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NEWSLETTER

MESSAGE FROM ILEP INDIA COORDINATOR



Dr. Srilekha Penna

Dear readers,

Welcome to the 11th edition of the ILEP India Newsletter! In this edition, we present a comprehensive roundup of the endeavours achieved during the second quarter of 2024.

From the impactful visits by Mr. Geoff Warne, CEO of the ILEP Federation, to the insightful discussions at the ILEP India CEO Meeting and the Regional COR-NTD Meeting for South-East Asia, each event underscored our collective commitment to implementing effective strategies in the fight against leprosy.

Notably, our engagement extended beyond conventional settings with the expansion of our Knowledge Sharing Series to all key stakeholders in leprosy, enhancing our dedication to fostering inclusive dialogue with thought-provoking sessions.

This edition gives more insights into the celebration of NLR India's 25th-year Foundation Day, the exemplary efforts of our member organizations like DFIT, Swiss Emmaus Leprosy Relief Work India (SEI), GLRA India, and NLR India, whose innovative approaches and unwavering dedication continue to drive progress in leprosy awareness, management, and rehabilitation across different regions. The edition also gives you an insight into the collective efforts of our ILEP-NLEP consultants in this quarter.

I hope you find this edition insightful and engaging!

Key activities and participation by ILEP India and member organizations

1 Strengthening partnerships and GLRA India project visits along with CEO, ILEP Federation

- Mr. Geoff Warne, CEO of the ILEP Federation visited India in April 2024 and participated in various Leprosy and NTD-related meetings and activities across the country.
- He took part in various key stakeholder meetings organized by the ILEP India secretariat including meetings with the Joint Secretary (Leprosy) and Chief Medical Officer (Leprosy) at the Ministry of Health and Family Welfare, Govt. of India, Director of the National Institute of Public

Health Training and Research (NIPHTR), State Leprosy Officer of Telangana, Global Medical Affairs Director, Novartis, Director of Bombay Leprosy Project to discuss the current local and global initiatives in Leprosy and ways to strengthen collaborative efforts.



Meeting with Dr. John Babu, SLO, Telangana



Different pads, insole and ulcer cap at Sivananda Rehabilitation Home, Hyderabad



CEO, ILEP Federation and ILEP India Coordinator visiting the facilities



CEO, ILEP Federation with Director, Bombay Leprosy Project

- Mr. Warne also visited GLRA India's leprosy project sites together with Dr. Srilekha Penna, ILEP India Coordinator and Regional Research Coordinator, GLRA India to gather insights into their work in Leprosy in high-priority states and districts.
- Visits were made to Sivananda Rehabilitation Home (SRH), Hyderabad, Vimala Dermatological Centre, Mumbai, and Dayanand Hospital, Palghar along with outreach skin clinics in tribal villages of Talasari which are supported by GLRA India.
- Various insights were exchanged by the medical and paramedical teams on their innovative efforts to manage leprosy in the hospitals. The team further interacted with persons affected by leprosy in the local communities who shared their success stories of overcoming stigma and discrimination and are now leading a life with confidence.

2 Participation in the Regional COR-NTD Meeting for South-East Asia

- A two-day Regional COR-NTD (Coalition for Operational Research on Neglected Tropical Diseases) meeting for South-East Asia was organized at New Delhi on 18th-19th April by WHO SEARO (South-East Asia Regional Office).
- Different officials and representatives from NCVBCP (National Centre for Vector Borne Control Program) – Govt. of India, WHO SEARO, NTD department – WHO HQ, Piramal Foundation, ILEP Federation, ILEP India members, several educational institutes of Public Health & Tropical Medicine and many other stakeholders joined the meeting.



Participants at COR-NTD meeting



ILEP India Coordinator (middle) with ILEP Coordinators from Sri Lanka (left) and Bangladesh (right)

- Various thought-provoking sessions and presentations were conducted on post-validation surveillance, active case detection, and contact tracing, public health surveillance platforms, integration opportunities, various toolkits, and funding opportunities regarding lymphatic filariasis, leprosy, Kala-azar, Malaria, etc.
- ILEP federation and ILEP India members participated in the technical sessions where the State Coordinator, LEPRA Society presented on Integrated active case detection in one of the breakout sessions.

3 Conducting the 4-monthly meeting of ILEP India CEOs and ILEP's key stakeholders

- The first 4-monthly meeting of the year was organized by the ILEP India secretariat at The Metropolitan Hotel on 22nd April 2024.



ILEP India Stakeholder meeting

- CEO, ILEP Federation, CEOs from ILEP India member organizations and their representatives joined the meeting where key discussions were conducted on updates on progress towards the ILEP India action plan 2024, budgetary aspects, ILEP coordination workshop for India, compiling of the NGO mapping and selection of states for the upcoming NLEP review meeting, etc.

- A meeting with ILEP India's key stakeholders was organized in the second half of the day and was attended by Dr. Lily Gangmei, CMO – Leprosy (MoHFW), Dr. Rashmi Shukla, NPO – Leprosy (WHO India) and Ms. Maya Ranaware, President (APAL India).

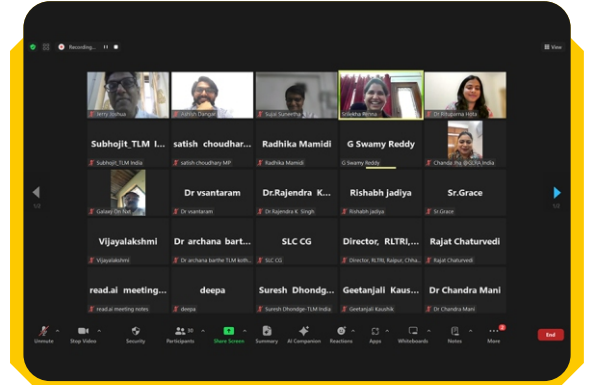
- Dr. Srilekha Penna, ILEP India Coordinator presented ILEP India's activity plan for 2024 to the stakeholders and discussions circled important aspects including the Formulation of ILEP's expert mobile team to conduct reconstructive surgeries in different states, strengthening collective efforts in research and NGO mapping.



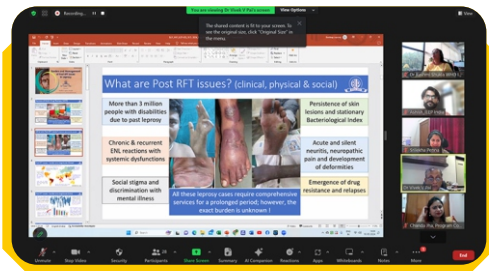
Participants at ILEP India Stakeholder meeting

4 Exchanging Knowledge and Learning – ILEP India Knowledge Sharing Series

- ILEP India’s continued efforts in expanding knowledge and learning resulted in hosting three exciting sessions in the quarter.
- A session on “Odisha’s progress towards declaring leprosy as a reportable disease” was taken up by Dr. Rituparna Hota, NLEP Consultant – Odisha, LEPRA Society on 16th April which provided the states and other stakeholders a momentum to step up for reporting every leprosy case.

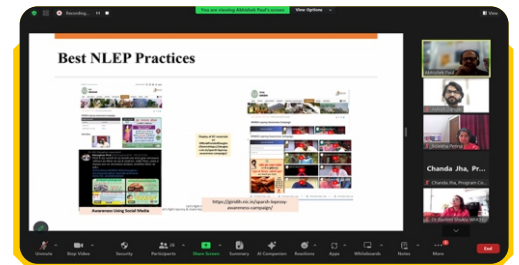


A session by Dr. Rituparna Hota, LEPRA Society



A session by Dr. Vivek V. Pai, Bombay Leprosy Project

- Another insightful session on “Burden and management of post-RFT issues in Leprosy” was presented by Dr. V.V. Pai, Director, Bombay Leprosy Project on 10th May which highlighted aspects related to clinical, social, and physical issues post RFT, strategies, and recommendations from WHO, ILEP and NLEP, Post RFT surveillance and Risk identification, ensuring and taking responsibilities of patients after treatment, etc.



A session by Dr. Abhishek Paul, WHO India

- On 20th June, a session on “Initiatives to strengthen the fight for leprosy elimination by fostering the 5 pillars of NSP as part of the state action plan, Jharkhand” was facilitated by Dr. Abhishek Paul, WHO state NTD-Coordinator for Jharkhand state. Discussions took place regarding Jharkhand state’s initiatives, implementing leprosy elimination monitoring tool, involving private practitioners, etc.
- Officials from CLD, MoHFW, senior officials from Regional Leprosy Training and Research Institutes (RLTRIs), State leprosy officers, officials from WHO India, and other NLEP partners together with ILEP India organizations took part in these insightful discussions.

5 Silver Jubilee celebration of NLR India

- NLR India celebrated its 25th-year Foundation Day Event at the Indian Habitat Center, New Delhi on the 23rd and 24th of April. Honorable Shri Bharat Lal, Secretary General of the National Human Rights Commission, Government of India, graced the occasion as the Chief Guest.



Session at Silver Jubilee



Group Photo

➤ Dr. Anil Kumar, Principal Advisor of the National Centre for Disease Control, Government of India, and Ms. Maya Ranavare, President of the Association of People Affected by Leprosy, were the guests of Honour. Ms. Linda Hummel, CEO of NLR International, The Netherlands, joined the event along with the ILEP India secretariat and a few other NLEP key stakeholders.

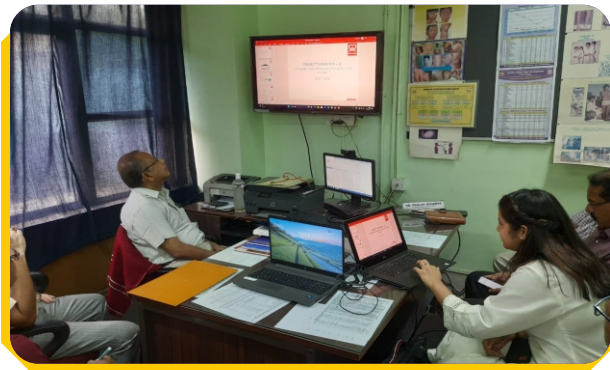
- ILEP India members took an active part in the celebration and facilitated various sessions as chairs.
- During the celebration, various other sessions on Disability Care Models, Disability Inclusive Development (DID), Urban Leprosy Programme, Call Centre/Vikalp project, Mental Well-being & Compassion, Needs Assessment of leprosy colonies, Research on leprosy chemoprophylaxis, etc. also delivered.
- At the Event, NLR India felicitated Dr. Jeyakumar Daniel, Founder of NLR India, and Dr Sudarsan Mandal, former DDG-Leprosy and Sr. Chief Medical Officer, Govt. of India as Leprosy Champions.



ILEP member CEO (GLRA India), chairing a session with others

6 GLRA India's Commitment to Zero Leprosy through its flagship project NIRAMAYA III

- GLRA India remains steadfast in its commitment to progress towards Zero Leprosy and strengthens its leadership, commitment, and partnerships with the National Leprosy Eradication Program (NLEP) in India.
- Through its flagship project NIRAMAYA III, GLRA India is working in 7 high-priority states (Andhra Pradesh, Chhattisgarh, Madhya Pradesh, Maharashtra, Telangana, Tamil Nadu, and West Bengal) supporting tertiary care facilities, outreach activities, urban leprosy programs, and ILEP-NLEP state coordination.
- On 28th June 2024, a meeting was held at Swasthya Bhavan, Kolkata, under the leadership of State Leprosy Officer Dr. Pralay Acharya together with Mr. Shibu George (Interim CEO, GLRA India), Dr. Srilekha Penna (ILEP India Coordinator and Regional Research Coordinator, GLRA India), Dr. Abhijeet Nandi (ILEP-NLEP Consultant, GLRA India), Dr. Arup Chakraborty (ILEP-NLEP Consultant, NLR India), and the paramedical team of GLRA India to discuss the GLRA India's strategic plan for the state from 2024-2026 under NIRAMAYA III.



Presentation of NIRMAAYA III to State Leprosy Office, West Bengal by Dr. Srilekha Penna

- GLRA India affirmed its ongoing commitment to supporting West Bengal and discussed enhancing ILEP-NLEP state coordination across 22 districts and strengthening the Urban Leprosy Program in Kolkata through 6 medical colleges ensuring a comprehensive approach to leprosy management.

7 Supporting the clinical services for persons affected (DFIT's quarterly update)

- Damien Foundation India Trust (DFIT) during the quarter has implemented a leprosy control programme in seven states across the country, through its own three hospitals, seven partnership project hospitals, 13 Disability Prevention and Medical Rehabilitation field teams, and its rehabilitation home for the persons affected by leprosy.
- Through OPD services, 18473 patients were treated and 174 new leprosy cases were detected out of these patients; 38 persons were detected with grade 2 disability and 67 patients were female patients.



Disability care camps at PHC by involving ASHAs



Physiotherapy being provided to patients

- Treatment to 292 patients with 7544 bed days was provided; 83 patients were treated for lepra reaction. Deformity corrective surgeries were conducted for 61 patients while MCR footwear was provided to 278 persons.
- DFIT reached out to 2678 patients through its field activities and counselled them for the self-care practice among them 1913 are practicing self-care. Besides the regular activities, field teams have provided leprosy training to ASHAS, M.O, and Physiotherapists.

8 Participation in the Annual Spring Meeting of Leprosy Research Initiatives (LRI)

- Annual Spring Meeting of Leprosy Research Initiative (LRI) was organized from 17th-19th April 2024 in Eindhoven, Netherlands. Dr. Suchitra Lisam, Head - Research & Knowledge Management, NLR India, and Mr. Sayantan Halder, Research Coordinator, PEP App, NLR India participated and presented research progress updates of NLR India's research studies.
- Dr. Suchitra Lisam presented the study titled "Compassion Training for Reducing Stigma and Improve the Quality of Care of Persons Affected by Leprosy".



Participants at Annual Spring Meeting of LRI at Eindhoven, Netherlands



Dr. Suchitra Lisam, NLR India delivering a presentation

- The team also took part in the Expert Group Meeting on "Development of Telacebec drug-related research proposals, funding opportunities: EDCTP3 deadline" which was chaired by Dr. Liesbeth Mieras, Coordinator, Research & Advocacy, NLR India.
- Mr. Sayantan presented the study titled "Testing an App supported delivery system LPEP". The LRI's Spring Meeting brought together over 100 attendees from over 30 countries including LRI-funded researchers, LRI committee members, partners of LRI, and other attendees with a particular interest in leprosy research.

9 Swiss Emmaus India held a national consultation on leprosy and migration

- Swiss Emmaus Leprosy Relief Work India (SEI) held a national-level consultation on leprosy and migration in India, with key ecosystem partners with the objective of finalizing the definition of a 'migrant' in the context of leprosy, and its integration in the National Leprosy Eradication Program (NLEP). The findings from The primary data collection to draw key recommendations for the NLEP program was presented.



Participants at National Level Consultation

- MIS was presented along with a live demonstration of its practical usage tracing and supporting follow-up for timely continued treatment. Key learnings and replicable solutions from tuberculosis and HIV/AIDS redressals were presented; it was previously presented by Dr. Benoy Peter, Executive Director at the Centre for Migration & Inclusive Development.



Chief Guest, Shri. Rajiv Manjhi, addressing the attendees virtually

- The event was graced by Shri. Rajiv Manjhi, Former Joint Secretary – Leprosy, MoHFW; Dr. Sudarshan Mandal, Senior Chief Medical Officer at NCVBDPCP, MoHFW; Dr. Rashmi Shukla, NPO – Leprosy, WHO India; and Dr. Srilekha Penna, ILEP India Coordinator.
- Dr. Manjeet Pal, SLO, Chandigarh, and Dr. Ritu Chowdhury, SLO, Delhi were the state representatives who made active contributions with their lived on-ground experiences on the treatment of leprosy from the lens of migration, giving perspective and holistic view on the challenges. SEI organized the consultation meeting under the guidance of Mr. John Kurian George, Executive Director, SEI.

- The research project was supported by Novartis Healthcare Pvt. Ltd.; Dr. Sunil Modali, Director of Global Medical Affairs; Dr. Siddharth Vishwakarma, Senior Manager, Medical Governance and Operations; Dr. Payal Laad; and Mr. Lokesh represented Novartis.

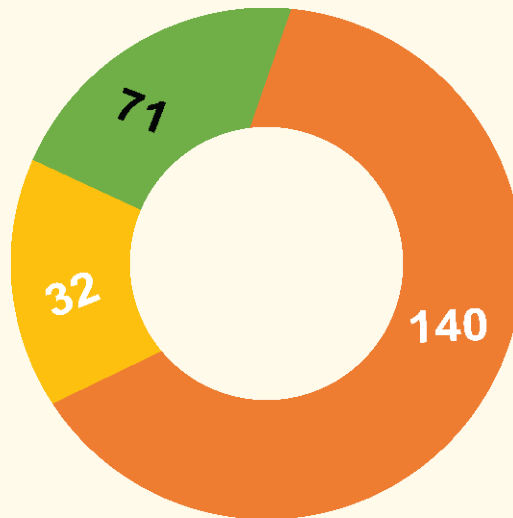


A screengrab of the last TTF meeting

- The day-long event saw active participation; the data presentations evoked invigorating engagement among the delegates; both online and offline.
- The national level consultation was followed by a meeting of the Technical Task Force (TTF) committee on the finalization of the agenda, i.e., finalizing the term ‘migrant’. The online gathering was also presented with draft IEC materials proposed in the project for community awareness of leprosy. The TTF members made active contributions with their feedback and viewpoints on how to better the communication efforts. The finalized IEC contents are translated into a graphical Hindi poster as additional IEC material for the NLEP program.

Key activities by NLEP consultants

Visits Trainings Meetings



From April to June 2024

ILEP agencies continued to support field and policy-level assistance to the National Leprosy Eradication Program (NLEP) through their 14 NLEP consultants across 11 high-priority states and few other states. These 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

71

Advocacy and Program Implementation Meetings

32

Trainings

140

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

Celebrating World Environment Day to Generate Awareness



Haspura, Bihar

NLR India Team organized a week-long Plantation Drive that was carried out from the 5th to the 13th of June 2024 in observance of World Environment Day (WED) which falls on the 5th of June 2024. Across several locations in six states namely Delhi, Rajasthan, Jharkhand, West Bengal, Uttar Pradesh, and Bihar, NLR India's staff planted 455 saplings in leprosy colonies, community parks, office premises, etc with the support of a total of 377 stakeholders from communities, peer supporters, beneficiaries, change agents and government agencies (Forestry Department, Health/Leprosy Cell, etc.).



During the drive, NLR India's staff also spread general awareness about WASH, heat stroke, etc. to the general communities, persons affected by leprosy, and their dependents. This is NLR India's first such initiative as NLR India has taken a pledge with USAID's Sustainable Action for Climate Health (SACH) towards a greener /healthier Planet. This effort not only brings more green spaces but also supports communities affected by leprosy. Each sapling represents hope, growth, and a commitment to a healthier environment for everyone.

Varanasi

