

QUARTERLY NEWSLETTER

JOURNEY TOWARDS ZERO LEPROSY

Vol. 03; Issue 9; Jan. - March 2025

- KEY HIGHLIGHTS
- RESEARCH
- **HEALTH**
- **EMPOWERMENT**
- LIVELIHOOD
- EDUCATION



Message from the Chief Executive Officer, NLR India

Dear Reader,

As we have stepped into a new year, I am proud to share the progress we have made together in the first quarter of 2025. This report highlights our continued efforts to fight leprosy, improve health services, and support the dignity and rights of persons affected by leprosy and disabilities.

From awareness campaigns and health trainings to supporting government schemes and creating livelihood opportunities, our work is creating real change. The dedication of our team, the strength of our communities, and the support of our partners keep us moving forward.

We are especially encouraged by the growing interest from media and government agencies, which helps bring more attention to the needs of our communities.

Let us continue working together to build a future free from leprosy, stigma, and discrimination.

Yours sincerely,

Dr. Ashok AgarwalChief Executive Officer, NLR India

KEY HIGHLIGHTS

- The new year 2025 began with renewed commitment from NLR India to eliminate leprosy and mitigate its devastating effects on affected individuals. Two ongoing projects from 2024 were merged into a single initiative to ensure a more focused and streamlined approach.
- In March 2025, NLR India Foundation was officially registered with the Department of Scientific and Industrial Research (DSIR) under the Ministry of Science and Technology, Government of India. With this, NLR India is now recognized as a Scientific and Industrial Research Organization (SIRO). This recognition marks a major achievement in our mission. As an evidence-based organization, we carry out research to improve the lives of people affected by leprosy, Neglected Tropical Diseases (NTDs), and disabilities It also adds to our credibility and commitment to scientific excellence, allowing us to continue creating a positive impact through innovation.
- NLR India field teams across various states commemorated Anti-Leprosy Day on 30th January 2025. They also actively supported state and district authorities in planning the fortnight-long Sparsh Leprosy Awareness Campaign (SLAC), which commenced the same day.



On 21st and 22nd January 2025, media teams from The Wire and Al Jazeera visited Jagat Mata Kusth Ashram (Tilak Nagar) and Nav Jyoti Association of Affected Persons (Piragarhi) to document the lives of individuals affected by leprosy. Accompanied by Ms. Sanjeeta Gawri (Lead – Policy Engagement) and Ms. Urmila Kumari (Colony Coordinator), the journalists engaged with residents through interviews and conversations. The visit focused on understanding the community's lived experiences, challenges related to stigma, healthcare access, and livelihood struggles. This interaction aimed to bring greater visibility to the voices of marginalized communities and foster public empathy and awareness through impactful media storytelling.

During the SLAC fortnight (30th January – 13th February), health awareness sessions were conducted for students in schools and colleges (including nursing institutions) across Delhi, Uttar Pradesh, Jharkhand, West Bengal, and Bihar. These sessions aimed to raise awareness among students and teachers about leprosy and its implications.





To address the lack of awareness about government welfare schemes among persons affected by leprosy, NLR India is developing a user-friendly Resource Directory (RD). This directory will include details of central and state schemes, eligibility criteria, application processes, and relevant links. The draft RD is currently being presented to residents in leprosy colonies for feedback.





Grocery items and dressing materials were distributed to residents of leprosy colonies in Jaipur and Delhi.

A Leprosy Awareness Campaign rally was organized by the NLR India Chandauli team, in collaboration with the District Leprosy Officer (DLO) office, on 31st January 2025.



Lymphatic Filariasis (LF), one of the Neglected Tropical Diseases (NTDs), causes significant suffering but can be managed effectively with proper care. A noteworthy development occurred when the district Vector Borne Disease (VBD) Cell of Aurangabad, Bihar, issued a directive to all Primary and Community Health Centres to support NLR India in implementing LF self-care programs.



Dr. Wim, Medical Director at the International Office of NLR, visited the PEP++ study sites in Chandauli and Fatehpur from 17th to 21st February 2025, where he closely monitored project activities, ensured compliance with study protocols and SOPs, supervised field teams, and gave inputs on the necessary corrective measures to strengthen implementation.

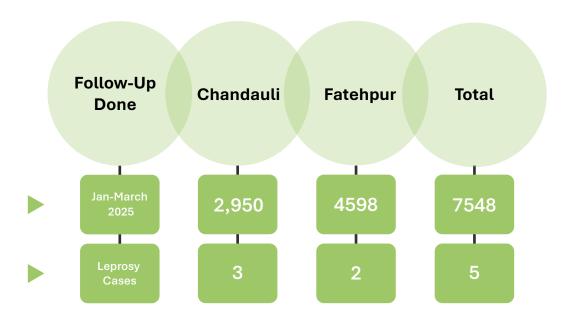
qPCR (quantitative polymerase chain reaction) testing is being conducted to confirm clinically diagnosed cases and monitor antimicrobial resistance to rifampicin, with the first sample for the PEP++ study collected at District Hospital, Chandauli by Dr. Ravi Bhushan in the presence of Dr. Wim, DLO Dr. Ramesh Prasad, and project coordinator of PEP++ Dr. Danish Suhail.





To observe the practice of diagnosis confirmation through qPCR testing, Dr. Wim and Dr. Danish Suhail visited the Stanley Browne Laboratory at The Leprosy Mission Trust India (TLMTI) in New Delhi, where they interacted with Dr. Itu Singh (Chief Research Scientist), Dr. Rabindra (Ravi) Turankar (Senior Research Scientist), and Dr. Ritu (Dermatologist).

Update on follow-up progress and new leprosy cases identification:



The Compassion Training initiative was launched to promote empathetic and stigma-free healthcare, especially for people affected by leprosy. It began with a pilot session on 3rd and 4th December 2024, with 16 participants including doctors, nurses, and paramedical staff. The training introduced the "Zone of Wellbeing" (ZOW) and received very positive feedback. Many participants said it was their first time attending such an interactive and emotion-based training. Based on their suggestions, the module was revised and sent for review. In January 2025, the final version was translated into Hindi and reviewed by Dr. Pravin (NLR India), Mr. Eishan Sharma and Ms. Tripti (Piramal Team), and Mr. Anil Kumar (NLR India). By February, three modules were ready—for doctors, paramedical workers, and mixed groups. The first official batch of training was held from 3rd to 6th March 2025, with 19 MBBS doctors from all eight blocks of Bokaro. The training helped improve their self-awareness, emotional strength, and commitment to patient cantered care.





Support in Developing State-Specific Strategic Plans (SSP)

NLR India continued assisting states such as Delhi, Uttar Pradesh, West Bengal, and Jharkhand in drafting their SSPs.

Training & Capacity Building (CB)

A total of 577 health staff were trained during January to March 2025 across Bihar, Jharkhand, Rajasthan, Uttar Pradesh, and West Bengal.

A one-day sensitization workshop on leprosy was conducted for 25 Indian Medical Association (IMA) doctors in Aurangabad on 10th March 2025. Topics included the objectives and goals of the National Leprosy Eradication Programme (NLEP), the Leprosy Post Exposure Prophylaxis programme, and rehabilitation measures.



Helpline

A unique initiative where counsellors contact patients currently undergoing treatment (fortnightly) and those Released from Treatment (RFT) (quarterly). The helpline received line lists from 17 districts. Feedback from patients was shared with concerned district authorities for follow-up.

Between January and March 2025:

- 79 cases were registered (55 on treatment and 24 RFT).
- 701 follow-up calls were made.
- 3 cases exhibited lepra reaction symptoms and were reported for further investigation.

Inspired by this initiative, the West Bengal Government launched a similar pilot project in Bankura district. "Rogi Sahayaks" are now reaching out to leprosy patients for counselling on drug adherence, adverse event management, and other concerns.

EMPOWERMENT

Key Updates

In Delhi, women residents of leprosy colonies were guided and supported in registering for the Mahila Samriddhi Yojana, a government scheme for women's empowerment.

LIVELIHOOD

- 43 Divyang Self-Help Groups were linked to Jeevika in Aurangabad, Bihar.
- An employment fair at the District Disability Rehabilitation Center in Aurangabad led to the distribution of battery-powered rickshaws to persons with disabilities (PWDs).

Support Facilitated:

BENEFIT	NUMBER
UDID Cards	26
Ration Cards	6
Disability Certificates	43
Disability Pensions	38
MGNREGA Cards	50
Railway Passes	2
Motorized E-Rickshaws	32

EDUCATION

Key Updates



Indira Gandhi National Open University (IGNOU) is the world's largest open learning university, offering flexible education to millions of learners globally. On the 24th of March 2025, IGNOU aired a live show on their channel Gyan Darshan on YouTube that covers an important and informative topic – Leprosy. Dr. Ashok Agarwal, CEO of NLR India Foundation, shared his expert insights on the subject. With his vast experience and deep knowledge, Dr. Agarwal explained the facts, myths, and modern treatments related to leprosy. This live show is an invaluable resource for students, and anyone interested in understanding the disease more comprehensively.

Upcoming Priorities (Next Quarter)

- Refresher training for Medical Officers 26th May 2025
- 21st National Task Force Meeting June 2025
- Advocacy meeting with State Leprosy Officer, Uttar Pradesh July 2025
- Finalization of State-Specific Strategic Plans
- Support for planned Leprosy Case Detection Campaigns (LCDC) in the states
- Development and finalization of the Resource Directory



Bank Details

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