

# FOR THE Elimination OF Leprosy

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



Schoolchildren attend a leprosy awareness event on Madura Island in East Java Province, Indonesia, in March (see pp6-7).

MESSAGE

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## Memory of the World

Around the world there are buildings and artifacts that tell the anguished history of people affected by leprosy. This history is often thought of as a 'negative history' or a 'negative legacy'. Now there is a growing movement worldwide to preserve this history and pass it on to succeeding generations.

In Japan, as well as historical buildings there are chronicles of the activities of the different sanatoria residents' associations, anniversary magazines and other records that trace the trajectory of people who lived through the past 100 years of leprosy history. There are also wonderful books, poems, paintings, ceramics and other artworks created by people who spent their lives segregated from society. Despite the harsh circumstances in which they lived, they sought to overcome the prejudice they faced and lead lives that shone with meaning.

From these various historical documents and artifacts, we can ascertain how the residents thought and felt and how they fought against discrimination. By preserving these records, we can ensure that even after the last person who

went through these experiences has gone, their history will not fade. I believe there is a need and a value in preserving the history of this discrimination so that humankind never forgets its mistakes.

The Nippon Foundation and Sasakawa Memorial Health Foundation have assembled a team of experts in Japan to carry out a survey on whether the history of people affected by leprosy can be added to the UNESCO Memory of the World Register. Working toward a deadline of June 2017, and with the cooperation with the All-Japan Hansen's Disease Sanatoria Residents Association, they are investigating what records to select and how to present this history.

With the cooperation of like-minded people, I would like to see this history added to the Memory of the World Register in other countries, too, and hope this will lead to World Heritage status one day. I welcome your guidance and suggestions.

— Yohei Sasakawa, WHO Goodwill Ambassador

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# A Race against Time

International meeting generates momentum for preserving leprosy history.



The makings of a network: participants pose for a group photo on the final day of the symposium in Tokyo.

A three-day conference on Leprosy/Hansen's Disease History as Heritage of Humanity was held in Tokyo from January 28 to 30. Organized by Sasakawa Memorial Health Foundation, the conference drew some 40 participants from around 20 countries.

In recent years, there has been increasing interest in preserving leprosy history, prompted in part by recognition of the need to act swiftly as facilities close and as those who experienced life in sanatoria and suffered the consequences of past policies of segregation pass away. A major purpose of the conference, therefore, was to take stock of who is doing what and where, share this information and chart a way forward with an emphasis on more cross-cutting initiatives.

A pre-symposium session on January 27 took delegates to Japan's National Hansen's Disease Museum, where they heard the story behind the museum and the role it plays from some of the key figures responsible for its establishment, including Yasuji Hirasawa (see page 5). Country overviews later that day and on Day 1 of the symposium proper covered Ethiopia, Pacific island states, India, Brazil, Taiwan, South Korea, Malaysia, the Philippines, China and Thailand.

A wide variety of actors are needed to preserve the different facets of leprosy history. The conference explored this with presentations from academics, including Dr. Jane Buckingham (see page 4), representatives of national agencies such as Dr. Zainah Binti Ibrahim of Malaysia's Department of National Heritage, and people affected by leprosy including Rosie Julaton Panganiban, who chairs the history committee of the Coalition of Leprosy Advocates of the Philippines.

## ARTISTIC LEGACIES

Showcasing some of the legacies that leprosy has left behind in the form of the arts, there was a session on art, literature and creative products, including a fascinating account by Dr. John Manton of the musical legacy of Nigeria's Ikoli Harcourt Whyte, as well as Patricia Devia Angarita's discussion of the rich creative output of the Agua de Dios leprosy colony in Colombia.

A session on future scenarios looked at prospects for regional networks of collaborators in Latin America, Asia and Europe, and this was one of the points emphasized in the resolution signed by all participants on the final day. In agreeing that the history of leprosy "contains vital messages and lessons for the present and future of humanity and is thus worth preserving", the resolution encouraged "in particular the formation of a network, both within a country and in regions, of groups of individuals of both public and private bodies interested in and working for the preservation of the heritage of leprosy."

The symposium also acknowledged the 15 years of accumulated work of the International Leprosy Association's Global Project on the History of Leprosy and served as an occasion to re-launch its database. Dr. Josephine Robertson of the University of Queensland talked delegates through some of the features of the new, more user-friendly website, which it is hoped will become a useful resource for all those working to preserve leprosy's legacy or simply interested in knowing more about the rich history of this age-old disease.

The website can be found at <http://leprosyhistory.org> ■

# A New Way of Seeing

The wisdom we gain from leprosy history can make us better human beings.

**AUTHOR:**

Kay Yamaguchi



Kay Yamaguchi is former advisor to Sasakawa Memorial Health Foundation. She retired at the end of March 2016.

I confess that the title, “Leprosy/Hansen’s Disease History as Heritage of Humanity” initially struck me as overreaching itself; in the end, however, it came to make complete sense.

In the decades I have been involved with Sasakawa Memorial Health Foundation (SMHF), our work in leprosy has evolved from disease control through elimination of leprosy as a public health problem to identification of the people affected as the main actors in health and social issues of leprosy and dawning recognition of leprosy history’s value.

Initially, the perception of this history was of a negative history. But if we describe it as negative history, then we must address the question of who made it negative. The answer points back to each of us.

Triggering similar questions is the title of a new publication about leprosy from the National Historical Commission of the Philippines. *Hidden Lives: Concealed Narratives* causes one to ask: Who has hidden them? Who has concealed them? Once again, it is difficult to exclude ourselves from the answers.

As we consider these questions, we come to see the value in leprosy history. It makes us stop and think, and dwell on what it means to live; it contains elements that, in the words of film director Hayao Miyazaki, challenge us not to live

life carelessly or inattentively.\*

This was the significance of the symposium. It drew participants from diverse backgrounds — academics, museum curators, government officials, people who have personally experienced leprosy — whose presence was an acknowledgment that the history of leprosy transcends a single disease. It encompasses diverse aspects of human existence that are woven into the fabric of every nation.

At a time when mementoes and memories of leprosy are fast vanishing, it was inspiring to hear of government initiatives taking shape to preserve leprosy history, to see the “second generation” actively involved in securing the legacies of their parents and know of academics who have discovered rich themes in leprosy.

Throughout history, people with leprosy have suffered, but they have also struggled to survive the darkness into which they were thrust. In the unforgettable words of Kaijin Akashi, “Unless I illuminate myself like a deep sea fish, nowhere would I find even a glimmer of light.”

As the light cast by this history grows stronger, our eyes are adjusting to a new way of looking at leprosy and ourselves. The wisdom we acquire can make us better human beings. Taking my leave of SMHF, I do so in the knowledge that the world is beginning to discover and share what the history of leprosy has to offer. ■

**FOOTNOTE**

\* See Issue #78, p.8.

**TRIBUTE**

**MR. HILARION GUIA**



Mr. Hilarion Guia, who died in March at the age of 73, was the first mayor of Culion, the island in the Philippines he was forcibly sent to as a boy in 1950 after developing leprosy.

Leprosy has been seen as a curse, an illness that closes off the doors of opportunity to those it affects, but Mr. Guia showed what can be achieved by a fighting spirit and a refusal to be

defeated by the disease. Growing up in what had been the world’s largest leprosy colony, he was determined to make the best of himself. He later pursued a college degree before returning to Culion to work as a teacher for more than 40 years.

He didn’t just want to be the best he could be; he wanted the best for Culion, too. Through his activism, he worked tirelessly to have Culion recognized as a municipality and for its residents to be given the right to vote. He was particularly concerned that healthy children born and raised on Culion were being tainted by their association with the island and unfairly victimized

by society’s prejudice. Not only did he succeed in his wish to see Culion become a municipality, he was also elected the first mayor of Culion in 1995, beating eight other candidates.

Mr. Guia showed that leprosy should not be a barrier to one’s ambitions. Until the end, he worked to improve the position of people affected by leprosy, as president of IDEA Philippines and as president of the Coalition of Leprosy Advocates of the Philippines.

In January, Mr. Guia was in Tokyo for the launch of Global Appeal 2016 to end stigma and discrimination against people affected by leprosy and the international symposium on leprosy history (see photo). “I never thought I would live to see the day when people took such an interest in our history,” he said during his visit. It is a remark that his passing has given a new and poignant meaning.

# Whose History Is It?

Perspectives on the ways leprosy history gets written and the viewpoint it represents.

The history of leprosy is multifaceted. At the simplest level, it can be thought of as having three distinct but interwoven strands.

It is a history of a particular microorganism and of its medical discovery, and of the efforts to combat and cure the disease it causes. It is also a history of government and non-government agencies, including religious groups, and of their intervention in health care. Most significantly, it is a history of a group of people whose individual lives and place within their family, community and nation is affected by a specific, typically stigmatizing disease.

Historians and other academic researchers engage in each aspect of this history to a greater or lesser extent, depending on their area of research and expertise. But in most instances, these three aspects of leprosy factor in the researching and writing of histories.



Patient records at a former Brazilian hospital-colony: documents such as these are one of a historian's resources

## DRAWN FROM ARCHIVES

In writing of the history of leprosy in south India, for example, my own work\* focuses on the 19th century British colonial period and draws primarily from government archival materials located in the Tamil Nadu State Archives, the National Archives of India and the India Office Records in London.

Understanding of medical treatment of the disease is drawn from public department records in the Indian archives but also from a range of medical journals, including those published in the Madras Presidency, and from Siddha Tamil texts relating to the traditional medicine of south India.

The book's effort at accessing and presenting something of the lives and experiences of those with leprosy during the 19th century is limited by the nature of the resources available. It strives to demonstrate the agency of leprosy-affected people in their interactions with the government and other organizations and with the

development and implementation of treatment regimes.

However, there is little trace of their experience and history except through the reports of the colonial archives. The raw materials of the history of patient experience are not offered directly by those affected by leprosy but through the voices and interests of the colonial medical and government officers.

**How to discover and hear the voice of people affected by the disease is a critical issue.**

## POWER RELATIONSHIP

This problem of how to discover and hear the voice of people affected by the disease is a critical issue in any writing of the history of leprosy. Without some effort to research and analyze the trace of the person in the archive, the histories become histories of medical systems and governance rather than of personal experience.

Anthropologists such as James Staples are less tied to the archive; personal interviews and prolonged personal contact with leprosy-affected people in Madras have given his work\*\* a far clearer sense of the personal experience of the disease. Even so, as he indicates, such personal encounters and the histories gained through oral testimony are frequently also expressions of a power relationship, the researcher being the person with the resources both to record and preserve the historical 'data' of another's personal experience.

How to access and communicate the history of leprosy as a human history drawing on materials from both the past and the present remains a central question for historians writing histories of leprosy.

Not only the method but the ethics of historical research must be considered in developing strategies for the preservation and study of leprosy as an aspect of human history.

In addition, historians have a critical role in teaching the next generation and showing that history does not have to be repeated. We do that partly by setting our own example, by being involved with people with leprosy, by not being afraid and by understanding that the core of the person is their humanity, not their disease. The fact that leprosy is a disease of stigma historically is not something which must become part of the future; it is completely unnecessary. ■

## AUTHOR:

Jane Buckingham



Jane Buckingham is an associate professor with the Department of History at the University of Canterbury in New Zealand. This article is based on a paper she presented in Tokyo at the International Symposium on Leprosy/Hansen's Disease History as Heritage of Humanity.

## FOOTNOTES

\* *Leprosy in Colonial South India: Medicine and Confinement* (2002)

\*\*In particular, *Leprosy and a life in South India: Journeys with a Tamil Brahmin* (2014).

# Our Story, Our Legacy

Why a leprosy museum is so important to those whose history it relates.

**AUTHOR:**  
Yasuji Hirasawa



Yasuji Hirasawa is a member of the steering committee of Japan's National Hansen's Disease Museum. Diagnosed with leprosy at 14, he has lived in National Sanatorium Tama Zenshoen for 75 years. This is an edited version of his presentation to delegates attending the International Symposium on Leprosy/Hansen's Disease History who visited the museum on January 27.

Japan's Leprosy Prevention Law, which lasted 89 years, confined people affected by the disease to sanatoria. Over time, as the number of new cases started to decrease, we residents began thinking about the future of the sanatoria as early as the 1970s.

Among the many suggestions was to preserve our history. We wanted future generations to know we lived with dignity and pride, despite all forms of discrimination. We wanted our legacy to give them hope.

We started with a library on Hansen's disease. In our desire to expand the library into a museum, we established a committee in 1991. We started from scratch, doing everything from planning to fund-raising. We went out on the streets, asking passers-by for support for the museum's construction.

Along with a building, we also needed to give thought to the displays and the management of the museum. Having no budget, we relied on volunteers.

**We wanted future generations to know we lived with dignity and pride, despite discrimination.**

We did everything. We drove to sanatoria, looked through documents and materials, brought them back, displayed them, gave tours of the museum, gave talks, and on top of all that, we raised funds so that the museum could operate.

The museum was officially opened on 25 June, 1993. It was our wish that people and the media could learn about the history of Hansen's disease. At the same time, we hoped that the policy of absolute isolation — the Leprosy Prevention Law — would be abolished.

This law was finally abolished in 1996. One



Life lessons: a visit to the Hansen's disease museum

of the people behind this historic victory was Dr. Fujio Ohtani, a medical doctor and health ministry official. Dr. Ohtani was a man of vision and integrity, and the abolition of the law would not have been possible without him. He believed that our voices — the voices of people affected — mattered and should be heard by society and the medical profession.

I would like to emphasize that it was not the government or medical doctors that instigated this: we did — with Dr. Ohtani's support. We took the initiative; we fought; and we won.

Five years later, we decided to sue the government over the segregation policy. Then-Prime Minister Junichiro Koizumi formally apologized to us after the court ruled in our favor. Following the court ruling, the museum was turned into a national museum with a steering committee and professional curators.

I was married in 1950, and like many others I was sterilized, just like a dog or a cat. I have been teaching about peace to over 5,000 children a year, but none of them are my own. Each one of the over 7 billion people on Earth, whether affected by Hansen's disease, AIDS, mental illness, or other disabilities, regardless of gender or age, are a part of this Earth. Each has a role and duty.

Many children suffer from bullying and many commit suicide in Japan, and the same goes for grown-ups too. It is my sincere wish that people facing such problems will visit the museum and learn how we have struggled just in order to live as human beings. We want our history to provide a life lesson — to lend strength, dreams and hope to many people, today and tomorrow. The museum is a place to realize our earnest wish.

There still remains injustice in the world. Economic disparity, gender inequality and racial discrimination are just a few of the problems. In order to attain true peace and prosperity, we need to be forgiving and appreciative of what we possess. I hope our museum is a place where people learn about life and compassion, and thus contribute to world peace.

I started giving talks to schoolchildren more than two decades ago. Those first children, who are now working, who are now parents, still come back to see me.

I am 89 years young, and I am a happy young man. When I leave this world, I am sure I will pass away content and happy. My legs, arms and throat are all paralyzed, but though I have a wide range of physical disabilities, I still cherish this body as my life's treasure. Children love me, and I love them. I proudly announce I am the happiest person on Earth. ■

# Sing a Song, Find a Patch

The Goodwill Ambassador travels to Indonesia, where a catchy song-and-dance routine forms the centerpiece of a new campaign to promote early detection of leprosy within families.

## INDONESIA (MARCH 13-16)

Indonesia eliminated leprosy as a public health problem in 2000, but continues to account for the third highest number of annual new cases in the world after India and Brazil. At the sub-national level, 12 out of the country's 34 provinces have yet to achieve elimination, defined as a prevalence of less than 1 case per 10,000 population.

Of these, East Java reports some 40% of Indonesia's cases. Annual new case numbers in the province have remained more or less constant between 2004 and 2014, and between 8% and 10% of newly diagnosed patients have Grade II or visible disability — a sign of late diagnosis.

To address the challenges posed by leprosy, the Indonesian government has come up with a "zero" strategy: zero illness, zero transmission, zero disability, zero discrimination and stigma. The strategy has a number of elements, including raising awareness of leprosy within communities and families.

It was to witness the start of new awareness campaign targeting families that I traveled to Surabaya, the provincial capital of East Java, after a stop-over in Jakarta for a briefing at the WHO Country Office.

My first order of business was a visit to Sumber Glagah Hospital, about an hour's drive from Surabaya, which I had last visited in 2009. It was established as a leprosy hospital by Dutch doctors in 1955 and today sets aside a proportion of its beds for the disease.

En route, I called at the adjacent Sumber Glagah village, whose residents include 93 people affected by leprosy and their families. On arrival I was taken to an assembly hall that had been built with the support of the social welfare ministry, where about 100 people of all ages were waiting for me. I told them that if they found a patch on a child's skin, they should go the hospital without delay — a message I requested the media covering my visit to report.

**It is certainly a snappy tune, and they clearly enjoyed performing it.**

Moving on to Sumber Glagah hospital, I could hear music as I passed through the gates. In the courtyard, staff greeted me with a song-and-dance routine. "Let's find a patch," they sang. This was the song that had been written for the new awareness-raising campaign to encourage families to check their skin for signs of leprosy. It is certainly a snappy tune, and they clearly enjoyed performing it.

I visited with some of the inpatients. The first patient I spoke with, a 50-year-old man, had been admitted two weeks earlier. He had ulcers on his right hand and leg. He was the only person in his village to have leprosy, but he didn't confide in anyone for five years because he thought it would cost money. It wasn't until a neighbor told him he should go to hospital and see a doctor that he did, but by now the disease had left its mark. It had also caused his wife and children to abandon him, he told me.

In a courtyard I spoke with two men practicing self-care. They turned out to be brothers, aged 30 and 36. The younger brother had a prosthetic leg and both showed after-effects of the



"Let's find a patch": students get with the beat at a leprosy awareness campaign in Sampang city on Madura Island in Indonesia's East Java Province.



Taking part in the campaign in Sampang city (right); chatting with residents of Sumber Glagah village (far right)



disease. I couldn't help thinking that if they and the previous gentleman had sought treatment sooner, their lives might have turned out differently. It is so important that people have access to correct information about leprosy and that they act on it.

The following day I departed for Madura Island for the official start of the campaign. The island is reached via the country's longest bridge, spanning the Strait of Madura. From the far shore, the island appeared shrouded in mist, but gradually came into view. It has a population of some 3.6 million. It took a further hour after crossing the bridge to reach the city of Sampang. There I met Sampang Deputy Regent Haji Fadhilah Budiono and the head of the Sampang District Health Office, Dr. Firman Pria Abadi.



Practising self-care: brothers at Sumber Glagah Hospital

Dr. Abadi told me: "There is still strong stigma attached to leprosy, but you have to keep in mind that 30% of the population lives in poverty and most children get an average of only four years of education. There are those who can't read or don't understand what's being said, and this makes it



Meeting the media: an essential part of the Goodwill Ambassador's work is spreading awareness of leprosy.

hard to spread knowledge about leprosy."

That's where the new initiative I had come to see has a role to play. The deputy regent told me: "We're starting a campaign to get families to look for skin patches. With the help of families and volunteers, we want to make efforts at early detection."

We moved to a city square for what was billed as a World Leprosy Day celebration. There were tents and a stage decorated with red and white cloth. A red carpet had been laid out. About 800 people had gathered, many of them elementary and middle school students. A health ministry official explained that in conjunction with World Leprosy Day, a new campaign was being launched that would become the driving force behind protecting each family's health. It would encourage family members to look for skin patches and, if they find any, have them examined at a hospital without delay.

To mark the start of the campaign, health ministry staff, children and dignitaries — myself included — began dancing in the high heat and humidity to the song, "Let's find a patch!" The lyrics go something like this:

*If there are patches on your body, friend  
Around the ears  
On your face  
On your hands  
On your back or your legs  
Do not be ashamed  
Go and get them checked immediately  
Let's keep the family healthy*

This year, the campaign rolls out in East Java, South Sulawesi and Central Sulawesi, and goes nationwide next year.

In the fight against leprosy, we need to persevere, no matter what the obstacles are. Along with India and Brazil, Indonesia is of particular importance to reducing the global disease burden. Next time I visit, I shall listen out for the song wherever I go. ■

# Japan's Leprosy Museums

Health ministry hands operation of national museums to The Nippon Foundation.



View of Tama Zenshoen, home of Japan's National Hansen's Disease Museum

From April 1, The Nippon Foundation has been entrusted by Japan's Ministry of Health, Labour and Welfare with the running of the National Hansen's Disease Museum in the Tokyo suburb of Higashi-Murayama City and a second national museum dedicated to a former punishment block for leprosy patients in Kusatsu, Gunma Prefecture.

The National Hansen's Disease Museum was

established in 1993 as the Prince Takamatsu Memorial Hansen's Disease Museum in the grounds of National Sanatorium Tama Zenshoen; it was re-launched as a national museum in 2007. The Jyu-Kanbo National Museum of Detention for Hansen's Disease Patients opened in 2014 in the

grounds of National Sanatorium Kuriu-Rakusen.

The purpose of the museums is to educate the public about leprosy, promote proper understanding of what people affected by leprosy have endured and what they have achieved, help restore their dignity as well as promote respect for human rights and the need to end discrimination and prejudice.

The Japanese government opted to transfer operational control of the museums to The Nippon Foundation, given the foundation's decades-long experience of working in leprosy. Making use of its extensive international network, the foundation has aspirations to turn the museum in Higashi-Murayama into a world museum of leprosy, working close with the museum's existing staff and curators.

By working to enrich each museum's offerings and increase the amount of information they disseminate, the foundation aims to boost annual visitor numbers, which currently stand at 30,000 for the National Hansen's Disease Museum and 8,000 for the Jyu-Kanbo National Museum.

## LEPROSY: A SHORT HISTORY

The Centre for Global Health Histories, a WHO Collaborating Center at the University of York, has published *Leprosy: A Short History*. The book presents a collection of vignettes that provide critical perspectives on the disease, exploring leprosy's impact on society at different times, from the medieval period up to the present day, and from regional, national and local perspectives. The editors hope the book will "inspire debate and further attention towards the disease and its significant role in the history of public health.\* ■



## FROM THE EDITORS

### 20 YEARS ON

In an issue that dwells a lot on history, it must not go unremarked that this year is the 20th anniversary of the abolition of Japan's Leprosy Prevention Law. This was the law, enacted in 1907, under which persons diagnosed with leprosy were involuntarily placed in sanatoria where they were consigned to spend the rest of their lives.

The 20-year statute of limitations on seeking compensation for damages over the segregation policy expired at the end of March. While not everyone eligible for compensation had come forward by the deadline, fearful that their medical

histories would be revealed, noteworthy was the mass lawsuit filed by over 500 kin seeking an apology and compensation for the discrimination and hardship they too have suffered.

Also of note this year is the rare apology issued by Japan's Supreme Court for authorizing the use of "special courts" to try leprosy patients between 1948 and 1972. But while the top court acknowledged that these trials outside standard courtrooms were unlawful and fostered prejudice, it stopped short of declaring them unconstitutional — and thus does a sense of injustice linger.

## FOOTNOTE

\* The book can be downloaded from York Digital Library <https://dlib.york.ac.uk>

## FOR THE ELIMINATION OF LEPROSY

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