ILEP INDIA
UPDATE
Quarterly publication on issues in leprosy
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What is in a name?

Name is defined by Oxford dictionary as "a word or set of words by which a person or thing is known, addressed, or referred to". Name is a celebration of inner self. Name by itself is meaningless. It assumes social –affirming message when it is connected to somebody. Long term continuous association and usage makes one see the person, animal or object behind the name. The best part of it is it gives identity. The worst part of it is it often causes frustration and conflict. In the social universe name has become an important commodity. It is an emotional response to questions related to identification. But in the continuous emotional journey for identity name becomes only a temporary ritualistic stop. It is more often than not given rather than taken, thrust upon rather than assumed. It can generate uncontrollable exuberance or deep dislike or profound feelings of disquiet depending on the attachment one carries. It is when 'name' hides behind attachments misery unfolds. This may sound absurd, but it has become as normal as any act of life.

Man was happy. He then invented language and has been suffering ever since. Name evokes intense personal reaction among individuals and parochial response among communities. Name provides a framework for social meaning, social interaction and social action. It is also important for personal, social and cultural development of individuals and communities.

A person may be called different by different people. Do they all mean the same because they are referring to the same person? It is not simple. For 'name' to assume meaning it requires connection, context and interpretation. It is when people do not get their critical choices right in the three realms they hit the rough, cause consternation and generate unrest.

Let me come to the central theme of this note. It is about leprosy disease and person affected by it. In both the cases I can easily sum up: the little that we know is not enough, the much we do is too little too late!

I hear the whisper, distant and near
From the unfriendly everyone
I close my ears, I hear them clear
I try to flee, I am not at liberty.
What is life, a deathbed to bear.

- P Krishnamurthy

Historically, leprosy the disease has succeeded in evoking intense reaction from the public. Imposed behind the name were people with disfiguring deformity living like inanimate objects confirming to the dictates of ill-informed society. They were incredibly buffeted by those around them by repulsive expressions that killed their bearings, alienated them from their moorings and made them lose their anonymity and freedom. They became outliers in society. This was the reaction of misinformed and misguided society. The decades of decadent view was bolstered by the helplessness of society in understanding and managing the disease. Now we have the cure for the disease. Advancement in medical technology and changes in operational strategy have made the disease controllable. It can no longer be considered a serious ailment. Have these succeeded in removing exaggeration from the reaction of the public? Unfortunately, despite all the successes in public health management, we have not succeeded in removing complexities and contradictions bordering on the irrational and illogical from the word leprosy. Image sensitivity not information naivety is the apologia for the disdain. The much-needed image repair is missing. There is a definite disconnect between what one sees and what one feels. The public blind spot on these ethical issues is a throwback to medieval times, an anachronism that has survived the passing

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years. Is the name leprosy to be blamed? Is leprosy an ugly word? Does the misery of millions of people afflicted with it change if it is called by some other name? Will the perception and attitude by the common people ever change? Is there any sweeping gesture which can remove idiosyncrasies and brand-defining attitude of the people? Attitude-trap is a subject we are touchy about and are ever willing to exclude from social agenda.

The second point of the theme is about those affected by leprosy. It is clear that people affected are sick of being referred to as leprosy patients for ever. And they have every right to be. A person with residual fibrosis following completion of treatment for TB is not referred to as TB Patient. Why, then, a person cured of leprosy and has residual disability be called leprosy patient? It is as if they have mortgaged their name and identity to leprosy! It is deeply insulting and deprecative. But then, will removing the L word remove the attitudinal transgression from the society? Will it bestow upon the affected the rights and freedom that they have lost? Could it become the escape route for the affected out of despair, indignity and frustration? The simple truth is that it is the attitude that matters not the name. As a matter of fact good attitudes in society are in short supply. It is not easy to unlearn a bad habit. Information sound bites by a chosen few will not goad the unwilling and orient them into the chosen path. Yes, desisting from using the L word is only a small step in reversing the identity crisis and bringing the affected persons within the parameters of social decency. Yes, it should become the lapsed word. But we need to do more than that. We need to become free-spirited anti-sociologists going beyond the scripted convention, bringing in non-conformism to bring about refreshing change in social order and attitudes. Even though this may look like a tall order, it is entirely possible, through sensible partnership and collaborative action.

The response of the well-meaning segment of the public and the programme alike has been pedestrian at best. B y restricting their obligation to a few palliative procedures they have not helped the cause. The predominantly public health approach, consciously deliberate, intended primarily to deal with the large number of new cases, and lack of social valence, became chronic imbalances in the focal points. The same public health agenda continues. Text-book-style strategy will not work in dealing with a disease with overt social connotation. It requires collective choices: sensible transformation of the aspirations of the affected into temperate choice through partnerships at all levels of society; and recalibration of public consciousness through well oriented social action that also makes them aware of the successes in the campaign against the disease. Fed on a staple diet of statistics we need new inspiration, to take us out of the distractions and making the person-affected, not prevalence or incidence, as the centre of gravity for all our aggregate actions. We should be willing to remove ourselves from the routine obsession and facilitate the inclusion of person affected as a constructive participant and a sovereign partner in the global campaign against the disease.

- P Krishnamurthy

"For many in this merciless world there is no meaning in life.

There is no beginning, no end. They don't remember the past, they cannot think about the future.

They see spectators, looking barely at their helplessness, inventing excuses, rationalizing their collective inaction.

They are fed up with false tears and fears.

Their only option is living by death."

- P. Krishnamuthy

Leprosy Training at TLM Community Hospital, Naini, India

TLM Community Hospital, Naini (TLM India), is a 150 bedded secondary level leprosy referral center catering to patients from Uttar Pradesh and neighboring states of Madhya Pradesh and Bihar.

The OPD averages 291 patients per day, mainly leprosy and skin (19526 leprosy visits/ 2877newly registered leprosy patients in 2009). It also caters to other medical, surgical and obstetric/ gynecological conditions of the leprosy affected and the community.

In-patient facilities provide quality care mainly for those affected by leprosy – ulcers/self care/footwear, reactions and neuritis, eye, reconstructive surgery, physiotherapy and occupational therapy, medical and surgical problems and geriatrics (1284 leprosy in 2009).

Approximately 300 Reconstructive surgeries for leprosy related deformities of eye, hand & foot are performed each year.

The Training Unit at Naini has been actively involved in Leprosy related training since 1980. Facilities include 2 air conditioned Training Halls capable of seating 40 and 25 people respectively, Hostel facilities (32 male and 8 female), comfortable Guest house facility (15) for senior staff/trainees, well stocked library, sports and internet facility.

Training includes Orientation courses or In-service Training for Doctors,

Physiotherapists, Occupational therapists, Nurses, Paramedical Workers, Lab technicians, Shoe technicians, Counselors, etc.

Trainees are from TLM, NGOs, Govt., ILEP organizations and the private sector in India, with occasional participants from other countries.

Training is practical, patient centered, job oriented and learner friendly (interactive discussions, self learning videos and books, seminars, case presentations and demonstrations) and the duration varies according to the need.

The strength of the training program is the large number and wide variety of cases and clinical materials available.

Orientation in "Physiotherapy in Leprosy" is a one month scheduled programme held almost every month of the year for physiotherapy and Occupation Therapy (OT) students studying in colleges mainly from Uttar Pradesh, Chattisgarh, Madhya Pradesh and also from other states in India (Karnataka, Bihar, Maharashtra, Sikkim, Tamil Nadu).Training focuses on Nerve Function Assessment, Prevention of Disability, Reconstructive Surgery, Splints and Clinical Leprosy. Trainees are also oriented to Podiatry, CBR, Counseling and Occupational therapy. This training also equips them to manage patients with peripheral nerve lesions of other etiology.

"Orientation in Leprosy for Medical Officers" is a 5 –day Program for doctors conducted twice a year, usually in March and November. The curriculum includes Diagnosis and Treatment of leprosy, Differential Diagnosis, Recognizing and Treating Reactions & Neuritis, Relapse and Prevention of Disability. Case presentations are conducted daily exposing participants to a wide variety of clinical manifestations and complications of leprosy and helping them realize the need to get involved in leprosy care.

Ad Hoc training: Apart from regular courses, ad hoc courses are conducted on request from organizations working with leprosy. The ILEP project is currently using the facilities on a regular basis for training Physios, Occupation Therapists and Nurses in Prevention of Impairment and Disability (POID), and Laboratory Technicians in skin smears for AFB, for staff working in government hospitals.

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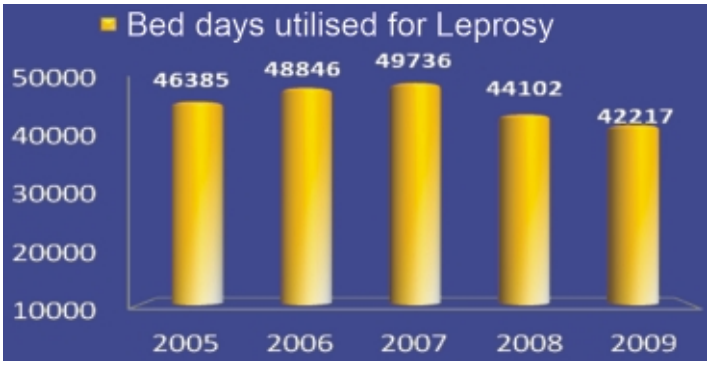

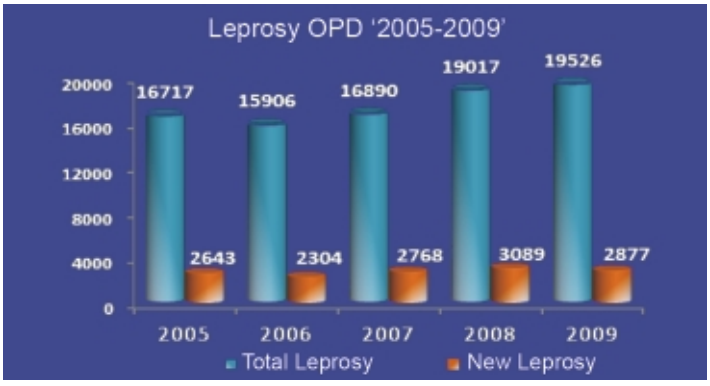

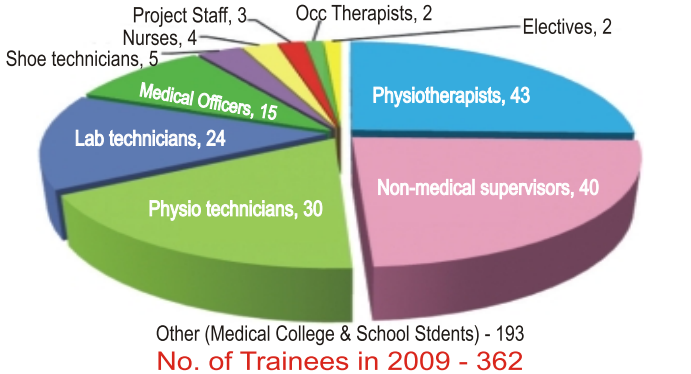

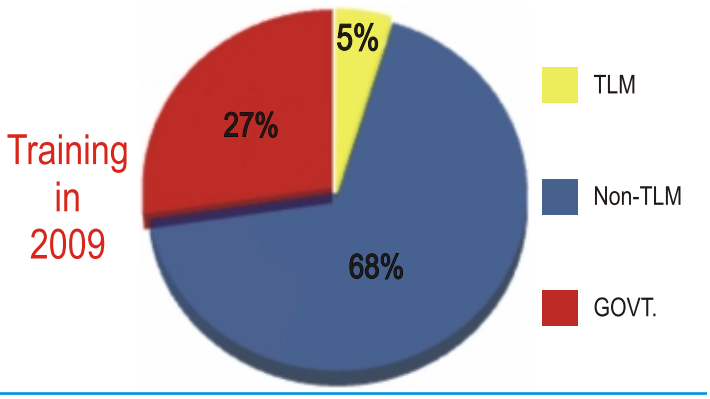

They have also conducted workshops on 'Orientation in Leprosy' for dermatologists and ophthalmologists working in District Hospitals in Uttar Pradesh

Certificate courses-Para Medical Worker (PMW) and Leprosy Physiotechnician-which were conducted in the past, have been discontinued. However these are still conducted on special request. 7 Brothers from the Missionaries of Charity were trained as PMWs (4 months) and 10 PMWs from ALERT Mumbai were trained in Physiotherapy related to leprosy (4 months).

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The Training Unit Naini welcomes requests for training from organizations / individuals working with the leprosy affected.

Calendar 2010

Dates	Course Title	Target Groups
March 08 – March 12 Nov. 15 – Nov. 19	Orientation in Leprosy for Medical Officers	Medical Officers of NGO's and Govt.
March 08 – March 19 Nov. 15 – Nov. 26	Orientation in Leprosy for Medical Officers	Medical Officers of T.L.M.
Jan. – Nov	1 month course x 11 – Orientation in Leprosy related physiotherapy for Physiotherapy/ Occupational Therapy students\	BPT / BOT students
Ongoing	In-service Training in Leprosy related work- Physiotherapy Occupational Therapy Nursing Doctors Laboratory (Skin smear for AFB) Internship training – physiotherapy, Occupational therapy and laboratory	(College students / Govt./ Vol. Org./ Others).
Adhoc course on request.		

Directorate General of Health Services

Central Leprosy Division, Nirman Bhawan, New Delhi

Report on the Annual Conference for State Leprosy Officer's and Partners

Varanasi, Uttar Pradesh – 6th & 7th November 2009

The State Leprosy Officers conference at National level was held in Varanasi on 6th and 7th November 2009, attended by about 78 participants. Out of the 35 State Leprosy Officers,

22 SLO or their representative attended the conference. The States/UTs not represented were Madhya Pradesh, Himachal Pradesh, Jammu & Kashmir, Meghalaya, Mizoram, Nagaland, Sikkim, A&N Islands, Puducherry, D&N Haveli, Lakshadweep, Daman & Diu and Uttarakhand. Other participants were from the WHO, ILEP, Govt. of India, Banaras Hindu University, Patna Medical College, RLTRI Aska, NOVARTIS CLC Project, National Institute of Medical Statistics, JALMA Institute Agra, FMR Mumbai, KGMC Lucknow and AIIPMR Mumbai. The conference was held with WHO fund. Local arrangement for organizing the conference was managed by the Institute of Medical Sciences, BHU, Varanasi.

The first Technical Session started under chairpersonship of Dr. P.L. Joshi and MS Fransesco Ortali, AIFO as Co-chairperson. Dr. P.R. Manglani and Dr. Amar Shah were the rapporteur. At the outset Dr. Joshi reiterated that this conference is basically for review of the performance of all concerned and therefore active participation in the deliberations are welcome. He then presented the theme of the conference which was "Human Rights Protection – Reduction of Stigma and Discrimination against PAL". Dr. Joshi showed the areas of actions taken by GOI in this regards and ended the presentations with actions that can be taken now as

- A Multipronged approach to fight leprosy related discrimination
- Empowering persons affected by leprosy and their family members
- Eliminate the use of discriminatory language (e.g. Leper), terminology and images
- Addressing issues through medical professionals, media, NGOs, Civic organizations and community

Dr. D.M. Thorat and Dr. A.K. Puri thereafter made presentations bringing out the issues under NLEP implementation, stating first the national status followed by region wise analysis against each point. State Leprosy Officers of the concerned states along with the coordinators in the state participated during the discussions and clarified their actions. Point wise details were as below –

1. New case detection

The trend of new case detection over last 5 years showed decreasing numbers at National level from 2.6 lakh cases in 2004-05 to 1.34 lakh cases in 2008-09. It is observed that number of cases detected during first six month of the year (April to September) remain much higher than cases detected in the later part of the year.

Recommendations:

(i) The gap between the number of reported cases and the number expected should be assessed quickly. The ILEP partners can do some quick study to assess this gap in states showing fluctuating or big reduction trend.

(ii) The new cases detected should be validated for correctness of diagnosis and disability grading. Based on these validation PHC medical officers should be trained to build up their knowledge and skill.

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(iii) Involvement of ASHA for suspecting new cases should be made quickly in all the states. Proper monitoring, recording and payment of incentive in time will help in better case detection by ASHA.

(iv) New case detection and their timely treatment completion are the main objectives of the programme and this is expected to reduce transmission potential for the future. This aspect needs constant monitoring at SLO/DLO level and should be reviewed in detail during the quarterly meetings.

2. Child Proportion

At the national level child proportion against new cases detected has come down from 13.28% in 2004-05 to around 10% from 2005-06 till date. It is also seen that PB child proportion is about 7% and MB 3%.

Recommendations:

(i) States like Bihar, Tamil Nadu with very high child proportion need to assess the reasons. District – wise analysis will be useful to look for areas with very high child proportion

(ii) States like Uttar Pradesh, Rajasthan, Madhya Pradesh showing very low child proportion along with low new case detection rate should remain alert as there may be more cases in children than reported.

(iii) Contact survey against all MB cases should be ensured along with validation of the diagnosis.

3. Treatment Completion Rate

State/UT wise assessment of TCR is being carried out under NLEP annually since the year 2006-07. The results shows that total TCR is showing improvement every year at National level and reached (92.7%) in the year 2008-09. However TCR in MB cases (89.6%) and urban areas (88.5%) are very low, needing urgent action.

Recommendations:

(I) TCR not being calculated properly through cohort analysis of the cases registered in the year 2006-07 (MB cases) and 2007-08 (PB cases) for reporting in the year 2008-09 as per the issued guidelines by the States of Bihar, Delhi, Manipur, Kerala, Tripura and Kashmir Division, which should be done on priority basis.

(ii) States/UTs have to put extra efforts for treatment completion in all patients reporting in urban localities and against the MB cases, as TCR is one of the main indicator in NLEP.

4. Disability

A. Grade – I disability

Grade – I disability cases are being recorded and reported by the States from the year 2007-08. As against 5985 Grade – I disability in the year 2008-09, a total of 2960 were reported during April – September 2009.

B. Grade – II disability

The Grade – II disability information submitted by the states shows about 3000 to 3800 cases annually since the year 2005-06. The States are also reporting about 2000 to 3500 RCS operations per year.

Recommendations:

(i) All the States should quickly streamline the process of recording and reporting of Grade – I cases correctly.

(ii) The States/UTs should modify the column "Visible Deformity" in LF-02 and LF-04 & 05 and replace with "Disability" – Grade – I and Grade – II.

5. DPMR Services

As against 17530 new Grade – II disabled cases recorded in last 5 years 13740 RCS were done from 2004-05 to 2008-09. Performance has shown improvement in all Regions except the North Eastern region. As per available records received from Tamil Nadu, Andhra Pradesh, Karnataka, Orissa, Chhattisgarh, Puducherry, West Bengal and Bihar as against 6480 cases eligible for RCS only 1631 RCS were done during the current year, leaving a backlog of 449 (74.8%).

Recommendations:

(i) More Govt. Medical Colleges/District Hospitals may be upgraded for RCS facilities. This is necessary to improve coverage to clear the backlog disabled cases and for future sustainability of services.

(ii) Incentive payment to the persons from BPL family undergoing RCS should be streamlined.

(iii) All States/UTs should work out list of PAL eligible for RCS each year and monitor performance regularly.

(iv) Monitoring quality of the post surgery care with physiotherapy is essential. Report from the institutions conducting RCS as prescribed in guidelines may be collected and reported to the Central Leprosy Division routinely.

(v) MCR footwear and self care kits should be regularly procured and supplied to all the PAL as per their need.

6. ASHA Involvement

States/UTs have started utilizing the services of the ASHA under NRHM after their training in Leprosy. Payment of incentive for new case registration and treatment completion has also been started in most of the States.

Recommendations:

(I) Few States were not aware about the procedure to include the service of ASHA for NLEP activities. It was clarified that State may work out their fund requirement for the year 2010-11 in the Annual PIP being prepared now get approved by the State NRHM and submit for GOI approval.

7. Training

While Karnataka and Andhra Pradesh could utilize full allotted amount, other States could utilize only about 30-50% of the budget sanctioned. No expenditure was incurred by Arunachal Pradesh, Bihar, Madhya Pradesh, Nagaland, Rajasthan, Uttarakhand, D&N Haveli, Daman & Diu, Lakshadweep and Puducherry.

Recommendations:

(i) Training is an important component of the programme for which adequate planning and implementation is necessary. Need based planning should be completed from District level upwards by all States and include in the PIP for the year 2010-11.

8. Information, Education, Communication (IEC)

Only 10 States/UTs utilized about 75% of the IEC budget allotted during the year 2008-09. Remaining States utilized less than 45% of the budget allotted. No expenditure was incurred by Bihar, Madhya Pradesh, Nagaland, Uttarakhand, Daman & Diu, Lakshadweep and Puducherry during the year.

Recommendations:

(i) The States/UTs have to plan and execute the IEC plan as a routine activity so that allotted budget is fully utilized.

(ii) Spreading awareness in the general population as well as advocacy amongst the selected groups with aim to reduce stigma and discrimination against Leprosy affected persons should be the main objective of the IEC plan.

9. Urban Leprosy Control Programme

Progress report awaited from 16 States/UTs. Co-ordination Committee not constituted in most states. Nodal agency / person not identified by most state. Sensitization meetings, involvement of local organization & private practitioners not done by most states.

Recommendations:

(i) More emphasis need to be given on the Urban Leprosy Control Programme with innovative measure to detect the hidden cases in different population groups living in the slums and also should ensure completion of treatment in all cases.

10. MDT supply and Management

Availability of MDT as against the number of cases under treatment found to be adequate in all the regions. It is clarified that States should submit indent in the prescribed format at Quarterly interval as per the MDT guidelines.

Recommendations:

(i) MDT stock should be regularly monitored at the peripheral institutions to avoid

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excess stock reaching expiry stage or to prevent situation where drug cannot be provided to the diagnosed cases promptly.

(ii) Guidelines on monthly indenting by the PHCs to the district should be strictly followed. Bad management should not affect services for the persons diagnosed as leprosy affected.

(iii) MDT required in the Medical Colleges for the patients under treatment should always be supplied on priority, so that patients attending these centres do not face difficulty. NMS in the district Nucleus should be given the responsibility to keep coordination with the Medical Colleges and other Leprosy Hospitals.

11. Budget and Financial aspect

Recommendations:

(i) The States/UTs should regularly monitor their budget expenditure through review meetings and periodic visit to districts, to ensure utilization of fund sanctioned.

(ii) Utilization certificate for the year 2008-09 has been received at CLD only from 14 States. U.C. should be sent by all States/UTs by end of November 2009, so that 2nd quarter fund can be released in time.

The Technical Session - II was held on the first day under chairpersonship of Dr. P.L.Joshi and Dr. M.A.Arif as cochairperson.

The first invited presentation was on the topic "Stigma against a disease like leprosy – ways and means to overcome stigma and discrimination" by Dr. C.P.Mishra, Associate Professor, Deptt. Of Community Medicine, IMS, BHU.

Next presentation was on the topic "Community Based Rehabilitation" by Dr. Atul Shah.

Technical Session - III chaired by Dr.P.L.Joshi and cochaired by Dr. Indranath Banerjee. Dr. Pramila Barkakati was the rapporteur. The session had five presentations.

First presentation was on the topic "Management of reactions in leprosy patients" by Dr.S.S.Pandey, IMS , BHU.

The second presentation was on the topic" Estimation of new leprosy cases in India – a Methodology" by Dr. Abha Agarwal, Scientist E, NIMS, ICMR, New Delhi.

The third presentation in the session was on the topic "ILEP support to states during the year 2010-11" by Dr. Vijay Kumaran DFIT on behalf of the ILEP India coordinator.

The fourth presentation was on the topic "A special survey conducted by Foundation of Medical Research (FMR) , Mumbai at Gadchirolli district, Maharashtra, by Dr. V.P.Shetty.

Fifth and final presentation of the session was on the topic "A pilot study on disability survey – Preliminary report", by Dr. Anil Kumar, JALMA Institute Agra.

Recommendations :

(i) In view of the survey reports indicating more hidden cases, all the state leprosy officers should draw up their own agenda for detection and treatment of such cases in the shortest period of time.

(ii) ILEP should work out strategy to verify the deficiencies brought out in the studies so that comprehensive action plan can be initiated.

(iii) MDT management need to be given priority. Poor management should not be cause of deprivation to the leprosy affected persons.

(iv) State leprosy officers while designing any study with the NGOs, the protocol should be carefully drawn up so that the study not only helps the persons diagnosed as leprosy but also helps in improving the future activities in the area. Any study with aim for publication of findings only should not be encouraged. Involvement of the GHC staff will help in their skill development.

The Technical Session - IV was chaired by Dr. P.L.Joshi and cochaired by Dr. Atul Shah. Dr. S.P.Sood was the rapporteur . Six presentations were made during this session.

The first presentation was on the Topic "Global Surveillance for drug resistance in leprosy" by Dr. Indranath Banerjee, NPO, WHO India.

The second presentation was on the topic "Proposed drug resistance Surveillance in leprosy in India" by Dr. B.N.Barkakaty , National Consultant, NLEP.

The third presentation was on the topic "Services being provided to PAL at AIIPMR , Mumbai and possible support to States/UTs" by Dr. T.Shreedhar, CMO , AIIPMR Mumbai.

The fourth presentation was on the topic "Offloading the foot in leprosy" by Dr.A.K.Aggarwal, Prof. and Head, Deptt. Of PMR , CSM Medical University, Lucknow, Uttar Pradesh.

The fifth presentation was on the topic "Simple RCS procedures for leprosy disability" by Dr. Atul Shah, Hony. Professor of Plastic Surgery, Grant Medical College & J.J.Hospital, Mumbai.

The sixth and the final presentation of the technical session was on the topic "How to plan and coordinate referral of RCS in Medical colleges for benefit of the PAL" by Dr.A.K.Verma, Head, Rehabilitation Dept. PMC, Patna, Bihar.

Recommendations:

(I) The identified states should urgently finalize the 4 sentinel sites in their states for collection of the skin smear in consultation with the identified laboratory and intimate to the Central Leprosy Division.

(ii) The reference laboratories may take steps to train the concerned persons from the states and districts as decided earlier.

(iii) All the SLOs can take help from the AIIPMR, Mumbai toward treatment for disabilities and Rehabilitation of LAP including procurement of items for rehabilitation like prosthesis.

(iv) States/UTs should contact and coordinate with the medical colleges in their state/region for services needed for the LAP including RCS. More and more surgeons need to be provided training in PMR.

The last Technical Session – V was held under Chairmanship of Dr. D.M. Thorat and Dr. A.K. Puri with Dr. P.C. Kanowjia and Dr. Sameer Bhatnagar as rapporteurs. The session had six presentations.

The first presentation of this session was on the topic " Monitoring of support provided by NGOs under modified SET scheme" by Dr. Ashok Ladda, SLO, Maharashtra.

The second presentation was on the topic " Epidemiological situation of Leprosy in Tribal area viz. a viz. non tribal areas" by Dr. P.K.B. Patnaik, SLO, Orissa.

The third presentation was on the topic "Working under NRHM umbrella – How the programme has benefitted" by Dr. G.R. Talsania, SLO Gujarat.

The fourth presentation was on the topic "Coordination of activities with municipality and the organizations providing services under Urban Leprosy Control Programme" by Dr. K.S. Baghotia, SLO, Delhi.

The fifth presentation was on the topic "How to function as a DLO with multiple job responsibilities in integrated set up" by Dr. P. Rajendra Prasad, Addl. District Medical & Health Officer (AIDS & Leprosy) Visakhapatnam, Andhra Pradesh.

Last and final presentation was on the topic "Integrated service delivery through GHC in the state of Andhra Pradesh and NGO support" by Dr. B. Sai Babu, SLO, Andhra Pradesh.

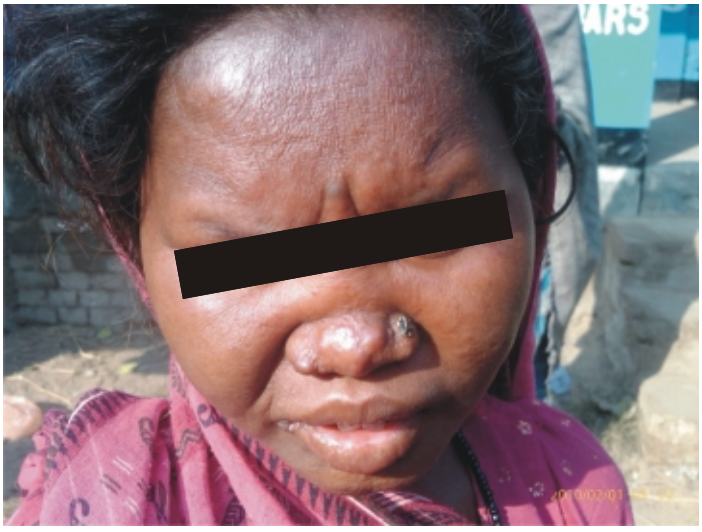
Recommendations:

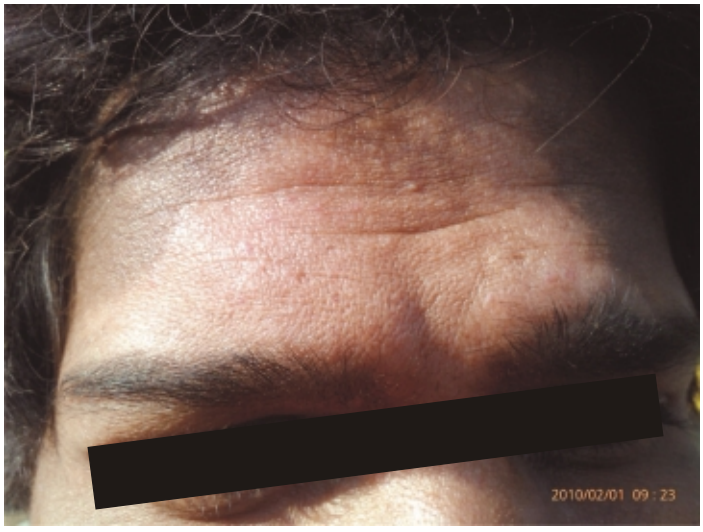
(i) Activities in the tribal areas need to regularly monitored including status of manpower and their capacity to deliver the services as required.

(ii) Urban Leprosy control activities need due attention towards coverage of all uncovered population group through innovative means and to ensure completion of treatment in all cases.

(iii) Integration of services in NLEP also need support of education department for spreading awareness which care only reduce stigma and discrimination.

Connect and Engage!





My recent visit to a State was as revealing as it was educative. It was to see a patient with Tuberculosis that I was there along with my team and the Government Staff. As people gathered around us looking for reasons for our presence I started interacting with them. It was obvious from the derisive snickers I received in response that such visits succeeded in generating curiosity, not confidence. It was not easy to convince them that they were our interest and it was genuine. Persistence seemed to pay off. People started seeking expert advice for any number of ailments from headache to heartache. It was very difficult to explain and convince them that we were not adequately prepared to manage their general disease. We explained that they had to go to Primary Health Centre and consult the Doctor there. I could hear a few sniggers and "I-told-you-so's". I caught sight of a lady inching forward with a baby in the crook of her arm. A lady pushed her forward and demanded that we had better do something for her disease. She said that she was very poor, was widowed, had a small child to take care of and had no shelter. The lady was probably 25 years old and had a stricken look. What was really obvious was the collapse of the bridge of the nose, infiltration on the face, nodules on the ear lobes. It was apparent to anybody who had worked in leprosy control that she had leprosy. We took her aside and examined her. It was definitely leprosy. She admitted that she had the disease for more than 15 years. When asked why she did not go to PHC she said she had been to the PHC about 6 months back. She was told that she did not have any disease and was given cough syrup. Her child of two years of age had multiple lesions all over the body. She admitted that her brother was with her. Even he had a huge raised patch on his forehead.

The lady must have had the disease for at least ten years. I understood that she had not moved out of the village at any time in the past. She belonged to a tribal group living outside the village. She had not heard of leprosy. But the people in the village had heard of leprosy. They said that they suspected leprosy and prodded her to go to the PHC.

When we asked ASHAs (there were two in the village) they said that they had not seen persons with leprosy in the past three years nor had they been trained to suspect leprosy.

We came to know that the MO in charge of the PHC had arranged a meeting of ASHA that day. We decided to take all the three persons with leprosy to the PHC. There was a huge crowd at the PHC. We met the MO In charge who appeared to be really interested in the welfare of the villagers. He said there were four doctors in the PHC and he could not say who had seen the patient when she visited the centre. It was obvious from our interaction and observation that he did not think that the disease was leprosy. I explained to him about the signs, demonstrated how to elicit sensory loss and examine the nerves. In the meeting with ASHA he could repeat whatever he was told. It was a very convincing talk he gave to the ASHA, urging them to look for suspects and refer them and subsequently treat them in their villages. He assured that he would keep his eyes open.

Every visit to the field should result in transformation in the knowledge, skill and attitude of people about Leprosy. People are willing to change. A spark is needed to spur them into action.

- P Krishnamurthy

IXth Meeting of ILEP-India Member Representatives

Chennai, 28th November 2009

The meeting commenced with welcome note by Dr. P. Vijayakumaran. Dr. Sunil Anand who took over as Director,TLMI recently was introduced to the members as this was his first ILEP India meeting. Dr. V. Pannikar's acceptance to participate in the meeting was appreciated and he was requested to provide his valuable suggestions.

Minutes of the VIII meeting of ILEP member representatives – India held at Udhagamandalam on 19th August 2009 were accepted with some modifications regarding allocation of states among members.

ILEP State coordination issues:

a. It was the unanimous opinion of ILEP member representatives regarding issues of participation and support at National and State level and Coordination mechanism, decision should be taken by themselves within the framework of the rules and budgetary limits of ILEP, with prior consultation and endorsement from the parent organisation.
b. With regard to local issues at sub-national level - local collaboration with other ILEP agencies, etc the decision must be from local representatives.
c. Bihar coordination was offered to any member if interested. GLRA intimated earlier that it would discontinue coordination of Kerala state from Jan 2010. DFIT offered to take over coordination of Kerala. Discussion regarding State level coordination led to revision of coordination as given below.
d. The members expressed concern over the fast-diminishing expertise with all the major agencies, GO, NGO and WHO. In order to prevent deterioration in quality of leprosy control it was essential to make ILEP stronger. It was also suggested that some of the ILEP supported referral hospitals could be promoted as training centres where leprosy related expertise could be nurtured.
e. The document on ILEP support to NLEP–state coordination prepared by Dr. Ranganadha Rao and Dr. Rajanbabu was appreciated and concepts overall endorsed. The document however, would be revised by Dr. P. Krishnamurthy and Dr. P. Vijayakumaran.

Monthly report of State Representatives of ILEP:

a. More than one ILEP agency is involved in many states. Individual ILEP agency is free to send report directly to CLD. It was requested that individual ILEP agency would also provide a copy of report on activities to the concerned ILEP state coordinator for overall reporting to CLD.
b. The reporting format from CLD included data is not related to ILEP coordination. It was suggested that activities carried out as part of ILEP coordination would be incorporated. This revised format should be prepared and introduced in 2010.
c. Members suggested convening a meeting of all state coordinators to discuss progress and familiarise the

Revised list of ILEP agencies / States for coordination with effect from January 2010

AIFO	Assam, Meghalaya, Arunachalpradesh, Karnataka
DFIT	Bihar, Andaman & Nicobar, Kerala
FAIRMED	Goa, Nagaland
GLRA	Tamil Nadu, D & N Haveli, Gujarat, West Bengal
LEPRA	Andhra Pradesh, Orissa, Madhya Pradesh
NLR	Delhi, Jharkhand, Uttarkhand, Uttar Pradesh
TLM	Maharashtra, Chattisgarh

Dr. P. Krishnamurthy presented the summary of discussions on ILEP Co-ordination in the ILEP meeting at London.

There were several focal points like quality of leprosy care services in integrated setup, implementation of DPMR activities as mentioned in the plan and state coordination. Changes in leprosy situation and in the global economics have led to many challenges in the way ILEP members operated and in the process of coordination. These challenges were, however, not serious.

The copy of communication from Mr. Douglas Soutar was sent to all members earlier. The suggestions were considered during discussion. Any new proposals/activities would be intimated to the concerned ILEP state coordination agency for information and/or possible collaboration. Members expressed consensus that local issues would be sorted out by mutual discussion.

The relationship with GOI has been very cordial. When the need for modification of MOU was discussed with DDG, he was not very keen. He was in favour of some flexibility. New MOU was not indicated. But situation might be different if a new person takes over. Members suggested to send a letter to DDG based on the discussions in this meeting (28 Nov 2009).

Dr. V. Panikkar informed that countries had not prepared plan as per the new strategy-Jan 2009 and targets. There would be a series of workshops for programme managers and personnel from ministry to enable them to prepare the plan as per the new strategy. The plans would be based on data for 2010 as baseline. The validity of data in terms of recording and reporting information on disability needed close scrutiny.

Dr. P.V. Ranganadha Rao and Dr. S.C. Pande presented details of various activities undertaken by LEPRA and NLR in different regions in India. Copy of the presentation is enclosed for information.

Discussion on Operational issues of common concern.

a. Many members were already carrying out activities addressing operational issues. To share the experiences.

Contd. in page 9

b. Form a group for discussing research issues.
c. Identify young professionals and encourage them to participate in discussion forums. The forum would receive reports on all research activities. This would result in developing technical expertise too.
d. Though NLEP had been integrated certain vertical components would be needed. To study the need/usefulness of this vertical component.
e. To prepare an inventory of ongoing research by ILEP members in India and share he same with GOI and WHO.
f. There was need for advocacy to high level officials in the states regarding NLEP. A workshop was proposed for policy makers – health secretary & director NRHM.

Presentation on 'Proposal for workshop on training / capacity building' by Dr. Mannam Ebenezar / Dr. Rajan Babu:

a. The document presented was accepted in general.
b. To review the participants
c. To have sensitisation of programme managers before the workshop
d. To formulate strategy to meet training needs of leprosy control programmes in different regions (global & with in countries).
e. Dr. V. Pannikar indicated that support to this workshop might be considered by WHO and suggested that both sensitisation and workshop could be done together.
f. Name of the workshop might be changed.
g. The revised version would be sent to all members with a tentative date being Feb 2010.

Support to staff at Central Leprosy Division, Delhi:

ILEP had been supporting CLD by providing salaries of three persons (DPMR consultant, two office staff). Recently ILEP coordinator received resignation letter from DPMR consultant which was accepted and communication was sent. There was another communication from DPMR consultant stating that his resignation letter was only preliminary intimation and the same might be considered as one month notice.

This was followed by letter from CLD forwarding the resignation with request for renewal of the contract and hiking the salary. The matter was placed before the members for discussion. It was decided that resignation should be accepted. Need for support to three persons would be discussed with DDG by ILEP coordinator.

Any other matter.

a. As it was agreed by the members the annual activity report would be sent to the ILEP coordinator by the end of Jan 2010 which would be compiled as a single report for use by CLD and ILEP.
b. Damien Foundation India Trust had been publishing ILEP UPDATE – quarterly newsletter on behalf of ILEP India. Many times DFIT had to make efforts to find materials for inclusion in the newsletter. It posed extra burden on DFIT to bring out every issue. Members were asked to contribute articles and news items.
c. Dr. V. Pannikar suggested to include TAG recommendation, London meeting and WER in ILEP UPDATE.

Felicitations to Dr. V. Pannickar.

Members appreciated the excellent leadership by Dr. V. Pannikar to push the global leprosy control to next higher level. His concern for leprosy affected persons was extraordinary. Members wished that his services would be available in future whenever needed and expressed their best wishes for a happy and health retired life.

Date for the next meeting

February 2010.

Anti-Leprosy Day-2010

AROGYA AGAM, AUNDIPATTI, THENI DISTRICT, TAMILNADU

AROGYA AGAM, Aundipatti NGO supported by DFIT observed Anti-leprosy day on 4th February 2010 in Theni district.

School students, NSS students and Theni Medical College Paramedical students joined Arogya Agam staff in large numbers for the procession organised by the Theni District Administration and Health Department on 5th February 2010 to create awareness in Leprosy.

Mr. P. Muthuveeran, I.A.S., District Collector, Theni, inaugurated the rally.

Dr. Subburaj, Joint Director, Dr. R. Balaji, DTO TB, Dr. Rajmohan DD(Leprosy) and other Govt. officials also joined in the rally. Participants carried the play cards on "Early symptoms of Leprosy", "Leprosy is curable", access and availability of free treatment etc.

Autorickshaws also joined the rally which had banners fixed on them and distributed leaflets with information about leprosy to the public.

This event has brought about a good rapport between the district Health authorities and Arogya Agam which should facilitate our involvement in the NLEP-DPMR activities in the district.

Summary of the discussions held by Dr. G.P.S. Dhillon and ILEP member representatives

15th February 2010, Central Leprosy Division, Nirman Bhavan, New Delhi

The meeting took place in the chamber of Dr. G.P.S. Dhillon, DDG(Lep).

Those present were:

1. Dr. G.P.S. Dhillon, DDG(Lep), Central Leprosy Division, Ministry of Health and Family Welfare, Nirman Bhavan, New Delhi
2. Dr. B.N. Barkakatty, Consultant, Central Leprosy Division,
3. Dr. P.V. Ranganadha Rao, LEPRA Society,
4. Mr. B. Vijayakrishnan-Fontiles
5. Dr. M.N. Casabianca, TLMI
6. Dr. N. Manimozhi, AIFO
7. Mr. John Kurien George, GLRA
8. Dr. Dinesh Jain, FAIRMED
9. Dr. P.K. Mitra, GLRA
10. Dr. M.A. Arif, NLR
11. Dr. S.C. Pandey, NLR
12. Dr. P. Krishnamurthy, DFIT

The meeting was called by Dr. G.P.S. Dhillon to discuss the support by ILEP to the National Sample Survey scheduled this year and to DPMR consultancy at CLD.

1. National Sample Survey:

Dr. G.P.S. Dhillon gave a quick overview of the proposed national sample survey aimed at assessing the leprosy burden in the country. He said that the exercise was planned following the recommendation of the Parliamentary Sub Committee. The responsibility for formulating the methodology was given to National Institute of Medical Statistics (a part of ICMR). A pilot testing of the methodology had been done in Bareili in Uttar Pradesh. The results of the exercise were presented in the first meeting of the task force on 16th December 2009 at ICMR in New Delhi. A Statistical task force which went into all the suggestions prepared the broad framework of the survey. Survey was planned in 34 of the 35 States (Except Lakshadeep Islands).Districts have been randomly selected (from two strata- high and low endemic) and from each district two blocks have been selected. Similarly in each state urban areas have been selected. (Dr. Barkakatty would send the list to ILEP members).

Totally 90 districts and 40 urban areas have been selected. In each selected sample unit the number of new cases to be identified is given (Inverse sampling). House-to-house survey will be done in the selected block till the required number of new cases are detected or till a maximum of population (50000) is covered. The population in which the new cases are detected is the denominator that is used for computing case detection rate. In order to take care of the clustering effect commonly seen in leprosy each block is divided into four quadrants and survey would be started in all the quadrants simultaneously. The primary house-to-house survey for identifying suspects would be done by Multi purpose health workers male and female, ASHA, panchayat members. All the suspects identified would be screened by a second team of Paramedical workers with experience in leprosy. All the confirmed cases would be validated by a third team of validators (two doctors, one each from ILEP and Government). The survey would also focus on disability and stigma.

i. JALMA would be the nodal agency for the exercise. The protocol is under preparation and would be ready soon;

ii. Survey would start in June and is likely to be completed by the end of August. The report would be prepared by the end of November and submitted to Parliamentary committee by March 2011.

iii. The Government has foreseen a budget of 25 million rupees for the exercise;

iv. There would a meeting of the teams from 34 States on 4th and 5th March when the SLOs would be asked to work out the operational details for their respective states under guidance from JALMA. ILEP members are invited to participate in the meeting on 5th. The meeting/ training would be at National Institute of Health and Family Welfare, New Delhi.

v. The state teams would in turn train the survey teams in their respective states;

vi. The SLO would collaborate with the ILEP Coordinating representative in at least 22 states in the whole exercise. In the other States the Government would identify experts from other agencies like regional leprosy institutes, regional directorates, etc.

vii. What is expected from ILEP:

   i. ILEP Coordinating representative in 22 States to be available during the whole exercise, participate in it and collaborate with the SLO. ILEP will reconfirm the list of coordinating representatives .

   ii. One validator from ILEP for each of the 130 sampling units. The ILEP State coordinating agency will identify the resource persons in consultation with other participating ILEP agencies and would submit the list to ILEP Country coordinator who would then finalise and submit it to CLD. Transport for the travel of the ILEP validator would be provided by the Government whereas the expenditure for their participation would be taken care of by ILEP.

viii. Suggestions from ILEP:

   i. The validation team could screen all the suspects instead of only the confirmed cases;

   ii. Person affected could also be involved in the primary survey team;

   iii. For validation, the form used during LEM could be considered;

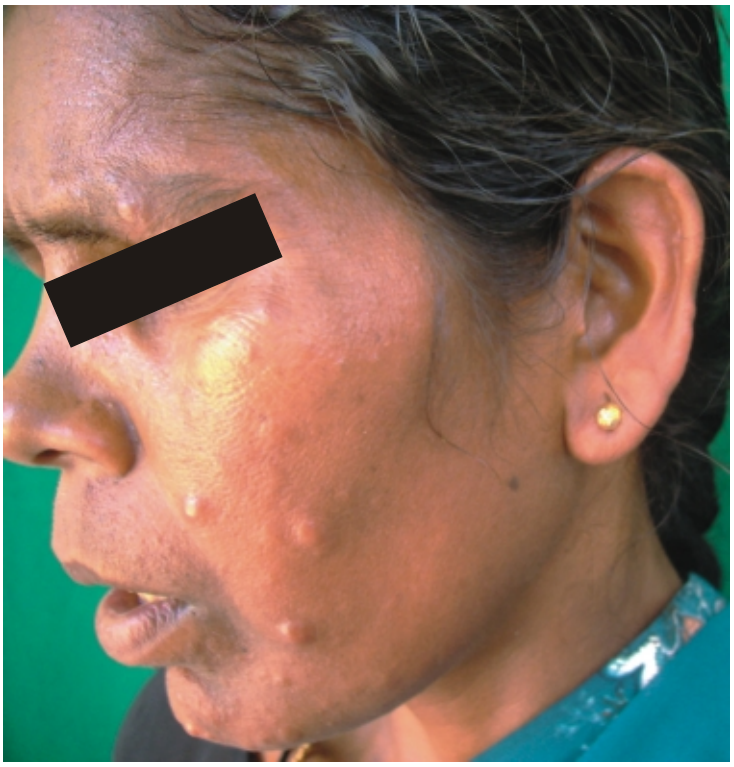
   iv. The final protocol would be shared with ILEP members;

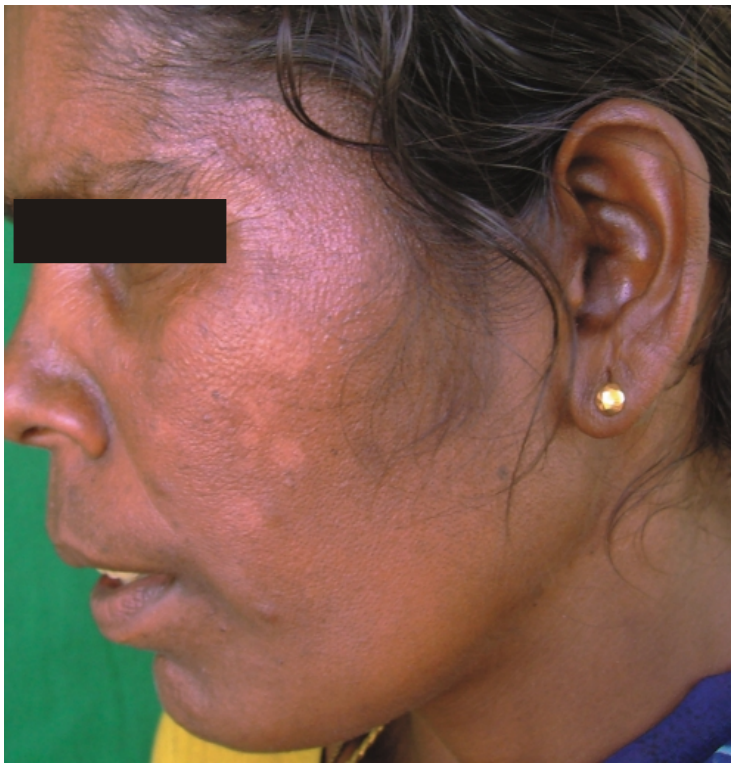
2. DPMR Consultant:

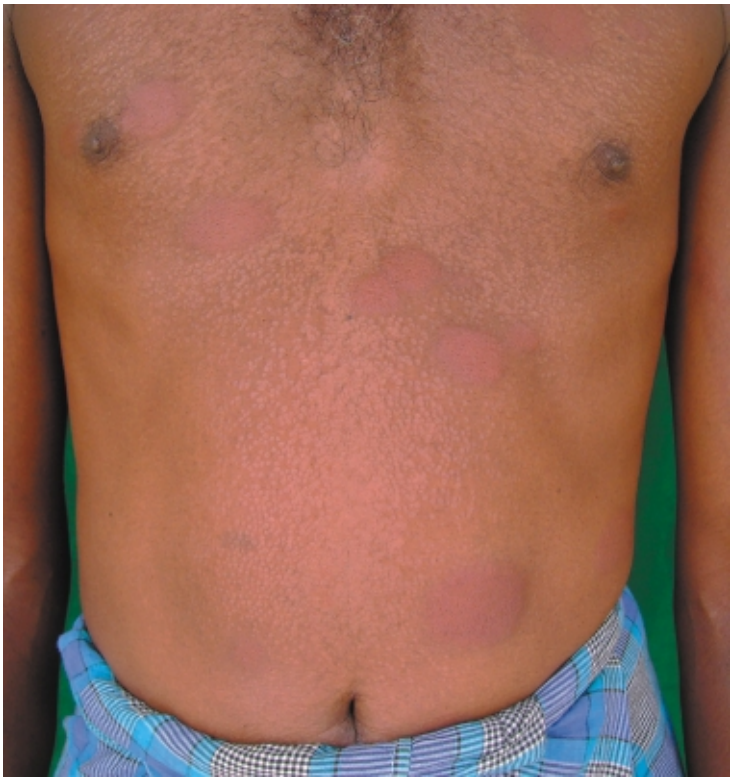
Dr. Dhillon requested that a DPMR consultant be provided by ILEP. ILEP member representatives agreed. It was decided that a suitable person would be identified by a committee consisting of CLD and ILEP. Guidelines on job responsibilities including reporting would be prepared by ILEP in consultation with CLD.

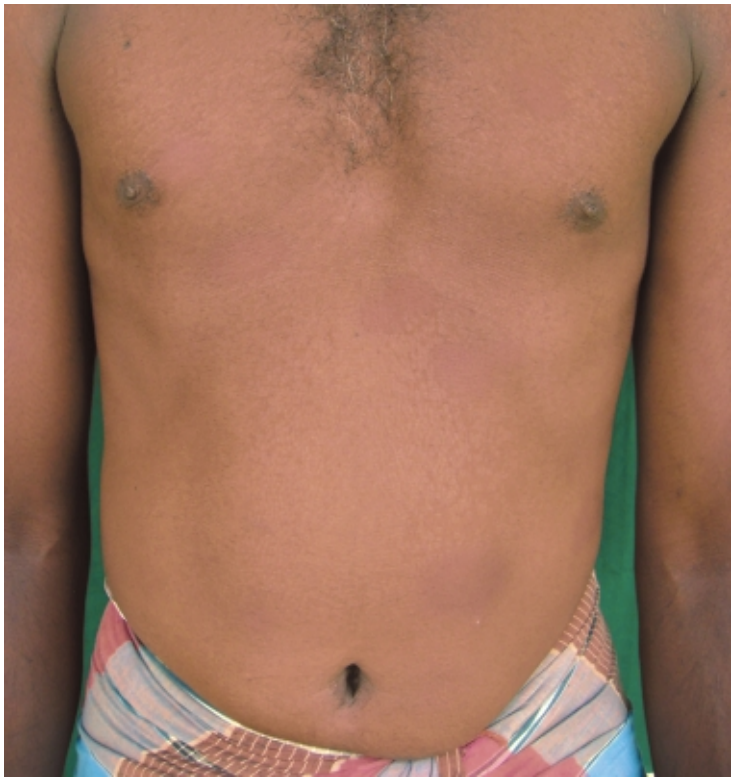
Lepra Reactions

BEFORE and AFTER treatment









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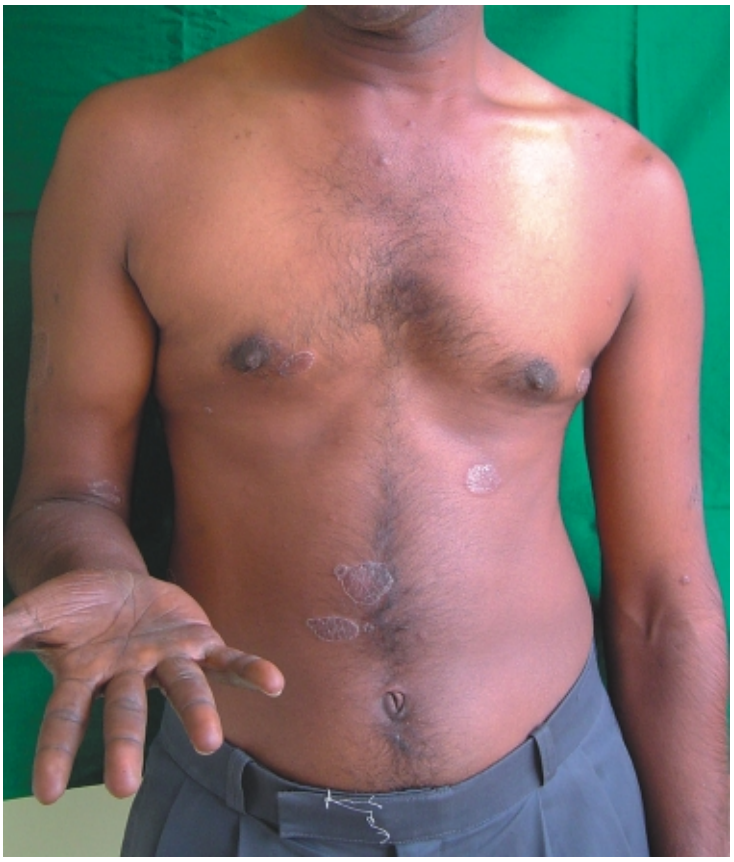

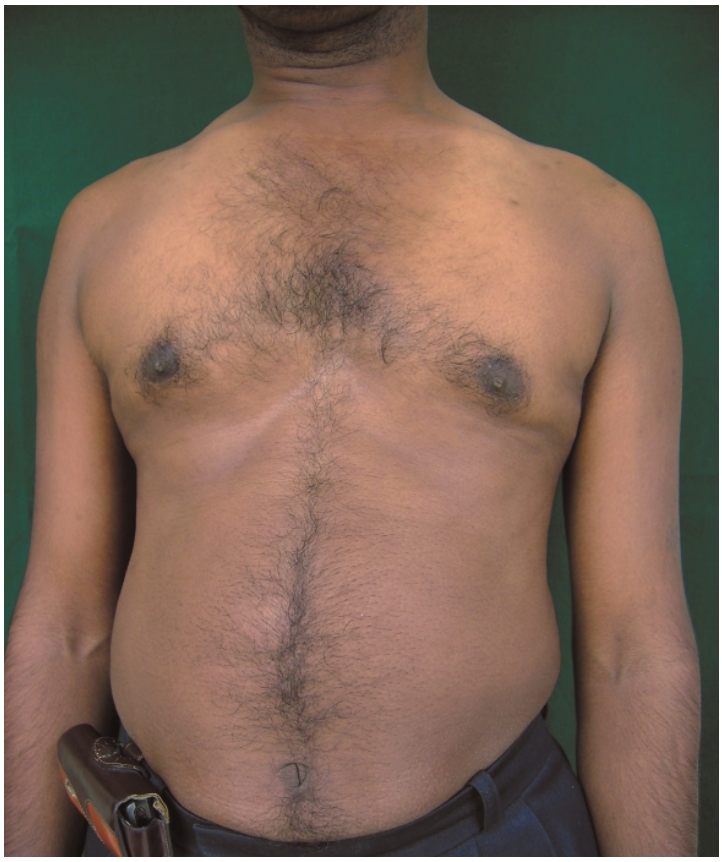

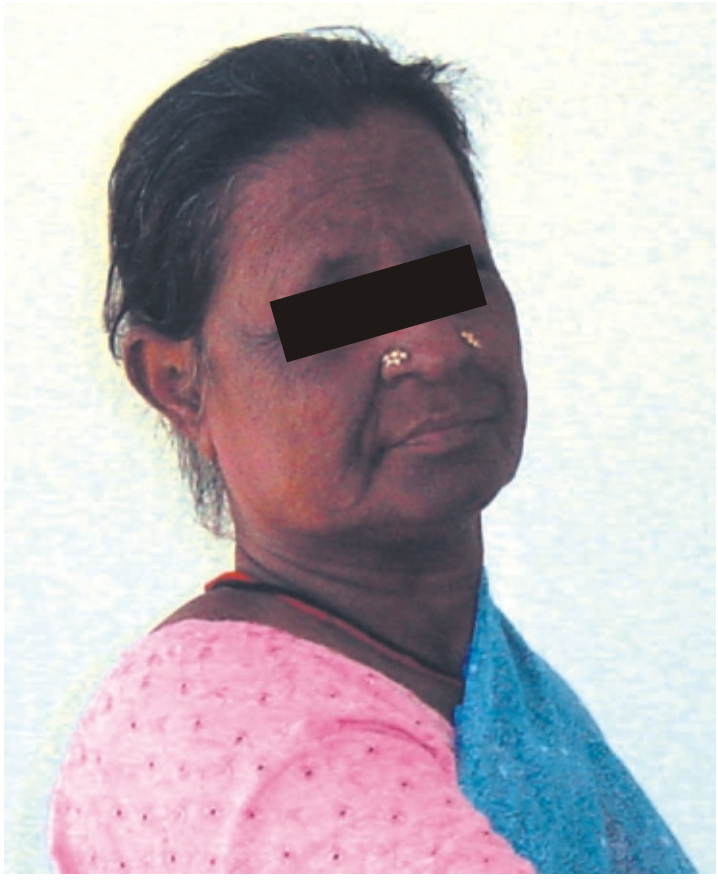

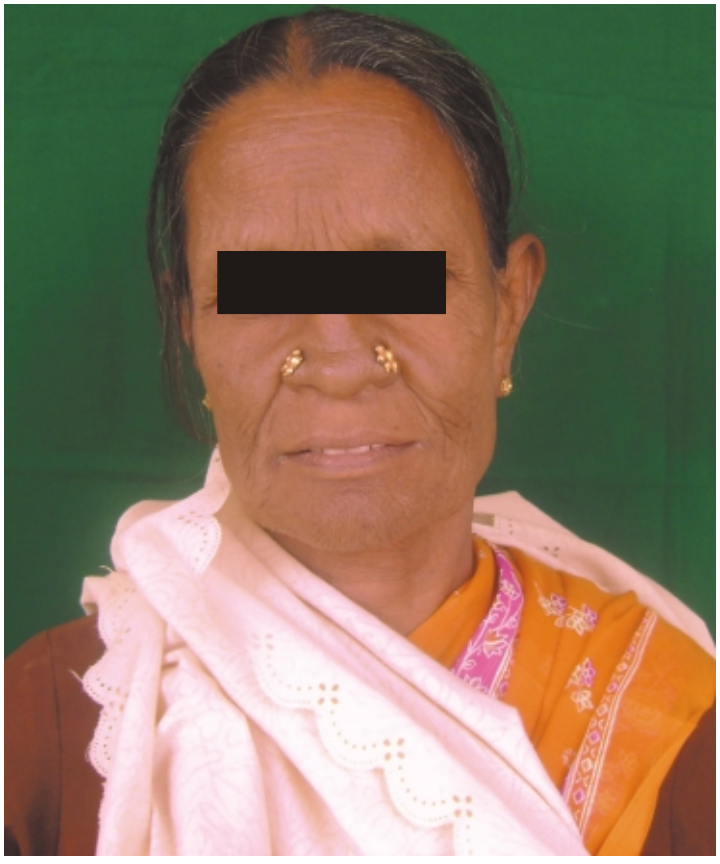

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