

# FOR THE Elimination OF Leprosy

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



Japanese Prime Minister Shinzo Abe addresses the Global Appeal 2015 launching ceremony in Tokyo on January 27.

**MESSAGE**

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## Make World Leprosy Day a U.N. Day

On January 27, the annual Global Appeal to End Stigma and Discrimination against People Affected by Leprosy was launched in Japan for the first time. The appeal, which is announced on or near World Leprosy Day, is the tenth in a series dating back to 2006. This year's appeal was endorsed by the International Council of Nurses, a federation of more than 130 national nurses' associations.

It was the French poet, journalist, lawyer and philosopher Raoul Follereau who started World Leprosy Day in 1954, on the last Sunday in January. This year it was being observed for the 62nd time. According to his book *Love One Another*, Follereau had been talking to a young priest whose suggestion for a day of prayer "gave me the idea of organizing an annual demonstration on a world scale." This was intended, Follereau said, to be "a sort of universal mobilization of hearts and minds in favor of those whom I call the saddest of the world's oppressed minorities, and a revolt against the cruel and often tragic fate reserved for them."

I know that every year there are awareness-raising events that take place in many parts of the

globe on the occasion of World Leprosy Day. But somehow I wonder if they really add up to a global movement. Individual events in different countries and regions only reach so far. If we want more people around the world to know about this day, and to share in the desire to see both leprosy and the discrimination it causes eliminated from the world, is there not more that we could be doing?

Why don't we think about having World Leprosy Day made an official U.N.-designated day, like World Cancer Day, for example? We already have a U.N. resolution on elimination of discrimination against persons affected by leprosy, together with accompanying principles and guidelines. Making World Leprosy Day a U.N.-designated day would, I feel, enhance its international status, give fresh impetus to our efforts, whether governmental or non-governmental, and organically connect them up into a global movement. I also dream, however, of the day when World Leprosy Day is no longer necessary.

— Yohei Sasakawa, WHO Goodwill Ambassador

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# From Tokyo to the World

Nurses back annual call for an end to leprosy-related discrimination.



Over 280 people from 11 countries gathered in Tokyo for the launch of Global Appeal 2015 to End Stigma and Discrimination against People Affected by Leprosy on January 27. Now in its tenth year, the annual appeal initiated by Goodwill Ambassador Yohei Sasakawa in 2006 was being launched in Japan for the first time.

Endorsing this year's appeal was the International Council of Nurses (ICN) and its member associations, who represent 16 million nurses worldwide.

Nurses form the world's largest group of primary care givers and ICN President Dr. Judith Shamian told the ceremony: "It is our professional and ethical duty to fight stigma and discrimination wherever it happens, to ensure that nurses are competent to provide care and counseling to patients and their families, and to uphold the human rights and fundamental freedoms of those affected by leprosy."

**"It is our professional and ethical duty to fight stigma and discrimination."**

With previous appeals launched in countries including India, Brazil, and Indonesia, where leprosy continues to loom large on the health agenda, the Goodwill Ambassador explained why the 2015 event was being held in Japan—even though the country sees only a few cases of the disease each year.

"The decision, he said, "came from our desire to encourage the Japanese public, especially the younger generation, to take notice of the issues surrounding leprosy and to take this opportunity to think about the disease's deeper meaning."

Along these lines, a number of related events to raise awareness of leprosy and the discrimination

it causes have been taking place throughout Japan, together with a social media campaign urging the public to "Think Now *Hansen-byo*" (Think Leprosy Now).

## PRIME MINISTER'S PLEDGE

Japanese Prime Minister Shinzo Abe, together with his wife Akie Abe, headed the list of dignitaries attending the ceremony, who included Japanese Minister of Health, Labor and Welfare Yasuhisa Shiozaki, former president of Timor-Leste Dr. José Manuel Ramos-Horta, and former secretary-general of ASEAN Dr. Surin Pitsuwan.

In his remarks, Abe acknowledged that Japan's past policy toward leprosy had severely restricted the human rights of people affected by the disease, but said that the government had since offered an apology and compensation. It was now focused on ensuring that elderly residents of national sanatoriums can live "comfortably and peacefully" and on bringing an end to stigma and discrimination associated with leprosy.

Following the speeches and short video messages from U.N. Secretary-General Ban Ki Moon and His Holiness the 14th Dalai Lama, the text of the Global Appeal was read out by 13 people. They included Vagavathali Narsappa, president of India's Association of People Affected by Leprosy, Kristie Lane Ibardaloza, a nurse at the Culion Sanitarium and General Hospital in the Philippines, Thiago Flores, a coordinator of the Movement for the Reintegration of Persons Affected by Hansen's Disease in Minas Gerais State, Brazil, Kazuo Mori, chairman of Japan's National Hansen's Disease Sanatorium Residents' Association, and Paulus Manek, the head of PerMaTa, an organization of people affected by leprosy in Indonesia.

"Our message is clear: leprosy can be cured. Drugs kill the bacteria. Early diagnosis and treatment prevent disability. There is no reason to isolate anyone with the disease." ■



# ‘We Reflected on This History’

Prime minister, other speakers call attention to the negative impact of discrimination.

## **Shinzo Abe, Prime Minister of Japan**



In Japan, because of past policy, the human rights of people affected by leprosy were severely restricted. We reflected on this history and around 20 years ago there was a major change in policy. Former patients

were offered an apology and compensation, and as part of the settlement a National Hansen’s Disease Museum was established.

Today there are over 1,700 former patients living in the nation’s sanatoriums. Their average age is over 83 and an increasing number require nursing care, without which their daily lives would be difficult. We will make efforts to help people still in sanatoriums live comfortably and peacefully, and to resolve discrimination and prejudice against leprosy.

## **Yasuhisa Shiozaki, Minister of Health, Labor and Welfare, Japan**



In the past, Japan had a policy of segregation that caused pain and suffering for patients. On behalf of the government I would like to issue a heartfelt apology to all patients and people affected by leprosy and say that we

are doing what we can to bring about an end to stigma and discrimination by educating the public about leprosy.

## **Dr. Judith Shamian, President, International Council of Nurses**



Discrimination against people with leprosy represents a serious violation of their human rights. As nurses, we understand the importance of equitable access to health services and of educating the

public about this disease. The stigma and discrimination felt by individuals can be major barriers to utilizing health services for prevention, diagnosis and treatment. In addition, stigma and discrimination marginalizes those with the disease and affects their ability to fulfill necessary culturally expected and economically productive roles in society.

## **Dr. José Ramos-Horta, 1996 Nobel Peace Prize Laureate, Former President of Timor-Leste**



There is no more noble cause than embracing our unfortunate fellow human beings, our brothers and sisters, beloved children of God, afflicted by this illness and, for this reason, cast aside by society. As a

result of the joint efforts of my own government, supported by WHO and the Nippon Foundation, my country, Timor-Leste, with less than one case per 10,000 people, eliminated leprosy a public health problem in 2010. However, countries like Brazil, India and Indonesia still have tens of thousands of new cases. The good news is that the new cases in these countries are gradually diminishing, leading us to be hopeful that with greater compassion and effort, leprosy can be eliminated in all afflicted countries around the world.

## **Dr Surin Pitsuwan, Former Secretary-General, Association of Southeast Asian Nations**



There is a cure for leprosy, it is free, and it is readily available. However, the stigma of leprosy causes many to refrain from seeking help, because they are afraid of having people find out about their condition. This in turn

impacts our ability to eliminate leprosy. In South and Southeast Asia, home to more people affected by leprosy than any other region in the world, this is a serious problem.

## **Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination**



In countries such as Japan, where leprosy is no longer a medical problem, the disease is for the most part considered a thing of the past. But I know of many individuals who, long after they have been cured, find that their

families are still unable to accept them out of fear that they themselves will be discriminated against. And although people are no longer compulsorily confined within the walls of the leprosy sanatoria, years of social rejection that continue to this day have made most of them hesitant to leave. ■



# Why Leprosy Now?

International symposium looks at some of the issues surrounding leprosy today.

Following the launch of Global Appeal 2015, an international symposium on leprosy organized by the Nippon Foundation and Sasakawa Memorial Health Foundation was held the same day to explore themes ranging from dignified nursing care to the preservation of history and how society should respond to leprosy now and in the future.

“Why Leprosy Now?” opened with two perspectives on life as a person affected by leprosy. Vagavathali Narsappa from India developed the disease at the age of 9. Cast out of his village, he found it impossible to return home, even after treatment. “Rejected by my family, I discovered that my true family were other people affected by leprosy,” he said. Narsappa went on to form a society in his home state of Hyderabad to fight stigma and discrimination. He now heads the nationwide Association of People Affected by Leprosy.

Kimie Yamauchi of Japan was diagnosed with leprosy and admitted to National Sanatorium Tama Zenshoen in Tokyo in 1957 at age 22. She married a fellow patient the same year, but not before her husband-to-be underwent a vasectomy, as patients were not permitted to have children under the policy at the time. Many years later, Yamauchi rented an apartment near the sanatorium and for a time was able to live back in society with her husband, until his health worsened. “As people affected by leprosy, we have had to fight for the right just to enjoy a normal life,” she said.

**“They do not have much longer to live. End-of-life care is very important.”**

## END-OF-LIFE CARE

The first of three panel discussions focused on “Leprosy, Medical Care and Nursing — Inclusive Dignified Care.” Presentations by Kristie Lane Ibardaloza, a nurse from the Philippines, and Dileep Kumar, president of the Indian Nursing Council, showed that educating the community, detecting cases early and seeing that patients take their medication are still important functions of nurses with regard to leprosy in those countries. By contrast, in Japan, which sees only a handful of new cases, the focus is on easing the final years of those who once had the disease.

Around 1,750 residents still live in Japan’s 13 national sanatoriums and more than half are over



Kimie Yamauchi: “As people affected by leprosy, we have had to fight for the right just to enjoy a normal life.”

85 years old. An increasing number suffer from dementia, few have contact with their families and many require extensive assistance and care, especially of the hands and feet. “They do not have much longer to live,” said Atsuko Kimura, assistant director of the nursing department at Tama Zenshoen. “End-of-life care is very important. Our mission is to make them feel, ‘I’m glad I have lived this long.’”

## LESSONS OF HISTORY

The past and its relevance to the present and future was the focus of the second panel discussion: “Leprosy — A History that Must Not Be Forgotten.” Yasuji Hirasawa, a member of the steering committee of the National Hansen’s Disease Museum in Tokyo, said there had been considerable opposition to the idea of making a museum about leprosy and the lives of those who suffered under Japan’s Leprosy Prevention Law. But when the forerunner of the national museum opened in 1993, it helped pave the way for the law’s abolition in 1996.

Hirasawa now has three goals: to see leprosy museums established in other countries; to have the education ministry include information about leprosy in school textbooks; and to ensure that the lessons learned from the history of leprosy are utilized by society in the future. “We want our history to be handed down,” he said.

Dr. Kazuhisa Kuroo, the museum’s chief curator, said that one of the biggest transgressions of Japan’s past policy of isolation was preventing sanatorium residents from having children. “There is no second or third generation for them to pass their stories on to; once we lose this generation, there will be no one.”

The museum thus has an important role and responsibility to record their stories for posterity, Kuroo said. “People need to know that this history existed. It is a crime not to know.”

From the Philippines, Dr. Arturo Cunanan, chief of the Culion Sanitarium and General Hospital, discussed the history of Culion, once the world’s largest leprosy colony, and its transformation from an island of despair to an island of hope and renewal. “Patients struggled to regain their dignity and humanity and to be normal within an abnormal environment,” he said. It helped that they were allowed to have families, unlike in Japan. Today, about 80% of the population is descended from the first patients, and this has provided a continuing legacy for succeeding generations to know about the past.

Brazil has many stories to tell about leprosy, said Artur Custodio, the national coordinator of the Movement for the Reintegration of People Affected by Hansen’s Disease, MORHAN. These include everything from its past policy of mandatory segregation to the activities of medical police who took people away by force to be quarantined.

Many of the former colony hospitals where patients were isolated no longer exist; seven that survive have projects to preserve history and MORHAN is involved in five of these. One of the urgent tasks is to make a record of the personal histories of those who experienced colony life, he said. “People are dying. We have to move quickly to preserve this legacy.”

### TOWARD INTEGRATION

The final panel discussion, which was chaired by Professor Yozo Yokota, focused on “Leprosy Today and Tomorrow — How Should Society Respond?” Joy in Action (JIA) work camps in China show one way forward. They involve students who spend time in some of that country’s 600 isolated leprosy recovery villages, working on building projects to improve living conditions, organizing social gatherings and offering companionship. “They go not as volunteers but as partners,” said Yinyue Lin, a JIA work camp coordinator.

The students forge relationships with the villagers that profoundly influence each other’s lives. They also act as a link between the leprosy villages and the surrounding community and help to break down the barriers of stigma and prejudice. “In China, people assume that leprosy villagers don’t know much, but in fact they are the wise men of local culture,” Lin said.

In Thailand, the government is pursuing a program to integrate 12 leprosy colonies into the surrounding community so as to “demolish the wall that keeps us apart,” explained Dr. Silatham Sermitirong of Raj Pracha Samasai Institute. To date, three colonies have been integrated and five more are in the process of integration.

In Brazil, MORHAN emphasizes the importance of involving a wide range of partners in order to



(Clockwise from top left)  
 Dr. Silatham Sermitirong,  
 Professor Yozo Yokota,  
 Kristie Lane Ibardaloza,  
 Yasuji Hirasawa and  
 Dr. Kazuhisa Kuroo

raise awareness of leprosy and help find solutions to the problems people affected by leprosy face, said Thiago Flores, MORHAN state coordinator for Minas Gerais state in Brazil. “Brazil is a big country and there are many leprosy-related issues. We cannot achieve anything big by ourselves.”

The NGO has developed good relations with government, both at the regional and federal levels; it works closely with the Catholic Church; it involves celebrities “because they can be very influential”; and it approaches universities, not just the medical schools but also architecture and media departments, for example, to engage in projects that improve quality of life and build awareness.

“Through different activities, we want to enhance the understanding that people affected by leprosy are ordinary people, like anyone else, who just happened to have had leprosy,” he said.



Thiago Flores: It is important to work with many partners.

## COLLECTIVE RESPONSIBILITY

Gaining that understanding from society at large is also an ongoing mission of the National Hansen’s Disease Sanatorium Residents’ Association in Japan. But as Kazuo Mori, the association’s chairman explained, that task is made harder by the long shadow cast by Japan’s past policy, namely the Leprosy Prevention Law and the seeds of stigma and discrimination it sowed.

Not only does the public in general continue to harbor misconceptions about leprosy, but also the family members of people affected by the disease. “We cannot escape this law when we talk about leprosy,” he said, “It is still a challenge for residents to meet with their relatives — and many have not.”

Moderators as well as members of the audience made valuable contributions to the discussions during the course of the afternoon. Dr. Josephine Robertson of the University of Queensland, who chaired the history panel, captured the spirit of the occasion when she said, “It has come through clearly that there are many people who are making individual efforts to break down stigma and discrimination. There is also a plea for families to accept people affected by the disease, and for society as a whole to do so, which is an issue of collective responsibility. What is required is a response on many levels.” ■

## ‘IDENTIFY STRENGTHS, ENHANCE RESILIENCE’

When faced with disease, disaster or any other trauma, human beings suffer; but they can adapt. Humans are equipped with resilience, and enhancing the resilience of people affected by leprosy is one of the important roles of nurses.

People affected by leprosy are considered to be vulnerable members of society; however, if you perceive a person as vulnerable, you cannot improve their resilience.

Everyone has his or her strengths. It could be mental strength, support from family or friends, or the ability to excel in a certain area. Nurses need to identify the strengths of each and every person affected by leprosy to encourage the development of resilience.

Medical professionals and people affected by leprosy must share the same goals and nurture a partnership for dignified care. Nurses need to understand the purpose of



Dr. Yamaguchi: Everyone has his or her strengths.

the person affected by leprosy’s life; it is not the job of nurses to decide what that purpose is. The wishes of people affected by leprosy must be respected.

— Dr. Nobuko Yamaguchi,  
Department of Nursing, School of Health  
and Social Services, Saitama University



# A Meeting with Their Majesties

People affected by leprosy receive an invitation to visit Japan's imperial couple.

(Right) Addressing the media following the visit; (far right) a beaming Vagavathali Narsappa in front of the Imperial Palace



Eight people affected by leprosy from six countries visited the private residence of Emperor Akihito and Empress Michiko of Japan on January 28 at the invitation of the imperial couple. They were accompanied by Goodwill Ambassador Yohei Sasakawa, who earlier in the month had called at the Imperial Palace to brief Their Majesties on the situation of leprosy in the world today.

Having visited all 13 of Japan's national leprosy sanatoriums over the years, the emperor and empress are well informed about leprosy and take a great interest in the lives of those affected by the disease. After the Goodwill Ambassador had explained to them during his January 13 visit that representatives of people affected would be coming to Japan from overseas for the launch of Global Appeal 2015, he received a call from the Imperial Household Agency at 9 a.m. the next morning to say that the emperor and empress would like to meet with them.

On the appointed day eight people affected by leprosy from Ethiopia, India, Indonesia, Japan, the Philippines and the United States, together with the Goodwill Ambassador, arrived at the private residence of the emperor and empress in the palace grounds. As Sasakawa looked on, the eight lined up in two rows of four to be presented to the Japanese imperial couple.

Separately, Emperor Akihito and Empress Michiko went down each row in turn, greeting each person individually, shaking them by the hand and asking them about their lives. The meeting had been scheduled for between 10 to 15 minutes, but ended up lasting for 40 minutes.

## THRILLED AND DELIGHTED

At a press conference afterward, the participants were understandably ecstatic. Kristie Lane Ibaldarosa, who works as a nurse in the Philippines, said, "I'm pretty sure the president of my country has not met the emperor and empress. I was extremely nervous beforehand, but when the emperor and then the empress came to talk with me, my nervousness disappeared. They were both so kind and listened to me from their hearts. I'm

just so thrilled and delighted."

Jose Ramirez, Jr., a social worker from the United States, said: "When I left the palace, my eyes were filled with tears. I felt something really special, something inspiring. When I was diagnosed with leprosy, it was as good as being dead. Now, as a living human being who has recovered from leprosy, I am inspired to go out and create a new world with my brothers and sisters. That is what I have gained from today's experience. I offer my heartfelt thanks to Their Majesties and to Mr. Sasakawa."

**"When I left the palace, my eyes were filled with tears. I felt something really special."**

Paulus Manek, the chairman of PerMaTa, an organization of people affected by leprosy in Indonesia, said he felt honored to have been given such a rare opportunity. "The empress told me she had twice been to Indonesia and feels very close to the Indonesian people. Hearing that gave me real confidence. I will take that confidence back to Indonesia and face the future with renewed strength."

Vagavathali Narsappa, the president of India's Association of People Affected by Leprosy (APAL), said: "It is hard for me to believe that I have met the emperor and empress and shaken them by the hand. I told them how I developed the disease, how I recovered and about the work I do now. The emperor listened very closely and praised me for what I am doing, saying he hoped I would redouble my efforts for all people affected by leprosy in India."

"Mr. Narsappa," Sasakawa asked, "Your own family won't shake your hand, but Japan's emperor and empress will. How does that make you feel?" APAL's president replied: "In that instant, I forgot everything I had been through as a person affected by leprosy. The suffering just evaporated. This is an experience I shall never forget." ■

# Reflecting on Leprosy's Literary Heritage

Talk event recalls Tamio Hojo, youthful author of *Life's First Night*.



Tamio Hojo

Tamio Hojo, often held up as the leading example of the genre of writing known in Japan as *hansenbyo bungaku* or leprosy literature, was the subject of a panel discussion in Tokyo on January 30 held in connection with Global Appeal 2015.

Co-hosted by The Nippon Foundation and Hojo's hometown of Anan in Tokushima Prefecture, western Japan, the event was attended by over 200 people.

Hojo lived from 1914 to 1937. Diagnosed with leprosy at 19 and committed to a sanatorium the following year, he wrote in fictional form about his experience of leprosy and of sanatorium life. Like many sanatorium residents, he lived under an assumed name to protect his family from discrimination.\*

His best-known work is *Inochi no shoya* (*Life's First Night*). It was published in the literary magazine *Bungakkai* (Literary World) in 1936, just one year before he died aged 23.

Yasunari Kawabata, who would win the Nobel Prize for Literature in 1968, championed Hojo's writing. He once wrote of him, "It is a wonder of literature to make us see a man living a more vital life than ours, in spite of the fact he has been effectively prevented from living in society."

Panelist Fumihiko Takayama, a non-fiction writer who has authored a book on Hojo, said, "I think what lay behind Kawabata's great enthusiasm for Hojo was the feeling of loneliness Kawabata experienced as a result of losing his parents when he was a child."

## 'OBSESSIVE' EFFORTS

Well-known actor Daijiro Harada read passages from *Life's First Night*, following which Takayama discussed why he wrote *Hibana — Hojo Tamio no shogai* (The Spark — The Life of Tamio Hojo). "Reading *Life's First Night* makes other novels seem trivial, such is its impact," he said. "In all likelihood, Hojo went to his death never thinking of himself as a leprosy patient. He made nightly entries in his diary and recorded his impressions. I think he felt he had to write to survive. He stood firm in resisting being seen as a leprosy patient."

It was the "obsessive" efforts of Kawabata that helped to get *Life's First Night* published, according to Takayama. Kawabata was also responsible for seeing that a collection of Hojo's writing was published posthumously, he said.

**"Life's First Night makes other novels seem trivial, such is its impact."**

Nippon Foundation Chairman Yohei Sasakawa, who was one of the panelists, said his late father Ryoichi and Kawabata had been elementary school classmates and kept in touch. "My father was dedicated to eradicating leprosy, and Kawabata was supportive of Hojo. Leprosy was a common thread and I believe they must have discussed Hojo," he said.

"In the midst of his fears, Hojo had to cling to literature," said Takayama, noting that the nation's sanatoriums were also fertile ground for writers of poetry. "Both as a record and as literature, in no other country have leprosy patients produced such a body of work." ■

## QUOTE

"Had he lived, he would have received the Nobel Prize before I did."

— Yasunari Kawabata



Fumihiko Takayama: Until his death, Hojo never accepted that he was a leprosy patient.



## FOOTNOTE

\* For decades, Hojo's true identity was never disclosed. Only last year, on the 100th anniversary of his birth, did the Anan authorities gain the consent of Hojo's descendants to reveal, for the first time, his real name — Koji Shichijo — in a booklet published by the town's cultural association.



# Turning a Lens on Leprosy

Photo exhibition depicts the lives of people affected by leprosy around the world.



“To think about leprosy is to think about people” was the title of a recent photo exhibition held in Tokyo featuring the work of Nippon Foundation photographer Natsuko Tominaga.

For the past 12 years, Tominaga has accompanied Goodwill Ambassador Yohei Sasakawa on many of his overseas missions and amassed thousands of images from all over the world of people affected by leprosy and the circumstances in which they live.

“It has become clear to me that the number one cause of prejudice is ignorance,” she said.



Tominaga: “The number one cause of prejudice is ignorance.”

“Through the photos I selected for the exhibition, I wanted viewers to have a better grasp of the often harsh realities that still surround leprosy, even today.”

The images she chose included those that reveal the physical disabilities that leprosy can cause if it goes

untreated, as well as the disease’s sometimes devastating social consequences — people forced to beg for a living, and a man whose son was burned to death after the family’s hut was torched by someone who wanted them off the land.

## KNOWLEDGE HELPS

In a booklet accompanying the exhibition, Tominaga wrote: “While I do not think that knowledge solves everything, I believe that by familiarizing ourselves with an issue we can help to lessen the stigma and discrimination through understanding.”

So she was encouraged by the different comments left by exhibition-goers, such as: “Seeing these photos has made the issue much more real for me”; and, “People need to know about this, especially children.”

Not all the images are from outside Tominaga’s home country, Japan, where a policy of segregation remained in place until 1996. “I feel strongly that we must not forget that there are still many people affected by leprosy living in Japan,” she says. “There is so much for us to learn from what they have been through.” ■

## FROM LIFE’S FIRST NIGHT

“Even though I’ll undeniably go blind, Oda-san, I’ll still write. If I become blind, I expect there will be another way to live. I’d ask you, too, to start a new way of living. Accept that you are a leper, and then discover a path to move forward. I’ll work hard until I can no longer write.”

With those words, the fearless Saeki he’d first met returned.

“We’ll probably be haunted by suffering until we die. But hasn’t it been said, only those with talent suffer. There are people who can’t suffer.”

Then Saeki took a deep breath, and his footsteps on the earth were firm and full of youth.

As the darkness around them slowly sank into the earth, the brilliant sun appeared above the woods, rays of light streaking the sky and flowing over the treetops, then flooding the strong tree trunks. Oda still had deep misgivings as to whether he could attain Saeki’s world, but while he looked at the streaming rays of sunlight, he determined that he would try to live.

Translated by Kathryn Tanaka\*

## FOOTNOTE

\* To read Kathryn Tanaka’s complete translation and introduction to *Life’s First Night*, visit *The Asia-Pacific Journal* at [www.japanfocus.org](http://www.japanfocus.org)

# Think Leprosy Now

Social media campaign builds awareness of leprosy in Japan and overseas.

A campaign inviting members of the public to “Think Leprosy Now” (written in Japanese as “Think Now *Hansen-byo*”) has elicited more than 1,600 video and written messages since it was launched in Japan last December. Authors, actors, politicians, the prime minister’s wife, and sports personalities including the country’s top sumo wrestler are among those who have recorded short messages available for viewing on a special website.\*

Matsuko Deluxe, a cross-dressing columnist and TV personality, said: “There is still a lot of discrimination and prejudice against leprosy in society. This is like a sign for me. The disease of leprosy, of course, needs to be eliminated from the world; however, if the prejudice and discrimination against leprosy can also be removed, I feel it is symbolic and could lead to the removal of many other such issues.”

Dorian Sukegawa, a poet and musician, recorded a message before going on stage for a concert. In it, he recalled writing a story about people who had been forced to spend most of their lives in a leprosarium. They were “like real heroes,” he said. “They should have been able to step outside that enclosure. But I believe many things happened and they were trapped inside.

They didn’t throw away their lives, though, and instead they tried to live the best they could. I believe we have much to learn from former leprosy patients. They have a lot of inner strength and we should think about the people who have lived through this.”

Kota Ishii, a non fiction writer, said: “What I would like to say to everyone is that leprosy still exists, in Japan and around the world. There is still discrimination against it, too; that’s the

kind of disease it is. I think that if everyone learns about leprosy, discrimination against it will decrease. Then the people who have to beg or hide away in leprosy villages can live freely. In that sense, I hope that everyone can learn little by little about leprosy and take action.”

The campaign has also received support from overseas. Among the contributions from abroad are those from Archbishop Desmond Tutu (see below) and His Holiness the 14th Dalai Lama, both of whom are past signatories of the annual Global Appeal to End Stigma and Discrimination against People Affected by Leprosy.

With the tag line, “To think about leprosy is to think about people,” the “Think Leprosy Now” campaign is set to run until the end of March 2015. ■



Some of the 1,600 contributors to the online campaign

## FROM ARCHBISHOP DESMOND TUTU



Myth, misconception, prejudice and stigma thrive in the absence of knowledge. For centuries we knew very little about the condition called leprosy, or Hansen’s disease. We knew only that we had no cure, and that we profoundly feared its disfiguring effects. Some suspected it was a form of divine punishment. Those living with the condition were shunned by their communities and physically isolated from the rest of humanity. In my home city, Cape Town, the island prison that was to hold Nelson Mandela for a large portion of the 20th century was once a leprosy colony.

Today, many of us know that leprosy is a mildly infectious bacterial disease mainly affecting the skin and peripheral nerves. It is completely curable, and with early diagnosis and treatment it leaves no trace.

But we mustn’t make the mistake of believing that because *we* know the truth about leprosy, *everyone* knows it. Too many people affected by leprosy continue to face discrimination and marginalization. Too many people still don’t know!

We need to spread the knowledge, and help people to think about leprosy for what it is: A curable disease. Working together we can end the misconceptions, dispel the myths and make leprosy history.

Think Leprosy Now!

## FOOTNOTE

\* <http://hansenbyo.wix.com/leprosy>

# Partnering for Progress

The launch of Global Appeal 2015, a visit to the Imperial Palace and visits by key partners make January a busy month for the Goodwill Ambassador in Tokyo.

## JAPAN (JANUARY)

This column usually deals with my travels away from Japan. In January, however, my place was in Tokyo for the launch of the tenth Global Appeal to End Stigma and Discrimination against People Affected by Leprosy. I am very grateful to the International Council of Nurses (ICN) for endorsing this year's appeal and I look forward to their continued support.

I am also extremely grateful to Prime Minister Shinzo Abe for taking time out of his busy schedule to attend, with Mrs. Abe, the ceremony and deliver an unequivocal statement of the government's commitment to resolving the outstanding issues of leprosy in Japan.

The various events taking place in connection with the Global Appeal are featured elsewhere on these pages; however, I would just like to record the wonderful scenes I witnessed on January 28, when Emperor Akihito and Empress Michiko invited people affected by leprosy from several countries to visit them at their private residence. This was a very generous and caring gesture on the part of Their Majesties, who are known for the interest they take in leprosy. It would be impossible for me to overstate the joy and excitement I saw in the expressions of eight people who, at different times in their lives, have found themselves in a very dark place due to leprosy.

Two of the most important partners in the fight against leprosy today are the Novartis Foundation, whose parent company is responsible for the free provision of multidrug therapy to leprosy patients worldwide through the WHO, and the International Federation of Anti-Leprosy Associations (ILEP). I was



With ICN President Dr. Judith Shamian (left) and First Vice-President Dr. Masako Kanai-Pak



Prime Minister Abe (center) headed the list of dignitaries at the launch ceremony.

very pleased to welcome to my office representatives of both these organizations in January.

In my

meeting with Dr. Anne Aerts, the president of Novartis Foundation, she briefed me on the foundation's continuing commitment to leprosy control and support for innovative new strategies to improve early diagnosis, treatment and prevention of the disease. These include pilot projects to treat contacts of new cases with chemoprophylaxis and a mobile-phone based leprosy referral system.

**This was a very generous and caring gesture on the part of Their Majesties.**

ILEP's president is Jan van Berkel, the head of Netherlands Leprosy Relief. Accompanied by ILEP's interim CEO, Marie Staunton, he outlined for me the organization's strategy going forward. In particular, ILEP is focused on stopping the transmission of leprosy, preventing disability and overcoming the barriers to inclusion of children, women and men affected by leprosy. I appreciate the support that ILEP has offered to help governments achieve the goals of the Bangkok Declaration toward a leprosy-free world, signed in July 2013 by the health ministers of 17 leprosy-endemic countries, as well as its stance on working for the repeal of laws that discriminate on grounds of leprosy.

I look forward to cooperating closely with Novartis and ILEP, together with other partners, as we strive toward our goal of a world without leprosy and the discrimination it causes. ■



# Women and Leprosy

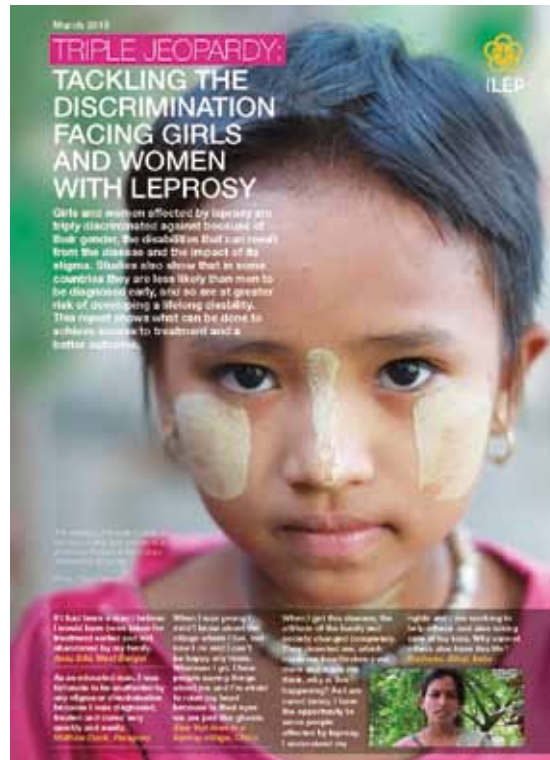
Girls and women affected by leprosy face “triple jeopardy,” says new report.

A new report to be published on March 8, International Women’s Day, argues that girls and women affected by leprosy are triply discriminated against because of their gender, the disabilities that can result from the disease and the impact of its stigma.

Prepared by the International Federation of Anti-Leprosy Associations (ILEP), “Triple Jeopardy: Tackling the Discrimination Facing Girls and Women with Leprosy” warns that the new United Nations Sustainable Development Goals, due to be agreed in October 2015, will fail in their aim to “leave no one behind” if discrimination against girls and women affected by leprosy is not tackled.

“Such girls and women have all too often become invisible and lost their rights to health, education, employment, and to marry and found a family,” the report states. This invisibility means that “not only do they receive treatment much later than their male counterparts, but they are often not included in official figures either.”

Among the report’s recommendations are that the WHO develop a target to ensure timely reporting for women — Grade 2 disability rates should be no higher than in men and decline at a similar rate — and that national health programs should identify the barriers to early detection in women, implement strategies to ensure early



The report can be downloaded from the ILEP website.

reporting and report all data at the national level disaggregated into female and male, children and adults. ■

## FROM THE EDITORS

### BOUNDLESS DETERMINATION

One of the reasons for launching the Global Appeal in Japan this year and hosting related events was to create an opportunity for younger generations of Japanese to learn more about the disease and the issues surrounding it. One of the people who can teach much in that regard is Mr. Yasuji Hirasawa, who spoke at the international symposium on leprosy that followed the Global Appeal.

He was placed in National Sanatorium Tama Zenshoen in Tokyo at the age of 14 and has lived there since. In describing a lifetime of activism from within the confines of a leprosarium, he recounted the discrimination he often ran up against in seeking to improve conditions not just for people with leprosy but for all persons with disabilities. He undertook this task even as his own disabilities were worsening.

“I decided if I couldn’t use my right hand, I would use my left; if I couldn’t use my left hand, I would use my mouth; and if I couldn’t speak, I would seek help. There is no shame in being disabled; there is only shame in giving up.”

Now well into his eighties, Mr. Hirasawa is far from giving up. He speaks to some 5,000 children a year. They are among the visitors to the National Hansen’s Disease Museum in Tokyo that he helped to establish to leave behind proof of the existence of people who had been forced to live in isolation. “It is not easy to live,” he tells them, “but I want you to be strong and endure hardship.” His determination that his experiences and those of his fellow sanatorium residents should serve as the foundation for a future free of discrimination is undiminished.

## FOR THE ELIMINATION OF LEPROSY

### Publisher

Yohei Sasakawa

### Executive Editor

Tatsuya Tanami

### Editor

Jonathan Lloyd-Owen

### Associate Editor

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: +81-3-6229-5388  
smhf@tnfb.jp

With support from:

Sasakawa Memorial  
Health Foundation,  
The Nippon Foundation

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