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NEWSLETTER

MESSAGE FROM ILEP INDIA COORDINATOR



Dr. Srilekha Penna

Dear readers,

Welcome to the 10th edition of the ILEP India Newsletter! In this edition, we present a comprehensive roundup of the remarkable endeavours achieved during the first quarter of 2024.

From the thought-provoking discussions at the Indian Association of Leprologists (IAL) Conference in Bangalore to the intensive training sessions conducted for Medical Officers in Dadra and Nagar Haveli, each event underscored our collective commitment to fostering knowledge exchange and implementing effective strategies in the fight against leprosy.

Notably, our engagement extended beyond conventional settings with joint evaluations of projects and the expansion of our Knowledge Sharing Series to key stakeholders in leprosy, exemplifying our dedication to fostering inclusive dialogue and collaboration.

This edition gives more insights into the launch of "Aagaaz- the beginning of the end of leprosy" by Swiss Emmaus Leprosy Relief Work India, the exemplary efforts of our member organizations TLMTI and NLRIF, whose innovative approaches and unwavering dedication continue to drive progress in leprosy awareness, management, and rehabilitation across different regions.

As we navigate through the year, we remain steadfast in our commitment to advancing the agenda of leprosy-free India with continued support and engagement of all the key partners.

I hope you find this edition insightful and engaging!

Key activities and participation by ILEP India and member organizations

1 Participation in the IAL Conference, Bangalore

- The Indian Association of Leprologists (IAL) has convened its 32nd Biennial National Conference of Leprosy (6th–7th January) in collaboration with Vydehi Institute of Medical Sciences and Research Centre, Bengaluru with a theme on "Leprosy Free India - Way Forward".
- On behalf of ILEP India, Dr. Srilekha Penna delivered a convincing presentation titled 'How to choose the best-case finding approaches based on the endemicity of a region.' Dr. Penna's insights into tailoring case-finding strategies to regional nuances added valuable perspectives, contributing to the conference's objectives.

- NLR India was represented by Dr. Ashok Agarwal (CEO, NLR India) and Dr. Suchitra Lisam (Head, Research & Knowledge Management); Dr. Ashok co-chaired a session and presented the PEP++ - stop transmission of leprosy project- a multi-country clinical trial of NLR that is being implemented by NLR India and three other countries.

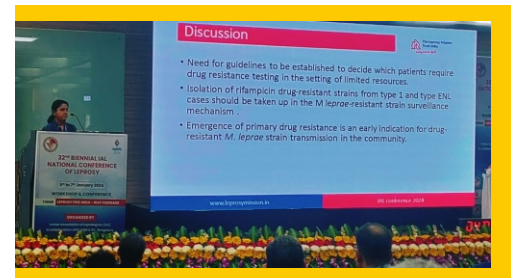


Dr. Suchitra Lisam representing NLR India at IAL conference, Bangalore

- Dr. Suchitra presented an oral session on “perception of health officials & frontline workers on PEP App for improving Leprosy Post-exposure prophylaxis (LPEP) service delivery”; 2nd oral session was on Active case detection through systematic surveillance for

contacts of index cases" and made a poster presentation on “Comparison of sustained and standard clarithromycin on reporting adverse events under PEP++ study.

- TLM was represented by Dr. Itu Singh and Dr. Joydeepa Darlong; Dr. Itu Singh presented the advantages of using TLM’s innovative MPCR-based diagnostic tool. This tool for point-of-care diagnosis of Leprosy was well appreciated. Dr. Joydeepa Darlong spoke about the approaches towards the management of drug resistance in Leprosy, and Karthik Govindasamy delivered an insightful session on Leprosy-related disabilities. Mr. Vinay Pathak from TLM research lab bagged the 1st position in the category of Award Paper for his paper on Leprosy reactions.



Dr. Joydeepa Darlong presenting approaches towards management of drug resistance

- A few other ILEP organizations i.e. FAIRMED India, GLRA India, and LEPRA Society also took an active part in the conference.

2 Leprosy Training for Medical Officers in Dadra and Nagar Haveli

- On 23rd & 24th January 2024, the two-day training cum review meeting for Medical Officers under NLEP (National Leprosy Elimination Program), organized by the UT administration of Daman & Diu and Dadra & Nagar Haveli (DD&DNH), brought together over 50 medical officers and NMAs.



Training on programmatic approaches by Dr. Anil Kumar, Principal Advisor, National Centre for Disease Control (NCDC)



Group picture of trainees with National Training team

- The agenda involved a thorough review of the leprosy situation in the Union Territories of DD&DNH followed by intensive training sessions.
- Dr. Srilekha Penna, ILEP India Country Coordinator and GLRA's Regional Research Coordinator led a comprehensive session on Disability Prevention and Medical Rehabilitation.

- The training initiative extended beyond conventional settings, as the team visited remote tribal areas in DNH, where leprosy endemicity remains high.
- The event provided a platform for knowledge exchange and facilitated practical insights through on-site visits, reinforcing the commitment to combating leprosy and promoting collaborative approaches to address the challenges.

3 Joint evaluation of Alert India’s project sites

- The ILEP India coordinator together with with Dr. Pemmaraju R. Rao (Sasakawa Health Foundation) went on a joint M&E mission to visit Alert India’s Human Rights Based Approach (HRBA) project in Gadchiroli and Chandrapur in Maharashtra from 5th to 8th February.
- The mission encompassed field visits to Leprosy Referral Centres (LRCs) in Gadchiroli and Chandrapur and various meetings and interactions took place with persons affected by leprosy, District Leprosy Officers and the medical officers at PHCs.



Visit to LRC Gadchiroli



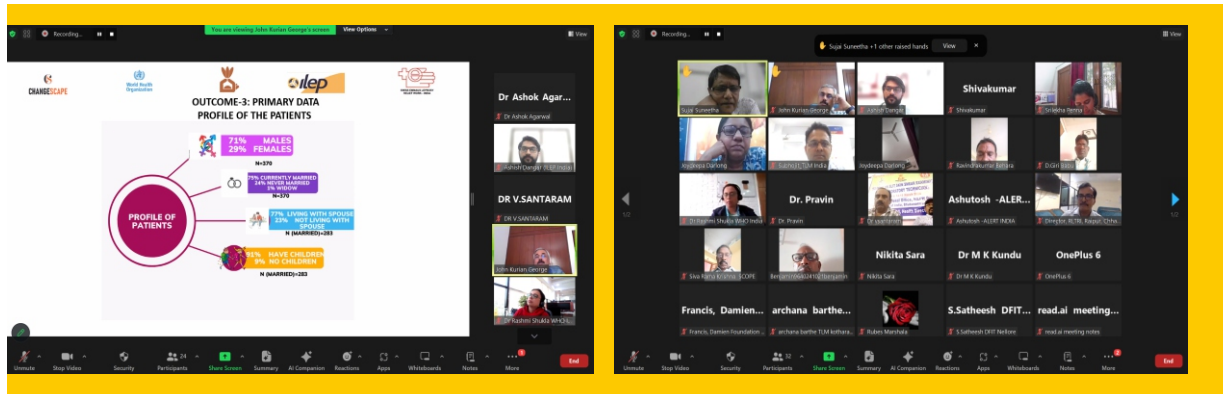
Mr. Ansari, Physiotherapist Providing ulcer dressing

- Alert India established an effective HRBA project to bring a change in perceptions towards leprosy in the local communities particularly empowering women affected by leprosy.
- The visit further involved insightful interactions with members of SKSS (a local organization of people affected by leprosy working in the communities) and a meeting with the Head-Leprosy Training Centre, Nagpur, and NLEP regional consultant, Nagpur region.

4 Expanding the ILEP India Knowledge Sharing horizons

- The ILEP India secretariat in consultation with member CEOs expanded the ILEP India Knowledge Sharing Series (ILEP-I KSS) to key stakeholders in leprosy.

- A session on “Leprosy and Migration in India” was delivered on 14th Feb. by Mr. John Kurian George, Country Coordinator, FAIRMED India. Another session was organized in March and delivered by Dr. Joydeeba Darlong, Head-Knowledge Management, TLMTI on “Protocol of an enhanced self-care to improve ulcers due to leprosy in the community”.

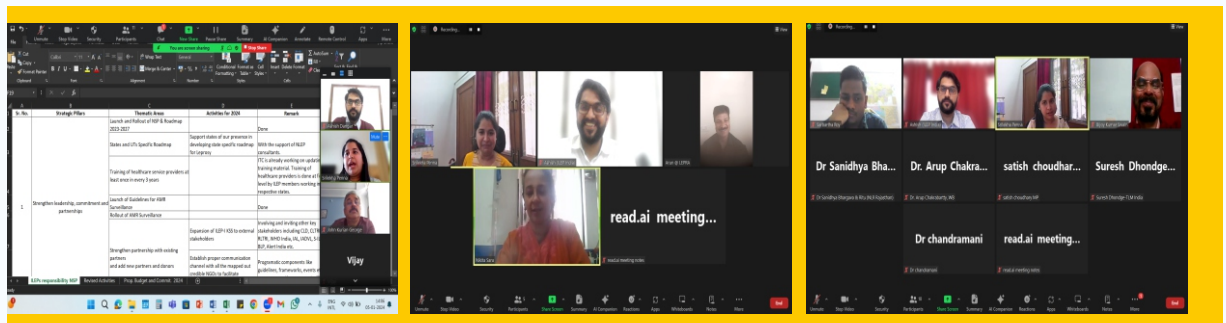


Left: ILEP-I KSS session by Mr. John and Right: ILEP-I KSS session by Dr. Joydeeba

- Both sessions were attended by various representatives of the Central Leprosy Division, WHO India, Regional Leprosy Training and Research Institutes (RLTRIs), State Leprosy Offices, Sasakawa Health Foundation, Alert India, IAL, etc. together with ILEP India members and witnessed insightful exchange amongst the experts.

5 Strengthening coordination within the ILEP India fraternity

- The year started with a virtual meeting with ILEP India CEOs on 5th January, aimed at seeking suggestions and approval for the ILEP India activity plan 2024.
- On the 28th of February, a virtual meeting took place between the ILEP India Secretariat and ILEP India working group representatives (Communication & Advocacy and Data Management) Ms. Nikita Sarah (Head-Advocacy & Comms., TLMTI) and Mr. Arun Kumar (Head-Programs,



Left: ILEP India CEO meeting, Middle: Meeting with WG representatives and Right: Meeting with NLEP consultants

LEPRA Society) to discuss the role of these groups as well as the development of the ILEP India dashboard and related indicators.

- On 29th February, another virtual meeting convened to review the progress and address challenges discussed by ILEP's NLEP Consultants. Topics included the progress of NLEP activities in their respective states, advancements in repealing discriminatory laws, and ongoing challenges and ways to address them. One of the key agenda points was to orient them on supporting the states to prepare state-specific strategic plans for leprosy and support the NGO mapping initiative of the ILEP India secretariat.

6 Supporting NLEP with rallies and awareness program under SLAC



Awareness rally during SLAC

- The Leprosy Mission Trust India (TLMTI) has been actively engaged in Nashik and Amravati districts for many years through their community projects in both districts, including the Jeevan project in Amravati and the Vocational Training Centre, Children United For Action, and College on Wheels projects in Nashik district.

- Govt. of Maharashtra rolled out the Sparsh Leprosy Awareness Campaign from 30th January to 13th February 2024 where the TLMTI teams in both districts collaborated and conducted leprosy awareness rallies and awareness programs in schools, colleges, PRIs, and communities.

- The leprosy champions from TLM (Suresh Dhondge and Mangala Dhondge) shared their own experiences to encourage the community to put an end to stigma and discrimination. They presented these testimonies during programmes conducted in collaborations with the Assistant Director, Health Services (Leprosy) and Panchayat Raj Institutions.



Awareness program in schools during SLAC

7 Launch of “Aagaaz... the beginning of the end of leprosy” by Swiss Emmaus Leprosy Relief Work India

- Swiss Emmaus Leprosy Relief Work India (SEI) declared Aagaaz on leprosy in the Durg district of Chhattisgarh, in the presence of the Chhattisgarh health department on February 15, 2024.
- The flagship project of SEI, supported by FAIRMED Bern is focusing on improving the health and well-being of marginalized communities in eliminating leprosy through health system strengthening and community empowerment.
- The key dignitaries of the project launch event were Dr. J.P. Meshram, Chief Medical and Health Officer, Durg District; Dr. Anil Shukla, District Leprosy Officer; Shri. Padmakar Shinde, District Program Manager; Dr. C.B.S. Banjare, Nodal – Malaria; Shri. Ghasiram Bhoi, APAL President; Shri. Dhaneshwar Nishad, Viklang Manch.



Chandravan Banjare, Nodal Officer, NVBDC Program addressing attendees



The panel of chief guests at the Aagaaz launch

- Mr. Bijoy Kumar Swain, National Program Manager, SEI India presented the key goal with objectives of the project along with presenting a comprehensive plan to achieve the project goals with the district stakeholders, which resulted in a detailed discussion and fruitful contributions from the community leaders.

- The project ensures universal access to healthcare and upholds dignity for all, prioritizing the marginalized. It incorporates disability and gender sensitivity to promote inclusive stakeholder participation. The event was organized by the Aagaaz project under the guidance of Mr. John Kurian George, Executive Director, SEI.

8 International Purple Fest

- TLMTI, in collaboration with the Vidhi Centre for Legal Policy, Association of Persons Affected by Leprosy (APAL), Sasakawa Health Foundation (SHF) and the National Centre for Promotion of Employment for Disabled People (NCPEDP) hosted a leprosy convention and attended a convention of the State Disability Commissioners at the International Purple Fest at Goa during 11-12 January.
- The events were focused on creating awareness among Disability Commissioners and common people about the medical, social and legal aspects of Leprosy, building a case for repealing of discriminatory laws, and pushing for adopting a multidisciplinary approach towards achieving zero leprosy.

- Both the events were attended by government officials, WHO India, SHF, APAL, TLMTI, Vidhi, medical doctors, staff from CHCs and PHCs, medical college staff, NGOs, and people with disabilities.



Panel and participants at purple fest

- The discussions ranged from the cause and transmissibility of the disease and importance of early diagnosis to discriminatory legal provisions, fundamental rights of people affected by leprosy, epidemiological scenario of the disease in India, community-level awareness, social schemes, etc.

9 Strengthening the NLEP in Uttar Pradesh

- Dr. Abdullah, State Program Lead and ILEP's NLEP Consultant (NLRIF) embarked on a series of visits to Etah, Aligarh, Mathura, Varanasi, and Sonbhadra (Uttar Pradesh) to strengthen the NLEP. In Etah, a pivotal meeting was held with the Chief Medical Officer (CMO) on engaging staff in the NLEP program, particularly in resource-scarce areas.



Awareness in the Jail compound, Mathura



Awareness and validation in Varanasi

- Following Etah, a visit to Aligarh was conducted to ensure that the efforts in combating leprosy are spread across various districts. A significant highlight was Dr. Abdullah's visit to a jail with the NLEP team in Mathura, aimed at raising awareness about leprosy and its implications for the incarcerated population.

- He further visited Varanasi, reaffirming NLR's and ILEP's commitment to reaching every corner of the region in our mission to achieve zero leprosy. Finally, in Sonbhadra, emphasis was placed on the importance of consistent efforts in combating leprosy at the grassroots level.
- These visits also facilitated meetings with CMOs to make decisions regarding NLEP activities, ASHA sensitization, video documentation of training sessions, NGO collaborations, IEC activities, and encouraging the CMO's involvement in IEC activities.

10 Spreading awareness and participating RCS & healthcare camps

- NLR India made waves at Jaipur International Film Festival (JIFF) from 6-10th January 2024, Jaipur where the film "SHUDDI" a work by James Higginson (director/producer) was not only screened but also honoured with an award. Dr. Ashok Agarwal CEO, of NLR India, seized the opportunity to educate the audience about leprosy and promote acceptance within society.
- His impassioned speech shed light on the misconceptions surrounding leprosy and emphasized the importance of embracing those affected by it as integral members of our community.



Screening of film "SHUDDI" at Jaipur



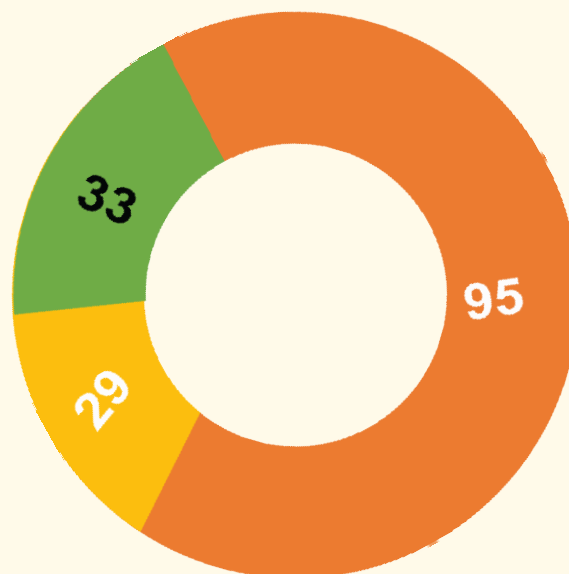
Team of reconstructive surgery camp facilitated by NLR India

- NLR India participated in Reconstructive Surgery (RCS) camps for Persons Affected with Leprosy (PAL); these camps were organized in West Bengal during various phases. One such camp took place at Nayagram Super Specialty Hospital in Jhargram district, serving two districts – Jhargram and Paschim Medinipur, from February 19th to 20th, 2024. A specialized team comprising plastic surgeons, anaesthetists, and physiotherapists was tasked with executing the surgeries.
- Before the camp, preparatory measures were taken to ensure the readiness of operation theatres, coordination among important stakeholders and facilitators, availability of equipment and drugs, and pre-admission of all patients, with completion of their preoperative anaesthetic assessments.
- Nineteen Persons with Disabilities underwent successful reconstructive surgeries during the camp, with no reported adverse events during or after the procedures.
- The health camps were organized by NLR India in leprosy colonies (Delhi) to raise awareness regarding leprosy in surrounding areas, diagnosis of suspects identified during the second round of LCDC, provide general health services, capacity building of ASHA/ANM/Disability cases/Community members regarding self-care practices and provide assistive devices to eligible cases with disability. A general health camp was organized along with an eye check-up camp.

- Self-care material (MCR footwear, scrub, oil, etc.) and spectacles were distributed based on assessment of disability/visual impairment to all the eligible persons. The camp was attended by SLO, NMS, DLO, NMA, ANM, ASHA workers, and officials from NLR India. Officials from CLD, Dte. GHS and MoHFW visited the camp to review NELP services in the leprosy colony.

Key activities by NLEP consultants

Visits Trainings Meetings



From January to March 2024, ILEP agencies continued to support field and policy-level assistance to the National Leprosy Eradication Program (NLEP) through their 14 NLEP consultants across 18 endemic 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 33 advocacy and program implementation meetings; 29 trainings; and 95 visits to the districts, different health facilities, and leprosy colonies.