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PTCC gears up for change

We have received a favourable response to Partners Speak’s revamped look, feel and content. However, we want to provide insights and perspectives on efforts around TB care and control from all over the country; in order to do so we welcome your contributions in the form of content, photos and ideas. In the meantime, expect coming issues to bring viewpoints from a variety of stakeholders such as: journalists, medical doctors, STOs and DTOs among others.

On another note, the Secretariat was excited to receive assurances from Germany and the UK of their continued support to Global Fund. While this is definitely great news, we as a Partnership should also begin to look for internal support from the Government and its corporate sector as the Indian economy continues its growth. How will the PTCC respond to this critical topic?

In this issue, our stories showcase our unsung heroes. These are not only the people who are committed to ending TB through civil society, but also the DOTS providers, those who have been sensitised about the disease and urge others to get their sputum tested, those who are helping patients stay the treatment course and, those working to stamp out stigma and discrimination against people suffering from the disease.

Also we feature a special section focused on World TB Day events. Partners share the highlights and the photos commemorating the day. Finally, Dr Giuliano Gargioni, Team Leader, National and Global Partnerships at Stop TB Partnership in Geneva visited New Delhi to offer guidance to the Partnership as it plans for its future. He shares the importance of national and global partnerships in the fight against TB.

Welcome to our new partners

Needs, Andhra Pradesh
Shohratgarh Environmental Society, Uttar Pradesh
Deshabandhu Club, Assam
Gautam Buddha Jagriti Society, Uttar Pradesh

“Activism, in the sense of creating awareness within society and generating a proactive approach to address the personal, social and even political problems posed by this epidemic, is absolutely critical.”

Dr. Giuliano Gargioni, Team Leader, National and Global Partnerships, Stop TB Partnership, page 4

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NEWS / EVENTS

Highlighting health on Women’s Day in UP

In Uttar Pradesh, the Asha Deep Foundation celebrated International Women’s Day this year by encouraging women to join their local Self Help Group (SHG) as a means of empowering themselves. This would in turn help to mitigate the risk of diseases like TB. As part of ADF’s programme female members from five SHGs in the Ghaziabad district were brought together to share their stories and successes. In addition, participants were treated to a cultural presentation focussing on women’s rights. The objective was to motivate women not only to join SHGs, but also to raise awareness about their human rights, health and nutrition.

Submitted by: ADF

IDF launches a Clean India Movement at Malwani - the Asia’s second biggest slum

IDF a partner of the Partnership along with other NGOs spearheaded a comprehensive clean-up programme to be rolled out on a nationwide basis over a period of time. They began the project at Malwani(Mumbai) the second largest slum in Asia. Post the success of the pilot, similar programmes will be replicated in other parts of India. The film industry from all disciplines - Iqbal Khan, Sushant Singh, Tanu Vidyarthi, Longinus Fernandes and Sumeet Kaul - came forward to participate in the Clean India Movement launch. Awareness campaigns/ skits/ street plays/ essay writing/ drawing competition and projects like induction of Student Clean Champions were adopted to bring focus on the benefits of sustainable cleanliness to the slum communities. Over 50 street plays on Clean India Theme were played by NSS, NCC and volunteers from Usodeum Performing Arts. Over ten thousand volunteers, residents and school students thronged to the ground to commit their support for the national movement. The event was supported by Indian Overseas Bank, Halliburton, Varun Industries Ltd and Rotary International.

Submitted by: IDF

Community participation key to TB-related MDG

Community participation is a key strategy identified by the RNTCP to achieve TB-related Millennium Development Goals (MDG). This participation includes DOTS and treatment support to patients by community members; community education and advocating for support from local administrative organisations.

India has several robust community-based institutional structures (e.g. “Panchayat”’, “Gaon Kalyan Samitis”’, and “Mahila Mandals”’), and a rich tapestry of community-based organisations (CBOs) that operate even in the most difficult areas of the country. These organisations are rarely utilised in the fight against TB, and represent a tremendous opportunity to strengthen programme implementation.

As a result of this recognition, REACH in collaboration with The Union organised a workshop on “Community Systems Strengthening (CSS)” in mid-January. Close to 30 participants from 21 different civil society organisations attended the session in Chennai. The workshop aimed to strengthen participants’ understanding of community systems through a facilitated session as well as sharing of experiences from organisations working in the area of CSS. The workshop aimed to strengthen participants’ understanding of community systems through a facilitated session as well as sharing of experiences from organisations working in the area of CSS. There was also guidance on how to engage with the community at all stages of implementation.

Submitted by: REACH
Agnes Kunze tackles stigma head-on

Agnes Kunze Society in Dehradun demonstrated recently that stigma and discrimination against HIV/AIDS patients remains rife. In February, an HIV-positive patient in critical condition who needed to be transferred to a city hospital was denied free ambulance service. Known as the ‘108 service’, it is run by the city health department and is a service provided to critically ill patients providing them a free transport and transfer from one health centre to another.

Mr. Bharat Singh was receiving treatment at Hope Community Care Centre (managed by Agnes Kunze Society (AKS)) when he became seriously ill. The duty nurse attending Mr. Singh (who) immediately called 108 service but the response by the 108 call centre was unsatisfactory informing the nurse that it could not make arrangements for patient’s pickup from the care centre.

However, the 108 service refused to help and even suggested the nurse try the city police. As Mr. Singh’s condition continued to deteriorate and the nurse sought an alternative. She contacted an AKS project co-ordinator and asked them to arrange a vehicle to transfer the patient. Two project staff members accompanied Mr. Singh to the hospital and stayed with him until he was seen.

The entire incident was widely covered in the local media. AKS wrote a letter to the state’s Secretary Health requesting appropriate action to improve 108 services and to prevent further cases of discrimination from happening in the future.”

Submitted by: AKS

Civil society plea yields responses from Germany and UK

The relevant departments of the UK and German governments sent a response to the letter written by the Secretariat on behalf of civil society requesting sustained financial support. The letter was sent to the offices of all G8 countries and asked that they reconsider their cuts to contributions to the Global Fund which supports TB care and control and impacts on millions suffering from the disease. Both the UK and Germany stated their continued support to the Global Fund.

PTCC’s call to action

After news reports that severe forms of multi-drug resistant tuberculosis (MDR-TB) cases were found in Mumbai, the Partnership for TB Care and Control in India sent out a call to action to all stakeholders working for TB control across the country. “There is an urgent and critical need to scale up services by stakeholders working for TB control across the country. “There is an urgent and critical need to scale up services by stakeholders working for TB control across the country. “There is an urgent and critical need to scale up services by stakeholders working for TB control across the country. “There is an urgent and critical need to scale up services by stakeholders working for TB control across the country. “There is an urgent and critical need to scale up services by stakeholders working for TB control across the country. “There is an urgent and critical need to scale up services by stakeholders working for TB control across the country.

Submitted by: Secretariat, PTCC
ANDHRA PRADESH
David & Lois Rees Hospital and the District TB Control Office's held two WTBD activities: a rally from the Government Hospital which was flagged off by the District Collector, Sri Solomon Arokiya Raj.

DELHI / NCR
REACH
Media Award function was organised by REACH to felicitate media personnel and young filmmakers who are trying to highlight TB through their work.

FIND
FIND chose to celebrate the day with special highlights from its EXPAND-TB project in India. They created a photo essay, which showed the impact of their work on patients, particularly within the context of improved detection of multi-drug resistant TB. The photo essay was displayed on FIND's website: http://www.finddiagnostics.org/programs/scaling_up/unitaid_expand_tb/india-photo-story/

The EXPAND-TB project aims to improve laboratory services in order to widen access to diagnosis for patients at risk of MDR-TB. As the main implementing agency of the project, FIND is responsible for training laboratory staff, providing manuals and developing quality assured processes, thus contributing to the successful introduction and proper use of the new diagnostic technologies in the countries that need them most.

PCI
PCI marked the day in Delhi through community engagement generating awareness about the disease, its causes and prevention through an awareness booth set up in the busiest market of New Seemapuri. A door-to-door campaign of homes, shops and other business enterprises was also carried out. They also organised a meeting with about 20 youth and counselled them about importance of early detection, signs and symptoms, availability of treatment facility and nutritional support. The activities overall reached out to nearly 1300 people.

OPASHA
In Delhi Operation ASHA team along with volunteer teams from Pharma Secure, The India Ladies Circle, and BD Pharmaceuticals distributed shirts provided by the Partnership for TB Control and Care in India.

HARYANA, RAJASTHAN
The World TB Day at Mahendragarh, Haryana was celebrated/observed with Hon'ble Health Minister-Haryana, Shri Rav Narendra Singh. During the event Hon'ble Health Minister flagged off the Mobile Van and observed Nukkad Natak Performance conducted by PSI and appreciated efforts of PSI and MAMTA.
Bulgam Bhai Signature campaign: This was organised in the states of Haryana, Bihar, Rajasthan which was signed by the STOs, DTOs, district health staff and community members.

The world TB Day has been celebrated/observed at rest of the program districts in collaboration with the District RNTCP and SR partners. During the entire event various activities were conducted by the RNTCP and PSI. i.e. Signature campaign, Flag off of Mobile van, Performance of Nukkad Natak/street theatres/street play shows, participating in the rally.

**PROJECT AXSHYA: BULGAM BHAII LAUNCH**

Launch of Bulgam Bhai media campaign. PSI also organised a signature campaign in other states and distributed Bulgam Bhai merchandise which displayed the campaign tag line: Do Hafta Ho Gaye Kya?“.

**KARNATAKA**

PSI

Corporate conference on TB held in Bengaluru on the 20th March 2012 which was participated by Dr. E V Ramanna Reddy, IAS., Secretary, Department of Health & Family Welfare, Govt. of Karnataka; Sri. Selva Kumar, IAS., MD, NRHM; Dr. Cheluvaraj, Director-Health and Family Welfare services, Govt. of Karnataka; Dr Nevin C Wilson, Regional Director, The Union South East Asia; Dr.M.D. Surya Kanth, JD (TB) & STO (In-Charge); Dr Balaji Naik.R, WHO State HQ Consultant, Dr.Chakrapani CHAI and Dr Daisy Lekharu (National Manager-TB), PSI.

**IDF**

IDF organized Essay Writing Competition in Karnataka and Tamil Nadu states with theme ‘Let’s stop TB’. The competition was organized in collaboration with Karnataka State TB Association in Bangalore while GREMALTES in Chennai and NILES in Coimbatore. Several students participated in the essay competition both in regional language and English. The winners were honoured at separate functions organized in Bangalore, Chennai and Coimbatore and were awarded at the hands of health department officials.

**MADHYA PRADESH**

**OPASHA**

This World TB day, Operation ASHA was honored by the city of Bhopal for its outstanding work in Tuberculosis treatment and prevention of MDR-TB. The DTC ended the World TB Day program by organizing a ‘Samapan aur samman samreshw’, where Operation ASHA was awarded a trophy and a certificate of honour.
Operation ASHA observed World TB day by focusing on awareness, a much needed area. In the city of Sagar, distinguished Doctors, medical officer, STS and TBHV, school children, teachers and patients of Operation ASHA along with their family members participated in an informal face to face discussion on how to stop the spread of TB and how to overcome the harmful effects of medicines.

In Gwalior this important day was celebrated at Sofia Nursing College. It was a joint venture of RNTCP and Operation ASHA. Students were given intensive education about TB, what are the steps involved in its treatment, and the kind of nutrition one must adhere to during the treatment.

In Bhopal, a marathon race was organized in which the staff of Operation ASHA participated with full enthusiasm. Also a program named ‘Hastakshar Abhiyaan’ was carried out drawing large number of people who signed in support of the work being done to eradicate TB.
AKS
More Than 2000 school children participated in “I will stop TB in my life time” Campaign in Dehradun. The event was organised by Agnes Kunze Society under TB awareness program. The Event was flagged off by Dr. Khatri, DTO Dehradun.

MSS
To knock each door to knock out TB campaign by MSS was organised in Haridwar along with a the Signature campaign of “Stop TB in my Lifetime, I want Zero TB Deaths, I want faster TB Treatment. Patient charters to AISWS was also carried out.

UTTAR PRADESH
ADF/PTCC/Opasha
Total 800 children in the age group of 5 to 15 years from class 3 to 12 participated in drawing and painting competition, slogan writing competition and “Stop TB in my lifetime campaign. Total 800 students participated. They expressed amazing ideas and thoughts on TB its and DOTS the sure cure for TB. A three day event was organized by Partnership for TB Care and Control in India in Collaboration with Asha Deep Foundation (ADF) and Operation Asha (Opasha)
PARTNER IN PROFILE

Dr. Giuliano Gargioni, team leader, national and global partnerships at Stop TB Partnership Secretariat in Geneva sees vital collaboration and support in evidence at the PTCC

Q: It’s been 11 years since the first meeting of the Stop TB Partnership (Partnership) what are the primary barriers preventing the Partnership’s vision to eradicate TB globally?

A: From my perspective, the global and national efforts to advocate for tuberculosis control and actions to mitigate its impact on patients and their families have significantly altered the fight against the disease. We have formulated and implemented effective policies and strategies in collaboration with technical partners and civil society organisations. However, to win the battle against TB, we still need many more resources and new tools particularly in countries with the highest burden of TB. To that end, we are looking forward to new drug regimens, point-of-care diagnostics and a new vaccine. You could say that we have turned the barriers to TB elimination into goals and targets for a global partnership to reach over the next several years.

Q: Why are national and global partnerships of such importance to TB care and control?

A: Until just a few years ago, the world of public health used to be considered the exclusive domain of public authorities whose mandate and responsibility was to address public health issues. There has been growing recognition that the civil society (in all its articulations and expressions, from the non-profit or faith-based organisations to private professionals or facilities) organises itself to meet the need for social services such as health and education. Thus providing a wonderful opportunity for complementary and synergistic initiatives. The Stop TB Partnership is precisely such a platform - built based on mutual efforts and trust in order to implement more effective interventions; to reach greater numbers with quality services, and to advocate for necessary resources.

Q: There is often a comparison drawn between the activism of NGOs working in HIV/AIDS versus the lack by NGOs working in TB. Is this a fair comparison? Can those working for TB care and control take a more activist approach to raise awareness?

A: Activism, in the sense of creating awareness within society and generating a proactive approach to address the personal, social and even political problems posed by this epidemic, is absolutely critical. It is not simply a matter of bringing those affected by TB to be represented at conferences. The positive challenge today is for policy makers and service providers to have a fruitful dialogue with civil society and affected communities. It’s to ensure that TB patients and their families are empowered enough to be part of the process of designing, planning, implementing and evaluating health services thereby leading to person-centered services.

Q: With your long experience in TB what do you say about partnership for TB care and control’s progress in India?

A: I visited the Partnership for TB Care and Control (PTCC) back in 2009. I had a more recent visit this year where I attended the 8th Steering Committee/Working Group meeting organised by the PTCC’s Secretariat. First of all, I was again impressed by the sustained commitment of the Union’s South-East Asia Office and by the professionalism of the hosted-secretariat that facilitates the PTCC’s work. I also saw the same support and commitment present during the Steering Committee meeting. A group of partners working together for a common purpose, ready to shoulder their part of responsibility.
and very respectful towards each other’s identity and contribution. This is a precious social capital and an effective partnership, which can also be used with public institutions. Back in 2009, this was certainly less visible and could only be hoped for.

Q: Are there any particular lessons or insight you can impart to the Partnership for TB Care and Control, India as it prepares to become a stand-alone entity focusing on advocacy?

A: Successfully complementing the work of the public sector requires all partners to identify a few strategic priorities and to focus their efforts and resources in those areas of work. Being part of a more structured collaboration, which may take the form of an NGO or of another legal entity, should be immediately perceived as an advantage in terms of sharing of knowledge and experience. And, I’m sure, that the new format of the PTCC will be regarded as an essential ally by the public health authority, because of its huge potential for reaching out to more people and for making services more accessible.

Q: Final question, how do should Partnerships be prepared for the inevitable highs and lows as they work towards a successful end - the elimination of TB?

A: Highs and lows are to be expected; what is important is to remember the issue that pushed us to work together in the first place. At the outset of partnership is the awareness that this formidable task can only be faced together - through every individual effort we all collectively stand to gain. It is this that people will need to remember as they meet difficulties otherwise they will just wear you out!

CASE STUDIES

A new extra pulmonary TB case successfully transferred out to adjacent district

Sangitabai is a 7 year old daughter of a young man called Munna who lives in Dindori district which is adjacent to Mandla district of MP. Munna is a labourer by profession and the only bread winner in his family and hardly able to manage two square meals, living from hand to mouth. in festive season Munna visited his relatives for celebrating Holi with her daughter. He had no information about TB and its symptoms. He was taking services of a traditional healer because his daughter Sangitabai was not able to move her neck in any angle. An Axshya project NGO representative noticed a tumour on his daughter’s neck and suspected extra pulmonary TB, he approached the ANM of the village to diagnose it properly and Sangitabai was referred to DTC Mandla directly. DTO Mandla confirmed her new EP case and immediately transferred out to her native district having given the lab no.683 dated 20-3-12, so that DOTs can be operated appropriately in her district in full duration course.

Mr. Munna took the opportunity to thank Axshya and DTO for their instant cooperation and right diagnosis and some good pieces of counselling. DC requested to DTO sir to communicate directly to Dindori DTO for immediate attention for this girl. DTO sir appreciated Axhaya NGO effort to bring such cases in his notice.

Submitted by: CHAI
MEERA FOUNDATION is involved in ACSM activities for TB Control with REACH under in Dindigul District of Tamilnadu. The team is responsible to carry out activities that can help change the health seeking behaviour of local community in that area. Recently this team had organized Mike Propaganda in hill station (Kodaikanal) and also distributed IEC material to people with information on TB. A poor fruit shop owner approached this team and asked for help for his daughter’s medical needs. The team members visited his daughter Ranjitha who is a 18 years old young girl and was a TB positive patient in the past but had not taken treatment. She was not only suffering with TB but also physically challenged as her eyes and limbs are weak.

The ACSM team took the initiative of bringing this particular case in the knowledge of DTO. Immediately the medical records were verified and sputum examination was done. The patient was found to be an MDR case. With this knowledge the correct treatment was started within 3 days. This was an excellent example for the entire team that can be used for educating the community groups to get involved in these activities.

The lesson learned is “If correct communication properly reaches the community; it can help them seek health”

Submitted by: MEERA Foundation/REACH

Sharing salt and TB success

Laxmi Rajput and Radha Rajput are respectively president and treasurer of Vaibhav Laxmi SHG of Taronkala Village (AXSHYA Model Village) in Pipariya Block under (Pipariya TB Unit) of Hoshangabad District in Madhya Pradesh and their own contribution to TB care in their locality.

CHAI organised two days Community Based Organisation Training in September last year at District TB Training Centre. Both Radha and Laxmi participated in the training. Radha’s husband suffered from TB in 2003 and she saw first hand her husband’s suffering due to the disease. This painful experience motivated her to attend the training along with Laxmi. At the end of the training session Radha said: “Humne Aapke Sanstha ka Namak Khaya hein to Aapka kaam pura kar ke dikhayenge” which translates to (“We have eaten your salt, so we will contribute to achieve success in your goal!”).

Both ladies called an SHG meeting to share their training experiences with other members. Shortly thereafter, they came to know about a person who was having compliance of blood in sputum and fever for a few days. They took the person to TU Pipariya unit where his sputum tested TB positive.

Radha and Laxmi also came across Dadu Kushwaha who is 40 years old and a labourer. He is married with four daughters and a son and is the sole breadwinner. He also has TB. The ladies met Mr Kushwaha while he was in the initial stages of the disease. He had been to private doctors and had purchased medicines costing between Rs. 1,000 and Rs. 1,500. His total medical expenses came to Rs. 10,000. Radha and Laxmi referred him to TU Pipariya.

Radha also sent her husband to accompany Mr Kushwaha to the TU to ensure he reached it. Laxmi also did her part and went with the patient to the private doctor to get his medicines replaced and after a hard struggle saw that the clinic refunded him Rs. 700. The patient and his family were thankful to the SHG members. He is now undergoing DOTS and able to go to work.

Laxmi and Radha show how to share salt and success through their dedicated efforts.

Submitted by: CHAI
SUCCESS STORY

Rural health care training at work

Dr. Suleiman has practised naturopathy for the past 17 years in the Sivanganga district in Tamil Nadu. The district is among the country’s most backward. It’s largely agricultural producing sugar cane, pulses and cereal among other crops. His practice is set near Kalayarkoil.

In May last year, Dr Suleiman attended a CHAI-organised, Project Axshya training for Rural Health Care providers which gave him detailed knowledge on both TB and RNTPC services in the district. After his training he wanted to become a DOTS provider. CHAI coordinated further training with a senior treatment supervisor who taught him how to give medicine and how to maintain a treatment card. Dr. Suleiman said, “I treat TB patients like family members and I have a great concern towards their treatment until the RNTCP declare them as cured. I will continue my service for the cause of TB.

Dr. Suleiman said, “I treat the TB patients as a family member and I have a great concern towards their medication treatment regimen until the RNTCP declare them as cured. I will continue my service for the cause of TB.”

Submitted by: CHAI

It takes a village

Sensitisation training aimed at village leaders is another Project Axshya initiative that can bring about revolutionary change as illustrated in Kirunka Kottai, a small village in Sivanganga district in Tamil Nadu. The Panchayat president, Mr. Rasiappan, set a goal for the village - to acheive 100% awareness about TB symptoms and treatment.

To reach the goal, villagers participated in a range of activities that included: one-to-one and group education, street plays, mass contact programme, wall paintings, health awareness programme and health education for school children. Mr. Rasiappan participated in a sensitisation workshop for the Panchayat administration which convinced him of the importance of patient support. He also realised the ill effects caused by the stigma and discrimination against those suffering with TB.

Further motivated by all he learned, he permitted a TB patient from his village, who earlier had faced stigma and discrimination, to work under the Mahatma Gandhi National Rural Employment Scheme (NRECS) at this village. He was welcomed and supported by other colleagues. This act by Mr Rasiappan sparked a big change in attitude towards TB patients within the community.

Submitted by: Mr. Mohamed, Meera Foundation
Attentive care puts a defaulter back on track

Arumugam, 30 years old, is a Category II three-time defaulter with suspected MDR-TB. He is from a village in Dharampuri district in Tamil Nadu. When he was first received, according to clinic staff, he was very close to death. He was extremely thin and undernourished with severe body pain. His mother carried him to the clinic for his first visit because he was unable to walk. According to Agape clinic staff where he was first received, he was very close to death—very thin and undernourished with severe body pain. Unable to walk, his mother carried him to the Agape clinic for his first visit.

He defaulted before because he didn’t stick to his treatment. However, because he was severely ill, he was more willing to receive treatment.

From the beginning, aware of his very critical state, the staff at Agape paid him very special attention. During the first few months of his treatment, Arumugam suffered frequent and debilitating side effects to the medication including vomiting and severe body pain. Agape staff consistently treated his symptoms along with providing TB medication. When he came to the clinic, he was given food and a bed to sleep in for a couple hours because staff knew of his discomfort from the one-hour auto ride. Medication was also taken to his home if he was unable to come to the clinic for physical or financial reasons.

The extra care by the staff ensured Arumugam’s compliance. He was close to death, but the Agape staff prayed for his healing and recovery daily while giving him the required care and treatment. After the first couple months of the Intensive Phase (IP) treatment, a marked change was seen: he complained less, his hospital stays shorter and his appearance brighter and neater. By the beginning of the Continuous Phase (CP) treatment, the transition was complete. When he came to the clinic for his weekly visit, he was full of energy, well dressed along with a big smile. Despite the auto ride, he no longer requested a bed. Arumugam soon began to work.

Arumugam has now completed half of the CP treatment. Now he is able to jump and run up and down the stairs. He and his family now have a bright future ahead of them.

“We thank God for the healing that has taken place in Arumugam and for using us in his life!”

Submitted by: Agape Foundation

Photo credit: Agape Foundation

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