



# Stop **TB** Partnership

**TB Journeys:** Our stories, our words





# Our stories, our words

Tuberculosis (TB) has been infecting humans for millennia and it still ranks as the leading infectious cause of death worldwide. Hundreds of thousands of reports, research manuscripts, news articles, books and other works have been written about the disease. We know the numbers, the statistics, and the policies. However, the TB community knows little about the millions of people who have experienced, struggled against, fought, and died – but also triumphed over TB. Our journeys are of resilience and strength!

In November 2015, the Stop TB Partnership, in collaboration with the Global Coalition of TB Activists (GCTA), hosted the first ever meeting of TB survivors in Bangkok, Thailand. We came from different parts of the world and walks of life, but we had common goals: to discuss the challenges we faced throughout our TB journeys, to share our experiences in surmounting them and to affirm our aspirations for engaging and supporting others who must embark upon similar journeys.
















We are the fortunate ones. As survivors, we are committed to lending our voices and stories in honor of those who were not as fortunate and died needlessly. We feel it is our responsibility to show the world the human face of TB, so that we all remember our fight is not only against a disease, but also for the people it affects!

As we move into a new era in the fight against TB, there is much talk about the urgency for doing things differently -- of a paradigm shift in the way people think about TB and in the way TB care services are delivered. It is essential for national TB programs, domestic governments and international donors to invest in patient-centered initiatives which ensures that every person with TB is diagnosed, treated and cured. We must keep the journeys of the millions of people with TB at the forefront of our minds and to think about the ways in which we, the survivors and people affected by TB, can constructively contribute to ending TB.

Here are some of our stories, in solidarity and in our own words.



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# Karsabo



Soweto, South Africa



**I grew up in a dysfunctional family.** After I was born, my dad ran away from my mum. But then she left me outside his front door. I stayed there with 15 people in the house. It was hard to concentrate in school when you have such an impoverished background. I thought I was dumb and useless, but it was because of my environment. I couldn't do much on an empty stomach.

Then I was adopted by a rich lady. Life was going to be a walk in the park! But the mad thing is that she was 37 years old and she wanted sexual favours from me. Nothing for free, she said.

It all went wrong when two guys broke in to her house. They told the police that I'd given them information. You go to jail in South Africa when you're waiting for trial, so I was taken to Sun City Johannesburg prison.

Prison was a hell on earth. When you enter that prison you know that you're in a bad place. They took our fingerprints, and then put us first time prisoners in with the gangsters. There were 130 of us in each cell. No one did any health screening.

When I first felt sick, the sister chased me back to my cell. She said we all act sick. Luckily for me she went on maternity leave and a Good Samaritan arrived in her place. I tested positive for TB and she gave me my medication.

The other prisoners were crushing up and smoking their TB pills. But I knew that this lady was trying to help me, so I had to swallow those big pills. After six months, I began to gain weight. The only problem was that I became more attractive in the eyes of the gangsters and they tried to rape me.

When I was moved to Pretoria prison, I decide to do something meaningful. I didn't just want to eat and sleep. So I learnt about TB and HIV and then taught the other prisoners about the diseases. After my experience with TB, I knew that I wanted to teach, to build up my life. It was the beginning of new things.

I suffered from stigma after jail. No one wants to hire a criminal. But I kept persevering. Now I have my own radio show and I am a speaker. I've also been married for three years, with a young son. I let go and now I'm free.



# Endalkachew Fekadu

**Life is a long, often surprising road**, with many hurdles to overcome and many opportunities to take advantage of. Back in 2003, I was in the land of opportunity — studying at university to become a pharmacist and dreaming of getting a good job. But after I finished my first year, the symptoms came.

I was struggling with a loss of appetite, fever, fatigue and night sweats, so I went to the campus clinic. A sputum test confirmed that I had TB. I wasn't too worried as it was quite common on the campus and I thought that I would make a full recovery if I took the medication.

I wasn't getting any better, but didn't want to delay my dream of finishing school. But it became clear that I was in a life-threatening condition. After returning home for some time, I went back to Addis with my family and had another sputum test. It was a shocking result for me. I had multidrug-resistant TB, a much more lethal type of TB that is more expensive to treat.

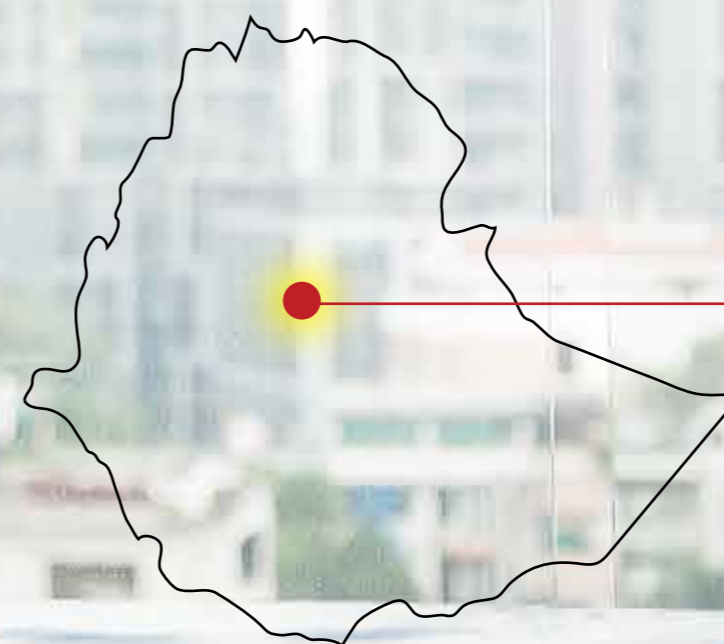
Diagnosis didn't lead to immediate treatment. The MDR-TB treatment I desperately needed was only available outside Ethiopia, and it was too expensive. My family and friends made contributions but it wasn't enough.

Everybody was waiting for my death, until a guardian angel appeared. Mr. Mike Hinckfoot from Compassion International offered to bring the drugs from the USA. They were difficult to import and weren't even registered with drug administration and control authority. But after many ups and downs I got the medicine.

The medication side effects became another headache. There were eight pills and an injection each day. They were so toxic, with many adverse effects. I remember my mama waking me up every morning to take me to hospital because sometimes I just vomited all night and became faint.

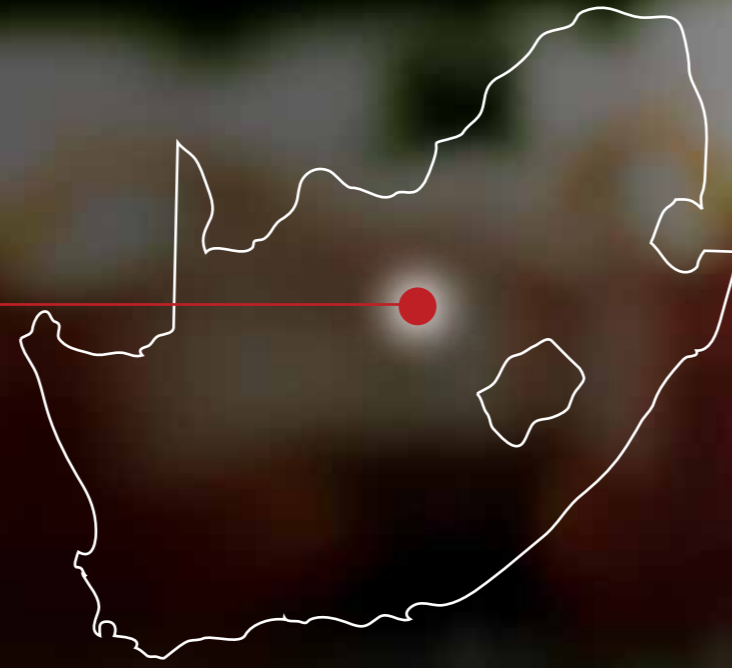
But with thanks to God I finished the medication on 6 June 2007. I am perfectly OK now! I want to show my great appreciation to Dr. Benium Feleke, because he made a lot of personal sacrifices to get me through treatment.

I feel like I've been given a second chance. In October I went back to school and graduated from the Addis Ababa University School of Pharmacy. I wrote my thesis on counterfeit drugs and their impact on drug resistance and global health. Now, I've been able to engage in a lot of activities. I'm the founder and chief executive of Volunteer Health Services and the Ethiopian Drug Information Network, the Chief Editor and Owner of Pharamet media and communication Company. That's not all and I have ambitions to do more. I have established a centre for monitoring the adverse effects of drugs. I would like to actively engage in politics. Someday I would like to be a minister.



**Addis Ababa, Ethiopia**

## Bloemfontein, South Africa



**I am openly living with HIV**, but dealing with the stigma and shame attached to TB was a new challenge.

It was difficult telling my employer and my family that I had TB. My job, which was at a charity working with children, required me to visit hospitals. After I told my supervisors that I had TB, they felt that I should stop going to visit the children. This was despite the fact that I had started treatment and was no longer infectious. My duties were changed and I was treated differently at work, so eventually I decided to quit the job.

The challenge of stigma comes on top of all challenges of getting diagnosed and treated. It took me a while to tell my parents and family that I had TB. I felt that having TB was dirty, so I told them that I had pneumonia that had been treated. But because of the side effects of medication, which everyone could see, I eventually came out and told them. They were shocked and wanted to know if I might have infected them. But as time went by, I received support from them.

Getting an accurate diagnosis was challenging. When I first went for a TB test and X-ray, no TB was detected. It was only after I was hospitalized for pneumonia and numerous additional tests were performed, did the doctors discover that I had TB.

When I moved back to Free State to be close to my family, my hometown clinic wouldn't give me medication, because there was some documentation that I didn't have. Maybe I should have checked before I left, but I just wanted to get home as quickly as possible. These bureaucratic issues definitely need to be fixed. Fortunately, after six months of treatment the TB could not be detected in my system, meaning that the treatment was effective.

Reflecting on my journey, there are a few areas for improvement. For one, I think that people who have TB should be better informed about treatment. I didn't feel that I had any control over what was being given to me. It would be better if healthcare workers better understood what people with TB are going through — the side effects of treatment and their wider social challenges.

What helped me? Well, at one point I had to live in a homeless shelter because I had to quit my job to recuperate and I could not afford to pay for my housing. The support from the shelter was very helpful because I was not in a position to work and earn an income. Also, I did a lot of my own research and I learnt that if I took my treatment properly I can lead a healthy life.

To other people with TB, I would say this: TB is a curable disease. You don't have to die from TB. If you think you might have symptoms, go to your nearest health facility and seek help.

# Duncan

# Moeketse

# Martita NPandey



Pokhara, Nepal

**I was training to become a nurse** when I first had TB. The TB was in my brain, which is very expensive to treat. I had constant episodes of fainting, fever, headaches and huge pain.

In lectures, the other students and teachers told me I should quit the nursing course and take a desk job. I felt stigmatized and I didn't want to have to take a job where I sat like a statue all day.

I used drugs to subside the mental and physical pain. But I became addicted and I was the victim of sexual violence.

There wasn't much support, besides from the people at the orphanage where I grew up. The important thing is that I supported myself. Finally, in 2003 I qualified as a registered nurse at Manipal Teaching Hospital.

I got TB again in 2006, this time in the lungs. I sold my gold chain so I could go to see the doctor. After he told me I had TB, he said that it was a very bad disease and that I shouldn't go outside. But although I was weak, I wanted to keep working for my community, so I pretended that I wasn't sick.

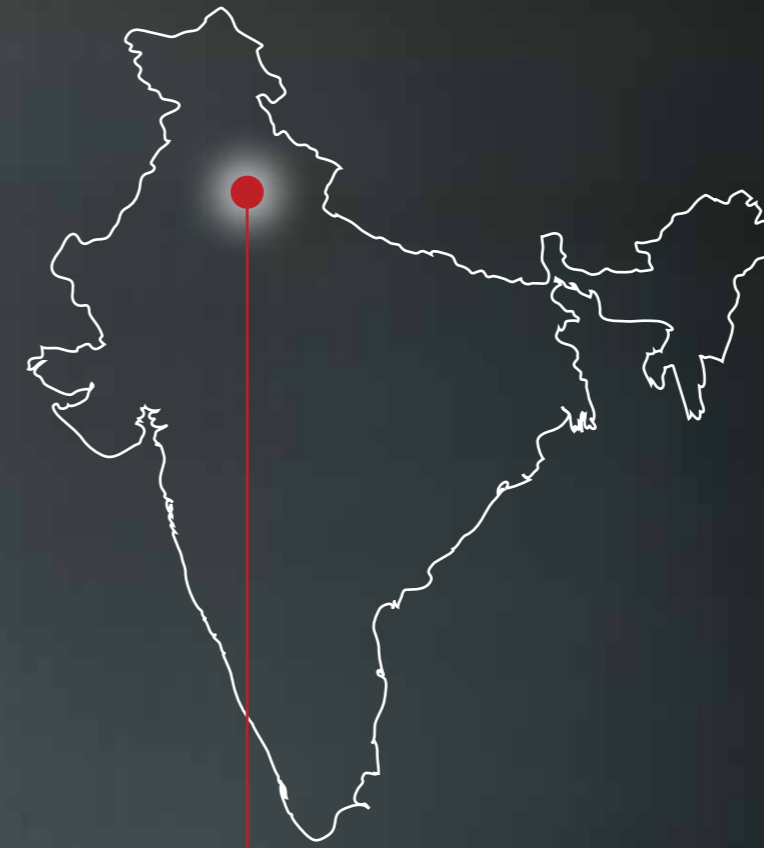
One day, a few great people from the media encouraged me to speak out in public. I felt that I'd had enough pain and started to express myself in the community and wider public. I might have used drugs and had TB, but I'm still a human being.

Now I work actively to help people who use drugs and are affected by TB and HIV, both as a national consultant and as a programme manager at a nongovernmental organization called Naya Goreto.

If we want a 100% treatment success rate, we need zero stigma and zero discrimination. When I meet people who have TB, I tell them that if they take their treatment properly, they will be cured and their TB is unlikely to come back. We need healthcare providers to provide the same level of psychological support.

TB advocacy in Nepal is not currently strong enough to hold the healthcare system to account, so I want to establish a national network of people who have TB and disseminate information and education programmes in every region and district, especially in areas that are hard to reach.

# Blessina Kumar



Delhi, India

When I started feeling ill, I was in a small town in southern India. I really couldn't get anyone to diagnose me properly. Then, the doctors put me on treatment anyway — without a confirmed diagnosis. I took the treatment for six months without knowing whether it was TB or not. So getting access to an accurate diagnosis was definitely one of my biggest challenges.

My family really helped me get through those six months. My children were very young and so my parents in particular helped me through. They didn't mention it to any of my larger family. It also helped that I had to travel outside of India for work, so people didn't really know about it. There were quite a few side effects, but my parents just helped me through that.

My experience with TB inspired me to become an activist. We have these challenges because the TB community hasn't had the courage to think differently. It's become accepted that there's only one way to do things.

If we look at the trends, we know that 'business as usual' isn't going to get the job done. The new targets of ending TB by 2030 demand greater urgency. We need be willing to change the way we think and bring about a total paradigm shift.

We also need to value people who have had TB, for their experience of being treated, for having gone through the challenges of accessing care and coming out of it successfully.

If we pay attention to what people who have had TB say, you'll see that it's not just a medical problem. If it were, TB would have been eradicated years ago. Instead we need partnership and we need to empower people with TB so that they can sit at the table as equal partners.

People need to have a say in what is being offered to them in terms of care. Right now you're at the mercy of a healthcare system that treats you really poorly and is really stigmatizing.

To really empower someone you need to lose some of that power yourself. So policy makers need to hand over a little bit of power to the people who are being treated themselves. We've seen that when you let communities take ownership in other areas, they seize the opportunity to improve their health.





# Melecio

## Mayta Ccota



Lima, Peru

**My TB journey inspired me to create a support group,** Aspat Peru. It's made up of people whose TB had been cured, as well as people who are committed to ending TB, and aims to respond to several challenges that people with TB face.

All the spaces and health facilities for TB are depressing. They're like forgotten, dangerous places. Getting access to health services is difficult in the first place, and if you do manage to get TB care, you're likely to come across discrimination and stigma, both from hospital staff and members of the community.

Fighting TB is hard. The treatment often has adverse side-effects and the impact on you physically makes it difficult to work or study.

One thing that really should be improved, along with the overall quality of care, is communication with people who have TB. There needs to be ongoing dialogue and agreement between healthcare workers and the people that they are helping to fight TB.

I received a basket of basic foods every month, which was key to my recovery. During treatment, I wasn't able to earn a decent income, but at the same time I had to make regular payments for medical examinations, drugs and household essentials.

The emotional support from my family and other people who had TB also made a big difference. I deeply appreciate their understanding at a very difficult moment in my life. Without their help I would not have been able to finish my treatment.

People with TB deserve to be supported by everyone. Healthcare workers need to provide a quality service in a friendly, respectful way. We also need communities to stop being afraid of people with TB and help stop the stigma and discrimination associated with the disease.

The support group I manage aims to provide emotional support to the poorest and most needy people with TB, as well as helping with the costs of TB care. One of our biggest successes so far is the introduction of a new law in Peru that aims to guarantee access to treatment for all.

If you've just been told that you have TB, don't despair. Take all the medicines recommended by your doctor. It will be a challenge, but if you finish your treatment you will be cured. You can also help to give hope to many other people with TB by sharing your experience.

I was 16 and studying for my board exams when I first started feeling sick. I couldn't stop coughing, but I thought it was just a normal cough. Our family doctor prescribed cough medicine, but my cough never really stopped.

I was finally diagnosed with TB after a month of waiting, but the treatment didn't help. My doctor kept changing the medicine, and it took several months before I was finally told that I had a dangerous form of TB called multidrug-resistant TB (MDR-TB). What's more, part of my left lung had become decayed and I required surgery to remove it.

I was confused and had no idea what MDR-TB was! My parents were distraught — as all parents would be — and they wanted to know how they could help. I was just 16 and didn't even realize the severity of the disease. I thought I would be cured after the surgery and my suffering would end. But after the operation, my condition continued to deteriorate despite the medicines and injections.

In complete exasperation, I started surfing the net to find a doctor who could treat me. I refused to believe that there was no alternative. Eventually I found Dr. Zarir Udwadia at Hinduja Hospital in Mumbai. For the first time, I felt hope creep back into my life. But my case had become critical and I required a further, very risky, surgery.

All the surgeons said that I had just six months to live and I had a one percent chance of surviving the surgery. So most of them refused to operate and advised my parents to keep me happy for the next six months and let me die in peace! Finally, after more internet research we found a surgeon who was willing to do the operation.

I was singing before going in to the operation theatre. Either way, the surgery was going to end my suffering. If the surgery was successful I would be cured, and if it failed I would die and my suffering would end. Somehow though, I felt that I would come back.

I was out of the intensive care unit the next day. How did that happen? Perhaps it was a miracle, perhaps it was the love of my family, or perhaps I just wanted to defeat medical science.



Mumbai, India

People tell me I am a survivor, but my TB journey wasn't without its challenges and doubts. The worst side effect of the medication was the darkening of my complexion. I looked like a skeleton and looking at myself in mirror was my worst nightmare.

People with TB and their families often ask me for advice. For them, it's important to be positive and optimistic. Your will power is the only thing that is going to help you fight this disease. Families and friends need to provide support too. My friends made it a point to come to my house and celebrate my birthday.

I genuinely believe that TB is India's ticking time bomb and we must deal with it on a war footing. Drug availability is crucial for people with TB, each person must have access to free and accurate testing and everyone must be given free drugs, regular support and nutritional supplements. We need to support individuals with TB — together we can defeat TB!

# Deepti Chavan

# Mrs X

**When I was diagnosed with extensively drug-resistant TB (XDR-TB),** the doctors told me that they'd never successfully treated this form of TB before. They said the longest survivor of XDR-TB did not live more than three months. The treatment is expensive and most of the drugs were not locally available. The Isolation ward was still under construction. Following its commission, it only operated satisfactorily for one year. At the moment the ward is still not operational. Consequently, though my condition was highly infectious, the doctors recommended a home based care.



I first had TB in 1979, when I was an 11 year old child. I took the regular TB drugs and was cured. But the TB came back in 1985 and this time I needed treatment for drug-resistant TB. Despite being a young child, I wasn't offered any counseling or an explanation of the drugs I had to take. It was just medication, injection, medication, injection.

When I got TB again in 2011, after a series of test I was put on treatment for drug-resistant TB. It was medication, injection, medication, injection again. After six months they said that I had multidrug-resistant TB and would need to start a new course of treatment – back to the beginning with more injections. It was another seven months before they finally diagnosed me with XDR-TB. By that time, I was weighing 40kg.

If it were not for KELIN, a civil society organization, I probably wouldn't be here today. Allan Maleche from KELIN heard about my case and highlighted it in the media. This triggered a more focused reaction from the Government and subsequently I got most of the drugs available locally from the Government and the donors procured the drugs that were not available within the country.

Finally, after 4 years of injections and medication, I have been cured and discharged. Now the medication has stopped I feel so good. No more side effects like swollen joints, headaches and electrolyte imbalances. If the first diagnosis had been done properly it could have ended so much sooner.

A lack of awareness and training are big problems. Most of the healthcare workers at the regional level do not have sufficient knowledge about TB, leading to poor diagnosis. By the time you come to the national level, your chances of survival are so low.

Stigma is really a problem too. At my place of work, people thought I was dead. At the hospital they were scared. Even my family was told to stay away but they refused to let go and stayed with me. Only two healthcare people would come to my house to give me home based care.

The doctors need to change the way that they handle patients. Many more healthcare workers need to be trained so they can help people with TB.

Despite my battle with TB, my message to others is do not fear. TB is curable. Treatment is long and tedious but we will manage.

# Prabhata

## Manesh Shankar

**I was diagnosed with extra-pulmonary TB** when my baby was one year old. I knew absolutely nothing about TB, except that it was a dreaded disease and could be fatal. I was scared and worried that stigma would leave me isolated.

Nobody in the family knew about TB. I wasn't even sure whom I should consult.

I had to go to a private doctor, as I wasn't aware that there was a public TB programme. Initially they said that I had cancer and would need a biopsy followed by surgery. I went through a period of turmoil.

I didn't tell my friends or colleagues that I had TB. I was afraid of stigma and absolutely didn't have the confidence or courage to face anyone. My family helped me to cope, but people at my work place came to know and I was isolated.

The doctor told me to stay away from my baby. I had to send her to my mother's place. I was told to take treatment for one year, but didn't receive any support from anyone besides my family. I didn't receive any information on the disease, on how to prevent transmission or how to stick to the treatment. I suffered from guilt and dreaded of the fear of infecting people around me.

The psychological support from my family was crucial. I felt insecure and worried that I wouldn't survive, as I suffered from side effects and pain. Moreover, I thought I would lose the love of my child and that she might forget me. I was so frustrated and despaired that I missed a few doses. Without my family I wouldn't have been able to cope with this disease.

We are not cases, but human beings. Health workers and government authorities need to be more sensitive to the needs and feelings of people with TB. They need to help increase knowledge about TB and the services available, foster healthy dialogue with people with TB and help them accept their diagnosis and adhere to treatment.



Mumbai, India

If you are diagnosed with TB, remember this — TB is absolutely curable. If you take your treatment regularly, you will be completely cured, like any other disease. Do not fear stigma, have a healthy diet and maintain a positive attitude in the face of challenges. You will survive TB with grit and determination.

What did I do after cure – Taking on from my experience, I educated several people who were receiving anti-TB treatment and their families about TB, counseled them to wipe off the misconceptions by sharing my experiences, made efforts to make diagnosis and treatment available and accessible for all the people with TB and motivated them throughout treatment adherence.

# Paul Moses



# Ndegwa Mutiga

**When my brother dropped me off at hospital** he didn't give his name. The hospital staff asked my family if they could bring a mattress for me, but they refused. Because of HIV and TB, I had become stigmatized by my own family.

I was fortunate to be the first person in Kenya to receive a free chest x-ray. I was given TB drugs, but how was I going to get to the hospital to take them? I couldn't even climb 3 feet.

If it wasn't for the Franciscan Missionary Sisters for Africa I wouldn't be here. They came to my house, provided me with nutritional support and took me to hospital. I started to gain my weight back. Their support allowed me to recover quickly, regain self-esteem and dignity and empower me to advocate for the rights of people with HIV and TB.

I have a good education and was planning to run for a parliamentary seat. Because of this education I made good decisions and pushed for and demanded treatment. Without this drive, and the support from the sisters, I would have been left to die.

I became an activist from my bed. I understood why people were dying, why they weren't accessing treatment. For one, the stigma needed to stop. The TB ward at the hospital was known as Bosnia. A place you go and never come back.

I was invited to a conference and told them that there was nothing free about treatment. They might pay for an x-ray, but who is going to pay for the cost of getting there, for food when you cannot work?

At a global level, we need increased funding for accelerated TB responses and programmes. Let's take inspiration from Polio campaigns and ensure that no one is left out.



Nairobi, Kenya

People with TB also have a role and responsibility to advocate for their rights and drugs. We need respect for rights of people affected by TB, early TB detection, diagnosis, treatment and care and support.

Now, I am comfortable with my family and at my workplace as a TB/HIV activist. I am knowledgeable about my rights and, by living openly with HIV, I have managed to combat stigma and discrimination in my family, community, among health providers and at the national level.

# Safar Nazimov



Farkhor district, Tajikistan

**We were more like friends, my brother Naza-sho, and I.** Being brought up in large family following the collapse of the Soviet Union and subsequent civil war in Tajikistan was hard. We grew up taking care of each other in difficult moments, worked hard at school and dreamt of a better life.

In 2002, Nazarsho fell ill with a cough that worsened, until one day he vomited blood. A decade later, at around 5am on November 27, 2012 and after years of persisting with TB treatment, he passed away at hospital. Nazarsho's last months were extremely difficult. He spent five months in hospital on an oxygen machine. It was so distressing to see life departing my brother, a wonderful person who had wonderful ideas — a person who wanted so much to live.

To make matters far worse, my other brother, Ismoil, also contracted TB in the same period. It was hugely heartbreaking to see Ismoil's health deteriorate. One night in December 2008, we were at the dinner table when Ismoil slowly got up from his bed and left for the bathroom. He didn't come back. Ten minutes later we found him dead inside the bathtub, surrounded by blood. Nazarsho felt guilty and blamed himself for what happened to Ismoil.

The physical and mental side effects of TB treatment are almost unexplainable. It was a severe punishment — vomiting, intense headaches, light sensitivity, depression, confusion and nightmares — that we all had to somehow tolerate.

Finding the necessary treatment was another of our great struggles. After Ismoil's death and Nazarsho's ongoing illness, we learnt about MDR-TB and of treatment available in India. So we travelled to New Delhi. As soon as Nazarsho started the treatment there, he said he felt the best he had in seven years. By the time we returned to Tajikistan, MDR-TB treatment was available, though only for people living in Dushanbe [the capital] and surrounding areas. Nazarsho had to interrupt his treatment for several weeks while he re-registered in one of those areas. At least when I was also diagnosed with MDR-TB myself, I could get treatment in Tajikistan.

Living with TB is a dark and scary place. So it was a great help for me to learn more about the disease and to meet TB survivors to tell me how they felt after treatment. The health centre was incredibly important in helping me find solutions and get back on track psychologically. Moreover, USAID's Project Hope organized TB support group meetings for people with TB, their relatives, and doctors. Here we shared our difficulties, learnt from each other and, and most importantly, no longer felt alone.

Our collective fight against TB brought us down financially, as well as physically. In that ten year period all of the family's income was spent on treatment — both the drugs and transport costs.

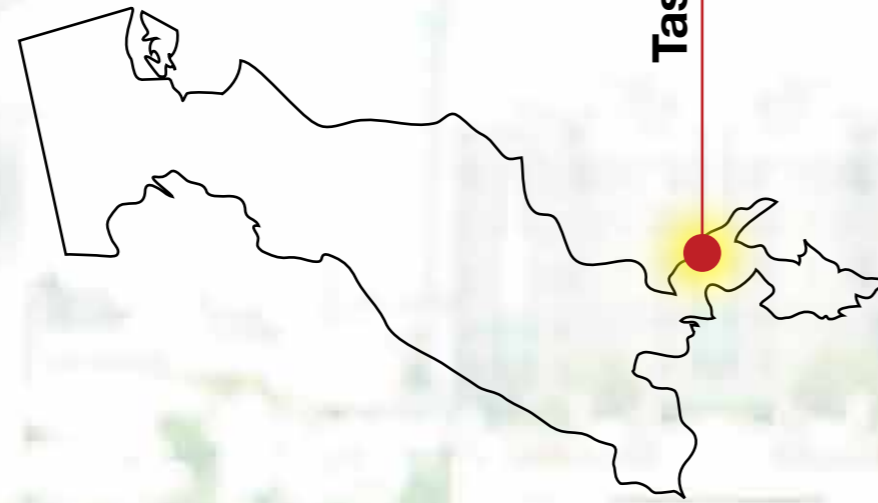
The same month that Nazarsho passed away, I completed my treatment and recovered. I'm now doing well, with my job and a healthy life. Only the pain of losing my loved ones remains in my heart. I am broken inside with memories but I am also revived and determined to support anyone sick and vulnerable. Other people with TB, please join me. It's a cause worth striving for.

**The biggest challenge for me** was not just dealing with the diagnosis, but also telling my closest family that I had TB. I have to be honest, I only told my wife, not my parents. In general, it's of course much easier to talk about having TB experience after you've been cured.

My previous experience in HIV activism was the main factor that helped me get through treatment. With that kind of background, I was more prepared to deal with TB, and I knew where to go to seek treatment and care. Unfortunately, what I didn't have was support from peers – this is something that is largely missing in the TB world. My only supporters were doctors, family and friends. This certainly helps, but I wish I had an opportunity to also be able to communicate with those who already had TB. That is one of the reasons for my commitment to mobilizing the community of people affected by TB.

The way that TB is seen needs to change – in the eyes of government officials, politicians, people in the healthcare system and donors. Those people who have the power to bring about a change. TB is not just one of many diseases. TB is now recognized as the number one infectious killer worldwide. It is a shame that an ancient disease like TB is not only a reality, it is actually on the rise, especially when it comes to its drug resistant forms.

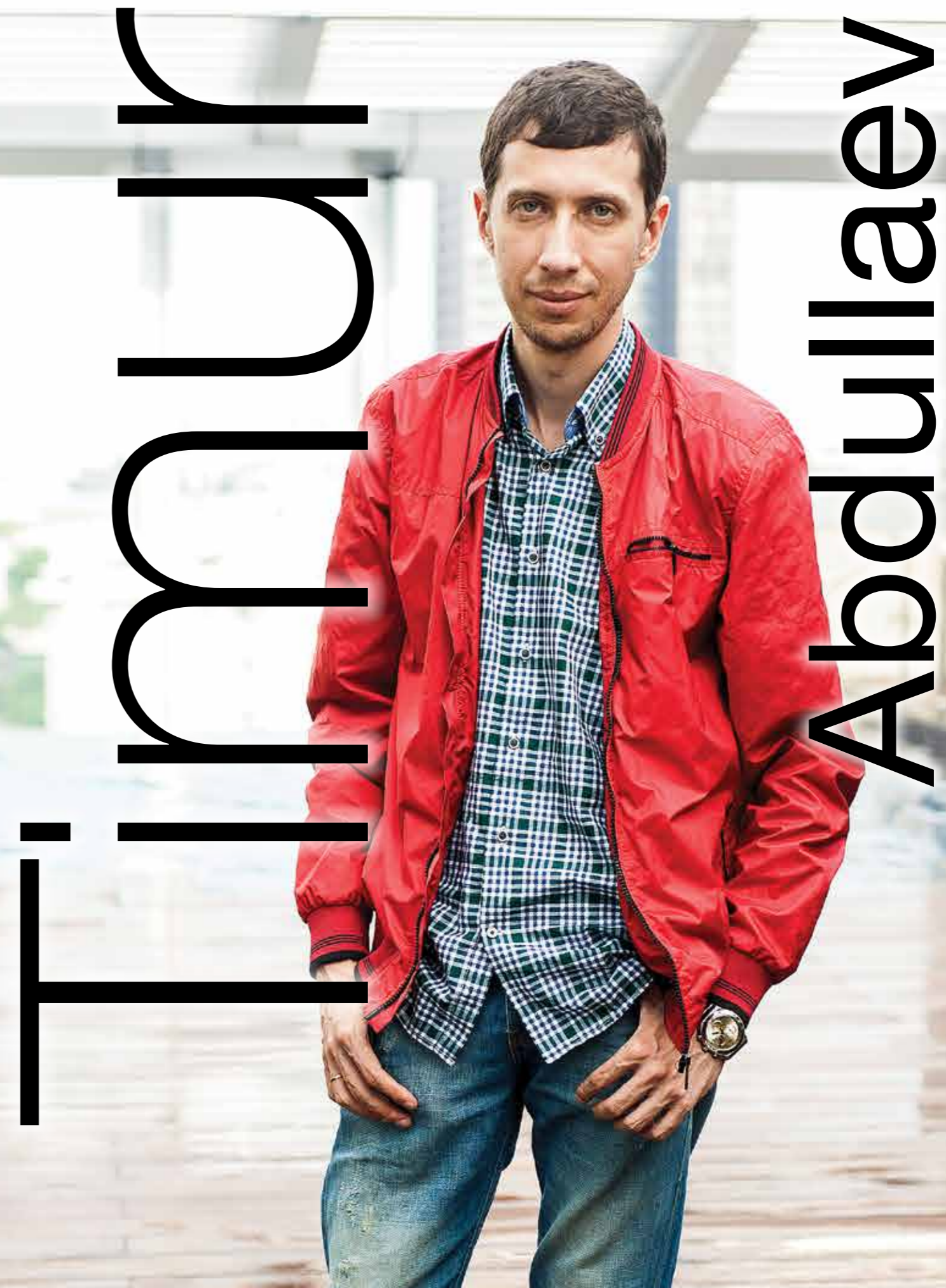
The way that TB has been addressed so far is no longer acceptable. It has to change. TB is not just a medical issue, it's a complex phenomenon that includes a lot of social and human rights aspects. TB has to be addressed in a comprehensive manner, in a spirit of partnership, but the way we have been responding to TB so far looks like a desperate attempt to clap with only one hand.



Tashkent, Uzbekistan

Governments will not be able to stop TB alone. TB response can't be the responsibility of the Ministry of Health alone, it has to be concerted action that we do together – governments, donors, technical agencies and communities of people affected by TB all working together. Monitoring and evaluation of TB programme to include civil society mainly those affected by the disease, resources are key which call for political will.

My message to other people with TB is simple: take the treatment and be done with it. And then, after being cured, become an activist and help others with TB. We have to spread activism, just like TB is spreading through society. We have to make activism a disease. Once we get over TB, we cannot and we should not forget about it as if it was a bad dream. We have to remember the experience and support others. This is how we will be able to build a community of people who have had TB, which becomes a strong and an indispensable partner in the fight against the disease.



# Valeriu Istrati

**I am a wine maker, photographer and philanthropist, and the only member of my family to have had TB.**

Accepting the diagnosis was a big challenge. It was heart-breaking to tell my mother that I had MDR-TB, but I only really wanted to discuss it with my family. Although they were worried, they understood. But otherwise, I largely avoided interacting with others. People who had been close or friendly to me in the past, started to distance themselves from me, which was very demotivating.

I also had to quit my job. The treatment regime required me to be isolated for two months at the clinic and my employer couldn't accommodate this.

After two years of treatment, both in Moldova and the United States, I was cured from drug-resistant TB in 2012. It was a complex, difficult journey that now, three years later, I continue to share with people who have TB in order to help them understand the importance of following treatment and reduce stigma.

Chisinau, Moldova



Getting access to healthcare wasn't a problem for me. The challenge was the quality of that healthcare. There was another case of MDR-TB at my university, but because there wasn't a database of people with TB, the doctors didn't make the connection between the cases and I only found out months later that I had MDR-TB from the sputum tests.

One big obstacle was the rigid, unfriendly health care system, that didn't allow for any flexibility in the mode of treatment. Another obstacle was the toxicity of the drugs, some side effects of the MDR-TB treatment are quite severe.

Before I got ill I knew absolutely nothing about the TB, besides the fact that it is treatable. To start with, the healthcare workers did very little to help me understand the disease and my treatment. Then, after the first weeks in the hospital, I couldn't stand not knowing what is happening to me and endlessly begging for information from the busy medical personnel, so I read everything I could find on the internet about TB, from Wikipedia articles to scientific research and countries' TB strategies.

Then very quickly I knew everything about TB, from the physiology of the Mycobacteria to the dosages and full spectrum of side effects for each of the TB drugs. Once informed, I was able to inspire the trust of the healthcare workers. I became a target for sympathy and astonishment, not fear and stigmatization.

I now have frequent opportunities to provide feedback on the quality of care. My recommendations? I would ask the medical personnel to treat people with TB as people and not as a disease. Sometimes TB is only part of the problem and there could be non-medical problems that are just as important. I would ask people with TB and patient groups to help stop stigma, provide feedback to the healthcare providers and help others complete their TB treatment. Finally, I would ask people who have TB to persevere with their treatment. Despite the fact that the treatment is basically poisoning yourself to within the limits of what your body can take, the drugs will kill the otherwise deadly TB bugs.



**My Name is Maggie Gama, a widow to a late Abraham Gama** who was Miner for over 9 years. Abraham left home to work at the mines, leaving me behind with 3 children whom I had to raise with the hope that with a salary, life would be much easier.

We had no proper housing, nor had a balanced meal and I struggled to pay school fees and cloth our children as the salary he brought home was not adequate to cater for all our needs. Due to all these hardships, our children had been finding themselves doing odd jobs, trafficked and slaved away at jobs for a meagre salary to ensure we had at least thin porridge to cook at home.

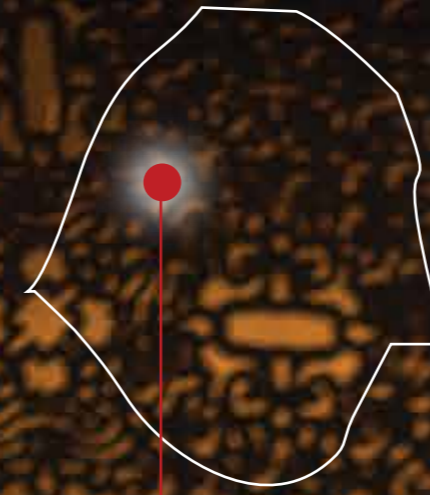
This is the case for other families where by the head of the home have been away to the mines. The kids are involved in prostitution, selling and abusing drugs, bombing in alcoholic beverages and these has grown at an alarming rate. They had to drop out of school and have lost respect for the elders in the community as they didn't have a father figure to teach and guide them in the principles of life.

As an Ex Miners widow, I am a great example of these hardships as I had to and still endure them every day. I am still hurt the way my husband died, having worked for so many years in the mines, he never accomplished, we did not even get compensation nor did he have a policy or pension when he died. We still live in the stick and mud house Abraham left behind. Sometimes heavy rains and storm come and we fear that the house is going to bury us. From time to time we have to fix it with more mud as the heavy rains washes it away leaving holes all over.

Another thing, when these miners work at the mines, they are not provided with medical aid, when they fall sick, they are sent home and neglected to fend for themselves. At first the symptoms are not visible, it takes a while for silicosis to show and for Tuberculosis. This led to hearing loss and poor eyesight. They are not even compensated not offered medical attention.

Never the less this is the life most Miners families have to endure In Swaziland. I am one out of a thousand more Ex Miners widows. Shakespeare once said ' A horse does not know what a win is so therefore it keeps running because of the pain given by the rider'. Our husbands kept working under extreme conditions but soldiered on with the hope that one day things will get better, but it has never been so.

All we request is proper care for miners, retirement funds, pension schemes, fairness in the treatment of Swazi miners working in South Africa, and a policy that will benefit all miners and their families should a husband or wife working in the mine passes away. This will surely help improve the lives of Miners, Ex Miners and their families.



Mbabane , Swaziland

# Maggie Gama

I want to offer my humble limited experience on TB to anyone who may need it to help end TB. I want to empower civil society on how to defend their rights with a special focus on TB.

My sister, Anselma, got pulmonary TB. After 3 months of treatment, the health center tested for contacts, and my sister Erika was positive on a microscopy test. Two months later, I got night sweats and tested positive. I only knew that TB was a disease that made you cough, produce a lot of phlegm and make you feel very tired and sleepy.

The diagnosis was quite easy. The challenge came later when I developed adverse reactions to drugs and the health center couldn't help me. I was transferred first to a second-level hospital to be evaluated, and then to a specialized hospital. I was really scared and anxious when I realized that there was no treatment in Bolivia for these adverse reactions. I thought the only future for me was to wait to die. We put a lot of pressure on the health workers of the hospitals to be able to gain access to proper treatment.

A patient almost always feels alone or that he/she is the only one in the world suffering from the disease, we need to have more interaction and support between peers. My biggest support was my family, they supported me at all times.

At the beginning I felt ashamed so I always said to my friends that I was just ill. There was a very horrible doctor who told me "You have TB (Eres una tuberculosa). Why do you want to live?" But many other treated me very well and gave me their support, they informed me well and gave reasons to keep on breathing.

Now I'm confident and I say I suffered from TB and I advocate so the symptoms and prevention methods are better known.

There was an urgent need for a change in the attitude toward people with TB, we are not numbers, but are human beings, and we need to be treated with kindness and respect. The person with TB needs to believe that his/her health center is his/her second home for the 6-24 months that the treatment will last.



La Paz, Bolivia

In Bolivia, there is an organization called ASPACONT that represents the MDR-TB patients in the country. Thanks to ASPACONT, National Center for Chest and Pneumology, and the Provincial Programme for TB, a fund for MDR-TB patients was established that covers hospitalization, laboratory costs, x-rays, complementary medicines, etc. Since 2011 it has been funded by the National Treasury and the budget has been increasing every year.

It is important for others to know that we all are human beings and need to be listened, and be granted a quality attention. We need to promote empathy between health workers and people with TB. And also to extend the working/attention hours of the centers.

We can support people with TB through support groups, peer groups, and by providing information to society, families and work places among others.

Today I can get TB and tomorrow could be you. Get informed and take precautions. Don't stop taking your treatment, ask your doctor, and be sure we are here to help you. Take care of your family and yourself. TB is curable.

Eva  
Limachi Salgueiro

Stop **TB** Partnership → **END  
TB**

Stop TB Partnership Secretariat  
Chemin de Blandonnet 2,  
1214 Vernier, Geneva,  
Switzerland

[communications@stoptb.org](mailto:communications@stoptb.org)

