LEPROSY AND HUMAN RIGHTS

Yohei Sasakawa's initiatives to eliminate the disease and to end stigma and discrimination against persons affected by leprosy

Yohei Sasakawa is chairman of The Nippon Foundation, a private, nonprofit grant-making organization based in Tokyo with its main focus on humanitarian aid activities. Sasakawa has made remarkable contributions to the betterment of people's lives both in Japan and overseas. He has dedicated his life to realizing an inclusive society in which those who are marginalized and isolated for whatever reason are embraced and accepted. Sasakawa is firm believer in Article 1 of the Universal Declaration of Human Rights, namely: "All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood." For Sasakawa, any type of stigma, prejudice and discrimination that results in marginalization and forcible isolation of people from society is unacceptable.

Of special note is the mission to which he has devoted himself for more than 50 years: eliminating the scourge of leprosy, also known as Hansen's disease, from the Earth. He has tirelessly worked toward this goal together with the World Health Organization (WHO), governments of leprosy-endemic countries, international and local NGOs, and organizations of persons affected by leprosy.

As WHO Goodwill Ambassador for Leprosy Elimination, a role he has filled since 2001, Sasakawa not only visits patients and people affected by the disease in sanatoriums and colonies around the world, but he also meets with frontline health workers and solicits support and cooperation from heads of state and media wherever he goes. His purpose is to give hope and encouragement to those with the disease and those treating them, and to spread three key messages: Leprosy is curable. Medication is free. Stop discrimination now.

He spends up to one third of each year on overseas visits and has traveled to around 100 countries since 2001. His latest book titled *Making the Impossible Possible: My Work for Leprosy Elimination and Human Rights* (C. Hurst & Company, 2023) describes Sasakawa's tireless efforts as WHO Goodwill Ambassador in support of eliminating leprosy and the discrimination it causes.

Leprosy Elimination

In an earlier work, *No Matter Where the Journey Takes Me—One Man's Quest for a Leprosy-Free World* (C. Hurst & Company, 2019), Sasakawa wrote that he was first drawn into the battle against leprosy when he accompanied his father, the late Ryoichi Sasakawa, founder of The Nippon Foundation, on a trip to South Korea in 1974 to visit a leprosy hospital. He saw the patients lying in their beds, many with severely deformed faces and limbs. What shocked him most, he recalled, was that they showed no trace of human expression. This is when he determined to devote himself, as his father did, to humanitarian activities—and especially activities related to leprosy.

Since 1975, The Nippon Foundation and its sister foundation Sasakawa Health Foundation have cooperated closely with the WHO, to date channeling more than US$200 million through the organization in support of measures against leprosy worldwide.

It was the introduction of multidrug therapy (MDT) from the early 1980s that provided fresh hope in the fight against leprosy. The regimen's effectiveness prompted the WHO in 1991 to target eliminating leprosy as a public health problem by the year 2000, with "elimination" defined as a disease prevalence rate of less than 1 case per 10,000 population.

Sasakawa made the bold decision to accelerate efforts against the disease by providing free MDT to patients. For five years, from 1995 to 1999, The Nippon Foundation spent US$50 million to fund the free provision of drugs worldwide through the WHO, curing as many as 5 million patients. Thanks to this initiative and the close collaboration between governments of endemic countries, the WHO, international NGOs and other stakeholders, annual new case numbers began to decline significantly. It was the first time that the WHO had used a private donation to fund the distribution of drugs for an infectious disease, and it would become a model for other infectious disease control programs. In this way, Sasakawa has played a pioneering role in the global fight against infectious diseases.

Elimination of leprosy was achieved at the global level by the end of 2000. By 2010, it had been achieved at the national level in almost all countries. Hovering above 200,000, case numbers had been decreasing very gradually, at a rate of 2% a year, until 2020, when the WHO reported a 37% drop globally in detection of new cases due to the significant impact of the coronavirus pandemic on case-finding activities. COVID-19 continued to affect leprosy programs in most countries in 2021 and 2022. The number of new cases reported in 2023 was 182,815, which is still 10% below the 2019 figure.

International efforts against the disease continue today under the WHO's *Global Leprosy (Hansen's disease) Strategy 2021-2030: Towards Zero Leprosy*. The strategy focuses on interrupting transmission and achieving zero autochthonous cases. Its targets for 2030 include 120 countries with zero new autochthonous cases, a 70% reduction in annual new cases detected, and a 90% reduction in rate per million population of new cases with grade 2 (visible) disability.

The Fight against Discrimination and a UN Resolution

While the fight against the disease has made much progress since the introduction of MDT, leprosy's social consequences continue to pose considerable challenges. Many myths and misconceptions color society's view of leprosy, and fear and ignorance of the disease still contribute to the social stigma that surrounds it. For this reason, Sasakawa looks at leprosy as more than just a medical disease. He also frames it as an issue of human rights. He likes to describe leprosy work in terms of a motorcycle. The front wheel represents the fight against the disease, while the rear wheel is the fight against social stigma and discrimination. Unless both wheels turn together, the motorcycle will not move forward toward its final destination of a world without leprosy and the discrimination it causes.

In 2003, in his capacity as a private citizen, Sasakawa took the unprecedented step of approaching the Office of the UN High Commissioner for Human Rights concerning leprosy-related discrimination. In 2005 and 2006, he sought to persuade the members of the then UN Sub-Commission on the Promotion and Protection of Human Rights to pursue this issue, and the Sub-Commission responded by adopting resolutions that recognized leprosy as a human rights problem. Sasakawa also urged the Japanese government to take up this issue at the then UN Commission on Human Rights. In September 2007, in recognition of his contributions, the Japanese government appointed Sasakawa to serve as its Goodwill Ambassador for the Human Rights of Persons Affected by Leprosy.

Sasakawa and his team proceeded to work closely with Japan's Ministry of Foreign Affairs and its representatives in Geneva to prepare a draft resolution to be presented to the newly formed UN Human Rights Council. As a result, on June 18, 2008, the 47 members of the Council unanimously adopted a resolution, co-sponsored by 59 countries, on "Elimination of discrimination against persons affected by leprosy and their family members." Sasakawa had dedicated himself to convincing representatives of these countries to support the resolution, meeting many of them before and during the sessions of the Human Rights Council and briefing them on the situation of persons affected by leprosy.

In accordance with the resolution, the Human Rights Council Advisory Committee was assigned to formulate a draft set of principles and guidelines for eliminating leprosy-based discrimination. After two years of intensive work by the committee, with which Sasakawa collaborated, a resolution to eliminate discrimination against persons affected by leprosy and their family members, accompanied by the principles and guidelines, was proposed by the Japanese government at the 15th Session of the UN Human Rights Council in September 2010; it was adopted unanimously. A resolution was then submitted to the Third Committee of the UN General Assembly, and finally, on December 21, 2010, it was formally adopted by the UN General Assembly. This was a truly historic event: it was the first time that leprosy had been recognized as a human rights issue by the international community, something made possible in large part by the persistent efforts of one individual: Yohei Sasakawa.

Not content with this achievement, Sasakawa organized a series of follow-up international symposiums on leprosy and human rights. The aim was to publicize the resolution and the accompanying principles and guidelines, to raise awareness of leprosy-related issues and to discuss how the principles and guidelines could be effectively implemented by governments and civil society. Five symposiums were held—in Brazil, India, Ethiopia, Morocco, and Switzerland between 2012 and 2015.

This was not the end of the story. The Japanese government and The Nippon Foundation then approached the UN Human Rights Council to request that the Advisory Committee undertake a further study on the situation in leprosy-endemic countries to determine whether the principles and guidelines were being implemented and, if so, effectively. A member of the Advisory Committee carried out extensive research and compiled a report recommending the appointment of a Special Rapporteur on elimination of discrimination against persons affected by leprosy and their families. In September 2017, the Human Rights Council duly nominated an expert on leprosy and human rights, Dr. Alice Cruz of Portugal, to be the Special Rapporteur and follow up on progress made and measures taken by states for the effective implementation of the principles and guidelines. In 2020, Dr. Cruz's term was extended by three years. She successfully fulfilled her duties with the submission of her final report to the Human Rights Council in July 2023, titled "Legal framework for eliminating discrimination on the grounds of leprosy". During the same month, the Human Rights Council agreed to extend the mandate of the Special Rapporteur for a third term, with a new appointee as term limits prevented Dr. Cruz from continuing in the post. Dr. Beatriz

Miranda-Galarza started her role as the Special Rapporteur on November 1, 2024. All these initiatives have been fully supported by Sasakawa, The Nippon Foundation and Sasakawa Health Foundation.

Together with People Affected by Leprosy

Sasakawa has always made a point of visiting communities of people affected by leprosy, seeing their situation for himself and hearing from them directly about their concerns. He has also promoted their empowerment and encouraged their activities to this end. To date, 34 organizations of persons affected by leprosy have been supported by The Nippon Foundation and/or Sasakawa Health Foundation around the world. Among these is India's Association of People Affected by Leprosy (APAL), which Sasakawa himself helped to found in 2005.
APAL began life as the National Forum, a networking organization of residents of India's leprosy colonies. Such communities are often found in isolated locations and information can be hard to obtain. In 2005, with the cooperation of people affected by leprosy, Sasakawa instigated a survey to investigate living conditions there. The survey revealed the existence of some 750 self-settled leprosy colonies, many of whose inhabitants relied on begging to survive. In order to improve the situation, Sasakawa proposed establishing an organization for and of people affected by leprosy in India, especially those living in colonies. Motivated by Sasakawa, local leaders of people affected by leprosy came forward and established the National Forum.

The National Forum later changed its name to the Association of People Affected by Leprosy (APAL) in 2013. Its activities include helping people affected by leprosy know and access their rights and entitlements, working for their socio-economic empowerment, and combatting prejudice, discrimination and rejection. At Sasakawa's direction, APAL has been financially supported by The Nippon Foundation and now by Sasakawa Health Foundation.

In 2012, Dr. P.K. Gopal, the organization's founder and former president, and winner of a Padma Shri Award—one of India's highest civilian honors—had this to say about Sasakawa and his impact:

"Leprosy colonies in India are rarely visited by important political or social figures, and on those few occasions when someone of status does pay a visit, they typically stand at a distance from the colony residents and leave in a hurry. Mr. Sasakawa is different. He has visited numerous leprosy colonies in India and in many other countries around the world, and he has always touched the persons he meets and spoken with them with love and affection. This is a new experience for the affected persons that makes them feel that Mr. Sasakawa will bring a solution to all their sufferings and enable them to lead dignified lives."

Around the same time as the National Forum was formed, Sasakawa established a private foundation in India with a focus on leprosy. Sasakawa-India Leprosy Foundation (S-ILF) was started in 2006 with an initial endowment of US$10 million from The Nippon Foundation. S-ILF's activities include providing microfinance for businesses that help people affected by leprosy to become self-reliant, and educational opportunities and job training for children and young people living in the colonies.

S-ILF provides opportunities to persons affected by leprosy and their families, especially those living in segregated colonies, to move out of begging and dependence on donations and into self or wage employment. To ensure sustainability of the move into dignified livelihood, S-ILF activities focus on training and capacity building so that persons affected and their children are able to get employable skills.

In 2019, Sasakawa initiated the first-ever Global Form of People's Organizations on Hansen's Disease organized by The Nippon Foundation and Sasakawa Health Foundation. Around 60 persons affected by leprosy representing organizations from 18 countries gathered in Manila, Philippines, for four days of discussions, following which they endorsed a set of Conclusions and Recommendations. These were presented at the International Leprosy Congress (ILC), a gathering of leprosy researchers, government officials, NGOs and others involved in leprosy issues, which immediately followed the forum, and gave delegates an opportunity hear the concerns of persons affected by leprosy. A second Global Forum was held in Hyderabad, India, in 2022 prior to the 21st ILC, and a third is planned for Bali, Indonesia, in 2025, ahead of the 22nd ILC.

Awareness-raising through the Global Appeal

Yet another initiative of Sasakawa's to draw attention to leprosy's human rights dimension is the annual Global Appeal that he launched in 2006. The Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy is issued on or near World Leprosy Day at the end of January and focuses attention on the barriers of prejudice that persons affected by leprosy and their families continue to face because of the way the disease is misunderstood by society. To develop momentum for change, Sasakawa invites globally influential individuals and organizations from different fields to endorse the appeal and its call for a world in which persons affected by leprosy can live in dignity enjoying all their basic human rights.

The first Global Appeal was launched in New Delhi, India, in January 2006 and endorsed by renowned world figures including Nobel laureates Elie Wiesel, His Holiness the 14th Dalai Lama and former U.S. President Jimmy Carter. Organizations that have endorsed the Global Appeal include the World Medical Association, the International Bar Association and the Inter-Parliamentary Union. The next Global Appeal, to be issued in January 2025, will be endorsed by the health ministers of leprosy-endemic countries. The full list of Global Appeal partners is as follows:

2006	World-renowned statesmen and laureates	New Delhi
2007	Representatives of people affected by leprosy around the world	Manila
2008	International human rights organizations	London
2009	Religious leaders	
2010	Business leaders	Mumbai
2011	World's leading universities	Beijing
2012	Members of the World Medical Association	Sao Paulo
2013	Members of the International Bar Association	London
2014	National human rights organizations	Jakarta
2015	International Council of Nurses	Tokyo
2016	Junior Chamber International	Tokyo
2017	Inter-Parliamentary Union	New Delhi
2018	Disabled Peoples' International	New Delhi
2019	International Chamber of Commerce	New Delhi
2020	International Paralympic Committee	Tokyo
2021	International Trade Union Confederation	Online
2022	Philanthropic foundations	Online
2023	Participants of the International Symposium at the Vatican on Hansen's Disease	Vatican & Online
2024	World Health Organization	Geneva
2025	Health ministers of leprosy endemic countries	New Delhi

International Symposium at the Vatican

There is another example of Sasakawa's awareness-raising activities. In June 2016, he collaborated with the Holy See to organize an international symposium, "Toward Holistic Care for People with Hansen's Disease, Respectful of Their Dignity," at the Vatican. This symposium was organized by the Pontifical Council for the Pastoral Care of Health Care

Workers, The Nippon Foundation and the Good Samaritan Foundation, in cooperation with Foundation Raoul Follereau, the Sovereign Order of Malta, and Sasakawa Health Foundation. The symposium drew some 250 participants from 45 nations, including persons affected by leprosy, representatives of nonprofit organizations, health care professionals, and representatives of the Catholic, Buddhist, Hindu, Islamic and Jewish faiths. The symposium urged religious leaders of all faiths to spread awareness that leprosy is curable and stress that there is no reason to discriminate against anyone affected by leprosy or members of their families. They also stated that the use of discriminatory language that reinforces stigma must cease. Six years later, a follow-up symposium was held at the same location as part of the Don't Forget Leprosy campaign detailed below.

Don't Forget Leprosy (Hansen's Disease) Campaign

In 2021, amidst the COVID-19 pandemic, the Sasakawa Leprosy (Hansen's Disease) Initiative, a strategic alliance comprising WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa, The Nippon Foundation, and Sasakawa Health Foundation, launched the "Don't Forget Leprosy" campaign to ensure that efforts to tackle leprosy would not be neglected.

During the period when on-site activities were difficult due to the pandemic, Sasakawa engaged in discussions with persons affected by leprosy, government officials, and NGO representatives worldwide through a series of webinars held as part of the campaign. One notable webinar, titled "Zero Leprosy for Whom in the Post-COVID World?" was a three-day event that gave a platform to organizations of persons affected by leprosy to call for efforts against the disease to resume in full once the pandemic was over. In addition, emergency support was provided to these organizations to assist communities severely impacted by the pandemic. A total of approximately 50 million yen was provided to 33 organizations in 14 countries.

In 2022, as the impact of COVID-19 began to subside, the campaign was expanded to include the message of "Leave No One Behind." Various international conferences and events were held under the campaign banner, reinforcing the message that no one should be left behind because of this disease.

In November 2022, the 2nd Global Forum of People's Organizations on Hansen's Disease was held in Hyderabad, India, with over 100 representatives from 20 countries participating, an increase from the first forum held three years earlier. Despite the lingering effects of COVID-19, the forum emphasized the importance of not forgetting those who suffer from stigma and discrimination due to their experience with leprosy.

In January 2023, the 2nd International Leprosy Symposium was held at the Vatican under the theme "Leave No One Behind." This event followed the first symposium held in 2016 and was co-organized by the Raoul Follereau Foundation of France, the Amici di Raoul Follereau Association of Italy, and the Sasakawa Leprosy (Hansen's Disease) Initiative, with the cooperation of the Vatican's Dicastery for Promoting Integral Human Development. After the symposium, Sasakawa had an audience with Pope Francis on January 26, requesting support in the fight against leprosy and the elimination of prejudice and discrimination associated with the disease.

In 2023, a series of events, including a ceremony, international conferences, and film festival, were held to commemorate the 150th anniversary of the discovery of *Mycobacterium leprae*, the bacterium that causes leprosy, by Norwegian physician Armauer Hansen. At the "Bergen International Conference on Hansen's Disease: 150th Anniversary of the Discovery of *Mycobacterium leprae*" held in June, Sasakawa highlighted the significant progress made in the medical efforts against leprosy over the past 150 years, while also stressing that the efforts to eliminate stigma and discrimination have not advanced as much, calling on the world to recognize that this issue is far from over.

In September 2023, Sasakawa called on Prime Minister Sheikh Hasina of Bangladesh, to hold a 2nd National Conference, following the first conference held in 2019. The conference duly took place two months later in November, during which it was agreed to accelerate efforts to achieve zero leprosy in Bangladesh by 2030.

In January 2024, with the endorsement of the WHO, Global Appeal 2024 was held at WHO headquarters in Geneva, Switzerland. The appeal pledged to help countries rebuild national efforts against leprosy that had been disrupted by the pandemic and called for a world where no one is left behind on account of a treatable disease, with Dr. Tedros Adhanom Ghebreyesus, the Director-General, affirming that WHO would support countries in implementing WHO's *Global Leprosy Strategy 2021-2030: Towards Zero Leprosy*.

In addition to the initiatives carried out through the campaign, Sasakawa also made personal efforts to promote the "Don't Forget Leprosy" message in unique and symbolic ways. Inspired by the action of his friend Mr. Minma David Sherpa, a Nepali mountaineer who raised a

“Don’t Forget Leprosy” flag at the summit of Mount Everest, Sasakawa climbed Japan’s highest peak in the summer of the same year and raised a “Don’t Forget Leprosy” flag on top of Mt. Fuji. Then, in February 2024, to further the global fight against leprosy, and particularly to strengthen activities in Africa, action has lagged, Sasakawa took on the challenge of climbing Mt. Kilimanjaro, Africa’s highest peak, successfully reaching the summit at the age of 85. There too, he raised the “Don’t Forget Leprosy” flag.

Sasakawa states, “My creed is overflowing passion, endurance in the face of any hardship, and persistent effort until results are achieved.” With this creed, Sasakawa continues to address the remaining medical and social challenges of leprosy to this day.

Significance of Sasakawa’s Work

Among the numerous initiatives Sasakawa has embarked on in support of a world without leprosy and problems associated with the disease, undoubtedly the most significant has been to raise leprosy as a human rights issue, resulting in the UN General Assembly resolution of 2010. Stigma and discrimination against persons affected by leprosy and their family members represents one of the oldest forms of discrimination in human society, cutting across politics, ideology, religion, race, and national boundaries. It is discrimination by one person against another, or by the wider community against a particular group, due to ignorance and fear of a disease (seen most recently in the early days of the COVID pandemic, when stories emerged of coronavirus patients and health workers who come into contact with them being stigmatized, and sometimes their family members too).

It is symbolic of a universal problem of humanity—the tendency to discriminate. Sasakawa’s work has helped society to better understand what discrimination means and what must be done to tackle it. In that regard, the UN resolution has shone a light on an age-old problem of humanity, and, at the same time, illustrates Sasakawa’s role in working to restore the human rights of one of society’s most vulnerable communities and eliminating the discrimination that they face. Sasakawa’s efforts over the past half-century to eliminate leprosy embody the Sustainable Development Goals’ commitment to “leave no one behind” and offer many insights into how the international community should engage with and support vulnerable groups in society. The many accomplishments of Sasakawa, who took it upon himself to make a difference by taking on the medical and social challenges posed by the age-old disease of leprosy, are proof that civil society can play an important role in solving global problems.

Awards

Yohei Sasakawa has been recognized for his activities to eliminate leprosy and leprosy-related discrimination from the world with a number of awards. Of particular note are:

"Rule of Law Award" from the International Bar Association

The International Bar Association presented its Rule of Law Award to Sasakawa on October 23, 2014. The IBA Rule of Law Award is conferred in recognition of outstanding contributions by an individual toward international justice, human rights and the rule of law.

IBA President Michael Reynolds said, "Mr. Yohei Sasakawa is one of those rare individuals who gives himself altruistically to the pursuit of improving the lives of others. His life-long commitment to eliminating leprosy and upholding the human rights of those affected by the condition serves as an example to us all."

IBA Executive Director Mark Ellis said, "In 1994, when Mr. Sasakawa pledged to provide multidrug therapy free of charge for five years from 1995 to accelerate international efforts to eliminate leprosy it showed him as a man of great vision. His preparedness to commit the considerable resources of The Nippon Foundation, his own time and energy to improving the lives of an untold number of people whom he would never meet is laudable. When the United Nations Human Rights Council, in 2008, unanimously approved a resolution proposed by the Japanese government to end stigma and discrimination against people affected by leprosy, it showed us that positive, significant and lasting difference can be made where true conviction resides. The passing of the resolution coincided with the 60th anniversary year of the Universal Declaration of Human Rights and focused minds on the defining principles of the Declaration, respect and dignity for all human beings. Mr. Sasakawa embodies these values and this is the reason why he is so deserving of the IBA Rule of Law Award."

"Health and Human Rights Award" from the International Council of Nurses

The International Council of Nurses (ICN), an international federation of more than 130 national nursing associations, presented its Health and Human Rights Award to Sasakawa for his outstanding contribution to the fight against leprosy and his exemplary achievements in the field of health and human rights. Sasakawa received the award on May 27, 2017, at the ICN's Congress in Barcelona, Spain. The Award was created in 2000 to recognize people who have made a major humanitarian contribution in the fields of health and human rights. Previous recipients have included Mary Robinson, former president of Ireland, and Stephen

Lewis, former United Nations Special Envoy for HIV/AIDS in Africa. Sasakawa is the second Japanese national to receive the prize, after Sadako Ogata, former United Nations High Commissioner for Refugees. Then-president of the ICN, Dr. Judith Shamian, said, “We are extremely honored that Mr. Sasakawa has accepted this award for having dedicated 40 years of his life to helping populations in need around the globe. His commitment to eradicate leprosy to levels that are no longer considered a threat is an example for us all.” Dr. Frances Hughes, ICN’s Chief Executive Officer said, “While leprosy is a curable disease, it continues to face many misconceptions, misunderstandings and stigma. As nurses, we understand the importance of equitable access to health services and of educating the public about the disease. The stigma and discrimination felt by individuals can be major barriers to utilizing health services for prevention, diagnosis and treatment. In addition, stigma and discrimination marginalizes those with the disease and affects their ability to fulfill necessary, culturally expected and economically productive roles in society.”

Gandhi Peace Prize from the Government of India

President Ram Nath Kovind of India on February 26, 2019, conferred the Gandhi Peace Prize for the year 2018 on Yohei Sasakawa. Presenting the award, President Kovind recognized Mr. Sasakawa’s work, commenting, “He has been instrumental in helping us win crucial battles in the war against leprosy—to prevent and eradicate the disease, and to end stigma and discrimination.” He added, “On behalf of India, I must appreciate the services of Mr. Sasakawa and his Foundation.”

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