

# LEPROSY BULLETIN

NO. 123 OCTOBER 2024



## Message from the ambassador

In September, I visited Nepal for the first time in 10 years. I met with President Ramchandra Paudel and Prime Minister KP Sharma Oli to ask them to reinvigorate leprosy control activities now that the worst of the COVID-19 pandemic has passed. They agreed to hold a national leprosy conference to kick off intensified efforts.

From Kathmandu, I traveled to Madhesh Province, which has the largest number of leprosy patients in Nepal. I met with Chief Minister Satish Kumar Singh, and I also visited the Lalghadh Leprosy Hospital and Services Centre. The hospital is located near the border with India, and Indian citizens account for 34% of the hospital's patients. I was impressed by how the hospital treats all patients equally and free of charge, regardless of their nationality.

The self-help groups established and supported by the hospital are more than just mutual aid organizations; they are actively involved in patient identification, disability care, peer counseling, livelihood improvement, and awareness-raising. Wherever they are present, stigma and discrimination are significantly lower than in other areas. The Madhesh Province self-help groups are a model for what is possible, and I want to support the emergence of more groups like this.

At the end of my trip, I was pleased to visit the Nepal Mountaineering Association (NMA), where Mingma Gyabu Sherpa, the mountaineer who held up a "Don't Forget Leprosy" banner at the top of Mt. Everest, is an executive board member. I am grateful to the board for agreeing to spread word of the campaign through its international network. I ended my visit to Nepal feeling inspired and freshly committed to achieving zero leprosy.

Yohei Sasakawa

WHO Goodwill Ambassador for Leprosy Elimination

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

50th Anniversary of WHO–TNF/SHF Partnership



**Dr. Lutz Hegemann**  
**President, Global Health & Sustainability**  
**Novartis**

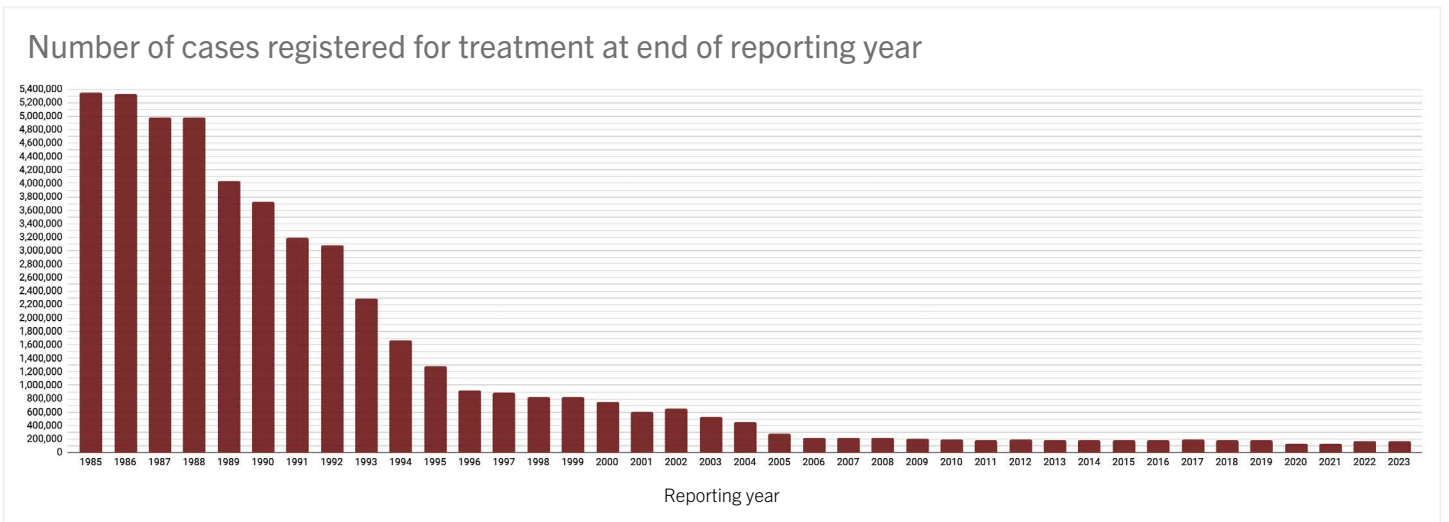
The Global Health & Sustainability unit at Novartis focuses on delivering innovation and improving access to medicine in low-resource settings worldwide, while integrating environmental, social, and governance (ESG) principles across the entire Novartis organization.

<https://www.novartis.com/esg/global-health>

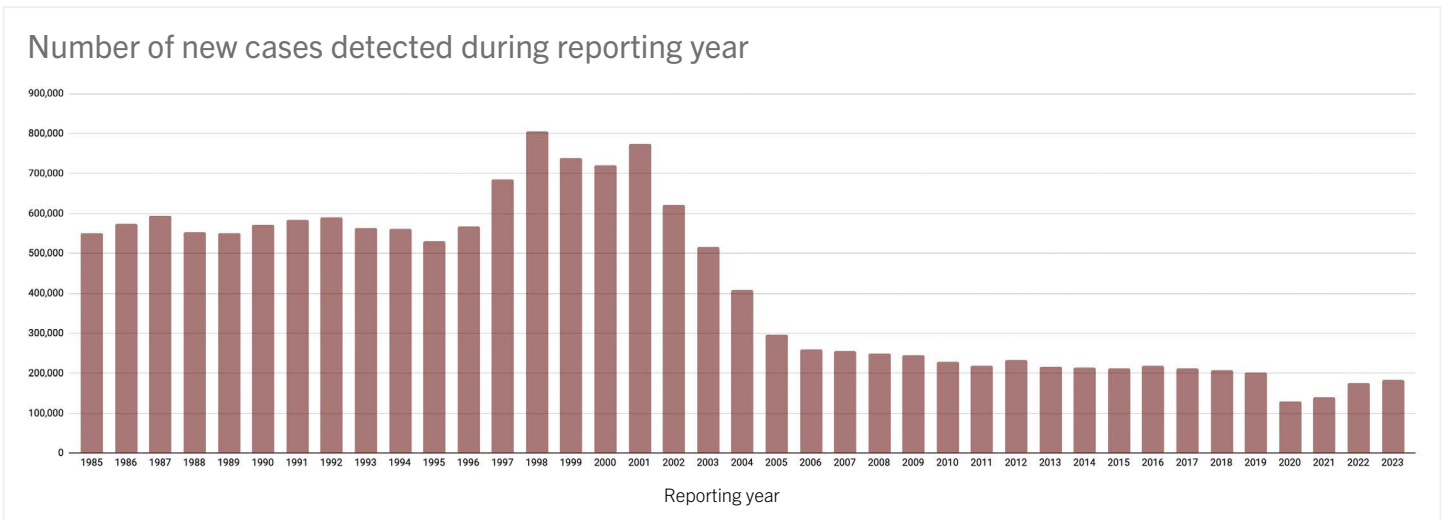
# Partnerships are the way to create sustainable impact

Novartis has been committed to eliminating leprosy for decades, with our multidrug therapy (MDT) as a cornerstone in treating approximately 18 million patients since 1981. Prior to the 1980s, leprosy affected millions of people. However, worldwide introduction of freely available MDT – supported in no small part by The Nippon Foundation (TNF) – marked the start of a massive downward shift in the number of patients. The global MDT donation model funded by TNF

and facilitated by the World Health Organization (WHO) from 1995 to 1999 paved the way for Novartis to continue to manufacture and donate MDT in the years that followed, and we continue to donate MDT worldwide via WHO today. Ultimately, the global prevalence of the disease has fallen by over 95% in the past four decades; yet, we have now reached a plateau.



Aside from a dip during the COVID-19 pandemic, the total number of cases being treated worldwide has stayed steady at around 200,000 since 2006. Stopping transmission in remaining endemic pockets is a global challenge. Data source: World Health Organization (WHO) Global Leprosy Programme.



The number of new cases is related to case finding activities, which stalled during the COVID-19 pandemic. As these activities have resumed, the number of new cases has been rising toward the former plateau at around 200,000 cases per year. Data source: World Health Organization (WHO) Global Leprosy Programme.

I began my career as a public health physician in India in the late 1980s, treating people with leprosy. Many people are surprised that leprosy still exists, but my personal experience means the fight against the disease is close to my heart. Today, we know how to diagnose the disease, and we have effective treatments, but we need to do a better job of reaching the remaining patients, who often live in remote places. The challenge is to go the last mile to eliminate the disease.

At Novartis, we are committed to leprosy elimination through innovations in access to therapies. Our strategy to support leprosy elimination is built around three guiding principles: access, countries, and partnerships.

## Access

Novartis is focused on optimizing access to MDT, while paving the way to use single dose rifampicin (SDR) as a post-exposure prophylaxis (PEP). The evidence for using SDR as a prophylaxis came from the Novartis Foundation Leprosy Post-Exposure Prophylaxis (LPEP) program, which drove the inclusion of this intervention in the WHO *Guidelines for the Diagnosis, Treatment and Prevention of Leprosy*. We are also working with WHO to support the use of NTDeliver, an online platform to monitor and optimize supply chains for medicines for neglected tropical diseases, including MDT for leprosy. Novartis has also expanded its leprosy donation program with WHO by including funding for SDR to interrupt transmission.

## Countries

We work with countries to develop customized action plans for leprosy elimination, especially the leprosy-endemic countries where Novartis has a presence. This involves working with the health ministries, NGOs, local communities, and international health agencies. We are also working with the Swiss Tropical and Public Health Institute and the German Leprosy and Tuberculosis Relief Association to launch a project in Tanzania called Morogoro Leprosy Elimination Program (MoLEP). MoLEP seeks to demonstrate the feasibility of interrupting leprosy transmission through comprehensive evidence-based interventions, including SDR-PEP.

## Partnerships

Novartis collaborates with global and country partners to work towards leprosy elimination. Alongside the Sasakawa Health Foundation (SHF) and the International Federation of Anti-Leprosy Associations, we are a founding member of the Global Partnership for Zero Leprosy (GPZL). Through GPZL, Novartis funds and provides technical expertise on topics such as diagnostics. We also have a long-standing partnership with WHO, as mentioned above.

## Supporting WHO's Global Leprosy Strategy

The Global Leprosy Strategy set by WHO is built around four pillars:

1. Implement integrated, country-owned zero leprosy road maps in all endemic countries;
2. Scale up leprosy prevention alongside integrated active case detection;
3. Manage leprosy and its complications and prevent new disability; and
4. Combat stigma and ensure human rights are respected.

As a pharmaceutical company, Novartis can leverage its long-standing expertise in developing, manufacturing, and supplying medicines to make unique contributions to pillars 1 and 2. SHF's broader involvement in all four pillars complements our work and ensures that the needs of persons affected by leprosy are being addressed. Novartis and SHF have a collaborative relationship that shows how organizations can cooperate to tackle society's most pressing issues.

According to WHO, the elimination of leprosy as a public health problem globally (defined as prevalence of less than 1 per 10,000 population) was achieved in 2000. Since then, we have seen control activities decline in most endemic countries. The challenges of leprosy elimination cannot be tackled by individual countries, sectors, or organizations. They can only be addressed through multi-sector partnerships, with shared visions, bringing complementary skills and experience. While partnerships are not always easy to create, they are the only way to create sustainable impact. We are proud to have worked alongside SHF for so many years on such a bold shared ambition as eliminating a disease.



Dr. Lutz Hegemann of Novartis shares a moment with WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa before the opening ceremony of the 21st International Leprosy Conference (Hyderabad, India, Nov. 8, 2022).

## VIEWPOINT



**Dr. Ritu Ghosh**  
Executive Director, Global Partnership for Zero Leprosy (GPZL)

GPZL welcomed Dr. Ghosh as its new Executive Director in August 2024. Her mission is to strengthen country partnerships and champion the rights of persons affected by Hansen's disease. She is expected to play a critical role in expanding GPZL's initiatives.

<https://zeroleprosy.org/>

## Leading GPZL to new heights in the global fight against Hansen's disease

Hansen's disease, also known as leprosy, is not just a medical condition – it affects every aspect of a person's life. It impacts independence, mobility, and is often linked to deformity, which in turn leads to severe social stigma and discrimination. This stigma creates barriers to employment, social standing, and mental health. When a person is diagnosed, their family is often affected as well, leading to generational hardship. It is heartbreaking to see how such an ancient disease continues to devastate lives.

Globally, national leprosy programs still detect around 200,000 new cases of leprosy each year, with the highest burden found in India, Brazil, and Indonesia. These cases are often found in marginalized communities with limited access to healthcare and support systems. The introduction of multidrug therapy (MDT) in 1981 was a breakthrough, making the disease curable. But humanity's work is far from over. We need to push for further research, especially in developing vaccines. Furthermore, early diagnosis is critical. To eliminate transmission, we must implement field-based rapid testing kits and launch post-exposure prophylaxis (PEP) programs.

One of my primary focuses at GPZL is to strengthen health systems in the public and private sectors, and thereby positively impact the lives of individuals with lived experience of Hansen's disease. I would like GPZL and our partners to direct resources where they can have the greatest impact. Ensuring that underserved communities receive the care they need involves scaling up research that looks beyond the medical aspects of the disease. We must examine the social determinants, such as water, sanitation, hygiene (WASH), nutrition, and gender equity.

In many countries, there is a lack of gender-disaggregated data. Women, for example, often face additional barriers to accessing healthcare. Addressing these inequities is crucial to eliminating the disease.

Despite medical advancements, stigma remains one of the most damaging aspects of Hansen's disease. In some countries, even after being cured, persons who were once

affected by leprosy are still denied basic rights, such as right to education or right to employment.

We need to focus on rehabilitation, not only in terms of physical recovery, but also in terms of social, mental, and occupational reintegration. Persons who have been affected by the disease need comprehensive support to rebuild their lives.

My vision for GPZL includes expanding our resources by drawing the attention of the private sector, particularly corporations, to leprosy elimination issues so they can invest their resources. Additionally, I want GPZL to build stronger partnerships at the country level by collaborating with governments, businesses, local leaders, and like-minded organizations to amplify our impact.

In the long run, I see GPZL evolving into what I like to call "GPZL 2.0." This version of our organization will be even more equipped to serve persons affected by leprosy, influence policy, and impact broader health and development sectors. My goal is to create a ripple effect across communities, leaving no one behind.

I am deeply committed to leading GPZL to new heights in our global fight against Hansen's disease. Together, we can work toward a future where the disease is not only eradicated but where those affected are fully reintegrated into society – free from stigma, discrimination, and inequality.



Dr. Ritu Ghosh represented GPZL at the Neglected Tropical Disease NGO Network (NNN) conference in Kuala Lumpur, Malaysia, Oct. 1–3, 2024.

## VIEWPOINT



**Dr. Venkata Ranganadha Rao Pemmaraju**  
Program Advisor for Medical Issues  
Sasakawa Health Foundation

As an epidemiologist and Acting Team Leader of WHO's Global Leprosy Programme, Dr. Pemmaraju contributed to the development of effective global strategies for elimination of leprosy. He joined the Sasakawa Health Foundation as a program advisor in July 2023.

## Commentary on WHO's Global leprosy (Hansen disease) update, 2023

In 2023, 184 out of 221 countries and territories reported on leprosy to the World Health Organization (WHO).<sup>1</sup> Congratulations to all who contributed to the combined efforts of national leprosy programs and WHO for this remarkable achievement.

Globally, 182,815 new cases were detected in 2023 – a 5% increase compared to 2022 – which yields a case detection rate of 22.7 per million population. The number of new child cases rose slightly, from 10,302 in 2022 to 10,322 in 2023, pointing to ongoing transmission. It is prudent to note that in 110 countries zero child cases were reported and these countries need technical assistance to pursue their journey towards “interruption of transmission” and “elimination of leprosy disease.”

The number of new cases with visible deformities (grade 2 disabilities, G2D) increased by 175 cases, from 9,554 in 2022 to 9,729 in 2023. The global G2D rate of 1.2 per million population calls for accelerated active case detection and improved contact examination to diagnose leprosy before visible deformities occur. New child cases with G2D is a sensitive indicator pointing to continued transmission and delayed detection. Among 2023's 9,729 new G2D cases, 266 were child cases (under age 15).

Nearly 72% of new cases are in the 11 countries of the South-East Asia Region (SEAR). This high percentage justifies positioning the Global Leprosy Programme in the WHO Regional Office for South-East Asia rather than in WHO headquarters in Geneva. However, SEAR has made significant progress in reducing its regional leprosy disease burden: Compared to 2014, the number of new cases in 2023 decreased by 15% and the number of new cases with G2D went down by 54%. Trends for the past ten years in the Region of the Americas (AMR) show that while the number of new cases decreased by 27% compared to 2014, the number of new cases with G2D has been hovering around 2,000.

In the African Region (AFR), the number of new cases detected in 2023 (21,043) is 11.6% higher than the number reported for 2014 (18,597). Increase is also noted in the number of new G2D cases: from 2,726 in 2014 to 3,026 in 2023. Moreover, nearly half of the global total of new child cases with G2D are in AFR for the second year in a row: 133/278 (48%) in 2022 and 131/266 (49%) in 2023. WHO Goodwill Ambassador Yohei Sasakawa is rightly emphasizing the need to consolidate political will in support of the zero-leprosy strategy in countries on the African continent.

Only a few countries have reported on prevailing antimicrobial resistance (AMR) in leprosy; hence additional investment is needed for establishing systematic AMR surveillance, particularly in global priority countries. The need for this investment becomes especially important in the context of 13,777 retreatment cases, including 3,644 relapses.

The update mentions that over 100 laws that allow discrimination on the basis of leprosy still exist and countries have been working on repealing them.

Information about acute and long-term stock-outs of multidrug therapy (MDT) was missing in the update. As uninterrupted MDT is the basic tenet for elimination of leprosy, reporting on MDT supply is recommended. Also, to prevent stock-outs, the timing of reporting epidemiological data and making requests for MDT should be synchronized.

The editorial portion of the update highlights the accomplishments of Jordan and Maldives. In August 2024, Jordan became the first country to receive WHO verification of “elimination of leprosy disease” according to the process outlined in the Leprosy Elimination Framework, and in October 2023, Maldives became the first country to adopt the tools of the Framework in pursuit of verification at the subnational level for “interruption of transmission.” The example of these two countries should inspire others to heed the words of the update's subtitle: “Elimination of leprosy disease is possible – Time to act!”

<sup>1</sup> World Health Organization, “Global leprosy (Hansen disease) update, 2023: Elimination of leprosy disease is possible – Time to act!,” *Weekly Epidemiological Record*, vol. 99, no. 37 (Sept. 13, 2024): 497–522, <https://iris.who.int/handle/10665/378893>.

## VIEWPOINT



**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.

## Strengthening people's organizations should be seen as part of the zero leprosy strategy for Africa

Although the world has come a long way towards the elimination of leprosy, we have not reached our goals due to a whirlpool of negligence and poor political and social commitment. In many countries, leprosy continues to be a complex medical and social problem that adversely affects the lives of individuals and the community at large. As reported in the *Weekly Epidemiological Record*,<sup>1</sup> in 2023 there were 182,815 new leprosy cases detected globally, of which 10,322 were new child cases. When considering case numbers on the African continent, we must add data from seven countries in the Eastern Mediterranean Region (EMR)<sup>2</sup> to the African Region (AFR) totals, yielding 23,404 new cases, of which 1,731 are child cases and 3,183 involve grade 2 disabilities (visible deformities). These numbers are not just about instances of disease; they often also indicate that affected individuals are not enjoying their universal human rights and that they and their communities are grappling with various psychosocial problems.



Visual deformities in children affected by leprosy indicate delayed treatment. Photograph taken during the author's visit to Sierra Leone (May 17, 2024).

With the high level of science and technology that we have today, humanity can confront and treat very complicated matters. But when many issues press for attention, leprosy gets forgotten. We end up seeing something that should never happen: children disabled by leprosy. The only way we are going to change this

unacceptable situation is to work hand-in-hand towards zero transmission, zero disability, and zero stigma and discrimination at all levels.

Leprosy is already a bio-psychosocial problem in most instances, and late treatment makes the problem worse. When the disease is allowed to progress, disabilities develop

and individuals often experience a crisis of dignity. In the African countries that I visited recently – Kenya, Nigeria, Ghana, Senegal, Sierra Leone, and Mozambique – I saw the depth of the problem and the consequences of neglect. In some countries, regrettably, tribal and political conflict diverts government attention, increasing insecurity and risk of death for already vulnerable people. Armed attacks in Arsi Zone, Oromia Region, Ethiopia have been killing residents of Tesfa Hiwot and Addis Hiwot leprosy settlements since October 2022. The situation is especially dire for those who are too old or disabled to defend themselves. Conflict also disrupts the efforts of people's organizations. During my visit to Mozambique, I heard from representatives of ALEMO that the organization has lost regular contact with 18 groups that had more than 650 members because of insurgency in the north corner of the country.

Addressing the disease alone is clearly not enough. Governments, NGOs, corporations, academic institutions, and other entities must all contribute their efforts to address leprosy as a multi-dimensional problem.

In closing, I would like to take this opportunity to note that in many of the African countries I visited, including Ethiopia, grassroots reports are unlikely to be providing reliable numbers. The various causes of the inaccuracies include reputational concerns as well as misguided efforts to provide a full report despite insufficient data management systems. I therefore implore all actors to look behind the numbers in reports while pursuing the Global Leprosy Strategy's zero leprosy vision and to consider the human rights and psychosocial issues that are at stake. Based on what I have learned from my experiences in Ethiopia and my visits to six other African countries, people's organizations can become effective advocates for the rights of persons affected by leprosy and their family members if they are supported to grow into visible, self-reliant organizations. I would like the strengthening of these organizations to be seen as a necessary part of the zero leprosy strategy.

<sup>1</sup> World Health Organization, *Weekly Epidemiological Record*, vol. 99, no. 37 (Sept. 13, 2024): 497–522, <https://iris.who.int/handle/10665/378893>.

<sup>2</sup> The seven EMR countries on the African continent are Djibouti, Egypt, Libya, Morocco, Tunisia, Somalia, and Sudan.

## Goodwill Ambassador Sasakawa is impressed by Nepal's Self Help Groups in Madhesh Province

From September 16 to 23, WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa visited Nepal for the first time in 10 years. Although Nepal achieved elimination of leprosy as a public health problem in December 2009, and declared elimination in 2010, new cases are increasing and there are many "hidden" (undetected) cases. After meeting with various officials and participating in media activities in the capital city of Kathmandu, the Goodwill Ambassador traveled south to Madhesh Province.

Located along the border with India, Madhesh Province contains 7 of Nepal's 14 high endemic districts. It is also the location of Lalgadh Leprosy Hospital and Services Centre, one of the world's busiest leprosy hospitals with 400 or more outpatient visits each day and nearly 100 beds for inpatients. In 2002, the hospital began ramping up its community outreach by establishing Self Help Groups (SHGs). There are now 116 of these groups, which are led by persons affected by leprosy and also welcome other persons with disabilities as well as those who are affected by lymphatic filariasis.

During his visit, the Goodwill Ambassador was especially impressed by how the SHGs facilitate case finding and early treatment. SHG leaders become well known in their communities as local authorities on leprosy. They are skilled at identifying skin patches that should be tested, and they immediately either refer affected individuals to the nearest health center or accompany them to Lalgadh. The Goodwill Ambassador is eager to strengthen the case finding and referral capacities of the SHGs even further, and he would like for this model to spread to other parts of the world.

With the support of the hospital in Lalgadh, the Madhesh Province SHGs are part of a broader community-based rehabilitation model that integrates health, social, and economic interventions. Members receive medical support for leprosy, including self-care training for managing ulcers and nerve damage, as well as psychosocial support. They engage in income-generating activities, contribute to and manage their own fund for microcredit, and help one another to learn to write their full names. Actions such as installing toilets to improve sanitary conditions benefit not only group members, but also the village as a whole as well.

The Goodwill Ambassador's visit to Madhesh Province confirmed his belief that the best place to find solutions is at the site where people are grappling with the problems directly. He will continue to make visits to endemic areas part of his life's work.



Mr. Yadav, the leader of the Yagyabhumi Self Help Group, takes the Goodwill Ambassador's blood pressure to show how he monitors the villagers' health.



At Lalgadh Leprosy Hospital and Services Centre, the medical director, Dr. Krishna Bdr. Tamang, shows the Goodwill Ambassador how the hospital keeps records. A well-organized data management system is essential for following up with patients and reporting accurate information.



The Goodwill Ambassador receives a tour from the medical director of Lalgadh Leprosy Hospital and Services Centre, Dr. Krishna Bdr. Tamang.

# Sasakawa Leprosy Initiative collaborates with Miss Supranational 2024 for leprosy awareness campaign in South Sulawesi, Indonesia

Sasakawa Leprosy (Hansen's Disease) Initiative conducted a series of leprosy awareness activities in South Sulawesi, Indonesia, in partnership with the Miss Supranational 2024 crown holder, Harashta Haifa Zahra, on August 26–27. The activities were carried out in collaboration with PerMaTa South Sulawesi, a regional branch of a national organization of persons affected by leprosy, and its support organization Yayasan Dedikasi Tjipta Indonesia (YDTI).

Miss Supranational, an annual international beauty competition launched in Poland in 2009, is distinguished by its "From the Ground Up" community service initiative, which emphasizes social contribution over physical beauty. All contestants are encouraged to use the most valuable resource they have – time – to make an impact in their communities. Miss Supranational winners have been collaborating with the Initiative to raise awareness about leprosy since 2023.

Harashta, the first Indonesian to win the Miss Supranational crown, was born in West Java in 2003. She is currently pursuing a degree in environmental engineering at the National Institute of Technology Bandung (ITENAS).

Indonesia has the third highest number of leprosy cases in the world, and discrimination against persons affected by leprosy remains a significant issue. The South Sulawesi branch of PerMaTa Indonesia is the most active part of the organization, and its members work closely with YDTI to combat stigma and provide much-needed support to those affected.

"Stigma and discrimination against persons affected by leprosy has decreased significantly compared to a decade ago, but we are far from eliminating it," said Al Kadri, Chairman of PerMaTa, whose members conduct home visits to offer emotional support and care assistance to people under treatment.

On August 26, Miss Supranational visited Jonggaya Leprosy Settlement in the provincial capital, Makassar. There she met with the head of the city's health department, provincial

and municipal officials, settlement residents, PerMaTa members, and other stakeholders at the local community hall. She shared her experience of being inspired by Princess Diana's compassion for leprosy patients and expressed her commitment to becoming a driving force for changing perceptions of leprosy. She also pledged to help ensure that no one suffering from the disease is left untreated, help prevent disability due to leprosy, and work toward elimination of the stigma associated with the disease.

The following day, August 27, Miss Supranational visited Maros District, where she discussed strategies for managing leprosy cases and improving service quality with the local health department. She also attended an event at a local school where she and PerMaTa members encouraged students to learn about leprosy as a step toward reducing stigma in the community.

Harashta's involvement in raising awareness of leprosy in her home country is a welcome development for campaigners in Indonesia, and the Initiative looks forward to working with her in other countries as well during her tenure as Miss Supranational 2024.



Following an enthusiastic welcome from students at a school in Maros, Miss Supranational 2024 Harashta Haifa Zahra encouraged them to learn about leprosy as a step toward reducing stigma in the community (South Sulawesi, Indonesia, Aug. 27, 2024).

**SASAKAWA  
LEPROSY**  
HANSEN'S DISEASE  
**INITIATIVE**

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