

Message from ILEP India Coordinator

Welcome to the first issue of ILEP India newsletter!

We intend to publish this newsletter every quarter. The purpose is to make you aware of the activities being done by the nine ILEP agencies jointly in India in partnership with the government and other development partners. We are working with the vision “An India free from Leprosy”. There is a lot of work for all of us to do for witnessing that day. Through this newsletter we also seek your feedback to strengthen our work.

This issue being the first one, has captured the key activities done by ILEP during different times of 2021. Next issue onwards, the focus will be the activities done during the last one quarter.

Hope you enjoy reading the newsletter.

Kindly share your feedback at feedback.ilep@nlrindia.org



DR. ASHOK AGARWAL

Introduction of ILEP

ILEP is a consortium of international non-governmental organisations with a shared desire to see a world free from leprosy, and an acknowledgment that none of us can achieve this on our own. Through the programmes of its Member associations, ILEP spans more than 60 countries and 1,000 project locations worldwide. Most of the global expertise in leprosy resides in ILEP’s Members and their in-country partners.

- **In the fight against leprosy, ILEP and its Members work with**
- People affected by leprosy
- Ministries of Health and other government departments
- Global Partnership for Zero Leprosy
- World Health Organization
- Other NGOs and civil society organisations
- Novartis (which provides anti-leprosy drugs for free)
- Philanthropic trusts
- Over 500,000 individuals

About ILEP India

ILEP members have been involved in India for many decades, as far back as the 1870s. Currently, nine ILEP members, with direct representation in India form the membership of ILEP India. Collectively, including contributions from other ILEP members, they invest approximately INR 61.3 crore for leprosy programmes in India each year. The members are:

- AIFO India
- American Leprosy Missions (ALM)
- Damien Foundation India Trust (DFIT)
- FAIRMED India
- Fontilles India
- GLRA India
- Lepra Society
- NLR India
- The Leprosy Mission Trust India (TLMTI)



ILEP India's presence

ILEP agencies are present in 13 states with high endemic districts

Priority Districts/States & Our Presence

States	No. of Priority Districts	ILEP Agency
Andhra Pradesh	8	LEPRA, DFIT, Fontilles, GLRA, FAIRMED
Bihar	23	DFIT, LEPRA, NLR
Chattisgarh	8	TLMTI, DFIT, LEPRA, GLRA
Delhi	2	LEPRA, NLR
Gujarat	5	Fontilles
Jharkhand	4	DFIT, LEPRA, NLR
Madhya Pradesh	4	LEPRA, Madhya Pradesh
Maharashtra	17	TLMTI, DFIT, GLRA
Odisha	13	LEPRA, Fontilles
Rajasthan	1	LEPRA, NLR
Tamil Nadu	2	GLRA, DFIT, FAIRMED
Uttar Pradesh	22	NLR
West Bengal	8	GLRA, NLR
Total	117	

Beyond these 13 states we are also present in 10 other states

AIFO : Karnataka, Meghalaya, Arunachal Pradesh & Assam

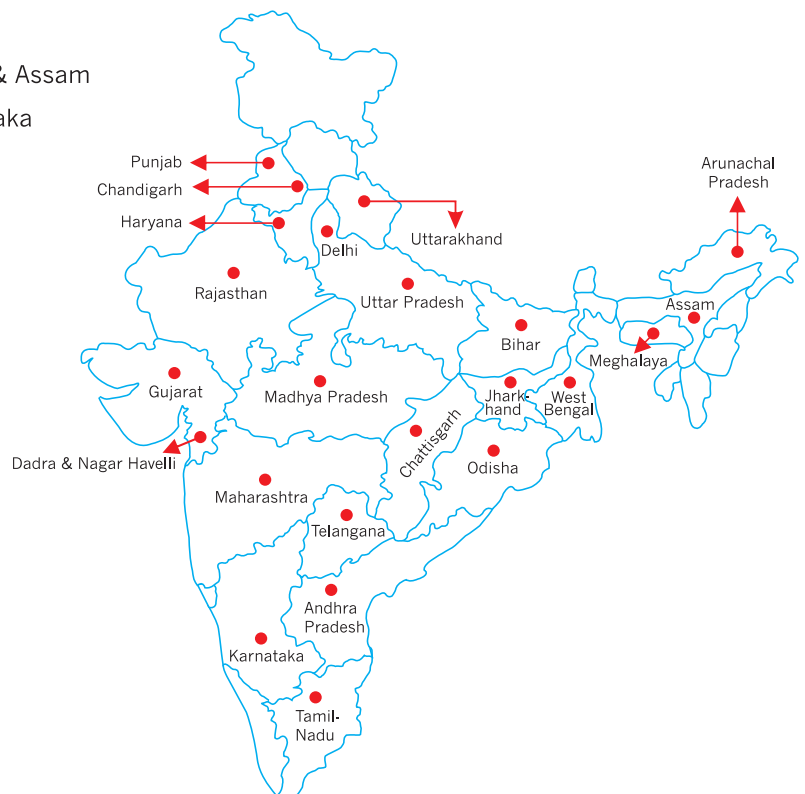
FAIRMED : Haryana, Punjab, Chandigarh & Karnataka

Fontilles : Karnataka, FAIRMED

GLRA : Dadra & Nagar Havelli

GLRA, Fontilles & LEPRA : Telangana

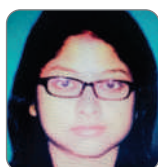
NLR : Uttarakhand



Key Activities done by ILEP India in 2021

1. Technical Assistance to the states by a team of National Leprosy Eradication Programme (NLEP) consultants

These consultants are employed by the ILEP agencies and placed in states requiring prioritized attention for achieving the mandate of NLEP. They made a total of 989 visits to district facilities, rural health facilities, tertiary health facilities and leprosy colonies. A total of 520 trainings were conducted including self-care, self-help groups, technical training for doctors/ medical officers and general health care (GHC) staff. A total of 390 meetings were conducted with State Leprosy Officers (SLOs), District Leprosy Officers (DLOs), and other state/ district level health authorities. The severe second wave of COVID did not deter them in executing their roles; rather they kept on providing the required support to the SLOs, DLOs and at sub-district levels remotely and physically (when possible) ensuring the leprosy programme kept on reaching to the leprosy affected with the essential services for leprosy, other health and survival needs.



Dr Arpita
(West Bengal)



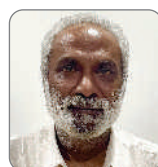
Mr Bijoy
(Chandigarh,
Haryana & Punjab)



Dr Chandramani
(Bihar &
Varanasi Zone
Uttar Pradesh)



Dr Gavish Kumar
(Jharkhand)



Dr Mani Moji
(North East &
Karnataka)



Dr S.N Pati
(Odisha)



Dr Sarbarta Ray
(Bihar)



**Dr Saroj Kant
Choudhary**
(Rajasthan &
Uttarakhand)



Dr Sarwat Naqvi
(Chhattisgarh &
Maharashtra)



Dr P.K. Mitra
(West Bengal)



Dr Brijesh Patwa
(Madhya Pradesh)



Dr Nishant Kumar
(Lucknow Zone,
Uttar Pradesh)



Dr S.P. Sood
(Delhi)

2. Mapping of reconstructive surgery (RCS) conducting and micro-cellular rubber (MCR) shoes manufacturing capacities of ILEP

ILEP has a combined capacity of conducting 3673 RCS annually and in the year April 20-March 21, we conducted 852; we are catering to 306 districts out of which 82 are high endemic. On MCR, we have an annual capacity of making 252,200 pairs of shoes; in the year April 20-March 21, we produced 60,809 pairs. And we are catering to 222 districts out of which 59 are high endemic. In our effort to strengthen the capacity of government districts hospitals, we developed a standard checklist for establishing RCS facility in a district hospital. The mapping information along with the contact details and the checklist was shared by the Central Leprosy Division (CLD) with all the states to help them in procurement of MCR shoes and seek assistance on RCS.



3. Assistance to CLD in tracking migrants

During the first and second waves of COVID, NLEP lost contact with a good number of migrants. It urgently wanted to reach out to them with the essential leprosy services e.g. the drugs for leprosy treatment (MDT) and management of lepra reactions. ILEP supported NLEP consultants and NLR Call Center project staff tracked 274 migrants. CLD informed the concerned states to reach out to them on a priority with the essential services.



Fairmed embarked on a three-year pilot project **“Migration in Leprosy Patients in India” in 2021**, to understand the impact of migration among people affected by leprosy and its consequences on treatment and other health seeking behaviour in 4 states namely Uttar Pradesh, Bihar, Delhi and Chandigarh. The project proposes to develop a 360-degree understanding of the issues and based on the understanding of the gaps which exist for leprosy patients who migrate, the project envisages to develop recommendations to address these gaps. Further, the project will develop a technology-enabled national-level management information system (MIS) framework for location-based tracking of the migrant leprosy patients and their households in India through the life cycle of the disease, which is compatible with NIKUSTH (government leprosy reporting system).

4. Monthly NLEP partners meeting

ILEP along with WHO coordinated with the key agencies involved in supporting the NLEP; besides the nine ILEP agencies and WHO, the others invited to the meeting were the Association of People Affected by Leprosy (APAL); Alert India; Bombay Leprosy Project; Indian Association of Dermatologists, Venerologists and Leprologists (IADVL); Indian Medical Association; and Sasakawa India Leprosy Foundation. During the year, the group discussed on the following topics to strengthen the NLEP: COVID emergency response, current status of leprosy services, making Leprosy a notifiable disease in India, and plan for developing the India zero leprosy roadmap.

5. Opinion papers developed

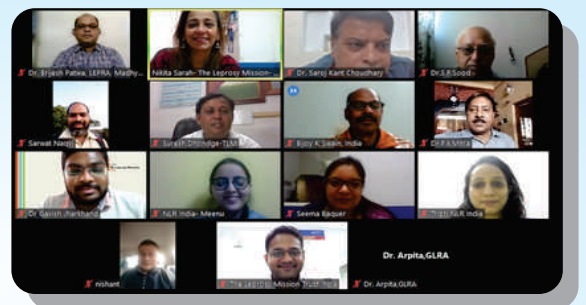
ILEP on request of the Central Leprosy Division (CLD) developed opinion papers on three important issues namely: 1] Central procurement for MCR, self-care kits, Rifampicin (SDR), Prednisolone. 2] Enrolment of ILEP agencies on GeM portal for MCR footwear and specifications to ensure quality; and 3] Making leprosy a notifiable disease.

6. Key concepts developed

ILEP in consultation with WHO developed concepts on the following topics: 1] District based model for Leprosy intervention, later it was adapted to develop the model intervention blocks project and implemented in 5 blocks per state (Chhattisgarh and Odisha) by WHO and partners; 2] Strengthen engagement of dermatologist for National Leprosy Eradication Programme (NLEP); and 3] Strengthen coordination between Leprosy stakeholders.

7. Capacity Building training of NLEP consultants

To strengthen ILEP contribution to the states, the NLEP consultants were trained for enhancing their skills in advocacy. This was one of the topics identified through training needs assessment. The training programme was designed and conducted by The Leprosy Mission Trust of India (TLMTI), one of the ILEP agencies. The topics covered were: What is Advocacy and people-centric advocacy; Rights and Entitlements and RPwD Act 2016; Understanding Accessibility; Stakeholder mapping; Legal Advocacy I Understand conventions, treaties and laws concerning leprosy; Building and mobilising communities to identify issues and champion the cause; and Understanding discrimination/ violation of human rights/ access to schemes and entitlements.





8. Organizing ILEP expertise

The nine ILEP India agencies have good amount of expertise on different aspects of leprosy e.g. technical, programmatic, monitoring, evaluation and research. For a more organized support to NLEP, ILEP India has put together the following three sub-groups of expertise:

Research

Members:

Dr. Aparna Srikantam and Mr. Rajni Kant Singh (Lepra), Mr. Shibu George and Dr. Debajit Sarkar (GLRA), Dr. Shyamala Anand (ALM), Dr. Ashish Wagh (DFIT) & Dr. Suchitra Lisam (NLR); Dr. Aparna Srikantam is the Lead

Data Analysis

Members:

Mr. Arun Kumar (Lepra), Dr Arpita Dey (GLRA), Dr. Shyamala Anand (ALM), Dr. Shivakumar (DFIT), Mr Amit Jain (NLR); Mr. Arun Kumar is the Lead

Communication & Advocacy

Members:

Ms. Nikita Sarah and Mr Subhojit Goswami (TLMTI), Ms. Kasturi (Lepra), Ms. Sushmita Yadav (GLRA), Mr. Camillus Rajkumar (DFIT), Mr. Aakash Arun (FAIRMED) & Ms Meenu Sharma (NLR), Ms. Nikita Sarah is the Lead



UPCOMING EVENTS

