

# FOR THE Elimination OF Leprosy

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



The Goodwill Ambassador meets with 101-year-old Perry Enriquez (left) in Carville, Louisiana, on October 2. (See page 7)

## MESSAGE

### A Necessary Delay

It has been six years since I first raised leprosy as a human rights issue before a United Nations body. Since my initial approach to the Office of the UN High Commissioner for Human Rights in 2003, much has happened.

With the cooperation of NGOs, people affected by leprosy and most recently the government of Japan, a draft set of principles and guidelines to end discrimination against people affected by leprosy and their families was drawn up in August. This was provided for by a Human Rights Council resolution unanimously approved in June 2008. At this stage, the principles and guidelines fully reflected the concerns of all interested parties, who had been consulted in the process of drawing them up.

The scene was set for the Japanese government to move to have them endorsed at the 12th Session of the Council in September. Unfortunately, when the draft document was being reviewed by the HRC Advisory Committee, a sentence was added condoning the practice of isolating people with leprosy.

While it specified that this should only be on a temporary basis, and in the context of public health consideration, there is no justification for this whatsoever.

I expressed my grave concerns about this to the Japanese government. Taking note of my concerns and the concerns of others, the Japanese government decided to refer the principles and guidelines back to the Advisory Committee for review. After further consultations, they are to be resubmitted to the Council at a later date. Fifty-two countries cosponsored this resolution. I thank the Japanese government for its decisive action.

Of course, this means there will be a delay in the ratification of these much-desired principles and guidelines. But my hope is that we will end up with a document that truly makes a difference to the lives of people affected by leprosy and their families. Let us do all in our power to see that this desired outcome is achieved.

— Yohei Sasakawa, WHO Goodwill Ambassador

## CONTENTS

<b>Message</b>	<b>1</b>
<b>Speech</b>	
Toward a world without leprosy	
By Yohei Sasakawa	<b>2</b>
<b>Opinion</b>	
Analyzing stigma	
By Wim van Brakel	<b>3</b>
<b>Feature</b>	
The Leprosy Mailing List	
By Salvatore Noto	<b>4</b>
<b>Book Update</b>	
Leprosy's recent history	
By Jo Robertson	<b>5</b>
<b>Journal</b>	
An afternoon at Carville	<b>7</b>
<b>News</b>	
Tama Zenshoen centenary; Koichi Kondo tribute	<b>8</b>
<b>From the Editors</b>	<b>8</b>

# Toward a World without Leprosy

Reviewing the progress made in the fight against the disease.

People with leprosy have long been subjected to discrimination. The disease is mentioned in the Bible, while in India there are references to it dating back to the 6th century B.C.

There is a history of discarding people with leprosy on islands. Here in Japan we have seen how people with the disease were isolated on island sanatoriums such as Nagashima Aiseien and Miyako Nanseien.

With the advent of multidrug therapy (MDT) in the 1980s, leprosy became a curable disease. Since then, some 16 million people have been cured. Currently there are less than 250,000 new cases of the disease annually.

I first believed there was a possibility to rid the world of leprosy when a target was set to reduce the prevalence of the disease to less than 1 case per 10,000 people, thereby eliminating it as a public health problem. An additional factor was the development of the blister pack. This made it easy for patients unfamiliar with medicines to take the stated dose.

At an international conference on leprosy elimination held in Hanoi in 1994, The Nippon Foundation pledged to distribute MDT free of charge in every country for five years. Today, MDT continues to be provided free of charge, thanks to the Novartis Foundation for Sustainable Development.

## MOTORBIKE

I often use the example of a motorbike in talking about leprosy. The front wheel represents curing the disease; the rear wheel symbolizes eliminating discrimination.

Until recently, the focus had been on the front wheel, with the effort centered on the WHO. Of 122 countries that had yet to eliminate leprosy as a public health problem in 1985, 119 have now done so. Of the three remaining countries, I believe that Nepal and Timor Leste will pass this milestone in the next year or two, leaving only Brazil.



Addressing the centenary event at Tama-Zenshoen

Wherever I go, I deliver three simple messages: leprosy is curable, treatment is free; and discriminating against people with the disease is wrong. I impress upon leaders the importance of keeping focused on leprosy. I also take every opportunity to talk to the media. In my office I must have two volumes of newspaper cuttings from India alone.

Fortunately, in the fight against leprosy, the WHO, individual governments and international NGOs are all pulling in the same direction. I believe that one day leprosy will be a thing of the past. However, it remains the case that many people who once had leprosy continue to face discrimination — even after being cured — because of society's deep-seated prejudices.

In 2003, I drew this issue to the attention of the Office of the UN High Commissioner for Human Rights and the back wheel of the motorcycle began to turn. Last year, the Japanese government tabled a resolution at the Human Rights Council calling for an end to discrimination against persons affected by leprosy and their families, which was adopted unanimously. The next step is to finalize guidelines for ending discrimination, a process that is currently under way. Ultimately, I would like to see a resolution adopted at the UN General Assembly.

Why didn't a human rights problem on this scale attract attention until recently? I think there are two reasons. First, communities of people affected by leprosy have tended to be isolated from the social mainstream. And second, for so many centuries, leprosy has been viewed as a fearful disease, hereditary, God's punishment... it's as if these ideas are in human DNA.

In India, I supported the establishment of the National Forum, which has created a network of people affected by leprosy and given them a platform from which they can engage with the authorities. I have also created the Sasakawa India Leprosy Foundation, which supports self-help efforts of people affected by leprosy through grant giving. More recently, The Nippon Foundation has begun a project with the ASEAN Secretariat to encourage inclusion of persons affected by leprosy in the agenda of leprosy control and rehabilitation work.

I believe we will reach our ultimate destination of a leprosy-free world only when both the front and back wheels of the motorcycle are turning at the same speed. We are moving in the right direction, but we still have a long way to go. ■

## AUTHOR:

### Yohei Sasakawa

Yohei Sasakawa is Chairman, The Nippon Foundation, WHO Goodwill Ambassador of the Elimination of Leprosy, and Japanese Government Goodwill Ambassador for the Human Rights of People Affected by Leprosy.

## Leprosy FACT

- There are 13 leprosy sanatoriums in Japan. As of May 2009, there were 2,568 residents with an average age of 80.2.

## Footnote

This is an edited and abridged version of a speech given by Yohei Sasakawa on September 28, 2009, to mark the 100th anniversary of the founding of National Sanatorium Tama-Zenshoen in Tokyo. For more details about Tama-Zenshoen, see page 8.

# Analyzing Stigma

Many aspects of stigma remain unknown, and more research is needed.

**AUTHOR:**  
Dr. Wim H. van Brakel



Wim H. van Brakel, MD MSc PhD, is head of the Leprosy Unit at the Royal Tropical Institute and Assistant Professor for Disability & Development at Athena Institute, VU University, Amsterdam, Netherlands.

Most people have a sense of what stigma is, but if asked to define it, many would struggle. Often it is described as discrimination, ‘negative attitudes’ or a ‘discrediting feature’.

From a scientific point of view, discrimination is either an outcome of stigma or, more commonly, one form of stigma, called ‘enacted stigma’. Importantly, stigma is nowadays recognized to be a social process, rather than a characteristic of a person or group. This implies that stigma is dynamic and can decrease or increase depending on social and personal factors.

We can distinguish three main components of stigma: perceived (or felt) stigma, enacted stigma (or discrimination) and internalized (or self) stigma.

Perceived stigma refers to a perception or fear of negative attitudes in society in general or in a particular group such as health services personnel or followers of a particular faith. Note that this perception is often shared by people in a given community, but is not uniform.

Enacted stigma includes any action or behavior that acts out a negative attitude toward a person or group. This may be something very obvious and severe, such as dismissal from a job on account of leprosy or HIV, or it may be more subtle, such as gossip or breaches of confidentiality.

Internalized stigma describes the situation of a person whose self-esteem has been eroded by prolonged exposure to negative attitudes or discrimination. People who internalize stigma begin to believe the negative stereotypes others have of them. They may start to feel bad and even blame themselves for having the condition.

“Leprosy is one of the oldest stigmatized conditions known.”

There is a misunderstanding that the term ‘self-stigma’ is used to blame the people affected for the stigma they experience. This is definitely not the intention. Internalized stigma is a psychological consequence of public stigma and discrimination and is often accompanied by depression and anxiety.

## STIGMA AND HUMAN RIGHTS

Human rights are universal. The UN Convention on the Rights of Persons with Disabilities adopted in 2006 has applied these concepts more specifically to the situation of persons with disabilities. Enacted stigma clearly violates the rights of persons or whole groups. Even gossip or name-calling violates



Change agent: Ahmad Zainudin of PerMaTa, Indonesia

the right to dignity. Other rights that are commonly violated include the right to access to justice, respect for privacy, respect for home and the family, participation in political and public life, being included in the community, personal mobility, education, and the right to health.

Leprosy is one of the oldest stigmatized conditions known. However, research has shown that many consequences of stigma for individuals and their families are not unique to leprosy. This is also true for the problems stigma causes to public health and rehabilitation programs. For example, people with mental illness, HIV/AIDS or epilepsy often suffer similar consequences of stigma to those suffered by people affected by leprosy.

Many aspects of stigma are still largely unknown. This is true for determinants of stigma — why are some people strongly stigmatized, while others with the same condition are not? And also for interventions — what are the most effective interventions against the various forms of stigma and discrimination? What can we do to make people less susceptible? How can we best empower people? How can we use rights-based approaches in stigma reduction?

Given that the impact of stigma on people with different stigmatized conditions is very similar, would joint interventions for different target groups be effective? Much more research is needed to answer these questions. Such research should be participatory, involving people with personal experience of leprosy (or other stigmatized conditions) at every level. Even better, people affected should be empowered to initiate and lead such research themselves, where necessary asking assistance from experts.

There is accumulating evidence from several disciplines, including leprosy, that people affected can be very effective as change agents to diminish stigma. However, serious and sustained efforts are needed by programs and organizations to involve them in a meaningful way and build capacity to increase their involvement as true partners in this process in future. ■

# 'Dear Dr. Noto'

The Leprosy Mailing List is a forum for information exchange — and for sounding off.

The Leprosy Mailing List (LML) is a free email list for sharing information via the Internet among people all over the world working in the field of leprosy. It was established in February 2001 at the Centre for Training and Research in Public Health (Cefpas) in Caltanissetta, Italy. Since June 2005, it has been hosted by the National Leprosy Referral Centre, Department of Dermatology, at San Martino University Hospital, in Genoa, Italy.

The specific objectives of the LML are to: 1) divulge information about leprosy, its causes, prevention and treatment; 2) share information about management of leprosy control activities and programs; 3) share information about socio-cultural aspects of leprosy and rehabilitation of patients with disabilities; 4) offer a distance learning tool in leprosy for health professionals; and 5) create a forum to discuss the main issues on leprosy and its control activities and programs.

At the beginning the list was circulated among a few friends who had experience of leprosy work in Africa. Soon it became popular among leprosy workers on all five continents. Today the LML has about 500 subscribers from a variety of fields and specializations including leprosy control, research, public health, dermatology, tuberculosis, ophthalmology, neurology, infectious diseases, charity work and publishing.

LML is an independent forum run on a voluntary basis. Contributions emailed to the moderator are edited in a common format and circulated among subscribers. Prior to distribution, there is an exchange of opinions between the moderator and the correspondent in order to clarify or modify points as required. All contributions to the LML are accepted as far as they are relevant to leprosy.

**"Over the years, various issues have aroused fierce debate."**

## 'EXPLOSION' OF MESSAGES

Over the years, various issues have aroused fierce debate. In 2002, some months before the 16th International Leprosy Congress in Brazil, word reach the LML that the WHO wanted to recommend a new, uniform six-month treatment regimen for both paucibacillary and multibacillary leprosy. There was an explosion of messages on the LML, pointing out that as yet no proof of the efficacy of such a regimen existed.

The use of thalidomide in the treatment of



The LML began as a list circulated among a few friends who had experience of leprosy work in Africa.

erythema nodosum leprosum reaction<sup>1</sup> has aroused much controversy. There has also been passionate debate about the "elimination" strategy adopted by the WHO, while the use of prevalence or incidence in leprosy statistics was a key topic for many months.

In the last year it has been interesting to note how some colleagues have repeatedly drawn attention to the difficulties in making timely diagnosis of leprosy in the lepromatous form of the disease, particularly when no slit-skin smear service is available.

## TIME CONSTRAINTS

Due to time constraints I am often tempted to give up the LML, and I find editing contributions in English is a difficult task that I would happily delegate to someone else. However, I receive messages from all over the world from people who say how much they appreciate the LML, so I assume there are people in the field for whom it is important in their leprosy work.

Colleagues working at the central level in health ministries of leprosy endemic countries tell me that they copy LML messages and circulate them at the peripheral level. Leprosy control officers write to me that they have used LML documents in their training activities, or as reference for papers to be published or to back up requests to their ministries. A WHO leprosy officer told me that he prints out and files all LML messages and documents, although, like some other readers of the LML I know of, he never posts messages himself.

Thanks to the kind help of Dr. Sunil Deepak of the Associazione Italiana Amici di Raoul Follereau (AIFO) in Bologna, Italy, past contributions to the mailing list dating back to 2003 can be found online in the LML Archives, which were started in 2006. To access the archives, and to subscribe to the mailing list, visit the AIFO website<sup>2</sup>. I look forward to hearing from you! ■

## AUTHOR:

**Dr. Salvatore Noto**



Dr. Salvatore Noto is Medical Officer, Leprosy and Dermatology, at San Martino University Hospital in Genoa, Italy. He is moderator of the Leprosy Mailing List.

## Footnotes

1 A serious immunological complication of leprosy that causes inflammation of the skin, nerves and other organs.

2 <http://www.aifo.it/english/resources/online/lml-archives/index.htm>

# Leprosy: A Recent History

New book to examine emergence of effective international effort against leprosy.

## AUTHOR:

### Dr. Jo Robertson

Dr. Jo Robertson was the coordinator of the International Leprosy Association's Global Project on the History of Leprosy between 2001 and 2007 and is now at the Institut d'Histoire de la Médecine et de la Santé, Centre Médicale Universitaire.

In June 1949, a delegation from the Government of India took a memorandum on leprosy to the Second World Health Assembly. The World Health Assembly (WHA), the World Health Organization, and the Government of India were all newly born; leprosy, on the other hand, was an ancient disease.

The year before, the Interim Commission for the First World Health Assembly had decided that diseases such as cancer and leprosy did not "lend themselves easily to international action." The commission had argued that "Nothing really useful can be done to fight these diseases at the present stage of medical knowledge ... the Organisation's entire budget would be merely a drop in the ocean."<sup>1</sup> Instead, they decided that diseases such as malaria, tuberculosis and venereal disease would be targeted first.

But by the time of the Second World Health Assembly, a change had taken place; leprosy had been accepted as a new subject for action. *The Chronicle*, the journal that recorded all the actions and decisions of the WHA, stated that "cogent arguments" had been made for an international campaign to combat leprosy.

## 'HIGHEST PRIORITY'

The delegation from India had been very persuasive, informing the assembly that 5 million people suffered from leprosy in both tropical and subtropical regions and that it was a "public health problem of great importance." Furthermore, the prevalence of leprosy was so high in certain countries in Asia and Africa that it should receive the "highest priority" in the "national health programmes" of those countries.<sup>2</sup>

The delegation explained very briefly what was known about leprosy and how much was still uncertain. In addition to the scientific uncertainties, it stated that the administrative and social problems were immense. The people who suffered most from leprosy were the poorest, living in crowded and abject conditions, and countries where leprosy was an important public health problem were the least equipped to deal with the expense and had the least developed health services. The delegation also argued that there was hope from a new therapeutic sulphone, but there was a great need for more research.

This key delegation was led by Rajkumari Amrit Kaur, the minister for health in the new Cabinet of independent India. She had also been the former vice president of the First World Health Assembly.<sup>3</sup>

Writing later that year to T.N. Jagadisan, a famous intellectual and spokesperson for people affected by leprosy, she told him: "I feel a special

responsibility towards the cause of leprosy not only because I knew Bapu's mind about it and would like to do something tangible for it, but also because I have brought it before WHO and my proposal received a most favourable reception in Rome last June..."<sup>4</sup> Of course, in referring to Bapu she was referring to Mahatma Gandhi.

## INTERNATIONAL EFFORT



Members of the consultative committee for the book, including coauthors Dr. Jo Robertson (front, second from right) and, seated next to her, Professor Bernardino Fantini.

This was the beginning of an international effort against leprosy that has brought us to where we are today. I am now in the process of writing a book about this with Professor Bernardino Fantini. Conceived by Dr. Yo Yuasa and Dr. S.K. Noordeen, and funded by The Nippon Foundation, the project is based in Geneva at Institut d'Histoire de la Médecine et de la Santé, Centre Médicale Universitaire, which is a WHO collaborating center. Professor Fantini is the institute's director.

Our study of the recent history of leprosy will focus on the dynamic between *M. leprae* and the work against it. It will show the emergence and development of activities to tackle leprosy, culminating in public health strategies that changed leprosy from being a problem without a solution to one that could be dealt with. It will trace the long-standing history of international activities against the disease that merged into effective global health initiatives at local, national and international levels.

We will also analyze the tradition of compassion and benevolence that has always been intertwined with leprosy work, and the way in which this is connected to advocacy of the human rights of people affected by the disease. Of particular interest, I believe, will be the changing local, national and international strategies of control and elimination in the context of other health strategies.

Publication is planned for 2011. ■

## Footnotes

- 1 *Chronicle* Vol.II, No. 8-9 (Aug-Sept 1948), p. 171
- 2 Second World Health Assembly: 1 June 1949 "Leprosy: Memorandum Submitted by the Delegation of the Government of India" (A2/40 1 June 1949, Supplementary Agenda Item 8.15.3.15) (471/1/1), p. 1
- 3 On 24 June 1948 in Geneva, she had been elected as one of three vice presidents of the inaugural assembly *Chronicle* Vol.II, No. 8-9 (Aug-Sept 1948), 164
- 4 Correspondence from Amrit Kaur to Jagadisan, October 28, 1949, cited in T. N. Jagadisan, *Fulfillment Through Leprosy*, (India: Kasturba Kushta Nivaran Nilayam, 1988), p. 159

# An Afternoon at Carville

A first visit by the Goodwill Ambassador to a place in Louisiana, USA, that occupies a very important position in the history of leprosy and leprosy research.

## CARVILLE, LOUISIANA (OCTOBER 2)

At the beginning of October I paid my first ever visit to Carville, Louisiana. For over a century, from 1894 to 1999, Carville was the location of the only in-patient hospital in the continental United States for treating leprosy. Some of the most important leprosy research of the 20th century was carried out here, and it formed an extraordinary community of men and women forced into exile in their own country because they had leprosy.

Although the leprosarium has since closed and patient care functions have been transferred to nearby Baton Rouge, various buildings remain, and the story of those years is told in the impressive National Hansen's Disease (Leprosy) Museum.

Carville's association with leprosy began in 1894 when the Louisiana state government purchased a rundown sugar plantation on the banks of the Mississippi levee between Baton Rouge and New Orleans to house patients with the disease. The first arrivals at the "Louisiana Leper Home" were five men and two women. It was styled as "a place of refuge, not reproach, a place of treatment, not detention."

The choice of Louisiana was dictated by the fact that the state had quite a large number of leprosy patients; in time, however, this "leper home" for Louisiana would become a leprosarium for the whole country. This duly occurred in 1921, when the U.S. Public Health Service took over the running of the home. The name was changed to U.S. Marine Hospital No. 66, or the National Leprosarium of the United States.

On arrival, I was met by Dr. James L. Krahenbuhl, director of the National Hansen's Disease Programs, who showed me around. I

was surprised at just how large Carville is. The leprosarium was situated on a 300-acre plot of land and in its time included an infirmary, patient and staff residences, a power plant, farm land for growing crops and raising dairy cattle, a school, a recreation center, Catholic and Protestant chapels, a cafeteria, library, post office, golf links and even a jail.

**Perry is 101 this year and first came to Carville in 1936. He doesn't look his age.**

To make it easier for the residents to move about, there were over two miles of covered walkways to connect patient residential housing, hospital offices, the infirmary, chapels and the recreation center. Patients used to ride bicycles along these corridors to travel between their residences and the infirmary. The small number of elderly residents who remain are more likely to use motorized wheel chairs, so it is very convenient for them to get about.

Some remarkable individuals passed their days at Carville as patients, and went on to record their experiences in print. Among its most famous residents was Stanley Stein, who was sent to Carville in 1931 and founded a newspaper called *The Star* ("Radiating the Light of Truth on Hansen's Disease"), which is still published today. Stein was a vocal crusader for the rights of persons affected by leprosy and wrote about his experiences in his autobiography, *Alone No Longer*. This book has been published in Japanese, and is one of



(Far left) Building that once housed patients at Carville; (left) Cartoon from 1946 by Carville patient Johnny Harmon, showing how miraculous patients thought Promin treatment was. (Originally published in *The Star*)

Display at the National Hansen's Disease Museum at Carville. On the left, with his back to the camera, is Pete.



the most inspiring books I have read. Another resident, Betty Martin, wrote *Miracle at Carville*, which entered the *New York Times* best-seller list. Just this year, Jose Ramirez Jr. published his moving account of his time at Carville, in *Squint: My Journey with Leprosy*. Jose, by the way, is now the editor of *The Star*.

Carville was a center of research and testing to find a cure for leprosy, as well as being a hospital for caring for people with the disease. It was at Carville that promin, a sulphone drug, was identified and used as a treatment for leprosy in 1941. In the 1950s, Dr. R. G. Cochrane pioneered the use of dapsone pills at Carville to treat the disease. While initially successful, the disease eventually developed a resistance to the drug, which is now used in combination with two other drugs in multidrug therapy.

As the 20th century progressed, the leprosarium underwent change. In 1986, it was renamed the Gilles W. Long Hansen's Disease (Leprosy) Center. Senator Long did much to support Carville and those who lived and worked there. In particular, he successfully lobbied Congress to ensure that Carville remained open when other Public Health Service facilities were closing.

In 1999, as the number of Carville's residents dwindled, the U.S. Department of Health and Human Services turned the property back over to the state of Louisiana, while allowing all long-term residents who wished to keep living there to do so. Today, a total of 13 remain. The state of Louisiana's Military Department now oversees the property, which is now known as the Gillis W. Long Center and used by the Louisiana National Guard. The facilities include a reformatory and a rehabilitation center for at-risk youth with a 98% success rate.

During the afternoon I toured the excellent National Hansen's Disease Museum. The museum was founded in 1996 to preserve the history of the site, commemorate those who lived at the National Leprosarium as patients and the medical community who served them. It tells patients stories, the history of the disease's treatment, and contains many cultural and medical artifacts from the more than 100-year history of the leprosarium. These include specially adapted scissors, eating utensils and keys, and special footwear known as the "Carville sandal."

The museum also serves the function of promoting understanding and treatment of Hansen's disease. According to Dr. Krahenbuhl, discrimination and prejudice persist in the United States, and there is a lot of misunderstanding about the disease, fuelled in part by the Internet. At the museum I met Simeon Peterson, known as Pete, who works as a guide. Pete is now 81 and has lived at Carville for 58 years.

Another gentleman I had the privilege of meeting was Perry Enriquez. Perry is 101 this year, and first came to Carville in 1936, just a few years after Stanley Stein. Originally from the Philippines, he arrived in the United States aged 18. Perry certainly doesn't look his age. When I asked him his secret, he said it was singing Frank Sinatra songs in front of people while playing the guitar one-handed, and not drinking or smoking.

Carville is home to some inspiring stories, but it also recalls darker times when patients were kept behind barbed wire and didn't have the right to vote. It occupies a very important place in the history of leprosy, and, having read so much about it, I am profoundly grateful that I have finally had the opportunity to visit. ■

# 100 Years of Isolation

National Sanatorium Tama-Zenshoen marks centenary of its founding.

On 28 September 2009, a ceremony was held at the National Sanatorium Tama-Zenshoen in Tokyo to mark the 100th anniversary of the establishment of the leprosarium there. About 180 people, including residents and local and national government representatives, attended.

Since its founding, Tama-Zenshoen has admitted a total of 9,542 patients. The population of the sanatorium today is 290, with an average age of 81.

Tama-Zenshoen was one of five leprosaria that opened in 1909 in different parts of the country as provided for under Japan's leprosy prevention law of 1907 that introduced a policy of isolating people with the disease. In April, four other sanatoriums in Japan marked their centenaries.

A special exhibition, "100 Years of Isolation — The Birth of Public Leprosaria," is being held at the National Hansen's Disease Museum adjacent to Tama-Zenshoen. It runs until 20 December 2009.

## KOICHI KONDO



Koichi Kondo, a recipient of the Wellesley Bailey Award\* in 2007, has died in Japan aged 83. Kondo developed leprosy at the age of 9 and two years later was forced to enter a government-run sanatorium. Over the next five decades, he lost all his fingers and his eyesight to leprosy. Undaunted, he taught himself to read Braille using his tongue and lips, learned music and formed a band with fellow residents. The Blue Bird Band went on to perform at concert halls in major Japanese cities, challenging public prejudices about persons affected by leprosy and inspiring residents at other sanatoriums to form their own bands. He also contributed to the revival of the band on Culion in the Philippines on the occasion of that colony's centenary in 2006.

A funeral service was held on 6 October at the Nagashima Aisei-en sanatorium in western Japan. ■

## Footnote

\* The Wellesley Bailey Award is presented every other year to two individuals who overcome severe hardship and discrimination to become symbols of hope to people affected by leprosy.

## FOR THE ELIMINATION OF LEPROSY

### Publisher

Yohei Sasakawa

### Executive Editor

Tatsuya Tanami

### Editor

Jonathan Lloyd-Owen

### Associate Editors

Sumiko Okamoto,

James Huffman

### Layout

Eiko Nishida

### Photographer

Natsuko Tominaga

### Editorial Office

5th Floor, Nippon

Foundation Building,

1-2-2 Akasaka, Minato-ku,

Tokyo 107-8404

Tel: +81-3-6229-5601

Fax: +81-3-6229-5602

smhf\_an@tnfb.jp

With support from:

Sasakawa Memorial

Health Foundation,

The Nippon Foundation

www.nippon-foundation.

or.jp/eng/

## FROM THE EDITORS

### WHAT TOOK SO LONG?

The fifth of the first five government-run leprosaria to be established in Japan marked its centenary in September. National Sanatorium Tama-Zenshoen and others like it were the product of a leprosy prevention law passed in 1907 that empowered the authorities to isolate patients with the disease. The law, which was subsequently strengthened, was not repealed until 1996 — decades after the practice of forced isolation had been discredited abroad.

Why did Japan take so long to dispense with this outmoded and unjust legislation? For a start, Japanese leprologists chose not to go along with evolving international opinion on the issue of forced isolation, and Japanese government policy reflected this thinking. Post World War II, Japanese leprologists continued to believe that compulsory segregation was necessary and effective, even as sulphone drugs became available and the International Leprosy Association was recommending against isolation.

A revision to the Japan's Leprosy Prevention Law in 1953 actually reinforced the policy and made no provision for a return to society.

Another factor highlighted in a 2005 Japan Law Foundation report was the lack of public appetite for change. When the Japanese government introduced a policy in 1935 to root out leprosy in 20 years by actively searching for people with the disease in every prefecture and forcing them in sanatoria, this had the effect of strengthening discrimination and prejudice against leprosy.

It also fuelled ignorance. Not only were patients isolated from society, but so were the sanatoria and the discipline of leprology itself. Patients' movements did their best to agitate for the law's repeal but ran up against a wall of indifference and prejudice. It was only in the 1980s that attitudes began to change, as more medical professionals voiced their support for the sanatoria's residents. Even then, it would not be until 1996 that the law was finally abolished.