

LEPROSY BULLETIN

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Driving progress towards zero leprosy in Africa

Message from the ambassador

During the COVID-19 pandemic, when leprosy elimination activities stalled worldwide, the negative effects in Africa were especially severe. In many places on the continent, affected persons cannot receive diagnosis or treatment, and unjust discrimination against persons affected by leprosy and their family members continues. I climbed Africa's highest mountain, Mount Kilimanjaro, in February of this year to call attention to these facts.

Of the 23 countries designated "global priority" by the World Health Organization (WHO), 13 are in Africa. I want to hold an "Africa Zero Leprosy Conference" to obtain commitments from the health ministers of these endemic countries and to encourage discussion among government officials, people's organizations, NGOs, research institutions, and international organizations about how to achieve zero leprosy.

At the most recent World Health Assembly, I received endorsement for the conference idea from WHO Director-General Dr. Tedros Adhanom Ghebreyesus; the African Union's Commissioner for Health, Humanitarian Affairs and Social Development, Ms. Minata Samate Cessouma; and various health ministers. In July, I met with Ethiopia's Minister of Health Dr. Mekdes Daba and Minister of Women and Social Affairs Dr. Ergogie Tesfaye to secure the government's approval to hold the conference in Addis Ababa in early 2025. The program for the conference will be finalized through working-level meetings that will include representatives from people's organizations of persons affected by leprosy.

As the WHO Goodwill Ambassador for Leprosy Elimination, I hope and expect that this conference will generate momentum for achieving a leprosy-free Africa. I would be grateful for the cooperation of all relevant parties.

A handwritten signature in blue ink, consisting of stylized Japanese characters, reading '佐川 陽平' (Sasakawa Yohei).

Yohei Sasakawa

WHO Goodwill Ambassador for Leprosy Elimination

Contributing to this issue:

Dr. Shigeki Sakamoto
Professor Emeritus, Kobe University

Dr. Beatriz Miranda Galarza
UN Special Rapporteur

Dr. Jessica Fairley
Associate Professor, Emory University

Tesfaye Tadesse Haile
Research Consultant, SHF

LEPROSY IS CURABLE. MEDICATION IS FREE. STOP DISCRIMINATION NOW.

Leprosy as a social as well as medical issue

For five years (1995–1999), The Nippon Foundation (TNF) provided the World Health Organization (WHO) with US\$10 million per year so that multidrug therapy (MDT) could be distributed to all leprosy patients worldwide free of charge. TNF's chairman, Yohei Sasakawa, and TNF's partner organization, Sasakawa Health Foundation (SHF), hoped that, in addition to controlling the disease as a public health issue, widespread use of MDT would transform the image of leprosy to that of a curable condition. Unfortunately, stigma and discrimination continued, interfering with medical efforts and preventing patients from resuming their regular lives once cured.

In 2003, Yohei Sasakawa began talking with the Office of the High Commissioner for Human Rights (OHCHR) about the problem of leprosy-related stigma and discrimination as a matter of human rights. His approach kicked off a process that led the main organ of the United Nations, the General Assembly, to adopt a resolution unanimously in 2010 that

encourages all governments and relevant actors in society to give due consideration to the Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members.

For the second piece in the six-part series recognizing the upcoming 50th anniversary of the WHO–TNF/SHF partnership for the elimination of leprosy, the *Leprosy Bulletin* invited the legal expert who drafted the Principles and Guidelines, Professor Shigeki Sakamoto, to reflect on the seven-year process that culminated in the General Assembly resolution.

Considering WHO's definition of health – “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” – the health of persons affected by leprosy depends on social change that supports their inclusion. TNF/SHF will continue to work with WHO and other partners to address leprosy from both medical and social perspectives.

How discrimination against persons affected by leprosy came to be recognized as a human rights issue within the UN system



Dr. Shigeki Sakamoto
former Member of the Advisory Committee to the United Nations Human Rights Council (2008–2013)
Professor Emeritus, Kobe University

Professor Shigeki Sakamoto specializes in international law. As a member of the Advisory Committee to the United Nations Human Rights Council, he led the drafting process for the Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members.

On July 2, 2003, Mr. Yohei Sasakawa met with the Acting United Nations High Commissioner for Human Rights, Dr. Bertrand Ramcharan, to gain recognition for discrimination against persons affected by leprosy and their family members as a serious matter of human rights. Until this meeting, leprosy-related stigma and discrimination had never been discussed as a human rights issue by the Office of the High Commissioner for Human Rights (OHCHR), let alone by the United Nations Commission on Human Rights (replaced by the UN Human Rights Council in 2006). The OHCHR concurred with Mr. Sasakawa's position and cooperated in securing the subsequent adoption of resolutions on leprosy-related discrimination by the Commission (and, later, the Council).

On June 12, 2008, the Council adopted resolution 8/13, which was proposed jointly by 59 countries, led by Japan. The resolution recognized that “the issue of leprosy is not only a matter of medicine or health but also one of discrimination that can give rise to a clear violation of human rights,” and called on governments to take effective measures to eliminate “any type of discrimination against persons affected by leprosy and their family members.” It also requested ongoing actions from the OHCHR, specifically that the Office would include the discrimination against persons affected by leprosy as an important matter in its human rights education and awareness-raising activities as well as collect information on the measures that governments have taken to eliminate it.



Dr. Bertrand Ramcharan, Acting High Commissioner for Human Rights, advised Yohei Sasakawa about working with the United Nations Commission on Human Rights (Geneva, July 2004).



Professor Shigeki Sakamoto of Kobe University (left, author) and Professor Yojo Yokota of Chuo University (right), were very active in the UN Human Rights Council (Geneva, January 2009).

Following the adoption of the resolution, the Council commissioned its newly established think tank, the Human Rights Council Advisory Committee, to develop guidelines to end discrimination against persons affected by leprosy. At the Advisory Committee's first meeting in August 2008, I was designated to formulate a draft set of "principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members."

At the time, the Convention on the Rights of Persons with Disabilities had been adopted by the General Assembly less than two years earlier, in December 2006. The Preamble to the Convention was known for taking a "social approach" to disability, recognizing that "disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others." In my working paper for the principles and guidelines, I stated that eliminating discrimination against persons affected by leprosy and their family members likewise

requires a social approach. I submitted a draft based on this approach to the Advisory Committee, and it was adopted during the fifth session, held Aug. 2–6, 2010.

This finalized draft set of principles and guidelines was then submitted to the Human Rights Council, and about a month later, on Sept. 30, 2010, the Council officially acknowledged the Principles and Guidelines (P&G) with the adoption of resolution 15/10. The resolution requested the OHCHR to disseminate the P&G and invited the General Assembly to consider the issue. A few months later, on Dec. 21, 2010, the General Assembly unanimously adopted resolution 65/215, which reaffirmed that persons affected by leprosy and their family members are entitled to all human rights and fundamental freedoms under law and encouraged all governments and relevant entities to give due consideration to the P&G in the formulation and implementation of their policies, measures, and activities.

This adoption of a resolution by the General Assembly in support of the P&G would not have been possible without the tireless enthusiasm of Mr. Sasakawa. Persons affected by leprosy and their family members have been marginalized and neglected all over the world. His efforts brought attention to the problem of discrimination against them in a way that could be addressed within the United Nations system. The various resolutions removed any doubt that they have human rights, and the P&G describe the actions that should be taken by governments and other entities to secure these rights. As the drafter of the P&G, I hope that Mr. Sasakawa will continue to bring attention to this framework during his visits to various countries as the WHO Goodwill Ambassador so that the social causes of stigma and discrimination against persons affected by leprosy and their family members may be eliminated.



The General Assembly meets annually at the permanent headquarters of the United Nations in New York City.

VIEWPOINT



Dr. Beatriz Miranda Galarza
United Nations Special Rapporteur on the elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members

Based on a mandate established by the UN Human Rights Council in June 2017, the Special Rapporteur undertakes fact-finding country visits and informs Member States and the Human Rights Council about alleged violations of the rights of persons affected by leprosy and their family members.

Leprosy as a human rights issue in the 21st century

In June, I presented my first annual report as the United Nations Special Rapporteur on the elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members to the United Nations Human Rights Council (HRC) in Geneva, detailing the mandate's achievements and ongoing challenges. Established by HRC resolution 35/9 in 2017, the mandate is a response to a long history of isolation and exclusion experienced by persons affected by leprosy, and their struggle to be recognized as individuals with rights. In the 21st century, shadows from the past linger in overlapping approaches to leprosy from religious, cultural, scientific, and administrative perspectives. Supporting the leprosy rights movement globally and facilitating societal change are necessary for realizing the enjoyment of human rights by persons affected by leprosy and their family members in all regions of the world.

To convey the mandate's importance and impact, I interviewed persons affected by leprosy, their allies, and representatives of international donor organizations. According to the interviewees, grassroots organizations have become more aware of the importance of their involvement in decision-making processes at the local level, with the mandate playing an encouraging role. One interviewee mentioned, "When persons affected by leprosy realize they have rights like any other person, their self-confidence changes, and there is assurance in what their organizations can achieve." Another added, "If a person affected by leprosy is heard and seen by somebody from an organization such as the United Nations, she feels important and thinks that her problems are important too. That makes a difference in her life." However, there is still a long way to go to eliminate discriminatory practices and laws, especially in countries where leprosy is endemic.

Interviewees identified five broad clusters of issues central to the mandate: human rights-based care and support systems; crucial intersectional issues and marginalized groups; social, political, and cultural aspects of leprosy; legal and economic dimensions related to leprosy; and conflict and environmental considerations. These issues imply that leprosy is both a human rights and a cultural and socio-political problem. Responses to leprosy evolve alongside global developments,

and consequently, the primary challenges confronting humanity appear in the experiences of persons affected by leprosy, often in magnified form.

The mandate commits me to supporting states in reviewing their legislation to align with main UN international instruments, facilitating the exchange of good practices, and promoting effective participation and consultation with persons affected by leprosy, their family members, and their organizations. Additionally, I will promote training national actors, including public servants, on the rights of persons affected by leprosy and the translation of these rights into public policies.

In discharging my mandate, I am guided by three main principles: (a) fostering an ethics of care where care involves, as the feminist Joan Tronto says, "everything that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible"; (b) contributing to a culture of listening, acknowledging, and appreciating the presence of persons affected by leprosy; and (c) promoting cooperation and co-production of policies and strategies to achieve the mandate's objectives and the goals set by the leprosy rights movement, such as "leaving no one behind."

I have begun establishing collaborative partnerships with other mandate-holders, United Nations bodies, and Member States. I am also promoting collaboration with academic institutions, local and international human rights and development organizations, and representatives of social movements linked to leprosy. This cooperative approach aims to develop strategies that enhance the lives of persons affected by leprosy. Above all, I have consulted persons affected about what matters to them and intend to focus on co-creating accessible materials and information with the leprosy rights movement to promote the defense of their rights.

Eliminating discrimination against persons affected by leprosy and their family members requires political and material support. Significant progress has been made, and I am committed to continuing this work. To achieve our goals, I need the collaboration of all social actors. You can count on me to develop and implement actions that support persons affected by leprosy, their allies, and their family members in transforming their communities and society as a whole.

VIEWPOINT



Dr. Jessica K. Fairley
Associate Professor of Medicine, Global Health, and Epidemiology
Emory University

Dr. Fairley is an infectious disease specialist based in Atlanta, Georgia, a city in southeastern United States with a humid subtropical climate. She directs the government-funded Atlanta Hansen's Disease Clinic at the Emory TravelWell Center.

<https://www.hrsa.gov/hansens-disease/ambulatory-clinics>

Despite low numbers, the United States offers unique perspectives in the fight against leprosy

The United States has a long history with leprosy, or Hansen's disease (HD), that continues to the present day. While there is debate about whether the bacillus was first introduced to the Americas along with the arrival of Europeans and enslaved Africans 500 years ago or earlier during human migration from Asia 12,000 years ago,¹ there is no question that the last 150 years has seen significant attention and developments around HD in the United States (US).

Less than 30 years after the Kingdom of Hawai'i established the Kalaupapa leprosy colony on Moloka'i in 1866, the State of Louisiana established the Louisiana Leper Home in 1894 at an abandoned plantation along the Mississippi River in a similar attempt to isolate individuals with HD. Following the US Public Health Service's purchase of the property in 1920, individuals with HD were sent to Carville from across the country as part of a national forced isolation policy. While the negative legacy of this policy must be acknowledged, it is also true that many developments occurred at Carville that shaped our current approach and understanding of HD, in particular the discovery of dapsone precursors in the 1940s.²

More recently, US-based research has brought to light the armadillo's role in the epidemiology of HD in the US. Groundbreaking research done by Dr. Richard Truman and others shows the correlation of armadillo genotypes with local human infections,^{3,4} a discovery that has led to the identification of nine-banded armadillos as reservoirs in other parts of the Americas.

What does the epidemiologic and clinical landscape of HD look like now in the United States? HD surveillance and clinical support are conducted by the National Hansen's Disease Program (NHDP), which is run by the Health Resources Service Administration of the Department of Health and Human Services. In 2023, 225 cases were reported to the NHDP, a 10-year high.⁵ It is unclear whether the 2023 incidence reflects a rebound from 2020/2021,

when cases went undiagnosed likely due to COVID-19, or if it represents a true upward trend. Either way, reports of autochthonous cases have brought more attention to a potential emerging infection in armadillo-inhabited regions of the US. In fact, a case report from Florida made it to lay press in 2023 due to its description of rising cases in the state in recent years, igniting fears of an HD "outbreak" in central Florida.⁶ While these fears were overblown, there is no doubt that non-immigrant cases have increased in recent years in the southeast from central Florida up through Georgia. This growth in the number of new cases has mirrored the migration of certain populations of the nine-banded armadillo from the western coast of the Gulf of Mexico into these regions.

As an HD physician practicing at a clinic in the southeast, I am concerned by these trends. Over the past 10 years, I have cared for a growing number of individuals who have no history of international travel to, or residence in, countries typically thought of as endemic for HD.

The current epidemiologic situation in the US makes it an ideal place to better understand environmental reservoirs and modes of transmission of the bacilli. The country appears to have minimal human-to-human transmission as evidenced by the fact that, anecdotally, household contacts rarely if ever get infected: At our Atlanta clinic, not one of our patient's household contacts have been diagnosed with HD in over 30 years. While the US has a clear alternative source of infection, the armadillo, the bacteria causing HD is the same as everywhere else in the world. Therefore, we have a golden opportunity to take these clinical and epidemiologic observations and describe, once and for all, the various ways that *Mycobacterium leprae* and *M. lepromatosis* are transmitted. Elucidating environmental and zoonotic transmission would not only benefit public health in the US, but would have implications globally, bringing us that much closer to our goals of zero transmission.

¹ <https://doi.org/10.1155/2017/6491606>

² Faget GH, Pogge RC, Johansen FA. Present status of dapsone in the treatment of leprosy. *Public Health Rep* (1896). June 28 1946;61:960-3.

³ <https://doi.org/10.1056/NEJMoa1010536>

⁴ <https://doi.org/10.3201/eid2112.150501>

⁵ See "United States Reported Hansen's Disease Cases by Year, 2014–2023" at <https://www.hrsa.gov/hansens-disease>.

⁶ <https://doi.org/10.3201/eid2908.220367>

REPORT



Tesfaye Tadesse Haile
former Managing Director, Ethiopian National Association of Persons Affected by Leprosy (ENAPAL)
Research Consultant, Sasakawa Health Foundation

Tesfaye Tadesse Haile studied sociology at Addis Ababa University and has a Master's degree in organizational leadership. He served as ENAPAL's managing director for over 10 years and contributed to the WHO Technical Advisory Group for Leprosy.

My observations in Kenya, Nigeria, and Ghana

As a research consultant for the Sasakawa Health Foundation, I visited six countries in Africa – Kenya, Nigeria, Ghana, Mozambique, Sierra Leone, and Senegal – between February and May of this year to survey the situation of persons affected by leprosy and people's organizations. In this first of two articles, I share what I learned about three of the countries: Kenya, Nigeria, and Ghana.

My visits were short, and I was only able to see the situation in a few places. As you read, please consider the limitations of my report. For each country, my visit was coordinated through a local people's organization. They helped me and answered my questions even though nearly all of their leadership and staff work without pay. I am grateful for their assistance, and I wish them success in strengthening their capacities.

Kenya (February, 3 days)

In Kenya, I stayed in the country's capital city, Nairobi. I heard about and saw firsthand that persons affected by leprosy must cope with stigma, discrimination, and poverty. Many of them end up living in informal settlements, known locally as slums, where they experience harsh and unsanitary conditions caused by overcrowding, lack of basic infrastructure and services, and limited opportunities for education and employment. The situation is especially bad for elders, persons who are severely disabled, and persons who migrate to a slum from another country without necessary documentation for living in Kenya.

Throughout my visit, I noticed a strong association between leprosy and disability. According to the head of a dispensary involved in skin screening activities, factors that prevent early detection and effective treatment include lack of leprosy-specific training for health workers; poor data management; insufficient efforts to ensure that patients complete treatment; and budget limitations related to lack of attention from the government.

Nigeria (April, 3 days)

I started my visit to Nigeria in Lagos, a megacity located on the coast of the Atlantic Ocean's Gulf of Guinea. As I found in Kenya, the association here between leprosy

and disability is strong. The existence of the Destitute Home, recently renamed the Home of Potentials, probably reinforces this association. Established in the early 1990s by a former military administrator of Lagos State, the rows of concrete block homes were meant to house persons affected by leprosy, persons who are blind, and persons with disabilities. Over time, more vulnerable people flowed into the area, erecting shanties and unintentionally contributing to overcrowding and worsening living conditions. Persons affected by leprosy who live in this community are doubly stigmatized, first for the disease and second for living in an area known for squalor.

From Lagos, I traveled east to the landlocked states of Enugu and Abia to visit Uzoakoli Colony, where approximately 72 households, mostly of persons affected by leprosy, also live in dilapidated houses without reliable access to water and electricity.

Based on what I saw during my brief visit, the situation of persons affected by leprosy and their family members in Nigeria must be worked on from all angles.

Ghana (April, 1 day)

My one-day visit to Ghana was confined to Ankaful, a town on the Gulf of Guinea coast where a leprosarium was opened in 1951. The leprosarium ceased being a facility for segregated treatment in 1994, when it was renamed Ankaful Leprosy & General Hospital. Four years later, in 1998, the World Health Organization (WHO) recognized Ghana's elimination of leprosy as a public health problem. When I visited the hospital, I saw six patients who appeared to be receiving good treatment. The consensus of everyone I met in Ankaful seemed to be that the incidence of leprosy in Ghana is low and patients who have been cured can go back to their families without suffering from stigma and discrimination.

It is unfortunate that I was not able to talk with any persons affected by leprosy and their family members outside of the hospital. I wonder about the experiences of those who have been reunified with their communities as well as those who live in other regions of the country. I hope that their voices are being heard.

Sasakawa Leprosy Initiative Young Scholar Program launches in Indonesia and Colombia

The Sasakawa Leprosy (Hansen's Disease) Initiative, in cooperation with YDTI/PerMaTa South Sulawesi of Indonesia and Felehansen of Colombia, launched a pilot program called the Sasakawa Leprosy Initiative Young Scholar Program in April 2024. The program supports persons affected by leprosy between the ages of 18 and 35 to gain skills for income-generating work while also nurturing their capacity to initiate projects and speak up on behalf of others affected by the disease.

Organizers held interviews in Indonesia and Colombia in June. They looked for young persons affected by leprosy who

demonstrate motivation to become knowledgeable advocates and role models for their peers. Seven scholars and one associate were selected to receive personal career guidance, job-specific training, general education about leprosy and leadership, as well as mentoring from senior leaders. Recipients are pursuing training in areas such as nursing, health administration, graphic design, and accounting.

The Initiative plans to expand the program to other countries starting from 2025. In each country, the program will be developed in collaboration with a local organization so that the content and format is appropriate for the participants.

Indonesia



Kasmawati

"I am very impressed and proud because this is a golden opportunity to learn from people who have such great experience."



Fichrin Hidayat

"I am extraordinarily happy and my hope is that in the future I can become a role model for friends who are affected by leprosy and to become an agent of change in the community."



Hasan Basri

"Being selected as a SLI Scholar is a very valuable and knowledge-rich experience. Hopefully, I can contribute significantly to the advocacy of leprosy issues. Thank you for this amazing opportunity."



Yusniati

"I am very grateful to be selected as an associate scholar and proud to meet great people. Hopefully, we can remove the stigma and discrimination in society about leprosy. Thank you."

Colombia



Jhon Alexander Bedoya Parra

"I just want to say that this process has given me respect, responsibility, and a lot of hope."



Maria Angelica Cañas Rodríguez

"For me, it has been a wonderful experience to meet such incredible people. I am full of expectations, and I am eager to get going and take this project to the next level."



Diana Patricia Medina Cordoba

"I am committed to supporting associations of persons affected by Hansen's disease. As a leader, I offer a unique perspective that I can use to help raise awareness, banish stigmas, and provide support to those in situations similar to what I experienced in my childhood."



Omar Zuñiga Melendez

"I feel very happy and grateful to be part of this beautiful family. The Sasakawa Leprosy (Hansen's Disease) Initiative helps people to dream, revive hope, and realize their dreams. May God grant that they continue to bring hope to people who need a helping hand to take the first step."

Goodwill Ambassador visits Ethiopia to secure cooperation for the Africa Zero Leprosy Conference

From July 23 to 24, WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa visited Addis Ababa, Ethiopia, and met with Dr. Ergogie Tesfaye, Minister of Women and Social Affairs; Dr. Mekdes Daba, Minister of Health; and Dr. Owen Laws Kaluwa, WHO Representative to Ethiopia. The Goodwill Ambassador revealed plans to hold a conference

in Ethiopia in March 2025 called the “Africa Zero Leprosy Conference.” He expressed hope that the conference would revitalize the continent’s efforts against leprosy, which stalled worldwide during the COVID-19 pandemic, and formally requested cooperation from Ethiopia’s government and WHO Country Office.



July 23 — Ministry of Women and Social Affairs — Minister Ergogie Tesfaye gave her support to the Africa Zero Leprosy Conference, expressing her hope that it will contribute to leprosy control and the elimination of stigma and discrimination. She noted overlap with the “leave no one behind” principle of the UN’s Sustainable Development Goals (SDGs), and pledged her full cooperation.



July 24 — Ministry of Health — The Goodwill Ambassador requested the cooperation of Minister of Health Mekdes Daba in organizing the Africa Zero Leprosy Conference. Minister Mekdes recognized the importance of the African continent uniting to eliminate leprosy and said that her ministry would be pleased to play a central role in assisting preparations for the conference.



July 24 — WHO Country Office for Ethiopia — WHO Representative to Ethiopia, Dr. Owen Laws Kaluwa, confirmed that the Country Office for Ethiopia will help to organize the Africa Zero Leprosy Conference. The Goodwill Ambassador thanked the Representative for WHO’s enthusiastic support.



In 2022, the Ethiopian National Association of Persons Affected by Leprosy (ENAPAL) completed construction of a six-story building. Rental income from the building gives the organization financial independence and stability. While in Addis Ababa, the Goodwill Ambassador stopped by to hear an update from ENAPAL’s members.

**SASAKAWA
LEPROSY
HANSEN'S DISEASE
INITIATIVE**

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Publisher Yohei Sasakawa
Executive Editor Takahiro Nanri

Editorial Office 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
leprosybulletin@shf.or.jp

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