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HIGHLIGHTS

MESSAGE FROM ILEP INDIA COORDINATOR



Dr. Srilekha Penna

Dear readers,

Welcome to the 15th edition of the ILEP India Highlights! This edition provides a comprehensive overview of our activities, progress, and strategic initiatives for the April to June 2025 quarter.

Our commitment to achieving Zero Leprosy continues through strengthened collaboration among ILEP members and key stakeholders. This edition highlights the impactful initiatives led by our member organizations, ranging from innovations and review meetings to workshops and research and capacity-building efforts. Key highlights include - Leprosy being declared a Notifiable disease, ILEP-NLEP Consultant Workshop, the ILEP India CEO Meeting, the showcase of assistive aids at TECH4ALL, the development of a Strategic Communication Roadmap for Leprosy Awareness, an inspiring story of resilience, and several other meaningful contributions. These efforts reinforce our strong commitment to improving lives and advancing the goal of achieving Zero Leprosy.

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

Key activities and participation by ILEP India and Member Organizations

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

- The ILEP India CEO 4-monthly meeting was organized in person, on 2nd May 2025 at The Leprosy Mission Trust India office, New Delhi, which brought together CEOs of ILEP India member organizations and key program stakeholders, including Dr. Sunil V Gitte (DDG – Leprosy, Central Leprosy Division) and Dr. Rashmi Shukla (NPO – WHO India) to discuss key activities carried out from January to April 2025.
- The ILEP India Coordinator presented ILEP India's presence and contributions to the key officials and further outlined the progress on the 2025 activity plan, including key activities, program priorities, ongoing challenges, potential stakeholder contributions, and strategies to strengthen partnerships.
- Mr. Arun Kumar, Programme Head (LEPRA Society), presented the ILEP India Dashboard, highlighting indicator-wise progress under all NSP pillars. Additionally, the ILEP India Deputy

Coordinator shared updates on the ILEP India website and showcased a prototype of ILEP India's dynamic map with consolidated information.

- The meeting concluded with a comprehensive summary of recommendations, action points, and commitments for 2025, underscoring the importance of strengthened coordination between ILEP India and its key partners.



2 ILEP NLEP Consultant Workshop: Enhancing the strategic focus and Programmatic Synergy:

- ILEP India organized the **ILEP-NLEP Consultant Workshop** on 3rd May 2025 at the Metropolitan Hotel, New Delhi, which was attended by ILEP-NLEP Consultants, ILEP India CEOs, and key government stakeholders, including Dr. Lily Gangmei (CMO, Central Leprosy Division), Dr. V. Santaram (CMO [SAG], RLTRI Aska), and Dr. Rashmi Shukla (NPO – WHO, India).

- The workshop aimed to enhance the quality of field visits, field-level challenges, monitoring, strengthening the understanding of key programmatic components, and strengthening stakeholder partnerships to support effective program implementation.



- Key sessions during the workshop included a presentation on program priorities for 2025–26 as per the NSP and an overview on LEMT by Dr. Rashmi Shukla, a session on strengthening field activities through monitoring visits by Dr. Shivakumar (Secretary, Damien Foundation India Trust), and a session on field-based clinical examination and case validation by Dr. V. Santaram.
- The workshop reinforced the importance of collaboration, knowledge sharing, and aligning the program priorities with the National Strategic Plan (NSP) and the Roadmap for Leprosy (2023–2027).



3 Fostering Learning and Knowledge Exchange: ILEP India Knowledge Sharing Series to strengthen the efforts:

- ILEP India has conducted three Knowledge Sharing Sessions on 22nd April, 23rd May, and 20th June 2025 to strengthen the efforts towards zero leprosy.
- A session on **“Bridging Gaps in Leprosy Care: Field Realities and Lessons from District Visits”** led by Dr. D. Santhi Priyadarshini, ILEP-NLEP Consultant, Andhra Pradesh, highlighted valuable field-level insights, capturing both systemic challenges and inspiring grassroots solutions observed on the ground.
- Another session on **“Collaborative efforts among NLEP, NTEP, and the Rogi Sahayata Kendra for MDT adherence”** led by Dr. Arup Chakrabartty, SPL and ILEP-NLEP Consultant, West Bengal, emphasizes that the Bankura model exemplifies a collaborative, system-strengthening approach that integrates the efforts of NLEP, NTEP, and RSKs to enhance the delivery of leprosy and TB care. By leveraging existing frontline health infrastructure, the model improves treatment adherence, patient satisfaction, and program coordination.
- Another key session on **“Orthotic Management in Leprosy”** led by Mr. Bijoy Kumar Swain, ILEP NLEP Consultant, Haryana and Chandigarh, highlighted the importance of Orthotics, which plays a vital role in the management of leprosy-related disabilities by providing mechanical correction of orthopaedic deformities, facilitating realignment and redirection of the body’s lines of force, supporting weakened structures, preventing undesirable movements, and offloading pressure from affected areas to prevent further damage.

Bridging Gaps in Leprosy Care: Field realities and Lessons from District Visits

Presented by
Dr. D. Santhi Priyadarshini
NLEP Consultant, Andhra Pradesh

Steps which can make a real difference

Expected Output:

- 100% participation in pre- and post test
- Improved post test scores by at least 30-50%
- Practical skills demonstrated confidently in DPHs and VHTs
- Increased understanding of empathetic patient handling through real world case demos

Expected Impact:

- Increased patient confidence in health workers
- Improved patient adherence to treatment
- Reduced disability due to leprosy
- Improved patient adherence to treatment
- Improved patient adherence to treatment

Collaborative efforts among NLEP, NTEP, and the Rogi Sahayata Kendra for MDT adherence

Bankura, West Bengal

Dr. Arup Chakrabarty, SPL, NLR India Foundation

until
No Leprosy Remains

Collaborative efforts NLEP-NTEP-Rogi Sayayata Kendras

- This collaborative model unites NLEP, NTEP, and RSKs.
- Officially launched in July 2024, the initiative was facilitated by the Chief Medical Officer of Health (CMOH), Dy CMOs, District TB Officer (DTO), District Leprosy Officer (DLO) & SPL, NLR India (West Bengal)

Orthotic Management in Leprosy

By
Mr. Bijoy Kumar Swain,
NLEP Consultant for Haryana & Chandigarh
Swiss Emmaus India

The orthoses used for conditions in Leprosy in Lower limb

Foot Ulcer Pressure relieving Insole Pressure relieving orthosis Modified shoe

4 Transforming Lives Through Technology: Assistive Aids Featured at TECH4ALL 2025 in Chennai:

- The Leprosy Mission Trust India (TLMTI) showcased innovative assistive aids, including protective footwear, at TECH4ALL 2025 during an event held from June 12–13 in Chennai, organized by the Commissionerate for the Welfare of the Differently Abled, Government of Tamil Nadu.
- Mrs. M. Lakshmi, IAS (Commissioner) and Mrs. S. Madhumathi, IAS (Secretary) from the Welfare of the Differently Abled Department, Tamil Nadu, interacted with the TLMTI team and took a keen interest in the assistive devices on display.



- Furthermore, the event featured live demonstrations of assistive products, notably 3D-printed prosthetics and orthotics, drawing significant interest from attendees.

5 NLR India Foundation Celebrates 26th Foundation Day:

- On 23rd April, NLR India Foundation marked its 26th Foundation Day, reaffirming its dedication to leprosy care and rehabilitation under the theme “**End Leprosy, End Suffering.**”
- The event featured esteemed guests, including Chief Guest Shri Rajesh Aggarwal, Secretary, Department of Empowerment of Persons with Disabilities, Mr. Justice V. Ramasubramanian, Chairman, National Human Rights Commission, Ms. Rupa Jha, CEO & Co-Founder of Collective Newsroom, Mr. Subhashish Nath, Head, Account Services, Indian Railways, Dr. Anil Kumar, Principal Advisor, NCDC, Dr. Rashmi Shukla, NPO Leprosy, WHO, Dr. Viswa Mohan Katoch, President of JIPMER and Chair of NLR India’s Research Advisory Committee, Ms. Nirmala Gupta, Chair of the NLR India Board and Dr. Ashok Agarwal, CEO of NLR India Foundation, underscored the urgent need to eliminate leprosy-related stigma, ensure legal reforms, and enhance ground-level action through surveys, skill training, and strong technical support.
- The event launched a “**Call to Action**” aligned with India’s leprosy elimination plan for 2027. It also paid tribute to Dr. Pawan Aggarwal, honoured as the “**Champion of NLR**” for his unwavering dedication in providing free reconstructive surgeries to over 400 individuals affected by leprosy, restoring hope and dignity to their lives.



6 Leprosy Cascade Care under Ayushman Arogya Mandir:

- To strengthen Comprehensive Primary Health Care (CPHC) through Ayushman Arogya Mandir (AAM), Community Health Officers (CHOs) have been deployed as a key frontline workforce to deliver a holistic range of services, including preventive, promotive, curative, rehabilitative, and palliative care, covering both communicable and non-communicable diseases.
- In alignment with this initiative, **GLRA India** conducted capacity-building sessions for Community Health Officers (CHOs) across two districts of Madhya Pradesh, Barwani and Khargone.
- A total of 101 CHOs participated in the training, with a focus on **Prevention, Promotion, and Prompt Treatment (PPP)**, aimed to strengthen an integrated approach to the cascade of leprosy care services at the grassroots level, focusing on early case detection and ensuring treatment adherence to contribute significantly toward achieving zero transmission.



7 Strategic Communication Roadmap for Leprosy Awareness in Chhattisgarh, India:

- **Swiss Emmaus Leprosy Relief Work India** conducted a communication needs assessment (CNA) in Raipur and Durg (Chhattisgarh) to identify leprosy awareness gaps among youth.
- The assessment, conducted through Focus Group Discussions (FGDs) and In-Depth Interviews with diverse stakeholders such as health officials, leprosy relief associations, community members, daily labourers, housewives, students, religious leaders, and medical staff, aiming to develop Information, Education, and Communication (IEC) materials to promote health-seeking behaviour, facilitate early diagnosis and treatment, reduce stigma, and address community-level barriers.
- The findings revealed major knowledge gaps and misconceptions about leprosy, especially regarding its transmission and treatment. Many were unaware that leprosy is treatable with MDT, leading to delayed care. Stigma, fear of side effects, and gender-based concerns like exclusion and marriage prospects affected treatment adherence. Men were more active in sharing health information. Access to care was further hindered by financial constraints, accessibility challenges, and reliance on private practitioners.

- To bridge the gaps, a culturally sensitive integrated strategy, combining traditional methods (street plays, folk performances like Nachha and Pandvani, loudspeakers, storytelling), and digital platforms (YouTube, Instagram, WhatsApp) for youth engagement is the key. Moreover, engaging local leaders and using simple, localized content in the Chhattisgarhi language in Hindi script can reduce stigma, correct misconceptions, and promote timely health-seeking behaviour across diverse communities.



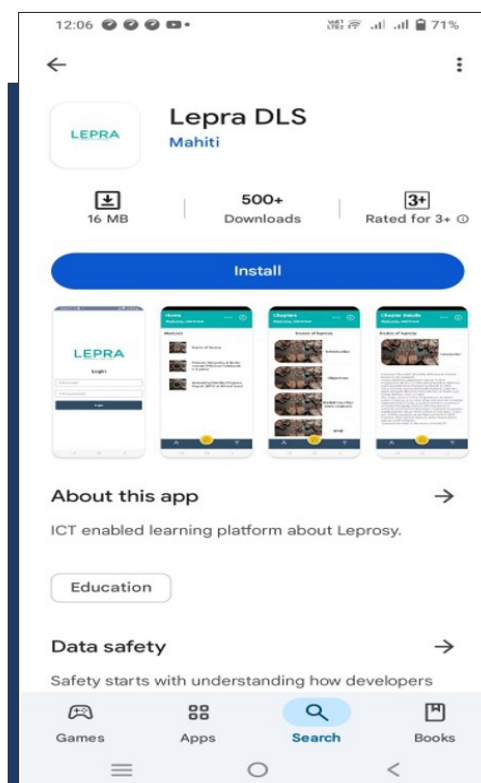
8 Empowering Communities, Eliminating Leprosy: The SHG Model

- Self-Help Groups (SHGs) are community associations formed to improve living conditions and empower women through collective action. Originating in the 1970s with the Self-Employed Women's Association (SEWA), SHGs gained institutional support in the 1990s through the National Bank for Agriculture and Rural Development (NABARD) and Swarn Jayanti Gram Swarozgar Yojana (SGSY).
- Later, in 2011, the National Rural Livelihood Mission (NRLM) and in 2013, the National Urban Livelihood Mission (NULM) further strengthened SHGs to promote sustainable livelihoods and financial inclusion.
- **GLRA India**, through its Project **NIRAMAYA-III**, collaborated with the District Livelihood Mission in Barwani, Madhya Pradesh, to integrate leprosy sensitization into SHG activities. Since January 2025, under the leadership of the District Leprosy Officer and District Livelihood Mission Manager, 4 orientation sessions have been conducted across urban and rural Barwani, engaging over **400 SHG members** to raise awareness on leprosy and promote community-led support for women affected with leprosy.



9 Impact of NIKUSTH Data Strengthening Project, Telangana, India:

- NIKUSTH is a web-enabled patient tracking system under India's National Leprosy Eradication Programme (NLEP) that ensures centralized data management for effective monitoring.
- Despite NIKUSTH's nationwide rollout in 2016, Telangana recorded less than 15% of new leprosy cases during the year 2020–21. To address this, the Telangana State NLEP Office, in collaboration with **LEPRA Society** and **Hope Rises International**, launched a two-year Data Strengthening Project (2023–2025) to enhance the completeness, timeliness, and accuracy of patient data entry across all 33 districts.
- The initiative was implemented in phases, beginning with State-level ToTs conducted by the NLEP team and LEPRA Society. Trained 272 Data Entry Operators (including District Data Managers), 77 NLEP staff, and 127 administrative personnel on leprosy basics, NIKUSTH 2.0 data entry, and report generation. These master trainers then led district-level sessions for 533 Nodal Persons from 594 functional PHCs. Moreover, to reinforce learning and enable real-time data support, a digital learning mobile app was also piloted alongside the in-person trainings across the state.
- As a result of the initiative, data entry completeness in NIKUSTH improved from 54.3% (1,394 of 2,951) of newly detected cases were entered into NIKUSTH in 2022–23; this improved significantly to 78.8% (1,874 of 2,376) by 2024–25, a 74% increase in data entry completeness within two years. Additionally, over 85% of mobile app users stated that it improved their accuracy in data entry.



10 The Leprosy Mission Shahdara Hospital and Rotary International Launch Active Case-Finding Initiative in Delhi :

- The Leprosy Mission Shahdara Hospital has signed a Memorandum of Understanding (MoU) with Rotary International to implement an **Active Leprosy Case Detection Project** in Delhi. This partnership aims to enhance early detection and treatment of leprosy cases in underserved communities, in alignment with the broader goals of eliminating leprosy.
- As a part of this partnership, TLM hospital conducted a leprosy screening camp in collaboration with the District Leprosy Office Central Zone at a children's home in Tis Hazari (Northeast Delhi), which is run by the Delhi Metro Rail Corporation.

- Out of the 63 children screened during the camp, 13 were identified as suspected cases of leprosy, and 2 were subsequently confirmed. The camp was attended by Delhi's State Leprosy Officer, Dr Shintoo Doomra, along with representatives from the Rotary Club of Delhi South.



11 NIRAMAYA III Annual Review Meet 2025: Strengthening Leprosy Referral Services:

- **GLRA India** has successfully conducted the first Annual Review Meeting of the NIRAMAYA-III project from 22nd to 24th May 2025 in Yercaud, Tamil Nadu. The event brought together 20 participants from 11 implementation sites, including representatives from the State Coordination Unit, partner hospitals, and the Urban Leprosy Programme across nine high-burden urban centres.
- Participants shared insights highlighting the testimonials, field challenges, and breakthroughs. Key discussions focused on active case detection through early diagnosis, contact surveys, skin camps, strengthening the hospital service, and timely treatment.
- The meeting featured Ms. Constanze Vettel, Inclusion and Development Advisor, and Dr. Felicitas Schwermann, Global Health Advisor from DAHW Germany, who interacted closely with teams to understand field realities, key challenges in urban leprosy control, delayed health-seeking behaviour, counselling gaps, and complexities within urban slum settings.



- Furthermore, they facilitated a session that encouraged cross-learning on hospital-specific strategies for diagnosis, treatment, data management, and service coordination.

12 A Journey of Hope and Resilience: Mrs. Gita Bai Patel's Story:

- Mrs. Gita Bai Patel, a 55-year-old resident of a village in Kharsia block, Raigarh District, began experiencing tingling sensations and weakness in her right hand about a year ago. Initially unaware of the underlying cause, she sought treatment from a private practitioner for nearly five months. Unfortunately, her condition gradually worsened, eventually leading to the development of a claw hand. She was then referred to the Civil Hospital in Kharsia, where she was diagnosed with Multibacillary (MB) Leprosy accompanied by Silent Neuritis. Upon diagnosis, she was immediately started on treatment.
- During a community field visit, a social worker from **Damien Foundation India Trust (DFIT)**, accompanied by DNT staff, visited Mrs. Patel at her home. They further provided guidance on self-care, including demonstrations of daily routines and passive exercises to support her recovery. Additionally, counselling sessions were conducted to help her better understand her condition and emphasize the importance of consistent, long-term care.
- By the end of the treatment, Mrs. Gita Bai Patel showed significant improvement, as her muscle function was fully restored, and she is now free from disability. She has confidently resumed her role as a homemaker and is now living a healthy and dignified life with her family.



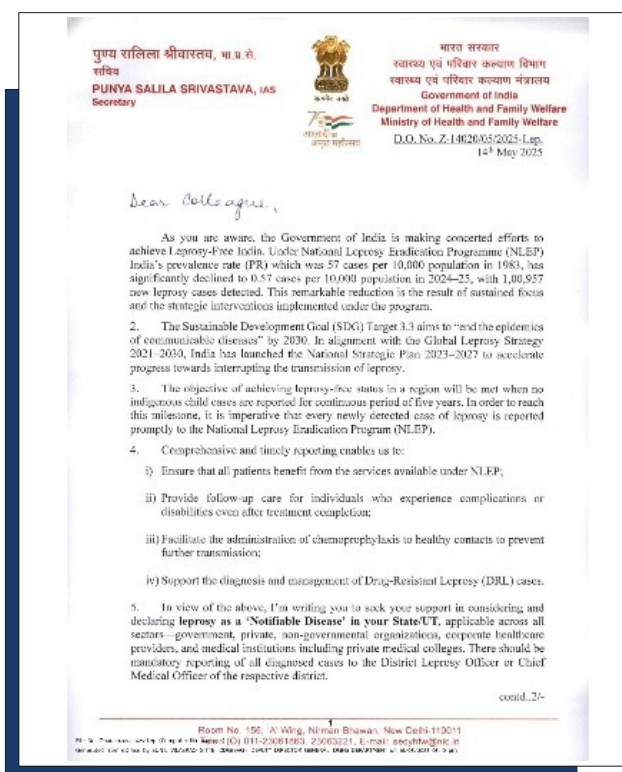
Before



After

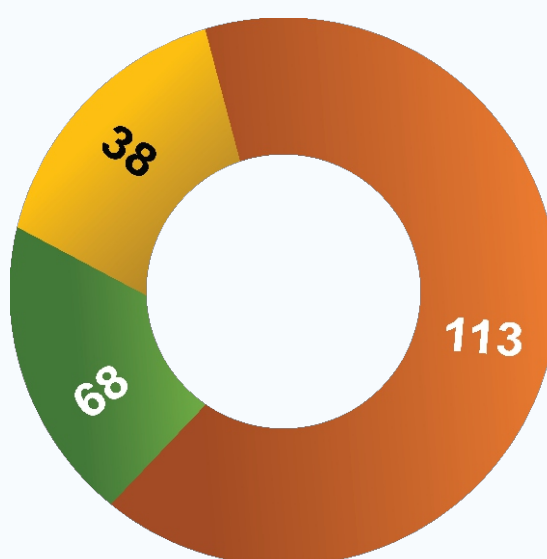
13 Leprosy Declared a Notifiable Disease under National Leprosy Eradication Programme (NLEP):

- Leprosy has been declared a notifiable disease under the National Leprosy Eradication Programme (NLEP), mandating that all diagnosed cases must be reported to local health authorities to ensure early case detection, timely treatment, and strengthened surveillance to prevent disability, curbing transmission, and progressing towards achieving Interruption of Transmission.



From April to June 2025

Visits Trainings Meetings



14 ILEP NLEP consultants supported the strengthening of the National Leprosy Eradication Program (NLEP) across 14 endemic states. During this quarter, they conducted 113 field visits to health facilities and leprosy colonies, ensuring effective implementation and monitoring of NLEP activities.

In addition, 68 meetings were held to support advocacy and coordination at state and district levels, and 38 trainings were conducted to build the capacity of health staff and frontline workers. These efforts contributed significantly to improving case detection, service delivery, and program outcomes.

113

Field visit

38

Training

68

Meeting