

NEWSLETTER

MESSAGE FROM ILEP INDIA COORDINATOR

Welcome to the ILEP India Newsletter Volume VII! I hope you are finding our newsletter updates interesting.

We had our very first ILEP India CEO meeting for the year 2023 in April after GLRA India took over the ILEP India Coordination from NLR India Foundation. One of the key points discussed was to focus on capacity building and knowledge sharing among ILEP members as well as with all the key stakeholders at the state and national levels. Taking this focus further, in this quarter (April to June 2023) ILEP India organized, supported, and participated in various review meetings, conferences, and workshops where capacity building and training stood out as key priorities. In this issue, you will discover more about our proactive involvement in the IAE conference, Regional NLEP review meeting of northeastern states, and data management workshop for ILEP consultants.

This issue also covers some intriguing activities happening in the field by various ILEP members including insights into the UP-state partners review meeting, training of ASHAs, activities from migration study on leprosy, initial outcomes from the public-private partnership and mental health projects, and an inspiring story from the field. I wish you a happy reading!

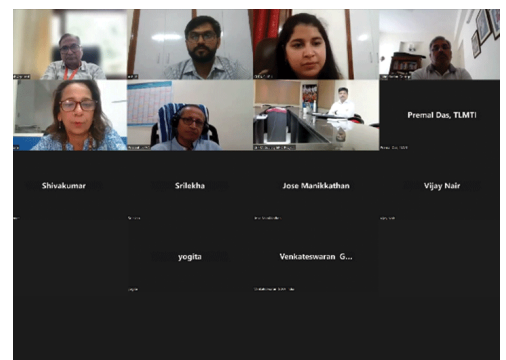


Dr. Srilekha Penna

Key activities

1 ILEP India CEOs Meet

- After GLRA India took over the ILEP India Coordination on 1st April 2023, the first ILEP India CEOs meet for the year 2023 was organized virtually on 12th April 2023
- The meeting was attended by CEOs from all member organizations, a few representatives, the ILEP India secretariat (GLRA India), and ILEP India working group representatives.



ILEP India CEOs meet in August (Virtual)

Objective

- To discuss Activity plan 2023; progress and way forward
- To share the progress of ILEP India working groups
- To discuss budgetary aspects and agency contributions for 2023



- The main agenda of the meeting was to discuss, review and agree on the activities planned for 2023, the ILEP India budget & contributions by member organizations.
- Few more topics like MoU between ILEP agencies in India and extending the state coordination for more states were discussed during the meeting.



ILEP India CEOs meet in August (Virtual)

2 Organizing IAECON 2023

- Indian Association of Epidemiologists (IAE) organized the 13th national conference focussing on collaboration and knowledge sharing between various public health programs in India.
- The conference was organized in collaboration with ILEP India, WHO India, and U.S. Centre for Disease Control and Prevention (CDC).
- Govt. officials from various public health programs, medical students, and members from partner organizations attended the conference and presented papers on wide array of topics.
- The sessions focussed on themes including Leprosy, Non-Communicable Diseases, PH emergency and disaster management, Oral Health, and Tobacco Control, Vector-borne diseases and NTDs, Mental health & Elderly care, International health, Environmental health etc.
- Thought-provoking presentations were delivered by Dr. Ashok Agarwal (Country Director, NLR India Foundation), Dr. Joydeepa Darlong (Head-Knowledge Management, TLMTI), and Dr. Srilekha Penna (ILEP India Coordinator, GLRA India) in the session focussing Leprosy.

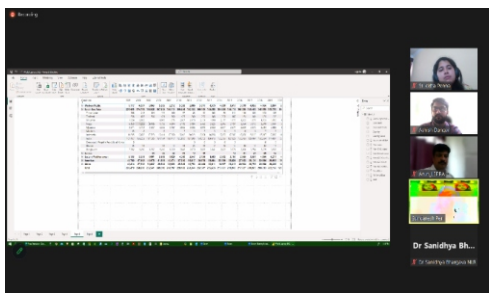
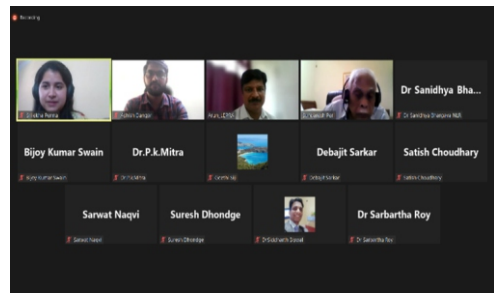


ILEP India as an official partner in organizing IAECON23

3 Strengthening Capacity Building of ILEP Consultants in Data Management

- A virtual capacity-building session for ILEP consultants on Data management was organized on 8th May 2023.

- The session was conducted by renowned data management system expert Dr Sundaresh Peri.
- ILEP consultants from various states, the ILEP India secretariat, and the Data management group leader (ILEP India working group) joined the session virtually.



Capacity building session conducted by Dr Sundaresh Peri

- The session strengthened the capacity of participants on the Data Management system, recent data management trends and software, data management cycle, and Excel dashboards. The follow-up sessions were proposed by the participants to get some more insight.

4 Support in conducting review meeting and training for north eastern states under NLEP

- Review meeting of the National Leprosy Eradication Program in the northeastern states of India was conducted in collaboration with Central Leprosy Division (CLD), Director General Health Services (Dte. GHS).
- The meeting and training was conducted on 29th and 30th May in Kohima, Nagaland (IN).



Address being delivered to participants by Dr Srilekha Penna (ILEP India Coordinator)



Government officials, WHO India officials and other participants from the meeting

- Principal Advisor, National Centre for Disease Control; Deputy Director General – Leprosy; Senior Regional Directors; National Professional Officers – WHO India (Leprosy and MHS); Country Director – NLR India Foundation; Director – Medical (AIFO India); State Leprosy Officers/representatives; District Leprosy Officers; Data Entry Operators and many other participants joined the meeting.

- The meeting was inaugurated by the respected Commissioner and Secretary, Govt. of Nagaland followed by the launch of the Framework for Integration between mental health and Leprosy program, Leprosy awareness posters, and ASHA flipbook in collaboration with WHO India, Nikusth 2.0 whiteboard animation video prepared in collaboration with NLR India Foundation.

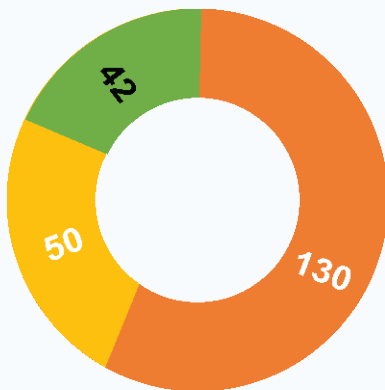


Regional review of NLEP (NE Indian states) jointly conducted by CLD, ILEP India and WHO India

- The review of eight states was conducted on the first day along with the presentations of senior govt. officials and program partners.
- Second day of the meeting was followed by training on Nikusth 2.0 (an online portal for entering leprosy patient data) and implementation of the National Strategic Plan for Leprosy.
- ILEP India supported the meeting arrangements and provided technical guidance to the various discussions.

Key activities in the field

■ Visits
 ■ Trainings
 ■ Meetings



The ILEP agencies continued to support field and policy-level assistance to 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. From April to June 2023, the state and district-level program was supported through 42 advocacy and program implementation meetings; 50 trainings; and 130 visits to the districts, different health facilities, and leprosy colonies.

1 Participating in program review and partners meeting for better support to the national program

- Partners meeting was conducted at Lucknow, Uttar Pradesh; State Leprosy Officer (SLO) and Joint Director (JD) joined the meeting along with TLM (The Leprosy Mission) Naini, TLM Ayodhya, TLM Barabanki, and WHO India. Reconstructive Surgery (RCS) cases, Micro Cellular Rubber (MCR) footwear, Grade II & child cases investigation and validation, Slit Skin Smear (SSS) test, training of National Leprosy Eradication Program (NLEP) staff, skill development training under rehabilitation, master training of five District Leprosy Officers (DLOs), etc were discussed during the meeting.



NLEP program partners meeting at Lucknow, Uttar Pradesh

- Districts where ILEP India (NLR India Foundation – NLRIF as ILEP organization) and WHO India are working, leprosy colonies and silent districts, the role of TLM Barabanki in the diagnosis of cases and line listing were also some other points discussed during the meeting.



District review of Uttar Pradesh state conducted by MD, NHM

- Participated in DLO review meeting conducted by Mission Director (MD) – National Health Mission (NHM); backlog cases, MB proportion, child cases, G2D, contact eligible for Single Dose Rifampicin (SDR) and Contact administrated SDR, etc were discussed while reviewing the district performances. Individual review of every district was conducted and discussed regarding staff training, and training of medical officer-in-charge (MOICs). NLRIF has given training to 39 DLOs and 41 District Leprosy Consultants (DLCs) regarding diagnosis and treatment of leprosy, neuritis and lepra reaction, Disability and Prevention, etc. Every district was also reviewed on entering the leprosy patient database in NIKUSHT 2.0 and training regarding the same.

2 Migration and Leprosy in India

- FAIRMED India in collaboration with CLD – Dte. GHS, WHO India, ILEP, State National Leprosy Eradication Program (NLEP), and the Association of Persons Affected by Leprosy (APAL) is implementing a study on migration and leprosy in Bihar, Chandigarh, New Delhi, and Uttar Pradesh.
- Pilot data collection and visit was carried out to Sitapur (Uttar Pradesh) district by the FAIRMED India team. The meeting with district officials and partners was conducted on aspects related to the study; SLO supported the coordination and required communication.
- During the visit, it was found that there are two patients who migrated to Karnataka and Ludhiana. The team enquired if some more patients are moving out of their locality during their treatment period and visited Parsendi, Biswan, and Mehmudabad Community Health Centers (CHCs) along with district officials.
- The interaction with the Non-medical supervisor (NMS), Non-medical assistant (NMA), and Accredited Social Health Activists (ASHAs) of these PHCs were conducted but no such migrated cases were found.
- A good practice came forward as finding where the frontline health workers are counseling and motivating patients to first finish the treatment on priority rather than moving to various places; in migration was not observed in the district. SLO has been requested to support data collection in some other districts as well.



FAIRMED team with the NMS and ASHA of Mehmudabad block during the visit to Sitapur district

3 Towards zero hidden leprosy cases by strengthening the capacity of ASHA workers

- ASHA workers are key players to achieve Zero Leprosy. TLM team, Maharashtra along with Assistant Director Health Services–Leprosy (ADHS–L), Amravati observed that Chandur Bazar and Warud are having a high prevalence rate of leprosy compared to other blocks.



Sensitization and Training for ASHAs of Chandur Bazar (Maharashtra) conducted by TLMTI team

- To reach out the last mile for case identification; motivation, training and sensitization of ASHAs is a vibrant need. TLM and ADHS-L jointly arranged a one-day training program for 161 ASHAs of Chandur Bazar at TLM Kothara Leprosy Hospital.
- The district administration also took part in training and motivated ASHAs of the block.
- Another training for ASHAs of Warud block is planned in July'23.

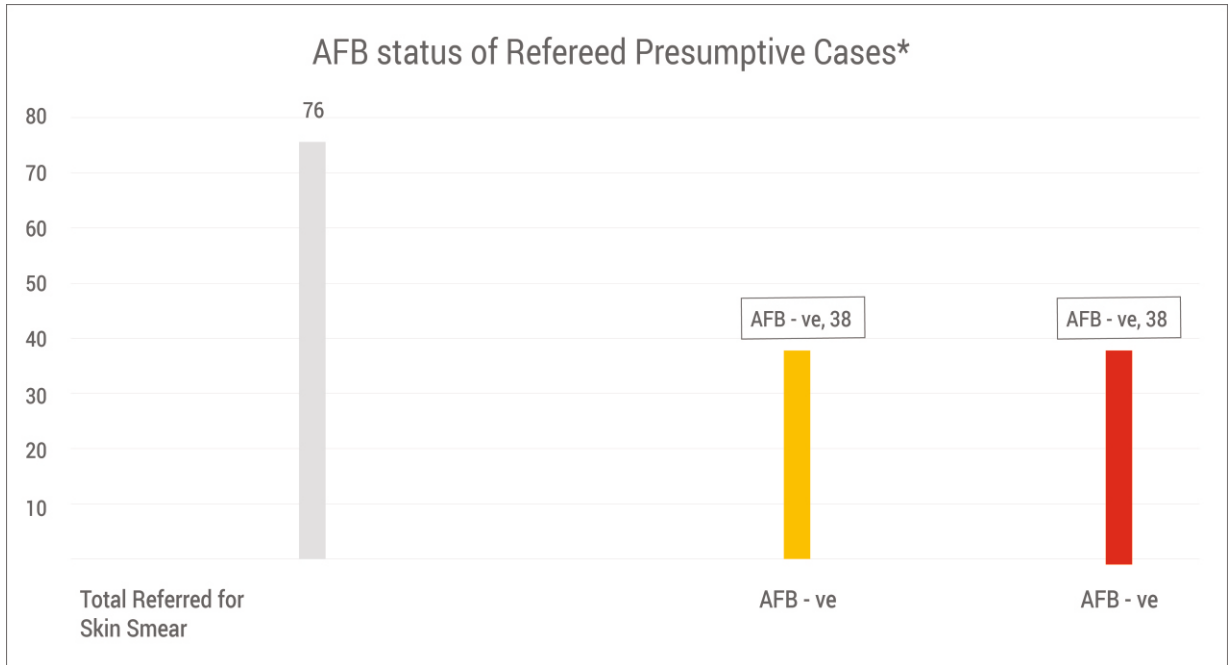
4 Promoting Public Private Partnership (PPP)

- GLRA India, in collaboration with state NLEP - Madhya Pradesh, is implementing a unique initiative through a public-private partnership for early leprosy case detection by establishing a skin-smear facility at private laboratories. Further, the project engages private practitioners in promoting early referral of presumptive leprosy cases to government health centres for the diagnosis and bacteriological confirmation of leprosy.
- The Project covers 14 administrative blocks in four districts (Barwani, Khargone, Bhopal, and Sehore).
- Jointly with the district administration, GLRA India promotes the training of private practitioners and engages private laboratories for the slit-skin smear facility in each District.
- The project trained 92 private medical practitioners resulting in referring 254 presumptive leprosy cases and the engagement of four private laboratories for skin-smear testing resulted in diagnosing 38 skin-smear positive cases.
- The interim (8 months) outcome shows promising results. About 50% of skin smears of the referred presumptive leprosy cases tested Acid-Fast Bacillus (AFB) positive.



GLRA India skin camp

- All the identified 38 skin smear-positive MB cases enrolled on MDT at the nearby Government Primary Health Centres (PHC).



*254 presumptive cases of Leprosy were referred by qualified, Ayush, and non-Qualified Practitioners to the Government health system of which 76 (30%) were referred for skin smear examination.

5 Project SAMARTH: A Pilot Project to Promote Mental Health and Psychosocial Well-being of Leprosy and LF Patients

- LEPRA Society, in collaboration with Effect Hope, is implementing a project to improve the health and psychosocial outcomes of people affected by leprosy and lymphatic filariasis (LF) in three blocks (Gaurihar, LavkushNagar, and Rajnagar) of Chhatarpur district, Madhya Pradesh State, India.



Integrated Prevention of Disability (IPOD) camp for Leprosy and LF patients

- The project aims to achieve the following
 - Enhance community-based morbidity management and disability prevention (MMDP) services, including mental health support, for individuals affected by leprosy and LF.
 - Foster improved health-seeking behaviour among individuals affected by leprosy and LF within the Self Support Groups (SSGs).
 - Mitigate social consequences resulting from leprosy and LF.
- The project has reached 1,200 patients (Leprosy and LF), with 60% LF and 40% leprosy cases, and established 109 SSGs for them.

- The SSGs have received training on how to identify signs, symptoms, and complications of LF, leprosy, and mental health. The project team is providing peer counselling, mindfulness sessions, Integrated Prevention of Disability Camps, and self-care kits on a regular basis.



Mindfulness session to Self-Support Group (Leprosy and LF patients) @ Benigunj

- The project outcomes have been positive in achieving its objectives and Project Edline Evaluation is scheduled in November 2023.

Story from the field

(Mr. Ritesh Das, West Bengal) – Detection to Counselling to Treatment

Ritesh Das, 45/M, MB (A). He runs a Sports equipment shop and his family consists of his wife, five-year-old daughter, and mother.

“About eight months ago, I saw patches all over my body. Assuming nothing was serious, I went to a local doctor for a check-up and took medicines for a few days but the patches remained the same. On my wife’s suggestion, I went to consult a skin specialist for further check-up. The doctor advised me to attend RG Kar Medical College & Hospital for proper diagnosis and treatment. From RG Kar Medical College, I was informed that I am suffering from leprosy. For a moment I was stunned. I was telling myself that the diagnosis may be wrong. I didn’t know what to do! How can I fulfill the responsibilities of my family?” – Ritesh



“After that, I met a GLRA counsellor as advised by the OPD Doctor. At the very beginning of the meeting, he told me that leprosy is curable,” the first thought of me was that my family members were in danger due to this type of serious disease. For the next 15 days, I could not sleep properly. My business was already hampered because this tension ultimately closed. Eventually, I started multi-drug therapy (MDT) to stop further damage and also the other medicines that were provided free of cost to me from RG Kar Medical College & Hospital.” – Ritesh



“Finally, I accepted that I had leprosy. After starting MDT, I stopped contact with my relatives and friends. I also hid my disease from them. I stopped going to any of my relatives, I thought my hands or legs would claw as I had seen leprosy patients with deformities. But I was assured by the counsellor that with regular intake of medicines, I can be cured. Every month I met a GLRA person and he counselled me very well. Gradually I started feeling better. Ultimately, I completed the 12th strip of medicine (MDT) and am feeling good. I am following the advice and suggestions of the doctor and GLRA person and yes, I am now recovering and have started my business again. At the same time my perception of leprosy changed a lot.” – Ritesh



Ritesh's case study should have ended here but it didn't...!

The tragic moment came a few days later. He came to RG Kar Medical College & Hospital again for a check-up and met with the GLRA Supervisor with a reaction and foot drop.

“A few days ago, I felt the back side of my left knee was tender. I thought this might be something else. So, I went to the hospital a few days later. But in the meantime, I felt that my left foot was not working properly. I couldn't lift my left foot. I contacted a GLRA person, he suggested that I come to the Hospital. Then Doctor said after the smear test that I need to take MDT again for 12 months (the SSS test was positive). After one year again, I cried, and I think that I have no chance to cure my disease. I have a family, a wife, a daughter, and my mother. My only concern is that my family doesn't suffer for me.” – Ritesh

Finally, Ritesh started taking MDT again with prednisolone. PEP also provided for his family members. After that, he started exercising with the guidance of the GLRA supervisor for his left foot droop. Ritesh used to attend the Hospital regularly with a worried face. His only question was, “Can I be cured and will recover fully again? I think my life seems to be over.” He was frequently counselled by GLRA Supervisor, and as a result, Ritesh became mentally strong day by day. Ultimately, he completed the last doses (24) of the MDT blister pack (MBA). But his smear result remains positive. Again, Ritesh is depressed and goes to the Doctor with great sadness. The doctor advised him no need to start MDT again and keep watch on himself until new patches or any problems develop. At present Ritesh is more or less healthy and able to lift his foot a little bit.

UPCOMING PRIORITIES

- 1 Assist in the roll-out of NSP.**
- 2 Technical support to Leprosy Case Detection Campaign under NLEP.**
- 3 Launch of ILEP India Knowledge Sharing Series (ILEP-I KSS)**
- 4 Advocacy to state authorities on repealing discriminatory laws.**