

TUBERCULOSIS

Voices in the fight against
the European epidemic



TB EUROPE COALITION

actbn
Advocacy to Control TB Internationally

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"TB takes people out of the workforce and puts them into a state of poverty. As they become sicker, they become more contagious and infect others with this deadly disease. They are not just faceless statistics, they are mothers and daughters, fathers and sons, and they are suffering"

Jonathan Stillo, medical anthropologist, Romania



ABOUT THE ACTION PROJECT

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 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 and donor countries. European partners of the ACTION Project include RESULTS UK, Global Health Advocates France and AIDES.

www.action.org

This report is the second publication from the ACTION Project aiming to give TB a 'human face' by looking behind the statistics to focus on the every-day challenges faced by patients and their carers. Their personal stories should inform any policy changes and must be taken into account by local governments in order to achieve a comprehensive TB response that respects the rights of the patients. A copy of ACTION's previous report can be accessed from the ACTION website:

www.action.org/site/publications

About the TB Europe Coalition

The TB Europe Coalition (TBEC) is an informal advocacy alliance of individuals associated with civil society organisations. We share a commitment to raise awareness of tuberculosis and to increase the political will required to effectively control the disease throughout the World Health Organisation European Region and worldwide.

www.tbcoalition.eu

GLOSSARY OF TERMS AND ACRONYMS

AIDS

Acquired Immune
Deficiency Syndrome

BCG

Bacille Calmette Guerin, the current
vaccine for TB, which provides only
limited protection against TB

DG SANCO

The European Commission's
Directorate General for Health and
Consumer Policy

DOTS

Directly Observed Treatment, Short
Course

DOTS-PLUS

DOTS to manage MDR-TB with
second-line drugs in resource-
limited settings

EC

European Commission

ECDC

European Centre for Disease
Control and Prevention

EU

European Union

FP

Framework Programme for
Research and Technological
Development

GLOBAL FUND

The Global Fund to Fight AIDS,
Tuberculosis and Malaria, which
provides grants to address these
three infectious diseases

HIV

Human Immunodeficiency Virus

MDR-TB

Multidrug-Resistant Tuberculosis

MDG

Millennium Development Goal

NGO

Non-Governmental Organisation

TB

Tuberculosis

WHO

World Health Organisation

XDR-TB

Extensively Drug-Resistant
Tuberculosis

FOREWORD

We have all heard that famous phrase: One death is a tragedy, one million deaths is a statistic. It has become a truism, but it is quite true. You can only understand what TB means when you hear individual stories of illness, mourning, courage and hope.

This unique report offers a window into the lives of people living in countries that rarely get the attention they should for the devastating impact TB has on them – the countries of Eastern Europe. And it focuses, in particular, on people belonging to vulnerable groups such as prisoners and Roma people, who often remain invisible.

I come from Romania, and working as a physician I have seen first-

“You can only understand what TB means when you hear individual stories of illness, mourning, courage and hope.”

hand how the stigma and lack of knowledge about TB makes people fearful of seeking the care they need and deserve. I believe that the stories of hope in this report will inspire people everywhere to see that with the right strategies and full involvement of communities, we can provide every person who needs it with high quality TB care.

The countries of Europe bear a dual responsibility:

» First, they need to address TB as the European problem it remains and in particular, scale up detection and treatment of MDR-TB and XDR-TB. European countries have it in their power to set high standards for active TB case finding, special support for vulnerable groups and for community involvement.

The challenges we face are daunting: nearly 4 million people are not receiving effective TB care each year; nearly half a million people with MDR-TB do not have access to reliable, low cost second-line drugs; and TB remains the leading killer of people living with HIV. Without the engagement of community groups, the private sector and large implementation and development partners, the world will not be rid of tuberculosis.

Our partners share the vision that a world free of TB is achievable. We can get there only by working in partnership.

Lucia



Dr Lucica Ditiu
Executive Secretary
Stop TB Partnership

» Second, European countries need to step up their commitments to addressing TB as a global problem. Specifically, they should be frontrunners in meeting the targets of the 'Global Plan to Stop TB 2011-2015' through financial commitments and contributions to research and innovation.

WHY WE NEED TO TELL THE HUMAN STORY OF TB

Many people think of tuberculosis as a disease of the past, but in reality almost 2 million people die of TB every year. TB is a global epidemic, causing devastating loss of life and hampering economic productivity. It is also a European problem, where TB rates have been on the rise over the past few decades.

TB can affect anyone, regardless of where they live. The WHO European Region's 53 countries include some very high burden TB countries as well as some of the lowest burden TB countries in the world. Eighteen countries in this region are designated as high priority for TB control by WHO Europe.

The TB problem is often described in statistics: the number of new cases that develop each year, the number of people that die from it and the monetary figure required to eliminate the disease. Within this narrative, the voices of those people whose lives

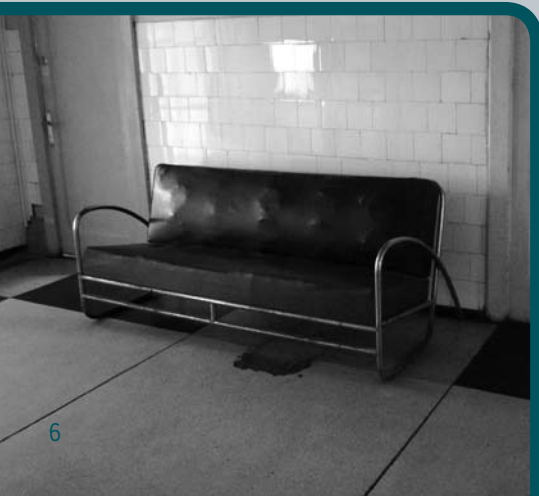
are most affected by TB are lost.

This report seeks to reenergise the fight against TB by telling the human side of the disease; giving a voice to the individuals and communities who have long been represented in numbers and figures. In the following pages, patients, doctors, advocates and healthcare workers from seven European countries – Georgia, Latvia, Moldova, Romania, Russia, UK and Ukraine – tell of their experiences.

The following case studies illustrate that while progress has been achieved; new challenges are emerging, reminding us that the fight against TB requires sustained political will and financial investment if we are to finally eradicate the disease.

European domestic governments and European institutions have a unique role to play in the global TB response by contributing to international financing and to TB research. However, this report clearly demonstrates that there is also much to be done closer to home. A concerted effort is needed to address the particular effect of TB on the lives and livelihoods of individuals and communities in the WHO European Region itself.

The voices of the epidemic are there, expressing the everyday challenges of dealing with TB, as well as offering solutions to tackle the disease. Decision makers just need to listen.



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

- **Research needs:** Investment in research for new tools to prevent, diagnose and treat TB is desperately needed in order to eliminate TB as a global health threat in the future. We cannot successfully fight TB until we have a TB vaccine that is effective for all populations, simpler and more cost-effective diagnostic tools and new drugs resulting in shorter and safer treatment of all forms of TB;

- **Childhood TB needs to be urgently addressed:** In 2009 over 1 million children developed TB and at least 176,000 died as a result. Action must be taken to address TB as a children's health issue, and new resources are needed to eliminate TB as a leading killer of children;

- **Funding:** Cuts in domestic funding for national TB programmes and changes in Global Fund eligibility criteria preventing many Eastern European countries from applying for general funding, could seriously threaten and potentially reverse the progress that has been made so far;

- **Community-based care must be part of the response:** A comprehensive TB response requires active collaboration and partnership at country and local level between government decision makers, national TB programmes, communities, private providers and NGOs, as well as the patients themselves;

- **TB-HIV co-infection requires increased collaboration:** TB is the

leading killer of people living with HIV, causing a quarter of all AIDS-related deaths. WHO policies on TB-HIV collaborative services have not been implemented consistently at funding or programming level, particularly those aimed at reducing the burden of TB among people living with HIV;

- **Stigma keeps the disease underground:** People suffering from TB are often stigmatised by society and ostracised by their friends or communities. Stigma means TB patients endure emotional rejection in addition to the physical symptoms of TB, and this often prevents them from seeking or completing treatment;

- **Support for vulnerable populations:** Accessible and quality services and care for the most vulnerable and socially marginalised, including prisoners, drug users, refugees and migrant workers, are often unavailable or extremely limited. More needs to be done to ensure that these groups are able to receive appropriate diagnosis and treatment that addresses their specific needs with personal and social support, respects their human rights and ultimately leads to long term treatment success;

- **Drug resistance requires greater investment:** The WHO European Region accounts for almost 20 percent of the global burden of MDR-TB and XDR-TB. There is an urgent need for further financial support to scale up interventions to address the spread of drug-resistant TB at both national and community levels.

TUBERCULOSIS RATES IN EUROPE



Incidence (all cases/100 000 pop/yr)

<70 11-30
31-69 >10

EUROPEAN COMMITMENTS MADE TO FIGHT TB

Tuberculosis remains one of the world's leading causes of illness and death. Every year, 1.7 million people die from TB and 62,000 of those deaths occur within the WHO European Region aloneⁱ. TB causes 49 new cases and kills seven people every hour in Europeⁱⁱ. Yet TB is a disease that is both treatable and preventable, which makes this needless loss of life even more tragic.

Over the past few decades, the rate of TB has fallen much more slowly than previously anticipated, both globally as well as within Europe. The European Union and its executive arm, the European Commission, are major donors in the fight against TB, but EU funding levels fall far short of a level commensurate with the wealth of its member statesⁱⁱⁱ.

The following sections illustrate political and funding commitments European governments and institutions have made so far in the fight against TB. However, these commitments and recommended activities need to be urgently implemented to eradicate TB. This cannot be achieved unless governments and institutions work in partnership with all stakeholders involved to include community-based approaches that focus on the human rights of patients.

In 2006 the Stop TB Partnership launched '**The Global Plan to Stop TB 2006-2015**'. The Plan provides a road map for TB control and sets forth strategies for scaling up prevention, diagnosis, treatment and funding for research and development. However, the projected funding gap for meeting all of the Plan's goals and targets over the next five years is US\$ 21 billion. Without rapid scale-up of TB prevention and treatment some 10 million people will die of this curable disease by 2015.

As one of the most effective bodies funding health in the developing world, **The Global Fund to Fight AIDS, TB and Malaria**, finances two thirds of all TB programmes in the world. Since its creation in 2002, the Global Fund has treated 8.2 million new smear-positive TB cases. Partly because it is so successful, the Global Fund is now facing a funding shortfall, meaning it has had to scale back funding for middle income countries, including for Eastern European countries with a high burden of TB. This could potentially lead to severe funding gaps for TB programmes in the region.

In 2007, health ministers from across Europe adopted the **Berlin Declaration on Tuberculosis**. Member countries committed themselves to provide political will and resources to combat TB. Governments also committed to greater community engagement, which is integral to any response to TB. However, since 2007 insufficient progress has been made, and member countries have yet to develop a framework to implement and monitor the commitments they agreed to.

The EU predominantly funds TB research through its **Framework Programmes for Research and Technological Development**. Its current Framework Programme, FP7 (2007-2013), has earmarked a total of €6.1 billion for health research, of which an estimated €90 million will go to TB research. The EU has the responsibility to ensure that the next Framework Programme, FP8 (2014-2020), provides sufficient budget for research and development for neglected and poverty related diseases, including MDR-TB and paediatric TB.

The **ECDC Framework Action Plan to Fight TB in the European Region** (2008) aims to evaluate the current situation in the Region and to develop a unified EU approach to the fight against TB and MDR-TB. It is based on four core principles, one of which includes building partnership and international collaboration. A detailed roadmap of activities to be put forward at the community level is yet to be completed by 2013.

The EU's **Programme for Action to Confront HIV/AIDS, Malaria and Tuberculosis** aims to address globally the existing funding shortfall in order to meet MDG 6. However, progress has been limited. There has been a lack of large scale collective action at both national and international levels. This programme should continue after 2012 with better operational indicators and an integrated response to scale up impact. Strong EU intervention is essential to make inroads in the fight against TB.

In September 2011, the WHO released its **Consolidated Action Plan to Prevent and Combat Multidrug- and Extensively Drug- Resistant Tuberculosis (M/XDR-TB) in the WHO European Region 2011–2015**. This Action Plan provides a unique opportunity for European nations to strengthen and intensify efforts to address the alarming problem of drug-resistant TB in the region. Governments must urgently develop and implement national DR-TB plans and ensure that implementation is centred around a community and human rights-based approach for treatment and support.

The Plan to Stop TB in 18 High Priority Countries in the WHO European Region 2007–2015 (2007) describes the main challenges, strategies and interventions to control TB in the 18 high priority countries in the European Region: Armenia, Azerbaijan, Belarus, Bulgaria, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, the Republic of Moldova, Romania, the Russian Federation, Tajikistan, Turkey, Turkmenistan, Ukraine and Uzbekistan. The Plan is intended to be a guide for the high priority countries to use in developing their own long and short term national plans on TB and as a reference for the WHO Regional Office for Europe and all other partners involved in fighting TB.

PERSONAL REFLECTIONS ON CHILDHOOD TUBERCULOSIS

Dr Marc Sprenger has been the Director of the European Centre for Disease Control and Prevention (ECDC) since May 2010. Dr Sprenger had TB as a child and in the following account, first presented at the International Meeting on Eliminating Childhood Tuberculosis organised by ECDC in March 2010, Dr Sprenger reflects on his personal experience and on the challenges Europe faces in addressing this epidemic.

The tuberculosis epidemic is a global problem, requiring a global response. But I would like to emphasise that TB is also a European problem. This is especially the case when we look at childhood TB, which is a marker of transmission of TB within the community. In other words, most of the children we see with TB in Europe were infected in Europe. Childhood TB is not an imported problem. It is a product of our inability to stop the TB epidemic on our own doorstep.

During the first decade of the 21st century, we saw nearly 40,000 childhood TB cases in the European Union. This means nearly 4,000 new cases being reported every year. Behind each one of these statistics is a child. I would like to introduce you to one of those children. His



Dr Marc Sprenger
Director of the European
Centre for Disease Control
and Prevention (ECDC)

name is Marc. He is three years old, and he lives in the Netherlands.

This is my story.

One of the other children at my kindergarten was diagnosed with TB. The health authorities immediately screened all the

children at the kindergarten. They found that I had been infected. My contacts were then traced, and they found that my father was also ill with TB. We both had active TB. I had to be hospitalised, while my father was looked after at home by my mother – though he did need to go into hospital for check-ups.

Reflecting on this experience now, I would say that the public health system in the Netherlands was rather effective. Their contact tracing worked. It picked up my infection, my father's infection, and indeed several other TB cases in our community. The cases were treated and the chain of infection was broken.

The lack of stigma attached to TB in the Netherlands at that time was an important factor here. It made people feel comfortable in coming forward for testing. At the time, though, the experience did not feel very positive to me.

I used to really hate taking my medicine. I remember that the pills were enormous. They seemed to fill my whole mouth. I would choke trying to swallow them.

I also disliked the diagnostic tests. I remember having a steel tube forced down my windpipe, so the doctors could take samples of my

lung fluids. It really hurt!

The worst thing was missing my parents. I was in hospital for a year, and it was a long way from my home. It was a big journey for my mother to visit, and of course she also had to take care of my father at home.

Looking back on this experience, are things better for children in Europe today? Some things certainly are. In EU countries, hospitalisation with TB is now kept to a minimum. In most countries, children would usually spend only a few weeks in hospital and then be treated as outpatients. This means they can continue living with their families and continue going to school. But if children are going to be in hospital for longer periods, arrangements clearly need to be made so they can keep up with their school work.

The diagnostic tests for children with TB are not quite as bad as in my day, but they are still invasive. The one area where things have not improved for many children is the drugs used to treat TB. A lot of young TB patients are having the same experience I had in the 1960s. They have to swallow big pills designed for adults. We need to help kids take their medicine. In Europe in the 21st century we should



be able to provide all children with TB with child friendly anti-TB drugs.

I also wonder whether we have become any better at active case finding since the 1960s. **Finding and treating cases early is absolutely key to successful treatment and to breaking the chain of transmission.** There may now be a bit more stigma associated with TB in Europe because of its link to poverty. This is a barrier to case finding.

Are we doing enough to counter stigma?

Are we doing enough to reach out to the most at risk groups in

Europe, who will also tend to be marginalised and poor?

We need to align our actions on childhood TB with the EU's wider effort to alleviate poverty and promote social inclusion.

To conclude, my story has a happy ending. I recovered. And my experience as a young TB patient inspired me to become a public health doctor when I grew up.

I was lucky.

Some stories of childhood TB do not end this well. That is what we must try to change.



GEORGIA

Although Georgia is one of the WHO's 27 high MDR-TB burden countries, Georgia has reached universal access to MDR-TB diagnosis and treatment in 2007 and 2009 respectively due to strong political commitment from the Government and due to immense support from the Global Fund, international donors and NGOs involved in TB programmes. However, even though DOTS coverage has reached 100 percent, treatment success rates remain a challenge for TB control in Georgia, underlining the need for more action in the fight against TB.

Incidence (all cases/100 000 pop/yr)	107
Of new TB cases, % HIV+	19.6
Of new TB cases, % MDR-TB	10
Case detection (all forms, %)	100
Treatment success (new ss+, 2008 cohort, %)	73

(Source: WHO tuberculosis country profiles <http://www.who.int/tb/country/data/profiles/en/index.html>.)



VERIKO

Veriko was a manager for a Global Fund supported programme for drug-resistant TB control in Georgia between 2007 and 2010. She worked at the National Centre for TB and Lung Diseases, which is a part of the National Tuberculosis Programme. She first became involved with TB when she was a medical student during her clinical rotation at the National Centre for TB and Lung Disease hospital in Tbilisi.

“I had to care for several very ill TB patients, and I realised that TB is not just a disease but that it carries with it a huge social and economic burden. Most TB patients were not able to afford even a visit to the doctor or to buy medicine. I also recognised that TB disease was stigmatised – TB patients were usually posing to keep their identity confidential as they were concerned that they might have trouble with their jobs or problems with family and friends.

More importantly, I understood that most of my friends and medical students I knew did not really have a desire to work in TB. Society does not view it as a prestigious profession. My primary motivation was to somehow contribute to the fight against TB, and I thought that

Investment in research for new tools to prevent, diagnose and treat TB is desperately needed in order to eliminate TB as a global health threat in the future. Veriko Mirtskhulava's story highlights the importance of political will to combat the disease and the need for increased funding in this area.

my input as a public health worker, rather than as a physician, would be more valuable for my country as Georgia suffers from a high burden of TB.”

“I want to be optimistic and say that if we mobilise all our resources, including political, financial and intellectual, communicate with each other in an effective manner and dedicate ourselves to fight against TB, in 15 years TB might not be such a major public health problem as it is right now.”



Veriko says that in order to reduce rates of TB, TB diagnosis and treatment must be provided free of charge and must be accessible to everyone. In addition, stronger advocacy is needed to secure the political and financial support crucial for a successful fight against TB. She emphasises that current tools available are insufficient and that more research is needed.

“TB treatment is very long and devastating and the BCG vaccine is not that effective. Consequently, TB



clinical research must be encouraged to facilitate development of new drugs and vaccines.”

Georgia has seen successes as the country reached universal access to MDR-TB diagnosis and treatment in the last five years due to strong political will from the Government and continuous support from the Global Fund, multiple international organisations, NGOs and donor countries. Veriko believes that more can be done as she looks to the future.



UK

Rates of TB in the UK continue to climb as the number of cases per year now exceeds 9,000. Despite a national surveillance system and excellent treatment availability, TB rates are now at the highest level they have been in 30 years. The majority of cases are concentrated in urban centres, particularly in London, which accounts for 38 percent of UK cases. Nearly 3,500 people contract TB in London every year.

Incidence (all cases/100 000 pop/yr)	12
Of new TB cases, % HIV+	6.7
Of new TB cases, % MDR-TB	1.2
Case detection (all forms, %)	94
Treatment success (new ss+, 2008 cohort, %)	78

(Sources: Source: UK Health Protection Agency Annual report on tuberculosis surveillance in the UK 2010; WHO tuberculosis country profiles <http://www.who.int/tb/country/data/profiles/en/index.htm>)



AURORA

As a nurse, Aurora was used to caring for others. Then she became seriously ill with unexplained pains in her neck, back and stomach. After nearly two years of investigation – and unnecessary treatment for cancer – Aurora was finally diagnosed with spinal TB.

From the outset of her symptoms, Aurora repeatedly visited her General Practitioner (GP) to find out what was wrong, but she was told her condition could be due to her age, osteoporosis or previous surgery: **“I asked to be x-rayed, but the GP didn’t think it would show anything.”**

Elias Phiri, who heads UK Awareness Programmes for TB Alert, an organisation that supports TB projects around the world, explains that this is not uncommon: **“TB Alert provides support and advice for people diagnosed with TB, and we regularly hear that their symptoms are dismissed or attributed to other causes.”**

Aurora was admitted to hospital after test results showed that she had a dangerously low blood count. While there she began to experience disabling, shooting pains throughout her body so her doctor ordered a scan: **“They told me that**

Aurora’s story demonstrates the need for more sensitive, simpler and cost-effective diagnostic tools to be developed and for more awareness about TB among healthcare professionals.

the scans had shown a large, white mass instead of my neck vertebrae, which looked like cancer.”

Aurora was immediately started on an intensive course of radiotherapy. Later biopsies finally revealed that she did not in fact have cancer – she had spinal TB, which was described as having ‘eaten’ a number of Aurora’s vertebrae. Aurora underwent emergency surgery to insert a metal column into her spine and awoke to find herself in a halo-traction.

Aurora's case demonstrates just how severe the impact of delayed diagnosis can be for someone who has TB. Aurora was cleared of TB six months after starting her antibiotic treatment. She underwent a final round of spinal surgery and can now finally rebuild her life. Aurora is thankful for her friends in the TB Action Group, a UK based network of people who are or have been affected by TB and who were there for her throughout her illness.



"It felt like I was in a cage. I couldn't move and I hated it when my surgeon returned to tighten the screws that were bolted to my forehead. I couldn't wash my hair or body for months.

Coming to terms with what's happened over the past few years, and with the TB itself, has been

extremely challenging. It's been full of ups and downs, uncertainty, anxiety and worry – not only for me but for my whole family. I can't drive, I can't go on an aeroplane, I can't plan holidays, I can't visit my family who are all mostly based in the US and Philippines and I was unable to attend my father's funeral."

JARVIS

In 2009 eleven-year-old Jarvis started experiencing chest pains, night sweats, spiking temperatures, loss of appetite and breathlessness. Despite this plethora of symptoms, it took another nine months before Jarvis was diagnosed with TB and received the necessary treatment.

“I’d been sick for a year and eventually my mum took me to the GP, and he did a sputum test. Before this I had been to the hospital, and they told me I had pneumonia and broncho spasm. I had been reviewed by 16 different healthcare professionals and given five courses of antibiotics and an inhaler.

Once I was diagnosed with TB I had to undergo treatment, which lasts for six months or more. It was hard at first when I was taking all the medicines (eight tablets plus syrup), but once it got cut down it was much easier. I had to take it all before school and wait 30 minutes before I ate, so it sometimes caused problems.

I missed two months of school after I had just started high school, and I couldn’t play football. I felt guilty when my friends had to undergo tests for TB, but they were fantastic – sending me get-well messages and chatting to me about TB on MSN.”

Jarvis' story reminds us that action must be taken to address TB as a children's health issue, and new tools and targeted efforts are needed to eliminate TB as a leading killer of children.

Jarvis's mum, Linda, says she and her husband felt guilty when he was finally diagnosed, as they are both nurses and felt they should have detected the TB themselves.

“We tried not to show it, but we were very worried. We knew he was sick and getting sicker, but no matter what treatment he received he was not getting better. Neither my husband nor I considered TB because Jarvis had had a BCG [TB vaccine] as a baby and he had tested negative after a teacher at his school was diagnosed with TB.”



Whilst TB is most common in those living in poverty, it can affect anyone in the world and often goes undetected. The BCG vaccine – the only TB vaccine currently available – was developed over 90 years ago and only protects children from some forms of paediatric TB. It offers limited protection for adults. Jarvis's case shows that new vaccines are desperately needed to prevent all forms of TB.

Jarvis has recovered from TB and is playing football again for his school and a community team. He says:

“I want people to know that TB can be cured, and you can still do what you want to do in life even if you have had TB.”



LATVIA

Although Latvia has been designated as one of WHO's 27 high MDR-TB burden countries, declines in rates of MDR-TB reflect the success of Latvia's TB control efforts. Latvia's TB control programme has been a success, with TB rates dropping by half since 1998 when rates in Latvia were at their highest. However, a cut in domestic funding for the TB Programme could threaten and potentially reverse the progress that has been made.

Incidence (all cases/100 000 pop/yr)	45
Of new TB cases, % HIV+	9
Of new TB cases, % MDR-TB	13
Case detection (all forms, %)	94
Treatment success (new ss+, 2008 cohort, %)	33

(Sources: WHO M/XDR TB 2010 Global Report on Surveillance and Response; Treatment and management of MDR-TB in Latvia <http://www.who.int/bulletin/volumes/85/5/06-037978/en/index.html>; WHO tuberculosis country profiles <http://www.who.int/tb/country/data/profiles/en/index.html>)



ANDRA

Andra Cirule is a pulmonologist who works at the TB and Lung Diseases Clinic in the central TB hospital in Latvia where she is the chief physician. Every year the hospital examines more than 5,000 patients and one out of every four is diagnosed with TB. The clinic is located in the Riga region, but the clinic treats patients from all over the country.

Andra describes how Latvia introduced DOTS in 1996 and DOTS-Plus for MDR-TB patients in 1997. Since then the rate of TB in Latvia has decreased every year until 2010 when it stayed the same. When asked what she thinks needs to be done in order to further reduce the number of people who get TB, Andra says:

“Early detection of TB cases and adequate treatment of TB patients is very important. Providing social support, providing DOTS in rural regions, home care for elderly and patients co-infected with TB and HIV would make a big improvement in TB control.”

Andra explains that the major barrier confronting the TB epidemic in Latvia is a lack of resources. Due to the economic crisis, financial resources for the healthcare system

As many European countries continue to feel the effects of the economic downturn, domestic political will matched with sufficient funding are needed to sustain successes in TB control and to prevent a reversal of progress already made.

were cut and the number of TB specialists employed was reduced.

“National politicians and health professionals know about the situation, but at the moment it is difficult to change anything because all healthcare systems are dealing with a lack of financial resources.

In a few cases, people with TB symptoms don't visit a doctor for examination because sometimes



Latvia's TB control programme has been a success with TB rates dropping by half since 1998, when rates in Latvia were at their highest. However, a cut in domestic funding for the TB Programme could threaten and potentially reverse the progress that has been made.

they are afraid that they will have to pay for healthcare, but examinations for TB and TB treatment are free of charge."

Latvia has had an effective National TB Control Programme since 1995. Successful aspects

of the programme include political commitment, early case detection using a microscope to examine sputum, DOTS, effective management of TB drugs and TB registration. The TB programme involves the civil sector as well as the prison system.



MOLDOVA

In 2009, 5,591 people in the Republic of Moldova were diagnosed with TB. Moldovan efforts to reduce TB rates are hampered by its high burden of MDR-TB: 19 percent of all new cases of TB are estimated to be MDR and 51 percent of all retreated cases. These percentages are also reflected in the success of treatment: the percentage of new cases that are successfully treated is 62 percent, whereas among people who have already been treated before, the success rate is 34 percent.

Incidence (all cases/100 000 pop/yr)	178
Of new TB cases, % HIV+	5
Of new TB cases, % MDR-TB	19
Case detection (all forms, %)	68
Treatment success (new ss+, 2008 cohort, %)	62

(Sources: ECDC TB surveillance in Europe 2009; WHO tuberculosis country profiles <http://www.who.int/tb/country/data/profiles/en/index.html>)



FEODORA

Dr Feodora Rodiucova, known to her students as 'Doamna Profesoara' and to everyone in Balti as 'Dora', is the driving force behind a community movement to give treatment support to TB patients. Seven years ago, when TB was raging in Moldova and in her beloved city, Balti, Dora realised that TB patients were abandoning treatment because they lacked a bus fare for the trip to the dispensary or were confused about drug regimens.

Dora joined forces with medics who wanted the community's help to increase treatment completion. Her community organisation, Speranta Terrei, manages a group of 21 treatment supporters called moderators. They carry TB drugs from the dispensary to patients' homes and explain and observe the treatment. Directly observing a patient swallowing their TB medications contributes to higher completion rates and a reduced risk of drug resistance.

"Of course, it is super crazy to not spend 800 Moldovan Lei (US \$70) a month for a moderator's allowance when we see what their steady encouragement does for a destitute patient."

Civil society participation is integral to providing patient-centred care, and national TB programmes must work in partnership with civil society to support these community interventions.

Dora has attracted a swathe of Balti to the TB cause. Some moderators have had TB themselves or watched their children regain health after a moderator's intervention. Others wanted to lend a hand to a neighbour. Medical college students wanted to act against a treatable disease in their midst. Former prisoners and the homeless offered to join when they saw that Dora did not stop at TB treatment but also tried to find them temporary housing or a



Dora's forceful yet polite voice brings hope to patients. She is determined to make it heard so that caring treatment support becomes the norm and not the exception in Moldova.

residency permit. Dora does not hesitate to knock on the doors of the Balti municipality because she understands TB is one of many impediments marginalising patients.

Nothing deters Dora from her pursuit of giving form to the term

'patient-centred care'. She thinks it should not only be words in a document. Dora associates 625 individual faces with patient-centred care. That is the number of TB patients who have received treatment support from Speranta Terrei in the last six years.

Igor Tcaci can count his association with TB and prison not in years but in decades. He knew both too well for two decades.

Now at the age of 43, Igor finally feels free of the burdens that marked half of his life. When he was 18 years old, he went to prison for the first time for two years on an assault charge. After his release, he was taken ill with severe coughing and fever and was diagnosed with TB. Igor was treated in hospital for ten months and tested regularly afterwards to confirm that he was cured.

Within a few years Igor was back in prison, this time for eight years. Igor recalls the conditions as deplorable, cramped into a damp basement room with other prisoners. About three years after being released, he was wracked by a cough and fever, coughing up bloody clots. He spent most of the time between 2004 and 2006 in Balti's TB hospital. In 2007 a drug susceptibility test revealed he was resistant to two of the TB drugs he was taking. Igor was told about the new DOTS-Plus programme available to only a few patients in Moldova and he insisted on being enrolled because he felt it was his only chance of beating TB.

Prison conditions can exacerbate the spread of disease through overcrowding, poor ventilation, weak nutrition and a lack of medical care. Catching TB is not part of a prisoner's sentence, and improving TB control in prisons benefits the community at large.

While undergoing treatment for MDR-TB, Igor became involved in Speranta Terrei's project to reintegrate former prisoners who had TB. He reached out to other ex-prisoners and encouraged them to participate in psychological counselling and job training. This gave them the strength to complete treatment, learn a trade,

Igor's message to TB patients is to not lose hope, to continue treatment even through the darkest days. His message to health officials is that TB patients need moral and psychological support, someone by their side.



earn a living and once again belong to society.

“Until this project, we were shunned and people did not want to speak to us. For the first time, former prisoners with TB felt someone believed in them, that they mattered.”

Igor's MDR-TB treatment was successful and he now advocates for other patients. He has no intention of returning to prison.

“When a patient finds out he has TB, he is overcome with fear. A patient needs more information and explanation about the disease and the consequences of TB drugs.”

Igor's message to TB patients is

to not lose hope, to continue treatment even through the darkest days. His message to health officials is that TB patients need moral and psychological support, someone by their side.

Igor says that he defended his right to access appropriate treatment for his drug-resistant TB strain and spoke up. But many patients do not know their rights or what treatment they should receive. He sees patients abandon treatment when a brusque medic does not have time to answer questions or lets a patient linger in the corridor. Igor and Dora have plans for Speranta Terrei to promote the Patients' Charter for Tuberculosis Care in Moldova, so medics and patients can learn about their rights and duties in TB treatment.



RUSSIA

Russia is considered one of the 22 'High TB Burden Countries' by the WHO. This is in part because of the high percentage of TB-HIV co-infection and of MDR-TB. HIV prevalence among people with TB is thought to be around 8 percent, and the Russian Federation also has the largest number of cases of MDR-TB (38,000 cases) in Europe. The problem in Russia may also be compounded by the fact that DOTS treatment in Russia is more expensive than in any other high burden country (US\$7500 per patient treated according to the DOTS strategy).

Incidence (all cases/100 000 pop/yr)	106
Of new TB cases, % HIV+	8
Of new TB cases, % MDR-TB	16
Case detection (all forms, %)	84
Treatment success (new ss+, 2008 cohort, %)	57

(Sources: WHO Global Tuberculosis Control Report 2010; WHO tuberculosis country profiles <http://www.who.int/tb/country/data/profiles/en/index.html>)



VALENTINA

It was a cold January morning when somebody knocked on the door of the Russian Red Cross office in Khabarovsk. A very thin and shy girl handed over a referral letter from the local TB service asking to include her in the target group of the Red Cross TB programme. **She needed social help.**

This young woman's name was Valentina. She and her family had moved to Khabarovsk from Okhotsk because neither she nor her husband could find a job there. The couple had hoped that by moving to the capital of the Russian Far East that their financial situation would improve, that both would find prestigious, well-paid jobs and that their two small daughters would go to a good school.

But reality was tough on the family.

Once in Khabarovsk, Valentina's husband could hardly find work and Valentina, even though she was a certified nurse, couldn't find any at all. They could only afford to rent a shabby apartment in the outskirts of the city that lacked even the most basic utilities. Valentina's husband's salary barely covered their rent and food for the children.

One evening, several months after moving to Khabarovsk, Valentina

TB interventions must include the provision of social support for the most vulnerable groups to ensure a comprehensive and holistic response.

started to feel unwell. **Valentina thought she simply had a cold and decided not to go to the doctor. She was afraid the doctor would prescribe medication her family would not be able to afford. Valentina stayed in bed for several days and hoped for the best. During the following days her condition deteriorated, and she could no longer avoid going to the doctor. Her diagnosis was a shock for her – she had tuberculosis.**

Valentina was immediately hospitalised. Valentina spent many months in hospital before being referred for outpatient treatment at the Red Cross programme.

Once Valentina began treatment, she was asked by the Red Cross

They say she is always there for the patients, always ready to help, always glad to solve problems related to treatment and to answer questions about it. Valentina knows how to approach 'difficult' patients who repeatedly interrupt their treatment, and she now uses her own story to encourage patients to continue treatment and to believe in their full recovery.



coordinator what she normally ate. Valentina said she was seldom hungry, and that her priority was feeding the kids and her husband so that he had the energy to go to work. **Valentina was given daily food aid as a reward for taking her medicines and received clothing for herself and her girls. She also worked with a psychologist who helped her to build self-respect, to gain self-confidence and to hope that her treatment would be successful.** Red Cross workers helped to send Valentina's daughters to kindergarten and assisted her husband in coming back to his job after he was fired on the grounds of his wife's disease.

Valentina fully recovered after her treatment ended, and she stopped being a member of the programme's target group. When she discovered that one of the DOTS nurses wanted to quit her job due to her own health complications, Valentina offered herself as her replacement. She was properly trained by the programme's health coordinator and was given the job as a visiting nurse.

Valentina now oversees DOTS for 45 patients, hands out the Red Cross social aid and assists those who interrupt their treatment. Red Cross beneficiaries note that Valentina is a very considerate, understanding and responsible nurse.



UKRAINE

Ukraine has the second highest burden of TB in the WHO European Region. The problems facing TB control in Ukraine are exacerbated by the rise in HIV; Ukraine has one of the fastest growing HIV epidemics in the world, and in 2009 it was estimated that 11 percent of TB patients are co-infected with HIV and more than 60 percent of AIDS deaths in the country are attributable to TB. Lack of action and funding to immediately address this joint epidemic could have serious consequences for disease transmission, amplify TB- and HIV-related mortality and significantly increase the costs of TB and HIV control in the country.

Incidence (all cases/100 000 pop/yr)	101
Of new TB cases, % HIV+	11
Of new TB cases, % MDR-TB	16
Case detection (all forms, %)	78
Treatment success (new ss+, 2008 cohort, %)	62

(Sources: WHO Review of the National Tuberculosis Programme in Ukraine 2010; USAID http://www.usaid.gov/our_work/global_health/id/tuberculosis/countries/eande/ukraine_profile.html; WHO tuberculosis country profiles <http://www.who.int/tb/country/data/profiles/en/index.html>)



ELENA

Elena Sukhova is 33 years old and lives in Odessa, southern Ukraine. She is a current TB patient, an NGO volunteer and is working towards becoming a social worker. She was an injecting drug user and is now infected with both HIV and TB. Drug users often have both higher rates of HIV infection and increased rates of TB infection. TB causes a quarter of all AIDS-related deaths, and people with HIV are more susceptible to developing active TB because of their weakened immune systems.

“Because of my work in a mini-casino I didn’t have time to go to a clinic, which is why I was diagnosed late. I just took flu and cold pills and drank hot tea. I coughed for a long time and had a temperature. I also had back aches, but I did not visit a doctor, I just hoped to get better.

When our mini-casino closed down, I finally had time to take better care of myself. As an injecting drug user, I wanted to enrol in a drug substitution treatment programme. However, in order to participate in the programme, I was required to pass a screening for TB. When I learned my diagnosis I was shocked – I had thought I only had HIV, but it turned out that I have TB as well.”

TB is the leading killer of people living with HIV, and TB-HIV co-infection requires an increase of collaborative services at both funding and programming levels. In addition, more needs to be done to ensure quality services and care are accessible to vulnerable groups, including drug users.

Current treatment of TB takes six months which, when combined with the serious side effects the drugs cause, increases the likelihood that patients will discontinue treatment and develop drug resistance. Kostiantyn Pertsovskyi, the Senior Communications Manager for the International HIV/AIDS Alliance

Elena wants decision makers in governments to pay proper attention to TB, MDR-TB and TB-HIV co-infection:

“Each year that passes it becomes more and more difficult to combat these epidemics effectively, thus the action should be taken here and now.”



in Ukraine, explains that one of the main challenges they face in Ukraine is ensuring patients adhere to treatment:

“Ukraine is among the world’s 27 countries that make up 85 percent of all MDR-TB cases globally. As patients do not complete the cycle of treatment in many cases, it causes development of drug-resistant TB.”

Elena can confirm this was also a challenge for her:

“I started drug substitution therapy and became a patient of the TB dispensary as well. I receive DOTS at the same site where I receive substitution treatment. At the start of the TB treatment I was in the clinic full-time for five months. Afterwards I had to get pills myself. But I was not

fully cured so the process began again, and again I had to be in the clinic full-time. My experience is fairly typical: many people return to TB clinics again, even those who do not have TB-HIV co-infection.”

In addition to the difficulties in adhering to a six month course of treatment, Elena believes that one of the biggest improvements that could be made to the experience of people who have TB would be the provision of proper nutrition and access to drugs to treat TB-HIV co-infection.

“People with contagious forms of TB should not leave the clinic, but due to the lack of food and drugs in clinics, patients often need to go to pharmacies and shops, putting others at risk.”



ROMANIA

Although Romania has a comparatively low rate of TB-HIV co-infection and MDR-TB, overall rates of TB remain one of the highest in Europe. TB control in Romania is financed by the Ministry of Health and supplemented by a grant from the Global Fund. The Global Fund grant has been used to provide two drugs for MDR and XDR-TB patients that are not available anywhere else in the country. Romania's Global Fund grant will end in September 2012. Due to changes in Global Fund eligibility criteria, Romania's next grant will be very limited and funds will likely not be available until 2013. This gap in funding will cause even greater stock-outs of necessary second line drugs needed to treat MDR-TB.

Incidence (all cases/100 000 pop/yr)	125
Of new TB cases, % HIV+	3.3
Of new TB cases, % MDR-TB	2.8
Case detection (all forms, %)	79
Treatment success (new ss+, 2008 cohort, %)	84

(Source: WHO tuberculosis country profiles <http://www.who.int/tb/country/data/profiles/en/index.html>)



FIRDES

In October 2010 Romania opened a TB counselling centre, the first of its kind, in the neighbourhood of Obor, Calasari. Dr Spiridon Dumitrescu, director of the Calarasi Pulmonology Hospital, explains the challenges of TB in the region:

“Calasari is a city with a population of 75,000, many of its people are poor and unemployed. A particularly vulnerable group include the Turkish Gypsies in the neighbourhood of Obor, which has high rates of poverty. The population is poorly educated and live in small, primitive houses made of clay and inhabited by large families. Food is not a certainty every day. Most live without drinking water, without a sewage system, telephone, TV or paved roads.

In this setting lives Firdes Mustafa, a young gypsy girl born in 1992. Firdes has TB but has yet to complete a full course of treatment, although she started treatment four times.

When Firdes was 17 and already had two children, she returned to the hospital pregnant. The gynaecologist assigned to her saw a young pregnant girl weighing only 30 kilos. Firdes was hospitalised for TB treatment. Nobody believed that the birth of her child was

More needs to be done to ensure that the most vulnerable and socially marginalised groups are able to receive appropriate diagnosis and treatment that addresses their specific needs with personal and social support.

imminent, yet Firdes gave birth to a boy in the TB hospital. The child was healthy but Firdes broke off her TB treatment as she had before. Firdes did not want to be hospitalised and did not want to receive treatment at the TB dispensary. Two of her children have since been admitted to the Children's Hospital for TB. A TB counselling centre opened near to Firdes' house and we try to bring Firdes her and her children's drugs, but often she is not found at home.

“When illness hits it breaks a family – not only because of the finances required, but also because of the sheer humiliation felt in being poor.”



The counselling centre is very modern, a big contrast to the neighbourhood. This centre is probably the only hope for these people – a place where they can build a new world, a new confidence. I think that when Firdes goes frequently to the centre, we will have won.”

Brian Douglas, Director of the Romanian Children’s Humanitarian Foundation, has personally witnessed how poverty and TB go hand in hand:

“So many times a mother will go to the family doctor at the first sign of illness, and the doctor will prescribe a medication, say goodbye and ask to please call for a check-up the next week. The woman then leaves, and because she cannot afford the medication the prescription gets thrown in the bin. She is too embarrassed to explain to the family doctor that she has no funds, and the doctor doesn’t often ask about such problems.”

Cassandra Butu is the National Professional Officer for the WHO Country Office in Romania. She spoke with an MDR-TB patient who was diagnosed with TB in June 2010.

The patient asked to remain anonymous due to the stigma she is afraid she would have to face if people found out she has drug-resistant TB. **“I would like to remain anonymous. I don’t want to say anything about this to anybody because a lot of people know my name. I have enough acquaintances and friends and for the moment I don’t want people to find out.”**

When asked if she thought people in general know enough about TB, she responded, **“No. This is why people react like this. If I didn’t know about the disease and I knew a person with MDR-TB, I would stay away from them. No doubt about it.”**

IULIAN

Iulian is from a village in Dambovită, a county in Romania with high TB rates. His life has been spent working in both agriculture and construction. Until he got ill with TB he had what he called a 'beautiful life'. Despite being poor, he and his wife, who is a seamstress, worked hard to raise two children. His daughter goes to kindergarten. His son is 18 and lives in a nearby city with his grandparents so he can go to high school.

Iulian first contracted TB in 2007 and now has MDR-TB. Initially he took his medication regularly, but was forced to interrupt his treatment to go back to work so that he could support his family. When he returned home to restart treatment, his local dispensary had run out of one of the four drugs needed to treat his MDR-TB, meaning only part of his treatment is available. The quinolone class of drugs that is currently out of stock at his local pharmacy, as well as at the hospital where he is staying, is the one drug that separates him from developing XDR-TB. **Drug stock-outs cause patients to lose faith in the system and increase the likelihood that patients will develop drug resistance due to uneven treatment.**

Iulian explains:

Drug-resistant strains are much more costly, difficult and sometimes even impossible to treat. Interruptions in drug supply are already a major problem in Romania, and there is an urgent need for further financial support to scale up interventions to address the spread of drug-resistant TB.

"I always feel that I have this disease. I have this fear in my heart that I'm never going to get better. The pills, there are a lot of them, and they are very strong. They give you headaches, stomach aches, and make you feel like throwing up. I'm upset, because I have two children. If I'm not at home to work,

“Here in Romania, if you don’t work, you starve to death. There are two options: you take the TB pills and get better but starve, or you work and have to come back to the sanatorium. So it’s a lose-lose situation. It’s a disease where people in society stay away from you, because they know you’re sick.”



to raise them... their mother has a very hard time at home with them, by herself.

My wife has a seamstress certification, but she doesn’t have a job. Nobody will hire her, because in Romania there’s a lot of unemployment.

The hardest part about having TB? Two things are the worst. The first thing is that I am sick, and the second is being away from my family, my children, my wife.”

Jonathan Stillo is a medical anthropologist who has been researching TB in Romania since 2006. He has witnessed Iulian’s battle with TB. **“I have watched this young man, who loves his family so much, waste away in just a year. He**

took his treatment conscientiously but had to go back to work in order to take care of his family. He knew it placed him at risk for a relapse and that is what happened. Iulian’s story demonstrates the helplessness and lack of choices faced by poor Romanian TB patients.

I have sat with Iulian and tried to explain to him exactly how dire his situation is, how close he is to developing XDR-TB and how I have seen so many patients like him die. I told him that he is running out of chances and that he must finish this present course of treatment. He wants to, but I know that given the choice between his own health and his family’s well-being, he will choose them every time. It is a choice he shouldn’t have to make.”

JONATHAN

Jonathan Stillo, a medical anthropologist, has explored various issues relating to TB in Romania, including rife stigmatisation, lack of political will and absence of case management to ensure treatment is not abandoned. These are just some of the issues common across the world that present seemingly insurmountable challenges to tackling the TB epidemic. Speaking of the shame associated with having TB, Jonathan describes it as 'Romania's best kept embarrassing secret'.

"In Romania, TB is a shameful disease to have, the general public associates it with poverty and irresponsible living. Many consider it to be incurable, and having a household member with the disease can mean being ostracised by neighbours and being fired from ones job. This causes people to keep the disease a secret, sometimes even hiding it from their own spouses. Patients who do get cured of the disease also rarely let their friends and neighbours know they were affected, so no one ever hears about the success stories."

Jonathan is keen to emphasise the fact TB can affect anyone. These people are not necessarily caravan dwelling Roma communities, they are wealthy families too. It is, he

Due to changes in Global Fund eligibility for grants for middle income countries, many eastern European countries may soon face funding shortfalls to address TB control. European governments and institutions must ensure that any gap in funding is filled and that patients don't risk losing their treatment.

describes, a national emergency.

"I have met lawyers, doctors, teachers, postal workers, nurses, office administrators and even a Romanian Olympic athlete who have been infected with the

"TB in Romania is not an insurmountable problem. There are many caring doctors, and I remain hopeful that with adequate resources and serious political commitment, not just from the Ministry of Health, but also from Parliament, that the problem can be addressed."



disease. However, after treatment, those individuals with economic and social support go back to their lives and do not, as a rule, engage in advocacy work because of the stigma the disease carries."

Jonathan has focused most of his work at one of Romania's largest TB sanatoria, high up on the Romanian mountain tops, interviewing cases of desperate poverty and illness. The rejection from their families and the lack of resources mean many patients will not be cured.

"Their families no longer want them, many will not be cured. Some of them have cell phones without credit and they wait for them to ring, but often they do not. Their doctors do not know what to do, and sometimes they burst into tears and tell me how much they want to help these patients but do not have

the resources to do so."

Jonathan says there are some good doctors and effective measures to confront TB in Romania, but he stresses 'apathy' is the missing piece of the puzzle, as people forget that TB is a disease that anyone can catch. He would like to see strengthening of the TB Patients Association in Romania and support for patients to take leadership and advocacy roles in the future.

"There are some brave patients, like Iulian, who want to make a difference and are not afraid, but the majority of Romanian TB patients remain in the shadows for now, calling their illness a 'lung disease' and lying to their friends and neighbours about it. We need to support them so they will make their voices heard."

WHAT NEEDS TO BE DONE?

The 'voices' in this report are of those who deal with the reality of TB on a daily basis. These patients, doctors, health workers and carers are integral to whether the fight against TB will be won or lost.

These case studies show that TB is not a disease of the past; nor does it respect borders, social status, age or gender. They highlight that the response to TB must be based on the particular needs of patients and challenges at local, country and regional levels.

As governments and communities are hit by the global economic downturn, it is essential that political and financial commitments to fight TB in the WHO European Region do not waver. In the long term, the consequences of this would be far more costly than sustained and increased investment now.

The governments of the WHO European Region indicated their political will to fight TB through 'The Berlin Declaration on Tuberculosis (2007)'. All parties committed themselves to regularly monitor and evaluate the implementation of their agreed actions, recognising that "civil society and affected communities should be considered

as essential partners in and integrated into TB control" ^{iv}.

To date, commitments made in this declaration have not been adequately monitored nor has progress been assessed. There remains a lack of civil society voices at all levels of TB control in the region. The fight against TB will not be won unless these voices are heard.

The TB response in the region now needs genuine political commitment matched by robust actions. Member states and the European Parliament, civil society organisations and patients themselves must work in partnership to track progress and hold decision makers to account.



Domestic governments in the WHO European region and European institutions, in particular the European Commission, must take urgent action in the following areas:

Policy, programme development and implementation:

- Fully implement commitments made in the Berlin Declaration, tracking progress towards recommendations every two years;
- Match political will with sustained or increased domestic financing to deliver a TB and HIV response based on individual country needs;
- Endorse and back, with clear political, financial and policy commitments, WHO's 'Consolidated Action Plan to Prevent and Combat Multidrug- and Extensively Drug- Resistant Tuberculosis (M/XDR-TB) in the WHO European Region 2011–2015';
- Increase financing for the Global Fund to Fight AIDS, TB and Malaria at levels that commensurate with the wealth of member states;
- Ensure sufficient domestic and, where necessary, regional financing to sustain TB control programmes



Image courtesy of the World Lung Foundation

in countries no longer eligible for financing through the Global Fund to Fight AIDS, TB and Malaria;

- Ensure TB programmes are fully integrated with HIV programming and planning at country and regional level and that financial commitment to support collaborative work is reflective of country burden of both diseases.

Research and New Tools

- Ensure that the next Framework Programme for Research and Technological Development (FP8/Horizon 2020) has a special focus on research and development for neglected and poverty-related diseases;
- The European Commission should boost expenditure on research and development for TB to its 'fair share' of €101 million a year;*



- Ensure that the European and Developing Countries Trials Partnership can fully fund clinical trials to bring new tools to the marketplace more rapidly;
- Fund research to develop child-friendly TB diagnostics, drugs, biomarkers and vaccines.

Civil society participation

- Governments in the WHO European Region must facilitate practical opportunities for civil society, including patients themselves, to participate in decision making regarding TB resources, policy and programming by:

- Including civil society and patient networks in all national planning, assessment, monitoring and evaluation processes.
- The European Commission should facilitate greater engagement of civil society at a regional level and enhanced stakeholder information sharing through:
- Creating a European Think Tank and Civil Society Forum coordinated and funded by DG SANGO. This structure should be established by the end of 2011.

Community-based treatment and support

- Through community strengthening and by seeking broader community input, ensure all TB patients, including the most marginalised in society, are able to access treatment that respects their human rights and ensures treatment success;
- Promote rights and responsibilities as described in 'The Patients' Charter for Tuberculosis Care' to people with HIV and other communities who are disproportionately impacted by TB.

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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

TB Europe Coalition

www.tbcoalition.eu

If you are interested in joining the Coalition, kindly contact tbcoordinator@gmail.com giving your name, organisation, contact details and nature of your interest or activity in TB.

THE LAST GARDEN OF MR POPA



Mr Popa was 53 and described himself as 'a man with a passion for electronics and flowers'. Before contracting TB, he was an electrical engineer. When I took this picture he could only lie in bed, unable to breathe without a machine, his heart is failing, no longer being able to sleep because he constantly worries about death. Joy in his world is this windowsill garden, where flowers and a pepper plant with one red pepper sprout in sour cream containers and a Coca-Cola bottle. We bonded over gardens that we miss, far away at our homes. He showed me pictures of what his flowers will look like in bloom. Mr Popa spent his days alone with his harvest. He wondered when he is gone, who would care for this little garden? I sat with him months later as he was dying, his flowers all dead. He cried angry tears, he wasn't ready to die, he waited and waited for a son who never arrived.

Jonathan Stillo, medical anthropologist, Romania

"Civil society and affected communities should be considered as essential partners in and integrated into TB control"

The Berlin Declaration on Tuberculosis 2007

Tuberculosis (TB) is a global epidemic. However, this report aims to draw much needed attention to the fact that TB is not a mysterious disease in a distant land. TB in Europe has been on the rise over the past decade; affecting men, women and children from across the region and from vastly different communities. Despite the devastating impact that TB has on these communities, genuine political action to tackle the disease at the regional level remains to be seen.

Contained in this report are seven case studies telling the human side of the story – patients, doctors, health care workers and advocates speak out about their experiences, achievements and the challenges faced in tackling this regional epidemic.

Governments of the WHO European Region, as well as the European Institutions, must work in genuine partnership with those that come face to face with TB every day. As identified in this report, these individuals offer a unique insight into the challenges related to tackling the disease and are integral to finding solutions. If decision makers in the region don't listen to these voices, the fight against TB will never be won.

