

Resource Group for Education and Advocacy for Community Health (REACH)

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KATHA

Tales of Hope for a TB-free India

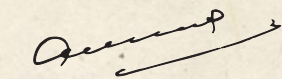
MESSAGE FROM CENTRAL TB DIVISION

India is committed to eliminating Tuberculosis (TB) by 2025, five years ahead of the global targets. As outlined in our ambitious National Strategic Plan, we are working to ensure that every individual with TB receives the highest quality of services, through a community-led and person-centred approach that recognises the socio-economic dimensions of the disease.

REACH has been a key partner of the Revised National TB Control Programme since the organisation's inception two decades ago. Since 2016, REACH has been implementing the TB Call to Action Project in six key states, with support from USAID. Over the last three years, CTD and REACH have worked closely together at the national, state and district levels to demonstrate various models of engaging different stakeholders including TB survivors and Champions, elected representatives, industries and the media.

In particular, REACH has demonstrated an innovative approach to identifying, training and engaging TB survivors as Champions – we know that we cannot win the fight against TB without the active participation of individuals and communities who are directly affected by the disease. Through their dedicated efforts, the trained TB Champions have made clear their deep commitment to supporting people with TB and improving awareness among their communities.

I congratulate REACH on the publication of this coffee table book, which bears testimonial to their efforts through the Call to Action Project. I call on all those engaged through the project, including those featured in this book, to renew and sustain their commitment to actively work towards a TB-free India.



Dr. K S Sachdeva
DDG-TB, Central TB Division
Ministry of Health and Family Welfare
Govt. of India
December 2019

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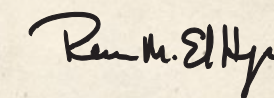
MESSAGE FROM USAID

India has made great strides in recent years in the fight against Tuberculosis (TB). As a part of the National Strategic Plan (NSP) for 2017-2025, India has introduced new tools, regimens, and gender-responsive, person-centered approaches to end TB. The NSP also stresses the need for a multisectoral, collaborative and community-led approach that is respectful of the rights of people with TB and places them at the center of the response to end TB.

The United States Agency for International Development (USAID) is proud to have supported the TB Call to Action project, implemented by REACH from 2016 to 2020. By designing and demonstrating innovative new models for engaging communities, industries, and others, the project was able to involve media, influencers, and elected officials who had previously been unengaged, and bring new stakeholders to the table for conversations around TB.

This coffee-table book features a diverse set of individuals and organizations that have pledged their commitment to ending TB in India, which represent a larger group of individuals who have gone from TB survivor to TB champion, mentors who support them, industries that have made significant commitments to addressing TB in the workplace, and elected officials who are urgently working to end TB. We thank every one of them for their steadfast determination in the fight against TB in India.

USAID has a long and successful partnership with the Government of India in the health sector. We will continue to work together, and with partners such as REACH, towards our shared goal of a TB-free India by 2025.



Ramona El Hamzaoui
Acting Mission Director
United States Agency for International Development
New Delhi, India
December 2019

MESSAGE FROM REACH

Since REACH's inception over two decades ago, our efforts have been gradually building towards putting in place a community-led, multi-sectoral national movement for tuberculosis (TB). We have been convinced that we can only win the fight against TB if we place those who are most affected – people with TB, TB survivors, their families – at the centre of our response, and find ways to engage them meaningfully.

In 2016, we got the opportunity to embark on a journey working in six states across the country, through the TB Call to Action project supported by USAID. We began our outreach to the many stakeholders we believed were essential to the TB response – elected representatives, industry leaders, the media, celebrities and most of all, TB survivors. Over the next three years, we were able to recognise, understand and address some of the challenges and opportunities that emerged, especially at the community level.

Today, we are proud that our efforts have resulted in the creation of a truly unique cadre of inspiring TB Champions and advocates. The commitment we have seen from other key stakeholders in the TB ecosystem – elected representatives, mentors to TB Champions, industry leaders, the media, celebrities – has been both gratifying and humbling. We are pleased to share with you this coffee table book, featuring a selection of exceptional leaders and inspiring personal stories, from among the over 600 stakeholders we have worked with.

At REACH, we have always believed in working closely with the TB programme and I am thankful for all the support we have received from the Central TB Division, and the State and District TB Cells. I also thank USAID for trusting our vision and supporting us to translate this into something meaningful. Finally, on behalf of all of us at REACH, I would like to express our sincere gratitude to every single person we have worked with through the Call to Action project, including those not featured in this book – together, we can win the fight against TB in India.

Nalini Krishnan

Dr. Nalini Krishnan
Director, REACH
December 2019

Emerging From Her Shell & Leading By Doing

Sushma Mahli. A TB survivor from Baharagora, Jharkhand, she was cured of TB in 2014. In 2018, she attended a capacity-building workshop for TB survivors.

In the months since, she has evolved into an active community leader and powerful motivational speaker. She has supported over 70 people with TB in six months, organised 12 community programs on TB and led three anti-stigma campaigns in her block.

She is actively involved in the TB-free Baharagora movement and leads the Baharagora chapter of TEJ, Jharkhand's first survivor-led network.

Sushma Mahli
TB Champion, Baharagora, Jharkhand



Never Giving Up... Rising Against All Odds

Arun Dutta. A 62-year-old TB survivor from Nagaon, Assam, who played football and hockey at the district level in his youth.

He lost his wife and son to TB. He developed TB himself and was cured in 2017.

To overcome his depression, he decided to help others with TB and attended a capacity-building workshop for TB survivors in July 2018.

In the next six months, he supported more than 200 people with TB. He identified people with symptoms, helped them get tested. He went door-to-door telling people about TB, its symptoms and that it could be cured.

Today, he has been recognised as a treatment supporter by the Nagaon District TB Cell. In October 2019, he attended the 50th Union World Conference on Lung Health in Hyderabad, as a scholarship recipient.

Arun Dutta
TB Champion, Nagaon, Assam



Bouncing Back With Grits, Guts and Gumption

Chinmayee. A trained Odissi and Bharatanatyam dancer from Ganjam district in Odisha, she was diagnosed with TB meningitis in 2017, after a considerable delay.

A paralytic attack left her unable to dance.

In February 2019, she attended a capacity-building workshop for TB survivors. Since then, she has extended psychosocial support to over 180 people with TB, including those seeking care in the private sector.

She centres her advocacy efforts on ending stigma surrounding TB. She has organised 22 awareness meetings and anti-stigma campaigns in railway coaches, during local festivals and in her neighbourhood.

In September 2019, addressing senior health officials at the launch of the TB Harega Desh Jitega campaign in New Delhi, she spoke of her determination to end TB stigma, and to dance once again.

B Chinmayee
TB Champion, Ganjam, Odisha



Bold and Brave Survivor, Now A Dynamic Young TB Champion

Abhishek Kumar. A 29-year-old MBA professional and TB survivor from Vaishali in Bihar. He was diagnosed with MDR-TB in 2014 when he was working in Bangalore and was on treatment for several years.

In 2018, he attended a capacity-building workshop for TB survivors and has since steadfastly worked to provide psychosocial support to families affected by TB. He has advocated with key local stakeholders including MLAs, PRI members, ASHA workers, SHGs and school teachers. He is a founding member of Bihar's TB Survivors' Network 'TB Mukta Vahini' (TMV) and has persuaded over 20 survivors to join the network.

His efforts led to the launch of a weekly counselling centre at the Hajipur District TB Cell, with guidance from the District TB Officer.

Abhishek Kumar
TB Champion, Vaishali, Bihar



A Doctor and a Leader, Working for a TB-Free Constituency

Dr Neeraj Bora. Member of the Legislative Assembly for the North Lucknow constituency, he is a medical doctor who believes TB is a social disease that needs a multi-sectoral response.

In March 2019, he launched the TB-Free North Lucknow campaign and spoke about ending stigma in his inaugural speech.

Since then, his leadership has resulted in an inter-sectoral meeting of representatives from nine departments; training of Anganwadi, ASHA workers and ANMs on TB; sensitisation of teachers from 28 schools in the area and a meeting of all city councillors chaired by the Honourable Mayor of Lucknow.

Dr Neeraj Bora
MLA, North Lucknow, Uttar Pradesh



A Strong Signal of Industry Commitment towards TB

National Aluminium Company Ltd. (NALCO) in Angul, Odisha. A 'Navaratna' group of companies under the Ministry of Mines, NALCO is the largest integrated Bauxite-Alumina-Aluminium Power complex in India.

In November 2018, NALCO signed a Letter of Intent for implementing the Employer Led Model for TB Care and Prevention, and developed an action plan for ELM activities.

Since then, they have organised awareness meetings on TB for their employees as well as for the communities that live around the establishment. They have also invested in hoardings with messages on TB, displayed at strategic locations in the area.

National Aluminium Company Ltd.
Angul, Odisha



A Journalism Student's Tryst With TB

Himani Verma. A TB survivor from Durg district in Chhatisgarh, who was cured in 2018.

A student of journalism, she feared discrimination from her friends and classmates, and kept her TB diagnosis a secret. In December 2018, she participated in a capacity-building workshop for TB survivors, and has not looked back since.

Over the next six months, she touched the lives of more than 90 people with TB. Her advocacy efforts with the District Collector led to the launch of the TB-free Bhilai movement.

A member of TB Mukta Chhatisgarh, she is working to strengthen the network and involve more young people in the TB response.

Himani Verma
TB Champion, Durg, Chhattisgarh



Molding Future Leaders: The Woman behind the Champions

Momi Bora. A social worker, womens' federation leader and livelihood expert from Assam, she has considerable experience in forming womens groups for social change.

In 2019, she became a mentor to four TB Champions from Dibrugarh, Dhemaji, Lakhimpur and Jorhat districts of the state.

Over six months, she guided the Champions to become more effective advocates, and accompanied them to help conduct activities in tea gardens and their communities.

She also helped them navigate complex relationships with various stakeholders, and to do justice to their role as TB Champions.

Momi Bora
Social Worker & Mentor, Dibrugarh, Assam



Cultivating a New Tomorrow for People with TB

Kamal Kishore. A farmer and resident of Lucknow in Uttar Pradesh, he was affected by TB in 2012.

In 2018, he attended a capacity-building workshop for TB survivors. Since then, he has personally been in touch with over 70 people with TB.

He has reached out to more than 250 people from the community through meetings and anti-stigma campaigns.

He shared his story at Sanji Pahal held on World TB Day 2019 and is today a treatment supporter with the District TB Cell.

Kamal Kishore
TB Champion, Lucknow, Uttar Pradesh



An MLA's Sustained Efforts for a TB-free Constituency

Kunal Sarangi. A member of Jharkhand's 4th Legislative Assembly from Baharagora Constituency, he launched one of the first TB-Free Constituency movements in March 2018.

His involvement triggered the launch of a multi-stakeholder movement with public health officials, Panchayat and other community leaders, other departments and people affected by TB, among others.

He visits people with TB and ensures that the programme receives feedback from the affected community in real-time.

He has been a strong supporter of TB Champions as advocates and was present at the launch of the Baharagora chapter of TEJ, Jharkhand's survivor-led network.

Kunal Sarangi
Former MLA, Baharagora, Jharkhand



A Support System for Bihar's Champions

Sweety Sinha. An MDR-TB survivor from Gaya in Bihar, she is a social worker associated with the Nehru Yuva Kendra for almost 15 years.

She drew on her prior experience of working in health and adolescent education to mentor four of Bihar's TB Champions.

As a mentor, she guided them to provide psychosocial support to over 300 people with TB and helped them organise anti-stigma and awareness campaigns at the community level.

As a TB survivor herself, she has been advocating with elected representatives, Self Help Groups, Panchayati Raj Institution members and others for their involvement in the TB response.

Sweety Sinha

TB Champion, Mentor & Social Worker, Gaya, Bihar



Man With a Mission

Kalageer Goswami. A TB survivor from Bilaspur in Chhatisgarh, he was diagnosed with TB in 2007. Over ten years later, he joined a workshop for TB survivors and subsequently a six-month mentorship programme.

A confident speaker, he likes to experiment with innovative ways to raise awareness about TB – he often combines the traditional dramatic art form of 'nautanki' with his acting skills during community meetings, and has sensitised over 700 people about TB.

He is a member of the State TB Elimination taskforce and has personally supported over 70 people with TB during their treatment period.

He is keen to involve more survivors and build their capacities to become TB Champions as well.

Kalageer Goswami
TB Champion, Bilaspur, Chhattisgarh



Towards TB-free Tea Gardens

The Employer Led Model for TB Care and Prevention was piloted, for the first time in India, in the tea garden districts of Dibrugarh and Tinsukia in Assam, in collaboration with the District TB Cells, the Assam Branch of Indian Tea Association (ABITA) and Bharatiya Cha Parishad (BCP).

Nearly 80 tea garden managers and medical officers were trained in ELM in April 2018. 39 Letters of Intent have been signed between the gardens and the district administration.

More than 150 awareness meetings on TB have been held, and over 3500 people screened for TB in the community.

ELM in Assam is a demonstration of partnerships for TB to ensure access to services for vulnerable communities.

Employer Led Model for TB Care and Prevention, Assam



Reaching Out to Thousands With Care and Empathy

Anjana Singh, seen here with her daughter. A TB survivor from Ara in Bihar, she has been working in the development sector for over a decade. She was cured of TB in 2008, and over ten years later, participated in a capacity-building workshop for TB survivors.

Since then, she is treatment supporter to nine people; has supported over 100 people with TB overall; identified several people with TB symptoms and referred them to the nearest health facility; and ensured that people with TB receive nutrition support through the Nikshay Poshan Yojana.

She has been part of Active Case Finding efforts and identified over 50 people with symptoms. She has evolved into a public health leader in her community and works closely with women's self-help groups, PRI members and others.

Anjana Singh
TB Champion, Ara, Bihar



Taking TB Awareness to the Vulnerable and Marginalised

Bibhuti Bhusan Sahu. A TB survivor from Angul district in Odisha, he was cured of TB in 2017, and attended the capacity-building workshop in the same year.

While on treatment, he openly spoke to his family and community about how his life was being affected by TB, and resolved to help others do the same. He has dedicatedly focused on creating awareness of TB in bastis in his area, and has worked closely with RNTCP and mining companies to improve understanding of TB symptoms.

As a member of the Angul District TB Forum and the Odisha State TB Forum, he represents affected communities and speaks on their behalf at forum meetings. He is committed to strengthening the Kalinga TB Survivors network in the state.

Bibhuti Bhusan Sahu
TB Champion, Angul, Odisha



Galvanised into Action for TB Care and Prevention

Jindal Power and Steel Ltd (JSPL). The Patratu unit in Ramgarh, Jharkhand employs around 1500 people. They expressed keen interest in implementing the Employer Led Model (ELM) for TB and signed the Letter of Intent with District TB Cell, Ramgarh in July 2019.

Since then, they have been raising awareness about TB among employees and their families through display of posters, meetings and role-play activities.

Two employees have so far been diagnosed through ELM activities and initiated on treatment.

They are committed to adopting a zero tolerance approach towards discrimination against people affected by TB.

Jindal Power and Steel Ltd (JSPL)
Patratu, Ramgarh, Jharkhand



The Silver Lining for Many Clouds

Minoti Puran. A TB survivor from Jorhat district in Assam, who was cured of TB in 2018.

In 2019, she participated in a capacity-building workshop for TB survivors and enrolled in a six-month mentorship programme.

She focuses on raising awareness about TB among the vulnerable tea garden population, and counsels and supports people with TB in her community. She accompanies Active Case Finding teams in the district when they go door-to-door.

In March 2019, she was felicitated by the Jorhat District TB Cell on World TB Day. In October 2019, she won a scholarship to attend the 50th Union World Conference for Lung Health and shared her story with a global audience.

Minoti Puran
TB Champion, Jorhat, Assam



Gentle but Firm, Mentoring Chhattisgarh's TB Champions

Deepak Singh from Durg in Chhattisgarh. Having previously worked on HIV and AIDS as well as child health, he was mentor to five TB Champions from four districts of the state.

Over six months, he built a strong channel of communication between the Champions and their respective district administrations.

He honed their skills to communicate about TB effectively and use local dialects and languages to do so.

He went the extra mile to personally advocate with key stakeholders and be present at community meetings organised by the Champions.

Deepak Singh
Social Worker & Mentor, Durg, Chhattisgarh



Waging a Relentless Battle Against TB Stigma

Sunita Kumari. An urban ASHA (healthcare) worker from Lucknow in Uttar Pradesh, she had TB in 2012. Her family's unwavering support was key to her successful recovery, and helped her get her life back on track.

In 2018, she attended a capacity-building workshop for TB survivors and has since supported over 70 people with TB, giving them information about TB and constantly motivating them to complete treatment. She first shared her survivor-to-Champion story at Sanjhi Pahal, organised on World TB Day 2018.

Through several community meetings, she has made over 700 people in her community aware about TB and its symptoms, as well as where to seek care. She is determined to end the stigma associated with TB, particularly for women.

Sunita Kumari
TB Champion, Lucknow, Uttar Pradesh



Helping TB Champions Help Others

Sr. Sangeeta, Mentor to Jharkhand's TB Champions. A social worker based in Gumla in Jharkhand, she mentored five TB Champions for over six months, including Mangra Khariya, pictured here.

During this period, she helped all the TB Champions build a good rapport with the TB programme staff.

She also supported them to become confident public speakers, and share their personal stories impactfully.

She was their constant sounding board, always there to listen, guide and advice!

Sr. Sangeeta
Social Worker & Mentor, Gumla, Jharkhand



TB Survivors Leading From The Front, Together

TB Mukht Vahini (TMV). A first-of-its-kind network, of and by TB survivors, TMV was born in 2017, after the first capacity-building workshop for TB survivors in Bihar. 13 TB Champions from seven districts came together to announce the formation of TMV, and their intention to work towards a rights-based, person-centred ecosystem for TB.

Since then, TMV members have supported people with TB through the mentorship programme, advocated with various stakeholders and become members of National, State and District TB Forums. Most recently, TMV members presented an abstract on the network's achievements at the Union World Conference on Lung Health, held in October 2019.

Today, TMV is a legally registered body under the Societies Act, with a membership of over 240 members from across 19 districts.

TMV members pictured here, left to right: Sweety Sinha, Satyendra Nath Jha, Arti Kumari, Sudeshwar Singh

TB Mukht Vahini Bihar's Survivor-led Network



From TB Survivor to Champion & Mentor

Dr. Reeta Sahoo, a TB survivor from Cuttack in Odisha, seen here with TB Champion Bibhuti. An Ayush practitioner by training, with a Masters in Social Work, she has worked for more than 20 years in the health sector. She first attended a capacity-building workshop for TB survivors in 2017, and subsequently became a mentor to six of Odisha's Champions in 2019.

Through one-to-one visits and regular communication, she helped the six Champions, including Bibhuti, develop good presentation skills and honed their advocacy abilities.

She supported the development of the anti-stigma campaigns held in March and August 2019, drawing on her knowledge of behaviour change communication.

Dr. Reeta Sahoo
TB Champion & Mentor, Cuttack, Odisha



Finding the Hero Within

Upendra Kumar. A TB survivor from Garwha in Jharkhand, Upendra first developed TB symptoms during his recovery from paralysis.

He faced a lot of stigma and discrimination from his family and neighbours, and tried to keep his TB diagnosis to himself.

He was cured of TB in 2017 and attended a capacity-building workshop for TB survivors in 2018. Since then, he has supported nearly 120 people with TB in the short span of six months, and has transformed from a shy and reserved person into a vocal and committed TB Champion.

He is the President of Jharkhand's survivor-led network TEJ (TB Elimination from Jharkhand), and dreams of a future free of discrimination for people affected by TB.

Upendra Kumar
TB Champion, Garhwa, Jharkhand



His Unwavering Commitment to End TB

Shyam Rajak, Minister of Industries, Government of Bihar, and Member of the Legislative Assembly from Phulwari Sharif constituency. He announced his commitment to ending TB on World TB Day 2017, and joined hands with the state TB programme to work towards a TB-free Phulwari Sharif a year later.

Since then, he has led a local convergence meeting with key stakeholders, including affected communities, PRI members, allied departments, educational institutions and others. He has taken a keen interest in understanding the available TB infrastructure and constantly sought inputs from the community to improve this. Through his leadership and sustained efforts, he has signalled his intention to ensure that every person affected by TB in his constituency can access high-quality TB care services.

Shyam Rajak
Minister of Industries, Govt. of Bihar &
MLA, Phulwari Sharif



'Communication is Key' - Her Mantra as a Mentor

Mridulika Sharma. A graduate in Social Work with a specialisation in Rural Development, from Lucknow in Uttar Pradesh, she came on board as a mentor in April 2019. She mentored TB Champions from the city and neighbouring Bahraich, and helped them build their communication and public speaking skills.

TB Champions mentored by her went on to be nominated as members of District TB Forums.

She also motivated and empowered them to speak with and on behalf of other survivors, thereby strengthening the voice of TB-affected communities in the state.

Mridulika Sharma
Social Worker & Mentor, Lucknow, Uttar Pradesh



Jharkhand's Survivors, United

TEJ – TB Elimination from Jharkhand. A network of TB survivors formed in 2018, with 14 founding members, who came together at a capacity-building workshop.

Most of the founding-members were occupied in agriculture and other daily wage activities. They had a lived experience of the struggles they had faced in accessing the health system, stigma, employment and coping with side-effects. When they met others like themselves, they resolved to change the status quo.

Today, TEJ has over 450 TB survivors as members from across the state and two district chapters. TEJ's members are part of National, State and District TB Forums. TEJ is a legally registered network under the Societies Act and committed to working with the programme for a TB-free Jharkhand.

TEJ-TB Elimination from Jharkhand A Survivor-led Network



Rosesh In A New Role - TB Ambassador

Rajesh Kumar. An actor from Bihar, he is best known for his portrayal of 'Rosesh' in the popular television show 'Sarabhai vs Sarabhai'. His current passion is working in agriculture to make 'smart villages'.

In 2018, he joined hands with the TB programme as Bihar's TB Ambassador, pro bono. He starred in a series of over nine audio and video messages on TB, on topics such as symptoms, diagnosis, stigma, drug-resistant TB, etc. His photos have also featured in posters, banners and hoardings.

These have been widely disseminated by the TB programme. He continues to use his social media handles to share the videos, and tweet about TB.

Rajesh Kumar
Actor & TB Ambassador, Bihar



Lending His Voice to End TB

Zubeen Garg. An award-winning singer, actor, film producer, director, and an active social worker from Assam.

In 2018, he joined the fight against TB in Assam as the State Ambassador. In addition to composing and singing a theme song on TB, Zubeen's powerful messages on TB currently feature in posters, television spots and radio jingles in Assamese and Sadri languages.

These communication materials have been widely disseminated by state and district officials as well as in tea gardens.

Zubeen remains an active advocate of TB and is involved in several TB awareness campaigns through his fan clubs and on social media.

Zubeen Garg
Musician, Film Personality &
TB Ambassador, Assam



Hitting the Bull's Eye to End TB

Padma Shri Deepika Kumari, an athlete and archer from Jharkhand. A former World Number One, she was the Gold medallist in the 2010 Commonwealth Games and has since received the Arjuna Award and the Padma Shri, in recognition of her contribution to Indian athletics.

She became Jharkhand's TB Ambassador in 2017, featuring in photos, videos and other communication materials on TB.

A youth icon, her involvement has the potential to influence people and bring about behaviour change, especially related to stigma and discrimination.

Deepika Kumari
Archer & TB Ambassador, Jharkhand



Odisha's Ambassadors: Leaving a Thousand Impressions Through Art

Padma Shri Sudarsan Pattnaik, renowned sand artist from Odisha, committed to spreading public health messages through his sand art on Puri beach. His sand art on TB in 2017 and 2018 attracted a multitude of visitors.

Kuna Tripathy, a popular Odia Cine Actor, TV show presenter and radio personality, whose funny yet powerful messages positively influence viewers.

Padma Shri Prafulla Kar, renowned Oriya musician, singer, lyricist, writer and columnist, who was aware of the burden of TB in the state and immediately agreed to lend his voice in support.

All Odisha's TB Ambassadors featured in short films, audio clips, posters and banners that were widely displayed and disseminated. This has contributed to positive messaging around TB using different art forms and reaching new audiences.

Sudarsan Pattnaik
Kuna Tripathy
Prafulla Kar

Odisha's
TB Ambassadors

