



until
No Leprosy Remains



ANNUAL REPORT 2020-21

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1. Abbreviations

Abbreviation Full Forms

ANCDR	Annual New Case Detection Rate	LPEP	Leprosy Post Exposure Prophylaxis
APAL	Association of People Affected by Leprosy	LPA	Leprosy Programme Advisor
ASHA	Accredited Social Health Activist	LF	Lymphatic Filariasis
CBR	Community Based Rehabilitation	MB	Multi Bacillary
CBRC	Community Based Rehabilitation Coordinator	MDT	Multi Drug Therapy
CHC	Community Health Center	MO	Medical Officer
CLD	Central Leprosy Division	MOHFW	Ministry of Health & Family Welfare
CD	Country Director	NLEP	National Leprosy Eradication Programme
CO	Country Office	NLR	until No Leprosy Remains
DNH	Dadra & Nagar Haveli	NLRIF	NLR India Foundation
DID	Disability Inclusive Development	NHM	National Health Mission
DPMR	Disability Prevention & Medical Rehabilitation	NMS	Non-Medical Supervisor
DPO	Disabled People's Organisation	NRHM	National Rural Health Mission
EPF	Employee Provident Fund	NUHM	National Urban Health Mission
GHC	General Health Care	ONGC	Oil & Natural Gas Corporation
Gol	Government of India	PEP	Post Exposure Prophylaxis
Govt.	Government	PHC	Primary Health Centre
G2D	Grade 2 Disability	PWD	Person with Disability
ICMR	Indian Council of Medical Research	RPWD	Rights of Persons with Disabilities
IEC	Information, Education & Communication	SDR	Single Dose Rifampicin
ILEP	International Federation of Anti-Leprosy Associations	SHG	Self Help Group
LCDC	Leprosy Case Detection Campaign	ST	Sensory Testing
		SLO	State Leprosy Officer
		VMT	Voluntary Muscle Testing
		WHO	World Health Organization



2. Message from the Managing Trustee

In its more than two decades of journey, 2020-2021 was the toughest for NLR India Foundation with the unprecedented COVID pandemic. The pandemic had disrupted the humanity with people getting infected in hordes, the services being scarce and many near and dear ones dying. The economy had come to standstill with no livelihood and guaranteed income for many. The leprosy affected, the community we serve, being one the most marginalized, often with disabilities were deprived of whatever little support system they had. Beyond leprosy, the basics for survival like the food became the most important need.

Keeping to the goal of NLRIF of zero leprosy with zero suffering; our staff across all the seven states of operation volunteered to provide COVID emergency support through field teams and remotely. Besides, providing for basic survival needs, COVID needs; they also prioritized early detection and treatment of lepra reaction and continuation of self-care for preventing disability and its worsening.

We thank the many donors who liberally supported us in reaching out the emergency services. One Indian Revenue Service (IRS) officer requires special mention; she on her own approached me and supported dry ration and hygiene needs worth lakhs of rupees through her association.

I am happy to share, in spite of the unparalleled COVID disruption; we were able to reach around 75% of our project targets. On 2nd October 2020, the PEP++ project (study for enhancing the protection by medicine) was launched. We closed the year with an exciting development of the renewal of our certification for receiving foreign grants (Foreign Contribution Regulation Act, FCRA) for five years. NLR India Foundation thanks the government at the center and the states, our donors, the communities we work with and other key stakeholders for collaborating with us in pursuance of our cause.



Dr Ashok Agarwal
Managing Trustee
NLR India Foundation

3. About NLR India Foundation(NLRIF) & Our Presence

3.1. About Us

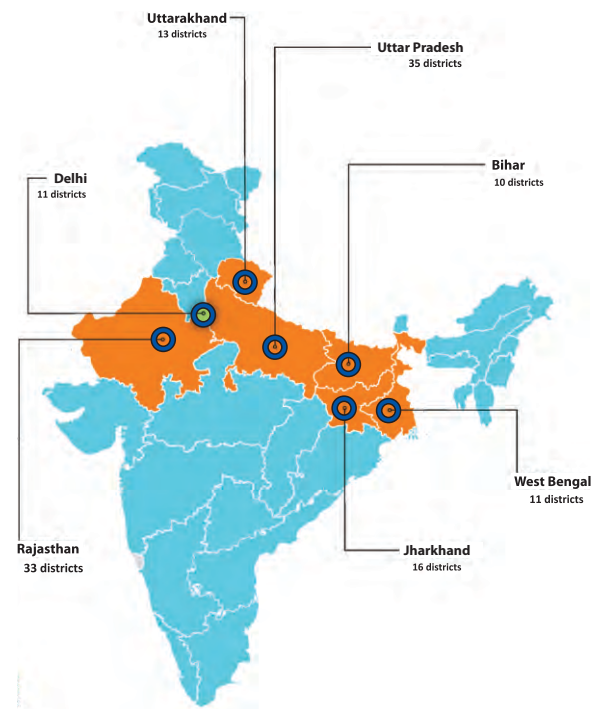
NLR India Foundation (NLRIF) is a non-profit, non-religious, non-governmental organization registered as public charitable trust as per the Indian Trust Act in 1999. NLRIF was certified under Foreign Contribution Regulation Act (FCRA) in 2004 and received tax exemption under section 80G of IT Act, 1961. In addition, NLRIF is a member of International Federation of Anti-Leprosy Associations (ILEP).

NLRIF aspires for a country free of leprosy and its suffering through inclusive development programmes encompassing prevention and cure for leprosy affected persons and disability inclusive development and disability care for the resultant disabilities.



3.2. Our Presence

NLRIF works in seven states, namely, Bihar, Delhi, Jharkhand, Rajasthan, Uttarakhand, Uttar Pradesh, and West Bengal in 129 districts. NLRIF works closely with 150 leprosy colonies in these states. Our dedicated employees support the implementation of National Leprosy Eradication Programme (NLEP). Through our cadre of Community Based Rehabilitation Coordinators (CBRCs), we support the programmes for rehabilitation of persons with disabilities due to leprosy and other causes, particularly lymphatic filariasis.



NLR works in 129 districts across seven states of India



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3.3. Our Vision and Mission

VISION - The Foundation vision for an India:

- Which is free of suffering due to leprosy and the disabilities and social exclusion that it causes.
- In which the health systems in all endemic states can diagnose and treat leprosy early and effectively.
- In which all people who are restricted due to disability or stigma will participate in society as fully and as independently as possible.

MISSION - The foundation aims towards:

- Societies in which leprosy will be under control. In these societies, health services at all levels ensure that every patient will be diagnosed and treated early so the disease will no longer be a major risk for disabilities and social exclusions.
- Societies in which governments, private companies, Non Governmental Organizations (NGOs) and Disabled People's Organizations (DPOs) join hands to ensure that people with disabilities are:
 - *Enabled to participate as fully and independently as possible.*
 - *Enabled to use their rights to develop their abilities and rightfully get equal opportunities for their personal development in the context of their families and society at large.*
 - *Treated with dignity.*

Leprosy, a scourge of mankind continues to affect the lives of many individuals. Even though it is curable, and treatment is available free of cost, this bacterial disease continues to be perceived as penance leading to stigma and discrimination against persons affected by leprosy. This leads to public fear, hate and discrimination from family and society. Despite the growth of medical treatments and social awareness, leprosy still affects many aspects of the lives of people including their mobility, interpersonal relationships, marriage, employment, leisure activities, and participating at social and religious functions and so on.

Disability care and Disability Inclusive Development are

two focus areas of NLRIF. Self-care, health-camps and aids & appliances support are the three major interventions under the first focus area of disability care. Through selfcare the patients are taught on how to take care of their disability by themselves. In selfcare, the disabilities of persons are assessed to understand their specific requirements for support and care. We establish sustainable 'Self-Care Groups', in which the members adopt self-care as a regular practice. The formation of such groups allows the individuals to acquire 'a sense of belongingness', minimizing the effects of stigma and discrimination. Through regular health camps and provision of assistive device, NLRIF ensures that the persons affected by leprosy are enabled in taking care of their disabilities (physical as well social) collectively and independently.

In the focus area of 'Disability Inclusive Development', the activities undertaken are community-based intervention in the form of livelihood promotion, education support, vocational training, the formation of Self-help groups (SHGs), strengthening Disabled People's Organization, and income generation activities.

4. Governing Board

NLRIF Board Members form the topmost decision-making entity in the organization's hierarchy. The highly experienced and qualified Board members supervise the policy development and execution; they make sure the internal controls are robust and the organization in full compliance to the national applicable regulations for a Trust. The Managing Trustee oversees the intricate operations and management ensuring the decisions taken by the Board are executed.

NLRIF ensured that gender diversity is maintained in the current board member group.

Ms. Nirmala Gupta,

Chairperson

Former Vice President, Bansidhar and Ila Panda Foundation

Former State Director, United Nation World Food Programme

Former State Director, CARE



Dr. Lalit Kant,

Vice Chairperson

Former Chief Executive Officer, India Tuberculosis Research Consortium /
Indian Council of Medical Research

Former Director India Programmes Resolve to Save Lives / Vital Strategies

Former Senior Scientific Advisor, Bill and Melinda Gates Foundation /

India Country Office

Former Head, Division of Epidemiology & Communicable diseases /
Indian Council of Medical Research, Headquarters office

Prof. K Srinath Reddy,

Trustee

Current President, Public Health Foundation of India

Current Member, Leadership Council, Sustainable Development
Solutions Network, United Nations

Former President, World Heart Federation

Former Chairman, Core Advisory Group, Health & Human Rights,
National Human Rights Commission of India



Dr. Ashok Agarwal

Managing Trustee, NLRIF

County Director, NLR India, Branch of NLR International

Former Project Director (HIV/TB/Malaria) and Chief of Party

Public Health Foundation of India

Former Project Director, FHI 360



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5. Highlights of the year 2020 – 2021

India accounts for 56.61% of total new leprosy cases reported globally. A total of 114,451 new leprosy cases were reported in India in the year 2019-20 compared to 120,334 in the year 2018-19.

NLR India Foundation works in seven states namely Bihar, Delhi, Jharkhand, Rajasthan, Uttarakhand, Uttar Pradesh, and West Bengal across 129 districts to achieve the goal – until No Leprosy Remains. NLRIF works in 47.2% (60 out of 127) high endemic districts of India; the 60 districts are in Bihar (23), Uttar Pradesh (22), West Bengal (8), Jharkhand (4), Delhi (2) and Rajasthan (1). In the seven states, NLRIF also supports 52% (150 out of 289) leprosy colonies.

In five out of seven NLRIF supported states, other ILEP (International Federation of Anti-Leprosy Associations) agencies are also working on leprosy. In Bihar, the other ILEP agencies are Damien Foundation, Lepra Society and The Leprosy Mission Trust of India (TLMTI); in Jharkhand, Damien Foundation, Lepra Society and GLRA are the other agencies; in West Bengal, GLRA and Lepra society are present; in Delhi, Damien Foundation, Lepra Society and GLRA are present; and in UP the other agency is TLMTI. In Uttarakhand and Rajasthan, NLR India Foundation is the sole agency. Except NLR India Foundation, all other ILEP agencies run health facilities and rehabilitation centres. NLRIF has not created any parallel structure, and all activities are aligned with the programmes of central and state governments.

The Covid-19 pandemic started in India in mid-2020. A countrywide lockdown was enforced by the Govt. of India. During the lockdown, all movements & public gatherings were prohibited. It resulted in a complete shutdown of all our field work. The Central Leprosy Division (CLD) India issued guidelines during Covid-19 on NLEP implementation. Covid-19 has impacted the lives of all sections of society especially the persons affected by leprosy with limited resources. There was loss of livelihood, in turn, leading to mental health problems among persons affected by leprosy.

During the pandemic, NLR India Foundation came up with a novel idea of 'Emergency Response' – NLRIF staff visited communities with the messages on awareness & preventive measures for Covid-19 and provided need-based assistance.

The key achievements of the Emergency Response were:

NLR India Foundations team reached out to 311,824 persons with the preventive messages on Covid-19; 4,316 persons were affected by leprosy, 3,385 of them were provided food and medical and hygiene kits, and 137 multi-drug therapy (MDT) packs for treatment of leprosy were distributed. A total of 1,645 villages were covered.

To increase the awareness against Covid-19 and train people on preventive measures against Covid-19; 11818 demonstrations were done on hand washing, social distancing & wearing masks.

We maintained regular communication with government officials to follow-up on the patients under treatment. In case of any arising need for the patient, it was promptly communicated to the concerned officials. It helped in the prompt delivery of MDT and other services to the needy.

The challenges during Covid-19 pandemic times were:

The entire pool of health staff engaged in activities related to the Covid-19 pandemic, slowing down the implementation of our planned activities. The detection of new cases and the administration of SDR-PEP to eligible contacts reduced drastically.

In spite of the COVID disruption, NLRIF was able to achieve 75% of its programme targets; and launch the PEP++ project (study to enhance protection of leprosy spread through medicine).

6. J(our)ney

- 1993 – NLR (International) started working in Bihar
- 1998 – Intervention expanded to Uttar Pradesh & Uttaranchal
- 1999 – Intervention expanded to Delhi | NLR India Foundation established
- 2000 – NLR India Branch Office established in March 2000, Delhi | Intervention expanded to Jharkhand
- 2001 – Intervention expanded to West Bengal
- 2002 – Memorandum of Understanding (MoU) signed with Government of India till 2007-08
- 2004 – Foreign Contribution Regulation Act (FCRA) certification | MoU signed with Govt. of Uttarakhand
- 2007 – Self-care group project 34 colonies 4 states | COMPLEP project (digitalization infrastructure) | MoU signed between NLR & Gol from 2007-08 to 2012-13
- 2010 - Comprehensive Socio-Economic Rehabilitation (education support, vocational training, livelihood promotion and infrastructure support)
- 2011 – NLR chosen as National coordinating agency for International Federation of Anti-Leprosy Association (ILEP) India from January 2011
- 2013 - 'Swavalamban' project in Delhi for self-employment
- 2014 - 'Wings to Fly' project started in Jharkhand in collaboration with a local NGO, Chhota Nagpur Sanskrit Sansthan (CSS) at Ranchi, Jharkhand
- 2015 – LPEP (Leprosy Post Exposure Prophylaxis) project launched | 'Lepclips' leprosy training video project launched | Intervention expanded to Rajasthan | Integrated Self-care project (Combined self-care)
- 2016 – Formation of 155 self-care groups completed | External Resource Mobilization Commenced
- 2018 – Piloting of Leprosy Post Exposure Prophylaxis completion & launched by the Central Leprosy Division as a component of National Leprosy Eradication Programme (NLEP)
- 2020 – PEP++ Multi country research project launched



7. Three Zeros & Our Projects

Three Zeros - the drivers of our interventions: NLRIF supports the National Leprosy Eradication Programme (NLEP) to achieve the “Three Zeros” - Zero Transmission, Zero Disability and Zero Exclusion.

NLRIF implements different projects under these three “Zeros”.

The year 2020 saw the first wave of the Covid-19 pandemic, and thus the activity implementation was hampered from March to September 2020.

7.1. Zero Transmission

In the year 2020-21, the projects implemented under Zero transmission were:

SI No	Projects' name	States/ Areas of implementation
1	Strengthening NLEP (National Leprosy Eradication Programme)	All seven states supported by NLRIF
2	Scaling up LPEP (Leprosy Post Exposure Prophylaxis)	All seven states supported by NLRIF
3	PEP++ Stopping the transmission	Fatehpur & Chandauli districts of Uttar Pradesh

Strengthening NLEP (National Leprosy Eradication Programme): NLRIF supports NLEP in implementation of all its programme components. Primarily NLRIF is involved in building the capacity of Medical Officers (MOs) and other health staff working in field of leprosy. The technical staff of NLRIF are experts and they train the health manpower on how to suspect and identify leprosy cases and initiate treatment. They also train on identification of disability and its grading and on how to manage them through self-care. NLRIF also contributes in planning, implementation, monitoring and supervision of special programmes like SPARSH leprosy awareness campaign (SLAC), Active Case Detection and Regular Surveillance (ACD&RS), and Focused Leprosy Campaign (FLC) etc.

In the year 2020-21, under this project:

- 425 medical officers (MOs) were trained – these comprise of State Leprosy Officers (SLOs), District Leprosy Officers (DLOs), and members of District Leprosy Cells (DLC) and the District Nucleus Team (DNT)
- 653 General Health Care (GHC) staffs provided hand-holding support
- 137 meetings were conducted with DLOs and other health staff for reviewing the progress of NLEP across seven NLRIF supported states
- 50 meetings with partners working in the field of leprosy. In these meetings, the focus was on improving the NLEP by motivating and lobbying with the government
- 36 NLRIF events/ stories covered by media

Scaling up LPEP (Leprosy Post Exposure Prophylaxis): LPEP is an intervention which can reduce occurrence of new cases among contact of leprosy patients by 60%. This is done by administering single dose of rifampicin (SDR) to eligible contacts. It is a dedicated project to support the NLEP in proper implementation of its LPEP programme. The LPEP has been an integral part of NLEP. Bihar, one of the NLRIF supported states had not started its implementation. In 2020, following continued advocacy by NLRIF, the Govt. of Bihar directed the districts to implement LPEP programme. This project has the objectives of building the capacity of healthcare staff on the operational guidelines of LPEP. The staff are

trained on how to do the contact tracing, contact screening, the understanding of inclusion and exclusion criteria and about the standard doses of SDR PEP (single dose of Rifampicin- post exposure prophylaxis).

Under this project, NLRIF built the capacity of:

- 1861 health staff on operational guidelines and other aspects of the SDR-PEP Programme; out of these, 818 were medical officers, and the rest (1043) were GHC staff members
- LPAs validated 269 contacts who have been administered SDR-PEP
- 103 representatives of different stakeholders sensitized on LPEP

PEP++ Project: Stopping the transmission of leprosy: It is a multi-country research programme, and a flagship project of NLR International which is being implemented in five leprosy high burden countries in collaboration with academic universities, ILEP members and Ministry of Health & Family Welfare (MoHFW), at central, state, and district levels. In India, its implemented in two districts of Chandauli and Fatehpur of Uttar Pradesh. Post the preparatory activities, the project was formally launched on 2nd October 2020.

In 2020-21, key preparatory milestones were completed as follows:

- The amended PEP++ study protocol was approved by Indian Council of Medical Research (ICMR) under Health Ministerial Steering Committee (HMSC) in May 2020
- The 2nd edition of PEP++ Brochure/newsletter was developed, printed in June 2020 and around 35 copies were widely disseminated across all key stakeholders and partners
- Agreements were signed between NLR and pharmaceutical firm Lupin Private Limited for rifampicin and with Shaksham Foundation for supply of Clarithromycin (manufactured by Glenmark), and these drugs were supplied by the firm/distributor as per the requirements, for use in the 1st initial quarter of PEP++ implementation in the 2 districts

A virtual Training of Trainers (ToT) on leprosy, PEP++ protocol and standard operating procedures (SOPs) was organized in June 2020 for the master trainers including PEP++ field staff in which total thirty-five participants attended the training. This was followed by training of local government health staff and ASHAs (community health volunteers). A total of 91 medical officers, 3128 community health volunteers (ASHAs/supervisors) and 10 non-medical assistants were trained, by the master trainers and project field staff.



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Official PEP++ project launch meeting: On October 2, 2020 the study was launched online and in the presence of the Health Directorate, Uttar Pradesh State Government, health officials from the two districts of Chandauli and Fatehpur, representatives from universities and persons affected by leprosy. Together they committed their support to this research programme. Subsequently, the first contacts of persons affected by leprosy received the new preventive treatment in both study districts.

A national and international press release was issued to highlight this momentous occasion through PR Newswire (ANP International distribution channel). The press release was spread across 5000 influential websites and was eventually posted on 130 external media platforms worldwide, such as KTVN in the United States, New Delhi Times in India, and the Exeter Daily in the United Kingdom.

The launch highlights were also shared on social media channels of both NLR International and NLR India.



7.2. Zero Disability

In the year 2020-21, the projects implemented under Zero disability were:

SI No	Project's name	States/ Areas of implementation
1	Combined Self-care (CSC)	Jharkhand, Rajasthan, and Uttar Pradesh
2	Combined Self-care - Medische Missie Zusters (MMZ)	Bihar & Uttar Pradesh (three districts each)

Combined Self-care (CSC): Combined self-care is a concept in which persons affected by leprosy and those affected by lymphatic filariasis (LF) are trained on self-care as a group at one place. This helps in reducing stigma among patients. Also, there is a component of building capacity of health care staff on various methods of self-care so that they can provide these services for the needy persons. The training for GHC staff includes nerve function assessment (Sensory Testing- ST & Voluntary Muscle Testing- VMT) for cases of leprosy and identification of entry points, swelling measurement and prevention of acute attacks in cases of LF to prevent disability through self-care. The CSC project is implemented in one primary health center (PHC) each of Jharkhand, Rajasthan, and Uttar Pradesh.



Under this project-

- 255 persons (179 persons affected by leprosy & 67 persons affected by LF) were trained on self-care practices
- To capacitate the service providers, 388 ASHA, 110 GHC staff members, and 25 members of PRIs, and DPOs were trained on self-care
- 158 GHC staff were sensitized on stigma and the mental well-being of the persons affected



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- 595 persons (including 547 persons affected by leprosy & 48 persons affected by LF) were provided with need-based assistive devices
- 16 reconstructive surgeries were facilitated

Combined Self-care - Medische Missie Zusters (MMZ): This is another Combined Self-care project which is externally funded. This project is being implemented in 61 PHCs of three districts each of the two states of Uttar Pradesh & Bihar. In UP, the districts are Unnao (15 PHCs), Kannauj (6 PHCs) and Kanpur Dehat (9 PHCs). In Bihar, the districts are Nawada (12 PHCs), Bhojpur (12 PHCs) and Aurangabad (7 PHCs). The project has the objective of enabling persons affected by leprosy and LF to take care of their disabilities through self-care. The general health care staff of Primary Health Centers are trained on how to conduct nerve function assessment (Sensory Testing & Voluntary Muscle Testing) in cases of leprosy and identification of entry points, swelling measurement and prevention of acute attacks in cases of LF to prevent disability through self-care.

Under this project, in 2020-21:

- 377 persons affected by leprosy & 277 persons affected by LF were trained on self-care
- 330 members of Health staff, ASHA (645), PRIs (26), and DPOs (17) were also trained on self-care practices
- 76 GHC staff were trained to become master trainers
- Ulcers improved in 96% of leprosy cases
- Swelling of limbs reduced in 94% of the LF cases
- A total of 32 persons (18 in UP & 14 in Bihar) affected by leprosy underwent reconstructive surgeries

The last three bullets depict major success of this intervention through participation and ownership by the general health care (GHC) system. The master trainers developed by the project will help sustain the self-care activities without supervision by NLRIF staff post the project closure.



7.3. Zero Exclusion

In the year 2020-21, the projects implemented under Zero exclusion were:

SI No	Project's name	States/ Areas of implementation
1	Empowering PWD and their dependents (DID)	All seven states supported by NLRIF
2	Making Change Agents	All seven states supported by NLRIF
3	Disabled Friendly Villages	Bihar
4	Need Assessment Survey in Leprosy Colonies	All seven states supported by NLRIF
5	Disabled Friendly Toilets (Funded by Oil & Natural Gas Corporation -ONGC)	Varanasi (Uttar Pradesh)

Empowering PWD and their dependents (DID)

NLRIF significantly increased awareness on the Rights of Persons with Disabilities (RPWD) Act 2016 to mobilize persons with disability for their rights. People with disabilities who received training on the RPWD Act were made aware of their rights and entitlements, so that they are able to express their concerns at the appropriate forum. Because of the extreme poverty and discrimination that people with disabilities face, socio-economic upliftment becomes a high priority sector of overall development & rehabilitation.

In 2020-21

- 290 self-help groups (SHGs) were set up by NLRIF and continue working under the project
- Members of 68 SHGs were trained on RPWD Act
- 28 SHGs were given refresher training
- 15 disabled people's organization (DPOs) were formed
- 84 persons were linked to vocational training
- 255 persons received assistive & protective devices; the devices were from the government. NLRIF had assessed the need, requested the government and facilitated the distribution
- 44 women obtained training in tailoring through NLRIF Mobile Training Centres

Making Change Agents

NLR India Foundations' staff have been providing education support for primary and secondary education to facilitate quality education by providing tuition/admission fees, stationary, uniforms and clothes, school bags, shoes, and other items as needed by individual children. The adolescents (15-18 years old) were trained and recognized by NLRIF's staff to serve as Change Agents on leprosy-related issues. The aim is to mentor them and keep track of their progress. During the year, 95% of youngsters who got educational assistance continued their studies (attending classes through virtual media or self-study). Most of them would continue without NLRIF's assistance, but only in terms of quantity of students, not quality of education. Quality education necessitates long-term assistance for coaching and stationery, admission and tuition fees, and other basic needs, particularly for schoolchildren. This will allow for both quantity and quality to be achieved. Long-term support, including for vocational training and higher education, is still required. Small financial assistance to many children has a significant benefit. It strengthens our relationship with the colonies and communities, which is necessary for us to continue our work there; otherwise, their real-world needs and expectations force them to become uncooperative, aggressive, and lose trust on us. They are also being provided Life Skill Education (LSE) and training on Sexual and Reproductive Health (SRH).

During 2020-21

- 997 children and youth were given education support in the form of tuition fee, stationery, books, school uniforms, tutor, school bags, shoes and vocational training



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- 150 children have been identified to be developed as change agent. These potential change agents have also been mobilised for career counselling and life skill education

Disabled Friendly Villages project

Under this project, 11 Model Disability Friendly Villages were developed in the Aurangabad district of Bihar wherein Persons with disabilities (PWDs) enjoy their rights and entitlements with a greater amount of accessibility.

The project is unique as it envisaged an inclusive society for persons with disabilities especially persons affected by leprosy.

During 2020-21

- 758 Persons (521 males & 237 females) affected trained on RPWD act
- A total of six public places were made accessible for disabled people
- 24 awareness raising meeting on leprosy and stigma were organised in which 1019 community members have actively participated
- 556 PWDs received disability certificates and 475 PWDs received disability pension with the support of NLR India Foundation

In this project, NLRIF worked with 13 DPOs and 25 SHGs.

Needs assessment survey in leprosy colonies

Over the last few decades, the position of leprosy-affected people living in leprosy colonies has transformed due to the rapid creation and successful execution of many national and state programmes, as well as intervention by various civil groups, including ILEP agencies. Bihar has more than 65 leprosy colonies (almost 8% of the country's leprosy colonies).

The methodology (along with a questionnaire for data collection & Focused Group Discussions) was developed, and the data collection tool (Open Data Kit Platform) has been finalised. In the year 2021-22, the data collection will be initiated.

The project will help identify the current needs of the persons affected by leprosy in leprosy colonies. It will help in defining strategies for effective implementation of NLEP in the state by incorporating the results of the study in future interventions.

Disabled friendly toilets

This project aimed to construct 16 disabled-friendly toilets at schools in Varanasi's Harahua Block with the support of India's Oil and Natural Gas Corporation (ONGC). There was also a provision for each school to form a school hygiene club to improve Water, Sanitation, and Hygiene (WASH) practises. By December 2020, all toilets were constructed. The maintenance of toilet constructions is primarily the responsibility of the school officials. NLR India Foundation reached out to 2300 children and 51 teachers in the schools as direct beneficiaries of this programme. In addition, 19,300 local and school community members were educated on safe WASH practises.

These schools' students followed healthy sanitation habits and encouraged their family members to do the same. They are also more knowledgeable about leprosy as a disease and its consequences for individuals and society. Differently abled persons, particularly people with impairments, have grown more welcoming and pleasant to the children. The teachers gained a better understanding of leprosy and related disabilities, as well as appropriate WASH procedures. The project closed in December 2020.

8. Covid Emergency Response

During the pandemic, the NLR India Foundation devised an innovative 'Emergency Response' strategy in which NLRIF staff visited communities with messages on Covid-19 awareness and prevention and provided need-based support. 14 districts and 1,645 villages across seven states, were covered during the “Emergency Response” activities.

The key achievements of the Emergency Response were:

- 3,11,824 persons were reached with the preventive messages on Covid-19 through public announcement system
- 11,818 demonstrations were done on hand washing, social distancing & wearing masks
- 4,316 persons affected with leprosy and their family members were provided need-based support (MDT, dressing materials, self-care kits, MCR, splint/ other protective devices, food/ dry ration, masks, soap, sanitizer etc.)
- We also trained and monitored persons affected by leprosy on self-care by virtual medium

We maintained regular communication with government officials to follow-up on the patients under treatment. In case of any arising need for the patient, it was promptly communicated to the concerned officials. It helped in the prompt delivery of MDT and other services to the needy.

The challenges during Covid-19 pandemic times were:

The entire pool of health staff engaged in activities related to the Covid-19 pandemic, slowing down the implementation of our planned activities.

The detection of new cases and the administration of SDR-PEP to eligible contacts reduced drastically.



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9. Media Coverage

Despite Covid-19 during the period 2020-21 we have 36 media coverage in all, out of which few were depicted below.

11 शौचालयों का हुआ आनलाइन उद्घाटन

जागरण संवाददाता, हरहुआ: एनएलआर फाउंडेशन के सहयोग से ब्लाक के 11 प्रा. विद्यालयों में दिव्यांग बच्चों के लिए शौचालय बनाया गया है। इसका उद्घाटन बुधवार को फाउंडेशन के कंट्री डायरेक्टर डा. अशोक अग्रवाल व आयल एवं गैस नेचुरल कारपोरेशन के जनरल मैनेजर जयंत वालिया ने ऑनलाइन किया। फाउंडेशन के स्टेट सीवीआर कोऑर्डिनेटर बिपिन सिंह ने बताया कि हरहुआ में 11 चिरईगांव ब्लाक में 4 व शिवपुर में एक शौचालय निर्माण कार्य कराया गया। बेसिक शिक्षा विभाग वाराणसी के जिला समन्वयक त्रिलोकी नाथ शर्मा, खंड शिक्षा अधिकारी हरहुआ बृजेश कुमार श्रीवास्तव ने अधूरे शौचालयों शीघ्र पूरा कराने का अनुरोध किया। फाउंडेशन के संसाधन विकास मैनेजर अरुण कुमार ने अध्यक्षता की। स्वागत डा. प्रवीण ने किया।

कोविड-19 में साझेदारी निभा रहीं एनएलआर इंडिया टीम



जोधपुर (प्रभात व्यूज)। हथगान एवं ऐराया विकासखंड के विभिन्न क्षेत्रों में एक बार फिर से एनएलआर इंडिया की टीम ने अपना बिगुल बजाया। अनुसंधान सहायक मनीष बाजपेयी और प्रतीक्षा शुक्ला एवं दूसरे अनुसंधान सहायक किशोर कुमार पांडेय और मानसी सिंह ने फुलता पूर्वक कोविड 19 जो कि पहले से जागरूकता पर कार्य कर

रही है उसको जारी रखते हुए कुछ रोगियों से भी मुलाकात की साथ ही उनका दवाओं का रुम जारी रहे उन्हें उनके घर पर एम डी टी दी गई जिला परिवे धक डॉ आतिफ सादिक ने कस कि जो भी प्रवासी कहीं से भी आ रहे है ओ अपने गाँव, परिवार और समाज को देखते हुए अपने आप को अपने परिवार और समाज से कम से कम 14 दिन तक दूरी बनाए रखे ऐसा करना वयु जरूरी है। इस पर भी विस्तृत जानकारी टी, साथ ही उन्हें भी सच घाना, सोशल डिस्टेंस, मास्क पहनने की विशेषता को प्रयोग करके बताया गया। इसी सिलसिले में वाम प्रधानों से भी मुलाकात की गई और जो प्रवासी स्कूलों एवं पंचायत घरों में ठहरे है उन्हें हर संभव मदद करे और इसका सोशल डिस्टेंस का पालन करवाये। सोशल डिस्टेंस को देखते हुए हथगान एवं ऐराया के क्षेत्र के गाँवों में घूले से गोला बनाया गया। जिससे भीड़ एकत्रित ना हो।

दिव्यांगों की हुई जांच



शिविर में जांच करते चिकित्सक .

दाउदनगर. प्राथमिक स्वास्थ्य केंद्र दाउदनगर में आयोजित विशेष शिविर में कुष्ठ से प्रभावित दिव्यांगों एवं फलोरिया अन्धास शिविर का आयोजन किया गया. इस शिविर में एनएलआरआई पटना से पहुंचे परियोजना पर्यवेक्षक अक्षय कुमार प्रजापति एवं दाउदनगर दिव्यांग मंच के डीआईडी कोऑर्डिनेटर उमेश कुमार भी मौजूद रहे. उमेश कुमार ने कहा कि विद्यार्थ श्रमाली कान्द कल्याण के तन्त्र

दिव्यांग प्रमाण पत्र और उसके बाद 1500 रुपया पेंशन भी दिया जाता है. डॉ अनिल कुमार गुप्ता ने दवा का वितरण किया. इस शिविर में 65 लोगों ने भाग लिया, जिनकी जांच की गयी. 20 लोगों को सैंडल भी दिया गया. कहा गया कि पुनः तीन महीने बाद अप्रैल माह में फिर शिविर का आयोजन किया जायेगा. मौके पर डॉ राजीव कुमार, विन्डुमती कुमारी, पारसनाथ प्रसाद मौजूद रहे.

कुष्ठ रोगियों को बताए गये उपचार व बचाव के तरीके



पटना : कुष्ठ रोगियों को जागरूक करती चिकित्सकों की टीम।

फोटो : एसएनबी

पटना (उन्नाव) (एसएनबी)। राष्ट्रीय कुष्ठ रोग उन्मूलन कार्यक्रम के तहत शुक्रवार को सुमेरपुर पोपचसी में कैप लगाकर चिकित्सकों की टीम ने रोगियों को फिजियोथैरेपी कराई। दिल्ली से आई डब्ल्यूएचओ एवं जिला कुष्ठ नाभिक टीम ने कुष्ठ रोगियों को बीमारी के उपचार व बचाव के उपाय बताए। डब्ल्यूएचओ से आए चिकित्सक डॉ. विशाल ने कहा कुष्ठ कोई अभिशाप नहीं है बल्कि एक सामान्य बीमारी है। कुष्ठ रोगियों के प्रति लोगों को जागरूक होने की जरूरत है। डॉ. सुधांशु अंगिहोत्री ने कहा यह कोई छुआछूत से

फैलने वाला असह्य रोग नहीं है। सरकारी अस्पताल में मिलने वाली एमडीटी की दवा खाने एवं नियमित एक्सरसाइज करने से इसका इलाज संभव है। डॉ. दिवाकर त्रिपाठी एवं डॉ. राहुल देव चर्मा ने कुष्ठ रोगियों की फिजियोथैरेपी कराई। उन्होंने कहा फिजियोथैरेपी उपचार में कारगर है, इसे नियमित करने की सलाह दी। टीम ने 14 रोगियों को उपचार सामग्री व धनराशि वितरित की। इस दौरान एमओआईसी ड विनय तोमर, गौरव चौधरी, रामआसरे प्रजापति, हरिनराम सिंह आदि मौजूद रहे।

10. Grass-root Tales:

10.1. The story of Amisha: Looking ahead and forgetting the bad memories

Amisha is better, and aspires to complete education

Amisha, an adolescent girl aged 14 years, is a student of class VIII. She lives at Lamkot, in Chamba block of Tehri Garhwal district, Uttarakhand with her grandparents. She belongs to a poor family; her parents are daily-wagers and grandparents are farmers. The family comprises of five people.

Life before she had leprosy:

Amisha remembers her life before leprosy as she says, “Before I had leprosy, I was living with my grandparents and studying. I used to go to school and participate in school activities like studying, and playing, etc. I was happy, but slowly, I started losing sensation in hands and my fingers started bending. It was the beginning of nervousness.”

Diagnosis for leprosy and her feeling:

Amisha was diagnosed with leprosy at a hospital. She said, “My parents took me to the Raipur Community Health Centre (CHC) before the lockdown (COVID) in 2020 for check-up, but at that time the doctors were unable to diagnose the disease. When I went to the Coronation Hospital, from where I was referred to Doon Hospital and there I was finally diagnosed with leprosy. After that, I was referred to Raipur for treatment and was registered in Raipur CHC; from there my treatment was started.

Describing her feelings, she says, “It was really stressful for me when I came to know that I had leprosy. I started feeling low and depressed. I kept myself alone from my friends and started avoiding and talking to them. I also avoided going to the school”. I started hiding myself and my disease from others”.

Impact on her and family after diagnosis:

That Amisha was having leprosy, was affecting her family too. As she said, “We had no knowledge about the disease earlier; with the diagnosis of leprosy, everyone in our family got nervous and stressed by thinking about my schooling, marriage and future”.

Treatment and support from health department:

Amisha says, “My treatment was started from the Raipur CHC. The District Leprosy Officer (DLO), Health Educator (HE) and Non-Medical supervisor (NMS) of Dehradun and Tehri regularly visited our place and provided all the medical and other support as needed. They regularly followed up with me and provided all support. They also looked for helping me in getting disability pension”.

People and family response after treatment

Amisha is now in better condition. She is still under treatment. She says, “As of now I am still on treatment but have started feeling alright. My parents, other family and relatives are also coming out of the stress and feeling much better. Now, I am trying to go to the school regularly and even trying to participate and engage in school activities and friends. School teachers and neighbours are also supporting me and consoling me every now and then.



Role and impact of NLR on her life:

Amisha says, “NLR India Foundation supported me a lot. NLRIF’s officials regularly visited my place and also my school along with the government health staff. They sensitized and generated awareness among school teachers, students, and villagers on leprosy. They also taught us self-care techniques for eye, hand and feet to prevent them from further damage. Now I am practicing the exercises regularly at home and have started gaining the sensation and strength in my hand. NLRIF has provided me education support (school bag, books, copy pencil etc.). They also explained us about the government disability pension scheme and the process to avail it. NLRIF is regularly following and supporting me in getting back to the normal life”.

Future ambitions:

About her future ambitions, Amisha says “As I am still on treatment for leprosy and feeling well, and returning to the normal life, I am very happy and want to get rid of all my bad memories. Thanks to NLRIF staff and government health staff (DLO, HE, NMS) who guided and supported me a lot during my tough times; they are still looking for my wellbeing by providing education and ration support. My only wish is to continue and complete my studies”.



10.2. The story of Mehroonisha: Becoming self dependent post Leprosy

Ms. Mehroonisha is a 36 years old single mother with two kids of village Falna, block- Bali of district Pali in the state of Rajasthan.

Life with leprosy:

Before leprosy, she was happily living with her husband and kids. When she was diagnosed with leprosy, her life changed suddenly. It was really shocking for her when she came to know that she had leprosy. She started feeling low and depressed. Her husband and other family members started ignoring and abusing her. Her husband left her 3 months after she was diagnosed with leprosy. She was devastated and couldn't think what to do. She started working as a maid in the neighbouring families for supporting herself and the children.

Diagnosis for leprosy and her feeling:

About two years ago in 2019, she started feeling redness in her eyes and some spots on her face. Initially, she didn't care much about it and kept ignoring. One day when the government non-medical supervisor (NMS) came visiting her village, she contacted him and informed about the condition. After the initial assessment, the NMS took her to the PHC where, she was diagnosed with leprosy. Immediately her treatment was started; it was in November 2019.

Impact on her and family after diagnosis:

Leprosy severely affected her and the family especially her husband. He abandoned her along with her children. But with the support and advise of the NMS and other health staff, she gained her strength and started working and slowly her life got better.

Treatment and support from health department:

She received her course of MDT free of cost. The NMS regularly followed her up during the treatment and provided all necessary support. The NMS also supported her in getting disability pension which she is receiving every month.





People and family response after treatment:

Even after a few months of completing the treatment, the family was still ignoring her and not contacting her or kids. But the neighbours are now good with her and they ask about her well being; they do not discriminate her and her kids.

Role and impact of NLRIF on her life:

As Mehroonisha said, “NLR India Foundation supported me a lot. They trained me on self-care techniques for eye, hand and feet to prevent them from further damage. Now, I am practicing these exercises regularly at home and have started gaining the sensation and strength. I am really feeling good and will keep doing these exercises. They also informed and detailed about the government disability pension scheme and elaborated the process and with the support of them and NMS, I have started getting the pension. They regularly support me in getting medicines like eye drops, goggles, and counselling”.

Future ambitions:

She is now very happy. “Now, as I am returning into the normal life, I am very happy and want to get rid of all the bad memories. Thanks to NLRIF staff and NMS who guided and supported me a lot during my tough times and still they are looking for my well being. My only wish is to educate my kids so that they will be able to stand on their feet and become independent”, she acknowledged.

10.3. The Story of Sanjay: How NLR India Foundation helped me rise from Leprosy and Joblessness

Mr. Sanjay Kumar is a 28 years male from Uttar Pradesh. He is married for four years and has one daughter. He decided to share his own story to the world.

Sanjay says, “I am Sanjay from Company Baag Rawatpur, Kanpur Nagar, Uttar Pradesh, India. I am a post graduate accountant. Here in India, even today; people think that leprosy is an incurable disease, so they keep themselves away from the leprosy affected persons. These neglected persons affected by leprosy find themselves unable to get a job and support their families, and they even think of committing suicide. The persons who come to know that they have leprosy, hide themselves and the disease. If they tell about their disease to anyone, it can affect their families and their social prestige”.

“About 12 years ago, the middle finger of my left hand became numb. At that time, I was working in a company as an accountant. Due to weakness in hand, I was not able to do computer work; so, I lost my job. I and family faced a lot of problems”, said Sanjay.

Sanjay further says, “I met many doctors and was treated for years for this ailment, but all were ineffective. People don't know about symptoms, and so they fail to go for treatment in time. Even doctors were not able to diagnose leprosy. Because of delay, I got reactions again and again. I was unaware of any government support and I reached Delhi in search of better treatment. From internet I got to know about NGOs and government schemes regarding leprosy. I mailed to many NGOs and government officials. I got a prompt response from NLR India office at New Delhi, and a team came to meet me in 2020. They called me to the nearest government hospital and arranged all my need including a full one-year drug treatment for free of cost. As a result; today I am running coaching classes of small children for my earning”.

“There are many educated persons like me who are unable to get a job due to leprosy. My left hand had clawed, and it made my life difficult, but NLRIF came forward, and has helped me a lot. From treatment to self-care, and from emotional to economical support, NLRIF has stood with me, and given me all I needed. I am really very thankful to NLRIF for saving my life from becoming miserable”, Sanjay further adds.

Showing his gratitude towards NLRIF, Sanjay says, “Thank you NLR India Foundation”.



10.4. The Story of Vikas: Reconstructive surgery reconstructed his life from leprosy

This is a story of a person named Vikas Saini, 20 years, single male from Kalana village of Deomia Block in Fatehpur district of Uttar Pradesh. His family run flower business, and he worked as a helper in local general store in his village. During the data collection for leprosy perception study under PEP++ project, the team conducting the study met this person with unique style- he always talked with other people with his hands in pockets of his trousers. He was a leprosy patient treated for leprosy. When he was further enquired by the team about this, he said that his finger got twisted/curved due to leprosy, that is why he used to meet people and friends less and always keeps his hand in the pocket.



The team examined him and found that there is still flexibility in his fingers. We first gave him self-care training and told him to do that regularly so that his fingers become more flexible and fit for surgical correction. The team kept on counselling him, but even after two years he was not fully motivated for getting the reconstructive surgery (RCS) done for correcting his fingers. He was being told that the surgery was free of cost in government hospitals and that he will also be provided with an allowance of Rs. 8000/- there for completion of the treatment.

After much persuasion and motivation, he became ready for surgery. He was admitted to an RCS center in the leprosy mission (TLM) hospital, Naini and now has returned after getting successful treatment of his finger. He is very much happy and filled with positiveness. He has stopped hiding his hand in the pocket and is now living his life with confidence; also, his father told the team during their last visit that now they were looking for a life partner for him.

During the interim visits to his family, the other family members were also examined. It was found that his younger brother and father were also suffering from leprosy, but they were not aware of it. The team got them registered and their treatment was started. Now both have completed treatment & healthy, and they thank all the people and the NLRIF family that because of one of its projects (here PEP++), we visited the village and they got benefited from it.

He expressed his gratitude by saying - Thank you NLR India Foundation.

10.5. The Story of Bimla: “I chose not to place “DIS”, in my ability”

The pressure to have sons is terrifying - mothers who bear daughters are cast aside by husbands and in-laws desperate to escape the financial burden of a girl's dowry. In a country where boys remain prized and having a daughter is considered by many to be a curse.

I, Bimla resident of Delhi – RK Puram, Asha Dan Leprosy Colony. My second daughter's birth was the happiest day of my life, yet I could sense grief in my family's expressions. A year later, I delivered a baby girl again, unfortunately the baby girl was deaf and dumb, that's when I was determined, whatever it takes, I'm going to raise her with all my grit and courage and give her the best life I can. I will make her independent and not let anyone see her as a burden and I chose not to place “DIS”, in her ability.”



I contracted leprosy at a very young age through my mother, one of the world's most stigmatised diseases, leprosy, also known as Hansen's disease. Life took a cruel turn and I was shunned by my family and forced to live almost in isolation from relatives and from the community. We had to migrate from our village because of discrimination and we decided to move out to Delhi in a hope of dignified life. I took MDT and was treated, and I am cured now; my studies lasted until the tenth grade; I wanted to continue, but because I had leprosy, my parents also wanted me to marry as I was looked upon as a burden on the shoulders of unlucky parents who can rid themselves of me only through marriage, so I didn't push them too hard. I married at the age of eighteen. But I wanted to raise my daughters to be self-sufficient, so I'll teach them as much as they want and only marry them when they're ready. NLRIF assisted and supported my children's education and I am also an active member of SHG facilitated by NLRIF. I have three daughters, one of them is deaf and dumb, and I received assistive devices from NLRIF. My daughters are studying, and I am a proud mother. I want public perceptions toward our daughters to improve, and I am joyfully taking steps in that direction.

Bimla Ji can be seen interacting with people in her community and spreading awareness about leprosy and its issues in all of the pictures below. She also encourages women in the neighbourhood to become self-sufficient by joining SHGs, where they can acquire a new skill while also earning a living.



until
No Leprosy Remains

11. Partners and Collaborations

Year 2020-21 has been quite challenging for NLRIF mainly due to the pandemic. Still we were able to collaborate with some partners for the development of the persons affected by leprosy and their family. During the pandemic, the usual services being provided by NLRIF took a backseat and the focus shifted towards mitigating the immediate challenges related to pandemic.

The pandemic brought havoc among people living in leprosy colonies as there were extreme uncertainties beyond anyone's control. Life of people had been affected tremendously. The focus was now more on providing them the immediate relief – food and healthcare.

Their normal livelihood resources were further affected. People lost their livelihood overnight because of countrywide lockdown announced by the government.

Daily wagers were in a miserable condition, no food, no healthcare facilities, mobility issues in rural setups was also a challenge.

During this devastating time partners like Centre for India Progressing (CIP) Noida, SNJ Charitable Trust, New Delhi; Goonj New Delhi and Oracle India Private Limited Bengaluru were some of the agencies who came forward to support the needy leprosy affected living in leprosy colonies.

Oil and Natural Gas Corporation Limited (ONGC) supported with a project on construction of 16 disabled friendly toilets in 16 government primary schools in Harahua Block of Varanasi district in Uttar Pradesh.

12. Get Involved

Volunteer and Interns, who work with us for a short period of time often leave with rich experience and knowledge about our programmes on leprosy, lymphatic filariasis and related disabilities and get acquainted with the communities we work across. We provide internships to students from India and abroad to work, as per their interests and suitability, with teams from programmes, research, strategic information, grant, finance, administration, communication and fundraising department.

If you are interested in doing internship or work voluntarily, please contact with us at –info@nlrindia.org

Donate:

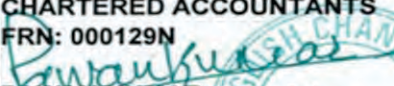




We are trying to achieve our goal of eliminating Leprosy in India. However, we need to accelerate prevention and care support to cover the last mile. International funding for Leprosy has been declining for a while. We are increasingly becoming dependent on domestic funding for sustaining and fast-tracking leprosy support across our seven intervention states in India. We urge and appeal to individuals and corporates to join hands and support us.

Here are some of the ways you can support us:

1. Make an online donation, please visit: www.nlrindia.co.in
2. Invest your CSR Funds meaningfully, collaborate on mutually benefiting ventures and initiatives.

Please connect us on info@nlrindia.org

13. Audit Report

NLR INDIA FOUNDATION BALANCE SHEET AS AT 31ST MARCH 2021			
(Amount in ₹)			
	SCHEDULE	As at 31st March, 2021	As at 31st March, 2020
SOURCES OF FUNDS			
Corpus Fund	2	1,91,14,943	64,55,069
Employee Benefits Payable	3	10,76,158	-
Other Payables	4	73,688	-
TOTAL		2,02,64,789	64,55,069
APPLICATION OF FUNDS			
Current Assets & Loans and Advances:			
Cash at Bank	5	1,65,33,697	53,89,870
Fixed Deposits with Bank		33,71,300	71,300
Cash in Hand	6	73,444	9,241
Advances	7	1,05,996	9,66,371
Other Current Assets	8	1,80,352	18,287
TOTAL		2,02,64,789	64,55,069
Significant Accounting Policies	1		
Notes to Accounts	9		
FOR JAGDISH CHAND & CO. CHARTERED ACCOUNTANTS FRN: 000129N  PAWAN KUMAR M.No:- 511057 		FOR NLR INDIA FOUNDATION  Dr. Ashok Agarwal (Managing Trustee) 	
PLACE: NEW DELHI DATE: 30.09.2021		 Ms. Nirmala Gupta (Trustee)	



until
No Leprosy Remains

NLR India Foundation



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