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Greetings from Vice Chair, NLR India Foundation

Dear Readers,

I am glad to share the 3rd issue of the Quarterly newsletter!

I hope you found the 2nd issue informative. Several of you provided your positive feedbacks on the newsletter. Thank you. Effective feedback, both positive and negative is very helpful.

Feedback motivates us to perform better. There were lot of activities in the quarter July to September 2023. We had a series of virtual events on interesting topics related to our project activities. They all were live on Facebook. With your active participation in the events, our outreach and impact on social media had increased tremendously. The live event highlighted the activities in our five thematic areas i.e. Health, Education, Livelihood, Empowerment and Research.

In this issue, we highlight the live events that were organized in this quarter: mobile tailoring training for livelihood support to women who are either persons affected with leprosy or their dependents; learnings from education support i.e. life skills education and sexual reproductive health being provided to girls and boys affected by leprosy, and living with disabilities; and learnings from disability inclusive development. These events had captured the essence of projects through sharing of insights and feedbacks for improvements from varied stakeholders. In coming months and next year 2024, we will continue to present and discuss our work at these virtual events that has helped us in reaching out to rest of the leprosy community, public health practitioners and the common people who continue to take part and join the discourse related to our work. We would be happy to extend an invitation if you and anyone you know are interested in joining these live events, and you may write to us. I also request each one of you to reach out to your network and make at least three new followers on our social media. Your gesture will enriched our network and facilitate extending our services to those persons whom we could help through these activities.

We eliminated leprosy as a public health problem, now the challenge is to reach zero leprosy. For this we would require better methods for prevention, early diagnostic tools and effective treatment. Hence, we are focussed and dedicated for development of innovative tools, interventions etc. in partnership with the National Leprosy Eradication Programme (NLEP), Government of India, academic institutes, and partner agencies. Once developed, and if found effective and useful, these innovations will support in achieving the goals of National Strategic Plan (NSP) for zero leprosy 2023-2027. We are on a mission to make leprosy a history and we are glad to have you with us and continue supporting our work and spread knowledge of the good cause.

I am happy that the Knowledge Management team of NLR India launched the newsletter and is continuing this important initiative which connects and informs us.

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

Sincerely,

Dr Lalit Kant

Vice-Chair of Governing Board



until
No Leprosy Remains

▶ MAJOR HIGHLIGHTS

- NLR India continued to organize regular monthly series of virtual events (Live) in the months of July, August and September 2023. The titles of these sessions were "Learnings from Mobile Tailoring Training of Women & Adolescent Girls Affected by Leprosy & Disabilities" held on 4th July; session on "Learnings from Life Skills Education (LSE) & Sexual Reproductive Health (SRH)-Guidance of girls and boys affected by leprosy and living with disabilities" and session on "Learnings from Disability Inclusive Development (DID) in Bihar" on 4th July, 18th August and 28th September 2023 respectively. Several stakeholders from the government agencies, partners and beneficiaries attended these sessions and shared their valuable insights, feedbacks and appreciated the efforts of NLR India in facilitation and supporting livelihood, education and empowerment for persons affected and living with disabilities including their dependents.



Learnings from MOBILE TAILORING TRAINING
of Women and Adolescent Girls Affected by Leprosy and Disabilities

SPECIAL GUEST: Mr. Bharat Jauhi, Member, Ministry of Health and Family Welfare, Government of Bihar

CHIEF GUEST: Ms. Somya Shakti, Joint Director, Health, Education and Welfare, Bihar

MODERATOR: Dr. Pradeep Kumar, Director, National Community Based Rehabilitation (NCBR) Centre, NLR India Foundation

CHAIRPERSON NLRIF: Ms. Nirmla Gupta, Chairman, NLR India

THE VIRTUAL EVENT IS ORGANISED BY NLR INDIA FOUNDATION
DATE-4TH JULY 2023
TIME- 3:00 PM - 4:00 PM

Join the conversation on Facebook

Virtual event Learnings from Mobile Tailoring Training of Women & Adolescent Girls Affected by Leprosy & Disabilities" held on 4th July 2023

[click here](#)



Learnings from Life Skills Education (LSE) & Sexual and Reproductive Health (SRH) Guidance of Girls and Boys Affected by Leprosy and Disabilities

A Virtual Event by NLR India

Chief Guest: Dr. Shivjee Kumar, Former State Commissioner of persons with disabilities, Department of Social Welfare, Govt. of Bihar

Guest of Honour: Ms. Rita Seth, Co-founder and Head of Mental Health Programmes of Saransh Health Foundation

Address by Board Chair: Ms. Nirmla Gupta, Chairperson, NLR India

Moderator: Dr. Ashok Agarwal, Country Director, NLR India

Date: 18th August 2023
Timing: 4:00 PM - 5:00 PM

Virtual event Learnings from Life Skills Education (LSE) & Sexual Reproductive Health (SRH)-Guidance of girls and boys affected by leprosy and living with disabilities on 18th August 2023

[click here](#)



Learnings from Disability Inclusive Development (DID) in Bihar:
How Empowered are the Persons with Disabilities?

A Virtual Event by NLR India

Chief Guest: Dr. Shivjee Kumar, Former State Commissioner of persons with disabilities, Department of Social Welfare, Govt. of Bihar

Guest of Honour: Ms. Rita Seth, Co-founder and Head of Mental Health Programmes of Saransh Health Foundation

Address by Board Chair: Ms. Nirmla Gupta, Chairperson, NLR India

Moderator: Dr. Ashok Agarwal, Country Director, NLR India

Date: 28th Sep 2023
Timing: 4:00 PM - 5:00 PM

Virtual event Learnings from Mobile Tailoring Training of Women & Adolescent Girls Affected by Leprosy & Disabilities on 28th September 2023

[click here](#)

- A delegation team from Research Triangle International (RTI), National HQ New Delhi Office had paid a visit to Sreenivas Puri leprosy colony in New Delhi on 25th July 2023. The team were briefed about the key activities and support provided to the residents of the colony by NLR India. They also took part in felicitation of young students of the leprosy colony who had achieved academic excellence in their respective schools.



Educational support provided to students of Sreenivas Puri leprosy colony, New Delhi



- A three members delegation team from NLR International Office (IO), the Netherlands visited India in the period from 3rd -11th August 2023. The team headed by Ms. Inge Klaassen, Head of Programme, Research and Partnership, NLR Netherlands along with NLR India's National Core Team i.e. Dr. Suchitra Lisam and Dr. Pradeepta Nayak, for the field visits. The team had visited the project sites of NLR India which included the leprosy colony in Varanasi, PEP++ research sites in Chandauli, Uttar Pradesh, education and livelihood support activities in leprosy colony, and PEP App study in Howrah, West Bengal and DID sites in Aurangabad, Bihar. They had met several state and district level government officials, pradhan of colonies, beneficiaries, and interacted with community' stakeholders etc. These visits provided the platform to understand the context, field level experiences, challenges and helped in transfer and exchange of ideas, new learnings and opportunities for improvement etc. The NLR IO delegation team along with Dr. Ashok Agarwal, Country Director, NLR India visited the office of Central Leprosy Division (CLD), Government of India and had a good meeting with Dr. Sudarsan Mandal, Deputy Director General (DDG)-Leprosy.



1. HEALTH

Technical trainings on leprosy

General health care (GHC) staff including Medical Officers (MOs) were trained on leprosy and National Leprosy Eradication Programme (NLEP) across five states i.e. Bihar, Uttar Pradesh, Uttarakhand and West Bengal. On-job training of General Health Care (GHC) staff had been ongoing, which had been carried out by NLR India's staff during their visits to NLR India's supported districts and blocks. NLR India's Bihar team supported the state in conducting supervision & monitoring of LCDC at Patna, Buxar, Nawada and Bhojpur districts. NLR is actively involved in integration of mental health and wellbeing in its projects and related trainings on leprosy. NLR India's Metal Health Officer had visited Jaipur (Rajasthan) and Shahjahanpur (Uttar Pradesh), and discussed the Basic Psychological Support (BPS) with respective state and district officials, and conducted training on mental wellbeing in Shahjahanpur district for GHC staff.

825



Self-care trainings cum camps

13 Self-care trainings cum camps were organized across Primary Health Centers (PHC) or Community Health Centers (CHC) in states of Bihar, Rajasthan, Uttarakhand and Uttar Pradesh. During the self-care trainings cum camps, the self-care methods were taught and demonstrated. Logistics such as tubs, scrubbers and oil etc. were provided to beneficiaries. The same trainings were also organized across five leprosy colonies in Uttarakhand.



2. EDUCATION

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

Children and Youths 43

were supported for education and vocational training in the NLR India's supported states. These children were given stationaries such as pens, pencils, erasers, note books, school bags etc. Besides, support for payment of school fees were also given to some children.

कुष्ठ रोग से बचाव प्रबंधन के तरीके बताए

कुष्ठ रोगियों को विकृति से बचाव के लिए जागरुकता कार्यक्रम का आयोजन

झारखण्ड। एनएलआर फाउंडेशन इंडिया के द्वारा स्वास्थ्य भवन कलेस हॉल में कुष्ठ रोगियों को विकरलंगता से बचाने के लिए एक दिवसीय संयुक्त सेल्फ केयर प्रशिक्षण कम प्रेक्टिस कार्यक्रम का आयोजन किया गया।

डिप्टी सीएमएचओ डॉ. लेखराज मालव ने बताया कि कुष्ठ रोग एक जीवाणु महसूकरोबैक्टेरियम लेप्रा से जो चिकित्सा तंत्र को क्षीणित

4 इसे जुड़ी मांसपेशियों को विकृत कर शारीरिक दिव्यंगता एवं विकृति पैदा करता है। विकृति एवं अन्य विकरल लक्षणों से बचाव के लिए एमसीआर स्लीपर्स एवं सेल्फ



झारखण्ड, कुष्ठ रोग उन्मूलन जागरुकता कार्यक्रम में मौजूद कुष्ठ रोगी।

बाह्य निम्नले पर चरमों का प्रयोग करो। एनएलआर फाउंडेशन इंडिया से आए डॉ. सानिध्य भागव एवं रितु सिंह ने कुष्ठ रोग प्रबंधन, रोगी अपनी केयर चम्पल, सेल्फ केयर किट, पानी के टब का विलग किया। सीएमएचओ डॉ. जीएम सैय्यद ने बताया कि राष्ट्रीय कुष्ठ रोग उन्मूलन कार्यक्रम



3. LIVELIHOOD

Persons were supported under our livelihood initiatives

55

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.



Support provided to persons affected by leprosy & persons with disability

NLR India facilitated the distribution of assistive devices to persons living with disability in Aurangabad, Bihar in partnership with Department of Social Welfare, Aurangabad.

167 persons were given assistive devices i.e. tricycles, motorized e-rickshaws, and crutches

183 persons received their disability certificates

243 persons received Universal Disabled Identity (UDID) cards, through NLR India's support in partnership with Organizations of People with Disabilities (OPDs)

23 persons affected by leprosy were supported in obtaining railway concession passes

97 Ayushman Bharat Health Account (ABHA) cards were made for residents of leprosy colonies of New Delhi.

96 persons received disability pension

5

4. EMPOWERMENT OF PERSONS AFFECTED

Self-Help group (SHG) trainings/ meetings

persons attended trainings cum meetings of Self-help groups (SHGs)

835



in states of Bihar, Rajasthan, Uttar Pradesh and West Bengal at which participants were briefed on functioning and maintenance of SHGs. The registers and records were reviewed, and feedbacks were provided for improvement etc. Issues related to process of opening a new account for a new group, linking to rural livelihood mission etc. were discussed at these meetings.

5. RESEARCH

5.1 PEP++ : Stop transmission of leprosy study:

In the reporting period from July- September 2023, total

870 leprosy index cases registered at

the Primary Health Centers (PHCs) from April 2015 to March 2022 in 2 districts of Chandauli and Fatehpur in Uttar Pradesh were enrolled in the PEP++ study.

Total **14,513** close contacts were screened and

medicated with either single dose rifampicin (SDR) or PEP++ regimen (rifampicin and clarithromycin) in the two study districts.



5.2 Study on “Testing of Post Exposure Prophylaxis (PEP) mobile App for strengthening Leprosy Post Exposure Prophylaxis (LPEP) services”.

- Training of master trainers was conducted on 16th and 17th August 2023 in Howrah and Paschim Bardhaman districts for Senior Public Health Nurses (PHNs) and PHN, chaired by the Chief Medical Officer of Health (CMOH) and co-chaired by the Deputy CMOH II of the respective districts. This was followed by training for ANMs on PEP App from 1st September to 18th September 2023 in six training sessions for different blocks in each district.
- Data collection was started using economic and data abstraction tools in randomized clusters.

- The 5th quarterly stakeholders' meeting was organized on 27th September 2023 under the chairmanship of Dr. Sudarsan Mandal, DDG (L), CLD and relevant stakeholders attended the meeting. Key progress updates of the study were presented and discussed with sharing of recommendations from the Chair.

5.3 Compassion training for reducing stigma and improving quality of care for persons affected by leprosy

- Drafted the Memorandum of Understanding (MoU) for signing with three international partner institutes and agencies to undertake the study.
- Proposal was resubmitted to Ethics Committee of Central Institute of Psychiatry (CIP), Government of India, Ranchi (Jharkhand) along with revised study tools.
- Organized monthly Partners' review meeting in July, August and September 2023 and formation of working group that will meet on fortnightly basis.



Disability Inclusive Development (Education Support)

Md. Shamsuddin Ansari, a resident of K.K.M. Kushth Ashram in Dehradun district of Uttarakhand, is a person affected with leprosy who has grade two deformities in both right and left upper hands (claw hands). His life was filled with uncertainty and hopelessness as he was the only breadwinner of the family.

During his regular participation in the self-care camp organized by NLR India, he became aware of the support being provided by NLR India to dependents of leprosy affected. With this ray of hope, he met Mr. Mantosh, State CBR coordinator for the educational support of his children. NLR India provided education support for his daughter, Rukshar, a 20 years old female, who is currently studying and planning for her better future. She has completed her XII schooling with NLR India's support further approached our staff for her higher studies. We supported in paying her college fees.

Presently Rukshar has equipped herself with secondary education and actively pursuing higher studies to achieve a dignified life (without poverty, stigma and discrimination) for herself and her family members.

Md. Shamsuddin had said NLR India came as an angel in his life at a time when he could not see any ray of hope and was afraid of his daughter's future. Now he proudly says that his daughter will not struggle much in her life as he had struggled so much in his life due to a lack of good education and financial assistance. Rukshar said that she does not feel the stigma of being a child of a leprosy affected person instead she educates others that leprosy is a curable disease and spreads the facts about leprosy related to its identification and treatment etc. She also mentioned that there was a time when her brother and sister were not invited to their friend's party and ignored in social gatherings but now due to her efforts in awareness generation and dealing with stigma-related issues related to leprosy, she and her family are welcomed to participate in social functions & gatherings etc.



**MS. RUKSHAR, 20 YEARS OLD FEMALE,
WHO RECEIVED EDUCATION SUPPORT**

► KEY MEETINGS ORGANIZED & SPECIFIC SUPPORT PROVIDED:

- NLR India organized a networking meeting on 31st July 2023 in Varanasi with participation of representatives from organizations such as Center for Advocacy & Research organization, Tata Trust, Prem Jyoti Society, Pratham Sanstha, Mamta Health Institute for Mother and Child (HIMC), Shivaji Youth Society. They were briefed about the work of NLR India, and discussion was held on functions of the organization and how the organizations can work together.

- State level Partners meeting was conducted on 11th July at Damien Foundation India Trust (DFIT), Patna office under chairmanship of State Leprosy Officer (SLO), Bihar where World Health Organization (WHO) and other ILEP Partners members attended the meeting.
- A campaign to plant 30 lakh saplings was launched in Uttar Pradesh. In this sequence, tree plantation work was done in Chahaniya block of Chandauli district by the members of 14 Divyang group of NLR India.



Networking meeting, Varanasi



Plantation campaign work in Chahaniya block, Chandauli

► UPCOMING KEY EVENTS / WORKSHOPS IN NEXT QUARTER 2023

- Organize live virtual event (Facebook) on “Learnings from Self-Care Projects implemented by NLR India” in November 2023.
- Organize and coordinate the 17th National Task Force (NTF) Quarterly meeting of PEP++ study on 26th October 2023 along with field visits by the Study Investigators in Chandauli and Fatehpur districts, Uttar Pradesh from 25th October to 27th October 2023.
- Organize and coordinate the 7th Quarterly Stakeholders' meeting of PEP App Study on 19th December 2023.
- Signing of MoU with International study partner agencies for Compassionate Training study and organize monthly review meetings with all partners.
- Supervision and monitoring of Leprosy Case Detection Campaign (LCDC) in the districts of states where LCDC will be undertaken.

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