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## Reach and Coverage



#### 124

Districts NLRIF is working out of 741 districts of India



#### 150

Leprosy colonies NLRIF is working out of estimated 1000 colonies in India



#### 10874

Persons affected by leprosy trained in self-care



#### 5202

Health staff trained on leprosy and its self-care



#### 1481

Persons affected from leprosy engaged from groups and organisations



#### 757

Dependents of person affected by leprosy received financial aid for education



#### 627

Persons affected by leprosy received assistive devices



#### 131

Persons and family members affected by leprosy received vocational training



## Highlights of the year

Alignment with Government of India's Programs and Initiatives

Awareness and Sensitisation on Leprosy

**Capacity Building** 

**Combined Self-Care and Healthcare Camps** 

Differently-abled friendly infrastructure

Educational, Vocational and Livelihood Support

## SWOT Analysis

#### Our Organisation

#### **St**rengths

- More than two decades of sustainable and diverse priority programmes on leprosy
- Research-based approach in close coordination with Government of India's existing health system and technical support from NLR International for leprosy, resultant disability and its care and management
- Inclusive and diverse innovative approaches (e.g. Combined Self-care, Lepclips, SHGs)
- Increased securing of funds besides NLR International

#### Weaknesses

- Requirement for a consistent learning and knowledge enhancement strategy and documentation
- Limited communication and branding efforts
- Limited documentation of learning
- Limited in-country resource mobilization

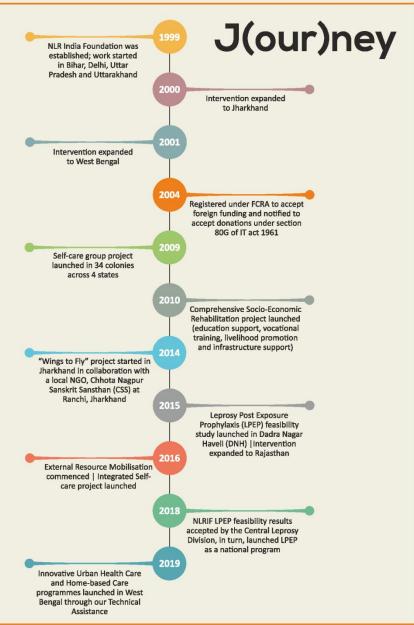
#### Our Environment

#### **Opportunities**

- Greater collaboration with the federation of autonomous anti-leprosy non-governmental organisations (ILEP) and other agencies/ institutes and experts on leprosy and other neglected and tropical diseases (NTD)
- Document and share best practices and models of intervention on NLRIF niche areas of work
- Tap opportunities available beyond NLRIF seven states
- Greater use of digital/social media for brand building and fund-raising

#### Threats

- Limited financial pool with dependency on NLR International Office for financial support
- Greater competition for the shrinking funds for leprosy
- Emergencies like Covid-19 leads to disruption of work and economy

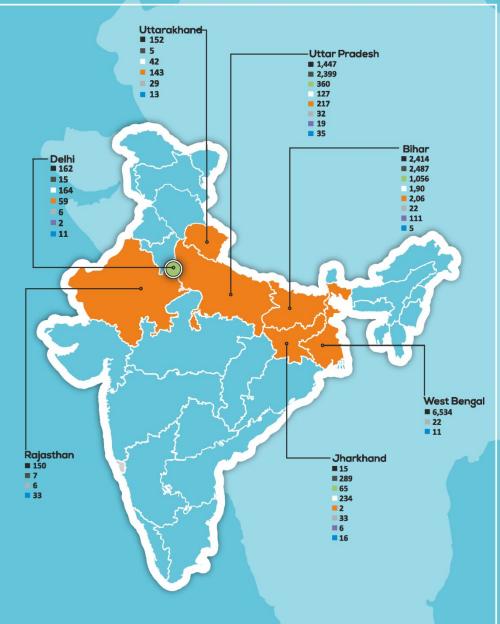


# Our Reach and Coverage

	Persons affected by leprosy trained in self-care	1087
•	Health staff trained on leprosy and its self-care	5202
	Persons affected from leprosy engaged from groups and organisations	1481
	Dependents of person affected by leprosy received financial aid for education	757
•	Persons affected by leprosy received assistive devices	627
	Leprosy colonies NLRIF is working in; out of estimated 1000 colonies in India	150
	Persons and family members affected by leprosy received vocational training	131
_	Districts All DIE is working out of 741 districts in India	12/

## Zero Leprosy Suffering

2019-20



## 2019 in review

#### **Message from Chairperson**

When NLRIF was established twenty-one years ago with a vision to remove Leprosy from communities in India, we did not want it to be only a "charitable" non-governmental organization (NGO) but a "development" NGO that is non-religious and non-political.

I am pleased to present the Annual Report of NLRIF for the fiscal year 2019-20; marking our accelerated efforts in making "THE NATION, free of leprosy suffering". All of us in NLRIF take pride in the fact that our development initiatives have so far impacted the lives of thousands of people across seven states of India. The success of our development model, which emphasizes working at the grassroot level and improving the quality of life of the communities; motivates us to do much more to bring a difference in the lives of thousands of Indians.

Our staff is playing a major role in the health systems strengthening and improving the implementation of the National Leprosy Eradication Programme (NLEP), and programs related to prevention of disability (POD).

During the year, NLRIF supported the Central Leprosy Division (CLD) in key activities like the Leprosy Case Detection Campaign (LCDC), SPARSH awareness campaigns (antidiscriminatory Behaviour Change Communication), and development of the Revised Operational Guidelines for LPEP (Leprosy Post Exposure Prophylaxis with Single Dose Rifampicin - SDR).

NLRIF, through its innovative combined selfcare program, trains the persons affected by Leprosy and Lymphatic Filariasis (Lymphedema cases) on methods and techniques of selfcare both to prevent and to ameliorate their disabilities. In the year 2019, this training was conducted through camps in different Primary Health Care Centres (PHCs) benefitting many persons with disabilities where each of them was trained on self-care and provided with kit for self-care.

To take care of sustainability, the camps were organized by involving General Health care (GHC) staff. Besides self-care, 967 children of affected persons were provided with education support; and 52 adolescents/youth were supported for vocational training. We facilitated provision of protective footwear to 178 persons with disabilities (PWD); seven Persons with

Disabilities (PWDs) were assisted in getting reconstructive surgeries done through Government of India's support. Six health camps were organized in leprosy colonies of Delhi and Jharkhand benefitting 1518 persons. With regards to Disability Inclusive Development (DID), 45 new Self-Help Groups (SHGs) were formed during the year making a total of 272 SHGs benefitting 4441 families under NLRIF to date.

The International Day for the persons with disabilities was observed on 3rd December, 2019 in which hundreds of persons, supported by NLRIF, took out procession in the state of Bihar to place their demands leading to issuance of disability certificates,

pensions and other benefits from the State Govt. NLRIF is committed to support the national program, to make India free of leprosy and support persons with disabilities, for their self-reliance and mainstreaming.

I wish NLRIF a successful journey ahead.

July 2

Ms. Nirmala Gupta

Chairperson, Board of Trustees, NLR India

OARD MEMBERS



Ms. Nirmala Gupta Chairperson



Prof. K Srinath Reddy Trustee



**Dr. Lalit Kant** Vice Chairperson



Dr. Ashok Agarwal Managing Trustee



#### Vision

### NLRIF's vision for an India with Zero Leprosy Suffering:

- Zero suffering due to leprosy, disabilities and social exclusion that it causes.
- Health systems in all endemic states which can diagnose and treat leprosy early and effectively.
- 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 that disease will no longer be a major risk for disabilities and social exclusions.
- Societies in which governments, private companies, NGOs and Disability People Organizations (DPOs) join hands to ensure that people with disabilities are:
- (a) Enabled to participate as fully and independently as possible.
- (b) 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.
- (c) Treated equally with dignity.

#### **About Us**

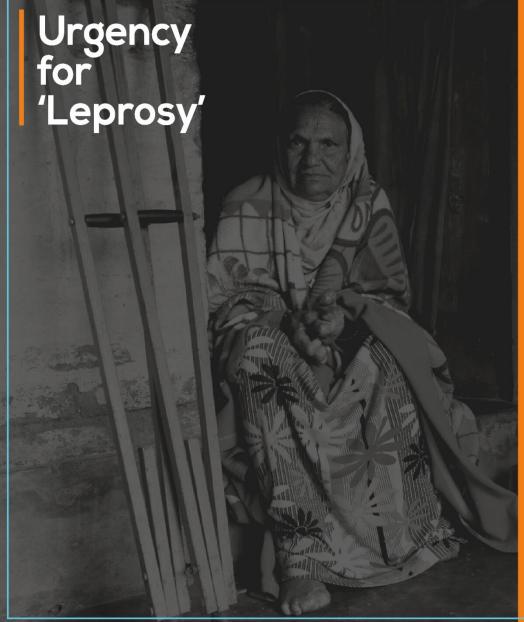
NLRIF is a non-profit, non-religious, non-governmental organization registered as public charitable trust as per the Indian Trust Act in 1999. NLRIF is certified for Foreign Contribution Regulation Act (FCRA) in 2004 and received tax exemption under section 80G of IT Act, 1961. In addition, NLRIF is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

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

#### Where we work

NLRIF works in seven states, namely, Bihar, Delhi, Jharkhand, Uttarakhand, Uttar Pradesh, Rajasthan, and West Bengal in 124 districts towards one aim – Zero Leprosy Suffering. NLRIF works closely with 150 leprosy colonies in these states. Our dedicated 20 employees also support the programs for rehabilitation of people affected by other parasitic and bacterial diseases and disabilities. Through our cadre of Community Based Rehabilitation Coordinators (CBRCs), we support the programs for rehabilitation of persons affected by Leprosy and other disabilities.

Annual Report 2019-20



From the medical standpoint, leprosy stands as one of the many curable diseases in the contemporary times with scientific breakthroughs. One such ground-breaking development was the multi drug therapy introduced by World Health Organisation (WHO). From a 1983 estimate of 11,525,000 cases by the WHO Study Group on Epidemiology of Leprosy in Relation to Control, the number of leprosy affected persons decreased to 2,08,641 leprosy patients in 2018 (Ref: Weekly Epidemiological Record, WHO Report 2018); still people across the globe continue to suffer due to leprosy as an outcome of late diagnosis and treatment, resultant disability, poor disability care, poor preventive measures, and stigma and discrimination.

Among the major contributors to new leprosy cases, South East Asian Regions (SEAR) accounted for 1,48,495 cases out of 2,08,641 cases globally, i.e., 71% new leprosy cases. Among the SEAR, 2 countries, India (1,20,334) and Indonesia (17,017), contributed 92% of the Region's case load.

India accounts for 57.7% new leprosy cases out of the world population affected by leprosy as per World Health Organization.
Among 1,20,334 new cases in India, 9,227 children were affected by leprosy.

Despite the alarming situation, it is a common perception across the country that leprosy is a 'historical' problem. This leads to the dilution of the required priority, due to the situation of leprosy. In 2019-20, we took steps to bring the urgency of leprosy to the attention of our beneficiaries, stakeholders and general audience through combined

selfcare, disability inclusive development and reduction of stigma and discrimination in the local community. With the surrounding stigma and discrimination, it can be expected that there are large number of people with leprosy who are undetected, undiagnosed and untreated. This coupled with delay of timely detection and cure contributes to the fact that India alone accounts more than half of new leprosy cases and its effects leading to disabilities.

NLRIF realized the dire need to control the sufferings caused due to Leprosy. They need to be encouraged and enabled to overcome disabilities, poverty and need support for earning a dignified income.

In 2019-20, NLRIF continued to work with state governments, non-governmental organisations, corporates, research institutions, Disabled People's Organisations (DPOs) and persons affected by leprosy to strengthen the existing health system.

NLRIF primarily provided services to people affected by leprosy and their dependents. However, with its noble vision, NLRIF has successfully expanded its horizon to disability-inclusive development programme where services are extended to the sufferers of another marginalized section including people affected by Lymphatic filariasis (LF) and diabetic neuropathy.

NLRIF focus of activities are on two major areas –

- 1. Disability care, and
- 2. Disability Inclusive Development.

Under the first thematic area of disability care, there are 3 major interventions i.e. Self-

Care, Health Camps and Aids and Appliances support. NLRIF undertakes self-care initiative to deal with leprosy and its consequences. Under Self-care, disability status of each individual is determined to understand their specific requirements for support and care. We help establish sustainable 'Self-Care Groups' and practices within the local communities to prevent disabilities in people affected by leprosy.

Under these groups, we ensure that differently-abled person (due to leprosy) learn and adopt self-care as a regular practice. The formation of such groups allows the individuals to acquire 'a sense of belongingness' eradicating the stigma and discrimination suffered. 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 thematic 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 SHG, Strengthening Disabled People's Organisation, and income generation activities are undertaken.

NLRIF's activities emphasise towards Sustainable Development which is vital for reaching our aim – Zero Leprosy Suffering and the required long-term futuristic empowerment of leprosy affected communities. During the year, NLRIF developed the Revised Operational Guidelines for LPEP (Leprosy Post Exposure Prophylaxis) with Single Dose Rifampicin – SDR. NLRIF made the community aware of the need for taking the post exposure prophylaxis (PEP) by the contacts of the leprosy cases and its availability at the local primary health centre; some of them were also connected with the concerned government health worker.



#### ALC: NO.

## Our Donors

## Each contribution matters

Believing that each contribution matters, NLRIF follows a mixed approach to ensure that our mission and essential costs are taken care of. Combining traditional and modern ways, NLRIF primarily entrusts its financial and resource requirements on Donation boxes, Individual and Institutional donors. The donor support received during 2019-20 enabled us to reach out to more and more leprosy affected persons across our seven intervention states. They were able to receive appropriate care and support for their current situation. Along with the medical support, NLRIF was able to eradicate discrimination and facilitate successful rehabilitation for persons affected by leprosy.

All of this became a reality with the kind-hearted support and donations from individual and institutional donors. The essential grants from

NLR (Until No Leprosy Remains) International, ONGC (Oil and Natural Gas Corporation Limited), CIBC (Concept International Business Consulting), CIP (Centre for India Progressing), SNJ Charitable Trust, Medische Missie Zusters (MMZ), and Novartis

provided us the platform for continuing our relentless work. In the coming times, we see the growing support from our individual donors who will help us achieve our one true aim – Zero Leprosy Suffering.



NLRIF undertakes a simple but effective way to raise funds through directly accessible channels – Donation Boxes. The practice and joy of giving has been instilled in the mindsets of the residents of Indian subcontinent since ancient times. Through these boxes, the practice of Dāna (means giving) has been undertaken. In India's traditional texts, it has been elucidated as relinquishing what one considered/identified as one's own and giving it to someone else without any expectation of return from those who receive the charity.

After placing these transparent donation boxes strategically in and around cash turnover points, i.e., Convenience stores, Food outlets, etc, these boxes act as a passive fundraising tactic. In the year 2019-20, using only 10 donation boxes, ₹ 14,406 was raised for serving the cause of leprosy affected persons. Using the conventional method, these boxes form an important part of NLRIF's branding and fundraising strategy for executing the mission and further the organisation operations. As our way forward, we plan to digitalize the donation box through 'Cashless Giving'.

# Fundraising & Communications

#### Seeing is believing

Reaching out to potential and existing donors through relevant channels form the centre of our fundraising strategy. NLRIF places the donor's convenience utmost and ensure the right information reaches to the prospective and current donors. The year 2019-20 has been a remarkable year for the highest everincreasing support by donors in comparison to the previous years. We aim to expand the donor-centric fundraising through continuing our service to the cause and simultaneously improving the communication.

#### Contact.Engage.Check

NLRIF's dedicated fundraising professionals seek time and interest of prospective donors through one-to-one calls and meetings. In addition, to ensure their interest and engage them with our mission, updated information and emailers are shared. After ensuring their interest and our mission intersect, we communicate and sensitise the potential donor about the organisation work and approach through collaterals like annual report, leaflets, project briefs, etc. Further, we check with the potential donors how they can possibly extend their support. The support can be either through Individual donation or donation boxes or fundraising/branding events.



"The year 2019-20 has been a remarkable year for the highest everincreasing support by donors in comparison to all the previous years."

#### Sharing the care

Though we have a long way to go on our journey to make 'leprosy' a priority area from a neglected tropical disease, we intend to communicate our regular interventions to the masses. For most Indians, leprosy is either non-existent or a disease of past in our country. Through the representation of our cause on digital channels, we aim to throw light to the major burden India accounts for leprosy cases.

We keep on updating the donors and masses by sharing personalised stories & on-ground insights of our beneficiaries. On social awareness and important days like World Leprosy Day, World Disability Day, Independence Day, etc, we bring our viewers' attention to leprosy care emphasising the resultant stigma and discrimination.



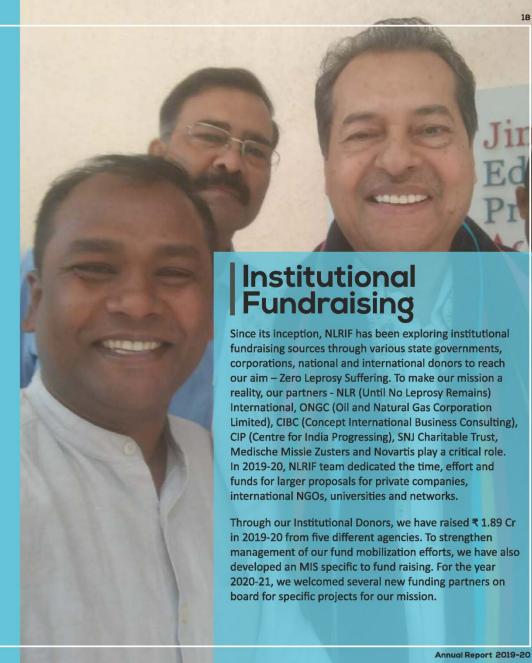
### Individual **Donors**

With each passing year, NLRIF is receiving the unending support of Individual donors. For any organisation, raising funds is an important task to move towards achieving its mission and meeting the underlying costs. Sustainability of an organisation can be achieved if funds are mobilized to support its administrative costs.

NLRIF began receiving support from individual donors in 2008. Starting from one individual donor to 258 donors, a total donation of ₹ 9,16,573 is raised in the year 2019-20. Valuing our donors, we customise our outreach around them. We ensure consistent interaction through all possible

communication channels including 80G certification which describe donations are tax free. Transparency and accountability are our highest virtues especially for those who lend a hand to help the ones affected by

In the coming year, the emphasis will be placed on innovative low-cost ideas and activities to increase the visibility of NLRIF. To further get more individual donors onboard, we aim to revolutionize our communication strategy reaching out to individuals from Government, Corporates, Institutions, Media, Philanthropies and even common masses.





#### Other ways of fundraising

In the year 2019-20, NLRIF Team approached a different set of potential donors and targeted groups. The future generations and general masses were approached through events and awareness sessions on leprosy. In the month of November 2019, we engaged four enthusiastic volunteers to create awareness on leprosy to the masses attending the International Trade Fair. People not only came forward to know more about leprosy but donated generously to NLRIF for its services for the leprosy affected.

On 22nd December 2019, an event was organised with support from Oracle India Private Limited in one of our intervention leprosy colonies in Delhi. The event witnessed participation of 14 volunteers from Oracle India Pvt. Limited. During the event, we engaged the residents into singing, dancing, drawings, Christmas tree decoration. Gifts, meals and cakes were distributed to the children. The residents and their children thoroughly enjoyed the organised event.

An awareness session was organised on 20th January 2020 for the young students of School of Architect and Planning, Delhi University through contact sharing. More than 30 students were sensitised who assured to be the champions for NLRIF creating awareness against the misbeliefs about leprosy to end stigma and discrimination.

Another awareness event was organised on 28th January 2020 in a school in Delhi

where more than 200 children were sensitised on leprosy its symptoms, treatment and where to report a leprosy suspect. The school was also informed about NLRIF and its various programs implemented for their socioeconomic development of the leprosy affected in seven states of India. Children came forward to donate generously for the cause.

Our approach to bring the urgency of leprosy to the light to the targeted audience brought little though valuable contribution of ₹ 26,632 from all the other sources of financial support.

#### Digital Imprints

Understanding NLRIF potential to grow on digital platforms, the foundation has been laid on virtual interactivity with the audience in the year 2019-20. Apart from sharing our journey, we see enormous potential in the use of online channels for fundraising. Timely updates and changes have been made on our website www.nlrindia.co.in and social media channels have been utilised to share the updates from the field.

## Brand promotion and communication

Tapping the untapped potential, NLRIF remains in its incubation stage of brand development in the year 2019-20. Though little, NLRIF team understands the present status especially in relation to other charitable organisations. The need exists to showcase the distinctiveness, reach and impact of our cause in our diverse country. The year saw a step towards developing the outreach strategy for the organisation's work and fundraising.

#### Re-branding NLRIF

Staying true to its unique leadership role in the country reaching out to the leprosy affected and caring for their disabilities, NLRIF reaches out to the largest number of leprosy colonies. NLRIF disability care initiatives are the oldest with more than 2 decades of learning with a capacity to provide an appropriate disability care model for the country. In the year 2019-20, to shed

## NLRIF: J(our)ney online in 2019-20 (Infographics)

2018-19 2019-20

Followers on Facebook

1322

1363

Unique users (Page Likes) on Facebook

1323

1359



387

465



25

634

more light on the neglected disease of Leprosy, NLRIF conducted an online campaign 'Leprosy Lives Matter'.

In addition, this year we analysed how effectively we can utilise our human resources while getting more qualified professionals to revamp our communication and fundraising strategy. Keeping up with the need, adjustments have been made to enrich our organisational guidelines.

These adjustments are communicated to our field staff to spread the word of our current brand image of NLRIF to beneficiaries and stakeholders. NLRIF's branding is crucial to maintain the standard and reach more and more audience. Branding collaterals and items like Planners, Coffee Mugs, Pens, Key Chains are shared with our donor partners and stakeholders while ensuring correct logos and relevant message are used and delivered.

#### Outreach and Fundraising

The fundraising arena is highly competitive in Indian market hence NLRIF needs to focus on innovative ideas which provide better gains with less investment. It is essential that visibility of NLRIF is improved and we do activities which help in expanding our donor base. We also need to innovate how to raise funds and remain connected with the donor. Hence, the fundraising team would need an effective support from communications unit in enhancing the reach of NLRIF to various sectors such as Government, Corporates, Institutions, Media, Philanthropies and common masses. The communication unit

will make considerable contribution through development of tools and strategies to reach out to every stakeholder.

#### The way forward

Learning from current situation, NLRIF aims to move forward. 'Swift and steady' – a difficult two-sided combination is what NLRIF looks forwards to. The mission to serve the cause of leprosy and raise enough funds to ensure continuity of NLRIF till Zero Leprosy suffering may seem like a mammoth task is achievable through consistent strategic efforts of our dedicated & qualified team. To engage new individual and institutional donors, outreach in physical and digital spaces will play a key role to achieve our noble objectives.

3 Zeros: Strategic Programmes

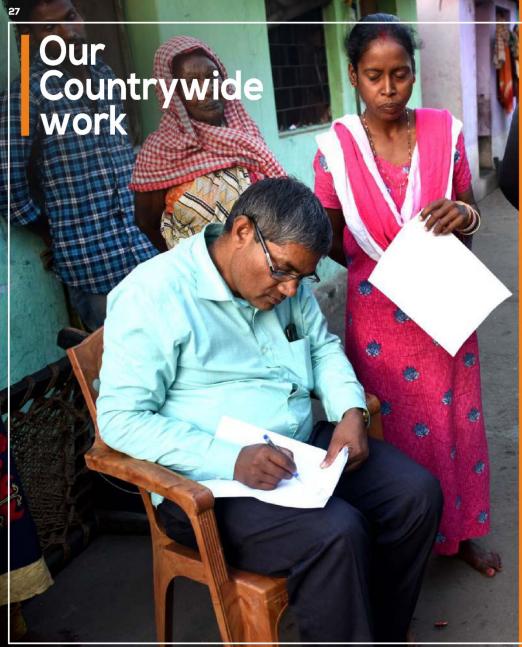
Transmission
Disabilities
Exclusion

In 2019-20, NLRIF following up the three strategic programmes: Zero Transmission, Zero Disability, and Zero Exclusion restructured our priority programmes to deal with leprosy and its consequences. The Zero Transmission programme aims to reduce the transmission of the leprosy bacteria.

The Zero Disability programme aims to prevent persons affected by leprosy from developing new disabilities during or after treatment. In the Zero Exclusion programme we aim to improve lives of persons with disabilities due to leprosy by enabling access to services and participation in community activities.

The three Zeros underline our vision of a country free of leprosy and its consequences. In all aspects of their lives, persons affected by leprosy are confronted with discrimination and stigma. This fuels a vicious circle of troubling

consequences: social exclusion, mental trauma and economic woes. Considering that these consequences have a lifelong impact, sometimes even continuing beyond one generation, NLRIF strategized and implemented their interventions focused on reducing stigma and discrimination in each Zero-programme. NLRIF programme on Zero Transmission of leprosy combines its experience of preventing leprosy among contacts of leprosy patients through single dose rifampicin done as a pilot study from 2015 to 2018 in Dadra Nagar Haveli, promoting the government leprosy post exposure prophylaxis programme (LPEP). Under the Zero Disabilities programme, NLRIF works toward stopping persons affected by leprosy developing new disabilities during or after treatment when they are cured. The Zero Exclusion programme consists of two major interrelated components - disability care, and disability inclusive development. Annual Report 2019-20



Working in 124 districts across seven states,
NLRIF works toward one ultimate aim – Zero Leprosy Suffering through 3 strategic Zero programmes.

Under Zero Transmission, NLRIF mainly strengthens the activities under National Leprosy Eradication Program (NLEP) of Govt. of India. NLRIF supports the NLEP and other government initiatives like Leprosy Case Detection Campaign, SPARSH, etc. by building the capacity of general health care (GHC) staff including District Leprosy Officers (DLOs), medical officers (MO) and front-line workers on early case detection and disability prevention. In the year 2019-20, a total of 385 health staff have been trained for leprosy prevention and testing.

Under Zero Disabilities, NLRIF undertakes Disability Care and rehabilitation through 'Combined Self-Care' and 'Comprehensive Socio-Economic Rehabilitation (CSER)'. NLRIF aims to stop persons affected by leprosy developing new disabilities during or after treatment when they are cured through Multi-Drug Therapy (MDT). NLRIF has promoted the combined self-care (CSC) projects training 10874 Persons affected by leprosy in self-care in the year 2019-20. Under it, NLRIF team train persons with disability due to leprosy and disabled persons due to lymphatic filariasis who all require self-care, platform to report

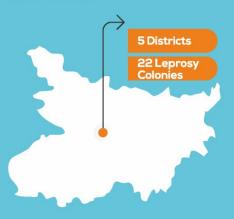
complications, and demand for assistive devices or reconstructive surgery. Through CSER, NLRIF positively impacted the lives of 1515 persons directly or indirectly affected by leprosy through Livelihood Promotion, Educational Support and Vocational Training.

Under Zero Exclusion, to enable inclusion and empowerment of persons with disabilities including persons affected by leprosy, NLRIF has successfully established community-based people's institutions in the forms of Self-Help Groups (SHGs), Village Development Committees (VDCs), Block Development Committees (BDCs), Disabled People's organisations (DPOs) and Leprosy People's Organization (LPO). Through inclusion and empowerment initiative, 1481 persons affected by leprosy from groups and organisations have been successfully engaged in the year 2019-20.

NLRIF work in 56% districts (124 districts out of 221 districts) of seven severely affected states by leprosy in India. In 2019-2020, the seven states reported 47,715 new cases out of which 23,290 cases were reported in the NLR intervention areas (49% of total). In 2019-20, these states reported 1,068 Grade 2 Disability (G2D) cases in which 523 cases were reported in NLR supported areas (49% of total). The recorded child leprosy cases went up to 3,268 out of which 1,347 were recorded in NLR supported areas in the year (41% of total). NLRIF expanded its reach to 150 out of 289 leprosy colonies in these seven states (52% of total).



## Story from Bihar



NLRIF team works in 5 out of 38 districts of the state; in 2019-2020, the 5 districts reported 1924 new cases (12% of total), 66 G2D cases (14% of total) and 176 child cases (10% of total). NLRIF team covers 43% (22 out of 51) of the leprosy colonies in the state.

Anjana Devi, aged 23 years, wife of Basant Kumar Gupta lives in a small village Khiriava in Aurangabad district in the state of Bihar. Coming from a financially poor background, she suffered from stigma and exclusion within the community due to her unknown illness.

The community outcasted her for being visually different from others. Despite receiving treatment from a village doctor for her sensory issues in feet and mobility, she was living her life as an 'untouchable'. Fortunately, she met a local self-help group who is working in close contact with NLRIF Team.

NLRIF Team assessed her illness and facilitated the necessary tests and analysis to determine her nature of sickness. After her assessment was completed, it was found that she has leprosy. Soon, relevant treatment and diagnosis was provided to Anjana. To ensure the disease doesn't lead to further issues and disabilities, she was advised about the self-care practices. In addition, NLRIF Team facilitated the provision of certificate for her 'Grade 2' disability. This ensured that she receive ₹ 1500 every month as a recipient of Bihar Shatabdi Leprosy Welfare Scheme (Govt. of India).

NLRIF Team saw potential in Anjana Devi for financial sustainability through self-employment. Previously, Anjana Devi took loan of ₹3,000 from the local Divyang Self Help Group. However, the money was insufficient for her in establishing a home-based firm which mentally tormented her. Seeing her acquired skill to make incense sticks, NLRIF lent a hand for livelihood support to Anjana and ₹25,000 for buying an Incense Stick Manufacturing Machine. Now, Anjani Devi makes incense sticks in her house and her annual income goes up to ₹2,50,000.



"I am thankful to NLR India Foundation for providing me a new life and now I am living a dignified life. Please help more people like me" – Anjana Devi

#### Challenges faced

Bihar is NLR's first intervention state where we started working more than 20 years ago. Through NLRIF dedicated approach to serve the cause of leprosy, several persons have witnessed the positive change in their lives. Despite our constant progress in the state, the team has faced numerous challenges. Lack of adequate human resources onground has been a setback for the field team. Since leprosy is one of the neglected tropical diseases (NTD), it does not receive priority leading to denial and neglect for leprosy affected persons.

This coupled with complicated process to acquire the support through Rights of Persons with Disabilities Act, 2016 discouraged individuals with developed disabilities to participate in rehabilitation and inclusive development initiatives. Due to lack of awareness and low education levels in the general community, the outreach for leprosy affected persons is stunted.



Story from Delhi

11 Districts
06 Leprosy Colonies

NLRIF team works in all 11 districts of the National Capital Territory region; in 2019-2020, the 11 districts reported 1,824 new cases, 256 G2D cases and 58 child cases. NLRIF team covers 17% (06 out of 36) of the leprosy colonies in the NCT region.

Guruswamy aged 65 years is the local Grassroots leader of leprosy colony in Peeragarhi, West Delhi. Being a person affected by leprosy and developed disabilities, Guruswamy is currently a differently-abled individual. Due to this, his lower limbs are severely affected leading to his reliance for mobility on assistive devices like tricycle and crutches. NLRIF Team facilitated the provision of a functional tricycle through local contribution in December 2017.

"I am duly satisfied with the support provided by NLRIF. Now I feel free to visit any place of my choice like any other normal person." Guruswamy

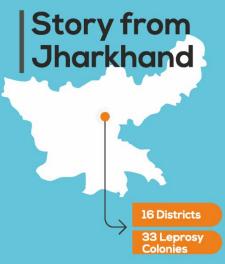
After almost 2 years of usage, the tricycle required maintenance and spare parts. NLRIF through the support of local contribution and a dedicated donor, Ms. Neha Jain ensured that Guruswamy's urgent needs are met. He appreciated the consistent support and thanked NLRIF for ensuring his essential mobility needs.

#### Challenges faced

Since 1999, the year NLRIF was established – Delhi became the fourth intervention state where our dedicated teams began their mission. In the year 2019-20, the continuation of self-care trainings was supplemented by 5 Health camps in 3 leprosy colonies where 496 persons received health check-ups and consultation from qualified doctors and professionals. The education support and formation of Self-Help groups brought socio-economic benefits to the leprosy affected persons and their families.

The main setback was the dedicated funding support to timely meet the urgencies in leprosy cases. Though the self-care training and health camps were successful initiatives, the persons affected by leprosy didn't comply to the learnings. A major area for improvement exists for general dissatisfaction that exists in the leprosy colonies for NLRIF transparency and accountability to their needs. Sustainability through collaboration with State Leprosy Officer requires increasing attention from NLRIF Team in the coming year.







NLRIF team works in 16 out of 24 districts of the state; in 2019-2020, the 16 districts reported 4,246 new cases (69% of total), 82 G2D cases (73% of total) and 308 child cases (70% of total). NLRIF team covers 58% (34 out of 59) of the leprosy colonies in the state.

Savitri Kumari and Baisakhi Kumari are residents of Mansa Singh Gate, Kurmidoh, Jharkhand. Coming from financially weak family backgrounds, their livelihood and education was at stake since their lives were affected by leprosy. NLRIF Team has supported both Savitri and Baisakhi for their education, essential amenities and vocational training for the past 10 years. After receiving their General Nursing and Midwifery training, they received employment in Govt. hospital.

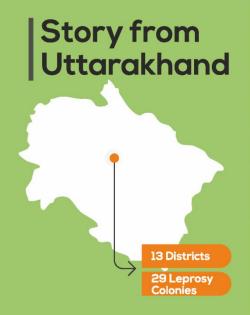


"For supporting us and for taking our lives forward, we express our gratitude towards the NLRIF Team" – Savitri and Baisakhi

#### Challenges faced

With Jharkhand state separated from Bihar in 2000, it became the fifth intervention state to work towards one aim – Zero Leprosy Suffering. Through planning, advocacy and capacity building activities, NLRIF Team supported the implementation of Nikusht portal and training of staff (NLEP and District Education Officer), establishing services in remote regions, medical diagnosis and treatment of leprosy affected persons, Training of Trainers, Urban Leprosy, developing Self-care group and empowering differently-abled persons with their rights and entitlement.

In these initiatives, NLRIF team confronted few issues including Self-Help Group collaboration with banks for establishing small business setups, scarce knowledge and awareness in Public Work Departments and provision of support and rehabilitation services in remote areas.





NLRIF team works in all 13 districts of the state; in 2019-2020, the 13 districts reported 320 new cases, and 12 child cases. NLRIF team covers all 29 of the leprosy colonies in the state.

Dhruv, currently an undergraduate lost his parents at a young age who were affected by leprosy. With the loss of parents followed the financial burden putting Dhruv and his younger sister's (presently, a high school student) survival at stake. In those testing times, the local Self-help group (supported by NLRIF) helped the young siblings for essential items and education support.

On assessing the priority support required, NLRIF Team whole heartedly supported the educational journey of the siblings especially Dhruv from school to college. The NLRIF field staff even made personal contributions to support Dhruv as and when required. With the provided resources and support, Dhruv has been a scholar throughout his academic journey in school life.

"Thanks to NLRIF
for giving us a
platform to fulfill
our goals,
otherwise we could
not go to school. I
am obliged and
grateful for their
support" - Dhruv

#### **Challenges faced**

Uttarakhand (then Uttaranchal) was the 3rd intervention state NLR began working in 1998. The key initiatives during the year 2019-20 were the distribution of assistive devices to leprosy affected persons and educational support for dependents of persons affected by leprosy.

Despite working for the past two decades, Uttarakhand remains greatly underbudgeted allowing limited scope of work with limited staff.



## Story from Uttar Pradesh



NLRIF team works in 35 out of 75 districts of the state; in 2019-2020, the 35 districts reported 10,272 new cases (66% of total), 90 G2D cases (57% of total) and 368 child cases (70% of total). NLRIF team covers 42% (32 out of 77) of the leprosy colonies in the state.

In the Chandauli District, Uttar Pradesh six Self-Help Groups for differently-abled people remained non-functional for many years. After realising the strategic value of these SHGs in the district for reaching out the leprosy affected persons, NLRIF team intervened to strengthen the SHGs. In the month of March 2020, NLRIF team organised a meeting with the SHGs for need assessment to understand their current situation and gaps to reboot their operations. The meeting was held in the presence of SHG leaders and Govt officials with Mr. Parmod Kumar, Block Manager of National Rural Livelihood Mission, Niyamtabad Chandauli.

During the meeting, it was advised that the SHGs should work in collaboration with the Govt. schemes especially National Rural Livelihood Mission. It was suggested that working together with Govt. will ensure the socio-economic development of the differently-abled people, in particular, the leprosy affected persons. Soon, two out of six SHGs - Khawaja Garib Nawaz Swayam Sahayata Samuh and Shiv Shakti Swayam Sahayta Samuh were linked with the National Rural Livelihood Mission. In addition, under National Rural Livelihood Mission direct support is provided to three senior members for their services with Rs. 250/- per day.

"Under National
Rural Livelihood
Mission, 15000
Rupees was given
for administrative
needs of SHGs
and a total of
₹ 1,15,000 will be
given as interest
free loan under
the Govt.
program."

#### **Challenges faced**

NLR started working in the state of Uttar Pradesh in the year 1998, making it the 2nd intervention state for NLRIF. Working extensively through our combined self-care initiatives, disability inclusive development, comprehensive socio-economic rehabilitation and leprosy awareness and stigma reduction campaigns, NLRIF continues to move towards our aim – Zero Leprosy Suffering.

The major challenge for working towards our cause came in the form of general election in Uttar Pradesh. Due to this, there were delays in relocation of medical staff for medical duties and the progress of routine NLRIF activities in the 1st quarter from March to June 2019. Inadequate human resources is also a challenge in effective implementation of routine activity.

The delayed participation from local and school community also delayed the rehabilitation support and initiatives to leprosy affected persons.

## Story from Rajasthan





NLRIF team works in all 33 districts of the state; in 2019–2020, the 33 districts reported 1,124 new cases, 18 G2D cases and 19 child cases. NLRIF team covers 67% (08 out of 12) of the leprosy colonies in the state.

In the year 2010, at the age of 23 years, Bhagwanlal a resident of Uttar Suderbas, Vidha Vihar Colony, Udaipur, Rajasthan first noticed discolouration and patches on his body. He neglected the symptoms back then. After two years, he observed that the fingers of his right hands are not functioning properly. This coupled with zero sensation on both hands and feet mentally troubled Bhagwanlal. He visited a local private clinic for his physically deteriorating condition and received his treatment from an informal medical practitioner. After receiving the diagnosis, he didn't experience any improvement. With his friend's advice, he finally visited the nearby government hospital for seeking treatment. After completing the diagnosis using Multi Drug Therapy his disease was cured, though his hands and feet suffered the gradual mild disabilities due to leprosy.

After hearing about the Self-Care Training by NRLIF Team through a general healthcare staff, Bhagwanlal joined the session organised in UPHC Dhanmandi on 24th and 25th November 2020. He received the initial assessment for his developed disabilities and learned the essential self-care practices. Apart from the valuable learnings, he received the medical kit and supplies from NLRIF Team to take care of his disabilities.

"I feel happy to learn how to take care of my disabilities myself, it makes me feel empowered. I thank NLRIF Team for giving me an opportunity to join the self-care training in a group exercise. Their life changing self-care practices and disability assessment can continue to do wonders to other people like me." -Bhagwanlal

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#### Challenges faced

NLRIF began working in the state of Rajasthan in the year 2015, making it the 7th intervention state for the Combined Selfcare, Capacity Building, Disability care, Disability inclusive development and Stigma reduction activities.

Being the latest intervention region, Rajasthan requires the increasing financial and human resources and support from our donors and partners for increasing the routine activities and visits to leprosy colonies.



## Story from West Bengal



NLRIF team works in 11 out of 27 districts of the state; in 2019–2020, the 11 districts reported 3,580 new cases (58% of total), 11 G2D cases (17% of total) and 406 child cases (79% of total). NLRIF team covers 76% (19 out of 25) of the leprosy colonies in the state.

NLRIF has actively contributed to the socioeconomic rehabilitation of leprosy affected persons and families. Educational support for dependents of leprosy affected parents forms one of the major undertakings for rehabilitation support. Since 2010, NLRIF has provided essential resources to children for academic support. In the year 2019-20, NLRIF Team assessed the changing needs of our beneficiaries. During the interaction with 'Jamuria' leprosy colony, it was found that the students require the right guidance and tuition support to understand the complex scientific and mathematical concepts.

Understanding the requirement, NLRIF went overboard and organised one-to-one meeting with the leprosy affected parents to extract the exact requirement for students. During the meeting, the leprosy affected parents expressed their low economic status and their inability to provide the right tutor support for their children's education.

Experiencing their plight, NLRIF decided to provide the tuition support to the students of Netaji Subhash Colony, Jamuria. The diploma holder in electrical engineering, Mr. Dipak Ghosh was appointed as the private teacher for the colony students. Mr. Dipak received monthly remuneration from NLRIF. Within few months, the tuition support

started reaping benefits for young children. They started understanding the complex concepts better and in turn, performed better in their examinations.

"The jamuria leprosy colony is happy and satisfied with NLRIF timely support for their children to make their future bright".

#### Challenges faced

Starting in 2001, West Bengal became the 6th intervention state for NLRIF activities. The state of West Bengal witnessed a set of unique initiatives which were appreciated and replicated by the Government of India. Under these initiatives, a sustainable simplified set of self-care activities are instilled in the leprosy affected persons under Home based self-care. NLRIF facilitated and build these capacities in the general health care staff to cater to the large population of leprosy affected persons (estimated 80-85% leprosy affected & disabled population) who are unable to reach and participate in Disability Prevention and

Management Rehabilitation Camps. Another initiative beginning in June 2019, Urban Leprosy programming was launched considering the high leprosy incidences approximately 2500-3000 new leprosy affected persons per year in urban areas (NLEP Statistics, 2018). Using this innovative approach, NLRIF addresses the challenges utilising the National Urban Health Mission (NUHM) health care providers and structures. Under it, emphasis was placed on follow-up mechanism for the detected cases of leprosy. Within a short span of 5 months, 250 Urban Public Health Centres began implementing the Urban leprosy initiative. By October 2019, 286 suspected cases were found in which 44 cases were confirmed from 4 regions.

Further, in the year 2019-20, 87 Girls received our educational support for their academic journey. 4 Self-Help Groups (SHGs) were newly formed making 11 SHGs functional. The unique feature of the newly formed SHGs is that the groups are formed by 190 women, out of which 38 females are leprosy affected persons. The involvement of the leprosy affected persons in the groups boost up their confidence to lead their lives more efficiently.

Major challenge for NLRIF activities comes in the form of hostile political environment creating a barrier for the formation and sustenance of local SHGs in the state. The learning levels of children required improvement through exclusive educational programs for slow learners. The lack of interest among the youth to participate in the vocational training for employment remains a major concern.



## Indicators

NLRIF undertakes a holistic approach to work towards our aim - Zero Leprosy Suffering. In the states where it works (Bihar, Delhi, Jharkhand, Rajasthan, Uttarakhand, Uttar Pradesh, and West Bengal) **NLRIF** supports the cause through Comprehensive Socio-**Economic Rehabilitation and Disability Care for all** stakeholders and beneficiaries. The indicators quantify our yearly progress and the change we imprinted in the lives of persons affected by leprosy and its consequences.



Districts NLRIF is working out of 741 districts in India. The organisation's intervention districts in 7 states where NLRIF Team is dedicatedly working to achieve the aim – Zero Leprosy Suffering through 3 strategic programmes – Zero Transmission, Zero Disabilities, and Zero Exclusion.



Leprosy colonies NLRIF is working in. A group of persons affected by leprosy and their family members live in a small area where basic facilities and medicines are provided by the govt. authorities. The leprosy colony has one colony head who is in regular contact with the health workers, NGO partners and other organizations.



Persons affected by leprosy and Lymphatic Filariasis trained in self-care Persons affected by leprosy and Lymphatic Filariasis are trained on self-care and disability prevention to prevent any further disability or worsening of disabilities and ulcer wounds. They are also being monitored and guided by NLRIF team on regular intervals.

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Health staff trained on leprosy and its self-care. Understanding the crucial role health staff (under the Govt. of India's national programs) plays in informing, counseling and treating persons with leprosy and surrounding community, they are trained on prevention of disabilities, sensory testing, voluntary muscle testing and self-care. The health staff includes Medical Officers, Paramedical Workers, Non-medical

assistants, Auxiliary Nurse Midwife (ANM) and the similar and community volunteers i.e. Accredited Social Health Activist (ASHAs). They are also sensitised on leprosy, stigma and mental wellbeing.

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Persons affected by leprosy engaged from groups and organisations.

NLRIF works for the development of local Self-Help Groups (SHGs), Self-Care Groups (SCGs), Disabled People's Organizations (DPOs) and others to ensure participation of persons affected by leprosy. Through the creation of such groups, leprosy affected persons are empowered in society. It provides them an opportunity to socialise in day-to-day community-based activities while empowering them financially through NLRIF's direct support. Through these groups, they also derive a platform to raise voice their rights and concerns. The Self-Care Groups allow the persons affected by to be trained in self-care practices for prevention of disabilities and/or healing ulcer wounds.



Dependents of person affected by Leprosy received financial aid for education. The children are identified from the families of persons affected by leprosy who require financial and other resource support. After identifying the recipients, adequate educational support is provided in the form of school bags, stationary, books, school fees, uniform, support for professional course, tuition fees and tutors.



Persons affected by leprosy received assistive devices. The persons affected by leprosy who have disability or ulcer wounds need assistive devices for better mobility and avoiding any further complications. A need-based assessment is done before providing them assistive devices such as modified grip, MCR footwear, goggles, crutches (Baisakhi), wheel chair, tricycle and prosthetic equipment. The regular use of protective footwear prevents sore wounds and in worst case, ulcers.

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Persons and family members affected by leprosy received vocational training. The persons affected by leprosy and their family members are identified and trained in vocational courses such as Motor mechanic, Motor driving, Electrician, Tailoring, Beautician, Painting and Decoration mostly through linkage with vocational trainings and centres run by NGO partners, Private Institutions or other organizations. NLRIF supported mobile tailoring training has proven to be an excellent low-cost support.





## Alignment with Government of India's Programs and Initiatives

NLRIF works in partnership with Central Leprosy
Division (CLD), MoHFW, Govt. of India (GoI) across all
124 districts in 7 states. Throughout the year, meetings
have been organised with govt. officials, health care
providers and community for early leprosy case
detection, its treatment and prevention, Self Help
Group expansion, Livelihood promotion, Stigma
reduction and outreach to remote areas. Keeping up
with the Govt. programs and schemes NLRIF Team
supported and implemented National Leprosy
Eradication Programme (NLEP), Sparsh Leprosy
Elimination Campaign (SLEC), Leprosy Case Detection
Campaign (LCDC), Nikusth Portal training among other
national, state and district level programs, campaigns
and initiatives.

NLRIF Team works alongside the state and district level officials under CLD – State Leprosy Officers and District Leprosy Officers providing technical and non-technical support and training to them and other health staff including Medical Officers, Paramedical Workers, ASHA workers, Auxiliary Nurse Midwifes, etc.

NLRIF's unique initiatives Urban Leprosy programming and Home-based Self-Care in West Bengal were applauded by government. For instance, the CLD requested NLRIF to present the innovative Urban Leprosy Program during the Annual review meeting of State Leprosy Officers (SLOs) held in Goa from 6th to 8th of December 2019.

## Awareness and Sensitisation on Leprosy

With the steps marching towards Zero Exclusion, NLRIF Team actively organises, supports and facilitates the awareness and sensitisation campaign in the intervention areas.

On social awareness days related to leprosy, local rallies, campaigns, role plays, and other engaging activities were organised to spread the word for early leprosy detection, and the availability of treatment. In these organised events, the leprosy affected persons and their families participate. These events witness the involvement of local, district and state level Govt. officials who are motivated to take necessary action and contribute to the cause of leprosy.

These days involve Anti-Leprosy Day, World Leprosy day, 150th Gandhi Jayanti, and World Disability Day observed across all the NLRIF supported states. Unique campaigns were seen in Bihar on 3rd December 2019, World Disability Day and in Uttar Pradesh on 2nd October 2019, Gandhi Jayanti.

On 3rd December 2019, World Disability day was celebrated in Bihar which witnessed participation from Govt. officials - Shri. Pramod Singh, Member of Parliament, Shri Manoj Sharma, Member of Parliament and Senior health staff - Divisional Hospital In

charge, Dr. Rajesh Kumar Singh and bank officials in different districts. These events were organised in collaboration with local NGOs - Jagriti Foundation, Savera Divyang Foundation, Divyang Chetna Manch Trust, Divyang Kalyan Samiti, Ujala Foundation, Sampurna Foundation, Unmukt Foundation. More than ₹ 30,000 were raised for supporting the leprosy affected persons and educational support was extended to 10 children through these events.

In Uttar Pradesh, a 25 Km long rally was organised with participation from District Magistrate, Chanduali for spreading awareness and sensitising masses for leprosy and its consequences.

During the combined self-care camps for leprosy and Lymphatic Filariasis, the health staff and the participants are sensitised on leprosy and NLEP guidelines. Sparsh Leprosy Eradication Campaign was also implemented by NLRIF Team in all the intervention regions.

Another noteworthy event was organized to mark the observance of "International Women's Day" on 8th March 2020. NLRIF Team presented Certificate of appreciation to four leprosy affected women from the leprosy colonies of Delhi to honor their immense contributions towards upliftment of lives of persons living in Leprosy colonies.





## Capacity Building

Since NLRIF started working in India, the major emphasis has been given on strengthening the know-how and building capacities in health staff in the intervention areas. Continuing two decades old legacy, NLRIF continues to impart training and conduct workshops for health staff including Medical Officers, Physiotherapists, Paramedical Workers, ASHA workers, Auxiliary Nurse Midwifes and empower local support groups including Self-Help Groups (SHGs), Village Development Committees (VDCs), Block Development Committees (BDCs), Disabled People's organisations (DPOs) and Leprosy People's Organization (LPO).

Further, distinct workshops are organised to instil knowledge in stakeholders. One such workshop was organised for Right of Persons with Disabilities (RPwD) Act 2016 at Indian Medical Association Hall, Aurangabad, Bihar. The workshop was attended by more than 200 participants including District Magistrate and Additional District Magistrate. The objective of the workshop was the provision of Disability certificate to leprosy affected persons, bank linkage of Disabled Self-Help Groups, and awareness about Rights for Person with Disability.

## Combined Self-Care and Healthcare Camps

NLRIF has been the pioneer organization which introduced the concept of 'Combined Self-Care' in India. Under the combined selfcare, persons with disability due to Leprosy and Lymphatic Filariasis are trained on how to take care of their disability themselves. The 'Self-Care initiative' runs across the NLRIF intervention states of the country since 2007. It involves a set of practices performed by the affected persons by themselves to enhance and restore health and their self-esteem. It requires active engagement by the persons affected by leprosy.

Regular Self-Care workshops were organised in leprosy colonies, Govt. hospitals and Public Health Centres across all states leading to prevention of secondary impairments while healing present ulcers, preserving eye sight and improving functioning of paralytic limbs. These workshops enhanced the mental health and promoted self-confidence, self-esteem and social justice to the persons affected by leprosy and helped in reducing stigma and discrimination.

Under Medische Missie Zusters (MMZ) project, the 'Self-Care initiative' was upgraded to 'Combined Self-Care' program



in 2015, implemented in three district each of Bihar and Uttar Pradesh. The combined selfcare project involves providing training and building capacities in persons affected by Leprosy and Lymphatic Filariasis and General Health Care (GHC) staff. Several training sessions were organised on self-care practices attended by more than 100 participants in each session. In addition, these sessions ensured 'Training of Trainers' through instilling self-care practices into Health staff including General Health Care Staff, ASHA workers, Medical Officers who attended these sessions.

To promote Disability Inclusive Development, Health Camps were organised as a model of Public-Private Partnership (PPP) as all the medicines and manpower (doctors and paramedics) are provided by the state government while NLRIF provides the logistical support.

Laboratory services like blood sugar, haemoglobin estimation, and blood smear for malarial parasites etc. were provided in these camps. District leprosy officer, medical officers, pharmacist, laboratory technician, public health nurse and other supportive staff from state Govt. of Delhi attended the camp and provided their services. Beneficiaries get acquainted with the government health staff and a barrier free access is created for availing services from nearby dispensaries and hospitals.

In Delhi, five health camps were organised in 3 leprosy colonies where 496 persons affected by leprosy benefitted and 145 blood samples were taken during the camp where 23 new

diabetic cases were detected. 17 cases were referred for further treatment in reputed Govt. hospitals including All India Institute of Medical Sciences (AIIMS), Vardhman Mahavir Medical College (VMMC) and so on.



## Educational, Vocational and Livelihood Support

Under the comprehensive socio-economic rehabilitation program, NLRIF apart from infrastructure support provides educational support, vocational training and promotes livelihood for the persons and families affected by leprosy.

NLRIF addresses the holistic rehabilitation needs of leprosy affected persons and their families to transform their lives towards a brighter future. The aim is to break social barrier and persistent stigma attached to the community while empowering through inclusive progress.

In addition to this, assistive devices have been provided free of cost to people who have suffered irreversible disabilities due to leprosy.

## Here are some noteworthy mentions for rehabilitation activities across our intervention states:

In Bihar, NLRIF supported the assessment camps organized by Pandit Deendayal Upadhyaya Institute (PDUI), New Delhi from 4th to 13th of March in four PHCs (Sadar, Obram Goh, Kutumba) in Aurangabad district, and in leprosy control unit, Gulzarbagh, Patna for distributing assistive devices for leprosy affected person and



other disabilities. A total of 585 persons with disabilities attended these camps.

In Rajasthan, NLRIF supported the assessment camps to assess the level of disability so that assistive devices can be provided to them based on their needs. These camps were attended by more than 500 persons with disability. These camps were organized by State health society, Rajasthan with collaboration of Pandit Deen Dayal Upadhyay National Institute of Persons with Physical Disabilities, New Delhi.

In Jharkhand, NLRIF team facilitated the provision of Govt. scholarship provided to Shakuntala Manjhi worth ₹ 45,000 for General Nursing and Midwifery Course.

In Uttarakhand, assistive devices were distributed by NLRIF in Haridwar colonies in the 'Distribution Camp for Assistive Devices to Persons affected by Leprosy".

In Uttar Pradesh, ₹10,000 was provided to Ramesh Kumar for establishing tailoring set-up.

In West Bengal, we have revamped our educational support initiative. From providing physical resources, we have hired qualified tutors to teach the students in need.



## Our Organisation

An organisational structure determines the internal and external affairs determining the efficacy in activities of coordination, task allocation and supervision. It determines which individuals get to participate in which decision-making processes, and thus to what extent their views shape the organization's actions. Keeping in mind the dynamic nature of growing

national presence of each organisation, new insights and discoveries in the structure require a readiness to make changes wherever and whenever necessary. For instance, by dedicating employees and functions into different departments, the company can perform different operations at once seamlessly.

#### Organisational Growth

In 2019-20, the IT infrastructure remained constant, continuing the previous year practices in both software and hardware. The onpremise servers and desktops continued to be utilised by the committed staff. Few administrative investments have been made to provide necessary resources to the staff. In addition, the organogram has been updated which led to a clearer understanding of work flow and work delegation. NLRIF followed all the legal and formal regulations regarding the compliance with Foreign Contribution (Regulation) Act, 2010.

#### Staff

NLRIF's India Office is based in New Delhi, India. As on 31st March 2020, our staff comprised 16 employees working across 7 states. In 2019 – 20, the management and execution of field activities were delegated to 5 state offices located in New Delhi (6 employees), Jharkhand (2 employees), Bihar (3 employees), West Bengal (1 employee), and Uttar Pradesh (4 employees). The overall staff absence percentage for 2019-20 was less than 10%.





#### **N**LR International

NLR International is a global leader on leprosy. It plays an important role in shaping the global policy and strategies on leprosy. One of its major contribution has been on prevention of leprosy; currently it is conducting a multi-country study on further enhancing the prevention of leprosy transmission from the cases to contacts through administration of two drugs instead of a single dose of rifampicin.

NLR International has supported the establishment of NLRIF; and has been providing most of the funding and technical support to NLRIF over the years for becoming self-sustainable. Like NLRIF, NLR International is helping establish local entities in Brazil, Indonesia, Mozambique and Nepal. All these five local entities also called Alliance partners, individually and together are intended to play a leadership role in ending the leprosy suffering.

## Association of People affected by Leprosy (APAL)

APAL works with over 15,000 people affected by leprosy in 784 Colonies in 16 states in India. NLRIF along with APAL facilitated local community empowering and effective capacity building training programmes for leprosy affected persons, families and groups.

This collaboration promotes human rights specifically for persons with leprosy derived disabilities under Right for Persons with

Disabilities, 2016. The grassroot level capacity building of local Self-Care groups, Self-Help Groups (SHGs), Village Development Committees (VDCs), Block Development Committees (BDCs), Disabled People's Organisations (DPOs) and Leprosy People's Organization (LPO) forms an essential aspect of the alliance.

## The International Federation of anti-Leprosy Associations (ILEP)

This is a group of nine international agencies working on leprosy in India. NLRIF is represented through NLR International, its lead supporting agency. The collaboration helps NLRIF strengthen its contribution in the states e.g. it makes referral for reconstructive surgery to the specialized hospital run by one of the ILEP agencies.

#### Novartis India Pvt. Ltd.

Since 2000, Novartis has helped fight leprosy by donating multidrug therapy (MDT) to leprosy patients worldwide through the World Health Organization. It supported NLRIF in conducting the LPEP feasibility study in Dadra Nagar Haveli. During 2019-2020, it granted a project to NLRIF for strengthening implementation of LPEP across the country. NLRIF will document the learning of LPEP implementation in DNH since 2015 and provide mentoring support to other states in collaboration with government and ILEP.

#### Medische Missie Zusters (MMZ)

NLRIF in 2019 launched a two-year project entitled "Improving the health of persons affected by leprosy and lymphatic filariasis (LF) in rural India" in association with Medische Missie Zusters Foundation, Netherlands. The project is implemented in three district each of Bihar and Uttar Pradesh.

Under this project, the beneficiaries and stakeholders involve persons with disability due to leprosy and LF, general health care staff, ASHA workers, members of the Panchayati Raj Institution (PRI), members of local Disabled People Organizations (DPOs), and social welfare/disability empowerment officers. This involves almost 3,345 persons affected by leprosy and LF with special emphasis on the vulnerable sections including women and children.

The project focuses on capacitating persons affected by leprosy and LF in disability care and management by teaching and adapting self-care. Support is also extended in assistive and protective devices to take care of their anaesthetic hands, eyes and feet. The project promotes early case detection and prevention of new disabilities through capacity building (Sensory Testing and Voluntary Muscle Testing) of general health care staff.

Those already suffering from permanent disability due to leprosy and LF are facilitated to undergo reconstructive surgeries. To make the initiative sustainable, trained persons from PRI, ASHA, general health care, and DPOs are identified and a

network of trainers on self-care is established at village, district and state levels.

### As on March 31st, 2020, the project has made the following progress:

- 2414 persons with disability due to Leprosy and Lymphatic Filariasis trained in disability prevention and care.
- 3489 Health Staff trained on Self-care and Sensory and Voluntary Muscle Testing.
- 19 People with disabilities caused by leprosy and LF received assistive devices.
- 64% Persons with disability due to leprosy have healed ulcers and 40% persons with LF have reduced swelling.
- 14 Persons with disabilities have undergone reconstructive surgeries.
- 164 Trainers identified for the network.
- 59 Primary Health Centres whose health care staff are trained in Sensory Testing, Voluntary Muscle Testing, and Self-Care.
- 60 Self-Care groups established.

## Oil and Natural Gas Corporation Limited (ONGC)

ONGC Corporate Social Responsibility intends to - 1) eradicate poverty, hunger, and malnutrition; and 2) promote preventive health care and sanitation; and 3) safe drinking water availability. ONGC partners with NLRIF for promoting safe sanitation practices through construction of 16 differently-abled friendly toilets in 16 Govt. Primary schools located at Harhua Block of Varanasi District of Uttar Pradesh. The project aims to improve access to Water,

Sanitation and Hygiene (WASH) facilities for young students with physical disabilities. The intervention will positively impact the lives of 1,348 students, 51 teachers and 20,280 surrounding families of students and staff by improving the performance and decrease the absenteeism of students, especially differently-abled students.

Apart from physical transformation, the initiative aims to provide equal opportunity and conducive environment through essential and basic amenities. The secondary aim has been achieved through making students aware about the good WASH practices through formation of school sanitation club, Hygiene clubs, and observing Global Handwashing Day.

## Concept International Business Consulting (CIBC)

For 'ensuring healthy life for the leprosy affected living in leprosy colonies of Delhi' (July 2019) we began a project to support specialised health camps in the leprosy colonies. The residents were screened and tested for cancer (oral, cervical, breast and prostate) and other diseases such as Heart problems, High blood Pressure, Diabetes etc. The suspected cases were further investigated for confirmation of the disease and referred to the listed health service providing Institutions for specialised treatment.

#### Centre for India Progressing (CIP)

### CIP supported NLR India for two projects during April 2019 – March 2020.

'Free Health Camp Project - Reaching the unreached in slums and leprosy colonies of Delhi for medical support' intended to generate awareness among the slum dwellers on symptoms of leprosy and good hygiene practices. During the year, 12 free health camps were conducted for the underprivileged especially the leprosy affected persons with disabilities.

'Navodaya Project' enabled and equipped 10 children with education support from most vulnerable and stigmatized families of the persons affected by leprosy living in Nav Jyoti Leprosy Association Peeragarhi West Delhi leprosy colony.

#### SNJ Charitable Trust

'Education Project' funded by SNJ Charitable Trust supported 31 children with school uniform and stationery living in the leprosy colonies of Delhi and Uttarakhand.





NLRIF ensures a holistic integrity management plan through the internal policies and processes and policies for external agencies.
Under internal policies and processes, NLRIF 'Code of Conduct' clearly lays out principles that state the charitable nature of NLRIF's income and contribute to correct use, correct spending, and sound accountability and transparency along with observing ethical behavioural practices.

In terms of dealing with grievances and disciplinary procedures, NLRIF undertakes Complaint and Whistle Blower policy, Grievance Handling, Anti-fraud and Anti-Corruption policy, prevention and combating inappropriate behaviour, etc. A constant inclusion policy for staff is maintained. A staff meeting is organised every month for discussion on administration and HR concerns. The core NLRIF team, grounded with the realities maintains a positive twodimensional relationship with the field staff.

Under policies for external agencies, NLRIF maintains high standards of fair, ethical, and professional business practices. This underlines a clearly defined procurement process that helps to make a material purchase transparent at a competitive price. The famous saying by Dalai Lama,

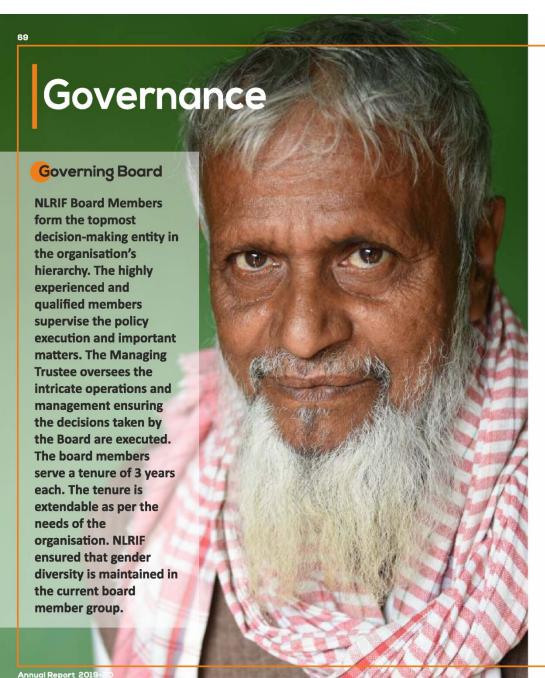
"A lack of transparency results in distrust and a deep sense of insecurity", inspires NLRIF Team to connect with prospective donors or retain the relationship with active donors while maintaining absolute honesty about NLRIF's efforts. We believe if we are not communicating what we stand for and why we seek their support explicitly, we cannot gain their confidence and convert it into a meaningful partnership. NLRIF has always emphasized maintaining overall integrity towards donors. However, the major consideration has been in the programmatic and financial aspects.

NLRIF has always put forward its best in project implementation as per the timelines stated in MoUs and at agreed expenses in a transparent manner. The team has been so well-equipped and structured that the programmatic activities are monitored and evaluated effectively, and the expenses are utilized efficiently as per the statutory compliances. Be it monetary or in-kind support, donation reaches out to the beneficiaries in due time. NLRIF places the donor family need an utmost priority for which 80 G certificates are issued and proper disclosure of resource mobilisation is maintained through regular interaction with donors.

In 2019-20, NLRIF focused on revamping internal processes and structures to improve the policies and framework. To ensure its execution, the HR Officer was appointed for the organisation. The changes were made in employee welfare schemes and organisational processes. NLRIF in line with the Employees' Provident Fund Organisation

(EPFO) and Employee State Insurance
Scheme (ESIC) under the administrative
control of the Ministry of Labour and
Employment, Government of India for a
compulsory contributory Provident Fund
Scheme, a Pension Scheme and an Insurance
Scheme for the workforce engaged in the
organisation. Under these schemes, the
salary structure was revised for an efficient
employee friendly tax saving remuneration.
In addition, voluntary contribution was also
requested from staff to avail further tax
benefits.

NLRIF collated the detailed initiatives into project-based programs, monitored and evaluated on a regular basis, by core team, board members and internal and external experts. This ensured that our expenditure falls in line with our strategy and accountability principles. The year-long mission activities and intervention underwent an annual financial audit, performed by an external auditor. The annual review meeting organised at Hotel Li ROI, Udaipur, Rajasthan from 18th to 20th December 2019 provided beneficial suggestions for revision of the existing Organisation Manual; by March 2020, the first draft was made ready. It will undergo review and finalisation by the Board.



#### 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**

- Current County Director, NLR India, Branch of NLR International
- Current Coordinator, International Federation of anti-leprosy associations (India)
- Former Project Director (HIV/TB/Malaria) and Chief of Party, Public Health Foundation of India
- Former Project Director, FHI 360

78%

10%

3%

7%

2%

## **Finances**

#### Status in 2019-20

The annual accounts of NLRIF are a consolidation of allotted grants and donations, and expenditure on achieving mission and fundraising activities. In the year 2019-20, total consolidated income was ₹ 2.61 Cr (2018-19: ₹ 1.75 Cr). Total expenses were ₹ 2.29 Cr (2018-19: ₹ 1.89 Cr). As on March 31st, 2020, our reserves are ₹ 39,08,917 (2018-19: ₹ 28,78,942).

## How was the money invested in 2019-20?

In 2019-20, we received a total of ₹ 2.61 Cr of income. In it, our total expenditure is 88% amounting ₹ 2.29 Cr. We spent ₹1.77 Cr on our objectives, which is 77.44% of our total expenditures (₹ 2.29 Cr). The continued support of our institutional and individual donors is vital as it enables us to diagnose, treat and cure persons affected by leprosy across seven states. Throughout the country, we received support from 317 donors and around 20 volunteers. NLRIF received a contribution of ₹2,03,48,281 from NLR International Office (IO); the rest was generated by us from different individual and institutional donors within the country. The constant financial support over the years, allows NLRIF to continue serving the noble cause of serving the persons and families affected by leprosy and related diseases.

#### Our expenses in 2019-20



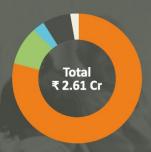
- Mission
- Administration and management
- Fundraising

77.44%

15.18%

7.38%

#### Our income in 2019



- Grants from NLR (IO)
- Grants from Novartis India
- Grants from ONGC Limited
- Individual Donations
- Other Income

Our expenses on meeting our mission in 2019-20



- Program Support
- Rehabilitation

53% 47%

## Financial Highlights 2019-20: income

#### Overall income

The total consolidated income stood lower than total expenditure in the year 2019-20. Our income from individuals was almost double compared to the previous year. The financial support from NLR International Office of ₹ 2.03 Cr remained our prime source of funds to serve the cause of leprosy.

Our income from other organisations and institutions totalled ₹ 0.58 Cr, which forms close to one-fourth of available funds for the year 2019-20.

This showcased our dependence on single source of financial support and our aim to attain local sustainability.

#### **NLR International Office (IO)**

The grants received from NLR IO primarily supported NLRIF Rehabilitation, Program Support and Administration activities and operations. The total support grants from NLR IO was ₹ 2.03 Cr for the year 2019-20.

#### **Novartis India**

NLRIF received the financial support from Novartis India for strengthening scale-up of the Leprosy Post Exposure Prophylaxis (LPEP) in India. A total financial grant of ₹ 25.75 Lakhs was contributed. The project is supposed to start from 1st April 2020. However, the nature of the project demanded the physical presence of Central

Leprosy Division national, state and district level officials which was postponed due to the rising health risks due to Covid-19.

#### **Oil and Natural Gas Corporation Limited**

The physical transformation for promoting safe sanitation practices and equal opportunity for differently-abled students in 16 rural Govt. schools received the financial grants in the form of Corporate Social Responsibility contribution from ONGC.

The contribution was worth ₹ 9.14 Lakhs for the completion of 9 out of 16 schools which was further supplemented by NLRIF own funds. The total expenditure went up to ₹ 10.72 Lakhs.

### Individual Fundraising and other sources of income

The individual donations received by NLRIF has been the highest in the year 2019-20. A total of ₹ 17.79 Lakhs funds was raised and the expenditure on it came in the form of the consulting agency fee of ₹ 6,86,548 to Exelon systems under third party agreement consultancy fees for fundraising.

The other sources of income involved the Bank interest and the surplus vehicle sale of NLRIF field offices amounting to ₹ 5.24 Lakhs.

## Financial Highlights 2019-20: expenditure

#### Overall expenditure

Total expenditure in 2019-20 is lower than

total consolidated income. The total reserves for NLRIF from 2018-19 increased from ₹ 28.78 Lakhs to ₹ 39.08 Lakhs in 2019-20. This year, we spent ₹ 1.77 Cr on our mission, which is 78% of our total expenditures.

#### Mission investments

To work towards our noble cause of serving the leprosy affected persons, NLRIF invested ₹ 1.77 Cr. Under this, program support expenses amounted to a total of ₹ 93.80 Lakhs. The second major contribution to NLRIF mission was utilised for Self-care project amounting to ₹ 53.97 Lakhs. The medical research, monitoring, detection, diagnosis and treatment required a financial support of ₹ 22.03 Lakhs. The non-medical rehabilitation interventions and activities utilised the investment of ₹ 7.44 Lakhs.

#### Administration and management

The staff and their operational requirements are essential aspects NLRIF invested in the year 2019-20. A total of ₹ 34.74 Lakhs was invested to meet the financial requirement of our administrative and management operations. Keeping up with our emphasis on our staff remuneration, ₹ 20.98 Lakhs was utilised for administration staff salaries and compensation for their services. This expenditure was followed by an amount of ₹ 4.31 Lakhs for our leased office premises. The office general expenses amounted to ₹ 3.55 Lakhs followed by Office equipment costing ₹ 2.50 Lakhs. Other administration and management costs involve Printing and Stationery ₹ 1.34 Lakhs, Financial Audit Fee ₹ 1.29 Lakhs, Public relations ₹ 0.24 Lakhs,

Bank Charges ₹ 0.24 Lakhs, Postage ₹ 0.19 Lakhs and Telephone expenses ₹ 0.08 Lakhs.

#### **Fundraising**

The consulting agency fee was paid to Exelon services of ₹ 6.16 Lakhs for the local fundraising activities.



























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