

# The News Letter I L U – HA

## About International Leprosy Union Health

The International Leprosy Union (ILU-HA) is one of the leading NGOs in the field of leprosy. It was formed in 1986 by voluntary organizations and leprosy workers from over twenty developing and developed countries who recognized the need for linkage and networking among like minded groups and individuals actively pursuing the cause of eliminating leprosy and

integrating those who are affected by leprosy into the mainstream of society. In 2008 ILU widened its scope of work to include other health concerns like

TB, HIV/AIDS and Cancer.

ILU-HA works as a catalytic agency with the unique objective to serve as the voice of NGOs active in developing countries to give leprosy, HIV/AIDS, Cancer and Tuberculosis a human face.

ILU-HA has taken up the challenges to sustain the quality of leprosy services & to ensure that all the affected get equal opportunity for treatment and their further rehabilitation. Along

with medical rehabilitation it is important to make them psychologically confident, economically independent and socially acceptable.

### National Leprosy Network (NLN)

A meeting was organized in Delhi among stalwarts who have worked in the field of leprosy to “Develop Collaboration in Areas of Mutual Interest in Leprosy” on 11<sup>th</sup> February’ 2010 at the TLM Conference Room, CNI Bhawan, and New Delhi. Dr. Noordeen During the course of discussions it was decided to have a National Leprosy Network in order to institute a common platform which would serve for

- a) Internal exchange of information which would include area specific problems and issues like Stigma & Rehabilitation in respect of Leprosy as well as best practices which would benefit all individual agencies in the network and
- b) Act as a pressure group and have external coordination with Central and State governments as well as corporate and other International Agencies to India which can facilitate both policy making and implementation.



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### ➤ Human Rights Grievance Redressal Cell-Phase II

ILU-HA has a Human Rights Grievance Redressal Cell. Human Rights grievances are received from the leprosy colonies. ILU studies these cases and forwards them to NHRC. Many colonies are benefitting from this intervention.

When the District Leprosy Hospital of Pandri Tarai ,Chattisgarh changed to District Civil Hospital the leprosy affected were denied treatment in the hospital. ILU-HA & NHRC intervention helped to remove this discrimination and now the leprosy affected can avail of medical facilities from the Civil Hospital. The colony members from Hanuman Nagar Kusth Ashram.

Kalyan,Maharashtra were neglected & had no civic amenities. After the NHRC intervention the Corporation is looking into their needs & is providing basic amenities to the colony.

### ➤ Jal Mehta Awards Of Excellence For NGOs working in Disability

ILU-HA in coordination with Jal Mehta Foundation gave away Jal Mehta Awards Of Excellence For NGOs working in Disability. The awards were given away at the hands of the Hon. Mayor. Mr. Mohan Singh Rajpal. Dr.K.H. Sancheti , Director, Sancheti Hospital and Mr. Surendar Moodliar, Secretary Dr. Jal Mehta Foundation were the guests of Honour.

The Awards – a cheque of Rs. 10,000/- and a Memento were handed out to the winning NGOs working in the field of Disability. The winning NGOs were



- The Federation Of Senior Citizens' Organization Of Maharashtra (FESCOM) Mumbai.
- The Leprosy Mission Trust ,Vocational Training Centre, Panchavati, Nashik
- Jeevan Vikas Pratishthan, Latur
- Helpers of The Handicapped, Kolhapur
- Residential School For The Blind Chikhaldara, Amravati
- Koshish Piramal School For the Deaf, Mumbai
- Jeevan Jyot Mandal , Pune

➤ The State level conference to Review Rehabilitation Needs & Practices for all Disabilities for the State of Maharashtra and how they can lead to a revised Policy formulation as a preparatory step toward National Rehabilitation summit was organized in Pune by ILU-HA. 23 NGOs from Maharashtra participated in the conference . The recommendations have been submitted to the State Government and WHO.



## **Empowerment of Colony Leaders through Capacity Building for Socio-Economic Rehabilitation of People Affected by Leprosy**

We believe that if the persons affected by leprosy are empowered they will be able to make use of the available opportunities for their development; they will be able to live a life of dignity which will facilitate their integration process in the main stream of society.

ILU-HA with support from Sasakawa India Leprosy Foundation, (SILF) and WHO trained state leaders and colony leaders from 75 Leprosy colonies from 10 States - West Bengal, Chattisgarh, Orissa, Bihar, Gujarat, Jharkhand, Lucknow, Maharashtra, Andhra Pradesh, Punjab to take up livelihood Projects individually or in a group in their respective colonies. About 185 participants benefitted from the training. The livelihood proposals are submitted to SILF.

The Women Self Help Group of Dr. Issac, Santrapalli, Orissa and Jamuna Bandh Leprosy Colony are involved in Goat rearing. Hanuman Nagar Kusht Vasahat, Kalyan are involved in Dairy The CBO formed by women from Ashadeep Colony, Bhillai is involved in weaving

### **ILU-HA will facilitate the coordination for the first three months to**

1. Circulate the minutes
2. Circulate the notes of justification
3. Send letter of invitation to all National Agencies and indicate the size of the membership fee.
4. Start an e mail & Face book.
5. Plan to appoint a coordinator

## **➤ Launch of the Global Appeal To End Stigma and Discrimination against the Leprosy Affected**

Fifteen world business leaders from ten countries have signed the fifth Global Appeal to End Stigma and Discrimination Against People Affected by Leprosy was Launched in Mumbai on 25<sup>th</sup> January 2010 by Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination and Japanese Government Goodwill Ambassador for the Human Rights of People Affected by Leprosy, the Appeal has been endorsed by the heads of major international corporations such as Fujio Cho, Chairman of Toyota, Sir Richard Branson, Chairman of Virgin, William C Weldon, Chairman and CEO of Johnson and Johnson, and Ratan N Tata, Chairman of the Tata Group.

Speaking at the launch ceremony, Yohei Sasakawa, who is also Chairman of The Nippon Foundation, paid tribute to the business leaders whose message "will be a source of inspiration to a great many people who want to be part of society and who are beginning to stand up for themselves. It will also help to deter the kind of outrageous discrimination that shuts off opportunities to people with the desire and the ability to work, simply because of a disease they once had."



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# India has highest number of new leprosy cases

## 35% Of New Patients Are Women: WHO

Kounteya Sinha | TNV

**New Delhi:** India continues to record the highest number of new leprosy cases in the world followed by Brazil and Indonesia.

While globally in 2008, 2.5 lakh new cases of leprosy were recorded, India accounted for 1.37 lakh of those cases followed by 38,914 cases in Brazil and 17,441 in Indonesia.

According to WHO's latest estimate, around 35% of new leprosy cases in India -- 48,000 -- are women. India also recorded the highest number of children newly detected with leprosy -- 13,610. India, which is home to over 700 leper colonies, was also ahead of all other countries in the number of relapse cases at 325.



Lakhpati, a 100-year-old leprosy patient, in Amritsar

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae* which mainly affects the skin, peripheral nerves, upper respiratory tract and the eyes. It is curable and treatment provided in the early stages averts disability.

Official figures show that approximately 2.49 lakh new

cases were reported globally in 2008. The leprosy causing bacteria multiplies very slowly and the incubation period of the disease is about five years. Symptoms can take as long as 20 years to appear.

India's National Health Policy 2002 had set the goal of elimination of leprosy (reduce the number of cases to less

than 1/10,000 population) by the year 2005. India achieved this goal in December 2005, when the recorded prevalence rate (PR) in the country was 0.95/10,000 population.

Health ministry official said lepers in the country were now being given a one-time grant of Rs 5,000 for undergoing reconstructive surgery. This, ministry officials said, compensated loss of wages during their stay in hospital.

In order to ensure that patients visit the hospital for post-operative care, including physiotherapy, on which depends the success rate of the surgery, the ministry has broken the grant amount into three phases. After completion of the surgery and release from hospital, the patient gets Rs 3,000. On the first follow-up visit after one month, Rs 1,000 more is given to the patient and final instalment of the incentive is given at the follow-up visit after the third month of operation.

## Objectives

1. Exchange of Ideas, information and experiences.
2. Identifying best practices in the activities like the prevention of disability, self care, rehabilitation and advocacy.
3. Develop coordination and collaborative action of NGOs to move from Elimination to Eradication through building a political will.
4. NGOs working in the non-leprosy field as well as in Development & health related issues to be involved in collaborative proposals of Research Training, Documentation & joint actions.
5. Assisting wherever necessary programs of the member NGOs .
6. Advocacy in print and electronic media.
7. Bring likeminded NGOs on one platform.
8. Create an environment to prevent stigmatization and positive participation.