# CHALLENGE TB NEWS

Welcome to the latest edition of the Challenge TB Newsletter which brings you a snapshot of Challenge TB work, with stories from Afghanistan, Ethiopia, India, Malawi, Tajikistan and Tanzania.



### SECOND TIME LUCKY

Twenty-one year old Neha Surve was first diagnosed with TB when she was only 13. After already surviving TB once before, she was diagnosed with multi-drug resistant TB (MDR-TB) in early 2016.

Neha was working as a customer service representative in Mumbai and was attending night school so she could complete her undergraduate degree in commerce. As her health got worse, her boss and colleagues noticed, and it was not long before she lost her job. With a retired father (who is also recovering from MDR-TB), and a mother who works as a part-time cook in several households nearby, the family is not doing well financially.

Despite the management of MDR-TB being scaledup to cover the whole country, there is still a wide gap between diagnosis and links to treatment. Challenge TB works to ensure early and accurate diagnosis, correct treatment, adherence, and completion, and to monitor the transmission of MDR-TB and Extensively-Drug Resistant TB.

Neha's treatment coordinators and counselors (Promod, Neeta, and Dnyanesh) made sure she



was diagnosed quickly and in coordination with Neha's private TB doctor, the treatment coordinator counseled and registered Neha at the public Drug-Resistant TB (DR-TB) Center to begin her treatment.

Her initial testing and diagnosis were completed in the private sector which helped her to initiate treatment early at the public sector DR-TB center. Linking private sector patients to public sector DR-TB centers for further treatment is a unique feature of the PATH/Challenge TB project that facilitates collaboration between public and private systems and ensures patients receive free treatment, for which Neha is especially thankful.

Neha had initially been hesitant about being treated in a public hospital, as she thought the process would be slow and the treatment not as effective. These sort of misconceptions about treatment in the public sector are found amongst many TB patients in India.

The constant support and counseling by the project's treatment coordinators restored Neha's faith in public health services. She is very happy with her treatment and shares a great rapport with her doctor, and she is adamant that her experience would have been very different without the counseling support the project offers. The assistance she received helped her to manage her treatment and was also a source of support for her family. Talking to the treatment coordinators reduced their emotional distress substantially. The trust that is formed between treatment coordinators and their patients has a positive impact on the patient's health, helps to reduce stigma, and leads to better results.

"I thought that treatment in a public DR-TB center would not be as effective as getting treated by a private doctor and that as a result, my recovery would be slow, but I was wrong, and the regular follow-ups by my treatment coordinators Neeta and Dnyanesh have been a great support." – Neha.

Neha's father has completed his treatment and is doing well. Neha herself is sure that she will fully recover too, and she is anxious to get on with her studies.



### ZAINAB'S STORY

**TAJIKISTAN** 

Zainab Jalolova was one of the first patients with extensively-drug resistant TB (XDR-TB) to be enrolled on the new anti-TB drug bedaquiline in Tajikistan. She is also one of the first patients who got a 'negative conversion' result after two months of treatment, which meant that the treatment was working.

Zainab said: "I used to be a very strong woman and I had never had any serious illness, but one day I felt very weak and had a fever. My family doctor examined me sent me to TB specialist, who told me I had MDR-TB and immediately started me on treatment."

Her doctors said she was the most disciplined patient they had ever met because she came every day at 9 am sharp to get her medicine and never missed an appointment. Nurse Savlatbi Hotamova said: "Many patients accept the treatment process, but it is tough so for those that don't, we communicate with their close relatives, explain all the details, the importance of treatment and problems that can occur if it is interrupted, we also involve psychologists to help." After Zainab had been in the hospital for two months, further testing revealed that she actually had XDR-TB, a much more complicated form of TB to treat as it is resistant to the usual drugs. She was lucky because USAID was just about the donate new drugs to treat this form of TB.

Zainab's husband said: "I had a difficult job to convince my wife to go through another two months

in hospital to get her treatment for XDR-TB. I promised to visit her every day despite the distance, and I did. After she was released I took her to the health facility every morning for five months so that she could get her medication, and I make sure she still takes her medicine each and every day. She is now so much better. We are fighting this disease together. I trust the doctors and the staff from Challenge TB, I trust the new drugs and I trust that Zainab will beat TB very soon, InShAllah."

In 2015, Challenge TB began working to ensure the necessary conditions were available to provide treatment under new treatment regimens. The new drug bedaguiline offers a chance to cure patients with XDR-TB and will help reduce the transmission of drug-resistant TB in the community. USAID donated enough bedaquiline for the first 50 patients, and there are currently 35 patients with XDR-TB enrolled on individual regimens containing the drug. In close collaboration with the National TB Program, Challenge TB supported the development of key policy and technical documents, procured equipment, established a sample transportation system, implemented drug safety procedures, and trained TB specialists from the pilot districts and those involved in primary health care.

In Tajikistan, Challenge TB is improving the capacity and quality of care for DR-TB patients, by focusing on new drugs, tools, and innovations. Together we are fighting back and giving people like Zainab the chance to live again.

### **REACHING OUT**

TANZANIA

<sup>66</sup>I had lost hope, I was sure that like my friends I was going to die. Things are very hard here. Two of my friends died after coughing, sweating and losing weight for a long time. At the end, they couldn't even walk." The words of Honest Mvula (17) who sleeps rough in Dar es Salaam's biggest fish market after he ran away from home in southern Tanzania five years ago. Honest works in the market during the day and sleeps nearby at night. Several months ago he started experiencing the very same symptoms as his friends had, and his health went downhill fast.

Shabaan Shamte (43) who is also homeless, took care of three of his friends who died after coughing for a long time. They thought that the salty air from the ocean was the cause, so they went to see a traditional healer, but it didn't help. Six months after a friend who used to sleep next to him died, he started to experience the exact same symptoms.

Challenge TB uses outreach activities such as stalls, announcements, music, drama, and magnetic theater in markets, mines and on the streets, to educate the public on TB and encourage people to get tested if they are experiencing symptoms.

A team from Challenge TB visited the fish market in June 2017 to screen fishermen, fishmongers and buyers. Public announcements were used to draw people to the Challenge TB tents, where they could listen to health talks, receive information, and be tested. Two hundred and forty people volunteered to be screened, 129 had TB symptoms and their sputum samples were sent for testing using GeneXpert at a nearby health facility. The volunteers were asked to provide their phone numbers so that they could be traced when the results came back the next day. Honest and Shabaan were among the 12 confirmed as having TB and started on treatment. Each person on treatment received counseling on adherence, and ex-TB patients act as community treatment supporters.

The outreach showed that the market has a high number of at risk people with undiagnosed TB, as all those who were confirmed to have TB disease were homeless men and women, who lived on the shores of the ocean around the market. These people are spreading the infection among themselves and potentially to their customers too. Visits were also made to the shoreline where many people were found sleeping under containers and in unused boats, some were very sick. Ten people volunteered for testing of whom four tested positive for TB and were started on treatment, the other six were referred for other medical services. Sadly those that were found are just the tip of the iceberg, as many more homeless people remain hidden and fear being tested as they don't want to attract attention. Challenge TB is working to find ways of making sure that everyone in the area can be tested and treated.

Outreach is continuing in more markets, mining communities, and places where people who inject drugs like to gather. In order to find even more of the missing TB cases, interventions targeted at vulnerable populations and raising the public awareness of TB are needed to encourage more people to seek help when they experience any TB related symptoms.

Honest has been helped to return home and at the moment his treatment is going well. All being well he will be cured by December 2017.



Honest receiving DOT, Tanzania - Photo: John Minde



### I'M A SUPPORTER...

Tuberculosis is an ongoing public health problem in Ethiopia, and finding people with TB and getting them treated quickly, is a critical part of ending the epidemic.

TB is a particular issue among high-risk groups, such as HIV patients, substance abusers, prisoners, and gold miners. In Ethiopia, around one million gold miners are at high-risk of TB as they are exposed to respirable crystalline silica that can build-up in their lungs and which is associated with the development of TB. In spite of strengthened TB control efforts, mining is an area that has been neglected in the fight to end TB. Delays in case detection, the initiation of treatment, and a lack of follow-up services are common, as there is no health system for the mining industry and the remoteness of the mines means it is difficult to access health services.

To address this problem, Challenge TB recruited volunteer TB treatment supporters from the mines in the Southern part of Oromia Region with an estimated population of 30,000 miners. They were trained on how to identify presumptive TB cases, TB screening and referral, counseling, and treatment supervision.

When Mustafa Abdi, a 24-year old miner at the Melka Soda Woreda gold mine, started to cough, lose weight, and suffer from a fever and severe chest pain, he visited the nearby health center. At the facility, he was tested for TB and was diagnosed with pulmonary TB and put on first line anti-TB treatment. He completed his treatment successfully was declared cured in July 2016.

Six months later, Mustafa's father, Abdi, developed similar symptoms. His father visited the same local

clinic and was given antibiotics, but his health got worse by the day. Mustafa, who volunteered to be part of the case finding team, told the Challenge TB program coordinator, that he had had TB not that long ago, and that he thought his father might have TB as well. He said that his father should be evaluated, and so should close family members he had come into contact with when he had TB. Mohammed screened Abdi and collected a sputum sample which was sent by motorbike to the Megado GeneXpert site for testing. Mustafa's father turned out to have bacteriologically confirmed pulmonary TB and he was linked to a nearby health center, where he was put on anti-TB drugs and received counseling on treatment adherence.

When Abdi began treatment in April 2017 he was too weak to travel to the nearby health center, so he stayed at home taking the TB treatment under the observation of his son. "I feel a lot stronger now," says Abdi, "Going to the health center for treatment every day would have been difficult because of the distance and the cost of transport."

Among the eight members of Abdi's family that were screened for TB, three were diagnosed with pulmonary TB using GeneXpert and put on treatment. Today, GeneXpert rapid diagnosis, shorter turnaround times, and appropriate anti-TB treatment are improving people's chance of early diagnosis and cure, as well as reducing the further transmission of TB.

Mustafa is committed to raising awareness of the disease, and continues to provide support for new TB patients: "Thanks to my training I now know a lot about TB and I'm teaching my peers in the mine so that our workplace and families remain safe."

### FINDING THE MISSING CASES

A fghanistan has made significant improvements in expanding essential health care services, but rural communities continue to face barriers to access. Each year, roughly 13,000 Afghans die from TB, and many of these deaths occur in rural regions where residents have limited access to TB screening and treatment. In hard to reach areas, TB detection rates remain very low, putting rural populations at higher risk of contracting the disease.

Challenge TB works with Afghanistan's National Tuberculosis Control Program to strengthen TB diagnosis, treatment, and care in 15 provinces, including Paktika, a rural province in south eastern Afghanistan.

In August 2016, Challenge TB established the Cure TB Patient Association at the Mota Khan Comprehensive Health Center (CHC). This association is comprised of six people cured of TB, two TB patients in treatment, three community members (e.g., religious leaders or school teachers) and one private health care provider. The association members were trained on communitybased interventions, such as active case-finding, patient support, directly-observed treatment, and community education.

Khial Mohammad (12) lives in the village of Moshikhil in Paktika. For over a year, he suffered the symptoms of a urinary tract infection. Private and public health practitioners and pharmacists all tried to treat him but nothing worked, he was finally diagnosed with a bladder stone and he was operated on to remove it. The operation was a success, but the wound left after surgery did not heal properly.

By chance, a member of the association met with Khial's father during a wedding ceremony and when he heard about Khial's condition he suggested it might be TB and encouraged him to take his son to the Mota Khan CHC. At the health center, Khial was diagnosed with TB of the urinary tract and he was started on treatment. After completing the two-month initial phase of treatment, his wound had finally healed, and he had already gained weight.

"I went to many health facilities, but no one knew I had TB," said Khial, "but thanks to the doctors at Mota Khan CHC, I am feeling better."

Khial continues to receive his TB treatment from a treatment center near where he lives and can he can continue to attend school.

"All my family members will also be screened. I am so grateful to receive free health care, without the assistance of Challenge TB, I probably would have died."

Challenge TB has already launched 150 Cure TB Associations in 15 provinces. These associations have so far identified and referred 29,000 presumptive TB patients for testing, of which over 2,000 were diagnosed with TB.





## AGAINST THE ODDS

f you know Edwin Mhango but have not seen him for a year, you would be very surprised if you were to see him today. This reason is simple: In August 2016, Edwin was so sick most people thought that he would not survive.

One day in 2016 as he was walking back home from his fishing business, Edwin stumbled on a stone and fell, "As I lay on the ground, my chest felt heavy," he said, "I had difficulty breathing and I coughed up some blood." With great difficulty, he managed to get home, where his wife Martha saw how bad he was and immediately took him to the hospital where he was diagnosed with MDR-TB.

This was not the first time Edwin had suffered from TB. Back in 2015 he was also diagnosed with TB and was put on treatment, but because his fishing business takes him from one place to another, he had not stuck to his treatment. The health center that was treating him tried to find him but couldn't and he was declared lost to follow-up. As he did not complete his course of treatment, he developed MDR-TB, a form of TB infection caused by bacteria that are resistant to treatment with at least two of the most powerful first-line anti-TB drugs, isoniazid and rifampicin. treatment and since then he has taken the drugs exactly as prescribed, he said, "Since I was put on TB treatment for the second time, my health has improved dramatically and I am now back in my fishing business."

Mr. Paul Chiwenkha, the District TB Officer for Karonga District is one of 35 health workers who have been trained by Challenge TB in TB Management and MDR-TB, he said, "As a health worker I am really happy with the progress Edwin has made and I thank Challenge TB for the technical support provided to Karonga district health workers."

Challenge TB has also supported a mentoring program, review meetings and coaching in the 15 districts in which the project works. All these efforts are designed to improve healthcare workers' knowledge and skills in diagnosing and managing TB cases effectively.

Edwin has now been on anti-TB drugs for 12 months and is currently in the continuation phase of his MDR-TB treatment. He has another 12 months to go but is confident he can do it and says: "I am very grateful for the help and support which the healthcare workers give me, without them, it would not be possible."

Soon after he was diagnosed he was put on

# PUBLICATIONS



### Making Sense of TB data - Guide for collection, analysis and use of TB data for health workers in Zimbabwe

This guide for health workers is designed to improve the quality of data. The principles of TB control are translated into key questions that the data should talk to and a list of key indicators to measure.

#### https://www.challengetb.org/publications/tools/country/Making\_ Sense\_of\_TB\_Data.pdf

#### Tuberculosis Infection Control Manual Myanmar – English/Burmese

This manual is complementary to the overall TB infection prevention and control policy in Myanmar and is designed to assist in the establishment of a framework for TB-IC in healthcare facilities, as well as in those congregate and community settings.

English: https://www.challengetb.org/publications/tools/country/ TB\_Infection\_Control\_Manual\_Myanmar\_Eng.pdf

Burmese: https://www.challengetb.org/publications/tools/country/ TB\_Infection\_Control\_Manual\_Myanmar\_Bur.pdf

#### Article:

Addressing tuberculosis control in fragile states: Urban DOTS experience in Kabul, Afghanistan, 2009-2015

http://journals.plos.org/plosone/article?id=10.1371/journal. pone.0178053

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#### What is Challenge TB?

Challenge TB is the flagship global mechanism for implementing USAID's TB strategy as well as contributing to TB/HIV activities under the U.S. President's Emergency Plan for AIDS Relief (PEPFAR).



Challenge TB is led by KNCV Tuberculosis Foundation and implemented by a unique coalition of nine organizations: American Thoracic Society (ATS), FHI 360, International Union Against Tuberculosis and Lung Disease (The Union), Interactive Research & Development (IRD), Japan Anti-Tuberculosis Association (JATA), Management Sciences for Health (MSH), PATH and the World Health Organization (WHO).

### Challenge TB contributes to the WHO End TB Strategy targets:

Vision: A world free of TB Goal: To end the global TB epidemic By 2025: A 75% reduction in TB deaths (compared with 2015) and less than 50 cases per 100,000 population.

Global Fund:

Challenge TB assists countries with the full Global Fund life cycle, from epi-analysis and national strategic plans to concept notes and full implementation.

#### Overarching:

Challenge TB is a cost-effective and efficient mechanism with a particular emphasis on reaching out to vulnerable communities. It assists countries to move towards universal access through a patientcentered approach that identifies and addresses the needs of all patients including women and children.

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