



SWISS EMMAUS LEPROSY
RELIEF WORK - INDIA

ANNUAL REPORT 2023

From the Director's Desk

Dear Well-wishers,

It is a pleasure to inform you about the developments in 2023, where Swiss Emmaus Leprosy Relief Work India (SEI) further committed itself towards accelerating in reaching out to the last case of leprosy.



SEI developed a new program strategy where we were keen to be closest to the action and be in the forefront to reach out to the last case of leprosy. While supporting medical rehabilitation of people through our supported leprosy hospitals, it was important to take learnings from implementing our field-based prevention of impairment and disability (POID) projects to design and implement a new field-based project in Durg District, Chhattisgarh, that significantly contributes to the new cases of leprosy nationally. 'Aagaaz' meaning the beginning and end of leprosy in Durg District is a community-based project that envisions a wholistic approach to empower people affected by leprosy in Durg District.

Prior to embarking on the project, two key activities were carried out, namely, the needs assessment of the project site along with developing a state plan involving the stakeholders. The inputs from the needs assessment formed a vital platform while developing the state plan for the Aagaaz project, which is designed as a model project that can easily be scaled and replicated across other endemic states in India.

SEI was also involved in the development of the Government of India's National Strategic Plan (NSP) for the National Leprosy Eradication Program (NLEP) in 2023. Hence, while the sustainable development goals (SGD) have committed to eliminating leprosy from India by 2030, which India is a signatory, the NSP has pegged an even ambitious target of eliminating leprosy by 2027. Two focus areas for the NSP includes more intense efforts in endemic blocks and districts. In addition, migrants were another important focus area where SEI's study on migration and leprosy in India provided the much-needed insights into this aspect for the NLEP program to adapt and incorporate.

The migration and leprosy project completed a few key milestones including designing and finalizing the definition for a 'migrant' in India. Secondly, the primary data collection was initiated after seeking an ethics approval from the Institutional Review Board (IRB). Both these key outputs will hold the research team in good stead to successfully complete the research study next year by March 2024.

While we come close to another productive year, 2024 holds some very exciting developments that SEI team and I are looking forward to. This includes the successful implementation of the Aagaz project along with designing a new community-based project in another endemic district in India.

On behalf of my people affected by leprosy along with my board members and my team, I take this opportunity to thank you for your continued support. It has helped me to reach the unmet needs of people affected by leprosy.

I take this opportunity to thank you and look forward to updating you in the coming year as well.

Thank you

Sincerely,

A handwritten signature in blue ink, appearing to read 'John Kurian George', is written on a light-colored rectangular piece of paper.

(John Kurian George)
Executive Director
Swiss Emmaus Leprosy Relief Work India

Projects: A Glance

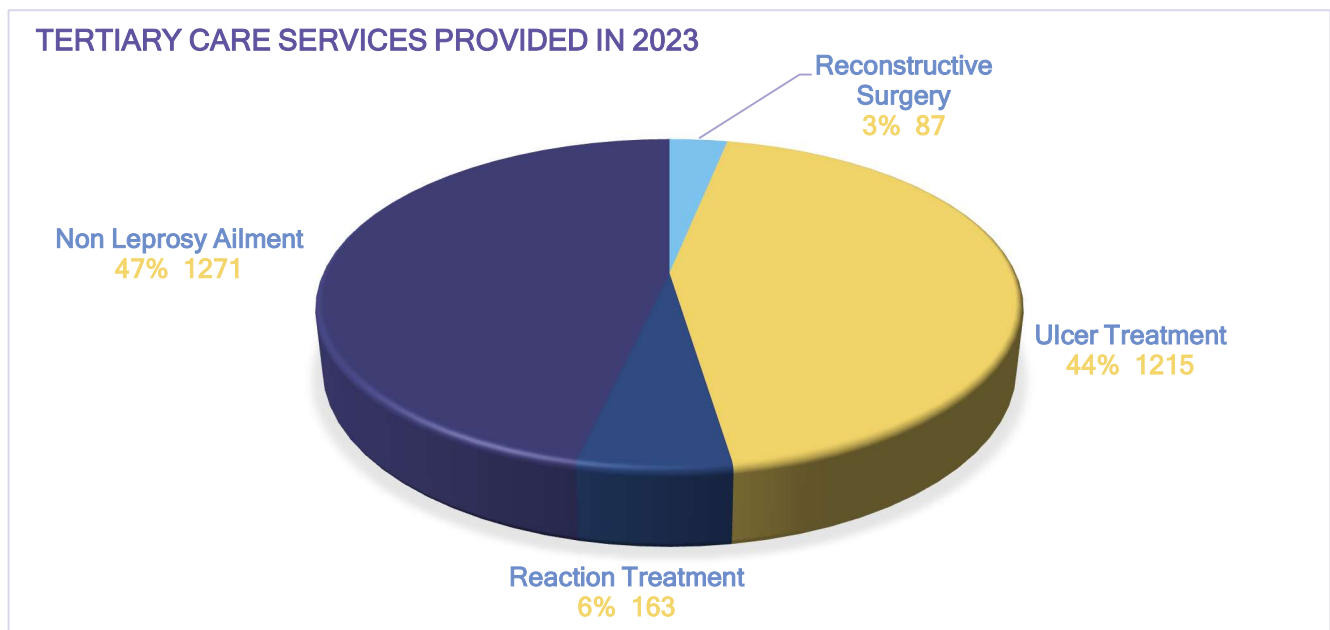
Tertiary care leprosy services

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 deformity, it is also important to prevent the worsening of existing deformity and prevent 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. These centers are recognized by the Central Leprosy Division, Government of India and provide both In-patient and Out-patient services to people affected by leprosy.

During 2023, our hospitals have cumulatively provided services to 2,736 people affected with Leprosy from our designated project area across 12 districts in 4 states. Among them, 87 reconstructive surgeries were conducted successfully, provided ulcer treatment to 1,215 people, 163 cases were treated for reaction, 1,245 and 1,271 leprosy patients were treated for non-leprosy related ailments.

Additionally, 1245 pairs of MCR footwear were provided to people affected by leprosy.



Graph 1: Graph showing both in-patient and out-patient services provided in 2023

A study on migration and leprosy in India

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 like the National Leprosy Elimination Program, Govt of India, WHO, ILEP, SILF, IAL and the Association of People with Leprosy.

As 2023 is the third year of the study and one of the productive years as the study developed the tools, the research module, received the approval from the Ethical board for the study, completed the main data collection, finalise the draft definition of “Migration in the context of Leprosy” and the like.

The definition of migration in the context of leprosy has been agreed and finalized in the technical task force meeting as;

- ✓ Person* who migrates from one location to another location temporarily or permanently–irrespective of district/state and place of diagnosis.
- ✓ A person affected by leprosy who moves outside his place of residence to another district/state for purposes of treatment ** and management of conditions caused during treatment.

*Men, women, transgender, children, also includes contact/cohabitants

** includes MDT, disability care, etc.

The team revised the tools and research module for the final data collection and got the approval from the ethical board Sigma (Institutional Review Board, New-Delhi).

Definition of a 'Migrant'

Chandigarh	Delhi	UP	Bihar
Person* affected by leprosy who move from their place of origin (source) to another location (destination/transit locations) – irrespective of district/state/country	Persons* who move from their place of origin (source) to another location (destination) – irrespective of district/state/country	Person* affected by leprosy who move from their place of origin (source) to another location (destination/transit locations) – irrespective of district/state/country	Person* affected by leprosy who move from their place of origin (source) to another location (destination/transit locations) – irrespective of district/state/country
Person who travel for treatment/care purpose to another location and stay there till partial/fully treated	Person who travel for treatment/care purpose to another location and stay there till partial/fully treated	Contacts/cohabitants of Persons Affected By Leprosy who move from their place of origin (source) to another location (destination/transit locations) – irrespective of district/state/country irrespective of place of diagnosis	Contacts/cohabitants of Persons Affected By Leprosy who move from their place of origin (source) to another location (destination/transit locations) – irrespective of district/state/country irrespective of place of diagnosis

*Men, women, transgender, children

Participants in the meeting: Deepali Nath (She/Her), Bijoy Kumar Swain, Maya President APAL, John Kurian George, Srilekha Perina, Alpa Puri, Sunil Modali, Sujal Suneetha – IAL.

Photo 1: TTF meet for finalising the definition of leprosy and tools & research module

Sigma-IRB (Institutional Review Board)
(A Division of Sigma Research and Consulting Pvt Ltd)
C 23, South Extension I, First Floor
New Delhi-110049
t (+91 11) 41063460
www.sigma-india.in
CIN No: U74140DL2008PTC182567
IRB REG No: IORG0008260

APPROVAL LETTER

Date: 14.11.2023

Name of Applicant : Mr John Kurian George
Name of PI : Mr John Kurian George
Name of Co PI : Dr Sudarshan Mandal, Dr Rita Chaudhary, Dr Manjeet Pal, Ms Deepali Nath, Mr Bijoy Kumar Swain, Ms Alpa Puri

Name of Organisation : Swiss Emmaus Leprosy Relief Work – India

Study Title : Migration and Leprosy - Pilot Study in 4 States of India

IRB Number: 10065/IRB/23-24

Date of Virtual Meeting of IRB : 21.10.2023

Final set of Documents Reviewed for Approval : 14.11.2023

Document	Version No	Date	Remarks if any
Sigma IRB Review Application	2	03.11.2023	
Study protocol	2	03.11.2023	
Study tools	2	01.11.2023	
Consent forms	2	01.11.2023	
IRB meeting minutes	2	01.11.2023	

This is in continuation to the submission of documents followed by virtual meeting of the IRB and submission of revised set of documents.

I am pleased to inform you that the above mentioned study has been approved by the Sigma IRB .

All research activities must be conducted in accordance with the approved submission. It is your responsibility to fulfill the following requirements of approval:

- Changes, amendments, and addenda to the protocol, informed consent, or other study materials must be submitted to the Sigma-IRB for re-review and approval prior to implementation.
- Any unanticipated problems, adverse events, protocol violations, social harm, or any new information becoming available which could change the risk-benefit ratio must be reported to the Sigma-IRB.

The Sigma-IRB concluded that the Applicant has taken sufficient safeguards to carry out the study. The Sigma-IRB approves the proposal for conducting the aforesaid study. This approval is based on your revised submission of application, study protocol, tools and consent forms and any deviation from this protocol would require further approval of IRB. This is valid for one year from the date of approval, mentioned geographical location and presented sample. After the completion of the study, please submit the study report to Sigma-IRB

Signature: _____
Dr U V Somayajulu (Member Secretary of Sigma-IRB)

Date: 14.11.2023

Signature: _____
Mr John Kurian George

Date: 14.11.2023

Photo 2: IRB approval from Sigma

The team completed the main data collection in three states in Delhi, Chandigarh and Uttar Pradesh and collected data in both quantitative and qualitative mode.

Sample Covered – for quantitative study

State	Total Migrant Patients*	Total Patients Invited by Health Facility	Patients currently on treatment interviewed	Achievement (%)	HH-F2F+ telephonic	FLW	PRI
Delhi	410	514*	349	68.0	193	9	9
Chandigarh	113	63**	47	75.0	28	2	2
UP					15	24	24
	523	577	396	69.0	236	35	35

Table 1: Details of quantitative data collected

Sample Covered – for qualitative study

Respondent Category	Target	Completed	Achievement (%)
Patients currently on treatment and migrant – case study	12	9	75
RFT and defaulters – case study	12	13	108
ILEP partners functionaries at the state/district level	3	3	100
District leprosy officials (high-endemic districts)/doctors at district hospitals/other tertiary care hospitals/state level health officials (SLO/other staffs like NMS)	22	18	82
Private-sector doctors/Traditional medical practitioners*	25	4	16
Medical officer at Primary Health Centre/Municipal Hospital*	34	21	62
Total	108	68	63

Table 2: Details of qualitative data collected



Photo 3: Photographs showing data collection in different states

Key action points of the study

The preliminary report of the study managed to identify eleven key points of importance for the Government of India to include in its National Leprosy Eradication Program.



Photo 4: Key action points from the study

Aagaaz, beginning of end of Leprosy Project in Durg district of Chhattisgarh state

Aagaaz is a new beginning to the end of leprosy in Durg district in Chhattisgarh. The project brings together people, influencers, service providers, politicians, academicians together to create an ecosystem that pushes forward to ensure that every person with leprosy is diagnosed, provided with medicines, and treated with the highest level of dignity and respect that every human deserves. The project envisions creating a model that can be replicated in the state and the country to eliminate Leprosy.

Aagaaz targets the most neglected and vulnerable groups, those affected by leprosy and potentially other neglected tropical diseases (NTDs), disabled individuals, tribals, migrants, women, and children in the Durg district of Chhattisgarh.

Prior to the implementation of the project, the SEI team developed a concept note and shared it with different stakeholders and followed by carrying out a rapid need assessment of the community and developed the project document.

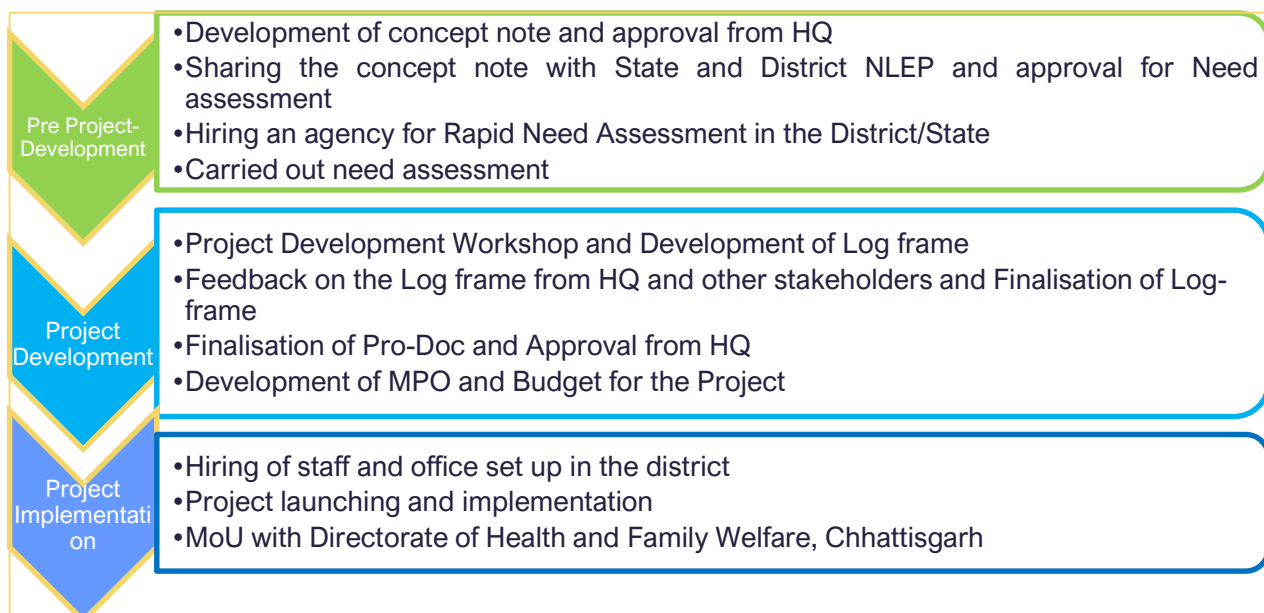


Photo 5: The phases of the project development

The Need Assessment

The rapid health needs assessment used a mix-methods design (Qualitative & Quantitative) and primary and secondary data available in the public domain and from the NLEP program. There were 44 respondents in total that include the NLEP officials at state & district, RLTRI, WHO, SHRC, ILEP, APAL, CVM, Medical Officers, *mitanin*, people's representatives etc. who were interviewed and shared their inputs.

The key areas of enquiry for the rHNA were:

- Trends in leprosy and other NTDs
- Gaps and challenges in access to quality services for leprosy patients.
- Priorities for the government, communities, and other stakeholders
- Potential project partners and opportunities for collaboration
- Possible synergies with government departments and programs other than health.

The gaps and challenges in the service delivery system prominently reflected from the need assessment are:

- Health Service Delivery: Supporting NLEP integration into general health system,
- Community Awareness: Absence of communication materials, job-aids, systematic planning and implementation,
- Strengthening monitoring, reporting, and supervision of NLEP at all levels,
- Access to social security schemes,
- Training & capacity building

Project Planning and Development Workshop

Based on the outcome of the need assessment, SEI organized a three-day project planning and development workshop in Raipur where representatives of all the stakeholders participated and contributed to the development of the project.

The project is designed to be implemented in partnership with National Leprosy Eradication

Programme (NLEP) Chhattisgarh. The project will also collaborate with other key stakeholders like Regional Leprosy Training and Research Institute (RLTRI) at Raipur (under Ministry of Health and Family Welfare, Govt. of India), State Health Resource Centre (SHRC) at Raipur (Under Ministry of Health and Family Welfare, Govt. of India), Chhattisgarh state World health Organization (WHO) unit, International Federation of Anti-Leprosy Associations (ILEP), Association of People Affected by Leprosy, and Chhattisgarh Viklang Manch.

Aagaaz aims to integrate and improve support systems. It enhances leprosy healthcare quality, raises community awareness with an emphasis on wider acceptance and inclusion, and broadens access to social security for those affected by leprosy, their families, and individuals with disabilities.



Photo 6: Participants during project planning

The project is designed with the following impact and outcomes.

The impact would be improved leprosy health outcomes and well-being of communities in Durg district of Chhattisgarh state in India through health system strengthening and community development.

The outcomes are:

Outcome-1: Improved quality of comprehensive health services for leprosy through general healthcare services

Outcome-2: Improved awareness of community about leprosy, with special focus on stigma reduction and inclusion

Outcome-3: Improved access to social security schemes for persons affected by leprosy, their household and other persons with disabilities

Outcome-4: Improved NLEP program monitoring and reporting systems for improved program implementation

Glimpse from need assessment



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

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. 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.

Leprosy Case Detection Campaign:

Haryana state organised leprosy case detection campaign in 6 endemic districts of the state from 1st of May till 14th of May 2023. Mr. Bijoy Kumar Swain in coordination with the state and district leprosy office carried out a supportive supervision of 2 CHCs and 2 PHCs namely Pataudi, Farukh Nagar, Ali Mandi and Sheetla colony of Gurugram district.



Photo 7: Supervision of LCDs in Ali Mandi PHC

He along with the district leprosy officer visited and suggested the following:

- Active surveillance in the catchment area of Pataudi CHC,
- Made necessary corrections in the reporting and clarified the doubts of the staffs in Ali mandi PHC and Farukh Nagar CHC,
- ANMs to monitor the work being carried out by ASHA, in no case ASHA should examine the suspects in the Sheetla colony UPHC.

Training cum Review meeting of DLOs: Haryana state organised a training for the DLOs and MOs from 13 districts from 3rd October to 5th October 2023 at the state training institute,

Panchkula. A total of 38 participants from these districts participated in the training. A team of 3 trainers from RLTRI attended and trained the participants. Mr. Bijoy Kumar Swain, the ILEP supported consultant took a session on LCDC.



Photo 8: Bijoy K Swain during the training session on LCDC

Development of State Strategic Plan and Roadmap to eliminate Leprosy: Central Leprosy Division (CLD) under the Ministry of Health & Family Welfare Govt of India, WHO and

ILEP along with participation of the National Leprosy Eradication Programme (NLEP) partners, experts and representatives of persons affected by leprosy have drafted the National Strategic Plan and Roadmap for Leprosy 2023-2027 for moving towards achieving interruption of transmission of leprosy in India in line with the WHO Roadmap for Neglected Tropical Diseases 2021-2030 and Global Strategy 2021-2030. Mr. John Kurian George, the executive director of SEI was a participant and contributed to the drafting of the National plan in 2023.

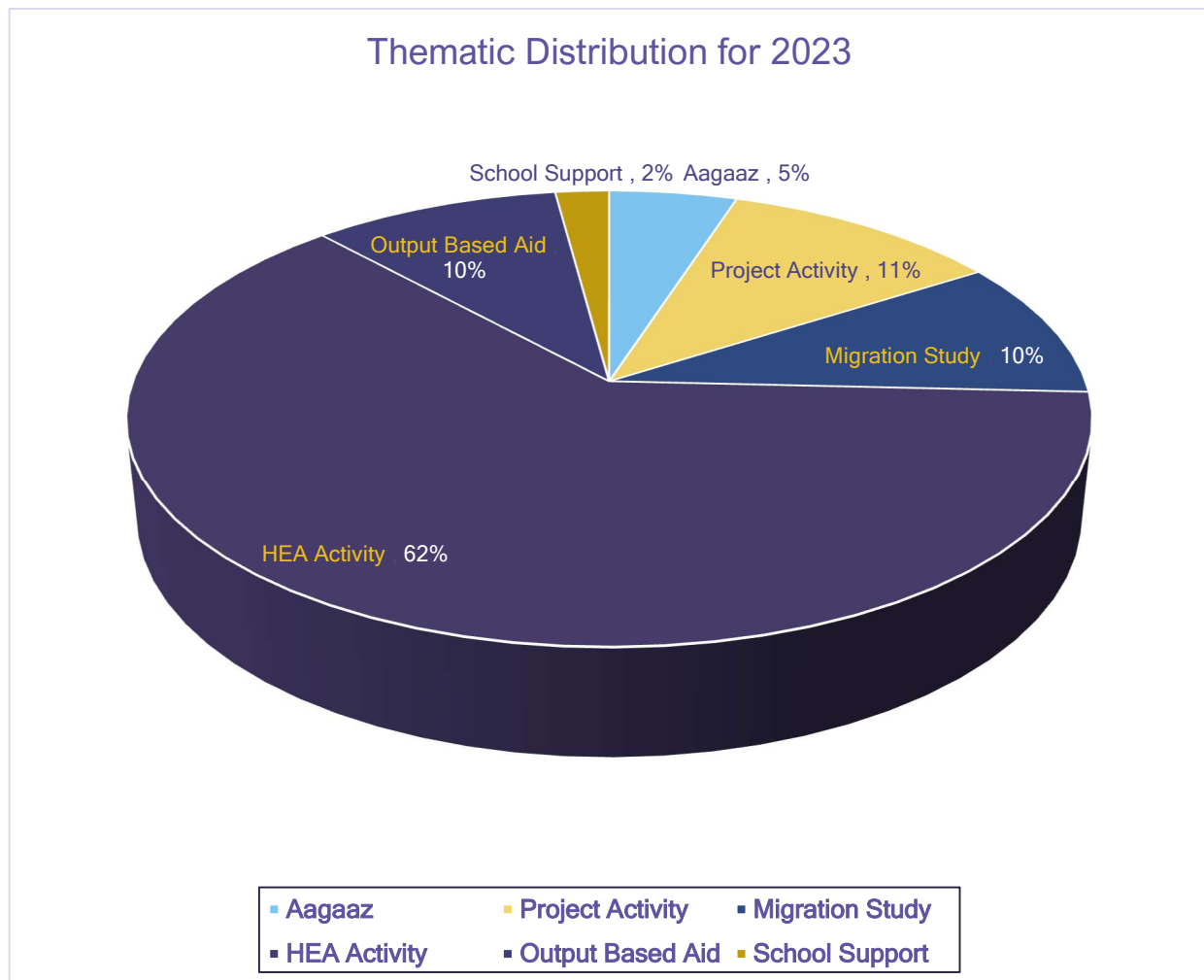
The National Strategic Plan and Roadmap for Leprosy targets to achieve complete elimination of the disease from the country by 2027. The roadmap also highlights key impediments which needs to be strategically addressed to achieve elimination, these include delay in detection, low level of community awareness, human resource shortage, limited lab and diagnostic availability, weak monitoring and surveillance system, limited engagement with partners and stakeholders, antimicrobial resistance, stigma, etc.

Swiss Emmaus India being the NLEP coordinator for the state of Haryana and Chandigarh in steering the process of developing the State specific Strategy and Roadmap to eliminate leprosy by 2027. The state level authorities will be engaged in a two-day workshop for the development of their respective plan and get it approved from the state NHM and then submit to the Central Leprosy Division. This will also allow the state to direct necessary directions and action plan to the high endemic districts and blocks of the state to amend the plan to achieve elimination at state and national level.

Fund Utilization: A Glance

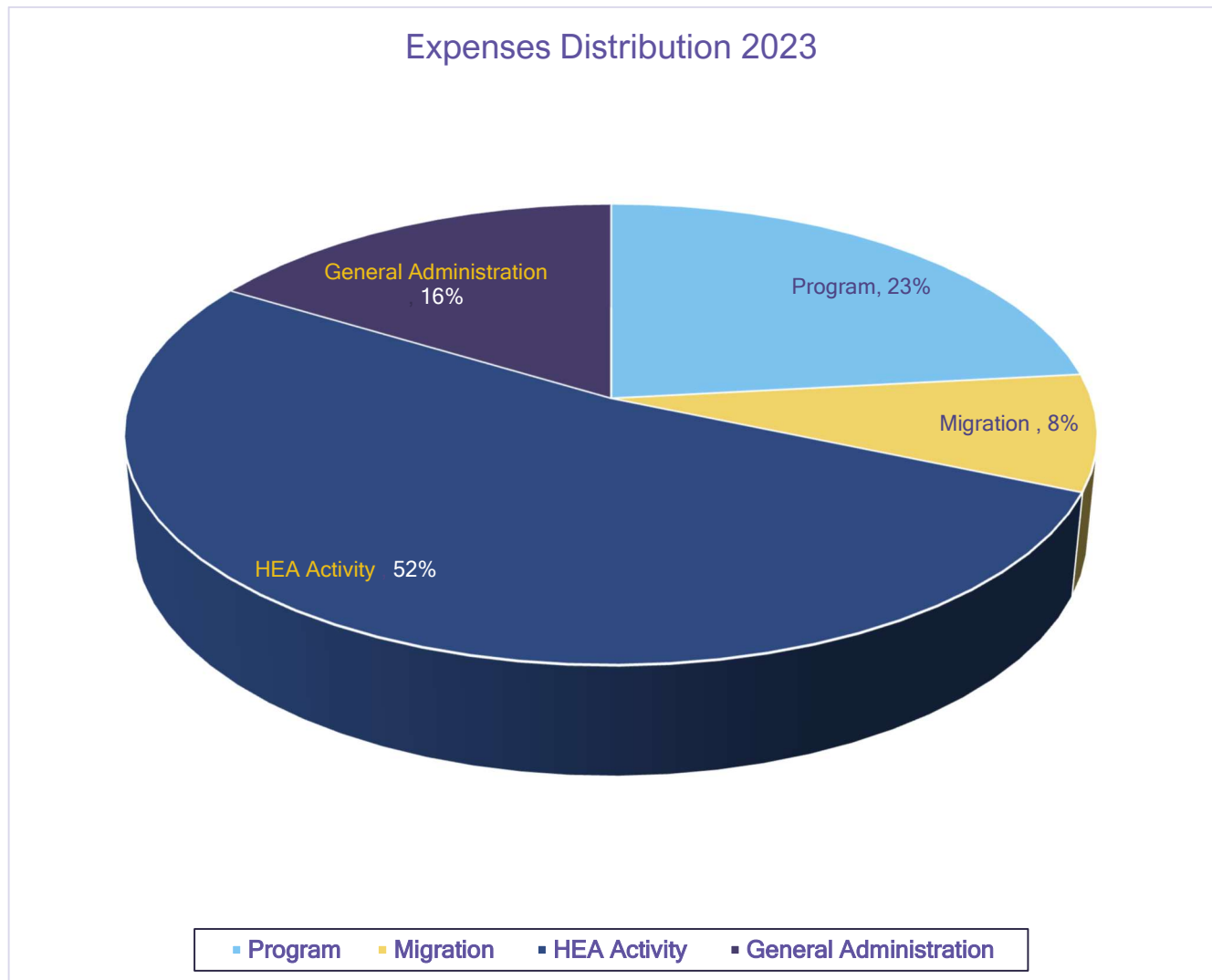
Swiss Emmaus Leprosy Relief Work India implements its programs through Partner NGOs (Non-Governmental Organisations). In 2023, Swiss Emmaus Leprosy Relief Work India has engaged local NGOs to implement its five core programs:

- Output Based Aid (OBA)
- Schools Support
- Migration Study
- Health Education & Awareness Activity
- Aagaaz Project & Project Activity



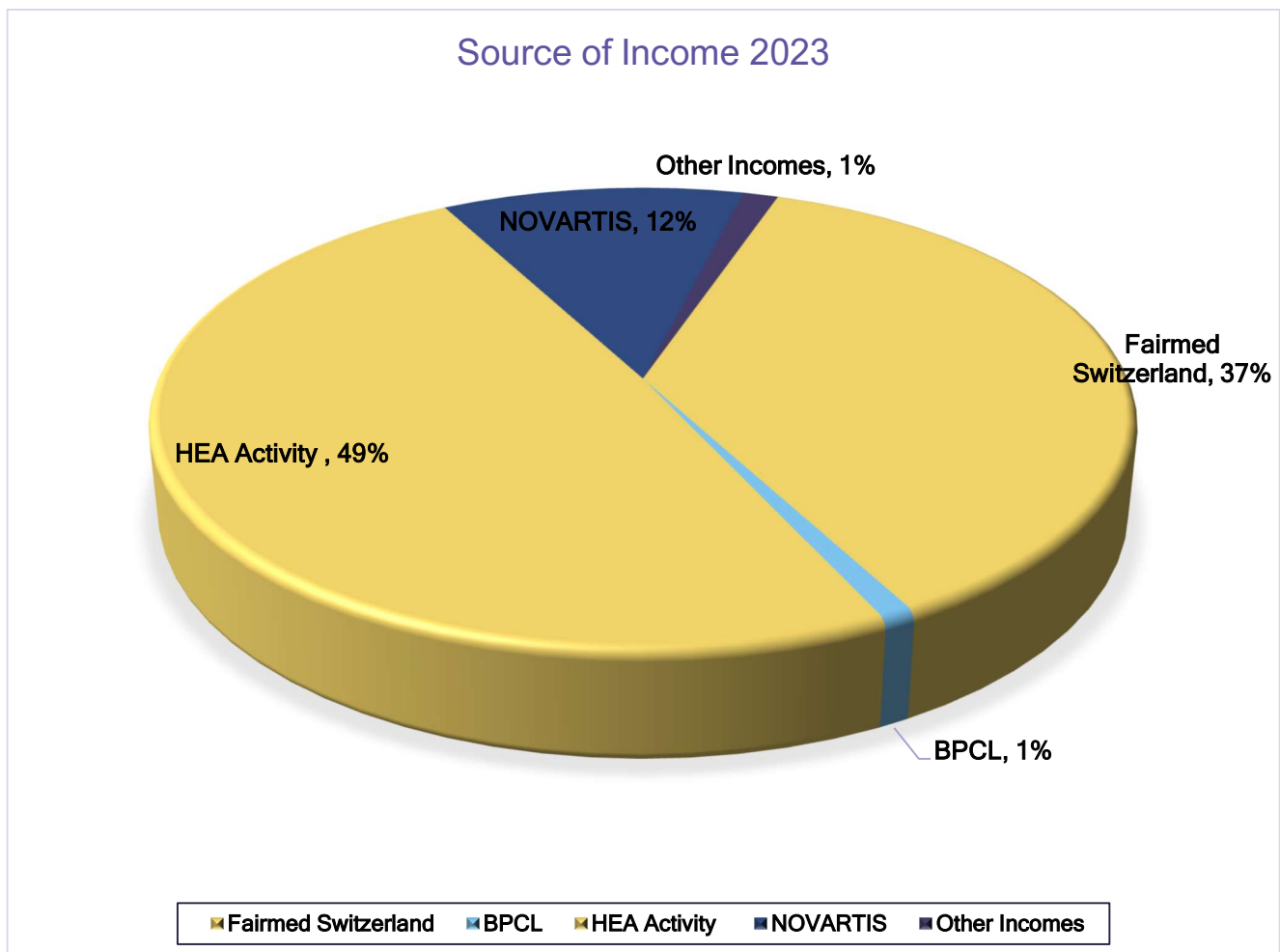
Graph 2: Thematic utilisation of funds in the year 2023

Swiss Emmaus Leprosy Relief Work India always tries to minimize its administration cost, to maximize the support to programs, and the same was replicated during the year 2023. In the year 2023, 31% of the funds were deployed towards program implementation including the migration study, 52% of the funds were utilized under Health Education & Awareness Activity (HEA), and 16% of the funds were utilized for general administration purposes.

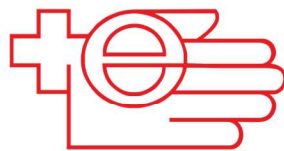


Graph 3: Expenses distribution 2023

During the year 2023, major source of Income i.e. 49% was generated locally by Health Education & Awareness Activity India (HEA) , 37% of the funds were received from HQ, Switzerland (FC funds) 12% of the funds from Novartis Healthcare Private Limited , 1% from Bharat Petroleum Corporation Limited (BPCL) and 1% of its fund were received from other income corpus fund.



Graph 4: Source of income 2023



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