# SASAKAWA LEPROSY (HANSEN'S DISEASE) INITIATIVE



Sasakawa Leprosy (Hansen's Disease) Initiative is a strategic alliance that links together the WHO Goodwill Ambassador for Leprosy Elimination, Sasakawa Health Foundation, and The Nippon Foundation for the purpose of achieving a leprosy-free world.

#### About the Goodwill Ambassador

World Health Organization (WHO) Goodwill Ambassador for Leprosy Elimination, Yohei Sasakawa, who is also Japanese Government Goodwill Ambassador for the Human Rights of Persons Affected by Leprosy and Chairman of The Nippon Foundation, has visited around 100 countries in this role to learn about and raise awareness of the challenges associated with the disease since his appointment in 2001. He has gained a global perspective and he is in a unique position to advocate for persons affected by leprosy and their families.

#### About Sasakawa Health Foundation

Sasakawa Health Foundation (SHF) was co-founded in 1974 by Yohei's father, Ryoichi Sasakawa, and Morizo Ishidate, a pharmacologist who was the first person to synthesize a drug treatment for leprosy in Japan. SHF is committed to a public health approach and collaborates with a wide range of stakeholders in order to address interrelated medical and social issues.

## About The Nippon Foundation

The Nippon Foundation (TNF), also founded by Ryoichi Sasakawa, has been providing funding to leprosy-related initiatives since 1967. In addition to providing the majority of funding for SHF and the WHO Goodwill Ambassador's activities, TNF has been the principal donor for the WHO's Global Leprosy Programme since 1975.

#### About Hansen's disease

Leprosy, also known as Hansen's disease, is an infectious disease that mainly affects the skin, peripheral nerves, upper respiratory tract, and eyes. Left untreated, it can lead to permanent disability. The disease has ancient origins and until the 20th century was without cure. Today, leprosy is treated with multidrug therapy available free of charge throughout the world. Fear of leprosy and social stigma remain deep-rooted, however, and much work still needs to be done to change leprosy's image and eliminate discrimination.

# Sasakawa Leprosy (Hansen's Disease) Initiative's priorities



The Goodwill Ambassador inspects stocks of MDT (Union of Comoros, 2018)

In countries where leprosy has been eliminated as a public health problem, governments tend to shift their priorities elsewhere. The challenge is to keep governments engaged so that detection and treatment of new cases continues, and people have access to leprosy services. The WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa makes a point of emphasizing to leaders of endemic countries that control measures continue to be necessary. Meanwhile, the Initiative cooperates with WHO, the International Federation of Anti-Leprosy Associations (ILEP), the Global Partnership for Zero Leprosy (GPZL), and other stakeholders to realize the goal of a world without leprosy.



NGO Atma Swabhiman spreads awareness (India, 2022)

Leprosy has been curable for decades, but prejudice and discrimination against persons associated with the disease persist, pushing them to the margins of society and limiting their opportunities in life. Moreover, fear of social stigma can lead those who suspect they have leprosy to hide their condition, hindering efforts at early detection and treatment. Fostering an activist consciousness among persons affected by Hansen's disease is an essential part of the journey to a leprosy-free world.

# 

Former chapel at Rovisco Pais Medical Rehabilitation Center, now a museum (Portugal, 2021)

As leprosy and its associated problems become matters of the past, the world is losing evidence of the highs and lows of how humans responded to the disease. Encounters with the stories of individuals and the places that they lived provide opportunities for reflection and formulation of ideas and hopes for the future. In order to advance history preservation, cooperation must happen among governments, experts, and individuals with direct experience.

## Our contributions and main accomplishments

#### **Tackling disease**

- Advocacy and awareness-raising by WHO Goodwill Ambassador for Leprosy Elimination, including media activities and issuing over 100 newsletters.
- Financial support for WHO's Global Leprosy Programme totaling over US\$200 million since 1975, including covering free distribution of MDT from 1995 to 1999.
- Established the Bangkok Declaration Special Fund (US\$4 million) in 2013.
- Major donor of Global Partnership for Zero Leprosy since 2020 as well as playing a key role as a member of the steering committee.
- Organized National Leprosy Conferences in Myanmar (2018) and Bangladesh (2019).

#### **Eliminating discrimination**

- Since 2006 have organized annual Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy with support of high-profile individuals and organizations.
- Advocacy led to adoption of landmark 2010 UN General Assembly Resolution on elimination of discrimination against persons affected by leprosy and their family members and accompanying principles and guidelines.
- Organized International Symposium "Towards Holistic Care for People with Hansen's Disease, Respectful of their Dignity" in Vatican (2016).
- Advocated for nomination of UN Human Rights Council Special Rapporteur on leprosy in 2017 and is providing support for her activities.
- To date have supported 37 organizations of persons affected by leprosy in 22 countries to empower them and promote their social and economic rehabilitation.
- Organized first Global Forum of People's Organizations on Hansen's Disease (Manila, Philippines, 2019).
- Implemented projects totaling 50 million yen in support of 41 people's organizations in 15 countries hard hit by the impact of the coronavirus pandemic. (2020 - 2021)
- Developed a worldwide "Don't forget leprosy" campaign. Together with 31 organizations in 13 countries, sent out the message that leprosy must not be forgotten amid the coronavirus pandemic. (2021-2022)

#### Preserving history

- Promoting network-building and activities to preserve Hansen's disease history and heritage in 14 countries.
- Operation of the National Hansen's Disease Museum of Japan since 2016.
- Operation of International Leprosy Association "History of Leprosy" website since 2016.
- Organized five international workshops/symposiums on Hansen's Disease/Leprosy as Heritage of Humanity (Japan, 2012-2017).
- Support for Culion Museum and Archives in the Philippines. The Culion Leprosy Archives were added to the UNESCO Memory of the World Asia-Pacific Register in 2018.
- · Supported the first European networking conference for preservation of leprosy history (Spain, 2019).





17th Global Appeal (Virtual, 2022)



Global Forum (Philippines, 2019)



"Don't forget leprosy" campaign by MORHAN



A International History of Leprosy website (https://leprosyhistory.org)

# Our Vision, Mission, Goals and Strategies towards a leprosy-free world

#### VISION

# **Zero leprosy**

A world free from all forms of suffering associated with the disease

#### MISSION

Tackle disease

Eliminate discrimination

Preserve history

#### GOALS

- Achieve WHO's numerical targets
- Improve health technologies and service delivery
- Empower people's organizations
- Reform laws based on UN Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members\*
- Develop robust networks for history preservation

#### STRATEGIES

- Coordinate with WHO Goodwill Ambassador for effective advocacy at all levels
- Work with WHO and others to support leprosy control activities in high-priority countries
- Strengthen capacities of people's organizations and promote their involvement in policy-making and implementation
- Identify discrimination and construct a framework for sustaining action toward its elimination
- Support model history preservation efforts and facilitate training and network formation for people doing the work
- Raise awareness of leprosy-related issues through effective communication methods
- Build partnerships with other stakeholders for more effective implementation of strategies

\*https://www.ohchr.org/sites/default/files/Documents/Issues/Leprosy/PrinciplesGuidelines\_EN.pdf





















Sasakawa Leprosy (Hansen's Disease) Initiative (sasakawaleprosyinitiative.org) 5th Floor, Nippon Foundation Building, 1-2-2 Akasaka, Minato-ku, Tokyo 107-0052 Japan Tel: +81-3-6229-5377 Fax: +81-3-6229-5388 Email: hansen@shf.or.jp