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NEWSLETTER

MESSAGE FROM ILEP INDIA COORDINATOR



Dr. Srilekha Penna

Dear readers,

Welcome to the 12th edition of the ILEP India Newsletter! This edition provides a comprehensive overview of our activities, progress, and strategic initiatives for the July to September 2024 quarter.

Highlights include the key initiatives organized by the ILEP India secretariat including the ILEP-NLEP consultant workshop together with Central Leprosy Division and ILEP experts and the second 4-monthly ILEP India CEOs meeting to discuss the progress of the ILEP India activity plan 2024. Our ILEP India knowledge-sharing sessions continued, bringing fresh insights into home-based self-care models, support services through telecommunication, and mental health aspects related to leprosy from ILEP experts.

This edition also gives a glimpse into our member organizations (DFIT, GLRA India, LEPR, TLMTI, and SEI) led impactful activities this quarter, including training workshops, community-based activities, program achievements, outcomes of Leprosy-Migration study and stories from the field. I extend my sincere thanks to all ILEP members, NLEP consultants, and our partners for their unwavering commitment.

I hope you find this edition insightful and engaging!

Key activities and participation by ILEP India and member organizations:

1 ILEP Workshop-cum-Review Meeting: Strengthening Leprosy Program Strategies and Targets for 2027

- A Workshop-cum-Review Meeting of ILEP's NLEP consultants was organized on 3rd July 2024 by the ILEP India secretariat at The Metropolitan Hotel, guided by Dr. S. Senthilnathan, Dr. Lily Gangmei, and Dr. Ranganath A.R. from the Central Leprosy Division, MoHFW together with experts from ILEP India.

- The consultants discussed crucial topics such as Active Case Detection, Stigma Reduction, Mental Well-being, Disability Prevention, and Post-RFT Surveillance from the states and were oriented on 125 priority districts, projected targets for 2027, and upcoming interventions, focusing on data digitization and consultants' roles in achieving these goals.
- Dr. Pravin Kumar (NLR India) presented a draft template for state and district strategic plans, followed by a productive exchange of insights and action points for the next steps forward.



2 Conducting the second 4-monthly Meeting of ILEP India CEOs

- The second 4-monthly meeting of the year was organized by the ILEP India secretariat virtually on 25th September 2024 which brought together CEOs of ILEP India member organizations to discuss key activities carried out from May to September 2024.
- The ILEP India Coordinator presented updates on progress towards the ILEP India action plan for 2024, budget updates, the ILEP Good Practices document, and strategies for improved NGO mapping across India.
- The meeting included a demonstration of the ILEP India Dashboard by Mr. Arun Kumar from LEPRA Society, facilitating a collaborative discussion on its utility for monitoring ILEP's initiatives and outcomes in line with NLEP targets.

- The session concluded with a summary of action points and commitments for the next phase of implementation, emphasizing the need for strengthened coordination among ILEP members, NGOs, and stakeholders.

Sno	Indicator	No
13	Number of health staff trained (MOs, Paramedical staff, ASHAs)	12761
14	Number of Lepra reactions treated/managed	1011
15	Number of persons affected by leprosy eligible for RCS undergone reconstructive surgery in ILEP Facilities	289
16	Number of MCR footwear provided for people affected by leprosy	9935
17	No. of people affected by leprosy received assistive devices	2360
18	Number of persons with disabilities due to leprosy availed disability care services	9837
19	No. of districts that have not reported stockouts of MDT/ prednisolone/ rifampicin longer than 4 weeks in the last 6 months	61
20	No. of cases validated	2198
21	No. of cases counselled	4687
22	Number of contacts screened	79748
23	Number of eligible contacts referred to NLEP for PEP	0
24	Number of persons supported to access livelihood	310
Total		214092

1. Strengthen leadership commitment and partnerships

3 Exchanging Knowledge and Learning - ILEP India Knowledge Sharing Series

- ILEP India's continued efforts to expand knowledge and learning resulted in hosting three sessions in the quarter.
- A session on “Home Based Self-Care Model for Leprosy Care in West Bengal” was conducted by Dr. Arup Chakrabarty, State Program Lead and NLEP Consultant, NLR India Foundation in July followed by another session on “VIKALP: The Call Centre Project” by Dr. Sanidhya Bhargava, State Program Lead and NLEP Consultant, NLR India Foundation in August 2024.
- The third session of the quarter was on “Leprosy and Mental Health” by Mr. Naveen Satle, State Coordinator, LEPRA Society in September 2024.
- These sessions underscored ILEP India's dedication to addressing diverse aspects of leprosy management, from self-care models and support services to mental health, thereby promoting a holistic approach to leprosy care in India.

ILEP India Knowledge Sharing Series
Please join us for the session on

HOME BASED SELF-CARE MODEL FOR LEPROSY CARE IN WEST BENGAL

Speaker:
Dr. Arup Chakrabarty
State Program Lead and NLEP Consultant (West Bengal), NLR India Foundation

16 July, 2024
3.30 PM - 4.30 PM

Please scan the QR or use the link to join

Join Zoom Meeting
<https://us06web.zoom.us/j/82062457390?pwd=I0U0dUk1c0RlW0A0Q0Zp44S4Yk9kLlM1>
 Meeting ID: 830 8345 7390
 Passcode: 506645

ILEP India Knowledge Sharing Series
Please join us for the session on

"VIKALP": THE CALL CENTRE PROJECT

Speaker:
Dr. Sanidhya Bhargava
State Program Lead and NLEP Consultant (Rajasthan), NLR India Foundation

13 August, 2024
3.30 PM - 4.30 PM

Please scan the QR or use the link to join

Join Zoom Meeting
<https://us06web.zoom.us/j/8922982829?pwd=dkkKpWU0c0JlU0NlR0YmE0P0p0CE1>
 Meeting ID: 892 298 2929
 Passcode: 35241

ILEP India Knowledge Sharing Series
Please join us for the session on

LEPROSY AND MENTAL HEALTH

Speaker:
Mr. Naveen Satle
State Coordinator - Madhya Pradesh, Lepra Society

27th September, 2024
3.30 PM - 4.30 PM

Please scan the QR or use the link to join

Join Zoom Meeting
<https://us06web.zoom.us/j/83323534975?pwd=MDk0ZDZlU0RlW0A0Q0Zp44S4Yk9kLlM1>
 Meeting ID: 833 2353 4975
 Passcode: 836972

4 Induction Workshop and MEAL training for the “NIRAMAYA III” Project

- GLRA India organized the induction workshop and MEAL (Monitoring, Evaluation, Accountability, and Learning) training for the "NIRAMAYA Phase III" Leprosy Project from July 29th to 31st, 2024, in Mumbai.
- The three-day workshop aimed to strengthen and improve the quality of leprosy care in India by supporting NLEP.
- Funded by DAHW Germany, the project will be implemented in 11 locations across 7 states, in collaboration with partner hospitals and through support for state leprosy programs.
- The project focuses on strengthening service delivery and capacity-building, ensuring comprehensive care and support for individuals affected by leprosy at both community and institutional levels.



5 Impact of Damien Foundation's Leprosy Control Program Across 7 Indian States: Achievements in Treatment, Rehabilitation, and Capacity Building

- DFIT has implemented a leprosy control program in 7 states across India which operates through 3 hospitals, 7 partner project hospitals, 13 Disability Prevention and Medical Rehabilitation field teams, and a rehabilitation home for individuals affected by leprosy.
- During the project period, a total of 2,725 patients were treated through outpatient department services, 93 new leprosy cases were detected, hospitals admitted 121 inpatients, managed 230 lepra reactions cases and 81 patients underwent deformity corrective surgeries.
- DFIT engaged with 2,274 patients through field activities, providing counseling for self-care practices and 1,871 patients are currently practicing self-care.



- Field teams conducted 94 training sessions for government health staff (medical, paramedical, and field staff), benefiting 3,656 individuals.

6 RC Surgery Follow-up Camp at St. Joseph Leprosy Center

- An RC Surgery Follow-up Camp was successfully organized by Lepira at ST. Joseph centre in Sanawad on September 14, 2024.
- The camp provided essential post-operative care to 32 patients who had previously undergone reconstructive surgery.
- Patients came from various districts, highlighting the camp's wide-reaching impact.
- Follow-up care was conducted by District Leprosy Officer Dr. Harishchandra Arya from Khargone, ensuring thorough evaluations and necessary medical attention for each patient.
- The camp played a crucial role in supporting the ongoing recovery and rehabilitation of patients, reflecting the center's dedication to improving the lives of those affected by leprosy.



7 Training on “Advance Safeguarding Champions” held in Kathmandu

- GLRA India, with support from DAHW Germany, conducted the "Advance Safeguarding Champions Training" from September 16th to 20th, 2024 at Tewa Centre, Kathmandu.
- The five-day training focused on protecting children, young people, vulnerable adults, and individuals with disabilities from abuse, exploitation, neglect, and harmful practices.
- Key topics included: Prevention of Sexual Exploitation and Abuse (PSEA), Non-Violent Communication techniques, and the Use of Whispli, a secure digital platform for reporting and managing safeguarding cases both in the office and the communities.



- The training strengthened GLRA India’s organizational capacity in safeguarding and provided a clear roadmap for PSEA implementation.

8 Empowering Frontline Health Workers: Training Program on Leprosy Awareness and Management

- A frontline health worker training program was held on September 10 in Sorva, Katthiwada, conducted by Lepra with 30 participants including ASHA workers, ASHA supervisors, Anganwadi workers, and ASHA Sahyoginis.
- Training emphasized increasing awareness of leprosy, including its causes, and symptoms, and the importance of early detection and treatment.
- Participants were educated on how to combat the stigma associated with leprosy and trained in the rehabilitation and community reintegration of affected individuals.
- It aimed to equip health workers to address not only medical needs but also the social and emotional well-being of patients.
- A representative from the Women and Child Development Department provided valuable insights into the challenges faced by frontline workers and effective strategies to overcome them.
- The program discussed government policies and support systems available for leprosy management, empowering health workers with knowledge and resources to improve community healthcare.



9 Leprosy and Migration in India – behind the numbers

- Swiss Emmaus Leprosy Relief Work India (SEI), in collaboration with Novartis Healthcare Private Limited (NHPL), conducted a study on migration in the context of leprosy to understand the social and demographic factors affecting treatment access for leprosy-affected individuals.



- The survey was carried out in Chandigarh, Delhi, and Uttar Pradesh, covering 396 newly diagnosed leprosy migrant patients, with 70% male and 30% female respondents.
- The primary reason for migration was better employment opportunities, but Delhi and Chandigarh were chosen for their "bigger hospitals" offering better healthcare services.
- 71% of respondents visited their homes once a year, with Delhi patients visiting more frequently. 85% stayed less than a day post-treatment.
- Nearly 50% of the respondents migrated once every couple of years. Men were more likely to visit their spouses (22%) than women (4%).
- The study highlighted the need for a clear definition of "migrant" in the leprosy context. This led to the Ministry of Health and Family Welfare adopting a formal definition, after consultation with stakeholders, to improve service delivery under NLEP.

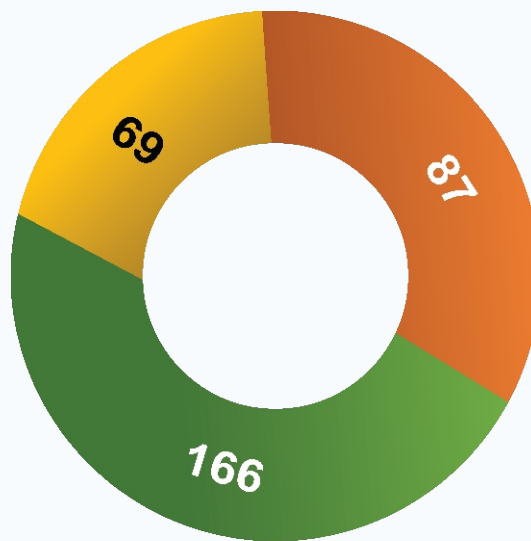
10 School Awareness Session on Leprosy Signs and Symptoms in Rajnagar Block

- On September 8, 2024, an awareness session was conducted by Lepra at Surajpura and Chandranagar Higher Secondary Schools in the Rajnagar block.
- The session focused on educating students about the signs and symptoms of leprosy, aiming to raise awareness and reduce the stigma associated with the disease among the younger generation. Approximately 300 students attended the informative session, which provided them with valuable knowledge about leprosy and its implications.
- By engaging with students in a school setting, the initiative encouraged open health discussions and helped dispel misconceptions surrounding leprosy.
- The involvement of school authorities further emphasized the importance of health education in fostering a supportive and informed community.
- This session is a significant step toward promoting awareness and understanding of leprosy among the youth, empowering them to contribute to a more inclusive society.



Key activities by NLEP consultants

Visits Trainings Meetings



From July to September 2024

From July to September 2024, ILEP agencies continued to support field and policy-level assistance to the National Leprosy Eradication Program (NLEP) through their 16 NLEP consultants across 14 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 166 advocacy and program implementation meetings; 69 trainings; and 87 visits to the districts, different health facilities, and leprosy colonies.

Life of Dr Durga Prasad Gabel

A Journey from Humble Beginnings to Medical Advocacy



Dr Durga Prasad Gabel was born on July 13th, 1984, in Jajang, Chhattisgarh, into a poor, illiterate family. Despite financial hardships, he excelled academically, completing his early education in village schools and later graduating with first-division honors from Saraswati Shishu Mandir in 2003. Driven by a deep sense of responsibility toward the underprivileged, Durga Prasad pursued a career in healthcare, completing his medical education at Katghora Medical College in 2006 and becoming a Rural Medical Assistant (RMA) after his internship at Korba District Hospital.

In 2009, Dr Gabel began his career as an RMA at PHC Portha, where he worked for five years, followed by stints in Masaniyakala and a return to Portha. His commitment to rural healthcare deepened when he underwent training on leprosy from The Leprosy Mission (TLM) through the Replicable Model (RM) Project. This training equipped him with the skills to diagnose and treat leprosy, a disease often misunderstood and stigmatized in rural communities.

Through the Project, Dr Gabel referred 60 leprosy patients for treatment, helping over 30 become leprosy-free. His efforts not only cured patients but also helped dismantle harmful superstitions surrounding the disease. In November 2020, he was posted at the Primary Health Centre in Hasaud, Jaijaipur block, where his work continued. In 2022, he received refresher training and referred over 20 more patients for treatment, further contributing to the National Leprosy Eradication Program (NLEP).

Today, Dr Gabel reflects on his journey with pride. “I feel proud that after receiving training from the TLM Champa hospital and with the support of the RM team, I can help people affected by leprosy get treatment,” he says. His tireless advocacy has transformed not only his own life but the lives of countless others, making him a vital part of India’s mission to eliminate leprosy and improve rural healthcare.

As in case of Dr. Gabel, there are numerous other health functionaries, especially at the grassroots level whose lives have been touched by the RM project and TLM Champa hospital who in turn are now able to identify leprosy patients and encourage them to access timely and complete treatment. **This document is an effort to narrate the processes that went into the project implementation**

The Story of Padma Kewat

From Stigma to Strength



Padma Kewat had always believed in the simplicity of life, living with her family in Odisha. They were an ordinary family, going about their daily routines with peace and dignity. But everything changed one fateful day. The quiet harmony of their lives was shattered when Padma, along with her father-in-law and mother-in-law, was diagnosed with leprosy. What followed was more devastating than the disease itself—the fire of discrimination, fueled by ignorance, spread throughout the village.

News of their condition swept through the village like wildfire. Almost overnight, they were ostracized by people they had known their entire lives. Friends turned away, neighbors whispered, and community members started treating them as though they had been cursed. They were no longer welcome to participate in village functions, celebrations, or even the simplest gatherings. They became invisible, except for the sting of judgment. The humiliation was constant. And then, the village took the cruelest step of all—they drove Padma and her entire family out.

Homeless, heartbroken, and desperate, they wandered from one place to another, seeking treatment. They consulted village-level doctors, self-proclaimed healers, and quacks. But nothing seemed to work. Instead, their condition worsened, deepening their despair. The disease, compounded by the weight of self-stigma, made it seem as though there was no way out.

Then, hope appeared where they least expected it. Word reached them about a place called the Leprosy Mission Hospital at Champa. It was said that this was not just another place of treatment but a sanctuary where people with leprosy could find both healing and dignity. With nothing left to lose, they made their way to the hospital. There, they were met with kindness and professionalism. The specialist doctors provided them with the right treatment, and slowly, they started to heal—not just physically, but emotionally as well. After months of care, they were cured of leprosy.

A new chapter began for Padma and her family. They were given a home in Champa, a symbol of stability after years of displacement. But Padma's journey was far from over. She had endured the pain of discrimination and knew firsthand how devastating it could be. Instead of retreating into the shadows of her past, she chose to transform her struggle into a mission for change.

Padma connected with an RM project team, where she underwent training. Armed with knowledge and empathy, she became a champion for those affected by leprosy. She began referring patients to the hospital that had saved her life, making follow-up visits to ensure they received the care they needed. Padma's heart extended beyond medical care—she would prepare and serve food to those suffering from leprosy, offer comfort, and help them regain their dignity.

But her work did not stop there. Padma became an advocate for those marginalized by society, helping people obtain ration cards and access to other resources they had been denied. She also joined a self-help group, where she not only worked on poultry farming but also contributed to the economic stability of her family. Her efforts turned into a ripple of change, lifting her family out of poverty and inspiring those around her to do the same.

In a community once filled with whispers of prejudice, Padma Kewat became a symbol of resilience, courage, and transformation. Her work has touched countless lives, and her own journey serves as a reminder that true strength is born out of struggle and patience.

As she continues to walk through her village, her head held high, the very people who once shunned her now see her as a beacon of hope. Padma Kewat is no longer the victim of stigma; she is the architect of change. And through her actions, she has proven that the wings of transformation are indeed born of patience and struggle.

Her story is a testament to the power of one person's courage to reshape not just their fate but the lives of many around them.