

SWISS EMMAUS LEPROSY RELIEF WORK - INDIA

Annual Report 2022

Together we can fight leprosy and bring smiles to faces of millions.

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Message From Country Coordinator's Desk

Dear Well-wishers,

I'm pleased to connect with you again as we complete another successful year with notable accomplishments. Firstly, I hope your respected families and you are in the pink of health following the prolonged impact of the coronavirus. The experience from Corona taught us a lesson that 'health is true wealth', and simple measures of personal hand hygiene and maintaining reasonable distance



along with sporting a mask could prevent life-threatening conditions such as Corona.

Incessant lockdowns limited our service delivery and people-to-people connection. With the lockdowns being lifted, my team and I were able to travel and meet people affected by leprosy to enquire about their health status. I should applaud the Government of India (GoI) which played a pivotal role in extending care and rehabilitation to people and businesses at a pan-India level. One of the biggest successes has been the continuation of the supply of the needed multidrug therapy (MDT) especially those who are on treatment before the onset of Corona. Government healthcare workers were able to make home visits to care for people affected by leprosy.

I am also very pleased to inform you about a change in guard at the pinnacle of the National Leprosy Eradication Program (NLEP), where Dr. Sudarshan Mandal has taken charge of the mantle of the leprosy program and brings with him decades of experience in TB control program with the Gol. I am very confident his guidance and leadership will pave the way for better care, treatment, and rehabilitation of people that will result in leprosy elimination by 2027.

Swiss Emmaus India was able to extend not just leprosy services but other livelihood support along with corona kits for people affected residing in leprosy colonies. All our hospital services were functional, and people affected continued to receive services at our supported hospitals.

Concerning the Migration in Leprosy project, there has been significant progress since I received the ethics clearance to undertake the pilot study. This resulted in making state visits to develop a definition of a 'migrant' in the leprosy program. State-level consultation was completed which resulted in developing a draft definition of a migrant that will be presented to the NLEP program on completion of the study. I also completed the secondary research on migration and leprosy in India. The highlights of the secondary research were presented at the International Leprosy Congress in Hyderabad in Nov. 2022. During the same congress, I facilitated a panel discussion on 'Migration & Leprosy: Lesson learned from Corona experience'. The discussion highlighted the importance of migrants, who need to be factored into the NLEP program for India to achieve elimination.

On behalf of my board, my people, and my staff, I take this opportunity to wish you tidings for the New Year and I look forward to our very valuable exchange.

Thank you,

Sincerely,

(Mr. John Kurian George)

Program Component for ANNUAL REPORT-2022

The program highlights of 2022

The multi-faceted country program of Swiss Emmaus India on one hand compliments the National Leprosy Eradication Program (NLEP) at the national and state levels, while on the other strengthens the three-tier service (primary, secondary, and tertiary care) provision system on the ground.

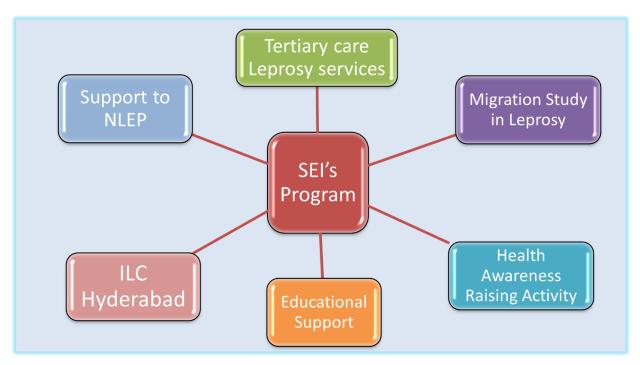
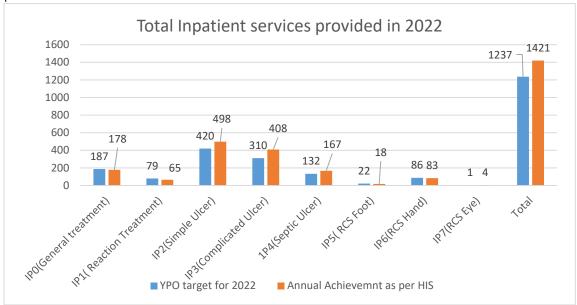


Figure 1: SEI's program profiles

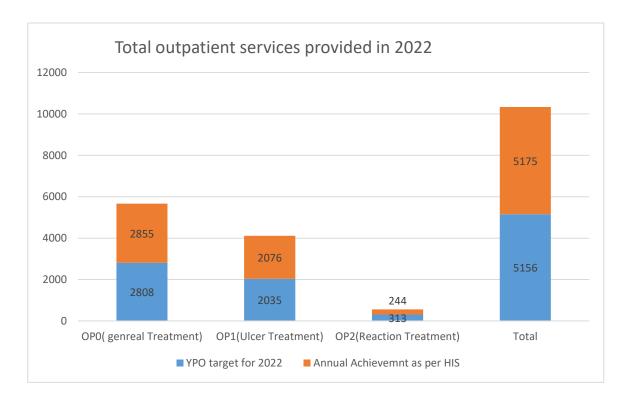
The Tertiary care leprosy services:

The tertiary care in leprosy is of immense importance in influencing the lives of people with deformity due to leprosy. While it is important to prevent the deformity, it is also important to prevent the worsening of existing deformity and prevention of secondary impairments like joint contractures in claw hand or ulcer occurring in an anesthetic foot. Swiss Emmaus India works mainly in collaboration with the Central and State Governments in the Leprosy Control Program in partnership with local NGOs. SEI has its presence in 3 states namely Andhra Pradesh, Karnataka, and Tamil Nadu supporting 5 tertiary care hospitals (3 in Andhra Pradesh, 1 each in Tamil Nadu and Karnataka states respectively) which are recognized by the Central Leprosy Division, Government of India. These centers provide both In-patient and Out-patient services to people affected by leprosy.

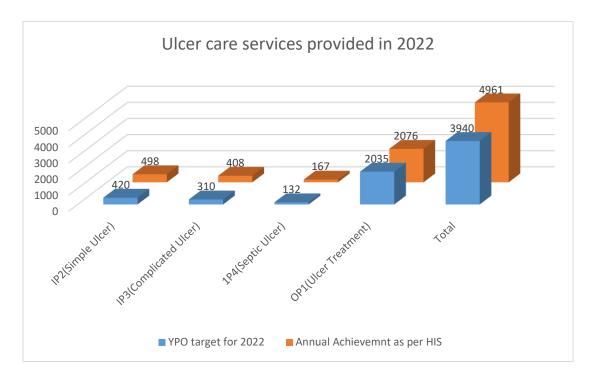
Graph-1: Total in-patient services provided in 2022: 114.87% (1,421 services out of 1,237 that were targeted) of the total in-patient services were rendered despite the covid pandemic as the hospitals reached out to the community for uninterrupted service provision.



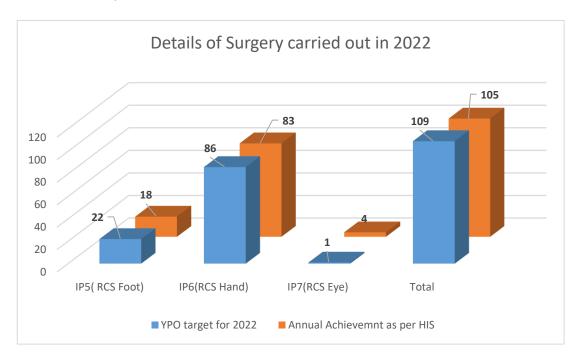
Graph-2: Total outpatient services provided in 2022: The total number of outpatient services provided was 5,175 as against the annual target of 5,156 thus recording 100.36% of achievement.



Graph-3: Ulcer care services rendered in 2022: Ulcer care services are basically delivered as in-patient and out-patient categories. A total of 1,073 in-patient ulcer care services were provided out of 862 as target and 2,076 services were provided as out-patient category from a target of 2,035 in 2022.



Graph-4: Reconstructive surgeries carried out in 2022: Due to the COVID-19 pandemic, the total number of reconstructive surgeries carried out was 105 against the annual target of 109. Out of the total surgeries, 83 (79%) surgeries were on hand and the rest 22 (21%) were on foot and eye.



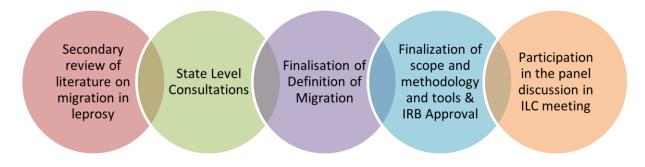
A study on Migration and Leprosy in four states in India:

Leprosy continues to exist in parts of the world, even though it has been eliminated as a public health problem. A large number of leprosy cases continue to be identified mainly in large parts of South-East Asia, namely India, Indonesia and in Brazil. Migration facilitates movement of disease between endemic and non-endemic areas and has been considered a possible factor in continued leprosy incidence. A review analysis of published studies¹ in PubMed and news articles related to migration in leprosy, identified migration as one of the important obstacles in achieving elimination of leprosy as the affected individuals may continue to spread the disease unknowingly and themselves may suffer from disabilities with social consequences.

With a goal to undertake a three-year pilot study to understand the impact of migration among people affected by Leprosy and its consequences on treatment and other health seeking behaviour in four states (Source states: Bihar and Uttar Pradesh and destination state/UT: Chandigarh and Delhi) in India, Swiss Emmaus India launched this study in the year 2021 in collaboration with multiple stakeholders. They are the National Leprosy Elimination Program, Govt of India, WHO, ILEP, SILF, IAL and the Association of People with Leprosy.

The project proposes to develop a 360 degree understanding of the issues surrounding migrant patients and their households, including the demand, supply as well as process aspects of the health care provision at the source of migration, along the routes of migration, and at the destination of migration. Based on the understanding of the gaps that exist for leprosy patients who migrate, the project envisages developing recommendations at all levels to address these gaps. Further, the project will develop a technology-enabled national-level management information system (MIS*) framework for location-based tracking of migrant leprosy patients and their households in India through the life cycle of the disease.

In the 2nd year of its journey, although Covid had an impact on the ongoing activities, the project was able to manage accomplishing the key activities till the end of the year.



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 $^{^{}m 1}$ Impact of Migration on Epidemiology and Control of Leprosy 1 2 3 S Rathod , A Jagati , P Agarwal



Figure 3: Meeting with WHO SEARO team

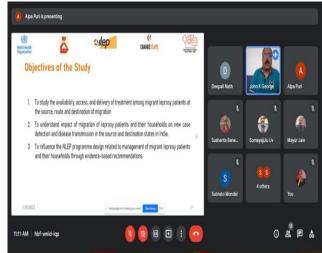


Figure 4: Technical Task Force meeting in progress

The activities to be carried out in 3rd year

Activities for 3rd Year

- Pilot data Collection
- Revision of Tools and Research Module
- Ethical Board Approval
- Main Data Collection
- TTF and National Level Consultation
- Dessimination of the Research Outcome and Final Recomendation to Govt. of India

Figure 5: Activities to be carried out in year 3

Participation in ILC-Hyderabad 2022:

A delegation from Swiss Emmaus India represented at the International Leprosy Congress(ILC), Hyderabad in 2022 and

- Presented e-poster titled "Study on Migration and Leprosy in 4 states in India(Bihar, Chandigarh, Delhi, and Uttar Pradesh)"
- Organisation of a symposium on Leprosy and Migration, coordinated and chaired by John Kurian George.
- John Kurian George Presented a paper on "Migration and leprosy Control-Challenges and possible solutions" as lead speaker, Chaired by Bijoy Kumar Swain.



Figure 6: John K George chairing and coordinating a special symposium on Leprosy and Migration

> John Kurian George chaired a session on "Capacity building and Others"

Health Awareness Activity:

Leprosy continues to be a public health concern primarily because of its potential to cause physical disability, social stigma, and discrimination, even for those who have been cured completely.

It is critical to note that for several years, the number of new cases globally has plateaued at about 200,000 per year, a troubling statistic that he attributed in part to a lack of awareness among public health bodies as well as people affected by the disease. During 2022, **174 087 new cases** were reported globally, this represented an increase of 23.8% over that in 2021 (140 594). The occurrence of new leprosy cases among children is an indicator of recent transmission. A total of **10 302 new child cases (5.9% of total new cases)** was reported globally. Most of the child cases were reported from SEAR (70.1%) with a child case detection rate of 14 per million child population. The rate of detection of child cases increased by 14.6% over 2021 (8991 cases), the increase being most marked in SEAR (27.4%). India contributed 59.63% of global leprosy burden, reported 103,819 new cases, where as 174,087 new cases were detected globally².

he social stigma attached to leprosy is a barrier to early detection of the disease, which is the key to slowing its rate of transmission. This happens because, on the one hand, patients are unaware of medical help available to them, unwilling, or otherwise unable to seek treatment due to stigma; and on the other, a lack of expertise and resources on

² No 37, 2023, 98, 409–430 http://www.who.int/wer

the part of public health departments due to a misunderstanding of the persistence of the disease.

Increasing awareness of the continuing existence of Hansen's Disease (leprosy) is critical to sustain effective public health efforts against the disease, eliminating the social stigma associated with it, and halting its transmission. Swiss Emmaus Leprosy Relief Work India started its Heath awareness activity in 2008, with an objective to sensitize the public about Leprosy and to minimize stigma.

Swiss Emmaus India used a dual approach in raising the awareness



Figure 7: Staffs of Swiss Emmaus India ready for awareness raising activity

among people, one by meeting people in public places and sensitizing them on leprosy. These places are generally the commercial locations, Railway/Metro stations, shopping malls, Banks and Tech Parks etc. The other one through direct calling and sensitizing on leprosy. In both the cases SEI takes the consents of the person/people before the activity.

Swiss Emmaus India and its implementing partners actively participate and sensitize people on leprosy during the Sparsh Leprosy Awareness Program, Leprosy Case Detection Campaign (LCDC) initiated by the National Leprosy Eradication Program by the MoH, Govt of India.

Table 1: Table-1 shows the population covered from different awareness raising activities

Population Covered through Awareness Raising Activity			
Mode of Awareness Raising	Number of people sensitised		
One to One meet	1,58,80,000		
Mobile Calling	30,00,000		
Sparsh Awareness Program	42,36,031		

Keys messages:

- Leprosy is curable 100% with MDT (multi-drug therapy) and is available at every PHC free of cost.
- Multi-drug therapy taken regularly ensures a complete cure of leprosy, prevents deformities, and stops transmission to other individuals.
- Early diagnosis, appropriate treatment, and completion of the full course will prevent disability due to leprosy.
- Leprosy is not hereditary; it does not transmit from parents to children.

- Leprosy does not spread through casual touch like shaking hands playing together
 or working in the same office. Close and frequent contact with untreated cases
 favor the spread.
- Leprosy is not the result of past sins or immoral behavior. It is caused by a bacterium called Mycobacterium leprae.
- People affected by leprosy have the right to livelihood and the right to live with dignity.

Educational support for children with Leprosy or children from affected families:

Stigma and leprosy are two sides of a coin and go hand in hand. Children either affected by leprosy or from an affected family usually face a high degree of stigma in the educational journey and often drop out of school. Swiss Emmaus India facilitates educational sponsorship programs for these students in the schools managed by its project partners. The scholarship was provided for both primary and secondary school education. This scholarship includes hostel charges, Food, School fees, Books, Uniforms Transportation facilities, etc. Currently, 56 children are being supported in fulfilling their educational dreams.

The children who sought scholarships are mostly recommended by the head of the village and then the school authorities make the final decision based on the availability of vacancy.



Figure 8: Preparation for board examination for the students

Supporting the Central Leprosy Division (CLD), Government of India (Gol):

Swiss Emmaus India as an ILEP (International Federation of Anti-Leprosy Association) agency coordinating the leprosy control program in Haryana, Punjab, and Chandigarh by placing a NLEP consultant, based **on mutually agreed upon terms between Swiss Emmaus India and Central Leprosy Division. Mr. Bijoy Kumar Swain**, the Program Manager

from Swiss Emmaus India has been assigned to the states of Haryana, Punjab, and Chandigarh as a NLEP consultant.

In the year 2022, the support to the state of Haryana State NLEP are as follows;

- a) Support the state office in compiling the Action taken report for NHRC.
- b) Discussion on actions taken for repealing the discriminatory laws.
- c) Planning of Training for Medical Officers in the state.
- d) Participation and facilitation of District Leprosy Officer's Training.
- e) Participation and facilitation of District Leprosy Officer's Training on LCDC. Supportive supervision to districts during LCDC.

In the year 2022, the state NLEP of Haryana organized a 3 day training for the District

Leprosy Officers in Panchkula in collaboration with RLTRI, Raipur from 17th may till 19th May 2022. As many as 25 participants from 21 districts participated in the training and Mr. Bijoy Kumar Swain in the capacity of the ILEP-supported state consultant facilitated the training.

The state scheduled a 14-day Leprosy Case Detection Campaign from 6th October till 19th October in 6 high



Figure 9: Trainer from RLTRI during the training

endemic districts namely Gurgaon, Faridabad, Ambala, Panipat, Karnal, and Jhajjar of Haryana state. The training for the District Leprosy Officers was scheduled for the 26th of August 2022 at Gurgaon.

Mr. Bijoy participated in the training and discussed various aspects of LCDC especially the guidelines, reporting, and monitoring by different health cadres during the campaign. He also visited 3 districts namely Gurgaon, Faridabad, and Jhajjar as a part of his supporting supervision to the districts during the campaign and helped the district authorities to take appropriate measures wherever required.

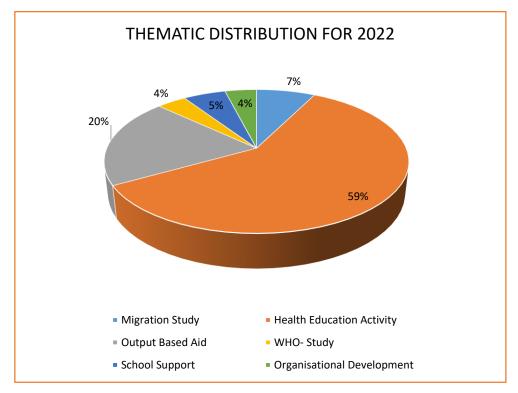
Financial Reports

Partnership & Thematic Utilisation of Funds in the Year 2022

Swiss Emmaus Leprosy Relief Work India implements its programs through Partner NGOs (Non-Governmental Organisations). In 2022, Swiss Emmaus Leprosy Relief Work India has engaged local NGOs to implement its 6 core Programs:

- a) Output Based Aid (OBA)
- b) Schools Support
- c) Migration Study
- d) Health Education Activity
- e) WHO Study
- f) Organisational Development

Graph-5: Thematic Utilisation of funds in the year 2022

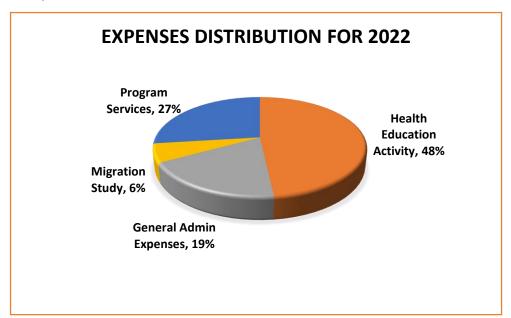


Deployment of Funds

Swiss Emmaus Leprosy Relief Work India always makes an effort to minimize its administration cost, to maximize the support to Programs, and the same was replicated during the year 2022.

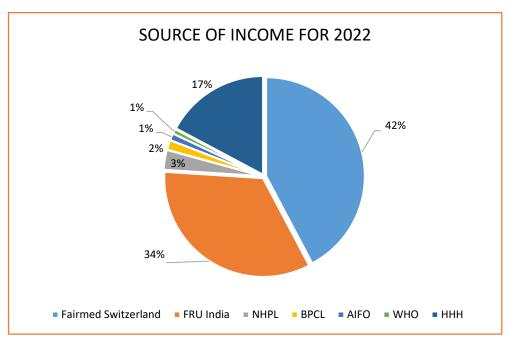
In the year 2022, 33% of the funds were deployed towards program implementation including the migration study, 48% of the funds were utilized under Health Education activity, and 19% of the funds were utilized for general administration purposes.

Graph-6: Expenses 2022



Source of Income

During the year 2022, Major source of Income i.e. 34% was generated locally by FRU India, 42% of the funds were received from HQ, Switzerland (FC funds) 3% of the funds from NHPL, and 17% of its fund were received from Hubli Hospital as corpus fund. Graph-7: Source of Income 2022



Acknowledgments

Swiss Emmaus India expresses its heartfelt gratitude to all donors, friends, and well-wishers who have not only recognized our efforts but have also made meaningful contributions towards our mission of eliminating Leprosy and addressing poverty-related illnesses. We extend sincere thanks to the dignitaries in FAIRMED, Bern, Switzerland, for their timely financial support and valuable guidance. Our appreciation also goes to the Government of India at the Central, State, and District levels for their essential support to our cause. We would like to acknowledge and express deep gratitude to our partners who diligently implement projects and activities with sincerity and professionalism. Lastly, we extend sincere thanks to our trustees, colleagues at the Central Office, and the resource mobilization office for their continuous guidance and motivation, driving us to serve our mission with even greater dedication.

Abbreviations

- TB: Tuberculosis
- ILEP: International Federation of Anti-Leprosy Organizations
- IP: In-patient
- OP: Outpatient
- SEI: Swiss Emmaus Leprosy Relief Work India
- WHO: World Health Organization
- OBA: Output Based Aid

SEI Project Map

