



**Sasakawa India Leprosy Foundation**  
*Working Magic*

**ANNUAL REPORT**

**2012-2013**

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## **SASAKAWA –INDIA LEPROSY FOUNDATION**

Instituted in November 2006, Sasakawa India Leprosy Foundation (S-ILF) is a registered Indian charitable trust that seeks to integrate persons with leprosy and their families into society and help restore dignity and meaning to their lives. It is committed to mainstreaming leprosy affected people and their families in India through socio-economic empowerment. S-ILF works towards enabling those cured of leprosy to regain independent and sustainable means of livelihood through measures that enhance their skills and abilities. S-ILF provided financial and technical assistance to enable leprosy affected people to shift from begging into dignified livelihoods. It also works with youths whose parents are affected in providing them opportunities for skill development and vocational training. S-ILF advocates for raising awareness among different sections of society against social and economic discrimination of leprosy affected people. S-ILF does this through its Pillars of Work.

### **S-ILF'S PILLARS OF WORK**

- (i) Facilitating Access to Vocational Training and Higher Education**
  
- (ii) Capacity Building and Training in Livelihood Activities**
  
- (iii) Arranging for Microfinance Opportunities**
  
- (iv) Acting as a Catalyst in Forming Self Help Groups**
  
- (v) Raising Awareness About Leprosy Among all Sections of the Society to Fight the Stigma**
  
- (vi) Working in Association with Other NGOs, Charitable Organisations, and Individual Mentors etc. to Achieve Its Objectives.**

#### **Our Vision:**

Integration of leprosy cured people and their families into society by ending the discrimination faced by them.

#### **Our Mission:**

To end the stigma against the disease and to ensure equal social, economic and cultural opportunities for those affected by leprosy.

## **MESSAGE FROM THE CHAIRMAN**

I am pleased to present the annual report of S-ILF for the year 2012-2013. The report highlights the significant achievements made by the foundation in the last year. Initiatives, both in creating livelihood and in raising awareness, have begun to help people affected by leprosy and their families build a better life for themselves.

This year S-ILF has ventured into new terrains. The Foundation has made steady progress and has expanded its reach from 14 states last year to 16 states. There are now a total of 148 livelihood projects currently running all across India. It has increased efforts to take the project beneficiaries for exposure visits where they can see first-hand the functioning of different micro enterprises and learn how to make their initiatives successful. There is noticeable progress not only in terms of financial success of the enterprises but also in terms of confidence of the beneficiaries in further expanding the projects and making a definitive move away from begging. This was clearly visible in terms of the proposals received as well as the three projects that won S-ILF's Rising to Dignity Award

The Education Programme has also progressed well in the last year. S-ILF was able to train 65 youths from the colonies and has placed 27 of them at in different places. Nursing scholarship has also gained popularity among the colonies and S-ILF has received overwhelming response as compared to last year.

S-ILF continued to strive towards achieving the goal of eradicating stigma associated with leprosy. It organized an International Symposium on 3<sup>rd</sup> and 4<sup>th</sup> October, 2013 and supported the formation of the Forum of Parliamentarians to free India of Leprosy. It has also collaborated with National Human Rights Commission to spread awareness among school children.

S-ILF will continue in its efforts assist people affected with leprosy to gain dignified living, to develop capacities of the youth and to spread awareness in different sections of society.

**Dr. S.K. Noordeen**  
**Chairman, S-ILF**

## **MESSAGE FROM THE DIRECTOR**

The year 2012-2013 has been a year of exploration and expansion. From working in fourteen states last year S-ILF has now expanded its work to sixteen states, with a total of 148 livelihood projects. The various trainings that we had developed are paying off. There is a visible improvement in the proposals that we have received for funding and in the acceptance of the processes for disbursement of funds. We are also developing different modules for trainings. These modules help not only in building business capabilities but also to increase the self confidence of the people that they can move away from begging.

Nursing scholarships have also gain popularity among the colonies. As anticipated, the knowledge that they could get the finances needed to pursue a nursing career has prompted girls to work hard for their Class 12 exams. We received a large number of queries and applications. Our scholarship holders are working hard and scoring well in their exams. Our youth training for employment programme is also doing well. We have been able to train 65 youths from the colonies and have placed 27 of them at different places.

Our major success was in organizing an International Symposium on Leprosy and Human Rights on 3<sup>rd</sup> and 4<sup>th</sup> October 2012. One of the successful outcomes of the International symposium has been the formation of a Forum of Parliamentarians to Free India of Leprosy. This forum cuts across all party lines and is formed with an objective to work for Sensitising the Government and general public about leprosy and situation of the people. There has been a good response from the MPs and the Forum has the blessings of some senior Parliamentarians of the country. S-ILF is working closely to help coordinate the activities of the Forum the aim of which is to lend its voice to raising awareness about leprosy and taking steps to ensure the integration of leprosy affected people in society. We hope that they will be able to bring about changes in laws that discriminate on the basis of leprosy and also ensure the inclusion of leprosy affected in the various welfare schemes of the government.

We have had strong support from our partners in our efforts. The National Forum of Leprosy Affected People has been generous in its support and cooperation and in helping us to reach out to remote colonies where little work is being done. SBI (State Bank of India) has been generous in supporting not only our Raising to Dignity Awards and has also funded some of the nursing scholarships as has SDTT (Sir Dorabji Tata Trust). NHRC (National Human Rights Commission) has supported our programme of creating awareness about leprosy in government schools in the Delhi region.

Even as we recount our successes we are conscious of the enormous tasks and challenges ahead especially as we move into new areas. With each successful initiative, the confidence of the community in us and our own confidence in being able to respond to their needs gets stronger.

**Dr. Vineeta Shanker**  
**Executive Director.S-ILF**

## **PROJECTS:**

### **CREATION OF SUSTAINABLE LIVELIHOODS**

Sustainable development and growth is the stepping stone for economic empowerment. Empowerment builds the capacity of people to contribute successfully to the growth process.

Due to stigma associated with the disease, the people affected by leprosy cannot readily access opportunities to improve their economic and social wellbeing. Low acceptance in society makes formal or informal wage based employment difficult to find. The need to depend on alms and donations for meeting their basic needs not only erodes their dignity but also their self confidence, making transition into self employment a risky and difficult proposition. Therefore assistance for creating dignified and sustainable livelihoods must not only match skills and market needs but also include efforts in capacity and confidence building.

S-ILF thus focuses on economic empowerment by not only providing financial assistance for sustainable livelihood generation but also invests in leadership and capacity building, technical project related trainings as well as providing mentorship support to the leprosy affected people in their efforts at self employment.

Continuing its effort to help the people affected by leprosy to get an opportunity to develop sustainable income earning activities in the FY 2012-2013 S-ILF approved funding of 24 new livelihood projects at Jodhpur and Jaisalmer in Rajasthan; Kurnool in Andhra Pradesh, Jamtara in Jharkhand, Kacheepuram and Coimbatore in Tamil Nadu, Sonapat in Haryana. Taking into account the previously approved grants, S-ILF has a total of 148 approved projects reaching out to beneficiaries in 16 states across the country.

This year too, the people from the colonies came forward with their ideas to develop different projects like Utensils/ Vessels Selling, Mini Tent House/ (On rent), Rice Selling, Sheep Rearing, Communication centre, Readymade garment stitching, Dairy and Pig Rearing.

#### **Trainings**

For the success of the project it is important that the beneficiaries develop and take full ownership of the projects proposed by them. To equip them to develop proposals and handle the projects on their own, S-ILF conducts trainings at different stages of the project and continues to give them guidance as and when needed.

#### **TSEC (Training for Socio Economic Change):**

TESEC is the first training the colony people attend in the process of developing their livelihood projects. Its aim is to orient the people on the need for socio-economic change with primary focus on developing viable livelihood proposals. During these trainings they are informed of S-ILF's livelihood initiative and processes, provided training on tools for assessing viability of projects, checking market situation, marketing and budget making.

In FY 2012-13 S-ILF conducted its 9th and 10th TSECs and trained 48 people. The 9th TESEC was conducted at Ahmadabad, Gujarat for 7 colonies of Rajasthan and Gujarat. The 10th TSEC was conducted at Siliguri, West Bengal for the colonies of West Bengal and Jharkhand.

### **SOW (Stakeholders Orientation Workshop):**

The beneficiaries' of the approved projects are given a training on S-ILF's funding mechanisms, financial management, roles & responsibilities, marketing etc. for the sustainability of the enterprise. They are also trained in livelihood & micro-entrepreneurship development and good practices. For better understanding they are taken for exposure visits as well.

In the FY year 2012-13 S-ILF conducted the 7th and 8th Stakeholder's Orientation Workshop. The 7th SOW was conducted at 2 different locations viz Adhaura, Bihar and Nellore, Andhra Pradesh. This SOW was attended by beneficiaries from 8 projects from Jharkhand and Bihar and 14 projects from Andhra Pradesh. The 8th SOW held in New Delhi, was conducted for the beneficiaries of 10 approved projects from Andhra Pradesh, Jharkhand, Rajasthan, Haryana and Tamil Nadu.

### **Partners**

#### **National Forum:**

National Forum continued to be our main partner. S-ILF worked closely with National & State level leaders relying on them to verify and motivate the leprosy affected people to undertake the initiatives of taking up livelihood projects with financial support from S-ILF as well as help in the monitoring of the project activities.

#### **Other Partners:**

This year too S-ILF worked with several local NGOs and individual consultants for developing and implementing livelihood projects. Our partner organisations are International Leprosy Union, Pune; PECSS (Priyanshi Education Cultural and Social Society), Madhya Pradesh; VSK (Vanvasi Sewa Kendra), Bihar; RISDT (Rural India Self Development Trust), Andhra Pradesh; NPdO (Network of Persons with disAbility Organisations), Andhra Pradesh; Add- India, Tamil Nadu; Bharat Sewa Sanstha, Uttar Pradesh, NEEDS (Network for Enterprise Enhancement and Development Support) and GRAVIS (Gramin Vikas Vigyan Samiti), Rajasthan.

## EDUCATION

The children from leprosy affected families are constrained from pursuing higher education due to their poor economic condition. Although, majority of the children from the colonies do go to some school, the lack of financial and physical opportunities to good schooling, results in high drop out rates and poorer education. S-ILF had started its Education programme to help the interested children at a chance for a better future through education.

Recognizing a strong need for vocational training among the youth, S-ILF developed two programmes- ***Nursing Training and Skills to Employment Programme (STEP-UP)***. These programmes are aimed at providing the necessary training and skills to the youth that guarantee employment and S-ILF helped in identifying and providing the required financial support

### **Nursing Scholarship Programme:**

Under its Nursing Training Programme, S-ILF has made provisions for providing financial assistance to the girls from self settled leprosy colonies spread across India. S-ILF has taken its 2<sup>nd</sup> batch of 10 girls for Bsc. Nursing of 4 years duration and GNM programme of 3 and a half years duration . S-ILF pays for the tuition fees, lab fees and books as well as hostel fees where applicable. The money is paid directly to the institutes. This year S-ILF received funds from SDTT (Sri Dorabji Tata Trust) and SBI (State Bank of India) to sponsor 10 candidates. A total of 15 girls are now availing of the scholarship for nursing studies.

### **Skills to Employment Programme (STEP-UP):**



S-ILF under its STEP-UP Programme aims to encourage youth of leprosy communities to obtain skills required for sustainable employment. Trainings are conducted for skill enhancement of youth living in self settled colonies in India so that they can be mainstreamed in the organised sector. The trainings are based on market needs. To ensure that this training results in gainful employment, S-ILF includes motivational and career counselling as an essential part of assistance given to the selected candidates.

S-ILF in collaboration with Youth4Jobs and Jeton HR Services have trained 65 youths in Andhra Pradesh and Odisha (50 in Odisha & 15 in Andhra Pradesh ) and have placed 27 youths with a salary of Rs 4500-5500 for sales executive profile. In Delhi GMR Varalakshmi Foundation provided training to 1 person for Cargo Officer. He is now earning Rs. 10,000 per month.



## COMMUNICATION AND AWARENESS BUILDING

Though easily treatable leprosy still strikes fear in the societies. Lack of knowledge about the disease and prevalence of misinformation and misconceptions for many-many years have resulted in the stigma against it. To tackle the discrimination faced by the people affected by leprosy it is important to eradicate social stigma against it. While capacity building and financial assistance help in building confidence and eradicating self stigma, concerted efforts have to be made to eradicate social stigma by changing mindsets in society through awareness generation and advocacy.

To tackle this problem S-ILF has developed a multi-faceted approach in its awareness building, communications and advocacy activities and reaches out to people in all walks of life like-educational institutions, media, politicians and parliamentarians, lawyers and social activists, government institutions and employers as well as corporate houses.

S-ILF engages in advocacy to provide a legal and institutional framework that in no way discriminates against the rights of the leprosy affected as equal citizens of the country, to ensure that any violation of the rights of the leprosy affected is treated as a human rights issue, to set in place mechanisms of redress of grievances and punitive action and above all to demonstrate through successes of those who have struggled against all odds, that change is not only desirable but feasible too.

### I. Advocacy and Awareness building

#### a. International Symposium



S-ILF in collaboration with The Nippon Foundation organized a two day Symposium. The objective of the Symposium was to raise awareness 'Principles and Guidelines' (P&G) adopted by the UN Human Rights Council and to discuss with different stakeholders how P&G can be put into practice.

Shri Mukul Wasnik, Honorable Minister for Social Justice and Empowerment inaugurated the Symposium. His Holiness, the Dalai Lama and Mr. Ban Ki-Moon,

United Nations Secretary- General though sent their video messages, which were aired at the opening of the symposium.

Three round table group discussions were held on the roles of Public Institutions (Government), Civil Societies (NGOs) and Persons Affected by Leprosy in implementing P&G. People from different countries and different sectors participated in the discussion and shared the experiences.

The symposium witnessed a gathering of 200 participants which included Dr. Samlee Plianbangchang, Regional Director of WHO South-East Asia Region; Shri Dinesh Trivedi, Member of Parliament; Smt. D. Purandeswari, Union Minister of State for HRD; Mr. V. Narasappa, Chairman, National Forum India; and Prof. Yozo Yokota, Director, Center for Human Rights Education and Training, Japan and Former Member

of the UN Sub-Commission on the Promotion and Protection of Human Rights and many national and international dignitaries, members of Parliament, Government representatives, delegates from United Nations, people affected by leprosy, lawyers, corporate houses, rights NGOs working in the field of rural development and poverty reduction, and government representatives.

One of the important outcomes of the Symposium was the announcement of the formation of an informal Forum of Indian Parliamentarians to fight the stigma against leprosy

#### **a.1. Forum of Parliamentarians to Free India of Leprosy**

The Forum of Parliamentarians to Free India of Leprosy is formed by like-minded Parliamentarians cutting across party lines, with support from S-ILF. The formation of the forum was announced during the International Symposium organised on 3rd-4th October 2012 by Shri Dinesh Trivedi, Member of Parliament; Smt. D. Purandeswari, Union Minister of State for HRD; and Mr. Madhu Gaud Yaskhi. The Forum is committed to work towards a leprosy free India and the members will offer their good offices and influence in the legislature to raise awareness about leprosy and bring about changes that would ensure the basic human rights of the leprosy affected. Through the Forum, the members will work to include leprosy affected in the existing government welfare schemes as well as create awareness and acceptability of leprosy affected people at the National, State as well as local levels.

#### **b. Launch of National Appeal:**

In its effort to spread awareness about leprosy S-ILF has joined hands with CII. To initiate this process a National Appeal by the corporate to end stigma against people affected by leprosy was launched at the dinner reception for the participants of the International Symposium on October 4th, 2012. Mr Salman Khurshid, the then Minister of Law and Justice, Mr. Brij Mohan Munjal, Mr. Subodh Bhargava, Mr. Madhur Bajaj and Mr Yohei Sasakawa launched the national appeal at The Lalit.

#### **c. Young Partner's Programme:**

In its effort to spread awareness about leprosy among different sections of the society, S-ILF in collaboration with NHRC (National Human Rights Commission) has launched Young Partners Programme (YPP) an Awareness Programmemes on Leprosy in government schools for young children from classes 7 to 9 to sensitise them to the issue of discrimination.

During the first phase of the programmeme a sensitisation programmeme for the Principals and teachers of 24 government schools in 3 districts namely-central, south and southwest, were invited for a workshop on Leprosy in Modern Times - Understanding Leprosy and Our



Attitude under our Young Partners Programmeme (YPP) at NHRC.

In the second phase of the programmeme S-ILF conducted sensitisation sessions in 2 government schools with students from Classes 7 - 9 to make them aware of myths related to leprosy and discrimination associated with it. The students were shown a documentary on leprosy and made to do role-plays for them to understand the stigma faced by leprosy affected people. A poster competition was conducted on the theme of leprosy and how it can be tackled.

### **Anti-Leprosy Day:**

S-ILF celebrated Anti Leprosy Day on the 30th January on Mahatma Gandhi's death anniversary at India International Centre (IIC), New Delhi. Mr. Dinesh Trivedi, Member of Parliament and Convenor of the Forum of Parliamentarians to Free India of Leprosy was the chief guest for the function. Mr. Madhu Gaud Yaskhi, Co-convenor of the Forum of Parliamentarians to Free India of Leprosy was the special guest. Prof. M.S. Swaminathan, Ms. Syeda Imam and Mr. B Sriram and Mr. Rakesh Puri from State Bank of India were also seated at the dais. Mr. Dinesh Trivedi gave away the Rising to Dignity Awards 2013.



The celebration witnessed a gathering of 125 people from different sectors. A small dance drama was presented by a group of under-privileged children giving the audience a glimpse in the life of a leprosy affected person.

### **Rising to Dignity Awards**

Given the disadvantaged circumstances of the colonies where the Leprosy affected people live in and the societal attitudes that they have to contend with, making a success of their micro enterprises needs a lot of effort and struggle on the part of the project participants. This success, achieved through sheer grit and determination, needs to be recognized and showcased so that it serves as a source of pride and motivation to the leprosy community and also sends a strong message to the outside world that access to opportunity can help the leprosy affected regain their dignity.

S-ILF thus instituted the Rising to Dignity Awards to recognise the hard work and commitment by those running Livelihood enterprises. Each Award carries a citation and a cheque of Rs 1, 00,000. The size of the group varies from 6 to 12 people. For the Rising to Dignity Awards 2013, the prize money was granted by The State Bank of India.

### **About the Awardees in 2013**



**NAME- Tile Fitting Unit**



**COLONY-Swadharnagar**

**LOCATION- Kolhapur**

**STATE- Maharashtra**

**NO. OF BENEFICIARIES- 25**

**MENTOR -ILU, Pune**

These 25 enthusiastic men and youth are models of social and economic empowerment. The working structure is impressive. The chain involves main head and under him are three other leaders. Under each

leader are 12 to 14 masons, and each mason works with a labour. The hard work and systematic planning has helped the daily income and business grow. An interesting achievement is that they have hired 10 additional people from outside their colony to support them in their tiling work. With increase in income, they have invested in expanding their enterprise as well been able to provide better education to their children. A noticeable improvement in their living standards is also visible.

**NAME- Goat Rearing**

**COLONY-Girigobardhan**

**LOCATION- Balangir**

**STATE-Odisha**

**NO. OF BENEFICIARIES-14 women**

**MENTOR -MASS**



An excellent example of women empowerment, the project was started by 14 women with 28 goats and now boasts of more than 120 goats. The

beneficiaries are highly motivated. This project has helped them reduce dependence on begging for their daily needs. This group has been working hard for the success of this project and adhering to set guidelines by S-ILF. Through the project with increasing income and financial stability, the women have become more confident and participate more actively in the community. They have formed an SHG and have started saving part of their incomes. There is a sense of collective ownership and entrepreneurial skill development, leading towards better ways of life.

**NAME- Hawker/Vendor Enterprise**  
**COLONY-Nav Nirman Kusht Ashram**  
**LOCATION- Allahabad**  
**STATE- Uttar Pradesh**  
**NO. OF BENEFICIARIES-13**  
**MENTOR - Nirman Sewa Sansthan**



Among, the poorest of the poor, all members of this colony were into begging. The thirteen beneficiaries have now been able to reduce their dependence on begging. Of these, 12 are selling articles for women in nearby Ghats and melas in Allahabad. One person has been provided a rickshaw to help these 12 beneficiaries get materials from city and also earn a living by pulling the rickshaw. They are trying their best to make this enterprise a success. They have adopted transparent and accountable practices but disadvantaged because of lack of basic infrastructure and land issues. However, the group is highly motivated and hardworking. They do not want to go back to begging, and their initiatives are appreciated by other colonies.

#### **S-ILF participates in a National Conference on Leprosy by NHRC:**

Dr. Vineeta Shanker, Executive Director, S-ILF was invited to a National Conference on Leprosy by NHRC (National Human Rights Commission) held in New Delhi, to make a presentation on “Economic and Social Rights: Current Scenario and Challenges focusing primarily on other challenges relating to economic, social and cultural rights.

#### **Press sensitisation workshop in Chandigarh:**

A press sensitisation workshop was organised in Chandigarh on 24th January 2013 to sensitise the Chandigarh media of the situation of the leprosy affected people in India with focus on Punjab. The interview with Dr. Vineeta Shanker, Executive Director, S-ILF, was covered by many of the leading newspapers like The Tribune, The Statesman, Hindustan Times, The Indian Express, Punjab Kesri etc.

#### **Interview on radio:**

Dr. Vineeta Shanker, Executive Director gave an interview on leprosy and stigma to radio channel FM 104 (Fever). The interview was aired during the programme ‘zara Si Life’ on January 25, 2013.

## Our Bankers:

- Oriental Bank of Commerce
- HDFC Bank
- State Bank of India
- IDBI Bank

## Our Board

- **Chairman**

Dr. S.K. Noordeen, *Chairman, Leprosy Elimination Alliance (LEA) and Former Director (Leprosy), WHO, Geneva*

- **Members**

Mr. Tarun Das, *Former Chief Mentor, Confederation of Indian Industry (CII)*

Ms. Syeda Imam, *Former Member, National Commission for Minorities*

Mr. Tatsuya Tanami, *Executive Director, The Nippon Foundation, Japan*

Ms. K. Yamaguchi, *Director, Sasakawa Memorial Health Foundation, Japan*

Ms. Rati Vinay Jha, *Retired IAS, Former Director General Fashion Design Council of India*

## Committees

- **Livelihood Project Selection**

Dr. S.K. Noordeen : Chairman

Dr. P.K.Gopal : Member

Dr. Vineeta Shanker : Member

- **Fundraising, Communications, Marketing & Advocacy**

Ms. Syeda Imam : Chairman

Ms. Rathi Vinay Jha : Member

Dr. Vineeta Shanker: Member

- **Finance**

Mr. Tarun Das : Chairman

Mr. Indresh Narianl : Member

Dr. Vineeta Shanker: Member

- **Hr & Admn.**

Ms. Rathi Vinay Jha : Member

Dr. Vineeta Shanker: Member

## **Our Team**

### **Executive Director**

- Dr. Vineeta Shanker

### **Livelihood Programme**

- Mr. Sanjeev Kumar : Project Manager
- Ms. Rituparna Sarangi : Project Officer
- Mr. Atul Kumar : Project Officer
- Ms. Ruth Paul : Project Officer
- Ms. Yogita D Parkale : Project Associate

### **Education Work Programme**

- Ms. Payal Gadhiok : Consultant

### **Communication & Advocacy**

- Ms. Nilima Monica Purti : Project Officer
- Ms. Rituparna Das<sup>1</sup> : Project Officer

### **Administration & Finance**

- Mr. Ram Autar : Admin & Accounts Officer
- Ms. Rajni Sharma : Consultant
- Mr. Ganesh Prasad Dhuria : Office Attendant
- Mr. Raj Kumar Masih : Driver

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<sup>1</sup> Joined on March 11, 2013