WHO GOODWILL AMBASSADOR'S

LEPROSY BULLETIN

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Cooperation opens a way forward

Message from the ambassador

In July, I traveled to Indonesia to take part in the 3rd Global Forum of People's Organizations on Hansen's Disease and the 22nd International Leprosy Congress (ILC). I also visited endemic areas in East Java Province together with Minister of Health Budi Gunadi Sadikin.

Guided by the belief that "solutions are to be found in the same locations as the problems," I have visited 125 countries. No one understands the issues at the local level better than the people who live with them every day. For their voices to be reflected in policy and carried into action, the government must demonstrate strong commitment and leadership.

At this year's ILC, the Minister of Health announced concrete steps to strengthen efforts towards zero leprosy in Indonesia. The following day, I joined him in Sampang Regency, where he stressed that a temporary rise in new cases should not be seen as shameful but as a sign of progress. Equally noteworthy was his pledge to personally conduct on-site inspections every three months, an exceptional gesture of commitment. I concluded my trip in Probolinggo Regency, where I met with the governor of East Java Province, who agreed, along with other local officials and representatives, to set up a cross-sectoral committee for coordination of leprosy control efforts.

Today, Indonesia has a favorable wind at its back. We must ensure that this wind reaches other countries as well. Steady progress along the difficult path towards zero leprosy can happen when persons affected by leprosy, local communities, and governments work together. I will continue my bridging role, connecting people at all levels of society so that this progress can be made.

笹川陽平

Yohei Sasakawa
WHO Goodwill Ambassador for Leprosy Elimination

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REPORT

Report on the 3rd Global Forum of People's Organizations on Hansen's Disease

From July 4 to 6, 2025, the 3rd Global Forum of People's Organizations on Hansen's Disease was held in Bali, Indonesia. Hosted by the Sasakawa Leprosy (Hansen's Disease) Initiative, the forum brought together over 110 representatives from organizations of persons affected by leprosy based in 21 countries.

Building on previous gatherings in Manila (2019) and Hyderabad (2022), the 3rd Global Forum increased emphasis on actions taken before and after the event. Under the leadership of Dr. Alice Cruz, former UN Special Rapporteur and current human rights advisor to the Sasakawa Leprosy (Hansen's Disease) Initiative, the forum was prepared over the course of a year in close collaboration with representatives of organizations of persons affected by leprosy. Nineteen of these organizations conducted needs assessments with support from the Sasakawa Health Foundation (SHF). Through surveys and analysis, they identified challenges and priorities specific to contexts in their home countries. They compiled their findings into reports, which then served as a foundation for discussion at the Global Forum.

Strategic scheduling of the Global Forum just before the 22nd International Leprosy Congress (ILC) created an opportunity for the people's organizations to share their reports in poster form with researchers, program leaders, policymakers, and advocates from around the world.

The Global Forum produced three action-oriented documents and elected an Oversight Committee to promote implementation. These documents provided participants with concrete frameworks to take back to their communities as well as a formalized means of communication with other stakeholders so that they may be informed by the voices of persons affected by Hansen's disease as they pursue zero leprosy.

Day 1

The Global Forum dedicated the first day to closed-door discussions exclusively for persons affected by leprosy, providing a safe, peer-led environment for open dialogue and reflection.

In the morning, participants shared the results of their preparatory needs assessments. Groups for discussion were designed to be cross-regional to encourage identification of shared challenges. Each group was assigned one facilitator and one note taker, and interpreters joined to support multilingual communication.

During the afternoon, the same groups worked intensively on responding to several guiding questions. The resulting discussions highlighted key changes needed to support persons affected by leprosy, including ending discrimination, enhancing mental health and rehabilitation services, and improving social inclusion. Ideas for accomplishing these changes focused on legal reforms, raising community awareness, integrating services, and empowering affected individuals. Related to the theme of empowerment, participants reflected on the capacity-building needs of their own organizations, including skills in advocacy, fundraising, digital literacy, and project management. They noted that, for sustainable growth, their organizations require ongoing support, digital tools, visibility, and strategic planning. They called for collaborative efforts to improve healthcare, legal frameworks, and social integration for marginalized communities.

Work Group D, one of several cross-regional discussion groups, included 21 persons affected by leprosy from eight countries.

Day 2

The second day started with an official opening session and inspiring messages from six leaders. Mr. Al Kadri (PerMaTa Indonesia) honored the resilience of persons affected by leprosy and urged collective advocacy to eliminate the disease and reshape public perceptions. Invoking the example of HIV movements in Africa, Mr. Brent Morgan (The Leprosy Mission International) called for coordinated action, fronted by persons affected by Hansen's disease, to end discrimination. Mr. Peter Waddup (The Leprosy Mission Great Britain) emphasized that leprosy is more than an illness, involving complex factors. Mr. Geoff Warne (ILEP) suggested strategies that persons affected by leprosy could use to shift power toward their communities and organizations. Dr. Beatriz Miranda (UN Special Rapporteur) spoke of her experience with a participatory action research project that started in Indonesia in 2010 and the many benefits of this approach for persons affected by leprosy. Dr. Takahiro Nanri (SHF) urged meaningful action and reminded participants that their voices represent many unheard people.

Later in the morning, experts and organizational representatives shared examples of successful advocacy practices and resource mobilization. Dr. Neeraj Mistry, a public health physician based in South Africa, presented examples of global coalitions that successfully tackled HIV and other diseases in order to prompt thinking about structures and strategies for generating a coordinated movement at all levels. The Nepal Law Society shared how their evidence-based approach to advocacy and lobbying is finding ongoing success in securing reform of laws that discriminate on the basis of leprosy.

The people's organization HANDA (China) described how their organization shifted from foreign aid to local sustainability through diversified funding and community engagement. Leprosy People Association (Sri Lanka) spoke of empowering members by reviving cultural traditions and promoting self-reliance, which in turn helped them to gain social respect and government support. BRAC, an international development organization founded in Bangladesh, outlined transformations that they achieved through microfinance and social enterprises.

In the afternoon, persons affected by leprosy had the option to join another closed session. In five groups, they discussed the morning's topics and shared their reflections.

Day 3

The third day of the Global Forum marked the culmination of collaborative efforts made over the previous days. The morning began with the presentation of group outcomes, reflecting the diverse insights and experiences of persons affected by leprosy and their organizational representatives from around the world.

A Drafting Committee, tasked with consolidating the outcomes into a collective statement, presented their efforts in the form of three documents:

- **Letter of Commitment** outlining shared values and unified intent
- **Letter with Recommendations to Stakeholders** to guide policy and programmatic responses
- **Action Plan for Capacity-Building** aimed at strengthening people's organizations at the national, regional, and global levels

The Letter of Commitment establishes a shared vision for ensuring that persons affected by leprosy live with dignity, equal rights, and full participation in society. At the end of the Global Forum, six representatives from three regions were elected to establish the Oversight Committee outlined in the Letter. This committee has a mandate to monitor policy implementation and hold governments, donors, pharmaceutical companies, and intergovernmental agencies accountable. Two Drafting Committee members, Mr. Al Kadri of PerMaTa Indonesia and Ms. Evarestus Lilibeth Nwakaego of Purple Hope Initiative Nigeria, presented the documents at the ILC's plenary session.

In the afternoon, eight representatives of stakeholder institutions and alliances[1] joined a roundtable discussion to provide feedback on the documents and to reflect on concrete ways that they could help with dissemination and support for realizing the documents' goals. The non-hierarchical format facilitated a frank exchange. The Q&A period addressed matters of strategy and accountability, with emphasis on the position of persons affected by leprosy as the experts with lived experience who should be consulted at the point of policy creation.

The Global Forum concluded with a powerful speech by WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa. He praised the leadership of persons affected by leprosy and urged all stakeholders to act with urgency and unity. He also reaffirmed his personal lifelong commitment to eliminating leprosy and associated discrimination.

The Global Forum closed with heartfelt thanks to all participants, gratitude for a renewed sense of shared purpose, and a call to transform words into action.

Group photo of all participants in the 3rd Global Forum of People's Organizations on Hansen's Disease held in Bali, Indonesia, July 4–6, 2025.

Video recording of 3rd Global Forum:
https://sasakawaleprosyinitiative.org/latest-updates/initiative-news/5957/

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[1] Dr. Vivek Lal, Team Leader, Global Leprosy Programme, World Health Organization; Mr. Brent Morgan, President, International Federation of Anti-Leprosy Associations; Dr. Beatriz Miranda, United Nations Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members; Dr. Regina Tiolina Sidjabat, Head, Neglected Tropical Diseases (NTD) Task Force, Ministry of Heath of Indonesia; Dr. M. Yulianto Listiawan, Chairman, International Leprosy Congress 2025; Dr. P Narasimha Rao, President, International Leprosy Association; Dr. Sunil Modali, Novartis Foundation; and Dr. Ritu Ghosh, Executive Director, Global Partnership for Zero Leprosy.

Report on sessions hosted by the Sasakawa Health Foundation at the 22nd International Leprosy Congress

The 22nd International Leprosy Congress (ILC) was held in Bali, Indonesia, July 7–9, 2025. The Sasakawa Health Foundation (SHF) hosted four sessions during the event, which were led by Dr. Alice Cruz, SHF Program Advisor for Human Rights Issues; Dr. Venkata Ranganadha Rao Pemmaraju, SHF Program Advisor for Medical Issues; and Mr. Tesfaye Tadesse Haile, SHF Coordinator for Programs in Africa. Dr. Cruz and Dr. Pemmaraju wrote summaries of the sessions, highlighting points that they consider to be especially important.

Session: "Maximizing the capacity and participation of organizations of persons affected by leprosy in Africa"

Contributed by Dr. Alice Cruz

In late 2024, SHF launched a program for supporting organizations of persons affected by leprosy in Africa. The program has two objectives: 1) to provide a platform for training leaders who can effectively manage the organizations and 2) to enhance the organizations' capability and sustainability. As the former manager of the Ethiopian National Association of Persons Affected by Leprosy (ENAPAL), Mr. Tesfaye brings years of relevant experience to his role as coordinator of the program.

At the ILC, Mr. Tesfaye chaired and facilitated a session where he explained that in the months before the program launched, he conducted field visits to Tanzania, Sierra Leone, Senegal, Kenya, Nigeria, Ghana, and Mozambique. He also conducted online surveys with organizations in Nigeria, the Democratic Republic of the Congo (DRC), Niger, and Liberia. SHF decided to prioritize providing support for people's organizations to strengthen their management capacities based on his findings.

In March 2025, the program worked with the Senegalese Association Against Leprosy and Neglected Tropical Diseases (ASCL/MTN) to host a leadership level capacity-building workshop in Dakar, Senegal. Representatives from Purple Hope Initiative Nigeria (PHIN), National Association of Persons Affected by Leprosy–Sierra Leone (NAPAL-SL), and Tanzania Leprosy Association (TLA) joined ASCL/MTN for discussions and practical exercises about improving the administrative and financial management of their organizations and designing two-year projects. With SHF support, the projects that were proposed at the workshop will launch in September. Representatives of three of the organizations – NAPAL-SL, PHIN, and ASCL/MTN – joined Mr. Tesfaye at the ILC to share their proposals.

NAPAL-SL's project, "Capacity building for better performance," seeks to improve organizational management capabilities by focusing on efficiency and effectiveness.

"Strengthening organizational capacity of PHIN for effective service delivery in Nigeria" addresses the need for training opportunities in practical skills such as developing a five-year strategic plan, writing reports and manuals, and creating an office environment conducive to work.

ASCL/MTN made an important observation about the persistence of barriers to effective participation and intervention in society experienced by organizations of persons affected by leprosy. They identified key areas that require more investment to ensure that participation is both enabled and impactful: capacity-building, access to funds, and integration in policy-making.

Session: "Monitoring discrimination and taking evidence-based action against it"

Contributed by Dr. Alice Cruz

In a landmark moment, two persons affected by leprosy presented the results of their organizations' emancipatory research projects. The projects were conducted in the context of a program organized by SHF aimed at facilitating the production of action-oriented knowledge and evidence-informed advocacy. Emancipatory research is a participatory and transformative approach, grounded in the traditions of critical theory and the disability rights movement, that seeks to empower marginalized and disadvantaged groups by involving them as active collaborators in all stages of research. SHF's program drew on this framework while also going further to guarantee that persons affected by leprosy owned the research from beginning to end.

The program's principles assert that persons affected by leprosy and their representative organizations should be the primary producers of knowledge and not just co-producers; any process aimed at knowledge production about persons affected by leprosy should always enhance their critical thinking and autonomic action; processes should emphasize strengthening the organizations, developing leadership skills among its members, and engaging new members; and outcomes should include practical steps aimed at solving the problems identified by research.

The two participating organizations of persons affected by leprosy, Saksham Kushthanteya Swabhimani Sanstha (SKSS)–India and MORHAN Piauí–Brazil, engaged in several collective discussions to design projects that that would be responsive to local priorities and achievable by members affected by leprosy.

SKSS, supported by ALERT-India, implemented a project titled "To Study the Impact of Stigma and Discrimination Due to Leprosy on Family and Marital Dynamics." Presenter Mr. Milind Barsinge shared that designing and participating in the project strengthened member skills in planning, decision-making, and knowledge application; improved coordination with health systems and legislators; increased membership; and resulted in a 10-year strategic roadmap informed by their research.

MORHAN Piauí's project, "Holding hands in search of knowledge and rights," was presented by Ms. Francilene Mesquita. The project's research team was composed almost entirely of women affected by leprosy. They focused on institutionalized and intersectional discrimination and developed their own methodology, which they called "escuta afetiva e qualificada" (listening with empathetic attentiveness and skill). Results showed that black women are disproportionately affected by discrimination on the grounds of leprosy and also that institutionalized discrimination persists, especially in healthcare and social protection services. The organization identified five main problems and then developed an advocacy roadmap based on solutions that emerged from discussions with participants.

Ms. Mesquita concluded with a powerful reflection: "In this project, people were not seen as *patients* nor as *objects of study*, but as *equals*." I would add that these projects were not only successful in producing relevant knowledge for policy-makers; they were also deeply transformative of individuals, collectivities, and communities.

Session: "Leprosy in children – a critical component of leprosy elimination"

Contributed by Dr. V R Pemmaraju

Approximately every tenth leprosy patient is a child, which reflects continued transmission of infection in the community. More concerning, 2023 global leprosy data indicated that over 250 children had grade 2 disabilities at the time that they received their diagnosis. Children, especially girls, also experience discrimination that stems from deeply ingrained negative social perceptions against leprosy.

During the ILC session, Ms. Lebora from the Leprosy People Association (LPA) Sri Lanka provided an overview of the challenges related to reaching children for diagnosis and treatment. Many children have dropped out from school for fear of stigma. Health staff are not comfortable and confident about diagnosing leprosy in children. Ms. Erei Remon, manager of Kiribati's national leprosy program, highlighted practical steps that her country has taken to diagnose every child in the islands early enough for treatment. Dr. Saba Lambert, an eminent clinical researcher who chairs the WHO Technical Expert Group on Childhood Leprosy, and Dr. Vivek Lal, team leader of the WHO Global Leprosy Programme, emphasized evidence-based strategies: in particular, those aimed at improving diagnostics and providing child-friendly medicine formulations in order to improve compliance to multidrug therapy.

The examples from Sri Lanka and Kiribati suggest promising practices for national programs to adapt to their local context. The need for initiatives to protect the rights of children with leprosy emerged as an immediate priority. The presentations showcased synergy between persons affected and national governments in addressing the issue of leprosy in children.

Session: "Treatment of reactions and prevention of disabilities – an important aspect of management of leprosy"

Contributed by Dr. V R Pemmaraju

Leprosy is a curable disease and treatment with multidrug therapy is uneventful in the majority of patients. However, immunological reactions occurring during the course of the disease can lead to physical impairments or serious complications. Though adequate data is not available globally, analysis of a small cohort of persons experiencing reactions found that a few of them had restricted life due to severe disabilities, some lost their lives, and the rest are showing side effects of steroid dependency.

SHF conducted a session to understand the problem from the perspective of the persons affected and to consult with experts to explore possible solutions. Mr. Al Kadri from the people's organization PerMaTa Indonesia spoke of the suffering that some members are experiencing because of reactions. He noted that some persons affected by leprosy struggle to report their condition promptly to health staff and find it difficult to explain their reactions.

Dr. Teky Budiawan from Indonesia presented effective practices in treatment of reactions. Dr. Indira Kahawita, a world-renowned expert on the topic, emphasized the importance of a referral level institution, a center of excellence to cater for management of reactions. Dr. Vivek Lal from WHO presented evidence-based treatment protocols currently recommended for use in countries. The need for focusing on prevention of disabilities as part of the management of reactions was presented by Dr. Sathish Paul, an eminent physical rehabilitation expert.

The session was successful in bringing management of reactions to the attention of national programs and emphasizing the importance of timely and effective interventions and a continuum of care to prevent disabilities.

VIEWPOINT

Dr. Ina Agustina Isturini
Director of Communicable Diseases
Ministry of Health of the Republic of Indonesia

Dr. Ina has a robust academic foundation in medicine and healthcare administration as well as over 20 years of practical experience. She has been leading efforts in disease prevention, mitigation, and control in her current position since October 2024.

Indonesia's leprosy management program

Leprosy remains a public health problem in Indonesia. In 2024, 14,698 new cases of leprosy were detected, with a Case Detection Rate (CDR) of 5.24 per 100,000 population. Of these new cases, 90.5% were MB leprosy, 5.9% were grade 2 disability cases, and 9.7% were pediatric cases. These findings indicate ongoing transmission and delayed diagnosis. Globally, Indonesia is in third place for new leprosy cases after India and Brazil, accounting for 8% of all cases worldwide. Leprosy-endemic areas are predominantly located in eastern Indonesia.

The burden of leprosy in Indonesia is not limited to the high number of new cases, but also includes the number of disabilities caused by leprosy. Disabilities lead to decreased productivity and can become grounds for discrimination against patients and their families. When people with disabilities due to leprosy become dependent on others for mobility and financial support, they are more likely to experience living in poverty.

As outlined in "Ending the Neglect to Attain Sustainable Development Goals: A Roadmap for Neglected Tropical Diseases 2021–2030," WHO has established the target of achieving leprosy elimination (interruption of transmission) by 2030 through the "Global Leprosy Strategy 2021–2030: Towards Zero Leprosy." In alignment with this global framework, the Government of Indonesia is committed to attaining leprosy elimination in more than 100 districts/cities by 2030.

Leprosy elimination efforts in Indonesia are not without obstacles and challenges faced by the government and relevant stakeholders. These problems include delays in early detection, stigma and discrimination, and technical constraints such as the lack of capacity of health workers to diagnose leprosy. The involvement of communities and civil society organizations remains low, resulting in people not recognizing the signs of leprosy in themselves and those around them.

The Indonesian government continues to seek solutions to these obstacles. The problem of MDT drug availability has begun to be addressed with the provision of leprosy drugs through the state budget. The Leprosy and Yaws Information System (SITASIA) was introduced at the end of October 2024 to enable real-time leprosy reporting.

However, to achieve the 2030 elimination target, accelerated strategies and innovation are needed. Efforts such as early detection, standardized treatment, health promotion, and robust surveillance are essential. Several efforts have been undertaken by Indonesia to achieve leprosy elimination, including providing chemoprophylaxis in the form of a single dose of rifampin for contacts and integrating leprosy screening with the Free Health Checkup Program (CKG) and other programs.

On July 7, 2025, the Ministry of Health held a high-level meeting with relevant stakeholders to discuss strategies, challenges, and solutions to the obstacles Indonesia faces in its leprosy elimination journey. The meeting secured commitment from regional leaders and collaboration from various parties to ensure the successful implementation of the 2030 leprosy elimination program.

Furthermore, the Ministry of Health continues to advocate with provincial and district/city governments to strengthen commitment, secure inclusive policies, encourage community empowerment, and increase educational efforts to eliminate stigma and uphold the dignity of every individual affected by leprosy.

On July 7, 2025, at a high-level meeting held in Bali, Indonesia's Ministry of Health presented five strategic steps to accelerate leprosy elimination: 1) expand the target area for leprosy elimination from 42 to 111 districts/cities by 2030; 2) conduct mass screening starting in July 2025 in five priority districts; 3) implement screening for populations at high risk of dapsone hypersensitivity syndrome; 4) strengthen availability of MDT treatment; and 5) participate in international leprosy vaccine research and clinical trials.

Press release about high-level meeting (July 7, 2025):
https://kemkes.go.id/id/kemenkes-ri-dan-sasakawa-health-foundation-perkuat-komitmen-eliminasi-kusta

WHO Goodwill Ambassador for Leprosy Elimination makes a four-day visit to Indonesia

From July 6 to 9, 2025, Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination, visited locations on Bali, Madura, and Java islands in Indonesia and energetically participated in various activities.

July 6: 3rd Global Forum of People's Organizations on Hansen's Disease

On the first day, the Goodwill Ambassador joined the 3rd Global Forum of People's Organizations on Hansen's Disease, which was hosted by the Sasakawa Leprosy (Hansen's Disease) Initiative in Bali. This forum, informed by the experiences of the past two gatherings, adopted a "people-centered approach," placing persons affected by leprosy at its core. The program was shaped on the basis of surveys, regional online meetings, and needs assessments conducted by persons affected by leprosy. Over 110 people's organization representatives from 21 countries participated in the event. In his speech, the Goodwill Ambassador expressed gratitude and encouragement, emphasizing that the efforts of persons affected by leprosy are essential to achieving zero leprosy.

July 7: 22nd International Leprosy Congress and government high-level meeting

At the opening ceremony of the 22nd International Leprosy Congress (ILC), also held in Bali, Goodwill Ambassador Sasakawa joined Minister of Health Budi Gunadi Sadikin in symbolically demonstrating their shared commitment to moving towards a world with zero leprosy. In his speech, the Goodwill Ambassador emphasized that the fight against stigma and discrimination can only succeed with the active participation of persons affected by leprosy. He closed his speech with words urging cooperation: "If we listen to the voices of persons affected by leprosy and unite our efforts, a leprosy-free world will be an attainable dream. Let us together make the impossible possible."

Following the ceremony, the Goodwill Ambassador and the Minister of Health attended a high-level meeting where enhanced measures for making progress towards elimination (interruption of transmission) were formally announced, including the implementation of large-scale screenings in five priority regions of the country. The participation of senior officials from the five regions underscored the Indonesian government's commitment to following through on the plan.

July 8: Visit to Sampang Regency, East Java

The Goodwill Ambassador and the Minister of Health visited Sampang Regency on Madura Island in East Java Province, one of the areas targeted for enhanced measures. At a ceremony held at the regency office, the Minister of Health encouraged staff to think of an increase in the number of new cases as a necessary step along the path towards controlling the disease. To reinforce the message and boost motivation, a competition was announced: among the province's 22 government-mandated community health clinics (puskesmas), those with the highest number of new cases will receive cash awards. The Minister of Health himself will conduct monthly monitoring meetings and on-site inspections every three months to help ensure ongoing effort.

Following the ceremony, the leaders moved from the government office to a local community where they had the opportunity to talk directly with persons affected by leprosy.

July 9: Visit to Probolinggo Regency, East Java

On the final day, the Goodwill Ambassador visited Probolinggo Regency on the island of Java in East Java Province, where he met with regency-level government officials as well as religious leaders and carried out awareness-raising activities. The governor of East Java Province agreed to establish a provincial-level committee for leprosy control involving the government, religious groups, and civil society representatives.

Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination, gave a speech at the 3rd Global Forum in Bali, Indonesia, on July 6, 2025.

At the 22nd ILC's opening ceremony, Goodwill Ambassador Sasakawa and Minister of Health Budi Gunadi Sadikin made a symbolic gesture of commitment towards a world with zero leprosy.

Ms. Evarestus Lilibeth Nwakaego of Purple Hope Initiative Nigeria (left) and Mr. Al Kadri of PerMaTa Indonesia (right) presented the results of the 3rd Global Forum at the ILC.

Goodwill Ambassador Sasakawa and Minister of Health Budi Gunadi Sadikin met directly with persons affected by leprosy in their communities.

VIEWPOINT

Dr. Sunil V. Gitte
Deputy Director General (Leprosy)
Ministry of Health and Family Welfare, India

With over a decade of experience at sub-national levels, particularly in tribal and geographically challenging regions of Central India, Dr. Sunil Gitte has led innovations and strategic interventions based on Geographic Information Systems (GIS) to advance leprosy elimination efforts nationally.

The importance of India's move to make leprosy a notifiable disease

Leprosy is known to have been prevalent in India since ancient times. A major milestone was achieved in 2005 when the National Leprosy Eradication Programme (NLEP) declared the elimination of leprosy as a public health problem at the national level, defined as a prevalence rate of less than 1 case per 10,000 population. Since then, India has made steady progress in reducing the disease burden. The prevalence rate declined from 0.69 per 10,000 in 2014–15 to 0.57 in 2024–25. Similarly, the proportion of child cases among new detections reduced from 9.04% to 5.18%, and Grade 2 Disability (G2D) among new cases declined from 4.61% to 2.17%. These achievements reflect the sustained implementation of NLEP interventions across the country. However, the goal of elimination at the sub-national level remains unfinished.

A challenge under NLEP has been coordination with private practitioners in reporting leprosy cases seeking treatment in private clinics, dispensaries, and hospitals. This affects the comprehensive understanding of the actual case burden and delays timely public health response.

For India to accelerate towards the elimination of leprosy (interruption of transmission), it is critical that every newly emerging case of leprosy be brought to the attention of leprosy program managers for initiating measures to contain the disease. Stringent measures need to be introduced for maintaining a strong and effective surveillance network and for following up every new case in any community.

To improve the reach and coordination of the program and to address the gap in reporting between private healthcare providers and the public health system, the Ministry of Health and Family Welfare issued a letter on May 14, 2025, directing all states and union territories to classify leprosy as a "notifiable disease." The "notifiable disease" designation mandates that every newly detected case, irrespective of the healthcare setting, be reported to the appropriate public health authority.

This requirement is intended to enhance inter-sectoral coordination, ensure treatment adherence, and reinforce the implementation of essential NLEP activities such as active case search, contact screening, administration of post-exposure prophylaxis, and provision of multidrug therapy (MDT) to every patient.

The inclusion of leprosy in the list of notifiable diseases is not merely an administrative requirement, but a program-enabling intervention that reinforces public health governance. Making leprosy a notifiable disease stands as a significant milestone along the path toward achieving the Government's goal of "interruption in transmission of leprosy by 2027" and its ultimate vision of a "Leprosy-Free India."

Editor's note: India's decision to include leprosy on its list of notifiable diseases has been positively received by both national and international experts. Making leprosy a notifiable disease enables effective surveillance, rapid case detection, and systematic monitoring, all of which are essential components of a program intended to interrupt transmission.

India's National Leprosy Eradication Programme:
https://dghs.mohfw.gov.in/nlep.php

SASAKAWA LEPROSY HANSEN'S DISEASE INITIATIVE

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