

LEPROSY BULLETIN

NO. 116 AUGUST 2023



Regaining momentum for a leprosy-free world

Message from the ambassador

This year marks the 150th anniversary of the discovery of the leprosy bacillus by Dr. Gerhard Armauer Hansen in Bergen, Norway. To prompt reflection on the past and build momentum for a zero leprosy future, the Sasakawa Leprosy (Hansen's Disease) Initiative and the University of Bergen co-hosted an international conference on June 21–22. The conference was attended by 200 people from 27 countries and opened with video messages from Dr. Tedros Adhanom Ghebreyesus, Director-General of the World Health Organization, and Mr. Volker Türk, United Nations High Commissioner for Human Rights.

In my remarks, I emphasized that progress in the area of human rights has lagged far behind medical progress. In 2010, the United Nations General Assembly unanimously adopted a resolution as well as principles and guidelines on the elimination of discrimination against persons affected by leprosy and their family members. In other words, the international community officially recognizes that leprosy is a human rights issue.

However, persons affected by leprosy and their family members still face severe discrimination in fundamental areas of social life, including education, employment, and marriage.

For me, hope comes from seeing persons affected by leprosy take the lead. At the conference, representatives from organizations of persons affected by leprosy shared the remarkable results that they are achieving in their countries. I will continue to make every effort to realize a truly inclusive society where all persons affected by leprosy and their family members feel like they belong.

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:

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ASCL/MTN (Senegal)

Faustino Pinto
MORHAN (Brazil)

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

REPORT



Yoshinori Takazawa
Director, Human Rights and Humanitarian Affairs Division, Foreign Policy Bureau
Ministry of Foreign Affairs, Japan

The Government of Japan has been promoting international initiatives with the aim to eliminate prejudice and discrimination against persons affected by Hansen's disease (HD, leprosy) and their family members. The initiatives include submission of resolutions on the elimination of discrimination to the UN Human Rights Council.

Japan's efforts to eliminate discrimination against persons affected by HD and their family members

The protection of human rights and fundamental freedoms is a basic responsibility of all countries and a matter of legitimate concern for the international community. Japan, based on the premise that human rights are universal values, puts efforts into improving human rights situations through bilateral dialogue, taking into account the historical and cultural background of each country. Japan also attaches great importance to multilateral dialogue and cooperation and is actively participating in international forums, including the United Nations (UN), to contribute to the protection and promotion of human rights worldwide.

Based on reflection on its own past Hansen's disease (HD, leprosy) policies, Japan has been initiating efforts in the international community to eliminate discrimination and prejudice against persons affected by HD and their family members. Since 2008, Japan has submitted seven resolutions on the elimination of discrimination against persons affected by leprosy and their family members to the UN Human Rights Council, each of which was adopted by consensus and attracted many co-sponsors. The resolution adopted in 2010 called on governments to give due consideration to "Principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members." Resolutions with the same content were also adopted by consensus at the Third Committee and General Assembly of the UN held in the same year. Furthermore, a resolution adopted at the Human Rights Council in 2017 created the mandate of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members for a period of three years, which was followed by the appointment of Dr. Alice Cruz. In 2020, a resolution was adopted to extend the Special Rapporteur's mandate for three more years.

At the 53rd session of the Human Rights Council, held from June 19 to July 14, 2023, Japan, together with Brazil, Ecuador, Ethiopia, Fiji, India, Kyrgyzstan, Morocco, and Portugal, submitted a resolution for the seventh time. The vigorous activities undertaken by Dr. Cruz during her six years as the

Special Rapporteur have promoted people's understanding about HD and greatly encouraged persons affected by HD and their family members. Organizations working on HD-related issues around the world highly appreciate these activities. At the same time, her investigations have revealed that large numbers of people continue to be affected by and suffer from discrimination and stigma due to lack of understanding about HD, which still persists in many parts of the world. Japan co-submitted the resolution with the aim of extending the mandate of the Special Rapporteur for another three years because it is crucial to continue to listen to those who are affected by HD and their family members and to support efforts to improve their human rights situations. Also, it has been decided to use the term *Hansen's disease* in tandem with *leprosy* in the text of the resolution, considering Dr. Cruz's recommendation in her latest report. To encourage the adoption of the resolution, Japan explained the resolution's importance to other countries on various occasions. As a result, the resolution was adopted unanimously on July 12, obtaining cross-regional support from 68 co-sponsors in total.

Japan will continue its active efforts as part of the international community to realize the enjoyment of human rights by persons affected by HD and their family members in all parts of the world and to eliminate discrimination and prejudice against them, which hinder their equal participation in society.



53rd session of the UN Human Rights Council (Geneva, Switzerland, July 12, 2023). The Human Rights Council was established in 2006 to strengthen the UN's capacity to deal with human rights issues. The Council meets regularly three times a year in Geneva to deliberate and make recommendations for the protection and promotion of human rights and fundamental freedoms.

¹ The resolutions were submitted in 2008, 2009, 2010, 2015, 2017, 2020, and 2023.

REPORT



Papa Mamadou Diagne
President, Association Sénégalaise Contre la Lèpre et les Maladies Tropicales Négligées (ASCL/MTN)

Papa Mamadou Diagne has been affected by leprosy since 2009. As president of ASCL/MTN, he is involved in advocacy for rights and access to care, awareness-raising for social and environmental behavior change, education and training, and development of individualized rehabilitation plans for empowerment and inclusion.

Discriminatory law repealed in Senegal

For 47 years, Senegal has had nine *villages de reclassement social* (VRS), created by the authorities and governed by Law 76-03 of 1976. At the time that they were established, the VRS were intended to isolate persons affected by leprosy and block transmission of the disease. The VRS system continued until 2023 even though leprosy has been a curable disease since the 1980s and “leprosy as a public health problem” was declared eliminated at the national level in 1995.



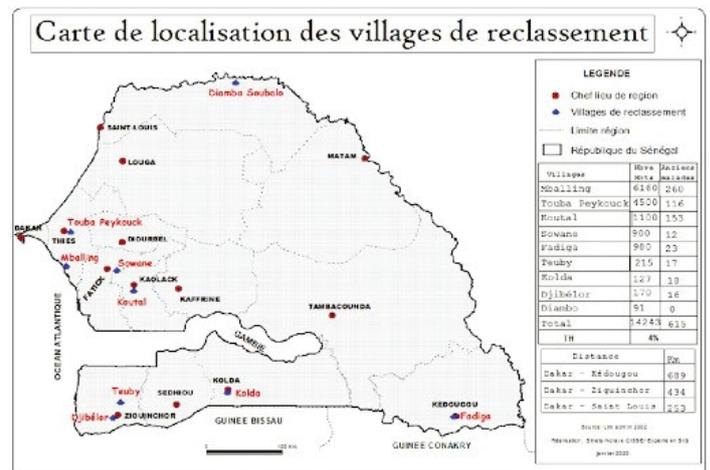
Sign marking the entrance to Teubi, one of Senegal's nine *villages de reclassement social* (VRS).

The organization of which I am currently president, Association Sénégalaise de lutte contre la Lèpre et les Maladies Tropicales Négligées (ASCL/MTN), is a national nonprofit association that acquired official legal recognition in 2015. ASCL/MTN has worked for years with the German Leprosy and Tuberculosis Relief Association (DAH) to push for the repeal of Law 76-03, and recently we engaged in several advocacy and awareness-raising activities within the framework of the Sasakawa Leprosy (Hansen's Disease) Initiative's “Don't Forget Leprosy” campaign.

On May 17, 2023, Senegal's Minister of Health and Social Action, Dr. Marie Khémesse Ngom Ndiaye, defended a bill that would repeal the law, and on June 5, 2023, the National Assembly voted to adopt it. In effect, the adoption of Bill 11/2022 abolished the VRS system.

Speaking on behalf of the state, the Minister told the members of the National Assembly that the VRS system was a source of stigmatization and that repealing the law was a necessary part of implementing policies for the social inclusion of vulnerable populations.

The law's repeal brings Senegal into alignment with its commitments to non-discrimination and human equality as set out in the Universal Declaration of Human Rights (1948), Article 7 of the Constitution of the Republic of Senegal (2001), and the International Convention on the Rights of Persons with Disabilities (2006).



Map showing the locations of Senegal's nine *villages de reclassement social* (VRS).

Timeline

- 1976** Law 76-03 establishes the *villages de reclassement social* (VRS) system
- 1995** Senegal eliminates “leprosy as a public health problem” according to standard set by WHO
- 2004** First draft of a bill to repeal Law 76-03
- 2018** Draft circulated for review and sent to the National Assembly
- 2022** National Assembly approves the draft, which becomes Bill 11/2022
- 2023** Minister of Health and Social Action presents Bill 11/2022 to the National Assembly on May 17
 National Assembly adopts Bill 11/2022 on June 5, repealing Law 76-03 and thereby abolishing the VRS system

Report on Bergen International Conference on Hansen's Disease, June 21–22

On June 21–22, 2023, the Sasakawa Leprosy (Hansen's Disease) Initiative and University of Bergen co-hosted an international conference in Bergen, Norway, to commemorate the 150th anniversary of the discovery of the leprosy bacillus *Mycobacterium leprae* by Dr. Gerhard Armauer Hansen. The idea for the conference came from WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa, and the Initiative supported it as part of the "Don't Forget Leprosy/Hansen's Disease" campaign that it launched in August 2021. The Bergen International Conference on Hansen's Disease was attended by approximately 200 participants from 27 countries, including experts on medical and social aspects of the disease, history preservation experts, non-governmental organization (NGO) representatives, and persons affected by leprosy.

During the opening session, Dr. Emmet McCormack, Professor of Pharmaceutics and Pharmaceutical Technology at the University of Bergen, read a statement on behalf of co-organizer representatives Rector Margareth Hagen and Goodwill Ambassador Sasakawa. The statement paid tribute to Dr. Hansen, recognizing the significant impact of his discovery for diagnosis and treatment of the disease, while also pointing out that stigma and discrimination remain. It affirmed the importance of working together to create a society that respects the rights and well-being of all persons affected by the disease.

Dr. Tedros Adhanom Ghebreyesus, Director-General of the World Health Organization, and Volker Türk, United Nations High Commissioner for Human Rights, contributed video messages, which were shared during the opening session. Ingvild Kjerkol, Minister of Health and Care Services (Norway), Lorentz Irgens, Professor Emeritus of the University of Bergen's Department of Global Public Health and Primary Care, and Yuliati, Vice President of PerMaTa Indonesia, also delivered remarks.

After acknowledging the progress that has been made since the discovery of the bacillus in 1873 and the establishment of the World Health Organization in 1948, Dr. Tedros highlighted that "much remains to be done towards our shared goals of zero disease, zero disability, and zero discrimination." He also noted that more effort is needed to recover from health system disruptions caused by the COVID-19 pandemic.

UN High Commissioner Türk said that to improve the lives of persons affected by leprosy, "We need to address the physical symptoms, but we also need social and behavioral measures to address stigma and discrimination. We need

comprehensive strategies with access to quality care, education, and social protection."

Goodwill Ambassador Sasakawa reminded participants that even though leprosy is now a curable disease, "The fight against leprosy as a human rights issue has only just begun."

Thematic sessions focused on the three pillars of the Initiative's strategy: medical challenges, human rights and dignity, and history preservation. Panel discussions included presentations and analysis from scientific and practical perspectives.

Poster sessions, which were divided into an academic section and a best practices section for organizations of persons affected by leprosy, attracted much attention. In the academic section, 19 organizations presented posters on themes that matched those of the discussion panels: medical challenges, human rights and dignity, and history preservation. In the section for organizations of persons affected by leprosy, posters from 12 organizations presented summaries of issues and measures being taken.

Special sessions featured Victoria Hislop, a British author whose best-selling fiction book *The Island* (2005) is set on Spinalonga, a small island off the coast of Crete that was used to isolate persons affected by leprosy from 1903 to 1957, and Abbi Patrix, an accomplished storyteller and great-grandson of Dr. Hansen who learned about his great-grandfather through an inherited archive.

Closing remarks for the conference were given by Dr. Takahiro Nanri, Executive Director of the Sasakawa Health Foundation. He explained that he thinks of international conferences as having three purposes: making the world aware of the large number of people still suffering from leprosy and its effects, building momentum for cooperation toward a world free of leprosy, and providing a forum for both formal and informal exchanges that can lead to innovative solutions. He also acknowledged, "Even if great recommendations and strategies are compiled as a result of the conference, if they are not implemented, they are meaningless." He ended his speech with a call for action and continued collaboration to achieve a world without leprosy.

Video recordings of the Bergen International Conference on Hansen's Disease:

<https://bit.ly/45a0p8C>



Posters of best practices exhibited by organizations of persons affected by leprosy:

<https://bit.ly/3sefV4M>





Commemorative photograph of speakers at the Bergen International Conference on Hansen's Disease (Norway, June 22, 2023).



Dr. Emmet McCormack reading a statement on behalf of co-organizer representatives Rector Margareth Hagen and Goodwill Ambassador Sasakawa.



Yuliati, Vice President of PerMaTa Indonesia, a national organization by and for persons affected by leprosy, giving a keynote speech during the opening session.



Dr. Paul Saunderson of American Leprosy Missions presenting on LepVax during the thematic session on medical challenges.



Jayashree P. Kunju, Director of IDEA International, introducing the speakers at one of the thematic sessions on human rights and dignity.



Dr. Aurturo Cunanan beginning his presentation on the preservation of heritage and memories on Cullion, an island in the Philippines that was once known as the largest leprosy colony in the world.



Representatives from organizations of persons affected by leprosy in front of their posters on best practices.



Dr. Takahiro Nanri, Executive Director of the Sasakawa Health Foundation, delivering closing remarks at the Bergen International Conference on Hansen's Disease.

VIEWPOINT



Faustino Pinto
National Coordinator, Movement for the Reintegration of Persons Affected by Hansen's Disease (MORHAN)

MORHAN is a nonprofit organization and social movement in Brazil that raises awareness of Hansen's disease as a curable disease and advocates for public policies that uphold human rights and support effective treatment.

<http://www.morhan.org.br>

Reflections on my first months as MORHAN's national coordinator

On June 1, 2023, Brazil's Movement for the Reintegration of Persons Affected by Hansen's Disease (MORHAN) held a live online event to honor and say farewell to Artur Custódio, who served as our national coordinator for many years. I have been challenged to step up and take over his role. Although I am still making peace with the whirlwind of responsibilities, I also know that I am surrounded by good and competent people. I will do my best to grow as an activist and coordinate our social movement.

I received my Hansen's disease diagnosis in 1989. At first, I thought that I had to be grateful merely for surviving, but then I started to question the cruelty that I experienced and witnessed around me in the treatment facility. I began to rebel and speak up, but I did so informally and without awareness that I might be engaging in social activism.

My life changed when I met a nurse named Marlene Barroso who was part of a supervision team from the Ministry of Health in my city. Nurse Marlene also happened to be part of MORHAN, and she responded to my barrage of questions by telling me that I have the profile of a social activist. Within months after connecting with MORHAN, I created a nucleus in the city of Juazeiro do Norte. Later, I served as state coordinator for two terms, and then I was invited to join at the national level, first as the secretary of communication and then as vice coordinator.

In 2022, I was invited by the presidents of Concurso Nacional de Beleza (CNB), Henrique Fontes and Marina Fusquine Fontes, to be part of a committee for one of their beauty pageants. Through my involvement, I saw firsthand how pageants that link beauty to purpose-driven action can be helpful to our cause. Contestants have training in public speaking, and they have connections and influence with a wide range of people.

MORHAN's relationship with beauty pageants started in 2013 when Mariana Notarângelo, a medical student who was crowned Miss Brazil World in 2012, assisted Dr. Alicy Scavello in treating people affected by Hansen's disease. Dr. Scavello suggested an ongoing partnership, and when Sancler

Frantz was crowned Miss Brazil World 2013, she became an ambassador for Hansen's disease in Brazil.

Over time, pageant winners began to act together with government agencies, taking petitions and speaking in public. They also started to help with fundraising and the acquisition of equipment and food kits. Media organizations started publicizing the partnerships, and our movement benefited from the attention at several key moments. Heartfelt interaction between the pageant winners and persons affected by Hansen's disease broke prejudices on both sides.

As MORHAN's national coordinator, my focus is on Brazil, but of course Hansen's disease is a global issue. Cultivating relationships with pageants on an international scale holds the potential to propel the movement for the reintegration of individuals affected by Hansen's disease worldwide. This point has been recognized by the Sasakawa Leprosy (Hansen's Disease) Initiative. In July, I participated in the Miss Supranational Hansen's Disease Forum, organized by the Initiative, where contestants from 65 countries learned about the disease and Sancler Frantz spoke about her decade of being part of our movement in Brazil.

The battle against prejudice, discrimination, and stigma continues daily. On behalf of MORHAN, I want to express our appreciation for pageant contestants who are eager to learn and use "the power of the crown" for the good of all.



Miss Supranational Brazil Sancler Frantz speaking to fellow pageant contestants about her experiences as a Hansen's disease ambassador and MORHAN partner (July 5, 2023).

Sasakawa Leprosy (Hansen's Disease) Initiative welcomes new program advisors

The Sasakawa Leprosy (Hansen's Disease) Initiative is a strategic alliance that coordinates the activities of the WHO Goodwill Ambassador for Leprosy Elimination, Sasakawa Health Foundation, and The Nippon Foundation for the purpose of achieving a leprosy-free world. The Initiative is pleased to announce that Dr. Venkata Ranganadha Rao Pemmaraju and Dr. Alice Cruz have joined the team as program advisors. Dr. Pemmaraju has decades of experience with leprosy control that is balanced by awareness from

time spent with persons affected by the disease. He will be providing the Initiative with advice on medical issues. Dr. Alice Cruz has held the mandate for Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members since it was first established by the Human Rights Council in 2017. She will be advising the Initiative on programs related to social and human rights. With great appreciation for their expertise, the Initiative warmly welcomes them both.



Dr. Venkata Ranganadha Rao Pemmaraju

Program Advisor for Medical Issues

As an epidemiologist and Acting Team Leader of WHO's Global Leprosy Programme, I contributed to the development of effective global strategies for elimination of leprosy. Patient-centered approaches were introduced while developing technical guidance to improve quality care. The inclusive approach followed in interacting with national programs, partners, and persons affected by leprosy helped improve rapport with all stakeholders.

I started my leprosy work as a field medical officer in the early 1980s in a remote village of southern India. I soon realized that "pills alone" cannot treat leprosy completely. My interactions gradually increased with persons affected and I learned to address leprosy from both medical

and social perspectives. My research covered areas of development of field-friendly nerve function assessment protocols and appropriate footwear for prevention of disabilities for persons affected by leprosy. Facilitating meaningful and effective participation of persons affected by leprosy remained my passionate approach. I involved persons affected throughout my work, and true to my conviction, global strategies and technical guidance protocols on leprosy care got enriched significantly with their inputs. My work has been very much influenced by Mr. Yohei Sasakawa and I continue to draw inspiration from his work.

I gladly accept the opportunity to work as part of the Sasakawa Leprosy (Hansen's Disease) Initiative team with heartfelt gratitude, and I look forward to contributing to the cause of leprosy with all enthusiasm and commitment.



Dr. Alice Cruz

Program Advisor for Human Rights Issues

Last June, I presented my final report to the Human Rights Council as the United Nations Special Rapporteur on the elimination of discrimination against persons affected by leprosy (Hansen's disease) and their

family members. The Human Rights Council is currently selecting the next Special Rapporteur, while I am preparing to hand over the mandate to my successor. Being the Special Rapporteur was the greatest honor of my life and I experienced unforgettable moments alongside so many people worldwide. But it was also just another step in my personal path as an activist for the human rights of persons affected by Hansen's disease. Besides being a scholar engaged with Hansen's disease, I have also been a volunteer

in MORHAN, the Brazilian organization of persons affected by Hansen's disease, for many years. I feel extremely grateful for the amazing opportunity to be a human rights adviser to the Sasakawa Health Foundation, a highly trusted organization among persons affected by Hansen's disease, and hence to continue contributing to the community. I hope that the in-depth knowledge I have gained over the years can be helpful to advance the human rights of persons affected by Hansen's disease at the subnational, national, and international levels. I look with great joy to the special opportunity of continuing to work for the empowerment of persons affected by Hansen's disease, the strengthening of their representative organizations, and the global enforcement of their rights. I embrace this opportunity with sincere gratitude, heartfelt enthusiasm, and deep commitment.

Goodwill Ambassador Sasakawa attends Bergen International Conference on Hansen's Disease

WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa visited Norway, June 21–22, to attend the Bergen International Conference on Hansen's Disease. The event was co-sponsored by the Sasakawa Leprosy (Hansen's Disease) Initiative and the University of Bergen. The Goodwill Ambassador met with Norway's Minister of Health and Care Services, Ingvild Kjerkol, and Dr. Hansen's great-grandson, Abbi Patrix, as well as other participants. He also enjoyed reconnecting with representatives from organizations of persons affected by leprosy, who had been selected to share posters of best practices at an exhibition. The Goodwill Ambassador was interviewed by Norway's National Broadcasting Corporation (NRK). He also met with officials from the Bergen International Film Festival who are planning to show Hansen's disease–related films as part of a thematic category at the festival in October.



Goodwill Ambassador Sasakawa with some of the representatives from persons affected by leprosy organizations that participated in the Bergen International Conference on Hansen's Disease (June 21–22, 2023).

INITIATIVE NEWS

Sasakawa Leprosy (Hansen's Disease) Initiative launches cooperative relationship with the Miss Supranational Organization

Miss Supranational is an international beauty pageant that emphasizes natural grace and community service. In 2020, the Miss Supranational Organization launched "From the Ground Up," an initiative meant to encourage grassroots projects that address local needs. This year's contestants showcased projects addressing issues such as education for disadvantaged youth and environmental sustainability. While contestants representing 65 countries were gathered in Poland for this year's competition, the Sasakawa Leprosy (Hansen's Disease) Initiative launched a collaborative relationship with the Miss Supranational Organization by hosting a two-hour "Miss Supranational Hansen's Disease Forum" on July 5. The Initiative hopes that contestants will use their platforms to inspire more people to learn about the

disease and what they can do to eliminate stigma and discrimination. For additional details about the forum, see <https://sasakawaleprosyinitiative.org/latest-updates/initiative-news/4307/>.



Miss Supranational contestants from 65 countries learned about Hansen's disease and related human rights issues at a forum hosted by the Sasakawa Leprosy (Hansen's Disease) Initiative on July 5, 2023.

**SASAKAWA
LEPROSY
HANSEN'S DISEASE
INITIATIVE**

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