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Training cum monitoring on self-care practices



Capacity building of Disabled People Organization (DLOs)



Information, Education and Communication (IEC) session with contacts of index case

KEY MESSAGE FROM CHAIRPERSON



It gives me immense pleasure to provide key note message to all our readers of the first newsletter of NLR India Foundation. This issue broadly includes major highlights of the 1st quarter 2023, key updates on different thematic areas such as Health, Education, Livelihood, Empowerment, Research, Case Study, key workshop organized, and important upcoming events of next quarter. This newsletter replaces the monthly reports shared till December 2022.

NLR India Foundation has been functioning since 1999 and is a member of International Federation of Anti-Leprosy Associations. We work in 7 states namely, Bihar, Delhi, Jharkhand, Uttarakhand, Uttar Pradesh, Rajasthan, and West Bengal across 130 districts and 150 leprosy colonies in these states. We primarily provide technical support to the National Eradication Leprosy Programme, Government of India in achieving the three “Zeros” – Zero Transmission, Zero Disability and Zero Exclusion. Our vision is to create an inclusive society free from leprosy, allied skin Neglected Tropical Diseases and related disabilities.

We welcome your valuable suggestions to make this newsletter a rich medium and repository of NLR IF's work.

I thank and congratulate the Knowledge Management team of NLR IF for bringing out this initiative.

Let us join hands to make India a leprosy free country.

Sincerely,

Ms. Nirmala Gupta
Chairperson, NLR India Foundation

MAJOR HIGHLIGHTS

Contributions to National Strategic Plan (NSP) and participation at launch of NSP



Launch of NSP and roadmap to zero leprosy by key dignitaries

Since the last 2 quarters of 2022 till Jan 2023, 7 technical experts of NLR IF had contributed in development and compilation of National Strategic Plan (NSP) /Roadmap to zero leprosy 2023-2027, Central Leprosy Division (CLD), Govt. of India (GoI) as working group members for thematic areas i.e. Programme Management, Research & Innovation, Information, Education & Communication (IEC) & Advocacy, Stigma & Discrimination, Socio-economic Rehabilitation, and Urban Leprosy.

At the observance of the National Anti-Leprosy day on 30th January 2023, which was organized by Director General of Health Services (DGHS), Ministry of Health & Family Welfare, GoI, the NSP and guidelines for Anti -microbial resistance (AMR) were launched, and released Nikusth 2.0 version. The solemn occasion was graced by the Honorable Minister of State, Health & Family Welfare, Special Secretary, Joint Secretary (JS) and key dignitaries such as Director General of Health Services (DGHS), Deputy Director General (Leprosy) and WHO representative to India.

Facilitation and participation at SPARSH Awareness Campaign (SLAC)

Field staff of NLRIF across 7 states had participated in SPARSH Leprosy Awareness Campaign (SLAC) which were started from 30th January 2023 for a fortnight, for generation of public awareness about leprosy. More than 15 rallies and other mass awareness activities were carried out in the month of February, during the SLAC fortnight event, which were organized by the governments at state, district and block levels etc. Our staff across 7 states had facilitated and participated at these rallies and awareness activities were also carried out in leprosy colonies. In these rallies, representatives from several stakeholders also took part.



Awareness rally with government officials

KEY UPDATES ON THEMATIC AREAS

➔ Health

1. Several trainings were organized for medical officers and general health care (GHC) staff on leprosy and on several components of National Leprosy Eradication Programme (NLEP) such as Leprosy Case Detection Campaign (LCDC), Leprosy post exposure prophylaxis (LPEP) and self-care related etc. Mental health component was incorporated in these trainings at state and district levels which were facilitated by NLR IF's staff. The beneficiaries were imparted training on guidelines of Basic Psychosocial Support (BSP) for Neglected Tropical Diseases (NTD). Peer counsellors were selected from those attending these trainings who were motivated to take care of the mental well-being of persons affected by leprosy and those living with disabilities.

Total 338 Medical Officers (MOs) including GHC staff attended these trainings that were held in states of Bihar, Jharkhand, West Bengal, Uttarakhand, and Uttar Pradesh.

2. On Disability Prevention and Medical Rehabilitation (DPMR) component of NLEP, staff of NLR IF facilitated in trainings on self-care for persons affected by leprosy and lymphatic filariasis (LF).

16 self-care trainings cum camps were organized at 9 community health centres (CHCs) in states of Bihar, Jharkhand, Rajasthan and Uttar Pradesh which were attended by 590 participants, comprising of 138 persons affected by leprosy, 19 persons affected by lymphatic filariasis, 7 medical officers, 103 ASHAs and 72 GHC staff. There were 6 other participants who were care takers / family members or dependents of persons affected, including representatives from other organizations.

During the camps, participants were trained on methods of self-care, and our staff demonstrated self care practices. At these camps, supply logistics such as plastic tubs, scrubbers, oil etc. were provided to all participants who were beneficiaries of self-care projects.



Induction training of MOs of Primary Health Centre



Self-care training cum camp organized in Community Health Centre

➔ Education

NLR IF always strives for the betterment of the lives of persons affected and their family. As part of this endeavour, the staff of NLR IF imparts training on life skills education (LSE) and sexual & reproductive health (SRH) to the youths and adolescents living in the leprosy colonies.

95 adolescents living in leprosy colonies were imparted training on life-skills in 6 leprosy colonies, in states of Jharkhand, Rajasthan, Uttar Pradesh and West Bengal, of which 79 of them were also trained on SRH across these 4 states.



Imparting life skill education to children in leprosy colony

➔ Livelihood



Girls and women receiving certificate

1. Our staff facilitated in organizing a 3 months vocational training on tailoring that was provided through a mobile training center at Aurangabad, Bihar and total 28 girls and women from families of persons affected by leprosy or persons living with disabilities (PWDs) had completed this course. Certificates were issued to participants at the end of training course.

- 25 persons affected by leprosy were provided food and ration support and 56 were given blanket at West Bengal and Bihar. 5 persons with disability were provided tricycles at Aurangabad, Bihar.



Blanket distribution for persons affected and media coverage

→ Empowerment

1. Through Self-Help group (SHG) trainings cum meetings organized, which were held in Bihar, Jharkhand, and Uttar Pradesh, total 277 persons had been oriented on SHG. Total 3 Divyang Self-help group (DSHG) in Chahniya block, Chandauli district, Uttar Pradesh received an amount of Rs 15000/- each as revolving fund through the Uttar Pradesh State Rural Livelihood Mission (UPSRLM).



Meeting with Self-help groups (SHG) members

2. In association with Disability People Organization (DPOs), we had facilitated in providing support to persons affected by leprosy. Total 66 persons affected received Micro-Cellular Rubber (MCR) footwear in Aurangabad, Bihar and Hazaribagh, Jharkhand. A total of 49 persons were given assistive devices such as tricycles (8), wheelchairs (3) and motorized e-rickshaws (33) and crutches (5). Total 1219 persons affected received benefits and entitlements that was facilitated by NLR IF's staff, and of which 154 of persons affected received disability certificates, 159 of them received disability pension, and remaining of them received Unique Disability ID (UDID) cards, ration cards, concession passes for railways etc.

→ Research

1. Under enhanced chemoprophylaxis study titled "PEP++ -Stop transmission of leprosy project", a multi country research programme which is being implemented in Chandauli and Fatehpur districts of Uttar Pradesh in India, the 15th Quarterly meeting of the National Task Force (NTF) was held on 31st March 2023, under the chairmanship of Dr. Anil Kumar, Additional Director General of Health Services, Govt. of India and Principal Investigator (PI) of the study. A side study under the main PEP++ project, for assessing the reporting of Adverse events (AE) for clarithromycin tablet-standard as compared to clarithromycin tablet- sustained release (SR) was completed.



Screening of contact of index case



Research Assistant (RA) administering syrup rifampicin to a child contact, under PEP++ study

2. Under Leprosy Research Initiative (LRI) funded study for testing a mobile App-based service delivery system for Leprosy Post Exposure Prophylaxis (PEP) that is implemented in 2 districts of West Bengal; an exploratory study along with testing of App named “Kusht-Rakshak” was undertaken. The cost effectiveness tool was finalized in consultation with experts from Dept. of Economics, Presidency University, Kolkata and Erasmus University Medical Center, Netherlands.



Orientation of ASHA workers and testing of PEP App

A special project titled “*the Call center - Vikalp project*” is implemented across 3 states, in which counsellor conduct telephonic follow up of persons affected by leprosy who are undergoing multidrug therapy (MDT) about the services provided to them, take their feedbacks and assess any gaps etc. In the quarter, total 107 follow up calls were made, for 19 new patients registered with the call center. 10 patients who had stopped taking MDT had restarted treatment.

CASE STORY



Picture of ulcer before adopting self-care practice

IMPACT OF SELF-CARE



Picture of healed ulcer post self-care practice

I, Mr. Sirajul Ansari, son of Mr. Allauddin Ansari, age 22 years old male living in village Rolagram (Momin Tola), Maheshpur, Pakur district of Jharkhand. I started treatment for leprosy on 25th January 2021 at Community Health Center (CHC), Maheshpur with the proper supervision and guidance by medical officer of CHC Maheshpur and Mr. Jyotishjee, PMW. In our locality Mrs. Pramila Biwi is working as a Sahiya, with her consultation I came to CHC with ulcers in my left feet and the medical officer diagnosed me as Multi- Bacillary (MB) leprosy and was also advised for continuing MB-MDT for 1 year and provided me training on self-care so that I could take care of my foot ulcer regularly. I completed treatment on 25th December 2021 and was declared me as Released from treatment (RFT) in the month of January 2022.

After adopting self-care practices as well as proper supervision and monitoring by paramedical workers (PMW) and Sahiya, my ulcer was completely healed.

I would like to convey my gratitude and thanks to our Medical Officer (MO) of CHC, PMW and Sahiya for providing me logistics support as well as self-care kit and MCR shoes. As a result, my ulcer is healed and there is no discrimination or stigma in our society and community.

KEY WORKSHOP ORGANIZED



LPEP and NSP workshop held at Faridabad, Haryana

NLR IF in collaboration with Central Leprosy Division organized a national level workshop for capacity building of State Leprosy Officers, and State Leprosy Consultants on Leprosy Post Exposure Prophylaxis (LPEP), National Strategic Plan (NSP) & Nikusth 2.0 on 31st March -1st April 2023 under a Novartis India supported project, at Faridabad (Haryana). It was attended by around 80 participants including national level master trainers, international Federation of Anti leprosy Associations (ILEP) partner and Association of persons affected by

UPCOMING KEY EVENTS / WORKSHOPS IN NEXT QUARTER

Research Workshop

NLR IF plans to conduct a capacity building workshop on research from 3rd to 7th April 2023 to enhance capacity of national core team and project staff

24th Foundation Day

A virtual live event to commemorate 24th Foundation Day of NLR IF will be held on 23rd April 2023

Roll out of the PEP App

A study titled "Testing of PEP App for strengthening the delivery of leprosy post exposure prophylaxis (LPEP)" is planned to roll out in West Bengal

13th National Conference of IAE

Indian Association of Epidemiologists (IAE) in collaboration with ILEP, WHO, and Centre of Disease Control and Prevention (CDCP) will organize a National Conference on 29th and 30th April 2023. NLR IF is member of organizing and scientific committee of the upcoming event.

Journey Towards Zero Leprosy

A documentary film will be shot across 5 project sites under the titled "NLR India Foundation- Journey towards Zero Leprosy" in May-June 2023

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