

FOR THE Elimination OF Leprosy

- Leprosy is curable
- Free treatment is available
- Social discrimination has no place



The Goodwill Ambassador (center) with staff of Kyun Kone Rural Health Center in Myanmar's Bago division on October 25.

MESSAGE

Maintaining Awareness

On a recent visit to Myanmar I had the opportunity to visit a health center about four hours' drive from Yangon and meet with healthcare workers and several people affected by leprosy. Over the years, I have visited many such facilities in different countries. The purpose of these visits is always the same: to see for myself the situation on the ground, to show my support and appreciation for the important work that frontline healthcare workers do, and to offer encouragement to people affected by leprosy and listen to their concerns.

With the integration of leprosy services into the general healthcare system, it is essential that health workers be familiar with the disease. However, as leprosy becomes less of an issue, they will encounter fewer cases, making it more difficult to recognize the signs. But it is a challenge that must be met, because early diagnosis and prompt treatment with multidrug therapy are the bedrock of leprosy control.

The onus is not just on health workers. There also needs to be greater community involvement

in efforts to control and eradicate the disease. This requires effective information, education and communication strategies reaching down to the grassroots level. This is particularly important in areas where there is still a high degree of stigma attached to leprosy, resulting in the disease being concealed rather than cured. Cases that go untreated perpetuate stigma and are a burden on families and communities.

Governments have made enormous strides in controlling leprosy, working closely with the WHO and with local and international partners. This cooperation will continue to be essential. But more must be done to involve people affected by leprosy as key partners in the process. Having experienced the disease themselves, they are the real experts and have an important role to play in promoting community awareness, breaking down stigma and ensuring that people affected by leprosy receive the treatment and understanding they need.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Speaking of SILF

Foundation aims to help people on a path to self-reliance and dignity.

The Sasakawa-India Leprosy Foundation (SILF) was launched in October 2007, with an endowment of US\$10 million from The Nippon Foundation, to create opportunities for people affected by leprosy and their family members. We asked SILF's Executive Director, Dr. Vineeta Shanker, for a progress report.*

What is SILF's mission?

SILF's mission is to make itself irrelevant. In other words, we would like to see an end to the stigma that denies people affected by leprosy and their families equal access to education and income-earning opportunities and their rightful place in society, and that also erodes their confidence and abilities.

How well-known is SILF?

It's a new foundation that started its program activities just last year. I think in the field of leprosy SILF is well known, not because of what it has done but because it is an initiative of Mr. Yohei Sasakawa, whose work in the area of leprosy eradication is recognized the world over.

What kind of feedback have you been getting from persons affected by leprosy?

The reaction has been mixed. On one hand, there is excitement that funds have been given by Mr. Sasakawa for their upliftment. On the other hand, there is disappointment that the funds are not going to be available as grants and gifts, but are going to be linked to a livelihood-generation initiative with oversight and monitoring by SILF and The Nippon Foundation. Moreover, those who were hoping to get assistance for the education of their children are even more disappointed as, in the initial phase, SILF decided to concentrate on livelihoods. We are now in a position to introduce a small education program, which will hopefully begin soon.

What has been the response of the business community to SILF? Are you making any headway encouraging employers to think about hiring persons affected by leprosy and members of their family?

We have not yet approached them in any systematic way, but overall there is interest and sympathy and a willingness to offer support. We will have to see how this translates into funds or training or employment in the coming months when we hope to approach them about their greater involvement.

SILF asked career counselors to conduct interviews with colony residents to find out

more about their needs and desires. What did you learn from this?

One of the major findings was that, although the young people had high aspirations, they had few life skills to translate these into reality. They were not well informed about the choices and the demands that different kinds of vocations and professions entailed with respect to technical, interpersonal, communication and emotional skills. Clearly, they need both motivational and career counseling to be successful in life. Also, they had all internalized the stigma against people affected by leprosy and their families and carried a sense of rejection and isolation.

In funding livelihood projects, what parameters has SILF set?

For the time being, SILF has decided to concentrate on the population living in self-settled colonies that are within the National Forum [of persons affected by leprosy] network. One of the guiding principles of our livelihood funding is that the proposals have to come from the people themselves. Often these proposals are just ideas of what people would like to do. We take these seriously and try and develop them with the persons concerned into viable and sustainable projects.

Initially there was an influx of proposals, not all of which were workable. To help bridge this gap we started organizing training for project identification, development and proposal preparation.

To ensure that there are concrete results from this training we insist that the workshop facilitators help develop at least one proposal from each of the participating colonies into a detailed project outline with market feasibility

INTERVIEWEE

Dr. Vineeta Shanker



Executive Director
Sasakawa-India Leprosy
Foundation



Skills training at Kusth Ashram Viklang Sahayata in Dehradun, Uttarakhand

Footnote

* For more information about SILF, visit www.silf.in

assessment and a business plan. This is done as a follow-up to the workshops.

What sort of proposals have you been receiving?

By and large, the demand is for starting simple and traditional activities such as livestock, tailoring, and candle-making. Eventually we would like to work toward activities that respond to the demands of a changing economy, and expect to include non traditional activities.

Please give some examples of recent projects SILF has funded.

Recent beneficiaries include 15 people from Hanuman Nagar Kusth Vasahath, Thane, Maharashtra, for buffalo rearing; 10 women from Sri Sai Ram Avtaar Kusth Sewa Samiti, Indore, Madhya Pradesh, for saree retailing; and 8 people from Swami Vivekanad Kusth Ashram, Bareilly, Uttar Pradesh, for battery renting. As a lot of rural and semi-rural areas do not have electricity, people rent batteries for operating TVs or for family functions. It's a lucrative business.

“We focus on eradicating stigma through social and economic rehabilitation.”

SILF has teamed up with well-known fashion designers. How did this come about? And what has resulted?

One of the Trustees of SILF introduced us to Ms. Rathi Jha, former director general of FDCI [Fashion Design Council of India]. Through her contacts, SILF was able to meet and discuss various possibilities for improving the products made by people affected by leprosy with well-known fashion designers such as Ritu Kumar, Anju Modi, David Abraham and Ria Ali.

One of the first initiatives was to persuade these designers to use some of the material woven by the leprosy colonies for their high-fashion clothes as their response to the products was very positive. Some of them did just that and displayed these clothes at a fashion show earlier this year. This got us some visibility, but not many orders. Many designers are keen to help improve the weaves, colors and designs of the textiles and we are in the process of working out how to do this, given their hectic schedules.

Where do you think SILF's priorities must lie?

We focus on eradicating stigma through social and economic rehabilitation. Within this mandate we have prioritized livelihood funding, but there are other equally urgent needs that people affected by leprosy and their families face, especially in the field of education and capacity building.

We are now going to begin our educational funding. We would like to initially focus on vocational training for youths who have had some schooling but are now at a loose end, without jobs and without skills to start something on their own. We are not going to be running the training ourselves, but helping people to tap into vocational opportunities.

Early days yet, but what has been SILF's biggest achievement?

The biggest achievement has been the acceptance, on the part of people affected by leprosy, of funding as a means to start on a path of self-dependant and dignified livelihood generation. This is clearly reflected in their agreement to treat the funding as a loan to be returned to the community so that others can also benefit from the same kind of opportunity, and not as a handout meant to be used for consumption purposes.

What is the biggest challenge SILF faces?

At this stage in our development we have to contend with a certain amount of doubt and distrust about SILF's intentions and processes among colony leaders, but I am confident that as we work together these issues will be resolved over time.

How would you characterize the situation of persons affected by leprosy in India today?

It is difficult to give a generalized answer to this. The situation varies from place to place. On the whole, the stigma against the disease and people affected by it is less than it was 25 years ago. But there are wide differences, and in some remote areas people still have to struggle against intense social rejection.

Do you think SILF can make a difference?

Of course we can! Not merely in terms of funding a discreet number of projects as we are doing but in helping create that sense of confidence and empowerment that will enable people affected by leprosy and their families to pursue their dreams and see themselves — and make others see them — as an integral and equal part of society. ■

Steady Progress

Strategies to spread leprosy awareness in Cambodia include factory visits.

Cambodia's National Leprosy Control Program achieved the goal of eliminating leprosy as a public health problem at the national level at the end of 1998. Since then it has sustained its elimination status with a further decline in prevalence and detection rates.

At the sub-national level, elimination has been accomplished in 23 out of 24 provinces and 75 out of 76 operational health districts.

At the end of 2008, there were 242 active cases of leprosy under treatment in Cambodia, making for a prevalence rate of 0.17 per 10,000 population. The same year, 306 new cases were detected with a case detection rate of 2.2 per 100,000 population.

The proportion of multibacillary (MB), child, and cases with grade 2 disability among new cases in 2008 was 71.6%, 7% and 13%, respectively.

Early detection and treatment of cases with MDT continues to be a high priority. Work related to prevention of impairments and disabilities and rehabilitation of needy leprosy patients is receiving due attention. Efforts are being made to integrate leprosy control activities into the general health services at various levels in a phased manner. However, some indicators show there is still work to be done in sustaining an effective leprosy control service.

Among these, the child rate has remained steady at around 10% over the past 10 years. There have not been activities targeted at children such as special IEC materials or school surveys. The fact that this indicator has remained steady suggests that transmission of leprosy is still ongoing in the community.

EMPOWERING PEOPLE

One of the main focuses of 2009 has been to bridge the gap between communities and



Booklet on leprosy

health systems by empowering people with the knowledge to access diagnosis and treatment of leprosy. Strategies to achieve this include factory visits.

For one week in March-April and again at the end of August, leprosy awareness activities were

carried out at a total of 12 garment factories. These visits enable information to be distributed directly to thousands of workers. In addition, labor union members receive training on leprosy and become important volunteers. Another 15 factory visits are planned for 2010.

Two regional workshops held this year highlighted the fact that there is limited knowledge of leprosy in the community, especially among women. It was recommended that leprosy activities be integrated with the activities of women's associations in the community; also, that information be conveyed through midwives at health facilities as an easy way to transfer leprosy awareness directly to women. The workshops also identified a need to improve knowledge of leprosy among high school students in order to decrease levels of stigma in the community.

PARTNERS

The national leprosy program receives support from a number of partners, such as the WHO, CIOMAL, and Netherlands Leprosy Relief.

Among these, CIOMAL has supported the program since 1995, with an emphasis on finding, treating and curing new cases of leprosy. In addition, following an agreement with the Ministry of Social Affairs, Veterans and Youth Rehabilitation, it has also focused on developing facilities and services for the rehabilitation of people affected by leprosy. In 2000, it opened the Kien Khleang Leprosy Rehabilitation Centre, within the National Rehabilitation Center for Disabled Persons.

The leprosy center operates as a national referral center for patients with leprosy-related complications, and as an outpatient center providing consultations for suspected or new cases of leprosy. It provides medical, physical and surgical rehabilitation services, including reconstructive surgery for eye, hand and feet, treatment for hand and foot ulcers, and severe leprosy reactions. In the first six months of 2009, it saw 672 patients on an outpatient basis. Of these 210 consulted as leprosy patients, of which 12 new patients were diagnosed with leprosy.

NATIONAL DATABASE

A National Central Database has been installed that allows for central registration of cases and provides a wealth of information for assessing epidemiological patterns, performance of the program including management of reactions and drug supply. The database will help to target improvements and future activities. ■

AUTHOR:
Dr. Lai Ky



Dr. Lai Ky is in charge of Cambodia's National Leprosy Program.

Making and Unmaking the Asylum

How a “high modernist” approach to leprosy control was subtly subverted.

AUTHOR:
Syed Muhd Khairudin Aljunied

Syed Muhd Khairudin Aljunied is a lecturer in the Malay Studies Department of the National University of Singapore.

Alongside modern diseases such as AIDS and SARS or the H1N1 strain of influenza that is currently in the headlines, leprosy does not attract as much attention or the same level of research. Often, too, the voices of those affected by leprosy have been neglected or simply ignored.

Providing a corrective is *Making and Unmaking the Asylum*. At the center of Dr. Loh Kah Seng’s study are men, women and children from different ethnic groupings in Singapore and Malaysia who, as a result of being diagnosed with leprosy, ended up in sanatoriums such as Singapore’s Silra Home and the Sungai Buloh leprosarium north of Kuala Lumpur.

The book examines how a “high modernist” development ethos impacted on the history of leprosy in colonial and post-colonial Singapore and Malaysia.

As defined by social scientist James Scott, cited by the author, this is “a self-confidence about scientific and technological progress.”

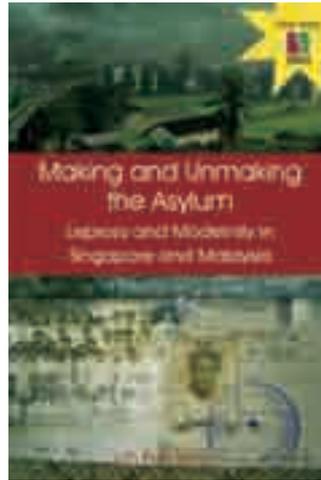
The ideology and practices that grew from this have had, according to Dr. Loh, paradoxical outcomes upon the management of leprosy in the two countries. On the one hand, the high modernist state’s will to clean up social

‘messiness’ — combined with the coercive powers to do so — led to the segregation of people affected by leprosy and near-total control over them by the state, which sought to protect society from an imagined social danger.

On the other hand, the author documents how the high modernist logic was subverted, or at least resisted, by the very people it sought to dominate. The majority for whom the asylums became their permanent home devised strategies to salvage their ‘bad’ lives. They formed friendships, married, practiced their religion and put on cultural performances. Some joined secret societies, gambled, smoked opium, trafficked in contraband items, and partook in riots and strikes. In so doing, they sought to contest and remake the terms of their confinement.

What this thoughtful and discerning study underscores is the need to be mindful of how people are treated, or mistreated, in the campaign against infection. Leprosy may be an old disease compared with modern pandemics, but the lessons it teaches are no less relevant for it.

Making and Unmaking the Asylum: Leprosy and Modernity in Singapore and Malaysia by Loh Kah Seng (SIRD, Petaling Jaya, Malaysia, 2009). ■



HERITAGE

SAVING SUNGAI BULOH

A small but committed NPO is engaged in an ongoing struggle to ensure that what remains of the former Sungai Buloh Leprosy Settlement in Malaysia is preserved as a heritage site. As the remaining population of people affected by leprosy declines, part of the site is already under redevelopment and the general public appears largely indifferent to its fate.

“The government has promised to preserve the place, but so far no official announcement has been made,” says Lim Yong Long, a core member of the Save Valley of Hope Solidarity Group who is currently working on a PhD at the University of Tokyo. Valley of Hope was the name given to what became one of the world’s biggest leprosy

settlements when it was built in 1930 in Malaya, then part of the British Empire.

In 2002, some 50 hectares were cleared to erect a hospital in the south of the settlement. More recently, in 2007, demolition work began in the eastern section of Sungai Buloh to make way for the medicine and dentistry faculties of Universiti Teknologi Mara (UiTM). The university buildings will include a number of high-rises. At the same time, residents from the western section are being relocated to wards adjacent to the construction site. “We are concerned about patients having to live next to such a high-density, high-rise environment,” says Lim. “It is not healthy for them.”

Some of the key research into leprosy

in the 20th century took place at Sungai Buloh. It was also a model of enlightened social control, with the leprosarium envisioned as a self-sustaining — albeit segregated — community.

Save Valley of Hope has held events to underline why it believes Valley of Hope is too important to be bulldozed and built on. Any chance of World Heritage status has been dashed, however, as the integrity of the site has been compromised by redevelopment.

“Malaysians don’t care much about heritage. They are utilitarian,” says Lim. But he hopes that Sungai Buloh will be preserved so that people now and in the future will be able to reflect on how their fellow human beings were treated in the name of disease control.

One-Woman Dynamo

Maya Prakash Ranaware is helping to improve conditions in Maharashtra's colonies.



Maya Prakash Ranaware: ambitious plans

When India's National Forum of persons affected by leprosy was established in 2005, it created a framework for realizing the potential of people like Maya Prakash Ranaware.

In 2006, Maya was selected as a National Forum state leader for Maharashtra. As a state leader, Maya represents the interests of some of Maharashtra's 58 self-settled leprosy colonies. Hard working and self motivated, she was chosen because of her leadership qualities and close association with affected persons and families in different colonies — as well as her zeal to improve their quality of life.

Maya's responsibilities include visiting 12 colonies in the southwestern part of the state, assessing their needs, informing them about National Forum activities, developing networks and forming self-help groups.

She lives with her husband and two daughters in Swadhar Nagar Shendapark Colony in Kolhapur. Swadhar Nagar is a self-settled leprosy colony that is home to 125 families. Maya is the child of a leprosy-affected mother and was born and brought up in the colony.

Now 30 years old, she was diagnosed with leprosy at the age of six, and completed her treatment in 1987. However, her family's economic circumstances meant she could not finish her education. Her mother was illiterate and was forced to beg. Even Maya had to beg once a week. She also worked as an agricultural laborer so that her family could survive.

Maya met her husband in 1996. Like her, he is a person affected by leprosy. The couple's children, aged 12 and 10, go to a local school in the city.

In addition to her work with the National Forum, Maya has established a women's association and three women's self-help groups in her community. The groups offer family

counseling, vocational training in tailoring and soap-making and are involved in environmental protection and AIDS awareness activities. With the help of various sponsors, they also provide educational assistance to children in the form of textbooks, notebooks and uniforms.

FAMILY PLANNING

Group members attach particular importance to family planning and Maya says they have all been motivated to undergo a family planning operation. As a result, among the younger generation living in the colony, two-child families are the norm.

Maya and colony members have to struggle very hard. She has organized *morchas*, which are meetings with local authorities, and she never hesitates to discuss the problems of the colonies with ministers and politicians.

She never hesitates to discuss the problems of the colonies with ministers and politicians.

As a result of her tireless efforts in Swadhar Nagar, Maya has helped people affected by leprosy to obtain ration cards, Below the Poverty Line (BPL) cards, financial aid under the Sanjay Gandhi Niradhar Yojana (government assistance scheme for the very poor), and housing under schemes such as the Valmiki Ambedkar Awas Yojana. Under these programs, central and state governments provide financial support to slum dwellers to construct residential housing. So far, 44 persons affected by leprosy have benefited, among them Maya and her family. A further 80 houses have been approved and work on them will commence soon.

Maya has already achieved a great deal for persons affected by leprosy, but there is much more she wants to do. Among her goals is to empower colony members by developing a cottage industry to produce thermacol plates, glasses, and bowls. She also wants to see that every child in the colonies goes on to higher education, that the older generation stops begging and that child marriages are prevented.

Says this determined lady, "We still have further to go." ■

Staying Focused on Leprosy

The Goodwill Ambassador visits a rural health center in south central Myanmar.



(Left) All smiles: Thida Myint, center, and friends; (above) health poster

MYANMAR (OCTOBER 25)

During a recent visit to Myanmar, I had the opportunity to visit a rural health center about 250 kilometers from Yangon. I was joined by Dr. Kyaw Myint, who is in charge of the Ministry of Health's Leprosy Control Program.

Myanmar achieved the goal of eliminating leprosy as a public health problem in 2003. Since then, it has worked to sustain the momentum of leprosy control activities, focusing on further reducing the burden of the disease, preventing disabilities and rehabilitation. The prevalence rate of the disease today is under 0.5 per 10,000 people.

Throughout the country, 3,383 new cases of leprosy were detected and treated with MDT in 2008. About 80% of these cases were detected by voluntary reporting, reflecting that fact that there was increased awareness of the disease in the community.

Notwithstanding the progress Myanmar is making, Dr. Kyaw Myint told me that it is crucial that the country continue its efforts to sustain leprosy control activities and establish an appropriate network for the care of persons with disabilities in order to minimize the physical, mental, economic and social consequences of the disease.

Kyun Kone Rural Health Center is one of five rural health centers in Taungoo township, Bago division, and serves a population of 36,000 people. The leprosy control program is represented by a district leprosy team leader,

a leprosy inspector and two junior leprosy workers.

In 2008, 37 new cases were discovered in Taungoo township as a whole. One patient was under 15 and seven had Grade II disability.

I met with seven people affected by leprosy — five women and two men — who told me about the various challenges they face as a consequence of the disease. One of these was Thida Myint.

Thida Myint is 36 and lives with her mother. She has two brothers and one sister. She was diagnosed with leprosy at the age of 18, when she was attending high school. She underwent treatment with MDT for a year, but had to drop out of school because of the state of her health and her family's straitened economic circumstances.

She is now attending sewing training for income generation. Although she has some disability, Thida Myint said she wants to be self-reliant, while looking after her mother as best she can. She also expressed her strong desire to give moral support and assistance to persons affected by leprosy and share her life experience with them.

I was very impressed with Thida Myint's attitude. Strengthening ties among people affected by leprosy is important, as is having a positive outlook in the face of adversity. I have no doubt that she will encourage and inspire many people. ■

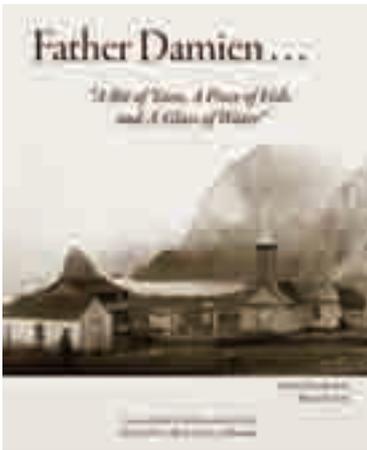
Keeping Tabs on Drug Resistance

Recent workshop underscores need for continuing surveillance.

A WHO Workshop of Sentinel Surveillance for Drug Resistance in Leprosy was held in Paris on October 26-27. The workshop, which was attended by approximately 40 participants including program managers and focal persons for surveillance from sentinel sites from endemic countries, agreed that continuing surveillance of drug resistance remained a relevant and vital initiative for the future.

A Sentinel Surveillance Network established by the WHO's Global Leprosy Programme (GLP) is currently operating in eight countries: Brazil, China, Colombia, India, Myanmar, Pakistan, Philippines and Viet Nam. Reference laboratories from Brazil, France, Japan, Korea, India, Switzerland and USA are collaborating with WHO and providing free testing services in support of the initiative.

'A BIT OF TARO'



Father Damien: 'A Bit of Taro, A Piece of Fish, and A Glass of Water' is a biography of Father Damien based on the accounts of people he lived and worked amongst at Kaluapapa in Hawaii. Published by the IDEA Center for the Voices of Humanity, the book came out in time for Father Damien's canonization in Rome earlier this year.

"With the recent canonization of Father Damien, we felt that it was important to include the voices of the people who knew him best and worked alongside him — those who had been sent to Kaluapapa because they had leprosy," says Anwei Skinsnes Law, who coauthored the book with husband Henry. "Most of the interviews in this book were done more than 70 years ago, yet they have not been included in previous histories/biographies. Thus, those who had leprosy, most of whom were Native Hawaiians, have been largely left out of previous accounts of Father Damien." ■

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FROM THE EDITORS

LIVING TESTIMONY

Three volumes of testimonies of residents of Kuryu Rakuseien Sanatorium in Japan have been published recently. As at the country's other leprosy sanatoriums, the population of Kuryu Rakuseien is elderly and in decline, and the residents took it upon themselves to produce a record of their experiences — often grim — of sanatorium life in days gone by.

While these books will serve as an important historical record when people look back on the era of forced segregation in Japan, they have a more immediate purpose. Because their numbers are decreasing, the aged residents anticipate the day when the sanatorium will be opened to other users. Indeed, both the surrounding community and the residents themselves are in favor of this — the former so that they have access to better medical care, and the latter so that medical personnel aren't cut back as the sanatorium's existing population shrinks.

Under such circumstances, the residents want the public to know about them, the discrimination they have endured, and what kind of lives they have led behind the sanatorium walls. If they are to share the space, they reason, they should also share their experiences. Behind this is a fear that they may be subjected to a new form of discrimination within the sanatorium that has become their home, if ordinary citizens question why the residents get their food, accommodation and healthcare for free.

To counter ignorance, suspicion, and prejudice, and in order to facilitate coexistence, these testimonies are the solution the residents devised. Without them, they feel, it may not be possible for others to truly understand what they have been through. Led by Mr. Yuji Kodama, the project took foresight, courage and tremendous determination. It represents a remarkable effort.