

# FOR THE Elimination OF Leprosy

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



Two residents of Quoc Qai Leprosy Treatment Center in Ha Tay Province, Vietnam, pictured in September 2007.

**MESSAGE**

**CONTENTS**

## Say No to the L-Word

In recent months, a couple of newspaper articles were brought to my attention in which reporters used the word “leper.” Both articles were about Sorok Island in South Korea, where a bridge has been built to link the island, once a leprosy colony, to the mainland. In these otherwise well-written accounts of the island’s history, and of the expected impact of the new bridge on the lives of residents, it was disappointing to see the *New York Times* and Britain’s *Independent* make use of this pejorative term.

I can’t say this came as a surprise. The L-word has long been used by journalists and headline writers, and there are many other examples I could cite; after all, the term has been around since the Bible, and is part of the English language.

But “leper” is a loaded word. It carries all the unfortunate associations from the days when people with leprosy were routinely treated as social outcasts and declared unclean. Stigmatizing and discriminatory, it is hurtful and odious to anyone affected by the disease.

To define a person, let alone his or her entire existence, by leprosy is unacceptable. This is even more so today now that the disease, which is completely curable, is just a chapter in a person’s life.

In some countries, including my own country Japan, even the word “leprosy” is considered stigmatizing. Nothing, however, compares with reducing a human being to the status of a “leper.”

I take every opportunity to dissuade people from using the L-word, including writing letters to newspaper editors, but it is an uphill battle. I feel that responsible media organizations, with their enormous reach and influence, should show more sensitivity. Simply by avoiding the use of discriminatory terminology, they can play an important role in correcting distorted views of leprosy, and in lessening the stigmatization of those it affects.

Once again, I urge everyone, please stop using the L-word.

— Yohei Sasakawa, WHO Goodwill Ambassador

<b>Message</b>	<b>1</b>
<b>Geneva Report</b> Lobbying the Human Rights Council	<b>2</b>
<b>Document</b> Written Statement submitted by The Nippon Foundation	<b>3</b>
<b>Feature</b> Leprosy in the Pacific By Jane Buckingham	<b>4</b>
<b>Opinion</b> We are not ‘lepers’ by Jose Ramirez, Jr.	<b>6</b>
<b>Ambassador’s Journal</b> Vietnam, Switzerland	<b>7</b>
<b>News</b> China; booklet; NTDs	<b>8</b>
<b>From the Editors</b>	<b>8</b>

# Lobbying the Human Rights Council

Making the case for leprosy to be treated as an issue of discrimination

WHO Goodwill Ambassador Yohei Sasakawa led a delegation to the Sixth Session of the United Nations Human Rights Council (HRC) in Geneva in September, on a mission to persuade council members to take up leprosy as a human rights issue. It was his first approach to the HRC, the successor to the Human Rights Commission, since it was formed last year.

A written statement submitted earlier by The Nippon Foundation, of which Sasakawa is chairman, described leprosy as an issue of “multifold discrimination on a far-reaching scale” and urged the HRC to develop a set of principles and guidelines “for defending the human rights of people affected by leprosy.”

This message was backed up during the plenary session by an oral statement delivered on Sasakawa’s behalf by Dr. P. K. Gopal, president of IDEA\* India, which noted that people affected by no other disease continue to suffer discrimination even after they are cured.

Representing the Japanese government, Ambassador Ichiro Fujisaki, Japan’s permanent representative in Geneva, requested that the issue of leprosy and human rights be taken up as a formal agenda item by the HRC. He also expressed his government’s commitment to work alongside Sasakawa, who he said had been appointed as Japan’s goodwill ambassador for promoting the human rights of people affected by leprosy.

## PARALLEL SESSION

Leprosy and human rights was also the subject of a September 25 workshop hosted by The Nippon Foundation and Sasakawa Memorial Health Foundation.

Chaired by Professor Kenzo Kiikuni of SMHF, the meeting began with introductory remarks by Goodwill Ambassador Sasakawa, followed by presentations by panelists from three countries.



At the parallel session on leprosy and human rights

Dr. Arturo C. Cunanan, head of the Culion Leprosy Control and Rehabilitation Program, Culion Sanitarium and General Hospital, the Philippines, provided a structural analysis of discrimination against people affected by leprosy and how it can be eradicated.

Dr. P. K. Gopal highlighted the existence of discriminatory legislation in India and cited examples of human rights violations in which people affected by leprosy had been denied access to public places such as temples and hotels.

From Brazil, Artur Custodio, national coordinator of MORHAN\*\*, and Dr. Lavinia Schuler Faccini, a professor at the Federal University of Rio Grande do Sul, described the leprosy situation there and MORHAN’s successes in empowering people affected by the disease.

There was also a videotaped message from Professor Yozo Yokota, former special rapporteur on leprosy for the Sub-Commission on the Promotion and Protection of Human Rights.

## GOVERNMENT RECEPTION

In the evening, Japan’s Permanent Mission to the UN in Geneva hosted a reception attended by about 140 guests, including ambassadors and ministers from 60 countries.

In his speech of welcome, Ambassador Fujisaki said that discrimination against people affected by leprosy was a blot on humanity and that Japan, which has its own history of such discrimination, was committed to raising awareness of the issue — hence its appointment of Sasakawa as a goodwill ambassador.

For his part, Sasakawa emphasized that the issue of leprosy and human rights must be dealt with as an issue of discrimination rather than as a “right to health,” since society continues to marginalize people even after they have been cured, and discriminates against their family members as well.

Also present was High Commissioner for Human Rights Louise Arbour, who paid tribute to Sasakawa for drawing attention to the way that ignorance and intolerance greatly aggravate the effects of leprosy on those who suffer from it.

IDEA India’s Dr. Gopal, who was making his third trip to Geneva to highlight the human rights aspects of leprosy, was upbeat about his latest visit. “This time there was much support from many people. I had good dialogue with ambassadors from different countries and they promised to support our work. This represents great progress, and we need to ensure that it continues.” ■

## Reference

\* International Association for Integration, Dignity and Economic Advancement

\*\* Movement to Reintegrate People Affected by Hansen’s Disease

# Discrimination Takes Many Forms

Need for greater awareness, and establishment of principles and guidelines

*The following is excerpted from the text of the Written Statement submitted to the Sixth Session of the United Nations Human Rights Council by The Nippon Foundation, an NGO in Consultative Status on the Roster, on August 31, 2007. The full text can be found on the UNHRC website.*

People affected by leprosy are denied the basic human rights, as proclaimed in the *International Covenant on Economic, Social and Cultural Rights*, to which all human beings are entitled. These include:

- **Self-determination** (Article 1): In the case of leprosy-affected people, they do not determine the course of their lives; instead, they are defined by a disease that places severe social and economic constraints on them.
- **Right to work** (Article 6): Attitudes toward leprosy make it harder for someone affected by the disease to find work, and a diagnosis of leprosy can result in dismissal.
- **Just and favorable conditions of work** (Article 7): Wage abuse is a serious problem. People who are desperate for a mouthful of food do not have the leverage to fight back, especially when stigmatized by leprosy.
- **Protection for the family** (Article 10): Leprosy can tear families apart, even today. Moreover, finding a marriage partner can be difficult for those affected by the disease, and even for their family members, depriving them of the opportunity to start families of their own.
- **Adequate living standards** (Article 11): In any given country, people in leprosy villages, colonies, or sanatoria face financial difficulties because of the lack of job opportunities open to them, forcing them to endure substandard living conditions.
- **Physical and mental health** (Article 12): Social rejection, lack of education and financial constraints make good health difficult to attain. Frequently, people affected by leprosy and their family members are seized by feelings of shame, thus adding “self-stigmatization” to the burden they must bear.
- **Education** (Article 13): Schools will often deny access to children affected by leprosy, or to the children of a parent affected by the disease. Further, lack of income and the

## Leprosy FACTS

At the Fifth International Leprosy Congress held in Havana, Cuba, in 1948, it was decided that the use of the term “leper” be abandoned in favor of “leprosy patient” or similar; that the use of any such term, in any language, to which unpleasant associations are attached should be discouraged; but that the term “leprosy” be retained as the scientific designation for the disease.



Dr. P.K. Gopal reads from the Oral Statement to the Sixth Session of the Human Rights Council on September 24, 2007: “Tens of millions of people cured of leprosy and their families are marginalized from society, suffering from stigma and social discrimination.”

remote location of leprosy villages also erect barriers to being educated.

- **Right to take part in cultural life** (Article 15a): A person affected by leprosy’s geographical as well as social isolation denies him or her access to culture.

... [W]e would like to call upon the Human Rights Council to:

- build on the work of the [UN] Sub-Commission [on the Promotion and Protection of Human Rights] and take up leprosy and human rights as an issue of discrimination, studying the subject as a distinct and separate item;
- appoint a Special Rapporteur to make fact-finding visits to countries concerned and investigate the condition and circumstances of individuals and groups affected by leprosy, interviewing not only residents of sanatoria and colonies, but also those living in the community, as well as persons working on their behalf;
- organize seminars to which all stakeholders, particularly representatives of persons affected by leprosy, are invited, and mobilize stakeholders to create a platform to formulate principles and guidelines ending leprosy-related discrimination; and
- issue a set of principles and guidelines that can be applied by all stakeholders, including governments, UN agencies, and NGOs, to eliminate the disease, end leprosy-related discrimination, and reintegrate all those subject to such discrimination. ■

# Leprosy in the Pacific Islands

Ongoing research project records memories of past patients.

*Interviews conducted are deposited in Macmillan Brown Library, University of Canterbury, New Zealand.\* Permission to consult these and other records in the Pacific Leprosy Foundation collection held in Macmillan Brown library must be obtained in writing from: Pacific Leprosy Foundation, 115 Sherborne St., Christchurch, NZ.\*\**

It is easy when considering a terrible affliction like leprosy to forget the humanity of those with the illness and the capacity of some sufferers to return to normal family and working life despite periods of separation from their community and the physical ravages and marks of the disease on their bodies.

In August 2004 I accompanied an oral historian to Fiji in the South Pacific to participate in interviewing a group of people who had experienced isolation and separation from their families and communities on the island of Makogai, off the coast of Suva.

The transportation of people with leprosy from the Pacific region to Makogai Island began in 1911 when Makogai became the base for leprosy care in the Pacific. The Central Leprosy Hospital was built on the island with Fijian government funds and the support of the British Colonial Office. It was staffed principally by Roman Catholic nuns who volunteered to nurse the patients despite the stigma and fear of the illness at the time. The Central Leprosy Hospital served the South Pacific and patients were sent to the island by government health authorities throughout the region.

Such was the stigma and difficulty of treating the disease that patients feared that they were being sent to their death. However, of the 4,500 patients treated on Makogai only 1,500 died and remain buried on the island. Most returned home, their condition improved or in remission.

## IMPACT OF DAPSONE

By 1969 the incidence of leprosy in the Pacific had declined and the facility was closed. Most of the few remaining individuals either returned home or were relocated to semi-permanent residential care at P.J. Twomey Hospital, built in the same year at Tamavua Heights, Suva, with funds from the New Zealand-based Leprosy Trust Board, now the Pacific Leprosy Foundation.

The closure of Makogai as a leprosy isolation and treatment area was largely a consequence of the emergence of Dapsone as the first antibiotic effective against *Mycobacterium Leprae*, the

organism that causes leprosy. Although the later development of drug-resistant strains of leprosy in some of the Makogai patients was to dampen the hope of the drug as a complete cure, from the 1950s when it was introduced, it offered hope.

As an easily distributed and administered oral antibiotic the drug gave patients on Makogai the opportunity to be free from their disease and from the constraints of in-patient hospital treatment, which had previously relied substantially on painful injections of Chaulmoogra oil. More than this, the early effectiveness of Dapsone enabled most patients to return home to their villages and towns throughout the Pacific.

Visiting the P.J. Twomey Hospital in Suva and some of the homes and villages in the neighboring areas we interviewed 15 people — 10 men and five women, of whom 12 were from the Fijian islands, two from Tonga and one from the Gilbert Islands. Most had been brought as children to Makogai by government boat, leaving behind home, family, friends and their schooling. Some of those interviewed had been on Makogai during the early days of Dapsone treatment and had been able to return home well before the closure of the Central Leprosy Hospital, their illness under control, if not completely cured.

While leprosy undoubtedly caused physical and personal hardship, what surprised us was

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Jane Buckingham



Dr. Jane Buckingham is senior lecturer in History at the University of Canterbury, Christchurch, New Zealand. She has published on leprosy in India and has just won a Marsden research grant to investigate the history of leprosy in the South Pacific.



Wati Maria (left) and Polutele: old friends from the Makogai days

the number of patients from Makogai who had been able to return to village life despite their years away.

Volau was one man who after being sent to Makogai as a child had been able to return to his home village on Lakeba Isand after successful treatment with Dapsone. On Lakeba he had taken up a traditional life of farming, had married and raised children and, though he was in his seventies, was fit and strong when we met him. Diabetes had made necessary a temporary return to hospital for leg amputation and it was this, rather than his long struggle with leprosy, that he feared would inhibit his continued active life.

**Some felt they would always be the refuse of Pacific society, 'thrown away like paper'.**

Not all were so fortunate to be able to resettle at home. Some had no family to return to or felt unwelcome there. Others were unable to manoeuvre a wheelchair in the confines of a village house and feared causing embarrassment to family unaccustomed to seeing them move around on the floor with their hands, the only other option when damage to feet and hands made either walking or moving with crutches impossible.

For those who remained at the hospital the friendships they had made at Makogai continued to sustain them and provided the core of community and home life they otherwise missed. They ate together and prayed together each day, shared the enjoyment of visitors and kept each other company through long and often tedious days. Many strived to practice some craft or trade.



Polutele and some of his shell carvings

Solute was an accomplished seamstress, continuing the skills taught by the nuns on Makogai to add to her income. Those men who were still able practised wood and shell carving, making pendants and earrings to be sold on the markets. Polutele, though barely able to hold a saw, still managed to carve out some beautiful shell work.

### NEEDLEWORK

One of the happiest stories was that of Maria, who after spending her childhood and much of her adult life on Makogai returned to Fiji to live with her daughter, son-in-law and three grandchildren in a home built for them with funds raised by her son and his wife's family in America. Maria and her daughter worked together making and selling patchwork quilts, rag rugs and other needlework crafts, all learned from the nuns on the island.

The family also remained close to their friends at Twomey hospital and the children visit and play with their grandmother's companions from the island days without fear of the illness that had originally set them apart from home, community and friends. Sadly, Maria's daughter has died since our visit. Many of the former leprosy patients have also died since being interviewed.

The vast majority of patients left Makogai, their illness arrested, and went back to village and family life and so were not part of the small group we interviewed on this occasion at P.J. Twomey Hospital. Other visits to Pacific Island communities to talk with those who returned home about their experience of building new lives after Makogai form part of a larger ongoing research project.

All those interviewed in Fiji had endured physical and personal hardship because of leprosy. Some felt they would always be the refuse of Pacific society, 'thrown away like paper' but for others life had offered family, home, work and a relatively normal existence, illness and long separation on Makogai notwithstanding.

Despite their initial fear, most had very happy memories of Makogai as a beautiful island where they made close friendships and felt loved by the sisters who cared for them.

*Funding for conducting these oral history interviews and preparing them for archival deposit was generously provided by University of Oxford, International Leprosy Association Global Project on the History of Leprosy, Wellcome Unit for the History of Medicine, 45-47 Banbury Road, Oxford OX2 6PE, United Kingdom. [www.leprosyhistory.org/](http://www.leprosyhistory.org/)* ■

#### Reference

\* <http://library.canterbury.ac.nz/mb/>

\*\*[www.pacificleprosyfoundation.co.nz/makogai.html](http://www.pacificleprosyfoundation.co.nz/makogai.html)

# We Are Not ‘Lepers’

Jose Ramirez, Jr. wrote this article 10 years ago. A decade on, his message still needs to be heard.

The recent deaths of two beautiful ladies — Diana, Princess of Wales, and Mother Teresa — have dramatically enhanced the opportunities for many individuals throughout the world to offer their support to a cause normally ignored by the public\*.

However, the untimely deaths of these two women have opened up old and painful wounds for those of us so heartlessly referred to as “lepers” — probably the most offensive word in the world.

Dictionaries define “leper” as “a person ostracized due to moral condemnation ... a pariah ... unclean ... the living dead.” While alive, Princess Diana and Mother Teresa embraced the acceptance and understanding of leprosy. Regrettably, after their deaths, the L-word has assumed an increased level of prominence and appears to be on everyone’s lips.

**“The first time I was referred to by the L-word was on the day of my diagnosis.”**

The Bible has historically legitimized the use of the L-word. Many journalists, gossip columnists, editors of religious articles, sports writers and users of the Internet have recently found it acceptable to use this odious word when attempting to cite examples of sin, hopelessness, failure, stigma, fear, dark humor and unacceptable comparisons.

Unfortunately, there have been instances that have perpetuated the spread of grossly inaccurate myths. For example, issuance of special money for use in leprosaria, sterilization of persons with leprosy, fumigation of mail, laws to incarcerate and/or divorce anyone with leprosy, and denial of rights such as voting.

## ‘NOTHING TO FEAR’

The first time I was referred to by the L-word was on the day of my diagnosis in 1968. After months of going to physicians, dermatologists and curanderos (folk healers), I was finally diagnosed with Hansen’s disease, more commonly known as leprosy. The public health official who informed me of my diagnosis attempted to reassure me that there was “nothing to fear” and that I would soon be back on my feet. He was telling me this while referring to me by the L-word. My family was morbidly silent and the hospital initiated a strict plan of isolation, forcing visitors and medical staff to be shrouded in caps, gloves, gowns and masks

when entering my room.

The necessary course of treatment forced me to be transported to the only leprosarium in the continental United States, located in Carville, Louisiana, 20 miles south of the gates of Louisiana State University in Baton Rouge. Ironically, the 700-mile trip from my home town of Laredo, Texas, was in a hearse — allegedly ambulances were not available for the trip.

This unique hospital\*\* is approximately 50 yards from the Mississippi River, separated by a carefully rounded levee and narrow road. “Carville” as the hospital is known worldwide, was my home for seven years. For others, this has been their only home for over half a century due, in part, to antiquated state laws that governed the mobility of persons with leprosy.

Carville has beautiful architecture, 300 acres of magnolia and pecan trees, meandering creeks full of wildlife, including the very popular crawfish, and a lake full of turtles, fish and alligators. This beauty, however, was not appreciated by my eyes while a resident at the hospital. All I could see was the isolation of the place, the sadness of my fellow patients, who were divorced and abandoned by their natural support systems, and the constant battle to keep their diagnosis a secret. The risk of having a hometown friend, or worse, an enemy, divulge their illness meant instant ostracism of their family, and also being branded as outcasts.

## A MISUNDERSTOOD DISEASE

The fear of leprosy is a worldwide phenomenon. It is a fear of the unknown because the myths of leprosy usually project images of lost souls, lost limbs, disfigurements, hellish punishment, contamination and death. This xenophobia is difficult to battle when the L-word continues to be uttered by members of the royalty and other world leaders.

However, the war will continue to be fought in an effort to eradicate the use of this term and thus eliminate the ignorance that is often associated with this most misunderstood of illnesses.

For those of us diagnosed with Hansen’s disease, the painful road to recovery has led to numerous detours of isolation, fear, ostracism, lengthy hospitalization, depression, misinformation and lost identity.

Exiting from this road has meant continuous self-education and education of others that we are not “lepers”. We are human beings with a rare diagnosis and demand to be treated and referred to with dignity and respect. ■

## AUTHOR:

**Jose Ramirez, Jr.**



Jose Ramirez, Jr. is department director, Mental Health and Mental Retardation Authority of Harris County (Houston, TX). He is a licensed master social worker and advanced clinical practitioner. His book detailing his journey with leprosy will be published soon.

## Reference

\* Princess Diana was patron of The Leprosy Mission. Mother Teresa, a Nobel Peace Prize winner, administered to the sick, poor and dying, including persons affected by leprosy. Both died in 1997.

\*\* The hospital was closed in 1998.

# Travels to Vietnam, Switzerland

The goodwill ambassador visits a leprosy treatment center near Hanoi and leads a mission to Geneva to attend the Sixth Session of the Human Rights Council.

Former WHO Director General Halfdan Mahler (third from left) and High Commissioner for Human Rights Louise Arbour (fourth from left) seen with Yohei Sasakawa (second from right) and panelists from a human rights workshop on leprosy, following a Japanese government reception hosted by Ambassador Ichiro Fujisaki (far right).



## VIETNAM (SEPTEMBER 17-19)

In September I made a brief visit to Vietnam, which achieved the WHO's goal of eliminating leprosy as a public health problem in 1995. At the end of 2006, Vietnam had 572 registered cases of leprosy, making for a prevalence rate of 0.1 per 10,000 population. During 2006, 666 new cases of leprosy were recorded. Of these, 5.56% were children, and 17.27% involved Grade II disability.

I understand that one reason for the high incidence of Grade II disability among new cases is the fact that information about leprosy isn't reaching Vietnam's 54 ethnic minorities. Part of the problem is related to language. Clearly it will be necessary to come up with some innovative interventions to reach these populations.

From Hanoi, I traveled to the Quoc Qai Leprosy Treatment Center in Ha Tay Province. There are a total of 20 such treatment centers in Vietnam. For the most part, they serve as residential homes for older affected persons suffering from disabilities.

Currently, Quoc Qai has 125 residents. They are looked after by a staff of three doctors, 12 nurses and various other helpers. In Ha Tay Province as a whole, there are said to be around 500 people affected by leprosy.

Residents of leprosy treatment centers get all medical care free of charge. They are also entitled to a monthly allowance of US\$12.

Quoc Qai currently receives support from Netherlands Leprosy Relief (NLR), which provides eye-care treatment and supplies artificial limbs. NLR is also planning to begin a scholarship program for children of people affected by leprosy living nearby.

I have been to many leprosy facilities on my travels, and I was very impressed with Quoc Qai, which I found to be clean and well run.

## SWITZERLAND (SEPTEMBER 24-25)

I first approached the United Nations about leprosy in 2003, calling on the Office of the UN Human Rights High Commissioner to raise the issue of discrimination against people affected by leprosy and explore ways to assist in their social rehabilitation. Since then, I have participated in meetings of the UN Commission on Human Rights as well as the UN Sub-Commission on the Promotion and Protection of Human Rights.

This September, I made my first appearance at the newly-constituted UN Human Rights Council. My hope is to see the council take up leprosy as an issue of discrimination and issue a binding resolution to end discrimination against persons affected by leprosy and their families, and to establish guidelines for national governments and others to follow. I believe such a resolution will be a vital component in the effort to guarantee the human rights of people affected by the disease.

What was significant about this meeting was that the Japanese government raised the issue of leprosy with the Human Rights Council. It has also started talking with other members of the council, aiming to propose a joint resolution. Having official government backing is highly significant, and I am delighted and encouraged by this move.

On a personal note, I was recently appointed Japan's goodwill ambassador for the human rights of people affected by leprosy. In that capacity, I am grateful to Japan's Permanent Mission to Geneva for hosting a reception attended by ambassadors from many countries, including those on the council, and by UN High Commissioner for Human Rights Louise Arbour and former WHO Director General Dr. Halfdan Mahler.

The occasion was an important one for emphasizing the human rights dimension of leprosy, and I know all those close to the issue felt the evening was a great success. ■

# China's Leaders Praise Lin's Efforts

Local official helps improve conditions at isolated leprosy village

An education official from Sichuan Province has been commended by Chinese leaders for improving the welfare and education of people living in a remote leprosy recovery village in the province, Xinhua reported last month.

According to the news agency, Chinese President Hu Jintao called on government and Communist Party officials to learn from Lin Qiang's example, with Vice-President Zeng Qinghong saying that officials "should put the interests of the common people first, just like Lin has done."

The 53-year-old Lin first came upon Abuluoha

village, one of several hundred in China dating back to the days when patients with the disease were sent to isolated recovery villages, in 2003. Although the residents had already been cured, many had been left disabled and were cut off from the outside world because of the fear surrounding the disease.

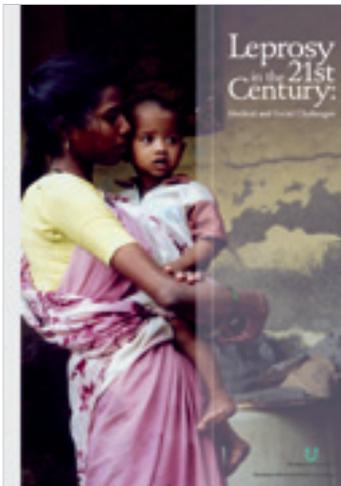
Stunned by the destitution and illiteracy he found, Lin has since made 10 trips to the village, helping residents to build a school, pave roads and gain access to electricity.

"I bumped into this village, I cried and couldn't just go away," he was quoted as saying.

## Leprosy LEXICON

### ● Tool-ready diseases

Diseases such as leprosy for which powerful and inexpensive control tools are currently available and for which well-developed implementation strategies exist. (Source: WHO Global Plan to Combat Neglected Tropical Diseases)



## LEPROSY BOOKLET

A 12-page booklet outlining some of the key medical and social issues in leprosy today has been prepared by The Nippon Foundation and Sasakawa Memorial Health Foundation. *Leprosy in the 21st Century: Medical and Social Challenges* was distributed at the Sixth Session of the Human Rights Council taking place in Geneva last month.

## GLOBAL PLAN ON NTDs

The WHO has announced a *Global Plan to Eliminate Neglected Tropical Diseases 2008-2015*. The plan provides measures for the prevention, early detection, diagnosis, treatment, control, elimination and eradication of NTDs and zoonoses that disproportionately affect poor and marginalized populations. Intensified efforts by WHO will initially focus on 14 diseases, among them leprosy. ■

## FOR THE ELIMINATION OF LEPROSY

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## FROM THE EDITORS

### DISAPPEARING LEGACY?

Since we first reported that the former Sungei Buloh leprosy colony near Kuala Lumpur might be preserved as a heritage site, media reports now indicate that demolition work has begun in order to make way for a new development there.

Sungei Buloh has a special place in the history of leprosy. Not only was it one of the largest leprosy colonies in the world in its day, it was also the place where key research was done that led to the development of the modern drug regimen that has made leprosy a completely curable disease today.

The development of an effective cure for leprosy in the early 1980s represents a remarkable victory over one of the oldest diseases to have afflicted the human race. But it was a victory achieved only after countless

individuals across the centuries had endured not only the physical suffering brought on by the disease but also the psychological trauma of being forced into isolation in order to "protect" the rest of society.

No other group of human beings has been treated quite like people with leprosy. As the disease gradually runs its course in the coming decades, we must not forget the tribulations so many have been through, and the lessons to be drawn from society's response.

Equally, there are inspiring stories that bear witness to the courage and spirit of individuals affected by leprosy, some of whom are living out their days in Sungei Buloh. Today, such places are not well known. This is all the more reason to preserve them for posterity.