
Towards a tuberculosis-free world

Advocacy report March 2011



International Federation
of Red Cross and Red Crescent Societies
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* All names have been changed unless otherwise stated.

Key messages

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↘ **Tuberculosis** (TB), a disease that, despite being curable, continues to kill nearly 2 million people each year and infect around 9 million.¹

↘ **Universal access** to affordable and effective diagnostics, treatment and care is urgently needed and should be placed at the top of the health agenda in TB-endemic countries.

↘ Strengthening local health systems – including their capacity to detect and treat patients – is crucial for addressing the rise of **multidrug-resistant and extensively drug-resistant TB (MDR-TB and XDR-TB)**, which are much more difficult – sometimes even impossible – to cure.²

↘ It's high time that we move rapidly towards a goal of zero deaths in patients with **TB and HIV co-infection**. In 2009, TB accounted for one in five deaths among people living with HIV.³ In some countries of sub-Saharan Africa, the HIV prevalence among people with TB can be as high as 80 per cent.⁴ Concrete actions are needed to scale up effective, integrated TB/HIV services and to tackle the factors that increase people's vulnerability to TB and HIV co-infection.

↘ Attaining the goal of eliminating TB will require **strong political will**, adequate resources, and a focus on the poorest and most vulnerable communities, who are disproportionately affected by TB and whose precarious situation is often exacerbated by the disease.

↘ Each **Red Cross or Red Crescent National Society**, as an auxiliary to its government, is a crucial connection to **civil society**, and through its volunteers and staff has the capacity to empower people with TB and mobilize communities to take stronger participation in TB care. Governments and partners must capitalize on this to effectively banish TB.



A call to action

The International Federation of Red Cross and Red Crescent Societies (IFRC) calls for accelerated scaling-up of tuberculosis interventions, faster screening of at-risk populations, and greater attention on prevention activities, tackling the broader social and economic determinants of TB

infection. We need to reframe how we think about TB, considering it not only as a public health issue, but linking it to development.⁵

TB and poverty go hand in hand, so we must deal with both problems if we really want to save and improve the lives of people affected by TB.

Preface

One in every three people worldwide is infected with tuberculosis and, while most will never become ill, those who do are often neglected or forced to live in silence with their disease as they are not on their health system's radar.

Members of the IFRC are mobilized to fight TB in their own communities through increased knowledge, as well as being empowered to actively contribute to all stages of TB control – prevention, care, treatment and support.

In 2010, more than 5 million community members were reached through Red Cross Red Crescent societies in endemic countries around the world. Currently, there are more than 80,000 active TB staff and volunteers, the majority of whom are women, serving their communities, identifying vulnerable groups, providing effective health education and finding those in dire need of treatment. The Red Cross Red Crescent network serves 150,000 patients on a daily basis. This community-based approach is crucial to saving lives.

The IFRC's strength lies in its volunteer network and community-based expertise. Without our volunteers, the fight against TB cannot be won. Active Red Cross Red Crescent volunteers donated nearly 6 billion US dollars worth of volunteer services in 2009 worldwide, or nearly 90 US cents for every person on earth. While many volunteers work across multiple fields, most volunteering work – and the greatest proportion of value – was related to health promotion, treatment and services. Volunteers working in health accounted for more than 2.4 billion US dollars in 2010 alone.

*Whilst the IFRC's **Strategy 2020** is asking its member National Societies to do more, do better and reach further, TB remains a killer. We know that tuberculosis can be cured in 85 per cent of all cases, but it is essential that the treatment is completed and managed properly. If not, we will witness the development of more strains of multidrug-resistant TB. Our TB community-based volunteers are central to the goal of significantly increasing the number of people who can be cured of TB, and they do this by working directly with vulnerable populations.*

This advocacy report focuses on TB and calls unequivocally for more information on the disease, more funding for TB research, more people to be tested, more people to be treated, more resources and better welfare for the poor.

It also offers our global membership of National Red Cross Red Crescent Societies, and you the reader, an advocacy tool that can be used to bring about change for the years ahead as together we commit to ridding the world of this ancient disease once and for all.

Matthias Schmale
Under-Secretary General, IFRC

Stefan Seebacher
Head of health department, IFRC

If we fail to take pertinent action, between now and 2015:¹

- more than 50 million people will develop active TB
- more than 10 million lives will be lost to this preventable and curable disease – including 4 million women and children
- millions of children will be orphaned unnecessarily
- more than 2 million cases of multidrug-resistant TB will emerge

Foreword

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Tuberculosis is an ancient illness. By rights, as a disease that is curable, it should belong to the past. When the World Health Organization's Stop TB Strategy and the Stop TB Partnership's Global Plan to Stop TB were launched in 2006, the epidemic was still believed to be growing. The fruits of that strategy and plan, now implemented all over the world, are now in evidence. Since 1995, 41 million people have been cured of TB and about 6 million deaths have been averted. The epidemic is in a steady, although very modest and slow, decline. But there is still a long way to go.

More than 9 million people still become ill with active TB each year and 1.7 million people died of TB in 2009. A third of the world's population harbours latent TB infection, which can emerge at any time as an airborne and transmittable disease. These figures should not inspire hopelessness, but rather an acknowledgment that TB is a unique pandemic. To reduce this human reservoir of infection will require many years of steady and indefatigable effort. Strong international and national commitment is absolutely essential.

The core of any TB control strategy remains the early identification and successful treatment of individual patients. This is precisely where National Red Cross Red Crescent Societies play an important role. The organization's contribution to TB control and care has long been recognized by all as a pragmatic community-based match for successful programmes. In most countries, national authorities alone cannot deal with the implementation of TB programmes. They therefore seek help by calling for broader community-based engagement, and the network of Red Cross Red Crescent National Societies fulfils this role.

The case studies in this advocacy report show the immense added value of such engagement. For example, in many different parts of the world, Red Cross or Red Crescent volunteers support national programmes by providing home-based services to patients affected by multidrug-resistant TB.

There are many compelling reasons to urgently scale up TB control. TB is an airborne, potentially lethal infectious disease, and in a world where millions of people are crossing borders and even continents every day, global security is at stake. The emergence of multidrug-resistant forms of the disease – some of them virtually untreatable – poses an additional and unacceptable risk.

But from our viewpoint, the most compelling reason to fight TB is that every person with TB has a face, a name and a life that is as precious to her or to him as it is to any of us. All women, men and children, who need TB diagnosis and care, have a right to it – no matter who they are or where they live – and they should be able to access TB services free of charge and in a manner that respects their dignity.

The members and volunteers of Red Cross Red Crescent societies follow this creed and play a crucial role in preserving TB patients' human rights, mitigating their alienation, and fighting stigma and discrimination. On behalf of all those who are affected by TB, we commend the Red Cross Red Crescent for its worldwide efforts against this human plague.

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

Dr Lucica Ditiu
Executive Secretary, Stop TB Partnership

Introduction and background

TB AND THE MILLENNIUM DEVELOPMENT GOALS (MDGs)

The health-related MDGs are interrelated, and achieving them will require strong commitment and an integrated approach.

MDG 6 includes reducing the global burden of tuberculosis and other diseases.

MDGs 4 (child health) and 5 (maternal health) will not be reached without additional emphasis on TB care and control, given the huge burden of TB among women and children.



1. South Africa: The real social value of our volunteers

Shirley, a volunteer working on the Nyanga Centre MDR-TB pilot project, explains that Red Cross volunteers carry out the 'Directly Observed Treatment Short Course', or DOTS. "We make sure that TB patients take their medicine every day. We walk with them to the clinic or we meet them there, and we keep a record of their treatment. Sometimes the patients are too sick to walk to the clinic themselves, so a volunteer will take them in a wheelchair."

The services provided by Red Cross volunteers don't end at the clinic door – they also carry out home visits. "We help families better understand how to look after a TB patient, and how they can protect themselves from getting the disease too," says Shirley. "And we help the patient cope and keep taking their medicine. It helps when you know someone will visit you every day, sick or not, and that you are not alone."

Tuberculosis in the world, 2009³

9.4 million
new cases of TB worldwide

1.7 million
deaths from TB

1.1 million
cases of TB among people living with HIV

Nearly half a million
cases of multidrug-resistant TB (MDR-TB)



2

Over the past 30 years, significant progress has been made in global health, with life expectancy increasing year on year in rich countries. Yet the poor face a different reality: tuberculosis, a preventable and treatable disease, continues to ravage poor communities, claiming 1.7 million lives in 2009 and affecting millions more.

TB is a potentially deadly lung disease that affects all parts of the world but thrives in impoverished areas in Europe, Africa and Asia. It can infect any part of the body but most often attacks the lungs, causing a persistent cough, weight loss, fever, night sweats, loss of appetite and the coughing up of blood.

TB is easily transmitted: when people with lung TB cough, sneeze or spit, they propel the germs that cause tuberculosis into the air. A person can be infected by inhaling just a few of these germs, although infected people may not feel ill or show any symptoms of the disease if their body's natural defence system can keep the bacteria under control. About one-third of the world's population is infected without showing symptoms.

The only way to cure tuberculosis is with a combination of drugs. The treatment lasts at least six months and the drugs only work when the TB bacteria, which grow slowly, are in the process of dividing.

2. India: The vicious circle of poverty, alcohol and TB

Maralur Dinne lies on the outskirts of Tumkur, a town of nearly 2.5 million people in Karnataka State. It attracts migrants and students because of its location near the highway and its cheap accommodation. It is classed as an underdeveloped area without clean drinking water or sanitation. A lack of knowledge and access to healthcare means that TB, diarrhoea and HIV are rife.

Shabbir is a migrant who takes on a different job each day; anything that comes his way. His wife wraps *beedis* – leaf-wrapped cigarettes – to support their four children. Shabbir is an alcoholic and was diagnosed with TB after a bout of fever and coughing.

At the district TB centre, he was put on a course of treatment, but it was difficult for him to travel to the hospital, pay the travel fare and still eke out a living. When he started to feel better after a few weeks, he decided to save the fare and start working. After a few days, Shabbir was soon feeling ill again and missing work. This drove him to drink more and more in a downward spiral of despair.

"I thought I was cured when I started feeling better. When a Red Cross volunteer explained that the germs inside me can only be cured after eight months' treatment, I understood why I was feeling ill again."

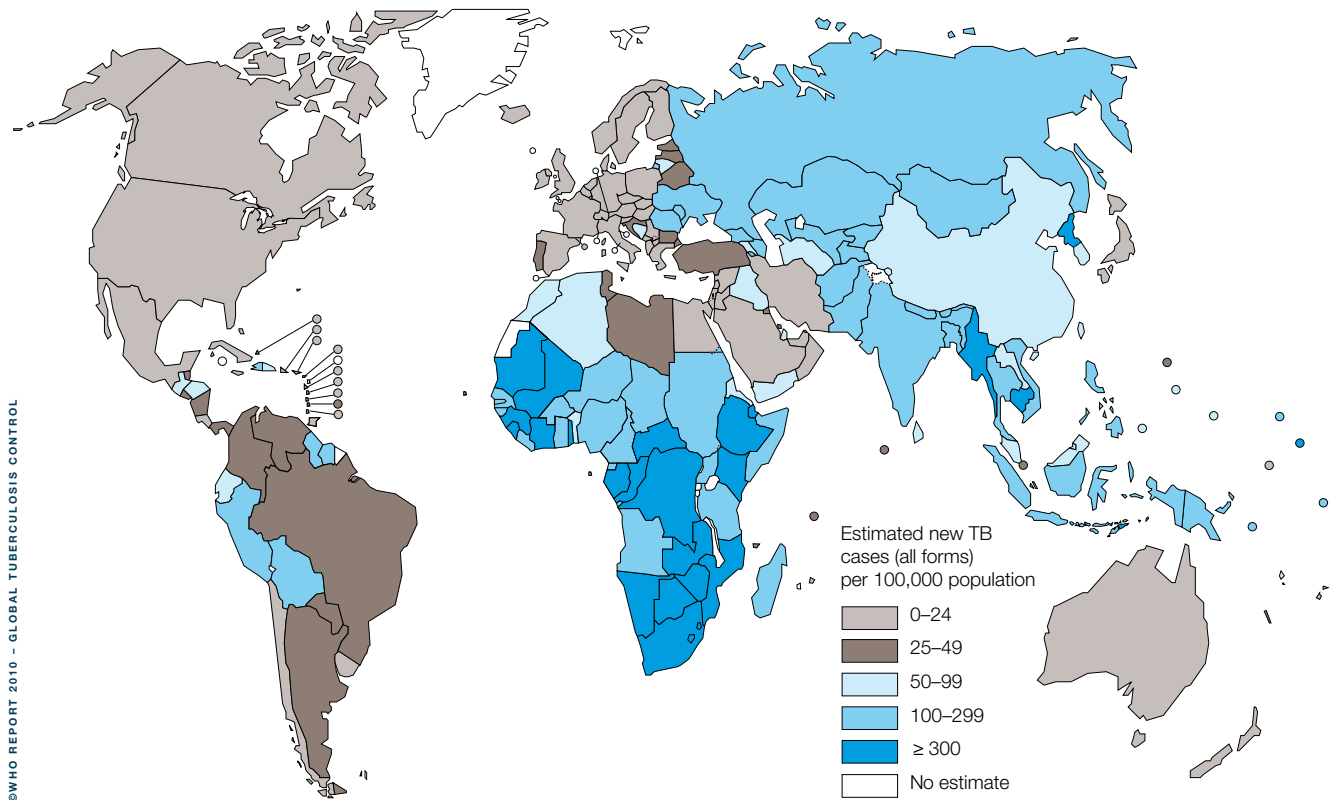
Shabbir has tested negative for TB at his last three check-ups and has just two weeks of treatment left. He is positive about a disease-free future, and his family now knows they can approach Red Cross volunteers for help or advice.



Chapter 1

The magnitude of the epidemic

Estimated TB incidence rates, by country, 2009



Globally, there were 9.4 million new cases of tuberculosis in 2009 and 1.7 million deaths from the disease. About one in five of the world's 1.8 million AIDS-related deaths in 2009 was associated with TB.⁶ Although the total number of new cases of TB is increasing in absolute terms, the number of cases per capita is falling as a result of population growth.

The World Health Organization (WHO) estimates that 85 per cent of TB cases occur in Asia and Africa (55 per cent and 30 per cent, respectively), with India and China alone accounting for 35 per cent of all cases.³

WHO has identified 22 high-burden countries that account for 81 per cent of the world's TB cases; these are a particular focus of TB control efforts.

With urban populations expected to swell to almost 5 billion by 2030⁷, cities will remain a hotbed for TB transmission.



Multidrug-resistant and extensively drug-resistant tuberculosis

Multidrug-resistant tuberculosis (MDR-TB) is a form of TB that is difficult and expensive to treat and fails to respond to standard first-line drugs.

While the overall rate of people becoming ill from TB has dropped in recent years, MDR-TB continues to be a huge threat. There were an estimated 440,000 new MDR-TB cases in 2009; of these, 86 per cent were in 27 countries (15 in the European region). The four countries with the largest number of estimated cases of MDR-TB in

2008 were China (22.7 per cent), India (22.7 per cent), the Russian Federation (8.6 per cent) and South Africa (2.9 per cent).³

MDR-TB can be cured with so-called second-line drugs – although cure rates are lower than for drug-susceptible TB – but it requires a long and expensive treatment that often causes severe side effects and can be difficult for patients to adhere to. Non-compliance with MDR-TB treatment can lead to resistance to second-line drugs, resulting in extensively drug-

resistant TB (XDR-TB) – for which treatment options are severely limited.

By July 2010, 58 countries and territories had reported at least one case of XDR-TB. The problem, as with MDR-TB, is that a large number of countries do not have the capacity to diagnose XDR-TB accurately.

When patients are diagnosed with drug-resistant TB, early detection and treatment of active tuberculosis among their close contacts is crucial.

3. China: Red Cross project contributes to preventing MDR-TB

Feng Wenli, 38, is racked by a fit of coughing as her husband, Li Jianbing, helps her to sit up. Her bed has been her refuge for the past year. “Every time I try to get up or exert myself, I start coughing up blood again.”

The couple’s home is strewn with boxes of medicine, but they do less and less to alleviate the symptoms of Ms Feng’s tuberculosis and, despite four stays in hospital, it seems to have worsened. Also heaped on the floor are empty packets of instant noodles. They provide inadequate nutrition, but they are almost all the family can afford, given that Mr Li rarely works now that he has his wife and elderly father to care for.

Relief in sight

Some relief is in sight though, in the form of a Red Cross Society of China pilot project. Supported by the IFRC, the project helps TB patients in this corner of Shanxi Province.

Red Cross volunteers help supervise an increased dose of medication to fight TB, while

offering psychosocial support. Patients also receive supplies of nutritious food and help with transport to hospital.

The project currently focuses on people who have been diagnosed with TB and have failed to complete their treatment. Although TB treatment in China is free, patients need to pay up front for medication and claim reimbursement from their health insurance, and this – combined with transport costs – is often an insurmountable obstacle.

“For various reasons, patients fail to complete their treatment. If the treatment is not completed and the patient is not cured, patients need to restart their treatment, which increases the risk of developing a multidrug-resistant strain of the disease,” says Dr Amgaa Oyungerel, the IFRC’s East Asia regional health coordinator. “This project contributes to the prevention of MDR-TB developing.”

Neighbourly volunteers

The Red Cross volunteers have been selected from communities near the patients. This is crucial

as they need to check on their patients five or six times a week to make sure they are taking their medication consistently.

In conjunction with this project, the government health authorities are providing additional drugs for TB patients who need close monitoring for regular medication and potential side effects. “Not taking the medication consistently is a major cause of TB becoming multidrug resistant,” says Li Meirong of the local centre for disease control in Changzhi City.

The volunteers receive a two-day intensive training course including role-play in dealing with patients’ doubts and fears, and how to communicate behaviour-change messages.

Set against the total number of MDR-TB patients in China and India – two of the largest countries in the world – this project is small-scale, but it is hoped that it will expand. And the hope is that while helping clients like Feng Wenli, this project will test an approach that could serve as a future model for other diseases.

4. Ukraine: Nursing an ideal

Ukraine has a high burden of tuberculosis, with one case among every thousand people. Co-infection with HIV is a real and present danger, as is multidrug-resistant TB.

There are dispensaries where people can get free treatment but, as ever, it's the most vulnerable that miss out: the homeless, the elderly, drug users, alcoholics and single mothers.

"The state services know we can take on the difficult cases, so they refer them to us," says Nina Muzalevska, a Ukraine Red Cross visiting nurse, who has worked with the TB programme for eight years. "We can follow up, we can persuade people to go into treatment or resume treatment. We provide that personal service, and we give a social service too: food parcels, home visits, hygiene items, second-hand clothes."

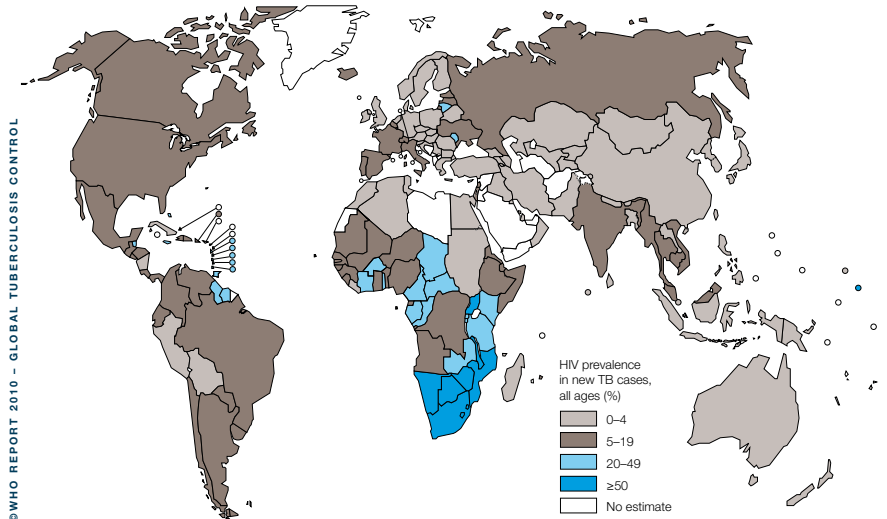
Every morning between 9am and 10am, Nina is in her 'surgery', a small but cheerful room in Kiev's Podil district. Her clients come in, take their medicine under her supervision, and leave. If they don't show up, she calls them, and if there's no reply, she takes the medicine to their home.

She rejoices when she sees her clients getting better, and it's as true for the 80-year-old man who is finally putting on weight as it is for the 30-year-old woman who wants to have more children.

Nina's work is bleak and depressing at times, but she sees hope in the recent news that the TB epidemic is stabilizing in Kiev. "We have a lot of drug abuse, a lot of alcoholism and people don't take responsibility for their health. Our work is contributing to that stabilization."

HIV and other diseases worsen susceptibility to TB

Estimated HIV prevalence in new TB cases, 2009



Some groups, such as people living with HIV and others with weakened immune systems, are more susceptible to TB. People living with HIV are up to 37 times more likely to develop TB than those without HIV.

A number of urgent actions are required in order to increase effective, integrated services for TB and HIV, and to tackle the factors that increase vulnerability to TB and HIV co-infection.

Bold national leadership is crucial. Comprehensive national plans will ensure the optimum use of available resources, and a timely and effective response to rapidly evolving epidemics.

Intensified case-finding for TB and HIV, better integration of TB and HIV treatment, counselling and prevention services, maternal and child health programmes, and sexual and reproductive health services – particularly at community level – will all form a vital part of stronger health systems.

Decentralized community-level care – requiring the meaningful engagement of civil society in

community mobilization, service delivery, and championing the needs of affected individuals – will improve access to healthcare for all.

Investment in new tools and the better use of existing tools are needed to prevent, diagnose and treat TB in people infected with HIV and address the worsening problem of MDR-TB and XDR-TB.

Global leadership from donors, countries of the Global South, and key health agencies is crucial to galvanize collective action and recapture the fighting spirit that has enabled the unprecedented response to tuberculosis and HIV in recent years. Stronger civil society engagement is necessary in individual countries and globally to emphasize the importance of collaborative interventions for TB and HIV.

Ministries of health and global agencies should not consider TB treatment as a vertical programme. It is important that TB treatment is integrated with the treatment of other co-infections or diseases such as HIV, diabetes, hepatitis and cancer, as well as cigarette smoking, alcohol, stress and substance abuse.

5



5. South Africa: Addressing the high rate of TB and HIV co-infection

The South African Red Cross Nyanga Centre in the Gugulethu township of Cape Town, despite its dilapidated building, runs one of the most successful Red Cross tuberculosis programmes in South Africa. It has been carrying out home-based care activities for over 15 years, focusing at first on HIV and AIDS, and then integrating TB care as well.

“We saw we had to look at both problems at the same time because of the high co-infection rate between HIV and TB,” explains David Stephens, the South African Red Cross national health and care coordinator.

“In South Africa, 80 per cent of the patients admitted with TB also have HIV. A few years ago, the TB programme was launched, but the problem was getting worse, and more and more people who didn’t have HIV were becoming infected with TB. So we started an education campaign.”

Shirley, who coordinates a team of 15 fellow volunteers in an impoverished neighbourhood where people live in crowded conditions, often without running water or indoor plumbing, describes their work:

“We help people with HIV, TB and MDR-TB, and we have groups for OVCs* and a group for the children’s grannies. We run support groups three days a week, which are so important because people learn from each other and know they are not alone.”

* “Orphans and vulnerable children” (OVCs) is a term often used to describe children who have been infected or otherwise affected by HIV and AIDS.





TB in prison settings:

Prisons, which frequently suffer from extreme overcrowding, poor nutrition and inadequate health services, provide an ideal breeding ground for tuberculosis to thrive and the prevalence of the disease is much higher in prisons than among the general population.

But while you can confine people to a cell, you can't keep TB behind bars. It spreads no matter what – whether it's the prison guard who catches it and takes it home to his unsuspecting family or the detainee who is released and finds it too difficult to stay on his medication once he's outside. Left unchecked, sooner or later, TB will find its way from prisons into communities. This is why efforts to stem its spread must include strategies for controlling it inside detention centres.

Experience has shown that the most effective way of doing this is to first make sure that the right tools and resources are in place to identify and deal with the problem. From infectious disease control and isolation upon entrance to on-site diagnostics labs and special training for prison staff, it is essential to develop an early detection system and invest in modern tools and medical facilities.

But screening and prevention are only half the battle. Experience has shown that supervised medical treatment inside prisons, such as the World Health Organization's DOTS approach, can significantly reduce the number of new cases among inmates and radically diminish TB-related deaths. Initiatives of this kind protect not only detainees, but also prison staff, visitors and the wider public.

Care and follow-up shouldn't stop when a person is released from jail, however. Frequently, ex-convicts wind up back in society without a safety net. Jobless, often homeless and many times alone, it's easy for them to stray off the strict regimen of daily drugs that TB treatment requires, especially if they have a multidrug-resistant form of the disease (MDR-TB), which is more complex to cure.

Providing former detainees with medicines at civilian dispensaries, and giving them food rations and other essential items as encouragement, can mean the difference between them staying on their drugs or not. Recent experience has shown that when prisoners are released but not abandoned, they are more likely to successfully finish their treatment and less likely to infect others.

As TB continues to spread around the globe, it's becoming increasingly critical that the threat it, and other contagious diseases, pose to public health be prioritized and tackled both inside prisons and out in order to stop this silent killer from claiming even more lives.

Dr Raed Aburabi

Health in Detention Coordinator for
the International Committee of the Red Cross (ICRC)

Near Baku, prison tuberculosis hospital, Specialized Treatment Institution. A lab technician keeps track of sputum samples provided by infected prisoners.

Sputum is a thick mucus produced by coughing which can be analysed for TB microbes.

© CICR/AHAD, Zalmai

The ICRC provides food and hygiene items to former detainees in Azerbaijan as part of an incentive programme to get them to stay on their tuberculosis drugs until they are cured.

© CICR/AHAD, Zalmai

Stopping a killer that can't be kept behind bars



In Azerbaijan, tuberculosis remains a serious threat to public health. The situation is made much worse by a drug-resistant form of the disease. The ICRC is working with the Azerbaijani government and other organizations to address the problem.

© CICR/AHAD, Zalmai

6. Azerbaijan: Fighting TB in prisons pays off

On the outskirts of Azerbaijan's capital, Baku, not far from the city's rich petroleum fields, the authorities are racing against time to stop a silent killer. For more than 15 years, officials have been working to halt the spread of tuberculosis inside prisons, where drug-resistant forms of the illness often flourish due to overcrowding, poor nutrition and inadequate health services. Being contagious, TB is easily transmitted to guards, staff, visitors and the families of infected former detainees.

"A man can kill another man with his bare hands... but he can kill hundreds of people with TB," says Nahmat Rahmanov, the lead physician at Baku's Special Treatment Institution (STI), which houses around 1,000 infected inmates from across Azerbaijan's penal colonies.

At first glance, STI looks much like any other prison: high walls topped by curls of barbed wire, armed guards in watchtowers and heavy iron gates separate the criminals from the outside world. But once inside, the facility feels distinctly more like a hospital than a jail.

The years following the collapse of the Soviet Union saw a sharp

increase in the spread of infectious diseases. When the International Committee of the Red Cross (ICRC) started visiting Azerbaijan's prisons in 1995, delegates discovered that TB was the main cause of death among inmates. Since then, the authorities and the ICRC have slowly but surely managed to drastically reduce the number of TB cases in detention centres by improving screening, prevention, treatment and follow-up.

"In 1999, we had 285 prisoners die from TB. A decade later, we had managed to get the number of deaths down to 20," says STI Director Nizami Guliyev as he shows off the elaborate ventilation system that has been put in place to provide a maximum of fresh air in the cells and communal sleeping areas. Posters on the wall explain through drawings that dark, confined spaces provide a perfect breeding ground for TB.

Modern surgical equipment was recently installed in a new wing, while the prison also boasts an on-site diagnostics laboratory and pharmacy. Over the years, the wardens have also learned that in addition to the tablets, x-rays and white coats, a dose of dignity and

humanity can have a big impact on patients' adherence to treatment.

That's why, here, the cells and communal rooms are bright and clean, relatives are allowed to bring food for their incarcerated loved ones and there is even a small library, where books are meticulously divided up into sections for highly contagious and less contagious readers.

In fact, these combined efforts have proven so successful that the ICRC plans to hand over its TB-related activities to the Azerbaijani authorities at the end of March 2011, although the organization will continue to provide training and technical support as needed.

"The kind of commitment, change and creativity that's needed to outsmart this disease won't happen overnight," says Nick Sadradze of the ICRC in Baku. "It takes time, but if the same level of progress we've seen in Azerbaijani jails could be achieved on a broader scale, we would stand a fighting chance of gaining the upper hand against this killer worldwide."

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The burden of the disease

The developed world may consider TB to have “gone out with the plague”, but the disease is still ravaging people living in the shadows of modern society: immigrants, homeless people, drug users, those living in overcrowded or badly ventilated areas like prisons, or people suffering from other diseases.

TB has a devastating economic impact. More than three-quarters of all TB cases are among people aged 15 to 54 years old – those in their prime working years. The disease is a major cause of poverty because people with TB are often too sick to work, and they and

their families have to pay for treatment.

TB is the third biggest cause of death among women and therefore has a massive impact on mothers and their children. The stakes are high – nearly 4 million women and children will die between 2011 and 2015, and millions of children will be orphaned without a rapid scaling up of TB care.

Children may drop out of school because they or a parent has TB, and infected women may be stigmatized, discriminated against or ostracized by their families and communities.

Even though TB is curable, it is greatly feared and people undergoing treatment are often rejected by their own families, something that tends to affect women. To escape this stigma, patients skip visits to TB centres or stop their treatment altogether. Many of the patients assisted by Red Cross Red Crescent programmes around the world report some form of discrimination due to their disease.

Combined with the fact that the average untreated TB patient infects 10 to 15 others, it is clear that the disease will have even more disastrous effects if left unchecked.



THE GLOBAL FUND TO FIGHT AIDS, TB AND MALARIA



7. India: How Iqbal was treated like a pariah

“We were strictly told to limit our interaction with him: we do not allow our young children near him, we have given him a separate plate for his food, and he washes his clothes himself. He cannot be cured. He is old and will not last long,” said a member of Iqbal’s large family. She also explained that they were worried that Iqbal’s tuberculosis would spread to other family members and that he was mostly confined to the far end of the house.

Iqbal, 60, lives in Sira Gate, a suburb of Tumkur in Karnataka State with a high population of migrants and residents from lower socio-economic groups. The area’s infrastructure is poor, as are the health and sanitation facilities. The family considered TB to be an irrevocable curse.

A Red Cross volunteer and government TB officer visited Iqbal’s house after he defaulted on his treatment. After repeated visits from volunteers, the family realized that the Red Cross wanted to help and they began to listen. With support from local health workers – an *anganwadi* (community health) worker and an ASHA (accredited social health activist) – the Red Cross volunteers explained TB, its treatment and how Iqbal could make a full recovery. They also explained how important it was for Iqbal to take his treatment consistently for eight whole months without defaulting. Most important of all was the information about the danger of stopping treatment halfway through, which could lead to multidrug-resistant TB.

Iqbal started attending the primary health centre, escorted by Red Cross volunteers. After the initial intensive course of treatment was over, the local ASHA took over the monitoring of Iqbal’s treatment. The family was advised on nutritious food available locally and how to prevent the spread of respiratory infections with thorough hand-washing, and covering the mouth and nose when coughing.

Iqbal successfully completed his treatment in November 2010 and has been declared free of TB. He profusely thanked the Red Cross for their commitment in sending staff and volunteers to advise and motivate him and his family. He now actively spreads the word on TB treatment.



THE GLOBAL FUND TO FIGHT AIDS, TB AND MALARIA

Chapter 2

The call to action

Preventable and treatable

DOTS remains at the heart of the Stop TB Strategy. To enable known constraints to be addressed and new challenges to be met, further strengthening of the basic five components of the DOTS approach is required.

Supervision and patient support

Services for TB care should identify and address factors that may make patients interrupt or stop their treatment. Supervised treatment, which may include Directly Observed Treatment Short course (DOTS), helps patients to take their drugs regularly and complete their treatment, thus curing the disease and preventing the development of drug resistance.

Supervision must be carried out in a context-specific and patient-sensitive manner, which ensures adherence on the part of both provider (in giving proper care and support) and patient (in taking regular treatment). Depending on the local context, supervision may be undertaken at a healthcare facility, in the workplace, in the community or at home. It should be provided by a treatment partner or treatment supporter, in agreement with the patient, who is acceptable to the patient and is trained and supervised by health services. Patient and peer support groups can also help to promote adherence to treatment. Selected patient

groups – for example prisoners, drug users, and some people with mental health disorders – may need intensive support including DOTS.

Improving access to treatment

Locally appropriate measures should be undertaken to identify and address physical, financial, social and cultural barriers – as well as health system barriers – to accessing TB treatment services. Particular attention should be given to the poorest and most vulnerable population groups.

Examples of actions that may be appropriate include expanding treatment outlets in the poorest rural and urban settings, involving providers who practise close to where patients live, ensuring that services are either free or heavily subsidized, offering psychological and legal support, addressing gender issues, improving staff attitudes, and undertaking advocacy and communication activities.⁸



8. Russia: “I will do all I can to complete my treatment”

Victor, 42, suffers from multidrug-resistant tuberculosis. He first met Red Cross staff when he was in detention, learning about the TB programmes that would be available to him after his release.

Upon his release, Victor continued treatment at the TB dispensary in Abakan, Eastern Siberia, but started to abuse alcohol, lost all his money and documents, and was expelled from the state programme.

As a last resort, he turned to counselling offered by a psychologist at the Russian Red Cross branch in Abakan, who explained to him that he would only receive support if he stopped drinking. He promised to stick to the conditions and continue treatment. He soon started receiving medication from the local dispensary.

“From now on, I will always try to stick to my treatment,” he said. A few months later, when he faced employment problems, the Red Cross provided financial support to help him move to a new area to find work. He regularly attends the local TB dispensary and Red Cross branch there, but regularly calls the Red Cross branch in Abakan to thank them for their help and to say “I am fine”.

Public health and development priorities

TB is a health and development priority for the International Red Cross and Red Crescent Movement. Between 1995 and 2009, 41 million TB patients were successfully treated in DOTS programmes and up to 6 million lives were saved, including 2 million women and children.³

Yet the DOTS programme alone has not been able to stop the disease from spreading because diagnosis remains a problem. There is no affordable, simple and fully reliable test that can diagnose active TB. In fact, the uncertainties, unavailability and inaccuracy of diagnosis remain the greatest obstacles to successful TB treatment and eradication. Poverty also plays a pivotal role, which is further compounded by the high cost of long-term care in terms of lost productivity.

What is needed is an accelerated increase in TB interventions

- It's time to move towards a goal of zero deaths from TB and HIV co-infection.
 - Countries need to focus more on TB and HIV. Only bold political leadership will guide countries out of their current TB crisis.
 - The screening of at-risk populations and faster case detection are crucial.
 - There needs to be a greater focus on upstream prevention.
 - Interventions based on social and economic determinants – such as malnutrition, alcohol abuse, poor housing, indoor air pollution and poverty – need to be assessed.
 - Governments need to take responsibility for health. There has to be a step change in firm commitments by governments to improve health, including TB, in order to achieve universal access.
 - TB must receive more resources, more research dollars and more attention from the global health community.
- TB is everywhere. It may not be very visible in developed countries, but it remains a threat to everyone. It is in everyone's interest to fight TB and prevent emergence of dangerous drug-resistant forms of the disease.

9. Turkmenistan: Red Crescent intensifies efforts against TB

The number of people cured of TB under the Turkmenistan Red Crescent's visiting nurses programme is constantly increasing. On the recommendation of the National Society's nurses and volunteers, many people visit doctors for lung screening, which offers a good chance of early diagnosis.

Myahri, a 40-year-old visiting nurse from Ashgabat, has had tuberculosis twice: once as a child and again at the age of 33, while working in a clinic.

"I felt really depressed, but the Red Crescent helped me to finish my treatment. After I recovered, I joined the Red Crescent to try to help people with TB find hope," says Myahri.

"I volunteered for a year and now I am working as a visiting nurse for TB patients. I have the opportunity to talk to patients and help them find inspiration through my own experience."



Chapter 3

The Red Cross Red Crescent response

The Red Cross Red Crescent network uniquely offers decentralized care to ensure improved access at local level. Volunteers contribute to the meaningful engagement of civil society in demand mobilization and service delivery, as well as championing the needs of affected people. Two in every thousand people in the world volunteered with the Red Cross Red Crescent in 2010. This global network of volunteers live within the very communities they serve and are deployed at local level to deliver basic curative and preventive health services.

What makes the Red Cross Red Crescent approach different from other tuberculosis programmes is its ability to bring tuberculosis treatment to the people. The Red Cross Red Crescent is unrivalled in its ability to bridge the gap where one in three people fails to obtain an accurate diagnosis and follow appropriate treatment.

In order to reach public health centres, the world's most vulnerable people – often living in remote areas or slums – have to travel long distances, miss work and lose valuable income. As a result, many will simply not seek a diagnosis or will miss out on treatment. To tackle this problem, Red Cross Red Crescent →

The Red Cross Red Crescent response in numbers

Number of patients with TB, receiving home-based care, and psychological and material support from the Red Cross Red Crescent	150,000
Number of patients with TB, receiving direct observation for treatment adherence	70,000
Number of patients with MDR-TB, receiving direct observation for treatment adherence	10,000
Number of people living with HIV and TB, receiving direct observation for treatment adherence	40,000
Number of patients with TB detected due to referral from the Red Cross Red Crescent for testing	30,000
Number of people reached with key messages on TB transmission and early detection	5,000,000
Number of community members volunteering in Red Cross Red Crescent TB services	80,000

10. Tajikistan: Thousands of hearts full of mercy

When 23-year-old Zarina found she was suffering from tuberculosis, volunteers from the Red Crescent Society of Tajikistan visited her every day, explaining her condition and helping her follow a long-term course of treatment. Zarina managed to take her medicines regularly for six months. Four months later, after regular testing, she was declared free of TB.

“I am so grateful to the volunteers who have been on my side throughout the treatment period, and without their help I couldn't have made it,” says Zarina during a visit to a Red Crescent TB dispensary in Dushanbe.

“Each volunteer's experience is unique. But what unites us is a spirit of service and a commitment to do what it takes to help people who, in the face of enormous obstacles, want to build a better future for themselves, their children and their communities,” says Karim, a young Red Crescent volunteer.

TB-related stigma and discrimination are often gender-based and, at the dispensary, a woman complains bitterly about the discrimination her friend's daughter faced after it came to light that she had TB. But the conversation ends on a lighter note when Zarina asks shyly if she could now get pregnant. “Yes, of course you can!” chorus the volunteers. Zarina's face lights up.

By providing support, be it just a few compassionate words, volunteers are rewarded with the opportunity to have a positive effect on their communities long into the future.

→ **volunteers go to the patient instead, providing access to treatment for those living in the most underprivileged areas of cities and rural areas. In this way, they avoid a loss of income or disruption of their daily lives. Volunteers also provide nutritious food, when necessary, as well as a crucial emotional boost to TB patients and their families.**

What have been the results? Worldwide, in 2010, the Red Cross Red Crescent provided daily care to 150,000 TB patients, out of which 10,000 were patients with MDR-TB, and 40,000 were co-infected with HIV. Furthermore, 5 million community members were mobilized, with 14 million hours allocated through 80,000 Red Cross Red Crescent staff and volunteers. The plan is to expand the programme to have, in total, 1.7 million of the most difficult-to-reach patients enrolled worldwide in the Red Cross Red Crescent TB programme by 2015.⁹

Engaging with care providers and the community



11. Myanmar: Red Cross volunteers help people fight off TB

Myanmar is one of the 22 countries with a high TB burden that account for 80 per cent of all new TB cases each year. It is also one of the 27 countries that contribute to 85 per cent of the global burden of multidrug-resistant TB. To address this high burden of TB, the Myanmar Red Cross Society is running community-based TB programmes in the townships of Tharkayta and Mayangone, which have a combined population of 200,000.

In 2007, Ma Ei Win, then 23, worked by selling hot food in front of her house. She was also responsible for the housework and taking care of her husband, a factory worker in Mayangone Township, their two children and her parents. During the winter, she developed a fever and a cough, and experienced tightness in her chest. She bought medication locally, but was forced to close her shop.

Then Ma Ei Win met a Red Cross volunteer, Myint Myint, a neighbour who had heard she was ill. Myint Myint had attended a TB training course and was aware of the symptoms of TB. She referred Ma Ei Win to a health centre for diagnosis and treatment. Her sputum was tested and showed up positive for TB. Every day for two months, Ma Ei Win took her TB treatment under the direct supervision of a Red Cross worker – the DOTS treatment or Directly Observed Treatment Short course.

On her next test, Ma Ei Win's sputum analysis came back as negative. She was overjoyed. Her neighbour continued to keep an eye on her for another four months and her sputum was checked regularly, but it was always negative. Thankfully, Ma Ei Win was cured quickly.

"I got an early diagnosis and treatment thanks to the referral by the Red Cross volunteer," she explains. "I was cured quickly of TB. Without the help of Myint Myint, I wouldn't have received proper treatment or support. She treated me like a sister. I am so grateful to her that I would like to be a volunteer in Red Cross TB services," she says with a smile.

Chapter 4

Obstacles and opportunities



12. South Africa and Swaziland: TB media tour, January 2011

More than 20 journalists from eight countries visited Red Cross tuberculosis programmes in South Africa and Swaziland as part of the Lilly MDR-TB Partnership* media tour in January 2011.

The journalists – from Austria, France, Italy, the Netherlands, Poland, Portugal, Switzerland and Turkey – were joined by local media at panel briefings and site visits designed to increase their awareness and knowledge of both TB and MDR-TB.

The tour began in Cape Town's Gugulethu township, where the group visited the South African Red Cross Nyanga Centre and the homes of Red Cross patients. The tour also included a visit to a community clinic and the launch of the 'Kick TB' campaign at a primary school. The campaign, led by the IFRC global TB ambassador Gerry Elsdon, uses football to help teach children about TB.

In Swaziland, the group visited the Sigombeni clinic, a primary healthcare facility run by the Baphalali Swaziland Red Cross Society in partnership with the Swiss Red Cross. In his welcoming address to the journalists, the secretary general of Baphalali, Nathi Gumede, said that the success of the clinic would "not have been possible without the excellent work of our health professionals and the voluntary services of the community, including the chiefs in the area".

Speaking at the end of the tour, Polish broadcast journalist Andrej Wrobel said: "My knowledge about TB has dramatically increased. We have seen all sides of the story, from prevention to treatment to care and support. And we have seen the excellent work carried out by Red Cross volunteers every day. So, we understand the issues much more in depth now.

"The most touching moment of the tour, for me, was meeting Blessing. He is a seven-year-old MDR-TB patient in a Johannesburg hospital. He proudly read to me the words he'd just learnt and showed off his homework. Then he asked me to give him my address so he could write to me. And then he asked if I could go back to see him in July. I asked him why in July and he replied, 'Because that's when I'll be cured'."

The tour participants were urged to help educate their compatriots about TB and to raise awareness, especially among the donor community, of the challenges faced in combating the disease.

* The Lilly MDR-TB Partnership is a public-private initiative that mobilizes more than 20 partners, including the IFRC, on five continents to tackle the scourge of TB and MDR-TB. More information available at: <http://www.lillymdr-tb.com>

13



CLAUDIA JANKE/BRITISH RED CROSS

Partnership

No single organization can tackle tuberculosis alone. It is essential to engage with public and private care providers in order to address the needs of the most vulnerable among affected populations and reduce the toll of TB. The Red Cross Red Crescent, United Nations agencies, NGOs and other humanitarian organizations, together with the private and public sectors, must work in partnership and voice their concerns about the major threat that TB poses to the health of vulnerable groups. The IFRC has been an active member of the Stop TB Partnership since 2004. It has served on its coordinating board as a representative of civil society and NGOs from 2004 to 2009. The IFRC and its worldwide membership have also signed various memoranda of understanding with WHO at global and regional levels, which aim to improve global health and strengthen collaboration with health ministries at local level. Finally, the IFRC, its member National Societies and community-based volunteers provide a unique bridge between government, civil society and vulnerable people. With their skills, compassion and unparalleled local knowledge, Red Cross Red Crescent volunteers can reach and transform the lives of those most in need, especially those facing discrimination and living on the margins of society.

13. Kazakhstan: Alexander's story – from convict to volunteer

“There is nothing good about the way I used to live,” says Alexander, 36. “I was into drugs and was eventually sent to prison for two years. After leaving prison, I fell back into drugs right away. When I was applying for a job, tuberculosis was detected in my lungs and I was immediately sent to a TB hospital. There was a terribly high amount of TB in the city, with two or three corpses removed every day from the hospital backyard.”

“I was one step away from falling over the edge,” he explains. “Faced with the grim reality of my life, I made a firm decision. I would carry on with my TB treatment. It is hard to get through, but I completed my intensive nine-month treatment and survived. I chose life.”

Alexander – no longer a drug addict – is a Kazakh Red Crescent volunteer and member of a peer-to-peer support team for sufferers of the dual TB–HIV epidemic. Alexander's life was turned around through the support he received from the Red Crescent. Now, he is giving something back to the community by supporting other co-infected patients with HIV like himself.

After prison

Three years after leaving the prison TB ward and his drug habit behind, Alexander felt compelled to share his experiences with others in the same predicament, as he understands what they are going through and can provide support during their treatment.

“Helping others to live with the same diagnosis of co-infection became my mission in life,” Alexander says. “This programme is about survival. Sometimes we are the only lifeline that people have, particularly if they were just released from prison.”

Working as a Red Crescent volunteer in areas with the highest prevalence of HIV, Alexander reaches out to the most vulnerable. Community volunteers, often ex-TB patients, have been trained to work in these ‘HIV hotspots’ to raise awareness of the signs and symptoms of TB and to motivate and encourage people to seek and continue the long course of treatment to completion. They provide food as well as education about the risks of drug use and unsafe sex.

Turning lives around

“I know the drug users and they trust me, so when I approach them with clean needles and advice, they listen to me,” Alexander explains. “I motivate them and they respect me because I have had the strength to get over TB and improve the way I live with HIV.”

“There was one man suffering from TB and HIV co-infection who was completely alone. I brought him food and kept an eye on him, especially to ensure that he took his medicine. Slowly but surely his condition improved. Medicine, food and a bit of personal care can go a long way. The rest depends on individual choice. If someone decides to turn his or her life around, I can offer my shoulder.”

“On another occasion, I managed to persuade an injecting drug user who didn't want to go for testing to get tested, and TB was diagnosed. It is really difficult to persuade drug users to take the time to get tested because they are always looking for drugs, so this was a big achievement.”

Alexander has a job, maintains his own health and takes care of the people around him. He smiles: “Life can be changed for the better. Now I know that for sure.”

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Funding global TB control

In 2009, the World Bank estimated that about 53 million people in developing countries will remain poor because of the world economic slowdown, thus reversing many of the gains made in reducing poverty in developing countries.¹⁰ Furthermore, if the current global economic crisis persists, there could be between 200,000 and 400,000 additional child deaths every year – between 1.4 million and 2.8 million before 2015 – and 100 million of the world's poorest people could be forced back into poverty.

Undoubtedly, any cut in healthcare funding will have devastating consequences for the sick, including those affected by TB, plunging new groups into poverty

and exposing them to greater health risks.

The IFRC and its partners will continue to engage stakeholders who share our vision and commitment to ensure that a well-balanced, effective and adapted response to TB is not only maintained, but scaled up.

- The cost of individual treatment varies on a per patient basis, and ranges from less than 100 US dollars to 7,500 US dollars.³
- The projected funding gap for meeting all the goals and targets of the *Global Plan to Stop TB 2011–2015* is 21 billion US dollars.
- The funding challenge for the Red Cross Red Crescent TB programme worldwide:

250 million US dollars over the next four years to cover the needs of 1.7 million TB patients.

- Flat-lining or reduction in investment will impede any response to TB and the world's ability to reach MDG 6 and the other related MDGs.
- There has been a considerable commitment from National Red Cross and Red Crescent Societies. Special credit should be given to Eli Lilly, AstraZeneca, The Global Fund and USAID, as well as key supportive National Societies.

In order to achieve radical change, innovative funding mechanisms need to be implemented with the active participation of different players.

14. Russia: Psychosocial care for TB patients

The Russian Red Cross Society in the Republic of Khakassia, Siberia, has established a social club – called White Camomile – for tuberculosis patients. Patients are provided with comprehensive information about the disease and its treatment, and – as they all have TB in common – they can share their feelings and support each other. Those who fully recover are invited to share their experience, helping to boost current patients' confidence. These former patients have established a team of volunteers providing regular psychosocial support to TB patients who are prone to defaulting on their treatment.

Vladimir, 42, is one such volunteer. Doctors discovered he had TB when they examined him for a broken rib. He treated the news as a death sentence and, while undergoing treatment, he became severely depressed and left the programme.

“My friends left me and people I knew tried to avoid contact with me even though I was not infectious. Then the woman I loved also left me. I felt like the whole world had abandoned me,” Vladimir recalls. His former doctor recommended he continue treatment through the Red Cross, and it was Red Cross staff who were there for him through the difficult times.

“When I was coming to take my medicine, I spent a lot of time talking to Red Cross nurses, which made me feel better,” he says.

Some time later he started to attend White Camomile, which he refers to as a “TB patients' brotherhood”. Vladimir is now completely free of TB. He is back to work and normal life, but he tries to visit the club from time to time in order to explain to newcomers the importance of a responsible and positive attitude to treatment.



15. South Africa: The story of TB survivor Gerry Elsdon, the IFRC's global ambassador for TB

Ten years ago, I was diagnosed with TB. It was at a time when my career was taking off and I was becoming a well-known face in South Africa, leading a glamorous life in the new South Africa. I never thought it would happen to me. I didn't know much about the disease, or how to treat it. Thankfully, TB is 100 per cent curable, and I was soon on the road to recovery. Then the rumours started that I must be HIV positive, and I had to deal with ignorance and stigma. That's when I knew that I had to personally get involved in the fight against TB in my country. I was the beautiful face of LUX*, appearing in a red evening gown on billboards all over the country. But under the billboards are slums and people living in very cramped conditions – and it's a country heavily stricken by TB.

I have become a TB activist, especially when it comes to better prevention, care and treatment of women. To be diagnosed with TB doesn't have to be a death sentence, yet women are suffering in silence; and their sickness affects the whole family. We have to look at who is the patient and who is helping her.

Today, I am involved in various TB education campaigns and partnerships. And I knew that I wanted to work with the Red Cross, because growing up in a township near Cape Town, my own life had been impacted by the work and the values of the Red Cross.

Red Cross Red Crescent volunteers, the majority of whom are women, play a critical role in carrying out action on the ground – engaging with at-risk communities – which is the most efficient way to fight the disease, not only in remote and inaccessible settings, but also in urban areas.

* Personal care company

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Towards a turning point

We are calling for a radical shift in approach that will revolutionize tuberculosis-related health services in the world's poorest countries. Despite significant progress made so far, we must recognize that we are falling short of our goals. We know, however, that a radical reframing of the way that we tackle TB will not happen overnight.

The IFRC, together with its partners, will continue to work closely with civil society organizations, international organizations and donors. It remains committed to urging governments to

take concrete action to bring about the radical shift that is needed, based on the principles of public health, development and human rights.

From a public health perspective, what is needed is an accelerated increase in TB interventions, intensified case-finding among at-risk populations, and a greater focus on upstream prevention.

From a development perspective, a new focus is required that assesses interventions based on social and economic determinants such as

malnutrition, gender inequalities, alcohol abuse, poor housing, low-quality education, indoor air pollution and poverty.

From a human rights perspective, TB patients need to live in dignity and with respect. We need to reach out to communities in order to prevent, treat, care and support all those either living with TB or at risk of being infected with the disease.

We hope that the turning point will be achieved in the near future, when we win the battle to provide TB healthcare to all.

The International Red Cross and Red Crescent Movement and its health activities

- The Red Cross and Red Crescent National Societies have a major impact on improving the health and care of vulnerable people in all four corners of the world. This worldwide network, its community-based volunteers, its public auxiliary role with national governments enable it to broker meaningful partnerships in favour of the most vulnerable.
- The IFRC's diverse health and care actions include long-standing activities such as first aid and emergency response as well as epidemic control, programmes in health promotion and prevention, addressing stigma, providing psychosocial support and empowering communities.
- The International Committee of the Red Cross (ICRC)'s health activities give people affected by armed conflict and other situations of violence access to basic preventive and curative healthcare that meets universally recognized standards. To this end, it assists – or may temporarily replace – local health services. The ICRC is also concerned with the welfare of anyone detained in connection with armed conflict or internal unrest.

The Fundamental Principles of the International Red Cross and Red Crescent Movement

Humanity

The International Red Cross and Red Crescent Movement, born of a desire to bring assistance without discrimination to the wounded on the battlefield, endeavours, in its international and national capacity, to prevent and alleviate human suffering wherever it may be found. Its purpose is to protect life and health and to ensure respect for the human being. It promotes mutual understanding, friendship, cooperation and lasting peace among all peoples.

Impartiality

It makes no discrimination as to nationality, race, religious beliefs, class or political opinions. It endeavours to relieve the suffering of individuals, being guided solely by their needs, and to give priority to the most urgent cases of distress.

Neutrality

In order to continue to enjoy the confidence of all, the Movement may not take sides in hostilities or engage at any time in controversies of a political, racial, religious or ideological nature.

Independence

The Movement is independent. The National Societies, while auxiliaries in the humanitarian services of their governments and subject to the laws of their respective countries, must always maintain their autonomy so that they may be able at all times to act in accordance with the principles of the Movement.

Voluntary service

It is a voluntary relief movement not prompted in any manner by desire for gain.

Unity

There can be only one Red Cross or Red Crescent society in any one country. It must be open to all. It must carry on its humanitarian work throughout its territory.

Universality

The International Red Cross and Red Crescent Movement, in which all societies have equal status and share equal responsibilities and duties in helping each other, is worldwide.