

Sasakawa-India Leprosy Foundation  
*Restoring Dignity*

# EMPOWERING THE SOCIALY DISTANCED

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Annual Report 2019-2020

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# Celebrating diversity and inclusion

**481**  
SHG members  
empowered

**+95**  
youth skilled

**Rs. 65,81,451**  
contributed by beneficiaries  
in respective colony  
development fund

**+50** meritorious  
students supported  
for higher education  
scholarship

**+400** children  
benefited from  
ASCLs

**100** girls from  
**13** states enrolled in  
nursing courses to  
become qualified  
nurses

**20 lakh**  
reached through  
awareness programs

**+3,150**  
direct beneficiaries

**+500**  
sustainable livelihood  
projects supported

**833** youth provided  
with vocational training  
till March 2020

working in **278** colonies  
across **18** states

**3600** leprosy families  
impacted through  
educational programs





# Contents

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07	In times when social distancing is ‘on the rise’	36	Education - Bridging the gap
14	Our guiding light	48	Communications & Advocacy - Changing mind-sets
16	Together towards a better tomorrow	68	Together for “the socially distanced”
20	Our board	70	Donors
21	Advisory members	71	Training partners
22	Creating stories that inspired many	72	Institutional partners
26	Livelihood - An attempt to restore dignity	74	Media
		80	Our team





# In times when social distancing is **‘on the rise’**

**for the marginalised communities, the novel  
coronavirus is simply another  
threat to an already fragile life.**

We live in uncertain times. For many of us, this is the first time we have been concerned about our health to the point that we cannot interact with others or leave our homes. However, for the marginalised communities, the novel coronavirus is simply another threat to an already fragile existence. It is even more pronounced for those who face deep stigma - the persons affected by leprosy living in secluded colonies. They face systemic isolation and segregation which puts them through untold misery.



# creating hope for those in despair



We at Sasakawa-India Leprosy Foundation are drawing on our extensive experience in building partnership to assist the leprosy affected persons and their families to cope with the coronavirus pandemic. If we can combat the corona virus pandemic early, we will be able to intensify our efforts to restore them with lives of dignity and hope. Before the lockdown most of the leprosy-affected persons were either in menial jobs or

into begging. But under a nationwide lockdown due to Covid-19, they can no more go to work or beg. This has made it difficult for them to even arrange a meal for themselves and their families. Getting into full action, S-ILF initiated a campaign in leprosy colonies of Bihar, Chhattisgarh, Delhi, Haryana, Jharkhand, Madhya Pradesh, Maharashtra, Odisha, Telangana and

West Bengal. With the unconditional help of organisations like CII, Nirankari Mission, Give India, Oxfam India, Subhan Foundation and some other prestigious individual donors, S-ILF was able to provide funds and dry ration to these marginalized members of society.

**+ 50,000 households provided dry ration**

**Rs. 5,000/- each to 36 distressed families in Bihar colonies via direct fund transfer**



# donors who worked with us to impact leprosy colonies

## CII in support with CLP India

Ration kits to 437 households in Haryana Colonies

Ration kits to 228 families in Raipur colonies, Chhattisgarh

## Give India

Cash donation of Rs. 1, 80,000/- to  
36 families in leprosy colonies of Bihar

Cash donation of Rs. 20, 450/- for ration kits to  
32 families of Pashupati Leprosy Colony, Ambala

Cash donation of Rs. 39, 48,510/-  
(Through UBS Optimus Foundation) for ration kits  
to 1975 households in the colonies of Bihar, Delhi, Jharkhand,  
Maharashtra, Odisha and West Bengal

## Nirankari Mission

Ration kits to 100 households of Tahirpur leprosy complex, New Delhi

Help in facilitation/distribution of ration kits to 228 households in  
Raipur colonies in Chhattisgarh.

## Residents of Mahagun, Noida

Ration kits to 65 households of Tahirpur leprosy complex, New Delhi

## Oxfam India

200 Ration kits and 200 safety kits in leprosy colonies of West Bengal



## SDM Office, Haryana

Ration to 25 households in leprosy colony at Kurukshetra, Haryana

250 ration kits in Tahirpur leprosy complex, New Delhi

## Govt. of Madhya Pradesh

Ration kits to 2,000 households of leprosy colonies in Dhar,  
Indore, Sehore and Ujjain

## Haqdarshak

Ration to 58 families in Bettiah colony

7 colonies of West Champaran

170 households in colony of Gaya, Bihar

## Subhan Foundation

250 ration kits in Tahirpur leprosy complex, New Delhi

## Celebrity Chef - Vikas Khanna

180 Ration kits to 6 colonies of Hyderabad in coordination  
with National Disaster Response Force

## Dilip & Devi Cherian

100 ration kits in Tahirpur leprosy complex, New Delhi

## S-ILF

Team S-ILF contributed their one day salary



# meeting the odds together

In these turbulent times, we would take this opportunity to thank our partners and all prestigious individual donors who went above and beyond to extend their help to S-ILF during this pandemic. A special thanks to Chief Minister of Madhya Pradesh Mr. Shivraj Singh Chauhan who made sure dry ration reaches every leprosy colony of Madhya Pradesh within 24 hours of getting information. It is a dedication like these that inspire us and we continue to have a well-functioning society with all of our needs being met. We would be remiss not to mention CII and Nirankari Mission who worked shoulder to shoulder with S-ILF reaching out to help those who are most vulnerable. We thank everyone involved for your continuing commitment, resolve and passion for coming forward in the face of this crisis.



शिवराज सिंह चौहान  
मुख्यमंत्री  
मध्यप्रदेश

World is facing an unprecedented challenge with the COVID-19 pandemic affecting both life and livelihoods. The stranded and the daily wagers have been affected the worst. They have to struggle hard even for the daily essentials.

The government of Madhya Pradesh is trying best at its level to provide essential facilities or goods to the needy people in this pandemic. We are helping all the people of deprived community in all the way possible. The infection has a specific target group and among the most vulnerable group are the patients suffering from leprosy. They have lost their jobs and have run out of stored ration.

To help such people and overcome the crisis, Madhya Pradesh government has also reached out to this marginalised community through various mediums. Sasakawa-India Leprosy Foundation, an NGO working for the socio-economic development of leprosy-affected people has reached out to us, with a request to help these marginalised members of the community. We Co-ordinated with this NGO and as a result of this Sasakawa-India Leprosy Foundation has distributed 2,000 dry-ration kits to cater to the needs of the members staying in these secluded colonies in Madhya Pradesh till now.

Let us all come together during this time of crisis and extend help in whatever way we can for the sake of humanity.

(Shivraj Singh Chauhan)

6, श्यामला हिल्स, भोपाल - 462 013

“We are all together in this fight against the pandemic and therefore it is our bounden duty as a nation to join hands to support people living in secluded leprosy colonies. We have partnered with Sasakawa - India Leprosy Foundation to provide a modest support with relief material to persons affected by leprosy. Please join forces with S-IL Foundation to help serve this community.”

**Pankaj Anand**

Director - Programme & Advocacy,  
Oxfam India

“The country is facing an unprecedented challenge with the COVID- 19 pandemic. A humanitarian challenge is unfolding day by day with people at the bottom of the pyramid, being the worst affected and struggling to arrange daily essentials such as food and medicine. To help the families, CII partnered with S-ILF to support 28 leprosy colonies across Chhattisgarh, Jharkhand and Haryana through provision of dry ration kits. We hope that many more organisations can collaborate in this partnership and extend support in positively impacting the lives of the affected communities.”

**Chandrajit Banerjee**

Director General,  
CII

“Sasakawa - India Leprosy Foundation has been very proactive in their Covid 19 relief work. GiveIndia has supported them for the wages and rations distribution. Together many beneficiaries from the vulnerable communities were being catered to. It has been the first time we are working with S-ILF, and we appreciate the promptness with reporting and on-ground execution of funds. Looking forward to future endeavors to help the leprosy-affected communities.”

**Neha Joshi**

Head - NGO Partnerships  
Give India

“The outbreak of Coronavirus and the subsequent lockdown are creating enormous difficulties for people especially the migrant, the poor and the marginalized. The stigma against leprosy puts the affected persons dependent on odd manual jobs and begging, into greater isolation & neglect. Residing in segregated colonies, they cannot go out nor do they get relief from because of social stigma. It was a joy to partner with Sasakawa - India Leprosy Foundation as we provided relief material to persons affected by leprosy. Thanks to the SILF team, we were able to distribute dry ration kits which catered to 85 families living in Tahirpur Leprosy Colony, New Delhi. We know, no donation is enough, but nothing is too small either. We did our bit and know that you too will come forward and support these marginalized members of the society.”

**Devi & Dilip Cherian**

Perfect Relations

# Our guiding light

## Moving all frontiers forward



**Yohei Sasakawa**

**WHO Goodwill Ambassador for Leprosy Elimination  
- Chairman, The Nippon Foundation, Japan**

The world is currently undergoing rapid and major changes due to the novel coronavirus pandemic. I would like to express my gratitude to the health personnel who are at the forefront of our efforts against COVID-19 in these testing times when we cannot predict how everyday life will turn out.

I would also like to acknowledge the efforts of S-ILF's directors and staff, beginning with Chairman Tarun Das, for providing emergency assistance and collecting donations for leprosy colonies when the whole of India has been in a state of lockdown.

Fifteen years have passed since India achieved the elimination of leprosy as a public health problem, something the international community believed would not be possible at the time that the World Health Organization came up with its definition. But thanks to the efforts of the government, persons affected by leprosy and all concerned, India achieved this “miracle.”

Now, under the strong leadership of Prime Minister Narendra Modi, India is working hard toward the ambitious new goal of making the country free of leprosy and stigma related to leprosy by 2030.

Many countries that have eliminated leprosy as a public health problem are today experiencing what I call “elimination trauma,” their activities

having stagnated out of fear of seeing numbers rise again. As a result, there has been no significant change in case numbers in recent years. But India has overcome this “trauma.” It has courageously strengthened its case-finding efforts without fearing a temporary increase in new case numbers, in the knowledge that detecting and treating all new cases will eventually contribute to a reduction in cases.

At the same time, we need to do more to eliminate leprosy-related stigma and discrimination. It has been 10 years since the UN General Assembly unanimously adopted a resolution on elimination of discrimination against persons affected by leprosy and their family members. Unfortunately, however, persons affected and their families in India still face persistent stigma and discrimination in different areas of society such as education, employment and the law.

To eliminate this stigma and discrimination, S-ILF is playing a commendable role in working to enable the mainstreaming of persons affected by leprosy and their families through measures to support their education and self-reliance, as well as carrying out activities to raise societal awareness of discrimination.

To fight stigma and discrimination, it is necessary to cooperate with people in different fields including government officials, health workers, community volunteers, journalists, businesspeople, opinion leaders and others.

I am thus pleased to note that this year S-ILF has signed a memorandum of understanding with the Confederation of Indian Industry (CII) to educate companies about leprosy and expand employment opportunities for persons affected by the disease. As I result, I expect to see a change from the time when being diagnosed with leprosy meant losing a job and being excluded from society.

Furthermore, it is essential to listen to the voices of persons affected by leprosy—the main actors. Closer cooperation than ever between the Association of People Affected by Leprosy (APAL) and S-ILF can only be an encouraging boost to persons affected and their families.

The goal of making India a country free of leprosy and leprosy-related discrimination by 2030 may seem like a dream, but the important thing is to believe one can achieve one's goal and work toward it. Let us continue to work together and make our dream a reality.





# Together towards a better tomorrow

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**since its beginning, S-ILF has worked  
relentlessly taking many new initiatives for the  
socio-economic development of the  
leprosy-affected persons and their families.**

## why S-ILF?

People affected by leprosy are often stigmatized. Their life is harshly affected by the disease. They have been pushed to the margins by the society. Living in leprosy colonies and bearing the burden of poverty and ostracisation has made their condition worse. This is where S-ILF steps in. A foundation that makes determined efforts in empowering millions of affected lives with opportunities. While mentoring them, honing their skills for livelihood and helping shape the future of their children.

Over the past decade and more S-ILF works for three overarching aims - Livelihood – Education – Communication & Advocacy. The endeavour is to give them a dignified means of acceptance as equal human beings.

In the year 2006, S-ILF was founded by Mr. Yohei Sasakawa - WHO Goodwill Ambassador for the Elimination of Leprosy; recipient of the Gandhi Peace Prize 2018, and Chairman of The Nippon Foundation. Mr. Sasakawa's dedication and relentless work have made a meaningful difference in this field.

## who do we work with?

We work primarily with the leprosy-affected population and their families, scattered in about 800 self-settled colonies all over India. Some of these people live in facilities run by the Government or missionaries. Most of them however, are settlements that came up on public land, near hospitals treating leprosy, close to railway lines or river banks. And some even in the vicinity of religious places or tourist spots.



## our vision

To integrate leprosy-cured persons and their families into mainstream society by ending the discrimination faced by them.



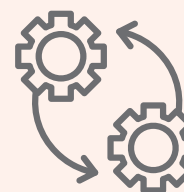
## our goals

- To create conditions that will enable them to have equal access to economic opportunities.
- To increase social acceptability of leprosy-cured people and their families through dissemination of scientific information.



## our mission

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



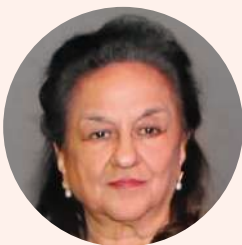
- To enhance the employability of persons affected by leprosy through livelihood generation, education and skill training for both formal and informal sectors.
- To match the capacity building with market demand.
- To provide access to financial resources for self-employment.
- To encourage social responsibility among different sectors of society to provide equal opportunities in gainful employment to those affected by leprosy.
- To build partnerships amongst NGOs, self-help groups, corporates and media to achieve our goals.
- To influence policymakers to achieve inclusion of leprosy-affected in the government welfare programs.



# Board of trustees



**Mr. Tarun Das**  
Chairman  
Former Director General  
Confederation of Indian Industry (CII)



**Mrs. Syeda Bilgrami Imam**  
Former Executive Creative Director  
J Walter Thompson (Central Asia) &  
Member, National Commission For  
Minorities, Govt. of India



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Special Advisor, The Nippon  
Foundation & Managing Director  
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**Dr. P. K Gopal**  
President, IDEA India  
Advisor, APAL India



**Mr. Sushanta K Sen**  
Former Deputy Director General (DDG)  
Confederation of Indian Industry (CII)



**Ms. Seema Arora**  
Deputy Director General (DDG)  
Confederation of Indian Industry (CII)

# Advisory board members



# Creating realities that inspired many

the girl who  
made it big

The Jagannath Leprosy Colony has witnessed many highs and lows. Little did they know that a newly born girl child whose grandfather and father were diagnosed with leprosy is going to steer the change in the times to come. Meet Subhashmita Das.

Abandoned by the native village, left alone by grandparents who died before she was born, representing the realities of the social seclusion, the young Subhashmita was growing up only to lose her father at the age of 5. They knew that nothing will be the same again, ever. To not give her a deprived life, her mother opted for a job of an Anganwadi worker. But young Subhashmita sought more from life. A life with dignity.

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**“my life wouldn’t have been easy if I had not got the scholarship support from the Sasakawa-India Leprosy Foundation.”**



During her schooling, her interest in studies was sparked off. She proved her abilities and her determination at every step. In 2015, she completed her 12th with flying colours. This was the year when Sasakawa-India Leprosy Foundation announced its scholarship program. In the quest to escape from a web of stigma and pervasive stereotypes, Subhashmita applied for the scholarship program through APAL leadership and got selected. She, for the first time, got a chance to create a life outside the colony.

She pursued an 'Optometry Technician' course from the LV Prasad Eye Institute. She worked tirelessly to succeed against all odds and eventually earned herself a recognized qualification.

While studying, she left no stone unturned to achieve her dream of dignity. She topped her exams with a gold medal. Post her course, the Institute offered her a job with a monthly salary of Rs. 20,000. It was not just a happy moment for her, it was a dream come true.

Today, Subhashmita Das is a successful Optometrist. A gold medallist, a role model, a scholar and a dignified health worker. She is a new generation from Odisha who took the baton forward by helping many leprosy-affected people to get treatment from the hospital under its social responsibility program.

In the last 4 years, Subhashmita Das has brought a new wave of hope in many leprosy colonies, making people believe in themselves.







# Livelihood

## An attempt to **restore dignity**

S-ILF works to transform the lives of the leprosy-affected by empowering them to build a sustainable livelihood. S-ILF's livelihood program steers the wheel by initiating, strengthening and scaling up livelihood activities through financial, technical and capacity-building assistance.

The support for the project's development comes from awareness generation & mobilization, business orientation workshops, feasibility studies and market surveys leading to capacity-building and market linkages.

The path to poverty eradication is challenging and S-ILF is prepared to give them a second chance to lead dignified and independent lives.

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**+ 500** projects till 2019-20

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**18 states** covered

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**+2500** families directly benefited

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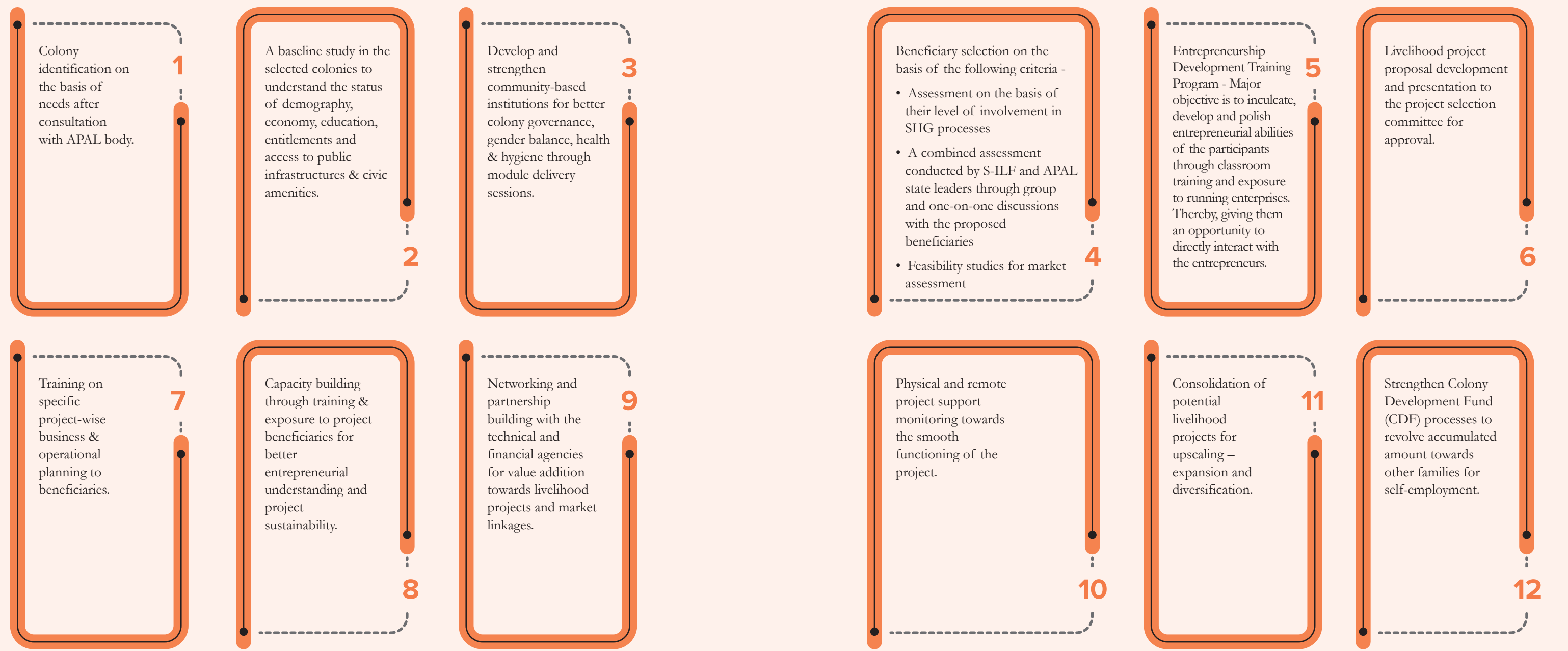
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**481** SHG members empowered

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# the process at a glance



Building  
skills,  
dissolving  
differences

S-ILF bridged the capacity gaps of the beneficiaries by conducting over 39 training and exposure workshops in diverse domains such as Livestock, Services, Retail and Production, EDP & Product Training, Business Operation Training, Account Book Keeping and Inventory Management Trainings.

Today, the average income of people accrued from the projects in West Bengal and Jharkhand (business activities) is Rs. 7,220 per month.

Empowerment  
through self-help  
groups

42 Self Help Groups comprising 481 women members in Jharkhand, MP, Bihar and Maharashtra have been supported through empowerment on issues related to health, hygiene & environment, SHG processes, colony governance and gender in addition to managing SHG operations. 31 SHGs have been linked with bank & 34 SHGs have started inter loaning.

Colony  
development  
fund

Under the fund, Rs. 65,81,451 has been mobilised during 2019-20. Of this, Rs. 25,12,301 has been distributed among 88 new beneficiaries for livelihoods generation in retail, livestock and services domains.

Telangana has charted out a distinctive path by being the state with highest number of new beneficiaries.



the rising

New initiatives

S-ILF's livelihood program expanded its preparatory activities of community mobilisation, baseline study, group formation and empowerment sessions for communities on colony governance, management of SHGs, health hygiene & environment along with gender concept & practices in 30 colonies of Bihar, Maharashtra and Odisha.

Extending the benefits of its livelihood program, S-ILF recommences its monitoring support for two years until its 150 projects catering to 235 direct beneficiaries become self-sustaining.



# community speaks



Alka, a beneficiary of the individual grocery project located at the Ashagram leprosy colony, Barwani is just another example of S-ILF’s success stories.

## The art of standing tall

Alka had a happy, normal life with a family of seven members: four children (three daughters and a son), her husband and a sister. But soon life got a little difficult when her husband lost the job of a labourer in an artificial limb manufacturing unit. The whole responsibility to manage the family came upon her. Working as an Anganwadi worker at the monthly remuneration of Rs. 2,500, she realised that it was insufficient to manage the family’s expenses.

She was determined not to let her children face the same set of challenges like her. She kept trying different things at work but failed to cope with its pressures. Soon, her life came to a standstill.

A ray of hope turned her life around. On the recommendation of the APAL state forum, S-ILF selected her for the grocery

shop group project which turned out to be a life-changing opportunity for her. She received a project amount of Rs. 1,18,000 to set up her grocery shop.

Since women running grocery shops is still a taboo in India, male residents of the colony discriminated her. But S-ILF's timely intervention boosted her morale and she managed to excel by expanding her business.

By giving training and exposure to the wholesale market in Indore for bulk purchasing at wholesale rates, she started a new chapter in her business. Thanks to training in bookkeeping and stock maintenance, she is now financially independent earning around Rs. 10,000 to Rs. 15,000 per month from the growing enterprise. Owing to her hard work and undaunting spirit, she is now able to provide quality education to her children.



Sonu started his own poultry business with monetary assistance and skill development training. Sonu's thorough understanding of the availability and supply requirement for local hotels and restaurants helped the group to establish their business.

## A life beyond limits

Since birth, Sonu Ratre has been living in the Gandhi Ashram Colony, Teesrapara, Janjgir Champa, Chhattisgarh along with his grandmother, who was leprosy affected.

Sonu attended school until grade 10 but had to quit studies to support his family. He struggled to make ends meet. His life took an unexpected turn when S-ILF identified him as one of the five beneficiaries and help them to start their own poultry business with monetary assistance and skill development training. Sonu's thorough understanding of the availability and supply requirement for local hotels and restaurants helped the group to establish their business.

Sonu received training by a local trainer for one month to kick-start the group project. And since then there has been no looking back. Under Sonu's leadership, each group member is earning Rs. 15,000 to Rs. 20,000 per month.

The group of beneficiaries remains constantly in touch and maintains transparency which helps them functions as a cohesive unit. Taking great steps to bring a positive difference to their community, Sonu and his group members have successfully collected Rs. 87,000 towards the community development fund.






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**“I have enrolled my children in an English medium school. I want my children to grow up and become doctors.”**

-Sonam

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## Walking towards the sunshine

**A** 27-year-old Sonam Satnami migrated to Charan Nagar leprosy colony, Ghogranala, Champa in Chhattisgarh from Kolkata post her marriage. She lives with her husband and three children. Educated until grade 9, she worked as a casual labourer.

She always aspired to give her family the very best in spite of her insufficient daily wages. She came to know about S-ILF's livelihood program through the state leader and applied for it. After completing the due process, she became one of the ten beneficiaries identified by S-ILF to start their own enterprise.

After the approval of the project, S-ILF provided the group with seed capital to

initiate the project and skill training. Having worked as labourers, all the beneficiaries had prior experience and understanding along with good relations with the contractors for construction work.

Today, each group member earns Rs. 6,000 to Rs. 7,000 per month and are happy with their economic growth. The beneficiaries wish to expand their work, buy more raw material and take up more work as they believe that their business has the potential to grow.

Sonam now leads a life she always dreamt of. By enrolling her children in an English-medium government school, she hopes to secure their future without letting them compromise with their dignity.







# Education

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## Bridging the gap

**600** direct beneficiaries

**3600** leprosy families impacted

**+50** meritorious students supported for  
higher education scholarship

**+95** youth skilled

**450** children supported in  
**11** centres in **4** states

**13** states reached

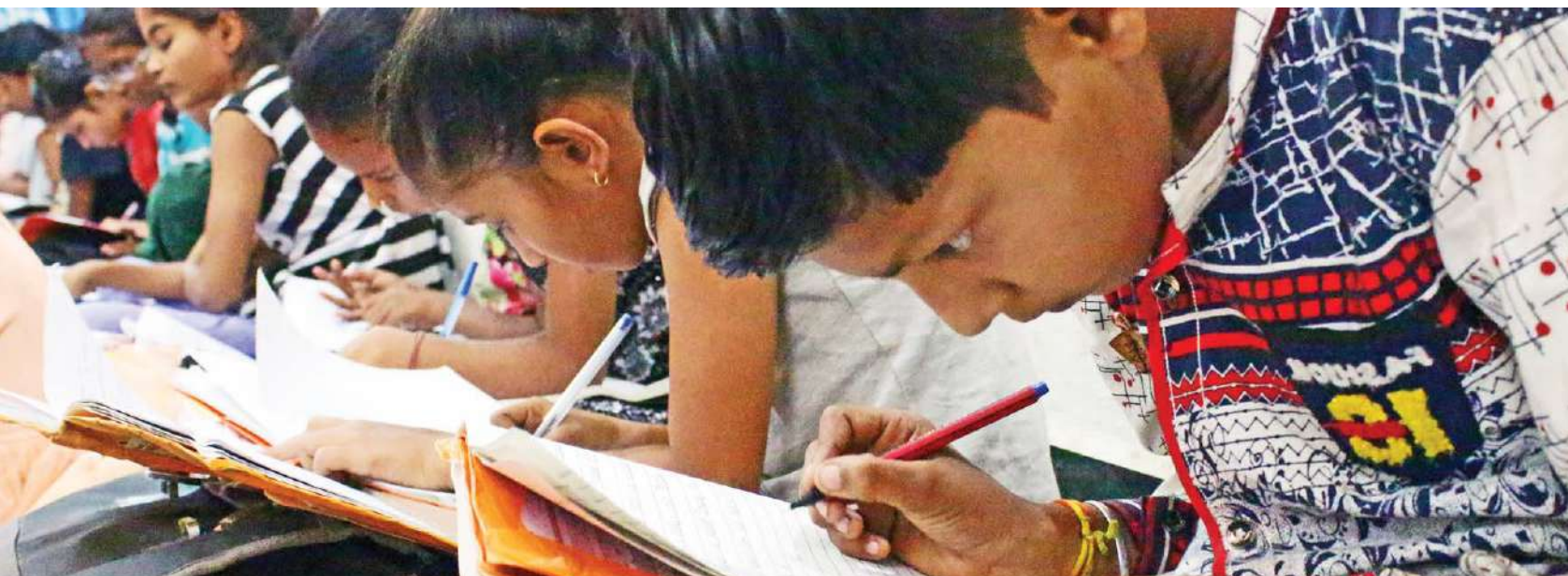
“Education is the most  
powerful weapon which  
you can use to change  
the world.”

- Nelson Mandela

It is the key to eliminating gender  
inequality, reducing poverty,  
creating a sustainable planet,  
preventing needless deaths and  
illness and fostering peace.



# building a strong foundation



## S-ILF After School Learning Centres (ASLC)

No child should be devoid of education. S-ILF’s ASLC works as a building block that enables children to make progress in school by providing support as well as adds to their independent learning outside the school. ASLC prepares children not only for what they encounter in school but for an increasingly complex and faster changing world around them. S-ILF aims to support the school-going children residing in leprosy colonies to improve their learning and educational outcomes and preventing dropout. ASLC in Madhya Pradesh has the highest attendance with 157 children.

Benefits verified by regular assessments in ASLC:

- Developed new skills and interests like being digitally inclined and developing an interest towards reading. (library)

- Improved school attendance, increased engagement in school and a reduced dropout rate
- Turned in more and better quality homework
- Showed higher aspirations for the future, including an intention to complete high school, go to college and investigate scholarship programs

10 centres in 10 leprosy colonies

+ 400 children supported

04 states (Jharkhand, Madhya Pradesh, Maharashtra & West Bengal)

# encouraging youth to walk an extra mile



## Skills To Employment Program (STEP-UP)

S-ILF’s STEP-UP Program aims to motivate drop-outs and unemployed youth of leprosy colonies to avail opportunities to improve their employability, productivity and decision-making.

Access to diverse expertise of NSDC-accredited training partners like Don Bosco Tech, GMR Foundation, Gram Tarang, Gras Academy, ICICI Skills Academy, IIJT, PAN-IIT, Pratham Education

Foundation, Simtej Seven Academy, Virohan, Wockhardt and more.

STEP-UP Program enables job seekers to attain sustainable livelihood through skill development training.

833 youth trained (in the last seven years)

+400 placed



# giving wings to aspirations



## Nursing Scholarship

The need for gender parity is not only socially and ethically necessary, but it is also economically beneficial. Keeping this in mind, S-ILF's Nursing Scholarship caters to those strong-willed girls from leprosy colonies who wanted to fill the gap, support their families and give back to the community a well-deserved life by pursuing nursing.

Girls from leprosy colonies usually drop out after completing high school due to a lack of funds. In the last nine years, S-ILF has provided scholarships to 100 girls from leprosy-affected families in 13 states of India.

Their salary ranges from Rs. 6000 to Rs. 40,000 respectively.

**41** scholars completed nursing course

**39** successfully placed

**20** scholarships provided in 2019-20

## His Holiness Dalai Lama - Sasakawa Scholarship Program (HHDLS-S)

Since 2015, this program offers financial opportunities to meritorious children from leprosy colonies to pursue higher studies and attain professional qualifications to secure employment. S-ILF is running this program in 9 states of Bihar, Chhattisgarh, Delhi, Jharkhand, Madhya Pradesh, Maharashtra, Odisha, Uttar Pradesh and West Bengal.

The most popular professional fields catered through this scholarship program are Medical Science/Healthcare followed by hospitality. Under its ambit, the selected students receive a monthly stipend, tuition fees and other benefits. In the last five years, this program has provided scholarships to 99 youngsters from affected families.

So far, 15 students have completed their studies. After securing a job, they are receiving salaries ranging between Rs. 6,000 to Rs. 60,000 per month.

Under its ambit, the selected students receive a monthly stipend, tuition fees and other benefits. In the last five years, this program has provided scholarships to 99 youngsters from affected families.

**99** scholarships since 2015

**15** scholars placed after completing studies & are now supporting their families

**25** new scholars selected for the scholarships in 2019-20

**one-year program** (diploma & certificate) offered to the candidates not selected for HHDLS-s





## One year scholarship program

In the course of our work we have realized that there are many students in the leprosy colonies who could not take up higher-level courses due to various reasons. Without any skills or education, they often take up petty jobs as daily labourers. Taking this into

account, S-ILF initiated a One Year Scholarship Program to enable these individuals to hone their talents in a specific skill. And thereafter, hopefully a livelihood and a dignified life.

## building valuable partnerships

We believe in building long-term relationships with all our stakeholders. By strengthening the ties with all the state leaders of Association of Persons Affected by Leprosy (APAL) we ensure genuine stakeholder participation and engagement.

Involvement of state leaders is critical to ensure thorough implementation of the education programs. As early engagement with them leads to data provision, insights, resources and support in program delivery. A buy-in of both state/colony leaders and beneficiaries especially youth is critical to ensure that the program has effective outcomes.

Beneficiary participation is being supported through state leader workshops that ensure that state leaders, colony leaders and active individuals from leprosy colonies can be a part of the planning, implementation and monitoring of the progress. Within this process, particular attention has been paid to the participation of state/local leaders in the workshops. Held annually, the first day of the workshop is reserved for informing all about new programs or activities. The day provides an opportunity for leprosy leaders to share their ideas, concerns and feedback on progress or challenges in implementing the program with S-ILF. Activities during the second day are designed to build the capacities of leaders giving them the confidence to communicate their opinions effectively.



# new steps forward

## MoU signed

Under the umbrella of the HSBC Skills for Life Programme, HSBC and Swades Foundation sanctioned Rs. 62,94,000 for a 18-month project. The amount will be used for the training of 200 youth from Jharkhand and Uttar Pradesh as Retail Sales Associate and Hospitality-F&B Services Steward.

## Initiative most innovative

### Hole in the Wall (HiWeL) & Digital Literacy Center

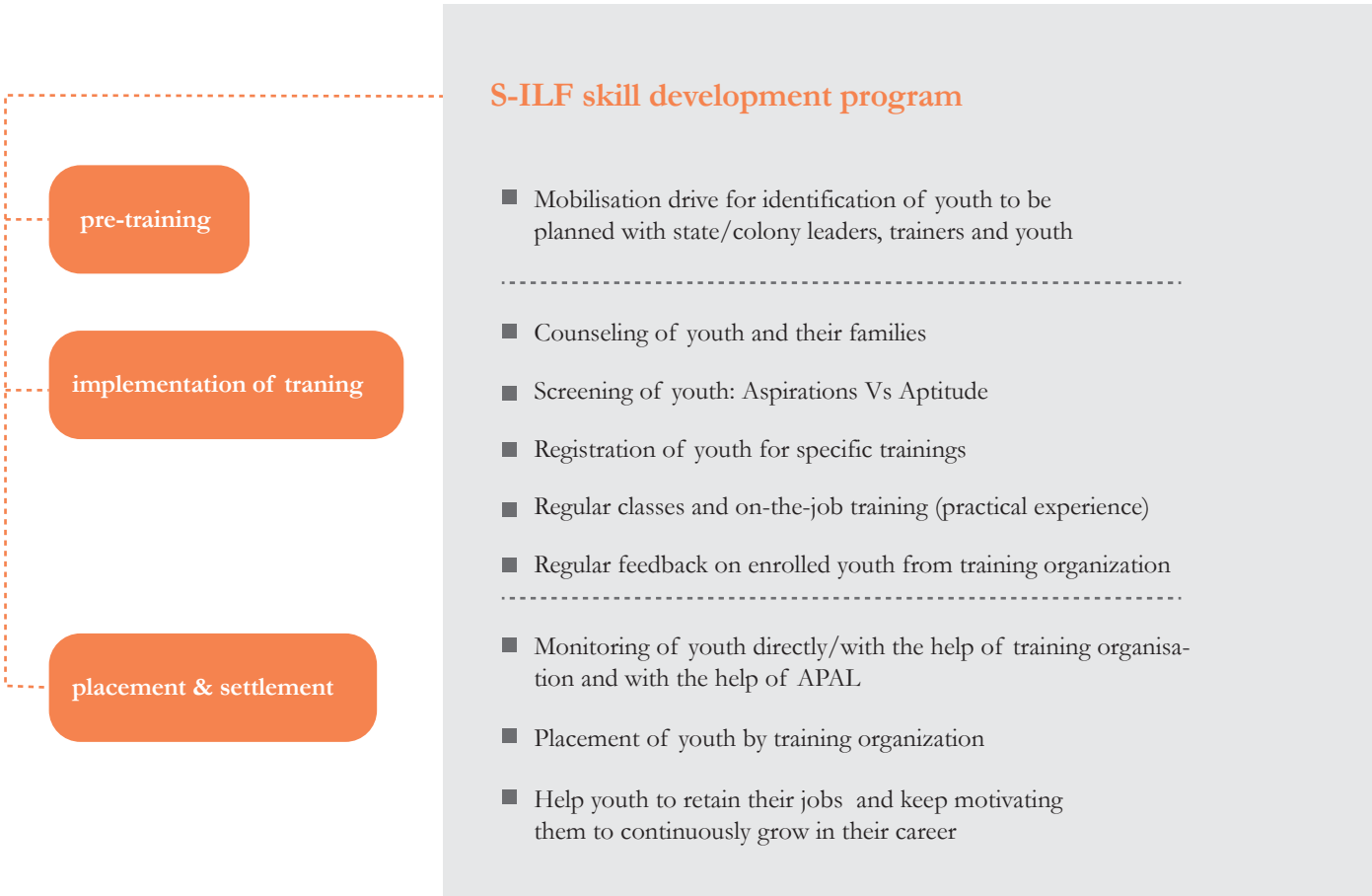
While leprosy-affected families are engaged in securing a life of dignity, S-ILF attempts to introduce their children into the fast-changing technological era.

S-ILF has initiated HiWel and DLC Program in collaboration with NIIT Foundation in Sai Seva Kusht Colony, Indore, Madhya Pradesh in August 2019. Embracing this opportunity, ‘Learning Stations’ – is a joyful self-learning platform for children of all age groups irrespective of caste, religion, and sex.

This innovative experience with free and unrestricted access primarily focuses on removing any mental barriers associated with using computers. Placing them in the middle of slums and playgrounds for easy usage will help India with a whole new generation of skillful leaders.

The program is based on an innovative pedagogy -‘Minimal Invasive Education’ which attracts the users to the learning station by sparking their curiosity and self-interest.

Digital Learning Centre is equipped to provide digitally-enabled education to colony residents from 12 to 60 years. They award a certificate for Digital Literacy Short Duration Courses (20 hours) spread over a minimum of 10 days to a maximum of 30 days.



+ 165 persons registered for the program

98 out of which completed the course

83 participants/candidates received certificates from DLC

60 children actively using learning station

## community speaks



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Without the support of S-ILF Anil could never think to move out of the colony and study further. He said “whatever I’m today I am because of S-ILF”

---

### Journey from learner to teacher

Anil was born in Ashadeep leprosy colony in Jharia, Dhanbad. He is a son of a poor labourer with a family of two sisters and one younger brother. He found his family fighting a battle of surrounding prejudice and social isolation since his father contracted leprosy. Life for him was never easy.

Living an ambition is the true worth of a man and this powerful statement looks true when we glance through the life of Anil. At the tender age of 26, he has become an inspiration for many. As a meritorious student, Anil bore the burden of his studies by taking tuitions.

He successfully completed B.Ed under the HHDLS Scholarship program from Loyola College, Jamshedpur. During the campus placement, he got selected in ICSE Board Ursuline Convent English Medium School, Purnia, Bihar which is a renowned school. He teaches Mathematics from Class IV-VII and draws a salary of Rs. 29000 per month. Anil firmly believes that he is getting a lot of exposure in his current job.

Today, Anil has repaid the loan his father took for his sister's marriage. With nerves of steel and learning attitude, he is planning to pursue M.Sc in the coming year. Many like Anil have in them the potential to go beyond and carve out a brighter future.

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“I am really grateful to S-ILF for believing in me and enlightening the self-belief in me” says Rani

---

### Determination has no disability

Opportunity does not come to those who are unprepared. But Rani, a 21-year old aspiring girl from Tahirpur leprosy complex, New Delhi was an exception. Born in a family of five, her life was not easy. Every day was a struggle as her father, who used to run a small shop was the only earning member in the family. Her wait for the right opportunity bore fruit when her friends told her about the 6-month Emergency Medical Technician course sponsored by the Sasakawa India Leprosy Foundation. She was confident that this course would open a world of new possibilities for her. She attended soft skills classes conducted during the training and eventually completed the course with flying colours.

Setting a new yardstick for herself, today, Rani is working efficiently and effectively with CATS Ambulance services and earning nearly

Rs. 17,000 per month. She is supporting her two younger brothers in completing their studies. During the time of Coronavirus outbreak, when all the staff refused to go for the Corona calls, Rani fearlessly took the responsibility and attended every call. She became the chosen one to receive special training to handle Corona cases.

With sparkles in her eyes, she says “**Now, after getting this job, I can help and support my father.**” To strengthen her abilities, she is continuing her studies through distance learning programmes. “**I am impressed that S-ILF has turned my child to a responsible person who cares for the family and supports me in fulfilling the family needs**” says her father.

Many like Rani are waiting for the right opportunity to earn happiness for themselves and their families.







# Communications & Advocacy

## Changing mind-sets

Though easily treatable leprosy still strikes fear in our minds. Lack of knowledge about the disease has led to the misinformation and misconceptions resulting in a deep-rooted and widespread stigma against the disease and those affected. This societal mindset has to be changed.

To tackle this problem S-ILF has developed a multi-faceted approach that reaches out to people from all walks of life such as educational institutions, media, politicians, parliamentarians, lawyers, social activists, government institutions and corporate houses. Their involvement is vital to spread awareness so that the leprosy affected persons and their families are treated without discrimination.

S-ILF also engages in 'Advocacy' to ensure a legal and institutional framework that doesn't discriminate against the rights of the leprosy-affected. Treating them as equal citizens of the country, ensuring that any violation of their rights will be treated as a human rights issue. This was aimed to set in place mechanisms towards addressing grievances and punitive actions.





# Anti-Leprosy Day

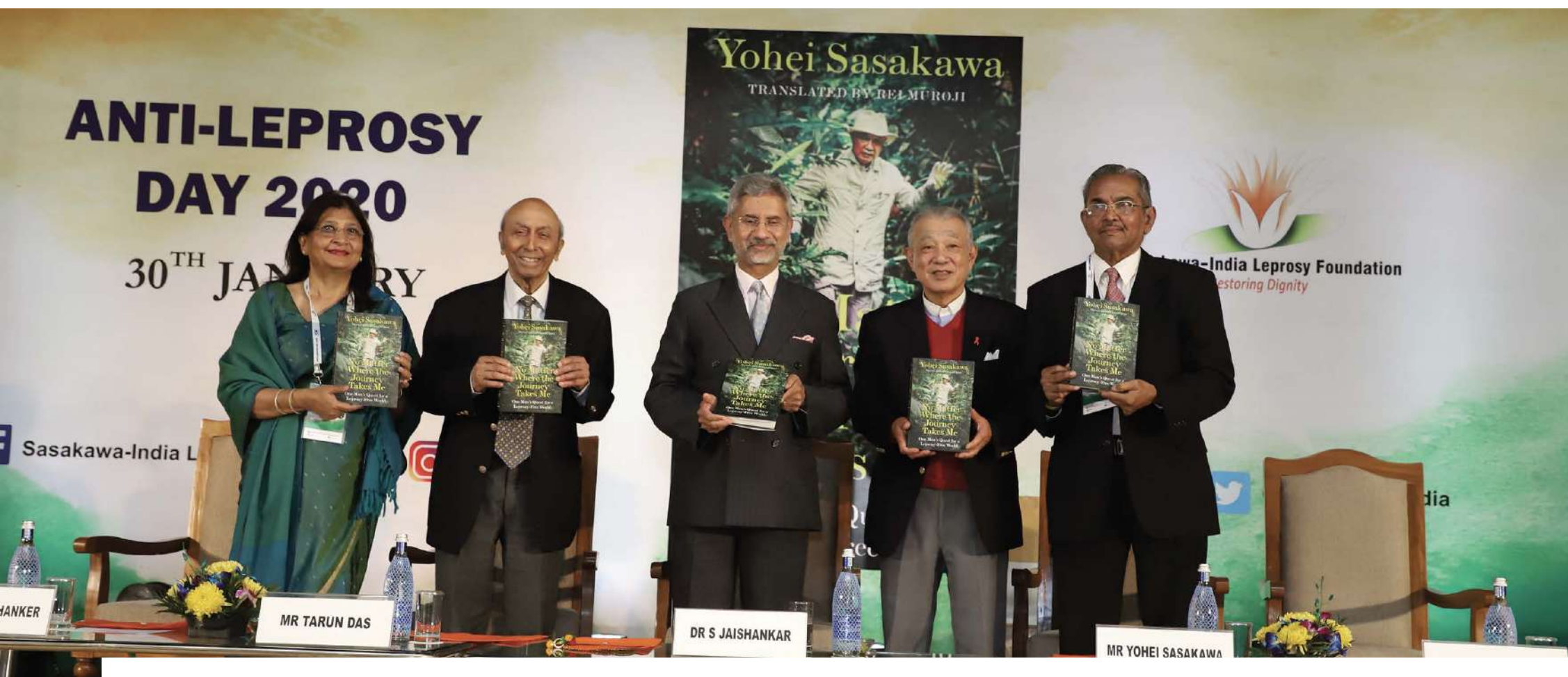


In memory of Mahatma Gandhi's crusade against leprosy, 30th January or Martyr's Day is also marked as Anti-Leprosy Day in India. A day when we honour his fearless crusade and immense contribution for persons affected by leprosy. Also renewing our pledge to raise awareness about leprosy and to end the stigma attached with it.

This year S-ILF signed an MoU with the Confederation of Indian Industry (CII) in the presence of Dr. Harsh Vardhan, Hon'ble Minister of Health & Family Welfare, Government of India. This MoU paved the way for a strong partnership where CII will help S-ILF in creating widespread awareness about leprosy. It will also encourage corporates to welcome deserving candidates from the leprosy background as employees in their organisations.







The day also witnessed the official release of the English version of Mr. Yohei Sasakawa's book "No Matter Where the Journey Takes Me" by Dr. Subrahmanyam Jaishankar, Hon'ble Minister of External Affairs. Present at the occasion were Dr. Rajiv Kumar, Vice Chairman NITI Aayog, CEOs and eminent dignitaries. The book illustrates Mr. Sasakawa's selfless journey in addressing leprosy across the world. Giving an account of his journeys, stories, challenges, hopes and aspirations in his own words. It also narrates the way he bettered the lives of many and advocated for the end of the social discrimination.



The closing of the Anti-Leprosy Day event witnessed a participation of more than 500 people which included CEOs, bureaucrats and people from leprosy backgrounds. The event ended with a captivating performance by Ms. Sonam Kalra, famous Sufi singer, who exhorted everyone to join the fight against leprosy through her songs. Team S-ILF also showcased a 3-minute short film highlighting Mr. Yohei Sasakawa's selfless work in the field of leprosy. The audience applauded, tweeted and retweeted the event while media covered it extensively.



# celebrating inclusiveness



## Youth festivals

Witnessing an increase in participation with each passing year, S-ILF's Youth festivals have become a major attraction. Drawing a large number of students and institutes year after year at national and regional levels.

S-ILF's Youth Festivals offer an unexpected opportunity for the youth from different colleges to interact with the youth from leprosy-affected colonies over common creative activities such as music, dance and drama. It has enabled the students to make friends, understand each other and erase differences. The bond gets strengthened as they stay and eat together while professional artists train them for performing acts.

The festival is not just attracting youth to cultural activities; it is also transforming all those from non-leprosy backgrounds into goodwill ambassadors for fighting the stigma. Transforming mindsets, it also changes the way people look at leprosy-affected persons. This year, a total of four youth festivals were organised. A National Youth Festival was arranged in New Delhi. The grand finale took place at India Islamic Cultural Centre, New Delhi on 29 January 2020. Ms Radhika Bharat Ram, Joint Vice Chairperson of The Shri Ram Schools honoured the winning teams with prizes at the finale.

75 scholars from S-ILF's education program participated

75 students from colleges/universities of Delhi-NCR participated

4 best entries showcased in folk & fusion dance & improvised & folk theatre categories

+165 youth participated

Three other regional youth festivals were held at Madhya Pradesh, Maharashtra and Uttar Pradesh respectively. All the youth festivals received a good response and were extensively covered by mainline media focusing on the micro-society these youth created in these events.



**Oriental University (OU), Indore**  
Chief Guest:  
Ms Sumitra Mahajan  
Former Lok Sabha Speaker



**College of Engineering (CoEP), Pune**  
Chief Guest:  
Mr C.P. Tripathi  
Consultant, CSR- Bajaj Automobiles



**Integral University (IU), Lucknow**  
Chief Guest:  
Mr Jai Pratap Singh  
Health Minister, Uttar Pradesh



# Testimonials **that cheer**



**Anjubala Maibam**  
Nursing student  
Bharati Vidyapeeth, Pune

“ It was a nice experience. In fact one of the best of my life. I never knew that I could become such a changed person in just 2-3 days. I have attended a few such festivals but this was very different. The exposure I got helped me in overcoming a lot of challenges. The best part was the socialising with new people. I am returning home with many new friends and a winning trophy in dance category!



**Vishal**  
S-ILF Scholar

“ First of all I would like to thank your team for calling us to this youth festival. I feel so proud that I got an opportunity to be a part of it. I was a bit afraid in the beginning because everybody was a stranger to me but with time I made some good friends and overcome my fear. I learned new things which I never did before, had new experiences which I never had before. Before this youth festival I have never been on a stage. Thanks S-ILF for making it possible for me.



**Abhilasha**  
Social Work student  
Delhi University

“ Learned the method of group work and its importance in our lives. We stayed together, we worked together, and we had food together which very well served the purpose of youth festival that is to bring youth from leprosy colonies and youth from different colleges at one platform. All is well if ends well, so the fest ends very nicely and I enjoyed it and learned a lot from you people. Indeed you guys are doing a great job. My sincere regards and thanks to all the team members of S-ILF.



**Swati Maurya**  
(Kathak Dancer)- Mentor  
Regional Youth Fest  
Uttar Pradesh

“ When I was told that there will be a youth fest with students from different backgrounds, I was sure that it will be like any youth festival in colleges. But I was taken aback when I got to know that half of the participants are from leprosy background. Keeping the stigma aside, I went to the fest with an open mind. Thanks to S-ILF staff for sensitising me and other mentors before the event, that leprosy was least on our minds. It was a complete different feeling at the fest. I also got to know that this was the first ‘all-female’ mentors’ fest of S-ILF. Everyone was so friendly and so helpful. We enjoyed a lot and had best of the time here. Thanks S-ILF for this wonderful journey. I’ll always work for the cause.



**Umar Saif**  
Law student  
Integral University  
Lucknow

“ Once a wise man said; happiness is not doing everything for yourself, but the bigger sense of happiness is doing something which makes others happy and brings a smile on their faces. The thing said latter is what I experienced in those 3 days. I can safely say, that those were one of the happiest and proud moment of my life, and no words are enough to give a feedback for that.



**Siroj Alam**  
S-ILF Scholar

“ When I got a call to attend this youth fest, I was very anxious. The fear of exposing my identity to people from other institutions was always there. I knew that there would be many from different leprosy colonies, but when I got to know that there would be students whom I have never met made me nervous. But in these three days, all these fears and anxieties have gone past. Now I feel no hesitation in telling people that I am from a leprosy background.



**Umar Raza Khan**  
(TV Actor and Director) – Mentor  
National Youth Fest, Delhi

“ Working with youth is full of challenges. To channelize their energies is a big job. Usually I prepare a new play in a month with my team. But here the challenge was to prepare a play in just three days! That too with people I have never met before! And they were new to each other too! And these people had no prior experience of theatre! It might sound very unrealistic but we all made it happen. And my team presented one of the best plays I have directed till now. Thank you S-ILF for showing confidence in me and eliminating the difference between ‘Them and Me’.



**Reyna Vashishth**  
(Film Actress)  
Mentor-Regional Youth Fest  
Maharashtra

“ S-ILF's Youth festival was one of the best experience of my life. I am grateful to S-ILF team for considering me to mentor art in dance form to those special gifted students. It was a beautiful event, so well organized and best was the enthusiasm and the non-stop energy of the Youth. I went as a mentor and returned as a student, nurtured in life. I am grateful that I could contribute to the greater cause that Sasakawa- India Leprosy Foundation has taken up.





## Workshops that empower

Addressing the lack of knowledge among the residents of leprosy colonies about the welfare measures offered by the governments, S-ILF organises special ‘residential empowerment’ workshops for the residents of leprosy colonies in clusters. These workshops assist in:

**Informing** them of the different schemes available.

**Enabling** them to identify the schemes under which they can seek support.

**Training** them to write their petitions and arranging interface with concerned officials to access welfare schemes offered by their departments.

These workshops are conducted with a focus on building the capacity of participants to take lead towards integration of existing welfare schemes such as BPL cards, housing under Indira Awas Yojana, Anganwadi schemes as well as getting access to rights of the land that they live on.

The first phase of the workshop in Dhanbad received an overwhelming response. Groups of women, youth

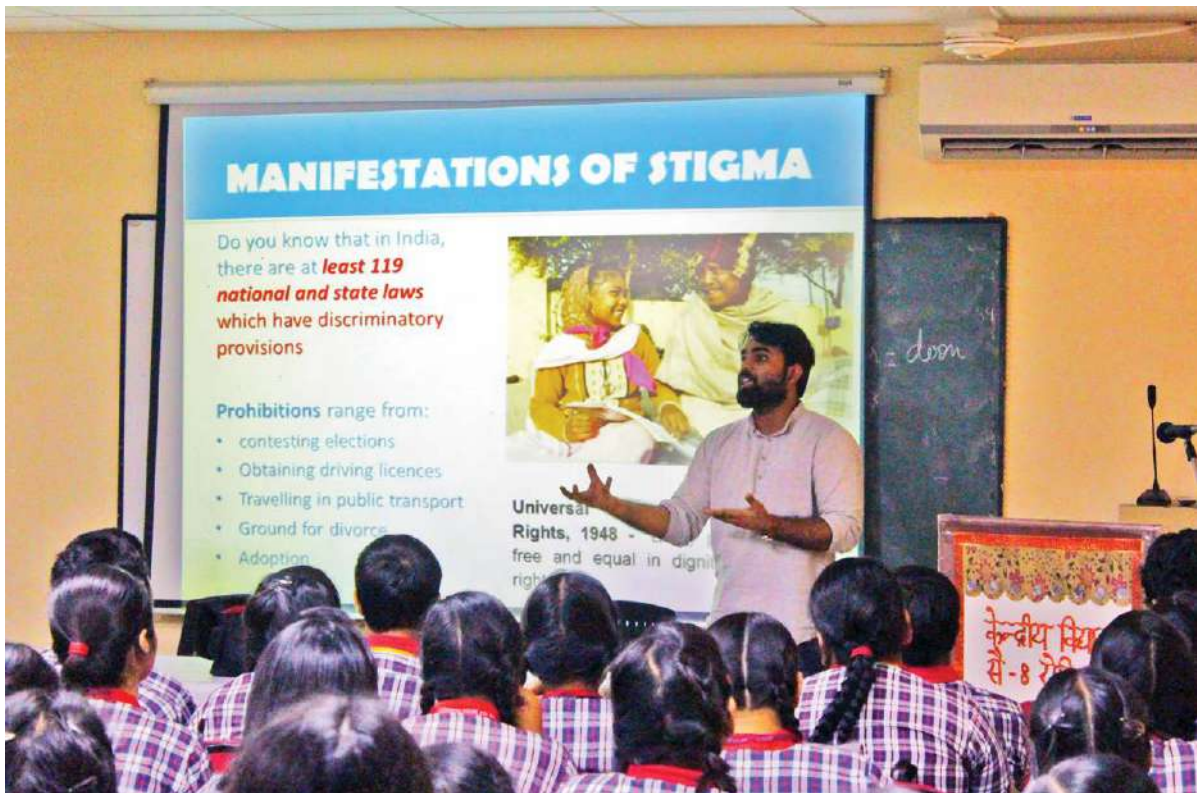
and elderly along with their respective colony leaders came forward and participated in the workshops. These residents had no proper knowledge about the existing govt. welfare schemes. They took this opportunity to address problems they have faced for long like land issues, unemployment, water and sanitation. A local NGO - Phoolen helped in facilitating these workshops which were organised into two groups for a better and concentrated understanding. S-ILF is looking forward to empower more such colonies in the near future.

**10 colonies shortlisted from Dhanbad in 2019-20**

**workshops conducted with local NGO partners & colony leaders**



# raising awareness



## Awareness program

Inspite of being a completely curable disease, there are some common misconceptions about leprosy that continue to cause confusion fuelling stigma and discrimination.

S-ILF continuously reinforces its efforts in eradicating these misconceptions through increased awareness in every stratum of society. S-ILF works with multiple stakeholders like school and college students, medical institutions, lawyers, social activists, policymakers, corporate and media houses to achieve this goal.

## Auto-rickshaw campaign:

*sadak se ghar tak*

S-ILF got into the 'auto mode' bringing its creative campaign "*Sadak Se Ghar Tak*" to life by engaging with commuters through an awareness generation drive. 500 auto-rickshaws were hired to reach every corner across Delhi. Every auto had a poster with significant facts about leprosy. Another initiative by S-ILF to raise awareness around the subject. Through this campaign, S-ILF reached out to around ten lac people to sensitise the general public..

## Young Partners Program (YPP)

Under YPP, S-ILF reaches out to schools (both Government & Private) to sensitize the young minds to end stigma & discrimination against Leprosy.

School going children have very little idea or understanding of leprosy as a disease. Whatever little they may know comes from family and friends and is often vague and reaffirms the stigma against the disease.

However, given the fact that children are the future citizens of this country and the fact that their minds and attitudes are still being formed, it's crucial to spread the

**Supported** by Ministry of HRD & Kendriya Vidyalala Sanghathan

**27** sensitization workshops conducted in Kendriya Vidyalayain Delhi-NCR in 2019-20

**+ 2000** students participated

word of eradication of stigma and discrimination against people affected by leprosy to school children. Under YPP, S-ILF reaches out to schools (both Government & Private) to sensitize the young minds to end stigma & discrimination against Leprosy.





## College sensitization

As part of the Awareness Program, S-ILF reached out to various colleges and departments of universities in the states of Delhi/ NCR, Madhya Pradesh, Maharashtra, Rajasthan and Uttar Pradesh. The sensitisation sessions are in the form of intense workshops of 4 to 6 hours.

This year, S-ILF has conducted such sessions with students of social work, paramedics, pharmacy, journalism, political sciences, economics, law, management and more. These interactive sessions exposed the students to the different aspects of leprosy and sought to generate academic interest to

study the stigma and its impact. The participants took an oath to end the stigma and joined hands to take this initiative forward.

A new component of '10/10' enjoins each participant to identify 10 people from their family and friends, sensitizing them about leprosy.

**19** interactive sessions conducted in 2019-2020

**+ 1,500** students & faculty members sensitised

## Corporate sensitization program

Though leprosy is completely curable, the stigma associated with the disease and social isolation of those affected still persists. As a part of the CII-S-ILF MoU, S-ILF conducted leprosy awareness sessions at CII National & Regional Council meetings. These sessions help in breaking myths associated with leprosy, thereby encouraging employers to hire employees from leprosy background who are fully cured.

After the sessions, CEOs and prominent personalities took a pledge for a leprosy-free India. About 40 CEOs and corporate leaders attended the session at the CII Northern Region Council Meeting.

**A short film on Dimple Kapadia was a turning point as they were completely amazed to know that the actress was once diagnosed with leprosy and yet she excelled in her career. Sachin Pilot, Deputy Chief Minister, Rajasthan along with Mr. Vishesh Chandiok, CEO Grant Thornton and other CEOs took an oath not to stigmatise leprosy and assured their support towards the cause.**



recognising endeavours



Training of the Trainers program (ToT)

S-ILF has always believed that the fight against leprosy cannot be won without coming together as a united society. Strengthening bonds and creating partnerships is the need of the hour. To drive this further, S-ILF has been making partners not only with students but also faculty members and paramedic personnel.

This year, under its ToT program, S-ILF partnered with the Fairfield Institute of Technology & Management (FIMT), New Delhi. Around 35 faculty members of Law and Journalism departments participated in the one-day training workshop. The institute has long been a staunch supporter of the cause and workshops have been organised in the past

too, with its students. This year, the special ToT workshop focused on medical, legal and social aspects of leprosy along with the challenges associated with it.

Dr. Derek Lobo, S-ILF Board member and Former-Regional Advisor for leprosy, WHO South-East Asia Region and Ms Shreya Shrivastatva from Vidhi Centre for Legal Policy were the resource persons. The workshop was well received by the faculty members, who pledged to spread the correct knowledge about leprosy in their classes. FIMT also agreed to take up leprosy as a part of its law curriculum.

This was the 3rd such workshop organised by S-ILF in the last three years.

Rising to Dignity Awards 2019

It is a fact that people affected by leprosy have suffered due to discrimination and stigma associated with the disease. It is also a fact that they endeavour to put in optimised efforts to succeed in their initiatives.

S-ILF's Rising to Dignity Award is presented to recognise their hard work and commitment to their livelihood enterprises enabling them a successful transition from begging to dignified livelihood.

For the year 2019, three winners were awarded in presence of Prof. Raj Mohan Gandhi (renowned social activist and author). The awards were given on the occasion of S-ILF's 13th Anniversary at Vishwa Yuvak Kendra, New Delhi.



Winner 1  
Scrap Collection Business  
Vimukhthi Leprosy Colony  
Kakinada, Andhra Pradesh



Winner 2  
Vegetable & Paddy Cultivation Project  
Teesrapara Colony, Champa, Chhattisgarh



Winner 3  
DJ/Tent House Project, Indira Leprosy  
Colony, Champa, Chhattisgarh





## commemorating Mahatma Gandhi - the prime crusader of leprosy

With all the achievements in fight against leprosy so far, S-ILF sets the stage for Mahatma Gandhi's 150th birth anniversary. He has played a significant role in destigmatising leprosy in India and it was time for S-ILF to pay homage by conceptualising and producing a short film showcasing his relentless efforts to abolish untouchability and his fight against the elimination of leprosy as well.

The film distinctively narrated the story of how even after abolishing untouchability, the societal mindsets still discriminate persons affected or cured of leprosy. Through this film, S-ILF urges the nation to join its mission in completing the unfinished fight of Gandhiji, making our minds and India leprosy-free.







# Together for “the socially distanced”

## allies

We at S-ILF believe that the fight against leprosy cannot be waged alone or in silos. To end the stigma and discrimination we have been working with our allies at every level to make every effort count. Be it on the field, at policy level, at program implementation or in spreading the word. Our friends have been constant companions all these years. We would like to name those, without whom, this year would not have been a great year.

## APAL

APAL is a national networking organization of persons affected by leprosy. Founded in 2006 with active encouragement and help from The Nippon Foundation, Japan. It is an essential part of Mr. Sasakawa's vision of mainstreaming the affected population and their families thereby restoring their dignity. APAL provides a platform where persons affected by leprosy can discuss their issues and take up matters relating to their rights and entitlements at various levels. Issues pertaining to their land rights, pensions and specific schemes for disabled people, human rights issues, education & employment, housing sanitation and more have been raised with State and Central Government. Working in close collaboration with APAL over the years, S-ILF has been able to strengthen its program, leading to increased trust and rapport between the two institutions.

“People do not recognise us by our religion, caste or state. They only identify us as leprosy-affected people. It is, therefore, very crucial for all leprosy-affected persons to unite and fight together to end the stigma. Discrimination against us should stop. We have a long fight ahead and we will not stop until our difficulties are addressed and needs are fulfilled. I invite everybody to come forward and lend a hand to help leprosy-affected persons to lead a dignified life.”



Mr. V. Narasappa  
President-APAL



# Donors



The Nippon Foundation (TNF)



State Bank of India (SBI)



Sir Dorabji Tata Trust (SDTT)



National Skill Development Corporation (NSDC)



His Holiness The Dalai Lama Trust (HHDLT)



Small Industries Development Bank of India (SIDBI)



Give India



ITC Limited



Alar Infrastructure Pvt. Ltd.



Pearl Global



Pearl Retail Solutions Pvt. Ltd.



LT Foods



Bajaj Auto Ltd.



Delhi Metro Rail Corporation



HDFC Capital Advisors Ltd.

# Training partners



Don Bosco Tech  
Bihar, Chhattisgarh, Jharkhand,  
Madhya Pradesh, Maharashtra,  
Uttar Pradesh and West Bengal



Empower Pragati  
Bihar, Delhi, Jharkhand



Pratham Education Foundation  
Bihar, Chhattisgarh, Madhya  
Pradesh, Maharashtra, Odisha



GMR Foundation  
Delhi



B-Able  
Odisha



VAG InfoTech  
Delhi



IJT  
Delhi



Gram Tarang  
Odisha



Simtej 7 Academy  
Maharashtra



Wockhardt  
Uttar Pradesh



# Institutional partners

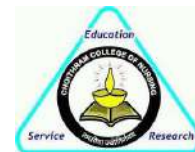


Bharati Vidyapeeth



**राजस्थान केन्द्रीय विश्वविद्यालय**  
**Central University of Rajasthan**  
(संसद के अधिनियम क्रमांक 25 वर्ष 2009 द्वारा स्थापित)  
(Established under the Central Universities Act, 2009)

Central University of Rajasthan



Choithram College of Nursing



**HERITAGE INSTITUTE OF HOTEL & TOURISM**

Heritage Institute of Hotel & Tourism



**INSTITUTE OF  
PUBLIC HEALTH & HYGIENE**  
विद्येव बलम्

Institute of Public Health & Hygiene



Integral University



**College of Engineering Pune**  
(An Autonomous Institute of the Govt. of Maharashtra)

College of Engineering, Pune



Delhi University



Jamia Millia Islamia



Kendriya Vidyalaya Sangathan



Oriental University, Indore



**DEVI AHILYA VISHWAVIDYALAYA, INDORE**  
(Formerly University of Indore), NAAC A<sup>+</sup> Grade  
State University of Madhya Pradesh, India

Devi Ahilya Vishwavidyalaya, Indore



**तेजस्वि नावधीतमस्तु**  
ISO 9001:2008 & 14001:2004

Fairfield Institute of Management & Technology



**PRESTIGE INSTITUTE OF MANAGEMENT  
AND RESEARCH, INDORE**

Prestige Institute of Management & Research



**TEERTHANKAR  
MAHAVEER UNIVERSITY**  
Moradabad

Teerthankar Mahaveer University



Wanless College of Nursing



Gautam Buddha University



**Gokhale Institute  
of Politics and  
Economics**  
(Deemed to be University)

Gokhale Institute of Politics  
and Economics



Govt Arts &  
Commerce College, Indore



I am only halfway along this journey

Yohei Sasakawa, recipient of the Gandhi Peace Prize 2018, on his debut book, which talks about the battle to rid the world of leprosy and the stigma that comes with the disease



Man on a mission Yohei Sasakawa pledged \$50 million to make multi-drug therapy available free to leprosy patients

While people commonly think of leprosy as a disfiguring disease from biblical times, an estimated three million people continue to live with leprosy-induced disability. The world sees more than 200,000 new cases each year, over half of which are in India.

Yohei Sasakawa, an 81-year-old Japanese philanthropic activist, had always been determined to carry on the work begun by his father, the politician and philanthropist Ryochi Sasakawa. As chairman of the Nippon Foundation, started by his father, he pledged \$50 million to the World Health Organization (WHO) in 1995 to provide multi-drug therapy (MDT) free of cost to patients in leprosy-endemic nations worldwide. The MDT combines two or more anti-leprosy drugs to prevent drug-resistant strains. Today, his efforts have helped several countries, including India, access free treatment easily, as well as challenge the stigma associated with the disease.

In his debut book, *No Matter Where the Journey Takes Me: One Man's Quest for a Leprosy-Free World*, published by Hurst and translated from Japanese by Rei Muroji, Sasakawa talks about his work with leprosy eradication and why India holds a special place in his heart.

When he arrived in New Delhi for the India launch of the book on anti-leprosy day (January 30), he promised free hard copies as a special gesture exclusive to India. The copies can be obtained by contacting the Sasakawa India

Leprosy Foundation. Edited excerpts from an e-mail interview with BLink:

Your book mentions how you saw the first leprosy patient in 1965 when you accompanied your father on a trip to Korea and visited a local hospital. How did this experience affect you?

I'm ashamed to say that until I saw the actual circumstances at this leprosy hospital, I hadn't known that there were people in society who had been abandoned by their families because of this illness and were leading such miserable lives. When I saw my father embrace the patients, shed tears and pray for them, I decided that I should carry on his work. It determined the course of my life. From that moment on, I began to live my life with a consciousness of death. I resolved that I would have no regrets nor face. For nearly half the UN General Assembly adopted a resolution in 2010 with guidelines for the elimination of discrimination. It was a landmark resolution, and adopted unanimously. But I am still only halfway along this journey.

How prevalent was leprosy in Japan, and what steps were taken to cure it?

Under Japan's Leprosy Prevention Law, patients were isolated in 13 national sanatoriums. The government issued an apology for this unjust policy in 2001, and Japan sees almost no new leprosy cases these days. The Leprosy Prevention Law wasn't abol-

There is still stigma associated with the disease. Has Japan been able to overcome it?

It is true that leprosy has attracted severe discrimination since the time of the Old Testament. Although leprosy is referred to as a Neglected Tropical Disease (NTD), there isn't any other disease that is accompanied by such stigma. And it is an unfortunate fact that countries still have laws that discriminate on the grounds of leprosy... deny one access to public places... make leprosy grounds for divorce. Japan has worked hard to eliminate discrimination through raising awareness. For example, the idea that leprosy is divine punishment, the result of ancestral wrongdoing or that it runs in the blood quietly permeated Japanese society until around 10 years ago. I would say I think that such notions have largely faded, but I can't say they have disappeared altogether.

Have you accomplished your mission? Is there still work left to do?

There's a Japanese saying that loosely translates as "On a journey of 100 miles, 90 miles is only halfway". My activities have not only been about seeing that people are cured of the disease, but also involve a humanitarian effort to eliminate the prejudice and discrimination that persons affected by leprosy and their families face. For nearly half the UN General Assembly adopted a resolution in 2010 with guidelines for the elimination of discrimination. It was a landmark resolution, and adopted unanimously. But I am still only halfway along this journey.

I will continue to work for the eradication of the disease and the complete elimination of stigma and discrimination for as long as I live.

SHIRYA MOHAN

Outlook

THE NEWS SCROLL

30 JANUARY 2020 | Liv Egholm et al | AFP/GETTY IMAGES

World Leprosy Day: India's efforts to trace leprosy cases still not sufficient, says WHO goodwill ambassador

By Rupesh Datta

New Delhi, Jan 30 (PTI). India may have intensified its fight against leprosy but its efforts to trace cases in the hinterland, particularly people in the mountain areas, are not sufficient, says WHO's goodwill ambassador against the disease Yohei Sasakawa.

A leprosy eradication programme should be included in the school curriculum to ensure widespread awareness about the stigmatic disease, said Sasakawa, who was awarded the Gandhi Peace Prize last year for his fight against leprosy, especially in India.

"India has a huge population and I recognise that its efforts to reach some population groups, like those in the mountains or any the tribal population, are probably not sufficient," Sasakawa told PTI in an interview.

"But relatively speaking I think the measures India is taking against the disease today are the most advanced in the world," the Japanese-based Sasakawa, who is on an India visit, added.

Thursday is World Leprosy Day.

According to the World Health Organisation, India has the highest number of new cases of leprosy in the world annually, followed by Brazil and Indonesia. India reported 135,485 new cases in 2016, which is 63 per cent of the 214,783 new cases reported globally.

India officially eliminated leprosy, an infectious disease caused by *Mycobacterium leprae*, in 2005 by bringing the prevalence rate below 1 in 10,000 of the national level.

Outlook India

Govt making efforts to eliminate sufferings of leprosy patients

New Delhi: The government is making all efforts to make India leprosy-free and eliminate the sufferings of those affected by it, Union health minister Harsh Vardhan said on Thursday.

Speaking at a function to mark Anti-Leprosy Day, Vardhan said it was shocking that over 100 laws, which discriminate against leprosy affected people, exist in the country, adding work has begun to eliminate them.

"It was shocking to learn there are over 100 laws that discriminate against leprosy patients. Process has already started to rectify the system and get rid of those laws. Our government has the heart, soul and mind to deal with these issues. Our PM is committed to deal with such issues and he has a very compassionate heart especially for those suffering from miseries. We will try to eliminate the suffering of



leprosy affected people as early as possible," he said. Last year in his letter to the law ministry, Harsh Vardhan had said, "Even though the disease is now fully curable, it is disturbing to learn that there still exist 108 discriminatory laws against persons affected by leprosy including three Union and 105 state laws." He had urged the ministry to expedite the process and introduction of the Elimination of Discrimination against Persons Affected by Leprosy Bill, which was drafted by the Law Commission of India and annexed in its 256th Report. In the function, the Confederation of Indian Industry signed an MoU with charitable organisation Sasakawa-India Leprosy Foundation with the objective to make the country free of leprosy. PTI

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THE LANCET Infectious Diseases

Volume 20, Issue 4, April 2020, Page 423

Media Watch

From boat racing to the love of leprosy elimination

Yohei Sasakawa, No Matter Where the Journey Takes Me: One Man's Quest for a Leprosy-Free World, C Hurst & Co Publishers Ltd (2019), p. 232, £21.25, ISBN: 978-1787381377

Vijay Shankar Balakrishnan

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The Lancet

THE INDIAN EXPRESS

How people in leprosy colonies are fighting stigma for a life of dignity

How people in leprosy colonies are fighting stigma for a life of dignity

While leprosy is curable and early treatment checks disabilities, the stigma associated with the disease continues to run deep. In 2017, there were 2.1 lakh new leprosy cases registered globally — India accounted for over half of them, according to the National Leprosy Eradication Programme (NLEP).

By: Express Web Desk | New Delhi | Published: December 2, 2019 6:09:13 pm



"I hope my children can now get married outside the leprosy colony," said Anita Kaur, 40, betraying her desire for social acceptance in the mainstream society.

Until 2013, Kaur, and six of his women friends from Tassuapara leprosy colony in Chhattisgarh's Jajpur District would go begging door-to-door. Though she never had leprosy — her parents lived and died with the disease — Kaur could not fight the centuries-old stigma that made her and others like her social outcasts.

Leprosy, a treatable disease, needs to be addressed early

At a recent event, Dr Harsh Vardhan brought attention to the intensification of government efforts to eliminate leprosy in India. This recent focus has been a welcome step, especially as it has been observed that, since 2006, when India achieved elimination of leprosy as a public health concern, the number of new cases has remained stagnant.

Even today, although leprosy numbers are small in comparison to those of other diseases such as malaria, tuberculosis etc, India has not won a decisive battle against the disease. Classified amongst the least infectious of diseases by the WHO, leprosy is now fully curable through antibiotics treatment. Yet its elimination remains a challenge for India.

The need to urgently address this challenge stands out even more sharply if we consider the share of India in the global burden of leprosy. Of the total annual number of new cases worldwide, 2,00,019, India accounts for 1,20,324 new cases resulting in the country being host to nearly 50 per cent of the total world population of leprosy affected people.

In recent years, India has shaken itself out of the complacency into which it had fallen after 2005 when it achieved the WHO defined elimination rate, i.e. less than one new case per 10,000 population. It has given a significant push towards early detection and treatment which is critical to both preventing disability as well as interrupting the transmission of the disease. These efforts are in line with the country's and the WHO's target of zero disability cases and zero child cases. India has undertaken and continues to undertake intensive leprosy detection campaigns in endemic areas where ASHA workers have been given the responsibility of going from house-to-house to find out early signs of leprosy and for bringing the suspected cases into the public health network.

Additionally, the National Leprosy Eradication Programme (NLEP) has introduced an anti-leprosy vaccine, Mycobacterium indicus pranii (MIP), in Gujarat on a pilot mode. NLEP is also trying to introduce this vaccine in Chhattisgarh, again on a pilot mode.

Another innovative approach has been to introduce a prophylactic dose of rifampicin in the contact population of new cases. It has been observed that most cases occur among the contact population of those affected by leprosy, even though the disease is not easily transmitted. There are however differences among experts whether a single dose would really be effective or whether it could lead to a resistance to rifampicin which is also used for treating TB.

The National Leprosy Eradication Programme has also undertaken awareness programs in the endemic areas — breaking myths that surround leprosy and educating people that it is a bacterial disease. The success of the medical program depends on the social perception and understanding of leprosy. The recognition that leprosy is a treatable disease and needs to be addressed early to avoid disability, that those affected become non-infective within 24 hours of starting treatment, of making isolation and exclusion unnecessary and unwarranted; all this will convert leprosy into just another disease in public perception.

Although laudable, government's efforts are likely to fall short in bringing about a radical change in the incidence of leprosy soon. Leprosy has a long gestation period and the benefits can be dominant for as many as seven years or more before the disease manifests itself. The answer, therefore, lies in combining current efforts with awareness building even in the non-endemic areas.

Subsequently, it is important for the government to mount a nationwide campaign to spread awareness about leprosy. The success of an initiative such as this is clear from the learning that in the eighties, the government made a major effort to spread awareness about TB, which helped to change the public perception of the need for isolation in remote areas to provide care within homes.

Finally, there is need to involve civil society and use new technology in this fight. Teachers, students, time data, social media, apps, twitter can all be used to reach out to the remote corners of the country. The battle against leprosy can be won.

The article is attributed by Dr. Vinodha Shankar, executive director, Sasakawa-India Leprosy Foundation

Asian Age

Retail, livestock, farming top 3 preferred professions for leprosy-cured people in India: Retail, livestock and farming top three preferred professions for leprosy cured patients in India, says Sasakawa-India Leprosy Foundation (S-ILF), an organisation which works towards social and economic empowerment of leprosy affected persons & their families. In Andhra Pradesh and Telangana, 37.5% of the leprosy cured patients took farming as the most preferred profession. In Chhattisgarh, 26% of them took livestock as the most preferred profession. S-ILF presented 'Rising To Dignity Awards' at a ceremony in Delhi on Wednesday. S-ILF instituted these awards to recognize the efforts of people affected with leprosy to rise above all odds and live a life of dignity. PTI

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The Times of India (Delhi Late City Edition)

The Hindu Business Line

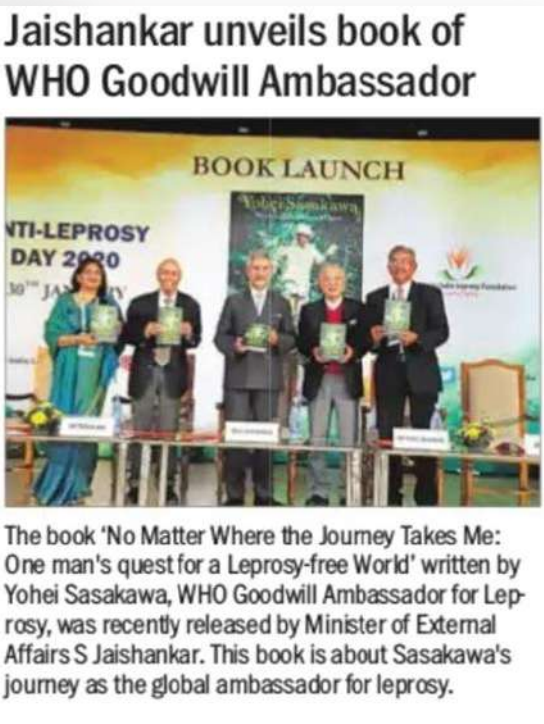
Times of India Late City

The Indian Express





The Hindu Business Line



The Tribune



The Pioneer



UNI




The Pioneer



UNI




# #CreatingHope



**Dr Harsh Vardhan** ✓ @drharshvardhan • Jan 30

महात्मा गांधी जी कुष्ठ रोगियों के प्रति सेवाभाव रखते थे।  
उनकी पुण्यतिथि पर आज दिल्ली में @Sasakawa\_India द्वारा आयोजित  
#AntiLeprosyDay कार्यक्रम में शामिल हुआ आइए संकल्प ले कि #polio  
की तरह इसे भी देश से पूरी तरह बाहर करेंगे व कुष्ठ से पीड़ित व्यक्ति से  
घृणा नहीं,प्रेम करेंगे।






**Dr. S. Jaishankar** ✓ @DrSJaishankar • Jan 30

On #MartyrsDay, released the autobiography of  
@SasakawaYohei who has led the battle against leprosy.  
Appreciate his contribution to a cause so dear to Mahatma  
Gandhi's heart.





**Rajiv Kumar** ✓ @RajivKumar1

Commemorated #MahatmaGandhi' death anniversary by  
attending the Anti- Leprosy Day function organized by  
@Sasakawa\_India Leprosy Foundation.



# #YouAreNotAlone

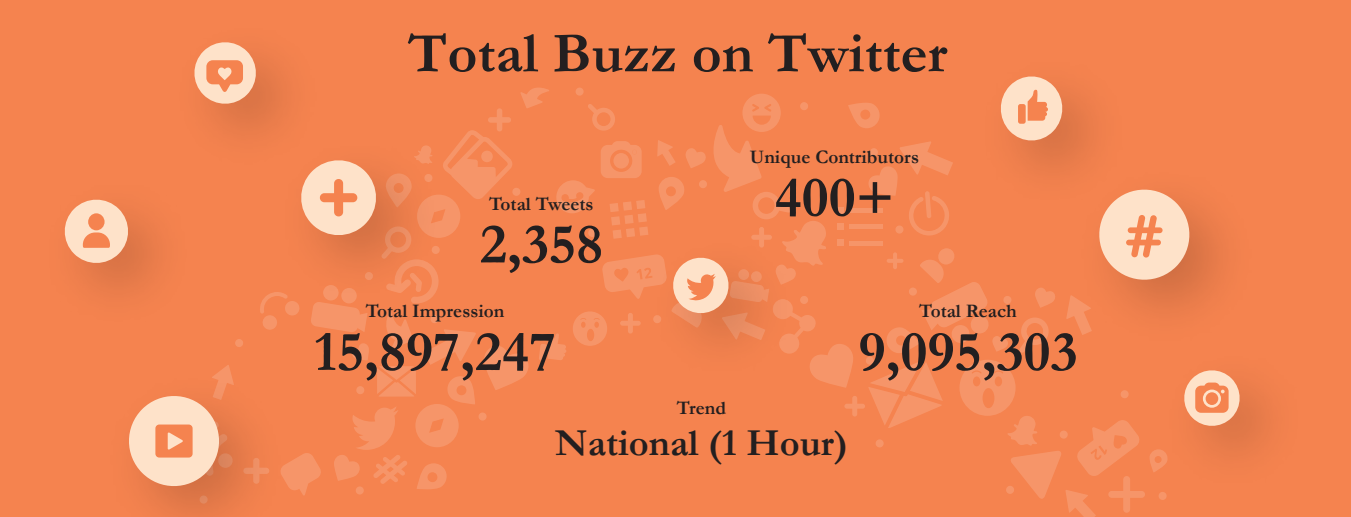


Eminent actress **Ms. Dimple Kapadia**  
in support of **#YouAreNotAlone** campaign  
for leprosy affected persons

The immense effectiveness of the treatment has no better ambassador or icon than India's celebrated very beautiful actress, Dimple Kapadia. She was highly supportive of S-ILF initiated #YouAreNotAlone social media campaign to give persons affected by leprosy (PALs) a sense of inclusiveness; a collective hope for a better tomorrow with a combined strength to fight the disease and the stigma associated with it. Renowned actress Ms. Dimple Kapadia who herself encountered Leprosy at a very early stage in her life was very active in supporting the campaign. Her message to patients affected by leprosy & their families:

“I would urge all patients and their families to come forward and get them treated. Leprosy is not to be feared; it is not contagious and can be treated if diagnosed at the right time. Most importantly remember that you are not alone in this fight. Let us together spread awareness to end the stigma and discrimination against those affected by leprosy and their families.”

S-ILFs #YouAreNotAlone campaign was supported by Mr. John Denton, Secretary General ICC, Dr. Rajiv Kumar, Vice Chairperson NITI Ayog, Mr. Suresh Prabhu, Minister of Commerce & Industry and Civil Aviation to name a few.





# Our team



**Dr Vineeta Shanker**  
Executive Director



**Rakesh Jha**  
Program Head  
(Livelihood & Education)



**Tehseen Zaidi**  
Program Manager  
Communications & Advocacy



**Charu Gaba**  
Program Manager  
Education



**Sanjeev Kumar**  
Program Manager  
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**Ramesh Chandra Pandey**  
Program Manager  
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**Darshan Singh**  
Program Manager  
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**Tanzeel Khan**  
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**Aftab Pasha**  
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**Mohd Zaid**  
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**Ritwik Mahapatra**  
Program Officer  
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**Ruchira Shree**  
Project Officer  
Livelihood



**Nidhi Singh**  
Project Officer  
Education



**Payal Gadhiok**  
Consultant



**Rajni Sharma**  
Finance Lead



**Ram Autar**  
Admin & Account Officer



**Sujatha**  
Krishnamachari  
EA to Executive Director



**Ganesh Dhuriya**  
Office Attendant



## How you can engage:

Each one of us can make a beginning by becoming a brand ambassador to fight the stigma and discrimination against the leprosy-affected and their families. Making the difference will be E.A.S.Y. as you can see:



# Passing the baton



**Dr. Vineeta Shanker**  
ED (till May 2020)

**Dr. Vineeta Shanker** who served as Executive Director of S-ILF since its very inception in 2006, retired in May 2020.

Under her leadership, S-ILF emerged with strength, dedicated to the cause of social and economic rehabilitation of persons affected by leprosy. With great sensitivity and understanding, she crafted strategies and led the S-ILF team to serve the real needs of the community. Her focused approach has enabled effectiveness of our programs and rendered sustainability to our efforts.

The Board of Trustees bid her farewell, with Mr Yohei Sasakawa leading the team in appreciation. We are thankful for her contribution and wish her good luck for her future endeavours.



**Dr. Vivek Lal**  
CEO (June 2020 onwards)

**S-ILF is happy to welcome Dr. Vivek Lal on board as the new CEO. A medical practitioner with specialization in Community Medicine from AIIMS (Delhi), Dr. Lal brings in years of experience working in the field of leprosy and humanitarian services. He has worked earlier as Director Health at German Leprosy & TB Relief Association.**

With his enthusiasm and experience in the field of leprosy, we are confident that S-ILF will rise to newer heights. Amidst the prevailing Covid pandemic, Dr. Lal's experience in humanitarian services will enable us to reach out to the persons affected by leprosy and their family members.





Sasakawa-India Leprosy Foundation  
*Restoring Dignity*

### Sasakawa-India Leprosy Foundation

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