



until
No Leprosy Remains



QUARTERLY NEWSLETTER

JOURNEY TOWARDS ZERO LEPROSY

Vol. 02; Issue 6, April- June 2024

INDEX

- 2 KEY HIGHLIGHTS
- 4 RESEARCH
- 6 HEALTH
- 7 EDUCATION
- 8 LIVELIHOOD
- 8 EMPOWERMENT
- 9 RESEARCH PUBLICATION
- 11 KEY UPCOMING EVENTS/
MEETINGS ETC.





Message from Trustee, NLR India Board, NLR India

Dear Reader,
Greetings from NLR India!

It's a great pleasure to welcome you to the 2nd quarterly newsletter of 2024!.

Our hearts are filled with gratitude as we reflect on the Silver Jubilee celebration at the India Habitat Centre. Your unwavering support and warm presence made this milestone truly unforgettable for us.

We were deeply moved and honoured to have so many esteemed government officials and professionals in the field of leprosy join us in acknowledging the impactful work of NLR India. Your recognition and encouragement resonate deeply within us, fuelling our resolve to continue our mission with even greater passion and dedication.

NLR India conducted a week-long plantation drive from June 5th to 13th. Together with 377 dedicated stakeholders, we planted 455 saplings across six states, a testament to our collective commitment to supporting leprosy-affected communities and nurturing a healthier, greener environment. Each sapling represents hope, resilience, and the promise of a brighter future.

From the bottom of our hearts, thank you for being an integral part of our journey. Your belief in our cause strengthens us. Together, we can achieve a world free from leprosy.

Yours sincerely,

Dr. Archana Singal
Trustee, Board



until
No Leprosy Remains

Annual Spring Meeting of Leprosy Research Initiative (LRI)



NLR India's representatives namely **Dr. Suchitra Lisam**, Head, Research & Knowledge Management, NLR India and **Mr. Sayantan Halder**, Research Coordinator, PEP App study attended the Annual Spring Meeting of Leprosy Research Initiative (LRI), the Netherlands from 17th-19th April 2024, Eindhoven, Netherlands. **Dr. Suchitra Lisam** presented the research study titled "Compassion training for reducing stigma and improve the quality of care of persons affected by leprosy" and attended the Expert Group Meeting on "Development of Telacebec drug related research proposal, funding opportunities" that was chaired by **Dr. Liesbeth Mieras**, Coordinator, Research & Advocacy, NLR International. **Mr. Sayantan Halder** presented the topic "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.

NLR India Silver Jubilee Celebration -Improving Leprosy prevention, care and combating stigma (Disseminate, Deliberate and Collaborate)

NLR India celebrated our 25th year of empowering and transforming the lives of the persons affected by leprosy including people living with disabilities at the India Habitat Center, New Delhi on 23rd -24th of April 2024. Honourable **Shri Bharat Lal**, Secretary General of the National Human Rights Commission, Government of India, graced the occasion as the Chief Guest. **Dr. Anil Kumar**, Principal Advisor of 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**, Chief Executive Officer (CEO), NLR International, The Netherlands, joined the event, and presented the Multi Annual Strategy (MAS) of NLR International and co-chaired several sessions. It was a special moment to reflect on our journey and renew our commitment to serving those in need. Total 101 participants representing several government agencies, partner NGOs, universities, civil based organizations and donor agencies etc. took part in the Event.



NLR India attended the inaugural of the Startup Clinic at Government Institute of Medical Sciences (GIMS)



NLR India's representatives namely **Dr. Ashok Agarwal**, CEO and **Mr. Brijendra Narain Choudhary**, Business Development Manager (BDM), attended the inaugural episode of the Startup Clinic at Government Institute of Medical Sciences (GIMS), Uttar Pradesh, which was held on 11th June, 2024 at GIMS. This initiative represents a crucial step towards fostering innovation and collaboration in healthcare, directly benefiting persons affected by leprosy, Lymphatic Filariasis (LF), and other skin Neglected Tropical Diseases (NTD).

The 19th Quarterly National Task Force (NTF) meeting of PEP++ Research Study



The 19th Quarterly National Task Force (NTF) meeting of PEP++ Project was held (in person) on 12th June 2024 in New Delhi, under the chairmanship of **Dr. Anil Kumar**, Principal Advisor, National Centre for Disease Control (NCDC), Govt of India (GoI) & Principal Investigator (PI-prog) of the Study. It was attended by **Dr. Jugal Kishore**, Director/Professor of Community Medicine Dept., Vardhman Mahavir Medical College (VMMC) & Safdarjung Hospital, MoHFW, Govt. of India and PI of study and Co-PIs such as **Dr. Sudarsan Mandal**, Sr. Chief Medical Officer (CMO), GoI, **Dr. Jaya Dehalvi**, State Leprosy Officer (SLO), Uttar Pradesh,

Dr. H. K. Kar, Professor, Kalinga Institute of Medical Sciences (KIMS), Odisha, **Dr. Ashok Agarwal**, CEO, NLR India and **Dr. Suchitra Lisam**, Head, Research & Knowledge Management, NLR India, Co-Investigator. The study progress and upcoming plans were presented by **Dr. Danish Suhail**, Project Coordinator and **Akshat Garg**, GIS/Data Manager, PEP++ study, NLR India. **Dr. Suchitra Lisam** updated the NTF members on the rationale and status of conducting qPCR test and briefed about outcome of the bilateral meetings between JALMA and NLR India. The NTF reviewed the progress of trial and upcoming plans such as conducting qPCR test, and blanket trial etc.

NLR India Team organized a week-long Plantation Drive in observance of World Environment Day (WED)

NLR India Team organized a week-long Plantation Drive which was carried out from 5th to 13th June, 2024 in observance of World Environment Day (WED) that fell on the 5th June 2024. Across several locations in six states namely Delhi, Rajasthan, Jharkhand, West Bengal, Uttar Pradesh and Bihar, our staff planted 455 saplings in leprosy colonies, community parks, office premise etc, with support of total 377 stakeholders from communities, peer supporters, beneficiaries, change agents and government agencies (Forestry Department, Health/Leprosy Cell etc.). During the drive, our staff also spread general awareness about Water, Sanitation and Hygiene (WASH), and on heat stroke etc. to the community. This is our first such initiative as we have taken a pledge with The United States Agency for International Development (USAID) 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.



RESEARCH



A. PEP++: Stop Transmission of Leprosy study

This quarter marked the completion of drug administration of the PEP++ study trial. The study achieved drug administration, either rifampicin and clarithromycin or only rifampicin to the eligible closed contacts of leprosy cases in intervention or control study arms respectively. A total of **60545** contacts were administered drugs. The follow-up of the contacts administered the drugs will begin in December 2024. Blanket campaign of single dose rifampicin will be conducted between July-November 2024.

- The follow up meeting on recommendations of NTF meeting was held on 19th June 2024 in virtual mode, which was participated by NTF members, **Dr. Wim van Brakel**, Medical Director and **Mr. Duane**

Hinders, Programme Manager, PEP++, NLR International.

B. Testing of PEP mobile App for strengthening Leprosy post exposure prophylaxis (LPEP) services

- The 8th Quarterly stakeholders' meeting was organized on 21st June 2024 under the chairmanship of **Dr. Sudarsan Mandal**, Sr. Chief Medical Officer (CMO), GoI and Co-PI of study. The meeting was attended by **Dr. Liesbeth Mieras**, Coordinator, Research & Advocacy, NLR International, Co-Investigator, **Dr. Ashok Agarwal**, CEO, NLR India, Principal Investigator, **Dr. Suchitra Lisam**, Head, Research & KM, Co-Investigator, **Ms. Nikita Jana**, HiLab, Indian Institute of Public Health (IIPH), Hyderabad, **Dr. Arup Kumar Chakrabarty**, State Programme Lead, West Bengal, NLR India, and **Mr. Sayantan Halder**, Research Coordinator, PEP App study. The study team took stock of the progress and had shared few recommendations.
- An error tool was developed to collect error data from control blocks. The tool was field tested, revised and finalized during the quarter.



- In Howrah, for the period from April-June 2024, contact tracing for **10** index cases was conducted using the LPEP App in intervention clusters, **180** contacts were screened out of which, **160** were found to be eligible and administered SDR-PEP. In Paschim Bardhaman, contact tracing for 10 index cases were conducted using the LPEP App in intervention clusters, and **217** contacts were screened out of which **211** were found to be eligible and administered SDR-PEP.

C. Compassionate training for reducing stigma and improving quality of life of persons affected by leprosy

- Training Programme on study protocol and baseline survey was conducted for project staff from 4th-6th April 2024 in Bokaro, Jharkhand. The training was preceded by inaugural session that was



chaired by **Dr. Sudha Singh**, District Leprosy Officer (DLO), Bokaro and attended by district leprosy staff. The training programme was participated by **Dr. Wim van Brakel**, Medical Director, and **Ms. Marente Mol**, Programme Officer from NLR International and **Dr. Ashok Agarwal**, CEO, **Dr. Suchitra Lisam**, Head, Research & Knowledge Management, **Akshat Garg**, Data Manager and **Amit Jain**, Manager - Monitoring, Evaluation & Learning from NLR India.



- The baseline survey for collection of quantitative and qualitative data from three types of study participants namely healthcare workers, persons affected by leprosy and family members of persons affected, was started from 9th May 2024 and till 30th June 2024, a total of 68 quantitative interviews and 61

qualitative interviews including one focus group discussions (FDGs) for male participants were held across several blocks, health facilities and villages in Bokaro.

- As part of the routine monitoring field visits undertaken by **Dr. Suchitra Lisam**, a briefing cum advocacy meeting was held with **Dr. Dinesh Kumar**, Civil Surgeon, Bokaro on 22nd May 2024.



D. Establishing the effectiveness of a peer support approach based Basic Psychological Support for NTDs (BPS-N) to address mental wellbeing, stigma and social participation of persons affected by and lymphatic filariasis in Jharkhand, India

- Introductory meetings were conducted with **Dr. (Maj) Ajay Bakhla Kumar**, Professor/Head, Dept of Psychiatry, Rajendra Institute of Medical Sciences (RIMS),

Ranchi, Govt of Jharkhand on 20th May 2024 and with **Dr. Birendra Singh**, State Leprosy Officer (SLO), and **Mr. Ranjit Pathank**, Budget Finance Officer (BFO) at State Leprosy Cell (SLC), Ranchi about the new study, and these meetings were led by **Dr. Suchitra Lisam**, Head, Research & Knowledge Management from NLR India and attended by **Dr. Siddhartha Biswal**, State Programme Lead (SPL), and **Mr. Kashinath Chakraborty**, Community Based Rehabilitation Coordinator (CBRC), Jharkhand state team, NLR India.

- The study protocol and the tools were submitted to RIMS, Ranchi for review by the Scientific Review Committee and Institutional Review Board, RIMS on 7th June 2024.



New partnership and collaboration forged:

- Memorandum of Understanding (MoU) signed between NLR India and ECHO India on 24th April 2024 for virtual training on leprosy, allied skin Neglected tropical diseases (NTD) and related disabilities to different stakeholders.
- An agreement signed between Piramal Foundation for Education Leadership and NLR India for the Compassion training study on 27th June 2024



HEALTH

Since 2024, NLR India started two new projects namely “Support for interruption of leprosy transmission” and “Support to Zero exclusion services”. Both of the projects are aligned with the strategic pillars defined in the National Strategic Plan (NSP) & Roadmap of leprosy 2023-27 launched by Central Leprosy Division (CLD), Government of India in January 2023.

As part of support for interruption of leprosy transmission project, NLR India is providing assistance in developing the state specific strategic plans (SSP), a mandate described in the NSP.

The State Programme Leads (SPLs) are supporting the drafting of SSPs in states of Bihar, Delhi, Jharkhand, Rajasthan, Uttar Pradesh and West Bengal. Majority of the states have developed the first draft.

Training is one of the most important interventions under this project. During April to June 2024, a total of **611** health staff have been trained on technical and programmatic aspects of leprosy. The training also included topics of prevention of leprosy with Single Dose of Rifampicin (SDR), Nikusht 2.0 (the reporting software) and Anti-microbial Resistance (AMR) surveillance. The participants were of different cadres including Medical Officers (MOs), Community Health Officers (CHOs), Auxiliary Nurse Midwives (ANMs), Non- medical Supervisors/ Assistants (NMS/A), Physiotherapists and Accredited Social Health Activists (ASHAs). Besides these, the SPL of West Bengal trained 20 postgraduate students of All India Institute of Hygiene & Public Health (AIIPH), Kolkata on role of NGOs & SDR-PEP in leprosy.

Assam and Madhya Pradesh are the new states where NLR India started working from 2024 to support the Leprosy Post- Exposure Prophylaxis (LPEP) implementation. In Madhya Pradesh, a virtual meeting of all District Leprosy Officers (DLOs) was held in May 2024 to discuss about the challenges of LPEP implementation and how to overcome them. A detailed plan for three months was chalked out. Another virtual meeting was conducted with the state officials of Assam about the status of LPEP implementation in May 2024.

The call centre or helpline is a unique intervention of NLR India. During April to June 2024, 38 new patients were registered with the call centre, total 197 follow up calls were made to the patients. The feedback received from the patients (regarding their drug, new signs and symptoms, self-care practices etc) were shared with the respective district health authority.

Under the project “Support to Zero exclusion services” trainings on Basic Psychological Support (BPS) for addressing mental health of leprosy affected, and guidance on Sexual & Reproductive Health (SRH) were conducted. The training participants on BPS were the MOs, ASHAs, peer supporters and change agents, while training on SRH was imparted to adolescents living in the leprosy colonies. A total of 410 health staff (including MOs) were trained on BPS during April- June 2024. 12 adolescents living in leprosy colonies were guided on SRH.



EDUCATION



NLR India strives for supporting the education of children living in leprosy colonies. There are multiple schemes of government and non-governmental organizations (NGOs) which provide support for the education of needy children. Staff of NLR India has been successful in providing education support to 59 children living in leprosy colonies through linkages to these schemes. Life skills are important needs of the young people to lead successful and productive lives. NLR India trains the young adolescents living in leprosy colonies on Life Skills Education (LSE) using a standard module. During the period of April- June 2024, a total of 17 adolescents were imparted training on LSE.

LIVELIHOOD

NLR India worked to promote livelihood for income generation for the affected persons. NLR India works to link the affected persons with the different social welfare schemes and services. During April-June, 2024; NLR India supported 206 affected persons and their family members, and connected them with different types of livelihood services and opportunities.

In Bihar, tailoring training was provided to 58 adolescent girls and women; this includes a fresh batch of 25 women and girls who joined NLR India Foundation's mobile sewing training center started on 7th June, in panchayat Pipra Bagahi, block Kutumba, Aurangabad, Bihar. On income generation, five women started earning after tailoring training in Aurangabad. Four women in Patna's Prem Nagar leprosy

colony were linked to livelihood i.e. shoes making. Two students of leprosy colony at Sitamarhi who were provided education support had started contractual jobs in government sector.

Through NLR India's support, a total of 42 ration cards, 58 Mahatma Gandhi National Rural Employment Guarantee Act (MNREGA) job cards and disability pensions to 24 Persons with Disabilities (PWDs) were facilitated by urging PWDs to apply and to follow up with the government officials. In West Bengal; six students were linked to vocational training opportunities. Three people from Kalyanpur colony were linked to Manabik pension (a pension scheme in West Bengal). In Uttar Pradesh, two persons affected by leprosy received money, Rs. 55,000/- each to start income generation activities from Sasakawa-India Leprosy Foundation (S-ILF) through facilitation by NLR India.



EMPOWERMENT

During April- June 2024, NLR India staff supported the persons affected with leprosy and disabilities in getting them organised, applying and receiving benefits from different services and schemes. During the period, the number of persons benefitting from NLR India's efforts through its linkage roles are - Unique disability ID (UDID) cards - 129, disability certificates - 155, bus passes -8, disability grade 2 certificates-10, E-rickshaws-42, railways pass- 35, self help groups (SHG) formed and supported- 15 and local forums formed-16

Apart from the above, different empowerment meetings and trainings were conducted with different stakeholders including peer supporters and change agents at different locations of the six



states. In these meetings, topics of community engagement, Rights of Persons with Disabilities (RPWD) Act, Basic Psychology Support (BPS), Tele-Manas, and govt. schemes etc were discussed.

In Bihar, two meetings with participation of 60 stakeholders including Panchayati Raj Institution (PRI), government officials, PWDs and social workers were conducted to integrate persons affected by leprosy for community participation and for accessing the government schemes. NLR India had supported the SLO Office, Delhi in identifying the existing discriminatory laws and documentation for requesting the concerned department.



Ms. Marisa Gerards, the Ambassador of the Netherlands to India, **Ms. Linda Hummel**, CEO of NLR International, **Dr. Ashok Agarwal**, CEO of NLR India and other NLR India staff visited the leprosy colony located in R.K Puram, New Delhi and interacted with the residents. They also joined the formation of the first local forum of the persons affected by leprosy.

Key Research publications on leprosy in 2nd quarter 2024:

1. Title of Published Paper:

The PEP++ study protocol: a cluster-randomised controlled trial on the effectiveness of an enhanced regimen of post-exposure prophylaxis for close contacts of persons affected by leprosy to prevent disease transmission

Extract: In 2016, NLR developed the idea for a large multi-country trial testing the effectiveness of an enhanced PEP regimen to significantly reduce the new case detection and stop the transmission of leprosy. An international expert meeting recommended a regimen consisting of three doses of a combination of two highly bactericidal and accessible antibiotics: RMP and moxifloxacin (MXF) for adults and RMP and clarithromycin (CLR) for children. In 2018, however, the European Medicines Agency (EMA) restricted the use of MXF as preventive treatment because of potential long-lasting and disabling side effects. In response to these restrictions, leprosy experts recommended to use the combination of RMP and CLR for both adults and children. This combination therapy using repeated doses has been tested in a nude mouse model. Results showed that the PEP++combination (RMP & CLR) has a greater effect compared to any single antibiotic. This increased effectiveness has not, however, been tested in human populations in endemic countries to date. In this trial, we hypothesise that the leprosy incidence will be reduced more substantially in areas where the enhanced regimen is administered, thus demonstrating the effectiveness of the enhanced regimen. Past studies have shown that the level of SDR-PEP effectiveness is not uniform across contexts or in relation to leprosy patients. To address this, a number of recent trials are seeking to strengthen PEP regimens either through the use of new medications or by increasing the dosage of the existing ones. However, few studies focus on the impact of multiple doses of chemoprophylaxis using a combination of antibiotics. The PEP++ trial will investigate effectiveness of both an enhanced regimen and use geospatial analysis for PEP administration in the study communities.

Ref: Hinders DC, Taal AT, Lisam S, da Rocha AM, Banstola NL, Bhandari P, Saha A, Kishore J, Fernandes VO, Chowdhury AS, van 't Noordende AT, Mieras L, Richardus JH, van Brakel WH. The PEP++ study protocol: a cluster-randomised controlled trial on the effectiveness of an enhanced regimen of post-exposure prophylaxis for close contacts of persons affected by leprosy to prevent disease transmission. BMC Infect Dis. 2024 Feb 20;24(1):226. doi: 10.1186/s12879-024-09125-2. PMID: 38378497; PMCID: PMC10877766.

2. **Title of Published paper:**

Experience with Administering Single Dose Rifampicin as Post-Exposure Prophylaxis (SDR-PEP) for Leprosy Through Blanket Approach in Uttar Pradesh, India.

Extract: No research has been done on administration of SDR-PEP using the blanket approach in India. The initiative of the Varanasi DLO was self-driven with the intention of addressing the occurrence of a very high number of new leprosy cases in this small population. Along with MDT he administered SDR-PEP to entire healthy population of the village, that was proven to be effective with negligible risk of inducing resistance in Mycobacterium tuberculosis (Mieras et al 2016). There are few examples of blanket use of SDR-PEP (Bakker et al 2005, Richardus et al 2021). Our experience shows that this blanket approach of using mass chemoprophylaxis with SDR-PEP is a promising strategy to interrupt transmission. A scientific comparison of the blanket approach and its (cost-) effectiveness in locations of varied endemicity and community mobility will help in better understanding of the approach. India aims to accelerate interruption of transmission by 2027 (NSP 2023-2027). This blanket approach deserves due consideration as per the evidence available as one of the strategies to hasten the stoppage of transmission.

Ref: Singh R and Agarwal A (2024). Experience with Administering Single Dose Rifampicin as Post-Exposure Prophylaxis (SDR-PEP) for Leprosy Through Blanket Approach in Uttar Pradesh, India. Indian J Lepr. 96: 159-161

3. **Title of Published paper:**

Hansen's Disease Presenting as Erythroderma in a Tribal Woman of South Gujarat

Extract: India is a nation that contributed nearly 62% of the global Leprosy cases to the world and a 37.7% increase in new cases detection in 2022 (WHO 2023), we always need to remember, that leprosy is the great imitator (Kundacki & Erdem 2019). Unusual presentations like BL leprosy with type 1 reaction presenting with erythroderma in our case though rare has been reported from India (Patki & Mehta 1989), Brazil (Miyashiro et al 2017) and Mexico (Romero et al 2020). Like our case, Romero et al (2020) didn't consider leprosy in the initial diagnosis, thought of psoriasis and lymphoproliferative disorders when asking for biopsy which on histopathology was confirmed as lepromatous leprosy and the patient responded well to multi-drug treatment. Patki & Mehta (1989) identified dapsone hypersensitivity as the cause for erythroderma. This case report highlights the importance of a thorough history taking and examination of erythrodermic patients, especially in a leprosy-endemic nation like ours which sometimes needs a high index of suspicion and ask for routine tests like slit -skin smear for AFB. Biopsy will help classify the spectrum but would not be needed to diagnose leprosy and initiate appropriate treatment to manage such rare cases.

Ref: Chaudhari D, Bharti A, Momin et al (2024). Hansen's Disease Presenting as Erythroderma in a Tribal Woman of South Gujarat. Indian J Lepr. 96: 171-178.

Upcoming key events/
workshops etc. in
next quarter
2024

- Organize virtual event on “Inclusion of persons living with disabilities in self-help groups”
- Signing of MoU between NLR India and GLRA for Randomized Control Trial (RCT)- Basic Psychosocial Support (BPS) study
- Organize National Task Force (NTF) meetings of PEP++ and for Quarterly Partners' Meeting on PEP App Study in September 2024
- Support development of state specific strategic plan
- Provide support to states of Assam and Madhya Pradesh on strengthening Leprosy Post Exposure Prophylaxis (LPEP)
- Signing of MoU with Kalinga Institute of Medical Sciences (KIMS), Bhubaneshaw and with Government Institute of Medical Sciences (GIMS), Greater Noida, Uttar Pradesh
- Recruitment of Lead, Advocacy, NLR International, based in NLR India Delhi office

click here

DONATE



Bank Details

NLR India Foundation

Bank name: AXIS Bank

Address : Vasant Kunj,

New Delhi- 110070

A/C No: 915010034733462

IFSC Code: UTIB000011

For any queries related to newsletter,
please write to info@nlrindia.org or suchitra.lisam@nlrindia.org

Developed & designed by Knowledge Management and Communication Team

Mervyn Basil
Fundraising &
Communication Officer

Dr. Suchitra Lisam
Head of Research & Knowledge Management

Sandipa Mudi
Graphic Designer



C-4/139, First Floor, Safdarjung Development Area, New Delhi 110016

For more information connect via

+91-11-26611215/16

www.nlrindia.org



Scan for more info
Follow us @nlrindia

