

FOR THE Elimination OF Leprosy

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



(L to R) Ram Barai Sah, Braj Kishor Prasad and Kamlesh Divyadarshi hand their report to Bihar Deputy Chief Minister Sushil Kumar Modi. (see pp.5-6)

MESSAGE

Unfinished Business

In May, the World Health Organization saw fit to extend my term as Goodwill Ambassador for Leprosy Elimination for another two years. I thank it for the trust it has placed in me and pledge to redouble my efforts.

An important part of my work is to keep leprosy and its attendant challenges in front of governments and health ministries. Fostering a better understanding of leprosy through responsible media coverage, giving encouragement to frontline health workers and promoting the involvement of people affected by leprosy in the fight against the disease are also key tasks.

In particular, I am keen to use my position to help build bridges between those affected by the disease and political and administrative leaders. This is important for ensuring access to appropriate diagnosis and treatment as well as for securing pensions, housing and better opportunities. I see this as part of the empowerment-building required to reintegrate this marginalized group into the social mainstream.

I have often used the image of a motorcycle in

describing leprosy work. The front wheel represents efforts to treat the disease and its aftermath, while the rear wheel is our work to reduce social stigma.

Thanks to multidrug therapy, leprosy is curable, and WHO has provided us with a road map for further reducing the disease burden, so the front wheel is running comparatively smoothly. But my travels have shown me that regular maintenance is necessary. To further reduce the case load, leprosy needs to remain a priority if we are to sustain quality services. Regarding the back wheel, I was able to be of some help in 2008 when the U.N. Human Rights Council passed a resolution to eliminate discrimination. I hope guidelines will be approved this year.

The word elimination has been given a specific meaning in the context of leprosy, and certain countries have yet to achieve this milestone. However, as Goodwill Ambassador, I stand for a world completely free from leprosy and the stigma and discrimination it attracts.

— Yohei Sasakawa, WHO Goodwill Ambassador

CONTENTS

Message	1
Report	
Sri Lanka	2
Interview	
Dr. Tilaka Liyanage, Director, Anti-Leprosy Campaign, Ministry of Health and Nutrition, Sri Lanka	3
Column	
Decoding Film for Social Change By Nick Deocampo	4
Ambassador's Journal	
India, Sri Lanka, Timor-Leste	5
News	
Everest Empowerment Expedition, Gandhi Prize	8
From the Editors	8

Keeping an Eye on Leprosy

Health ministry working to improve monitoring, focus on disability care.

Sri Lanka was one of the first countries in the WHO's Southeast Asia Region to eliminate leprosy as a public health problem at the national level. It reached this milestone — a prevalence rate of less than 1 case per 10,000 people — in 1995, 12 years after multidrug therapy (MDT) was introduced to the country in 1983.

Contributing to this achievement was a social marketing campaign launched in 1990 with the support of the Novartis Foundation for Sustainable Development. The aim was to change the image of leprosy and portray it as just another disease, in order to encourage persons with skin lesions to come forward for treatment and dispel the stigma associated with the disease.

The campaign made use of television and radio spots, TV soap operas, buses, billboards and more. It drummed home the message that leprosy is 100% curable and that skin patches are an early sign of the disease. Even today, people still sing songs from those TV dramas.

The year following the social marketing campaign, case detection increased by 150%. Self-reporting rose from 9% in 1989 to 50% in 1991, and has since become the norm.

CURRENT SITUATION

Sri Lanka is divided into nine provinces and 25 districts. Each district is further divided into administrative units known as Divisional Secretariat Divisions (DSDs). Health care is provided through Medical Officer of Health (MOH) areas that for the most part follow DSD boundaries. Each MOH office includes Medical Workers (MWs) and Public Health Inspectors (PHIs). On average, there is one MW for 3,000 people and one PHI for 10,000 people.

In 2009, 1,875 new cases of leprosy were detected nationwide. Almost half of these (47%) were found in Western Province, which includes the capital Colombo. There is one leprosy hospital in Hendala, outside Colombo.



Postage stamp commemorates tricentenary of Hendala Leprosy Hospital in 2008.

Established in 1708, it is home to 47 persons affected by leprosy. Compulsory admissions to the hospital were stopped in 1977, and admissions ceased altogether in 1982.

FULL INTEGRATION

Leprosy control was fully integrated into the general health services in 2001. It is coordinated at the central level by a team of four doctors headed by Dr. Tilaka Liyanage, director of the Anti-leprosy Campaign (ALC) under the Ministry of Healthcare and Nutrition (see Interview). The team is responsible for policy making, planning, monitoring, evaluation, training and research.

Since integration, it is mandatory for a diagnosis of leprosy to be made by a dermatologist. There are 48 dermatologists in the country.

However, although dermatologists may diagnose and treat patients, the follow-up is left to the patients themselves, and because of this there is a rather high number of defaulters. Treatment completion is difficult to confirm. Reaction and disabilities cannot be followed up.

Dr. Liyanage assumed her position last year. Since then, she and her team have been redesigning the system to improve defaulter tracing, contact tracing and health education of patients, including released-from-treatment (RTF) cases.

They have updated all registered cases since 2001 so that the trends of various indicators can clearly be seen. These indicators show that there is no reduction in case detection, even though Sri Lanka has achieved the elimination milestone; the number of patients with multibacillary leprosy as a proportion of all cases is increasing; the number of child cases remains static, indicating active transmission in certain pockets; and Grade II disability rates are still high in some districts, a sign of late diagnosis.

The ALC team have also revised Individual Patient Forms (IPFs) to make follow-up easier and to avoid duplicate registration. The forms also include 'relapse' and 'defaulter' information.

DISABILITY CARE SESSION

Starting this year, ALC has begun a series of Disability Care Sessions, with a focus on districts where there are cured cases of leprosy that have not been followed up on. Dr. Liyanage feels the disability aspect of leprosy has been neglected and that people have not been educated in self-care or made aware of the possibility of having corrective surgery.

At a Disability Care Session in Colombo in

May, around 15 people with varying degrees of disability attended. This was out of 30 who had been contacted about the session by postcard. Some came with family members. The session consisted mainly of teaching with the aid of PowerPoint presentations and foot-soaking exercises for people with ulcers.

There were talks by Dr. Liyanage and Dr. Kaushalyo Kastisaratchi of the ALC team, and by a physiotherapist and a nurse. A surgeon also attended as an observer. Participants received self-care kits containing medicine and bandages,

as well as a pair of sandals made from microcellular rubber (MCR). The MCR is imported from India and the sandals are made locally. Each patient with foot wounds gets two pairs a year. The program is funded by FAIRMED, a Swiss-based NGO working for Health for the Poorest.

At time of writing, 10 of these Disability Care Sessions had taken place, and more are planned, especially in districts where there are known to be cases that have been cured but where there has been no follow-up. ■

INTERVIEW

'STILL PLENTY TO DO'



Dr. Tilaka Liyanage, Director, Anti-Leprosy Campaign, Ministry of Healthcare and Nutrition

What were you doing before you took up your post at the Anti-Leprosy Campaign (ALC)?

Between 1989 and 2008 I worked for the filariasis elimination program. Sri Lanka was the first country in the WHO's Southeast Asia Region to eliminate filariasis and now is at the certifying stage. I was a member of the Global Alliance on Filariasis Elimination expert committee.

How did you feel about being assigned to ALC?

In the beginning I was a bit upset because I thought leprosy had already been eliminated and there would be nothing for me to do. Then I spent two days looking at the statistics and found there was plenty for me to do. There are still problems. I did not expect to find as many 'pockets' of leprosy and as many patients as there are. So I personally went to get a wall map and mapped out the situation. Then I saw how much there was to do and that gave me energy.

What did you do during your first year?

The whole of last year, I did my homework. I upgraded the software so as to have all the statistics in order at least since 2001. The leprosy control office has an outpatient clinic and I saw patients coming for ulcer care. I felt that disability care was a neglected area, and as a Buddhist I thought I should do something for all the patients. From this year we have started disability care sessions.

Did the civil war impact leprosy services in any way?

No it did not. Throughout those difficult years, health services continued and multidrug therapy (MDT) treatment was never disrupted.

Is stigma against leprosy prevalent in Sri Lanka?

No. The level of stigma is very low here. Most patients, including those with deformities, are accepted by their families and society. The general public knows that this disease is 100% curable. This is true in all parts of the country. There is no such thing as colonies of people with leprosy.

What challenges does the program face?

Leprosy still exists, but awareness of symptoms and the need for prompt presentation is lacking among the general public and even among health workers. More should be done to make early diagnosis possible and to reduce the leprosy burden, including leprosy-related disabilities, especially at the district level where there are hot spots. Another challenge is to reorganize and improve information systems for better defaulter tracing and follow-up reaction cases to ensure quality leprosy services.

Decoding Film for Social Change

Films can liberate us from our prejudices and fears if we understand what they mean.

Leprosy is no longer the scourge of times past. Yet the drugs that cure it hardly take away the scars of being misunderstood. Anyone suffering from leprosy continues to inherit the discrimination and stigma of the disease. The hardest wound to heal is human prejudice.

Film, in its representation of leprosy, can multiply our fears of the disease. But a few have the power to change our attitudes. In the Philippines, one film from the 1970s deserves notice.

In Lino Brocka's *Timbang Ka Ngunit Kulang* (You were weighed but found wanting, 1976), Berto suffers from leprosy. Assigned to the margins of society, he lives near a cemetery, inhabiting a space determined by human prejudice. Not yet dead, he is already made invisible in the eyes of a righteous society. Joining him is the crazed Koala, who becomes the village idiot after losing her mind due to forced abortion. Both end up as unlikely partners suffering from a small town's scathing verdict of their predicament. Together, they find that life is worth sharing despite their fates.

In representing these social "outcasts," does Brocka's film only mirror reality and so sensationalize the issue of disease? Or does the film reveal a truth about reality and give us a better view of ourselves, no matter how painful the sight we see on screen?

By yielding its capacity merely to entertain, the film fulfills its role as healer, even as teacher. It speaks a visual language that, while articulating marginality, produces empowerment, since knowledge helps us to understand even our own human errors and makes us better persons.

ALLY OR ENEMY?

In the introductory scene where Berto walks against a crowd leaving a cemetery, he is located in a film space that underlines his marginality. He is found at the extreme left of the frame close to the tombs, almost scraping them as if to disappear into their dark catacombs. No one takes notice of him until a child falls and the mother utters words filled with horror and intimidation upon seeing Berto help her child get up: "Don't hold her, Berto! She might get infected." These are words that — even if not meant to condemn — condemn the speaker of her own prejudice. A judgment has been rendered. And we know why. The next shot shows a disfigured face, the face of leprosy.

The scene is emblematic of how "normal" people harbor fear toward those who are different. And it is contentious: in showing a person discriminated against because of leprosy, one could argue that the film perpetuates discrimination. This is where film may be seen either as an ally or an enemy.

Knowledge is created through the camera's

gaze diagnosing what is wrong with the scene. The way the scene is set up, it is as if we are looking at ourselves in the mirror in a ritual of self-examination. And like the mirror, the screen gives us back an image that we must work upon: a face that must be cleaned of dirt.

Knowledge is created through the camera's gaze diagnosing what is wrong with the scene.

But the film is not all self-recrimination; it also seeks redemption. In the only scene showing nature, three characters — Berto, Koala and the young protagonist, Junior — are framed in a triangular composition. The first two are at the base and Junior is at the apex. The triangle symbolizes what is being implied by the scene.



A lesson encrypted in the sign of a triangle

Berto talks about the discrimination cast on characters like him. He does so with understanding rather than anger. He offers compassion to those who commit prejudice because, he says, we must look at people with our hearts.

Junior, at the apex of this composition, is held up as the new bearer of this knowledge. With identification as film's powerful trait to make audiences empathize with the story, Junior becomes us. Thus, as Berto passes on the lesson of understanding and compassion to Junior, the knowledge is passed on to us. We are the ones who must change.

This lesson is encrypted in the sign of a triangle, which, since ancient times, has been an archetypal image loaded with metaphysical meanings about eternal ideals and universal truths.

Film can be a powerful medium to discriminate, but it can also liberate us from our prejudices and fears if we try enough to understand what they mean. Film, as a collective mirror, becomes a redemptive tool for social change. ■

AUTHOR:

Nick Deocampo



Nick Deocampo is a prizewinning Filipino filmmaker, author and film historian. Between 2001 and 2002 he was a fellow under The Nippon Foundation's Asian Public Intellectuals Fellowships Program.

Empowerment in Action

The Goodwill Ambassador visits India — twice — as well Sri Lanka and Timor-Leste.

INDIA (APRIL 9-14, MAY 9-11)

In April and May I visited India twice, on both occasions traveling to Bihar State. As it turned out, these visits yielded significant results, as I shall relate below. But my first item of business was in New Delhi, where I attended the board meeting of the Sasakawa-India Leprosy Foundation on April 10.

Established in 2007 with an endowment of US\$10 million, SILF provides micro-credit loans to individuals and groups in India's self-settled leprosy colonies. With these loans, residents are able to start or expand their businesses. To date, SILF has supported 59 projects, approving loans totaling over 10 million rupees.

Expectations among colony residents are so high that it is not possible to act on every loan request. To meet this need, it will be necessary to solicit donations within India and increase the size of the SILF endowment, which generates the interest that finances the loan program. SILF has formed a fund-raising committee which will start work soon.

The next evening I flew to Patna, capital of Bihar State. Home to some 100 million people, Bihar has a bigger population than many countries. During the year from 1 April 2009 to 31 March 2010 there were 21,431 cases of leprosy detected in the state. The prevalence rate at the end of March was 1.08 per 10,000 population. Of its 38 districts, just 10 have a prevalence rate of less than 1. There is much unfinished leprosy business in Bihar, yet at the time of my visit, the position of state leprosy officer was vacant.

During my stay, I had several meetings with top officials to discuss the problems of people affected by leprosy in the state — one of India's poorest. Beforehand, however, I went to see situation on the ground for myself.



SILF board meeting in New Delhi on April 10

I visited three colonies in East Champaran District, about a two-hour drive from Patna. My guides included members of Bihar Kashta Kalyan Mahasangh (BKKM), an umbrella group of associations of people affected by leprosy in Bihar, and representatives of the National Forum of people affected by leprosy. The three colonies I visited were Motipur, Chakia and Pipra. The latter was the scene of a tragedy earlier this year when a young boy died in an arson attack related to a land dispute.

The colonies contend with a range of issues. Motipur lacks toilets, has homes that leak in the monsoon season and suffers from the non-payment of pensions to which some residents are entitled. At Chakia, residents' homes are under threat as the road they live alongside is to be widened. Generally speaking, the colonies lack basic amenities; job opportunities are few and many residents must beg to make ends meet.

I also took the opportunity to visit the Lalganji Primary Health Center in Vaishali District. The health center serves a population of 320,000 and sees around 200 outpatients a day. In April, there were no new cases of leprosy registered. Currently, 22 people are receiving multidrug therapy. I was told that some people with leprosy prefer to go to Patna for treatment to keep their condition a secret from their neighbors.

On April 13, accompanied by BKKM president Kamlesh Divyarshi, I called on State Health Minister Nand Kishore Yadav. I requested that he find a good candidate to fill the vacant leprosy program officer's position, and also that he take steps to improve conditions for people living in colonies.

The minister said he would think about creating a category of disability pension that would cover people affected by leprosy. He also said he would consider giving priority to persons affected by leprosy under schemes for the welfare of those sections of society living below the poverty line.

Next I met with Sanjay Kumar, the executive director of the National Rural Health Mission (NRHM). Mr. Kumar is a no-nonsense figure who radiates authority. He said that if he was given the base-line data, he would quickly deal with the issue of pensions and living conditions.

This was an opportunity not to be lost. Leaders of the National Forum met with representatives of Bihar's leprosy communities and agreed to compile a list of names of affected persons and their >>



A resident of Chakia colony, one of 63 self-settled leprosy colonies in Bihar State that were surveyed earlier this year.

circumstances and present it two weeks' later. I agreed to return and accompany them when they handed over their fact-finding report.

Early in May, receiving word that the survey had been completed, I traveled back to Bihar from Sri Lanka, where I had been visiting. Sitting down with BKKM's Ram Barai Sah, Braj Kishor Prasad and Kamlesh Divyadarshi the night before we were due to present the findings, I marveled at their achievement. In just 15 days, they visited 997 households in 63 colonies in Bihar and found out all they needed to know about land ownership, living circumstances, and whether the householders were receiving pensions. It was a remarkable effort.

In just 15 days, they visited 997 households in 63 colonies in Bihar.

The next day, survey in hand, we called on Executive Director Kumar of the NRHM, Health Minister Yadav and Bihar Deputy Chief Minister Sushil Kumar Modi. After Executive Director Kumar had heard us out, he said that he would like to arrange discussions over four or five days between BKKM representatives and the state government. He promised that the issue of land and pensions could be solved in a month or so.

When we met with Minister Yadav, he studied the report with a stern expression. "While existing measures may be able to deal with some of these issues, we will need to outline some new policies to extend assistance to people affected by leprosy. I will discuss this with the appropriate officials," he said. For his part, Deputy Chief Minister Modi also pledged his assistance and undertook to see

that the issues were taken up.

Given that state governments wield considerable power in India, I believe it can be more effective to work at the state level than at the national level in order to improve the lives of people affected by leprosy. Therefore, it is important to create opportunities for dialogue between leaders of affected persons and top state officials, of the kind that took place in Bihar this time.

Moreover, it made all the difference that the survey was conducted by people affected by leprosy as they are familiar with the issues and have a good rapport with the people they were surveying. Indeed, their survey showed there were 63 colonies in Bihar, whereas government records listed only 25.

I would like to see similar surveys carried out in other states, with Bihar as the model. In the meantime, I await the outcome of the state officials' deliberations.

SRI LANKA (MAY 2-8)

In early May I made my first visit to Sri Lanka in three years, and my third visit in total. Sri Lanka eliminated leprosy as a public health problem in 1995. It also has an excellent record of reducing the stigma attached to the disease. However, a number of leprosy hotspots remain. Therefore, in my meeting with Health Minister Maithripala Sirisena on May 3, I sought his cooperation in ensuring that the ministry remains focused on leprosy and that it continues to build on the very good work that Sri Lanka has already done (see Report on pp. 2-3).

After a briefing from Dr. Tilaka Liyanage, who heads the ministry's leprosy program, I visited Hendala Hospital, a leprosy hospital about 10 kilometers north of the capital, Colombo. The hospital was founded by the Dutch over 300 years ago, and on my tour of the premises I was shown a foundation stone inscribed with the date 1708.



The men's ward at Hendala Hospital, outside Colombo

In times past, leprosy patients were forcibly admitted to Hendala, but the hospital stopped taking new admissions in the early 1980s. Today Hendala is home to 47 men and women ranging in age from 35 to 103 who have chosen to remain there because they have nowhere else to go. The oldest inhabitant, 103-year-old Mr. Tisahami, is even older than Perry, a resident of the former National Leprosarium in Carville, Louisiana, whom I met when I visited the United States last year.

Sri Lanka has made great progress in fighting leprosy, despite the disruptions caused by the prolonged civil war, and I feel certain that one day it will be able to eradicate the disease altogether.

TIMOR-LESTE (MAY 19-21)



Scene from the Goodwill Ambassador's recent visit to Oecussi-Ambeno enclave, Timor-Leste, in May

In May I also made my third visit to Timor-Leste, when I was invited by the government to attend the eighth anniversary of the country's independence. Timor-Leste is one of just two countries that have yet to eliminate leprosy as a public health problem, so I used the opportunity to meet those engaged in leprosy control activities and to encourage them in their efforts.

When the Health Ministry of the newly

independent country launched its national leprosy elimination program in 2003, Timor-Leste had a leprosy prevalence rate of 7.5 per 10,000 people. Together with the WHO and The Leprosy Mission International (TLMI), it engaged in capacity-building of personnel, early detection and ensuring access to a stable supply of the drugs used in multidrug therapy.

As a result of these efforts, the prevalence rate fell to 1.52 by 2009. Today, of Timor-Leste's 13 provinces, 8 are already past the elimination milestone. However, there is still work to be done.

During my stay, I called on the TLMI offices in Dili, the capital. TLMI is the only international NGO operating in Timor-Leste on behalf of people affected by leprosy. Next, I sat in on a training session for health volunteers from surrounding villages who were being taught about leprosy. The Integrated Community Health Service (SISCa) volunteers, who are drawn from the local community, play an important supporting role given the country's small number of medical personnel.

On my last day in Timor-Leste, I flew by helicopter to Oecussi-Ambeno District. This was my second visit to this coastal enclave separated from the rest of the country by West Timor, which is part of Indonesia. Oecussi-Ambeno has a very high PR of 6.39 per 10,000 in a population of 60,000. By way of partial explanation, this was an area where people with leprosy congregated at the beginning of the 19th century.

My destination was a rehabilitation center about 40 minutes by car from the helipad. This was built by TLMI in 2008 and is jointly operated with the health ministry. It serves both persons who have been treated and cured of leprosy but have residual disability, as well as others with disabilities unrelated to leprosy. When I visited, some 40-50 persons were undergoing rehabilitation.

While in Oecussi-Ambeno, I was concerned at the talk I heard about the high number of cases in children aged between three and five. If true, this would be most unusual, and the WHO needs to dispatch an expert to find out exactly what is going on.

After eight years of independence, Timor-Leste still faces a mountain of challenges. However, I am hopeful that it will be able to resolve one of them — the elimination of leprosy as a public health problem — in the not too distant future. It has my full support. ■

Scaling the Heights

Mount Everest 'Leprosy Empowerment Expedition' Planned for 2011



Rehabilitation, Empowerment and Development (READ) Nepal and Helping Assist Nepal's Disabled (HAND) USA have announced plans to conduct a joint Mt. Everest Leprosy Empowerment Expedition in spring 2011.

The object of the expedition is to change the behavior and attitude of the community toward

leprosy and inspire those affected by the disease by showing that leprosy need not be a barrier to ascending the world's highest mountain.

From 15 people affected by leprosy selected for training, five will be chosen for the Everest expedition. The successful candidates will be accompanied by two sherpas each on the climb.

Brian Smith, the founder of HAND, reached the summit of Mt. Everest in 2007.

READ President Raj Kumar Shah, himself a person affected by leprosy, says, "We want to show that people affected by leprosy are capable of doing anything and that the disease should not act as a physical or mental barrier to achieving one's dreams."

For more information, visit www.readnepal.info

INTERNATIONAL GANDHI AWARD

The winners of the 2009 International Gandhi Award for persons or organizations that have made an outstanding contribution to leprosy work have been announced. They are Vidarbha Maharogi Sewa Mandal, a non-governmental organization in the Amravati District of

Maharashtra, India, and Dr. Vijaykumar Pannikar, former team leader of the World Health Organization's Global Leprosy Program.

The award, established in 1986, is in memory of Mahatma Gandhi's service to leprosy and his scientific approach to the disease. ■

FROM THE EDITORS

OUT OF AFRICA

As an African, Dr. Bide Landry is justly proud of the achievements his continent has made in tackling leprosy. When the WHO first committed to the idea of globally eliminating the disease as a public health problem in 1991, few thought that Africa would be up to the challenge. But time has proved the doubters wrong. Africa as a whole reached this milestone in 2000, and by 2007 every country had done so.

But as well as being proud, Dr. Bide, the leprosy point man at the WHO's Africa regional office, is also concerned. Although every country in Africa has achieved elimination, leprosy is still there. High morbidity diseases and high mortality diseases are attracting more attention, while program capacity and financial support at the country level are decreasing. Political commitment is also waning as leprosy is no longer seen as a public health problem. Health workers trained in leprosy are losing their knowledge and motivation as they see fewer

cases. Meanwhile, the stigma attached to leprosy remains strong, and is difficult to root out.

To make sure that leprosy continues to disappear and does not make a comeback, there needs to be an effective surveillance system, says Dr. Bide. There must be a focus on pockets of leprosy where new cases are being observed. He also favors a regional target, one that suits Africa yet supports globally agreed strategic goals. "We need to have more advocacy, we need more political commitment. We need more visible success to show politicians," he says.

These and other issues are to be discussed at the National Leprosy Program Managers Meeting for the WHO's African Region, which takes place in Brazzaville, ROC, this month. "In my opinion," says Dr. Bide, "we should consider the eradication of leprosy as an important and ambitious target, not a dream. But in the current context, it is a long way off." He anticipates some lively discussions when the meeting begins.

FOR THE ELIMINATION OF LEPROSY

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