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The role of NGOs in leprosy control in India

History of leprosy control in India is the history of coordinated involvement of all the major players including Non Governmental Organisations (NGOs). National Leprosy Eradication Programme (NLEP) is unique in that it is one of the few public health programmes with active participation from the largest number of NGOs thereby putting the programme in forward gear, livening up the pace and helping chart a course that culminated in the achievement of reduction of leprosy burden to manageable levels and integration of leprosy service in general health. Major NGO contribution to the programme is coming from the ten-member ILEP (International Federation of Antileprosy Associations) which have been associated with leprosy control for several decades. From isolated institutions in the middle of nowhere, providing direct care to leprosy affected to supporting the actions of the Government the progress and transition in the dynamics of engagement of NGOs has been indelible, and worthy of mention. While the one-to-one good actions from these NGO centres benefited a large number of patients and offered them the much needed hope, they gave the programme a sense of momentum and transformed it into a successful enterprise only when they made a pitch for supportive actions. Years ago when leprosy was barely recognized as a major public health concern and those affected with the disease were left to fend for themselves from the invading disease and the discriminating society, NGOs took the lead in establishing support and care centres especially in places where they were most needed. With the realisation of the seriousness of the leprosy problem and the availability of drugs, initially of Dapsone and later MDT, to cure the disease, a Public health approach to manage the disease and its consequences was introduced by the Government which worked its way up and became the principal provider of Antileprosy services. Persons affected with leprosy began to be managed outside the NGO run leprosy-specific hospitals and/or leprosaria by a clutch of leprosy-specific staff. Soon, NGO centres took the cue and started extending their reach to seek and treat people affected with leprosy in the field like the Government. They asked for and were allotted geographical areas for programme coverage. In the field programme there was not much of a difference in what the NGO and the Government did. One should not forget that geographical coverage by NGOs did not amount to even one percent and in terms of results obtained in their respective areas they were almost evenly matched. When numbers became unmanageable and threatened to overwhelm the response, the Government steamrolled measures to contain the epidemic. In its effort to accelerate MDT coverage, campaigns were launched and in a fundamental departure from long-standing ambivalence the general health staff were engaged and help was sought from partners including ILEP which placed District Technical Support Teams (DTSTs) in districts in 12 endemic states. While the involvement of general health staff injected a bolt of life to the programme, introduction of DTSTs raised expectations and put leprosy control in the right perspective. The teams, each consisting of a medical officer and a supervisor, started initially with actions aimed at strengthening the effort of the vertical staff and later shifted the emphasis, on common consensus, to uplifting the intensity of involvement and capacity of the general health staff. The participation of ILEP in the programme became more meaningful with the execution of agreement with the Government which stipulated continued support to bolstering the capacity of the general health staff in effective implementation of all leprosy-related activities. They provided the much required on-the-job guidance which resulted in considerable improvement in the quality of leprosy services. Almost seven years of continuous, relentless involvement by the DTSTs has given a fundamental shift in the pace of programme implementation. Independent evaluation of DTSTs done in early 2006 which also took into consideration the myriad elements that factored into the process and output in leprosy control brought out clearly a scenario with a high

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success quotient - there was almost near complete involvement of the general health staff in leprosy control and quality of leprosy services provided to persons affected with leprosy without complications was reasonably good. The favourable situation led to the decision to withdraw the teams and it was brought into effect at the end of March 2007. The contribution of ILEP in all the actions and endeavours, successes and achievements, may be difficult to quantify but impossible to deny.

The year 2007 is a watershed, a turning point in leprosy control and partnership efforts. Achievements in leprosy control have been tremendous. New cases which used to be more than 400000 annually has come down to about 150000 and leprosy burden in terms of prevalence has reached the point of elimination. The programme is well integrated and the general health staff are reasonably good in managing simple cases of leprosy. The strengths of the system are its vast majority of personnel and other resources which, given the right environment and supportive guidance, can rise up to the challenges and face the problems head on and eventually make a difference to the situation. Even though the health facilities in the periphery are able to diagnose and manage simple cases of leprosy, the staff may not be able sustain their efficiency in the absence of a support supervisory structure. This hinges on a functioning supervisory system which hitherto was provided by the District Technical Support Teams. In the absence of this transplanted outside structure it is important that the resource unit which is supposed to play the crucial support role in the districts, the Government district nucleus, is fueled into action. In many districts the district nucleus is not functional for various reasons- lack of staff, lack of training, lack of logistics support, etc. NGO partners including ILEP could use their wares and evocations of experience and expertise in assisting the Government in fixing the reasons for ambiguities of action and in lending them a helping hand to be the architects of their own transformation.

The second most significant problem is the establishment of an appropriate referral system in the districts so that all cases with complications would get suitable remedies. Even though the idea has not broken through in the mainstream programme there has been recognition of the overwhelming need for this which entails training of all the peripheral staff in managing cases with complications, identification and training of key staff in the District hospitals and also identification of tertiary referral centres for reconstructive surgery. The system needs to create a referral loop where sites of different interventions and those responsible for them are identified, listed, trained, and guided. One should not forget that the system needs disengaged rather than hands on support. ILEP is in an eminently suitable position to take up this task immediately.

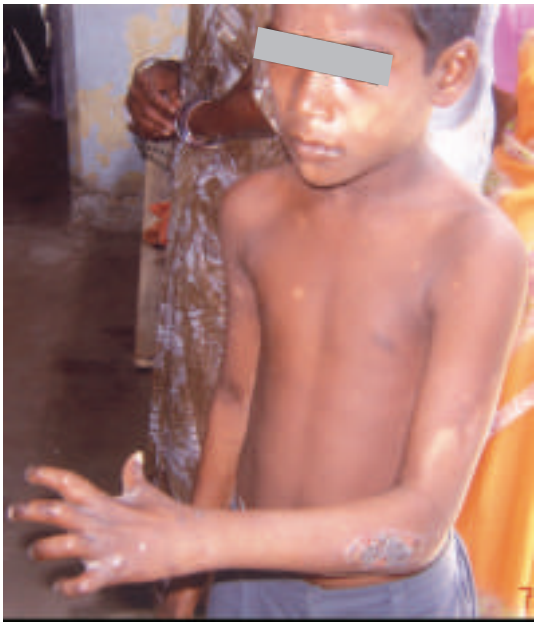
The third most important task in which the continued engagement of ILEP is essential is in the area of providing tertiary care to those in need. It would not be prudent to establish new centres in Government institutions; it would be cost-effective to limit the tertiary care service to ILEP supported hospitals. Each such hospital can be allotted certain number of adjacent districts for taking care of surgical needs of persons affected with leprosy. They can also train the surgeons in district hospitals in simple operative procedures like septic surgery.

Finally, even within the gamut of leprosy services those with irreversible disability and are therefore in a socially disadvantageous position need timely succor, both for their sustenance and for effacing the overarching social handicap. ILEP is in an exceedingly favourable position in engaging themselves in social preoccupations that promote upliftment of the forlorn few.

It is time for all the well-meaning NGOs to come together on a single platform and use their collective strengths to collaborate with the Government and dovetail their resources and commitments as per the immediate needs of the most important stakeholder, patients. They have one simple goal: make themselves eminently useful, not usable. Both the Government and the ILEP have an enviable opportunity to bring about a change from the provider-oriented stratagem to patient-friendly plans and thereby put the programme into a higher orbit with potentially significant consequences for the patients. Let us hope that this will be cheered into place.

NEW LEASE OF LIFE

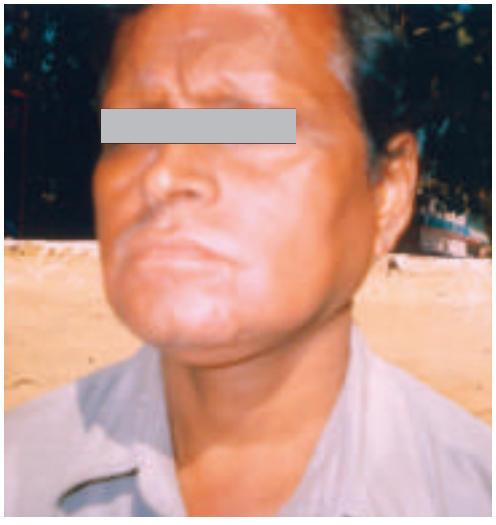
Master Sundar (name changed), aged 11, comes from a poor family, in Salem District. He has one brother and two sisters. His father, a mason, migrated to Mumbai when the boy was very young. A lesion was noticed when Sundar was 9 years but it was not taken seriously by his parents. It was during a visit to their relative's house in Trichy they were advised to go to the nearby PHC for treatment. The doctors at PHC confirmed it as a case of Leprosy, registered him as MB leprosy and started treatment. The boy took MDT for 3 months but discontinued the treatment despite the advice of the Doctors and returned back to Mumbai with his father. During the floods in Mumbai, the family took shelter in a hospital building. A Nun of the hospital found him and referred him to one of their hospital in Andheri. MDT was started again and surgical decompression of his left ulnar nerve was done. He was in the hospital for 3 months. His left ulnar and median nerves were affected and the boy had clawing of all fingers. Fearing that the disease might affect his other children the father was secretly planning to do away with the boy. But destiny had other plans; he was forced to return to his native place in Salem due to loss in business. At Salem, Non Medical Supervisor and Village Health Nurse (equivalent to ANM in other regions in India) of the area during their routine field visit found the boy and motivated his father to bring him to the POD camp organised locally, gave them counseling and convinced him about the treatment and surgical correction of the deformity. The MDT was started immediately along with physiotherapy. Health Inspector and Village Health Nurse visited the boy's house regularly to monitor the progress.



Sundar has shown good progress. Reconstructive surgery will be done for his claw hand on completion of MDT. He will be joining school shortly. Local NGO, St.Marys Leprosy Centre came forward to support his father financially to start a small business in order to anchor them in a place. Now the family members have accepted the boy and he is happy.

SMLC,
Arisipalayam,
Salem

TO BE INFORMED IS TO BE EMPOWERED



Mr.Govind (name changed), Aged 45, resident of New Delhi developed Erythematous, infiltrated lesion over left cheek about six months back. The lesion extended from left to his right cheek and both the upper and lower lips. He was convinced that it must be due to a dental infection. He visited a dentist for treatment. He was given antibiotics and pain killer tablets for 15 days, but there was no improvement. He came across a handbill informing about Leprosy and the treatment facilities being provided by the Government health facilities. He consulted skin department at Dr.Ram Manohar Lohia Hospital. The doctors diagnosed MB leprosy and referred him to DMC III at Ghasi Pura (run by DFIT) for MDT as this centre was nearer to his residence. The patient had both the ulnar nerves thickened and had developed Type-1 lepra reaction. He was started on MB-MDT along with steroids on March 2007. The lepra reaction had subsided and leprosy lesions are regressing.

Margaret Leprosy & TB Centre, *New Delhi*

"SUCCESS COMES TO THOSE WHO SEEK IT, NOT TO THOSE WHO WAIT FOR IT"

Strategic Planning Workshop for NLEP in Jharkhand

A "Strategic Planning Workshop using Logical Framework Approach" was organized successfully by NLR branch office India, in the state of Jharkhand, at Jamshedpur on 21st – 25th May 2007.

Log Frame approach is a methodology for planning, managing and evaluating programmes and projects, using tools to enhance participation and transparency and to improve orientation towards objectives.

All the related stake holders i.e. program officers from state & district level, ILEP partners- NLR, TLM & DFIT, WHO active in the state, community representatives, patients and local NGOs, were involved in it. Dr. Dhillon, National Program Officer also participated. During initial 2 days, situation analysis was carried out and problems identified were analyzed by all stake holders. On the basis of needs identified and problems analyzed, expected results / objectives were formulated. A complete matrix was prepared along with the objective defining its indicators & source of indicators, leading to 'Action Plan'. During last (5th) day, its management part was discussed specifying steps & preparations required to implement the plan.

The main facilitators were Mr. Jos Brand and Mr. J. W. Dogger. Government teams from Delhi, Uttarakhand and Uttar Pradesh states also participated for all 5 days to learn & follow 'Logical Frame work approach'.

A draft plan, outcome of this workshop will be discussed further with Central Leprosy Division and among partners to finalize and implement it.

Input based planning was being done so for. This workshop is being seen as an important milestone and revolutionary because result (objective) oriented planning is being introduced in NLEP.

Dr. M.A. Arif, NLR

Topics discussed during the meeting of ILEP Member Representatives working in India on 6th June 2007, at Bangalore.

- Procurement of Prednisolone Pack by TLM for use by ILEP members.
- Procurement of Clofazimine capsules for use by Central Leprosy Division and ILEP members.
- Study on quality of leprosy services from the Clients perspective.
- Requirement of MDT blister pack for ILEP supported hospitals.
- National forum of major partners to discuss on technical issues.
- ILEP support to NLEP from April 2007 to March 2012.
- Technical committee of ILEP India-for development of Health system research topics, learning materials, curriculum for medical students (orientation in Leprosy) etc.
- Study on relapse in Leprosy after MDT in NLEP.
- Development of referral system (Lep) for General Health Care Services.
- Information on reconstructive surgeries done in ILEP supported hospitals in India.

Operational guidelines for Leprosy control activities

(World Health Organisation SEA/GLP/2006.2)

Contd. from April 2007 Issue

1.5 What are "quality leprosy services"?

The Global Strategy emphasizes quality leprosy services as an essential component of an effective programme. Quality is based on appropriate training of staff at every level, regular technical supervision and monitoring of key indicators. The pursuit of quality assumes the willingness of staff to make changes aimed at improving their skills and the functioning of the health services in which they work.

Quality leprosy services:

- Are accessible to all who need them.
  - Coverage: MDT treatment can be provided at all health units.
  - No geographical, economic or gender barriers.
- Are patient-centred and observe patients' rights, including the rights to timely and appropriate treatment and to privacy and confidentiality.
- Address each aspect of case management, based on solid scientific evidence:
  - Diagnosis is timely and accurate, with supportive counselling
  - Treatment with MDT is timely, free-of-charge and user-friendly
  - Prevention of disability interventions are carried out appropriately
  - Referral for complications and rehabilitation is done as needed
  - Maintain simple records and encourage review and evaluation

1.6 What are "principles of equity and social justice" in this context?

Communities have wide-ranging health needs. Resources (staff, time, money) should be allocated fairly to different programmes, including the leprosy services, according to the disease burden, so that each can function as effectively as possible. 'Equity' means that leprosy patients have the same opportunity to attend health services that are of sufficient quality to deal with their problems. It also implies that leprosy services should be neither worse nor better than other health services available in a given community. Social justice means an absence of discrimination for any reason, including type of disease, level of disability, race, gender, social class or religion; it includes the principles of privacy and confidentiality.

2. Integration and referral

2.1 How does referral work in an integrated health service?

Effective leprosy control requires an integrated approach, which provides wider equity and accessibility, improved cost-effectiveness and long term sustainability. This implies that leprosy control activities should be implemented by the general health services, including integrated referral facilities. Integration not only improves accessibility to treatment, but also reduces the stigma and discrimination faced by persons affected by leprosy.

Integration means that day-to-day patient management, recording and reporting become the responsibility of general health staff. However, integration does not mean that specialist expertise disappears from the health service. On the contrary, this expertise must be available within the general health service at the central and intermediate levels for planning and evaluation, provision of training, technical supervision, advice, referral services (including those at hospitals) and research. A system should be in place for the referral of difficult or complicated cases to the hospitals or specialists (e.g., general medical officers with some additional training in leprosy, dermatologists or surgeons) and referral by specialists back to the peripheral health facilities for continuation of treatment. The specialized referral services for leprosy are part of the general health services, just like a surgeon in a district hospital is part of the general health services.

Depending upon local conditions (e.g. the availability and level of training of various categories of health staff), each country or region must decide at which level of the health system such specialist expertise should be made available. Peripheral general health workers should be capable of diagnosing and treating leprosy under the technical supervision of specialized health workers who are positioned at the intermediate level. This category of specialized staff will usually have responsibility for other diseases in addition to leprosy.

Where leprosy is less common, the ability to suspect leprosy and refer the patient to a referral unit is the most important skill required for peripheral general health workers. These referral units (including district hospitals and selected health centres) should diagnose leprosy and start treatment. Continuation of treatment could be delegated to the peripheral health facility

serving the community in which the patient resides. The community should be informed about symptoms of leprosy and the availability of services. In areas with small patient loads, management of nerve damage will have to be concentrated in referral units. Centres treating the difficult complications of leprosy and providing rehabilitative surgical services will be even more centralized, but could also provide some referral services through mobile units.

An adequate referral system means that specialist services should be accessible and available to any patients who need them. The main obstacle to referral in many countries is the difficulty for the patient to reach the referral unit at the right time. In such situations, the visiting supervisor should prove useful in providing the necessary support services.

All peripheral health staff should know the clinics and health staff to whom they will refer patients, so that they can advise their patients accordingly, in order to minimize their difficulties. Good communication should be maintained, to allow discussion of patients' progress and as an opportunity for further training. The convenience of mobile phones and text messaging can make this easy and timely.

Six basic principles for successful integration are advocated by WHO:

- Every health facility in an endemic area should provide
- MDT services on all working days
- At least one trained staff member should be available in every health facility
- Adequate amounts of MDT drugs should be available, free of cost, for patients
- Information, Education and Communication (IEC) materials should be available for the patient and their family members
- A simple treatment register should be available
- Referral services should be available and accessible, and general health staff should know where and how to refer patients

Peripheral level

Staff at the Peripheral level should develop good links with the referral units they are most likely to use regularly:

- The visiting technical supervisor
- Nearest Health Centre (with staff with additional training in leprosy) or District Hospital
- Eye clinic for anyone with eye problems
- Leprosy or dermatology specialist: for diagnosis, skin smears, reactions
- Local rehabilitation networks for anyone with long-term disability

Referral level

Staff at the Referral level should know the specialist clinics and other professionals to whom they may refer patients, such as:

- Ophthalmology for significant eye pathology
- Dermatology for diagnosis of difficult skin conditions
- Laboratory for skin smears and histopathology
- Physiotherapy for assessment and management of reactions
- Podiatry for the feet and footwear
- Occupational therapy for rehabilitation and adaptations
- Reconstructive and plastic surgery
- Social worker for assessment and further referral
- Rehabilitation specialists and CBR programme

2.2 Which conditions in leprosy require referral?

Staff should refer patients whose condition they are not able to deal with – this may be because they have not been trained to deal with it, or because they do not have the necessary resources (drugs, equipment, other staff, etc.) to manage the condition.

Routine referrals: non-urgent conditions include:

- Diagnosis: if leprosy is suspected but the diagnosis is uncertain (section 4.4)
- Suspected relapse (section 5.5)
- Any stable, long-standing disability which may be suitable for surgery or any other rehabilitation intervention (sections 6 and 7)
- Non-medical referrals, for example, to a social worker or to a CBR programme
- Other health problems, unrelated to leprosy

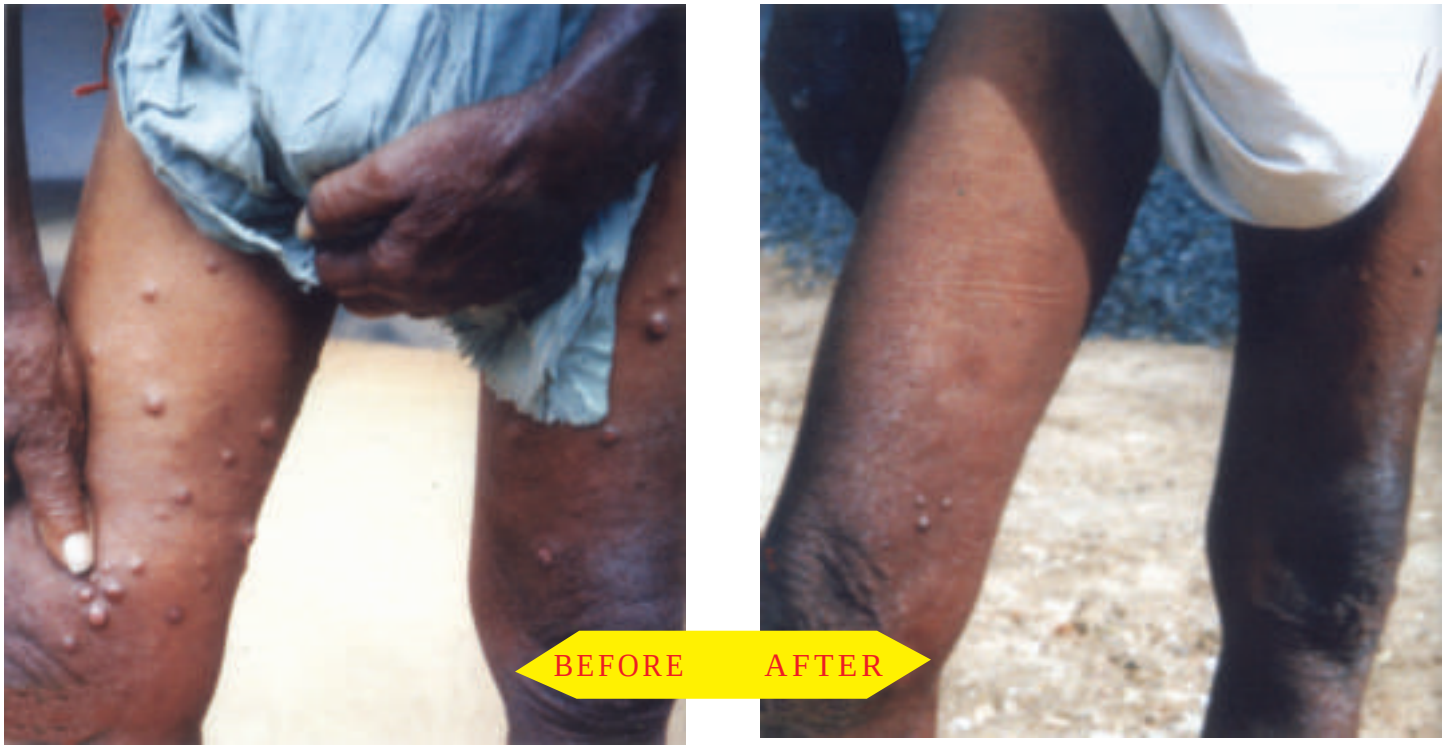
Emergency referrals: conditions that require urgent treatment such as:

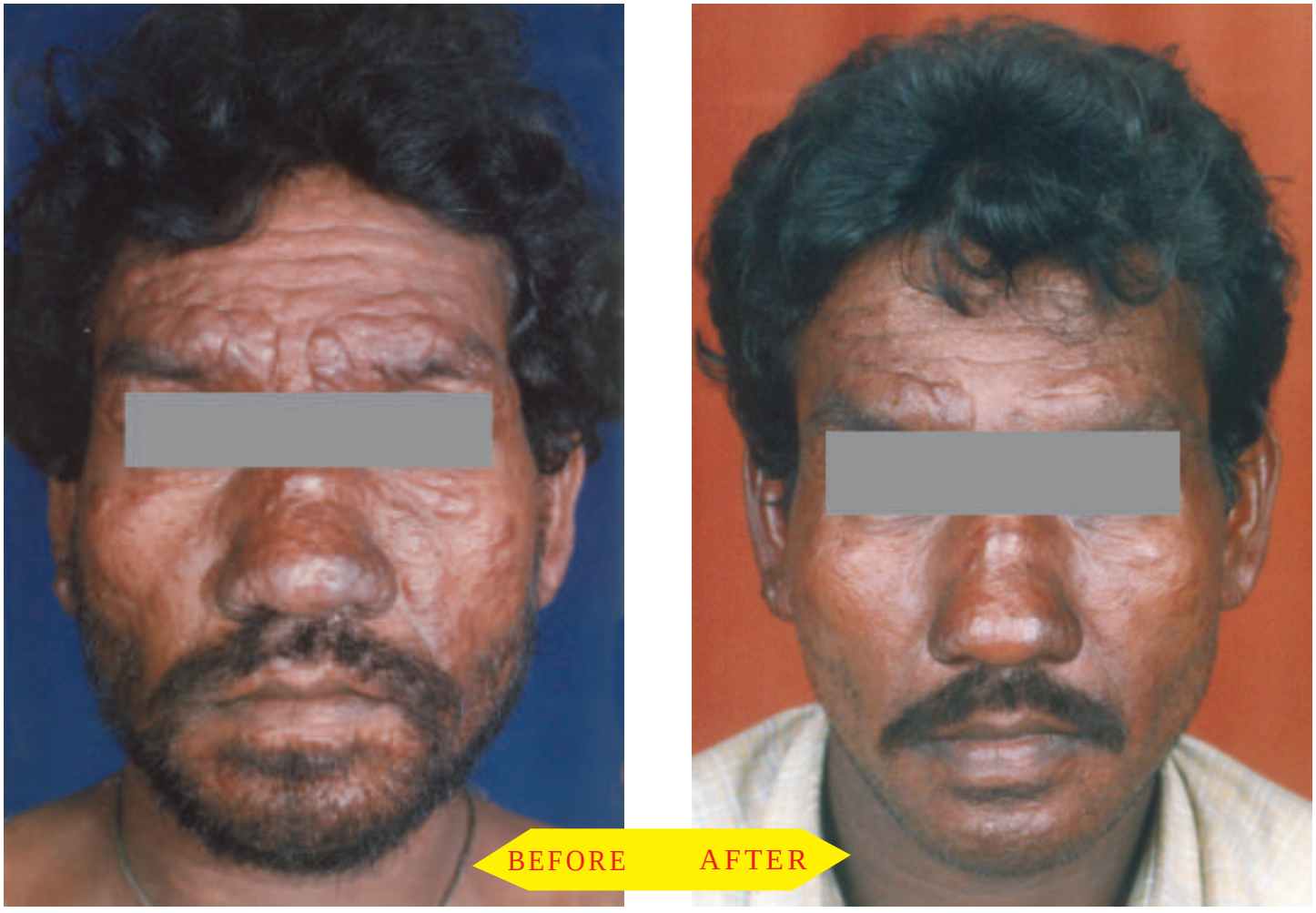
- Severe leprosy reactions (section 5.7), including:
  - Severe reversal reactions
  - Reversal reactions overlying a major nerve trunk
  - Neuritis, including silent neuritis
  - Erythema Nodosum Leprosum (ENL) reactions
- Severe infection of the hand or foot (usually related to an ulcer with foul-smelling discharge); the hand or foot will be hot, red, swollen and probably painful (section 6).
- Eye involvement in leprosy – four specific problems which need urgent referral:
  - Recent loss of visual acuity
  - A painful red eye
  - Recent inability to close the eye (lagophthalmos)
  - A reaction in a leprosy skin patch on the face
- Serious adverse drug reactions (section 5.6)

National programmes should document and circulate contact details of clinics and consultants ready to see leprosy-related referrals, in order to establish a more efficient system of referral.

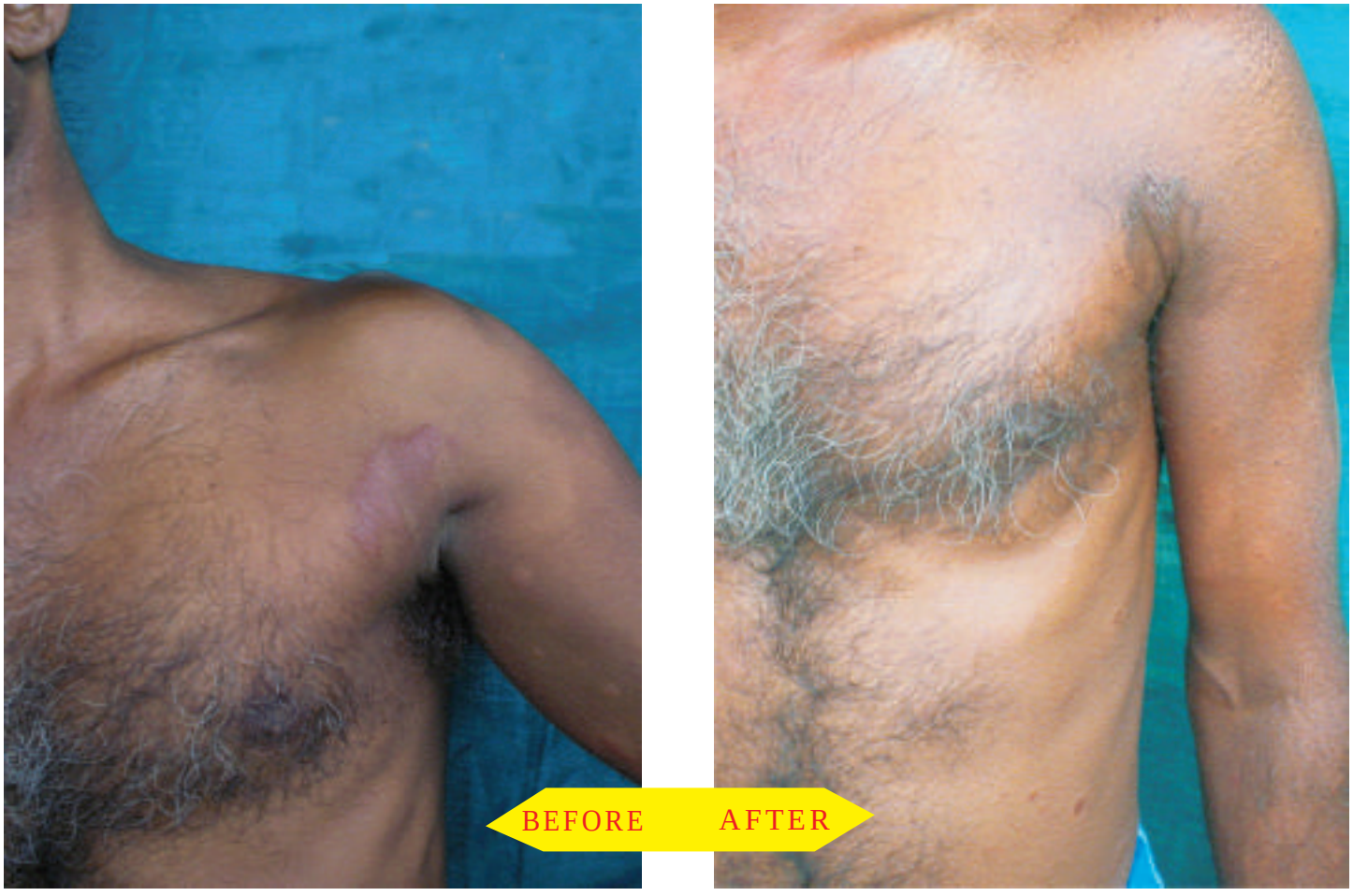
To be continued …

BEFORE AND AFTER MDT TREATMENT





BEFORE AND AFTER MDT TREATMENT



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