

# UPDATE

Quarterly publication on issues in leprosy

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## 'ILEP UPDATE'

Change is unsettling for some, a challenge or an opportunity for others. An opportunity to do something different, something more, something better. UPDATE, the bulletin of Damien Foundation India Trust (DFIT), starts its new incarnation as ILEP UPDATE from this issue which marks the beginning of an effort by member organisations of ILEP in India to have a forum to voice the opinions, feelings and experiences of theirs and those of other like-minded individuals or organisations in a way that will have some bearing on the ideas of wider community in general and on the lives of the leprosy-affected in particular. ILEP UPDATE will be a quarterly bulletin devoting itself to dissemination of useful information about events and happenings both within and outside ILEP projects, dispassionate presentation of discussions on various technical and operational issues of common concern and interest, of case histories of those who have successfully battled against the disease and discrimination and of humane interventions that make an essential difference to the lives of the leprosy-challenged.

UPDATE was started by Damien Foundation India Trust in 1993 as a means of continuing medical education for the technical personnel working in projects supported by DFIT. The readership number has gone up from the initial 500 to about 4000 now. It is made available to Medical Officers in districts with DTSTs from DFIT. Even though impact analysis has not been made the bulletin has contributed to expanding the capacity of the general health staff in managing the disease and the programme. Hopefully, the new edition under the new title will reach a wider audience and continue to fulfill the stated objective. It will be one of the new initiatives of ILEP in India.

The International Federation of Anti-leprosy Associations (ILEP), a conglomeration of ten International NGOs, has been involved for decades in supporting leprosy control through their various projects spread throughout the country. The ten member organisations are Association Francaise Raoul Follereau (AFRF India), Associazione Italiane Amici di Raoul

Follereau (AIFO India), Aide aux lepreux Emmaus – Suisse (ALES India), American Leprosy Missions (ALM), Damien Foundation India Trust (DFIT), Fontilles-India, German Leprosy and TB relief Association (GLRA), LEPRAS Society, Netherlands Leprosy Relief Association (NLR) and The Leprosy Mission International (TLM Trust India). ILEP member organisations in India support National Leprosy Eradication Programme (NLEP) through three main types of projects: own, NGO-run and District Technical Support Teams. Own projects are generally hospitals which are operated directly by the concerned ILEP member organisation and they provide a broad spectrum of services including management of leprosy and its complications, reconstructive surgery, socioeconomic rehabilitation. NGO-run projects are generally managed by local NGO with total or partial support by ILEP member organisation for leprosy control activities. The third type of project, DTST, involves provision of technical support to the district staff at all levels through an experienced senior level team consisting of a Medical Officer and a supervisor with a vehicle for mobility. There are totally 18 own-run, 122 supported and 174 DTST projects belonging to the ten member organisations of ILEP. The contribution of ILEP to leprosy control in India has

been conspicuous, considerable and consequential. It has enabled the Government to establish and maintain integrated leprosy services in endemic states through mainly the DTSTs. In all the 12 endemic states, thanks to the committed involvement of the Government staff facilitated by DTSTs, a reasonably well functioning mechanism of detecting, diagnosing and treating the leprosy-affected has been installed. In addition ILEP has produced learning material in 12 different languages for various categories of Government workers, trained the District nucleus team and other staff in all the 590 districts in the country, helped establish reconstructive surgery service in two medical college hospitals each in Bihar and Orissa, established POD programme in four districts,



ILEP



Fontilles  
LUTTA CONTRO LA LEPROSA

**Editor :**  
**Dr. P. KRISHNAMURTHY**  
Secretary,  
Damien Foundation India Trust.

**Associate Editor :**  
**Mr. D.V. PREMKUMAR VELU**  
(DFIT)

**Advisers :**  
**Dr. P. VIJAYAKUMARAN** (DFIT)  
**Dr. G. RAJAN BABU** (TLM)  
**Dr. D. SAMUEL THOMSON** (GLRA)  
**Mr. ANANTH RAMANATHAN**  
(FONTILLES)

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assisted the Government of India in developing DPMPR guidelines, and disseminated essential information on best practices to Medical students, undergraduate and post graduate, in several medical colleges through seminars and symposia.

ILEP involvement in leprosy control in India has evolved from providing hospital-based services directly to persons affected with leprosy through field activities to supporting the Government programme in key areas. One of the reasons for the success of leprosy control in India is the participation of a large number of NGOs in the programme. A large proportion of the local NGOs are still supported by ILEP member organisations and they continue to provide their expert assistance in areas of need. One of the strong features of ILEP in India has been the healthy, reciprocally beneficial partnership with major players in leprosy field which has resulted in remarkable progress in leprosy control and has become a model worthy of emulation. We hope that with your help ILEP UPDATE would strive to disseminate stories of success and achievements, of challenges and opportunities, of needs and desires of stakeholders.



## Association Française Raoul Follereau (AFRF)

**Mr Jean-Michel Rondot**  
*Head of Programmes*  
31 rue de Dantzig VP 79  
75722 PARIS CEDEX 15  
FRANCE  
Phone : 33-1 53 68 98 98  
Fax : 33-1 56 56 80 24  
E-mail : Direction-aide@  
raoul-follereau.org  
Web : www.raoul-follereau.org  
(No branch in India)

Raoul Follereau created the Latin Union League in 1927. After several name changes it became known as the Association Française Raoul Follereau in 1968. AFRF is composed of 78 voluntary committees based throughout France and in overseas territories. These aim to distribute information on leprosy throughout the year and to organise a major annual collection for World Leprosy Day on the last Sunday in January. AFRF was one of the founding Member Associations of ILEP. AFRF made a significant contribution to the national leprosy programmes of 33 countries in 1998, providing financial support towards drug supply, medical equipment, building maintenance, vehicles as well as development actions such as the renovation of leprosy villages and education activities. AFRF has always worked closely with the national governments in the countries where they are working, particularly in French-speaking Africa. More than 70 years since its creation, AFRF is successfully continuing the battle against leprosy. It is taking direct action in 13 countries and is supporting the work of partner associations (mainly ILEP Members) in 17 others. AFRF is also working to combat leprosy's sister diseases of tuberculosis and buruli ulcer, as well as more general work of health and development promotion.

AFRF does not have representative in India, but financial support is given to projects in India. AFRF is supporting two projects in Pondicherry, Certh India and Rawthakuppam Hemerijckx Rural Centre. It is also supporting the following projects through LEPRAs: Blue Research Centre; Bihar, Rayurlep, Bolep, Koralep, Junlep and Bargarh. The major activities of AFRF are support to Leprosy and TB activities in education, detection, treatment, medical rehabilitation, socio-economic reinsertion, health education and training center.



## Associazione Italiana Amici di Raoul Follereau (AIFO)

**Mr. M V Jose**

*Representative*

58, 4th Cross, Kavery Layout

Thavarekere Main Road

Dharmaram College Post

Bangalore : 560 029

Phone : 080 25531264

Fax : 080 25520630

E-mail : aifo@airtelbroadband.in

Web : www.aifoindia.org

AIFO stands for 'Associazione Italiana Amici di Raoul Follereau', 'Italian association of friends of Raoul Follereau'. A non governmental organisation with its head quarters in Bolgona, Italy. AIFO is founded on the spirit of love for the destitute which found full expression in Raoul Follereau a great social reformer. His tireless work for the leprosy affected persons spanned four fruitful decades, until his death in 1977.

AIFO collaborates its activities with the United Nations and is recognised as an official collaborating organisation of the World Health Organisation. It is recognised by the European Union and by the Italian Foreign Ministry for Projects of Development Co-operation.

AIFO is a founder member of

- ILEP International Anti-Leprosy federation
- IDDC International Disability and Development Consortium
- CSFD Circle of Solidarity Follereau-Damien

With Leprosy work as its focus, AIFO provides support to projects in developing countries, without any discrimination on the basis of colour, race, religion, gender etc. It also supports rehabilitation of persons with disabilities and programmes for vulnerable children with a community based approach.

AIFO supports projects in India connected with

- Leprosy control in an integrated primary health care setting
- Community based rehabilitation focussing on marginalised groups
- Community development projects focussing on children

### **AIFO in India**

AIFO began its operations in India in the 1970s. It first began supporting leprosy projects through German Leprosy Relief Association. In 1979, Dr V Ekambaram, an eminent leprologist was chosen to be the AIFO representative in India. His expertise and experience as the First State Leprosy Officer, Tamil Nadu helped to lay the solid foundation for all future activities of AIFO. In 1983, AIFO extended its support to National Leprosy Eradication Programme of the Government of India. In 1989 Dr. Daisy Kandathil was appointed as the Indian representative of AIFO till the year 2001. Since then, it has been functioning under the leadership of Mr Jose M V.

In 1996, AMICI di Raoul Follereau, was formed as a public charitable trust, with its head office at Bangalore. At Present AIFO is giving technical and financial support to 49 projects categorised as Children, Leprosy-CBR and District Technical Support Teams (DTST).

AIFO India is also supporting 2 projects in Bangladesh.



## SWISS EMMAUS – INDIA

**Mr. T. Jayaraj Devadoss**

*GLRA/ALES - India*

*Southern Regional Secretariat*

2112, 13th Main Road

Anna Nagar, Chennai : 600 040

Phone : 04426442724 / 26443184

Fax : 04426446479

E-mail : Sugumarandst

@glra-ales-india.org

Web : www.glra-ales-india.org

Swiss Emmaus started its activities in 1960. It is a relief organisation which lives in the spirit of Emmaus motto "Serve those most in need" and aims to help leprosy patients in order to fight the disease on the medical, scientific, social and humanitarian front. Similarly the organization may also dedicate itself to the fight against Tuberculosis and other diseases which are recognized as requiring urgent treatment. The support that Swiss Emmaus is providing is irrespective of social ethnic and religious affiliation.

Swiss Emmaus India was formed in 1992 and is actively involved in the leprosy and TB services following the National Guidelines of the Government.

### **Participation in the National Leprosy Eradication Programme**

Swiss Emmaus India is involved in the National Leprosy Eradication Programme through the different activities in the following areas:

Providing support service at the District level; Extending funding support to 24 NGOs; Prevention of Disability services at the District level; IEC and Advocacy through the NGOs; Socio economic Rehabilitation services; and Participating in need based support to Govt. of India as part of ILEP.

### Participation in the Revised National TB Control Programme (RNTCP)

Swiss Emmaus is involved in the RNTCP through its partner NGOs by extending support in the following areas:

Promoting the participation of NGOs in RNTCP; Participation in promoting TB work in urban slums; Providing support service at the District level to enhance case finding and case holding; IEC at the District level and through the NGOs.

### Management and Service delivery

For operational convenience the activities of Swiss Emmaus are monitored through its Central office at Chennai and its four Regional offices. Swiss Emmaus through its supported projects are employing 504 staff which includes 41 Doctors, 149 supervisory and field staff and the remaining constitutes the hospital, maintenance and administrative staff.

It is the expressed desire of Swiss Emmaus that leprosy patients are treated with dignity and respect, possibly healed, rehabilitated and reintegrated in the society.



## AMERICAN LEPROSY MISSIONS (ALM)

**Mr. K. Thomas Mathew**  
ALM India Representative  
325, 1st "E" Cross  
3rd Block, HRBR Layout  
St. Thomas Town Post  
Bangalore : 560 084  
Phone : 080 25498594  
E-mail : almindiarc  
@rediffmail.com  
Web : www.leprosy.org

Founded in the year 1906, American Leprosy Missions (ALM) is a non-denominational Christian ministry of hope and restoration for those suffering with leprosy, buruli ulcer and related disabilities.

The **mission** of the organisation is to serve as a channel of God's love to those with leprosy and buruli ulcer and disabilities helping them to be healed in body and spirit and to be restored to lives of dignity and usefulness in their communities.

ALM reaches out to affected people through projects that are in the nature of :

Leprosy control (MDT): training of health workers for diagnosis and treatment and provision of equipment and supplies; Prevention of disability: wound care and reconstructive surgery, self care training, provision of footwear and prostheses; Socio-economic assistance: housing, micro credit, vocational rehabilitation, educational support, emergency relief, counseling and long-term care; Research: development of a vaccine and chemoprophylaxis for leprosy.

Currently ALM's support stretches over to fifteen countries in Asia, Africa and South America. ALM's focus for the decade is research: transmission & vaccine, community development, prevention of disability, training and buruli ulcer.

ALM has field offices or representatives in Angola, DR Congo, Myanmar and Philippines besides India.

In India, ALM supports leprosy programs in the States of Maharashtra, Chattisgarh, Karnataka and Tamil Nadu and its partners include the government (through ILEP), hospitals and NGOs. Programs assisted are generally in the nature of those listed above.



## Damien Foundation India Trust (DFIT)

**Dr. P. Krishnamurthy**  
Secretary  
14, Venugopal Avenue  
Spurtank Road, Chetpet  
Chennai : 600 031  
Phone : 044 28360496/28361910  
Fax : 91 44 28362367  
E-mail : damienin  
@airtelbroadband.in  
Web : www.damienfoundationindia.org

The roots of Damien Foundation Belgium (DFB) in India can be traced to the establishment in 1953 of a leprosy control project in Polambakkam situated about 100 kms from Chennai, in Tamil Nadu State by Dr Frans Hemerijckx, a dynamic force in leprosy control programme in India. Dr. Claire Vellut who was associated with Dr. Hemerijckx right from the beginning continued the tradition of providing humane service to the people affected by leprosy in the project area. She was responsible for founding the Damien Foundation India Trust (DFIT) in 1992. From the single project in Polambakkam the organisation has grown with extensive reach in India.

Damien Foundation India Trust consisting of 7 members with the President of Damien Foundation, Belgium (DFB), being the Chairman, executes all the leprosy & TB control activities through the Secretary of the Trust. Damien Foundation India Trust has a work force of around 300 staff, which includes 40 Doctors,

Damien Foundation is currently involved in supporting leprosy and tuberculosis control in several states in India, the activities include....: Support to the Government of India at the National level in monitoring and evaluating the Leprosy elimination campaigns and the Leprosy cases validation programmes; Support to the State Government by placing District

Technical Support Teams (DTSTS) to augment the capacity of all the cadres of the government staff in integration of Leprosy and Tuberculosis in the General health services; Support to NGO's in establishing Tuberculosis Unit and Microscopic centers; Establish referral system to extend support to treat complicated cases; Establish Reconstructive surgery unit in Medical college hospitals; Reconstructive surgery facilities in 3 NGO centers; Establish external quality assurance (EQA) in laboratory services in TB control supported by DFIT; Produce and supply Sputum cups with WHO specifications at cost price; Publish and circulate newsletter "UPDATE" to enhance the technical knowledge of the health personnel; CME to health professionals on Leprosy; Seminar on leprosy by post graduate to medical students; Endowment prize examination in leprosy for undergraduate medical students; Training of project staff in areas of management, supervision, communication, computerized data processing etc; Conduct annual internal and external evaluation of all the projects supported by Damien Foundation India Trust; Construction and repair of Health Centres with the help of Chantier Damien.

The activities are executed through a network of 10 NGO - leprosy and TB support, 2 Own - leprosy and TB support, 8 Districts - Leprosy support, 25 District Leprosy and TB support, 3 Districts TB support.



## **FONTILLES - INDIA**

**Mr. Ananth Ramanathan**  
FONTILLES  
Lucha Contra La Lepra  
(Spanish Leprosy  
Relief Association)  
Ground Floor  
7 Ambalathadayar Madam Street  
Pondicherry 605 001  
Phone : 0413 2213596  
E-mail : ananth.baratwaj  
@gmail.com  
Web : www.fontilles.org

Fontilles from Spain has been working for Leprosy since 1902. In the early days in Spain, but today in the countries most affected by the disease. In 1902 The Jesuit Father, Carlos Ferris and the lawyer Don Joaquin Ballester joined together in a common dream to care for those with leprosy and to help those who suffered alone without any comfort or help, isolated by a fearful society. After 7 years of struggle and endeavour the Sanatorium of Saint Francisco de Borja opened its doors to take those with leprosy from all over Spain.

Patients were attended, as nowadays, by volunteers, Sisters "Franciscanas de la Inmaculada", Jesuits of the "Compañía de Jesús" and doctors.

In 1969, Fontilles joined ILEP, the International Federation of Anti-Leprosy Associations. Fontilles is the only Spanish member of the Association.

In 1989 Fontilles began its work abroad. The first dispensaries were set up and help given in zones chronically affected in India

Fontilles is now working with projects in China, India, Equatorial Guinea, Brazil, Bolivia, Columbia, Nicaragua, Cuba, Haití, Nepal, México, Ivory Coast, Ghana, Angola and Rwanda.

The objective, as was the founders', is to overcome leprosy and its consequences, but also to fight against other neglected diseases as Buruli Ulcer, Leishmaniasis, Chagas Disease, etc.

### **Fontilles in India**

In the year 2006, Fontilles continued to support the work against leprosy in some hospitals in Gujarat. In this State, Fontilles collaborates with the centers of Surat, Bhavnagar and Junagadh. In Karnataka State, Fontilles collaborates with Franciscan Sisters in Harapannahalli, supporting a CBR project not only for leprosy patients but with disabled people too. In Pondicherry Fontilles collaborates with CERTH in the rehabilitation of former leprosy patients, all through their India representative Mr. R. Ananth.

Fontilles also takes care of children stigmatized by the disease through educative programs in Gujarat and Karnataka, and through collaboration with IDEA in the scholarship program in Tamil Nadu State. The agency is also collaborating with LEPRO in Sanawad with the Saint Joseph Leprosy centre and in Orissa with the JUNLEP project.



## German Leprosy and TB Relief Association-India (GLRA-India)

**Mr. T. Jayaraj Devadoss**

*Director*

*German Leprosy and*

*TB Relief Association-India*

*Swiss Emmaus Leprosy*

*Relief Work-India*

4 Gajapathy Street,

Shenoy Nagar, Chennai : 600 030

Phone : 044 26442724/26443184

Fax : 044 26446479

E-mail : devadas@glra-ales-india.org

Web : www.glra-ales-india-org

### Introduction

GLRA was founded in 1957 as an association supporting the work of a Doctor caring for leprosy patients in Ethiopia. Since then GLRA extended support to many other projects numbering well over 350 in 46 countries. GLRA is one of the founder members of ILEP (International Federation of Anti Leprosy Associations)

The primary objectives of the organization: to initiate and support leprosy and Tuberculosis control activities; to foster medical and social rehabilitation; to support research in leprosy and Tuberculosis; to support Training activities in leprosy and Tuberculosis; to promote health education and information; and to support public awareness campaigns.

The Indian operation of GLRA also commenced in 1957. GLRA is working in close co ordination with the Govt. of India and State Governments following the National Guidelines and in partnership with the ILEP Member organizations working in India.

### Participation in National Leprosy Eradication Programme(NLEP)

GLRA-India is involved in the National Leprosy Eradication Programme through the different activities in the following areas: Providing Support services at the District and State levels; Extending funding assistance to 61 NGOs; Prevention of Disability services at the District level; IEC and advocacy through NGOs; Socio economic rehabilitation services; and participation in extending need based support to Govt. of India as part of ILEP

### Participation in the Revised National TB Control Programme (RNTCP)

- GLRA-India is involved in the RNTCP through its supported NGOs by extending support in the following areas:
- Promoting the participation of NGOs in the RNTCP; Participation in promoting TB work in Urban Slums; Providing support service at the District/State level to enhance case finding and case holding; and IEC at District level and through NGOs

### Management and Service delivery

For operational convenience the activities of GLRA is managed through 4 Regional offices situated at Chennai, Kolkatta, Delhi and Mumbai and it is co ordinated by the Central Office at Chennai. The supported projects and programmes of GLRA in India is employing nearly 1600 committed staff which includes 133 Medical Officers and 220 supervisory and Technical staff and 431 field staff apart from nursing, maintenance and logistics staff.

It is the expressed desire of GLRA that the services delivered by its projects and programmes should have quality topped with human touch and there by fostering good will between the benefactor and the beneficiary.



## Netherlands Leprosy Relief (NLR)

**Dr. M.A. Arif**

*Country Representative*

*Netherland Leprosy Relief - India*

U-9 Green Park Extension

New Delhi : 110 016

Phone : 011 26107959

Fax : 011 26107963

E-mail : nlrindia

@airtelbroadband.in

Web : www.infolep.org

Netherlands Leprosy Relief (NLR), a member organization of ILEP, was established in 1967 at Amsterdam, the Netherlands, as a private initiative, supporting leprosy control activities in Tanzania and Nepal. Presently NLR is active in 16 countries worldwide; India, Indonesia, Nepal, Myanmar, Vietnam, Laos, Thailand, China, Nigeria, Mozambique, Ethiopia, The Gambia, Kenya, Brazil and Surinam. Apart from leprosy control, NLR spends about 9% of their budget on scientific research, which focuses on early detection of reactions and nerve function impairments, on prevention of disabilities, on early diagnosis of leprosy and chemotherapy and on incidence & transmission.

NLR's main interest is to work together with Governments for the establishment of sustainable, integrated leprosy services, which are capable to provide quality treatment to patients and to prevent occurrence of disabilities. The main strategies are capacity building of health staff at all levels, provision of technical support, provision of inputs for training, monitoring, and supervision and for Information, Education & Communication. In principle NLR works through 4-5 year Project Agreements with Governments, which are jointly evaluated halfway and towards the end.

NLR's involvement in India started in Bihar in 1993. In the following years the support was extended to other states: in 1998 to Uttar Pradesh and present Uttaranchal, in 1999 to Delhi, in 2000 to Jharkhand and in 2001 to West Bengal. Presently NLR supports the National Leprosy Eradication Programme (NLEP). In the year 2000 the NLR Branch Office was established in Delhi where the Representative and his staff are based who advise, supervise and administrate the projects in the field. 'NLR foundation' trust was established in 2004. The staff consists of one Country Representative, assisted by one Medical Advisor, One Manager Accounts & Administration, one Accounts Assistant and one Personal Secretary cum office assistant.

Netherlands Leprosy Relief, through its Branch Office in India, is supporting NLEP jointly at central level, and at peripheral level the support is provided by placement of Technical Support Teams in, above mentioned, states. At present NLR is supporting 70 districts in 6 states of India through placement of 35 district and 1 state level technical support teams. These teams are visiting PHCs, APHCs, Subcentres, Hospitals and dispensaries and providing on-the-job training and supporting other activities as per Govt. of India guidelines.



## The Leprosy Mission (TLM)

**Mr. Jeyakumar Daniel**

Director

The Leprosy Mission

CNI Bhavan,

16 Pandit Pant Marg

New Delhi : 110 001

Phone : 011 23716920

23718261

23718264

Fax : 011 23710803

E-mail : [tlmindia@tlm-india.org](mailto:tlmindia@tlm-india.org)

Web : [www.leprosymission.org](http://www.leprosymission.org)

### The Birth of a Commitment

A young Irishman, steered by a divine urge and with an expectant heart hankering for some unknown mission, disembarked on the shores of India. The twenty-three year old Wellesley Cosby Bailey thus after reaching India, joined the American Presbyterian Mission at Ambala in Punjab in 1869 as a teacher. A visit to a nearby 'leper asylum' was a metamorphic episode in his life – the stark reality of the subhuman lives of the victims ripped apart his scruples, so much so that, then and there, he pledged his life for these unfortunates. A vision rooted on the bedrock of conviction resulted in a commitment which later took the form of a Mission *par excellence* when the Baileys (Wellesley Cosby Bailey and his wife Alice) after returning to Ireland in 1874, formed a society known as 'The Mission to Lepers in India'. The name was changed to 'The Leprosy Mission' (TLM) in 1962 to take the sting out of the word 'Leper'.

### The Leprosy Mission (TLM) – The Organization and its Operations

TLM is an international non-denominational Christian charity head quartered in the United Kingdom. TLM has its wings spread in 20 Support Countries, 26 Field Countries and 5 Field and Support countries. It is governed by 16 board members, representing Field Countries, National Councils and people affected by leprosy, from 12 countries. The Board, besides formulating international policies, approves strategic plans and budgets. TLM's Indian operations commenced in 1874 and India with 69% of the world leprosy case load remains central to the activities of TLM where 50% of the resources are being directed.

### Activities in India

TLM's focus is increasingly on '**caring for the whole person**' affected by leprosy. To accomplish this holistic goal, health education and rehabilitation of people affected by leprosy has been brought into the ambit of TLM's activities together with the regular medical services. TLM reaches out to the victims and their families in 15 States of India by providing them comprehensive healthcare and allied community development services through a vast network of facilities.

### Hospitals

TLM has 18 hospitals in 10 States of India providing inpatient and outpatient leprosy care. 5 of these have been upgraded to community hospital status, providing general as well as specialized medical services, in addition to the conventional leprosy care. TLM hospitals provide other value-added services like reconstructive surgery, ophthalmic services, POD training, etc.

### Vocational Training Centres (VTCs)

TLM has 6 VTCs located in 6 States of India. VTCs were established in the 70s with the express objective of imparting diverse vocational skills – automobile mechanics, carpentry, computer application, driving, DTP, diesel mechanics, electrical mechanics, printing, to name a few - to young people from leprosy background, thereby empowering them for a socially meaningful

life. TLM also provides placement assistance to students once they acquire the necessary skills.

### Field Projects

TLM has initiated and is managing 20 field projects in the core delivery area of leprosy and also other areas where need for intervention is felt. The spectrum of projects include empowerment of the physically challenged (rights awareness building, poverty mitigation and social integration), advocacy campaigns, crusade against social stigma (due to leprosy, AIDS, disability etc), self-care for leprosy-cured persons, community-based rehabilitation, community eye camps, capacity-building of government health workers, facilitation of self-help groups, construction of low cost houses and educational support to victims and their dependents.

### Other Activities

9 Snehalayas (Mercy Homes) affiliated to various TLM hospitals tend elderly patients forsaken by their kith and kin; 29 District Technical Support Teams (DTST) support the government in 56 districts in 10 states in leprosy management; a state-of-the-art research laboratory – 'Stanley Browne Research Laboratories' – is on the perennial pursuit of finding newer and effective means for combating the scourge; a communication and health education wing – 'Diana Princess of Wales Health Education and Media Centre' – with high-tech resources for print and electronic content programming and dissemination of health education is effectively influencing the community.



## Lepra Society

Dr. P V Ranganatha Rao  
Chief Executive, LEPRA Society  
P.B. No. 1518, Krishnapuri Colony  
West Marredpally  
Secunderabad - 500 026  
Phone :040 27802139/27807314  
Fax :011 27801391  
E-mail :rangnadh  
@leprasociety.org  
Web :www.leprasociety.org

It was in 1924 that the British Empire Leprosy Relief Association (BELRA) started leprosy relief work in India. After independence in 1947, the Indian branch of the organisation became Hind Kusht Nivaran Sangh, while the parent body, renamed as British Leprosy Relief Association. At the advent of MDT Govt of India invited several international funding agencies to implement this massive programme. BLRA came forward to strengthen the program by establishing LEPRA. LEPRA was established 1988 and registered as LEPRA Society in February 1989.

The primary objective of LEPRA is to combat leprosy. Extending health care activities into other allied diseases like Tuberculosis, HIV/AIDS, Malaria and prevention of Blindness programmes are LEPRA's initiatives towards ensuring better health for the needy people. LEPRA's endeavour is to help persons with disabilities and enable them to contribute meaningfully to the mainstream of society be it social, economic or cultural that the community values. It is with this aim that LEPRA has imbibed a holistic approach towards the development of needy and downtrodden people. The benefits to the needy emphasis on human rights, social inclusion and basic services like treatment and rehabilitation. LEPRA's task is to: create awareness among the people, educate them about the diseases; secure better livelihood for the needy; strengthen the capacity of poor and marginalised people to protect, rebuild and improve the quality of their lives; provide support and care for people living with the effects of HIV, and challenge the stigma and discrimination associated with the virus.

LEPRA Society started its operation by participating in the National Leprosy Eradication Programme (NLEP) by undertaking Multi Drug Therapy (MDT) programme in five districts in Andhra Pradesh, Karnataka and Orissa. Later the Society extended its operation in 53 selected districts in Andhra Pradesh, Orissa, Madhya Pradesh and Bihar covering a population of 12 million. The activities are implemented through its 9 directly managed projects, 3 reconstructive Surgical units in Madhya Pradesh, 1 research center at Hyderabad, 4 DTST teams caters to the patients with disability. Personnel from medical and social work background and general sectors coordinate the programs. LEPRA has also diversified its activities in Tuberculosis, HIV/AIDS, Malaria, Blindness and IEC programmes.

LEPRA Society functions from its headquarters at Secunderabad and regional offices in Secunderabad and Bhubaneswar.

# Operational guidelines for Leprosy control activities

## (World Health Organisation) **Executive Summary**

The *Global Strategy for further reducing the leprosy burden and sustaining leprosy control activities (2006 – 2010)* has been widely welcomed and endorsed. The overall goal is to provide access to quality leprosy services for all affected communities following the principles of equity and social justice. The purpose of these *Operational Guidelines* is to help managers of national health services to implement the new Global Strategy in their own countries. This will be done as they develop detailed policies applicable to their own situation, and revise their National Manual for Leprosy Control.

Leprosy services are being integrated into the general health services throughout the world; a new emphasis is given here to the need for an effective referral system, as part of an integrated programme. Good communication between all involved in the management of a person with leprosy or leprosy related complication is essential. These Guidelines should help managers to choose which activities can be carried out at the primary health care level and for which aspects of care patients will have to be referred. This will depend on the nature of the complication and the capacity of the health workers to provide appropriate care at different levels of the health system.

The promotion of self-reporting is now crucial to case detection, as case finding campaigns become less and less cost-effective. It is important to identify and remove barriers that may prevent new cases from coming forward. The procedures for establishing the diagnosis of leprosy remain firmly linked to the cardinal signs of the disease, but the accuracy of diagnosis must be monitored. The Guidelines suggest a greater emphasis on the assessment of disability at diagnosis, so that those at particular risk can be recognized and managed appropriately.

The treatment of leprosy with MDT has been a continuing success; neither relapse nor drug-resistance are significant

problems and the regimens are well tolerated. Clear procedures are given for managing irregular treatment with MDT. Leprosy reactions are a serious complication affecting some patients. The Guidelines contains this aspect, with additional references under Further Reading. A key decision for programme managers is to determine how and at which level of the health system leprosy reactions are to be managed in their country. Different countries must develop their own detailed guidelines on this issue.

Prevention of disability (POD) is also described in some detail as there is a need for much greater coverage with basic POD activities. This is an important component of 'quality leprosy services' emphasized in the Global Strategy. Items mentioned under Further Reading will be essential for programmes planning to build capacity and increase their service provision in this area. Rehabilitation may include a medical component (such as reconstructive surgery) but its scope is much broader. It is likely that some people affected by leprosy would benefit from socio-economic rehabilitation (for example, vocational training or a small loan). Staff in the health services need to be familiar with what is being done in the locality, and know how and where to refer people who need these services. Recording and reporting are essential to maintain quality in any programme. The indicators selected in the Global Strategy are useful for monitoring and evaluation, and they determine which data must be recorded. The data needed to monitor POD activities have not been collected routinely in the past, so this represents a significant change – national managers must therefore decide for themselves which indicators will be used to ensure quality as these will vary from country to country. Programme management is a broad subject; the topics covered in this Section are those that are central to the running of integrated leprosy control services, including supervision, supply of MDT, partnerships, training and programme evaluation.

**Beginning with this issue, we are reproducing with permission from WHO the document  
"THE OPERATIONAL GUIDELINES FOR LEPROSY CONTROL ACTIVITIES".**

# International Federation of Anti-Leprosy Associations (ILEP)

ILEP, founded in 1966, is an international federation of fifteen autonomous non-governmental organisations that work together for the common goal of a world without leprosy in different countries. ILEP Members are involved in most countries where leprosy exists and where people affected by leprosy need support.

ILEP was born out of a need to co-ordinate the work of anti-leprosy organisations supporting activities in leprosy endemic countries, in order to prevent overlap and avoid duplication in funding. By pooling resources ILEP Member Associations were and are able to use them in a more effective way and reach more patients. Equally this unity extends to a sharing of expertise and local knowledge, thus optimising the impact of the Federation on the global campaign against leprosy.

ILEP's vision is of a world where the rights of every person affected by leprosy to receive appropriate treatment and rehabilitation are fulfilled, and where all people affected by leprosy are able to participate as fully as they choose at every level of society.

The common mission of ILEP Members is to support medical, scientific, social and humanitarian activities throughout the world for the treatment, care and rehabilitation of persons affected by leprosy; to promote the prevention of impairments associated with leprosy and to work towards the long-term goal of a world without leprosy.

In India, there are ten ILEP member Associations who are actively involved in leprosy work with their offices, staff and other infrastructure and working in close partnership with the Government of India for the common goal of a world without leprosy.

Co-ordinatorship is taken up by one of the members in turns. Currently The Leprosy Mission Trust India is functioning as ILEP Co-ordinator for India.

*Address:*

Mr. Jeyakumar Daniel  
Director, The Leprosy Mission Trust India  
16 – Pandit Pant Marg, New Delhi 110001  
Phone no: 011 23716920

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## Consultation meeting of ILEP India with Dr. Samlee Plianbangchang., Regional Director, WHO SEARO, New Delhi (16 January 2007)

### **Participants:**

1. Dr.Rajanbabu, ILEP India.
2. Dr.V.K.Pannikar, Team Leader,  
Global Leprosy Programme, WHO.
- 3.
- 4.

**Purpose:** To appraise about ILEP activities in India, share information about future support to NLEP with a view to synergise resources for NLEP, to facilitate transparency among partners.

**Proceedings:** Continuation of support to NLEP by ILEP (India) is based on the fact that new cases of leprosy will continue to occur; disability care is still needed by persons affected by disabilities due to leprosy and need of enhancing access to comprehensive health care for leprosy affected in line with WHO definition of health.

The future support to NLEP by ILEP (India) is planned on learning from previous evaluations, need for sustaining quality leprosy control activities in line with global strategy, retaining ownership of the programme by Government health care system and synergising resources for effective partnerships. The ILEP support is envisaged on the following thematic areas.

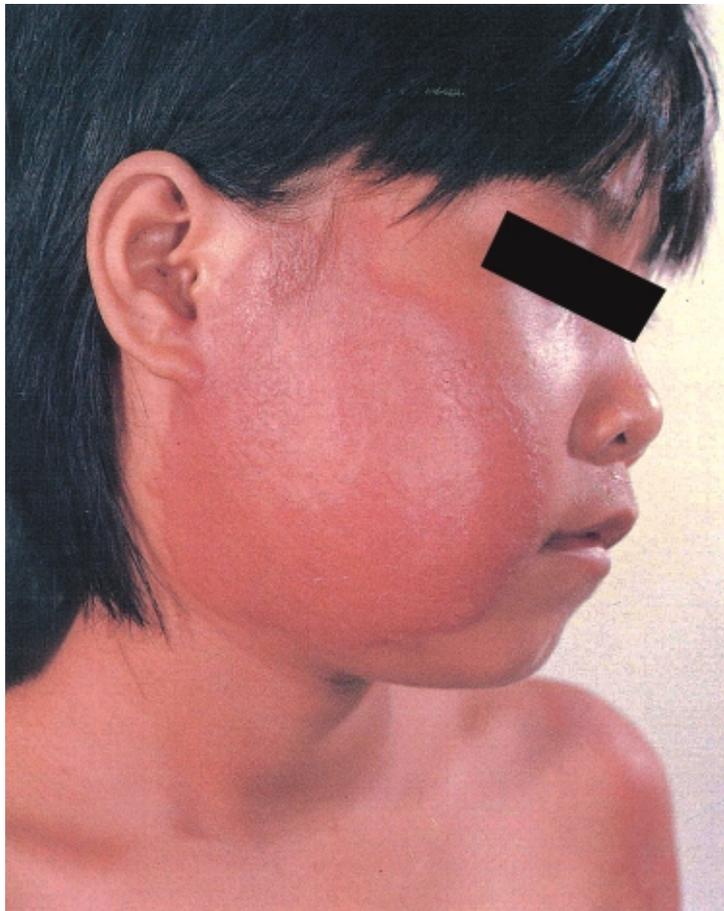
- Monitoring and supervision
- Capacity Building
- Support to DPMR
- Operational research
- Support to local NGOs
- Socio-economic rehabilitation and community participation.

The process of discussion and possibilities of collaboration among partners was appreciated by all participants.

# TYPE 1 LEPROA REACTION



Single patch in Type 1 Reactions



## TYPE 1 LEPROUS REACTION - Contd.



Multiple patches in Type 1 Reactions

### Type 1 Reactions

- May occur in single patch leprosy and multiple patch leprosy
- Sudden onset
- Swelling of patches (raised)
- Erythema (Redness)
- Tenderness over swollen patch
- Swelling in hands and feet in severe leprosy reaction
- Nerve involvement is common



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New No. 14, Venugopal Avenue, Spur Tank Road, Chetpet, Chennai 600 031. Telephone: 2836 0496, 2836 1910  
Fax : 2836 2367 • E.Mail : damienin@airtelbroadband.in • Website : www.damienfoundationindia.org