WHO GOODWILL AMBASSADOR'S

# LEPROSY BULLETIN

**NO. 129** DECEMBER 2025

## Achieving our goals with dedication and compassion

## Message from the ambassador

On Nov. 28, 2025, I met with the 14th Dalai Lama for the first time in 11 years. The year before that last meeting, in 2013, we visited one of India's approximately 750 leprosy colonies together. His Holiness was moved and surprised me by offering to use his own book royalties to support young people living in the colonies to pursue higher education.

The Nippon Foundation matched his contribution, and the Sasakawa–India Leprosy Foundation (S-ILF) joined as an administrative partner to implement the Dalai Lama–Sasakawa Scholarship in 2015. To date, approximately 260 students have received support through this program to study for a degree in fields such as law, pharmacy, computer science, or hospitality. Many of the graduates have secured well-paying, socially respected jobs that have transformed their family circumstances. They have become role models in their communities.

I had heard that the Dalai Lama had undergone surgery about a year ago in the United States, and so I was concerned about his health. However, he appeared as compassionate and serene as ever. While looking over some photographs I had brought with me, we warmly and peacefully renewed our old friendship.

Considering our respective advanced ages – he is 90 and I am 86 – this meeting was particularly special. It served as an opportunity to engrave in my heart once again my resolve to continue dedicating my full efforts to the mission of eliminating leprosy from the world.

笹川陽平

Yohei Sasakawa
WHO Goodwill Ambassador for Leprosy Elimination

Contributing to this issue:

**Al Kadri**
3rd Global Forum Drafting Committee

**Francilene Carvalho de Mesquita**
3rd Global Forum Drafting Committee

**Jayashree Kunju**
3rd Global Forum Drafting Committee

**Lilibeth Nwakaego Evarestus**
3rd Global Forum Drafting Committee

**Lucrecia Vasquez Acevedo**
3rd Global Forum Drafting Committee

**Ashutosh Prabhavalkar**
ALERT-India

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

VIEWPOINT

# Empowerment cannot exist without ownership: Members of the Drafting Committee reflect on the 3rd Global Forum's outcome documents

The 3rd Global Forum of People's Organizations on Leprosy/Hansen's Disease, facilitated by the Sasakawa Leprosy Initiative, took place July 4–6, 2025, in Bali, Indonesia. More than 110 representatives of organizations of persons affected by leprosy from 21 countries participated. Whereas the first two forums successfully focused on strengthening solidarity and horizontal relations among the representatives, the third forum emphasized enhancing their ownership and delivering outcome documents aimed at sustainable, long-lasting, and transformative collective action.

The 3rd Global Forum had five working groups, each with its own facilitator and rapporteur. Each group also selected one member to serve on a Drafting Committee charged with the responsibility of producing collective outcome documents.

The Drafting Committee created three documents based on information collected from the local needs assessments that each organization carried out prior to the forum as well as the matters raised during the discussions held by the working groups. The three documents are titled 1) Letter of Commitment, 2) Letter with Recommendations to Stakeholders, and 3) Action Plan for capacity-building, development, and empowerment of organizations of persons affected by leprosy/Hansen's disease.

Here the five members of the Drafting Committee – Al Kadri, Francilene Mesquita, Jayashree Kunju, Lilibeth Evarestus, and Lucrecia Acevedo – share their thoughts on their experiences at the forum, the three outcome documents, and their expectations for action.

**Al Kadri**
**Chairman**
**PerMaTa Indonesia**
*Indonesia*

The 10-point Action Plan produced by the Global Forum serves as a set of strategic steps that must be implemented by policymakers to strengthen and empower organizations of persons affected by leprosy. Through the implementation of this action plan, organizations of persons affected by leprosy are expected to take a more active role in eliminating the stigma and discrimination that continue to surround leprosy.

The Letter with Recommendations to Stakeholders is expected to serve as a strategic reference for policymakers in leprosy control efforts, thereby accelerating the achievement of sustainable leprosy elimination.

Meanwhile, the Letter of Commitment reflects a collective determination to strengthen community participation in the global movement to end stigma and discrimination against persons affected by leprosy. This joint statement stands as a symbol of solidarity and cross-country collaboration as well as a strategic call for policymakers at national and international levels to open wider and more meaningful spaces for the active engagement of organizations of persons affected by leprosy in all decision-making processes related to leprosy issues.

**Francilene Carvalho de Mesquita**
**Deputy Coordinator**
**Department of Policies for Women**
**MORHAN National**
*Brazil*

For me, being a member of the Drafting Committee for the 3rd Global Forum was a new and challenging experience. I learned that this kind of self-challenging is necessary. As persons affected by Hansen's disease, we need to start showing what we are capable of by making ourselves available for any kind of work, whether in our own organization or in other spaces such as the Global Forum. It is a way for us to be trained continuously and directly in what concerns us most: the cause of Hansen's disease.

Considering the emphasis on inclusion, I would like to highlight the role played by linguistic inclusion. Specifically, I would like to put a spotlight on the translators, who conveyed what was said in all the different languages with responsibility and emotion so that we could feel and assess what was said. They enabled us to interpret, document, and respect the various speeches.

The documents produced as outcomes of the Global Forum reflect the voices of persons affected by Hansen's disease. These voices must be relayed comprehensively to the people who need to hear them. By ensuring that our organizations read, discuss, and circulate these documents in our home communities, we can foster meaningful dialogue with decision-makers on how to follow up.

If our voices are respected, we will achieve changes and advances in the reality of Hansen's disease in the world, especially in the lives of those affected by it.

**Jayashree Kunju**
**Vice Chair**
**IDEA International**
*India*

The Letter with Recommendations to Stakeholders, Letter of Commitment, and Action Plan together represent a vital turning point from words of sympathy to systems of accountability. My expectation is that these documents will not remain aspirational but will drive tangible, measurable change at the country level.

The 2024 multidrug therapy (MDT) fiasco in Nigeria where thousands were left without timely access to the drugs for leprosy is a stark reminder that when systems fail, lives are directly endangered in terms of permanent disabilities, loss of economic freedom, and impact on family and community life, not to speak of the misery of being stigmatized. In spite of global commitment, medicine shortages persist because of poor planning, lack of transparency, and, most importantly, weak accountability. This must end. These letters must compel governments, pharmaceutical partners, the World Health Organization, and other stakeholders to establish early warning systems for drug shortages. These systems should include local stock monitoring that involves organizations of persons affected by leprosy. The focus should be on creating reporting mechanisms that can trigger immediate corrective actions where need be.

It is also important that stakeholders take the affected community members seriously and implement the recommendations along with them, not just for them. Empowerment cannot exist without ownership. Persons affected by leprosy also have an important role to play in prioritizing leadership development within their organizations. In the current era, we must help our leaders with digital literacy and clear data-driven advocacy so that no one can silence our collective evidence.

The true spirit of these letters will be fulfilled when no person affected by leprosy ever faces a preventable lapse or experiences indignity again.

**Lilibeth Nwakaego Evarestus**
**National Coordinator**
**Purple Hope Initiative Nigeria**
*Nigeria*

I believe that the two Letters and the Action Plan provide actionable insights and direct guidance for meaningful engagement of organizations of persons affected by Hansen's disease, which will produce desirable results going forward.

My expectation is that our various stakeholders will prioritize collaboration, ensuring impact and inclusion of organizations of persons affected by Hansen's disease in the decision-making processes that affect them at all levels. I also expect to see focus on sustainable empowerment initiatives, leveraging one another's strengths.

My advice for our stakeholders is for them to be committed to total adherence to the provisions of our letter recommendations and listen to us in all matters!

To the community of persons affected by Hansen's disease, I say let's show determination, willingness to grow, and commitment to the sustainability of our various organizations.

**Lucrecia Vasquez Acevedo**
**Legal Representative**
**Felehansen**
*Colombia*

The 3rd Global Forum brought together key actors such as Novartis, human rights groups, supporting organizations, and the World Health Organization. The presence of these key actors enabled persons affected by Hansen's disease to engage in advocacy and lobbying as part of their strategy for leadership, strengthening, and empowerment.

To monitor the agreements reached, an Oversight Committee was created for the first time and it will be kept informed of progress and achievements as part of an assertive communication strategy.

The 3rd Global Forum was a space where people openly shared the reality of issues that they face in their countries, hoping that their input would result in more than just documents. By strengthening leadership and improving communication, we are bringing the documents created during the forum to life and pioneering a way of being included in decision-making as key players.

The dissemination of the documents among affected people allows us to highlight the work done by the team, to analyze how the documents can be put to use locally, and to measure the impact that they can have, both positive and negative.

Organizations of persons affected by Hansen's disease must have autonomy, a strong moral backbone, and the ability to make decisions when needed. We cannot allow ourselves to keep being used. We have enormous potential and we have strategic allies who provide us with guidance and advice so that we can keep moving forward. We must affirm our dignity, know our rights, and be the agents of our own development.

VIEWPOINT

# Persons affected by leprosy research stigma and discrimination in India and Brazil

**Ashutosh Prabhavalkar**
**Head of Program (Leprosy)**
**ALERT-India**

ALERT-India (Association for Leprosy Education, Rehabilitation and Treatment—India) is a Mumbai-based non-governmental organization dedicated to improving the health, social status, and rights of persons affected by leprosy and other communicable diseases.

Saksham Kushthateya Swabhimani Sanstha (SKSS), an organization of Kusthanteya (persons affected by leprosy/Hansen's disease) living in non-colony settings in Maharashtra, India, implemented a pilot research project titled "Impact of Stigma and Discrimination Due to Leprosy on Family and Marital Dynamics." This initiative, supported by the Sasakawa Health Foundation (SHF), stands as a pioneering and empowering example of community-led research.

Uniquely, the project was conceptualized, led, and implemented by Kushthanteya themselves, and because evidence was gathered from non-colony communities, the findings are more generalizable than those of studies focused on leprosy colonies.

With technical support from ALERT-India, Mumbai, and guidance from Dr. Alice Cruz, SHF's Program Advisor for Human Rights Issues, a team of 25 SKSS members undertook all core research activities: sampling, tool development, training, field surveys, case studies, and preparation of a 10-year advocacy roadmap (2026–2035).

A key strength of the study was the trust-based data collection approach: respondents felt more comfortable sharing personal experiences with fellow Kushthanteya. The study revealed that 26% of affected individuals reported experiencing stigma and discrimination and 29% noted adverse impacts on their marital relationships. Of the 26% who reported experiencing stigma and discrimination, over half were women (63%).

SKSS members who were part of the team strengthened their understanding of rights, research methodology, and advocacy. The project created a cadre of informed community advocates whose self-esteem and confidence were visibly restored.

In my firm view, this initiative marks a paradigm shift that transforms Kushthanteya from subjects of study to active partners in knowledge creation and social change.

**Francilene Carvalho de Mesquita**
**Volunteer and Deputy Coordinator, Department of Policies for Women, MORHAN National**
**Volunteer, MORHAN Piauí**

MORHAN Piauí is a regional branch of Brazil's national Movement for the Reintegration of People Affected by Hansen's Disease that brings together persons affected by the disease in the state of Piauí to defend their rights, combat stigma, and promote social inclusion and access to care.

Coordinating the project "Holding hands in search of rights and knowledge," with all the challenges it presented, was a unique opportunity to see how much we are capable of. As a woman affected by Hansen's disease, I have often been in the position of being studied by researchers aiming to publish papers and contribute to science. But until this project, I had never imagined the challenges of being in the researcher position.

We held conversation circles according to our original methodology: *escuta afetiva e qualificada* (listening with empathetic attentiveness and skill). In my view, the most significant outcome of the project was the empowerment that each person affected by Hansen's disease experienced from participating in the circles.

As we went through the process of conducting the circles, listening, synthesizing statements, identifying problems, and building strategies for possible problem solving, each one of us discovered our ability to listen, interpret results, and direct action research. In short, we became researchers.

The most frequently mentioned problem was the lack of access to legally guaranteed social security benefits. MORHAN Piauí therefore plans to hold an advocacy workshop with persons affected by Hansen's disease to develop a strategy for overcoming bureaucratic and stigma-related barriers. Then, we would like to organize a seminar to discuss our strategy with those responsible for implementing social protection policies.

# Goodwill Ambassador Sasakawa attends national conference in Sri Lanka

On Nov. 6 and 7, the Sri Lanka National Leprosy Conference “Join Hands to End Leprosy” was held at the Cinnamon Grand Hotel in Colombo. The conference was jointly organized by Sri Lanka’s Ministry of Health, the Sasakawa Leprosy (Hansen’s Disease) Initiative, and the World Health Organization. Sri Lanka’s head of state and government, President Anura Kumara Dissanayake, attended.

Dr. Nalinda Jayatissa, Minister of Health and Mass Media, informed attendees that while Sri Lanka successfully eliminated leprosy as a public health problem in 1995, approximately 1,500 to 2,000 new leprosy cases are detected annually, with about 10% of these being children. He stated that the current administration will implement a systematic program to make Sri Lanka a leprosy-free country by 2035.

During technical sessions, presenters shared details of the country’s current situation, examples of regional practices, and research findings. Discussions focused on how to eliminate discrimination and stigma, to involve persons affected by leprosy, to strengthen medical systems, to interrupt the chain of infection, and to utilize research outcomes.

A roadmap outlining the government’s strategy to achieve elimination (interruption of transmission) in Sri Lanka by 2035 was announced, and an action plan and enhanced cooperation mechanisms were confirmed.

WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa expressed respect for the government's continuing efforts to conduct screening, diagnosis, treatment, and awareness campaigns in collaboration with district and regional health authorities despite challenging circumstances. He also commended the cooperation of organizations of persons affected by leprosy for working to eliminate the disease and associated stigma and discrimination. He further expressed his conviction that this national conference will serve as a catalyst to further advance efforts toward zero leprosy. He called for everyone to join forces to realize a future where those who have experienced the disease and their children can have hope, emphasizing that a world free of leprosy is not just a dream.

The Goodwill Ambassador also met with around 35 representatives of organizations of persons affected by leprosy, where he heard directly about the challenges that they face in Sri Lanka. He shared knowledge about the experiences of persons affected by leprosy in other countries, leading to discussion about common challenges and potential solutions.

WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa gives a keynote address on the opening day of the Sri Lanka National Leprosy Conference in Colombo (Nov. 6, 2025).

Leaders and health officials stand together on stage after President Anura Kumara Dissanayake (fifth from right) launched Sri Lanka’s roadmap for achieving leprosy elimination (interruption of transmission) by 2035.

## Meeting with the Dalai Lama

WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa was thrilled to receive a playful tug of his beard when meeting with the 14th Dalai Lama on Nov. 28, 2025, in India. See page 1 for further details.

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 for medical issues in July 2023.

# Commentary on Global Leprosy Update 2024

Leprosy still exists: the data from 188 countries published by the World Health Organization (WHO) as the Global Leprosy Update 2024 confirms it. As per the update, 172,717 new leprosy cases were reported from 133 countries. WHO listed 23 countries as global priority countries, which together accounted for 96% (165,578) of new cases detected during the year.

WHO's South-East Asia Region contributed 72% of the new cases globally. The high prevalence of leprosy justifies continued positioning of WHO Global Leprosy Programme within the Regional Office for South-East Asia (SEARO), rather than at WHO headquarters in Geneva.

## New case detection

Though multidrug therapy (MDT) has reduced prevalence considerably, new cases continue to occur in most leprosy-endemic countries. Over the past nine years, the number of new cases detected per year has declined from 214,339 in 2015 to 172,717 in 2024. Correspondingly, the global new case detection rate decreased from 29.1 per million population in 2015 to 21.11 in 2024.

The number of new cases detected in WHO's African Region (AFR) remained at more or less the same level that it has been at since 2015. In contrast, there has been an obvious reduction in the number of new cases in the rest of the world. Figure 1 illustrates the difference between the trend in AFR compared to that of the rest of the world. Brazil, India, and Indonesia collectively continue to account for nearly 80% of the world's new cases.

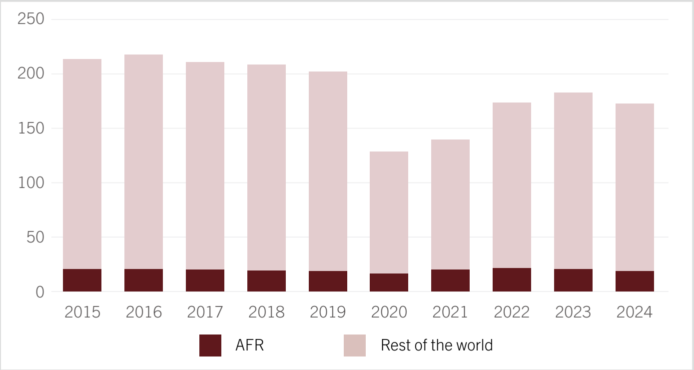

Figure 1. Number of new cases in AFR and in the rest of world 2015-2024.

## Autochthonous cases in European Region

The European Region (EUR) has been low endemic for the past century. About seven years ago, countries began distinguishing between cases acquired locally (autochthonous) and cases imported from elsewhere (non-autochthonous), as part of improved disease tracking systems. In 2024, of the 79 new cases reported in EUR, 14 were locally acquired (6 in Türkiye, 3 in Uzbekistan, 2 in Ukraine, 2 in France, and 1 in Portugal). The occurrence of these autochthonous cases in a low-endemic region needs to be respected with Critical Instance Investigation[1] to understand the possible sources of infection and other factors pertaining to transmission. Post-exposure prophylaxis by tracing contacts for each of those patients will help minimize further transmission in the community.

## Grade 2 disabilities (G2D)

According to the Global Leprosy Update, 9,157 new cases with grade 2 disability (G2D) were reported in 2024, corresponding to a G2D case detection rate of 1.1 per million population. This continues a downward trend in the number of new cases with G2D observed over the past decade. Between 2015 (14,385 cases) and 2024, the number of new G2D cases fell by approximately 36%. At the higher-burden end of the spectrum, two countries reported more than 1,000 new G2D cases and 13 countries reported more than 100. Because the occurrence of G2D in new cases reflects delayed diagnosis, countries are encouraged to strengthen and expand early detection activities.

## Leprosy in children (under age 15)

The incidence of a new child case reflects active transmission in the community. Globally 9,397 new child cases were reported with a corresponding new child case detection rate of 4.7 per million children. The number of child cases has nearly halved in ten years.

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[1] The term "Critical Instance Investigation" (CII) in public health refers to a specific, intensive case investigation protocol used primarily in national and subnational leprosy control programs, particularly in areas nearing or having achieved disease elimination (defined as a prevalence rate of less than one case per 10,000 population).

While there is a general decrease in WHO Regions overall, the Western Pacific Region (WPR) reported 96 more new child cases than last year, with increases notable in Kiribati, the Philippines, Papua New Guinea, Solomon Islands, Micronesia, and Vanuatu.

New cases with G2D among children reflect delay in detection in addition to continued transmission. In 2024, 289 new child cases were diagnosed with G2D, of which 115 (40%) were in AFR. Trends of new child cases with G2D from 2016–2024 are presented in Figure 2. It is a major concern that new cases with G2D among children were detected in 2024 despite the target of "zero child cases with G2D by 2020" set by the WHO Global Leprosy Strategy 2016–2020[2].

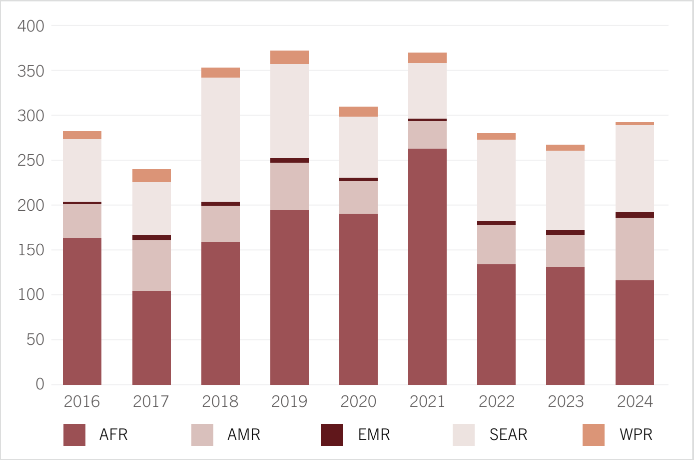

Figure 2. Trends of new child cases with G2D, 2016–2024, by WHO Region. EUR is not shown because the number of new child cases with G2D for this region was zero for all countries.

## Immunological reactions (*lepra* reactions)

Immunological reactions, called *lepra* reactions in the medical field, can suddenly worsen symptoms and may cause serious disabilities or life-threatening complications. In 2024, there were 20,341 reported cases of *lepra* reactions, though this figure primarily reflects reactions documented at the time of initial diagnosis and the true burden is likely higher, as many patients develop reactions after starting treatment. Management of *lepra* reactions remains an enigma to frontline health staff. An effective referral system and a standardized protocol for management of reactions should be developed to prevent disabilities and improve health.

## Post-exposure prophylaxis (PEP)

The case detection details from contact examination were found encouraging and can be recommended to countries where it is not practiced. Coverage of contact examination needs improvement (from 59% to 90%). Single dose rifampicin (SDR) was administered to 1.7 million people in 2024 as reported from 37 countries, which indicates considerable progress in implementation.

## Stigma and discrimination

Six countries reported that 81 discriminatory laws are still active in 2024. WHO is advised to make a comprehensive inventory involving relevant stakeholders like persons affected and civil society. Information about instances of discrimination was not reported. Considering the need for understanding prevailing stigma, it will be useful to consider using a systematically developed diagnostic device.

## Critical issues requiring action

**Persistent global endemicity:** 133 countries report one or more new cases of leprosy. Sustained and intensified case detection campaigns are essential to break the cycle of transmission.

**Stagnant case detection:** New case detection continues at relatively the same level, with 172,717 cases reported in 2024. Improved case-finding campaigns and preventive initiatives are needed to accelerate the decline.

**Concentration of burden:** The 23 global priority countries account for 96% of new cases. National and international resources must be strategically concentrated in these high-burden settings.

**Delayed diagnosis in children:** Nearly 300 children are diagnosed with visible impairments (grade 2 disability, G2D) annually. Early detection systems must be strengthened.

**Management of *lepra* reactions:** Over 20,000 cases of *lepra* reactions were reported in 2024. Better treatment protocols to manage severe reactions must be prioritized to improve quality of care.

**Discrimination and legislative reform:** At least 81 discriminatory laws reported to WHO remain in force globally. Repealing all laws that allow discrimination should be brought back as a target in national strategic plans.

**Underreporting of stigma and discrimination:** Instances of discrimination are not getting registered and addressed. Systematic tools and mechanisms must be developed to diagnose and monitor discrimination in health systems and communities.

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[2] World Health Organization, *Global Leprosy Strategy 2016–2020: Accelerating towards a Leprosy-Free World* (New Delhi: World Health Organization, Regional Office for South-East Asia, 2016), https://www.who.int/publications/i/item/9789290225096.

OBITUARY

# Chiemi Sanga passed away on September 20, 2025

Contributed by Dr. Takahiro Nanri, President, Sasakawa Leprosy (Hansen's Disease) Initiative

Chiemi Sanga joined the Sasakawa Health Foundation in 2012. She started in the General Affairs Department, and then, in 2017, she moved to the Leprosy Division, where she served as Chief Program Officer and Director for eight years.

She consistently played a central role in the Nippon Foundation–Sasakawa Health Foundation Joint Leprosy Program Office, established in 2018 to enable the Nippon Foundation Group to tackle leprosy more effectively. The joint program office was renamed the Sasakawa Leprosy (Hansen's Disease) Initiative in 2020. As the public relations officer, she laid the foundation for the Initiative's communications activities and managed all public relations for Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination. As one example, after this publication was renamed the *WHO Goodwill Ambassador's Leprosy Bulletin* in December 2020, she served as its de facto editor-in-chief, dedicating herself to improving the quality of its content.

She also devoted herself to spreading accurate knowledge about leprosy, launching a variety of awareness campaigns. In recent years, she spearheaded the "Global Appeal to end stigma and discrimination against persons affected by leprosy," which is held annually around World Leprosy Day at the end of January. She also played a central role in establishing the "Ms. Supranational Hansen's Disease Forum," held every June in collaboration with the Ms. Supranational Secretariat, organizer of one of the world's five major beauty pageants.

Furthermore, she was deeply involved in supporting organizations of persons affected by leprosy worldwide. She was dedicated to eliminating discrimination against patients, those who have recovered, and their families. In particular, the "Sasakawa Leprosy Initiative Young Scholar Program," launched in 2024 to cultivate the next generation of leaders and expected to become the core of the Initiative's work to support the community of persons affected by leprosy, would not have been possible without her efforts.

Chiemi worked tirelessly to strengthen the systems that support the Initiative's activities and to create the conditions for more effective operations. She was a sun-like presence for all staff, sincerely committed to realizing the Initiative's vision of "a world free from leprosy and its impact on human beings" until the very end. The news of her passing was received with profound shock by the global leprosy community, particularly by persons affected by leprosy, and the Initiative received numerous expressions of condolences and deep sorrow.

With profound respect and gratitude, we sincerely pray for the peaceful repose of the soul of Chiemi Sanga.

Chiemi Sanga (seated) cared deeply about the development of leadership capacity among young persons affected by leprosy. Here she is shown looking at a database after attending a capacity building training in Pangkep, South Sulawesi, Indonesia (June 2024).

## From the Goodwill Ambassador

"I am at a loss for words at this sudden tragedy. Chiemi was an exceptionally dedicated activist. It feels like losing a family member. Yet we must not stop. I believe the best way to honor her memory is for us to overcome this grief and continue striving towards a leprosy-free world."

—Yohei Sasakawa

SASAKAWA LEPROSY HANSEN'S DISEASE INITIATIVE

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**Publisher** Yohei Sasakawa
**Executive Editor** Takahiro Nanri

**Editorial Office** 5th Floor, Nippon Foundation Building,
1-2-2 Akasaka, Minato-ku, Tokyo 107-0052 Japan
Tel: +81-3-6229-5377 Fax: +81-3-6229-5388
leprosybulletin@shf.or.jp

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