Leprosy and Human Rights

Yohei Sasakawa's initiatives to end stigma and discrimination against persons affected by leprosy 2020

Yohei Sasakawa is chairman of The Nippon Foundation, a private nonprofit 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 the past 40 years: eliminating the scourge of leprosy 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, Sasakawa not only visits patients and people affected by the disease in sanatoriums and colonies around the world, 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 it, and to spread three key messages—namely, that leprosy is curable, treatment is free, and social discrimination has no place. Up until the COVID-19 pandemic, he was spending up to one third of each year for overseas visits, many of these involving travel to countries where leprosy is still an issue. Now 81, he has visited more than 90 countries for this purpose since 2001.

The spread of COVID 19 all over the world, and the stigma and discrimination it has provoked against patients, their family members and the health workers who come into contact with the disease, are extremely serious challenges for humanity. The fear generated by myths and misperceptions about communicable diseases, and the social stigma and discriminatory behavior caused by that fear, have been a feature of human society throughout our history—and the most symbolic example is the stigma and discrimination faced by persons affected by leprosy. To fight against COVID-19 discrimination, there is much we can learn from global efforts to erase the stigma attached to leprosy, a mission to which Sasakawa continues to devote his life.

Leprosy Elimination

Sasakawa wrote in his book, *No Matter Where the Journey Takes Me—One Man's Quest for a Leprosy-Free World* (2019, C. Hurst & Co.) 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 1965 to visit a leprosy hospital. He saw the patients lying in their beds, many with severely deformed hands or feet or faces. What shocked him most, he recalled, was that they failed to show any 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 around US$190 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. Its 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 $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 close collaboration between governments of endemic countries, the WHO, international NGOs and other stakeholders, annual new case numbers began to decline significantly.

Elimination of leprosy as a public health problem was achieved at the global level in 2000. By 2015, it had been achieved in almost all countries at the national level, with annual new cases worldwide currently hovering at around 200,000. International efforts against the disease continue, with a new global strategy for 2021-2030 that targets reducing by 70% the number of new patients by 2030, and reducing by 90% the number of new patients with disabilities.

Fight against discrimination and a UN Resolution

The fight against leprosy has made much progress, but the disease's social consequences continue to pose considerable challenges. Many myths and misconceptions color the public's view of leprosy, and fear and ignorance of the disease still contribute to the social stigma that surrounds it.

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 anti-leprosy activities 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, Sasakawa took the unprecedented step of approaching, in his capacity as a private individual, the Office of the UN High Commissioner for Human Rights concerning leprosy-based discrimination. In 2005 and 2006, he sought to persuade the members of the 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 Human Rights Commission. 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 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 adopt 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, accompanied by the principles and guidelines. This was a truly historic event, and it was made possible in large part by the persistent efforts of a private individual: Yohei Sasakawa.

This was not the end of the story. The Japanese government and The Nippon Foundation approached the UN Human Rights Council to request that the Advisory Committee conduct further study on the situation in leprosy-endemic countries to see whether the principles and guidelines were being effectively implemented. One of the members of the Advisory Committee carried out extensive research and compiled a report recommending the appointment of a Special Rapporteur. In September 2017, the Human Rights Council duly nominated an expert on human rights and leprosy to be the Special Rapporteur and further examine implementation of the principles and guidelines. In 2020, the Special Rapporteur's term was extended by three years. All these initiatives have been fully supported by Sasakawa and The Nippon Foundation.

International Symposiums

In parallel with these efforts, Sasakawa has also undertaken a number of other initiatives to promote an end to leprosy and the discrimination it causes. Following the 2010 UN resolution, he organized a series of international symposiums on leprosy and human rights to publicize the resolution and accompanying principles and guidelines. Five symposiums were held—in Brazil in February 2012, in India in October 2012, in Ethiopia in September 2013, in Morocco in October 2014, and in Geneva in 2015. Representatives from state governments, national human rights organizations, international organizations, NGOs, the media and organizations of persons affected by leprosy took part to explore in detail the stigma and discrimination against persons affected by leprosy in each region, to generate awareness of the issues surrounding leprosy, and to discuss how the principles and guidelines could be effectively implemented.

In addition, The Nippon Foundation also organized an International Working Group (IWG) consisting of human rights experts, representatives from international organizations and people affected by leprosy. The IWG produced a comprehensive report, proposing model action plans and a monitoring mechanism for implementation of the principles and guidelines, which was presented at the fifth and final symposium held in Geneva. The IWG's output helped to shape the UN Advisory Committee's report and recommendations submitted to the Human Rights Council in June 2017.

In June 2016, Sasakawa 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 Fondation Raoul Follereau, the Sovereign Order of Malta, and Sasakawa Health Foundation. The symposium drew some 250 participants from 45 nations. On hand for the gathering were persons affected by leprosy, representatives of nonprofit organizations, health care professionals, and religious leaders from the Catholic, Buddhist, Hindu, Islamic and Jewish faiths. Conclusions and Recommendations issued at the end of conference called on 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.

Global Appeal

Sasakawa also began an annual Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy, which is issued on or near World Leprosy Day at the end of January. The appeal 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. The most recent appeal was launched from Tokyo in 2020 and supported by the International Paralympic Committee. Other organizations that have given their support to the Global Appeal over the years include the World Medical Association, the International Bar Association and the Inter-Parliamentary Union.

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, 22 organizations of persons affected by leprosy have been supported by The Nippon Foundation and/or the 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 come by. 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; their inhabitants had been marginalized and many relied on begging to survive.

In order to improve the situation, Sasakawa proposed to establish an organization for and of people affected by leprosy and their family members 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. It is focused on a number of activities including helping people affected by leprosy know and access their rights and entitlements, working for 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.

Now and for the Future

Since March 2020, Sasakawa's visits to leprosy-endemic countries have been suspended due to the COVID-19 pandemic, but he looks forward to the day when he can resume his overseas missions. Writing in the 100th edition of the *WHO Goodwill Ambassador's Newsletter* issued in May 2020, he remarked, "My dream is for an inclusive society—one in which not only persons affected by leprosy but all vulnerable groups have a place. Hence my journey continues. Zero leprosy and zero discrimination may not be achieved in my lifetime, but I will do my best to help us get there."

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.”

See also:
"Elimination of Leprosy" page on The Nippon Foundation’s website
“The Global Appeal” page on The Nippon Foundation’s website
Leprosy Today website (External link)
Sasakawa Health Foundation websit (External link)
WHO Goodwill Ambassador's Newsletter on Sasakawa Health Foundation website (External link)
Sasakawa-India Leprosy Foundation websit (External link)
Association of People Affected by Leprosy websit (External link)
No Matter Where the Journey Takes Me, Hurst Publishers websit (External link)
The Last Mile on the road to eliminate leprosy official website (External link)
“Leprosy: the world’s oldest human-rights issue,” *Nature* (March 4, 2019) (External link)
“From boat racing to the love of leprosy elimination,” *The Lancet* (February 18, 2020) (External link)
A documentary film, *The Last Mile - on the road to eliminate leprosy* (External link: YouTube 104 minutes)

(as of January 2021)