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NEWSLETTER

MESSAGE FROM ILEP INDIA COORDINATOR



Dr. Srilekha Penna

Dear readers,

Welcome to the 13th edition of the ILEP India Newsletter! This edition provides a comprehensive overview of our activities, progress, and strategic initiatives for the October to December 2024 quarter.

Our commitment to achieving Zero Leprosy continues through strengthened coordination among ILEP Members and with the other Stakeholders. This edition provides an overview of the impactful initiatives undertaken by our member organizations, including training workshops and community-focused programs. Key highlights include the ILEP India CEO Meet, capacity-building and targeted contact tracing efforts through LCDC in Madhya Pradesh, community empowerment through traditional healer sensitization, insights into Inclusive India Summit, Dissemination of findings from Leprosy and Migration Study, Skin Health Camp in West Bengal, State Review Meeting in Haryana and many others. These efforts reaffirm our steadfast dedication to improving lives and accelerating the efforts to achieve Zero Leprosy.

I extend my sincere thanks to all ILEP members, NLEP consultants, and our partners in India and globally for their unwavering commitment.

Key activities and participation by ILEP India and Member Organizations:

1 ILEP India CEO Meeting 2024: Strategic Review and Planning for 2025

- The ILEP India CEO 4-monthly Meeting was organized in Hybrid mode on 12th December 2024 at Hotel Aditya Park, Hyderabad which brought together CEOs of ILEP India member organizations to discuss key activities carried out from January to December 2024.
- The ILEP India Coordinator presented updates on progress towards the ILEP India action plan for 2024, budget updates, and the ILEP Good Practices document.



- The meeting also aimed to propose and discuss the activity plan and budget for 2025, ensuring alignment and strategic planning for the upcoming year. The session facilitated updates and in-depth discussions on ongoing initiatives and future goals to guide ILEP India's efforts in the coming year.
- The session concluded with a summary of suggestions, action points, and commitments for the year 2025, emphasizing the need for strengthened coordination among ILEP members and other stakeholders.

2 Strengthening Leprosy Care Support in Delhi

- NLR India's team visited the Nav Jyoti Association Leprosy Colony in Piragarhi and engaged with residents to understand their challenges and distributed iron and calcium tablets to females aged between 15 - 60 years. Moreover, Ms. Jaya from Lok Mata Kushth Ashram, interacted with NLR India leaders, showcasing the resilience and entrepreneurial efforts of people affected by leprosy.



- NLR India organized a self-care camp at Jagat Mata Kushth Ashram, Tilak Nagar, attended by 12 residents, providing essential supplies like tubs, scrubbers, mustard oil, and creams. The camp was attended by key figures, including NLR International guests Ms. Linda Hummel and Mr. Hans, along with Dr. Ashok Agarwal, Dr. Pravin Kumar, and Ms. Urmila Kumari.



- Visits to TLM Hospital, Hindu Rao Hospital, and Lal Bahadur Shastri Hospital highlighted the diligent record-keeping by NLEP staff and the timely, effective care provided to people affected by leprosy from Delhi and neighbouring areas, including consistent follow-up for comprehensive management.
- The team including SPL Dr. Neha Singh, Colony Coordinator Ms. Urmila Kumari, and Mental Health Officer Mr. Rohit Kumar, facilitated the registration of colony residents for UDID cards across 6 leprosy colonies in Delhi. Additionally, donated items such as clothes, diapers, rations, nutritional supplements, and toys were distributed among the residents.
- A camp organized by the Delhi State Leprosy Office was held in three locations within the Shahdara Leprosy Colony, where NLR India participated, providing essential support to ensure the camp's success.



3 Inclusive India Summit 2024: Advancing Leprosy Elimination, Rights of Persons with Disabilities, and improved access to disability management services

- The Leprosy Mission Trust India (TLMTI) hosted the first edition of the Inclusive India Summit on November 14, 2024.
- The event brought together diverse stakeholders from healthcare, technology, public policy, grassroots organizations, and media to exchange knowledge on cross-cutting sectors—leprosy, social determinants of health, disability inclusion, and technology.
- Three panel discussions focused on a) the role of social determinants in leprosy elimination, b) the rights of persons with disabilities, and c) access to disability management services.
- The discussions led to the emergence of key ideas, including the involvement of communities in disease elimination strategy, looking at leprosy not just as a medical problem but also as a socio-economic problem as well, removing the institutional and attitudinal barrier for persons with disabilities (PWDs) to enable them access to a life of dignity.
- There were also suggestions for involving persons with lived experiences of disability in drafting policies meant for them and creating an ecosystem where innovators and NGOs working with PWDs can come together to co-create solutions



4 Empowering LCDC Impact through Capacity Building and Targeted Contact Tracing: Insights from Purulia district in West Bengal

- NLR India Foundation conducted two rounds of LCDC training for Public Health Nurses (PHN) and Para Medical Workers (PMW) in one group, and Medical Officers (MO) in another, complementing state-led efforts. The training focused on leadership, team building, LCDC preparedness, performance monitoring, daily reporting review, quality screening, and organizing camps in high-risk areas.

- The training emphasized enhanced contact tracing for the last 10 years and improved efficiency in referral systems, with a strong focus on high-risk zones surrounding old cases.
- Purulia district showed a remarkable 40.9% increase in suspect examination rates and a 24.0% rise in case detection rates per 10,000 population in 2024 compared to 2023.
- The combined efforts of capacity building and targeted interventions improved screening quality and enabled more effective organization of referral camps in areas with a high disease burden.



5 Integrated Skin Health Camp Highlights: Kantatala, South 24 Parganas, West Bengal

- GLRA India organized a Skin health camp at Kantatala FP School in Bhangor-2 block, South 24 Parganas district, West Bengal, in collaboration with the Health Department. The initiative aimed to address healthcare access challenges and undetected leprosy cases in this remote area.
- The campsite was chosen to improve access for villages with limited connectivity. Frontline workers, including Accredited Social Health Activist (ASHA) and Anganwadi Worker (AWW) conducted door-to-door awareness drives and public announcements using auto-rickshaws to ensure mass participation.
- A team of healthcare professionals, including Dy. CMOH-2, Doctors, Public Health Nurses (PHN), Community Health Officers (CHOs), Auxiliary Nurse Midwife (ANM), Accredited Social Health Activist (ASHA), a pharmacist, and GLRA India staff, provided screenings for skin conditions, blood pressure, and blood sugar levels, along with medicines based on individual needs.
- The camp witnessed a participation of 154 individuals, including 85 women, with the remaining attendees, offered free health screenings and medicines, promoting participation and reduce the stigma associated with leprosy.





6 Two-Day Strategic Review of Haryana's Leprosy Eradication Programme

- A two-day District NLEP review meeting, organized in collaboration with Swiss Emmaus Leprosy Relief Work India, was held at Sona Hospitality Hotel, Haryana, with District Leprosy Officers from 22 districts. Dr. Parvinder Jit Singh, State Leprosy Officer of Haryana, emphasized the need for District Strategic Plans aligned with the State Plan, while Mr. Bijoy Kumar Swain presented the National Strategic Plan & Roadmap 2027, providing districts with a template to develop their local plans.
- Districts reported challenges in following SDR guidelines, particularly with lower intake levels and issues related to migratory populations, prompting a suggestion for localized health camps for better outreach. All districts received master trainer training on Skin Smear Testing, with 185 tests conducted and local lab technicians trained. Collaboration with district RBSK and RKSK programs was emphasized to improve early identification and referral of leprosy suspects.
- It was recommended that each district prepare a line list of all released-from-treatment (RFT) patients (last 5 years for MB and 3 years for PB cases) and develop an action plan for regular follow-up every six months to ensure continued care and support.



7 Capacity building initiatives in Madhya Pradesh under Project NIRAMAYA-III

- Madhya Pradesh's Leprosy Eradication Program has been upfront in enhancing disease control, prevention, and management measures through various approaches highlighted in the National Strategic Plan.
- Supporting the state leprosy program, GLRA has taken up the initiative for sensitizing and building the capacity of various key stakeholders to strengthen the referral system in the Indore region of the state.
- Over the quarter, under Project NIRAMAYA III, GLRA India's team sensitized and trained 96 Community health officers, 70 paramedical students, Accredited Social Health Activist (ASHA) workers, and members of 4 panchayat raj institutions (PRI) on leprosy.
- In collaboration with the state and LEPRA Society, the team organized Nikusth 2.0 Training for Eight districts of the Indore Division where 24 Districty Leprosy Officers (DLOs) and Data operators (DO) participated.
- Further under the initiative "**Empowering Communities: Traditional Healers' Sensitization Initiative**," the team has sensitized a batch of 20 traditional healers in the Barwani district of Madhya Pradesh who in return refer people with suspected skin patches to the nearest health facilities



8 The Leprosy Mission Marks 150 Years: A Legacy of Service and a Vision for the Future

- The Leprosy Mission observed 150 years of its service across all its units in India and the world, engaging with local, state-level, and national stakeholders to share the vision for the future and relive the journey so far.
- TLM also took this opportunity to create large-scale awareness of leprosy through targeted and sustained campaigns, especially in Uttar Pradesh. The campaign culminated with a mega health camp, **Mohalle Ka Mela** (Neighbourhood Fair) to attract people of all ages. Through games and magic shows, informed the audience about the signs and symptoms of leprosy, the importance of early diagnosis, and ways to prevent disability. Screened over 300 people and 700+ people turned up at the event.

- The Union Health Minister, Shri J P Nadda, extended his greetings and encouraged the organization to continue to serve people affected by leprosy and work towards disease elimination.
- Global team members had gathered for a celebratory evening and the launch of the new global strategy of The Leprosy Mission for accelerating the progress towards leprosy elimination.



9 Addressing Leprosy and Migration in India: Insights from the study dissemination

- Swiss Emmaus Leprosy Relief Work India held a dissemination meeting for the Leprosy and Migration Study on December 12, 2024, at Hotel Aditya Park, Hyderabad. The event brought together stakeholders, including state leprosy officers, experts, people affected by leprosy, ILEP agency leaders, and research teams to share findings and discuss actionable insights.
- The study engaged 396 individuals affected by leprosy (69% response rate), along with 236 household members, 35 frontline workers, and 35 Panchayati Raj Institution (PRI) members. It also included inputs from defaulters, released-from-treatment patients, health professionals, NLEP consultants, and ILEP partners, ensuring a well-rounded understanding of the challenges.
- Of the respondents, 76% were married, 77% lived with their spouse, and 43% were sole earners in their households. Alarming, 17% had Grade 1 Disability (G1D) and 20% had Grade 2 Disability (G2D), emphasizing the need for better healthcare access and awareness.
- The study revealed significant migration patterns, with patients traveling an average of 368 km from Uttar Pradesh and 1,289 km from Bihar to Delhi for treatment. Better employment opportunities and healthcare access were key migration drivers. Women predominantly migrated due to the breadwinner's relocation.



- A major finding was that 64% of respondents were unaware of leprosy diagnosis points, and while 58% recognized symptoms in their source state, 93% were only diagnosed at their destination, highlighting critical gaps in early detection and treatment pathways

10 Reach of integrated approaches through key interventions across various high endemic states

- Over the quarter, Lepira Society has taken up various initiatives across different states in India to improve integrated quality care and services for persons affected by Leprosy and Lymphatic Filariasis (LF).
- LEPRAs Jagruti Bihar Project Phase 2.0 established 130 Self-Support Groups (SSGs) to empower individuals with leprosy and Lymphatic Filariasis (LF) disabilities, focusing on self-care, advocacy, and sustainable livelihoods.



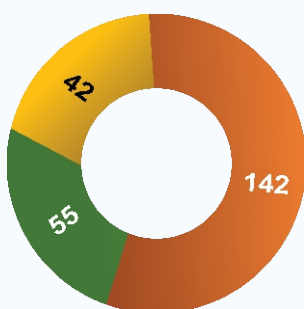
- Madhya Pradesh conducted Leprosy Case Detection Campaign (LCDC) in December, across 21 selected districts. As part of this campaign, training sessions and supervisory visits were organized by the state in the respective districts. Mr. Naveen Satle, Mr. Satish Choudhary from Lepira India, Dr. Vishal Dessai from GLRA-India, and Dr. Abdullah participated in the training and monitoring team for the LCDC.
- Lepira's school awareness programs in Odisha, Andhra Pradesh, and Telangana promoted early detection of leprosy and Lymphatic Filariasis (LF). Accredited Social Health Activist (ASHA) and community leaders in Bihar, Jharkhand, and Odisha received training for improved detection and treatment.

- Further, Integrated NTD clinics in Bihar, Odisha, Andhra Pradesh, and Maharashtra provided foot hygiene education, hydrocele surgery referrals, and custom footwear. Reconstructive surgeries in Madhya Pradesh and Andhra Pradesh improved mobility, while self-care camps in Odisha, Telangana, and Chhattisgarh promoted independence and improved quality of life for individuals affected by leprosy and Lymphatic Filariasis (LF)



From October to December 2024

■ Visits
 ■ Trainings
 ■ Meetings



The NLEP consultants routinely visit the health care facilities, organize self-care camps, assist district and state leprosy officers, train the self-help groups, monitor the drug availability in the districts, and assist in active case detection activities. During this period, the state and district-level program was supported through **55 advocacy and program implementation meetings; 42 trainings; and 142 visits** to the districts, different health facilities, and leprosy colonies.

55

Advocacy and program implementation meetings

42

Trainings

142

Visits to the districts, different health facilities, and leprosy colonies