



until
No Leprosy Remains

QUARTERLY NEWSLETTER

JOURNEY TOWARDS ZERO LEPROSY

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INDEX

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





Message from Head, Research & Knowledge Management, NLR India

Dear Reader,
Greetings from NLR India!

It's a great pleasure to welcome you at the third edition of our quarterly newsletter of 2024!

I am excited to share some of our major highlights, achievements and upcoming events etc. including recent publications in leprosy. We continue with our endeavour towards contribution to National Leprosy Eradication Programme (NLEP) with respect to prevention of leprosy, disability including its management through provision of technical support, trainings & capacity building, development of state specific strategic plans (SSP) for the states where we work and through generation of new evidence and best practices for scale up.

Leprosy as one of the most ancient diseases ever known to mankind, and we have many miles to cover to eradicate it. There exists a huge scope and dire necessity for all relevant stakeholders to work together in bringing out hard evidence and feasible solutions towards maximizing our efforts to zero transmission, zero disabilities and zero exclusion. Our vision of zero leprosy free society and country can be achieved faster and better through integrated approach with allied skin NTDs, also addressing key social determinants such as WASH, nutrition, environment factor and climate change etc.

Hope you will enjoy reading this edition. We look forward to your support in this important journey of making a difference.

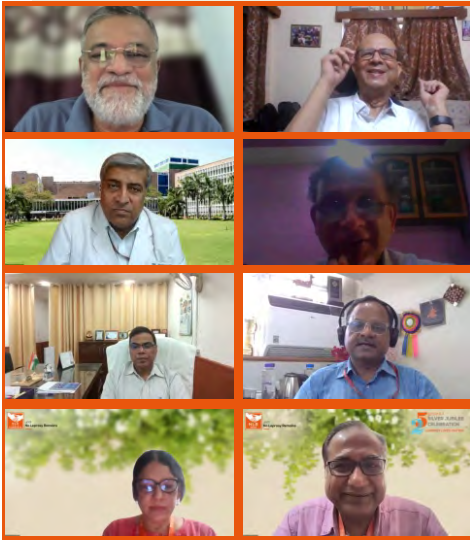
Yours sincerely,

Dr. Suchitra Lisam
Head, Research and Knowledge Management



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1st Meeting (virtual) of Research Advisory Committee



NLR India organized the first meeting (virtual) of the Research Advisory Committee (RAC) on 16th July 2024. The meeting was chaired by **Dr. Vishwa Mohan Katoch** (Chairperson of RAC), President of JIPMER, Pondicherry & Editor, Indian Journal of Leprosy, and attended by **Dr. Anil Kumar** (Co-Chairperson of RAC), Principal Advisor, Govt. of India, **Dr. Ranganathan Rao Pemmaraju**, Programme Advisor, Medical Issues, Sasakawa India Leprosy Foundation, **Dr. Sanjay Wadhwa**, Prof. & Head, Dept. of Physical Medical & Rehabilitation, All India Institute of Medical Sciences (AIIMS), Govt. of India, **Dr. Atul Ambekar**, Prof. & Head, Dept. of Psychiatry, AIIMS, **Dr. Vivek Pai**, Director of Bombay Leprosy Project, **Dr. Ashok Agarwal**, Chief Executive Officer (CEO), NLR India and **Dr. Suchitra Lisam**, Head, Research & Knowledge Management, NLR India. Dr. Suchitra Lisam presented the overview of NLR India-25th year's journey, key achievements, research portfolio, and terms of references (ToR) for RAC as key agenda items.

All India Convention for the Welfare of Leprosy affected persons

Dr. Sanidhya Bhargava, State Programme Lead (SPL), and **Ms.K. Ritu**, Community Based Rehabilitation Coordinator (CBRC) from NLR India Rajasthan Team, participated at the "All India Convention for the Welfare of Leprosy affected persons" that was held on 18th July 2024 at Rajasthan International Convention Center, Jaipur. **Shri Kalraj Mishra**, Honourable Governor of Rajasthan, **Shri Ram Naik**, former Governor, Uttar Pradesh, **Mr. Suresh Kaul**, President, Sarthak Manav Kusht Ashram, Patron, Sarthak Manav Kusht Ashram and **Dr. Vijay Laxmi Godara**, State Leprosy Officer (SLO), Rajasthan. Key sessions discussed were on disability laws, the current scenario of Leprosy in Rajasthan, and the work areas of Sarthak Manav Kusht Ashram etc.



Rajasthan State Media Coordination Committee Meeting



On 30th July 2024, **Dr. Sidhartha Biswal**, State Programme Lead (SPL), Jharkhand, NLR India attended the state media coordination committee meeting at R.C.H Campus, Conference Hall, Namkum, Ranchi. **Dr. Birendra Singh**, District In-Charge, (DIC), Health, Jharkhand chaired the meeting. At the meeting, total 11 media houses, Doordarshan and digital media representatives had participated in this meeting. Key discussion points were around Leprosy Case Detection Campaign (LCDC) activities, areas to make it more successful and mitigation plan to face the challenge on leprosy, and means of awareness generation among the community through different stakeholders. **Dr. Biswal**, NLR India provided an audio bite to F.M (Radio Dhum) and Doordarshan on preparatory activities of LCDC and overview of National Leprosy Eradication Programme (NLEP).

Sewing Machine Distribution Ceremony



NLR India hosted a sewing machine distribution ceremony on 30th July 2024, at Prithviraj Chauhan Smriti Bhawan, Sadar Block, Aurangabad, Bihar. This event was organized with the noble aim of empowering women, especially persons with disability who belong to socio-economically weaker sections. In this program, 25 females living with disability were selected from various blocks of the district to receive sewing machines. These women were out of more than 500 women trained on tailoring by NLR India through a mobile training school. Several dignitaries including **Mr. Amrit Kumar Ojha**, Assistant Director, **Mr. Dharampal Piyush**, District Program Manager and several Panchayati Raj members graced the event. **Mr. Amrit Kumar Ojha** distributed the sewing machines, marking a significant step towards women's empowerment. **Dr. Chandramani Singh**, State Program Lead, **Mr. Shambhu Nath Tiwari**, State CBR Coordinator and **Mr. Akshay Kumar Prajapati**, Disability Inclusive Development (DID) Coordinator from NLR India, Bihar Team played a crucial role in making this event a huge success. A total of 80 people including 25 beneficiaries and their guardians, participated at this ceremony.

Inclusion of Persons with Disabilities (PWDs) in Self Help Groups (SHGs)

NLR India organized a virtual (live) event titled "Inclusion of Persons with Disabilities (PWDs) in Self Help Groups (SHGs)", held on 22nd August 2024. **Dr. Rahul Singh**, Chief Medical Officer (CMO), District- Mau, Government of Uttar Pradesh was the Chief Guest, and **Ms. Nirmala Gupta**, Chairperson, Governing Board, NLR India addressed the event. The Guest of Honour was **Shri Amrit Ojha**, Additional Director Social Security (ADSS), Department of Social Welfare, Aurangabad, Government of Bihar and it was moderated by **Dr. Ashok Agarwal**, Chief Executive Officer (CEO), NLR India.



RESEARCH

A. PEP++: Stop Transmission of Leprosy Study

- The Data Management Committee (DMC) Meeting was held on 2nd July 2024 and it was attended by **Dr. Anil Kumar** (Chairperson), Principal investigator (PI) of PEP++ Study & Principal Advisor, National Centre for Disease Control, Minister and Health & Family Welfare (MoHFW), Prof./**Dr. Jugal Kishore**, PI of PEP++ & Director/Head of Community Medicine Dept., Vardhman Mahavir Medical College (VMMC) & Safdarjung Hospital (SJH); **Dr. Sudarsan Mandal**, Co-PI of PEP++, Senior Chief Medical Officer (CMO), MoHFW ; **Dr. Jaya Dehalvi**, Co-PI of PEP++ & State Leprosy Officer (SLO), Uttar Pradesh; **Dr. H. K. Kar**, Co-PI of PEP++ and Head of Dermatology Dept. Kalinga Institute of Medical Sciences (KIMS), Odisha; **Dr. Ashok Agarwal**, Co-PI of PEP++ & Chief Executive Officer (CEO), NLR India; **Dr. Suchitra Lisam**, Head of Research & Knowledge Management cum Co-Investigator, NLR India; **Dr. Danish Suhail**, Project Coordinator, PEP++ &

Convenor of DMC, NLR India and **Mr. Akshat Garg**, Senior Manager (Data, IT & GIS), NLR India (invitee).

- The Blanket Contact (BC) Arm of PEP++ was completed in Haswa block of Fatehpur district and Chandauli block of Chandauli district during this quarter. A total 50,481 BC were enrolled in Haswa block, Fatehpur and Chandauli block, Chandauli district, of which Single Dose Rifampicin (SDR) was administered to 49,104 BC and 83 BC who were suspected of having leprosy were referred, of which 34 BC suspects were confirmed for leprosy.



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

- Feedback from the district and the block supervisors was collected for the Rifampicin tracker tool that is currently under trial. This input was used in further refining the tool to enhance its practicality for field use.
- Dr. Ashok Agarwal**, CEO NLR India visited Chakbeldubi Shishu Shiksha Kendra , Pachla block, Howrah for observing live demonstration of LPEP through the LPEP App and monitored the overall status of LPEP App Study. He interacted with ASHA and ANM who are the primary users of the App, discussing their experience with the implementation of the new system.
- In Howrah, contact tracing for 10 index cases were conducted using the LPEP App (intervention clusters). In the process, 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 was conducted using the LPEP App (intervention clusters). In the process, 217 contacts were screened out of which, 211 were found to be eligible and administered SDR-PEP.



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

- In-depth interviews for qualitative data were completed among 30 study participants, of which 10 were persons affected, 10 were families of persons affected and 10 were health-care providers. Total four focus group discussions (FGDs) were conducted, two each for persons affected (male and female) and health-care providers respectively.
- Transcription and translation of these 30 in-depth interviews and 4 FGDs groups were completed. The analysis of primary data was started, and draft report was developed. On basis of the draft report, the development of training module on cognitive based compassion training (CBCT) was initiated.



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

- The ethical approval for the study was obtained from the Rajendra Institute of Medical Sciences (RIMS), Govt. of Jharkhand, Ranchi.
- The Memorandum of Understanding (MOU) was signed between German Leprosy Relief Association (GLRA) and NLR India for the BPS-N study in September 2024.
- The process for submission of the BPS-N study protocol to Indian Council of Medical Research (ICMR)- Health Ministerial Steering Committee (HMSC), Govt of India was under process.

HEALTH



A. Technical Support to National Strategic Plan (NSP)

NLR India developed the template for state specific strategic plan and district specific strategic plan. It was shared with all National Leprosy Eradication Programme (NLEP) consultants during a review meeting organized by International Federation of Anti-Leprosy Associations (ILEP) on 3rd July 2024. The meeting was attended by the officials from Central Leprosy Division (CLD), Government of India (GoI), ILEP Coordinator and NLEP Consultants from across the country. The template was well appreciated and is being referred/ used by different states to develop their plans for developing state specific strategic plans.

B. Training and capacity building

The trainings of health-care staff were organized in Uttar Pradesh (Etawah, Farrukhabad and Mathura districts), Bihar (Buxar, Aurangabad, Nawada and Patna districts) and West Bengal (Asansol, Bankura and Purulia districts). The trainings were on different components of technical and programmatic aspects of leprosy and LCDC. A total of 453 health staff including medical officers attended the trainings.



C. Helpline

A unique project of NLR India in which the counselor calls the patients on treatment and those who are Released from Treatment (RFT) fortnightly and quarterly respectively. The line lists of patients are received from 17 districts. The feedback received from the patients is shared with concerned districts for follow up. Total 88 new cases were registered in the call center and more than 385 follow up calls were made to patients. They have been counselled on adherence of drugs, addressing their fears and concerns regarding disease, drugs and their effects; selfcare and prevention of leprosy.

D. Information Technology (IT) Advisory Committee

The IT Advisory Committee was established and the first meeting of the committee similar to the RAC was organized.

E. Self-Care Camp

23 ASHA workers and 24 Person affected by leprosy attended a selfcare camp organized in Pali, Rajasthan on 27th August 2024. In the camp, leprosy, self-care practices, exercises, stigma reduction, and pension-related issues, were discussed. The persons affected by leprosy were provided MCR footwear, oil, Tub, Povidone iodine solution, brush, Vaseline and crutches by government.

EDUCATION

- Support to leprosy colonies on life skill education (LSE) and sexual reproductive health (SRH).
- LSE & SRH trainings were organized at Barakar and Lachhipur colonies of West Bengal which were attended by 14 young adults.
- Two students had been supported through Sasakawa India Leprosy Foundation (SILF) from Kalyanpur Leprosy colony, Bankura, West Bengal.



LIVELIHOOD

Support to colonies- facilitate linkages:

On 29th July 2024, Kanpur Nagar's District Disability Empowerment Department held a camp in block Chaubepur to assess various forms of impairments for the scheme beneficial to the persons with disabilities including impairments pension, leprosy pension, assistive equipment, livelihood scheme, Reconstructive surgery (RCS), and Unique Disability ID (UDID) cards. In this camp, around 150 people with disabilities got benefitted. NLR India with support of Self-Help Group (SHG) members, helped the affected persons in getting the following items, such as 146 persons received UDID cards, 3 persons applied for loan for small business, 40 persons received ration cards, 204 persons affected given disability certificates, 40 persons received disability pension, 36 persons given railway passes and 85 persons given motorized e-rickshaw.



EMPOWERMENT

A. Resource Directory

The development of resource directory on different available government schemes for persons with disabilities in six NLR India states, the provisions, eligibility criteria and the process of application was under process.

B. Stigma Reduction

Total 80 persons (51 male & 29 female) General health-care staff who are Auxiliary Nurse and Midwife (ANM) & Paramedical Workers (PMW) were trained under NLEP regarding Zero Exclusion on 23rd & 25th July 2024 at General Nursing and Midwifery (GNM) training School, Buxar district, Bihar. Key sessions covered were stigma discrimination, reaction management, prevention of disability Self-care, Basic Psychological Support (BPS), and Govt Schemes. In August, 95 medical doctors (MO) and paramedical workers (PMW) were trained on mental well-being in Jaipur. In the same training 23 ASHA workers and 24 (14 Male and 10 Female) persons affected by leprosy were trained on mental well-being in Bali block, Pali district of Rajasthan.



Key research publication on leprosy in 3rd quarter 2024:

Title of Published Paper:

Comparative analysis of leprosy detection rate regarding its clinical spectrum through Polymerase Chain reactions (PCR) using the 16SrRNA gene: a scientometrics and meta analysis

Extract: There is evidence that 16S rRNA gene can be used in PCR for complementary detection with high sensitivity and specificity. However, there is no literature convention on its diagnostic correspondence regarding the particular operational classification of the leprosy disease and the study aimed to correlate through a meta -analysis, the detection rate of leprosy between the PCR method with the 16S rRNA gene in the clinical forms Pauci bacillary and Multi bacillary in relation to confirmed cases. The systematic review and meta -analysis study was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 guidelines. The PCR diagnosis method for 16S rRNA gene of M. Leprae has low viability and diagnostic sensitivity in both clinical biopsy samples and leprosy skin smears. This implies little validation of it as a PCR target gene for diagnosis the disease highlighting limitations in the actual technique.

Ref: Silva MJA, Brasil TP, Silva CS, Frota CC, Sardinha DM, Figueira LRT, Neves KAS, dos Santos EC, Lima KVB, Ghisi NdC and Lima LNGC (2024) Comparative analysis of the leprosy detection rate regarding its clinical spectrum through PCR using the 16S rRNA gene: a scientometrics and meta-analysis. *Front. Microbiol.* 15:1497319. doi: 10.3389/fmicb.2024.149731.

**Upcoming key events/
workshops etc. in
next quarter
2024**

- Supporting the NLR India supported state governments in finalizing the state specific strategic plans (SSP)
- Organize the quarterly meetings of PEP App and PEP++ studies
- Pilot the training module on compassion care among the medical officer (MO) & general health- care (GHC) of Bokaro district, Jharkhand for the compassion training (CT) study.
- Conduct the annual strategic meeting of NLR India.

[click here](#)

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