

Annual Activity Report
on
Hansen's Disease

Fiscal year 2010
(April 2010 ~ March 2011)

Sasakawa Memorial Health Foundation

Abbreviations

AIFO	Italian Association Amici di Raoul Follereau
DFB	Damien Foundation Belgium
ENAPAL	Ethiopian National Association of Persons Affected by Leprosy
GLRA	German Leprosy and TB Relief Association
GMLF	Gandhi Memorial Leprosy Foundation
HANDA	HANDA Rehabilitation and Welfare Association
Hanoi BDVG	Hanoi Blue Dreams Volunteer Group
HKNS	Hind Kusht Nivaran Sangh
IDEA	International Association for Integration, Dignity, and Economic Advancement
ILEP	International Federation of Anti-Leprosy Associations
ILU	International Leprosy Union
INF	International Nepal Fellowship
JIA	Joy in Action
LCC	Leprosy Care Community
MAM	Myitta Arr Marn
MLAC	Manipur Leprosy Rehabilitation Centre
NESA	Nepal Education Support Association
NLT	Nepal Leprosy Trust
PerMaTa	Perhimpunan Mandiri Kusta Indonesia
PLM	Philippine Leprosy Mission
RCS	Rural Community Services
READ Nepal	Rehabilitation, Empowerment And Development – Nepal
SMK	Sarthak Manav Kushthashram
SVHSG	Save Valley of Hope Solidarity Group
UMDSL	Umemoto Memorial Dental Service for Leprosy
TLM	The Leprosy Mission
TLA	Tanzania Leprosy Association
VSK	Vanvasi Seva Kendra
VU University	Vrije University
WPRO	WHO Regional Office for the Western Pacific
YTLI	Yayasan Transformasi Lepra Indonesia

Overview of Fiscal 2010

When SMHF was established in 1974, 12 million people were estimated to be suffering from Hansen's disease (HD). Since the introduction of Multidrug Therapy (MDT) in the early 1980s, the number of annual new cases has come down to approximately 240,000 today, yet stigma and discrimination due to HD are deep-rooted in the society.

In order to realise a world with no stigma and discrimination against HD, SMHF set the following three mid-term goals for fiscal 2009 to 2011.

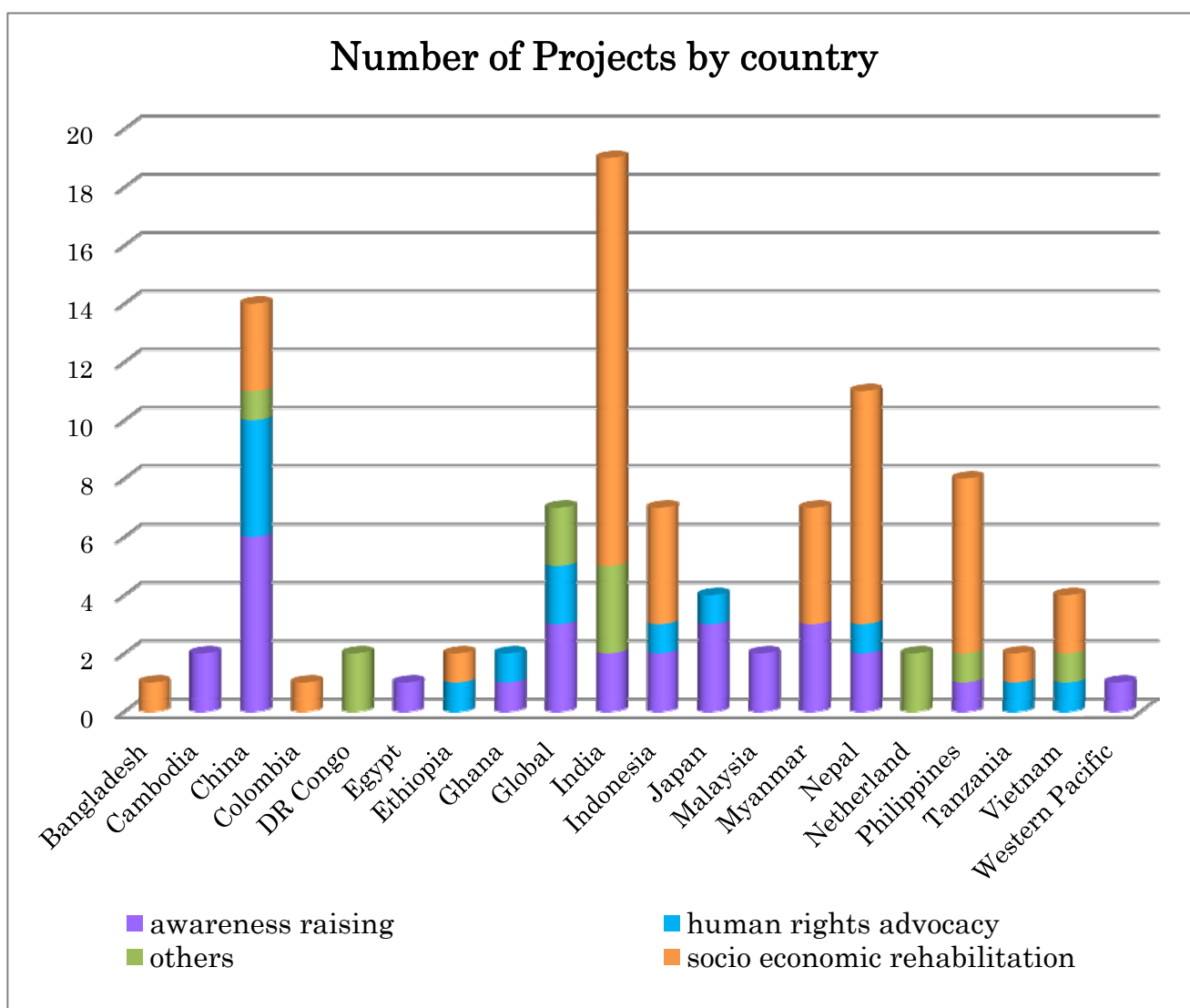
- 1) To raise awareness about Hansen's disease,
- 2) To support people affected by Hansen's disease and their families to be socially and economically independent, and
- 3) To work for a society where human rights of people affected by the disease and their families are respected

In FY 2010, the second year of the three year mid term goal, projects in **17 countries** and some projects that are not country specific were supported. The majority of the projects fall into one or more of the above three goals. In addition, some projects to encourage elimination of the disease were also supported, given its importance in HD control activities.

We believe changes were made and steps were taken to meet the above three goals. Much was achieved at each project site. More people learnt about HD. People affected were empowered to be socially and economically independent, and became literate about their rights. Many of them learnt about the importance of self-care to prevent from developing and worsening disabilities which often results in discrimination. Many of those have developed the habits of self care and are practicing them regularly. HD control activities were supported, and more people participated in our challenge to realise a world without stigma and discrimination against HD.

There were two important and welcome advances made. One was the WHO Guidelines to Strengthen Participation of Persons Affected by leprosy in HD Services, and the other was the UN Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members. This was a **sign that the issues on Hansen’s disease and the important role of people affected by the disease in HD control services are more widely recognised at the international level.**

Our challenge to realise a world without leprosy related problems continues to work for an inclusive society for people affected by HD and other needs, their family, and anyone in society.



What Was Done and Achieved

1) To raise awareness about Hansen's disease

- Awareness raising campaigns

A number of projects were supported to raise public awareness of the disease. Some organisations published and distributed newsletters as a means of providing correct and useful information about the disease and positive images of people affected by it, while others broadcasted weekly radio programmes, allotting time to answer telephone calls from listeners. One organisation in Ghana formed an awareness raising team and travelled to distant communities to advocate for the rights of the people affected. Many organisations held events on World Leprosy Day (last Sunday of January) and the International Day of Dignity and Respect (11th March).

World Leprosy Day 2011 in Ethiopia

Ethiopian National Association of Persons Affected by Leprosy (ENAPAL) celebrated World Leprosy Day for the 12th time in January 2011. ENAPAL chooses one branch to host a national campaign each year, and it was Jimma in 2011.

Carefully and thoroughly coordinated with various partners, from the Ministry of Health and the Oromiya Regional State President's office, to the local city administration and NGOs, ENAPAL held a number of events in Jimma. Radio programmes were broadcasted, magazines, posters, and brochures were printed, a song was prepared specifically for the day, a poem contest was undertaken, a panel discussion with more than 600 people was organised, a public rally was held and a short message on the disease and people affected by it was sent to more than 200,000 mobile phone users in Ethiopia.

ENAPAL's other regional associations and local branches joined to celebrate the special day in their localities.



- Preservation of Heritage

The history of Hansen's disease is woven with entangled threads of different factors. The history of medicine of pre- and post-MDT, of isolation in the name of 'protecting' the general population, of tradition, literature, myths, culture and religion. However, the rich and diverse histories of HD worldwide are in danger of being lost. History offers us opportunities to learn from the past and to utilise the lessons learnt for a better future.

An attempt was made in Culion, Philippines, to publish a comprehensive history book of their roots while a film which documented people's lives in a HD colony was made in Egypt.

As part of history preservation, the stories of people who have personally faced and overcome the challenges of HD were collected in several countries. The stories serve as a powerful tool to change people's perception of the disease and people affected by it.

Awareness raising campaign		¥27,533,805
China	JIA, HANDA	
Ethiopia	ENAPAL	
Ghana	IDEA Ghana	
Myanmar	Ministry of Health	
Nepal	READ Nepal, NLT	
Tanzania	TLA	
Global	IDEA International	
Global, Japan	SMHF	

Recording Legacies		¥10,217,443
Cambodia	Ministry of Health	
Egypt	Colony Film Team	
India	SMK	
Indonesia	PerMaTa	
Malaysia	SVHSG	
Myanmar	MAM	
Philippines	Culion Sanitarium	

Now it feels like I have been reborn. I have no qualms in going out during the day time without covering my face and hands. I hold my head proudly and without being mortally afraid that somebody will point an accusing finger at my scars and ask with mock sympathy, "What are those scars, Afsana?"

Ms Afsana Begum, India (from *Dignity Regained*, 2005)

2) To enable people affected by HD and their family to be socially and economically independent

- Supporting people affected by HD

It is only recently that people affected by HD had started to become visible and heard after centuries of silence. People are uniting and forming groups, organisations and associations so that their voices can be properly heard and their needs are met.

In FY 2010, capacity building of six organisations of people affected were supported. Educational assistance, socio-economic rehabilitation, and empowerment workshops for the people to lead a dignified life were also supported through organisations of people affected and also other NGOs.

Coalition of Association of Persons Affected by HD in the Philippines

There are eight national HD sanitarium in the Philippines. Each has a number of groups of people affected, religious groups, supporting NGOs, all working for their own causes and missions. Until now, their past experiences, knowledge and lessons learnt have not been shared with other groups and organisations. Their activities are mostly quite localised to meet immediate needs, and there have been few opportunities for people to voice their opinions and hopes about their rights and future, which are beyond their immediate needs, at the provincial and national level.

A new and innovative project started in 2010. Groups of people affected, supporting organisations and institutes, religious groups, sanitarium and relevant ministries is being loosely networked. A baseline survey of the eight sanitarium was done which will be the basis of the network. Sensitisation workshops were conducted at each sanitarium, and concrete steps were taken to form the 'Coalition', which is hoped to be formally established in 2011.



Capacity building of organisations of people affected by HD		¥14,304,117
Colombia	Corsohansen	
India	IDEA India	
Myanmar	MAM	
Nepal	IDEA Nepal	
Philippines	Coalition	
Tanzania	TLA	

Vocational training and socio economic rehabilitation		¥16,628,038
Bangladesh	TLM Bangladesh	
India	GLRA India, IDEA India, RCS, LEpra Society	
Indonesia	PerMaTa	
Nepal	NLT, INF, NESA	
Philippines	Culion Sanitarium and General Hospital, PLM	
Vietnam	Quy Hoa Leprosy Sanatorium	

Educational assistance		¥9,545,175
China	HANDA	
Ethiopia	ENAPAL	
India	IDEA India	
Indonesia	PerMaTa	
Philippines	Culion Sanitarium and General Hospital, PLM	

Empowerment workshops		¥ 2,872,903
India	IDEA India	
Indonesia	PerMaTa, YTLI	
Myanmar	MAM	

"I never dreamed that I would have a job" - Ms Subina Gurung

Ms Subina Gurung is resident of Kaski district. Her mother is affected by HD. When Subina was 12, her father left his family simply because his wife had HD. Her mother had a cleaning job at Green Pastures Hospital but the income was insufficient to raise her children.

Ms Gurung requested Partnership for Rehabilitation (PFR) to support her as she took an auxiliary midwifery nurse training course (18 months). Seeing her family status and trouble, PFR decided to provide training fees, uniforms and other necessities for her.

She completed the training with good marks. Green Pastures Hospital gave her an opportunity for on the job training. She is now working full time at Green Pastures hospital, and is able to support her mother and also her brother and sister's education.

I never dreamed that I would have a job one day and help my family, said Subina.

Special thanks to INF for sharing this story



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- Prevention of impairment and disabilities (POID)

In order to prevent impairment and disabilities, which can often cause discrimination and physical and psychological suffering, we supported projects such as self-care training, reconstructive surgery, and a mobile eye clinic in Nepal, China, and Myanmar.

2) POID		¥ 16,087,674
China	READ Nepal, NLT, INF	
Myanmar	Ministry of Health	
Nepal	READ Nepal, NLT, INF	

I am proud of myself - Ms Sangita

Sangita from Bihar, India, developed symptoms of HD and had nerve damage when she was a child. Nobody in her family knew at the time that the symptoms indicated HD. She developed a chronic ulcer on her foot, and in time her toes dropped and the fingers of both hands were severely clawed. She felt very ashamed of her deformed hands and ulcer and from that time she never smiled and had to stop going to school. Fortunately, she continued to receive love from her family throughout her illness, which allowed her to remain integrated with them. It was only her aunt and some community people who suggested that her father should exclude her from his house.

In 2009, she visited Lalgadh Leprosy Services Centre (southeast Nepal) for her deformity care and joined a two week course in disability prevention at NLT's self care training centre. She then received reconstructive surgery for her left hand. She is now practicing post-operative exercises regularly in the physiotherapy department and here's a completely different girl with a big smile on her face and self confidence!



*Special thanks to NLT
for sharing this story*

My ulcer is healed, and I want to help others now - Mr. Cai Ping

My name is Cai Ping. It was in 1979 that I came to Hepu HD village.

Around 1995, I was busy working on the farm, and sometimes hurt myself.

Unfortunately, the wound developed into an ulcer. Like other villagers, I did not know what to do. I saw the wound expanding and sometimes it gave off a bad smell. I avoided people and I was afraid that whoever passed by would smell the awful stink.

After several years the ulcer got worse.

A doctor told me that my ulcer had no cure and that I had to amputate it. As if sentenced to death, I felt hopeless. What was the meaning of all my effort? I lost confidence in life...

HANDA came to our village for wound-care training in 2003. They told us the ulcer could get better through self care. I persisted in self-care the way the doctor taught me. After some time, I found the ulcer was not that smelly and became smaller. I cannot describe how happy I was. After a year, at the end of 2004, my ulcer was totally healed. Since then I've never developed ulcers because I now have the habit of doing self-care. Had it not been for HANDA's help, my life would have never been so meaningful.

"I am still quite young, I should do something for others"

In 2005, encouraged by HANDA staffs and villagers, I became a health care worker in Beihai village. I valued this opportunity and appreciated their trust. I used my own experience as the example to encourage villagers to join in the self care campaign. Teaching them the simple knowledge and method, I began to let them do the self care. Now, every villager in Beihai village can carry out self-care conscientiously without my supervision.

I feel proud of myself. HANDA has changed me greatly and I want to teach more people about the importance of self care. I will keep doing this job, spreading what I have learned and what I believe to more people.



Special thanks to HANDA for sharing this story

- Living conditions

Various attempts were made to improve living conditions of people affected by HD and their families in India, Nepal and the Philippines. Houses were reconstructed and repaired and wells were installed among other things.

A House Repair Project Turned Into...

18 houses in Baba Christodas HD colony in Bihar, India, needed repair urgently as the walls were cracked, and roofs were damaged badly.

All 18 houses were repaired within a little over 2 months, and the houses now looked clean and safe, but that was not all. The renovation brought unexpected impacts to the residents and people living nearby.

The Lions Club started a school where children of up to primary level could go to, a retired doctor began to pay regular visits to the colony for free medical check ups, and people nearby and community leaders wanted to help improve the colony. The residents of the colony, motivated to make a fresh start, promised to keep their colony clean and tidy.

They also formed a self help group. The group set up a fund by regularly saving certain sum, and also through donations. Utilising the fund, the group started a loan project for the residents of the colony for emergencies and also for starting small business and other things.

The repaired houses brought not only a safe living environment to the residents, but also positive changes in minds of people in the colony and awareness and a sense of support for people living nearby.



Improvement of living condition		¥ 12,081,069
India	RCS, VSK, GMLF, IDEA India, MLRC	
Nepal	NLT	
Philippines	Culion Sanitarium and General Hospital	
Vietnam	Quy Hoa Leprosy Sanatorium	
Others		¥4,975,764
China	JIA	
Myanmar	ILEP Liaison Office	
Vietnam	UMDSL	

3) To work for a society where human rights of people affected by the disease and their family are respected

- Work camp activities

Work camps at HD villages in China, Indonesia and Vietnam were supported. The series of activities originally aimed at improvement of living condition of the colonies but recently turned out to have also facilitated personal and social change for the residents and society, such as reducing stigma in neighbouring communities, drawing media interest and raising the awareness of the wider community, building familial relationships between residents of the colonies and youths of the camps.

Changes in society - work camps

In 2001, the first work camp was conducted in a HD village in South China by Japanese and Korean students. They started their activities by constructing toilets, repairing roofs and walls, and paving roads to improve living conditions to the HD village.

The students stayed in the village and they talked, ate and drunk together with the villagers everyday. Slowly, the villagers and the youths developed a special bond which grew stronger as they spent more time together.

People living in nearby villages were awestruck looking at the students spending time with the villagers, and going to the nearby market hand in hand. Before long they started to realise that HD may not be as frightening as they thought.

Gradually, Chinese students started to join the work camps and in 2004, a work camp coordination centre, Joy In Action (JIA) was established.

JIA now mobilises more than 2,000 volunteers annually and organises over 50 work camps in HD villages in several provinces in China, and they are growing quickly and steadily. The physical, spiritual and social changes that were brought about by the work camps have been recognised by many people in and outside China.



The work camp approach has been expanded to Indonesia, Vietnam and India and is expected to be held in other countries.

Work camps (including baseline study and publication)	¥1,557,061
China	JIA
Indonesia	LCC
Vietnam	Hanoi BDVG

- Participation of persons affected by HD in HD services

We supported people affected by HD to participate in a WHO meeting as experts on HD in Manila, Philippines. The guidelines, which recognise and encourage active participation of the persons affected by HD in HD services, were published and distributed in May 2011 by the WHO Global Leprosy Programme. It is hoped that they will be utilised as a useful and powerful tool to accelerate more active participation of the people concerned. We welcome innovative trial and pilot activities that enhance health services in the field.

Participation of persons affected in HD services		¥1,551,976
Global	WHO	

- Human Rights

A major step in the area of HD and human rights was made with the adoption of the UN resolution and Principles and Guidelines on elimination of discrimination against persons affected by HD and their family members.

An approach to ensure human rights of people affected in India has been supported since 2007. The project helps people to know their rights, and when their rights are violated, a legal resource is devised and sought with professional help. The project has also worked to support the movement of amending or abolishing discriminatory laws related to HD in the country and empowered the leaders and groups of people to fight for their own rights.

An international workshop on HD and human dignity to provide opportunities to share experiences and create common ground to surmount the challenge was held in December 2010 in Maharashtra, India.

Human rights		¥10,495,526
Global, Japan	SMHF	
India	ILU	

4) Other areas

Although much focus was given to the social side of HD control activities in fiscal 2010, some equally important areas were supported. Those supported were related to elimination of the disease, research on stigma and Community Based Rehabilitation (CBR), and journals on HD and on human rights.

Elimination		¥7,199,664
DR Congo	DFB	
Global	WHO	

Research		¥9,505,620
CBR Research	AIFO	
Stigma Assessment	VU University	

Journals		¥918,785
Indian Journal of Leprosy	HKNS	
Leprosy Review	LEPRA Health in Action	