

AMICI NEWS

January 2017

**IT DOES NOT
MATTER HOW
SLOW YOU GO**

**SO LONG AS YOU DON'T STOP TILL THE
GOAL IS ACHIEVED**

#LEPROSYFREEINDIA



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Inset : two young friends at the Catholic hospital Borgang waiting to undergo reconstructive surgery for leprosy related deformity.

COMMEMORATION OF WORLD ANTI LEPROSY DAY



January 29th 2017 Sparsh Oath taking with Asha's in Mandya.

SPARSH LEPROSY AWARENESS PROGRAM

The programme aims at intensifying leprosy detection through community participation and treatment of the disease at early stages besides eradicating the social stigma associated with it.

SPARSH CAMPAIGN ACROSS INDIA

2017 Anti- Leprosy fortnight: witnessed a paradigm shift of activities moving focus into campaign mode. " Sparsh Leprosy Awareness Campaign (SLAC), Central Leprosy Division had brought innovation in the NLEP programme for the first time. The thrust of this campaign is to promote community participation to reorient the delivery of service, diagnosis and treatment of leprosy empowering the Panchayat Raj institutions and local communities, to take over the responsibility of sensitizing the community, motivating people and fighting stigma and discrimination.

AIFO India along with our partners around the country, pledged our support to the newly launched SPARSH leprosy awareness campaign. Through an oath taking, information session and awareness drive, community health workers , ASHA'S and NGO's were called upon to fight for the cause of leprosy eradication.

WHY DO WE OBSERVE ANTI LEPROSY DAY

On the last Sunday of January each year Anti Leprosy Day is observed throughout the globe, while on the 30th of each January - on the day of martyrdom of Mahatma Gandhi, the father of our nation, Anti Leprosy Day is observed. This day , serves to remind people that leprosy still plagues hundreds of thousands of lives and it is important that we recognize this as a disease and that it is easily treatable and curable through a course of multi drug therapy that is available free of cost through the Primary Healthcare centres of the Government of India.

During this fortnight of campaigns and programs, priority is given to the National Leprosy Eradication Program activities. This years campaign focused on stigma and discrimination and encouraging citizens and policy makers to take responsibility along with the Health system. It is important to dedicate ourselves to the cause of leprosy during the start of the year and continue supporting persons affected by leprosy , treating with with dignity and providing them with their rights and entitlements that have been denied to them in the past.



Above: AIFO Manikbond, Assam

ANTI LEPROSY DAY CELEBRATIONS IN NEIGRIHMS- SHILLONG, MEGHALAYA

As part of AIFO India's activities supporting the NLEP in the North East, this program materialized after a gap of 5 years , where no progress could be made due to various limitations. The Department of Dermatology, Community Medicine came together with AIFO and successfully carried out anti leprosy day celebrations. In addition to AIFO staff , the department of dermatology, community medicine and Indian association of Dermatologists/Virologists came together along with the Meghalaya NLEP, medical undergraduates/ post graduate students, nursing students and students from BSc and MSc and all faculty members from the Department of Pharmacology and Opthamology participated in the Programme.

The State Leprosy Officer - Dr. Suklanglin Rynthathiang inaugurated the program highlighting the situation of leprosy situation in the state. Following this , Dr.Lanong briefed about National Leprosy Eradication Program in the 8 NE states. Dr. Manimozhi focused on Basic Leprosy, and Dr. Ashish Wagh briefed out about Disability/ Deformity management. This was followed by a question answer sessions which went for more than an hour. 7 teams had participated in Poster competition - and all the 7 teams were rewarded. It was unanimously agreed to support the institution further in collaboration to improve and develop expertise in the NE region.

Dr. Star Pala Associate Professor Community Medicine, Dr. Mrs Deepti Dermatology Professor and Dr. Apurba Marak, MO DNT , East Khasi Hills were the key persons along with Dr.Lanong , responsible in carrying out this activity as planned earlier.



Above: Dr.Manimozhi Natarajan, Head Aifo NLEP leading the leprosy training program in Shillongh



Above: Rabi after his reconstructive surgery at the Borgang Catholic hospital

20 Reconstructive Surgery at Catholic Hospital Borgang

The AIFO India team with the support of the state NLEP staff successfully completed the reconstructive surgery of 20 individuals with leprosy related deformity/ disability. This surgery

Rabi Ghatwar, a young man determined to overcome the odds

Rabi is an 18 year old young man, from Badolipar village, Golaghat Assam. His mother Dhaim is a tea garden worker and he has an older brother and two younger siblings (A brother and a sister). His young brother aged 9 years is unable to go to school, due to lack of finances and his 5 year old sister has displayed a patch on her skin which doctors are keeping under observation. His mother is the sole bread winner and his father passed away some years ago.

The family lives in temporary housing made out of tin, bamboo and mud. While Rabi studied until class IX he stopped going to school after his deformities caught up with him and he experienced clawing of his left hand. He had not yet lost the use of his right hand and was optimistic of his return to school post RCS. Rabi first noticed patches on his back three years ago and he was treated at Golaghat Civil Hospital.

However, he developed weakness of his hands followed by clawing and inability to close the left eye during treatment with MDT. Despite attempts at physiotherapy aimed at improving the clawing, the situation worsened. The disease also caused anesthesia of both his feet.

It was then, that he was referred to Borgang Catholic Hospital and his long journey to recovery began in 2015.

He underwent debridgement of his left foot ulcer in November 2015, followed by reconstructive surgery of his left lagophthalmus in February 2016. After months of physiotherapy, counselling and rehabilitation Rabi is ready to go back to his education.

HOW CAN YOU HELP?

Rabi needs to get back to school. His mother is the sole bread winner, working as a tea garden worker and she earns a meager 3000 rupees a month. Rabi is a keen learner and now with his regained health and confidence needs a little more help, to get back on his feet.

**PLEASE DONATE INR 10,000 TO
SUPPORT RABI'S EDUCATION**



Angavikalara samavesya - Commemoration of Disabled Day at the Assisi Leprosy Centre

December 2nd 2016, Huvinagadagali

Our partner the Assisi Leprosy Centre, Huvinagadagali has been working for persons affected by leprosy and for persons with disability for nearly three decades reaching out to lakhs of people in needs. On December 2nd 2016, the centre held an event commemorating Disabled Day. The staff shared positive messages and inspirational stories from the many years of their service to the community.

Mrs.Ambujashi, an eminent lawyer in Hadagali court shared her message about women empowerment and the importance of the girl child. The local community members came together to organize a dance and drama program, which entertained and enthralled all present. Among the dignitaries was Fr.Denzil vages, Director of NGO Carmel who gave an inspiring talk on the special talents of persons with disability. Finally, Assisi Leprosy Centre, Staff member Sr. Jyothi shared the history of the leprosy centre and the work done by the staff in empowering and enabling the community , identify and improve its health needs. Akamma, an early beneficiary shared her life story and the positive changes brought about because of the centre. The event concluded with a felicitation ceremony, recognizing sporting achievements as well as distributing tailoring certificates to candidates who had successfully completed their course.

Celebrating 25 years of SRMAB – Sri Ramana Maharishi Academy for the Blind

In December 2016, AIFO India participated in the 25 year celebration of SRMAB, whose activities span special needs education, training of special educators, empowering persons with disability and persons coming from backgrounds of poverty, marginalization and vulnerability. AIFO and SRMAB have been partners for over two decades and we are delighted to share in their celebration and successes.

We wish them every success as they grow from strength to strength.

AIFO Partners Meet.

AIFO India met with 14 of our partners working on leprosy and community based rehabilitation work in January 2016. The goal of this meeting was two fold: a. to explore new and innovative ways to deliver healthcare services to the communities they serve b. to deepen the impact of their existing work using innovation, networking and upgrading of skills. Another key theme of this meeting, was to support our partners in designing and deploying strategies for financial sustainability. A detailed program, finance and impact audit was done by the AIFO team and recommendations were made to support our partners in their quest to continue doing the amazing work their do.



Passage of the Rights of Persons with Disability

The Rights of Persons with Disabilities Bill 2016, replaced the existing PWD Act 1995, which was enacted 21 years back. The New Act will bring Indian law in line with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), to which India is a signatory. The new law will not only enhance the rights and entitlements of Divyangjan but also provide effective mechanisms for ensuring their empowerment and true inclusions into society.

Did the law translate into action in the recent budget? The Prime Minister made it clear that he held the disability sector close to his heart, even spending his birthday distributing aids and appliances to persons with disability. The Sugamya Bharat Abhiyaan (Accessible India Campaign) launched in 2015 is another highlight of the administration's commitment.

Despite the passage of the Rights of Persons with Disabilities Act in 2016, the budget allocated only about 0.0039% of the GDP to the differently abled. Despite the shortcomings, the Act is important for the disabled in India. It makes specific provisions for social security, health , rehabilitation and recreation, which is an improvement, given that affirmative action for the disabled until now referred to reservations, with a few concessions thrown in.

AIFO has supported the drafting of this bill and participated in numerous stakeholder consultations and roundtables.

Full text of the Bill can be read here - <http://164.100.47.4/BillsTexts/RSBillTexts/PassedRajyaSabha/PWD-RSPE%20141216.pdf>

Research and Publications

In the special issue of knowledge management for development (KM4D) journal , focused on disability. It includes a paper on persons with intellectual disabilities from AIFOs project in Mandya district and is co-authored by Head Programs AIFO India, Dr.Jayanth Kumar.

Link here- <http://journal.km4dev.org /index.php/km4dj/index>

Policy News

In the first week of February 2017 the Supreme Court asked the Centre to prepare a comprehensive policy for the implementation of a plan within four weeks for eradication of leprosy. A bench of Chief Justice JS Khekar and justices NV Ramana and DY Chandrachud said the Centre should also submit a plan as to how it intends to fill the large vacancy at the ground level. The bench was hearing a PIL filed by advocate Pankaj Sinha had earlier rapped the authorities for their “apathy” in eradicating leprosy from the country, saying despite it being “curable”, the disease still remains a stigma.

Earlier too, the apex court had granted time for filing of replies by the centre and others and has said, “This is a case which should have been take on a priority basis. Leprosy as on today, is curable yet, because of apathy shown by the authorities concerned, it still remains a stigma”.



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Like many organizations we want to create lasting impact. One way to do this, is to invest in the the lives of young people and children and ensure they have a chance at a brighter future. Support our work by making a donation on www.aifoindia.org.

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