# PANEL DISCUSSIONS

**Panel discussion 1**

## MANAGEMENT OF LEPROSY IN HIGH ENDEMIC DISTRICTS/ POCKETS

**Moderator**: Dr V M Katoch

**Panellists:**

Dr PV Ranganatha Rao, Dr Sunil Anand, Dr Rajendra Prasad, Dr Micheal, Ananth Reddy and Dr John Babu

**Observations:**

- India has achieved the target of 'Elimination of leprosy as a public health problem'. However, there are high endemic pockets in the country and several districts reporting over 1000 new cases each year.
- There is migration of patients from high endemic districts to low endemic regions resulting in continued transmission of disease.
- One of the reasons for high endemicity is that some of these districts are difficult to access both for the health system as well as for patients.
- The goal of reducing grade II deformity has not been achieved. On the other hand there is an increase in the number of grade 2 deformities since 2010.
- There is an increase in the children affected by leprosy in the country.
- There is also an increase in MB leprosy cases.

•**Recommendations**

- Reasons for high endemicity and continued transmissions of disease should be studied and addressed specifically.
- A vertical programme of case detection activities can by implemented in the high endemic pockets/districts.
- Awareness on leprosy, case detection and treatment completion activities should be delegated to the community including PAL's (People affected by leprosy).
- Utilize the services of retired health personnel with experience in leprosy in high endemic pockets.
- Increase the awareness about leprosy in the general population; specifically among children; among ASHA workers; medical students, post graduate students and other key groups in the community as well as specifically in the high endemic districts.
- Introduction of Chemoprophylaxis and Immunoprophylaxis to prevent leprosy should be considered.
- Political commitment and resource mobilization for leprosy should be sustained.
- Build the capacities of general practitioners, Dermatologists and other health staff to diagnose and treat leprosy.

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**Panel discussion 2**

## IS ONE YEAR MBMDT SUFFICIENT FOR ALL FORMS OF MB LEPROSY?

**Moderator:** Prof P Narasimha Rao

**Panellists:**

Dr Sunil Dogra, Dr PVS Prasad, Dr Vittal Jadav, Dr Vanaja Shetty and Prof Ben Naafs

**Observations:**

- WHO-MB MDT is unable to completely clear the BI in MB leprosy within one year in patients with high BI. Similarly, 1 year MB-

MDT is unable to clear the signs and symptoms of leprosy within one year in some of the cases.

- Some patients continue to have ENL, Type 1 reaction, neuritis, reactivation etc even after completion of 1 year MBMDT.
- Histoid leprosy is developing de-novo as well as due to ug resistance and is being increasingly seen all over India.
- There is rise in the proportion of MB leprosy patients in India.
- MBMDT is not capable of dealing with persister organisms.
- Prolonged steroid therapy to treat reactions can compromise the effectiveness of MDT.
- Leprosy is both a bacterial diseases as well as an immunological disease.

**Recommendations:**

- It is better to treat Histoid leprosy with two years of MBMDT. Combining immunotherapy and an intensive phase with Rifampicin may be considered.
- Since the numbers of new cases is low it calls for a move from a public health approach to a individual patient approach to management
- There is a need to look for newer, more effective drugs to treat leprosy and lepra reactions. These drugs should be aimed at overcoming the problem of persisters, control reactions/neuritis and prevent relapse.
- MDT does not address the problem of reactions and neuritis adequately. There is a need to develop an approach to treatment which ensures complete clearance of bacilli & disease activity and preventing deformity/disability.
- IAL need to develop Guidelines for management of individual patients till complete clinical and bacterial cure for use at clinic level.

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**Panel discussion 3**

## PEOPLE LIVING WITH LEPROSY: PRIORITIES AND CHALLENGES

**Moderator:** Dr J Subbanna

**Panelist:**

Dr Rajan Babu, Mr. Syed Muzaffarulla,
Mr Ankit Jain, Mr. Narsappa, Dr K Udaya Kiran,
Mr. Robert Jerskey

**Observations:**

- There is still stigma associated with the word 'leprosy'.
- Leprosy is declining but deformities in leprosy have been increasing due to lack of awareness and late detection.
- Treatment of household contacts (chemo prophylaxis) of a leprosy patient is a human rights violation since it uncovers the index case and produces stigma for the family.
- Persons affected with leprosy (PAL) experience social exclusion especially when they have facial patches or other visible deformities.
- PAL's are our best teachers about their needs and priorities.
- There are over 15 discriminatory laws against PAL's since the last 6-7 decades at national and state level.

**Recommendations:**

- Because of the stigma associated with the term leprosy it should be replaced with the term 'Hansen's Disease'
- Further the term 'Leper' should be removed from all public documents. Once a person is cured of leprosy there is no need for the tag

'Person affected by Leprosy' (PAL) to be applied to the person.

- Early detection, completion of treatment & prevention of disability are key priorities in leprosy control.
- Besides caring for the physical aspects of leprosy, there is a need to care for the psychological & social aspects of the disease.
- There is a need for more centers that carry out reconstructive surgery and which have good physiotherapy support. A special need is for eye surgery.
- PAL's are more effective in creating awareness on leprosy; in training and in supporting leprosy control activities and should also be included in the decision process in NLEP.
- Camouflage is a simple method to cover facial patches due to leprosy and helps to prevent social exclusion.
- PAL's should live like other normal citizens with dignity; with social participation, with livelihoods restored and have a right to good quality of life.
- PAL's should receive all the information about leprosy including the efficacy of MDT; this gives confidence to the patient and the family.
- The whole family should be counseled to ensure family support for the patient; this helps adherence and completion of treatment.
- The discriminatory laws against PAL's should be addressed and repealed one by one or with a substantive law nullifying all the discriminatory laws.
- The judiciary, the law commission, law ministry, the Government and the general public need to be sensitized about these discriminatory laws and ultimately repeal them.
- Affirmative action is needed for the social inclusion of PAL's.
- Involvement of PAL's in NLEP planning, implementation and capacity building activities are important for the early diagnosis of leprosy and strengthening POD services.

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**Panel discussion 4**

## MANAGEMENT OF STEROID DEPENDANT ENL (SDENL)

**Moderator:** Dr Kiran Katoch

**Panellists:**

Dr Joydeepa Dorlong, Dr KK Mohanty,
Dr Diana Lockwood, Prof Swapan Samanta,
Dr VV Pai, Dr KV Krishnamoorthy

**Observations:**

- Sterioid dependent ENL (SDENL) is still a problem that is encountered in many centers.
- Sterioid dependence and steroid toxitity are two phenomenon and both need to be recognized and addressed.
- Prolonged high as well as low doses of steroids can lead to steroid dependence.
- There is suppression of the hypothalamic-pituitary axis and the body is unable to produce steroids.
- It is important to recognize the precipitating factors for ENL and treat them. This will help to prevent the development of steroid dependence.
- The problem of self medication with steroids contributes to the issue of steroid dependent ENL and needs to be recognized and managed through counseling.

**Recommendations:**

- Thalidomide is a drug of choice in managing ENL and should be initiated early. It should

be used with caution especially in women in child bearing age due to its known teratogenic effect.

- There should be more centers where Thalidomide is available.
- In the absence of Thalidomide, high doses of Clofazimine, upto 300mg daily is beneficial in controlling ENL as well as bringing down the BI.
- *MIP (*Mycobacterium indicus pranii*) immunotherapy is beneficial and recommended for treatment of chronic and acute ENL as well as for rapid tapering in steroid dependence.
- Steriods should be used sparingly and judiciously while looking for better alternatives.
- Patients should be counseled on the danger of self medicating with steroids and the risk of developing steroid dependent ENL.
- Oral minipulse of steroids, alternate day steroids or twice a week steroids are therapeutic options to consider to prevent steroid dependent ENL.
- There is need for more clinical research on ENL to develop a clinical scale of severity of ENL & a management protocol: and a need for lab research to identify early markers for ENL.

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**Panel discussion 5**

## PROMOTING LEPROSY RESEARCH IN DERMATOLOGY DEPARTMENTS

**Moderator:** Prof Bhushan Kumar

**Panellists:**

Dr Geeta Kiran, Dr Sunil Dogra,Dr Terrance Ryan, Dr R. Subba Rao, Dr Sujai Suneetha

**Observations:**

- Dermatologists, both in the government and private set up are seeing a large proportion of the leprosy patients and they play a key role in leprosy control.
- Dermatologists may need to collaborate with other clinical and laboratory departments for good quality research on leprosy.
- Funding leprosy research is a challenge and depends largely on the status, genuine interest and capability of the individual seeking funding.
- Community Dermatology is an important approach to increase the reach to find / serve more leprosy patients, and by its impact it can also increase chances for research funding.
- There is a increasing interest in cosmetology and less interest in classical clinical dermatology and in research among young dermatologists, we should accept this and exhort them to contribute towards care of leprosy patients as much as they can.
- Good clinical records are key to research studies.

**Recommendations:**

- Considering that Dermatologists see and treat a significant proportion of leprosy in the country, they should ideally take a lead in carrying out leprosy research.
- The key is developing good proposals which include collaboration with other departments like pathology, microbiology, immunology, epidemiology etc. This will strengthen the proposal and increase the chances for funding.
- Possible funding agencies for research include LEPRA, TLM, ICMR etc.
- Combining leprosy with other neglected tropical disease research can increase the chances for funding.

- The capacities of Dermatologists should be strengthened to enable them to identify and manage leprosy. This can then lead to development of better atmosphere for research in leprosy in the Dermatology Departments.
- Dermatology department can collaborate with PSM department to carry out field based / community based research.
- Good research conducted by Dermatologists should impact national policy and lead to more dermatologists playing a key role in defining leprosy control strategy and policy.
- Dermatology departments in teaching hospitals should have a Research establishment in their department linked to one in the institution to facilitate capacity building and to provide specialized services like skin smears, biopsy etc
- For encouraging research incentives like career advancements may be considered.
- Dermatology Departments should have a sustained commitment to leprosy research as a departmental objective and not just adhoc or short term PG student dissertation project etc.
- Networking among Dermatology departments in the country is important for good research in ug surveillance, relapses, reactions, neuropathy, contact tracing etc.
- Collaboration and networking between IADVL and IAL as sister bodies can increase the reach and impact of leprosy research.