

# Working for a World without Leprosy

The Nippon Foundation and Sasakawa Health Foundation's Initiatives against an Age-Old Disease

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1962▶

# Introduction

The forerunner of the Nippon Foundation, the Japan Shipbuilding Industry Foundation, was established in 1962 as an organization administrating grants from boat racing. The grants were initially used to support reconstruction and development of Japan’s shipbuilding and shipping industries, which had been devastated during the Second World War, but in line with the demands of society the foundation’s field of activities gradually expanded to include health and hygiene projects, fire and disaster prevention, and eventually projects to eradicate starvation and epidemics from the world. Among these, activities commenced to relieve leprosy patients and to eradicate leprosy, following the fervent wish of Ryoichi Sasakawa, the founder and first chairman of the Japan Shipbuilding Industry Foundation. Especially after the establishment of the Sasakawa Memorial Health Foundation (now the Sasakawa Health Foundation), the efforts to bring leprosy under control grew more dynamic. These efforts have continued under the second chairman, Ayako Sono, and the current chairman, Yohei Sasakawa. Yohei Sasakawa was also appointed WHO Goodwill Ambassador for the Elimination of Leprosy, which has helped to raise the profile of the disease among political leaders and policy makers and led to significant progress in addressing leprosy as a human rights issue.

In the last 50 years, the situation around leprosy has changed dramatically. Still, there are many difficult issues that remain to be solved. The Nippon Foundation and Sasakawa Health Foundation’s struggle against leprosy will go on, in cooperation with persons affected by leprosy, governments, international organizations, NGOs, the media, etc. This booklet has been created in order to present the Nippon Foundation and Sasakawa Health Foundation’s efforts to conquer leprosy thus far, as well as to convey the feelings of the many people involved.

# What Is Leprosy?

**Leprosy is a bacterial infection.**  
The bacterium causing the disease was discovered by the Norwegian physician Gerhard Armauer Hansen in 1873, and leprosy is also known as Hansen’s disease. The disease is rarely fatal, but if left untreated it may lead to various complications due to nerve damage. Muscles become paralyzed, vision can be affected, loss of sensation in the limbs leads to constant injuries and burns, and secondary infections by other bacteria cause wounds, ulcers and suppuration. If still left untreated, leprosy eventually causes disfigurement and permanent disabilities.

**Leprosy has been a target of discrimination since ancient times.**  
It is easy to imagine people’s fear and horror of leprosy back in the days when its cause was unknown and there was no effective remedy. Leprosy has been around since ancient times, and since it was very hard to treat once symptoms had broken out and since it would eventually lead to disfigurement and disabilities, it was regarded as incurable and called a “divine punishment” (for sins committed in previous lives) or “the shameful disease.”

**Leprosy is a curable disease.**  
Effective treatment for leprosy emerged in the mid-20th century. Today, leprosy is completely curable with multidrug therapy (MDT), a combination of drugs that kill the disease-causing bacteria. If the disease is discovered and treated early on, it will not leave any visible signs or disabilities.

**Over 95% of people are immune.**  
Even though leprosy is classified as a contagious disease, it is actually one of the hardest diseases to contract. According to the World Health Organization (WHO), more than 95% of people are immune, which means that even if they are exposed to the bacteria, they will not develop the disease.

**Leprosy is not a disease of the past.**  
It is certainly extremely rare that people in the West or in Japan contract leprosy nowadays. In India, and other parts of Asia, Africa, and South America, however, many new cases of leprosy still occur. Even in the United States, around 100 new cases are discovered every year. (As many as 185 in 2018, in fact.)

**Even persons who have been completely cured are still excluded from society.**  
Old prejudices regarding leprosy are deeply rooted, for example that it is hereditary or extremely contagious or incurable or “a punishment by God.” Although we now live in the 21st century, even persons who have been completely cured may find they are unable to get an education, marry or find work, have to live apart from mainstream society and are reduced to begging.

**Prejudice is preventing treatment.**  
Societal prejudice also leads to the situation where patients are unable to receive treatment, even though effective remedies are available. When it becomes known that a person suffers from leprosy, they – and sometimes even their family members – become the target of severe discrimination, and so they conceal the fact that they have developed the disease. Although they are aware that they may have caught leprosy, they hesitate to seek medical care, fearing discrimination. If diagnosis and treatment are delayed, the disease progresses and can lead to permanent disabilities.

Introduction.....002

What Is Leprosy?.....003

History A Brief Chronology of Leprosy.....006

Pre-History Patient Relief Activities until Recent Times.....008  
Japan in the Early 20th Century and Ryoichi Sasakawa’s Dream.....008  
Tofu Kyokai and the Japan Christian Medical Association.....009  
The 7th International Leprosy Congress Is Held in Tokyo in 1958.....009

1962 The Establishment of the Japan Shipbuilding Industry Foundation (The Nippon Foundation) and Cooperative Aid Projects Overseas in the Early Days.....010  
1969 The Opening of the Leprosy Center in India.....011  
1973 The Establishment of the Life Planning Center and the Encounter between Ryoichi Sasakawa and Morizo Ishidate.....012  
1974 The Birth of the Sasakawa Memorial Health Foundation (Sasakawa Health Foundation).....013

Memories of the Establishment of the Sasakawa Health Foundation and the Determination to Tackle Leprosy.....014

1975 A Million Dollar Donation to WHO.....016  
1976 The Construction of the Korean Leprosy Institute.....017  
1976–1980 Financial Support for Anti-Leprosy Measures and Leprosy Control Promotion in Various Countries.....018  
1977–1980 Resistant Bacteria and the Search for New Chemical Cures.....019  
1981 The Development and Distribution of *An Atlas of Leprosy*.....020  
1982 WHO Recommends MDT.....021  
1983 Start of Full-Scale Support for Control Activities in China, and Appreciative Words from the Pope.....022  
1984 WHO Establishes the Sasakawa Health Prize.....023  
1986 The Sasakawa Research Building (SRB) Is Donated to Thailand.....024  
1987 Attempts to Develop a Leprosy Vaccine.....025  
1991 WHO Adopts a Resolution to Eliminate Leprosy by the Year 2000.....026  
1994 The Hanoi Conference and Free Distribution of MDT.....027  
1996 The Leprosy Prevention Law Is Abolished in Japan.....028  
1994–1998 Persons Affected by Leprosy Make Their Voices Heard.....029  
1999–1998 The Formation of the “Global Alliance” and the Creation of a “WHO Goodwill Ambassador for the Elimination of Leprosy”.....030

2001 The Start of Full-scale Efforts to Treat Leprosy as a Human Rights Issue.....031  
2003 Publication of the WHO Goodwill Ambassador’s Newsletter Begins.....032  
2003–2005 The Approach to the United Nations Commission on Human Rights and Statements by Persons Affected by Leprosy at the UN European Headquarters.....033  
2005 The Formation of “National Forum,” a Nationwide Network of Persons Affected by Leprosy in India.....034  
2005 India Achieves its Leprosy Elimination Target.....035

Leaders among the World’s Persons Affected by Leprosy.....036

2006 The First “Global Appeal” Is Launched in Delhi.....038  
2006 The Establishment of the Sasakawa-India Leprosy Foundation (S-ILF).....039

“Global Appeal” 2006–2020.....040

2007 Yohei Sasakawa Is Appointed “Japanese Government Goodwill Ambassador for the Human Rights of Persons Affected by Leprosy”.....042  
2010 The United Nations General Assembly Adopts a Resolution to Eliminate Leprosy Discrimination.....043  
2012–2015 Regional Symposiums on Leprosy and Human Rights.....044  
2012– Preserving the History of Leprosy.....045

Map Major Leprosy Sanatoriums and Islands around the World where Patients Were Isolated.....046  
Leprosy Sanatoriums and Archives in Japan.....047

2013 The “Bangkok Declaration” toward Further Progress in Leprosy Control Activities.....048  
2016 An International Symposium on Leprosy and Discrimination Held at the Vatican.....049  
2017–2018 Solving Both Social and Medical Issues.....050  
2019 Yohei Sasakawa Receives the WHO Gold Medal and the Gandhi Peace Award.....051

Our Lives, Our Voices.....052

Main countries visited by the Goodwill Ambassador for the Elimination of Leprosy.....056

[Notes]  
For simplicity’s sake, the Japan Shipbuilding Industry Foundation (which formally changed its name to The Nippon Foundation in 2011) is referred to as The Nippon Foundation below. Similarly, the Sasakawa Memorial Health Foundation (which was renamed the Sasakawa Health Foundation in 2019) is referred to as the Sasakawa Health Foundation. When there is no qualifier, the word “Foundation” refers to The Nippon Foundation. Some honorific titles have been omitted in the text. The titles listed are basically those valid at the time.

# A Brief Chronology of Leprosy

BC 1500

A description of what appears to be leprosy in India.

1000–1400

The leprosy epidemic in Europe reaches its peak.

1500–1800

Leprosy is transmitted from Europe to Central America, and from Africa to South America.

1700–1800

Leprosy is transmitted from Europe to North America.

1865

Kalihi Leprosy Hospital opens in Hawaii.

1850–1930

Leprosy spreads from Asia to the islands in the Pacific.

1873

The Norwegian physician Gerhard Armauer Hansen discovers the bacterium causing leprosy. Awareness that the disease is infectious spreads, and many patients are driven out of their hometowns and regions.

1897

The First International Leprosy Congress is held in Berlin, and isolation policies are recommended.

1898

Leprosy regulations are promulgated in India.

1907

Leprosy isolation is legislated in the Philippines. The Leprosy Prevention Law is enacted, In Japan.

1909

The Second International Leprosy Congress (Bergen, Norway) stresses the need for isolation and segregation policies, and recommends early separation of children from parents with leprosy. In Japan, several institutions open, such as Tama Zensho Hospital, the precursor to Tama Zenshoen sanatorium. Compulsory confinement begins, based on the theory of absolute isolation.

1923

The Third International Leprosy Congress (Strasbourg, France) recommends that the children of patients are separated from their parents.

1930

Japan’s first national leprosarium, Nagashima Aiseien, opens in Okayama Prefecture. In 1938, the Jyu-kanbo (“special hospital ward”) detention center for leprosy patients opens on the premises of Kuriu Rakusenon sanatorium in Kusatsu, Gunma Prefecture.

1941

The American doctor Guy Henry Faget tries using the drug Promin, administered intravenously, to treat leprosy. From the 1950s, dapsone (DDS), the active ingredient of Promin, is used in tablet form to treat leprosy worldwide.

1956

The “International Congress for the Protection and Social Rehabilitation of the Leper” is held in Rome. The “Rome Declaration” is adopted, promoting the restoration of humanity to patients, home care, and a minimum of institutionalization.

1958

The Seventh International Leprosy Congress is held in Tokyo, advocating the immediate abolishment of isolation policies.

1964

The first dapsone-resistant strains of bacteria are discovered. Resistant bacteria are discovered all over the world throughout the 1970s. The Philippines abolishes its isolation policy.

1969

The Hawaiian isolation law is abolished.

1981

A WHO research group recommends MDT for treatment of leprosy. The recommendation is published in 1982. The Movement of Reintegration of Persons Affected by Hansen’s Disease (MORHAN) is formed in Brazil.

1984

Leprosy regulations are abolished in the Indian state of Maharashtra, and then gradually in other states.

1985

Leprosy is recognized as a public health problem (a prevalence rate of more than 1 case per 10,000 population) in 122 countries around the world.

1991

At the 44th World Health Assembly, WHO adopts a resolution to eliminate leprosy as a public health problem at the global level by the year 2000.

1994

At the First International Conference on Leprosy Control, held in Hanoi, Vietnam, government health ministers, NGOs and WHO affirm the leprosy elimination strategy. The International Association for Integration, Dignity and Economic Advancement (IDEA) is established in Petropolis, Brazil.

1995

The Nippon Foundation starts distributing free MDT worldwide through WHO.

1996

The Ethiopian National Association of Persons Affected by Leprosy (ENAPAL) is established in Ethiopia. The Leprosy Prevention Law is abolished in Japan. In 1998, former patients file a lawsuit against the government, arguing that the Leprosy Prevention Law was unconstitutional. In 2001, they win the case.

1999

WHO and major partners agree to form a Global Alliance for the Elimination of Leprosy. The leprosy hospital at Carville in the United States closes.

2005

India eliminates leprosy as a public health problem. The first national conference organized by persons affected by leprosy in India is held.

2006

The National Forum, a nationwide network of persons affected by leprosy in India is formed. (In 2013, the name is changed to the Association of People Affected by Leprosy, or APAL.)

2007

In South Korea, a special law is enacted to compensate persons affected by leprosy who have been victims of past policies of isolation and ill-treatment. Through Law 11520, Brazil decides to pay out a monthly pension as compensation to all those compulsorily interned in leprosy colony hospitals.

2008

The UN Human Rights Council unanimously adopts a resolution to eliminate discrimination against persons affected by leprosy.

2010

The UN Human Rights Council adopts principles and guidelines on elimination of discrimination against persons affected by leprosy and their family members. Subsequently, the UN General Assembly unanimously adopts a resolution to eliminate discrimination against leprosy, accompanied by the principles and guidelines.

2011

Bangladesh abolishes the colonial-era Lepers Act.

2013

At the International Leprosy Summit, 17 endemic countries adopt the “Bangkok Declaration,” signaling a renewed commitment to work toward a leprosy-free world.

2016

The Leprosy Act of 1898 is abolished in India, but other discriminatory laws remain.

2017

The UN Human Rights Council appoints Ms. Alice Cruz of Portugal as UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members.

2018

ILEP (the International Federation of Anti-Leprosy Associations), the Novartis Foundation, Sasakawa Health Foundation, WHO and other stakeholders form the Global Partnership for Zero Leprosy.

2019

The Kumamoto District Court orders the government to pay damages to family members of former leprosy patients.



# Patient Relief Activities until Recent Times

Until modern times, Christian groups played the leading role in leprosy patient relief activities in most parts of the world. When Christianity was introduced in Japan in the 16th century, so-called Christian relief work also began there. Those activities were temporarily suspended during Japan's long era of isolation in the Edo period (1603-1868), but soon after the country opened up to the world in the mid-19th century, leprosy relief work was taken up again, mainly by missionary groups. Meanwhile, the Japanese "Leprosy Prevention Law" was enacted in 1907, starting a policy of absolute segregation, initially for homeless patients. Back in the days when there was no effective treatment, most patients around the world were forced to live in isolation, and relief work had a strong religious or spiritual flavor. However, the situation slowly began to change with the discovery of the drug Promin in the 1940s. In 1956, the European Federation of Anti-Leprosy Associations (ELEP, the predecessor of ILEP, the International Federation of Anti-Leprosy Associations) was launched, and the role that Christian organizations should play in leprosy work in the age of chemotherapy was actively discussed.



Patient injected with chaulmoogra oil at the Culion Island colony. Until the 1940s, chaulmoogra oil was the main treatment for leprosy, but its effect was extremely limited. (Photo courtesy of the Culion Museum and Archives.)

# Japan in the Early 20th Century and Ryoichi Sasakawa's Dream

In the early 20th century, there were still many leprosy patients in Japan. Morizo Ishidate, who was the first chairman of the Sasakawa Health Foundation, recalled his schooldays: "On Ochanomizu Bridge, the leprosy patients were lined up begging. It was the same at the Senso-ji temple in Asakusa. It was a scene you saw all over town." There are reports that Japan had more than 20 patients per 10,000 inhabitants at the time. It is estimated that there probably was a similar ratio, if not higher, in the world as a whole. Moreover, the patients and their families were suffering from severe discrimination. In the background to the rare enthusiasm that Ryoichi Sasakawa, the founder of The Nippon Foundation, showed for leprosy relief initiatives was a memory from his boyhood. "There was a pretty girl living in the neighborhood, but although she was nearing 30 she was still single. When I asked my mother why that girl didn't marry, I was told that she was from a leprosy-related family so nobody would have her. I thought it was unreasonable and felt sorry for her. That was when I decided that I had to fight to rid the world of leprosy when I grew up."



Admission gate to the Zensho Hospital (now National Sanatorium Tama Zenshoen). Beyond the gate was a small world where only patients lived. (Taisho period)

# Tofu Kyokai and the Japan Christian Medical Association

After the enactment of the Leprosy Prevention Law in 1907 and its principle of absolute segregation, beginning with homeless patients, the major measure against leprosy was the "Prevention and Eradication" movement. The Leprosy Prevention Association was established for this purpose in 1931, and worked with a slogan of investigating, researching and publicizing leprosy, and supporting various projects to prevent and eradicate the disease. In 1951, the organization changed its name to Tofu Kyokai ("Wisteria Maple Association"), in honor of Empress Teimei, who had worked hard to help leprosy patients. Its relief activities are now carried on by the Fureai Fukushi Kyokai. Meanwhile, in 1925 Toyohiko Kagawa had founded the Japan Mission to Lepers (subsequently, the Japan Leprosy Mission), an organization devoted to preaching the Gospel to patients and raising societal awareness. In 1946, doctors and medical students who had been active overseas during World War II founded the Japan Christian Medical Association (JCMA), and in 1962, the Japan Overseas Christian Medical Cooperative Service (JOCS) was established. Kiyotsuna Watanabe, Kazuo Saikawa, Shigeaki Hinohara, Morizo Ishidate, Kenzo Kiikuni and other people connected to The Nippon Foundation and the Sasakawa Health Foundation were also involved with JCMA and JOCS.



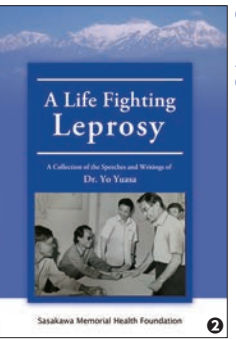
Memorial Hall at National Sanatorium Nagashima Aiseien, Okayama Prefecture, which was constructed with funds donated by Empress Teimei.

# The 7<sup>th</sup> International Leprosy Congress Is Held in Tokyo in 1958

The 7<sup>th</sup> International Leprosy Congress was scheduled to be held in India in October 1958, but that proved impossible due to circumstances in the host country. Instead, Kikuo Hamano, the managing director of the Tofu Kyokai, offered to hold the event in Japan at short notice. Among the topics discussed at the congress were relapses and countermeasures after treatment with dapsone (diaminodiphenyl sulfone, DDS, the active ingredient extracted from the anti-leprosy drug Promin, and taken orally, as opposed to Promin, which is administered intravenously), epidemiological factors, prevention, and changes in social conditions, and a resolution was passed that the current patient isolation policy should be abolished and replaced with outpatient treatment. Helping run the congress was Yo Yuasa, who at the time was a staff member of the Tofu Kyokai, and his skills as a member of the steering committee received much attention from the delegates from each country. Both the president and the executive director of the International Leprosy Association recommended that Yuasa become a doctor to work with leprosy, so he went to study at University of Edinburgh in the UK. He was subsequently sent by the Leprosy Mission to Nepal, and participated as the representative of Nepal at the first international conference on leprosy control in Asia, which was organized by the Sasakawa Health Foundation in November-December 1974. In 1975, Yuasa became the medical director of the Sasakawa Health Foundation.



❶ Dr. Yuasa (standing) participating in the 1st International Workshop on Chemotherapy of Leprosy in Asia, in Manila, 1977.  
❷ Collected speeches and writings of Dr. Yo Yuasa, published in 2015.





# The Establishment of the Japan Shipbuilding Industry Foundation (The Nippon Foundation) and Cooperative Aid Projects Overseas in the Early Days

The Nippon Foundation started its activities in October 1962 as the Japan Shipbuilding Industry Foundation. Its original purpose was to promote Japan's shipbuilding and shipping industries using grants from boat racing revenues, but the foundation also sponsored projects related to welfare, medicine, sports, education, and other areas. Full-scale overseas cooperative support activities commenced with the enactment of overseas cooperation assistance regulations in 1981, but the initiatives to eradicate leprosy in Asia began much earlier, including for example a subsidy to set up the leprosy center of the Japan Leprosy Mission for Asia (JALMA) in India 1967. The Nippon Foundation also viewed the Asian population explosion as an urgent and important problem facing the world. It supported the establishment of the Japanese Organization for International Cooperation in Family Planning (JOICFP) in 1967, and has provided long-term assistance for population and family planning projects in Indonesia, Nepal, China, the Philippines, South Korea, Malaysia, Bangladesh, and other countries. When traveling to these countries, Ryoichi Sasakawa always visited a leprosy sanatorium to give personal comfort and assistance.



- ① The Benisei building (left), where the Japan Shipbuilding Industry Foundation originally had its office, and The Nippon Foundation building, completed in 1964, (right).
- ② The town of Agua de Dios, Colombia. Sixteen buildings that speak of the town's history have been designated national historical and cultural heritage sites. (2013)
- ③ The Bridge of Sighs in Agua de Dios, Colombia, has been designated a historical monument. Formerly, crossing this bridge meant saying farewell to your family. (2013)



## 1962

**October** The Nippon Foundation starts its activities as the Japan Shipbuilding Industry Foundation.  
In Brazil, the leprosy quarantine law from 1923 is abolished in all states except Sao Paulo. Leprosy control measures are transferred from the federal government to each state. In 1967, the quarantine law is abolished in Sao Paulo as well. However, actual segregation doesn't end with the abolition of the quarantine law, and remains until the 1980s in some states.

## 1963

Forced segregation having been abolished in Colombia, Agua de Dios, one of the former quarantine sites, is established as a self-governing body and is exploring ways to develop so as not to lose the memory of its past.

## 1964

Bacteria strains resistant to the leprosy drug dapsone (DDS) are discovered. Further resistant strains are discovered all over the world through the 1970s.

## 1966

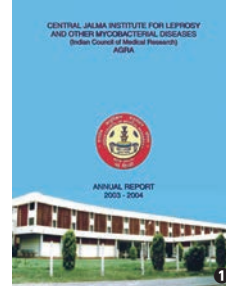
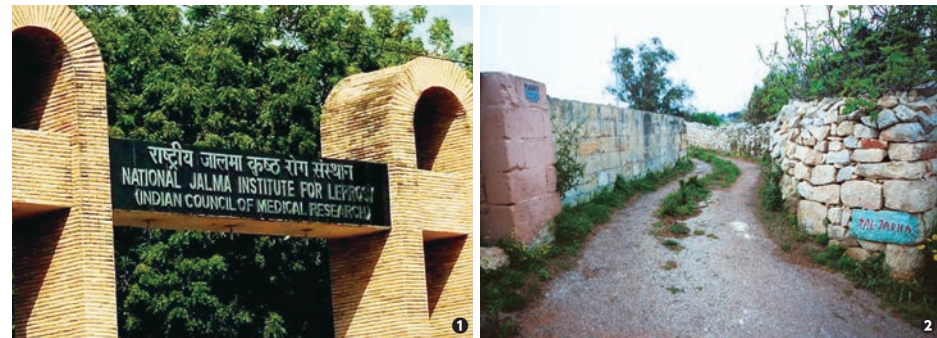
Ryoichi Sasakawa visits the Losheng Sanatorium in Taiwan. Later, The Nippon Foundation donates a vehicle and money to repair the aged facilities.

## 1967

The Foundation starts sponsoring the India leprosy center of the Japanese Leprosy Mission for Asia in India.

# The Opening of the Leprosy Center in India

In August 1963, the Japan Leprosy Mission to Asia (JALMA) concluded an agreement with the Indian government regarding relief work, and decided to build a leprosy center in India. In order to secure construction funds, an organization was set up for the Indian leprosy relief project. Earning sponsorship from various fields, construction of the center commenced in Agra, Uttar Pradesh, in December 1963. In parallel with the construction, JALMA also dispatched a medical team that traveled around and treated patients. In April 1969, when the center was almost completed, in-patients were accommodated and full-scale diagnosis, treatment and research activities began. Efforts were also coming along on the Indian side: as the center went into operation, the local Catholic church sent specialists once a week to provide lessons in reading, writing and physical education. The Nippon Foundation had long thought that Japan should actively share its leprosy treatment know-how and research results in order to eradicate leprosy in Asia, and subsidizing JALMA's leprosy center in India from 1967 thus became the Foundation's first overseas aid project. An electrostatic therapy ward was constructed and electrostatic therapy equipment was furnished, and a second hospital ward, a boiler, disinfection and laundry ward, dormitories for the Indian staff, a guest house, a low temperature laboratory, research equipment, air conditioners, vehicles, etc were prepared. The construction work was completed in 1970. In particular, the installation of high-voltage static electrostatic therapy equipment at the Indian leprosy center greatly contributed toward the treatment, recovery and social rehabilitation of leprosy patients.



- ① Annual report of JALMA's leprosy center in India (now the National JALMA Institute for Leprosy & Other Mycobacterial Diseases) and the front gate. Photo courtesy of <https://collegedunia.com>.
- ② The stone walls of Tal Ferha Estate, Malta, 2004.
- ③ Article in the Shipbuilding Industry Foundation's Bulletin introducing the support for JALMA's leprosy center in India (Issue no. 15, April 1967).

## The Japanese Leprosy Mission for Asia

The Japanese Leprosy Mission for Asia was established in November 1962 for the purpose of promoting basic research on leprosy and medical activities in various Asian countries, in order to contribute to international cooperation with the countries of Asia.

## Ryoichi Sasakawa's resolution (conversation with Kazuo Saikawa)

"When I was in Taiwan in 1966, Chairman Ryoichi Sasakawa came to Taiwan and wanted to visit a Taiwanese leprosy sanatorium so he asked me to show him around. By that time, he had already seen facilities in the Philippines and South Korea, and said that Japan had to do something about the leprosy situation in Asia."

## 1969

**April** JALMA's Indian leprosy center commences operation.

**1969** The Hawaiian quarantine law is abolished.

## 1970

**April** JALMA's Indian leprosy center starts full operation.

## 1972

An eradication project is undertaken on Malta, led by the Ministry of Health with the support of the Knights of Malta, the German Leprosy Relief Association, and the Borstel Research Institute. In addition to dapsone (DDS), patients were given the three anti-tuberculosis drugs rifampicin, isoniazid and prothionamide, a combination therapy that was named "isoprodian-RMP." A total of 261 patients, including 201 registered with the Ministry of Health and some people diagnosed later, took RMP for periods ranging from 6 months up to 7 years, and all were cured.



# The Establishment of the Life Planning Center and the Encounter between Ryoichi Sasakawa and Morizo Ishidate

The Japan Overseas Christian Medical Cooperative Service (JOCS) had created an International Preventive Center (IPC), and in 1967 they opened an IPC Clinic under Dr. Shigeaki Hinohara that managed commissioned health control projects. Due to management issues, IPC was dissolved in 1972 and was relaunched as the Life Planning Center Foundation (LPC), independent of JOCS. Dr. Hinohara, who became its first president, also became the family doctor of Ryoichi Sasakawa. In April 1973, LPC became a public interest corporation approved by the Ministry of Health and Welfare, and the LPC Inaugural Public Lecture was held on May 22 the same year at Sabo Hall in Tokyo. After the lecture, Chairman Ryoichi Sasakawa, Yohei Sasakawa, Shigeaki Hinohara, Morizo Ishidate and Kenzo Kiikuni went to a restaurant in the basement of the Japan Shipbuilding Industry Foundation Building. During the meal conversation, Dr. Ishidate asked Dr. Hinohara to address leprosy, but was told it was difficult right then. Instead, Chairman Sasakawa proposed establishing a new foundation, and this became the trigger for the launch of the Sasakawa Health Foundation.



① Ryoichi Sasakawa (right) and Morizo Ishidate (left) in 1991.  
② Ryoichi Sasakawa at a leprosy hospital in Indonesia around 1973.  
③ Dr. Shigeaki Hinohara, 105 years old, with current Chairman of the Nippon Foundation Yohei Sasakawa in 2016.

**From the conversation between Dr. Morizo Ishidate and Ryoichi Sasakawa after the LPC Foundation Inaugural Public Lecture**  
**Ishidate:** There are still many patients in the world who are suffering without medicine. Japan's leprosy patients received an indescribable amount of help from foreign missionaries back in the Meiji period, and no other developed country has as many leprosy experts as Japan. Now is the time for us to cooperate in the sense of giving something back to the world. This is something I really wanted to do.  
**Sasakawa:** Actually, I have also been interested in leprosy patients for a long time and wanted to do what I could to comfort the people with this unfortunate disease. Wherever I go, to the Philippines, India, Taiwan, or South Korea, I always visit a leprosy sanatorium to comfort the patients. If you are prepared to take care of the practical side, I will take care of the funding.

1973

**April** Life Planning Center, established the previous year, becomes a public interest corporation.

# The Birth of the Sasakawa Memorial Health Foundation (Sasakawa Health Foundation)

On May 4, 1974, the Sasakawa Memorial Health Foundation (now the Sasakawa Health Foundation) received the stamp of approval from the Ministry of Health and Welfare (now the Ministry of Health, Labour and Welfare) and commenced its activities. As a foundation for the relief of leprosy patients, there was already Tofu Kyokai, but its activities were basically domestic. The main activities of the Sasakawa Health Foundation were overseas, but both The Nippon Foundation and the Sasakawa Health Foundation have continued to conduct domestic activities as well, such as providing assistance with facilities and transportation, history preservation, and arranging international exchanges for persons affected by leprosy in Japan.

- Basic Activity Policies for the Sasakawa Health Foundation**  
(confirmed at the founding meeting on April 3, 1974)
1. Activities should be based on simple humanism without desire for rewards.
  2. Promotion of scientifically based solutions to leprosy issues.
  3. Helping each country with the plans they have prepared themselves, rather than imposing cooperation.
  4. Consistency with globally accepted control measures.
  5. Taking integration with other public health programs into account.
  6. Focusing on specific programs in order to make effective and efficient use of limited resources.

Founding members (in alphabetical order)	
Terutaka Akutagawa	Chairman of the board, Japan Shipbuilding Industry Foundation
Hirokuni Dazai	Chairman of the board, Japan Community Healthcare Organization
Shigeaki Hinohara	Chief physician, St. Luke's International Hospital
Morizo Ishidate	Chairman, Japan Pharmaceutical Association
Hisatake Kato	President, Fukui Broadcasting
Kenzo Kiikuni	Researcher, Ministry of Health and Welfare
Kazuo Saikawa	Director, Okinawa Airakuen Sanatorium
Ryoichi Sasakawa	Chairman, Japan Shipbuilding Industry Foundation
Kazuchika Shiga	Director, National Sanatorium Kikuchi Keifuen
Shigetaka Takashima	Director, Nagashima Aiseien Sanatorium
Kiyotsuna Watanabe	Standing director, Life Planning Center
Yoshio Yoshie	Director, National Institute for Leprosy Research



① Board Chairman Ishidate greets Prince and Princess Takamatsu at the opening ceremony of the Sasakawa Memorial Health Foundation.  
② Reception for the 1st Seminar on Leprosy Control Cooperation in Asia, 1974.



1974

A survey is undertaken of the leprosy situation in various countries in Asia (South Korea, the Philippines, Indonesia, Malaysia, Singapore, Vietnam, Laos, Thailand, Myanmar). Provision starts of dapsone (DDS) in Thailand, the Philippines, South Korea and Taiwan. UNICEF's 10-year worldwide dapsone grant, which had been running since the mid-1960s, is nearing its end. The Sasakawa Health Foundation prolongs dapsone provision to 1983, and increases the number of target countries to 10. In addition to drugs, bicycles, motorcycles and cars are also sent to enable leprosy workers in the field to become more proactive, while microscopes, medical materials and research equipment are given to each country as needed. **May 25** After celebrating the anniversary of the Sasakawa Health Foundation, 60 domestic leprosy specialists hold a symposium on "problems and promotion of international cooperation on leprosy." They agree to "work in close cooperation with international organizations such as WHO to implement cooperation projects with a long-term view, fully taking into account the uniqueness, history and cultural background of each country, and respecting the independence of each country." **June - July** Morizo Ishidate of the Sasakawa Health Foundation travels with Kenzo Kiikuni and Kazuo Saikawa to the WHO Headquarters in Geneva, ELP, WHO's office for the Western Pacific Region in Manila, the Philippines, and WHO's office for South-East Asia in New Delhi, India, to discuss future cooperation. **November-December** The 1st Seminar of Leprosy Control Cooperation in Asia is held at three locations in Tokyo, Oiso and Okayama, with 70 participants including 21 overseas participants from 12 countries.



# Memories of the Establishment of the Sasakawa Health Foundation and the Determination to Tackle Leprosy



I grew up the son of a pharmacist in Aomori Prefecture and have lived my whole life together with medicine. Back in Aomori, I had many occasions to visit a leprosarium, and I wanted to study pharmacology so I could do something for the patients there. That was my dream ever since I was a small boy. When I was able to synthesize the leprosy drug Promin at the Department of Pharmaceutical Sciences at the University of Tokyo for the first time in Japan, my dream came true. There are still many patients in the world who are suffering due to lack of drugs. We established the foundation to help those people in gratitude for the assistance we ourselves received from abroad. (1973)  
**Morizo Ishidate** (Co-founder of the Sasakawa Health Foundation, first chairman of the board of directors).



When I started the campaign to abolish the Leprosy Prevention Law, many people told me that no matter what I said, leprosy was still contagious. So I asked Dr. Yo Yuasa to declare in the Japan Medical Journal that “there is no need to worry about contagion, the law can safely be abolished.” Dr. Yuasa’s achievement was great. (2004)  
**Fujio Otani** (Director of the Sasakawa Health Foundation from 1985 to 2010)



“A world without leprosy” must also be “a world without medical and social problems caused by leprosy.” We need to be clearly aware that people affected by leprosy suffer from discrimination and segregation due to our mistakes. In order to prevent people from repeating the same mistakes, it is increasingly important to properly pass down the history and records of leprosy. (2015)  
**Yo Yuasa** (Medical director of the Sasakawa Health Foundation from 1975 and executive director from 1980 to 2010)



Our foundation [the Sasakawa Health Foundation] has a social mission focused on leprosy, so we must never forget all the social misery that leprosy has caused. (2004)  
**Kenzo Kiikuni** (Co-founder of the Sasakawa Health Foundation, member of the first board of directors and senior advisor from 2017)



When planning for leprosy, the vision must be as large as possible, like drawing a big circle in the sky, and our work is one arc of that big circle that connects to the next generation. Instead of trying to complete the whole circle in our time, we must describe a great vision to transmit the spirit of a long-running theme to our successors. (2004)  
**Shigeaki Hinohara** (Co-founder of the Sasakawa Health Foundation, member of the first board of directors and later president)



I first got to know the reality of leprosy in 1976, when I accompanied my father, Ryoichi Sasakawa, on a trip to South Korea and visited a leprosy hospital. For the first time, I saw with my own eyes how people whose leprosy was progressing, whose hands and legs were deformed, whose whole face shape had collapsed were kept in isolation, and were living huddled together. When I got back home, I could not forget the tremendous impact of what I had witnessed in South Korea, and immersed myself in gathering knowledge and information about leprosy. I thus learned the sad history of the ordeals leprosy patients have had to suffer through since ancient times. Since then, I have been working on leprosy control for over 40 years.  
**Yohei Sasakawa** (Chairman of the Nippon Foundation)



I went to Manila in 1979, but the failure of chemotherapy at that time was because patients forgot to take the drug, or if they received some rifampicin they would sell it for money. Even worse was the attitude that you shouldn’t take the medicine, because if you could enter a sanatorium your livelihood would be guaranteed. That was the reason for creating calendar blister packs. (2004)  
**Hiroshi Nakajima** (Director-General of WHO from 1988 to 1998)



Rehabilitation is a big problem internationally and one that will remain long into the future, so international cooperation is necessary. Unless each country thinks of it as part of the issue of disabled people in general, however, detailed solutions will be difficult. But international cooperation is the greatest common factor, I think. (2003)  
**Kazuo Saikawa** (Co-founder of the Sasakawa Health Foundation, member of the first board of directors)



## A Million Dollar Donation to WHO

In 1975, Ryoichi Sasakawa, the chairman of The Nippon Foundation, decided to donate a million dollars to African countries that were suffering from leprosy. (With the exchange rate at the time, this was approximately 300 million yen.) He discussed the matter with Kenzo Kiikuni, who suggested offering the funds to WHO. Kiikuni, Ishidate and Saikawa went to Geneva and met with Halfdan T. Mahler, the director-general of WHO. Back then, leprosy was almost becoming a “forgotten disease” even at WHO, but Mahler accepted The Nippon Foundation’s offer and promised to reconsider leprosy as a major issue. As soon as they got back, however, there was a call from Mahler. “Right now, WHO is in the middle of a battle to eradicate smallpox. May we use Mr. Sasakawa’s donation, or at least a part of it, in our fight against smallpox?” he asked. By then, the only countries where smallpox remained to be stamped out were Somalia and Ethiopia, but civil wars were raging in both countries and it was believed to be very expensive to transport vaccines there. Chairman Sasakawa trusted Mahler as a person and let him use the funds freely. Five years later, in 1980, WHO were able to announce to the world that smallpox had finally been eradicated. The Foundation’s financial support at that time raised interest in leprosy within WHO, and it became a major cornerstone for subsequent leprosy control efforts in cooperation with WHO.

### 1975

From this year until 1983, doctors, dentists, nurses and laboratory technicians are dispatched long-term to South Korea, the Philippines, Indonesia, Malaysia, Singapore, Vietnam, Laos, Thailand, Myanmar, Taiwan, Nepal, India, China, Central African Republic, Venezuela, Paraguay and the United States for local technical cooperation.

► Start of an overseas technical training program (the Sasakawa Foundation Fellowship & Scholarship). The first year, 10 trainees from Taiwan, South Korea, Thailand, and the Philippines are accepted in Japan, and receive training at various sanatoriums and universities around the country.

► Chairman Ryoichi Sasakawa decides to donate a million dollars toward global leprosy work.

**August** The 2nd Seminar of Leprosy Control Cooperation in Asia is held in Tokyo, with 146 participants, including 18 people from South Korea, the Philippines, Myanmar, Indonesia, Malaysia, Nepal, Taiwan, Thailand and Singapore, as well as delegates from WHO and ELEP.

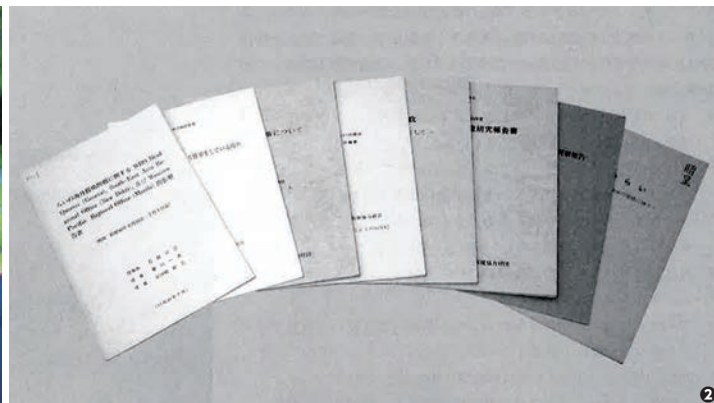
**1 December** The Sasakawa Health Foundation joins ELEP. Since The American Leprosy Mission is admitted at the same time, the organization changes its name from ELEP to ILEP (International Federation of Anti-Leprosy Associations).



① Kenzo Kiikuni and Yohei Sasakawa reunite with Halfdan T. Mahler (center) in Geneva in 2006.

② At the same time as the Sasakawa Health Foundation was established, researchers were dispatched to investigate the medical situation of leprosy overseas, and many reports were produced.

③ Delegates from each country are presented on stage at the 2nd Seminar of Leprosy Control Cooperation in Asia in 1975.



## The Construction of the Korean Leprosy Institute

In August 1974, Morizo Ishidate, the chairman of the board of the Sasakawa Health Foundation, conducted a survey of the leprosy situation in South Korea. This was in response to a request from Masahide Kanayama, the Japanese ambassador to South Korea, to build a leprosy hospital in South Korea. At the time, there were about 50,000 patients in South Korea, out of which over 20,000 were not being treated. It was a major public health problem. Ishidate decided to donate a leprosy facility to the Korean government. The Nippon Foundation provided the construction funds, and the Korean Leprosy Institute was completed on September 24, 1976, in Anyang on the outskirts of Seoul. The cost of the facility’s equipment was largely covered by contributions from Japanese citizens and assistance by Shoroku Shinto Yamatoyama, a religious organization that Ishidate was close to. Later, the Korean Leprosy Prevention Association moved from Seoul to the Korean Leprosy Institute’s grounds, and this became the center of leprosy control in South Korea. Shoroku Shimto Yamatoyama have since also expanded their contributions to leprosy facilities in Taiwan, Thailand, Indonesia, Nepal, and China.

The completion ceremony of the Korean Leprosy Institute was attended by Ryoichi Sasakawa, Ishidate, former ambassador Kanayama, Yasusaburo Tazawa, the leader of Shoroku Shimto Yamatoyama, and Park Geun-hye, the daughter of South Korea’s president at the time, Park Chung-hee. Yohei Sasakawa of The Nippon Foundation was also present at the ceremony. Witnessing the harsh conditions of leprosy patients for the first time, and seeing how his father, Ryoichi Sasakawa, touched and talked with the patients, had a tremendous impact on him.

### 1976

**September** Construction of the Korean Leprosy Institute completed.

**November-December** The first international workshop for leprosy training in the Asian region is held in Bangkok and Pattaya in Thailand, to examine appropriate measures with regard to the necessity of training leprosy workers in the field. A second workshop is held in January 1979, and a third in January 1982, both in Bangkok.



① One of the participants at the completion ceremony of the Korean Leprosy Institute was Park Geun-hye, then 24 years old.

② At the Korean Leprosy Institute in 2017.

③ Establishment plate of the Korean Leprosy Institute.



Ryoichi Sasakawa at the completion ceremony of the Korean Leprosy Institute.



# Financial Support for Anti-Leprosy Measures and Leprosy Control Promotion in Various Countries

In the early 1970s, Nepal was a heavily endemic country with an estimated 1 patient per 100 people. In 1976, the country’s government implemented a 5-year plan against leprosy, but the actual execution of the plan was delayed in some areas due to a lack of funding and staff. For that reason, The Nippon Foundation decided to step in and fund the construction of a leprosy research center in 1977 and a training center in 1981 at the hospital in Anandaban.

In Taiwan, a 10-year government project to eradicate leprosy started in 1976. Here too The Nippon Foundation provided part of the funds in 1977 toward the construction of a leprosy clinic and training facility for out-patient treatment and rehabilitation. In South Korea, following the establishment of an operation fund for the Korean Leprosy Institute, The Nippon Foundation supported the production and distribution of an educational film in cooperation with the Korean Leprosy Association in 1979.

Meanwhile, workshops were held in five countries from 1977 to 1983 to discuss issues related to leprosy control. At the time of the second workshop, which was held in Kathmandu, Nepal, in 1979, Chairman Ryoichi Sasakawa visited the Khokana Leprosarium, a 40-minute drive from the capital. His expression of deep sympathy as he held the hand of an elderly lady on her sickbed was reported all over the world through the footage of Grammy Award-winning cameraman Dick Young.



**1977-1980 [1] Leprosy control activities**  
**November-December 1977** The First International Workshop on Leprosy Control in Asia is held in Jakarta, Yogyakarta and Bali, Indonesia. Subsequent workshops are held in Kathmandu, Nepal, in October 1979; Taipei, Taiwan, in November 1980; Kuala Lumpur, Malaysia, in June 1982; and Singapore in October 1983.  
**January 1979** The second international workshop for leprosy training in the Asian region is held in Bangkok, Thailand.  
**February 1979** A domestic control workshop is held in Kathmandu, Nepal.  
**October 1979** The Second International Workshop on Leprosy Control in Asia is held in Kathmandu, Nepal.  
**November 1980** The Third International Workshop on Leprosy Control in Asia is held in Taiwan.

① Ryoichi Sasakawa at the Khokana Leprosarium, Nepal.  
② Ryoichi Sasakawa in Kathmandu, Nepal, 1983.  
③ Mother Teresa at a leprosy hospital in India with Ryoichi Sasakawa 1984.  
④ On the last day of the First International Workshop on Leprosy Control in Asia, an agreement was signed with the Sasakawa Health Foundation to promote cooperation in the leprosy field, at the request of the Indonesian government.  
⑤ The Second International Workshop on Leprosy Control in Asia.

# Resistant Bacteria and the Search for New Chemical Cures

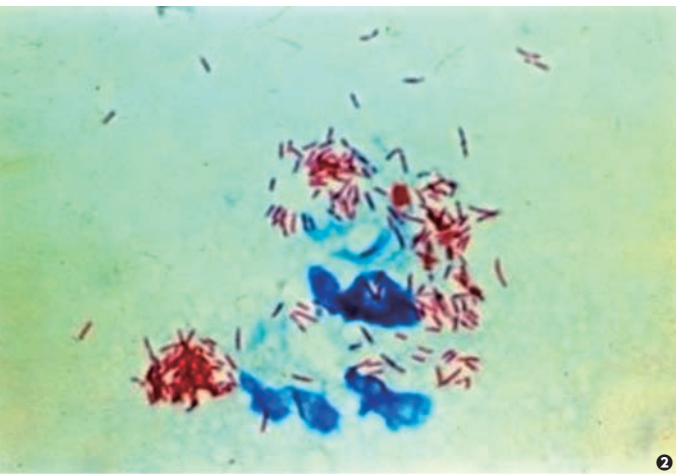
In the 1970s, bacteria that were resistant to the prevailing drug dapsone (DDS) emerged, and it became necessary to reconsider the methods of leprosy control.

New hope was seen in 1977. Thanks to further research, two other drugs – clofazimine and rifampicin – that were considered highly effective in treating leprosy were recommended for use in combination with dapsone. This drug combination was also shown to suppress the generation of resistant bacteria.

The Sasakawa Health Foundation first announced this result at the First International Workshop on Chemotherapy of Leprosy in Asia, held in Manila in the Philippines, and then conducted corroborative trials in South Korea, the Philippines and Thailand, which clearly showed the effectiveness of the new method.



① The 1st International Workshop on Chemotherapy of Leprosy in Asia marked the start of international joint research on chemotherapy of leprosy between experts from the Philippines, Thailand, South Korea and Japan.  
② Leprosy bacteria (*Mycobacterium leprae*). Photograph courtesy of the Infectious Disease Surveillance Center, Japan.  
③ Before chemotherapy in the form of Promin was available, chaulmoogra oil and fruits were used.  
④ Promin (Protophen is a brand name).



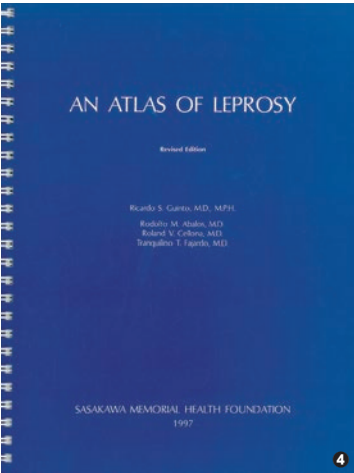
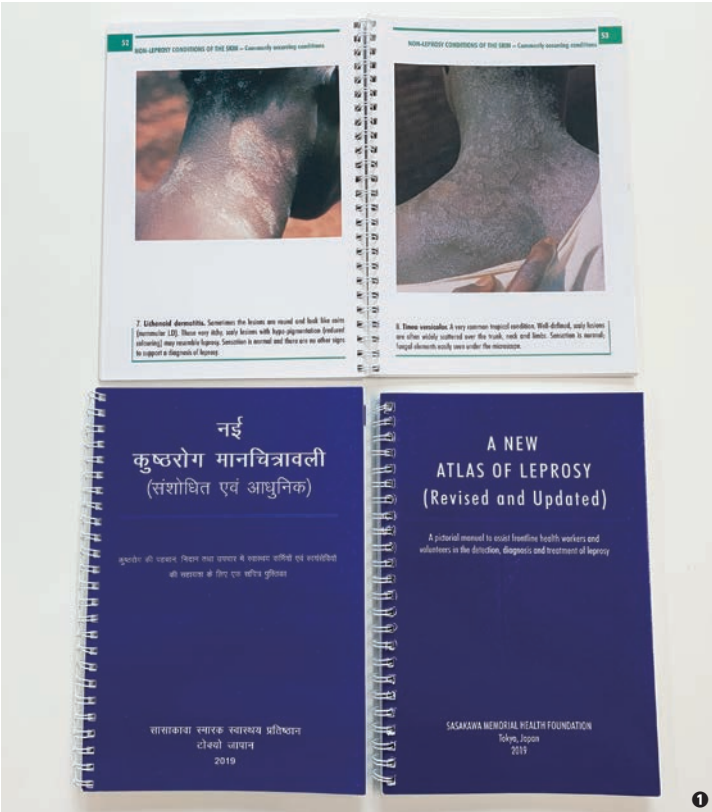


# The Development and Distribution of *An Atlas of Leprosy*

In 1981, the Sasakawa Health Foundation produced the booklet *An Atlas of Leprosy* in order to support and train people involved with leprosy control activities. It met with a great response. The English-language booklet was compiled from a vast collection of photographs of skin symptoms and microscopic images gathered over several decades at the Leonard Wood Memorial Center for Leprosy Research in Cebu in the Philippines. The first edition was a handmade album of 36 large 23 x 19 cm photographs, and 230 copies were distributed. The booklet proved very popular, however, and demand was high, so in 1983 a second edition of 3000 copies was printed, including pathological microscopic images and photos for differential diagnosis. It has since been revised several times and translated into Chinese, Spanish, Portuguese, French, Arabic, Indonesian and Hindi.

## 1981

The Sasakawa Health Foundation creates *An Atlas of Leprosy*.  
**MORHAN** (Movement for the Reintegration of Persons Affected by Hansen's Disease) is formed in Brazil.  
**June** The Fifth Joint Leprosy Research Steering Committee Meeting and the Third Leprosy Chemotherapy International Liaison Conference are held in Thailand  
**September** An international symposium on the epidemiology of leprosy is held in Geilo, Norway.  
**October** The WHO Study Group on Chemotherapy of Leprosy for Control Programs meets in Geneva, Switzerland. Multidrug therapy (MDT) is discussed.



1 The latest edition of *An Atlas of Leprosy*, 2019.  
2 Indian health workers with the Hindi edition of *An Atlas of Leprosy*.  
3 The 1997 edition of *An Atlas of Leprosy* was in a larger format than the current one.

# WHO Recommends MDT

Following the International Symposium on Leprosy and Joint Chemotherapy Trial Meeting in Seoul, South Korea, in 1978, joint chemotherapy research started in South Korea, the Philippines and Thailand to clinically prove the efficacy of MDT (multidrug therapy). This research continued until 1988, but by that time the optimal dosage and duration had been determined and the effectiveness of MDT had been confirmed in the Philippines, Thailand, South Korea and Japan.

In October 1981, WHO invited close to 40 experts to Geneva for a symposium on chemotherapy research for the prevention of resistant bacteria, and the effectiveness of MDT treatment was confirmed. One of the participants was Dr. Yuasa, executive and medical director of the Sasakawa Health Foundation. In March 1982, WHO published its recommendation on MDT and started promoting MDT worldwide. Quick and efficient distribution of MDT in each affected country all over the world became the focus of leprosy countermeasures.



1 MDT is always provided free of charge at medical facilities around the world. Guinea, 2008.  
2 Calendar blister packs contain medicine in daily doses. One of the barriers to the spread of MDT was the distribution method. At first, the drugs were simply handed out from a large bag, which took time and it was easy to make mistakes. Furthermore, since rifampicin is also effective against tuberculosis, there was a problem with the drug being diverted to other uses. Dr. Yo Yuasa of the Sasakawa Health Foundation and Hiroshi Nakajima, who was the bureau chief of WHO WPRO, came up with the idea of using blister packs to solve the problem. The daily dosage was described in the local language and enclosed in the blister packs, making them easy to use. Another merit of blister packs is that they preserve the quality of the medicine even in difficult environments.  
3 MDT is always available at health centers in Indonesia. 2017.



**Early diffusion of MDT**  
**October 1981** WHO recommends MDT.  
**1983** MDT starts being provided to patients in parts of South Korea, Thailand, and the Philippines.  
**October 1984** The 2<sup>nd</sup> International Workshop on Chemotherapy of Leprosy in Asia is held in Manila, the Philippines, in order to disseminate MDT and implement its use.  
**1985** MDT is provided in parts of Indonesia, China, Myanmar, and India.  
**From 1985** The Sasakawa Health Foundation conducts educational activities for health care workers for early diffusion of MDT. In the 10 years from 1984 to 1993, MDT drugs are provided in the Philippines, South Korea, Thailand, China, Indonesia, Vietnam, Zambia, Micronesia, Peru, Brazil, Nepal, Angola, Mexico, Papua New Guinea, Ethiopia, Myanmar, Nigeria and other countries. MDT-related spending exceeds 300 million yen.  
**November 1989** An "All-African MDT Conference" is held in collaboration with WHO to ensure the implementation of MDT in Africa.  
**February 1991** Since the implementation status of MDT varies, an International Conference on MDT is held in the MDT model country of Thailand to study more effective implementation methods.

## 1982

**January** The first international workshop for leprosy training in the Asian region is held in Bangkok, Thailand.  
**June** The Fourth International Workshop on Leprosy Control in Asia is held in Kuala Lumpur, Malaysia.  
**June** The Seventh Joint Leprosy Research Steering Committee Meeting and the Fourth Leprosy Chemotherapy International Liaison Conference are held in Anyang, South Korea.  
**November** An International Symposium on Leprosy Immunotherapy and Prevention (International Chemotherapy Conference) is held in Tokyo.



# Start of Full-Scale Support for Control Activities in China, and Appreciative Words from the Pope

In the 1950s, China reportedly had 470,000 leprosy patients, a number that was successfully reduced to 120,000 over the following 30 years. In order to bring leprosy under control by the year 2000, the Chinese government asked for help from the International Federation of Anti-Leprosy Associations (ILEP). The Sasakawa Health Foundation joined this effort in 1980 as a member of ILEP, and in 1983 commenced full-scale support activities by providing 1.2 million capsules of clofazimine. Since then, support for treatment and education has been provided on a massive scale in the form of large quantities of drugs, vehicles for MDT administration, microscopes, and more.

In 1983, Ryoichi Sasakawa also received a personal letter of invitation from Pope John Paul II. His long-standing efforts to eradicate leprosy had been recognized. On May 9, Chairman Sasakawa had an audience at the Vatican, and received the Pope's words of appreciation for his hard work.



1 Pope John Paul II with Ryoichi Sasakawa at the Vatican, 1983.  
2 The Chinese Leprosy Control Research Center  
3 The First International Leprosy Conference in China.  
4 Chinese nurses training at a national leprosy sanatorium in Japan.

**Control activities in China**  
**1985** The First International Leprosy Conference in China is held in Guangzhou, co-sponsored by WHO and the Sasakawa Health Foundation. The Chinese Leprosy Association is established, triggered by the conference.  
▶ The Chinese Leprosy Control Research Center is constructed on the outskirts of Guangzhou with money from the Kinoshita Fund (based on donations by Toshio Kinoshita from 1977 onward).  
▶ At the request of the Chinese Ministry of Public Health and in cooperation with the Damien Foundation in Belgium, The Nippon Foundation provides assistance to renovate and equip a factory in Hubei Province manufacturing protective shoes for the prevention of plantar ulcers, a common disability resulting from leprosy.  
**1998** The 15th International Leprosy Congress is held in Beijing.

**1983**  
**May** Ryoichi Sasakawa receives an audience with the Pope.  
**October** The Fifth International Workshop on Leprosy Control in Asia is held in Singapore.

# WHO Establishes the Sasakawa Health Prize

At the World Health Assembly on May 8, 1984, WHO passed a resolution to establish the “Sasakawa Health Prize” as a part of WHO’s drive toward “Health for all by the year 2000.” A prize of \$100,000 and a commemorative trophy is awarded each year to individuals or organizations that have accomplished outstanding innovative work in the health sector around the world. The fund for the prize is managed by the Sasakawa Health Foundation, and was subsidized by a million dollar donation by The Nippon Foundation in March 1984. Ever since the first award in 1985, the prize has been presented at a special ceremony during the World Health Assembly in Geneva, Switzerland.



1 MORHAN (Movement of Reintegration of Persons Afflicted by Hansen’s disease) were the winners of the 26th Sasakawa Health Prize in 2008. At UN European headquarters, Geneva.  
2 Yohei Sasakawa with Mother Teresa during his first visit to India, in 1984.  
3 The WHO Sasakawa Health Prize trophy.  
4 The work of the first winner of the WHO Sasakawa Health Prize, Dr. David Bersh Escobar of Colombia, contributed to the development of health education, health philosophy and primary health care. In particular, it led to improvements in oral hygiene and ophthalmic care for rural children

Leprosy regulations are abolished in Maharashtra, India. Other states gradually follow suit.  
**February** Director Yohei Sasakawa makes his first visit to India in order to attend the 12<sup>th</sup> International Leprosy Congress in New Delhi. Prime Minister Indira Gandhi and Mother Teresa are also present at the conference. Since then, he has visited India more than 60 times.  
**May** WHO establishes the Sasakawa Health Prize.  
**October** The 2nd International Workshop on Chemotherapy of Leprosy in Asia is held in Manila, the Philippines.

Main leprosy-related Sasakawa Health Prize recipients		
Year	Country	Recipient
2003	Yemen	Yemen Leprosy Elimination Society
2006	India	International Leprosy Union (ILU)
2008	Brazil	MORHAN (Movimento de Reintegracao das Pessoas Atingadas pela Hanseníase)
2014	Dominican Republic	Leprosy Control Foundation, Instituto Dermatológico Dominicano y Cirugía de la Piel “Dr. Huberto Bogaert Díaz”



# The Sasakawa Research Building (SRB) Is Donated to Thailand

In a fund-raising campaign in 1986, over 870 million yen was received in donations from people who shared Ryoichi Sasakawa's wish to eradicate leprosy. To make effective use of this money, the Sasakawa Health Foundation set up a "Leprosy Eradication Activity Fund" and decided to donate a medical research facility to be called the Sasakawa Research Building (SRB) to Nonthaburi, a northern suburb of Bangkok in Thailand. The facility was intended as a leading leprosy research center with sophisticated functions not just for Thailand but for the whole of Southeast Asia, and by extension for the whole world. It has an animal complex with biosafety level P3 (a classification that indicates high-level containment laboratories and facilities that handle microorganisms and pathogens). Construction began in 1988, and was completed in October the following year. Since its opening, SRB has organized the "Leprosy Histopathology Research Group by Thai Researchers," the "Thai Leprosy Researchers Association" and the "International Research Group on Leprosy Diagnosis." From 1990 to 1997, a "study of the therapeutic effect of ofloxacin on leprosy" was carried out. Leprosy control in Thailand is progressing rapidly, and SRB has also been utilized for research on other diseases. In 1997, the facility was transferred to the Thai government and is now used for AIDS vaccine development projects among other things as well.



1 The Sasakawa Research Building (SRB), Thailand.  
2,3,4 Scenes from the McKean Rehabilitation Center, Chiang Mai, Thailand, 2010.

# Attempts to Develop a Leprosy Vaccine

To develop a vaccine against leprosy was the dream of Professor Ishidate, the first chairman of the Sasakawa Health Foundation. Various attempts to develop leprosy vaccines have been made in Japan and other countries, but the bacteria that cause leprosy are hard to cultivate, and development is also hindered by the fact that apart from humans, only a handful of animals such as armadillos are susceptible to the disease. A certain degree of success was achieved with BCG and with killed leprosy bacteria in experiments on armadillos by Dr. Jacinto Convit in Venezuela. In September 1986, the Sasakawa Health Foundation and IMMLEP (the WHO program for research on immunology of leprosy) co-sponsored an international symposium on immunology of leprosy in Oslo, Norway, where the development of an immune vaccine for leprosy was discussed, and on December 8 the following year, Ryoichi Sasakawa received the first leprosy vaccine inoculation at the WHO headquarters in Geneva. Work continues today to develop an effective vaccine for leprosy as a way to stop transmission and prevent people from developing the disease.



1 Ryoichi Sasakawa became the first person vaccinated against leprosy at the WHO Headquarters in Geneva in 1987.  
2 Dr. Kirchheimer (Carville Research Institute, USA) transplants human leprosy bacteria to an armadillo around 1980.  
3 Stuffed nine-banded armadillo on display at the Leprosy Research Institute in Astrakhan, Russia.

**Vaccine development-related activities**  
**September 1986** International Symposium on Immunology of Leprosy in Oslo, Norway.  
**December 1987** Ryoichi Sasakawa becomes the first person vaccinated against leprosy. The Sasakawa Health Foundation had been exploring leprosy vaccine research and development since 1980. In July 1982, delegates from related organizations such as the Ministry of Health and Welfare, national sanatoriums, universities and research institutes gathered at the call of Dr. Ishidate, and the Leprosy Vaccine Development Research Council was formed. Research was commissioned from the National Tama Research Institute, Osaka University and Kyoto University in Japan, and from the US Army Pathology Research Institute and the National Leprosy Center in the United States. Meanwhile, independent research had produced results in Venezuela, and as part of the Japanese project, Dr. Convit and his collaborators were invited to an International Symposium on Leprosy Immunotherapy and Prevention in Tokyo in November, 1982.  
Since then, partially because of the great effect of MDT on leprosy treatment, efforts to develop a vaccine have declined, but developing a vaccine remains an important task in order to eradicate leprosy. Attempts at vaccine development are still continuing in various places in the world, for example at Louisiana State University, where leprosy bacteria are cultivated using armadillos, and also at the Infectious Disease Research Institute (IDRI) in Seattle, Washington.

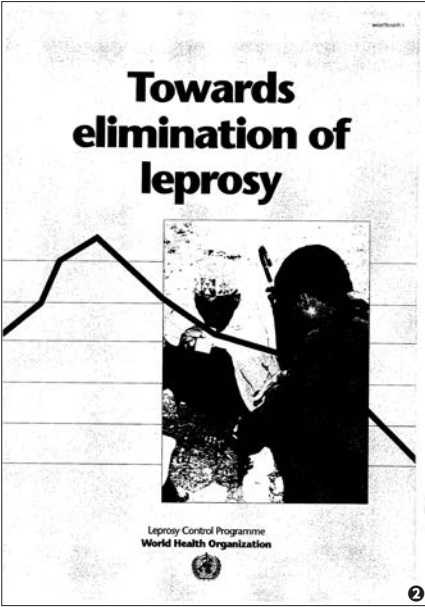
**1987**  
**October** International seminar on implementation of MDT in Vietnam.

**1988**  
**September** The 13<sup>th</sup> International Leprosy Congress is held in The Hague, Netherlands.  
**October** The Sasakawa Research Building (SRB) in Thailand is completed.



# WHO Adopts a Resolution to Eliminate Leprosy by the Year 2000

Thanks to the significant therapeutic results of MDT, WHO saw it as a historic opportunity to actively take the initiative in treating leprosy. One manifestation of this was resolution WHA44.9, which was passed at the 44th World Health Assembly in May 1991, to eliminate leprosy as public health problem by the year 2000, defining elimination as a level of prevalence of less than 1 case per 10,000 population. Leprosy has a very low infectivity, and the thinking went that if the prevalence could be brought below that level, the health services in each country should be able to deal with it. Then leprosy would no longer be a “major public health problem.” At the same time, setting an easy-to-understand numerical target was a unique approach that had not been tried before. Key proponents of this approach were Dr. S.K. Noordeen from India, who was the director of WHO’s leprosy unit at the time, and Dr. Yo Yuasa from the Sasakawa Health Foundation. It became the starting point for the development of a more comprehensive, overarching approach to leprosy control.



1 Dr. S.K. Noordeen and Dr. Yo Yuasa, 2003.  
2 “Towards elimination of leprosy,” a pamphlet in Japanese and English published by WHO in 1991.

## Activities related to the elimination declaration

**1989** According to Dr. Yuasa of the Sasakawa Health Foundation, prior to WHO’s elimination resolution in 1991, a similar resolution had already been passed by the “Leprosy Council” at the WHO Western Pacific Regional Office in Manila, the Philippines, in October 1989. At that time, the prevalence of leprosy in the region averaged 1/1,000 and the case detection rate was 1/10,000, and it was judged fully possible to reduce the prevalence rate to the level of the case detection rate in 10 years thanks to MDT. It was also estimated that 20 million dollars would be needed to reach this goal. The region aimed to achieve its goal in 1998, ahead of the rest of the world.

**May 1991** The 44th World Health Assembly adopts the resolution to eliminate leprosy as a public health problem by the year 2000.

**June 1991** Following the WHO resolution, delegates from 14 countries using MDT and from WHO, ILEP, etc. hold an International Conference on the Epidemiology of Leprosy in Jakarta, Indonesia, to discuss “how to accurately grasp the number of leprosy patients,” “grasping the actual changes in prevalence and new patient incidence due to MDT,” and “predicting the number of leprosy patients at the end of MDT,” urging efforts in the countries concerned.

**June 1992** The Western Pacific Regional Conference on Leprosy Control is held with mainly delegates from 25 countries in the region, co-sponsored by WHO WPRO and the Sasakawa Health Foundation. At the WHO Western Pacific Regional Workshop in Manila in June 1989, it had been proposed to “reduce prevalence and incidence in the Cook Islands, Fiji, Samoa and Tonga by 1995, and to achieve control of leprosy in the whole region by the year 2000.” This goal is reaffirmed, and active efforts are encouraged in each country. Similar conferences are held in other regions, and the world begins to move toward achieving the elimination target in 2000.

## 1991

**February** International conference on implementation of MDT in Thailand.

**June** International Symposium on Immunology of Leprosy in Jakarta, Indonesia.

## 1992

**June** International conference on leprosy and MDT in Manila, the Philippines.

## 1993

**August** The 14<sup>th</sup> International Leprosy Congress is held in Orlando, USA.

# The Hanoi Conference and Free Distribution of MDT

In July 1994, the First International Conference on Leprosy Control was held in Hanoi, after a strong appeal by Hiroshi Nakajima, the Director General of WHO. It was co-sponsored by WHO and the Sasakawa Health Foundation, and the participants included representatives from 28 leprosy-endemic countries, along with experts and NGOs. Yohei Sasakawa, the then president of The Nippon Foundation was there, as were Sasakawa Health Foundation Board Chairman Hinohara, Managing Director Kenzo Kiikuni, and Medical Director Yo Yuasa, with the latter also representing the International Leprosy Association. The main priority of the conference was to reaffirm WHO’s decision to eliminate leprosy from the face of the Earth during the 20th century, and to stiffen the resolve of the 28 countries where leprosy was not yet under control.

At the conference, Yohei Sasakawa noted that provision of MDT was indispensable in order to bring leprosy under control by the year 2000, and offered to provide WHO with 10 million dollars per year for leprosy drugs for a period of 5 years, or a total of 50 million dollars. This gave momentum to efforts to eliminate leprosy. The conference also adopted the “Hanoi Declaration,” which stated that governments, NGOs and WHO should work together toward the goal of eliminating leprosy by the year 2000.

Free distribution of MDT drugs also has a major secondary effect. Governments in developing countries suffering from a lack of funds for control activities are freed from the financial burden of purchasing drugs, and can instead allocate their funds to health workers and social workers in order to discover patients, and to educational activities regarding leprosy treatment. The same goes for NGOs engaged in leprosy relief activities. When relieved of the burden of purchasing MDT drugs, they can redirect their budgets toward for example reconstructive surgery, the manufacture of artificial limbs, and other patient needs. For those active at the grassroots level, the message that “there is an effective cure for leprosy, and moreover it’s free” was a big boost.



1 The First International Conference on the Elimination of Leprosy, 1994.  
2 The Second International Conference on the Elimination of Leprosy was held in New Delhi in 1996.

## Participating nations in the Hanoi Conference

**[Africa]**  
Chad, Côte d'Ivoire, Ethiopia, Guinea, Madagascar, Mali, Mozambique, Niger, Nigeria, Zaire (now the Democratic Republic of Congo)

**[The Americas]**  
Brazil, Colombia, Mexico

**[Middle East]**  
Egypt, Iran, Pakistan

**[Southeast Asia]**  
Bangladesh, India, Indonesia, Nepal, Myanmar, Thailand

**[Western Pacific Region]**  
Cambodia, China, Papua New Guinea, the Philippines, South Korea, Vietnam

► Occasioned by the Hanoi Conference, WHO upgraded its leprosy division that had previously been under the Department of Infectious Diseases to the same level, and changed its name to APEL (Action Programme for the Elimination of Leprosy).

► Since the Hanoi Conference and the participation of The Nippon Foundation in control activities, the Sasakawa Health Foundation has functioned as coordinator between WHO and The Nippon Foundation, in addition to its role as an NGO and a member of ILEP.

► After the Hanoi Conference (the First International Conference on the Elimination of Leprosy) in 1994, the Second International Conference on the Elimination of Leprosy was held in New Delhi in 1996.

► Since 2000, leprosy drugs are provided free of charge by the Novartis Foundation, taking over the baton from The Nippon Foundation.

## Major countries achieving their elimination targets after the Hanoi Declaration

- 1994** Egypt, Mexico
- 1995** Thailand, Sri Lanka
- 1996** Colombia
- 1997** Togo, Benin, Venezuela, Chad
- 1998** Ghana, Nigeria, Bangladesh, Cambodia, the Philippines
- 1999** Sudan
- 2000** Ethiopia, China, Malaysia, Indonesia, Papua New Guinea
- 2001** Mali, Côte d'Ivoire
- 2002** Niger
- 2003** Myanmar
- 2005** Angola, India
- 2006** Tanzania, Madagascar, Guinea
- 2007** D.R.Congo, Mozambique
- 2009** Nepal
- 2010** Timor-Leste



# The Leprosy Prevention Law Is Abolished in Japan

Following the Leprosy Prevention Law of 1907, which called for patients to be placed in leprosaria if they had no one to support them, the Leprosy Prevention Law of 1931 now required all leprosy patients to be placed in compulsory isolation. Regardless of their condition, patients were unable to leave these institutions for life. Several of these facilities were located on remote islands, separated from society by the sea. The Japanese name of the law was changed after the war, but its provisions remained in essence the same. With the discovery of a cure, the number of new patients fell to practically zero, but the law still remained in force until it was finally repealed on April 1, 1996. Thanks to the law’s abolition, leprosy and the difficulties suffered by persons affected by the disease became known to the general public, and the issues increasingly came to be regarded as a problem for which everyone bore some responsibility. Persons affected by leprosy in Japan also began cooperating with their counterparts in the rest of the world.

The year before the abolition of the Leprosy Prevention Law, Ryoichi Sasakawa, the chairman of The Nippon Foundation, who had devoted his life to fighting leprosy, passed away in July 1995. His work is carried on by his son, Yohei.



1 A reconstructed disciplinary cell in the Kuryu Rakusen-en sanatorium in Kusatsu. The official name was “special ward,” but it was used for severe punishment of patients. It was installed in 1938 and was used until 1947. During that time, a total of 93 patients were confined in the cells, and 23 of them died due to the harsh conditions where the room temperature dropped to 10 degrees below zero in the winter.  
2 Oku-Nagashima Ohashi bridge is also known as the “Bridge of Recovery of Human Dignity.” The two sanatoriums of Aiseien and Komyo-en on Nagashima are separated by only 30 meters of water from Mushiake on the opposite shore, but for many years the islands were worlds apart. The bridge opened to traffic in 1988.  
3 A special pier for patients at Nagashima Aiseien, Japan’s first national sanatorium, located on an isolated island in the Seto Inland Sea.

**Activities toward the abolition of the Leprosy Prevention Law, and afterwards**  
**1963** The movement to revise the Leprosy Prevention Law gathers momentum. Patients in Japan’s national sanatoriums form the National Leprosy Sanatorium Resident Association (Zen-Ryo-Kyo, now the National Hansen’s Disease Resident Association), and submit a request for revision of the Leprosy Prevention Law to the Minister of Health and Welfare.  
**1991** The National Leprosy Sanatorium Resident Association submits a request for revision of the Leprosy Prevention Law to the Minister of Health and Welfare.  
**1993** The National Hansen’s Disease Museum is completed in Higashimurayama City, Tokyo.  
**1996** The Leprosy Prevention Law is abolished.  
**1996** The National Leprosy Sanatorium Resident Association changes its name to the National Hansen’s Disease Resident Association.  
**1998** A lawsuit claiming that the Leprosy Prevention Law was unconstitutional and demanding compensation from the government is filed with the Kumamoto District Court.  
**1999** Lawsuits demanding an apology for human rights violations related to the Leprosy Prevention Law and compensation from the government are filed with the Tokyo and Okayama District Courts.  
**2001** The Kumamoto District Court hands down its verdict: a complete victory for the plaintiffs (persons affected by leprosy). The government refrains from appealing the decision.  
**2002** A leprosy verification committee is established. (Its final report is published in 2005.)  
**2005** The Tokyo District Court hands down its decision on a medical malpractice suit at Tama Zensho Sanatorium, a victory for the plaintiffs.  
**2008** The “Act to accelerate the resolution of Hansen’s disease problems” is passed.  
**2019** The Kumamoto District Court orders the government to pay damages to family members of former leprosy patients.

# Persons Affected by Leprosy Make Their Voices Heard

In 1994, the international leprosy network IDEA (International Association for Integration, Dignity and Economic Advancement) was established in Petropolis, Brazil. Support for the social and economic independence of persons affected by leprosy was a comparatively new approach, but was being factored into leprosy work. As Cristiano Torres from Brazil put it, “Persons affected by leprosy don’t need charity. What we need is an opportunity to display our own powers and change the world.” How to return to society after the disease has been completely cured by MDT, how to recover dignity as a human being, and how to wipe out prejudice and discrimination became major themes. In October 1997, an exhibition called “Quest for Dignity: A Victory over Leprosy” was held at the United Nations headquarters, led by IDEA and co-sponsored by WHO and The Nippon Foundation. It was a wonderful opportunity for the voices of persons affected by the disease to be heard. The opening was attended by UN Secretary-General, Kofi Annan, former Director General of WHO, Hiroshi Nakajima, and Yohei Sasakawa of The Nippon Foundation, along with Dr. P.K. Gopal from India and other persons affected by leprosy from around the world.



1 The exhibition “Quest for Dignity: a victory over leprosy” in the lobby of the United Nations headquarters.  
2 The Ethiopian National Association of Persons Affected by Leprosy (ENAPAL) was formed in Ethiopia in 1996. It is run with membership fees paid by its members, and is working with the Ministry of Health in various ways to raise awareness about leprosy and to make its members self-reliant. One unique activity is the sale of embroidered handicrafts by a women’s group. In addition to being persons affected by leprosy, they also suffer double discrimination as women. For most of these women, it is the first time in their life that they are able to earn their own income. Photo from 2010.  
3 The singer Elke Maravilha (right) and Cristiano Torres (1939-2017, former chairman of MORHAN) (center) sing during an event in Brazil, 2012.

**“Former patient”**  
Because of the stigma surrounding leprosy, people who have been treated and cured of the disease still tend to be defined by it, unlike those who have recovered from other diseases.

## 1994

The international leprosy network IDEA is formed during a meeting in Brazil.

## July 1995

Ryoichi Sasakawa passes away. The novelist Ayako Sono is appointed new chairman. The following year the foundation changes its informal name to “The Nippon Foundation.”

## 1997

**July** A joint ILEP/WHO workshop is held in Geneva, Switzerland, to promote SAPEL (Special Action Projects for the Elimination of Leprosy) and LEC (Leprosy Elimination Campaigns).  
**October** The exhibition “Quest for Dignity: A Victory over Leprosy” is held at the United Nations headquarters in New York.

## 1998

**September** The 15<sup>th</sup> International Leprosy Congress is held in Beijing, China. The theme of the congress is “Toward a world without leprosy.” Persons affected by leprosy, who have previously been seen as objects of health care, are accepted as partners in future leprosy control activities, and 80 persons from 13 nations, mainly IDEA members, participate. The host country China announces that leprosy control has been successfully achieved in the whole country from this year.



# The Formation of the “Global Alliance” and the Creation of a “WHO Goodwill Ambassador for the Elimination of Leprosy”

The Third International Conference on Leprosy was held in Abidjan, Côte d'Ivoire, in November 1999 to identify countries where it might prove difficult to eliminate leprosy by the year 2000, and to discuss concrete countermeasures. At the meeting, a new Global Alliance for the Elimination of Leprosy (GAEL) was formed to break the deadlock, and the target was reset to the year 2005. The members of the alliance included the governments of countries that had yet to reach the elimination target, WHO, ILEP, The Nippon Foundation, the Sasakawa Health Foundation, and the Novartis Foundation for Sustainable Development, among others. The Nippon Foundation offered to support leprosy control activities with 24 million dollars based on this new framework from the year 2000 to 2005, and Novartis offered to continue the free provision of MDT.

GAEL's first international conference was held in New Delhi, India, in January 2001, where the target of eliminating leprosy in all countries by 2005 was reconfirmed and the “Delhi Declaration” was adopted. Furthermore, at this conference Yohei Sasakawa of the Nippon Foundation was appointed “WHO Special Ambassador to the Global Alliance for Elimination of Leprosy,” later becoming “WHO Goodwill Ambassador for the Elimination of Leprosy” after GAEL was dissolved.



① The 3rd International Conference on Elimination of Leprosy and the first Global Alliance meeting were held in Abidjan, Côte d'Ivoire.  
② The first Global Alliance meeting was held in January 2001 in New Delhi.  
③ Goodwill Ambassador Yohei Sasakawa talking with the media at a leprosy colony in India, 2017.

# The Start of Full-scale Efforts to Treat Leprosy as a Human Rights Issue

At the Fifth Forum 2000 Conference in October 2001, Chairman Yohei Sasakawa of The Nippon Foundation spoke for the first time about the human rights issues surrounding leprosy. Forum 2000 is an international conference that started in Prague in 1997 at the initiative of then Czech President Vaclav Havel, Nobel Peace Prize laureate Elie Wiesel, and Yohei Sasakawa. Its aim is for leaders in various fields around the world to explore solutions to issues common to the whole of humankind, such as ethnic, religious and regional conflicts, and population and environmental problems. Sasakawa's remarks about leprosy had a huge impact on the other participants, and many of them became aware of the problem of leprosy and human rights through this conference. Approaches to the United Nations Commission on Human Rights of behalf of people affected by leprosy soon followed.

**Health and human rights**  
While international health issues are classified as WHO's area of work, leprosy has always been accompanied by the additional problems of stigma and discrimination. These do not fit readily into WHO's category of “health and hygiene,” so that the only organization that can handle leprosy as a human rights issue is the United Nations. However, for over 50 years after the founding of the UN Human Rights Commission in 1945, it never addressed the leprosy issue. It wasn't until the early 2000s that leprosy as a human rights issue appeared on the agenda.

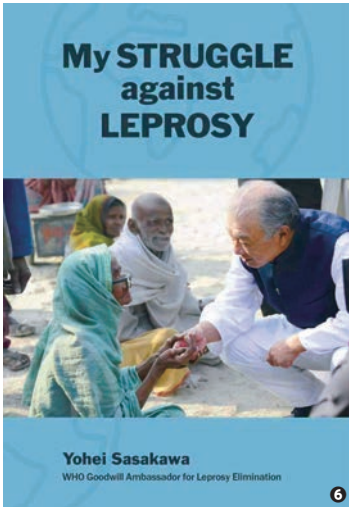
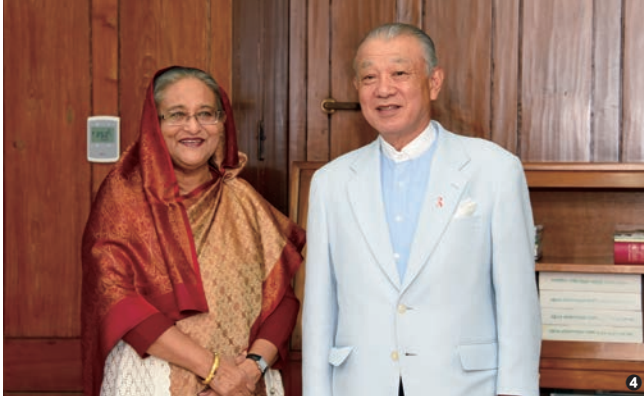
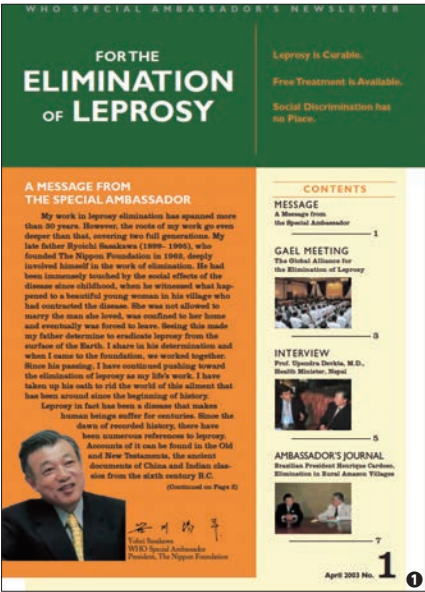


① At the 5th Forum 2000 conference in October 2001.  
② Yohei Sasakawa addressing the 5th Forum 2000 conference.  
③ Cristiano Torres (former chairman of MORHAN) speaking at the International Conference on Leprosy and Human Rights in Rio de Janeiro, Brazil, 2005.



# Publication of the WHO Goodwill Ambassador’s Newsletter Begins

In January 2001, then-President Yohei Sasakawa of The Nippon Foundation was inaugurated as the first Special—later, Goodwill—Ambassador for the Elimination of Leprosy, and drew attention for his energetic activities toward achieving the 2005 elimination target in each nation. The Sasakawa Health Foundation established a “Goodwill Ambassador’s Office” and in 2003 it began publishing the English-language “WHO Special Ambassador’s Newsletter for the Elimination of Leprosy” (later renamed the “WHO Goodwill Ambassador’s Newsletter for the Elimination of Leprosy”). Published bimonthly, each issue starts with a message from Ambassador Sasakawa. The newsletter is widely distributed to people affected by leprosy and government officials, media, NGOs and other stakeholders in 130 countries. In May 2019, the Goodwill Ambassador’s messages were compiled into the book *My Struggle against Leprosy*, which was published by the NPO Festina Lente.



- 12 The first and most recent issues of the Goodwill Ambassador's Newsletter.
- 3 The 3rd Global Alliance meeting is held in Yangon, Myanmar, in February. The Global Alliance is subsequently dissolved.
- 4 The Goodwill Ambassador meets with Prime Minister Hasina in Bangladesh in February 2019.
- 5 Visiting a leprosy-affected family in Amazonas.
- 6 *My Struggle against Leprosy*

# The Approach to the United Nations Commission on Human Rights and Statements by Persons Affected by Leprosy at the UN European Headquarters

The approaches to the United Nations regarding leprosy and human rights began in July 2003. An explanatory meeting was held together with the UN Acting High Commissioner for Human Rights, Dr. Bertrand Ramcharan, and the UN Special Rapporteur on Health and Human Rights, Professor Paul Hunt, for the secretariat staff members of the office of the High Commissioner for Human Rights. In addition, a photo exhibition and seminars featuring persons affected by leprosy and NGO representatives were held as a side project at the 55<sup>th</sup> UN Sub-Commission on the Promotion and Protection of Human Rights in the Palais des Nations (the United Nations' European Headquarters) in Geneva. At first, interest from the UN delegates was weak and little progress was made, but in March 2004, Yohei Sasakawa had the opportunity to speak at the 60th plenary session of the Human Rights Commission. This speech was the first public statement regarding leprosy and discrimination at a UN body. In August, Sasakawa invited 25 experts on the 56<sup>th</sup> UN Sub-Commission on the Promotion and Protection of Human Rights to lunch to explain the issue of leprosy and human rights to them directly. Thanks to these approaches, the Sub-Commission decided to formally investigate the issue of discrimination against persons affected by leprosy and their families.

On August 5, 2005, Chairman Sasakawa (who had ascended to that post in May) had another opportunity to address a plenary session of the 57<sup>th</sup> Sub-Commission on the Promotion and Protection of Human Rights. He made a quick decision to let four persons affected by leprosy from India, Ghana and Nepal, who had come along to the conference hall, each make a brief statement. As soon as they began to speak, the mood in the hall instantly changed and all eyes focused on them. It was the first time persons affected by leprosy had addressed a formal session of the United Nations. Later, a second Sub-Commission resolution was adopted that went one step further on the issue of “discrimination against persons affected by leprosy and their families” and immediately prohibited governments from such discrimination. It was also decided to let the Special Rapporteur continue with his investigation.



- 1 Yohei Sasakawa makes his presentation on leprosy and human rights before the Human Rights Sub-Commission, summer 2005.
- 2 Lunch meeting with members of the Human Rights Sub-Commission in Geneva, 2004.
- 3 Explanatory meeting at the UN Human Rights Commission, 2003.
- 4 Ms. Nevis Mary, a person affected by leprosy from India, at the 57th session of the UN Sub-Commission on the Promotion and Protection of Human Rights in Geneva, August 5, 2005.
- 5 UN Acting High Commissioner for Human Rights, Dr. Bertrand Ramcharan.



# The Formation of “National Forum,” a Nationwide Network of Persons Affected by Leprosy in India

On December 19, 2005, the first national conference organized by persons affected by leprosy calling for the elimination of discrimination and restoration of dignity and human rights was held in Delhi, India, and it was decided to form a nationwide network of persons affected by leprosy to be called the National Forum. (The organization was established in 2006, and in 2013 changed its name to the Association of People Affected by Leprosy, or APAL.) The conference was supported by The Nippon Foundation and the Sasakawa Health Foundation, and hosted by the Leprosy Colony Project Secretariat. APAL has continued to grow steadily since this first conference, and now persons affected by leprosy who had previously almost never left their colonies go to APAL meetings to exchange information, increase cooperation, and expand activities toward social and economic improvement.

APAL was incorporated on February 21, 2011, and in accordance with its statutes, its first board meeting was held the same day in Delhi. Dr. P.K. Gopal was elected chairman. The board also decided that the three themes of APAL’s activities should be “strengthening local organizations,” “fostering young leaders,” and “establishing pension plans for recoverers.”



❶ The first national conference organized by persons affected by leprosy in India. The decision to establish the “National Forum” (later renamed the Association of People Affected by Leprosy) was made at this conference.  
❷ Dr. P.K. Gopal, the first chairman of APAL.  
❸ Chairman Paulus Manek (right) and Vice Chairman Al Qadri (left) of PerMaTa, an Indonesian organization of persons affected by leprosy 2018.  
❹ The current chairman of APAL, Mr. Narsappa (right), and vice chairman, Mr. Venugopal (left), 2017

**The establishment of APAL**  
**December 2005** The decision is made to form the “National Forum.” The organization is established in 2006.  
**February 2011** Incorporation.  
**December 2013** The name is changed to APAL: Association of People Affected by Leprosy.

**Major organizations of persons affected by leprosy around the world**  
Japan: Zen-Ryo-Kyo (established in 1951)  
Brazil: MORHAN (1981)  
International: IDEA Int’l (1994)  
China: HANDA (1996)  
Ethiopia: ENAPAL (1996)  
Nepal: Association for IDEA Nepal (1998)  
Ghana: IDEA (2003)  
Angola: ARPAL (2004)  
India: APAL (formerly National Forum) (2005)  
Myanmar: Myitta Arr Marn (2005)  
Mozambique: ALEMO, AMPAL (2005)  
Indonesia: PerMaTa (2007)  
Philippines: CLAP (2012)  
[Others]  
Malaysia: Sungai Buloh Sanatorium Committee  
South Korea: HANVIT  
Colombia: Corsohansen

# India Achieves its Leprosy Elimination Target

India had the highest number of leprosy patients in the world, and it was expected to be very difficult to bring the situation under control. In June 2002, a conference was held in Tokyo, co-sponsored by The Nippon Foundation, the Sasakawa Health Foundation, and the WHO South-East Asia Regional Office (SEARO), to pursue leprosy elimination in India. The participants included delegates from the Indian government and NGOs working with leprosy in India, as well as the Danish International Development Agency. At the end of the conference, the “Tokyo Declaration” to eliminate leprosy in India by 2005 was adopted. In 2002, the prevalence in India was 3.8 cases per 10,000 population (according to WHO’s data). In January 2004, a “National conference on elimination of leprosy” was held in Raipur, India, which adopted the “Raipur Declaration” aimed at stepped-up initiatives toward leprosy control activities in India.

Then, at the end of 2005, India finally achieved the target of “less than one case per 10,000 population.” Announced on January 30, 2006, elimination in India was truly a historic event that many had thought impossible. After that, Madagascar, the Democratic Republic of Congo, Angola, Mozambique, Nepal and other countries where the control target had also been considered unachievable overcame many difficulties to eventually reach their targets as well, just like India.

**Toward leprosy control in India**  
**June 2002** Tokyo Declaration  
**January 2004** Raipur Declaration  
**India 2005** India reaches its elimination milestone. (Officially announced in January 2006.)



❶ World Leprosy Day, January 30, 2006. On this day, India announced that it had eliminated leprosy as a public health problem.  
❷ Leprosy colony in Bihar, India, 2010.  
❸ Hut belong to a person affected by leprosy, Tamil Nadu, India, 2010.  
❹ A man affected by leprosy with his son, Delhi, India, 2012.



# Leaders among the World’s Persons Affected by Leprosy



I was supported by my family even when I developed leprosy. That is very rare. In most cases, patients are abandoned by their families, or run away from home themselves in order not to inconvenience their families. Now I am focusing on educational support. The generation of children of persons affected by leprosy is very important. Unless they are able to receive proper education and become independent, we will face yet another round of discrimination.  
**P.K. Gopal** (India)



I have been a beggar myself. I have also lived naked for months. But the situation for people affected by leprosy is changing little by little even in India. A world without beggars is no longer just a dream. The UN’s “Principles and Guidelines for the Elimination of Discrimination” gave me great strength. However, many people affected by leprosy still don’t understand the idea of human rights. A lot of effort is still necessary to make them feel that they too have human rights.  
**Vagavathali Narsappa** (India)



I developed leprosy and met a missionary group at the hospital and started living with them, but the missionaries used my photo to collect donations. I hated it that they used me to collect money, and ridiculed my dream to get married and have a family. That is when I rebelled. Since then, I have trusted my own will. I rode around on my bicycle encouraging other people affected by leprosy. I was also able to have a family. Whether we can overcome discrimination and stigma is up to us people affected by leprosy ourselves. If we can change, the world will change too.  
**Kofi Nyarko** (Ghana)



The devil of prejudice is lurking everywhere. The people who listen to my talk may say that “prejudice and discrimination are inexcusable,” but how many of them would give their blessings if they learned that their daughter was about to marry a man whose father has leprosy?  
**Yasuji Hirasawa** (Japan)



When my diagnosis was announced, my mother, who had little medical knowledge, believed that it was a punishment from God. While crying, she confessed that “this disease is my fault, the punishment for all the sins I have committed.” My mother went on to live with that pain for 36 years, but when I told her the words of Pope John Paul II, “All leprosy patients are my brothers,” she replied, “Finally I can die with a clean soul.”  
**José Ramirez, Jr.** (U.S.A.)



The most important thing in my life is to be involved with the movement and struggle to help people with leprosy and disabilities and secure them a place to live. We have such rights too, of course. Equality and liberty free from prejudice and discrimination, rights and obligations are exactly the same for us as for other citizens.  
**Valdenora da Cruz Rodrigues** (Brazil)



One day, a man with leprosy came to our village. He got a little food and as he was looking for a place to sit down and eat it, he came to my hut. I had been ostracized from the village, and the moment he saw me he realized that I also had leprosy and asked me what medicines I was taking. Until then, I had no idea that there was a treatment for leprosy.  
**Ramavarai Sah** (India)



The status of Ethiopian women is not very high, neither in society nor in the family. Most people with leprosy marry another person with the same disease, but the women in such families are weak. The men go out to work and bring home money, so their standing in the family is high, while women have little say. Therefore, I taught women embroidery and sewing to improve their status. Women who bring home some income have a greater influence in their families.  
**Birke Nigatu** (Ethiopia)



Through PerMaTa, I want to make sure that people don’t have to go through the same things that I did. I’ve experienced discrimination and isolation. Now I am able to help other persons affected by leprosy and give them opportunities to lead a normal life. What we need is a change in society’s mindset. I have some small residual disability as a result of leprosy, but it’s not a problem. I could have had my fingers straightened, but I keep them this way as evidence that I once had leprosy. The problem is social stigma, and the fact that people think leprosy is a curse, or that it’s very contagious.  
**Paulus Manek** (Indonesia)



## The First “Global Appeal” Is Launched in Delhi

The first “Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy” was broadcast to the world from the India Habitat Centre in Delhi on January 29, 2006, World Leprosy Day, which is observed on the final Sunday in January every year. It was signed by former U.S. President Jimmy Carter, the Dalai Lama, Desmond Tutu, Oscar Arias, Elie Wiesel, Luis Inácio Lula da Silva (Brazil’s president at the time) and several other world leaders and Nobel Prize laureates who had answered Yohei Sasakawa’s call. The Nippon Foundation-sponsored “Global Appeal” is aimed at making the reality facing people affected by leprosy better known to the world and lending a helping hand of support. Endorsed by different individuals and organizations each year, the Global Appeal has been consistent in its call for an end to discrimination and the formation of a truly inclusive society where the human rights of each member of society are respected.



①② The First Global Appeal announced from Delhi, India.  
③ Text of the first Global Appeal.

### 2006

**January** The First Global Appeal is announced from Delhi.

**January** Conference on the global history of leprosy held in England.

**May** 100<sup>th</sup> anniversary of founding of the former Culion Leper Colony.

**October** Workshop on health issue-related stigma and discrimination held in Turkey.

### GLOBAL APPEAL TO END STIGMA AND DISCRIMINATION AGAINST PEOPLE AFFECTED BY LEPROSY

Leprosy is among the world's oldest and most dreaded diseases. Without an effective remedy for much of its long history, it often resulted in terrible deformity. It was also thought to be extremely communicable. Patients were abandoned, forced to live in isolation and discrimination against as social outcasts.

In the early 1980s, an effective cure for leprosy became available. Multidrug therapy has successfully treated over 14 million people to date. Contrary to popular belief, leprosy is extremely difficult to contract. With prompt diagnosis and treatment, it can be medically cured within 6 to 12 months without risk of deformity.

Yet fear of leprosy remains deep-rooted. Misguided notions endure — that it is “highly contagious,” “incurable” and “hereditary.” Some even regard it as “a divine punishment.”

Ignorance and misunderstanding result in prejudice and discriminatory attitudes that remain firmly implanted as customs and traditions.

Consequently, patients, cured persons and their entire families suffer stigma and discrimination. This limits their opportunities for education, employment and marriage, and restricts their access to public services.

Fearful that by speaking out they will invite further discrimination, for long years people affected by leprosy, including their families, have been forced into silence. Such silence reinforces the stigma that surrounds them.

The world has remained indifferent to their plight for too long.

Article 1 of the Universal Declaration of Human Rights states that “All human beings are born free and equal in dignity and human rights.” This article, however, is meaningless to people affected by leprosy, who continue to suffer discrimination.

We appeal to the UN Commission on Human Rights to take up this matter as an item on its agenda, and request that it issue principles and guidelines for governments to follow in eliminating all discrimination against people affected by leprosy.

We further urge governments themselves to seriously consider this issue and act to improve the present situation with a sense of urgency.

Finally, we call on people all over the world to change their perception and foster an environment in which leprosy patients, cured persons and their families can lead normal lives free from stigma and discrimination.

January 29, 2006

Oscar Arias  
Former President of Costa Rica  
Nobel Peace Prize Laureate

Jimmy Carter  
Former President of the United States of America  
Nobel Peace Prize Laureate

The Dalai Lama  
Nobel Peace Prize Laureate

El Hassan bin Talal  
Prince of the Jordanian Hashemite Royal Dynasty

Václav Havel  
Former President of the Czech Republic

Lula Inácio Lula da Silva  
President of the Federative Republic of Brazil

Olasengun Oluwalanle  
President of the Federal Republic of Nigeria

Mary Robinson  
Former President of Ireland  
Former UN High Commissioner for Human Rights

R. Venkataratnam  
Former President of India

Elie Wiesel  
President, The Elie Wiesel Foundation for Humanity  
Nobel Peace Prize Laureate

Contact The Nippon Foundation (<http://www.nipponfoundation.org>) or Tel 81-3-6271-1600 for more information.

## The Establishment of the Sasakawa-India Leprosy Foundation (S-ILF)

At the first Global Appeal ceremony in Delhi, plans were announced to establish a fund and raise money in Japan and India to help people affected by leprosy in India become self-reliant. The Nippon Foundation contributed 1 billion yen as the initial fund, but calls for support were also made to the Confederation of Indian Industries (CII), the Chamber of Commerce and Industry and other economic organizations, as well as NGOs, academic associations and the media. The Sasakawa-India Leprosy Foundation (S-ILF) was established according to these plans in November 2006. As for its purpose, the following three projects were mentioned: to provide a place for vocational training for people affected by leprosy, and promote their employment with the cooperation of the Indian business community; to establish a microfinance system to support women affected by leprosy and families who are suffering from poverty to acquire skills such as embroidery or handicrafts so that they can make a living; and to overcome the current state of affairs, where persons affected by leprosy or their children are unable to go to school due to poverty or discrimination, and create an environment that enables them to attend regular schools with ordinary children through scholarships and the like.

### S-ILF microfinancing

One of the major features of S-ILF's wide-ranging activities is the “livelihood project” microfinancing system. The loan amount is 23,500 - 309,000 rupees (approx. 45,000 - 600,000 yen) per group. When the business is successful, the loan is not repaid to S-ILF but collected by the colony to create new opportunities for other colony members to work.

### OUR PROGRAMMES



#### LIVELIHOODS

S-ILF is working to change the lives of the leprosy-affected by empowering them to build sustainable livelihood. Our Livelihood program is designed to enable people to free themselves from the generational cycle of...

[Read more](#)



#### EDUCATION

Enhancing skills for employment S-ILF is currently running 03 projects under its STEP UP education and skill development program for children from Leprosy affected families in India. S-ILF is running programs on education in 11 states of India...

[Read more](#)



#### AWARENESS & ADVOCACY

Opening minds fighting stigma Though easily treatable, leprosy still strikes fear in a country like India. Lack of knowledge about the disease has led to the perpetration of...

[Read more](#)



#### SPECIAL PROGRAMMES

Tribal Empowerment Program It is a fact that, all affected people & their family members have confronted terrific shock of stigma associated discrimination for an elongated duration...

[Read more](#)



#### FILMS

S-ILF has engaged in producing and sponsoring films on leprosy to disseminate information about its program and leprosy related issues. Films have been a strong tool in fighting stigma and breaking myths about leprosy...

[Know more](#)



#### EVENTS

Youth Against Leprosy (YAL) Youth are effective harbingers of change in social attitudes and behaviours, not only as future leaders of the country but also as public awareness campaigns...

[Read more](#)



① From the S-ILF website.  
② S-ILF logo.  
③ Candy shop opened with a small loan from S-ILF at a colony in Tamil Nadu, 2010  
④ S-ILF goat breeding project at the Jay Durga leprosy colony in Uttar Pradesh, 2013.  
⑤ S-ILF staff, 2016.



“Global Appeal” 2006–2020



**2006** First Global Appeal Delhi, India  
With 12 world leaders and Nobel Peace Prize laureates, including the 14th Dalai Lama, former U.S. President Jimmy Carter, Archbishop Desmond Tutu, Elie Wiesel and Oscar Arias.



**2007** Second Global Appeal Manila, the Philippines  
With people affected by leprosy from 13 countries around the world.



**2008** Third Global Appeal London, UK  
With nine major international human rights organizations, such as Amnesty International and Save the Children.



**2009** Fourth Global Appeal London, UK  
With 17 leaders of the world’s main religious faiths.



**2010** Fifth Global Appeal Mumbai, India  
With 15 top executives from world-leading companies, including Toyota, Virgin Management, Tata Group, Johnson & Johnson, Renault and Novartis.



**2011** Sixth Global Appeal Beijing, China  
With the heads of 110 leading universities in 64 countries.



**2012** Seventh Global Appeal São Paulo, Brazil  
With members of the World Medical Association and medical associations of 50 countries.



**2013** Eighth Global Appeal London, UK  
With members of the International Bar Association and 46 bar associations in 40 countries and 1 region.



**2014** Ninth Global Appeal Jakarta, Indonesia  
With national human rights institutions from 37 countries and 2 regions.



**2015** Tenth Global Appeal Tokyo, Japan  
With the International Council of Nurses and 132 national bodies.



**2016** Eleventh Global Appeal Tokyo, Japan  
With Junior Chamber International and its branches in 117 countries.



**2017** Twelfth Global Appeal New Delhi, India  
With IPU, the Inter-Parliamentary Union of 171 parliaments around the world.



**2018** Thirteenth Global Appeal New Delhi, India  
With 90 national member assemblies of Disabled Peoples’ International (DPI).



**2019** Fourteenth Global Appeal New Delhi, India  
With the International Chamber of Commerce, a business organization with a global network of 45 million companies in over 100 countries.



**2020** Fifteenth Global Appeal Tokyo, Japan  
With IPC, the International Paralympic Committee.

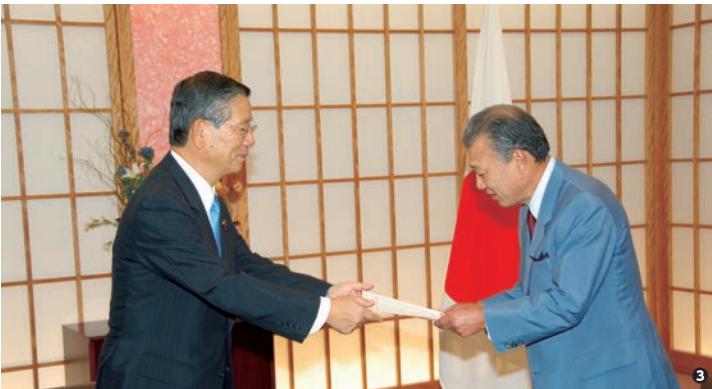


# Yohei Sasakawa Is Appointed “Japanese Government Goodwill Ambassador for the Human Rights of Persons Affected by Leprosy”

Our initial approach to the United Nations in July 2003 bore fruit when persons affected by leprosy themselves were able to speak before the UN Sub-Commission on the Promotion and Protection of Human Rights in August 2005. In 2006, however, the Human Rights Commission was dissolved and replaced by the Human Rights Council, and the Sub-Commission on the Promotion and Protection of Human Rights was abolished. The commission members, who had just recently shown understanding for our cause and issued a request to the new Human Rights Council to continue deliberations on ending discrimination, went their separate ways, while at the same time the new organization strengthened the powers of government representatives and weakened the voices of NGOs. Therefore, The Nippon Foundation decided to work with the Japanese Ministry of Foreign Affairs to address the issue. The Japanese government showed a consistent attitude of cooperation with us during the process of reorganizing the Human Rights Commission into the Human Rights Council, and eventually “Leprosy and Human Rights” was taken up as the second item on the Human Rights Council’s agenda, after the “Declaration of the Rights of Indigenous Peoples.” In 2007, the Japanese government resolved to make “the appeal to the international community to abolish discrimination towards leprosy” one of the pillars of Japan’s foreign diplomacy. As one of the central figures in these activities, Chairman Yohei Sasakawa of The Nippon Foundation was appointed “Japanese Government Goodwill Ambassador for the Human Rights of Persons Affected by Leprosy.” In active support of these efforts, Ichiro Fujisaki, the then Ambassador of the Permanent Mission of Japan to the United Nations in Geneva (and former Ambassador to the United States), renewed the request that the issue of “Leprosy and Human Rights” be taken up at the plenary session of the Human Rights Council. In this way, thanks to the cooperation of the Japanese Ministry of Foreign Affairs, our activities at the United Nations became better organized than ever.



① Yohei Sasakawa meets President Costea of the UN Human Rights Council in Geneva, 2008.  
② International conference related to the UN Human Rights Council's leprosy resolution in Geneva in January 2009, sponsored by The Nippon Foundation.  
③ On September 21, 2007, Chairman Sasakawa was handed a letter appointing him as Japan's Ambassador for the Human Rights of Persons Affected by Leprosy by the Minister of Foreign Affairs, Nobutaka Machimura.



# The United Nations General Assembly Adopts a Resolution to Eliminate Leprosy Discrimination

On June 18, 2008, at the 8th Session of the Human Rights Council held in the large hall at the United Nations’ European headquarters in Geneva, the Japanese government’s proposal on “elimination of discrimination against persons affected by leprosy and their family members” was unanimously adopted, co-sponsored by 59 countries. The co-sponsoring countries included Cuba and China, which were said to always oppose any proposition by the Japanese government. Then, in September 2010, the 15th Session of the Human Rights Council unanimously adopted a resolution to eliminate leprosy discrimination, accompanied by a set of “Principles and Guidelines.” Finally, on December 21 the same year, the resolution submitted by the Japanese government to the United Nations General Assembly on “elimination of discrimination against persons affected by leprosy and their family members,” and accompanying Principles and Guidelines calling for the elimination of discriminatory laws against persons affected by leprosy and concrete actions in each country, was co-sponsored by 84 countries and unanimously adopted by the 192 member countries of the United Nations. To date, the UN Human Rights Council has adopted five resolutions on leprosy (2008, 2009, 2010, 2015 and 2017).

## Principles

- 1—Persons affected by leprosy and their family members should be treated as people with dignity and are entitled, on an equal basis with others, to all the human rights and fundamental freedoms proclaimed in the Universal Declaration of Human Rights, as well as in other relevant international human rights instruments to which their respective States are parties, including the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, and the Convention on the Rights of Persons with Disabilities.
- 2—Persons affected by leprosy and their family members should not be discriminated against on the grounds of having or having had leprosy.
- 3—Persons affected by leprosy and their family members should have the same rights as everyone else with respect to marriage, family and parenthood. To this end:  
a—No one should be denied the right to marry on the grounds of leprosy;  
b—Leprosy should not constitute a ground for divorce;  
c—A child should not be separated from his or her parents on the grounds of leprosy.
- 4—Persons affected by leprosy and their family members should have the same rights as everyone else in relation to full citizenship and obtaining identity documents.
- 5—Persons affected by leprosy and their family members should have the right to serve the public, on an equal basis with others, including the right to stand for elections and to hold office at all levels of government.
- 6—Persons affected by leprosy and their family members should have the right to work in an environment that is inclusive and to be treated on an equal basis with others in all policies and processes related to recruitment, hiring, promotion, salary, continuance of employment and career advancement.
- 7—Persons affected by leprosy and their family members should not be denied admission to or be expelled from schools or training programmes on the grounds of leprosy.
- 8—Persons affected by leprosy and their family members are entitled to develop their human potential to the fullest extent, and to fully realize their dignity and self-worth. Persons affected by leprosy and their family members who have been empowered and who have had the opportunity to develop their abilities can be powerful agents of social change.
- 9—Persons affected by leprosy and their family members have the right to be, and should be, actively involved in decision-making processes regarding policies and programmes that directly concern their lives.

## 2008

**January** The 17<sup>th</sup> International Leprosy Congress is held in India. The Anandaban Leprosy Hospital in Nepal celebrates its 50th anniversary.  
**June** The UN Human Rights Council adopts a resolution to “eliminate stigma and discrimination against people affected by leprosy and their family members.”  
**September** An “Indian Human Rights Conference” is held in Delhi.  
**October** The Nippon Foundation and the Sasakawa Health Foundation receive the Damien-Dutton Award for their large contribution toward the elimination of leprosy.  
**November** Yohei Sasakawa publishes the book *Ningen to shite ikite hoshii – Watashi ga mita sekai no genba* (“I Want You to Live as Human Beings – The conditions of the world as I have seen them”; Kairyusha).

## 2010

**January** Yohei Sasakawa publishes the book *Fukano wo kano ni: sekai no Hansen-byo to no tatakai* (“Making the Impossible Possible – The Fight against Leprosy in the World”; Akashi shoten).  
**September** The UN Human Rights Council passes a resolution to eliminate leprosy discrimination.  
**December** The UN General Assembly adopts a set of “Principles and Guidelines” on “elimination of discrimination against persons affected by leprosy and their family members.”



① The UN Palais des Nations in Geneva.  
② In 2008, the International Leprosy Congress was held in Hyderabad, India, with over 1200 participants, including representatives from health ministries, WHO, doctors and health workers.



# Regional Symposiums on Leprosy and Human Rights

Since 2011, the only country with a population of over 1 million that has yet to eliminate leprosy as a public health problem is Brazil. But even in countries that have reached this milestone, persons affected by leprosy still suffer severe discrimination. The fact that the United Nations Human Rights Council or the General Assembly passed resolutions doesn't mean that stigma and discrimination against people affected by leprosy or their families vanished overnight. It was necessary to make as many people as possible aware of the “Principles and Guidelines” accompanying the UN resolution to eliminate discrimination. To publicize them around the world, The Nippon Foundation organized international symposiums on leprosy and human rights held in Rio de Janeiro, Brazil (2012), New Delhi, India (2012), Addis Ababa, Ethiopia (2013), Rabat, Morocco (2014), and Geneva, Switzerland (2015). At the final conference, a follow-up report on the United Nations resolution and proposals for an action plan were presented, based on the discussions at the previous symposiums.



1 1st Symposium, Rio de Janeiro, Brazil, 2012.  
2 2nd Symposium, Delhi, India, 2012.  
3 3rd Symposium, Addis Ababa, Ethiopia, 2013.  
4 4th Symposium, Rabat, Morocco, 2014.  
5 5th Symposium, Geneva, Switzerland, 2015.



## Regional Symposiums on leprosy and human rights

**January 2012** Rio de Janeiro, Brazil.  
**October 2012** New Delhi, India.  
**September 2013** Addis Ababa, Ethiopia.  
**October 2014** Rabat, Morocco.  
**June 2015** Geneva, Switzerland.

## Abolition and revision of discriminatory laws

Since 2011, the following laws discriminating on the grounds of leprosy have been abolished or revised. Particularly in India, where many discriminatory laws relating to leprosy still remain, the abolition or revision of 12 laws was a major achievement.

**China** Marriage Law, 1980→abolished 2011  
**India** Juvenile Justice, Care and Protection Act, 2000→revised 2011  
**India** The Lepers Act, 1898→abolished 2016  
**India** The Odisha Zilla Parishad Act, 1991→revised 2016  
**India** The Odisha Gram Panchayats Act, 1964→revised 2016  
**India** The Odisha Act, 1959→revised 2016  
**India** The Rajasthan Panchayati Act, 1994→revised 2018  
**India** The Bombay Prevention of Begging Act, 1959→revised 2018  
**India** The Dissolution of Muslim Marriage Act, 1939→revised 2019  
**India** The Special Marriage Act, 1954 →revised 2019  
**India** The Hindu Marriage act, 1955 →revised 2019  
**India** The Hindu Adoptions and Maintenance Act→revised 2019  
**India** The Divorce Act, 1869→revised 2019

# Preserving the History of Leprosy

In October 2012, an International Workshop on the Preservation of Leprosy History and Heritage took place in Tokyo. The Nippon Foundation and the Sasakawa Health Foundation had already been involved with efforts to preserve the history of leprosy through recording the life histories of persons who had experienced the disease and supporting the conservation of facilities and sanatoriums as historical sites. Overseas, the foundations supported the preservation of the history of Culion Island in the Philippines and the rebuilding of its museum and archives in 2004. In 2018, the Culion Leprosy Archives were inscribed in the UNESCO Memory of the World Regional Register for Asia/Pacific. In Japan, the foundations support the preservation of materials at Nagashima Aiseien sanatorium in Okayama Prefecture. In all parts of the world, leprosy patients have been forced to live under harsh conditions and been subject to discrimination. No coherent records remain for many places, but there are still living witnesses to their history and traces of the sites and materials. Even among persons affected by leprosy and their supporters there are those who think that in order to build a new future it is necessary to turn the “negative” history of leprosy into “something that never happened.” However, discrimination is very much a part of both human history and our current reality. To confront the temptation to discriminate that can sprout in anyone’s mind, it is our responsibility and mission to first of all clarify our own history. Furthermore, the history of leprosy is not only a negative one; it is also the history of people powerfully alive in the midst of discrimination and despair.



1 The Culion Museum and Archives in the Philippines.  
2 Diorama at the Nagashima Aiseien History Museum, Okayama Prefecture. Shown here is a cliff where many interned patients tried to take their own life.  
3 As yet unsorted documents at the Medical Museum of Leprosy in Agua de Dios, Colombia.  
4 Exhibition at the National Hansen's Disease Museum in Carville, USA.

## Historical preservation

Five international workshops and symposiums on leprosy history and heritage were held between 2012 and 2017.

## 2011

**April 1** The Japan Shipbuilding Industry Foundation officially changes its name to The Nippon Foundation, as a recognized public interest corporation.

## 2012

**October** The 1st Workshop on the Preservation of Leprosy History is held in Okayama.



# Major Leprosy Sanatoriums and Islands around the world where Patients were Isolated



- 1

Rovisco Pais, Portugal
- 2

Umbaki, Azerbaijan
- 3

Jerusalem, Israel
- 4

Uzuakoli, Nigeria
- 5

Sitanala Hospital, Indonesia
- 6

Si'an, China
- 7

Culion Island, Philippines
- 8

Sungai Buloh, Malaysia
- 9

Kalaupapa, Hawaii, USA
- 10

Carville, USA
- 11

Agua de Dios, Colombia
- 12

Asilo-Colônia Aimorés, Brazil
- 13

Saaremaa Island, Estonia
- 14

Pulau Jerejak, Malaysia
- 15

Chacachacare Island, Trinidad and Tobago
- 16

Spinalonga Island, Greece
- 17

D'Arcy Island, Canada
- 18

Île Désirée, Ivory Coast
- 19

Peel Island, Australia
- 20

Hei Ling Chau Island, Hong Kong, China
- 21

Penikese Island, USA
- 22

Makogai Island, Fiji
- 23

McKean Rehabilitation Center, Chiang Mai, Thailand
- 24

Moloka'i Island, USA
- 25

Robben Island, South Africa
- 26

Sorokdo, South Korea
- 27

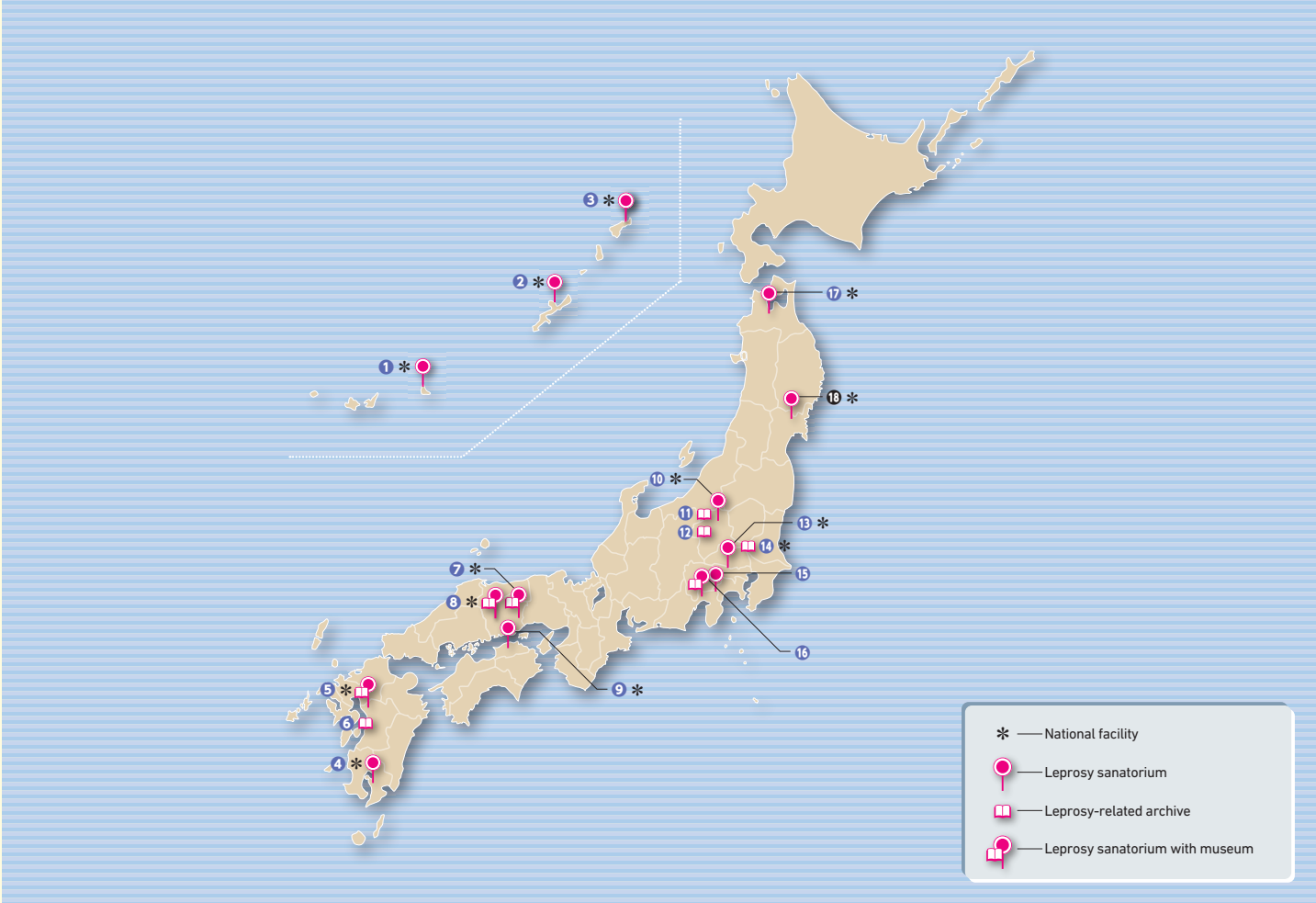
Daqin Island (Tai Kam Island), China
- 28

Acworth Leprosy Hospital, India
- 29

Anandvan Leprosarium, India
- 30

Schieffelin Leprosy Research and Training Centre (Karigiri), India

# Leprosy Sanatoriums and Archives in Japan



- 1

Miyako Nanseien (Okinawa Prefecture)
- 2

Okinawa Airakuen (Okinawa Prefecture)
- 3

Amami Wakoen (Kagoshima Prefecture)
- 4

Hoshizuka Keiaien (Kagoshima Prefecture)
- 5

Kikuchi Keifuen (Kumamoto Prefecture)
- 6

Riddell-Wright Memorial Hall (Kumamoto Prefecture)
- 7

Nagashima Aiseien (Okayama Prefecture)
- 8

Oku-Komyo-En (Okayama Prefecture)
- 9

Oshima Seishoen (Kagawa Prefecture)
- 10

Kuryu Rakusen-en (Gunma Prefecture)
- 11

Jyu-kanbo National Museum of Detention for Hansen's Disease Patients (Gunma Prefecture)
- 12

Lekh Kasama Memorial Hall (Gunma Prefecture)
- 13

Tama Zenshoen (Tokyo)
- 14

National Hansen's Disease Museum (Tokyo)
- 15

National Sanatorium Suruga (Shizuoka Prefecture)
- 16

Koyama Fukusei Hospital & Memorial Hall (Shizuoka Prefecture)
- 17

Matsuoka Hoyoen (Aomori Prefecture)
- 18

Tohoku Shinseien (Miyagi Prefecture)



# The “Bangkok Declaration” toward Further Progress in Leprosy Control Activities

The achievement of the elimination target in India and several other countries created a sense of accomplishment and relief concerning the fight against leprosy around the world, and a slackening off in control activities began to be seen. Government awareness of treatment activities declined in many countries, budgets were reduced, and the annual number of newly discovered cases worldwide varied between 200,000 and 250,000. A proportion of patients already have disabilities due to late detection, and the number of new cases among children remains a concern. In some countries where leprosy is endemic, there are still many “hot spots” with extremely high prevalence in areas that are difficult to access, and some estimates put the number of undetected cases in the world as high as 3 million. In order to rise above this situation, The Nippon Foundation and WHO co-sponsored an International Leprosy Summit in Bangkok in July 2013, and invited Ministers of Health or their deputies from 17 countries where leprosy is prevalent. The meeting resulted in the Bangkok Declaration, aimed to promote and invigorate further activities against the disease. The Nippon Foundation announced that it was ready to provide a total of 20 million dollars over a five-year period from 2014 to tackle leprosy, including a fund for special initiatives to improve early case detection.

Renewed efforts at case detection can lead to a temporary increase in the prevalence rate. While this can be a source of discomfort for countries, in the long run it will help bring the number of cases down by detecting and treating sources of transmission. Countries such as India and Indonesia are now redoubling their efforts to detect new cases.



① Discussion at the International Leprosy Summit in Bangkok.  
② Members of the Indian ASHA project with Yohei Sasakawa, 2017.  
③ Dancing and singing the song “Let’s find patches” (about early symptoms of leprosy). An educational campaign in Indonesia, 2016.

**Efforts in India and Indonesia**  
India has been conducting Leprosy Case Detection Campaigns (LCDC) in each state since 2016, and has achieved great results. Grassroots activities in the form of door-to-door visits by government-appointed ASHA female health volunteers to discover patients are now well established.  
In Indonesia, songs and dances that enlighten people about leprosy and lead to early detection are broadcast on TV. To overcome the situation where people don’t want to go to the hospital because they are afraid to be seen by their neighbors, health centers conduct campaigns targeting skin diseases in general, not just leprosy, to remove the psychological barriers to medical examination. This method has proven successful in discovering new patients, and is now being implemented in other countries as well.

**2013**  
**July** The International Leprosy Summit is held in Bangkok, Thailand.

**2014**  
**March** The Dalai Lama visits the Tahirpur Leprosy Colony in India.  
**May** Yohei Sasakawa publishes the book *Zanshin: Sekai no Hansen-byo wo seiatsu suru* (Togensha), an autobiographical account of his activities to fight leprosy. (Published in English in 2019 as *No Matter Where the Journey Takes Me: One Man’s Quest for a Leprosy-Free World*.)  
**November** The Dalai Lama-Sasakawa Scholarship is established.

# An International Symposium on Leprosy and Discrimination Held at the Vatican

Pope Francis is actively working on reforming the Vatican, and his unaffected manner has endeared him to many among the faithful. However, in a lecture in 2013 he inadvertently used the expression “careerism is a leprosy” to criticize excessive personal ambition among the clergy. In consideration of the enormous influence of the Pope and his “slip of the tongue,” The Nippon Foundation sent him a letter of protest, but unfortunately it may never have been seen by him since he subsequently made several similar remarks, such as “the papal court is the leprosy of the papacy” and “pedophilia is a leprosy in our house [the Catholic Church].” In order to stop “leprosy” being used as a negative metaphor and end the use of the discriminatory term “leper,” The Nippon Foundation proposed holding an international, interfaith symposium on “Leprosy and Discrimination” in cooperation with the Vatican. In 2015, the Pope had an opportunity to meet with persons affected by leprosy from Brazil, where he assured them that he and the clergy would avoid using the discriminatory word “leper” in future. The international symposium took place at the Vatican in June 2016. The “Conclusions and Recommendations” approved at the end of the symposium started with the sentence “Every new case of Hansen’s disease is one too many.” The declaration also recommended refraining from the use of discriminatory words like “leper” and the use of “leprosy” as a metaphor, and stated that “the leaders of all religions—and this is an important and urgent matter—should, in their teachings, writings and speeches, contribute to the elimination of discrimination against persons affected by leprosy by spreading awareness that leprosy is curable and stressing that there is no reason to discriminate against anyone affected by leprosy or members of their families.”

**Unconscious discrimination**  
Discriminatory terminology such as “leper” is still found in media coverage of leprosy, and The Nippon Foundation and other organizations have repeatedly appealed for such usage to be avoided. In recent years news organizations have become more sensitive to how persons affected by leprosy are represented and have guidelines on how those affected by diseases, disabling conditions and health impairments are portrayed. Meanwhile, “leprosy” continues to be used as a metaphor for social or other ills. While the people using language in this way may not be doing so with malicious intent, for persons affected by leprosy, this usage, along with that of the pejorative term “leper,” causes pain and anguish and helps to perpetuate the stigma surrounding the disease.

**2016**  
**February** The book *Hansen’s Disease, Japan and the World* is published by Kousakusha, based on a project by The Nippon Foundation.

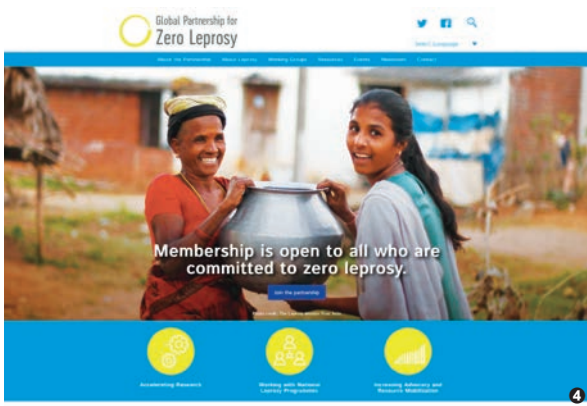


① Valdenora da Cruz Rodriguez, a person affected by leprosy, meets Pope Francis at the Vatican in June 2015.  
② Nuns participating in the Vatican symposium.  
③ Commemorative photo of participants of the Vatican symposium.  
④ Yohei Sasakawa delivers a message to the Pope at St. Peter’s square.



# Solving Both Social and Medical Issues

The circumstances around leprosy have changed dramatically in the world thanks to the introduction and free provision of MDT, as well as the UN human rights resolution. However, Brazil is a major country that has yet to reach the elimination milestone, and even among the countries that have reached their targets, there are still so-called hot spots with many cases and areas where surveys have yet to be carried out. Even now, approximately 200,000 new cases are still reported worldwide every year. These include children and persons with visible disabilities. A lot more time and effort will be required to solve the problem of discrimination against people affected by leprosy and to restore their dignity. The Nippon Foundation and Sasakawa Health Foundation uses the symbolic metaphor of a motorcycle: the front wheel represents efforts to cure the disease and the back wheel the fight against discrimination, and both must turn at the same time in order to move ahead. Ever stronger efforts are being made to solve these issues internationally as well. In 2017, Ms. Alice Cruz of Portugal was appointed UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members. In 2018, ILEP (the International Federation of Anti-Leprosy Associations), the Novartis Foundation, Sasakawa Health Foundation, WHO and other organizations and people working with leprosy formed the Global Partnership for Zero Leprosy. New initiatives toward a leprosy-free world are under way.



## 2017

Yohei Sasakawa begins a column on the American news site HuffPost in his capacity as Goodwill Ambassador for the Elimination of Leprosy. The columns are first published in English, and later translated into Japanese. In 2018, some of the columns are collected in the book *Leprosy in Our Time*.

**April** Yohei Sasakawa is awarded the WHO Gold Medal.

**September** Ms. Alice Cruz, is appointed UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy by the UN Human Rights Council.

**December** The book *Shukumei no senki: Yohei Sasakawa Hansen-byo seitsu no kiroku* ("My Life's Work: Yohei Sasakawa, the Battle against Leprosy") by Fumihiko Takayama is published by Shogakukan.

The documentary movie *The Last Mile*, about the activities of The Nippon Foundation and the Goodwill Ambassador, is completed.

## 2018

**January** The Global Partnership for Zero Leprosy is launched.

**April** The Nippon Foundation and the Sasakawa Health Foundation establish a joint program office to integrate their leprosy programs.

**December** A national leprosy conference is held in Myanmar.

① A three-dimensional model of the "motorcycle metaphor" created by young people in India, 2018. The front wheel represents treating the disease, and the rear wheel represents addressing human rights issues. Both must turn together in order for the motorcycle to move forward.

② High school students taking part in the "Spash" leprosy awareness campaign. Rangghar, India, 2018.

③ Ms. Alice Cruz, UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy, and Yohei Sasakawa, 2018.

④ Global Partnership for Zero Leprosy website.

# Yohei Sasakawa Receives the WHO Gold Medal and the Gandhi Peace Award

In April 2017, the Global Partners Meeting on Neglected Tropical Diseases (NTDs) was hosted by WHO in Geneva, Switzerland, attended by Bill Gates and former UN Secretary-General Kofi Annan, among others. At the meeting, Chairman Yohei Sasakawa of The Nippon Foundation was praised for his contribution to leprosy control and was awarded the WHO Gold Medal by Director-General Margaret Chan.

In 2018, Chairman Sasakawa received the internationally prestigious Gandhi Peace Award for his leprosy work over many years. The award is named after Mahatma Gandhi, the father of Indian independence, and is presented by the Indian government to individuals or organizations who have made major contributions to world peace and development. Previous recipients include the former president of South Africa and Nobel Peace Prize laureate Nelson Mandela. The award ceremony took place in February 2019 in the Indian capital of New Delhi.

## 2019

Regional meetings of persons affected by leprosy (in Asia, Africa, South America/Caribbean) are held

**February** Yohei Sasakawa receives the Gandhi Peace Award from the Indian government.

**May** A selection of Yohei Sasakawa's messages from the "Goodwill Ambassador's Newsletter" are published in English as *My Struggle against Leprosy* by the NPO Festina Lente.

Chairman Sasakawa is awarded the Grand Cordon of the Rising Sun.

**July** A substantially revised version of *Zanshin* is published in English under the title *No Matter Where the Journey Takes Me: One Man's Quest for a Leprosy-Free World* (Hurst & Co Ltd).

**September** An international conference of people's organizations on Hansen's disease is held in the Philippines.

**October** Yohei Sasakawa is selected as a Person of Cultural Merit.

**December** A national conference on leprosy is held in Bangladesh.



① Yohei Sasakawa receives the Gandhi Peace Award from President Kovind (right), 2019. In the center is Prime Minister Modi.

② Yohei Sasakawa receives the WHO Gold Medal from Director-General Chan, 2017.

③ The Gandhi Peace Award ceremony.

④ The WHO Gold Medal bears the inscription "HEALTH FOR ALL" on the back.



Our Lives, Our Voices



“I left home so my brothers and sisters wouldn’t face any consequences.”  
**Ganesh Prasad**, 45, worked as a day laborer. He eventually got a job at a government warehouse but had to leave because he couldn’t carry the sacks. Asked to describe what leprosy means to him, he replied, “Helplessness.”  
Nav Nirman Kushth Ashram, Allahabad, UP, India.



“When I was a kid, I said I was going to become a boy soldier in the air force. But that dream was cut short. When I entered the sanatorium they told me I would be able to go home in three years at the most, but I’ve ended up spending almost 70 years here. There was a time when I resented my mother for bringing me into this life, but everybody here helped me to get over it. The biggest relief was the abolition of the Leprosy Prevention Act in 1996. It felt as if a great burden had been lifted off my shoulders.”  
**Akihiro Kawakami**  
Ooshima Seishoen Sanatorium, Kagawa, Japan.



“When I was told I had leprosy I thought I was going to tie a rope to my bed and hang myself. But my mother always said that while it was OK to give up one’s life for others, one mustn’t die like a dog. That’s how I was brought up, so I decided to live my life with the disease. Once you realize that whether you live or you die is all in God’s hands, there is no grudge nor pain anymore.”  
**Sanshiro Fujita**  
National Sanatorium Kuryu Rakusen-en, Gunma, Japan.



“I contracted leprosy when I was six, and was not able to go to school due to discrimination. The hardest of all was when my friends’ parents told them they mustn’t play with me. A person who had recovered from leprosy gave me MDT and introduced me to a hospital. After three years of rehabilitation and thirteen operations I was able to move my fingers, which made me very happy. But I didn’t move back to my family, because I realized I would be a burden to them. Instead I moved to this village for recoverers, where I got married and now I have two daughters. I feel there is less discrimination than before. The most important thing is for us ourselves to change first. That takes courage. That is what we are working to convey to other recoverers.”  
**Al Qadri** (center), Vice Chairman of an organization of persons affected by leprosy, PerMaTa, with two men living at a leprosy center, Indonesia.



“Things changed after the deformity appeared.”  
**Kailash Sen**, 65, lives with his son Subhash and his family. In his time he has experienced plenty of discrimination, such as shopkeepers refusing him to sell him anything. “There is no need for that kind of behavior. Everyone deserves to be treated with respect,” he says.  
Ma Saraswati Kushth Ashram, Indore, MP, India.





“Leprosy is written in my fate.”  
**Tarabai Rajaram Gharat**, 65, contracted leprosy in her teens. She married a man also affected by leprosy. “Leprosy made me a dependent person,” she says. Today she lives with her son, daughter-in-law, and her two grandchildren.  
Hanuman Nagar Kushta, Maharashtra, India.



“If it wasn't for leprosy, I'd be living a normal life, like you.”  
**Lala Soni**, 80, worked as a decorator. He contracted leprosy at the age of 35. Now he can't stand, and he can't work. He has experienced many instances of discrimination as a result of the disease. “Leprosy has made life frustrating,” he says.  
Sai Baba Kushth Ashram, Allahabad, UP, India.



“Be happy and thanks for looking at our photos.”  
**Kapil Dev**, 67, lives with his son, daughter-in-law, and grandson. He contracted leprosy at 20. One of the hardest periods of his life was when he was undergoing treatment and was too poor to support his wife. Family is very important to him, as these photos show.  
Sai Baba Kushth Ashram, Allahabad, UP, India.



“There shouldn't be any discrimination. We should be treated as part of society, even if we look different.”  
**Babita Kishore Ajnare**’s great grandfather was buried alive because he had leprosy, back in the days before the disease had a cure. “Now it's curable and just an ordinary disease,” she says. Although she herself is not disabled, Babita, 40, has noticed how the disabled get ignored or are given strange looks, and it upsets her.  
Ma Saraswati Kushth Ashram, Indore, MP, India.



“I spent ten years in a hospital bed without hopes or dreams. I felt abandoned and feared getting out. But as time went by, I realized that it was necessary to find ways to create jobs for persons affected by leprosy, so I formed an association. Now my goal is to expand those activities.”  
**Naima Azzouzi**  
Presidend of an organization of persons affected by leprosy in Morocco.



“I came to Hoshizuka Keiaien with my father when I was 13, and was diagnosed with leprosy. When I woke up the next morning, my father was suddenly gone. I thought my parents had abandoned me and screamed until I was hoarse. One of the hardest things was when the man I married at the sanatorium had a secret vasectomy. Otherwise, we wouldn't be able to move into the building for married couples. It was a great shock, since I had always believed we would one day return to society and live like a normal family with kids. Now I teach children the lessons I have learned from life, especially the importance of life, so that we can create a world without prejudice and discrimination.”  
**Masako Ueno**  
Hoshizuka Keiaien National Sanatorium, Kagoshima, Japan.



**Main countries visited  
by the Goodwill Ambassador  
for the Elimination of Leprosy**

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**2001**

January: India.  
May: Switzerland.  
October: Switzerland.

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**2002**

January: Brazil.  
May: South Korea.  
September: Mozambique.  
November: Papua New Guinea, Philippines.  
December: India, Bangladesh.

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**2003**

February: Myanmar.  
March: India.  
July: India, Angola.  
August: Switzerland, UK.  
September: Madagascar.  
November: India.

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**2004**

January: India.  
March: Malta, Switzerland.  
April: Nepal.  
May: Switzerland.  
June: India, Bhutan, Chile, Brazil.  
July: Switzerland.  
August: India.  
September: India.  
December: Philippines, India.

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**2005**

January: India, South Africa.  
February: Madagascar, Brazil.  
March: India, Cambodia.  
April: Mozambique, Tanzania.  
May: India.  
August: Switzerland, DR Congo.  
September: Timor-Leste, India.  
November: Indonesia.  
December: India.

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**2006**

January: India.  
February: Ethiopia.  
March: Vietnam.  
April: India.  
May: Philippines.  
June: Brazil.  
July: India, Lesotho.  
August: South Africa, Angola, Mozambique.  
September: India.  
October: India, Mali.  
November: Laos, Nepal.

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**2007**

January: Philippines.  
March: India.  
April: India.  
May: Madagascar, South Africa.  
May: Mozambique.  
September: Vietnam.  
October: India, Nepal, Azerbaijan.  
November: DR Congo, South Africa, Tanzania.

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**2008**

January: UK, India.  
February: Nepal, Cambodia.  
March: India.  
June: Switzerland, Equatorial Guinea.  
August: Niger, RO Congo.  
September: India.  
October: India.  
November: Costa Rica, Peru, Brazil.  
December: Nepal.

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**2009**

January: Switzerland, UK.  
February: India.  
April: India, Nepal.  
June: Zambia.  
July: Singapore.  
September: Cambodia.

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**2010**

January: Nepal, India.  
March: Mozambique.  
April: India.  
May: India.  
May: Jordan, Timor-Leste.  
May: Sri Lanka.  
July: Ethiopia, Chad.  
August: Indonesia.  
September: Norway.  
October: Vietnam.  
November: Palau, Malaysia, Cambodia.  
December: India, Egypt, Lebanon.

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**2011**

January: China.  
February: India.  
July: Malawi, Ethiopia, Central African Republic, India.  
September: India.  
November: Mali, Burkina Faso, Brazil.  
December: Myanmar.

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**2012**

April: Bangladesh.  
June: Russia.  
July: Ukraine.  
August: India.  
October: India.

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**2013**

January: Vietnam.

April: India.  
July: Uzbekistan, Tajikistan, Turkey, Thailand.  
August: India.  
September: Belgium, Ethiopia, India.  
October: India.  
December: Colombia.

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**2014**

January: Indonesia.  
March: India, Nepal.  
April: South Korea.  
May: Romania.  
June: Myanmar.  
October: Morocco, Spain.  
November: Portugal, India.

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**2015**

March: India.  
April: Ethiopia, DR Congo, RO Congo.  
June: USA, Switzerland.  
August: Brazil.  
September: India.  
October: Kiribati, Fiji.

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**2016**

March: Indonesia.  
May: India, Switzerland.  
June: Bulgaria, Vatican City.  
July: Cameroon.  
October: Ecuador.  
November: India.  
December: Indonesia.

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**2017**

January: India.  
March: India.  
April: Switzerland.  
May: Spain.  
July: India, Vietnam, Indonesia.  
October: Azerbaijan.  
November: Indonesia.  
December: India.

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**2018**

January: India.  
March: Indonesia.  
April: Cambodia, India.  
June: Switzerland.  
July: Ethiopia, Comoros, Mozambique.  
October: Indonesia.  
December: Myanmar.

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**2019**

January: India.  
February: Bangladesh, India.  
April: Marshall Islands, Hawaii.  
May: India, UK.  
June: India, Brazil.  
September: Philippines.  
December: Bangladesh