

LEPROSY BULLETIN

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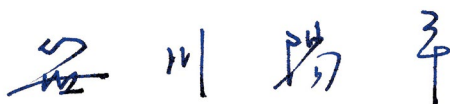
Leprosy should not be a silent disease

Message from the ambassador

From May 20 to 23, 2025, I attended the 78th World Health Assembly held in Geneva, Switzerland. This year marks the 50th anniversary of support from The Nippon Foundation and the Sasakawa Health Foundation (TNF/SHF) for WHO's leprosy elimination efforts. At the invitation of WHO Director-General Dr. Tedros Adhanom Ghebreyesus, I joined this year's investment round meeting, where I announced that TNF/SHF will continue to support WHO's Global Leprosy Program by providing 23 million US dollars over the next 10 years.

In addition, I met with delegations from 16 countries to encourage progress toward zero leprosy. Tentative agreement was reached to hold two national conferences: one in Sri Lanka in November 2025 and another in Brazil in March 2026. I also confirmed that health ministers of African countries are continuing to work toward a regional "Africa Zero Leprosy Conference." With the health minister from Indonesia, I spoke about my upcoming visit in July, when we will go together to see conditions in endemic areas.

Leprosy is known as a "silent disease" because it starts without noticeable symptoms like pain or fever. The disease tends to be "silent" in other ways as well. Persons affected by leprosy may have difficulty speaking up because of the way the disease is known in their community. If they stay "silent," they become undiagnosed "hidden patients" and they will be unrepresented, or "silent," in public health data as well. We cannot achieve zero leprosy without addressing these various kinds of silence. I may be 86 years old, but that will not stop me from speaking up about them.



Yohei Sasakawa

WHO Goodwill Ambassador for Leprosy Elimination

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Felehansen mentor team

Sasakawa Young Scholar Program (Colombia)

PerMaTa South Sulawesi—

YDTI mentor team

Sasakawa Young Scholar Program (Indonesia)

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

VIEWPOINT



Krishna Man Pradhan
Executive Director, Nepal Law Society

As the Executive Director of the Nepal Law Society (NLS) since 2000, Krishna Man Pradhan has led numerous initiatives aimed at strengthening the rule of law, promoting democracy, and ensuring an independent judiciary.

<https://nepallawsociety.org>

How the rights of persons affected by leprosy have been brought to public attention in Nepal

In Nepal, approximately 200,000 individuals are currently affected by leprosy, with over 2,500 new cases reported annually. The Government of Nepal has committed to achieving a leprosy-free nation by 2030.

Pervasive social stigma associated with leprosy often deters individuals from seeking medical attention, leading to delayed diagnoses and continued transmission of the disease. The government's limited capacity for providing early detection, diagnosis, continuous treatment, and social rehabilitation, as well as the socio-economic hardships faced by many persons affected by leprosy and their family members, present additional systemic challenges.

The Constitution of Nepal guarantees fundamental rights to all citizens, including the right to live with dignity, equality, freedom from untouchability and discrimination, privacy, health, social justice, and social security. But policymakers, lawmakers, and administrators have seldom recognized leprosy-based discrimination as a violation of constitutional rights. Notably, the Civil Code introduced in 2018 includes a provision allowing leprosy in a spouse to be grounds for seeking divorce, further entrenching stigma and discrimination.

The Nepal Law Society (NLS) – which has been involved for the last four decades in promoting constitutional rights and human rights, in partnership with the government, the parliament, and the judiciary – was itself unaware of the legal situation pertaining to the persons affected by leprosy for far too long.

In 2024, the NLS worked with Sasakawa Health Foundation (SHF) and the Ministry of Health/Prime Minister's Office to conduct research on the elimination of discrimination against persons affected by leprosy. The NLS conducted a legal review and promoted legal/human rights capacity-building of organizations. The effort involved wide consultations at federal, provincial, and local levels with stakeholders. It was found that most of the policy makers were unaware of continued legal discrimination against persons affected by leprosy.

NLS and SHF followed up by planning and organizing a national conference for shedding public light on the matter. On May 8–9, 2025, the National Conference on the Elimination of Leprosy and the Discrimination against the Persons Affected was held in Kathmandu. The key objectives of the conference included conducting advocacy for the highest political commitment; acceleration of efforts to eliminate leprosy and improved care; and inclusion of persons affected by leprosy.

Prime Minister of Nepal KP Oli was the chief guest. Other participants included the Health Minister, senior officials, senior parliamentarians, and stakeholders from all provinces of Nepal. The Prime Minister addressed the conference and expressed that he, too, was unaware of the continued discrimination against persons affected by leprosy.

The major outcomes of the event included public commitment from the highest level of government about improving not only the care situation but also the legal rights of persons affected by leprosy. The Prime Minister himself said that he will support efforts to bring about necessary legal reforms and urged the Health Minister, parliamentarians, and other stakeholders present at the conference to go ahead. Health Minister Pradeep Poudel expressed full commitment to move an integrated amendment proposal to reform the laws pointed out as discriminatory by NLS/SHF research. The research showed the necessity of reforming eight different laws, including the civil/criminal code.

In short, the conference successfully presented this matter as a national issue, garnered the government's as well as parliament's commitment for legal reforms, and brought together all stakeholders. The conference concluded with the issue of a 10-point declaration.

After the event, NLS and SHF started discussing two-year programs that will follow up and lobby for the early conclusion of legal reforms; programs to support the law/policy amendment process; provision of legal aid to persons affected by leprosy on human rights grounds; and continued support for awareness programs.

Participants reflect on Nepal Leprosy Conference, held in Kathmandu on May 8–9, 2025



Amar Bahadur Timalisina
Global Network Coordinator
IDEA International

IDEA International promotes the equal participation, human rights, and dignity of persons who have experienced a neglected tropical disease.



Attending the historic Nepal Leprosy Conference 2025 was both inspiring and deeply moving. Witnessing the unified commitment of national leaders, experts, the Prime Minister of Nepal, and especially the strong commitment of WHO Goodwill Ambassador Yohei Sasakawa toward a leprosy-free world reaffirmed the urgency of our shared mission. Voices of those affected and calls for joint collaboration emphasized that leprosy is not only a medical issue but also a matter of social justice. The conference's focus on inclusive healthcare and dignity for all was impactful. It renewed my commitment to actively engage, advocate, and ensure no one is left behind."



Dinesh Basnet
President
IDEA Nepal

Founded in 1998, IDEA Nepal is a national-level nongovernmental organization run by persons affected by leprosy.



The Nepal Leprosy Conference 2025, supported financially by the Sasakawa Health Foundation, created a huge stir in the country because it helped increase the self-confidence in us, the people affected by leprosy. It effectively captured media attention and raised awareness as all three layers of government – federal, provincial, and local – were present along with persons affected by leprosy from across the country. We, the people affected by leprosy, have really felt dignified. I express my utmost gratitude to the Sasakawa Health Foundation for its authentic passion, commitment, and continuous support for reducing stigma and discrimination in Nepal."



Taranath Sigdel
Secretary
National Leprosy Affected Welfare
Association (NLAWA)

NLAWA is a nonprofit organization dedicated to enhancing the well-being of persons affected by leprosy and their family members.



The Nepal Leprosy Conference 2025 was a historic and impactful event. I was deeply honored to participate as a person affected by Hansen's disease. The inclusive and meaningful involvement of persons affected by Hansen's disease from across provinces made the conference truly empowering. Updates on progress and challenges shared by health workers at all levels, including national and sub-national, were insightful. The Prime Minister's opening speech and the Health Minister's strong call to end discrimination inspired hope nationwide. The focus on early detection, human rights, and social issues was commendable. The conference left me feeling supported and optimistic about Nepal's journey toward zero leprosy."



Nathuni Sah
Facilitator
Gourishankar Self-Help Group
President
Sarlahi District Self-Help Group

Nepal has over 115 self-help groups (SHGs) that facilitate self-care, stigma reduction, and mutual aid.



Discussions at the Nepal Leprosy Conference 2025 focused on early case detection, stigma reduction, integrated health services, and community-based rehabilitation. While the conference provided a critical platform for dialogue and strategy, the significant contributions of Self-Help Groups (SHGs) in empowering individuals affected by leprosy and combating stigma were notably underrepresented.

SHGs remain a proven grassroots mechanism for promoting inclusion, dignity, and long-term resilience in affected communities. As Nepal moves closer to eliminating leprosy, it is vital that the voices and roles of affected individuals – especially through SHGs – are fully recognized and supported."

Young leaders affected by Hansen's disease reach for their dreams with mentors' support in Colombia

Contributed by the Felehansen mentor team for the Sasakawa Leprosy (Hansen's Disease) Initiative Young Scholar Program in Colombia, pilot year April 2024–March 2025



Mentor team members Martha Cecilia Barbosa Ladino (left) and Carolina Méndez Pulido

Due to the physical alterations caused by leprosy, persons affected by Hansen's disease have historically faced rejection and social isolation. Various organizations have stepped in to provide charitable support to improve their living conditions and ensure their well-being. While this support has improved the immediate quality of life for persons affected by the disease, it has also had the effect of making some individuals dependent on external aid.

In Colombia, charitable support peaked during the 1980s and 1990s, when not only technical and food assistance but also equipment and housing were provided to promote rehabilitation. However, from the perspective of those living with the disease, there were problems with this type of support: namely, it reached only a few due to geographical barriers and it turned people into passive recipients.

In recent decades, interest in Hansen's disease in Colombia has declined to the point that many professionals and community members are unaware of its existence, its symptoms, and the severity of consequences when diagnosis is delayed. This decline in interest, combined with highly stigmatizing popular beliefs surrounding leprosy, has significantly reduced efforts to mitigate the disease and its impact on persons affected.

In response to the needs of those living with the disease and the changing context of leprosy in Colombia, the German Leprosy and Tuberculosis Relief Association (DAHWA) launched the Community-Based Rehabilitation (CBR) strategy for persons affected by Hansen's disease in 2008. This initiative empowered persons affected by Hansen's disease to act on their desire to improve the living conditions of their peers, reduce stigma in the community, and reach those who remain undiagnosed and suffer in silence.

Some of the participants in CBR activities grew into leaders who then established local associations, and in 2014 they came together to found a national federation called Felehansen. Through the federation, they have engaged in advocacy with public and private entities, helping themselves

and those they represent to fulfill their long-standing dream of being the protagonists of their own development.

For Felehansen, the Sasakawa Leprosy (Hansen's Disease) Initiative Young Scholars Program fits with what we know about the importance of the experience of being a protagonist in one's own life. The program is meant to provide comprehensive training to young leaders affected by Hansen's disease, helping them to define and achieve their personal, professional, and community goals.

In Colombia, the Young Scholars Program is structured to address three themes in parallel: leadership, individual technical/professional training, and design and execution of a community project. The young scholars participate in various individual and group learning spaces alongside experienced leaders from Felehansen, who have more than 10 years of expertise in working with persons affected by Hansen's disease.

Over the past year, the young scholars have enhanced their knowledge of the disease, improved their public speaking skills, and cultivated their personal and professional leadership abilities for community work. The program has also had a positive impact on their peers and family members, who enjoy seeing them looking happier and more motivated to continue dreaming of a better future for those affected by the disease.

At Felehansen, we are convinced that the Young Scholars Program has potential to reach a considerable number of young persons affected by Hansen's disease and create a lasting impact in affected communities worldwide. The program provides the right kind of support to help these young people grow in self-belief that they are, and can always be, the architects of their own development.



Sasakawa Young Scholar Program participants hold their new laptop computers alongside mentor Martha Cecilia Barbosa Ladino (left) and President of Felehansen Lucrecia Vásquez Acevedo (right) in Bogotá, Colombia (July 2024).

Sasakawa Leprosy Initiative Young Scholar Program: Experiences and lessons learned in Indonesia

Contributed by the PerMaTa South Sulawesi–YDTI mentor team for the Sasakawa Leprosy (Hansen’s Disease) Initiative Young Scholar Program in Indonesia, pilot year April 2024–March 2025



Mentor team members (from left) Roni Saputra, Kerstin Beise, Al Kadri, Muh Arfah, Salmawati, Yuliaty, Rahmawati, and Ermawati

The Indonesian people’s organization PerMaTa South Sulawesi, in collaboration with the nonprofit organization YDTI, participated in the pilot phase of the Sasakawa Leprosy (Hansen’s Disease) Initiative Young Scholar Program for one year beginning April 2024. Four young persons affected by leprosy were selected as “scholars” to participate in a program for strengthening their skills as role models, activists, and leaders for the rights of persons affected by leprosy.

The scholars participated in a three-month intensive course in Makassar, South Sulawesi’s capital city. The course, provided by a number of experienced trainers, covered a wide range of topics – from leprosy, human rights, and advocacy to proposal writing and English. The scholars were also involved in the field activities of the PerMaTa South Sulawesi–YDTI team and learned the ins and outs of NGO work.

Following the intensive course, the scholars developed and implemented their own small projects in their home towns. They also participated in further individual studies of their choice, which can help them earn a living and become even more professional activists.

As a mentoring team, we accompanied the scholars on their not-always-easy path. Initially, three of the four scholars still suffered from frequent reactions. Two of them were able to persevere with greater self-confidence and ease of mind because of the peer support that they received as part of the Young Scholar Program. Unfortunately, one of them, our dear friend Fikrin, passed away as a consequence of his condition.

All these experiences led to a very acute awareness among the scholars of the complex challenges faced by persons

affected by leprosy in a world that assumes that leprosy is no longer a problem. Their dedication to addressing these challenges grew as a result of the program. Likewise, our own team at PerMaTa South Sulawesi benefitted from accompanying the scholars: As team members realized how far they had come already and how important they were as role models for their junior peers, they made progress in conquering their own self-stigma. A strong network among the young people was formed, which we hope to expand further with future scholar programs.

For a small organization such as ours, the Young Scholar Program presented some challenges. We had to bring people from different areas in Indonesia together, and we had to find time for training sessions and mentoring in addition to our other activities. For the scholars, it was challenging to participate in the program while also taking care of other obligations related to livelihood and family. But everyone was happy to take on these challenges! The success of the scholar program in Indonesia has helped to secure the future of the individual scholars and further expanded and strengthened our rights-based leprosy movement. Thank you to the Sasakawa Leprosy (Hansen’s Disease) Initiative for your support and trust in us.



PerMaTa–YDTI mentor Arfah shows Young Scholar Program participants how to write a report (Aug. 8, 2024).

Editor’s note: The application period for a second round of the Young Scholars Program closed on May 30, 2025. Following interviews, PerMaTa South Sulawesi–YDTI will announce results on June 30. For more information see

Sasakawa Young Scholars Program – 2nd Round:
<https://ydti.org/project/current-project/shf-young-scholar-program/>



Goodwill Ambassador Sasakawa attends conference in Nepal and World Health Assembly in Switzerland

In May, WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa participated in the Nepal Leprosy Conference 2025 held in Kathmandu (May 8–9) and met with health ministers from various countries and senior WHO officials during the 78th World Health Assembly in Geneva, Switzerland (May 19–27).

Nepal Leprosy Conference 2025

Under the leadership of Prime Minister KP Sharma Oli, Nepal took the historic step of holding the country's first national-level conference for accelerating the elimination of leprosy and related stigma and discrimination. Over 200 participants, including all provincial leprosy program heads, gathered for two days of presentations and panel discussions.

In his remarks at the opening session, the Prime Minister encouraged aiming for the eradication of leprosy and called for intensification of efforts to eliminate discrimination against persons affected by leprosy.

Minister of Health and Population Pradip Paudel pledged that all ministries would work together and secure resources under a national strategy to achieve zero leprosy by 2030.

A panel discussion on the second day of the conference highlighted the importance of revising laws and systems that enable discrimination.

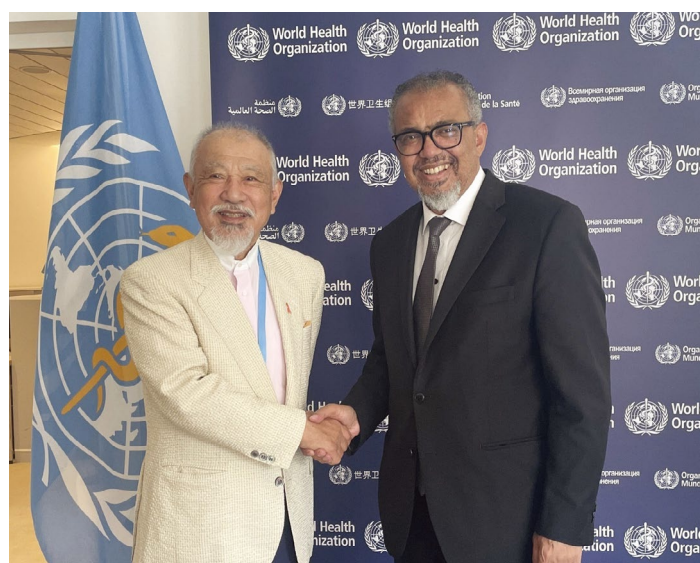
The Goodwill Ambassador thanked the Prime Minister for his support for the conference, noting that the national leader showed immediate enthusiasm for the idea when it was first suggested during a meeting in September. He also expressed his deep respect for the important role played by self-help groups (SHGs) of persons affected by leprosy in early detection, treatment, and awareness-raising activities.



WHO Goodwill Ambassador Sasakawa gives a speech at the Nepal Leprosy Conference 2025 in the presence of Minister of Health and Population Pradip Paudel (seated center left) and Prime Minister KP Sharma Oli (center right) on May 8, 2025.

Meetings during 78th World Health Assembly

In Geneva, Switzerland, over the course of three days, May 20–22, the Goodwill Ambassador met with delegations from countries attending the 78th World Health Assembly as well as with high-level officials, including the African Union Commissioner for Health, Humanitarian Affairs, and Social Development; the WHO Director-General; and WHO Regional Directors.



The Goodwill Ambassador, who is also the Chairman of The Nippon Foundation, announced during the investment round on May 20 that the Sasakawa Health Foundation would be donating 23 million US dollars over the next 10 years to cover the cost of WHO's Global Leprosy Program. WHO Director-General Dr. Tedros Adhanom Ghebreyesus expressed his appreciation.

Since his appointment as WHO Goodwill Ambassador, Yohei Sasakawa has attended the World Health Assembly almost every year and has conducted intensive advocacy activities to gain cooperation in the fight against leprosy. This year, the World Health Assembly took place under the cloud of an announcement from the United States of America that the country intends to withdraw from WHO and, as of Jan. 20, 2025, would “pause the future transfer of any United States Government funds, support, or resources” to the organization. Amid widespread concern about WHO's financial stability, the Goodwill Ambassador met with delegations from 16 countries, exchanging views on the status of efforts in each country and possibilities for future cooperation.

For eight of the 16 countries, the Goodwill Ambassador was able to meet directly with health ministers to discuss details of their plans for reaching zero leprosy. Topics addressed included advocacy, active case-finding, elimination of discrimination, and meaningful involvement of persons affected by leprosy.



Dr. Alexandre Rocha Santos Padilha, Minister of Health, Brazil

Brazil will hold a national conference in March 2026. President Lula's support has been confirmed. Brazil and India, the two states with the highest number of leprosy patients, are in communication about how they might cooperate.



Dr. Ussene Hilário Isse, Minister of Health, Mozambique

The Minister shared information about leprosy in Mozambique and challenges in the northern region. The country's policy emphasizes the importance of prevention and awareness activities at the community level.



Dr. Nassuha Oussene Salim, Minister of Health, Solidarity, Social Protection and Gender Promotion, Comoros

Active case-finding is yielding results. The Goodwill Ambassador was asked to visit and evaluate the program.



Ms. Jenista Joakim Mhagama, Minister of Health, Tanzania

Tanzania is making coordinated efforts to promote case detection in rural areas, train health workers, and conduct monitoring, while also placing emphasis on the social integration of persons affected. Agreement was reached that the Goodwill Ambassador will visit before the end of the year.



Mr. Pierre N'gou Dimba, Minister of Health, Public Hygiene and Universal Health Coverage, Côte d'Ivoire

The country is focusing on the role of nurses. They are committed to optimizing treatment systems and strengthening interregional cooperation.



Mr. Budi Gunadi Sadikin, Minister of Health, Indonesia

The Minister is strongly committed to achieving zero leprosy by 2030. Under

his direction, screening goals are being accelerated, starting with 200 districts that have not yet met the "elimination as a public health problem" target. The Ministry of Health is also working on responding to instances of fatality linked to severe leprosy reactions as well as developing a system of post-exposure prophylaxis for close contacts. At the 22nd International Leprosy Congress to be held in Bali in July, the Minister and the Goodwill Ambassador will hold a joint session, after which they will travel together to visit endemic areas.



Dr. Teodoro Herbosa, Secretary of Health, Philippines

The Secretary explained how the country has reduced misdiagnosis through a teleconsultation system based on mobile phones. He stated emphatically that he wants to achieve zero leprosy during his lifetime.



Dr. Nalinda Jayatissa, Minister of Health and Mass Media, Sri Lanka

The Minister confirmed that Sri Lanka will hold a national conference in November of this year. The Goodwill Ambassador emphasized the importance of the president's attendance and the participation of persons affected by leprosy.

Representatives from Nepal, Indonesia, and Bangladesh speak at academic conference

The Sasakawa Leprosy (Hansen's Disease) Initiative recently supported representatives of organizations of persons affected by leprosy from Nepal, Indonesia, and Bangladesh as well as representatives of their local NGO partners to speak at the 13th ISTR Asia-Pacific Regional Conference held on the University of the Philippines campus in Cebu. ISTR (International Society for Third Sector Research) promotes academic exchange and knowledge generation about the "third sector" – including philanthropy, nonprofit organizations, volunteering, and social movements – to inform and support civil society around the globe.

The team spoke on Apr. 23, 2025, at a roundtable that explored organizations of persons affected by leprosy as examples of social and solidarity economy (SSE) organizations that can contribute to sustainable, rights-based development. Representatives from Nepal and Indonesia joined in person; those from Bangladesh joined remotely.

Participation in the conference established connections with the ISTR secretariat and local members of the ISTR Asia

Pacific Regional Network. These connections are expected to be valuable for ongoing dissemination of information about the situations of persons affected by leprosy within academia and the third sector.

The next day, on Apr. 24, the group visited the Eversley Childs Sanitarium and General Hospital. The facility has an inpatient care ward for leprosy patients experiencing reactions or complications as well as a residential area, where 35–40 persons affected by leprosy who have been cured of the disease live in cottages. During the visit, hospital officials explained the country's medical system and the situation of support for persons affected by leprosy.

Attending the conference and visiting the hospital gave the representatives knowledge and connections that they can put to use for their respective organizations and countries. The opportunity to spend time together in person also contributed to promoting international exchange among organizations of persons affected by leprosy.



Representatives of the Sasakawa Leprosy (Hansen's Disease) Initiative, organizations of persons affected by leprosy, and their local support organizations stand together after making a joint presentation at the 13th International Society for Third-Sector Research (ISTR) Asia-Pacific Regional Conference held in Cebu, the Philippines (Apr. 23, 2025).



The representatives visited the Eversley Childs Sanitarium and General Hospital in Mandaue, Cebu, the Philippines. The residential area of the sanitarium, which was established in 1930, continues to house 35–40 persons affected by leprosy who have been cured of the disease (Apr. 24, 2025).

**SASAKAWA
LEPROSY**
HANSEN'S DISEASE
INITIATIVE

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