during the 6-month treatment.

If the TB patients have money, they can use the regular non-free service. The doctor costs around 50,000 IDR [Indonesian Rupiahs [IDR] = US$4.2], the sputum test costs around IDR 15,000 [US$1.3], and transportation costs IDR 100,000 [US$8.4] for a one way trip. If there is no government program for free treatment then it is quite expensive because one package of treatment costs IDR 6,500,000. But now it is free.

The treatment is effective, though if we stop the medication, then it will be a category II case, which means the germ is resistant.

I conduct health education sessions, so the community know how to prevent themselves from catching the disease. If their houses have windows, they should open them. TB happens a lot in slum areas. It can happen in clean areas, but not too often.

I participated at a training at Lombok Taya [a hotel in Mataram, Indonesia] for 5 days; the community health centre sent me [facilitated by the Lombok Barat Coalition (KulS local coalition) under a Global Fund scheme in 2005].

Many community members are starting to care, and even motivate others to take their medicine. The patients are always ready to be taken for treatment. Some community members would say, why should we pay attention to everything? But nobody is preventing me. I always consulted what I do to TuanGuru [Muslim religious leader]. I cooperate with the TuanGuru; when he sees somebody with the symptoms of TB he will refer that person to me.

TB is very contagious. In one year, it can spread to 15 houses to the left and to 15 houses to the right. If we don't manage it well, then the whole of Kampong will get it.

One day, a young man came up to me. When he coughed, the blood splattered onto his white shirt. He wanted to be taken to the community health centre. Unfortunately, my motorcycle ran out of gas. That's one of the challenges. Sometimes it rains and I don't have a raincoat, the gas ran out. Especially at night.

Since the DOTS system started, I have been trained and was the only participant who represented three villages. The important thing is that people can see my work, to see what is lacking.

From the government, they haven't noticed me. They haven't noticed much less given any payment or reward to me. There was an information session on the village ambulance program where they promised to provide torchlight and raincoat, but there is nothing yet.

There was once a IDR 10,000 [US$0.8] incentive when I brought a patient to the community health centre; only once since my involvement with TB. We are only trained when the community health centre want something from us. There are even trainings that did not involve us. From the community, I got rewarded through their prayers. It's the best kind of reward

Most of the TB patients I helped were between 21-40 years old. They live close to each other, in a dirty environment.

Sometimes we have economic challenges, because our children need to go to school. Yesterday for instance, my child asked to buy a sports uniform for school. I have to work to get the money, but at the same time there was a patient that needed treatment. I asked my child to be patient; I usually prioritise the patients.

For TB knowledge, it is never enough. We can be greedy for knowledge, but we should be satisfied with the wealth we have.

Note:
Currency exchange values as of 24 February 2009.

Tuberculosis in Indonesia

As a country with over 500,000 cases of TB per year, Indonesia has the 3rd highest burden of TB in the world. Whilst Indonesia has achieved the DOTS target for treatment success and is close to achieving the detection target, this masks wide variations throughout the provinces and growing problems such as drug-resistance.

Key TB Statistics

Incidence (all cases/100 000 pop/yr)	234
Of new TB cases, % HIV+	3.0
Of new TB cases, % MDR-TB (2002)	2.0
DOTS coverage (%)	98
DOTS case detection rate (new ss+, %)	68 [target 70%]
DOTS treatment success (new ss+, 2005 cohort, %)	91 [target 85%]

Source: Global Tuberculosis Control, WHO Report 2009

Achievements of Indonesian National TB Programme to date	Key challenges
Successful engagement with non-NTP public providers and private health-care	Achieving DOTS detection and treatment targets in all 33 provinces
Community-based TB care – participation by communities in TB care including workshops and village TB posts	Expanding community-based DOTS and supporting community health volunteers with financial and technical support
Produced NTP strategic plan for 2006-2010	Monitor and identify key issues in TB care at the local level and prioritise key interventions to achieve the Stop TB Strategy
National TB-HIV symposium held and piloted collaborative TB-HIV activities in 6 provinces	Scaling-up activities to control MDR-TB and XDR-TB, including: developing guidelines for management and implementation guidelines for all health-care facilities
National TB awareness campaign conducted and Advocacy, Communication and Social Mobilisation (ACSM) training modules produced and pilot-tested	Strengthening the partnerships between Government, Private sector and NGOs, and implement PPMs
Achieved DOTS detection and treatment rates in 2006	Formalise collaborative links between TB and HIV/AIDS programmes
	Overcome delays in Global Fund grant disbursement

Kenya

A Complex Disease Requires a Full Response

In Kenya, communities and health systems are tackling the full spectrum of TB challenges: drug resistance, co-infection, a lack of health workers, and general poverty. Although stigma and misunderstanding about TB remains, patients and advocates have shown that we know how to tackle each of these challenges if enough resources are available and political leaders are committed.

Paul Wachira, 34, an accountant by profession, has multidrug-resistant tuberculosis (MDR-TB) and is currently undergoing treatment with the help of the international medical and humanitarian aid organisation Médecins Sans Frontières (MSF). Paul is married with two children.

"I first had TB in February 2006. Around the 5th month of treatment I remember a time when I coughed a glass full of blood, then I realised that the treatment wasn't working.

When I got diagnosed with MDR-TB there was no medication in the country. I learnt however that the cost of the drugs needed were over 2 million Kenyan shillings [US$25,000] and the therapy would be another 500,000 shillings [US$6,260].

One day I was talking to a doctor and he told me of an NGO called MSF offering the treatment in a trial phase. The treatment has 16 tablets, four different types of drugs and you have to get an injection everyday for 6 months. You can lose hearing power and it can create complications with your liver or kidneys plus other side effects.

The treatment is provided free but I have to look for money to buy my food and to pay my house rent, so it is not easy for me. I lost my job and I am depending on people for survival. I only cater for myself, I am not able to cater for my family. My family had to look for other ways to sustain themselves and we don't stay together, because there was the risk of passing the disease.

DOTS has assisted me but it would be better if you could take the medicine at your bed so that you don't have to go to hospital every day.

I was cautioned by my doctor not to reveal the information that I have MDR-TB because it would have a negative impact on my life. I think there is still stigma; knowing that it's an airborne disease means that it can get to anybody. People still don't know this.

I believe the leadership of Kenya has a very big responsibility to ensure that people can access essential medicine particularly for diseases that can kill masses of people like MDR-TB.

No proper sensitisation has been done to people about TB. People are still stigmatising tuberculosis. I wish that this stigma be done away with and people who are sick can get tested and treated. Otherwise this situation is going to degenerate to a level which is very difficult to take care of in the future."

Photo : Gary Hampton

Dr. Ignacious Kibe, a private medical practitioner and TB expert, works for the City Nursing Home and St. Mary's Cottage Hospital Ltd in Nairobi, Kenya. Dr. Kibe has become a TB activist, engaging NGOs and media (TV, radio, and newspapers) on the issue of TB.

"My two brothers got infected with TB and I saw a lot of challenges particularly in access and availability of drugs and nutrition. My family and I take care of very poor people in a slum called Kiandutu in central Kenya. I realised there is a crowd of HIV and AIDS implementers, and TB is hidden.

I realised that is impossible to tackle HIV without TB and TB without HIV because they are intermarried, yet the existing structures in Kenya starting all the way from the Global Fund to Fight AIDS, TB & Malaria led structures of ICC TB and ICC HIV [Interagency Coordinating Committees for TB and for HIV/AIDS] have never identified common ground. There is a disconnect between the implementation of TB programmes and the implementation of HIV programmes.

65% of our TB patients are HIV positive. One patient with both conditions goes to a different clinic for TB and the following day goes to a different clinic for HIV. Our resources are disconnected and there is also a lack of information on nutrition.

There is very little information. If I did knock on the door of a Minister for Health and start discussing TB they would initially wonder where I am coming from. There is also a lack of flow of funds. Our Global Fund Round 5 which is a TB round has been clogged; we would like to see more funding directly to the National TB and Leprosy Programme.

The political statements that are made are isolated from action against TB and frustrated by bureaucracy. TB has been place in the periphery and we are not doing enough.

Our TB programme is one of the best in developing countries yet it is bedevilled by problems, one of them being a mass exodus of senior staff. It is time that TB experts were retrained and retained by proper remuneration, by better terms, and by putting the dollar where the activity is and not where the politics is.

Africa declared TB an emergency several years ago yet Kenya has not declared TB a national disaster. We are calling upon his Excellency the President and upon the highest offices to declare TB a national emergency in Kenya before the end of 2009.

We would like to see more of the giants of the world putting more money in TB. We would like to hear TB being given the first line of discussion in country investments."

Dr. Bernard Langat, from Nairobi, is 35-years-old and works for the Ministry of Public Health and Sanitation of the Government of Kenya. His work involves TB-HIV co-infection and the management of MDR-TB. Dr. Langat is married with 3 children.

We did launch the Stop TB Strategy and we are addressing TB-HIV collaborative activities including offering HIV testing and treatment to TB patients, and if they are HIV negative we try to foster preventative measures.

MDR-TB has been a challenge to Kenya and initially people were managing MDR-TB on a private or individual basis but we have a treatment program through the support of the Global Fund; we have recruited over 46 patients and we are doing it in the two national hospitals.

There is a need for political commitment and greater advocacy. As the government we need to talk to all the stakeholders and ensure that we adhere to the Stop TB Strategy.

The biggest problem is lack of human resources and being a developing country the lack of finances. There is a need for greater resource mobilisation and we need to improve the social development of the country.

We need to address stigma, especially with dual TB/HIV infection. We do already have measures through advocacy and social mobilisation. We are also working with those affected by TB and the communities.

The health workers, local leaders and MPs are knowledgeable about TB but there are gaps. We believe there is a need for forums with MPs so that we can get a greater political commitment, and also within the community there should be continuous advocacy and social mobilisation.

Politicians need to get more involved in TB control; wherever they meet the public TB should be one of the agendas being given.

Kenya is one of the few African countries to achieve the WHO 70% TB detection target and we are on course to meet the 85% treatment success target. A key reason is the rapid decentralisation of diagnostic and treatment services, involving both the private and public sector. We are now engaging the community in observation of treatment that is DOTS. 80% of our people are being observed by household members.

We need to come together to look at new diagnostic and treatment technologies. We really need new drugs in the market. We have been relying on very few regimens and with MDR-TB we really need other options so that we can control and successfully treat TB.

Tuberculosis in Kenya

In Kenya, a country with a TB and HIV co-infection rate of almost 50 per cent, TB is a public health emergency alongside HIV/AIDS, and both diseases are fuelling each other. Despite recent successes in efforts to achieve TB detection and treatment success rates, major challenges remain, particularly in the management of MDR-TB.

Key TB Statistics

Incidence (all cases/100 000 pop/yr)	353
Of new TB cases, % HIV+	48
Of new TB cases, % MDR-TB	1.9
DOTS coverage (%)	100
DOTS case detection rate (new ss+, %)	72 [target 70%]
DOTS treatment success (new ss+, 2005 cohort, %)	85 [target 85%]

Source: Global Tuberculosis Control, WHO Report 2009

Achievements of Kenyan National TB Programme (NTP) to-date	Key challenges
NTP established as separate division in the Ministry of Health	Overcoming financial, staffing and infrastructure constraints to further implementation of collaborative TB-HIV activities at national and sub-national levels
TB-HIV collaborative activities scaled-up nationwide; 79% of notified TB patients tested for HIV and 37% of HIV-positive TB patients accessing ART in 2007	Management of MDR-TB including developing infrastructure and access to treatment
Developed national guidelines for the management of MDR-TB	Decentralising DOTS and TB care including MDR-TB treatment to the community level
Strengthening Community DOTS and participation of patients and communities in TB control	Developing human resources, including staffing
Developed advocacy strategy and sensitised public health officers on ACSM in 90% of country	Strengthening the partnerships between Government, Private sector and NGOs and scaling up PPMs
Carried out PPM in 31 of 136 districts; 41 districts offering community-based treatment support	Overcoming stigma through sustaining effective advocacy and social mobilisation
	Overcoming delays in disbursement and implementation of Global Fund-funded activities

South Africa

TB-HIV Integration Is Not Optional

In South Africa, TB has been re-ignited by HIV, resulting in a co-infection pandemic. People living with HIV, and especially health workers who are HIV-positive, need a holistic response to the twin diseases that includes infection control, preventive therapy, and effective care and treatment. Places like the MSF project in Khayelitsha show this is not only possible—it is the only option for good medicine.

Vathiswa Kamkam, originally from the Eastern Cape, is a TB Co-ordinator and Treatment Literacy Trainer in the Khayelitsha District of Cape Town, for the Treatment Action Campaign (TAC).

"

In 2002 I was tested for HIV and I became HIV positive. I came to Cape Town to search for information and fortunately for me I found a clinic that was dealing with HIV.

Most of Khayelitsha is made up of squatter camps where people don't have adequate services; in the shacks, there can be one room that is composed of five people. In those rooms mostly we don't have windows that can be open so that we can get fresh air because we are afraid of crime.

Most people in Khayelitsha are unemployed and not skilled enough to get a job. If they work they are not paid enough to support their families.

Site B and site C clinics [HIV clinics] offer ARV's but the services for TB are not integrated in the same space. When a person has to go to different clinics that are far from each other you can mix up when and where you get your TB and HIV treatment.

Now there is progress. For example in Town Two Clinic MSF is rolling out ARV's and you can also get TB treatment. The Ubuntu Clinic is a clinic that has integrated HIV and TB services; you become familiar with everyone on the TB and HIV side.

In a small TB and HIV centre I was an educator. As a person living with HIV I wasn't on ARVs then and I was exposed to TB. I started to take my INH [Isoniazid] preventative therapies; I took it for 6 months and I did not have any side effects; it was effective.

INH is one of the most important drugs for people with TB, if you do not have the most important drug you could default and become resistant.

In terms of infection control, we have done a lot with MSF; encouraging people to open windows, and in the clinics, they have masks and toilet paper for coughing. Also, there are posters where they illustrate different things.

When we are doing education, we try to tell them how they are exposed to HIV, and what the statistics are about having TB in Khayelitsha. The co-infection rate for TB and HIV is about 70% in Khayelitsha. We are telling people that if you have a compromised immune system, then you can also have TB. We are encouraging people to go to the clinic and get tested.

In terms of drug resistance, it is something that is growing within Khayelitsha. What MSF is doing is having a nurse, a practitioner and an adherence counsellor. Which is good because some of these counsellors have had drug-resistant TB; people are talking.

The community had some resistance around having a centre for drug-resistant TB but it helped the community to have a workshop that enabled them to understand what is happening with TB and the drug-resistant TB.

Most of the people had challenges to going to the isolation hospital centre which is too far and their families aren't able to visit. When there is something that is near home your family can visit regularly. At the very same time there is stigma in the community; people will know this facility is for people living with drug-resistant TB and there will be discrimination and fear.

DOTS providers ensure that people are taking their medication. At the very same time I am not sure whether there is any evaluation that has been done to those who are employed to give people medication. In some places you can go and you will find out that there is a DOT support test in this house, community based, and people will come and take the treatment; in terms of disclosure and in terms of infection it is challenging.

I would urge people to support South Africa, to assist in terms of infrastructure, with health care workers and with housing. Where I am from, the Eastern Cape, you have to walk many, many kilometres to go to the clinic that is a six room clinic that is servicing the entire community.

I think politically people are focusing on housing. It is a challenge; we need to equalise all of the government departments. If a department is about education, the department also has to educate about health. Life skills have to be taught within the community.

Photo : Gary Hampton

Tuberculosis in South Africa

South Africa has the highest TB incidence rate per capita in the world, and according to the WHO, has the fourth highest burden of TB worldwide. In a country already ravaged by HIV/AIDS, the TB epidemic has taken a lethal toll on the lives and livelihoods of thousands.

Key TB Statistics

Incidence (all cases/100 000 pop/yr)	948
Of new TB cases, % HIV+	73
Of new TB cases, % MDR-TB (2002)	1.8
DOTS coverage (%)	100
DOTS case detection rate (new ss+, %)	78 [target 70%]
DOTS treatment success (new ss+, 2005 cohort, %)	74 [target 85%]

Source: Global Tuberculosis Control, WHO Report 2009

Achievements of South African National TB Programme to date	Key challenges
Developing a Tuberculosis Strategic Plan and a TB Crisis Management Plan	Ensuring routine screening for TB among HIV patients is included as policy for the National AIDS Programme (NAP)
Revised TB data reporting and registers to include information on collaborative TB/HIV activities	Scaling-up TB-HIV collaborative activities at the national, district and community level in funding, policy and programming
Improved reporting and better case finding (TB detection target met in 2006)	Scaling-up activities to control MDR-TB and XDR-TB, including: developing infrastructure and surveillance
Strengthening the integration of HIV/AIDS and TB services at the sub-district and facility levels through training	Sustaining the quality of DOTS, and expanding the quantity and quality of community-based DOTS
Involved communities in all 53 districts in TB control; provided care, counselling and education	Strengthening the partnerships between Government, Private sector and NGOs beyond the NTP to strengthen the health system
Included poverty alleviation as part of the long-term planning of the Stop TB activities	Developing human resources, including staffing
By 2007, community-based care for MDR-TB patients introduced in selected districts in KwaZulu Natal and Western Cape provinces	

Conclusion

The people whose voices tell the story of this pandemic are the unsung heroes in the fight against TB – the patients, advocates, and health workers living and working in communities around the world on the frontline in the response to TB. These people play a vital role in efforts to confront tuberculosis, and without them, we would not be making the progress that we are today.

The stories from Asia and Africa testify to the overwhelming need – and demand – for greater investment in the fight against TB and a comprehensive response that addresses the particular challenges experienced by patients living in different communities around the world.

TB prevention, treatment, and care efforts are working – they save lives and improve the economic conditions of families, communities, and countries as a whole. Efforts to address the major challenges of TB-HIV co-infection and drug-resistance are proving successful even in the poorest settings and now must be made universally available to all of those who need them.

Although we are on track to achieve one of the targets of the sixth Millennium Development Goal, which aims to halve and then reverse deaths from TB by 2015, four out of ten people who become ill with tuberculosis do not get accurate diagnosis and effective treatment (WHO, 2009). The fight against TB will not be won until all cases of the disease are identified and treated. However, a large percentage of those infected with TB are among the poorest, most marginalised populations in the world and the hardest to reach.

In order to find and support all TB patients, health workers delivering care and treatment in villages, towns, and cities must be properly trained and rewarded and provided with the tools that they need to do their job. Governments and the international community must listen to the voices of people affected by TB and ensure that their views are heard in the planning and implementation of TB services.

Photo : Pierre Virot

References and Sources of Further Information

Cavalcante, S; Soares, E; Pacheco, A; Chaisson, R; Durovni, B; DOTS Expansion Team. (2007) Community DOT for tuberculosis in a Brazilian favela: comparison with a clinic model. International Journal of Tuberculosis and Lung Disease, Vol. 11, 5, pp. 544 – 549.

International Conference on Primary Health Care, Alma-Ata (1978) Declaration of Alma-Ata (WHO, Geneva). Accessible online: **http://www.who.int/hpr/NPH/docs/declaration_almaata.pdf**

Laxminarayan, R. et al. (2007) Economic Benefit of Tuberculosis Control. World Bank Policy Research Working Paper 4295.

Russell, S. (2004) The economic burden of illness for households in developing countries: a review of studies focusing on malaria, tuberculosis, and human immunodeficiency virus/acquired immunodeficiency syndrome. American Journal of Tropical Medicine and Hygiene 71(2 Suppl): 147-55.

Stop TB Partnership (2008) 'Funding gaps by area of activity' Global Plan to Stop TB: 2006-2015. Accessible online: **http://www.stoptb.org/globalplan/funding_p1s2.asp?p=1**

Wei, X; Liang, X; Liu, F; Walley, J; Bonb, B. (2008) Decentralising tuberculosis services from county tuberculosis dispensaries to township hospitals in China: an intervention study. International Journal of Tuberculosis and Lung Disease, Vol. 12(5), pp. 1-10.

World Health Organization (2008a) Global Tuberculosis Control 2008: Surveillance, planning, financing (WHO, Geneva).

World Health Organization (2008b) Community involvement in tuberculosis care and prevention: Towards partnerships for health (WHO, Geneva).

World Health Organization (2009) Global Tuberculosis Control 2009: Surveillance, planning, financing (WHO, Geneva).

For more information about TB or the organisations involved in this report, please visit the following websites:

Advocacy to Control TB Internationally (ACTION)
www.action.org

BRAC
www.brac.net

Indian Network for People Living with HIV / AIDS (INP+)
www.inpplus.net

KANCO
www.kanco.org

KuIS
www.koalisi.org

Stop TB Partnership
www.stoptb.org

Treatment Action Campaign (TAC)
www.tac.org.za

action
Advocacy to Control TB Internationally

The ACTION Project
c/o RESULTS Educational Fund
750 First Street NE, Suite 1040
Washington, DC 20002

Tel: +1 202 783 4800
Fax: +1 202 783 2818
Email: action@action.org
Website: www.action.org