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*to transform the lives of*  
*people affected by leprosy!*



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**ANNUAL  
REPORT  
2014**



## CONTENT

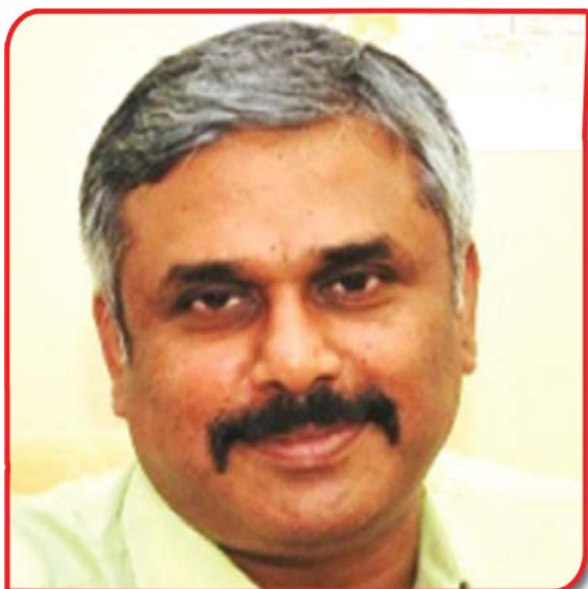
1)	Message from the Directors Desk.....	1
2)	Programmatic features.....	3
	o Hospital services.....	3
	o Monitoring of hospital services.....	4
	o Highlights of POID Pilot project.....	5
	o Launch of MH- POID project.....	6
	o Comprehensive District Leprosy Control Program (CDLCP).....	7
	o LEPCON – Chandigarh.....	8
	o National Consultation at Indian Habitat Centre.....	8
3)	Financial Reports.....	9
4)	Healthfirst India (Fundraising Unit of Swiss Emmaus India).....	12
5)	Human Resource.....	14
6)	Visitors to India.....	15
7)	Introduction to Ms. Ingrid Mason- Head of Programme Unit, FAIRMED BERN.....	15
8)	Acknowledgements.....	16
9)	Abbreviations.....	16
10)	SEI - Project Map.....	18

## Message from the Director's Desk

**Dear Well-wishers,**

It gives me immense pleasure sharing our experience over the last year (2014) and how our work has impacted the lives of people affected by leprosy! After our successful campaign towards implementing the prevention of impairment and disability (POID) project it was time to scale up our operations and approach in other parts of India. Firstly, the existing POID project in 2 high endemic districts (East Godavari and Guntur) in Andhra Pradesh was further expanded in to the Comprehensive District Leprosy Control Project (CDLCP) where the field-based activities were integrated with our tertiary hospital services. The 110 services delivery centers in each district were divided amongst 5 divisional coordinators who monitor the uptake of services. The project was essentially trying to ensure all the good practices that were implemented during the pilot phase were being continued as a part of the CDLCP project.

The focus continued to be on early case detection and treatment of people along with strengthening the local health systems. Collaboration with other government departments such as the DRDA (District Rural Development Authority) and National Blindness Control Program was also strengthened while implementing the project. Although monitoring the uptake of services was critical, it was equally important to capture the field-based information that gave a better understanding of the project.



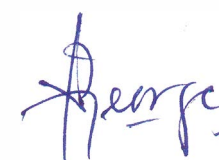
A tablet based information system was introduced to capture the field-based information. Each divisional coordinator was given a tablet that was 3g enabled and had a customized software to collect information about the patient as well as the public health system. 5 sources of early detection of people were identified and information regarding the same was captured in the tablet along with seeking their audio-visual consent.

This information was subsequently being transferred to a hospital-based information system once the divisional coordinator returned from his field visits to the base hospital.

While the emphasis was also to expand to other part of India with a similar approach of early diagnosis and treatment of people, a similar POID project was initiated in 2 high endemic districts of Maharashtra namely Dhule and Jalgaon districts. Comparatively, the Maharashtra project focuses on all 3 levels that is, primary, secondary, and tertiary levels of the public health system. In the Andhra Pradesh model, the emphasis is only at the primary level as in the same districts 2 tertiary referral hospitals are being supported by Swiss Emmaus India.

This renewed approach to leprosy control work is what we believe will lead us to the last case of leprosy in the designated districts. I take this opportunity to express my gratitude for all the efforts and commitment of my colleagues and the unconditional support of my HQ colleagues and my board. I also stop of thank my supporters without which the leprosy control work in India will be incomplete.

Thank you,



*(John Kurian George)*



## Hospital Services:

During 2014, a total of 23,234 cases were provided services through the supported hospitals. This was lower than the numbers from the preceding year where a total of 29,224 cases were provided services. The number of outpatient (OP) cases out weighed the number of inpatient (IP) cases in 2014 across all the 5 hospitals (please refer to table-1 [a]). Out of the total number of IP cases (4,777 cases), around 63% (N= 2,993) cases required admission for ulcer care (please refer to table-1 [b]). The remaining cases were mainly to attend to reconstructive surgery (RCS).

A total of 340 RCS were conducted in 2014 of which around 230 cases were hand RCS that constituted close to 68% (please refer to table-1 [c]). The remaining cases were shared between the foot RCS and lagophthalmus. As the National Blindness Control Program was attending to cataract surgery, the SEI supported hospitals only undertook surgery to correct lagophthalmus.

**Table -1(a): Total number of cases (IP & OP) attended in each SEI supported hospital**

Category	ESLP	RISDT	GRETNALTES	HHH	SHLC	Total
IP	1,039	1,718	638	296	1,086	4,777
OP	3,814	5,180	6,535	1,043	1,885	18,457
<b>Total</b>	<b>4,853</b>	<b>6,898</b>	<b>7,173</b>	<b>1,339</b>	<b>2,971</b>	<b>23,234</b>

**Table-1(b): Total number of Ulcer cases admitted in hospital**

Category detail	No. of patients	% of Cases
Ulcer Care	2,993	63
RCS	340	7
Other Care	1,444	30
<b>Total</b>	<b>4,777</b>	<b>100</b>

**Table-1(c): RCS conducted under different categories**

RCS category	No. of Patients	% of Cases
Foot	97	29
Hand	230	68
Eye	13	4
<b>Total</b>	<b>340</b>	<b>100</b>

With the introduction of the POID projects, there is going to be a steady decline in the numbers attending the OP services of the SEI India supported tertiary hospitals. The same number of people will be provided services at their respective PHC's who have been capacitated in providing both services to OP reaction as well OP ulcer care cases.

## Monitoring of Hospital Services:

While technical visits by the central office as well as the HQ teams are taken periodically during the course of the year, the CO engaged an external consultant to visit the SEI India supported hospitals to monitor the quality of services being provided to people affected by leprosy. Since the services are supported by the donors and the patient receives the service at no cost, it's crucial to ascertain whether prescribed standards are being maintained and the patient is satisfied with the service being provided.

Hence a checklist was developed to ascertain the quality of services from the entry point of the patient till their exit. The consultant was expected to visit each hospital to observe and share the findings in consultation with the hospital staff.

One of the key recommendations were to make the hospitals more patient friendly by providing ramps to ensure better access to key services. Also, better liaisoning with district officials are required to ensure prompt supply of supplies including MCR footwear, self-care kits, and vital medicines.

## Highlights from the evaluation of the POID project

The pilot POID project in 2 high endemic districts of Andhra Pradesh namely, East Godavari and Guntur successfully completed its tenure by Dec. 2013. Prior to the completion 2 external consultants were engaged in undertaking the end evaluation of the project.

Some of the key findings from the end evaluation are listed below:

1. A total of 10,519 people were provided services during the 3 year pilot phase from the 2 endemic districts of which 36% (3,802) were grade-0, 7% (752) were grade-1, and 57% (5,965) were grade-2.
2. There was a clear evidence of the PHC system being strengthened where the ASHA's (Accredited Social Health Activist) were able to refer suspects to the PHC and medical officer were able to diagnose and treat people.
3. Key consumables including MDT and other steroid medicines to treat complications were made available across all centers.
4. Collaboration with key government departments such as the DRDA as well as the National Blindness Control Program were forged that enabled the project to leverage important services to the people.
5. Field based data was being captured using the tablet that was very unique to the leprosy control program in India.
6. Strong referrals and linkages were forged with the tertiary leprosy hospitals to facilitate RCS as well as treating for complications.
7. One of the prime recommendations were also to undertake operations research as a part of project.

## Maharashtra (MH) POID project:

SEI India implemented the POID project in 2 high endemic districts in Maharashtra namely Dhule and Jalgaon where close to over 60% of the population are tribal. This falls well within the strategic direction as underserved or neglected population is a key focus area for SEI India. The project was implemented in collaboration with the State Leprosy Society, Maharashtra, Alert India (NGO working in the field of Leprosy in Maharashtra), and SEI India. In January 2014, a tripartite agreement was entered in to amongst the abovementioned partners to implement the project that was meant to be a pilot.

The prime objectives of the project was to:

1. Reduce the incidence of disability due to leprosy and discrimination against persons affected by leprosy.
2. Increase the capacities of health personnel at all levels of GHC system – primary, secondary and tertiary – and ensure availability of quality leprosy services.
3. Promote innovative strategies for sustaining leprosy control activities by GHC system with relevant policies and mechanisms.

The MH-POID project's paradigm differs from the Andhra Pradesh's POID project where in the former the intervention aims at all 3 levels. That is, primary, secondary, and tertiary levels. Whereas the Andhra Pradesh model aims solely at the primary level intervention. The intent was to better inform by making comparisons among the different models and share good practices among all stakeholders.

The project's core program activities strengthen all the 3 tiers of the Indian public health system. The State Society is responsible to support the capacity building of health care workers along with establishing the tertiary care facility for leprosy in both the districts. Likewise, Alert India with its expertise in strengthening the secondary level care by establishing leprosy referral centers (LRC) and SEI India with its knowledge and experience in strengthening the primary health care level.

## Comprehensive District Leprosy Control Project (CDLCP):

Following the successful implementation of the POID project, the field-based services of the POID project were integrated with the hospital-based services together to form the CDLCP project. Integration of both the services facilitated in the continuum of care for people affected by leprosy either in the primary health care and where required referral to the tertiary care hospital for specialized care. Hence the project was able to collaborate closely with the public health system to train the government health care workers, ensure the availability of key consumables such as self-care kits and MDT, engage the ASHA's in early referral of suspects, collaborate with other government departments for leverage along with a strong monitoring and supervision with stakeholders.

How is the CDLCP different from the POID project? The CDLCP identifies 5 sources of early diagnosis that includes ASHA, School Health Education Program, Private Practitioners, Contact Surveys, and Self-referrals. While the 2 mobile actions teams (MAT) were engaged and the 110 service delivery centres were divided amongst the 2 MAT, in the CDLCP project 5 divisional coordinators (DC) were engaged to oversee the good practices of ASHA's referring suspects and medical officer's (MO) confirming diagnosis. The 110 services delivery centers are divided amongst the 5 DC's per district.

In addition, a tablet based information system was developed to capture the field-based information from the 110 service delivery centers. It's the DC's responsibility to capture the field-based information and store in the tablet. On returning from the field the DC is expected to transfer the field information to the hospital-based information on the desktop. The tablet is 3g enabled that ensure real transfer of data along with capturing key information of the patient and the treating facility.

Finally, to add to the rigour a backstopping mission by an independent Consultant is being undertaken to give an independent view of the progress of the project. This was being undertaken once every 6 months. The Consultant refers to the original proposed planned activities and budget against which the progress is monitored.

The project also held district and state steering committee meetings with key stakeholders including the district leprosy and state leprosy officer's (SLO) twice a year to address policy related matters or gaps identified in the program. In addition to all of the above, the project also factored in 2 quality circle meetings to discuss and share amongst partners their experiences from the field and also find solutions to their persistent issues.

## Lepcon (Leprosy Conference) Chandigarh

A leprosy conference (Lepcon) is held annually to discuss and share the innovations in leprosy. In 2014, the Lepcon was held in Chandigarh, where SEI India presented 2 papers and both were accepted as the poster presentations. These include:

- Kumar, Akshay; George, John Kurian; Comprehensive information system capturing hospital and outreach POID intervention using advanced android based tablet, paper presented at the Lepcon, Chandigarh, India, Apr. 2014.
- Verma, Deepali; George, John Kurian; Review of human resource structure within Swiss Emmaus India supported (NGO) hospitals, paper presented at the Lepcon, Chandigarh, India, Apr. 2014.

## National Consultation on Prevention of Deformity (PoD):

Following the success of the POID intervention in Andhra Pradesh, SEI India initiated a discussion with the Central Leprosy Division (CLD) and ILEP India members for a stakeholders meeting to determine and deliberate regarding 'Prevention of Deformity' with an focus on early diagnosis and treatment of people. It was meant as a platform to share and learn from each member's experience on PoD. The Consultation was jointly supported by the ILEP in India.

In the Consultation various models were discussed with an idea to integrate the PoD in the Disability Prevention and Medical Rehabilitation (DPMR) program. As the DPMR program primarily focuses on medical rehabilitation, the purpose was to integrate the recommendations into the DPMR guidelines so as to provide a more holistic perspective.

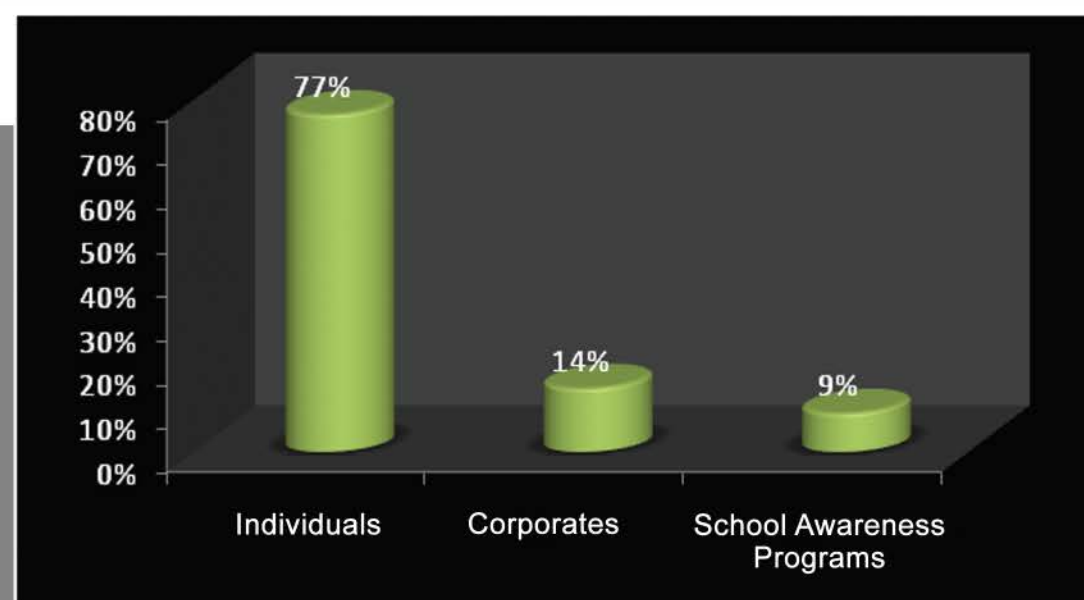


One of the key recommendations was to engage the Accredited Social Health Activist (ASHA) in the early diagnosis program by referring suspects to the nearest PHC. This early diagnosis was also considered as one of the key objectives of the NLEP program in the 12th 5 year planning document.

## Finance

During the year 2014 different fundraising activities were conducted by Swiss Emmaus India (SEI). Funds were raised through individuals, corporate and schools (please refer to Diagram-1). These were used towards the support of our hospital, field and educational support programs.

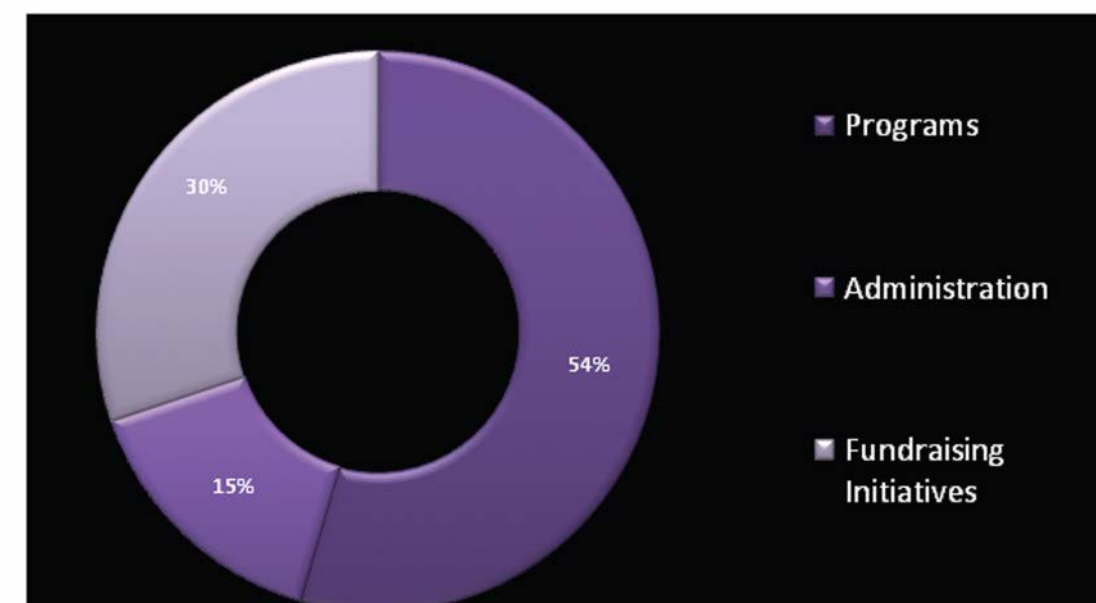
**Diagram 1 : Source of donation**



## Thematic Utilization of fund

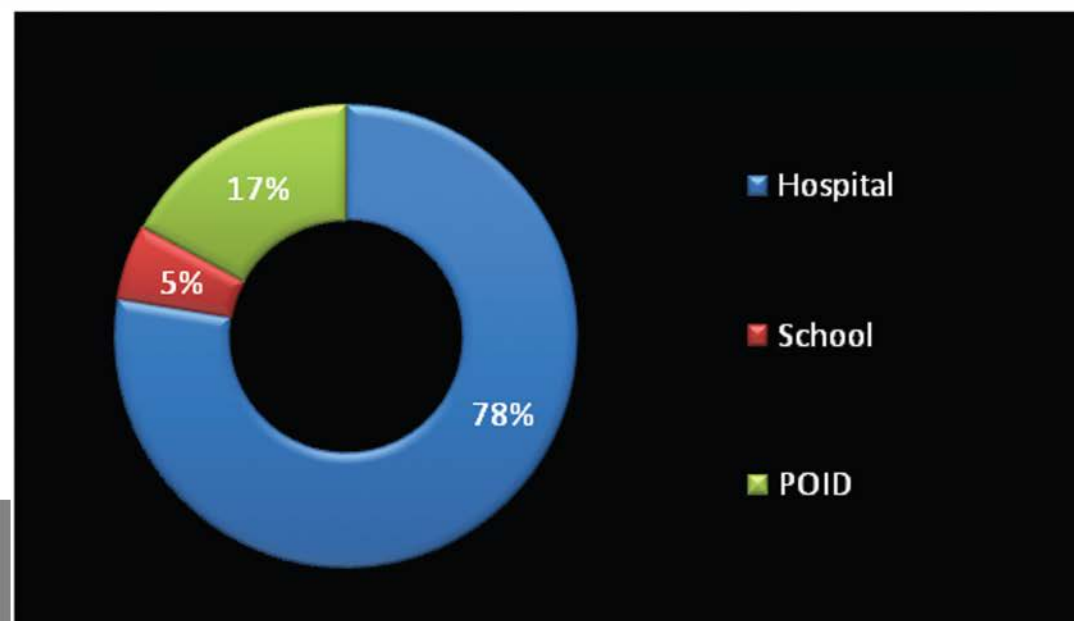
- 1) Funds received and raised through different sources were used under expenses heads, such as Program, General Administration and Fundraising. During the year 2014, 54% of funds were utilized towards core programmatic objectives, 30% towards fundraising

**Diagram 2: Utilization of funds**

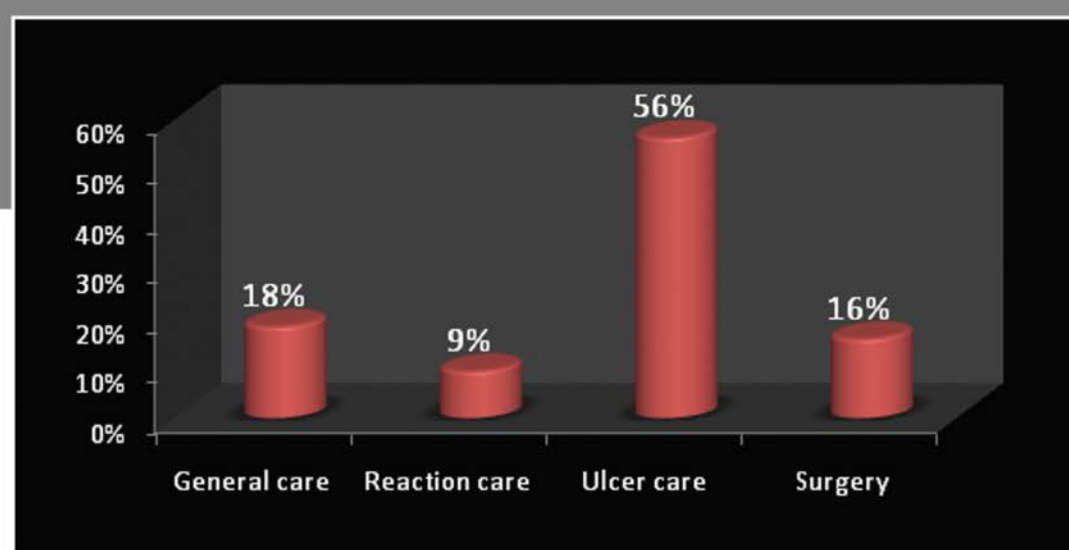


Funds allocated towards Programs were divided into 3 core activities of SEI. Major utilization was done towards hospital support (78%) where the different types of treatment is provided to Leprosy affected people (details of types of services provided in hospital is presented in Diagram : 4). Additional 17% was utilized towards the field based project such as Prevention of Impairment & Disability (POID) and balance 5% is provided towards Educational support to the Children with Leprosy or from leprosy affected families (please refer to Diagram-3).

**Diagram 3: Utilization of funds under different programs**



**Diagram 4: Utilization of funds for different Hospital services**



## Fundraising Initiatives – Healthfirst India



The year 2014 was eventful and we made some significant strides in local fundraising. Following are the fundraising activities conducted during the year 2014.

### Direct mailing

We sent out mailers to SME, during the year seeking support for people affected by leprosy in India. During the year we concentrated on festivals and pre-tax period. Various activities were conducted to understand the best practices in sending cold mailers. The mailers were aimed at those people who want to receive tax benefit for the New Year. It also gives them a golden opportunity to use their money for a good cause besides benefitting themselves too. During the third quarter we focus on Diwali mailers. As part of the direct mailing – Warm, appeal letters are sent to our warm donors. Direct mailing is a very successful activity.



## Lucky Draw Event

Swiss Emmaus Leprosy relief Work India Planned Lucky Draw as one of its activities to raise funds dedicated to support the medical care and social rehabilitation of people affected by leprosy, tuberculosis and other poverty related diseases through its supported projects in India. The learning from the Lucky draw event held during the year 2012 was incorporated for better performance. The Lucky draw event was conducted on 20th Nov 2013 at our Gretnaltes project.

## Sensitization of School Children

During the year 2013 we approached few schools at Chennai to spread the awareness about Leprosy. All the students above the primary class were involved. Apart from raising funds, the students were also involved in educating the mass about our initiative for Leprosy. The principal and staff of the School extended their full support throughout the campaign.



*School Awareness Program*

## Direct Marketing

Telemarketing is the hybrid of telephone and face to face fundraising. It is a modified extension of the major donor process to encompass cold solicitation. Swiss Emmaus Relief Work opened its office in Chennai, where in-house tele-calling activity was conducted. The objective of this activity is to expand the warm & cold donor base and simultaneously encourage monthly giving through ECS.



*Inauguration of Mumbai FRU Office*

## Corporate Fundraising

Corporate fundraising is one of the core strategies for raising funds in India. SEI approached various corporate bodies to support the cause of Leprosy. Proposals were submitted; few corporate extended their support for the cause of leprosy. During the year corporate events were organized and funds were raised through these events.



*School bus, for Emmaus Swiss High School, Palamaner*

## Human Resources

All employees working with Swiss Emmaus India play an important role in the organization and are working towards a common goal i.e. to provide their support to the people affected by leprosy. Staffs are being provided remuneration based upon their experience and job responsibilities handled by them.

S. No.	Designation	Band
1.	Senior Management Staff	50,001 - 300000
2.	Middle Management Staff	30,001 - 50,000
3.	Supervisory Level	10,001 - 30,000
4.	Junior Level	5,000 - 10,000

*Table 2- Staff salary distribution between different levels of management.*



## Visitors to India-Ms. Mirjam Staeheli:

As a part of the monitoring visit, Ms. Mirjam Staeheli (Institutional Fundraising Officer) visited the India office to further facilitate her understanding of the work being carried out through support from Swiss Institutional donors. Although her visit to Delhi was brief she travelled to the project sites in Dhule and Jalgaon districts, Maharashtra State, and subsequently to the resource mobilization office in Mumbai as well.

Besides visit of Mirjam to India, Rene (Managing Director) also visited India on couple of occasion during the course of the year. The most recent visit was during the National Consultation on Prevention of Disability (PoD) in New Delhi during July 2014.



## Introduction to Ms. Ingrid Mason:



Ms. Ingrid Mason joined as Head of Program in Bern. She is a trained Anthropologist and comes with extensive experience in background in disability affairs having work with CBM Africa. The India team welcomes Ingrid to the family and wishes her the very best for all her endeavours.

## Acknowledgements

Swiss Emmaus India acknowledges all the donors, friends and well-wishers for recognizing its work and making a meaningful contribution in the best possible ways towards our endeavors in elimination of Leprosy, control of TB and other poverty related illnesses. We are grateful to the dignitaries in FAIRMED, Bern, Switzerland for their timely support and guidance.

We are also thankful to the Government at Central, State and District level for extending the necessary support towards our cause. Our heartfelt gratitude is to ILEP, CCM and National TB Consortium (NTC) for giving us the opportunity to strive for a "World free of TB".

We take this opportunity to express our deepest appreciation towards our partners who implement the projects and activities with sincerity and professionalism. Finally, sincere thanks to our trustees, colleagues at Central Office who have continuously guided and motivated us to serve better to achieve our goal.



## Abbreviations

AP: Andhra Pradesh

CEO: Chief Executive Officer

DOTS: Directly Observed Treatment with Short course Chemotherapy

DRDA: Department of Rural Development Agency

ESLP: Emmaus Swiss Leprosy Project

TB: Tuberculosis

HHH: Hubli Handicapped Hospital

IDF: Indian Development Foundation

IEC: Information, education and communication

ILEP: International Federation of Anti-Leprosy Associations

IP: In patient

MD: Managing Director

OP: Out patient

NTC: National TB Consortium

POID: Prevention of Impairment & Disability

RISDT: Rural India Self Development Trust

RNTCP: Revised National TB Control Program

SEI: Swiss Emmaus Leprosy Relief Work India

SET: Survey, education and treatment

SHG: Self Help Group

SHLC: Sacred Heart Leprosy Centre

WHO: World Health Organization

## SEI - Project MAP

