

# Amici News

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## Life Story



Karthik is a 11 year old boy. He is the youngest of three children and has two older sisters. His father earns a living through painting works and his mother is a house wife. Karthik , is mentally challenged a condition he has had since birth. His condition has left him with several development delays such as inability to meet milestone of speech , learning and motor skills. Today, he struggles with behavioural challenges such as fear of sound, poor attention, aggressive behaviour, poor concentration, poor social skills , and mild autistic features as well.

Upon discovering their sons condition, his parents were frightened and they did not know what to do. They ran from pillar to post , spending large sums of money consulting with hospitals and places of worship for a solution. All the doctors whom they consulted with, stated in no uncertain terms that Karthik suffered from a case of intellectual disability and there was nothing much that could be done.

When he was five years old they took him to the Arogyamata centre for physiotherapy and day care centre. For nearly a year Karthik and his parents received training and counselling. The following year, they admitted him into a special school. Today, Karthik is able to use the bathroom on his own, he is able to manage basic issues such as drinking water and eating meals with utensils. Today, his aggressive behaviour has abated and his family is better equipped to manage his condition in a safe and healthy way.

Karthiks mother has gained confidence in her own skills , after seeing the significant improvement in Karthiks condition. She is also a vocal champion of this cause and is supporting AIFO , in its work spreading awareness about mental impairment to other parents who have similar children as well as to community at large.



## CBR Initiatives 2016

As part of AIFO's extension programme of Disability, CBR and inclusive developmental effort, MOB Mysore and SRMAB Denkanakote CBR projects have been extended to rural areas of the neighboring districts. MOB Mandya project was extended to Jayapura Hobli in Mysore district –Karnataka state and Malavalli project has been extended to Thali Block of Denkanakote Thaluk in Krishnagiri district in Tamilnadu State. Both the organisations have been facilitated by AIFO (Dr. Jose and Dr. Jayanth) to prepare their action plans for 2016 to 2018. AIFO team also made observational field visits to both the areas and provided inputs on implementing the interventions of project initial phase. The basic rehabilitation activities such as survey of PWDs, community meetings, networking meetings with governmental officials, need assessment, referral, and initiation of SHGs were already

## REMEMBERING NEPAL – One year since the Earthquake

Last year AIFO along with its partners set out on the ambitious goal of rebuilding homes for persons living in a leprosy colony in a remote area on the outskirts of Kathmandu city, Nepal. This village comprised 50 families of persons affected by leprosy and related disability and was badly damaged during the multiple earthquakes that struck the nation. While rehabilitation work has continued over the past year, our goal has been to ensure that the long term future of the young people from this leprosy colony is ensured. In partnership with ECHO , 8 young people travelled to Bangalore last year and are studying for a diploma in Hotel Management. This summer ( March, April ,May 2016) they are interning with the Leela Palace in Bangalore, a premier luxury hotel , where they are learning vital career and life skills. We are very proud of what they have accomplished and the hope that they bring to their families back home in Nepal.

## NLEP Updates

AIFO has been working tirelessly in the North East of India to expand leprosy control activities and improve access to the general health care system through up skilling the healthcare system. There have been several major developments in our NLEP work in 2016 -

- ✓ AIFO – NLEP Referral Centre in Kamrup Assam – With the assistance of the local administration, State Leprosy Officer and the NLEP program, an old PHC has been taken over by the NLEP and will serve as a leprosy referral centre dealing in secondary complications from May 2016 onwards. AIFO has been instrumental in this development and AIFO staff doctors and team will be supporting the referral centre over the course of the year. The broader goal is to train local healthcare staff and ensure a sustainable mechanism for diagnosis and referral. This centre is of particular importance since there is no referral centre in any of the surrounding districts. This centre will now reach out to over 35,00,000 people and will work closely with the Urban PHC and the Guwahati Medical College. Effectively setting up and managing a referral centre requires Significant expertise. AIFO lead a training team of staff from the SLO office to learn from a referral centre in Orissa.



Pictures: Dr.Jose, Director AIFO India, along with AIFO field staff from Assam and NLEP staff came together to chart out the finer points of the operation of the Referral Centre.



Pictures: The recently assigned NLEP referral centre serving Kamrup district ( rural and urban) providing consultations for secondary complications.

## AIFO lends a hand – House Construction.



Picture:- Shereens house before construction and her new House built by AIFO

Shereen , from the Ri Bhoi district of Meghalaya was identified with leprosy and began treatment in November 2014. She has 5 children and her husband is a daily wage worker. Her family is extremely poor. During the course of her treatment, AIFO learned about her plight. Together with her family she lived in a dilapidated home which posed many dangers to her and her children. However, her poverty prevented her from undertaking even the slightest improvements. AIFO undertook the work of rebuilding her house and today, she and her family are reside in a sturdy, safe and healthy environment. Not only has she successfully recovered from leprosy, but her new home has given her and her family a new lease on life.

While AIFO does not ordinarily undertake work such as this, we felt the need to support Shereen and her family in building a healthy future , free from disease and stigma and full of hope .

## Partnership with Dr.N.Tunel Hospital in Jaintia Hills

Two training sessions on leprosy have been conducted at the Dr.N Tunnel Hospital , with 25 nursing students from this college. The module includes classroom lectures as well as travel to Nongpoh, where they participate in practical training at Shantivan. This combined methodology will ensure they are ready to tackle a range of cases. The administration and the faculty of the college are delighted with this initiative by AIFO and are excited at the prospect of expanding this program by supporting NLEP in the region on case detection.



Picture – Nursing college student pictured during the classroom training module

Dr. Mani participated in the preparatory workshop for LCDC ( Leprosy Case Detection Campaign) which was conducted across 30 districts in India. Expertise from ILEP, Government and other organisations joined together to conduct the workshop at C.L.T & R.T Chengalpattu.

For the first time since the inception of our RCS program, local doctors have taken the initiative to perform surgeries on their own Nongpoh district government general hospital



## AIFO – ALERT EXCHANGE PROGRAM

The AIFO NLEP team lead by Dr.Manimozhi participated in a four day exchange program where they interacted, learned and shared with the ALERT team. Through this program, practitioners were able to share insights from their diverse field experiences, update and upgrade their skills, explore collaborations and conceptualise new projects within the framework of the NLEP program and leprosy control activities.

## AIFO field office staff training program

A two day training program which included 23 participants, who work in leprosy control was conducted in January with a focus on DPMR training at Kharapara , Guwahati. Participants came from 14 districts across Assam.

## Event Spotlight

On February 14<sup>th</sup> 2016, at the Indian Institute of World Culture, Basavangudi, Bangalore over 200 persons affected by leprosy and persons with disabilities and their families gathered to celebrate their journey of healing, organised and supported by AIFO India. Coming from across rural Karnataka, this event focussed on learning and sharing stories of recovery with the support of experienced facilitators. Stigma, illiteracy, lack of access, lack of mobility and poverty prevent persons affected by leprosy, disabled and the poor and vulnerable from accessing their entitlements. Additionally, participants were educated on their rights, entitlements, duties and responsibilities as well as benefits of enrolling themselves in organisations such as APAL ( Association of Persons affected by Leprosy) , KSDPF ( Karnataka Disabled Persons Federation ) and local self help groups. Also supporting the event were AIFO trustees, Dr.Nagendra Prasad and Kunju. Several volunteers and well wishers ensured that food , supplies and

Community based rehabilitation experts facilitated discussion among different groups of participants to identify the key challenges they are facing and seek short term and long term solutions. Addressing the participants was widely acclaimed freedom fighter H.S. Doreswamy aged 99 years , who said that a “fighting spirit , is critical to overcoming the stigma of leprosy”. Women, children and volunteers worked together to express



Above : Person with leprosy and visually impaired , travelled from interior Karnataka to participate



Picture:- Dr. Ashish conducted 6 reconstructive surgeries for persons affected by leprosy and



Above: Children and volunteers engaged in an art and craft activity.

themselves creatively and enjoyed themselves immensely. Dr. Jose, Director AIFO said that “inclusive growth is about ensuring that every individual – whether they are persons affected by leprosy, persons with disabilities or anyone who is on the fringes of society has enjoys a good quality of life”.

Many inspiring stories were shared over breakfast and lunch ,and a lively dance performance by a physically challenged young man enthralled all who were present. When asked about why she choose to travel for hours from Mandya to attend the program , Davamma said “ Persons like me who have been affected by leprosy are rarely involved or invited to a celebration. I wanted to feel special and heard, that is why I am here”.

AIFO India is grateful to the support of NLEP, APAL, KSDPF and all its partners whose tireless support is ensuring that the battle to eradicate leprosy is won.



Above: Men’s group discussion on rights/ entitlements and sharing their journey.



Above: Mr.Narsappa from APAL, Mr.Chelavaraju, President Karnataka Disabled persons federation looking on as Mrs.Jayashree, AIFO Trustee is being felicitated.



Alongside :Mr.Doreiswamy Iyengar (Centre) With Dr. Jose( Director AIFO) Seated Behind him and AIFO trustee Dr.Nagendra prasad (Right)

# www.aifoindia.org

To support our work in leprosy control, support for persons with disabilities, education and livelihood opportunities for children, women and poor and vulnerable communities please Donate on our website.

AIFO currently works across 10 states with 17 grassroots organisations. We are proud of our partnership with the National Leprosy Eradication Programme ( NLEP) and ILEP agencies.



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