

# LEPROSY BULLETIN

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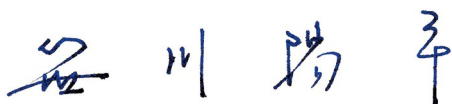
## Finding mutual inspiration in Hyderabad

### Message from the ambassador

In early November, I visited India for the first time in three years. My packed one-week schedule included a meeting with Dr. Poonam Khetrupal Singh, WHO Regional Director for South-East Asia, in Delhi; an official visit to the state of Jharkhand; attendance at the 2<sup>nd</sup> Global Forum of People's Organizations on Hansen's Disease; and delivery of the keynote address at the triennial International Leprosy Congress.

Here I would like to highlight the participation of two beauty pageant winners in the Global Forum. Invited to join as special guests, Miss World Brazil 2022 Leticia Frota and Miss Supranational India 2023 Pragyna Ayyagari actively engaged in dialogue with and listened intently to the more than 70 persons affected by leprosy from 17 countries around the world who attended. Both pageant winners expressed their commitment to spreading correct knowledge of leprosy among young people, and I was happy to see that they quickly followed through with social media posts directed to their thousands of followers.

I have always believed that it is important to spread awareness-raising activities beyond circles of those already involved in leprosy and related issues. Every influencer has a different audience, and seeing the beauty pageant winners use their platforms has given me ideas for future initiatives. I am grateful to the two pageant winners, and I hope that their willingness to learn and speak up will inspire other influential people in society to do the same.



Yohei Sasakawa

WHO Goodwill Ambassador for Leprosy Elimination

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

# Summary of 2<sup>nd</sup> Global Forum of People's Organizations on Hansen's Disease

The 2<sup>nd</sup> Global Forum of People's Organizations on Hansen's Disease was held in Hyderabad, India, Nov. 6-8, 2022. As with the inaugural Global Forum held three years earlier in Manila, Philippines, the event preceded the International Leprosy Congress (ILC) and ensured that persons affected by leprosy would be able to speak up for themselves.

Leading up to the 1<sup>st</sup> Global Forum in 2019, three regional assemblies were held in Africa, Asia, and Latin America/Caribbean to help shape its agenda. For the 2<sup>nd</sup> Global Forum, an organizing committee consisting of people's organizations' representatives voted on by their peers<sup>1</sup> met a couple of months earlier in Bangkok, Thailand, to decide on the agenda.

The organizing committee selected three topics for exploration in 2-hour sessions at the Forum: 1) capacity building; 2) inclusion; and 3) partnerships. The sessions included "sharing good practice" presentations, Q&A, group discussions, and presentations at the end to share results.

More than 70 persons affected by leprosy representing 21 people's organizations from 16 countries and one international organization took part in the three-day event, which was hosted by Sasakawa Leprosy (Hansen's Disease) Initiative as part of its "Don't Forget Leprosy" / "Don't Forget Hansen's Disease" campaign launched in August 2021 amid the coronavirus pandemic.

Including observers, interpreters, representatives of supporting organizations, and members of the International Federation of Anti-Leprosy Association (ILEP)'s advisory panel, more than 100 people attended the Forum each day.

Attendees included WHO Goodwill Ambassador Yohei Sasakawa as well as special guests Miss World Brazil 2022 and Miss Supranational India 2023, both of whom pledged their commitment to using their public profile to raise awareness of leprosy/Hansen's disease.

Also taking part was UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members Alice Cruz, for whom the event was a valuable opportunity to gather material for her final report as special rapporteur, which will be presented to the UN Human Rights Council in June 2023.

The last day of the Forum included a series of side events at which participating organizations made detailed presentations on their activities, allowing for further knowledge- and experience-sharing among participants.



Participants in the 2<sup>nd</sup> Global Forum of People's Organizations on Hansen's Disease gathered for a commemorative photograph following the opening session on Nov. 6.

The Forum ended with Conclusions and Recommendations drawn up by a drafting committee to be read by a representative at the ILC's inaugural function.

The Conclusions and Recommendations took into account that COVID-19 and measures against the disease, such as lockdowns and other restrictions, had a heavy impact on the lives of persons affected by leprosy/Hansen's disease living in marginalized communities. Attention was diverted from treatment and services for leprosy/Hansen's disease to other areas. In some countries, the support provided by people's organizations, which worked in partnership with NGOs and other organizations, was a lifeline.

Capacity building was highlighted in the Conclusions as being essential to ensuring the stability and realizing the potential of people's organizations. The Recommendations reflected points discussed in each of the three thematic sessions: 1) capacity building; 2) inclusion; and 3) partnerships.

Additionally, it was noted that many of the issues raised in the Conclusions and Recommendations from the 1<sup>st</sup> Global Forum in Manila have yet to be adequately addressed. People's organizations urge governments, non-governmental organizations, and other stakeholders to take all necessary steps to implement the recommendations coming out from both Global Forums.

For many participants, the Forum was a special opportunity to meet in person for the first time in three years.

"It brought us together. It was inspiring. Just to say hello is very important," said Tesfaye Tadesse Haile, the managing director of the Ethiopian National Association of Persons

<sup>1</sup> Selected representatives were from the following six organizations: MORHAN (Brazil, Americas); IDEA Ghana (Ghana, Africa); ENAPAL (Ethiopia, Africa); IDEA Nepal (Nepal, Asia-Pacific); HANDA (China, Asia-Pacific); and APAL (India, Asia-Pacific).

Affected by Leprosy (ENAPAL), who briefed the Forum on the recent opening of the organization's new headquarters building in Addis Ababa and stressed the importance of working ceaselessly for one's dream.



Jayashree P. Kunju, a member of the drafting committee, explains the draft of the Conclusions and Recommendations to Forum participants to obtain their approval.

"I felt comforted, energized, and valued to be here, interacting with people affected from different parts of the world. It has been an honor for me," said Mohamedi Ally Mtumbi, president of the Tanzania Leprosy Association. "We are still small. We started functioning properly four years ago. We aspire to be like ENAPAL one day."

"The smaller sessions involving presentations by the groups, where it was possible to ask questions and interact a little



Members of IDEA Nepal and ALO (Bangladesh) at a group discussion table.



Members of Bogura Federation (Bangladesh) at a side event on the third and final day sharing their stories

more — so much valuable work was being done," said Zoica Bakirtzief da Silva Periera of ILEP's advisory panel.

"I learned a lot and heard many different points of view," said Brima Kpoh of Sierra Leone's National Association of Persons Affected by Leprosy. "We need to strengthen people's organizations and put them at the forefront. They know their people, they know their situation, they know what they need better than any third party."

As well as the feel-good factor it generated and the sense of solidarity it created, the Forum also provided participants with practical ideas to take back to their respective countries.

"We run an organization of women and children affected by Hansen's disease and other NTDs," Lilibeth Nwakaego Evestus of Purple Heart Initiative Nigeria, said. "I heard someone talk about an initiative called 'goat bank' in terms of empowering women. Women are given a goat; they raise the goat and if it gives birth to two kids, they keep one for themselves and give one to the goat bank."

"I also heard women in Bangladesh say they have a rice bank where they put aside rice for them and their children for use in times of need. I think my women in Nigeria will be very eager to put this into practice. We will look at the idea that best suits our own environment. We will see how it aids us in terms of social and economic empowerment of women."



Representatives of people's organizations share the results of their discussion groups.



Members of MORHAN (Brazil) and Purple Hope Initiative (Nigeria) at a side event presenting on how to support women affected by leprosy.

## Collaboration with beauty pageant winners to raise awareness of leprosy (Hansen's disease)

Starting in 1972 with the implementation of a "Beauty with a Purpose" contest by the Miss World organization, beauty pageants worldwide have raised expectations that winners will be informed and effective advocates for humanitarian causes. In 2012, three women associated with the Miss World Brazil competition — a contestant studying dermatology, a contestant studying medicine, and a pageant presenter — contacted Movement for the Reintegration of Persons Affected by Hansen's Disease (MORHAN) with a proposal for partnership. After starting out in Rio de Janeiro, the partnership has been refined and expanded as the two organizations have continued to work together over the past 10 years.



Miss World Brazil 2022 and Miss Supranational India 2023 making a speech from the podium at the 2<sup>nd</sup> Global Forum of People's Organizations on Hansen's Disease. As is appropriate for a spokesperson who is expected to connect with youth, Miss Brazil's notes for her speech were on her phone.

The decade-long partnership in Brazil inspired organizers of the 2<sup>nd</sup> Global Forum of People's Organizations on Hansen's Disease to invite two current pageant winners to Hyderabad as special guests: Miss World Brazil 2022 Letícia Frota and Miss Supranational India 2023 Pragnya Ayyagari. The two pageant winners participated actively, sitting in on many of the presentations and sharing their thoughts at a special session on the final day. They also took part in a press conference as well as a dialogue with WHO Goodwill Ambassador Yohei Sasakawa.

Frota has been an official "Hansen's Disease Ambassador" for MORHAN since being crowned Miss World Brazil 2022.

At the Global Forum, she shared, "This struggle together with MORHAN started 10 years ago, and we have been doing a lot of hard work to be able to give voice to the cause of Hansen's disease in Brazil."

In particular, she emphasized the importance of reaching out to children. "By working with young people, we will be able to change the future landscape of the disease and spread awareness. I want to bring them the message that they should include others in society. Regardless of who we are, we have the right to be included in society and this message should be spread throughout the world," she said. "I want to use the power of the crown and the position I have to draw attention to this cause."

Beauty competitions in India do not have the same history of collaboration with leprosy-related people's organizations, and so Miss Supranational India 2023 knew only of Mother Teresa's work for leprosy patients before attending the Global Forum. On the last day of the Forum, Ayyagari shared, "I learned a lot about the disease. I heard all the stories and journeys (of persons affected), how they have been fighting and how COVID-19 has adversely affected the cause because people might have forgotten about Hansen's disease."

Going forward, Miss Supranational India also plans to focus on raising awareness among young people: "It is very important to educate children, because they are the future of our nation. When we tell them what leprosy/Hansen's disease is, that is when they will understand. They will look at persons affected by leprosy differently. It is our duty to change their perspective. I am really proud to be raising awareness and using the power of the crown to amplify the cause. I see myself working on this even after I pass down my crown."

Vice President of India's Association of People Affected by Leprosy (APAL) Jawahar Ram Paswan told the two pageant winners, "I would like you to spread awareness that the people who are going through this disease need to be integrated into the mainstream. We are people who need your love, we need your hugs. We have the right to live as normal people. Please spread awareness."

WHO Goodwill Ambassador Sasakawa likewise expressed his hopes and gratitude: "Although we have taken various actions, discrimination still exists, so your involvement will have a real impact on raising awareness. We treasure your engagement in this cause."



Special guests Miss World Brazil 2022 and Miss Supranational India 2023 taking a commemorative photograph with participants in the 2<sup>nd</sup> Global Forum of People's Organizations on Hansen's Disease.



Miss World Brazil 2022 and Miss Supranational India 2023 listening attentively during the 2<sup>nd</sup> Global Forum of People's Organizations on Hansen's Disease.



Panel discussion with Miss World Brazil and Miss Supranational India held on the third and final day of the Forum.



**pragnya.ayyagari and missdivaorg**  
Novotel Hyderabad Convention Centre



**pragnya.ayyagari** It was a great privilege to be a part of 2<sup>nd</sup> Global Forum of People's Organisation on Hansen's Disease. Hansen's Disease, also known as leprosy has been one of the oldest diseases in the world. With the help of modern technology we can detect the disease in the early stages and use medication to prevent the disabilities caused by the disease in the later stages. India accounts for over half (almost 60 per cent) of the world's new leprosy patients. Hence it is very important to spread awareness and educate everyone about the disease to end the social stigma and discrimination against the people affected by the disease. Getting to know and hear the stories of people affected and cured from the disease from across the globe inspired me to continue working for the cause to eliminate the disease. Most importantly, I'm inspired by WHO goodwill ambassador, Mr. Sasakawa who at 83, rose the "Don't Forget Leprosy" flag on Mount Fuji and continues working selflessly for over five decades.  
@letticiafrota you are very kind, lots of love to you! ❤️  
Thank you so much @missdivaorg for this opportunity!

Instagram post by @pragnya.ayyagari and @missdivaorg (Nov. 11, 2022). Miss Supranational India 2023 Pragnya Ayyagari using her social media platform to spread awareness of leprosy and expressing her intention to work for the cause to eliminate the disease.



**missbrasiloficial** Ontem foi dia da nossa Miss Brasil Mundo, @letticiafrota , conceder entrevista à Onda Digital Rádio TV, em Manaus, contando a sua experiência na Índia, onde recentemente atuou como embaixadora do luta contra a hanseníase no Brasil, junto ao @morhannacional ❤️

Instagram post by @missbrasiloficial (Nov. 18, 2022). Translation from Brazilian Portuguese: "Yesterday Miss World Brazil, @letticiafrota, gave an interview to Onda Digital Radio TV, in Manaus, telling her experience in India, where she recently acted as an ambassador of the fight against Hansen's disease in Brazil, with @morhannacional."

## Summary of 21<sup>st</sup> International Leprosy Congress held in Hyderabad, India

The 21<sup>st</sup> International Leprosy Congress (ILC), which was organized around the theme “Early Diagnosis – Better Knowledge – Improved Care,” was held in Hyderabad, India, Nov. 9-11, 2022. Taking place in the wake of the COVID-19 pandemic, the triennial gathering of key stakeholders adopted a hybrid format to encourage participation regardless of ability to travel. Of the total number of 480 papers, 300 were presented in person and 180 were presented virtually. In addition, 400 e-posters were shared either on LCD monitors at the venue or on the virtual platform.

On the theme of “Early Diagnosis,” a number of sessions looked at possibilities for an early diagnostic test for leprosy. Concerning “Better Knowledge,” advances in molecular biology and genome sequencing that were presented have implications for drug testing and fieldwork. On the subject of “Improved Care,” a convincing case was made for there to be a safer multidrug therapy regimen that has fewer side effects. “Patients have a human right to be treated with less toxic drugs,” said Professor Diana Lockwood in her plenary presentation.

The role artificial intelligence can play in aiding diagnosis — “alongside humans, not replacing humans” — was discussed, as was the role persons affected by leprosy can play in leprosy services, from counseling the newly diagnosed and allaying their fears to being a good companion during treatment and offering support and advice during reaction.

A session on funding for leprosy research called for connecting funders to researchers and revealed that a leprosy vaccine is now a priority for the United States Agency for International Development (USAID).

Representing the host nation, Dr. Anil Kumar laid out India’s road map to zero leprosy, and noted that “a leprosy-free India would represent a milestone to achieving a leprosy-free world.”

WHO Goodwill Ambassador Yohei Sasakawa gave the keynote address, telling Congress participants he was “proud to work with you on the goal of zero leprosy.”

Projects supported by Sasakawa Leprosy (Hansen’s Disease) Initiative — ranging from innovative case finding to history preservation — featured in a number of sessions.

Conclusions and Recommendations from the 2<sup>nd</sup> Global Forum of People’s Organizations on Hansen’s Disease, hosted by the Initiative as part of its “Don’t Forget Leprosy” campaign and held prior to the ILC, were read out on the opening day by Maya Ranavare, president of India’s Association of People Affected by Leprosy (APAL).

The 22<sup>nd</sup> International Leprosy Congress will convene in Bali, Indonesia, in 2025.



Maya Ranavare, president of India's Association of People Affected by Leprosy (APAL), reading the Conclusions and Recommendations of the 2<sup>nd</sup> Global Forum of People's Organizations on Hansen's Disease at the inaugural function of the 21<sup>st</sup> International Leprosy Congress in Hyderabad (Nov. 9, 2022).

## Case detection innovations for achieving interruption of transmission

Sasakawa Health Foundation (SHF) annually supports the national leprosy programs of nearly 40 countries through the World Health Organization’s Global Leprosy Programme (WHO GLP). SHF and WHO GLP organized a session on projects initiated by the national leprosy programs of four countries — Bangladesh, Brazil, the Democratic Republic of Congo, and India — on the theme of early case detection to achieve interruption of transmission. Opening remarks were

provided by Takahiro Nanri, SHF’s executive director, and Dr. V. R. Pemmaraju, WHO GLP’s acting team leader.

Representing Bangladesh, Dr. Shakil Ahmed shared how extended contact surveys revealed hidden cases in areas that had previously reported no cases for a number of years. In response, Bangladesh began training persons affected by leprosy to be “champions” who can help with

awareness raising and identification of suspected cases in the community. During the COVID pandemic, Bangladesh also introduced telecare for treating complications.



A trained "champion" in Bangladesh assisting with identification of suspected cases in the community.

On behalf of Brazil, Dr. Carmellita Ribeiro Filha Coriolano presented on a project that gave training in case finding and case management to staff at basic health units and mobilized patients and contacts in the community to help spread awareness for the purpose of increasing case detection. The project also addressed stigma and discrimination.

Speaking for DR Congo, Dr. Ngondu Lobuta Florent described a leprosy detection intensification project that was implemented in nine provinces from 2021 to 2022. The project led to an increase in the detection rate and 100% multidrug therapy (MDT) coverage of new cases in the target areas and reduction in the proportion of new cases with grade 2 disability. One of the keys to making the project work was using political-administrative authorities to raise awareness and mobilize populations.

India's Dr. Anil Kumar focused on the country's use of Accredited Social Health Activists (ASHA) for case detection under its ASHA-based surveillance for leprosy suspects (ABSULS) program. Introduced in 2017, ABSULS was designed to strengthen routine case detection and address the need for quality surveillance for leprosy in the community. Each ASHA is responsible for around 200 households and reports the number of suspects (zero or above) for the previous month. The information is compiled by supervisors and validated by field visits. This active surveillance in the community is designed to ensure early detection and reduce disability at diagnosis.

The four projects align with WHO's *Global Leprosy Strategy 2021-2030: Towards zero leprosy*.

## REPORT from HYDERABAD

# Testing for rifampicin-resistant *M. leprae*

As a tool to achieve the goal of zero leprosy, post-exposure prophylaxis in the form of a single dose of rifampicin (SDR-PEP) given to contacts of leprosy patients has a major role to play. However, due to the existence of rifampicin-resistant *M. leprae* throughout the world, applying SDR-PEP to persons with drug-resistant strains of the leprosy bacillus is not only ineffective; it also results in active selection of resistant strains.

Since polymerase chain reaction (PCR) and DNA sequencing are difficult to perform in most endemic countries because of the costs involved, lack of expertise, and other factors, Dr. Kei Mikita of the Department of Infectious Diseases at Keio University and Professor Koichi Suzuki of the Department of Clinical Laboratory Science at Teikyo University, both in Tokyo, have developed a simple and cost-effective diagnostic method for rifampicin-resistant *M. leprae* using loop-mediated isothermal amplification (LAMP). The research is being funded by Sasakawa Health Foundation.

Their LAMP-based diagnostic method has been able to confirm the presence of known mutations causing rifampicin resistance. The COVID-19 pandemic has delayed testing of the diagnostic method in endemic countries, but research

to date shows it can be an accurate tool for the detection of rifampicin resistant strains of *M. leprae* in contacts to be given SDR-PEP.

Based on the LAMP-based diagnostic method, Dr. Mikita and Professor Suzuki are now developing an even simpler, more field-friendly method that will be able to detect all known drug-resistant leprosy strains. They expect that development of the underlying technology will be completed in 2023.



Dr. Kei Mikita making a presentation about his research in Hyderabad.

## History preservation as a third pillar in the fight against leprosy

In a plenary session sponsored by Sasakawa Health Foundation (SHF) on the second day of the 21<sup>st</sup> International Leprosy Congress (ILC), SHF's executive director, Takahiro Nanri, called for making history preservation the "third pillar" of strategies for fighting leprosy.

Since its establishment in 1974, SHF has been evolving its approach to leprosy in relation to progress made against the disease. In addition to "tackling disease" and "eliminating discrimination," the organization took on "history preservation" in the 1990s based on growing awareness that records, testimonies, artifacts, and spaces were being lost to the world as leprosy ceased to be a major public health problem.

SHF developed its approach to history preservation along three lines: 1) building the foundations of history preservation at selected locations; 2) creating a network of those involved; and 3) establishing an information platform. The organization has supported the collection and preservation of relevant documents and records, the recording of testimonies of persons affected by leprosy, and other conservation efforts in the Philippines, Malaysia, Spain, Portugal, and other locations. SHF hosted five international workshops and symposiums over the past decade on leprosy/Hansen's disease as heritage of humanity in order to build a network of persons affected by leprosy, non-governmental organizations, researchers, academics, and government officials committed to history preservation. SHF has also developed a portal site and database on the history of leprosy (<https://leprosyhistory.org>) in cooperation with the International Leprosy Association.

UN General Assembly resolution 65/215 on elimination of discrimination against persons affected by leprosy and their family members, together with accompanying principles and guidelines, provides a roadmap for addressing discrimination, but other initiatives are needed to sensitize society and create awareness. To achieve the goal of zero leprosy, it is necessary to break not only transmission of the disease, but also barriers of discrimination that prevent people coming forward for treatment and stop them from living as full-fledged members of the community.

Nanri finished his presentation with the assertion that working on history preservation will contribute to progress against leprosy both medically and socially, by enhancing the quality of leprosy services and promoting respect for the dignity of persons affected, and should be made the third pillar of the fight against the disease. Furthermore, in alignment with the core principle of the Sustainable Development Goals, it can also provide pointers on how to realize a society where no one is left behind.



Takahiro Nanri, executive director of the Sasakawa Health Foundation, giving a presentation about including history preservation as a third pillar in the fight against leprosy.

## Preserving Europe's historical heritage of leprosy

Along with Eduardo de Miguel Selma of Fontilles, a leprosy sanatorium established in Spain in 1909 that remains active as a treatment facility and referral center, Sasakawa Health Foundation (SHF) hosted a thematic session as part of the virtual session on "Initiatives to preserve and disseminate the historical heritage of leprosy in Europe." The session looked at history preservation activities in three countries: Spain, Norway, and Portugal.

Antonio García Belmar of the University of Alicante spoke on "Fontilles Heritage: A worldwide project to fight against exclusion and oblivion." Since 2017, the

Fontilles Foundation and University of Alicante have been collaborating on a heritage project with funding from SHF to preserve and highlight the value of the Fontilles Historical Archive. One result of this collaboration is the portal site "Fontilles and Leprosy in Spain." Housed in the Miguel de Cervantes Virtual Library hosted by the university, it provides access to an extensive collection of journals, images, documents, testimonies, and objects. The heritage project is dedicated to ensuring that the stories and lived experiences of those affected by the disease are neither excluded nor forgotten.



Grete Eilersen of the Bergen City Museum/Leprosy Museum tackled the topic of “Who are our museums for? Finding new ways to reach a broader audience.” Bergen’s Leprosy Museum opened in 1970 in St. Jørgens Hospital, which served as a leprosy hospital from when it was established in the 15th century until the last residents passed away in 1946. When the museum opened, it focused on Norway’s contribution to leprosy research. It subsequently underwent a transformation, putting the individuals who formed the hospital community in the foreground, while continuing to tell the story of Bergen as a former center of leprosy research and the city where Hansen discovered *M. leprae*. To reach out to a broader audience and make the museum accessible to those who are not able to visit in person, museum directors are planning to open a virtual museum. The new initiative will make use of 3D imagery and other techniques to engage online visitors.

Cristina Nogueira of Culture Age presented the “Holistic revitalization of the heritage of Hospital Colónia Rovisco Pais.” Rovisco Pais opened in Portugal in 1947 as a self-sufficient hospital colony for treating and researching leprosy. In 1996, it was converted into a rehabilitation medicine center while continuing to provide leprosy services and care for the remaining residents.

The rehabilitation center assumed responsibility for preserving the cultural heritage of the former hospital colony. With funding from SHF, the center restored and inventoried the photographic

and documentary archives of the scientific library, collected oral testimonies from former residents and staff, and recovered objects of historical interest. A “Hansen’s Stories” website was created with information about the history of the hospital, oral testimonies, a photo gallery, and a digital library.

To foster engagement with the heritage, a museum was opened in a wing of the old chapel in 2021 and oral testimonies were used to create a traveling exhibition. Based on responses received so far, engagement with the cultural heritage of the hospital colony encourages critical thinking and learning.

With support from SHF, European institutions — led by Fontilles and including the museum in Bergen and Rovisco Pais — are working toward the creation of a regional network for history preservation.



3D image of a church in Bergen City Museum/Leprosy Museum built for their website.

## REPORT from HYDERABAD

# Results of “Don’t Forget Leprosy” grant-supported surveys in Brazil

As part of its “Don’t Forget Leprosy” campaign” launched in August 2021 amid the coronavirus pandemic, the Sasakawa Leprosy (Hansen’s Disease) Initiative has provided grants for surveys on the impact of the pandemic on persons affected by leprosy, on discrimination against persons affected by leprosy, and on the socio-economic situation of communities of persons affected by leprosy. At a virtual session of the 21<sup>st</sup> International Leprosy Congress led by Artur Custodio of MORHAN, results of two surveys conducted in Brazil were shared with participants.

The first survey collected information about the health situation of women affected by Hansen’s disease during the COVID-19 pandemic in 28 municipalities and 10 federative units in four regions of Brazil, using volunteers from MORHAN who were trained and empowered to conduct interviews and collect data. Analysis of the data found that more than 60% of the women surveyed experienced feelings of anxiety and stress ranging from mild to extremely severe and more than

50% experienced feelings of depression. Many of the women had very low income and low education, and had issues relating to self-esteem, prejudice, and stigma because of living with Hansen’s disease. The results indicate the need to plan and carry out “collective health actions” (ações de saúde coletiva), which intervene at the level of social groups based on an understanding of health as a dynamic process that is inseparable from socio-cultural and economic factors.

The second survey looked at the impact on the lives of persons affected by Hansen’s disease and on the organization of care services for them in the city of Recife, capital of the state of Pernambuco in northeastern Brazil, with both persons affected by Hansen’s disease and health professionals as participants. Survey results highlighted the financial impact of the pandemic on persons affected by Hansen’s disease and the challenges faced by health managers in the context of the pandemic to ensure health care for them.

# WHO's annual global leprosy update (2021 data)

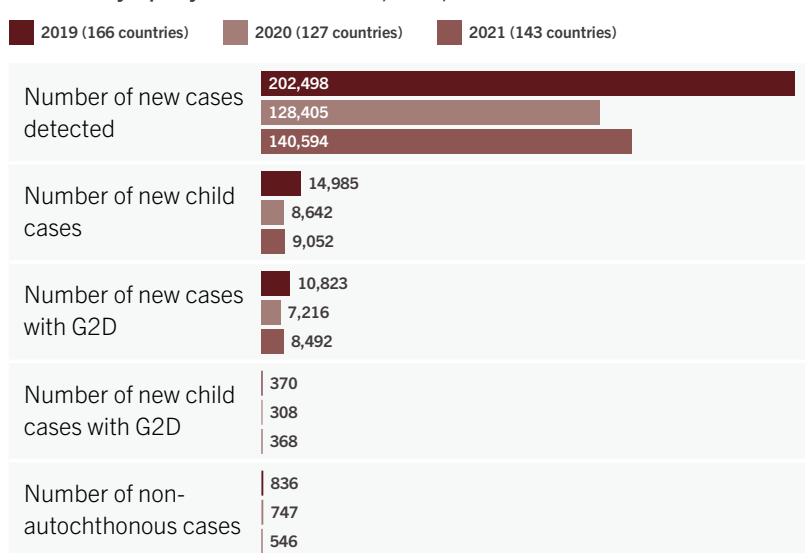
In September 2022, WHO published its annual global leprosy (Hansen's disease) update.<sup>1</sup> The update presents statistics based on 2021 data reported by 143 countries, including all 23 global priority countries.

The total number of reported new cases of leprosy in 2021 increased by 10.2% in comparison to the number reported in 2020 while showing a decrease of 30.6% in comparison to the number reported in 2019. This pattern — increase in comparison to 2020; decrease in comparison to 2019 — presented similarly for all other key indicators, except for the number of non-autochthonous<sup>2</sup> cases. The pattern should be considered in the context of the COVID-19 pandemic.

Pandemic-related restrictions and diversion of resources disrupted early diagnosis and continuous surveillance activities, which are necessary for preventing transmission and the development of visible deformities (grade 2 disability, G2D). While the number of undetected cases is by definition

unknown, the number has probably increased. The update emphasizes that “surveillance should be promoted to ensure detection of a maximum number of patients” (p. 448).

Selected key leprosy indicators for 2019, 2020, 2021



Source: World Health Organization, Global leprosy (Hansen disease) update, 2021.

## Interruption of transmission

Global leprosy update analysis of new case detection rates showed that 14 countries have reported zero new autochthonous<sup>3</sup> child cases for the past five consecutive years and can be considered for verification of interruption of transmission.

Phase	Description
<b>Interruption of transmission</b>	no local transmission of <i>M. leprae</i> , evidenced by zero new autochthonous cases among children $\leq 15$ years for at least 5 consecutive years
<b>Elimination of disease</b>	after “interruption of transmission,” zero new autochthonous leprosy cases for all ages for at least 3 consecutive years
<b>Post-elimination surveillance</b>	after WHO has verified “elimination of disease,” a country conducts “post-elimination surveillance” for 10 or more years

Sources: World Health Organization, Global leprosy (Hansen disease) update, 2021 (<https://apps.who.int/iris/handle/10665/362412>), p. 448–449. World Health Organization, Regional Office for South-East Asia, Task Force on definitions, criteria and indicators for interruption of transmission and elimination of leprosy: Report of the final meeting, 2021 (<https://apps.who.int/iris/handle/10665/342172>).

## Treatment completion rates

Treatment completion rates in cohort analyses were 89.3% for multibacillary (MB) and 95.85% for paucibacillary (PB) leprosy.

## Antimicrobial resistance

Eight countries reported data on antimicrobial resistance. Of 3,452 patients tested, 51 were found to have *M. leprae* strains resistant to rifampicin, 49 to dapsone, and 3 to ofloxacin; 4 had strains resistant to more than one antimicrobial.

## Post-exposure prophylaxis (PEP)

WHO advises that administration of a single dose of rifampicin reduces the risk of leprosy and can be given as post-exposure prophylaxis to eligible contacts of leprosy patients, i.e., adults and children aged  $\geq 2$  years, after excluding leprosy and tuberculosis and in the absence of other contraindications.

## New self-paced online course

Based on recognition that clinical and programmatic expertise must be strengthened, WHO has developed an online course for frontline health workers in national programs. The course takes approximately two hours to complete, and it is available free of charge through the OpenWHO platform: <https://openwho.org/courses/NTDs-leprosy>.

<sup>1</sup> World Health Organization, “Global leprosy (Hansen disease) update, 2021: moving towards interruption of transmission,” *Weekly Epidemiological Record* 97 (36): 429–450 (<https://apps.who.int/iris/handle/10665/362412>).

<sup>2</sup> “Non-autochthonous new cases of leprosy (previously referred to as foreign-born cases) are those in

which the person is assumed to have been infected in another country than that in which leprosy was diagnosed” (p. 436).

<sup>3</sup> An autochthonous case of leprosy is presumed to have been acquired by local transmission in the reporting area, indicating that the case resulted from a locally acquired infection.

# WHO Goodwill Ambassador's active week in India

WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa started his first visit to India in about three years in New Delhi at the WHO Regional Office for South-East Asia, which also houses WHO's Global Leprosy Programme, to meet with Regional Director Dr. Poonam Khetrpal Singh. He then headed south, first stopping in Jharkhand to meet with state authorities and community-based frontline health workers known as ASHAs, and then moving on to Hyderabad in Telangana, the location for the 21<sup>st</sup> International Leprosy

Congress (ILC). In Hyderabad, he participated in the 2<sup>nd</sup> Global Forum of People's Organizations on Hansen's Disease, visited a colony on the outskirts of the city, met with the representatives of endemic countries' national leprosy programs and other relevant officials, gave the keynote address at the ILC, and held two press conferences. The Goodwill Ambassador was pleased to be resuming an active schedule after years of restrictions because of the COVID-19 pandemic.



**New Delhi (Nov. 4)**

**Dr. Poonam Khetrpal Singh, WHO Regional Director for South-East Asia**

There are many people in India who do not have proper knowledge of leprosy. For persons affected by leprosy to even just meet with state officials is a meaningful step that raises awareness. We are grateful to Goodwill Ambassador Sasakawa for making an effort to visit each of India's states.



**Ranchi, Jharkhand (Nov. 5)**

**Press conference**

Persons affected by leprosy face a variety of problems that make their lives difficult. State leaders are involved in social security issues, housing, employment assistance for those willing to work but without a place to work, disability care issues, and so on. I want them to seek out persons affected by leprosy to hear from them directly.



**Ranchi, Jharkhand (Nov. 5)**

**Mr. Hemant Soren, Chief Minister of Jharkhand**

Although on a tight schedule, the chief minister of Jharkhand made time to listen to Maya Ranavare, president of the Association of People Affected by Leprosy (APAL), and Mohammad Jinauddin, APAL state leader for Jharkhand.



**Ranchi, Jharkhand (Nov. 4)**

**Mr. Banna Gupta, Minister of Health, Medical Education & Family Welfare, Jharkhand**

It is important to bring persons affected by leprosy into the mainstream. I have already visited many colonies in the state myself and have been active in sending the message that leprosy is not something that should be discriminated against. I would like to work on matters such as establishing a special pension plan for persons affected by leprosy with severe disabilities and providing vocational training programs for them.



**Pithauriya village, Kanke subdivision, Ranchi, Jharkhand (Nov. 5)**

**Ayushman Bharat - Health and Wellness Centre (AB-HWC)**

In this region, Accredited Social Health Activists (ASHAs) are called SAHIYA. They are holding flipcharts that they will take to health centers and homes to raise awareness of the importance of early diagnosis. The state of Jharkhand has been conducting a case detection campaign since the beginning of 2022 and as of August had already detected more cases than in all of 2021.



**Hyderabad, Telangana (Nov. 6)**

**Shanthi Nagar Leprosy Colony**

Goodwill Ambassador Sasakawa received a grand welcome with a dance from the children and many honorary flower garlands. He thanked everyone for the hard work that had gone into preparing for his visit and urged the community to care for the colony's future by making sure that the children receive an education.



**Hyderabad, Telangana (Nov. 6-8)**  
**Participating in the 2<sup>nd</sup> Global Forum of People's Organizations on Hansen's Disease**

Goodwill Ambassador Sasakawa was pleased to reunite with representatives of people's organizations from all over the world, and he was grateful for the cooperation of Miss World Brazil 2022 Letícia Frota and Miss Supranational India 2023 Pragnya Ayyagari. He called for global solidarity and awareness under the motto "Don't Forget Leprosy/Hansen's Disease" so that a more inclusive society can be realized as soon as possible.



**Hyderabad, Telangana (Nov. 9)**  
**Keynote address at the inaugural function of the 21<sup>st</sup> International Leprosy Congress**

Acknowledging that many leprosy control activities stagnated during the COVID-19 pandemic, Goodwill Ambassador Sasakawa urged participants in the 21<sup>st</sup> International Leprosy Congress to apply what has been learned during the pandemic period to strengthening efforts in the direction of zero leprosy based on WHO's Global Leprosy Strategy.

**Snapshots from the 2<sup>nd</sup> Global Forum of People's Organizations on Hansen's Disease**



With Ms. Francilene Mesquita of Brazil's Movimento de Reintegração das Pessoas Atingidas por Hanseníase (MORHAN).



With Ms. Alice Cruz, UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members.



With members of Bangladesh's Bogura Federation and Advancing Leprosy and Disadvantaged Peoples Opportunities Society (ALO).



With members of India's Association of People Affected by Leprosy (APAL).



At a press conference, speaking about the Global Forum and spreading correct knowledge of leprosy.



With Mr. Papa Mamadou Diagne, ILEP Advisory Panel member from Senegal, and Mr. Yohanna Abdou, representing IDEA Niger.

