

FOR THE Elimination OF Leprosy

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



Family portrait: a father and daughter photographed earlier this year at Kasturba Gram Kushta Ashram in Tahir Pur, Delhi, India.

MESSAGE

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World Leprosy Day

Every year, the last Sunday in January is commemorated as World Leprosy Day. The day was started by the late Raoul Follereau to raise awareness of the disease. On January 27, 2013, World Leprosy Day will be observed for the 60th time. My own initiative, the annual Global Appeal to end stigma and discrimination against people affected by leprosy and their families, which I launched in 2006, is also held around this time.

The French journalist, poet, lawyer and philosopher Raoul Follereau engaged in a wide range of causes. He is one of the humanitarian activists I respect the most. In particular, the deep love and fellow feeling he showed people affected by leprosy make him a true embodiment of love for all mankind.

In an era when the disease was still incurable and there was no magic bullet such as multidrug therapy (MDT), Follereau dedicated himself to his mission. We must recall, too, that transport and communications back then were not as convenient as they are today. He gave hope and

courage not just to people affected by leprosy but also to so many others involved in leprosy work. In 1954, the year he started World Leprosy Day, he wrote to the leaders of the United States and the Soviet Union, asking them to donate the cost of one bomber apiece to the treatment of leprosy patients.

There have been other great individuals as well, such as Mahatma Gandhi, Mother Teresa and Baba Amte, who devoted themselves to fighting the disease — and the stigma and discrimination — before there was an established cure.

Today we live in very different times. Medicine has advanced. Now we have MDT. With early detection and prompt treatment, people can be saved from the stigma and discrimination they might otherwise face if the disease proceeds unchecked. So as the 60th World Leprosy Day approaches, let us recall the efforts of those who have gone before us and take further strong steps forward in the fight against leprosy.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Heritage Matters

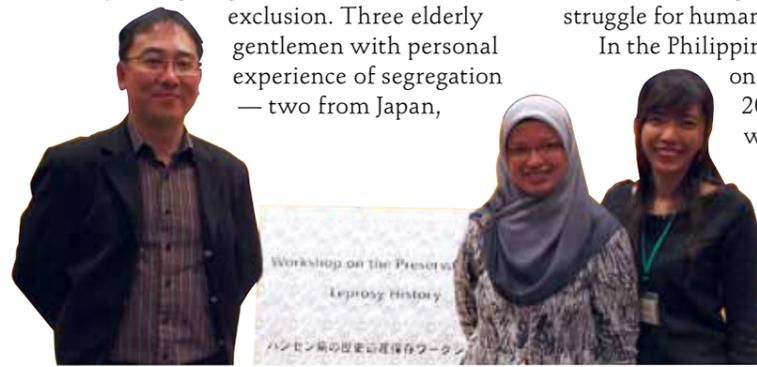
A Tokyo workshop focuses on the importance of preserving leprosy history and heritage.

The first international workshop on preserving leprosy history and heritage was held in Tokyo on October 24 and 25, aiming to encourage networking among leprosy museums, archives and heritage sites in different parts of the world. Jointly organized by the Sasakawa Memorial Health Foundation (SMHF) and Japan's National Hansen's Disease Museum, the two-day event drew participants from Brazil, Malaysia, Portugal, the Philippines, Australia and Taiwan.

With leprosy fading from public memory, records disappearing and heritage sites under pressure from developers, SMHF's Kay Yamaguchi injected a note of urgency into the proceedings, suggesting there was a "last chance" to take action to preserve leprosy history and place these efforts on an international footing.*

The need to move quickly also stems from the diminishing number of people who were subject to past policies of isolation and

exclusion. Three elderly gentlemen with personal experience of segregation — two from Japan,



one from Brazil — attended the workshop. Their contributions underlined the importance of involving such "primary stakeholders" in discussions on how their history should be preserved and represented.

ROLE MODELS

With heritage preservation at different stages in different countries, discussions focused on how experiences could be shared to mutual advantage. Japan has a national leprosy museum — a manifestation of the state's apology for its mistaken policies of the past — but its founders and curators acknowledge its shortcomings and look to others to help make it more international in scope. Brazil does not have an equivalent museum, but there are plans to build one by MORHAN, the Movement for the Reintegration of Persons Affected by Hansen's Disease, which noted the important role Japan's national museum and its predecessor have played in the struggle for human rights.

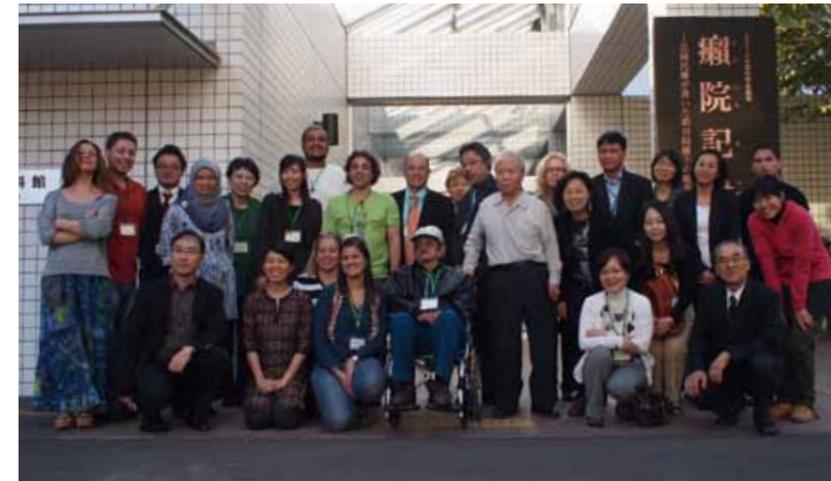
In the Philippines, a museum and archives on leprosy were established in 2006 on Culion, once the site of world's largest leprosy colony.

But as the island's economy develops, some of its historic buildings are under threat. "We have to find a way of preserving the past

Three delegates from Malaysia

FOOTNOTE

* For another initiative to promote the cultural heritage of leprosy/Hansen's disease historic sites, visit the International Coalition of Historic Sites of Exclusion and Resistance www.leprosyheritage.com



Group portrait in front of the National Hansen's Disease Museum

COLLABORATIVE NETWORKS

Participants also agreed on the need to encourage and support the efforts of networks of people affected by leprosy, local and national advocacy groups, NGOs and scholars to talk to and collaborate with relevant governmental entities so that comprehensive plans for the preservation of leprosy history and heritage are furthered.

while taking account of the needs of the future," said Dr. Arturo C. Cunanan.

One solution was put forward by Dr. Lim Yong Long, who is closely involved in efforts to preserve what remains of the Sungai Buloh leprosarium complex in Malaysia. "Architectural planning and design can solve the problem of how to balance the desire to preserve the past and the needs of the future," he said.

The adaptive reuse of sites such as Sungai Buloh was one of the recommendations drawn up by participants, who stressed the need to "actively and sensitively preserve and adapt these sites in innovative ways that retain their identity and integrity."

Two experts from the Philippines, Dr. Maria Serena I. Diokno of the National Historical Commission and Victorino Mapa Manalo of the National Archives, brought fresh perspectives to the topic and made some practical suggestions. One outcome of the workshop is that the commission will undertake preparatory research to install a historical marker on Culion.

Following the two days of discussions in Tokyo, delegates traveled to western Japan, where they visited Nagashima Aiseien, a leprosy sanatorium located on an island in the Inland Sea, and toured the museum there. They also took part in a public symposium on leprosy history in the nearby city of Okayama. ■

TALKING POINTS

Alice Cruz (Portugal)

One of the issues to emerge during the workshop is the separation of children from parents who had leprosy. These children were not sick, but they were separated from their parents and from society and their lives were severely damaged. How can we attach the preservation of leprosy history to the struggle for human rights? How can we make this linkage now?

Cristiano Torres (Brazil)

I was born in a hospital-colony. Many people now talk about the historic preservation of this hospital. But to preserve history, we first need to know who separated me from my parents. Did

they have the right to do that? Did they have the right to put us in the colony? For me, the most fundamental thing is the history of the people inside the colonies. The history of leprosy is not the history of a disease. It's the history of human beings and of human rights.

Artur Custodio (Brazil)

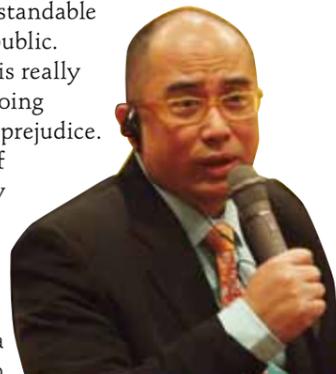
The museum we plan for Rio de Janeiro will be one built out of the struggle of the social movement and at the initiative of the social movement. It will be very much a project linked with the community and undertaken by listening to the community—to the people who have, or have had, leprosy. As such, it is also a political project

aimed at public policy and at the preservation of this story.

Victorino Mapa Manalo (Philippines)

We need to make the history of leprosy understandable to the wider public. Ultimately, it is really about the ongoing occurrence of prejudice. The history of leprosy is very much the history of prejudice—

Victorino Mapa Manalo



and prejudice has killed more people than disease has. Prejudice occurs everywhere and takes many different forms. The fight against it must be understood all over the world and an understanding of the history of leprosy has a lot to contribute to this. In the end, prejudice is always the biggest problem we need to face.

Maria Serena I. Diokno (Philippines)

We all agree that we want to preserve the past for two fundamental reasons. One, as a source of our identity—who we are, how we have evolved over time and what we have become. And two, as a matter of justice,

because we recognize that wrongdoing was done and inequities created that favored certain groups or sectors in society. By remembering the past we can redress these grievances. We cannot change the past,



Jo Robertson

but we can change the consciousness of people in the present, especially the young, on how they understand the past.

Jo Robertson (Australia)

We want to arrive at a common understanding on how we can preserve the history of leprosy, representing the different views of people affected by the disease, the families of those affected, the medical professions, governments and society in general. We would like to arrive at a shared view in order to form a loose international network of leprosy museums and archives whose individual histories complement each other and make a unique contribution to the history of leprosy.

The Meaning of Our Museum

Veteran activist tells workshop of his vision for Japan's national leprosy museum.

On October 25, Yasuji Hirasawa addressed participants of an international workshop on the preservation of leprosy history and heritage. This is an edited and abridged version of his remarks.

Welcome to the National Hansen's Disease Museum. I am heartened by this international gathering to discuss the preservation of leprosy history and heritage.

I would like to address three points: why we established this museum, what its mission is, and why it looks to the future rather than dwells on the past.

Down the years, many remarkable people have lived in Tama Zenshoen, the sanatorium next door to this museum. Hidden from society, they retained an interest in the outside world and were very productive. The hub of this cultural activity was the sanatorium library.

But in the second half of the 20th century, as new cases of leprosy in Japan declined and as the sanatorium population decreased, fewer people were using the library. Those of us on the residents' committee were faced with the challenge of keeping it going.

We decided to turn it into a specialist library on leprosy that would serve as a center to explain the history of the disease to people in the 21st century. This was around 1974-75. We collected documents and other objects — such as everyday items of residents who had passed away — and put them on display.

As time passed, the question arose: What

would happen to the library after we died? Around 1990, we arranged a meeting with Dr. Fujio Otani, the chairman of the Tofu Kyokai, an association to help sanatoria residents. We asked him what would have been the point of our lives if this history were to disappear once we were gone. We said that we wanted to establish a museum and were prepared to do so ourselves.

This was a minority opinion among sanatorium residents. The majority gave the idea a chilly reception. They said that if we started telling people about the history of leprosy, we would only stir up the prejudice that exists in society. Our response was to explain why we felt it was important to have a museum and how we hoped it would benefit society.

From the 1990s, we started collecting materials, raising funds and putting up displays. We did everything ourselves. We didn't receive any support from the government or the medical community. We made this museum with our own hands.

INSPIRATIONAL VOICES

The museum was influenced by the ideas of three people I have known. The first was a tuberculosis patient who, in the 1950s, took the Japanese government to court over his constitutional right to life. He won in the district court but the verdict was overturned in the high court and the ruling was upheld in the Supreme Court. Coughing up blood, he told me of his regret to be dying on the losing side. "This

PROFILE : Yasuji Hirasawa



Diagnosed with leprosy at 14, Yasuji Hirasawa has lived in Tama Zenshoen sanatorium for 71 years. In 2005 he was awarded the Yoshikawa Eiji Cultural Prize for his efforts to restore the human rights of people affected by leprosy and his contribution to educating children about human rights.



The National Hansen's Disease Museum: a place to think about what it means to live

movement isn't just about us," he said. "It's for the sake of society as a whole."

The second person was Masao Ogura, the founder of Yamato Transport Co., a parcel delivery company. Through the foundation he started, he was very active in supporting persons with disabilities. He told me: "You are sure to succeed if you can make everyone happy."

The third is a person I have mentioned already, Dr. Fujio Otani. His dying wish was to realize a society in which all people can live together.

As human beings we need to build mutual trust. That is what this museum is all about.

The museum opened in 1993 as the HIH Prince Takamatsu Memorial Hansen's Disease Museum. It helped to pave the way for the abolition of the Leprosy Prevention Law in 1996. Following a landmark legal judgment in 2001, the museum was nationalized. Construction of a new building began in 2005 and it reopened in April 2007 as the National Hansen's Disease Museum.

Today the museum receives around 30,000 visitors a year. It's a place where the likes of educators, bureaucrats and public welfare

providers can reflect on the meaning of human existence and what it is to live.

Yesterday, 100 schoolchildren visited. When children come, they listen attentively, write essays and make newspapers. Then they go home and tell their parents, relatives and others about the disease. But 100 times more effective than what I tell them in terms of helping to bring an end to stigma and prejudice is when they shake this disease-scarred hand of mine.

LIFELONG ACTIVIST

I have been a patient activist for more than 60 years. As a person affected by leprosy I have worked with groups of people with tuberculosis, with mental and physical disabilities and with incurable diseases all over the country.

I am fighting for a society in which people can live as human beings, whatever barriers they have to face. I take the position that a society in which we can be happy is a society in which healthy people can be happy too.

In the past, we were discriminated against by people in the community. Places I visited were disinfected. I wasn't allowed in taxis. People refused to sell things to me. But is there anything to be gained by bearing grudges and meeting animosity with animosity? As human beings we need to build mutual trust. That is what this museum is all about. ■

MUSEUM PIECE

ROTATING EXAMINATION TABLE

When a child or grandchild of segregated leprosy patients sets eyes on the "Rotating Examination Table" currently on display at the Culion Museum and Archives, a big smile is sure to cross his or her face. Most if not all children born and raised inside the "leper section" of Culion Island in the Philippines stood upon this table in their younger days. As the table turned, every inch of their skin would be carefully examined and recorded. Suspicious lesions were tested for sensation and peripheral nerves were palpated to see if they were enlarged.

Few of them can forget how, twice a year, the local policeman assigned to the clinic would come to the classroom with a list of names of those scheduled for examination. Known as "reconoser," this routine examination for leprosy continued up until the early 1980s on Culion, which was once the world's largest leprosy colony.

Outside the examination room, the children would wait silently and anxiously for the nurse to call their name. Once summoned inside, the child would mount the table and be meticulously examined by Dr. Casimiro B. Lara, a dedicated leprologist who spent almost 60 years on Culion

Positive signs of leprosy necessitated further tests and a longer stay at the clinic. Those pronounced negative or "clean" were sent home with candy, a can of condensed milk or a bag of powdered milk.

For students who had not prepared their assignments or done their homework, the visit of the local policeman summoning them to "reconoser" was a godsend. It gave them an excuse to miss class and the chance to get a treat

— Dr. Arturo C. Cunanan



Mr. Positive

Once a depressed young boy, Nilkanth Koli now radiates self-assurance.



Standing tall: Nilkanth Koli addresses youth camp participants at Shantivan.

Nilkanth Koli works as youth camp coordinator at Shantivan, a 120-acre community established by rural service organization Kustharog Niwaran Samiti in India's Maharashtra state. Initially founded to treat and rehabilitate persons with leprosy, Shantivan has broadened its scope to include rural development.

Koli was just eight when his parents were summoned to his school to be told their son had leprosy, which had been diagnosed following a routine examination by a visiting leprosy technician. Within a few months he was developing deformities to his hands and feet, and had begun to suffer from foot ulcers. His family could not care for him properly, so his father decided he would be better off at Shantivan.

"I was very upset because I had to leave my family. At first I couldn't stop thinking about them," Koli recalls of that time. "I felt so lonely."

Shantivan's general secretary arranged for him to attend a nearby school, but Koli stopped going after a few days because he felt depressed and self-conscious about his hands and feet. Shantivan was a very friendly place, however, and being the only child there at the time, he found himself showered with affection.

TRANSFORMING EFFECT

Several years before Koli arrived, Shantivan had begun organizing student youth camps. Young people from Mumbai and surrounding areas would stay for three days, learning about leprosy, doing voluntary work and spending time with Shantivan's residents.

Koli found himself being asked many questions. "It was a great opportunity to share my feelings with young people from the community," he recalls. "I gradually developed an interest in these camps and started working

as a program assistant. I could feel my self-confidence returning."

If the camps had a transforming effect on Koli, they also had a similar effect on the visitors. He recounts the story of one of the first batches of students returning unannounced and saying, "Today is Raksha Bandhan and we want to tie sacred threads on your wrists."* It was a joyous moment. "Never before in the experience of people affected by leprosy at Shantivan had their brothers and sisters from the community remembered them in this way," Koli says.

I started working as a program assistant. I could feel my self-confidence returning.

Another group of students was very shy and reluctant to take part in any of the cultural activities that had been organized for them, in spite of Koli's best efforts to involve them. Some months later, he received an invitation from their school principal. "To my surprise, I found myself watching the same group of students performing in a drama and winning a prize," he says. "The school attributed this change in the students to the encouragement they had received at Shantivan."

To date, some 200,000 students have passed through Shantivan. They go on to spread awareness of leprosy, raise funds for Shantivan's activities and come back to celebrate personal milestones. "It's a social movement," Koli says. "It makes me very proud that we have conveyed the message that 'leprosy is curable' to so many students and have turned them into ambassadors for Shantivan." ■

FOOTNOTE

* A festival that celebrates the relationship between brothers and sisters.

Myanmar's Path to Democracy

Appointed Goodwill Ambassador for the Welfare of the National Races in Myanmar earlier this year, Yohei Sasakawa hopes his work in helping to bring peace to Myanmar will prove useful in his role as Goodwill Ambassador for Leprosy Elimination.



With Aung Sang Suu Kyi at her residence in Naypyidaw on July 28

Myanmar's transition from long years of military rule to democratic government is proceeding at a bold pace. Although the process is by no means complete, the constitution has been revised and pro-democracy icon Aung San Suu Kyi has been elected to parliament.

The biggest challenge for building a democratic Myanmar is to end more than 60 years of insurgency against the government, waged chiefly by 13 armed ethnic groups, and achieve genuine peace. The cease-fire agreements that have been signed are a move in the right direction. I have met repeatedly with President Thein Sein and National League for Democracy leader Aung Sang Suu Kyi, and they are in agreement on this.

For decades, The Nippon Foundation has been engaged in anti-leprosy activities in Myanmar. We have also built 200 elementary schools in regions inhabited by ethnic minorities and delivered medicine chests containing traditional Myanmar remedies for diarrhea, fever, colds and other ailments to 7,500 villages.

Because of our track record, Japan's Foreign

Ministry appointed me Goodwill Ambassador for the Welfare of the National Races in Myanmar in June. My role is to work with the Japanese government to help ethnic minorities and assist in their true reconciliation with the Myanmar government.

TOKYO VISIT

On October 18, representatives from 10 of these ethnic minority armed opposition groups visited The Nippon Foundation in Tokyo for a briefing. The groups have been cornered by government forces in mountainous areas, creating about 1 million internally displaced persons. Conditions are harsh and there are shortages of food and medical supplies. The situation remains tense and difficult to clarify.

Fortunately, I have been able to build a relationship of trust with the various armed opposition groups. To spearhead the realization of peace, The Nippon Foundation plans to distribute US\$3 million in food and medical supplies to areas controlled by these groups — the first time this has been done. If all goes well, we would like to request additional support from international organizations and humanitarian bodies. We also plan frequent fact-finding missions to these areas for monitoring purposes.

This brings me back to leprosy. Myanmar achieved the elimination of leprosy as a public health problem in 2003. But the situation is not at all clear in terms of case numbers and related issues in those parts of the country that have been in the hands of armed ethnic groups. This, too, is something I am keen to pursue as I engage with Myanmar. ■



The deputy head of the United Nationalities Federals Council (UNFC), an umbrella organization of Myanmar's leading ethnic groups, and representatives of 10 of the 11 groups that make up the UNFC, meet with the Goodwill Ambassador at The Nippon Foundation in Tokyo on October 18.

Uniting to Combat NTDs

Washington meeting explores synergies across neglected tropical diseases.

Following the launch of the London Declaration on Neglected Tropical Diseases in January 2012, a conference of donors, endemic country governments, NGOs and other partners was held in Washington in November to look at ways to translate the London Declaration into action.

The London Declaration is a commitment to work to control or eliminate 10 neglected tropical disease (NTDs), including leprosy, by 2020 in

line with targets set by the WHO.

During the Washington conference, a side meeting on leprosy was organized by the International Federation of Anti-Leprosy Associations (ILEP). Attended by representatives of organizations working in leprosy as well as those working in other NTDs, the meeting explored cross-cutting issues among NTDs and ways of collaborating on common areas of work.

NARSAPPA HONORED

Vagavathali Narsappa, the chairman of National Forum India, has been selected to receive a National Award for the Empowerment of Persons with Disabilities, 2012. The awards are administered by the Department of Disability Affairs of the Ministry of Social Justice and Empowerment. Narsappa was chosen in the category of Best Individual Working for the Cause of Persons with Disabilities. The award was to be conferred by the president of India on December 3. The National Forum India is a networking organization of persons affected by leprosy.

DR. CHAN IN TOKYO



Goodwill Ambassador Yohei Sasakawa met with Dr. Margaret Chan, the WHO director-general, during her visit

to Tokyo for the annual meetings of the IMF and World Bank in October. Sasakawa thanked her for the WHO's ongoing drive against leprosy and its support for efforts to address the disease's human rights dimension. ■

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FROM THE EDITORS

REMEMBERING KAZUMI SOGANO

This issue devotes several pages to the topic of leprosy history and heritage, so it is fitting to mark the passing of man whose signature is attached to a document of historic significance. Kazumi Sogano, who died in November at the age of 85, signed a basic accord with the Japanese government on July 23, 2001, under which the state agreed to compensate people affected by leprosy for their forcible segregation under the Leprosy Prevention Law. Sogano signed as the representative of plaintiffs who had sued the state for redress in Kumamoto District Court and two other courts.

When the Leprosy Prevention Law was repealed in 1996, Sogano was not initially inclined to pursue compensation. He was prepared to accept the law's abolition and a guarantee that residents could remain in the sanatoriums that had become their homes. He also felt that, had sanatoriums not existed, his family would not have survived taking care of him for 50 years. But when he came to learn that the government did not acknowledge the outrageousness of its past policies, including forced

sterilization, his attitude changed and he assumed a lead role in the fight for justice.

After Kumamoto District Court issued a landmark ruling on May 11, 2001, ordering the state to pay compensation to 127 plaintiffs, it was Sogano who led a sit-down protest in front of the prime minister's residence, calling on the government not to appeal the ruling to a higher court. He was one of a number of plaintiffs who met then-Prime Minister Junichiro Koizumi, shortly before Koizumi announced on May 23 that the government would not appeal. As Sogano told a news conference at the time, "To appeal against people as old as us would be the same as killing us."

Sogano developed symptoms of leprosy at the age of 18. It was near the end of World War II and he was training to be a kamikaze pilot. Many of his fellow airmen went to their deaths, but Sogano's diagnosis saved him. In 1947, he was sent to Oshima Seishoen sanatorium, where he would live for the rest of his life.