

FOR THE Elimination OF Leprosy

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



Residents of Khokana settlement near Kathmandu, Nepal

A MESSAGE FROM THE GOODWILL AMBASSADOR

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My Resolve to End Discrimination

This spring I had the opportunity to attend the 60th session of the United Nations Commission on Human Rights (UNCHR), where for the first time I addressed members on the stigmatization of people affected by leprosy. From times past, people with the disease, as well as their families, have traditionally been shunned by communities. Even though leprosy is now curable, many people still suffer deep-seated discrimination.

The reason why this has not been taken up as a human rights issue before is because the response to the disease has been primarily a medical one. Furthermore, patients and even those cured of leprosy have been segregated from society and unable to speak out. By bringing this before the UNCHR, I wanted to expose the social discrimination that people affected by leprosy face, and seek a global solution.

Ingrained prejudice and discrimination are not easily eradicated, however. In order for persons affected by leprosy to gain social acceptance, not only must the disease itself be eliminated, but social attitudes must also be changed.

Organizations concerned with human rights must

become involved and create a climate in which the human rights of those affected by leprosy are acknowledged. I am therefore much encouraged by the way that WHO Director-General Dr. Jongwook Lee is speaking out on health and human rights issues.

Eventually, I want to see the U.N. come up with a set of guidelines concerning legislation, education and awareness activities, showing governments and NGOs what they must do to get rid of prejudice and discrimination. First, though, we need the UNCHR to adopt a draft resolution that advocates the human rights of people affected by leprosy. This will serve as the basis to study measures necessary to eliminate discrimination. The support of all countries will be essential, and those that express interest must be fully encouraged.

Much work still needs to be done. But presenting the issue before the UNCHR was an important first step and I am confident of seeing steady progress from now on.

—Yohei Sasakawa, WHO Goodwill Ambassador

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Making the Case for Human Rights

Yohei Sasakawa puts leprosy on the agenda at the U.N. Commission on Human Rights.

At the end of March, WHO Goodwill Ambassador and Nippon Foundation President Yohei Sasakawa led a delegation to Geneva to take part in the 60th session of the United Nations Commission on Human Rights held from March 15 to April 23, 2004. The issue he brought before the commission was the discrimination in societies around the world toward those affected by leprosy and the need for guidelines to recognize and protect their human rights.

Comprising a rotating membership of 53 states, the commission meets each spring for six weeks at the U.N.'s Geneva headquarters. Over 3,000 delegates from member and observer states and NGOs attend the annual session, during which the commission adopts about 100 resolutions and decisions pertaining to human rights.

The UNCHR is assisted in its work by the Sub-Commission on the Promotion and Protection of Human Rights, a number of working groups, and a network of individual experts, representatives and rapporteurs mandated to report to it on specific issues.

Sasakawa's bid to get leprosy taken up as a human rights issue at the commission started last July, when he met Acting High Commissioner Bertrand Ramcharan in Geneva. At Ramcharan's suggestion, he organized a panel briefing for members of the sub-commission on August 5,

2003, on the social and human aspects of leprosy.

With the cooperation of Professor Paul Hunt, special rapporteur for the right to health, Sasakawa returned to Geneva this spring to present an exhibition on people affected by leprosy, host a panel discussion with participants from Japan, Brazil, India and the United States, and present an oral statement to the commission.

Behind the initiative is the fact that while progress is being made toward eliminating

The Commission on Human Rights meets every spring in Geneva.



TAKING AIM AT DISCRIMINATION

Panelists share their thoughts on the urgent need to tackle stigma.

A panel discussion organized by the Nippon Foundation on the sidelines of the 60th session of the Commission on Human Rights provided moving testimony as to why the social aspects of leprosy must be addressed.

Chaired by Professor Kenzo Kiikuni, Sasakawa Memorial Health Foundation,

WHO's Helena Nygren-Krug



the seven-member panel included two persons affected by leprosy.

Dr. P.K.Gopal, president, IDEA, noted how fear and unscientific beliefs among lay people about the nature of the disease resulted in the stigmatization of those with leprosy that persists today. The presence of a leprosy-affected person affects the whole family, he said, making it hard for a son or daughter to get married, and for the family to find accommodation. He also pointed out that discriminatory legislation remains on the statute books in India, and that some hotels and temples still display signs refusing entry to those with the disease.

Zilda Maria Borges, IDEA-MORHAN Brazil, said that the end of leprosy will not come with the elimination of the disease, but when those who have been affected by it are recognized as having the same human rights as everyone else in society. She cited a couple of encounters with women cured of leprosy, one of

whom felt 'dead inside', and the other who contemplated killing herself because she despaired of her future. When such suffering exists, said Borges, we must not delay in working to achieve human rights for all.

Anwei Law, international coordinator, IDEA, described society's response to those with leprosy as "the most persistent and pervasive form of social injustice that society has forced on its fellow human beings." People were segregated because they were deemed to be undesirable, expendable and inferior, she said, and even today, the historical tradition of discrimination and seclusion continues. "There are young people living in leprosy hospitals even though they are completely cured," she said. "We should be ashamed."

Professor Paul Hunt, UNCHR special rapporteur on the right to health, noted that the right to health was a fundamental human right found in the 1948 Universal Declaration of Human

leprosy as a public health problem by the end of 2005, social discrimination remains a deep-seated problem.

Millions live in isolation. They have no homes to return to. They are dead to their families.

Although national isolation policies have been largely abandoned and laws changed, and although leprosy is now curable, in some cases the social reaction to the disease remains so severe that even those who have been completely cured are unable to take their place in society.

Given only three minutes to make his presentation, Yohei Sasakawa ran through the list of problems faced by those affected by the disease.

“Mr. Chairman, discrimination is still rampant. Those cured of leprosy still can’t marry. They can’t get work. They can’t go to school. They are still treated as outcasts. ... Many still think leprosy is dangerous or hereditary. Many still see it as a divine punishment. And so millions live in isolation. They have no homes to return to. They are dead to their families.”

Afterward, many people came forward to request copies of the oral statement. It was encouraging to see the level of interest, given the

fact that this was just one of dozens of presentations made by NGOs on the day.

Elsewhere, there was interest, too, in the photo exhibit sponsored by The Nippon Foundation showing the plight of those facing leprosy-related discrimination.

During his stay in Geneva, Sasakawa had meetings with Acting High Commissioner Ramcharan, Special Rapporteur Hunt, and with officials of IDEA, an international network of leprosy-rights groups that is striving to bring dignity to the lives of those affected by this discrimination.

He also met with Helena Nygren-Krug, WHO health and human rights advisor, who took part in the panel discussion and stated WHO’s eagerness to tackle leprosy from a human rights perspective.

Ambassador Sasakawa plans to continue participating in commission meetings in the future, working to see that the commission adopts a resolution that calls on governments to tackle the issue of discrimination. In particular, he wants to see the commission create guidelines for governments, NGOs and other stakeholders that will give impetus to efforts to end discrimination.

In that regard, the visit to Geneva this spring was extremely valuable and will hopefully serve as an important stepping stone on the way to seeing discrimination of the affected individuals and their families officially recognized as a human rights issue. ■

Rights. Discrimination on grounds of health status, former health status or a family member’s health status is unlawful, he said. The state is obliged to take measures to ensure its officials do not discriminate against those affected by leprosy, to make reasonable efforts to ensure that third parties don’t, and to educate the public.

Yohei Sasakawa, The Nippon Foundation, spoke of his “frustration, horror and disappointment” as he discovered that many of those cured of the disease were unable to take their place in society because of the discrimination they faced. Political leaders and the media need to be made more aware of the problem, he said, and efforts must be made to improve education.

Helena Nygren-Krug, WHO health and human rights advisor, commented that WHO is turning its attention to the social as well as the medical aspects of leprosy, now that WHO Director-General Jong-wook Lee has made human rights a



Yohei Sasakawa (far right) with (from left) P.K. Gopal, Acting High Commissioner for Human Rights Bertrand Ramcharan, Zilda Maria Borges and Anwei Law.

priority area. “Stigma and discrimination can be one of the most serious impediments in successfully tackling a disease,” she said.

From the floor, a member of a Nigerian human rights NGO suggested that the cause of people affected by leprosy would be helped by

collaborating with mainstream human rights organizations, and she offered to raise awareness of the issue in her own country. It was a positive note on which to end the discussion, and showed what stands to be achieved if more people are made aware of the issue and decide to act. ■

From the Mediterranean to the Himalayas

WHO Goodwill Ambassador Yohei Sasakawa visited two very different nations recently: Malta, where leprosy is considered to have been eradicated, and Nepal, one of the world's six major leprosy-endemic countries.

MALTA

At the end of March, I had the opportunity to visit Malta, an island republic of some 400,000 people located south of Sicily, more or less in the middle of the Mediterranean Sea. As multidrug therapy (MDT) becomes the standard approach to treating leprosy throughout the world, Malta has succeeded in eradicating the disease through what might be called Malta-style MDT. I was very interested to learn more about this and find out where Malta stands today vis-à-vis leprosy.

One of the earliest recorded cases of leprosy on Malta dates back to 1629, but the disease is thought to have existed much earlier. At one point, more than 200 patients were listed, which by today's WHO elimination yardstick of less than one case per 10,000 people would indicate a very high prevalence rate given the population at the time. In 1918, there were 4.72 patients per 10,000, or 4.7 times today's elimination standard.

Malta was part of the British Empire for many years, and in common with other British colonies, it was thought necessary to isolate and confine those with leprosy. Accordingly, a leprosarium was constructed near the site of the "poor house" on Malta island, based on an 1893 ordinance, and a second leprosarium was built on the island of Gozo in the 1930s.

In 1953, however, the segregation policy was abolished, reflecting both the progress made since the 1940s in the development of drugs for treating leprosy and changing attitudes worldwide. Thereafter, people with leprosy were mainly treated as outpatients, and both leprosaria were closed in the 1970s. The former poor house is now a nursing home for the aged, but nothing remains of the leprosarium.

In 1957, a few years after the switch to

outpatient treatment of leprosy patients, there were 152 patients in a population of 314,369 — still a considerable number. At the time, the only treatment available was dapsone, which had to be administered over a long period; however, because of emerging resistance to dapsone, the search continued for a new form of chemotherapy.

In 1972, Malta initiated a leprosy eradication program. Led by the Ministry of Health, it was supported by the Order of Malta, the German Leprosy Relief Association, and the Research Center Borstel of Germany, which came up with an MDT called Isoprodian-RMP combining rifampicin, isoniazid, prothionamid and dapsone.

Over time, 261 patients were treated with the new therapy, for a period of six months to a maximum of seven years, depending on their symptoms, and all of them were cured. A follow-up survey continued for 27 years until December 1999. Today, about 100 people who once had leprosy are still alive, with the last known case of the disease diagnosed six years ago. Leprosy on Malta is considered eradicated.

I was told that in 1974, when St. Bartholomew Hospital (as the leprosarium on Malta island was later renamed) and Sacred Heart Hospital (the facility on Gozo) were both closed, 22 individuals who had no homes to return to were transferred to the site of a former army barracks on Malta called Tal-Farha Estate. There, they were provided with accommodation and land for cultivation, and given pensions and access to medical treatment. But when I sought out the location, the only traces to be seen were the words Tal-Farha written on the bottom of a stone wall.

Malta has done away with leprosy. I applaud this success, but we must never forget the history of human suffering that preceded its elimination.

LEPROSY LEXICON

● MDT

Multidrug therapy (MDT) is the standard treatment for leprosy. A combination of two to three drugs — dapsone, rifampicin, and clofazimine — MDT kills the bacillus that causes leprosy and interrupts transmission of the disease. Treatment takes six to 12 months and there is virtually no recurrence.

(Left) Malta's old quarantine station, or lazaretto, where new arrivals, including those with leprosy, were detained; Tal-Farha Estate: these walls are all that remain.



NEPAL

In April, I finally realized a long-held wish to visit Nepal. This is one of the six major countries where the leprosy prevalence rate is rather high, and with this trip I have now been to all six in my capacity as WHO ambassador.

Nepal has a population of some 24.8 million. According to health ministry figures as of mid March 2004, the leprosy prevalence rate was 2.4 people per 10,000, down from 3.4 per 10,000 as of February 2003. Given that the prevalence rate was 70 per 10,000 about 15 years ago, Nepal is making steady progress toward elimination. However, although 31 out of the country's 75 districts have now achieved the elimination target, in the mountainous west and in the southeastern *Terai* (lowlands) bordering on India, there are places where the prevalence rate exceeds five per 10,000, so still more effort is needed if the elimination target is to be reached by the end of 2005.

During my visit, I met with then-Prime Minister Surya Bahadur Thapa and Health Minister Bhekh Bahadur Thapa in the capital, Kathmandu. I requested that the government make all efforts for leprosy elimination from an awareness as well as a medical standpoint. They replied that the government had made elimination a high priority both on the policy side and in practice, and were working toward elimination by the end of 2005.

In Nepal, leprosy education is now part of the school curriculum.

The prime minister said leprosy education was now part of the school curriculum and that the government was determined to spread information about the disease throughout the country by making greater use of the media. For my part, I said that in order to turn leprosy



Outside the Khokana settlement leprosarium

elimination into a major social movement, it was necessary to involve a broad spectrum of NGOs, as well as forge even closer ties with NGOs that specialize in leprosy, and both the prime minister and health minister agreed with me about this.

I also had discussions with Health Secretary Lock Man Singh Karki, Director General Dr. B.D. Chataut, and Public Health and Policy Advisor to the Health Ministry Dr. Rita Thapa. They gave me their commitment that they were working toward the elimination target by involving government, NGOs and the private sector in activities at every level, training human resources, and fostering a social movement all over the country from village to national level.

Dr. Bimala Ojha, director of the Leprosy Control Division, said that Information, Education and Communication (IEC) programs were being strongly pushed, and that leprosy featured in >>

Overview of Khokana settlement, home to some 200 recovered individuals and their families.



elementary school textbooks.

Given the key role played by NGOs in the drive to eliminate leprosy, I visited the Social Welfare Council, the government agency that coordinates the work of NGOs, and asked that it spread my three messages that “leprosy is curable, treatment is free, and social discrimination has no place” among all NGOs operating in Nepal.

Because this was a short visit, and because of antigovernment demonstrations organized by Maoist rebels, I wasn’t able to travel widely and see what was happening in the field. However, I was able to visit a couple of leprosy-related facilities in the outskirts of Kathmandu. One was the Anandaban Hospital, operated by The Leprosy Mission International (TLMI), and the other was the Khokana settlement, a residential and rehabilitation complex handed over to the Nepal Leprosy Relief Association (NELRA) by the government. Both are closely associated with my late father, Ryoichi Sasakawa. He visited the region in 1979 when he was head of The Nippon Foundation and held the hand of an elderly woman lying on her sickbed to pray for her recovery.

Furthermore, he donated training centers to both the Anandaban Hospital and what is now the government Leprosy Control Department at Teku in Kathmandu. I was delighted to visit these facilities and see they are well maintained and being used for their original purpose.

Khokana settlement is located in the village of Khokana along the Bagmati River about 40 minutes by car from Kathmandu. On the premises are a clinic, the original leprosarium, new nursing homes, and a job training center. I had the chance to visit with the 200 or so recovered individuals

Meeting with a patient from neighboring Bihar, India



and their families and saw people being taught how to make furniture at the training center.

I also paid a short visit to one of two hostels on the outskirts of Kathmandu operated by NELRA for children of rural families affected by leprosy, which enable them to commute to schools in Kathmandu.

Anandaban Hospital, which was established by TLMI in 1957, is Nepal’s biggest leprosy hospital, and the main hospital of the Central Development Region. It has a total of 121 staff (of whom 115 are Nepalese), and 115 beds. The hospital undertakes a variety of activities, including early detection and treatment, prevention of disability and reconstructive surgery, rehabilitation and elimination campaigns. Dr. Yo Yuasa, executive and medical director of Sasakawa Memorial Health Foundation, served as medical superintendent at the hospital in the 1970s when he worked for TLMI.

I visited both inpatients and outpatients, including those with complications and those undergoing rehabilitation. I also saw the laboratory where research is being conducted on a leprosy vaccine. The wards were clean and well-run, and the patients seemed to be in good spirits.

I was interested to learn that some of the patients were from Bihar State in India. Leprosy-affected people living in the border regions of both countries pass back and forth across the frontier, making it difficult to keep track of them and provide treatment. I proposed that the relevant parties of both countries have a meeting on this issue at the earliest possible date.

It was very important for me to see for myself the commitment of senior Nepalese political leaders to achieving the goal of elimination. According to the health officials concerned, the infrastructure to achieve leprosy elimination in Nepal is in place. I was also impressed that education about leprosy begins at elementary school level.*

However, on the human resources front, numbers are lacking, and a lot of training will be needed for the infrastructure to be properly utilized. Another problem is that because of social disturbances, leprosy elimination campaigns are restricted to 25 of the country’s 75 districts.

Still another concern is that cooperation between government departments and NGOs, which have traditionally been at the heart of social activities in Nepal, including leprosy elimination, could be better.

At any rate, I look forward to paying another visit to Nepal, when hopefully time and circumstances will permit me to travel the country and see the situation in the field at first hand. ■

Reference

* The following is summarized from a Nepalese school book: “Leprosy is caused by a bacterium. It is not hereditary, punishment for sin or the result of a curse. Early diagnosis and multidrug therapy cures leprosy without any disabilities or deformities. People who are receiving regular treatment or have completed treatment do not transmit the disease and can lead a normal life. People with leprosy should not be discriminated against; they should be loved.”

A Quilter's Tale

Leprosy broke up her marriage, but Yang Qian Mei was able to make a fresh start.



These cloth bags are among the products made by Handa Quilt.

Reference

* Handa Rehabilitation & Welfare Association was founded in Guangzhou, China in 1996 to promote respect and dignity among all human beings, especially those who have personally faced the challenges of leprosy.

I was born into a peasant family in a mountainous area of northern Guangdong, China in 1958. I came from a happy home and married a man from a nearby village in 1980. We had three children, one son and two daughters. I managed the land and household while my husband worked as a truck driver. Eventually we bought a two-story home. Life was sweet.

One day in 1991, my husband commented on changes in my face. When the doctor told me I had leprosy I couldn't believe it. "I have never done bad things so why should God treat me like this?" I cried. I lost all confidence. I refused treatment because I knew it would affect my family. My face and legs began to develop ugly blisters.

Finally, in 1994, I was forced to check into hospital. In two years, my husband only came to see me once. I excused him, thinking that he was busy working to support the family. The children had gone to live with their grandparents, but I later heard they had been sent back home by my brother-in-law because I had leprosy. I wanted to visit them, but my face was dark from drugs, and I was afraid. At age 10, my oldest daughter had to drop out of school to care for the younger children. I was in despair.

After two years I was cured, but didn't dare go

back home because my face was still discolored. I worried constantly about my family.

Then I had the chance to join a sewing class started by Handa* in Guangzhou and learn a skill. I worked very hard and was able to do well. The other women were much younger than me and I felt that I could comfort them and be strong for them.

In July 1996, my husband came to see me. I was so happy, thinking he had come to take me back. To my shock, he asked for a divorce, and I discovered he was living with my niece. I felt as if I had been stabbed, and could not understand why hardship followed me around like this. If it wasn't for leprosy, this wouldn't have happened.

Handa encouraged me through the hard times and gave me the opportunity to work. I became a teacher in the Handa Quilt project and now help to design new products. I am fast on the machine and don't mind working overtime to make items for sale in bazaars and other outlets. People admire my work and I have regained my self-confidence.

Recently I married a man who himself had leprosy. He is very attentive and loves me very much. He has accepted my children as his own. Life is sweet again. ■

PARTNERS

ZEN RYO KYO

Zen Ryo Kyo, or the All Japan Hansen's Disease Sanatoria Residents' Association, dates back to 1951, when its forerunner, Zen Kan Kyo, an association of sanatoria patients, was founded. Zen Ryo Kyo represents the interests of residents of Japan's 13 national leprosy sanatoria, established between 1909 and 1945 in accordance with government policy to confine leprosy patients. Leprosy was considered a "national disgrace" and with the passage of the 1931 Leprosy Prevention Law, all who contracted the disease faced compulsory exclusion from society.

From the beginning, Zen Kan Kyo (renamed Zen Ryo Kyo in 1996 when the Leprosy Prevention Law was abolished) was a movement initiated and managed solely by and for individuals with leprosy. From the day it was established, it was an expression of the collective will of the residents, at first to seek a drastic revision of the Leprosy Prevention Law, later to improve the quality of their lives, and then to restore their integrity and dignity in the face of stigma and prejudice. It continues to address



Zen Ryo Kyo members meet with Japan's health minister (right) on October 20, 2003.

issues that are relevant to the needs of the times, particularly in educating and enlightening society not only about leprosy but also the broader issues of human dignity and human rights.

From a high of 12,092 patients in 1958, there are 3,522 residents in the nation's sanatoria as of March 2004, with an average age of 76. As Zen Ryo Kyo's membership ages and its numbers diminish, it is determined to inspire Japan's younger generation to create a society free of prejudice and discrimination, to leave an accurate record of the history of leprosy in Japan, and to see that the remaining residents live out their lives as they wish.

Brazil Launches Elimination Drive

President Lula wants to see leprosy eliminated from the country by the end of 2005.

In the presence of hundreds of people cured of the disease, public officials and volunteers from MORHAN, a reintegration movement for people affected by leprosy, President Lula of Brazil earlier this year launched the National Plan to Eliminate Leprosy from Brazil by 2005.

Brazil is one of the top leprosy-endemic countries in the world, with a reported prevalence rate of more than four per 10,000 population in 2003.

The plan foresees the expansion of free diagnostic and treatment services integrated into the basic health services in 213 cities, access to rehabilitation procedures such as plastic surgery, and restructuring of residential treatment

facilities to provide a more adequate care structure for people with the disease.

Among the country's five regions, the North, Northeast and Southeast contributed to 80 percent of new cases detected in 2003.

Dr. Jarbas Barbosa, secretary of health monitoring at the Ministry of Health, reaffirmed the ministry's goal "to carry out our commitment to eliminate the disease as a public health problem" and said that both the ministry as well as state and municipal departments of health "will spare no efforts to lower the prevalence of Hansen's disease to less than one case for every 10,000 inhabitants by 2005," in line with the WHO target.



WHO's DR. LEE VISITS JAPAN

World Health Organization Director-General Jongwook Lee met with WHO Goodwill Ambassador Yohei Sasakawa at The Nippon Foundation in

Tokyo on April 23, 2004. The two reaffirmed their commitment to eliminating leprosy as a public health problem by WHO's target date of 2005. They were joined by Sasakawa Memorial Health Foundation chair Kenzo Kiikuni and other foundation executives. ■

FROM THE EDITORS

LEPROSY AND HUMAN RIGHTS

"I can endure losing fingers and toes, hands and feet, but what I cannot tolerate is being cut off from the human race through rejection." These words, quoted by Dr. P.K. Gopal at a panel discussion on leprosy and human rights in Geneva in March, starkly illustrate a side to the disease that modern medicine alone cannot tackle. For while multidrug therapy (MDT) has meant real progress toward the elimination of leprosy as a public health problem, the stigma associated with the disease remains a major cause of suffering.

It was to focus attention on this aspect of leprosy — the discrimination, marginalization and isolation of people affected by the disease — that WHO Goodwill Ambassador Yohei Sasakawa visited Geneva this spring to address the 60th session of the United Nations Commission on Human Rights (see pages two and three). At the related panel discussion organized by The Nippon Foundation, speakers gave reasons why this issue needs to be tackled urgently, among them that discrimination can

impede medical treatment and deny a normal life to people who have nothing wrong with them. "We should be ashamed," said panelist Anwei Law.

Some of those affected by the disease have banded together to act for themselves. On page seven we profile Zen Ryo Kyo, or the All Japan Hansen's Disease Sanatoria Residents' Association, a remarkable organization formed over 50 years ago by patients to fight for their rights and dignity as human beings.

Ambassador's Journal, meanwhile, takes us from the Mediterranean to the Himalayas. Malta is a country where leprosy has been successfully eradicated; Nepal, by contrast, is high on the list of endemic countries, and must work hard to achieve the elimination target. But Ambassador Sasakawa was impressed on his visit there to learn that leprosy is featured in school textbooks. Educating people about the disease from an early age is the best way to break down discrimination, so this bodes well for the future.

FOR THE ELIMINATION OF LEPROSY

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With support from:

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Health Foundation,

The Nippon Foundation

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