News from the partnership...

Partners Speak

PARTNERSHIP FOR TB CARE AND CONTROL India

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"Lack of care in TB is a symptom of the lack of care for any disease at primary health care level."

Dr. Nalini Krishnan, director, REACH, page 4

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What do Global Fund cuts mean for TB in India?

The Partnership newsletter is overhauling its content and look. The newsletter will be a resource and forum for partners. We are excited about bringing you relevant content over the coming year.

To help us achieve this goal, we invite you to continue to contribute your stories to the newsletter. Send your content and photos in jpeg format to the Secretariat. We want to hear not only your thoughts and stories on the issue of TB, but also send us data about TB in your area, the problems encountered and how you surmounted them.

In the meantime, top news over the last quarter is the announcement in November that donors will cut funding to The Global Fund to Fight AIDS, Tuberculosis and Malaria. Our partners and friends came together to make a public plea and issued a press release not to cut essential "TB life support", outlining reasons to reconsider the cuts.

Undoubtedly, the Global Fund's support has been vital to TB. However, there is the alternate view that current economic realities in the West could be an opportunity for the Indian government and the corporate sector to step into the breach.

Is it time for civil society organisations to consider funding alternatives within India? In this issue, Dr Nalini Krishnan, director of Chennai-based, REACH, discusses in the new Q&A feature, *Partner in profile* (page 4), this question as well as how partners can utilise platforms like Project Axshya to create a movement against TB.

Welcome to our new partners

Rural Medical College & Hospital, Pravara Institute of Medical Sciences (PIMS), Maharashtra

Indian Pharmaceutical Association (IPA), Mumbai

Humana People to People India, New Delhi

Improving Healthy Behaviors Program, New Delhi

NEWS

Indian journalist wins Stop TB Award for excellence in reporting on TB

Bharathi Ghanashyam of India gained top recognition for her blog, "Children and TB – the diagnostic challenges", which won Stop TB Partnership's Award for Excellence in Reporting on TB and Images to Stop TB in the low- and middle-income country category.

The journalism award, supported by the Lilly MDR-TB Partnership, recognises outstanding reporting and commentary in print and on the web that materially increases the public's knowledge and understanding of TB and multidrug-resistant TB (MDR-TB), in countries affected by the disease. The Partnership confers first, second, and third prizes in two categories: for journalists based in low- and middle-income countries and those based in high-income countries. Ms Ghanashyam's blog recounts the stories of three children affected by TB and highlights the challenge of diagnosing the disease in children in India, where the problem is dire.

Bharathi Ghanashyam, journalist

TB Tales

the Lilly MDR-TB partnership
SPEAK UP TO STOP TB
REACH
TB TALES
a short film competition on tuberculosis
Open to all filmmakers including students
Entries of duration less than 5 minutes (minimum 30 seconds)
Citations and cash awards for three best entries
Screenings in Chennai and New Delhi (tbc)
No entry fee
TB kills 2 people every 3 minutes in India.
This is YOUR chance to speak up to stop TB!
Last date for submitting your entries
15 January 2012
To find out more, see www.media4tb.org
or email tbtalesreach@gmail.com

Chennai-based REACH is in the process of reviewing film entries for its inaugural 'TB Tales' short-film competition on TB. The competition, which was launched in November last year, was open to filmmakers across India, including professionals, amateurs and students. Entries closed in mid-January and will be judged by an eminent jury that includes actor Suriya, film director Gautham Menon, Dr P R Narayanan, former director, Tuberculosis Research Centre, Blessina Kumar, activist and vice chair, Stop TB Partnership Board and Dr Subhash Yadav, technical officer, Project Axshya, The Union South East Asia Office.

According to REACH, the graphic power of films can change perceptions and influence behaviour and filmmakers were invited to submit films of up to five minutes duration covering the topic of tuberculosis. The initiative is supported by Lilly MDR-TB Partnership. The best entries will receive citations and cash awards of Rs. 30,000 (first place), Rs. 20,000 (second place) and Rs. 10,000 (third place) to be awarded on World TB Day 2012. Shortlisted entries will also be screened in New Delhi and Chennai. To learn more about the competition visit www.media4tb.org.

Global Fund slashes Aids, Malaria and TB grants

The Global Fund to Fight Aids, Malaria and TB announced it was cutting grants due to a substantial shortfall in funding. The cuts were laid primarily at the doorstep of current difficult economic conditions.

Revelations from an internal investigation highlighted financial misuse and corruption by some recipient countries also gave many donors added impetus to halt funding at current levels or to cut their contribution.

The Fund said no new grants or funding would be made until 2014. Many organisations in developing countries reacted with dismay at the news as the prospect of less funding could bring an end to much-needed programmes benefitting the most vulnerable populations.

The Partnership for TB Care and Control, India also issued a plea to donor governments on behalf of civil society, not to withdraw

support that saved lives. In a released statement, reasons were outlined why cuts could have a profoundly negative effect on the fight against TB in India. It cites among other reasons the current characteristics of Indian landscape with a weak health system; lack of a basic social or health net for those in abject poverty; presence of large tribal, migrant, remote and slum populations who are more vulnerable to diseases like TB. It also raised concern that the cumulative effect from the current and biggest push in history towards TB control could be rolled back if financial support is withdrawn. The full statement can be found on the Partnership's website: http://www.tbpartnershipindia.org/

Winstone Zulu, HIV and TB activist

Obituary

Winstone Zulu, world HIV and TB activist dies

Winstone Zulu, a prominent HIV and TB activist in Zambia known world wide died in October 2011. Mr. Zulu played a major role in the fight against TB and AIDS in Zambia and on the world stage. According to Aidsmap, he was credited by Nelson Mandela as a pioneer in TB activism. Mr. Zulu was diagnosed with HIV in 1990 and became the first person in Zambia to publicly acknowledge his HIV status at a time when those with HIV/AIDS faced significant stigma and discrimination. He contracted tuberculosis in 1997 and became cured after effective medical treatment and was among the first to champion the need to address TB. Mr Zulu's own devastating experience of TB through the deaths of his four brothers also made him an eloquent champion promulgating a world plan to stop TB. To read more about Mr Zulu and to view his address to a TED audience in October 2011 go to http://www.action.org/tb_champions/winstone_zulu/

EVENTS

WLC 2011 Lille, France

Speaking out at Advocacy Corner

For the fifth year running, TB Alert managed an 'Advocacy Corner' at the World Conference on Lung Health. The Corner provides a TB-specific hub for delegates to hear from leading TB advocates; to discuss the latest TB research and developments and to explore how best to advocate for action against the global TB epidemic.

In 2011, the Stop TB Partnership called for the TB world to sharpen its message and harness social media in the fight against TB. To respond to this challenge, visitors to Advocacy Corner were invited to browse the latest TB research on a website developed specifically for the event and to share their thoughts across social media platforms. Delegates were also invited to share their own key TB advocacy messages on the display panels at the stand.

WORLD AIDS DAY 2011

Meera Foundation in Dindigul district, Natham in the state of Tamilnadu pulled together a number of events focussed on raising awareness of HIV and TB among the student population.

Supported by Project Axsya, the activities aimed to increase awareness among youth on HIV/AIDS and TB; to clarify any misconceptions of HIV/AIDS and TB; to sensitise youth on the care of both infectious diseases and how youth can support HIV positive and TB patients.

Students participated in a roster of activities organised by Meera staff including an awareness rally in which 200 students participated along with staff and other volunteers.

Students also participated in a quiz competition answering questions on HIV prevention and TB control and a speech competition on the topic "Role of students on HIV prevention and TB Control". A film on HIV/AIDS and another on TB were shown to students. The World Aids Day campaign resulted in local media coverage.

Photo credit: Meera Foundation

PATH India supports microbiologists in evolving challenges in TB diagnosis

PATH's third 'Intermediate Reference Laboratory (IRL) experience sharing workshop' for microbiologists held in early December in New Delhi, brought together RNTCP consultants representing 15 states to discuss experiences, challenges and solutions for several important issues related to IRL. The supply of reagents and chemicals, external quality assessment, human resources and training, maintenance of equipment (AMC), recording and reporting and the process of accreditation were all shared and analysed.

It was recommended that a forum be provided for key stakeholders to share experiences and address issues so that the accreditation of IRLs nationwide can happen more quickly.

State specific work plans were also reviewed and an innovative gap analysis was used to help identify weaknesses in the plans.

The workshop allowed different state working groups to consolidate their IRL up-gradation plans with expert input from CTD, NRL, WHO RNTCP consultants and other microbiologists in attendance. There were assurances from Dr. Prahlad Kumar (Director, NTI, Bengaluru), that there would be all round support for training and external quality assessment within the RNTCP.

PARTNER IN PROFILE: REACH

Dr. Nalini Krishnan, director of Chennai-based REACH discusses customised care for TB patients, getting around fund barriers and why it's time to create a mass movement to end TB

Q: Tell us about REACH?

A: Our organisation began more than 12 years ago in Chennai, in response to the rolling out of the Revised National TB Control Program (RNTCP) in our state. We act as an intermediary between RNTCP and private providers and work with seven community-based hospitals in Chennai, which offer free care, and function as DOT centres. We provide training to private providers. Early on, we discovered we couldn't just put the patient in touch with the doctor and hope for them to be cured, we needed to do far more than that So we also began offering patient care and to help them with affordability as well.

Q: How has REACH made an impact on TB?

A: Right away, we recognised that more than 50 percent of patients go to the private health care providers for any complaint. However, these private providers actually had no knowledge of treatment of tuberculosis and were unaware, for example, of the importance of microscopy for diagnosis or even that the government was offering free diagnosis.

Dr. Nalini Krishnan, director, REACH

We piloted a model network of around 30 private practitioners which is very successful. Today, we have a network of about 500 doctors who work with us in Chennai as partners to end TB.

However, private providers really could not do the kind of all-around treatment that is required for TB patients from vulnerable populations. We needed to provide hands-on guidance, counselling, motivating patients and follow-through for defaulters.

From the start we built a huge network of wonderful community volunteers, which of course is now widely used. Nevertheless, when we first started, it was amazing and unique how very ordinary people came forward to become DOTS providers.

Q: What are the challenges?

A: We have an excellent model but we can't scale up or transfer it to other states because we don't have the funds. However, through the Global Fund Round 9 Project, we have expanded laterally into other districts in Chennai and Tamilnadu.

We've worked in urban slums for a long time, but a real revelation for us are the challenges unique to working in rural areas and where we have had to be innovative to overcome them. Frankly too, in rural areas and some other communities, where there are pressing problems such as access to water and sanitation or poverty and hunger issues, tuberculosis is not a priority.

We've been working hard to put TB on their radar by emphasising its links to these major social issues.

It is accepted at policy level that to cure and control TB you must address all the factors social and environmental simultaneously. we could not do this without the dedication of our amazing bunch of field workers some of whom have been with us for more than ten years.

> "In fact, I think all of our partners should convert TB-free India into a sort of movement."

Their help and dedication in retrieving a defaulter or supporting a patient who has alcohol problems and getting them on detoxification is essential.

Q: What are some of the realities at field level?

A: We have found that the hidden costs of TB treatment can be hard on a family. Although technically it's free treatment, patients still need financial support.

For example, sometimes travelling to the nearest doctor can be an issue. Also many are unemployed while they are sick. Patients and their families can be driven into dire circumstances by the disease. Unless the social and cultural issues and the stigma are addressed, we are not succeeding at treating the patient.

Treating a TB patient has to be an individual story for each. Only civil society has that kind of connection with the community and can step in and support the RNTCP. A busy government medical officer cannot do the kind of evaluation needed nor is it realistic to expect it.

The lack of equitable access to care for a TB patient is very much what happens to anyone who is sick and poor in this country.

The first point of contact for many villagers is a small primary health center, which is often unmanned. Lack of care in TB is a symptom of the lack of care actually for any disease at primary health care level.

Q: What advice do you offer to other organisations working on TB?

A: There is much more strength to our voice through Project Axshya, which as a national project, is giving us an increased opportunity to work in the area of advocacy. Now we are heard in the government at both local and national level and we are being taken seriously.

A great thing has happened in Tamilnadu in that the Health Secretary has a whole cadre of people called health inspectors who are now stationed in the family health center to look at TB apart from other things.

We find a lot of receptivity from the State TB Officer or the Health Secretary sitting together with us and trying to solve problems.

REACH also works with the media, and journalists won't cover TB without us putting it in front of them and helping them to understand the urgency and to raise awareness of TB.

In fact, I think all of our partners should convert TB-free India into a sort of movement. We talk about political will, I think civil society also has to develop a connected will to push a movement through. Let's have that kind of high aspiration let's not just talk about control, let's talk about ending TB.

We should leverage Project Axshya to push ending TB nationwide. We need to be center stage then not only the government but the media too will notice and then our communities and patients too. We are just not making enough noise.

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BEST PRACTICE

TB Forum spearheads change in Tamilnadu

Where: Dharmapuri district in the state of Tamilnadu.

What: Bringing an end to TB in the district. We launched Project Axshya in October last year in Dharmapuri to support the RNTCP, improving its reach and visibility across India through community engagement.

How: Social mobilisation interventions by the four mother NGOs: Agape Foundation, O.M Good Shepherd Hospital, Snehasadan, and Thaenkoodu Federation aimed at improving community participation and care seeking of symptomatic persons; complementing campaign efforts to debunk locally prevalent myths and misconceptions.

It includes among other things providing community-based care to TB patients and training of health care workers and volunteers to provide DOTS, generate awareness and educate the community on prevention and treatment.

Methods: To ensure an effective programme, the NGOs and CHAI united with the DTO, Dr. Asha Fredrick, last year to form a TB Forum.

Results: Through this forum, many initiatives have taken place. For example, there was information, education and communication material to create awareness through a sticker release programme. We also set up a Counselling Care Centre for TB patients and their families in the district.

Community meetings are held that include tribals in hard-to-reach areas. Defaulters are also receiving special focus in the district through the combined efforts of the four NGOs.

The TB Forum felt the need to open a counselling centre exclusively for TB patients and their families (see box below: *All-encompassing individual treatment for defaulters*) in order to address other social issues.

All-encompassing individual treatment for defaulters

When a person is diagnosed with TB, they are referred to a local DOTS provider who is trained through the RNTCP – a mode of treatment that is effective. However, an ongoing issue that prevails in India is the issue of defaulters. Defaulters are active TB-infected patients who begin the course of treatment but do not complete it. Thus TB continues to be active in their bodies and they continue to be infectious. A huge problem is defaulters tend to become multidrug-resistant (MDR), making the disease even more difficult to treat and cure. Defaults of this kind are largely due to the stigma associated with TB and a lack of awareness about TB, its treatment and spread as illustrated by Saira's story.

Saira's story

Saira* is 32 and from the Kakanjipuram village in Dharmapuri. She was identified as TB symptomatic in April 2011 during a TB community meeting conducted by Agape Foundation. She was a CAT II patient, and a defaulter, but her circumstances added other layers to her TB status. Saira has three children and her husband is an abusive alcoholic. Treatment was immediately put in place for TB as well as the environmental and personal factors that complicated treatment of the disease. For example, Agape took extra measures to ensure Saira received her medication on the appointed day. If she was unable to attend the clinic, a DOTS provider would go to her home to administer the medication or they would pay for an auto to pick her up and bring her to the clinic. Agape also provided food if she was unable to eat before coming to the clinic or did not have food. Staff provided counselling to her husband to stop drinking and abusing his wife and helped him to get a job as a painter. This comprehensive treatment worked as Saira was TB free when tested in October 2011.

** Name changed to protect privacy*

Submitted by: CHAI

Treat poverty, treat TB

REACH and PFWA ensure nutritional support

In India, curing a patient involves a whole network of activities from different stake-holders as well as tackling intrinsic social factors that are often an inherent part of the disease.

In the state of Tamil Nadu, Positive Friends Welfare Association (PFWA) works with HIV-positive patients in the Tiruvallur district. Project Axshya through its strategic partner, REACH, gave PFWA an opportunity to reach out to TB patients too.

Equipped with the training received on TB, PFWA identified Mani, 40-years old and HIV positive, who lives in the village of Thiruvelankadu with his blind mother in the western suburbs of Chennai, as a Category-1 TB patient.

> “Unemployed and pushed into a state of dire poverty, Mani was unable to eat a healthy meal, an essential, especially during his treatment regime.”

Mani, severely weakened by the disease and unable to walk, lost his job as a driver. Unemployed and pushed into a state of dire poverty, Mani was unable to eat a healthy meal, an essential, especially during his treatment regime.

PFWA recognised it had to treat not only the disease but also address Mani's lack of food. PFWA became Mani's DOTS provider and gave him nutrition packs worth Rs. 600 throughout his treatment period. Mani was also referred to a care center ran by a Community- Based Organisation (CBO) in his local community. This multi-faceted support is necessary when it comes to curing TB patients as PFWA, REACH and Project Axshya show.

Submitted by: G. Shankar, REACH

CASE STUDIES

Trained to recognised TB symptoms helped to save a life

Ira Laxmi* lives with her parents in a slum in Hyderabad. She is a normal teenager and was studying and readying for her graduation. However, Ira began to suffer from fevers during the evenings accompanied by a mild cough.

Her father took her to a local private medical practitioner (PMP) (an unqualified doctor) who had received training on TB in 2010 from TB Alert India, under Project Axshya's programme for rural health providers.

Not all of Ira's symptoms were present initially, only cough and weakness, the PMP observed Ira over three weeks and found she was unresponsive to treatment.

Not all symptoms present

However, due to his training in TB, he suspected that Ira may have TB symptoms, particularly after he learned that her brother had also had the disease some time ago.

He immediately referred Ira to a nearby government-designated microscopy centre for a TB sputum examination. Her sputum result tested positive for TB.

She was placed on DOTS with a private health provider and eventually completed her treatment with the aid of the doctor. “Now I am happy that I could help Ira to write her final exams,” smiled the doctor.

“I thought I will not write my exams after missing my classes for about a month. Fortunately to cure my illness doctor has come to me as a savior with DOTS at free of cost and now I am anxiously waiting for results”, said Ira.

Advice? don't wait

TB Alert India, the project organisation, have advised PMPs that at initial stages patients can be referred for a sputum test. They do not have to wait for other symptoms to appear.

**Name is changed to protect identity*

Submitted by: TB Alert India

SUCCESS STORY / COMMITTED

From traditional mid-wife to DOT provider in West Bengal

Mukhi Mandi, a 62 year old tribal woman, lives in Ballaldighi village in the Hooghly district in West Bengal. Ballaldighi is a backward village and many villagers are daily wage earners.

Ms. Mandi married at a very early age, had three children and was subsequently deserted by her husband. Ms. Mandi's life is a constant struggle. She too earns a daily wage and does seasonal work in agriculture. Yet, even in the midst of this struggle she has demonstrated her deep social obligation towards her community.

Early on, as she battled to make ends meet, Ms. Mandi used to serve as traditional Dai (mid-wife). In due course, she received formal training and is now a trained Dai.

Ms. Mandi was identified as a potential DOTS volunteer through the IMPACT project of CARE India which is being implemented in five districts in the state of West Bengal.

Training adds new dimension

She was sensitised on TB and DOTS, and since then her life has taken a different direction. With enhanced knowledge on signs and symptom of TB and importance of treatment compliance of the disease, Ms. Mandi started extending efforts to combat TB in her village.

> "I do not mind whether I get any money for providing DOTS...I am happy to see that my neighbours are getting well and cannot spread the germ of TB."

Over the last 18 months, Ms. Mandi has provided DOTS to five TB patients in her village and already two have been declared cured. All of these patients are symptomatic TB and three are female.

DOTS provider finds solutions

Ms. Mandi had provided DOTS to patient who is getting Category II treatment and arranged to provide injections through a private medical practitioner since she cannot give injections.

All patients are daily wage labourer and as a result the treatment center timing did not match with their schedule. Ms. Mandi came forward to provide DOT at the convenient time of these patients.

Ms. Mandi's job has not been restricted to DOTS provision only. She also refers TB suspects and one of them turned out to be sputum positive. Not surprisingly, she has taken the responsibility of providing DOTS to this patient too.

Ms. Mandi also educates TB patients on cough hygiene and proper disposal of sputum to prevent the spread of infection.

As she described, "I do not mind whether I get any money for providing DOTS, but I am happy to see that my neighbours are getting well and cannot spread the germ of TB. In the future we will not have the chance of being infected by this life-threatening disease. It gives me immense pleasure to feel that I am associated with such a noble service."

To the patients of the village, Mukhi Mandi is like a mother who takes care of them.

Submitted by CARE India

LAST WORDS

The Partnership for Tuberculosis Care and Control in India brings together civil society across India on a common platform to support and strengthen national TB control efforts. Add your voice to our efforts. Contact: Darivianca Laloo, dlaloo@theunion.org

Disclaimer: The information and views expressed in the newsletter is of the authors only.
The Union does not take responsibility for any of the views expressed here.
We would like to thank all our partners for sharing their stories, information and news.

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