

FOR THE
**Elimination
 OF Leprosy**

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



Professor Yoza Yokota (right) interviews Anjan Dey, who trained as a physiotherapist after recovering from leprosy, in Pune, India in 2005.

MESSAGE

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In Memory of Professor Yokota

I wish to respectfully offer my condolences upon the death of Professor Yoza Yokota, who supported me in my leprosy elimination activities.

When I first became heavily involved in leprosy elimination, my efforts were mostly in support of medical initiatives led by the WHO. At some point, however, I came to see leprosy in terms of the two wheels of a motorcycle: the front wheel represented interventions against the disease, and the back wheel symbolized the fight against stigma and discrimination. Unless both wheels turned at the same time, it would not be possible to truly eliminate leprosy.

In 2003, I called on the Office of the UN High Commissioner for Human Rights in Geneva to raise the issue of leprosy-related discrimination with the Acting UN High Commissioner, Dr. Bertrand G. Ramcharan. Professor Yokota, who was a member of the Sub-Commission on the Promotion and Protection of Human Rights at the time, quickly grasped the human rights dimension of the problem and gave me his strong support.

Appointed by the Sub-Commission as the

UN's first rapporteur on leprosy, Professor Yokota accompanied me on visits to Ethiopia, India, Brazil and other endemic countries. Like a kindly parent or sibling, he lent an ear to those who had been rejected and abandoned, and from a professional standpoint elicited valuable testimony about the severe discrimination they faced.

Without the efforts of Professor Yokota, I don't believe that the December 2010 UN General Assembly resolution on elimination of discrimination against persons affected by leprosy and their family members, adopted without a vote by 193 countries, and accompanying principles and guidelines, would have been possible.

The loss of a comrade such as Professor Yokota leaves me profoundly saddened. But as I push ahead with my activities, I will carry with me the thought of all he did for persons affected by leprosy and their families, rooted in his love of humanity. This, I believe, is the way to repay the deep friendship that he showed.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Lingering Legacy

Japan still has plenty to discuss when it comes to Hansen's disease.

In May I attended the 15th annual general assembly of the Hansen's Disease Association for the People. The association, comprising academics, lawyers, journalists, sanatoria residents and others, was formed in 2005 to seek a resolution to issues arising from past policies on Hansen's disease in Japan.

Although the law mandating the forced isolation of patients was repealed in 1996 and sanatoria residents subsequently won compensation and an apology from the state for the violation of their human rights, there was still plenty to discuss at the assembly.

Held on consecutive days on the islands of Ishigaki and Miyako in Japan's southernmost prefecture of Okinawa, the theme was how to achieve a peaceful and prosperous society free from discrimination.

DEEP ROOTS

Leprosy was once prevalent in Okinawa Prefecture, and in small island communities such as Ishigaki and Miyako, stigma and discrimination put down deep roots. Okinawa coined its own slur for a person with Hansen's disease: *kunkya* refers to the bent fingers that the disease can cause and is still in use as a derogatory term for a social reject.

Masako Ueno, now 92, was originally from Ishigaki. She was diagnosed with the disease at the age of 13 and sent to a sanatorium in Kagoshima Prefecture; the sanatorium has been her home ever since. "On a small island, everybody knows everybody. You just couldn't let on if someone in the family came down with leprosy. My family ran a store and customers would have stopped coming."

Sekichi Miyara, 73, was diagnosed just as he was entering 5th grade and taken to Airakuen, a sanatorium on Okinawa Island. "I couldn't return home. Since then, in the whole of my life, I've only been back to Ishigaki three times."

He and Ueno were among only three former Ishigaki islanders affected by leprosy who had returned for the assembly. I had the impression that there were others who did not want to participate, who are hiding their past even now and do not feel they can speak out because of social prejudice.

SELF-STIGMA

Finding strategies to cope with self-stigma resulting from labels such as *kunkya* was a topic addressed by Asako Kawaguchi of the University of Nagasaki. She said it was important to explore with the individuals concerned how they want to live their lives, and work with them to develop their self-efficacy.

Pointing out that self-stigma was a reason why some people refrain from seeking medical attention for ulcers and other injuries stemming from Hansen's disease, she recommended involving local social workers to help them access care.



Testimony from former Ishigaki residents: "You just couldn't let on if someone in the family came down with leprosy."

Photo credit: Yaima Time website

On raising public awareness, there was a session on the role of museums that I found especially interesting. Chikako Miyamae, a lecturer at Kansai University, drew on her experience as a former curator at the Osaka Human Rights Museum to urge that museum exhibits not become "frozen in time."

The human rights museum, which tackles topics such as HIV/AIDs, sexual minorities, and Japan's ethnic Korean population, aims to renew its permanent exhibitions every 10 years in order that they stay relevant. Keeping the contents up to date also aids its mission to "encourage the majority to engage with minority issues and see them from every angle," she said.

Yoshihiko Kimizuka of Tokyo Gakugei University, while commending the fact that Japan has a number of museums that treat Hansen's disease as a human rights issue,* said that many people are under the illusion that because museums have been built, all the problems have been resolved. "We need people to see that there are ongoing issues."

COURT CASE

One such issue concerns the impact of the forcible segregation policy on family members of patients. Over 500 relatives filed a lawsuit against the government in 2016 claiming they had faced discrimination, and the assembly heard a progress report on the case from their lawyers. (See *News*, page 8).**

Japan sees only a handful of new cases of Hansen's disease today, and most of these are foreign born. I feel we are entering the final stages of being able to discuss the disease while still hearing from those who personally experienced its impact. I was very moved by the recollections of people such as Ms. Ueno, but it made me sad to think that there are others who will never be able to speak publicly or privately because of the lingering stigma. And when I think about that, it's clear that the issues surrounding Hansen's disease are by no means over. ■



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Poster for 15th general assembly of the Hansen's Disease Association for the People

FOOTNOTES

* In addition to the National Hansen's Disease Museum located at National Sanatorium Tama Zenshoen in Tokyo, Japan's other 12 national sanatoria all now have museums.

** Around half the plaintiffs were from Okinawa

A Champion of Human Rights

Recalling Professor Yozo Yokota's work toward ending leprosy discrimination.



Professor Yokota (4th from left) addresses a workshop in India in 2005.

Professor Yozo Yokota, who died this month at the age of 78, helped lay the groundwork for the 2010 UN General Assembly resolution on elimination of discrimination against persons affected by leprosy and their family members, and was responsible for the initial draft of the principles and guidelines that the resolution referred to and endorsed.

A professor of law, he had a distinguished academic career, served as legal counsel to the World Bank from 1974 to 1976 and was actively involved in human rights work throughout his life.

At the International Leprosy Summit in Bangkok in 2013, Professor Yokota recalled how the United Nations took up leprosy as a human rights issue, describing a visit by Yohei Sasakawa to Geneva in 2003 to host a lunch for members of the UN Sub-Commission on the Promotion and Protection of Human Rights.

“After lunch, Mr. Sasakawa explained how serious the issue of discrimination against persons affected by leprosy was. At that time, most Sub-Commission members were not aware of this serious human rights problem. Very much impressed and moved by Mr. Sasakawa’s powerful and convincing presentation, the chairperson of the Sub-Commission, Mr. [Soli Jehangir] Sorabjee of India, immediately proposed the topic of ‘discrimination against persons affected by leprosy and their families’ as a new agenda item and appointed me as rapporteur to study and report to the next

session of the Sub-Commission. The proposal was unanimously approved. This was how the issue of leprosy and human rights was first taken up at a UN human rights forum.”

Professor Yokota subsequently submitted three reports to successive sessions of the Sub-Commission. In the process of carrying out his mandate, he interviewed many persons affected by leprosy. He said it was hearing their wrenching personal stories that persuaded him to include a set of draft principles and guidelines in his last report submitted to the Sub-Commission, “as I felt we should do something to change the attitudes of us all through actions by UN human rights organs.”

This was how the issue of leprosy and human rights was first taken up at a UN human rights forum.

With the dissolution of the Commission on Human Rights in 2006, it would be another four years before the Human Rights Council, with the help of its Advisory Committee, finally adopted the principles and guidelines in August 2010—and they became an official UN document when the General Assembly adopted resolution 65/215 in December that year.

Professor Yokota went on to chair an International Working Group of human rights experts, legal scholars and persons affected by leprosy on how to follow up the principles and guidelines. Its final report in June 2015 urged the Human Rights Council to revisit the issue, paving the way for two further resolutions and the appointment of a Special Rapporteur, Dr. Alice Cruz, who is currently in the middle of her three-year mandate and continuing the work that Professor Yokota began. ■

‘AN EXTRAORDINARY HUMAN RIGHTS DIPLOMAT’

I was fortunate to know Professor Yozo Yokota as a diplomat, a scholar and a friend during our work together in international human rights, *writes Barbara A. Frey.*

Professor Yokota was an extraordinary human rights diplomat who took on many important and sensitive assignments. He was, for instance, the first Special Rapporteur on Myanmar from 1992-95, raising the visibility of the serious violations there. In the early 2000s, he brought international attention to the issue of discrimination based on work and descent, touching on the discriminatory aspects of caste in South Asia. Professor

Yokota also served for 10 years, from 2003-13, as a member and then chairperson of the International Labour Organization’s Committee of Experts on the Application of Conventions and Recommendations, confronting governments on their violations of workers’ rights. Those expert assignments exemplified his critical role as an investigator and jurist on complex global issues.

Professor Yokota was deeply committed to ending discrimination against persons affected by leprosy, having worked on that issue since the early 2000s. It was a great honor to serve as a member of the

International Working Group on Leprosy and Human Rights, which Professor Yokota chaired, and to participate in the global movement to end leprosy and its stigma. I appreciated the chance to work with him on this effort and to spend many enjoyable hours together in our travels. In addition to his brilliant diplomatic, linguistic and legal skills, what will endure for me are memories of Professor Yokota’s kindness, good humor and indomitable commitment to the common good. *Barbara A. Frey, J.D., is Director of the Human Rights Program, University of Minnesota*

‘Don’t Tell My Husband’

Keeping leprosy a secret on the Marshall Islands.

Meretha Pierson has been a nurse for the past seven years, working in the government-run leprosy clinic in Majuro, the capital of the Marshall Islands. Her patients come in all ages, from different economic backgrounds and different professions. But, aside from their diagnosis, they all have something else in common: everyone wants to keep their illness a secret.

“Everyone requests me not to tell their neighbors. But women who are young, request me to not inform even their spouses. ‘Please don’t tell my husband,’ they say. Sometimes, such a request is really hard to keep,” Pierson says.

There is a reason why Pierson, one of the handful of trained health workers who can detect a case of leprosy, also known as Hansen’s disease, can’t always promise full confidentiality to her patients.

“They do not want us to go to their houses. So we call them to a place outside of their homes.”

Marshall Islands is believed to have 50 to 80 new cases of leprosy every year. For a country with a population of some 53,000, that means it has yet to eliminate leprosy as a public health problem, with elimination defined as a prevalence rate of less than 1 case per 10,000 population.

But it is a classification that the government is eager to get rid of. In mid-2018, the Ministry of Health ran a three-month-long health screening campaign where over 27,000 citizens were tested for both leprosy and tuberculosis so that every affected person could receive treatment.

A PROMISE THAT’S HARD TO KEEP

Health workers like Pierson have been instructed to keep a close eye on the patients who do not return to report on their health and who stop treatment in the middle of the course. And this is why it makes it really difficult to keep the promise of not alerting anyone to their illness as health workers are often compelled to seek out the patients.

Tracking these patients down and convincing them to restart their medication is both a necessity and a requirement that forms part of the government’s new campaign to curb the disease.

But as they do so, the requests for confidentiality become more frequent.

“They do not want us to go to their houses. So, we make phone calls, call them to a place outside of their homes and their neighborhood and that’s where we do our counseling and advise them to return to



Pierson: “They think because I work in a leprosy clinic, I am carrying the germ or the disease myself.” ©Stella Paul/IPS

AUTHOR:

Stella Paul

Stella Paul is a correspondent for Inter Press Service, for whom she filed the original version of this story on a visit to the Marshall Islands in March.

the clinic for a checkup and continue the treatment. But it’s hard,” Pierson says.

However, it is not only patients who are stigmatized on this island nation. Health workers themselves often bear the brunt in a society where over 80 percent of the population are of Christian faith.

Pierson, a Mormon, says that she has often faced discrimination from her neighbors and relatives who have suspected her of having leprosy.

“They think because I work in a leprosy clinic, I am carrying the germ or the disease myself. Some even ask why I do not give up this job. I have to always tell them that I am a nurse and I do not have leprosy myself. Even in the church, I get those stares,” she says. Fortunately, her husband is supportive and has never asked her to leave her job.

HOT SPOTS

There are around 30 atolls that comprise the Marshall Islands and about a quarter of them are known as hotspots of leprosy, according to Dr. Ken Jetton, the main physician at the country’s Department of Public Health. These ‘hotspots’ include the atolls of Kwajalein, Ailinglaplap, Mili, Arno, Wotje and Ebon.

Jetton officially diagnoses and confirms leprosy cases after Pierson detects a possible case and refers the patient to him. However, Pierson says that despite the screening and follow-up activities, social stigma, especially toward the female leprosy patients, might take longer than expected to fade away. This is because the island nation is still largely ignorant of the fact that leprosy is a curable disease, she explains.

Patience, therefore, is the key, she reminds. “We must be patient and also have empathy for those who hide their diseases from others. They are vulnerable and scared of losing their dignity and we need to understand this.” (Inter Press Service) ■

Pacific Journey

The Goodwill Ambassador makes a first trip to the Marshall Islands and tours Kalaupapa leprosy settlement on Molokai Island, Hawaii. He also attends a book launch in London.

REPUBLIC OF THE MARSHALL ISLANDS (April 23-24)

This was my first visit to the Republic of the Marshall Islands, a country made up of two chains of coral atolls and more than 1,000 islands and islets located in the Pacific Ocean. Along with Micronesia and Kiribati, Marshall Islands has yet to eliminate leprosy as a public health problem. However, I was encouraged to hear President Hilde Heine tell me the country is committed to achieving “zero leprosy” and promising that her government will do whatever is necessary to achieve this goal.

In 2018, the Health Ministry carried out a mass screening for leprosy and TB in Majuro, the capital, where some 30,000 people out of the country’s 53,000 population live. Marshall Islands has one of the highest rates of TB in the world, and the screening followed a similar campaign for TB the previous year on Ebeye Island, the country’s second largest population center.

The screenings were carried out in conjunction with the WHO and the Centers for Disease Control and Prevention (CDC) in the United States. I understand about 80 percent of the population has been covered, but that more funding and personnel are required in order to cover the entirety of this far-flung atoll nation.

During my two-day stay in Majuro, I took the opportunity to meet with some persons affected by



With President Hilde Heine, who said she is committed to achieving “zero leprosy.”

leprosy. Monica, 56, is taking multidrug therapy after recently being diagnosed as a result of screening. We met at her daughter’s house, where she was staying during her treatment. Fortunately for Monica, her disease had been caught early, and I told her she could expect make a full recovery if she continued to take her medicine.

Later, at the Majuro leprosy clinic, I met a young man who had been cured of leprosy but was now receiving treatment for leprosy reaction. He had been diagnosed with leprosy after presenting himself for a checkup. He told me he suspected he might have the disease because his symptoms had been similar to those of his mother, who had been treated for leprosy in the past.

Health and Human Services Minister Kalani Kaneko explained to me that the Marshallese >>>



A press conference with Health Minister Kaneko; an aerial view of one of the Marshall Islands' many atolls and islands.



(Above left) Kalaupapa leprosy settlement on Molokai Island; (above right) Kalaupapa Peninsula became a National Historical Park in 1980.

>> people traditionally attach great value to family and have a culture of mutual respect and helping others. I wondered if this might influence attitudes toward leprosy in the country, given that Monica was staying with her daughter and the young man I had met at the clinic had come forward to seek treatment of his own accord.

I gather, however, that Marshall Islands is by no means free of all prejudice against the disease, so I took the opportunity to address this point at a joint press conference with Minister Kaneko that was recorded for broadcast later. I told the assembled journalists that leprosy is not a punishment or a curse, or something to be ashamed of; it is a curable disease and the treatment is available for free. “There is no cause to discriminate against a person with leprosy,” I said.

I went on to say that if every household was to check family members for signs of leprosy, this would assist the country in its efforts against the disease. “If you find any discolored patches on the skin with no sensation, please have them examined by a health professional.”

As a follow-up to my visit, I have instructed The Nippon Foundation and Sasakawa Health Foundation to examine how they may assist Marshall Islands in achieving its goal of zero leprosy, in particular through its mass screening programs in conjunction with the WHO and the CDC. I look forward to reporting back at a later date on the progress the country is making against the disease.

UNITED STATES (April 25)

On April 25 I visited Molokai Island in Hawaii to tour the Kalaupapa leprosy settlement. It was here that Father Damien, the Belgian priest now known as St. Damien of Molokai, devoted himself to the care of patients between 1873 until his death in 1889.

The history of the settlement dates back to 1866 when the first 12 patients were transported to the isolated Kalaupapa Peninsula, one year after the Kingdom of Hawaii passed a law to prevent the spread of leprosy. Over the next 103 years, until the law was abolished in 1969, some 8,000 patients were sent there.

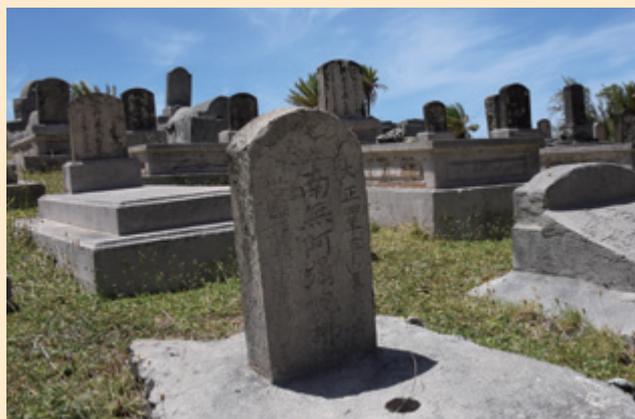
I was interested to see that quite a few of the tombstones bore Japanese names.

In the early years, the patients lived in Kalawao on the eastern side of the peninsula, on land obtained for that purpose. Later the kingdom acquired the rest of the peninsula and there was a gradual shift to the Kalaupapa settlement on the peninsula’s west side.

The peninsula was chosen because of its geographical location. It juts into the Pacific from the north side of Molokai Island and is cut off from the rest of the island by a 600-meter-high cliff. The only land access is via a steep trail down the cliff, but the trail is currently blocked by a landslide

My journey to Kalaupapa was very different from those of the first patients. I flew from the Hawaiian state capital Honolulu to Molokai Island, a journey of about 30 minutes. From Molokai airport it was a four-minute flight to Kalaupapa airport.

I was welcomed by Ka’ohulani McGuire, an anthropologist working for the U.S. National Park Service. She explained how the Kalaupapa Peninsula, including the leprosy settlement, had been turned into a



Headstones of Japanese immigrants who died at Kalaupapa



A wheelchair said to have been used by Father Damien



(Above left) Leprosy patients were brought by boat to the beach below the steep cliffs behind me; (above right) in front of Father Damien's original grave in Kalawao

National Historical Park in 1980 in response to the wishes of settlement residents who wanted their lives to be remembered.

Today there are only around 10 elderly residents who personally experienced leprosy still living in Kalaupapa. While some reside in their own homes, others have moved into a care facility. Among the latter is a gentleman of Japanese descent by the name of Mr. Hashimoto. He told me his parents had emigrated to Hawaii from Toyama Prefecture in Japan. Mr. Hashimoto, who is 88, developed signs of leprosy at the age of 11 and was sent to Kalaupapa. He has been there for the last 77 years.

Not far from the care home is a cemetery. I was interested to see that quite a few of the tombstones bore Japanese names. There are also the ruins of a Buddhist temple. Later I was shown several paintings and artworks by persons of Japanese descent, further evidence of Japanese immigrants who had been sent to Kalaupapa after coming down with leprosy.

During my visit I also met with Valerie Monson, the executive director of Ka 'Ohana o Kalaupapa, an association formed in 2003 to preserve the memory of those exiled on the peninsula. The association is proceeding with plans to build a monument that will bear the names of all 8,000 people who were sent to Kalaupapa and will be a focal point for their descendants.

The site chosen for the monument is near St. Philomena Roman Catholic Church. The original church was built in 1872. After Father Damien's arrival the following year he helped to expand it.

After paying my respects at Father Damien's tomb, I entered the church. I noticed there were holes in the floor next to the pews. Father Damien had been keen for patients to participate in Mass, but many of them had trouble controlling their saliva because of the effects of the disease, and were reluctant to enter in case they ended up spitting on the floor. Father Damien's solution was to drill holes that his congregation could spit into when they needed, using long, rolled-up palm leaves they inserted in the holes. I thought this was a wonderful illustration of his thoughtfulness.

As with many such sites around the world, the

number of residents who have experienced leprosy and are still living there is fast declining. Before I left Molokai, I wanted to know what the future held for the leprosy settlement. Ms. McGuire told me that when the last person affected by leprosy has passed on, the settlement will come under the management of the National Park Service. With Kalaupapa already designated a national historical park, I feel sure that this means the story of those who were exiled there will never be forgotten, just as they had wished.

UNITED KINGDOM (May 24)



With Professor David Heymann (left), who wrote the Foreword to *No Matter Where the Journey Takes Me*.

In May I was in London for the launch of my book *No Matter Where the Journey Takes Me: One Man's Quest for a Leprosy Free World* published by Hurst Publishers. Its publication also coincided with the appearance of *My Struggle against Leprosy*, a compilation of my messages in this newsletter dating back to 2003 as well as pieces I wrote for *Huffpost* that appeared online in 2018.

It is my hope that these works will draw attention to the continued existence of leprosy in the world, the great progress that has been made against the disease and the challenges that persons affected by the disease still face in being fully accepted by society.

I am often asked why I became involved with this issue and what motivates me to keep going. Readers will find the answers in these books. ■



Ka'ohulani McGuire of the U.S. National Park Service

Special Rapporteur Visits Brazil

Urges government to take 'vigorous steps' against leprosy discrimination.

On her first official country visit since the creation of her mandate, the UN Special Rapporteur on elimination of discrimination against persons affected by leprosy and their family members assessed the situation in Brazil, which reported 26,875 cases of the disease in 2017.

"I welcome the commitment of the Brazilian Government to become a global leader on the elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members and on the full protection of their rights, but the Government should take vigorous steps towards this objective," Alice Cruz said in a statement at the end of her eight-day visit in May.

She expressed serious concerns about the prevailing stigma associated with the disease, and the lack of understanding about transmission and treatment. "Contrary to popular conception, leprosy is a curable disease, it is difficult to transmit and after the first doses of treatment there is no risk of transmission," Cruz said.

She noted that the rate of children diagnosed with physical impairments was still very high and that many were denied access to schooling on the grounds of leprosy.

"More must be done to ensure early detection, prompt treatment, rehabilitation and reconstructive surgery," Cruz said. "An adequate standard of living must be ensured by poverty reduction policies, as well as accessibility and reasonable accommodation at schools and work settings."

During her visit, Cruz met federal and local government representatives in Brasilia, Rio de Janeiro and Belem, as well as representatives of civil society organizations, academics and health professionals. She also met people affected by leprosy and their family members in Curupaiti, Rocinha, Marituba and Combu island.

Her final report, including findings and key recommendations, will be presented to the UN Human Rights Council in June 2020.

LANDMARK RULING IN JAPAN

On June 28, a Japanese court ordered the state to compensate the relatives of patients segregated in Hansen's disease sanatoria in the past, recognizing that they too had been harmed by the policy.

In ordering the state to pay over ¥376 million (around US\$3.5 million) to the plaintiffs, the Kumamoto District Court in southwestern Japan found that the isolation policy had exposed family members to prejudice and discrimination from the rest of society and had led to the break-up of family ties.

The 561 plaintiffs had been seeking ¥5.5 million each for the financial and psychological hardships they have endured, and the damage done to their education, employment and marriage prospects.

It was the same court that in 2001 ordered the government to pay compensation to sanatoria residents after declaring the segregation policy unconstitutional. But the latest ruling is the first to acknowledge and provide redress to their families for the impact it had on their lives. ■

FROM THE EDITOR

'A CREATION OF THE HUMAN MIND'

One of the most telling details in this month's Japanese court ruling awarding compensation to family members of persons forcibly isolated in leprosy sanatoria is that most of the plaintiffs did not reveal their real names.

Some could not tell their own families they were part of the class action suit for fear of the consequences. One plaintiff whose mother's disease became known after the lawsuit was filed was asked by his wife for a divorce. Years after the official end of the segregation policy in 1996, discrimination runs deep.

Family members in Japan are not alone in suffering from the stigma of leprosy. The late Yozo Yokota, who is remembered elsewhere in these

pages, interviewed many people affected by leprosy and their family members. They included an Indian woman whose husband divorced her after her sister was diagnosed with leprosy, and an Ethiopian man who had been shunned at school because one of his parents had the disease.

"Discrimination, and in particular discrimination against a particular category of person, is the worst kind of human rights violation," he once told this newsletter. "Such categorizations are a creation of the human mind. They have nothing to do with the objective character of a person. Disease is a condition of being human. It could happen to anyone."

FOR THE ELIMINATION OF LEPROSY

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