

Annual Review 2015-16

## Welcome

It is a pleasure to welcome you to this year's review of TB Alert's work and describe how, with your support, we are continuing to help people access life-saving treatment.

I am writing this a few days after the UK pledged £1.1 billion towards the next three years' work of the Global Fund to Fight AIDS, TB and Malaria. This fantastic commitment will save millions of lives and reinforces the UK's position as a global leader in fighting poverty and disease. The Global Fund is the world's largest single funder of treatment for tuberculosis and TB Alert is proud to be working in India and Africa as a partner of the Fund to help implement their programmes on the ground.



But how much do most people understand of the three diseases the Global Fund tackles? For many people the answer is 'two out of three'. They understand malaria is spread by mosquitoes and can be prevented using bed nets. And most people know HIV is transmitted by bodily fluids and how the risks can be minimised. But tuberculosis is less well understood; ask a group of people what they know about TB and one response you are sure to hear is "hasn't it been eradicated?"

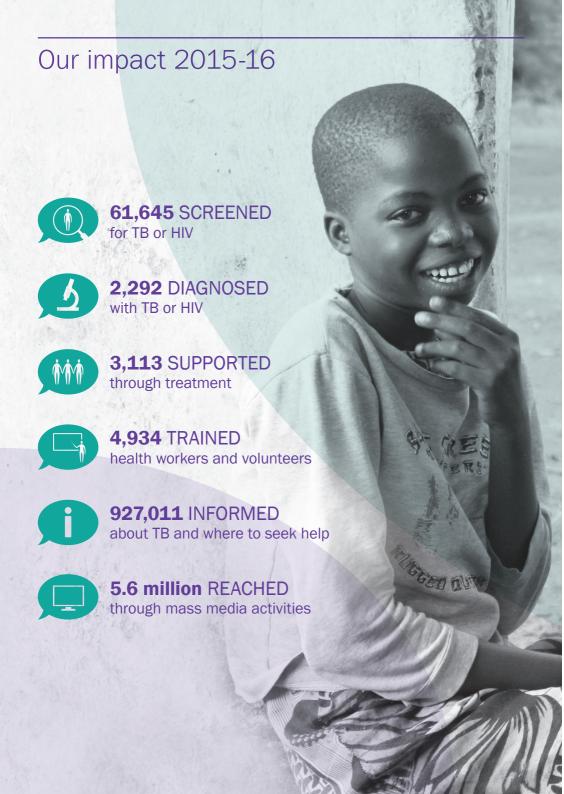
No, TB has not gone away. The number of people dying is slowly reducing – by 1.5% a year – but over one and a half million people around the world still lose their lives every year to this curable disease.

We need the world to sit up and take notice of the global TB epidemic. And for that to happen we need people to better understand this complex disease. That is why, like last year, our annual review describes our work by breaking it down into the five key stages of tackling TB: Prevention > Access > Diagnosis > Treatment & Care > Control.

This year's review also shines a spotlight on our sister organisation TB Alert India and its work in the country which carries over 20% of the world's burden of tuberculosis. And it's a year when we are proud to tell you that, for the first time, TB Alert's work was supported by the UK's three main funders of charities working in developing countries – Comic Relief, the Big Lottery Fund and the Department for International Development – which validates the high quality of our work.

Thank you for supporting TB Alert and our work to reach the many people – some three million every year – who don't receive the diagnosis or treatment they need. It is for them we exist, and it is with them in mind that we aim to deliver our mission statement of "access to effective treatment for all".

Mike Mandelbaum
Chief Executive



## Money matters 2015-16





For every £1 we received

**96p** was spent on programmes to tackle TB

**3p** was spent on raising vital funds

1p was spent on governance

## Spotlight on TB Alert India

In a country where over two million people develop TB each year and over half a million of them do not receive a proper diagnosis or treatment, India is at the epicentre of the global fight against TB.

So from TB Alert's earliest days the charity saw both a need and the potential to make a major contribution to India's fight against TB. The chosen route was to set up a sister organisation, TB Alert India. Founded in 2004, our younger sister quickly grew up and today we are like twins, working hand-in-hand to support each other's programmes and advocacy work.

Based in the southern city of Hyderabad, TB Alert India's work is based on a belief that successful projects are planned in consultation with the communities they help. So community engagement, social mobilisation and advocacy run through its work.



## TB Alert India's projects are today benefiting over 12.5 million people. This is a snapshot of just some of its work:

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- In Delhi, the Divine project is based in urban slums that lack basic health services. The project's awareness activities help people understand that TB is curable, while its diagnostic centres located in the heart of the slums make it easy for people to attend for a sputum test. For patients diagnosed with TB, the project links them to the local TB hospital for treatment and helps make sure they receive the support they need for a successful cure.
- In 13 districts across the states of Andhra Pradesh and Telangana, TB Alert India is entrusted with delivering the nationwide Axshya project funded by the Global Fund to Fight AIDS, TB and Malaria and led by World Vision India. The project bridges crucial gaps in India's National Strategic Plan and aims particularly at increasing the number of cases of TB found among the most vulnerable populations.

If you would like to know more about TB Alert India's work or to visit its projects, our UK office would be glad to put you in touch with TB Alert India. Please do get in contact!



- In rural areas of Telangana, the innovative PRATAM project tackles the fact that most sick people go to practitioners who have barely any medical training. As a result people's TB is often not diagnosed. By training these practitioners as well as local pharmacists, the quality of healthcare for whole communities is being improved and TB patients are being diagnosed and successfully treated.
- In the state of Tamil Nadu, TB Alert and TB Alert India are working together on our Educate, Prevent and Treat project. It focuses especially on tackling the stigma and discrimination which prevent women, children and people living with HIV from seeking treatment. Through a team of outreach workers the project helps ensure people with TB are found and treated.

## Control

When someone is diagnosed with TB, healthcare services try to find out if the patient has infected anyone else, or indeed if they can find the person who originally infected the patient. Since TB is most easily transmitted between people who spend a lot of time in close proximity to each other, especially in poorly ventilated conditions, 'contact tracing' usually begins at the patient's home.

In the Mukundpur district of Delhi, 19 year old Anjali lives in a small room with her parents, brother and two sisters. She had already been feeling ill for two months when she attended an awareness event run by TB Alert India's Delhi Divine programme. Our staff noticed Anjali's symptoms and the next morning gave her a sputum test at our microscopy centre. When her test came back positive, Delhi Divine staff visited her home to counsel the family about TB and encourage them to be tested themselves. As a result, her sister Chandni was also diagnosed with TB and began her own course of treatment. Delhi Divine's visit is also likely to have prevented more members of Anjali's family, and other people in the wider community, from becoming ill.



The number of patients identified this way shows the critical importance of contact tracing. During the year, Delhi Divine tested 1,113 family contacts of whom 51 had TB – a diagnosis rate of over 4.5%. That is why our projects focus not just on working with individual patients, but also their families and the wider community.



## **Treatment and Care**

TB treatment is challenging for all patients; it lasts at least six months and the drugs can cause difficult side effects. For children, treatment poses additional challenges. Already weakened by TB, they may have difficulty swallowing adult sized pills or ingesting them crushed into a bitter drink. Both the TB symptoms and the unpleasant medication, can leave children without an appetite to sustain their recovery. Nutritious food could counteract this, but poor families with little education lack understanding of nutrition and, even if they didn't, they don't have the money to buy enough food.



all these problems when she began treatment for pulmonary TB. But since she lives in the Thyolo district of Malawi where one of our projects operates, her care-giving aunt could attend nutrition training provided by our outreach team. She learned about the different food groups and what kind of diet would best help Tamardani during her treatment.

She was also given seeds and shown how to set up their own vegetable garden to provide a steady supply of nutritious food now and in the future. The project also gave Tamardani high protein food packages including peanut butter, cooking oil, soy and corn, which helped her tolerate the medicine and complete her treatment.

"I used to feel tired and could not attend my classes in the beginning. But with the food I got, I felt healthy and did not miss my classes anymore", said a happy Tamardani.



# WORKING FOR A FUTURE WITHOUT TB

## TB alert

## Prevention. Access. Diagnosis. Treatment and Care. Control.

Each stage in the TB pathway is intrinsically linked to the others: for example, if someone is helped to access health services they need to be correctly diagnosed and then treated. So TB Alert's approach is based on understanding the needs of each patient, each family, or each community, and then providing the help they need.

## Diagnosis

Low awareness of TB among healthcare providers means people often experience delays in diagnosis – if they are diagnosed at all – even after they seek help for their symptoms. We see this every day in India where most people favour private healthcare providers, who often lack formal training, over government health services. The story of 19 year old college student Shruti illustrates this and shows the importance of TB Alert working with healthcare providers as well as with patients and communities.

When Shruti fell ill with a cough, fever and night sweats, her parents took her to an unqualified local provider. Although he gave her antibiotics they were the wrong ones for TB so she did not improve. In desperation, they took her to a traditional healer who said Shruti had fallen victim to black magic and tried to break the spell by beating her, shaving her head and giving herbal remedies.

Then Shruti's brother visited a local pharmacist whose owner, Mr Mukesh, had been trained by TB Alert India as part of the PRATAM project. This initiative, spanning seven districts of Telangana state, recognises that in rural areas pharmacists and unqualified healthcare providers are the first port of call for most people. By providing training on the symptoms and correct treatment of TB, pharmacists and providers know to refer patients to the local government TB clinic.



That is exactly what happened for Shruti. Mr Mukesh recognised her symptoms as typical of TB, referred her to the TB clinic and informed our outreach worker about her case. The outreach worker made a home visit to ensure Shruti went for testing, and after she was diagnosed he made sure Shruti's brother stayed in close contact with the local health visitor to monitor Shruti's progress.

Shruti has now been successfully treated and is back at college continuing her studies.

## Prevention

When someone breathes in TB bacteria which their immune system cannot clear, they will not necessarily become ill. More often they will get latent TB, the sleeping form of TB with which one-third of the world's population is infected. For 5-10% of these people, their latent TB will wake up, or 'reactivate', in later years and develop into the 'active' disease we usually mean when we talk about tuberculosis.

Latent TB can however be treated to greatly reduce the chance of it reactivating in later years. While it is impossible on a global scale to identify and treat everyone with latent TB, in a well-resourced country like England where TB is concentrated among specific population groups, diagnosing and treating latent TB can be a powerful tool.

This is why England's national TB strategy calls for health services to test and treat latent TB among people moving to England from countries where TB is more common and where – possibly many years ago – they are more likely to have been infected.

This new latent TB programme presents a number of challenges, including how to promote the programme to people who usually will not have heard of latent TB, and how to plan TB services to best support patients during testing and treatment. At the request of NHS England and Public Health England, TB Alert developed a toolkit to guide health services on all these patient-centred issues.



Our 'Access, testing and treatment' toolkit provides guidance and resources to help ensure that everyone who is eligible has the chance to be tested and, if they are shown to have latent TB, successfully treated.



### Access

Helping people access TB treatment is at the heart of TB Alert's work. Over three million people each year are not treated at all or receive sub-standard treatment, which endangers their lives and risks them infecting other people within their families and communities.

When patients do receive the right medication, it is often after a delay of many months. This may be because they do not recognise their symptoms could be TB or do not know that TB is curable, or because they fear the stigma a TB diagnosis can bring. For other people, they do not know that medication is free or they cannot afford the diagnosis costs some clinics charge. This is why TB Alert provides information and hands-on support to help people access diagnosis and treatment.



We help people like 31 year old Zororai from Chimanimani in Zimbabwe, who first sought help from a 'prophet church' for his stomach ache and fever. He was told his pains were caused by witchcraft and he was given a mixture to make him vomit out the evil spirits inside him. But his condition only worsened. When he began to cough, a relative asked him to go to a nearby hospital but Zororai did not go because he could not afford the consultation fee.

Fortunately, Zororai was visited by a volunteer from TB Alert's TB-HIV Action project. The trained volunteer recognised Zororai's symptoms as suggesting TB and arranged for his sputum to be tested. Zororai was quickly diagnosed with TB and started on the free treatment. He made a full recovery and is now getting on with his life. "Without the volunteer's support, I would have continued suffering and paying money to traditional healers" said Zororai.

## www.tbalert.org

## You make it possible - Thank you

Our life-saving work comes about through a wide range of inspiring partnerships involving many individuals and organisations. But without money we could do nothing, so every day we are grateful for the support of our donors who allow us to link people to diagnostic and treatment services, be a source of expert advice and information, and to provide practical support to patients and their families. It is also thanks to your support that we can invest in developing the high quality programmes which go on to be funded by larger, institutional funders.

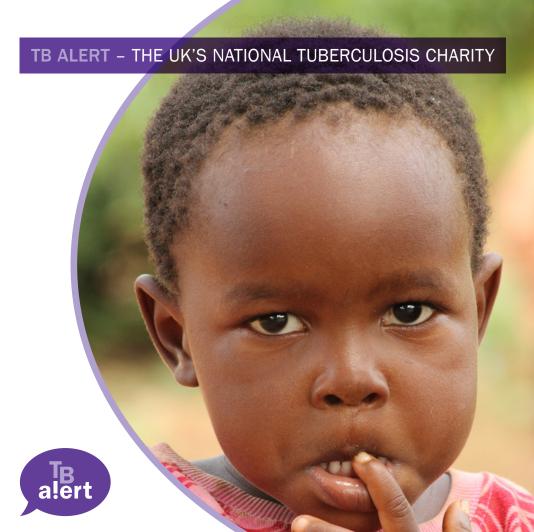
We are exceptionally grateful to those of you who are inspired by your own experience of TB to give your time, money or effort to help others. We know that many of you have fought TB yourselves, or supported loved ones through the illness, and do not want others to endure the same experience.

Our supporters also include those with a professional interest in TB, who recognise TB Alert's crucial role in helping people access the treatment they need. Thank you – your passion and commitment is invaluable to us.

"TB has a profound impact on the people it affects as well as those who care for them. I have experienced TB in my own family, so I've seen first-hand how devastating it can be. In my work as a doctor I have also helped TB patients who do not have the love and support of family and friends, or who worry about having food to eat or somewhere to live. This is why I support TB Alert's work on top of my work as a physician. A TB free world is my ultimate dream!"

Dr Balaji (pictured with his wife, Ramah). Together they raised over £800 for TB Alert by running the Lichfield 10K.





Our vision is the control and ultimate elimination of TB

Our mission is to increase access to effective treatment for all

www.tbalert.org • www.thetruthabouttb.org • www.tbalertindia.org

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