

**TB
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INDIA**

for a future without tuberculosis

Annual Report 2018-19





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Abbreviations used

AP	Andhra Pradesh TBAI - TB Alert India
BCC	Behaviour Change Communication
BLF	Big Lottery Fund
CB-NAAT	Cartridge Based Nucleic Acid Amplification Test
CBOs	Community based organisations
CCM	Country Coordination Mechanism
CEO	Chief Executive Officer
CHW	Community Health Worker
CSR	Civil Society Representatives
CTD	Central TB Division
DMCs	Designated Microscopic Centres
DfID	UK Department for International Development
DRTB	Drug-Resistant TB
HIV	Human Immuno Virus
IEC	Information, Education and Communication
IT	Information Technology
J&J	Johnson & Johnson
KOLs	Key Opinion Leaders
LTFQ	Less than fully qualified doctors
MDR TB	Multi-drug Resistant TB

NGOs	Non-government Organisations
NSP	National Strategic Plan
ORW	Outreach Worker
PPs	Private Providers
PPSAs	Patient Provider Support Agencies
UK	United Kingdom
RNTCP	Revised National Tuberculosis Control Programme
RRA	RESEARCH - REPORT - ADVOCATE
STCI	Standards of TB treatment in India
STLS	Senior TB Laboratory Supervisors
STS	Senior Treatment Supervisors
TB	Tuberculosis
TCs	Treatment Coordinators
THALI	Tuberculosis Health Action Learning Initiative
TN	Tamil Nadu
ToTs	Training of Trainers
TUs	Treatment Units
USAID	United States Aid for International Development

Note to readers

It gives us at TB Alert India (TBAI) great pleasure to share this Annual Report for 2018-19 with you. We view our Annual Report as a duty and obligation that we owe to our donors, associates and to the people whose lives we wish to make a difference to. However, we also view it as a celebration of our work, and as an initiative that helps us to critically review our work over the year, rejoice over our successes, learn from our mistakes, and gear up with renewed enthusiasm for the next.

It is an exciting time to be working in the field of TB prevention and care as there is strong international and national commitment towards eliminating TB. This however will not be possible if TB is not eliminated in India as it carries the highest burden in the world. Further, elimination of TB is not possible without the involvement of all stakeholders. This places TBAI in a very crucial position, as over the years, the organisation has placed special focus on drawing all stakeholders be it private providers, pharmacies or any other, into its fold with special initiatives.

TBAI has also embarked on an ambitious growth path, which has been mapped out by its three-year strategic plans. This has come out of some key learnings over the years that for real progress, there is a need to have a few clear strategic priorities, with sub-strategies housed within. The priorities that have emerged are:

- ☞ Sharp and effective communications strategy and plan
- ☞ Regular reviews and recognition of areas for improvement
- ☞ Networking and representation on various TB forums
- ☞ Publishing impactful interventions in peer-reviewed journals and collaboration with academic institutions for enhancing brand value
- ☞ Building sustainability through multiple avenues for resource mobilization aside of institutional donors

TBAI is taking serious note of these learnings and has incorporated them into the latest Strategic Plan. We thank the Governments of Telangana, Andhra Pradesh, and Delhi, all our donors, and communities and associates for their unstinting support and trust in us. We will continue to engage with you all and we urge you to follow our progress and continue to encourage us. Please do join hands with us in our efforts to eliminate TB.

Team TBAI!

About TB Alert

TB Alert was registered in the United Kingdom (UK) in late 1998 and launched at the Houses of Parliament on World TB Day (24th March) 1999. The charity was set up by people who felt that with its long tradition of TB work, there should be a greater response in Britain to the resurgent threat of tuberculosis, which was declared a global emergency by the World Health Organization in 1993. Active trustees include several leading UK-based TB experts. Currently, TB Alert is present in the UK, India, Malawi, Zambia, Zimbabwe and Southern Africa.

About TB Alert India (TBAI)

TB Alert India (TBAI), the Indian arm of TB Alert works to the vision of a 'TB Free India'. It aims to prevent morbidity and mortality associated with TB by providing holistic TB care i.e. addressing psycho-social and economic aspects which affect uptake of TB testing and treatment. Transparency, quality consciousness, responsiveness and integrity are the key values and guiding principles of TBAI. TBAI has a clear strategic approach to:

- ❖ Increase access to information about TB, TB testing and TB treatment;
- ❖ Work with service providers, disease affected people and communities;
- ❖ Build the capacities of local communities and other stakeholders to tackle TB;
- ❖ Integrate TB management approaches with that of other **infections** such as Diabetes and HIV/TB and into other social development themes;
- ❖ Address social determinants of TB i.e. poverty, malnourishment and economic support.

Over 15 years of work towards fighting TB, TBAI has addressed a wide range of essential issues. TBAI has implemented projects which focus on four key aspects:

- ❖ **Create** awareness and facilitating TB testing;
- ❖ Treatment **Adherence**;
- ❖ Sustainable engagement of key stakeholders who directly or indirectly influence the response to TB;
- ❖ Building capacities of stakeholders and communities for greater involvement in the fight against TB.

TBAI is aided in its work by a diverse funding base that includes multilateral, bilateral, corporate and other donors and a strong team of frontline workers. TBAI is working at present in Telangana, Andhra Pradesh and Delhi in India. TBAI has served as the Civil Society Representative (CSR) for TB on India's Country Coordination Mechanism (CCM) from 2012 to 2015.

In the reporting year 2018-2019

TBAI worked across all its projects on thematic areas emerging from the three core pillars of End TB Strategy. The thematic areas were designed to address the needs of TB prevention and care holistically by involving all stakeholders. TBAI adopted an integrated approach that cross-cut the thematic areas to benefit the most affected and needy populations.

In all its operational states, TBAI worked closely with local state governments on prevention, awareness, diagnosis, referrals and treatment support. TBAI teams actively identified people from the community who had symptoms suggestive of TB and referred them for diagnostic tests at designated microscopy centres (DMCs) housed in the localities.

TBAI also facilitated awareness and capacity building for government health care providers on TB care and treatment. This included provision of IEC materials, training programmes and community awareness efforts.



Private provider engagement

The private sector is the first point of contact for 50-80% of patients seeking health care services. Therefore TBAI adopted several approaches to engage a wide spectrum of private health care providers ranging from informal providers (less than fully qualified providers), qualified providers and pharmacists. Two approaches are used with respect to engaging private providers. The first approach was to encourage private providers like informal providers /pharmacies to link TB symptomatic people to the nearest RNTCP facilities for testing and treatment initiation. The second approach was to sensitize qualified private providers (PPPs) on standards of TB treatment in India (STCI) and ensure enabling environment for effective testing, treatment follow up and notification of TB patients (treated by private providers) to RNTCP. User friendly IT platforms were piloted for notification and treatment and follow-up with patients put on treatment.



Community Engagement

Engaging communities is very crucial in the fight against TB. In the reporting year, TBAI worked to a goal of gaining a 10% improvement in TB notification and treatment success rates. The key activities were community-centric TB case-finding, TB case-holding for treatment completion through a helpline, operational research and leveraging resources. Additional efforts were made to build greater awareness among communities and encourage them to seek timely diagnosis and treatment. Cured patients were also encouraged to come forward and speak about their experiences with the aim to dispel fears and myths so that greater numbers would seek help. Community based organisations (CBOs) were engaged for identification and referral of presumptive TB cases and act as sustainable structures for TB services. Rallies and community meetings were held to encourage open discussions around TB, a disease which is clouded in stigma and resistance. The overall message was that TB is both preventable and curable.

World TB Day to World Health Day - a campaign to End TB

On the eve of World TB Day, in line with the WHO theme of 'Wanted: Leaders to End TB! TBAI organized an event in collaboration with the state RNTCP to celebrate partnerships to eliminate TB. Katherine B. Hadda, US Consul General for Hyderabad, was the chief guest at the event, which was also attended by state RNTCP officials. Community volunteers, key opinion leaders and outreach workers were awarded for their extraordinary efforts to eliminate TB in Hyderabad. A photo exhibition depicting implementation components of the THALI project, implemented by TBAI was also organised. Over the two-week period, the TBAI team organized road shows, set up information kiosks and conducted TB sensitization sessions for school children and daily wage labourers, with the support of the RNTCP.

Patient advocates nominated to Telangana state-level TB forum

Two patient advocates and Mr. Vikas Panibatla, CEO of TB Alert India, were part of the State level TB forum meeting organized by Telangana RNTCP. This meeting was held under chairmanship of Ms Santi Kumari, Principal Secretary, Health and Dr Yogitha Rana, Commissioner of Health and Family Welfare in Telangana, Joint Director-TB, Telangana were part of the programme.

The state-level TB forum will involve participants from allied government departments and NGOs, as well as TB officials and TB champions. It will advise the state government on strategies for engaging with communities and increasing community participation in the TB program. This forum will meet once in three months. The patient advocates, Mr Ramachander and Ms Saraswati are active members of the community who take part in TB prevention and cure efforts and in patient support groups. They were invited to share their experiences at the meeting.

Enlisting livelihood and nutrition support from the community

The TBAI field team in Andhra Pradesh makes continuous efforts to mobilise nutrition support for poor and needy patients. Through a government employee, they got in touch with Dr Vijay Kumar, a medical officer at a steel plant in Vishakhapatnam who agreed to support 15 TB patients with nutritious food worth INR 6000.



Rashida, a community health worker (CHW) in Vijayawada mobilized livelihood support for a patient who was unable to work. She approached World Vision, which donated a handcart worth INR 6500 under its Premadhara project. The patient's wife is now using the cart to sell vegetables and earn an income with which she can support the family and provide nutritious food to her husband.

Harnessing the community's potential to support TB patients

Akshita's father is an electrician in Hyderabad who works hard to provide a good life to his wife and three daughters. Afflicted with TB, he struggled with treatment adherence and passed the infection to Akshita and her sister. With three patients in the family, he could no longer afford 15-year-old Akshita's school fees. She was determined to appear for her exams despite having TB, but the



school refused to allow her until the fees were paid. The community health worker (CHW) realized the situation and the TB Alert team contacted a local philanthropist and retired Army officer, Major Shankar Narayana. Not only did Major Narayana agree to help the family with Akshita's school fees, he personally accompanied her to make the payment. He also pledged to support the whole family with nutritional food during their treatment period. Akshita is now seriously involved in exam preparation and Major Narayana is rooting for her. "Akshita's success in her exams will be a return gift to me," he says.

Rally to end TB

TBAI participated in a rally and meeting organized by the state government in Hyderabad on March 25. Over a thousand people, including TB Champions, key opinion leaders (KOLs), patients and families, health officials, NGOs and medical students attended the event. TBAI - THALI's TB Champions and CHWs shared with the gathering, their efforts towards ending TB and sang a song composed by the TBAI team on eliminating TB. The state government released a set of behaviour change communication (BCC) materials developed under THALI and expressed its appreciation for TBAI's work.



Patient advocates actively engage with TB programs across Telangana and AP

Patient advocates identified by TBAI in Telangana and Andhra Pradesh (AP) have been raising their voices and sharing their experiences at state events and stakeholder meetings. At World TB Day events organized by the states, patient advocates inspired audiences with their testimonies about beating TB and helping those in their communities. All these patient advocates were felicitated by the RNTCP for their involvement in TB control efforts at the community level.

Capacity Building

Capacity building for stakeholders is a vital part of TB prevention and cure. TBAI has identified areas that need to be strengthened and has intensified capacity building efforts in order to create cadres of informed community members, health care providers, and others. In the reporting year, TBAI conducted several capacity building programmes, which are outlined below.

Training for health care professionals

TBAI supported the Telangana state RNTCP to facilitate two Training of Trainers (ToTs) programs, covering 71 RNTCP project officers and District TB Control Officers on technical operational guidelines and the programmatic management of drug resistant TB (PMDT) in Hyderabad and Warangal. The training was conducted at Hyderabad by state officials and WHO Consultants and the funding for this was leveraged from Johnson & Johnson (J&J). Judith Kallenberg, Program Lead of the TB focus area at J&J visited Hyderabad to understand how J&J's support for information, education and communication (IEC) activities is improving TB awareness in the urban slum community. The team met with officials at the State Tuberculosis Office.

Counselling skills for RNTCP staff in Telangana

TBAI along with technical experts conducted training of trainers (TOT) workshops to create a pool of state master trainers with the ability to provide counselling to TB patients. From October 23-25, the first workshop in Hyderabad engaged 36 participants from 16 districts of Telangana. These included Senior Treatment Supervisors (STS), Senior TB Laboratory Supervisors (STLS), district public-private mix and advocacy, and communication and social mobilisation coordinators. The training involved case-based discussions and role plays, based on the counselling training manual developed by the team.



ToTs and trainings on approach to community structures

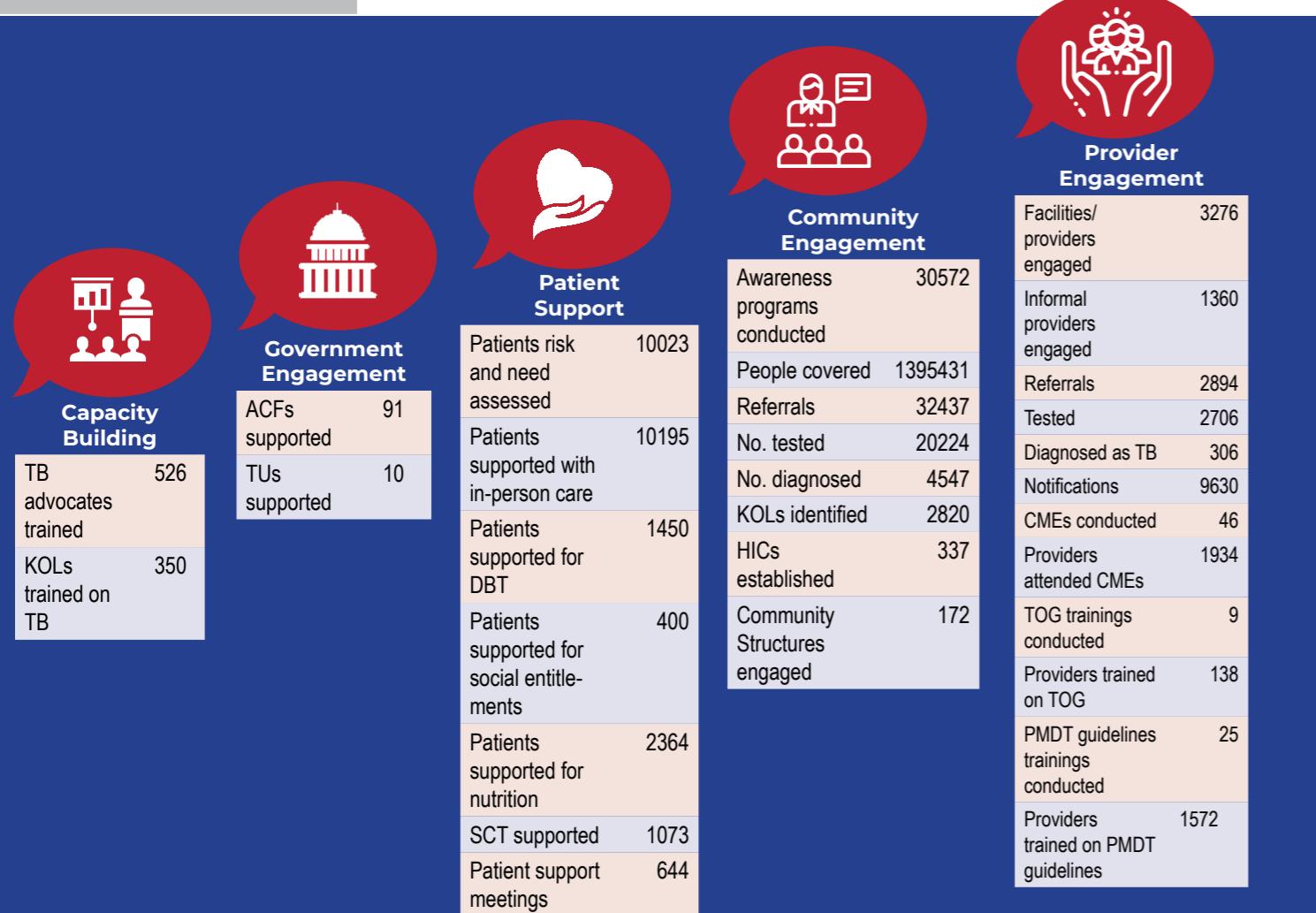
TOTs were held for zonal and community coordinators in Telangana to facilitate clarity on working with community structures. The team emphasized the need for sustainable structures at the grassroots level to continue patient-centred care and support efforts beyond the project period in alignment with the RNTCP's principles.

The strategy focused on engaging with existing group-driven, context-specific and representative community structures that can potentially expand their scope to include TB activities in communities. Participants of the workshop identified various community structures with which they could associate to continue the program's approach to prevention, care and support such as self-help groups, slum associations and labour unions etc.



TB Alert INDIA – THE YEAR THAT WAS for a future without tuberculosis

Outreach # Counselling # Research # Partnership
Education # Community Awareness # Advocacy
Innovations # Capacity Building



News and Events

In the reporting period, TBAI organized and participated in several important events. These events were dedicated to TB prevention and cure, capacity building for TB advocacy among patient advocacy. Brief capsules of all events and happenings are listed below:

Awards and recognition

TBAI received a TB Champion award from Dr Yogitha Rana, IAS, the Commissioner, Health and Family Welfare and the Mission Director, National Health Mission, in Telangana for its hard work and support to the RNTCP in the state. The field staff and patient advocates received no less than seven awards for their contributions to TB control at district level events marking World TB Day.

For the second year, TBAI received the state award for contribution to TB elimination in Telangana. The award was received by Vikas Panibatla, CEO of TBAI at an event organized by RNTCP, Telangana State.



services provided by the government and encouraged local leaders to be part of India's mission to eradicate TB by 2025.



RNTCP participates in TBAI community consultation

The Commissioner of Health and Family Welfare, Telangana, had expressed interest in attending a large group meeting, which TBAI organized in Amberpet, Hyderabad on February 22, mobilizing 200 slum dwellers. The State TB Officer Dr Rajesham attended on the Commissioner's behalf, along with other state TB officials and Ms K Padma, the Municipal Corporator of the area. Dr Rajesham urged the community to come forward and avail the

Participating in the Preparatory Meeting for The Union's 50th World Lung Health Conference

TBAI has been steadily building the capacity of patient advocates to improve their abilities to represent the TB patient community at various platforms. 18 patient advocates shared their experiences at a preparatory meeting for The Union's 50th World Lung Health Conference to be held in Hyderabad from October 30 – November 2. TBAI CHWs also began involving patient advocates in individual interactions and counselling sessions with patients. They found that matching patient vulnerabilities was effective during counselling, a Drug-Resistant TB (DRTB) or diabetic patient was more receptive to a patient advocate with DRTB or diabetes.

Voices from the field:

"I knew two ladies who died of TB. They couldn't even tell us women that they had the disease. Our people are dying of shame, instead of going to the doctor. I want support to bring them out of their houses, and get them free treatment." - **Parveen Ayesha**, who helps run a health information centre with a friend in Hyderabad

"When I was 17, my maternal uncle died of TB, and his family was driven into poverty. Had he taken the correct medicine, he would have survived. I now treat every patient as I would have wanted my uncle to be treated. No family should have to go through what his family did." - **Uma Maheshwari**, Outreach Worker (ORW), Hyderabad

"I've worked so hard for TB, my family jokes that I'm no longer interested in my household. But it is important work, and I am proud to do it. People come together in the slums when I visit. They bring presumptive TB cases to me when they see symptoms. They trust us to help them." - **Parveen**, ORW, Hyderabad

"THALI supported us in carrying out ACF activities in a very efficient manner. I have requested the support of the TBAI and THALI team in our future campaigns as well and am happy to hear that they will be extending their support in Ranga Reddy district." - **Mr. Madhu Babu**, Senior Treatment Supervisor, Rajendra Nagar TU, Ranga Reddy district

"Through the monthly (patient support group) meetings I facilitate, more and more cases of TB are coming to my attention from the patients at the support group."

Nasreen Sultana, CHW, Hyderabad, Telangana

"The Differentiated Care Model as an innovation sounds good to us as it may result in better treatment outcomes among high-priority patients." - **Dr Rajesham**, State TB Officer, Telangana

"I am delighted that the voices of my daughter and the entire community of people affected by TB will be heard at the **Union World Conference**. We cannot end the TB emergency unless TB survivors are positioned at the front and centre of the response."

N Saritha, a TB advocate identified by TBAI. Her 13-year-old daughter Maheswari has been cured of TB.



Case Stories:

Building peer support through positive experiences shared at Patient Support Group meetings

Mehboob is an auto driver living in the old city of Hyderabad. Years ago, his wife had contracted TB and although she recovered fully, he remembers not fully understanding her condition, which compounded the stress of seeing her unwell. Recently, when his daughter was diagnosed with TB at her marital home in Belgaum, Karnataka, he brought her home to get her treated. The TBAI - THALI community health worker(CHW) reached out to the family, and gave them clear and accurate information on TB, which helped Rehana and her family overcome their fears and understand that recovery was possible through a complete course of medication.

Parveen, the THALI CHW working with them, saw in the family an exemplary story of support, which could motivate other families to pull together, guide, and support patients through treatment. As Rehana's condition improved, she attended support group meetings to share how her parents' help with the care of her young child, and her husband's visits from her marital home helped her feel cheerful and confident that she would get better, motivating her to take every single dose of medicine.

Discussions during patient support group meetings have revealed how women particularly bear the brunt of isolation and stigma from their families during treatment, causing them to abandon their hopes of getting better, and affecting treatment adherence. By bringing voices from patients like Rehana and her parents into support groups, CHWs work towards making patients and caregivers understand the importance of family support in keeping a patient on the road to recovery.





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