

*Tuberculosis: Forgotten, But Far From Gone.*

# FIGHT TB BACK

## TIMEBOMB

DR. LEE REICHMAN SOUNDS OFF  
ON POLITICAL WILL, INNOVATION  
AND EMPOWERING PATIENTS

*Are medical schools  
today focusing  
enough on TB?*

5 Questions with  
ERS President-Elect  
Francesco Blasi

## UPDATES:

**PHILIPPINES**  
STRENGTH IN NUMBERS

**ESTONIA**  
THREE FRIENDS, FIGHTING  
MDR-TB TOGETHER

**PERU**  
IN HOUSES, TB INFECTS ALL –  
INCLUDING THE CHILDREN



**ERS** EUROPEAN  
RESPIRATORY  
SOCIETY  
every breath counts

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*A nurse outside Makati  
Medical Center in Manila,  
Philippines.*



## LEADING THE WAY TOGETHER

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*...we sought to offer portraits of hope that may be able to inspire those who are currently battling TB...*

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We at Otsuka are extremely proud to partner with the European Respiratory Society (ERS) for the development of this project. Sometimes when confronting deadly infectious diseases there is a tendency to focus on the clinical aspects of fighting the illness and forget about the lives of individual patients. With this project, we sought to emphasize the very personal nature of TB – the individual struggles, successes, and stories of patients from three very different countries but all sharing in one common fight. Most importantly, we sought to offer portraits of hope that may be able to inspire those who are currently battling TB, letting them know this is a curable disease that can be overcome.

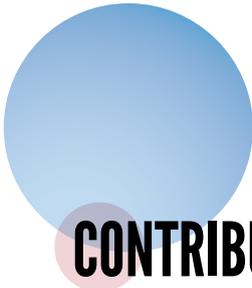
In 1971, Otsuka selected TB as one of its first research themes. TB remained a serious threat, particularly in the company's own

backyard. Otsuka saw its Asian neighbors with limited access to new medicines available in the West left helplessly to die. The company knew there was more that could be done to benefit their healthcare and that one new treatment option alone would not be enough to help the millions of people who were dying of TB every year. Thankfully, researchers at the time had the vision and foresight to recognize TB is an extremely tenacious pathogen that finds new ways to attack the human body and resists many forms of antibiotics.

Our efforts in TB are symbolic of Otsuka as a whole. Adapting our approaches to transitions in healthcare, we have made it Otsuka's mission to address medical challenges through research and development that bring truly innovative solutions to patients worldwide.

Early morning rush hour in downtown Manila, Philippines.





## CONTRIBUTORS

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*Journalist **John Donnelly** and photographer **Riccardo Venturi** are no strangers to global health issues and TB. But working together on assignment for the first time, they were impressed to find strong TB programs at work, personally invested healthcare workers, and resilient patients with the will to live.*

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**John Donnelly** is an award-winning writer based in Washington, D.C., who specializes in global health issues. For a decade, he worked for the Boston Globe, covering foreign affairs from Washington and global health and development issues based in South Africa. Prior to that, he was the Middle East correspondent for the Miami Herald. He is the author of *A Twist of Faith*, a book about the vast faith-based movement to help orphans in Africa. He also has written and produced books for Harvard University, the World Health Organization, Johns Hopkins University, Management Sciences for Health, and the Consultative Group for International Agricultural Research.



**Riccardo Venturi** graduated from “Istituto Superiore di Fotografia” in Rome in 1989 and began his career documenting Italian and European social issues such as illegal immigration and the rise of Nazi movements in Germany, and the early years of democracy in Albania. In the mid 1990’s his attention was mainly drawn towards countries in conflict, foremost Afghanistan, winning the prestigious World Press Photo Prize in 1996. In 1997 he won the Leica Honorable Mention for his reporting of the war in Kosovo. Ever since, he has travelled to countless countries at war among them Somalia, the Gaza strip, Liberia, and Sierra Leone.

Recently, Venturi has covered significant global events, such as the tsunami in Sri Lanka and the earthquake in Iran in 2003, alternating with personal investigations, such as a long-term project about the spread of tuberculosis throughout the world, realized in collaboration with the World Health Organization (WHO), winning in 2008 the “Marco Lucchetta” Award and the UCSI Award for Photography in 2009.

Most recently, Venturi has been covering the earthquake in Haiti and its aftermath. With his project “Haiti Aftermath” Venturi received several awards such as: the World Press Photo, first prize General news; Luis Vultena Award, second prize; Sophot Award; Picture of the Year Award, honorable mention; Sony World Photography, finalist; Care International Award, finalist.

Riccardo Venturi is represented by Contrasto photo agency since 2001.



# THE IMPORTANCE OF POLITICAL WILL IN TB CONTROL

By Dr. Lee Reichman

**When I** was given the opportunity to participate in this project and visit Estonia I immediately jumped at the chance to observe a program I had heard so much about over the years and meet several patients face to face. Estonia, like many other Eastern European and former Soviet countries, is burdened with a mind-boggling MDR-TB problem, caused by previously poor programs, poor follow up, poor adherence, and lack of political will, among other reasons. But what I found upon arriving in Estonia was truly eye opening: an unprecedented level of communication between TB doctors, nurses, public health officials and government ministers.

Ten years ago in my “Timebomb” book I gave a dire warning of what could happen if public health authorities did not place greater emphasis on measures that prevented the spread of TB and particularly multidrug-resistant varieties of the disease. Yet in this decade, little seems to have changed.

We all agree that we need new tools: new diagnostics, drugs and vaccines. But while we wait for such new tools to be introduced, are there other innovations in practice or theory that might be considered or reconsidered to improve the situation?

What I observed in Estonia – dedicated professional staff, innovative programs, and effective Directly Observed Treatment (DOT) not only putting a crimp into TB control, but possibly, MDR-TB rates as well – told me the answer was unquestionably, yes. But the centerpiece is something called the TB Consilium – an ad-hoc group of professionals that together help manage all 303 TB cases<sup>1</sup> throughout the country. They meet on a frequent basis – no less than monthly – and review each and every pending case. They discuss challenges, needs, strategies, and most importantly, their activities and recommendations are fully backed by the government.

<sup>1</sup> 2010 figures

The first element of the World Health Organization’s Stop TB Strategy is political will. This cannot be overemphasized as it is the lynchpin to all other aspects of TB control which include case detection, directly observed therapy with case management, reliable drug supply, recording and reporting. And all this is exactly what is seen in Estonia, quietly and effectively.

Not just in Estonia, but in the other countries explored in this magazine we see the importance of political will resurfacing time and again. In the Philippines, a strong movement on the part of the Ministry of Health and the National TB Program (NTP) has gradually moved to decentralize services across the 7,107 island nation so that patients in rural communities can gain access to the same level of care rather than having to go great distances to cities for treatment or seek hospitalization which can often increase infection risk and drug-resistance. The move to decentralization in the Philippines will take time, but the NTP has a multi-step plan in place and is on-track to meet their millennium challenge goals.

In Peru, the level of political will rises all the way to the top, with President Ollanta Humala making it clear, for the first time that I can remember in any country, that fighting TB is a top priority of his presidency. He has organized various levels within all ministries –from Health to Transportation - to meet and communicate on the subject of TB. The goal: to address not only the medical, but the social aspects of the disease. And of course, he’s invested his own country’s resources behind that, scaling up TB control funds to US\$32 million in 2011 from US\$5 million previously.<sup>2</sup>

The results from each of these countries will not be seen overnight. As stated, TB is a tenacious disease that lays dormant in the body for generations, long before these political plans took shape. But investing in TB control and

prevention today will yield dividends tomorrow. Countries cannot simply abandon course or re-adjust their thinking if there is not a sharp decline in a graph or chart by next year. Tackling TB just doesn’t work like this. It requires a long-term vision and a long-term approach.

Excitingly, the focus we are beginning to see on political will is intersecting at the same time new TB tools and innovations are hitting the scene. These innovations didn’t happen overnight either – they took time to develop and research, some over a span of decades or more.

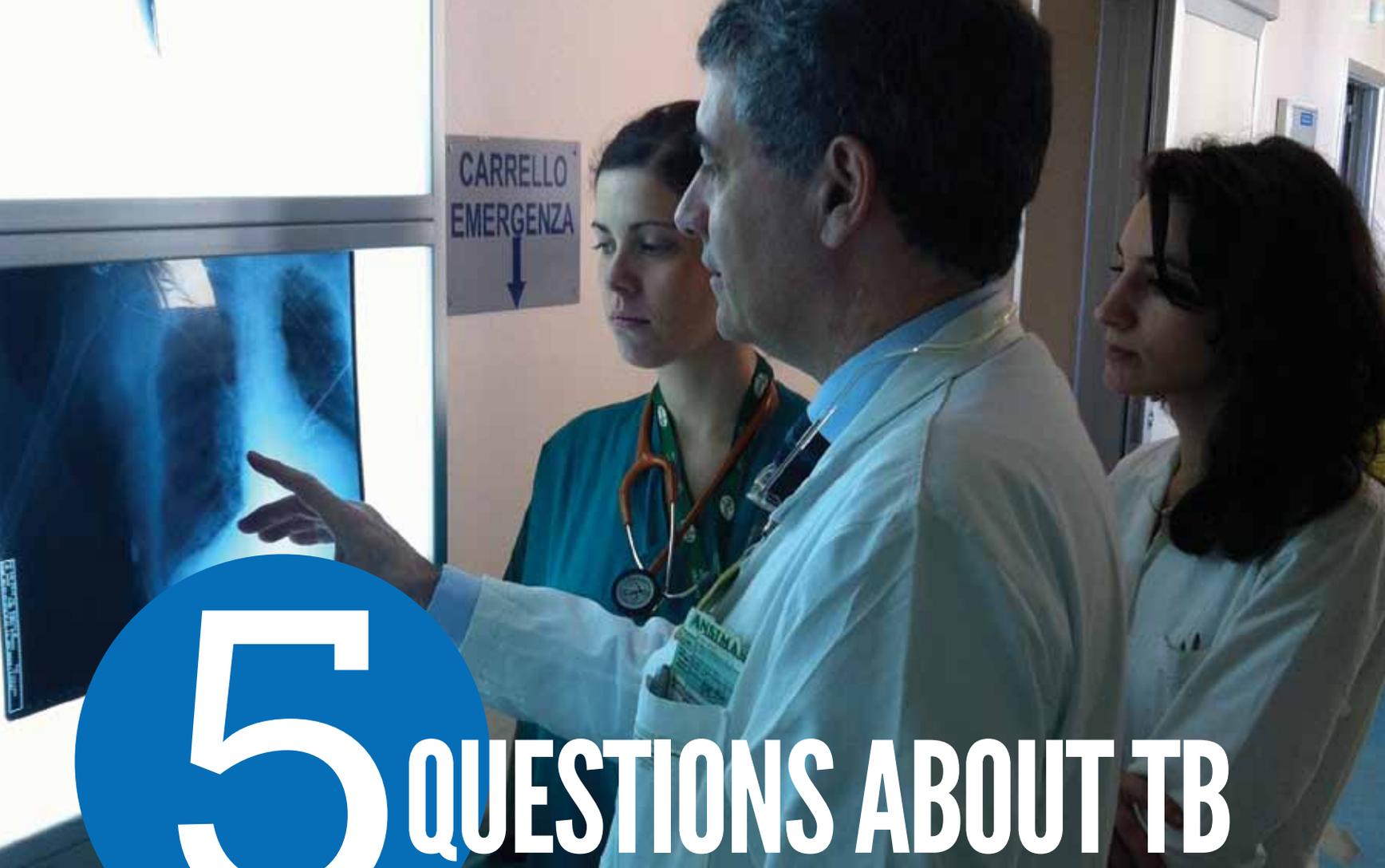
And of course, good tools are only half the equation: it is the way they are implemented and used that makes all the difference. This must be done at the local level, making the importance of community-based care equally important. One of the reasons the HIV community has been so successful advancing their agenda is because they have been remarkable at empowering the patients themselves. The same must be done in TB. Reducing hospitalization so that patients can be treated in their local towns and villages means they can remain a vibrant part of the community and not treated like social pariahs. Like those I saw in Estonia, if patients everywhere had the opportunity to stay with their families, work a job or go to school once they are no longer infectious, we could dramatically reduce the stigma associated with the disease.

New TB innovations are the vehicles that can take us to our goal of the first generation free from TB, but strong political will is the only fuel that can move them forward. For those of us who have been involved in TB control for many years, we are more optimistic than ever before by the developments currently taking place. My great hope is that the political leadership of all nations affected by TB will respond to the challenge as Estonia, Peru and the Philippines have.

<sup>2</sup>Peru NTP



**Lee B. Reichman, MD, MPH**, is the Founding Executive Director of the New Jersey Medical School Global Tuberculosis Institute, and Professor of Medicine, Preventive Medicine and Community Health at the New Jersey Medical School, in Newark, New Jersey. He also serves on several national and international committees, advisory boards, professional organizations and societies including the National Coalition to Eliminate Tuberculosis (now Stop TB USA) (past chair); American Lung Association (past president and recipient of the 1999 Will Ross Medal, their highest award); American Thoracic Society (honorary life member); and the World Health Organization Stop TB Partnership, among others. Dr. Reichman has published well over 200 articles, scientific reviews and book chapters, particularly about the diagnosis, treatment, prevention, control, patient adherence with therapy and the epidemiology of and advocacy for tuberculosis. He is also the author of *“Timebomb, The Global Epidemic of Multidrug Resistant Tuberculosis”* with Janice Hopkins Tanne, McGraw-Hill, 2002 which was named first prize winner as the best trade medical book for 2002 by the American Medical Writers Association.



# 5 QUESTIONS ABOUT TB

with ERS President-Elect Francesco Blasi

## 1. What do you see as the greatest challenge to TB control today?

The main point now is that even though we have an overall reduction of the TB burden, we have not yet achieved any major success in controlling the TB drug-resistance epidemic. The challenge, particularly in Eastern Europe, is the lack of rapid diagnostic testing and good treatment for MDR-TB. New diagnostic tools may have a great impact but sometimes the lack of communication between the lab, the physician, and the patient leads to a delay in treatment. The last data published in the European Respiratory Journal (ERJ) shows that the Eastern European region is somewhat worse off today than before. We need new control approaches and a better prophylaxis of patients with latent TB in order to address these challenges.

## 2. What's the one thing that could happen tomorrow that would make the biggest difference in the fight against TB?

Better prevention measures. At the end of the day you can stop the disease if you can prevent it.

Of course better drugs are always needed but the best way of stopping the flood is to block the water at the tap! One of the main problems is the approach to the treatment of latent TB. [Physicians] are not used to preventing disease. We have infection control measures that are very easy to implement – wearing masks, keeping those still infectious in isolation – but on the other side you have the problem that most physicians didn't think eradication of the disease could happen by dealing with latent TB. Here in Italy if you see a patient with a positive skin test and you offer them six months of isoniazid, most of them would say, 'No way! I'll wait for TB!' So we have to change our approach with regards to latent TB.

One other point is that there is a new TB drugs pipeline which is a positive development for the future. The good news is that the TB pipeline is showing significant progress compared to the past and probably in the field of vaccination we may have some interesting developments. So at the end of the day I hope to have new weapons in our arsenal for treating TB in the future.

### 3. What role does ERS have in helping bring about innovations in TB treatment?

ERS is working a lot on TB right now. I think we need more advocacy at the EU level on TB because there is mounting evidence that we are facing a big problem now and in the future. Not just in the Eastern European countries but everywhere. There is massive immigration from countries where the level of TB is high. So ERS has decided to work on a Forum for TB Innovation which is a sort of think-tank to provide an interface for discussion and new thinking about TB control. Our hope is to try in some way to complement the work of other organizations like the WHO and ECDC. It's a small group but we try to think outside the box on TB and find new ideas and tools that can be implemented at the EU level but in the future perhaps even at a global level.

Simultaneously, ERS is also working on another project – a TB Consilium – where we will work with the WHO to provide advice to physicians who have patients with particularly difficult cases of MDR/XDR-TB. The idea is for a panel of TB experts to provide advice to these physicians, helping them better manage these tough TB cases.

Finally, we're also working through our journal, the ERJ, on a series of papers on TB. Many of them are jointly authored with the WHO and ECDC to help set the scene in Europe on TB. This is very important also to raise awareness among the respiratory community on TB.

### 4. How did you personally become invested in TB issues?

I started far from the TB field. I'm a cardiologist by training and practice internal medicine. But I started working in infection and my main area of interest

was pneumonia. I also started looking at where the real health needs were in Europe. And with ERS I knew we had to focus on tackling the main problems facing the continent. There are enormous health inequalities between Eastern and Western Europe that lead to varying treatments of TB. I thought it was very important for ERS - and for me - to work in the TB field and indeed I found many other people who started their careers with other medical interests and now are very keen to work in TB. For me, TB is not an antiquated disease. I see it as something that is very topical and relevant in medicine today.

### 5. Are medical schools today placing enough emphasis on TB issues?

In medical schools for sure no. The issue is that only now are we rediscovering the problems of TB. Until about ten years ago there was this thinking in the medical community that TB wasn't a problem anymore for Europeans. Then we discovered TB was there and a lot of cases were passed through respiratory disease wards because healthcare workers were not aware of the disease and not used to making a TB diagnosis. And this leads for sure to a delay in the diagnosis. So now we are rediscovering the disease, even in medical schools. In Italy TB is one of the main topics in respiratory and infectious disease schools. In the next decade we will improve and increase the knowledge of TB in our students and physicians.

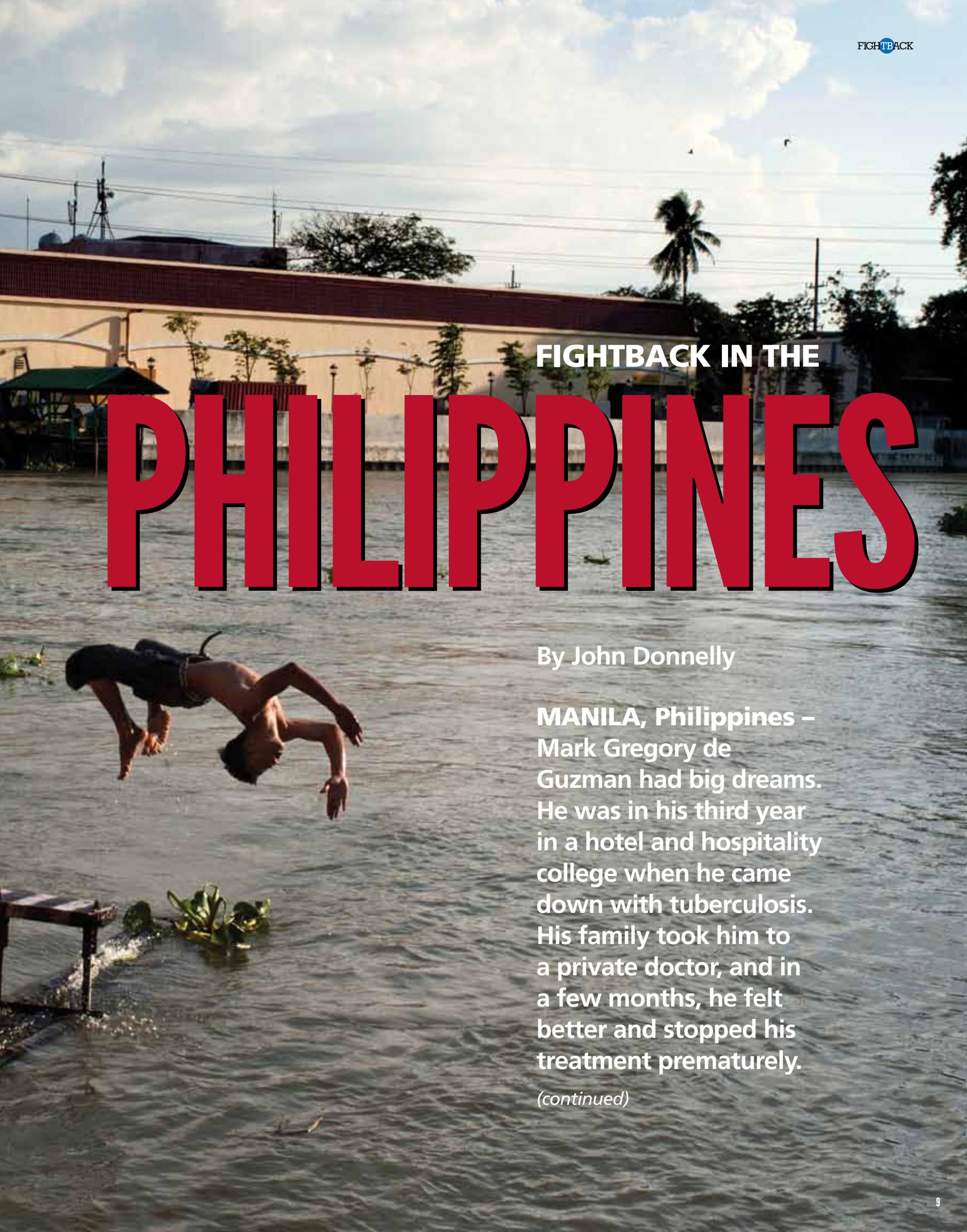
And the increased media coverage we've seen in TB - in newspapers, not just scientific journals – will help to enhance this awareness. Thanks to the press you see there was an outbreak in Rome with children involved or an epidemic in another city because of lack of prevention and poor diagnosis. So the pressure from mainstream media is good pressure that will lead medical students and medical schools to pay attention to this disease.



**Francesco Blasi, MD**, is a Professor of Respiratory Medicine and Head of the Respiratory Medicine Section Cardio-Thoracic Department at the University of Milan. He is also Director of the Respiratory Diseases Unit IRCCS Fondazione Cà Granda Ospedale Maggiore in Milan, Italy.

Professor Blasi is President-elect of the European Respiratory Society (ERS). He has published more than 160 papers in international journals and is a member of the Editorial Boards of Pulmonary Pharmacology and Therapeutics (Associate Editor), Respiratory Research (Associate Editor), Clinical Respiratory Journal (Associate Editor), Therapeutic Advances in Respiratory Disease (Associate Editor), American Journal Respiratory and Critical Care Medicine (member of the Editorial Board). His research interests include the effects of atypical bacteria infection on cellular immunity in chronic bronchitis, and the role of atypicals and viral infection in asthma onset. He is interested in the role of antibiotics in the treatment of COPD exacerbations and asthma and is actively working on pneumonia and tuberculosis research trials. Prof. Blasi has served on ERS-ESCMID guidelines on LRTIs and is a member of the European Respiratory Society, The American Thoracic Society and the Italian Respiratory Medicine Society (SIMeR).



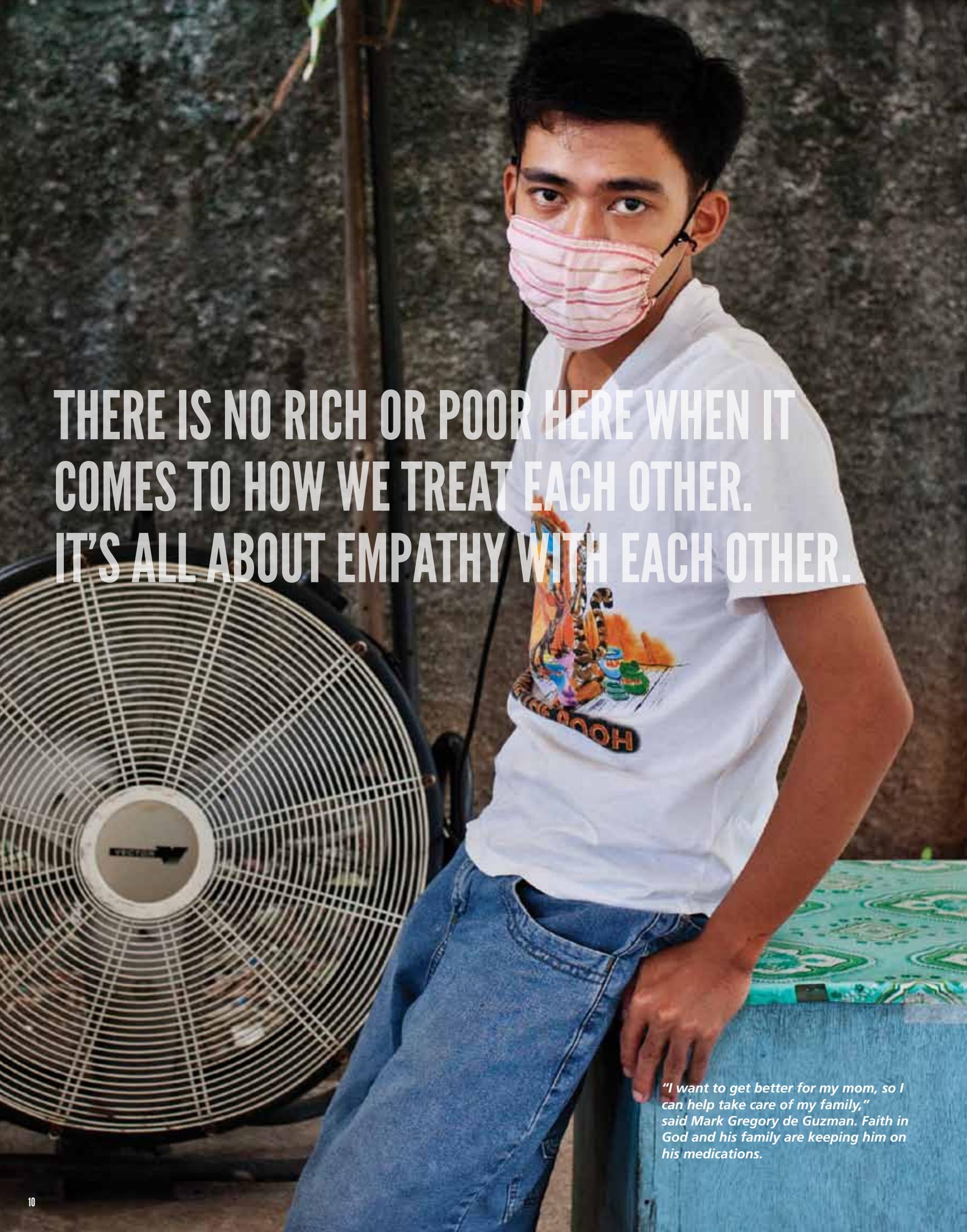
A young boy is captured mid-air, performing a backflip in a flooded area. The water is murky and reflects the sky. In the background, there is a long, low building with a brown roof, palm trees, and utility poles under a cloudy sky. The boy is wearing dark shorts and is shirtless. The overall scene suggests a flooded urban environment.

# FIGHTBACK IN THE PHILIPPINES

By John Donnelly

**MANILA, Philippines** – Mark Gregory de Guzman had big dreams. He was in his third year in a hotel and hospitality college when he came down with tuberculosis. His family took him to a private doctor, and in a few months, he felt better and stopped his treatment prematurely.

*(continued)*



THERE IS NO RICH OR POOR HERE WHEN IT COMES TO HOW WE TREAT EACH OTHER. IT'S ALL ABOUT EMPATHY WITH EACH OTHER.

*"I want to get better for my mom, so I can help take care of my family," said Mark Gregory de Guzman. Faith in God and his family are keeping him on his medications.*

## STRENGTH IN NUMBERS

*TB can often tear people apart; in the Philippines, it's bringing many together.*

I FEEL  
BLESSED,  
BECAUSE OF THE  
SUPPORT I HAVE  
FROM MY SOCIAL  
WORKER, FROM  
MY MOTHER  
AND MY FAMILY,  
AND FROM MY  
COUNCILOR WHO  
HAS PROVIDED  
FINANCIAL  
RESOURCES.

A

few years later, in April 2011, de Guzman became sick again, and this time it was more serious: he had multidrug-resistant TB (MDR-TB), which takes 18 to 24 months to treat, because he had defaulted on his earlier treatment. This time, he went to a government clinic. The care was free and his social worker made sure he and his family had enough food. The attention to his well-being, and the financial support, has made all the difference, he said.

*"I feel blessed," he said, "because of the support I have from my social worker, from my mother and my family, and from my councilor who has provided financial resources."*

The Philippines has long been a center of innovation in the fight against MDR-TB, starting with its ground-breaking push more than a decade ago to allow patients on treatment to live in the community as opposed to hospitals or sanatoriums. TB is an airborne contagion, but the danger is greatly reduced with proper ventilation; in the tropics, treating patients outdoors – with proper precautions such as wearing masks around those still infectious – has worked well.

Now the country in the middle of the Western Pacific Ocean, home to 7,107 islands, is in the midst of decentralizing its services. This great challenge is aimed at enabling many patients in rural communities to get treatment in a nearby clinic instead of moving to cities for treatment.

One unsung part of the Philippines' innovation, one that has benefitted de Guzman and several thousand others, is the attention the country gives toward supporting patients. Treatment isn't just about providing drugs. It also includes social workers visiting their homes, financial assistance for transportation and food, and communities of patients coming together at clinics to encourage one another to continue taking their drugs until they are well.



*Louie Zepeda is adjusting to living with her disability as a result of TB. "I now live separate from my parents and am trying hard to overcome the detachment anxieties."*

Dr. Mamel Quelapio, regional focal point for MDR-TB in the WHO-Western Pacific region, said that the program in the Philippines benefits from the support system for patients coming from families, health providers and fellow patients.

*"In the beginning, we were very focused on the clinical aspect of MDR-TB treatment," she said. "We did not spend much time learning how the community could participate. But as the years went by, we realized that the framework to manage MDR-TB is such a complicated strategy that the more people involved in the care of patients, the better. Every person counts for the treatment of each patient."*

The move toward decentralization of services also is seen as part of that strategy to support patients, as it will be easier for them to access treatment.

*"It means they can go back to their home, instead of renting an apartment in a city," said Hernando Caseria Jr., 23, a nurse at the Lung Center of the Philippines.*

*"It also means they save money on transportation. When I give them the news that they can access treatment in a clinic close to their home, they are so happy. They bring us food."*

Dr. Rosalind Vianzon, National TB Control Programme Manager in the Philippines, said that the TB control effort has to involve many more players in the coming years, including regional health officers overseeing MDR-TB treatment and municipal managers who make stopping TB transmission a high priority.

*"Our strategic plan is moving toward localizing TB control," Vianzon said. "We need to empower local services. We need to engage all care providers. We want everyone working in concert with the national plan."*

A photograph of two nurses in a hospital hallway. The nurse on the left is wearing a white polo shirt with a red collar and dark pants, holding a folder and looking at a document. The nurse on the right is wearing a patterned scrub top and grey pants, also holding a folder and looking at the same document. The hallway has blue window shutters on the left and blue doors on the right. An 'EXIT' sign is visible in the distance.

**I TELL PEOPLE THAT THERE'S NO  
ALTERNATIVE. YOU CAN'T GET CURED UNTIL  
YOU TAKE THE MEDICINES AS DIRECTED.**

*Nurses at the Lung Center of the Philippines  
see more than 500 patients per day who  
come for ambulatory DOT therapy.*

Vianzon and others understand that the push to decentralization will take time. One of the concerns is that the safety net for patients – social workers checking on them and other patients supporting them, for instance – stays intact in order to turn back the number of people who have MDR-TB or drug-susceptible TB.

In Manila, for instance, a group called the Association of Cured Patients now is helping current patients stay on their medicines. The motivation for many members was simple: They wanted to help others just as people had helped them.

*“My concern was the growing number of people who were defaulting on their TB treatment,”* said Anacleto Del Rosario, 58, a member of the group who was cured in 2007 of MDR-TB. *“I also tell people that there’s*

*no alternative. You can’t get cured until you take the medicines as directed.”*

At TB clinics in the Philippines, this bond among patients is obvious. They naturally gravitate to one another, often lingering at the centers to socialize before they return home. On one day late in 2011 at the Lung Center, a group of patients stayed for a couple of hours to plan a Christmas party for all the other patients.

Roland Torres, 53, a former teacher, described his fellow patients as family. *“We are here for 18 months taking medicines together,”* he said. *“That’s 18 months of being here six days a week, and so we have time to form bonds with each other, to care for each other. We are all equal here.”*

***Some MDR-TB patients must receive daily injections which can be painful. Doctors hope future therapies may one day be able to eliminate the need for these injections.***





## BROKERING PARTNERSHIPS IN TB CONTROL TOWARDS **ZERO TB DEATHS**

TB elimination can only happen if there is vigilance and commitment from all healthcare providers. Ensuring quality TB diagnosis, treatment and a cure for all TB patients is a shared responsibility for both public and private health sectors. And it's something we're working hard to accomplish together right here in the Philippines.

A close-up photograph of a female lab analyst in a dark blue uniform, focused on examining a sputum sample under a microscope. The microscope is a Zeiss model, with the brand name visible on the base. The analyst is wearing a silver watch on her left wrist. In the background, another person in a light blue lab coat is working at a desk, slightly out of focus. The setting is a laboratory with various equipment and a computer monitor visible.

**OUR STRATEGIC PLAN IS MOVING TOWARD LOCALIZING TB CONTROL. WE WANT EVERYONE WORKING IN CONCERT WITH THE NATIONAL PLAN.**

*A lab analyst at the Lung Center of the Philippines reviews sputum samples for signs of TB bacteria.*

*"There is no rich or poor here when it comes to how we treat each other," said Denice de la Cruz, also a teacher. "It's all about empathy with each other."*

They were enjoying a meal in the shade on a warm day. It was a collective effort. De la Cruz had brought in rice. Conchita Castro brought tilapia, a local fish. Joyce Garcia contributed a mix of squash, oca, eggplant, and string beans. And Angelito Miranda made fish buro, which was a mix of rice, tomato, bits of fish, ginger, and vinegar.

The bonding, though, also is due to shared difficulties. The drugs often make patients feel sick, causing nausea or worse. Eloisa 'Louie' Zepeda, 29, is an example. She had TB meningitis, and the drugs she took caused the loss of her eyesight, a known but uncommon side effect.

In 2007, Zepeda was working as an architect in Manila when, her body run down, she collapsed on a stairway. She couldn't move. She was taken to a hospital, where she was diagnosed with TB meningitis, and her condition steadily worsened. She had partial paralysis on her left side.

*"It was all so mysterious," she said. "I was fortunate to have friends help me. I was thankful that I was not poor. I had people telling me to continue taking the drugs, and if it was not that setting, I don't think I would have continued. Not being able to see and losing my sense of smell, it's like you are moving but you are already dead."*

Zepeda now is able to use email through computer software programs that read aloud all messages. She works as a website manager for a government-owned company and has served as an advocate for the blind, frequently speaking at events. *"I am very lucky I went blind in this era, otherwise I would be asking for coins on the street," she said.*

Her grandmother said the family supported Zepeda through the illness. *"When she needs help, we are always there," she said. "We are always by her side. Sometimes we are sleeping by her side."*

Zepeda laughed: *"My grandmother tells me you have to accept your situation. Then she tells me if I wasn't blind, I'd be rich!"*

She can laugh about it, but the loss of income for a TB patient and their family can be crippling. For de Guzman, who was forced to drop out of hotel and hospitality school, the impact on his family has been harmful.

*"We haven't been able to save any money because anything extra pays for costs associated with my treatment,"* said de Guzman, sitting in the cramped living room of his family's home in the Quezon City neighborhood in Manila.

De Guzman said he often seeks solace in reading and re-reading the Book of Job in the Bible. The story is about how Job was assailed by Satan, losing all his sheep, oxen, and camels, and then all his children. Job's belief in God is tested, but he holds on to it, questioning God why these horrible misfortunes have happened to him. In the end, God rewards Job for his faith.



**Dr. Rosalind Vianzon,**  
**Philippines National TB Control Programme Manager.**

Getting TB, de Guzman said, made him identify with Job. *"Just as Job was afflicted of all those things, I've also suffered,"* he said. *"Most of my friends have avoided me, left me. My family has been hurt. I asked the Lord, 'Why me? I have many things to do. I am the eldest in my family and I need to be well to support everyone.'"*

But de Guzman said he has not lost faith. He expects to recover from MDR-TB. And he expects to go back to school and embrace those dreams he once had.

*"In the end, when I finish my treatment, I pray that I will be rewarded with a healthy body by my faith in God,"* he said. *"I have had so much support, from my faith, my family, and my social worker. I've needed all of them."*



**IF THE LORD SAYS, 'YOU CARRY THAT CROSS,'  
YOU CARRY THAT CROSS.**

*Mildred Fernando has overcome many hurdles to beat her TB but she is finally ready to live her life again.*

## FACES OF TB: MILDRED FERNANDO

*What happens if you get extensively drug-resistant tuberculosis twice? One woman's story.*

**M**

Mildred Fernando is 29. Many of her friends are married with children. Many have graduated from college and their careers are in full swing. She thinks about them, and she knows she's far behind. But it doesn't bother her.

She's happy to be alive. Fernando had two bouts with a dangerous strain of tuberculosis, called extensively drug-resistant TB, or XDR-TB. She has been sick with TB since she was 19.

There are no good global estimates about survival rates for XDR-TB patients, but anecdotal stories tell of very low odds of beating the disease in HIV-fueled TB epidemics such as South Africa. This type of TB was first named XDR in 2006 when 53 patients in a rural hospital in Tugela Ferry were found to have it. All but one died. Nearly 70 countries had reported documented XDR cases. TB remains one of the world's biggest killers; every year, an estimated 1.4 million people die from it, according to the World Health Organization.

Now, though, there are several hopeful developments from laboratories and clinical trials around the world to significantly reduce that death toll, and the question may soon become whether countries will be ready to act and pay for these new breakthroughs that could save millions of lives.

Already, several countries, including the Philippines, have been purchasing the GeneXpert machine, which can accurately diagnose multidrug-resistant TB in two hours, a vast improvement from the most common test that takes two months.

Fernando's story underscores the urgent need for better tools. TB could have killed her whole family. Her father died from it in 2003. Both her sisters had it. They survived after six months of treatment. (Their mother died four days after Mildred was born from complications following the birth.)

**I JUST WANT TO  
ENJOY LIFE, ENJOY  
MY WORK, AND  
ENJOY MY FAMILY.  
THERE'S NO NEED  
TO HURRY.**

In November 2001, a doctor first diagnosed Fernando with the disease. That led to a series of missteps over the next several years by private doctors who made such simple errors such as continuing her on treatment that wasn't working.

By 2004, a test found that she had drug-resistant TB. Fernando didn't look ill. But she felt horrible. She had regular episodes of hemoptysis, or coughing up blood from her lungs or trachea. Each time, her family rushed her to the hospital.

When someone has drug-resistant TB, doctors put them on what is called second-line drugs. Fernando's drug combination therapy caused hearing loss in both ears. One of the drugs made her itch horribly. A second caused her to vomit often within a minute of swallowing the pill. At one point, her condition deteriorated so much that doctors put her in the Quezon Institute in Manila; her family couldn't see her because of the risk of infection.

She finished the first 18 months of treatment, but six months later a test found she was positive again for TB. She started another 18 months of treatment and a surgeon cut out part of her right lung. She finished the treatment in 2011, and so far, so good.

*"I've always asked why did it happen to me," Fernando said in the house of her aunt outside of Manila. "I always took the drugs religiously, but I was not getting well. My grandmother always told me to never stop praying and that we were all given our own cross to carry and you cannot choose what cross you have to carry. If the Lord says, 'You carry that cross,' you carry that cross."*

Fernando said she has learned many lessons. She knew that working was important to her so she started a job as an accountant at the Tropical Disease Foundation, where she was a patient; in 2011, she was hired by Management Sciences for Health to be an accountant on its TB project.

She learned that she had to fight for herself. *"You must take an effort to learn your disease,"* she said. *"You need to ask the right questions. You always are dealing with people who shy away from you for fear of getting infected. This happened when I knew I was not infectious. But still I couldn't get upset. It's not my problem."*

She has a boyfriend, a nurse, John Stuart Pancho, 26, who met her during treatment. Fernando said they are moving slowly in their relationship.

*"It's only now that I am starting to live,"* she said. *"I just want to enjoy life, enjoy my work, and enjoy my family. There's no need to hurry."*



*Mildred Fernando with a colleague at work in Manila, Philippines.*



One bright spot to her ordeal: Mildred met John Stuart Pancho, her nurse who later became her boyfriend.



Having recently been cured, Mildred is taking advantage of some simple joys in life, like picking up her young nephews from school.

## FINDING STRENGTH: *A patient's story*



**Mark Gregory De Guzman**, a college student studying to go into the hotel and restaurant industry, was diagnosed with tuberculosis in 2007. He saw a private doctor and started and stopped treatment several times over the next three years because his family often couldn't afford to pay for the medication. In 2011, he was diagnosed with multi-drug resistant tuberculosis (MDR-TB) and started treatment at the Lung Center of the Philippines, under the country's national TB program.

“Many of my friends don't want to see me now. So I stay away from my friends.”

**Q: You are now seven months into your treatment. How are you feeling?**

**A:** I've seen a great improvement. I've gone from a weight of 36 kilograms to 42 kilograms.

**Q: After treatment, what will you do?**

**A:** I will go back to school and learn hotel and resort management. After I finish my studies, I hope to get a job and support my family.

**Q: How do you look at your experience with MDR-TB? Do you feel cursed that you contracted the disease or blessed that there is a system in place to treat you?**

**A:** Blessed. I don't feel blessed to have the disease, but I feel blessed to have the support of my family and to have the support of my social worker and health workers here at the Lung Center. They have been so helpful to me.

**Q: What's been the hardest part of the treatment?**

**A:** It's been the stigma. Many of my friends don't want to see me now. So I stay away from my friends. I mostly stay at home.

**Q: What do you do with your time?**

**A:** I watch TV, I read books.

**Q: What books?**

**A:** The Bible.

**Q: And what in the Bible gives you strength?**

**A:** The story of Job.

**Q: Why?**

**A:** When Job was afflicted with disease, and when his life became ruined, his friends avoided him. Then he lost all his property. But he still believed in God. When God saw that Job still believed in him after all he had gone through, he rewarded Job.

**Q: What does that story mean to you?**

**A:** I can relate to it. I believe when I finish with this treatment, I will be rewarded like Job – with my health, my body intact, and my faith in God stronger than before.



Mark Gregory de Guzman at home with his mother and younger sister.

Mark used to enjoy running but his cough prevents him from much physical activity. He looks forward to resuming his runs following treatment.



# BREAKING BARRIERS: *A nurse's story*



**Nurse Hernando Caseria, Jr.**, has been working at the Lung Center of the Philippines for 18 months treating multidrug-resistant TB patients. His father is a deck officer on a ship, his mother a doctor treating TB patients. He said he didn't join his profession because of his mother but rather because "it was something useful that I could do in life, something I could offer to help the health of others."

**I had a patient who for five months remained positive for TB. When I told him that he was negative, I saw the joy in his eyes.**

**Q: What have you learned in the first 18 months in treating MDR-TB patients?**

**A:** The main thing is that it takes perseverance when it comes to patients. How you help motivate them to be cured is very important. It's very difficult and painful at times to take these medicines. So I talk to them very casually.

**Q: Why casually?**

**A:** It lessens the tension and breaks down any barriers between us.

**Q: So you use psychology with patients?**

**A:** You have to think of ways to help the patient continue with the medications. You have to find the right way to motivate them.

**Q: Is that hard to do?**

**A:** It is hard when patients are hard-headed. There are those who do adhere to the treatment, and those who do not understand the gravity of the sickness and the disease. Sometimes they ignore what we tell them about treatment.

**Q: How do you talk to these patients?**

**A:** I tell them about the seriousness of the disease. I tell them what will be the consequence of not following

the treatment, and what will be the consequence of following the treatment. I tell them that I see patients come here on a stretcher or in a wheelchair and in a few weeks or months, if they take their treatment, they are walking on their own.

**Q: What gives you joy in your job?**

**A:** I had a patient who for five months remained positive for TB. When I told him that he was negative, I saw the joy in his eyes. When they become negative, they can go to our tent for those who are negative. Everyone knows the tents here – one for those who are positive, where they must always wear masks, and one for those who are negative.

So I have been able to tell this patient and others that they could now go to the negative tent. That makes them very happy. When this happens, other patients notice and they will applaud as the patient goes to the tent for the negatives. They will give the patient a standing ovation.

I had another time in which I presented to the doctors a case of a patient who was in treatment for over one year after which the doctors gave the approval that the patient could stop taking the treatment. I told the patient,

and the patient was very happy. In fact, I was very happy myself. I was part of the patient's life.

**Q: How could things improve in the treatment of patients?**

**A:** I hope for better medications, for improved treatment. It would be a major advancement if the treatment period was much shorter.

Also, many patients are in very bad financial situations. It's very hard for them to even get here, to pay the transportation. So it would be good to give them more financial assistance. One of the things that I do in my job is to help decentralize the treatment of patients and assign them to a health center closer to their home. That can eliminate the transportation costs. This makes them happy, of course, and they often bring food to me as a thank you.

**Q: Food?**

**A:** Yes, sandwiches, juices. One patient even invited me to his house for a meal. He lived two hours away.

**Q: Did you go?**

**A:** Yes.

**Q: How was it?**

**A:** Oh, so much food! It was great.



Like so many other healthcare workers, Hernando Caseria, Jr. brings a personal dedication to his job.

Every morning from approximately 8 am to 12 noon a rush of patients arrive at the Lung Center of the Philippines to take their daily TB medications. This is typically the busiest part of Caseria's day.



## SNAPSHOT: PHILIPPINES

Children are particularly vulnerable to TB. The disease occurs in its most severe form among the youngest such as in Glenn Canoy, 13, who suffers from a severe form of extra pulmonary TB attacking his fragile spinal cord.



Children play in the Quezon City neighborhood of Manila, Philippines.





**Top left:** Two girls gaze at the Pasig River running through metro Manila.

**Top right:** The Philippines is a deeply religious country. About 80% of the population is Catholic.



Patients receiving DOT at the Lung Center of the Philippines have formed unlikely bonds. Each day they share their lunch and support each other through treatment.





*The greater Manila area contains more than 11 million inhabitants, comprising 13% of the national population.*

## TB BY THE NUMBERS: PHILIPPINES 2010

*With 93 million people in total spread across an archipelago of 7,107 islands, TB treatment must be localized so that patients can receive the care they need, even in the most remote settings. According to the WHO, the Philippines ranks 9th in TB prevalence on its list of 22 high-burden countries. An average of 75 Filipinos die every day from TB.*



Sources: Philippines National TB Programme; the World Health Organization.



**FIGHTBACK IN**

# **ESTONIA**

**By John Donnelly**

**TARTU, Estonia** – Estonia had to do many things right in its fight against multidrug-resistant tuberculosis (MDR-TB). It needed to treat ordinary TB effectively. It needed to control the distribution of drugs to minimize the risk of resistance spreading. It needed trained workers. It needed strong laboratories with the best tools to diagnose the disease quickly. It needed political will.

**And it needed good patients.**

*(continued)*

**WE KNEW THAT CONTROLLING TB IS  
COST-EFFECTIVE – YOU SAVE WHEN YOU  
STOP THE SPREAD OF CASES.**

*Agne Nikandrove sits in a local restaurant in Vorumaa, near her hometown. She is proud to have beaten her TB and wants to help others who are going through what she did.*



## THREE FRIENDS, FIGHTING MDR-TB TOGETHER

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*Their story of supporting each other is one of the countless unsung reasons for Estonia's success.*

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IT WAS MOST  
IMPORTANT  
THAT THESE  
THREE PEOPLE  
SUPPORTED  
EACH OTHER.



When planners sketched out a blueprint on how they would control MDR-TB, an unstated given was that patients took their medicines daily. The strategy is to directly observe the treatment, but the daily grind is not easy for patients. Some give up.

Not giving up becomes critical.

So it was in the case of Margot Anitskin, an MDR-TB patient, who wasn't going to give up, and nor was she going to let that happen to two fellow patients in an isolation ward for tuberculosis patients at Tartu University Clinics. Their story of supporting each other is one of the countless unsung reasons for Estonia's success, and it's still cited by caregivers as a part of their model for success.

*"It was most important that these three people supported each other, especially with Margot's help," said Evi Kivi, an assistant nurse at the clinic who closely observed the three patients. "She actually helped everybody. She saw the situation very clearly. She knew what she had to do."*

Their relationship, in microcosm, mirrors the country's persistent efforts to control drug-resistant strains of TB after it began to spread alarmingly in the years after independence from the Soviet Union in 1991. In the early 1990s, Estonia's economy had slipped, its health system had faltered, and cases of drug-resistant tuberculosis grew. By the end of the 1990s, Estonia, along with several other countries once under Soviet control, had some of the highest rates of MDR-TB in the world, and the world took urgent notice of an emerging health menace.

But Estonia bounced back and regained control of MDR-TB. Experts say the main reason was that political leaders made the fight a priority.

*“We had political support and commitment at the highest levels of our government,”* said Piret Viiklepp, the head of the Estonian Tuberculosis Registry at the National Institute for Health Department. *“We knew that controlling TB is cost-effective – you save when you stop the spread of cases.”*

Since the late 1990s, the situation has improved dramatically. In 1998, the numbers of notified TB cases in Estonia totaled more than 800, and the TB rate was five times that of the Nordic countries; by last year Estonia had cut that rate in half, to 2.5 times the number. The figures are still much higher than health authorities want, but they see progress.

Dr. Manfred Danilovits, head of the Department of Tuberculosis at Tartu University Clinics and a coordinator of the National TB Program who has worked to control the disease since 1981, also said that staff training has been a key factor in reducing MDR-TB.

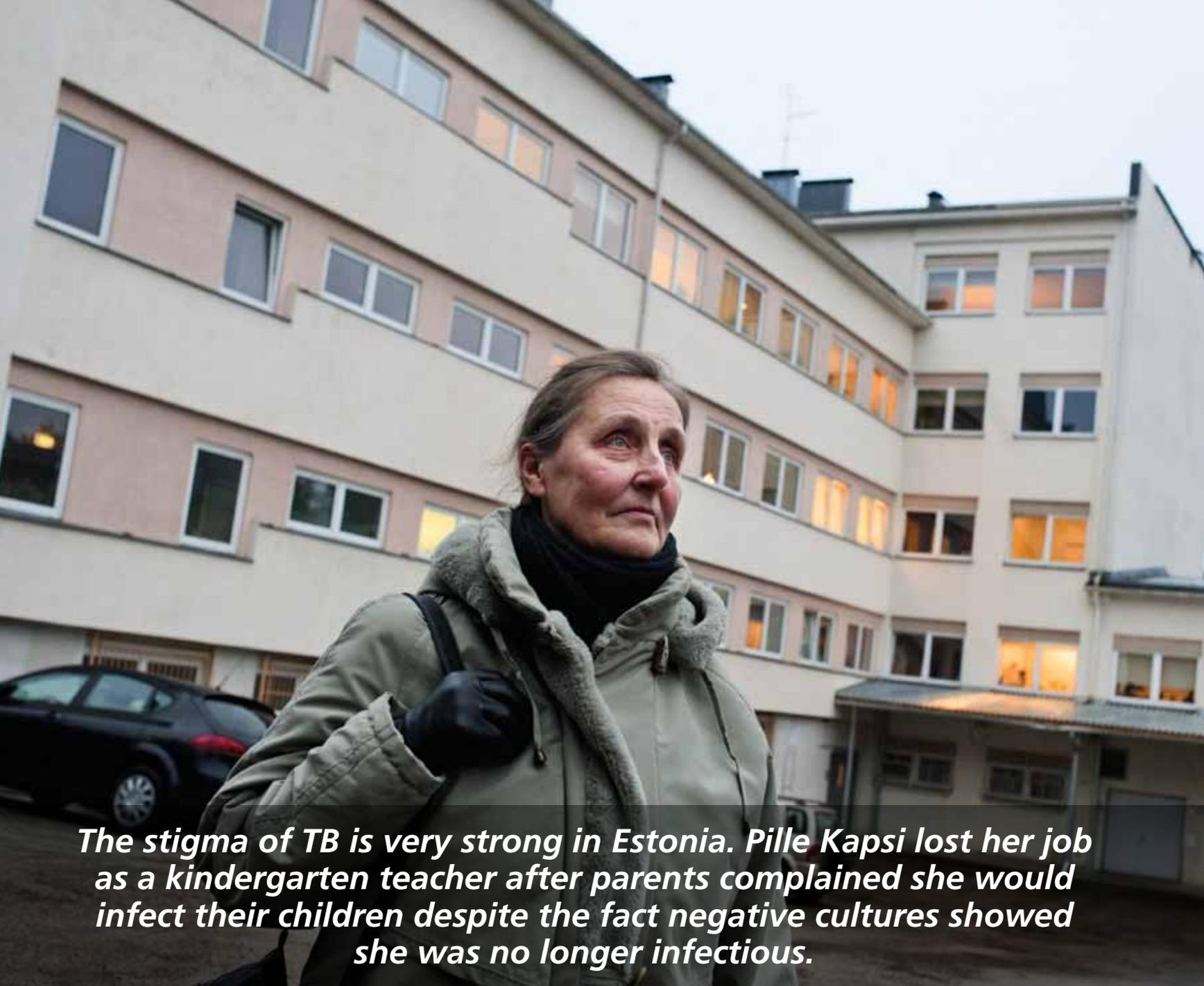
*He explained: “In 1998, in the framework of our national TB strategy, we started training our staff. We trained not only those directly in the TB program but also all administrative staff, pulmonary specialists, family doctors, and nurses in the country. In addition, every year since 1996, we have had international training courses on TB control, where experts come to do training mainly for doctors from former Soviet countries. These courses are still ongoing.”*



*Many former patients like Agne Nikandrove (left) develop close friendships with other patients such as Raido Remmeblas (right), still in treatment.*

*Dr. Lea Pehme and  
nurse Evi Kivi examine  
a chest x-ray.*

**WE TRAINED NOT ONLY THOSE DIRECTLY IN THE  
TB PROGRAM BUT ALSO ALL ADMINISTRATIVE  
STAFF, PULMONARY SPECIALISTS, FAMILY  
DOCTORS, AND NURSES IN THE COUNTRY.**



***The stigma of TB is very strong in Estonia. Pille Kapsi lost her job as a kindergarten teacher after parents complained she would infect their children despite the fact negative cultures showed she was no longer infectious.***

The government also decided to fully fund the TB program, including treatment of those with MDR-TB and extensively drug-resistant TB, or XDR-TB. Added to that was the guidance of key strategists such as Viiklepp, Danilovits, and others, who built a strong surveillance system that would alert them to new threats.

Inside the Ministry of Health, Ivi Normet, the deputy secretary general of health, said that while the TB control program is *“rather strong,”* officials are looking out for potential problems. One persistent issue involves TB patients who abuse drugs or alcohol. In those cases, some patients don’t care much about getting better and stop taking their medicines.

*“Those who are alcoholics and drug abusers are very difficult to provide medical and social services,”* Normet said. *“Many of these patients do not want to have any treatment. We are doing our best, but it is hard.”*

Alcoholics comprised 41 percent of all TB patients in 2010, and drug addicts were another 7 percent. Six percent of all patients defaulted on drug treatment, and nearly three-quarters of them were alcohol and drug abusers, according to government statistics.

Margot Anitskin, now 40, saw the problems of treating alcoholics and drug abusers firsthand in the Tartu TB clinic. *“I was friendly with every patient, young or old, whether they were an alcoholic or not,”* she said. *“But sometimes in the hospital it just felt like death.”*



For more than seven years the UK Ukrainian AIDS Response has provided expertise, project development and oversight to organizations in Ukraine and Russia, and in the Central Asian Republics, the Baltic States and the Caucasus.

Working with communities at high risk of TB disease such as MSM, street children, drug users, vulnerable families and deinstitutionalising HIV-positive orphans.

Now working in partnership with the tuberculosis survival project to build HIV/TB advocacy networks across Eastern Europe.



*"Every day I think about that day when I wake up in the morning and won't have to take my pills anymore," says Annika Negin.*

**SHE HAD TO TAKE THE DRUGS, NO MATTER HOW BAD THEY MADE HER FEEL.**

In 2007, Margot, married and with two young children, had a persistent cough and saw a family doctor, who diagnosed her illness as pneumonia. But antibiotics didn't make her feel any better, and a year after that first visit, she was diagnosed with having MDR-TB. Then she learned a secret: her brother-in-law, with whom she was living, also had MDR-TB. Her sister had hid the diagnosis, and Margot, determined not to repeat the error, decided that no one in her circle of friends would be taken by surprise.

She phoned 30 friends and told them, encouraging all to get tested, as she set off on a long period of getting treatment in hospitals. In the TB clinic in Tartu, she met Agne Nikandrove, a single woman in her late 20s, and Raido Remmeblas, who was in his early 20s.

The three lived in rooms next to each other, and they looked forward to their time together every day. For hours at a time, they played cards, listened to music, or just laughed about the stories of their pasts. Sometimes Margot and Agne would go ice skating in a mall that was within walking distance. Sometimes the three of them went sledding on a nearby hill, or they would go out to eat in the mall because the food at the clinic was so bad. *"In the beginning, because of the side effects of the treatment, I went into a serious depression,"* Agne said, sitting in a small restaurant near her village of Antsla in southern Estonia and looking back at that time. *"But in those days, the three of us helped each other."*

In particular, Agne said that Margot, who had been on the medications for more than a year, told her she had to take the drugs, no matter how bad they made her feel. *"I would say that I feel so awful, and she said to me, 'It doesn't matter. You have to take them, and if you take them, the disease will go away.'"* She said, *"You have to live."*

Margot, too, reflecting upon the time from a restaurant 100 miles north of Tartu, in Tallinn, also remembered those times as a period of being close but also *"full of struggle with many difficulties."*

In February 2010, Raido was scheduled for surgery to remove his entire right lung, which was full of TB bacteria. Raido was bereft, worrying not only about the surgery but also in mourning over the death of his mother from a car accident.

*"I felt like I had to be a mother for him,"* Margot said. *"I felt I had to be as supportive as a mother would be."*

Agne said she and Margot did all they could. *"Raido was really nervous about the operation,"* she said. *"He wanted to run away from the hospital. So Margot and I sat in his room, holding his hand, told him jokes, funny stories, anything to get him laughing."*

Doctors told Raido that it was a difficult operation. When they brought him into the operating theater, the assistant nurse Kivi accompanied him. Kivi, now 66, remembered the moment well.



**Annika Negin and Margot Anitskin share stories from their treatment.**  
*"Talking about the disease is important," says Negin. "You can go crazy otherwise."*

A man with a shaved head, wearing a dark t-shirt, is shown in profile, looking towards the left. He is in a hospital room, with a window and a poster visible in the background. The lighting is soft and natural, coming from the window.

**RAIDO WAS REALLY NERVOUS  
ABOUT THE OPERATION. HE WANTED TO RUN  
AWAY FROM THE HOSPITAL.**

*Raido Remmeglas still has a long road ahead of him. He has been in treatment for more than four years and underwent an operation to remove his right lung. His body has become resistant to many TB medications.*

*"Raido is very kind, he has a warm heart, and he is very thankful for everything," she said in the clinic. "He needed to talk. The most important thing was to let Raido talk. So we listened to him. When he went into the operating room, in my heart, I was afraid, I cried as well."*

Raido survived. But he has yet to fully recover from MDR-TB; his lungs are diminished. A long line of TB medications haven't worked. Doctors and nurses, don't know if he can get well.

In December 2011, though, there was something to cheer about. Agne successfully finished two years of treatment. Margot will also soon finish her treatment. There is no end date yet for Raido, four years into treatment and still at the clinic.

On a blustery day in December 2011, Agne returned to the TB ward for the first time since she was discharged in April 2010. She felt uncomfortable. Old ghosts appeared as she walked past her room, smelled the hospital food, and looked at the bookcases full of musty hardbacks in Estonian. But when she entered Raido's room, those feelings washed away.

*"Good to see you,"* Agne said, giving Raido a hug. Raido, sitting on his bed, lit up, and they quickly caught up with the changes in their lives.

Agne asked how he was doing. *"It's not easy here,"* Raido said. *"But it's important to stay optimistic."*

*"That's right,"* Agne said.

*"Hey, tomorrow's Margot's birthday,"* Raido said.

*"I know, are you going to call her?"*

*"Of course."*

They laughed and talked about their old card games, and even how in celebration of their birthdays they would put on music and dance in the hallways of the clinic. It was a moment of joy, of free movement, and of a passing pleasurable time of forgetting where they were.

The day after her birthday, her 40th, Margot said she heard from both her friends. She said it was wonderful to talk to them. She was so happy to hear about Agne and the end of her treatment. As for Raido, she didn't want to think about it.

*"I hope he'll be OK,"* she said. *"I worry he won't be. We always say things will be fine because he's such a young man, he's such a nice person. But I think we are now hoping for a miracle."*

# ESTONIA'S TB TURNAROUND

**TARTU, Estonia** – Estonia had long been known as one of the world's centers for multidrug-resistant tuberculosis, or MDR-TB.

For several years after the breakup of the Soviet Union, Estonia and several other recently liberated countries suffered from the collapse of the socio-economic system, which dealt a severe blow to health care. In particular, drug-resistant TB cases grew exponentially around the rim of the former Soviet bloc, as well as deep inside Russia.

But today, Estonia is becoming known as something entirely different: It is now an example of how to fight TB. The number of cases here has been cut in half since 1998, thanks to a strong control program.

Experts in Estonia cite many reasons for the decrease in new TB cases, even if the level of MDR-TB remained high, 22 percent of all cases. They included: a decision by government leaders to fully fund anti-TB efforts; banning sale of TB drugs in pharmacies in order to cut down on misuse; annual training of all TB medical staff by international experts; and the country ensured it would have enough of the scarce drugs needed to fight MDR-TB.

On one bitter cold evening in Tartu, Estonia's university town, two TB control leaders – **Dr. Manfred Danilovits**, head of the Department of Tuberculosis at Tartu University Clinics and a coordinator of the National TB Program, and **Dr. Lea Pehme**, a TB doctor – talked about the intimate details of a few dozen patients.

The two rattled off stories about patients who had done incredibly well on the medications, as well as those who weren't improving. The conversation kept returning to one patient, Raido Remmelgas. Both of them were extremely worried. They had tried several regimens of TB drugs with him over several years, but he remained infectious.

**Dr. Lee Reichman**, the founding executive director of the New Jersey Medical School Global Tuberculosis Institute, asked several questions about the patient's care.

Danilovits answered each one, but at the end of the questions, there was no new big idea on how to proceed. He sighed. *"The end of this story, we don't know,"* he said. *"We are waiting for new drugs. We need them for Raido."*

Although the evening ended on a somber note, Reichman saw a positive.

*"Did you see how much they cared?"* he said about the doctors. *"We need that in TB. MDR-TB treatment can take forever, and we need doctors and nurses to care. They do and that makes a difference."*

*There is a*

*space to fill.*

*Share Your Story Here: [www.TBinnovation.org](http://www.TBinnovation.org)*

*TB can affect anyone, anywhere. The stories in this magazine represent only a fraction of the millions of lives all around the world who are affected by TB every day. They are patients, family members, friends, doctors, nurses, social workers, public health officials – anyone at all who knows someone who has struggled with TB. Help us to complete the story.*



**WHAT I DIDN'T KNOW, OR DIDN'T SEE,  
WAS THAT THEY ALSO GAVE ME TB.**

*Former patient Ave Peetsman has a special bond with her daughter. "My other children are all boys. They are wonderful but they are boys," she says. "There's not the same kind of affection as with Karoliis."*

## TB AND ALCOHOLISM: BREAKING THE CYCLE

*TB doesn't just affect alcoholics in homeless shelters or dingy quarters. It also affects children in their own homes.*



Like Peetsman's parents drank and drank when she was a girl. They fought bitterly. But their battles left more than emotional scars. Mother and father carried drug-resistant strains of tuberculosis, infecting both their children.

*"I saw terrible things as a child," Peetsman said. "What I didn't know, or didn't see, was that they also gave me TB."*

In Estonia, Peru, and the Philippines, stories of offspring of alcoholics grimly echoed each other: alcoholics weren't just passing TB to other alcoholics in homeless shelters or dingy quarters. They also were infecting their own children, many of whom harbored the bacteria unknowingly until it became active years later, as adults. This time bomb was a cruel twist of a disease that has hung around for millennia.

*"A lot of people think that TB is a disease of alcoholics and drug abusers, people who live alone in single room occupancy buildings," said Dr. Lee Reichman, a global TB expert and founding executive director of the New Jersey Medical School's Global Tuberculosis Institute. "But here you see all these young women and men who get multidrug-resistant TB. Their alcoholic father or mother gave it to them."*

In Estonia, 41 percent of the country's 330 new TB cases last year were patients who were considered alcoholics. Another 7 percent were drug abusers, according to the country's tracking of TB cases.

*"The profile of our cases is all over the place – some are drug users, some alcoholics, and some are young mothers," said Piret Viiklepp, head of the Estonian Tuberculosis Registry at the National Institute for Health Department. "Many are getting TB from family contact."*

HERE YOU SEE  
YOUNG WOMEN  
AND MEN WHO  
GET MULTIDRUG-  
RESISTANT TB,  
THAT THEIR  
ALCOHOLIC FATHER  
OR MOTHER GAVE  
TO THEM.

A paper published three years ago in the BMC Public Health journal did a systematic review of studies on whether there was a relationship between alcohol problems and TB and found that alcoholics had a “substantially elevated” risk of getting active TB. *“This may be due to both increased risk of infection related to specific social mixing patterns associated with alcohol use, as well as influence on the immune system of alcohol itself and of alcohol related conditions,”* the paper concluded.

Estonian health officials said they often saw children of alcoholics in TB treatment centers. Agnes Nikandrova, 31, is one. Nikandrova’s stepfather had tuberculosis. *“My stepfather never told me that he had TB,”* she said. *“I guess he was afraid of the stigma.”*

Dr. Manfred Danilovits, head of the Department of Tuberculosis at Tartu University Clinics and a coordinator of the National TB Program, listened to her and nodded knowingly. *“In Estonia, this situation is not rare,”* he said. *“I’ve had patients who say, ‘Don’t tell my wife. Tell her I am being treated for pneumonia.’”*

For Peetsman, whose father, mother, and brother all died from TB, her experience with the disease – including how she contracted it – made her even more determined to raise her four children well and in good health.

*“I’m always taking care of my children very carefully,”* she said. *“My children know they have my support every minute and every day.”*

Her experience with TB impacted all her children emotionally, she said, but none more than her youngest: her only girl, Karoliis, who was three years old when Peetsman was diagnosed with MDR-TB in 2008.

Peetsman went to the hospital when she learned she had TB. Only a few months before, the family cat had been put to sleep by a veterinarian and she had told Karoliis that the cat had “gone to see a doctor.” The child’s father told the girl that same thing when Peetsman was hospitalized, and the girl thought her mother would die as well.

*“Almost every day she made a drawing for me,”* Peetsman said. *“Most of them had a girl holding hands with her mother and father next to a house. So we have a really emotional connection. I am actually surprised at how this child can have so many good feelings toward me. For me, she’s the most important person in my life.”*

Peetsman finished her TB treatment in 2010. *“My childhood was very difficult,”* she said. *“But I feel very lucky right now.”*



*“During my treatment when I was in the hospital and had to be isolated from my family, that was a very difficult time,” says Ave Peetsman.*



Ave Peetsman and her daughter Karoliis at home with the family cat.



Mother and daughter enjoy drawing together. When Ave was sick, Karoliis drew her a picture almost every day like the one seen here.



# TAKING CONTROL: *A doctor's story*



**Dr. Manfred Danilovits**, *the head of the Department of Tuberculosis at Tartu University Clinics and a coordinator of the National TB Program, has been involved in the fight against TB in Estonia since 1981. He reflects on the progress made against TB and the challenges ahead.*

**Q: After Estonia's independence from the Soviet Union some 20 years ago, the incidence of TB soared. What were the factors behind this?**

**A:** The main reason was that we had a socio-economic disaster. We were euphoric for independence but the economy and health care system collapsed for a while. There were multiple factors behind this, not just one reason.

**Q: How did the country rebuild the TB control system?**

**A:** In 1993, we realized something was going very wrong. That year, the WHO (World Health Organization) declared that TB was a global health emergency. Latvia was in the same situation as us, and Lithuania as well. All of us received help from the outside with money and technical assistance. We started with the preparation for a written TB strategy in 1995 and finalized it by the end of 1997. It took five years to set up and prove that we needed to make changes. It involved new diagnosis, new drugs, health reform, and health insurance.

In 1998, we started training our staff. We trained not only those directly in the TB program, but also all administrative staff, pulmonary specialists, family doctors, and nurses in the country. Besides that, every year since 1996, in August, we have had international training courses on TB control. Experts come to do training mainly for doctors from previous Soviet countries. These courses are still ongoing. From 2001, international courses for nurses started as well.

**Q: How did you specifically address the emergence of MDR-TB?**

**A:** We were quite concerned. It seemed in the beginning that all we had achieved before was gone. It seemed all had gone wrong. In 1989, we had the first recorded MDR cases. From 1997 to 2002, we had 100 MDR-TB cases every year. We had a lab built with Finnish/Swedish and other Nordic assistance to diagnose and monitor cases. We understood that diagnosis was important for MDR in Estonia and also for the world. The government took responsibility for this, including securing the drugs through the Green Light Committee at the WHO. That gave us a reduced price for the drugs, and we set up a strict centralized system of distributing the drugs.

What was most important for us was government support. Many places lack that, and a lot of places receive Global Fund support for their TB programs. We had early financial support from the No-TB Baltic assistance program, but after that all the TB control activities were financed by government money. It showed that we were committed to fighting MDR-TB.

**Q: Looking at this from a technical perspective, what was the most important step Estonia took to control TB?**

**A:** It was that all staff received training. That was most important. We also set up a centralized procurement of drugs, with very strict control of those drugs and reorganization of treatment services with prioritizing ambulatory care.

**Q: What do you see as the biggest challenge ahead for controlling TB in Estonia?**

**A:** I think it's HIV. We have a high HIV incidence. It's influencing the TB rate quite a lot, but not as bad as the earlier prognoses. Second, we need new drugs. We can't treat XDR-TB without new drugs. We face an ethical problem related to XDR-TB: What do we do with an XDR-TB patient who is living for maybe five years after all the treatments are finished and there are no more options? Where do you put them so they are not infecting others? Now we do not force them to take treatment or to go into isolation. But if we can't treat them and they are not in isolation, they are infecting society. It's a tough issue. It's very sad.

A third problem is managing alcohol and drug abuse with the TB patients. They constitute about half of all TB cases in Estonia. It's more complicated to keep them on treatment. Some don't care about their health and the health of others.

**Q: How many XDR-TB patients do you have now in the country?**

**A:** It's about 20 to 25 patients. I think we need to find them a new environment in which to live. It should be like a hospice, a nursing home or we keep them in hospitals for a longer period. Wherever they are, the place should have good infection control measures. We will need to face this problem as soon as possible.



“What was most important for us was government support.”

Raido Remmeglas has been a patient of Dr. Danilovits for nearly five years.

From left to right: Kaja Hurt, Tartu University Hospital, TB Department, Head Nurse; Manfred Danilovits M.D., Tartu University Hospital, Head of TB Department, pulmonologist; Lea Pehme, M.D. Ph.D, Tartu University Hospital, TB Department, pulmonologist.



## PROVIDING HOPE: *A nurse's story*



**Evi Kivi**, is an assistant nurse at the Department of Tuberculosis at the Tartu University Clinics.

Several patients singled her out for her kindness. In particular, she has grown close to one patient, Raido Remmelgas, who by the end of 2011 had been in the hospital for nearly four years with multidrug-resistant tuberculosis, or MDR-TB. Kivi talks about her job and about her relationship with Raido and other patients in trying to cure them of TB.

**Q: How long have you been working with TB patients?**

**A:** I started in the TB department here eight years ago. Before that, I worked in a nursing home.

**Q: Is it difficult working with TB patients?**

**A:** No, not at all. You have to protect yourself from infection, and we do that well. I'm not afraid.

**Q: Several patients, including one, Raido Remmelgas, who has been in the hospital for roughly four years, say that you have been particularly kind to them. Tell me about your relationship with Raido.**

**A:** From the very first days, I saw Raido like my own son. I have a son and a daughter, but I also consider him like a son as well.

**Q: Why?**

**A:** Raido was very kind, he has a very warm heart. He has been very thankful for everything that has been done for him. He smiles every day.

**Q: When his mother died two years ago – and he was closer to her than any other member of his family – what did you do to try to help?**

**A:** I listened a lot. Raido wanted to talk about his mother. He needed to talk a lot. He missed her very much. He showed me his mother's picture every day. On her birthday, he lit a candle in his room. What was important to me was that I never told Raido that I was busy or I had to leave to do something – even if I did have to leave. The most important thing was for me to be there to listen to Raido.

And then there was another difficult situation, right before he went to have surgery (to have his right lung removed). I felt like I was leaving my own son to somebody. I could understand it was necessary. But when they brought him into surgery, I cried. It was a sad situation.

**Q: Did you feel you would lose him?**

**A:** Not so much. But in a hospital a lot happens.

**Q: How is his situation now? He is not improving on the TB medications and he still has a large open wound from his second operation (which is kept open because of the presence of bacteria in his lung cavity)?**

**A:** I try to be optimistic. Raido is optimistic as well. He has a lot of hope. In my heart, though, I am afraid.

**Q: In this hospital, at times patients form informal support groups. How important is that for recovery?**

**A:** The most important thing is to have support around you. And our work in medicine also has to be done with a warm heart, and hope that everything will go OK for people. You have to express that hope to the patient. We have a lot of young people who come in here with TB. We have to help them. And we can be very optimistic with them because we have seen very good results with people who have taken their medications. Most of the young people – except Raido – have recovered.

“You have to protect yourself from infection, and we do that well. I'm not afraid.”

*Evi Kivi, a TB nurse, tries to support the younger patients in the hospital.  
"They need people just to listen to them.  
The most important thing I can do is be there to listen."*

**OUR WORK IN MEDICINE ALSO HAS TO BE  
DONE WITH A WARM HEART, AND HOPE THAT  
EVERYTHING WILL GO OK FOR PEOPLE.**

## SNAPSHOT: ESTONIA

Nestled along the Gulf of Finland, Tallinn is Estonia's largest city and its capital with a population of nearly half a million. The Old Town of Tallinn is a designated UNESCO World Heritage site.

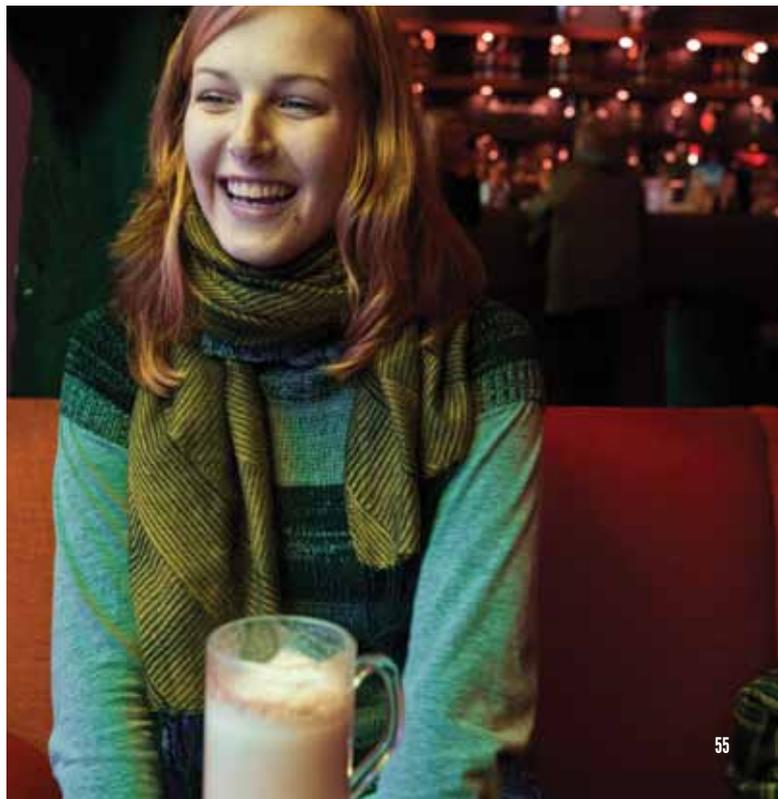




Agne Nikandrove is finally enjoying a TB-free life. During her treatment she would go sledding on a hill near the clinic or eat in the mall she likes to visit with her friends.

Margot Anitskin on a cloudy day in Tallinn, Estonia. "I was friendly with every patient," she remembers from her time in the TB clinic.

"I have never seen myself so happy during the therapy before!" said Annika Negin. Although she is not yet finished with her treatment, she tries to find joyful moments each day and has begun working again after 9 months of treatment.





Margot Anitskin at the Tallinn Christmas Market.

Dr. Piret Viiklepp of the National Institute for Health Development has been a tireless advocate for TB patients in Estonia. She works long hours and has familiarized herself with almost every TB case in the country.





*Agne Nikandrove and her sister walk through their hometown on a cold December morning. Support from family members like her sister helped get her successfully through the treatment.*



*"People who have TB need help," says Annika Negin. "They don't want to speak about their illness but you have to speak with them."*

## TB BY THE NUMBERS: ESTONIA

*Following the collapse of the Soviet Union there was a great deal of disruption to health systems such as that in Estonia. Today, Estonia is back on track but facing new challenges like drug-resistant TB and increasing rates of HIV.*



Sources: Estonia National TB Registry; the World Health Organization



FIGHTBACK IN

# PERU

By John Donnelly

**LIMA, Peru** – On the chest X-ray, the doctor pointed out an area of inflammation on the left lung. Inez Youri Naola leaned forward in her seat. Her stomach was a ball of knots and she thought to herself, *“Please, God, let there be no problem for Ariana.”*

*(continued)*



**PLEASE, GOD, LET THERE BE  
NO PROBLEM FOR ARIANA.**

*Dr. Epifanio Sánchez examines 5-year old  
Ariana Naola for TB.*



## IN HOUSES, TB INFECTS ALL – INCLUDING THE CHILDREN

*Adults are giving TB to their children because of the close proximity of their lives.*

**PRESIDENT  
OLLANTA  
HUMALA HAS  
MADE THE FIGHT  
AGAINST TB A  
TOP PRIORITY  
ACROSS ALL  
MINISTRIES.**



Ariana, her daughter, just five years old, sat on her mother's lap, not knowing what has happened, and she looked at her mother, looking for a signal.

*"You can see in the X-ray, here,"* said Dr. Epifanio Sánchez, a pulmonologist, *"that Ariana has tuberculosis."*

The mother listened with a blank expression as the doctor talked for nearly a minute, and then her face fell, and tears streaked over cheeks. Ariana edged closer, trying to comfort her mother, trying to understand.

In Peru, this awful news is given nearly 2,000 times a year: A child has TB. It speaks of a terrible reality that adults are giving TB to their children because of the close proximity of their lives. The response from health providers and policymakers is not only to treat the children, but also to attack the problem by trying to stop transmission. In Peru, the cases of pediatric tuberculosis, long an afterthought in the public health world, is drawing more attention as part of the country's ambitious new TB control strategy in schools, workplaces, and in medical settings to stem the epidemic.

President Ollanta Humala has made the fight against TB a top priority across all ministries, instead of leaving it to just the domain of the Health Ministry. Only with that multi-sectorial approach, he said, can the country dramatically scale back the number of TB cases. Recently, the government has also greatly scaled up its funding for TB control to US\$32 million in 2011 from roughly US\$5 million in the years before. The country's TB program had been largely funded by the Global Fund to Fight AIDS, Tuberculosis, and Malaria, but much of those funds ended in 2010.

*“In his travels around the country, the president saw TB as being the biggest health issue in Peru,”* said Dr. Antonieta Alarcón, the coordinator of the National TB Program. *“He has all the ministries drawing up plans on how they will fight TB.”*

The problem isn't limited to ordinary TB. Peru was treating more than 32,000 cases of TB in 2010. It included roughly 1,800 on treatment for multidrug-resistant TB (MDR-TB) and another 100 treated for extensively drug-resistant TB (XDR-TB). Those numbers of MDR-TB cases were higher than any other country in the region. But part of the reason is Peru's successful efforts to test more people on whether their TB strains were resistant to the most commonly used drugs, or first-line medications.

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*We've scaled up detection testing.  
We have developed laboratories  
throughout the country.*

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In 2004, for instance, 1,096 patients were tested for MDR-TB. Six years later, 5,687 were tested. *“We have the largest problem of MDR-TB in the region and that is true because we're doing the diagnoses with much more intensity,”* Alarcón said. *“We've scaled up detection testing. We have developed laboratories throughout the country. The development of labs has really been a major instrument in our fight against TB.”*

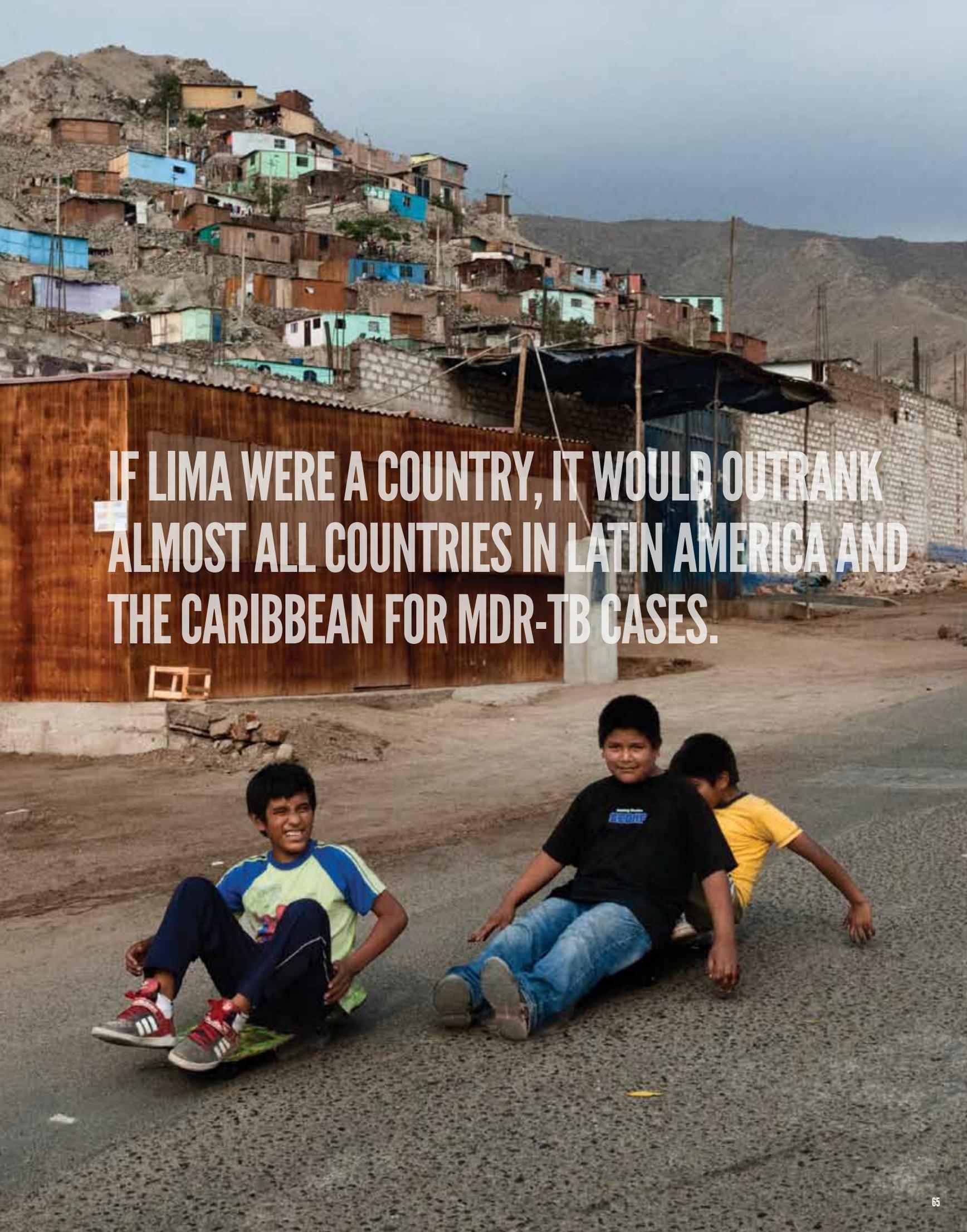
Some 1,350 labs now do basic sputum tests to detect TB; 67 perform more sophisticated culture tests; seven centers can detect MDR-TB; and four labs are doing rapid diagnostic tests.

But even as Peru expands and decentralizes its services to fight TB, by improving TB control efforts from the Amazon region in the north to the high mountains of the Andes in the center and to the deserts in the south, the center of gravity for its TB problem rests in one place: Lima.

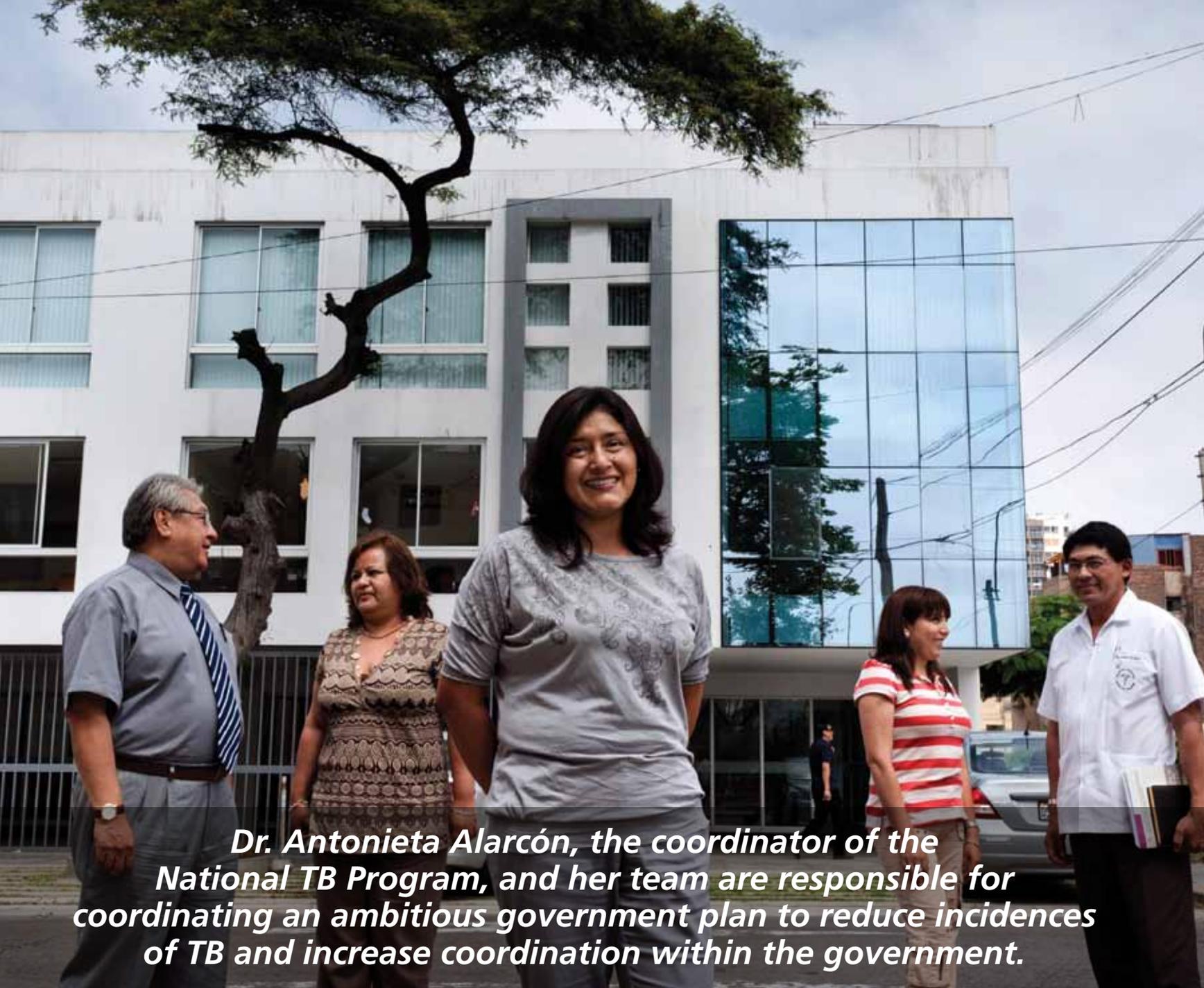
The capital of 9 million people is home to roughly 60 percent of Peru's TB cases. If Lima were a country, it would outrank almost all countries in Latin America and the Caribbean for MDR-TB cases, surpassing, for instance, the poorest country in the hemisphere, Haiti.



*The Juan Pablo II neighbourhood of Lima has some of the highest incidences of MDR-TB in the city. Overcrowding is a contributing factor.*



**IF LIMA WERE A COUNTRY, IT WOULD OUTRANK  
ALMOST ALL COUNTRIES IN LATIN AMERICA AND  
THE CARIBBEAN FOR MDR-TB CASES.**



***Dr. Antonieta Alarcón, the coordinator of the National TB Program, and her team are responsible for coordinating an ambitious government plan to reduce incidences of TB and increase coordination within the government.***

And when experts look at MDR-TB and XDR-TB cases in Lima, the city has an even higher percentage of cases than in the countryside. Of Peruvians with MDR-TB, 82 percent live in Lima. As for XDR-TB, the experts estimate that 90 percent are in the capital city.

*“The government is very aware that we need to do something that will tackle this problem,”* said José Carlos Yamanija Kanashiro, the director of projects and investigations for *Socios En Salud*, an NGO that first led efforts in Peru in the 1990s to treat patients with MDR-TB. *Socios En Salud* has turned over its programs to the government, but still provides medical and logistical support. *“The issue in Peru now is not a matter of budget, it’s a matter of managing the problem.”*

In both the government and civil society, Peru has had a succession of TB control leaders who have been strong advocates and technical leaders in dealing with MDR-TB. One of those leaders was Dr. Jaime Bayona, who led *Socios En Salud* for many years and now is director of Global Health Programs and Practice at the Dartmouth Center for Health Care Delivery Science.

One of Peru’s innovations was helping patients who were poor by giving them food baskets, transportation money to go to health clinics, and even improving their homes to build separate rooms so those who were infectious would not pass TB to other members of the family.



*Partnering for better diagnosis for all*

## 3 million people every year fail to get appropriate care for TB

FIND's aim is to help drastically reduce this figure, especially for the most vulnerable populations that are often missed.

FIND is developing affordable, easy-to-use and cutting edge diagnostic tools for those who need them most.



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



**CHILDREN, ESPECIALLY IF THEY ARE MALNOURISHED, ARE AT GREAT RISK.**

*Children of all ages are treated for TB and other diseases at the Instituto Nacional de Salud del Niño in Lima.*

*“This is key,” Bayona said. “I can have the best drugs to give to patients, but having the best drugs will not guarantee that the patient will stay on treatment for two years.”*

Dr. Oswaldo Héctor Jave, a former national TB director and now a pulmonologist at the Dos de Mayo Hospital in Lima, agreed with Bayona. *“TB won’t be stopped if you only give drugs to the patients,”* he said in the courtyard of the hospital. *“You need to attack the root causes of TB.”*

Jave said that people from all parts of society in Peru get TB, but the highest rates remain in the lower classes. *“Why are TB rates so high in poor people?”* he said. *“It’s because they live in crowded houses, and the transmission goes from family member to family member. Children, especially if they are malnourished, are at great risk. We see houses when a mother or father has MDR-TB and they pass that to their children – sometimes to all their children. So we need to do more to support the nutrition of the children in these families.”*

In the Juan Pablo II neighborhood of Lima, Eva Davita Espinoza Gomez, the mother of eight, said she has been

grateful for all the support. It includes a delivery of flour, rice, beans, and other essentials, as well as building two new bedrooms so that her two sons, both with MDR-TB, would sleep in their own rooms.



*“Several of the children were sleeping together in one room, so this is a lot better,”* she said. The two bedrooms, built at a cost of several thousand dollars using money originally from the Global Fund, were built on the rooftop of the house.



*Inez Youri Naola returns home after just receiving the diagnosis that her daughter has TB.*

*Antonia Naola breaks down after hearing her granddaughter has TB.*

**WE ALWAYS WORKED HARD SO THIS COULD NOT HAPPEN. AND NOW IT HAS.**



**Ariana Naoloa, at home with her family in North Lima.  
She is one of three children living in the house who is infected with TB.**

It's particularly important now because one of her sons has stopped taking his treatment and remains infectious. The other son, Steven Castro Espinoza, 19, who is taking his TB medicines faithfully, said the situation with his brother has created great tension in the house.

*"I'm not happy about what he's doing," he said. "He is contagious. He could be infecting our mother."*

The issue of passing TB from one family member to another is a reality in many families. It happened in Inez Youri Naola's family. Her five-year-old daughter, Ariana, was just the latest to become infected.

In the north Lima middle-class neighborhood, the disease entered through the patriarch of the house, Jesus Youri, 76, Inez's father. He underwent six months of therapy and became cured, and during his treatment he tried to isolate himself from the others.

It didn't work. Five adults and six children live in the home and the children, all under the age of 10, run in packs from room to room. At least one child is infected and another one is likely sick with the disease.

When Inez Youri returned with Ariana to the house after learning of the girl's TB diagnosis, most of the family was

waiting for them in the living room. Inez whispered the news to her mother, Antonia Naola, 66. Antonia put her hands to her mouth and started to weep.

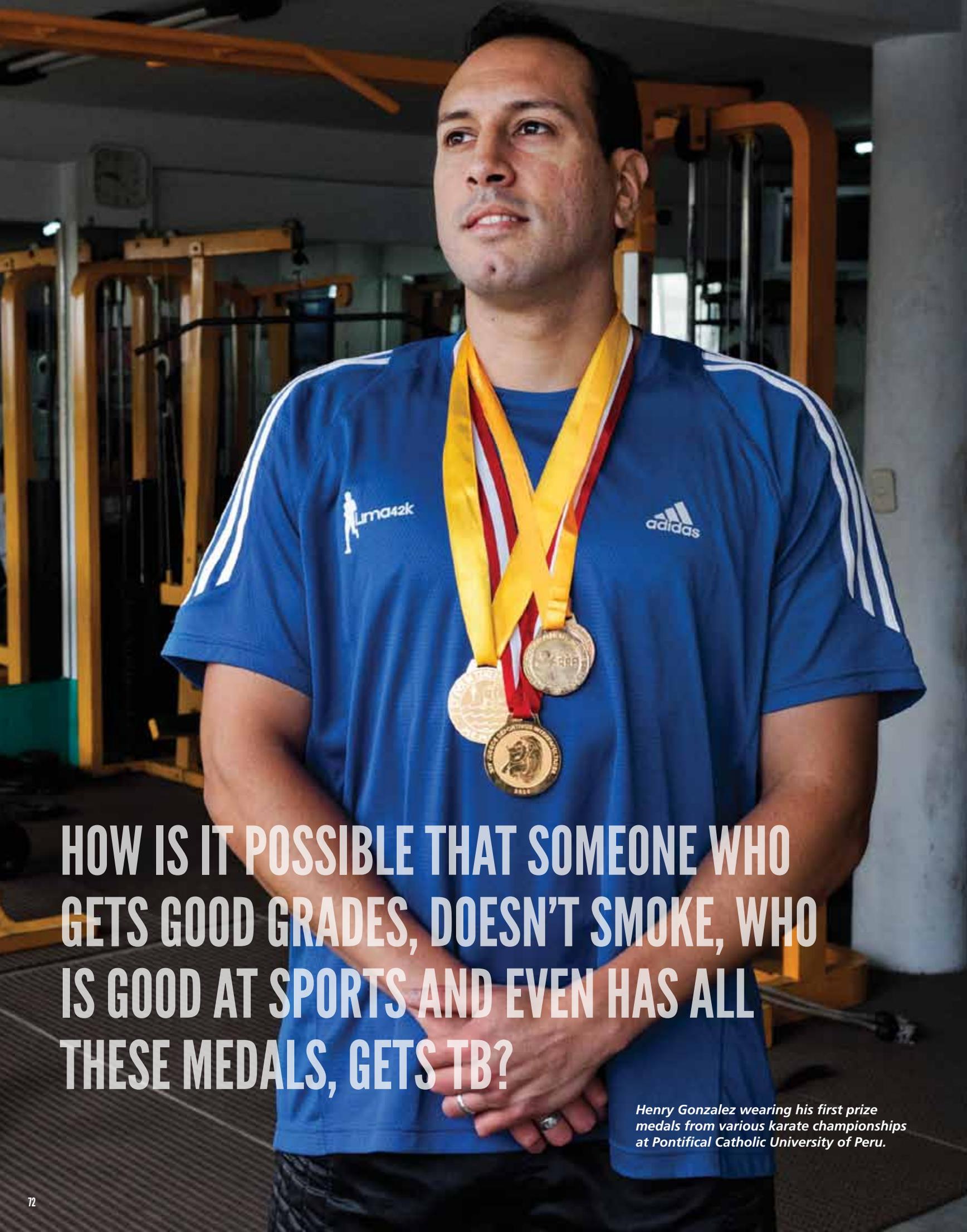
*"Oh, I'm really shocked," she said through her tears. "We worked so hard to prevent this."*

Ariana squeezed on a couch in between her two sisters and her cousin, Leondro, 6. Leondro also had come down with TB, and was on treatment. Upstairs, another cousin was sick, coughing all hours of the day, but his mother had refused the pleas from the family to have him tested for TB.

Ariana hopped off the couch and announced, *"I want to go to my room and watch Speedy Gonzalez!"*

Just those words prompted her grandmother to start crying again. Ariana looked on, confused. Her mother said she could go play, but no television for now, and the children all left en masse to a back room in the house.

The grandmother wiped her eyes. *"This illness, I don't know how it happens like this, how it passes so easily,"* Antonia Naola said. *"I took care of these children. I fed them well. We always worked hard so this could not happen. And now it has. The poor girl."*



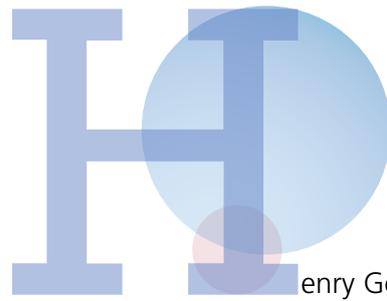
**HOW IS IT POSSIBLE THAT SOMEONE WHO GETS GOOD GRADES, DOESN'T SMOKE, WHO IS GOOD AT SPORTS AND EVEN HAS ALL THESE MEDALS, GETS TB?**

*Henry Gonzalez wearing his first prize medals from various karate championships at Pontifical Catholic University of Peru.*



## FACES OF TB: HENRY GONZALEZ

*Cured of TB, Peruvian tackles new challenge:  
Running a marathon.*



Henry Gonzalez seemed to have it all. He was young, handsome, a champion karate competitor, and was excelling in classes at the prestigious Pontifical Catholic University of Peru. But in 2003, on the sidelines of a karate competition, he began spitting up blood.

Soon, Gonzalez learned he had tuberculosis – and not just ordinary TB, but multidrug-resistant TB (MDR-TB), which would take 18 months to two years to treat.

*“I got really angry because how it is possible that someone who gets good grades, who doesn’t smoke, who is good at sports, and even has all these medals, how could I get TB?”* he said.

That began Gonzalez’s personal fight against TB. He faced many obstacles along the way, but today he says he is stronger for it and wants to share his story to give hope to others with MDR-TB.

Gonzalez said he approached his disease as he did anything else: with vigor. But not everything went his way.

First, when university officials learned of his disease, they asked him to suspend enrollment until he was finished with treatment – a two-year proposition. Gonzalez tried to explain to them that he was no longer contagious, thanks to the medications, but the university stood firm. He was ordered off campus.

Then, his father also received a diagnosis that he had MDR-TB, and his mother learned she had breast cancer. His family household, always a vibrant place, had three members with major illnesses.

**TODAY HE SAYS HE IS STRONGER FOR IT AND WANTS TO SHARE HIS STORY TO GIVE HOPE TO OTHERS WITH MDR-TB.**

*“There was definitely a moment when our extended family was very worried about us, but the whole experience also made us stronger,” he said.*

What made him stronger? One thing, he said, was seeing a therapist and then participating in support groups made up of other people who had MDR-TB.

*“I saw the lives of others and saw that many of them had much harder lives,” he said. “Some were single mothers, some divorced, some lost their father, many live in poverty, and many infected their children. There was a lot of sadness.”*

Gonzalez said the sessions made him think deeply about his situation and the plight of others also with MDR-TB.

*“I thought, ‘Should I really feel bad about myself?’ I decided I should try to help others and so I would talk to them, tell them to keep fighting, tell them that their health wasn’t just a physical thing but it was a mental thing as well,” he said.*

Gonzalez laughed in recalling these sessions. Often, he said, the other patients would feel sorry for him.

*“It was unbelievable,” he said. “They said I had it worse. They said, ‘We had nothing, and you had something, but now you have nothing, too.’ They made me feel good not just for encouraging them but because they encouraged me as well.”*

Today, Gonzalez and his father are cured. His mother is doing much better. Gonzalez not only went back to his university classes and graduated, but he also started working out again, this time running long distances. In the last few years, he has competed in several long races, including a 42-kilometer marathon in Lima in three hours, 22 minutes in 2009.

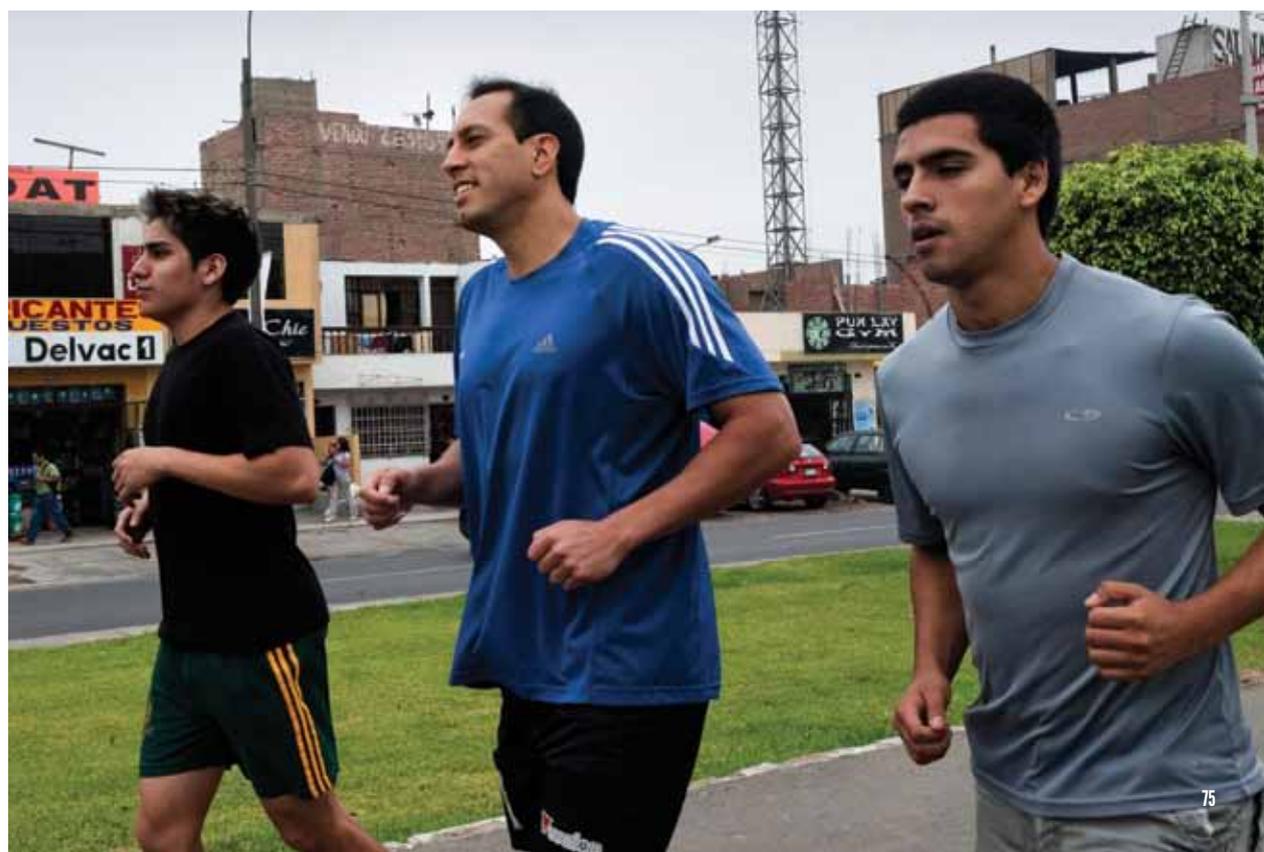
*“I’m the proof,” Gonzalez said, walking around his neighborhood and watching boys play football in a small field. “TB doesn’t mean you can’t get back to good health. Nothing is impossible – not even running a marathon.”*



*Henry Gonzalez and his mother walk through the neighbourhood where they live. His mother suffered from breast cancer at the same time he was battling TB. Today, both are doing much better.*



"I didn't feel sick at first. I was still competing in karate tournaments even though I was infected with TB and didn't realize it."



Henry training for an upcoming marathon with two friends.

## DOCUMENTING CHANGE: *A journalist/filmmaker's perspective*



**Sonia Goldenberg**, a journalist and filmmaker, produced a documentary film called *Amor en el Aire* (Love is in the Air), which documents Peru's fight against multidrug-resistant tuberculosis (MDR-TB). She is one of the global Stop TB Partnership Ambassadors. Goldenberg talked to John Donnelly in early 2012 about her experiences and perspectives on Peru's battle against TB.

“We have a tremendous amount of political will to fight TB for the first time ever in Peru.”

**Q: Why did you become so involved in the efforts to stop tuberculosis, particularly drug-resistant TB?**

**A:** It's simple: TB is the biggest health issue in Peru. In the region, there's more MDR-TB and XDR-TB than anywhere else in the region. If you just look at one part of Lima, San Cosme, that tells a story. There are 20,000 people there. In 2009, they had 689 cases of TB in that community. That's one for every 29 people.

**Q: When did you first get interested?**

**A:** It was several years ago, when I was living in Haiti. I was working for the United Nations there. There was a huge TB problem. I thought to myself, this is a curable disease but so many people are dying from it. It wasn't getting anywhere near the attention that it deserved. So I wanted to help put it on the agenda in Peru. I felt that I could make a contribution.

**Q: So what is happening in Peru now?**

**A:** We have a tremendous amount of political will to fight TB for the first time ever in Peru. The president has made it a priority. But it's a very complex technical issue, and it's a

particularly difficult problem in Lima, which has nearly 60 percent of all the cases of TB in the country.

**Q: What impresses you about the fight against TB in Peru?**

**A:** The health workers. They really stay connected to the patients. They get into the homes of the patients and they know all their stories. It's like an old-fashioned yet avante-garde way of practicing medicine. I'm so taken by this. You see inspired people doing amazing things.

**Q: So what's ahead for Peru in its efforts to control TB?**

**A:** Peru is very aware of its TB problem. Now with it so strongly on the political agenda, with our president pushing for more action, there are major challenges in the effort to decentralize the services. I'd like to be instrumental in helping stop it. People in all sectors of society know that in the next 10 years we should have a much lower level of TB, like any other civilized country. It's a complex problem to do it, but it can be done.



*Sonia Goldenberg,  
Stop TB Partnership Ambassador.*

## TAXI CAB CONFESSION: *A husband's story*



**When we started** *work on this magazine, we knew that TB could affect anyone, anywhere. But we didn't realize how true these words were until we met Carlos Franco, the driver who accompanied us during the Peru portion of this project. Arriving promptly each morning at our hotel in Lima, Carlos cheerfully took us to each TB hospital, clinic, and neighborhood we wanted to visit. We chatted about his family, his work, passengers he had driven from other countries. But it wasn't until nearly the last day of our visit when, in a quiet moment in his car, he confessed something. "Excuse me sir," he said. "There is something I need to tell you. My wife had TB." Carlos Franco wanted to participate in this project. He wanted her story to be told.*

**Q: What happened to your wife?**

**A:** My wife sold breakfast foods to morning commuters. We think she got TB from a customer who was coughing or sneezing in the street. We went to different health posts for her to get her treatment. The treatment has taken place over several years. She stopped before she was supposed to. I begged her not to, but she said she couldn't take it anymore.

**Q: What was the hardest part for her?**

**A:** It was the injections of one of the drugs. She suffered a lot from them. She had them every day for over a year. In the end, they had no place to give her more shots because she was in such pain.

**Q: What happened when she stopped taking the medicines?**

**A:** She stayed on it for one year, three months. She said she felt better and didn't see why she should continue. I asked her not to stop. I was afraid she could make others in our family sick, too.

**Q: Did she improve after she finished the medicines?**

**A:** She was feeling better, gaining weight. But three months after she stopped, she started coughing again. I pleaded with her, and my children pleaded with her, to go back to the doctors. She didn't want to. Finally she did. She went on the medicines for another three years. At the end, a doctor said she may have to go back to the medicines if she wasn't careful. She has diabetes, so she has to monitor that carefully.

**Q: How is she doing now?**

**A:** She's OK. She's coughing a little, not much.

**Q: Are you worried?**

**A:** Yes. I've told her, she has to watch her diabetes.

**Q: What has helped you through this ordeal?**

**A:** I read a lot so I could take care of her. When we spent time at the health

posts, I talked a lot with the nurses and the doctors. They would tell me things. So I would keep talking to my wife, telling her how important it was to not only take the medicine, but also to eat well and to have good nutrition.

**Q: So you are still talking about this with your wife?**

**A:** (Laughs) Every time I talk to her about it, she throws a shoe at my head. She doesn't want to talk about all these things. But this is serious. My children tell me, 'Let her live in peace, don't talk to her about it.' She does get upset, and when she gets upset, her blood sugar jumps up. I don't want to upset her, but I want her to take this seriously and to deal with it, to get regular check-ups. I'm not worried for myself –they have an expression here, 'The bad weed never dies' – but I am worried about her and the rest of my family.

**I don't want to upset her,  
but I want her to take this seriously and to deal  
with it, to get regular check-ups.**



Lima Cathedral on the eastern edge of Plaza Mayor.

Carlos Franco is a taxi driver in Lima, Peru. He and his wife had four children; three are living and one died as a young man in an accident. In 2005, his wife, who sold breakfast foods from a street cart, contracted TB. He said fighting the disease has been an ordeal for his wife, for him and his family.



## SNAPSHOT: PERU

With nearly 9 million inhabitants, Lima is the fifth largest city in Latin America. It's sprawling size covers an area of approximately 800 square kilometers that runs from coast to mountain.





Dr. Oswaldo Héctor Jave examines a patient at the Dos de Mayo Hospital in Lima.

Locals gather at lunchtime in the University Park of San Marcos in Lima, Peru.

Frank Bilcas is an XDR-TB patient. Bilcas first contracted TB when he was 17 and because of the illness had to drop out of high school. "One thing the illness did for me was that it turned me into a strong person," he said. "I was drifting when I was 17; now I must be focused." One other reason for his focus: he and his partner, Brenda, have a two-month-old son, also called Frank.



Dr. Jave with medical students in the TB ward of Dos de Mayo Hospital.



*Dr. Hernán Del Castillo Barrientos is a pneumologist at the Instituto Nacional de Salud del Niño in Lima. "The TB threat in Lima is serious," says del Castillo, "particularly for children in infectious households."*



*Lima is comprised of thirty densely populated districts and a mix of architectural styles ranging from early Spanish colonial to French neoclassical.*



## TB BY THE NUMBERS: PERU

*Peru has one of the highest TB burdens in Latin America with the vast majority of cases concentrated in the capital of Lima. On paper, the number of cases appears to be increasing, but this is partially a result of improved case detection and diagnostic tools which are helping get more patients the treatment they need. The country has a long way to go, but Peru is up to the challenge.*



Sources: Peru National TB Program; the World Health Organization.





# TAKING TB PERSONALLY

By John Donnelly

**LIMA, Peru** – In this capital's brown hillsides, in villages nestled in the dark-green forests of Estonia, and inside the crowded riverside communities in Manila, there is one constant in the fight against multidrug-resistant tuberculosis: so much depends on health workers.

*(continued)*

**VARGAS, A MOTHER OF TWO YOUNG BOYS,  
PRESENTED AN OMINOUS CHALLENGE:  
SHE WANTED TO DIE.**



*Melissa Vargas with her son. "I kept going for my children," she says. "I thought of them every day."*



## CAREGIVERS: THE FRONTLINE OF TB TREATMENT

*For some healthcare workers, treating patients with TB is more than a job, it's a life calling.*



To help a person with MDR-TB get well, there are multiple issues.

**TO HELP  
A PERSON  
WITH MDR-TB  
GET WELL,  
THE HEALTH  
WORKER  
MUST FIND  
AN APPROACH  
THAT HELPS  
THE PERSON  
STAY ALIVE.**

The health worker has to make sure the person takes the drugs every day for 18 to 24 months – 540 to 730 days.

They have to understand the person's home life.

They must visit them at home.

They must listen.

They must find an approach that helps the person stay alive.

For Ruth Espinoza, a nurse in Lima, the story of nurturing one patient, Melissa Vargas, back to good health tested her in ways she never expected.

Vargas, a mother of two young boys, presented an ominous challenge: She wanted to die.

The TB drugs made Vargas sick and depressed. She couldn't sleep. She had no energy. And she was just a few months into two years of taking her medications every day.

Espinoza weighed the situation carefully. She believed that the deep depression felt by Vargas, 23, was partially a byproduct of the TB medicines. She made an appointment for Vargas to see a psychiatrist.



**SHE SAID SHE WAS THERE TO TAKE HER TO  
A PSYCHIATRIST. THE MOTHER REFUSED.  
THE NURSE DEMANDED IT. THE MOTHER WENT.**

*Ruth Espinoza of Socios en Salud in the home of Melissa Vargas. She visits her every week to make sure she is taking her medicines and see how she is feeling emotionally.*

The next morning, the nurse appeared at the young mother's house. She said she was there to take her to a psychiatrist. The mother refused. The nurse demanded it. The mother went.

Today, several months after that first visit to the psychiatrist, Vargas wants to live.

*"Ruth has helped me so much that I agreed to go with her to see the psychiatrist, even though I didn't want to," Vargas said in her in-laws apartment in Lima, looking back at the moment four months before. "I feel much better now. It's not only the medications but also the conversations that I have with the doctor. Just being able to talk about all the things that bother me has helped a great deal."*

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*Espinoza has spent the last year seeing her patients in the clinics as well as in their homes, checking up on them to see if they are coping with life.*

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Espinoza, who works for the non-profit group Socios En Salud, has spent the last year as much a social worker than as a traditional nurse, seeing her patients in the clinics as well as in their homes, checking up on them not only to make sure they are taking their medicines but also to see if they are coping with life.

*"Melissa is getting a lot stronger," Espinoza said one day recently in the Juan Pablos II neighborhood of the capital city. "Her case shows how important it is with TB patients not just to pay attention to the physical part of it but also to the mental aspect of dealing with this disease. Her state of mind was key to making her well."*

The more she works with TB patients, Espinoza said, *"the more I see that having psychological support really makes a difference."*



***A nurse at a clinic in Estonia keeps track of each patient's medication and makes a note of who came in and reports those who did not so that clinic staff may conduct appropriate follow-up. Making sure the patients come in each morning for their medicines is crucial to preventing resistance.***

## **THE DIFFICULTIES OF THE JOB**

Is there any job harder than a health worker who helps MDR- or XDR-TB patients in the developing world?

It has to be among the most challenging and difficult. The tools to fight the disease are ancient – a commonly used diagnostic for TB is more than a century old, the most recent drug developed for TB is nearly half a century old, and there's no highly effective TB vaccine.

The story is similar in other countries as well. In Estonia, Evi Kivi, 66, an assistant nurse at the Tartu University Clinics, could retire if she wanted. But she said she loves her work.

*"I always want to help people, and I've always wanted to work in this field," she said. "I've never had any problem with patients. Everybody needs help. They very much need our help."*

In Southeast Asia, Maria Anna Katrina Atienza, 24, a clinic nurse at the Lung Center of the Philippines, said that they empathize with patients because they see the multiple difficulties in their lives. *"Many are so poor that they don't have bus fare to get here," Atienza said. "And so they default on their drugs."*

## THE IMPORTANCE OF A CAREGIVER

Asked how many defaulted, she said 12 out of 480 had stopped taking their drugs last year.

Told that number seemed low compared to many HIV treatment programs, Atienza said she looked at it differently. She said the number, to her personally, was high.

*"It's bad," she said. "It's a lot – at least to me. We want zero people defaulting. That's success."*

Another burden for health workers is often unspoken: the danger of contracting the disease. From 1997 to 2009, 224 health care workers in Peru contracted MDR- or XDR-TB, an average of 18 a year. In the clinic near the Juan Pablo II neighborhood, the TB nurses spend six-month shifts in the clinic in order to lessen the risk for any one health worker.

But Espinoza said she wasn't overly concerned with her exposure to TB. Most of her patients are not infectious. For the few who are, she wears a mask.

Vargas said she knew from the start that Espinoza cared for her.

*"Ruth has counseled me like she was my mother," Vargas said, whose boys are five and four years old. "She always worries about my kids, and asks about them. Whenever I see Ruth, she asks about the kids."*

Vargas likely contracted the disease from her brother- and sister-in-law. The sister-in-law died last year from TB.

*"I think the biggest reason she died was that she didn't have the support of someone like Ruth. You need that support. You need someone to look after you," Vargas said. "Without Ruth, I don't know what would have happened. I know without my kids, I would have died."*

Espinoza said that her patient, who was once so weak that a doctor in a hospital told her that her case was terminal, has showed enormous strength.

*"I feel good because I've seen a big difference in her," Espinoza said of Vargas. "When she was very sick, I told her, 'For your two sons, you should make this final attempt to live.' And she did."*

The two smiled, if only slightly, at the memory. Vargas is not in complete good health. TB has eaten away more than half of her lungs. She has to move slowly at times. But she is determined, Espinoza said.

*"Now, she wants to study, to go to school, she wants to work," said the nurse. "She wants to recover her life."*



*A doctor from the Philippines examines a TB patient at the Quezon Institute in Manila, Philippines.*

*We hear a lot of statistics quantifying the TB crisis, but there's only one number the TB Community is focused on: zero. Zero new infections, zero deaths, zero stigma and zero discrimination. Today, partners from all over the world are working on a new goal that starts with ZERO.*

**FIGHTBACK**

