Annual Report
2020
TBAI acknowledges the support of the following:

- Governments of Andhra Pradesh, Delhi, Haryana, and Telangana
- NTEP
- District units of NTEP
- STOs of Andhra Pradesh, Delhi, Haryana and Telangana

Donors:

- The Global Fund
- Clinton Health Action Initiative (CHAI)
- FIND India
- Johnson & Johnson Pvt Ltd
- Karnataka Health Promotion Trust (KHPT)
- Stop TB Partnership
- TB Alert - UK
Dear Friend,

It gives us at TB Alert India, great pleasure to present to you a brief report of our activities in the year 2020.

It was an unprecedented year and brought with it challenges that no one in the world had probably foreseen. The COVID-19 pandemic threw a shadow over the world as we had known it. Nothing was the same; education, health, livelihoods and existence itself was thrown out of gear. There were no textbooks or examples we could refer to, which could tell us how to cope. And yet, the world over, people persevered. People suffered, endured and overcame, like humanity is known to do.

The TB sector was no different, but we had special challenges to cope with. We had patients linked to us who looked to us for regular support - be it medication, nutrition or moral and other kinds of help. And confined as we were to our respective homes, we were challenged. But as always, TB-Alert looked for linkages and found them. Linkages are what help the world go on and we at TB-Alert believe in the power of linkages and networks. Our Annual Report this year is themed around this, as was our work.

Please read on. We are proud of what we have achieved and we hope you will be satisfied too.

Warm Regards,

Board of Trustees, TB-Alert India
DIVINE - Delhi Integrated Community Volunteers Initiative

The ‘Delhi Integrated Community Volunteers Initiative’ (DIVINE) project, initially proposed for three years (2008-2010), has been extended and was still operational in the reporting year. It focusses on involving communities actively in generating awareness and motivating patients to seek testing and treatment for TB. DIVINE operates in Burari and Santhnagar in the North Delhi region and uses a community-centric approach (COACH) to strengthen RNTCP. This is done by sensitising community volunteers, Private Health Providers (PHPs), paediatricians and Directly Observed Therapy Short-course (DOTS) providers. Private Health Providers (PHPs), paediatricians and Directly Observed Therapy, Short-course (DOTS) providers. DIVINE has had strong impact as the table below demonstrates.

<table>
<thead>
<tr>
<th>DOTs Centre Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Presumptive people subjected to sputum microscopy</strong></td>
</tr>
<tr>
<td><strong>People diagnosed with TB at DMC Labs</strong></td>
</tr>
<tr>
<td><strong>People with TB put on treatment</strong></td>
</tr>
<tr>
<td><strong>Patients registered for DSTB treatment</strong></td>
</tr>
<tr>
<td><strong>Patients on treatment at DOTS centres (both new &amp; old)</strong></td>
</tr>
<tr>
<td><strong>Patients completed treatment during reporting period</strong></td>
</tr>
</tbody>
</table>

“I am from Bihar, India and came to Delhi in search of employment with my husband, parents-in-law and two children. My parents and brother reside in Mukundpur (Divine Project area). We lived in rented accommodation and life was good till my husband lost his job during the COVID-19 lockdown. He then began to work as a daily wager. My health also began to deteriorate at this time. I lost weight, developed a fever and cough with sputum. When I did not get better for over three weeks, my parents persuaded me to visit the local TB-DOTS centre.

My condition deteriorated despite my taking CAT-1 treatment and I was admitted to RBIPMT Hospital where I was diagnosed with HR resistant TB and put on treatment. I suffered from severe side-effects which included disorientation, suicidal tendencies and sadness. I got no support from my husband who did not understand my side effects. But the support I got from the project staff was invaluable and this helped me successfully complete my treatment.”

Unedited Mail from the District TB Officer, NTEP District – Kingsway Chest Centre, Delhi.

Dto Kingsway <dtodlkcc@rntcp.org> 29 December 2021 at 15:47
To: Khasim TB Alert India <khasims@tbalertindia.org.in>

To,
The Project Manager/CEO
Delhi Divine Project, TB Alert India

Dear Sir,

Delhi Divine project, TB Alert India has been NGO partner to NTEP District, Kingsway Chest Centre in North Delhi since almost a decade now. They have been doing excellent job in implementing National programme in the outreach and unauthorised areas of the district devoid of government health facilities in successful coverage of national programme to the most needy and deprived. With their sincere and dedicated efforts with activities like public awareness campaign, active case finding efforts, sensitisation trainings of social volunteers and private practitioners, diagnosis and treatment of TB patients both drug sensitive and drug resistance patients is great support towards our most ambitious goal of elimination of TB by 2025 and 2030; target set by Govt of India and WHO respectively.

I do Congratulate and request TBAI to keep up their good work in serving the nation in augmenting our efforts towards TB free World.

With good Wishes and regards,

**Dr Ngilang Taley**, CMO (SAG)
District TB Officer, NTEP District-Kingsway Chest Centre, Delhi 110009
email; dtodlkcc@rntcp.org
Joint Effort for Elimination of Tuberculosis (JEET)

Extends quality TB care to patients seeking care in the private sector by developing effective partnerships with private health service. JEET is being implemented in 400 districts of India since 2018. The following are the main components of the project:

- Mapping private health care providers and identifying champion providers
- Following up and engaging private providers through visits and continuing medical education (CME)
- Facilitating private sector notifications on the Nikshay national registry portal
- Establishing linkages to quality-assured free diagnostics and treatment (FDCs) services under RNTCP
- Supporting treatment adherence

The impact

<table>
<thead>
<tr>
<th>Samples transported for CBNAAT testing</th>
<th>Patients detected positive</th>
<th>Total notifications</th>
<th>Patients allocated to TCs for follow up</th>
<th>Patients contacted by TCs at least once</th>
<th>Percentage of patients followed up at least once</th>
<th>Patients declared successfully cured after completion of treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>15148</td>
<td>4067</td>
<td>31646</td>
<td>29000</td>
<td>24643</td>
<td>84.9759</td>
<td>23339</td>
</tr>
</tbody>
</table>

Balaraju (27), a young single male, lives with his parents and sister. He was employed as a technician when he developed a cough and began to lose his appetite and weight, and decided to seek treatment at a local nursing home. The doctor prescribed a biopsy, which revealed that Balaraju was suffering from TB of the lymph nodes, after which he was started on the TB medication regimen for nine months. Balaraju had already been on medication from the private sector for a month by this time. He was transferred to the Boinpally Government hospital facility with the support of the project staff from JEET. Additionally, he got support from JEET in the form of information from Nikshay Poshan Yojana, which provided nutritional support. This consisted of six months of Direct Benefit Transfer (DBT) of Rs 3000/- on completion of the 9-month course of treatment month. He is now cured.

Sumaiah is a mother of 5 children including her 12-year-old (in 2019) daughter, Arshya Khantoon. A home maker, Sumiaiah stays together with her husband and children in a 2-room shelter in Indira Nagar, Musheerabad. Her husband is a daily wage labourer. When Arshya began suffering pain in her spine, Sumiaiah consulted several doctors but Arshya continued to suffer from pain. The family had also spent a lot. Doctors from a corporate hospital advised Arshya to undergo a spinal operation costing INR 200,000, which was unaffordable for the family.

The entire family, neighbours and relatives were distressed. Then a person from the project called the family having got her name from NIKSHAY. Sumiaiah was counselled and told that her daughter was suffering from extra pulmonary TB which was not contagious and referred to a near-by public hospital where treatment was free. She was started on treatment; her side effects were monitored and gradually she began to improve. She is now cured and leading a normal life.

“We were constantly in touch with the doctor and counsellor. There were days my husband and I cried looking at her suffering. We are so glad to see our daughter normal again. There have been many challenges during the process but she is finally healthy and fine. TB is a deadly disease but with proper treatment and awareness it is absolutely curable. We thank God for providing us with right treatment and counselling.”
Testimonials

Beneficiaries’ quotes
The project was implemented in New Delhi, India with the objectives to link and refer patients from the private sector to NTEP DR-TB centres for pre-treatment evaluation and initiation of appropriate treatment where required. It also vested in the patient, the right to choose his/her healthcare provider, by giving them the choice to avail treatment from the public sector, but still stay connected to the private healthcare provider, who they trusted, or preferred. The project rested on three key innovations that could ensure accurate and prompt diagnosis, timely referrals and initiation of DR-TB treatment. These innovations and their components were:

Impact data

- Patients with drug susceptible (DS-TB) identified from the private sector - 19,088
- Patients who received CBNAAT tests - 8,377
- Patients diagnosed with MDR or RR TB - 360
- Patients who consented to be linked to NTEP - 284
- Patients provided treatment - 220
- Patients transferred out of Delhi and initiated on treatment - 19
- Patients found RR negative in repeat CBNAAT - 23
Pre-treatment evaluation includes drug-susceptibility testing (DST) with counselling to ensure that patients are provided prompt, need-based optimised care with follow-up and support. This was an important component of the project.

Access to Treatment Coordinators
- Identify, refer, and link patients to the public sector;
- Ensure timely completion of PTEs and further initiation of treatment in the public sector;
- Facilitate DR-TB counselling services for both patients and caregivers;
- Follow up with patients and caregivers in the first two months of treatment.

Establishment of Call Centres
- Follow-up with patients and caregivers;
- Facilitate tele-counselling services for both patients and caregivers.

The Connect for Life™ (CfL) platform is an adherence tracking patient support tool provided with a free license by Johnson & Johnson Global Public Health R&D to the project. J&J also supported customisation of the platform and the creation of voice modules in Hindi and English.

Creation of a DR-DOST cadre (with members from the community) through Connect for Life™
- Ensure timely reminders and support were provided to patients and caregivers through text messages;
- Support high-risk patients and attend to specific needs of patients such as adverse drug reactions, motivation to complete treatment and identification of risk factors;
- Document specific clinical information;
- Monitor visits of treatment coordinators.

Some voices

“It was only after struggling for over four months that I was referred to the programme. I am now on correct diagnosis and treatment. Counselling helps me deal with the side-effects of the medication and my family feels assured that I will be alright soon. The calls I received from the call centre helped my family take all preventive measures to protect themselves.”

“I received a message while on treatment that made me realise that I had been ignoring my side effects for two days and this was also causing me difficulty in taking medicines. My treatment coordinator helped me visit the doctor who cured the side effects.”

“The counselling provided by TCs and call centre agents has helped my 14-year-old daughter to fight the disease. There were times when she completely lost hope, but their regular calls and messages kept hope in her alive and reminded her that this is just a minor hurdle. She is now back to studying for her pre-board exams.”
Tuberculosis Health Action Learning Initiative (THALI) began as a programme as a partnership between TB Alert India and Karnataka Health Promotion Trust (KHPT). It is a patient-centred, family-focused initiative targeted at urban populations living in resource-poor settings. THALI ensures better treatment by supporting the vulnerable in getting access to quality TB prevention and care services from the healthcare providers of the patient’s choice.

As a part of the programme, initiatives have been taken to reduce stigma and innovative tools such as the Risk & Needs Assessment (RANA) tool are administered to all newly diagnosed TB patients. This helps to identify risks and devise special care packages for those in need of them. An additional highlight of the programme is that cured patients, identified as TB Champions take on the responsibility of further creating awareness and helping other TB patients to complete treatment by offering solidarity and hope. THALI is operational in Hyderabad, Warangal and Karimnagar districts of Telangana and in Krishna, Vishakhapatnam and Guntur districts of Andhra Pradesh.

**K. Padma, Corporator from Golnaka says**

“There is a lot of stigma about TB within the community. The way to fight stigma is through awareness programmes. The THALI team had helped my driver’s wife seek treatment for TB and linked her with nutrition support, and now she is healthy. I want patients in my area to have the same kind of support. I want THALI to work extensively in my area and they have my support.”

**Achievements at a glance**

- **Aarogya Sandesh campaign** was started in the month of April 2020 by TBAI team involving more community representatives and community structures.
- **Community structures** were engaged through WhatsApp groups to disseminate right messages on COVID-19. Materials from the Government and messages by TBAI staff were posted in the group and CRT members were engaged to distribute these messages to their family members, friends and union members. Needy TB patients were connected with community structure members for nutrition support. The reach of this campaign showed good increase in the reporting period.
- **Key opinion leaders** were encouraged to use audio visuals to sensitize their family and community members on TB. Life style changes, immunity boost through healthy diet, sanitizing belongings and protecting the vulnerable members by isolation were few of the important topics discussed. Precautions to be taken even after relaxation of the lockdown were shared and discussed. NTEP staff and Medical Officers were involved in disseminating these messages.
The TB sector has evolved and seen a need to build the clinical and programmatic acumen of TB care providers for quality TB and DR-TB care in the country. An initiative to address this need is ongoing which helps providers diagnose patients suffering from DR-TB and put them on appropriate treatment and improve their treatment outcomes. It began by disseminating updated TB Care guidelines amongst key health care staff to ensure patients living across Delhi receive quality TB care in line with the standards/guidelines laid down by the Central TB Division.

District level workshops and online meetings were conducted to build the capacity of health care providers working in the space of RNTCP programme and efforts were made to improve treatment outcomes at nodal and DR-TB centres even during COVID-19.

Project highlights

- PMDT review meeting held;
- Data collection format developed and revised;
- DR-TB pilot project treatment coordinators introduced to state officials and nodal centre staff to improve coordination;
- Sessions conducted on data entry and management and NIKSHAY monitoring;
- Delay in SL-LPA results escalated to IRL;
- Discussions held on various programmatic and operational challenges;
- Gaps in various centres identified. RTRM Chest clinic has minimum PTE and SL-LPA TAT; Malviya Nagar Chest clinic has shortage of HR;
- NIKSHAY data entry challenges discussed and improvement evident;
- IRL proactive part of all the meetings;
- WhatsApp groups formed for coordination between key and peripheral staff;
- State initiated UDST and DBT review held;
- Patient pathway streamlined.
Pilot of Connect for Life mHealth Platform for improved TB patients management

Drug-susceptible TB (DSTB) was implemented as a pilot project in three high burden clinics in Delhi. The areas were selected because of the significant number of TB cases receiving treatment in the private sector, which has been established by IMS drug sales analysis in UP, Bihar, Maharashtra, Delhi and Rajasthan. The analysis showed that Delhi itself accounts for 6 per cent of all sales. Despite this, as per Central TB Division’s 2017 report, only 5,121 TB patients were notified from the private sector, which is significantly lower than the public sector notifications. This pointed to a need for an intervention to close the gap.

The numbers addressed by the project, disaggregated by clinics, are below:

<table>
<thead>
<tr>
<th></th>
<th>Sir Gangaram Hospital</th>
<th>St. Stephens Hospital</th>
<th>Dr. Vinod Kharana Clinic</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Died</td>
<td>0</td>
<td>2</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>Found resistant in CBNAAT</td>
<td>1</td>
<td>4</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Loss to follow up</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Opted out</td>
<td>2</td>
<td>0</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Referred out</td>
<td>0</td>
<td>0</td>
<td>33</td>
<td>33</td>
</tr>
<tr>
<td>Treatment completed</td>
<td>75</td>
<td>121</td>
<td>71</td>
<td>267</td>
</tr>
<tr>
<td>Wrong diagnosis</td>
<td>0</td>
<td>4</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Still on treatment</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>79</td>
<td>138</td>
<td>119</td>
<td>336</td>
</tr>
</tbody>
</table>

Supported by: Johnson and Johnson
RIPEND (Roping Informal Providers for Enhanced TB Detection)

RIPEND was started in **2018** as a unique field intervention for TB management and care. It addresses an important segment of the healthcare community and links informal private providers (IPP) and Rural Health Care Providers (RHCP) they are vital for early identification and care of TB patients. They are often the first points care for patients seeking care and addressing this segment is important in order to reduce delay in diagnosis and link the patients to the right source for quality treatment. The project was implemented in 19 TB units (TUs) across four districts of Warangal, Jangaon, Karimnagar and Jagtia of Telangana, a Southern state in India. As a part of the project, IPP and RHCP were sensitized and training was conducted for them.

Around **700** Informal providers were trained on the basics of TB and use of mobile applications for treatment and follow-ups. The trained IPP and RHCP responded well to the activities, as can be seen from the impact below:

<table>
<thead>
<tr>
<th>People screened</th>
<th>People tested referred for TB</th>
<th>Patients provided with PCS services</th>
<th>People diagnosed for all types TB</th>
<th>People tested by contact tracing</th>
<th>Contact tracing index percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1,59,7221</td>
<td>13,124</td>
<td>13,025</td>
<td>2406</td>
<td>2230</td>
<td>92.685</td>
</tr>
</tbody>
</table>

"I work in a private school hostel as a peon. Separated from my husband, I stay with my children aged 6 and 7 years old. When I became ill, I visited an RHCP and was screened for suspected TB. One week after treatment initiation, I was visited by the RHCP and project staff who found that I was missing my drug doses because I lacked nutrition support and could not tolerate the strong medication. I received help from local philanthropists and resumed my treatment. I have completed my treatment successfully and am healthy. I have also resumed work."

Jungapalli Pushpalatha

Supported by: **Stop TB Partnership**
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