

FOR THE Elimination OF Leprosy

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



Yohei Sasakawa meets the Dalai Lama in Delhi, India, on November 21, a day after their joint scholarship program was announced.

MESSAGE

CONTENTS

My Promise to the Dalai Lama

In March, His Holiness the Dalai Lama joined me on a visit to a leprosy complex in Delhi, India. Alighting from his car, he was soon moving among the colony residents eagerly awaiting him. Reaching out, he took people by the hand and gave them his blessing.

We first met in Prague more than a decade ago at a conference I organized with then-Czech President Vaclav Havel. During one of our conversations, I told him I was working to eliminate leprosy from the world. I said my efforts were focused particularly on India, where my dream was to bring an end to begging by people affected by leprosy.

He told me he had supported the work of Baba Amte, who devoted his life to helping people affected by the disease, and that he himself took a great interest in their welfare. Subsequently, the Dalai Lama has twice been a signatory of the annual Global Appeal I launched to end stigma and discrimination against people affected by leprosy; he has also recorded supportive video messages.

At the time of the colony visit, he announced he would make a donation to people affected by leprosy and their families through his foundation.

Wishing to do something to see that the Dalai Lama's generosity bore fruit, I proposed that the Nippon Foundation provide funds as well, and that we create a scholarship program for children affected by leprosy, or whose parents are affected by leprosy, living in colonies. The Dalai Lama agreed, and the scholarship program was officially unveiled in November.

For many of these youngsters, stigma and discrimination, coupled with a lack of financial resources, rule out the chance of higher education. My promise to His Holiness is that the Dalai Lama-Sasakawa Scholarship will help them to surmount the obstacles of stigma and poverty and one day make their mark on society.

In any case, it is my wish that by the time these young people finish their education and start work, colonies will have been integrated with the rest of society. When that happens, the isolation and discrimination their residents endured will be a thing of the past.

— Yohei Sasakawa, WHO Goodwill Ambassador

Message	1
Report	
Human rights conference in Morocco	2
History workshop in Japan	3
Ambassador's Journal	
Notes from Morocco, Spain, Portugal, and India	4
News	
India mid-term evaluation; Global Appeal 2015	8
From the Editors	8

Building Momentum in Morocco

4th regional symposium on leprosy and human rights paves way to Geneva in 2015.



Naima Azzouzi (far right) and friends in Rabat

A recent symposium in Morocco on leprosy and human rights was an opportunity for Naima Azzouzi to speak publicly for the first time about the disease she was diagnosed with at the age of 9. Azzouzi is the president of an association of people affected by leprosy in Morocco formed this year to promote social integration, job opportunities and the alleviation of poverty.

"I want to thank the organizers for hosting this event. It is the first time we have been able to convey our feelings," she told an international audience of 120 government officials, human rights experts, NGO representatives, journalists and people affected by leprosy in Rabat on October 28. "We want people to know we have fundamental human rights."

Sponsored by the Nippon Foundation in cooperation with Morocco's Ministry of Health, the symposium was the fourth in a series taking place in different regions of the world to disseminate Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and Their Family Members endorsed by a UN General Assembly resolution in 2010.

Although leprosy is completely curable, deep-rooted stigma and discrimination associated with the disease remain widespread. For those affected, this can mean living on the margins of society, where opportunities for education, employment and access to public services are severely curtailed.

"Even though you may be medically cured, you



Around 120 people attended the symposium.

still have the disease as long as there is stigma and discrimination," Alem Galeta, a board member of the Ethiopian National Association of People Affected by Leprosy (ENAPAL), told a session on Women and Leprosy. Describing the desperate circumstances she used to live in, Galeta said that joining ENAPAL had been a turning point in her life. "Change is possible. Women can change, because I have changed."

Speaking at the opening of the symposium, Professor Abderrahmane Maaroufi, Morocco's director of epidemiology and disease control, said that the rate of leprosy had been going down in his country, but that leprosy still remains a social disease affecting rural and poor populations. "This symposium is an opportunity to trigger new actions against stigma and discrimination," he said.

INTERNATIONAL WORKING GROUP

Previous symposia have been held in Brazil, India and Ethiopia. Following the first symposium in Rio de Janeiro in 2012, an International Working Group was formed to develop plans of action to help governments implement the Principles and Guidelines, and to propose a mechanism to monitor their efforts.



Professor Barbara Frey

Professor Barbara Frey, director of the University of Minnesota's Center for Human Rights and a member of the working group, called the UN resolution "a landmark achievement." She said the Principles and Guidelines have their roots in the UN Charter and "confirm

and build upon the core international guarantee of non-discrimination, which is so deeply embedded in international human rights law."

While the Principles and Guidelines are initially aimed at states, she said, there are other important actors with a role to play, especially people affected by leprosy. "Useful alliances need to be forged. We need to work together."

The day-long symposium included a session on leprosy heritage. Speakers from India, Brazil and Japan stressed the importance of not forgetting what generations of persons affected by leprosy have endured. Dr. P.K. Gopal, president of IDEA India, suggested that preserving history can serve as a guideline for future generations on the behavior to avoid in dealing with people with a disease such as leprosy.

The fifth and final symposium is scheduled for Geneva in June 2015, when the International Working Group will issue its recommendations. ■

Why Heritage Matters

International workshop motivates participants to do more to preserve the past.

The Second International Workshop on Preserving the History of Hansen’s Disease was held in Tokyo on October 31 and November 1. Delegates from Colombia, Malaysia, Nepal, the Philippines and Thailand joined those from Japan at the National Hansen’s Disease Museum for the two-day event organized by the Sasakawa Memorial Health Foundation.

It was at the same venue two years ago that the inaugural workshop brought together participants from Australia, Brazil, Japan, Malaysia, the Philippines, Portugal and Taiwan to encourage initiatives to preserve leprosy history. As a result of that workshop, the National Historical Commission of the Philippines is now overseeing a project that will produce, in 2015, a multifaceted history of leprosy, placing the neglected disease within the larger framework of the Philippines’s national history. The country’s eight national sanitariums are also undertaking history projects, with the full support of the commission and the National Archives of the Philippines.

Different countries are at different stages of their historical preservation efforts. Of the countries participating at the workshop for the first time, participants from Nepal and Thailand presented their plans to build national leprosy museums. Colombia, meanwhile, has four separate leprosy-related museums in the town of Agua de Dios, a former leprosy colony; they are now exploring ways to coordinate their activities in order to better promote the town’s heritage.

Among the recommendations to emerge from



Seven countries were represented at the Tokyo workshop.

the workshop were to:

- pursue the development of an Internet-based network linking countries implementing or embarking on the preservation of leprosy history and memories;
- secure a place for presentations on preservation of leprosy history on the agenda at appropriate national, regional or international meetings, e.g. history of medicine meetings, the International Leprosy Congress;
- develop a pool of international multidisciplinary technical experts to help guide and supervise preservation efforts;
- sensitize national governments and international bodies and agencies on the importance and urgency of the preservation of leprosy history and memories, so as to encourage support and favorable policies; and
- include advocacy and other efforts for the preservation of leprosy history as part of activities on World Leprosy Day. ■

QUOTE

“There are stories of courage and perseverance that have to be told. They can educate the public against discrimination. Residents (of Sungai Buloh leprosarium) do not realize how their stories can be an inspiration to younger generations. Telling their stories is a marking of their place in history. By telling their stories, they can reclaim the dignity they once lost.”

— Joyce Wong, Malaysia

A SENSE OF URGENCY

As leprosy ceases to be a public health problem in many countries as a result of modern medication, it is coming to be seen as a disease of the past. Sanatoriums are closing, experts are retiring and leprosy services are being incorporated into the general health services. The history of those who have lived with the disease, of the disease itself and the quest for a cure — and of society’s response to leprosy — are in danger of being forgotten. But the rich history of leprosy is replete with experiences and lessons for building a society where people with special needs, including those resulting from leprosy and other diseases, are fully accepted.

As our foundation became aware of the importance of preserving leprosy history, we came to appreciate how leprosy has left footprints all over the world. We were struck by the universality of the themes we encountered, but also by the unique ways the disease presented itself in different countries, and the particular political, cultural and societal responses it triggered.

We began to realize that we were looking at much more than the history of a disease. The history of leprosy and its legacies are full of potential for analyzing human relationships — individual, communal, societal,

national and international — now and in the future.

Leprosy has long been a symbol of separation, uprooting the lives of those diagnosed with the disease, and those of their families. But leprosy also unites. People affected by leprosy today are united by a strong sense of comradeship and solidarity, and a desire that their stories be told.

Without the viewpoints of those who have experienced the disease and its consequences, the history of leprosy will not be complete. There is a need to act while their memories are still within reach.

— Sasakawa Memorial Health Foundation

The Road from Rabat

Learning about Morocco's leprosy elimination activities, sanatorium visits in Spain and Portugal and an appointment with the prime minister in India are among the Goodwill Ambassador's recent activity highlights.

MOROCCO (October 26-30)

Visiting Morocco for the latest in a series of regional symposia on leprosy and human rights being organized by The Nippon Foundation gave me an opportunity to learn more about the leprosy situation in this North African nation.

With a population of 33 million, Morocco sees about 30-40 new cases of the disease annually. It achieved the WHO's target of eliminating leprosy as a public health problem in 1991 and is now aiming to reduce the number of cases to zero by 2025. Its strategy is based on early detection and treatment, and the use of chemoprophylaxis to treat contacts of index cases to protect them from developing the disease. The health ministry began administering single-dose rifampicin to contacts from late 2012.

In Casablanca, I visited the National Leprosy Center, which was created in 1952 at Ain Chok Hospital. In the past, someone diagnosed with leprosy would be hospitalized here for three months. That requirement ceased with the decentralization of healthcare from 2006.

During its busiest period, the hospital had around 200 inpatients. Now, on average, there are between 8 and 16 inpatients, but only those with severe symptoms. It sees around 30 outpatients a month.

Taken on a tour of the facilities by Dr. Eddaoule Asma, who has worked here for three years, I was shown cabinets of patient records dating back to the opening of the center. Dr. Asma told me a very good database had been established by Dr. Rene Rollier, the French doctor who ran the center for many years.

I met with some of the inpatients and saw the work of an NGO based at the hospital, the Association for Reintegration through Tapestry, where people affected by leprosy are taught to make high-quality tapestries that they sell to provide an income for themselves and their families.

In days gone by, the hospital was home to people such as Naima Azzouzi, who heads a newly formed association of people affected by leprosy in Morocco. She lived here for 10 years after both her parents died, because she had nowhere else to go, along with others rejected by their families.

As patient numbers have declined, so budgets have been cut, leaving areas of the hospital unused and falling into disrepair. The lab has closed, with patients requiring biopsies referred to a nearby TB



At the National Leprosy Center, Casablanca

hospital. The operating theatre hasn't been used since 2006. "As you can see, the hospital is very old. The government says it is going to renovate it, but who knows when?" Dr. Asma said.

To see the situation in the field, I headed northeast from the capital, Rabat, toward the mountains of Chefchaouen Province. I was going to meet a nurse specializing in leprosy in one of the four endemic regions of Morocco where 60% of cases are found. For the past 36 years, Nurse Ramadanani has been looking for new cases, tracing contacts and developing close ties with people in the region.

After meeting at a local health center that serves 48 villages and hamlets with a combined population of around 31,000 people, we traveled to the village of Beni Bouhar, 700 meters above sea level. It has a population of 230 and its inhabitants earn an income from olives, figs and mountain honey.

After visiting the house of a man he had treated, we traveled by four-wheel-drive vehicle to the home of another of Nurse Ramadanani's former patients. There, he showed me how he took skin smears from Redouane el Moudeu and tested for anesthetic skin patches. The same tests



In Beni Bouhar



Nurse Ramadanani



(Above) A view of Fontilles and its wall; (right) some of the 35 remaining residents

were carried out on his family members and it was found that three of his younger brothers also had leprosy.

“I’m extremely happy at the progress we have made since I first started this work,” Ramadani told me. Showing that leprosy can be cured means people are more willing to talk about the disease and look for the signs in others, he said. “Visiting villages is a process of sensitization.”

SPAIN (October 30-November 2)

Set in wooded hills high above Spain’s Costa Blanca, Fontilles sanatorium has a history going back more than 100 years. It opened its doors on January 17, 1909, but its origins trace back to 1902, when two friends — a Jesuit Father and a lawyer — were moved to help those with leprosy who had been rejected by society.

One of the founders’ tasks was to build a wall around Fontilles, as local residents were fearful of inmates escaping. But the wall was never completed and nearby communities, which in any case had been a source of leprosy patients, came to appreciate the value of Fontilles as an employer.

Fontilles grew into a small village with its own facilities — a bakery, carpenter’s shop, blacksmith’s, printing office, bindery, shoemaker, hairdresser’s, a church, a theatre and even a bar. “It’s bigger than the Vatican,” Ramon Trenor, the president of the Fontilles Association, told me with a smile after I arrived by road from the city of Valencia.

In the past, the Valencia region was one of four focal points of leprosy in Spain, along with Andalusia, Galicia and the Canary Islands. Today there are only around 15 to 25 new cases registered each year; of these, 75% consist of immigrants from South America and Africa.

At its peak in the 1940s, there were 438 people affected by leprosy living in Fontilles; today there are just 35. After attending Mass, I had an opportunity to meet with some of them. Many have lived here for decades.

Visiting the well-run laboratory, I heard from

Pedro Torres, the head of the lab, that Fontilles receives about 65 referrals a year from major Spanish cities, of which nine or 10 cases prove to be leprosy. The lab also examines biopsy samples from abroad, as part of its international cooperation efforts.

Fontilles first began to work overseas in 1989, when it set up dispensaries in India. It now works on projects in Asia, Africa and Latin America relating to the treatment and cure of leprosy and other diseases of poverty, and also focuses on social rehabilitation. With decades of expertise to draw on, it also runs courses on leprosy for doctors and paramedics, and trains volunteers to work in leprosy overseas.

One of the jewels in Fontilles’s crown is its library. The mostly Spanish-language books and journals are a valuable source of research material for the academics and scholars who visit. Fontilles also boasts a Spanish-language scientific journal on leprology, which marked 70 years of unbroken publication in November.



Not all of the Fontilles complex is devoted to leprosy these days. In addition to the sanatorium, there

is a geriatric center specializing in the care of the elderly with different physical and psychological needs. There is also the Hospital Ferris, for patients needing to convalesce after surgery and for rehabilitation. Most recently, some rooms in the hospital have been made available to care for the terminally ill and those recovering from serious operations or injuries among the large expatriate population in the region.

Fontilles continues to make an important contribution to leprosy work in terms of diagnosis, training, research and care. I think there is much to be learned from Fontilles’ long and distinguished history and how it is adapting to society’s present and future needs. >>>



Commemorative plate



PORTUGAL (November 2-4)

It had been 10 years since I last visited Hospital Rovisco Pais, which is located about an hour's drive from the historic university town of Coimbra. The hospital was established in 1947 as Portugal's last leprosarium. It served exclusively in that capacity until 1996, when it became a general hospital with a focus on the rehabilitation of victims of accidents and strokes. On the occasion of my last visit, there were around 40 of the original residents still living here; now there are just 12 — ranging in age from 75 to 93.

On arrival, I was given a short presentation on Rovisco Pais's history. In the year it opened, 374 leprosy patients were admitted. In total, 2,298 people with the disease have lived here. The sanatorium had its own shoe-making factory, football teams, cinema, agricultural land and other facilities, providing both recreation and employment for its inmates.

I was then taken on a tour of the grounds, first being shown a modern, brightly lit rehabilitation complex. This stood in contrast to one of the original hospital buildings where I was taken next to meet with some of the now-elderly residents living with the consequences of leprosy.

to imagine the scenes that must have played out here in the past.

The last stop on my visit was the hospital's church. It was designed so that people affected by leprosy were kept apart from the rest of the congregation; in a further act of segregation, male and female inmates sat in separate wings.

The health authorities have expressed an interest in preserving the history of Hospital Rovisco Pais and the role it played in controlling leprosy in Portugal. I was told that there are plans to convert the church into a museum. The building will need extensive renovations before a museum can open; but this is an important initiative and I hope it will come about.

Before leaving Portugal, I visited the University of Coimbra where I called at the Anthropology Dept. There, Dr. Vitor Matos and his colleagues introduced me to their work on the origins and spread of leprosy. Showing me skulls and skeletal remains, Dr. Matos explained how it was possible to detect whether a person had had the disease from changes in the bone structure. I was impressed by the research they are carrying out and how they are helping to further our understanding of this ancient disease.

Discussing a 10-year-old photo at Rovisco Pais (far left); the glass panels that kept children and their leprosy-affected parents apart (left); discarded records (above)

The intervening years have taken their toll on Rovisco Pais's residents.

Among those I chatted with was a lady I had met a decade earlier. I gave her a photo from my previous visit of her and her husband, who has since died. As the decline in numbers attests, the intervening years have taken their toll on Rovisco Pais's residents, while diseases of aging are also leaving their mark on those still living here.

Near the hospital entrance I was shown a small building that played a poignant role in the leprosarium's history. It was here that children born to parents affected by leprosy were periodically taken to meet them. Separated by glass, they could not touch one another because the authorities forbade physical contact for fear of spreading the disease. The building appears to serve as a storeroom today, but it was possible

INDIA (November 17-24)

In November I traveled to the Indian state of Uttar Pradesh, my first visit in just over a year. Uttar Pradesh annually reports the most new cases of leprosy of any state in India.

Accompanied by Vagavathali Narsappa, the president of the Association of People Affected by Leprosy (APAL) and his colleagues, I had meetings in Lucknow with Principal Secretary (Health & Family Welfare) Arvind Kumar and Chief Minister Akhilesh Yadav. I expressed my hope that the state would fill the post of district leprosy officer in every district, and that it consider increasing the pension paid to people affected by leprosy, many of whom — especially the elderly and disabled — have to beg for a living.

On November 19, I visited a leprosy colony in Faizabad, a three-hour drive from Lucknow. The Shri San Sewa Kush Ashram is home to 66 people, including 50 affected by leprosy. Some of the younger residents work as rickshaw drivers or sell ornaments, but most have no work and go begging each day. With a heavy heart, I

In Faizabad, where many elderly colony residents must beg in order to make a living



accompanied them to their usual spot by the side of a river, knowing that my dream of seeing an end to begging among people affected by leprosy in India is far from being realized.

Three years ago, the colony applied for funding from the Sasakawa-India Leprosy Foundation (SILF) for a sustainable livelihood project, but the enterprise had to be abandoned because of a legal dispute over land ownership. Now that the issue has been resolved, the residents wish to try again. I hope they will be successful this time.



With Governor Ram Naik of Uttar Pradesh

Returning to Lucknow, I had a meeting with an old acquaintance, Uttar Pradesh Governor Ram Naik. The governor has a deep understanding of leprosy: several years ago, he was among prominent individuals who submitted a petition to Parliament about the problems that people affected by leprosy face. In 2010, the Parliamentary Petitions Committee issued its report and recommendations, but these have yet to be followed up. The governor, who knows Prime Minister Narendra Modi well, said he had received an undertaking that the report would be discussed.

Moving on to Delhi, I attended a press conference on November 20 to announce the launch of the Dalai Lama-Sasakawa Scholarship for children living in leprosy colonies. The fund is worth US\$100,000 a year and will be jointly

administered by SILF and APAL. Meeting with His Holiness the next day, I thanked him again for his generosity.

The press conference was held at the residence of Member of Parliament Dinesh Trivedi. He is convener of the Forum of Parliamentarians to Free India from Leprosy. Seven members attended the press conference and a meeting with me afterward. They expressed a desire to visit colonies, which I encouraged. "Speak to the residents, relay your impressions to the media and ask questions in Parliament," I urged them.

The next day, I attended a debriefing meeting on a mid-term evaluation of the Ministry of Health and Family Welfare's current strategy for leprosy (2012-2017), held jointly with the WHO. India eliminated leprosy as a public health problem at the end of 2005, but despite its subsequent efforts at further reducing the burden of the disease, case numbers have leveled off. A number of recommendations were made at the meeting; for my part, I proposed holding an Indian Leprosy Summit in Tokyo in 2015.

My last appointment was with Prime Minister Modi. When we met in Tokyo in September, I said I hoped that on my next visit to India I could introduce him to the head of the Association of People Affected by Leprosy. The prime minister had not forgotten, and now I looked on as he and Mr. Narsappa shook hands.

Mr. Narsappa presented the prime minister with a list of the issues that APAL would like to see resolved; they include those relating to land ownership, pensions and discriminatory laws. I added that I hoped the prime minister would issue a message on India's Anti-Leprosy Day on January 30, stating that leprosy is curable and discrimination has no place. I feel this would have a very big impact.

I am most grateful to the prime minister for making time for this meeting. I intend to redouble my efforts to work for an India without leprosy and its consequences. ■

India's Midterm Report Card

Evaluators make recommendations to strengthen leprosy eradication program.

India has held a mid-term evaluation of its National Leprosy Eradication Programme (2012-2017), oriented toward achieving the elimination of leprosy as a public health problem in every district by 2017.

India achieved elimination at the national level in 2005, defined as a prevalence rate of less than 1 case per 10,000 population, and has gone on to achieve leprosy elimination in all 35 states and Union Territories except Chhattisgarh and Dadra Nagar Haveli. Currently, 115 out of 640 districts have a prevalence rate of above 1.

Evaluators went to nine states, and two districts in each state, visiting health facilities and meeting with patients under treatment, persons with disability, health workers and others in compiling their findings, which were presented at a meeting in New Delhi on November 21.

They made some two-dozen recommendations. For early case detection, these included: strengthening the involvement of ASHA (Accredited Social Health Activists); carrying out contact examinations on a routine basis; and coming up with a challenging and more appealing target and slogan, such as "No child with disability due to leprosy" or "Detect all cases before disability."

For patient management, they included: instituting a viable referral system for managing



reactions and complications, including disabilities; managing data on disabilities; and involving the community, including persons affected by leprosy, in key areas such as counseling.

For program management, meanwhile, listed among the recommendations were: implementing a results-based plan at district and state levels with the participation of other government sectors and other public health programs to improve effectiveness and optimize resources; strengthening technical support at state and district level; and carrying out periodic independent monitoring exercises.

The evaluators also noted a need to strengthen political commitment at state level, for additional human resources at the health ministry's Central Leprosy Division and for vacant positions in states to be filled out of Government of India funds.

national nursing associations. The launching ceremony will be followed by an international symposium on leprosy featuring sessions on nursing and medical care, history preservation, and societal responses to the disease, now and in the future. ■

GLOBAL APPEAL 2015

The 10th Global Appeal to End Stigma and Discrimination against People Affected by Leprosy will be launched in Tokyo on January 27, 2015. Global Appeal 2015 is being endorsed by the International Council of Nurses and its member

FROM THE EDITORS

REACHING OUT

One of the highlights of the recent symposium on leprosy and human rights that took place in Morocco was to see a veteran activist for the dignity and rights of people affected by leprosy from India reach out to the president of a fledgling organization of people affected by leprosy from the host country.

Dr. P.K. Gopal is president of IDEA India and the past president (now advisor) to the organization today known as the Association of People Affected by Leprosy. Naima Azzouzi is a mother of two who heads Apamh and is filled

with a desire to improve the quality of life of people affected by the disease in Morocco.

India sees tens of thousands of new cases of leprosy each year; Morocco sees only a few dozen. But despite the difference in scale, the issues people affected face are the same when it comes to aspiring to a life of dignity, free from discrimination and with access to fundamental human rights.

"Get in touch with us," Dr. Gopal said to Ms. Azzouzi. "Speak with us. You can learn from us. We can learn from each other."

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