NEWSLETTER OF NLR INDIA

JOURNEY TOWARDS ZERO LEPROSY

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### Greetings from Managing Trustee, NLR India

Dear Readers,

Leprosy is a disease that some people are afraid of, and it makes life hard for those who have it. We, at NLR India are doing our best to make things better for the people affected by leprosy through several interventions like

training of health care staff for better service delivery under National Leprosy Eradication Programme (NLEP), providing education, and livelihood support, empowering persons affected and living with disabilities and conducting innovative research etc.

2023

One big thing we are doing is fighting against the idea that people with leprosy are different. We believe that everyone should be treated with empathy and respect, no matter what disease they have. To make this happen, we are generating awareness about leprosy, getting communities involved, and talking to leaders about the importance of treating everyone fairly. We are also working really hard to understand leprosy better.

None of this would be possible without your help. Your support, whether it's spreading information about leprosy and our work, or giving fund to support our activities is incredibly important. Together, we are making progress, and we want to say thank you for being a part of our mission.

We are on a journey to make leprosy a thing of the past, and we are glad to have you with us. Together, we can make a world where everyone is treated kindly and leprosy doesn't bring fear or discrimination.

Let's come together to work towards the goal of making India a leprosy-free country.

Thank you for being a part of our team!

Sincerely, **Dr. Ashok Agarwal** Managing Trustee, NLR India



### MAJOR HIGHLIGHTS

- NLR India had organized a virtual event (live) on 19th May 2023 to share the learnings of project called Call Centre (VIKALP). The event was chaired by
   Dr. Sudarshan Mandal, Deputy Director General (DDG-L), Central Leprosy Division (CLD),
   Ministry of Health & Family Welfare (MoHFW),
   Government of India (Gol). He had appreciated the initiative of NLR India and had suggested for scaling up across India.
- NLR India had participated in the 13th National Conference of Indian Association of Epidemiologists (IAE) organised on 29th & 30th April 2023 at India Habitat Centre, New Delhi. The theme of the conference was "Epidemiology Driven Collaboration and Resource Sharing to Achieve More in National Public Health Programs and Activities". NLR India had felicitated **Dr. Anil Kumar,** Principal Advisor, MoHFW, Gol with the "Leprosy Champion", award along with a Lifetime achievement certificate, which was presented by **Ms. Nirmala Gupta**, Chairperson of Governing board of NLR India.



Virtual event Call Centre (VIKALP) on 19th May 2023





13th National Conference of Indian Association of Epidemiologists (IAE) organised on 29th & 30th April 2023 at India Habitat Centre, New Delhi.



### **• KEY UPDATES OF THEMATIC AREAS**



# 1. HEALTH

#### Technical trainings on leprosy

General health care (GHC) staff 37( including Medical Officers (MOs) were trained on leprosy and National Leprosy Eradication Programme (NLEP) across five states i.e. Bihar, Uttar Pradesh, Uttarakhand, Jharkhand, West Bengal.

of Suspects Identified Detection Campaign" अभियान के तहत में में रोग पुचिर शिविर strict NLEP program cell har Found

#### Self-care trainings cum

camps

40

cum camps were
 organised at Primary
 Health Centers (PHC)
 Community Health

Centers (CHC) in Bihar, Jharkhand Rajasthan, Uttarakhand & Uttar Pradesh.

1071 Participants

Persons affected by leprosy

Affected | | Iymphatic filariasis

**23** 

Accredited Sc

BC Health Activis

General Health Care Staff

others such as family members • of persons affected, and, persons representing other organisations et



#### NLR India provides education support to children of persons affected by leprosy

2. EDUCATION

and - 60 Youths

supported for education and vocational training in the states of Jharkhand, Rajasthan, and Uttar Pradesh. These children were given stationaries such as pens, pencils, erasers, note books, school bags etc. Besides, support for ayment of school fees were also given to some children.

कुष्ठ रोग और प्लस पोलियो **54100 SUPPOR** सफल संचालन को लेकर हुआ ष्र<sup>4</sup> Discrimation by Empore Attected by Lapros **DUNDA** 

आवाज प्रतिनिधि

राजमहल/साहिबगंज : अनुमंडल अस्पताल सभागार में कुष्ठ खोज अभियान एवं अनु राष्ट्रीय पल्स पोलियो कार्यक्रम के सफल संचालन को लेकर अस्पताल के प्रभारी उपाधीक्षक डॉक्टर गुफरान आलम के नेतृत्व में बुधवार को एक दिवसीय प्रशिक्षण का आयोजन किया गया। मौके पर मुख्य रूप से प्रदेश से आए स्टेट कोऑर्डिनेटर डॉक्टर सिद्धार्थ विशाल एवं

## **• KEY UPDATES OF THEMATIC AREAS**



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426

# **3. LIVELIHOOD**

Persons were supported under our livelihood initiatives

# 15,4

NLR India provides livelihood support to persons affected by leprosy and living with disabilities including youths who are dependents of persons affected, through vocational training, jobs or self-employment. We play our role through both linkage and financial assistance.

# 4. EMPOWERMENT OF PERSONS AFFECTED

Self-Help group (SHG) trainings/ meetings

> persons attended **751** trainings cum meetings of Self-help groups (SHGs

in the states of Bihar, Jharkhand, Uttar Pradesh and West Bengal at which participants were briefed on functioning and maintenance of SHGs. The registers and records were reviewed, and feedback was provided for improvement etc.

persons affected by leprosy & persons with disability NLR India facilitated the

Support provided to

NLR India facilitated the distribution of assistive devices to persons living with disability in Aurangabad, Bihar and Hazaribagh, Jharkhand.

> persons were given assistive devices

112 persons received disability pension

**226** th

 persons received
 their disability certificates

ते ची मी

 persons received Universal Disabled Identity (UDID)
 cards, through NLR India's support in partnership with Disabled People Organization (DPO).

66 persons affected by leprosy were given microcellular rubber (MCR) footwear.

183

### **• KEY UPDATES OF THEMATIC AREAS**



# **5. RESEARCH**

#### PEP++ : Stop transmission of leprosy study

The 16th meeting of the National Task Force (NTF) was held on 14th June 2023, under the chairmanship of **Dr. Anil Kumar**, Principal Investigator (PI) of PEP++ Study and Principal Advisor (Non-Communicable Diseases), Director General of Health Services (DGHS), Govt of India.

In the reporting period, index cases got enrolle in the study and
 11663

eligible close contacts were screened and medicated with either single dose rifampicin (SDR) or PEP++ regimen (Rifampicin and Clarithromycin) in district Chandauli and Fatehpur, Uttar Pradesh.

#### Study on "Testing of PEP mobile App for strengthening LPEP services"

Under this study that

 is implemented in 2 districts
 of West Bengal;
 demonstration of 2nd Beta
 version of PEP App was
 organised. The App was tested,
 feedbacks were used to improve
 and finalize the App.

# Compassionate care for persons effected by leprosy

- Sanction letter for conducting the study was received from Leprosy Research Initiative (LRI), Netherlands, and preparatory work for hiring of staff were initiated.
- All the tools and questionnaire for data collection etc. were translated into local language

#### **Evaluation of key NLR India's Projects**

- Preparatory activities for evaluation of key NLR India's projects had been initiated.
- The evaluation will be guided by a Technical Advisory Committee (TAC) chaired by **Dr Sudarsan Mandal,** DDG (L), CLD.
- Quarterly review meeting of stakeholders was held on 29th June 2023 under chairmanship of
   Dr. Sudarsan Mandal, DDG (L), CLD and Co- Principal Investigator (PI) of the study. Relevant stakeholders attended the meeting.
- In May 2023, the proposal was resubmitted to the State Institute of Health & Family Welfare (SIHFW), West Bengal for ethical clearance, and the approval was granted on 22nd June 2023. The data extraction form was field tested and finalized.



#### Impact of self-care practices

Miss Seema Kumari, 16 years old female, daughter of Mr. Mohan Choudhary, residing in Jori master Mohalla, Hunter Ganj block in Chatra district of Jharkhand, was diagnosed as a leprosy case on 15th September 2019 with the help of ASHA/ Sahiya and **Mr. Arun Kumar Yadav**, Paramedical worker (PMW). When she visited the Community Health Center (CHC) at that time, she had slight clawed left hand little and ring finger and had with more than five patches all over her whole body as well as sensory loss of palmar surface in left hand.

As advised by the Medical Officer (MO), Yadav ji started her treatment for Multi Bacillus (MB) i.e. Multi Drug Therapy (MDT) and counselled her to take regular medication and advised to take care of her





**BEFORE SELF-CARE** 

AFTER SELF-CARE

left-hand disabilities through self-care practices using HOPE method (H-hydro, O-oleo, P-physio, E-exercise). At present, she had completed 12 monthly pulses of MDT under proper supervision and monitoring by PMW, ASHA and MO of Hunter Ganj CHC. She was practicing self-care regularly as a result there is no clawing in her left hand. NLR India's staff had been constantly supporting her on self-care related activities and following up with the PHC.

### KEY WORKSHOP ORGANIZED & SPECIFIC SUPPORT PROVIDED

- A five days National training program on "Qualitative and Quantitative Research" was organised from 3rd to 7th April 2023 in New Delhi for NLR India's staff.
- NLR India participated in National Leprosy Eradication Programme (NLEP) review of the North-Eastern (NE) states and facilitated a session on Leprosy Post Exposure Prophylaxis (LPEP).
- NLR India's staff undertook joint visits to monitor the Leprosy Case Detection Campaign (LCDC) at Jharkhand, as assigned by the CLD. During the LCDC, our staff visited and monitored LCDC in three districts of Jharkhand namely Palamu, Latehar and Lohardaga. Large number of suspects were identified and referred through LCDC in these districts.
- Members of Governing Board of NLR India visited Bharatpur, Rajasthan, Varanasi, and Chandauli in Uttar Pradesh and met the residents of leprosy colony and other beneficiaries of projects. Ms. Nirmala Gupta, Chairperson of Board visited "Apna Ghar organisation" at Bharatpur which shelters the persons affected by leprosy with mental health problems.
   Dr. Lalit Kant, Vice-Chair of Board visited Varanasi & Chandauli, Uttar Pradesh and observed the activities under PEP ++ research project and "Disability Inclusive Development" project.

# UPCOMING KEY EVENTS / WORKSHOPS IN NEXT QUARTER 2023



- Organise a live virtual event (Facebook) on "Learnings of Life Skill Education & Sexual Reproductive Health" and "Learnings from Disability Inclusive Development (DID) in Bihar".
- Organise Quarterly stakeholder meetings for two research studies i.e. PEP++ and PEP App
- Roll out of randomized trial intervention under PEP App Study in Howrah and Paschim Burdhmann, West Bengal
- Audio-video documentation of NLR India's work across five locations i.e. Bihar, West Bengal, Uttar Pradesh, Jharkhand, and New Delhi.
- Development of NLR India Multi Annual Strategy (MAS) based on National Strategy Plan (NSP).



#### Bank Details NLR India Foundation

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