WHO GOODWILL AMBASSADOR'S

LEPROSY BULLETIN

NO. 101 DECEMBER 2020

Challenges and strategies amid the COVID-19 pandemic

Message from the ambassador

Welcome to the *Leprosy Bulletin*, a new version of the newsletter that I have been publishing since 2003. The new title and design are meant to signal that leprosy and problems associated with it are contemporary issues that require attention now. Along with continuing to share my views and reports on my activities, and I will also be seeking contributions from experts, officials, activists, and persons affected by leprosy.

I hope that the *Leprosy Bulletin* will facilitate timely exchange of information and network building. For easy access and sharing, all of the content will be made available online.

With countries around the world in the grip of the coronavirus pandemic, it is a major challenge to keep leprosy programs functioning effectively. Governments can help by having clear policies regarding how comprehensive leprosy services are to be provided within their country's mainstream healthcare system.

At the same time that services are in jeopardy, persistent stigma and discrimination render persons affected by leprosy especially vulnerable. Because they know the issues that they face better than anyone else, strengthening their organizations should be a priority. I hope that national governments will coordinate with the reappointed UN Special Rapporteur and quickly find ways to offer support.

I am determined to spend the rest of my life continuing to fight against leprosy and the stigma and discrimination associated with it. I hope that you will fight with me so that together we can realize a leprosy-free world.

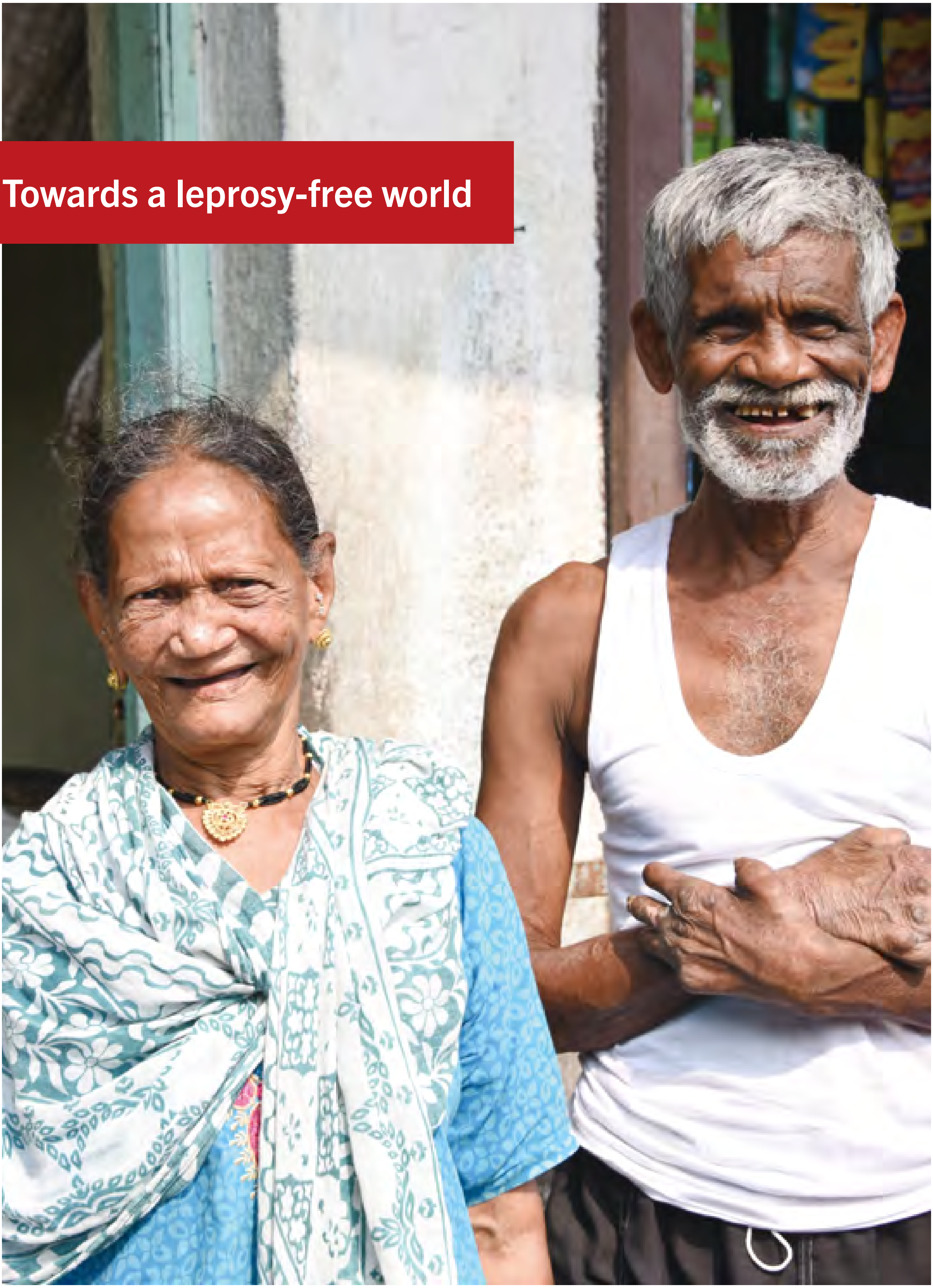
Yohei Sasakawa
WHO Goodwill Ambassador for Leprosy Elimination

Contributing to this issue:

- Bill Gallo (GPZL)
- Artur Custódio (MORHAN, Brazil)
- Yuliati (PerMaTa, Indonesia)
- Ramesh Choudhary (LLHSC, Nepal)

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

Towards a leprosy-free world



ANNOUNCEMENT

Introducing the Sasakawa Leprosy (Hansen's Disease) Initiative

In April 2020, the WHO Goodwill Ambassador for Leprosy Elimination, The Nippon Foundation (TNF), and the Sasakawa Health Foundation (SHF) completed a two-year reorganization project to leverage knowledge, networks, and resources more effectively. Under the name Sasakawa Leprosy (Hansen's Disease) Initiative, the WHO Goodwill Ambassador, TNF, and SHF work in a coordinated way to achieve a leprosy-free world.

Responding to the COVID-19 pandemic is one of the Initiative's first challenges. As countries divert resources from national leprosy programs in order to cope with sudden pandemic-related needs and people everywhere attempt to adjust to a "new normal," the Initiative has launched the following activities:

Support for organizations by and for persons affected by leprosy

A new grant program supports persons affected by leprosy facing difficulties stemming from the coronavirus pandemic. The Initiative will be providing a total of US$340,000 to 22 organizations in 14 countries spread over three continents.

All of the supported organizations are by and for persons affected by leprosy. The grants are awarded to fill an immediate need for pandemic-related support and, at the same time, to further our longer term goal of strengthening these organizations.

Webinar series

Countries worldwide are facing the challenge of maintaining comprehensive leprosy services (diagnosis, treatment, prophylaxis, rehabilitation, and surveillance) within their mainstream health systems amid the coronavirus pandemic. Success depends upon cooperation among key stakeholders.

To provide an opportunity for these key stakeholders to share information about challenges and strategies, the Initiative has launched a new webinar series. The series is free and open to everyone. Participants are expected to include representatives from governments, international organizations, organizations of persons affected by leprosy, NGOs, and research programs.

The webinar series will be held over a five-month period running until March 2021. The first webinar, held on Oct. 30, focused on "Schemes to support organizations of persons affected by leprosy during the coronavirus pandemic and their significance." Details about the remaining sessions and how to participate will be posted on the Sasakawa Health Foundation website, accessible via the QR code on the back page of this bulletin.

Facing page: A couple in Hanuman Nagar Kushta, Maharashtra, India (Dec. 9, 2017).
Above: Webinar held on Oct. 30, 2020. Representatives from organizations of persons affected by leprosy reported on providing emergency support during the COVID-19 pandemic.

INTERVIEW

Bill Gallo
Secretariat Director, Global Partnership for Zero Leprosy (GPZL)

Bill Gallo joined the Global Partnership for Zero Leprosy (GPZL) in September 2020 as Secretariat Director. Prior to joining, he worked for the US Centers for Disease Control and Prevention (CDC) for 33 years, mostly in field assignments where he served as the primary link between local health department/ministry leadership and the CDC.

https://zeroleprosy.org

New Secretariat Director aims to maintain consensus as GPZL moves forward

Bill Gallo is used to sudden changes in conditions from his years of working in the field for the CDC. *Leprosy Bulletin* interviewed him in October, while he was required to work from home because of the COVID-19 pandemic. He shared ways that GPZL is staying focused on zero leprosy so that both short-term needs and long-term goals can be met.

LB (*Leprosy Bulletin*)**:** GPZL is a global partnership. In your experience, what's the secret to getting international collaboration to succeed?

BG (Bill Gallo)**: Collaboration begins with a shared vision and clear goals. While there has certainly been collaboration in the leprosy community before the formation of GPZL, this level of consensus among shareholders is new. We all envision zero leprosy: no disease, no disability, and no discrimination. This shared understanding was the first step toward successful international collaboration, which resulted in the creation of our research agenda and best practices toolkit. Now we are working to maintain consensus as we move forward with country program implementation, research acceleration, and resource mobilization.**

LB: It's not easy to get governments to give priority to leprosy at the best of times. How has GPZL been adapting its strategies during the COVID-19 pandemic?

BG: GPZL first took action in March with the formation of three working groups that address the needs of the leprosy community in the face of the pandemic.

Working Group 1: Leprosy Emergency Operations Committee (LEOC) released a report addressing issues in the supply of leprosy treatment drugs and the treatment of leprosy and leprosy reactions. This group supports the work of National Leprosy Programmes.

Working Group 2: Emergency Advocacy for Persons Affected works with persons affected to gather information on their needs during the pandemic and share information about government and NGO response to those needs.

Working Group 3: Post COVID-19 focuses on thinking critically about future health scenarios and developing a path forward for the leprosy community in a post-COVID-19 world.

LB: Public health messaging, especially for a stigmatized disease such as leprosy, is always challenging. How does GPZL approach messaging?

BG: Consensus on public health messaging from within the Partnership is key to reaching a broader audience with a clear and consistent message. We work with our partners to develop understanding and build knowledge. For example, our COVID-19 Response Working Group 2 facilitated consultative calls with persons affected by leprosy around the world to collect data on ways the pandemic has impacted persons affected. The working group published a report detailing the challenges facing persons affected at this time, which is available on our website.

LB: Do you have any suggestions for the WHO Goodwill Ambassador? How can he help GPZL achieve its goals?

BG: The WHO Goodwill Ambassador's work to amplify the voices of persons affected by leprosy has been enormously valuable to the leprosy community. This continued support for persons affected organizations and individuals is aligned with our work to support advocacy efforts of organizations of persons affected by leprosy, as well as individuals with first-hand experience of the disease. We recognize that persons affected by leprosy are often the individuals leading leprosy care and advocacy efforts at the regional and community levels, and we look forward to continued collaboration with the Goodwill Ambassador in supporting the efforts of persons affected by leprosy.

For the complete interview, visit
https://www.shf.or.jp/information/9854?lang=en

Yuliati
Head of PerMaTa South Sulawesi
S.Kep., Ns. (Bachelor level nursing degree)

PerMaTa (Perhimpunan Mandiri Kusta) Indonesia is a nationwide people's organization established in 2007 to eliminate stigma and discrimination associated with leprosy. PerMaTa South Sulawesi is the largest provincial branch.

http://www.permataindonesia.org/

If I don't do something, who will?

When I was first diagnosed with leprosy in 2012, I felt my life had been destroyed and there was no hope. I thought about committing suicide. Now, eight years later, I have confidence and I feel that my life is meaningful because of the support that I have received from PerMaTa Indonesia.

I live in a regency called Gowa in the province of South Sulawesi. In 2012, a new branch of PerMaTa was being established in Gowa, and I was invited by the leprosy officer who treated me to join a meeting. Even though, at the time, I had absolutely no idea what PerMaTa was, I was elected to be the head of the Gowa branch of the PerMaTa board.

I wanted to cry when I was elected because I didn't know what to do. But my heart said just try, and as time goes by you will understand. And indeed this has happened.

I have a nursing degree. I had wanted to be a nurse in order to work in a hospital and improve my own standard of living. After joining PerMaTa, my dream for myself changed. PerMaTa is the only organization by and for people who have or have had leprosy in Indonesia that aims to eliminate stigma and discrimination. I experienced this stigma and discrimination myself, and I relate to the experiences of other people who have or have had leprosy. If I don't do something, who will?

With the support of PerMaTa friends and various donor supporters, I now serve as the head of PerMaTa Indonesia for all of South Sulawesi province. Activities that we carry out at PerMaTa include awareness-raising about leprosy in the community, advocacy to the government, empowerment of people who have or have had leprosy, socio-economic assistance, and assistance to people who are experiencing leprosy.

Since the end of 2019, the world has been shocked by the COVID-19 outbreak. In this situation, people from marginalized groups such as people who have or have had leprosy are largely unable to access government assistance. With the support of Sasakawa Health Foundation (SHF), we are doing several things, such as awareness-raising about COVID-19 to people who have had leprosy and their families, providing personal protective equipment, providing basic foodstuffs, providing psychological support, and advocating to the government regarding assistance.

We are grateful that the lockdown has been lifted so that we can go out of our homes and carry out our activities, but compared to before there are differences. We are obliged to comply with the "new normal." We used to go into the homes of people affected by leprosy. We would come close to people and touch them. Now we avoid touching and we try to talk outdoors. This is difficult for everyone. I hope that I can give them enough support and motivation, because I know from my life experience how very important this is.

Distributing staple foodstuffs to persons affected by leprosy in Gentungan village, Gowa District, on May 21, 2020.

Packing foodstuffs to be distributed to persons affected by leprosy in Romang Lompo village, Gowa District, on May 20, 2020.

Distribution of masks and soap to persons affected by leprosy in Masino village, Takalar District, on May 21, 2020.

REPORT

Taking responsibility for our own safety and the safety of those we serve

Artur Custódio
National Coordinator, MORHAN
Movimento de Reintegração das Pessoas Atingidas pela Hanseníase
(Movement for the Reintegration of People Affected by Hansen's Disease)
http://www.morhan.org.br

Brazilian culture is strongly linked to physical contact, to touching and hugging, and this is especially important in the context of Hansen's disease because of the stigma. Most of MORHAN's activities involve gathering together for lectures and events, and all of these have been interrupted by the pandemic. Under "new normal" conditions, we are learning to smile and kiss with our eyes and shake hands with our elbows.

Since the beginning of the pandemic, MORHAN has reviewed its activities daily and adapted at each moment to continue pursuing its objectives as a social movement. We quickly authorized all our groups and volunteers to provide aid in order to help people who were not being assisted by the Brazilian government. We distributed hundreds of food baskets and thousands of masks.

By mid-November 2020, Brazil had recorded more than 5.8 million cases of COVID-19 and more than 160,000 deaths. Many people from former Hansen's disease colonies were affected, and we know of a few dozen deaths. Among MORHAN volunteers, we had at least ten deaths. We think that most of these lives could have been saved if there had been clear guidelines from the central government and an adequate system to protect the public.

In the absence of governmental guidance and protection, MORHAN developed a set of mandatory guidelines on preventive measures and harm reduction strategies that will allow the gradual reintroduction of our face-to-face activities. Our priority is to protect MORHAN's network of volunteers and the people affected by Hansen's disease on whose behalf we work across the country. In line with MORHAN's mandate as a social movement, these guidelines are a form of resistance against a state that does not protect us and an assertion of our commitment to a principle of mutual care.

Meeting for the founding of a MORHAN group in Santana do Ipanema in the state of Alagoas.

We have since condensed the guidelines into a safety protocol. We are fortunate that one of the greatest infectologists in Brazil, Dr. Celso Ramos, agreed to discuss the protocol with us in a video call. He affirmed that our protocol reflects current public health standards and indicated that we had, in fact, perhaps been a bit overzealous in our rule-making. He followed this point, however, with the observation that it would be better to "sin by excess" than to do too little. To facilitate adoption and dissemination of the protocol, we arranged for the creation of explanatory cards and an animated video on YouTube.

We believe that the adoption of this protocol can serve as an example of how to take action with an intent to reduce damage and risks. We have an opportunity to practice solidarity and love now that can stay with us long after the crisis of the COVID-19 pandemic has passed.

YouTube video
https://youtu.be/nfOZMzxCKF4

Top left: Masks and alcohol gel marked with MORHAN's logo are made available at face-to-face meetings. **Top right:** View of the city of Delmiro Gouveia in Alagoas from the window of the Municipal Health Department. **Bottom:** Meeting for the founding of a MORHAN group in Arapiraca in the state of Alagoas, elected board.

DATA BOX

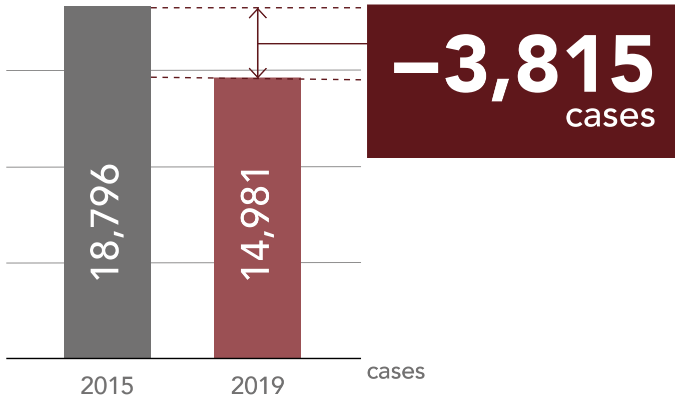
WHO's latest global leprosy update (2019 data)

Every year, the World Health Organization (WHO) receives official data on leprosy from national programs in member states worldwide. For the calendar year 2019, WHO received data from 160 countries. WHO released a report on this data in September 2020.

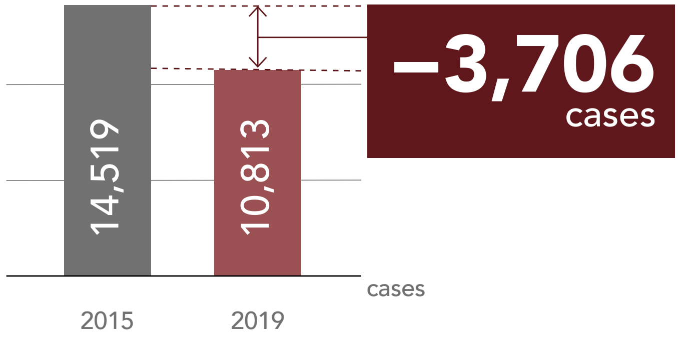
As part of its current 5-year Global Leprosy Strategy (2016-2020) to accelerate towards a leprosy-free world, WHO has recommended enhanced case detection. Compared to 2015, the year before the Strategy started, the 2019 data shows little change in the number of registered cases and the number of new cases detected. The prevalence rate per million population and the case detection rate per million population decreased, continuing a trend of gradual decline.

The number of new child cases decreased by about **20%**. The number of new cases with visible deformities (grade 2 disabilities, G2D) decreased by **25.5%**, and in Southeast Asia, the decrease was even more dramatic at **45.2%**. A lower number of new child cases is considered to be an indirect indicator of a decrease in ongoing transmission in a community. A lower number of new cases with G2D indirectly indicates fewer instances of delayed detection.

Number of new child cases



Number of new cases with G2D



Data reported from

+24 countries (136 → 160)

Number of new cases

−8,573 cases (210,758 → 202,185)

Case detection rate (per million population)

−3.37 (29.27 → 25.9)

Number of registered cases at the end of the year

+2,567 cases (174,608 → 177,175)

Prevalence rate (per million population)

−6.6 (29 → 22.4)

Comparison of 2015 and 2019 statistics

The report also shares information about progress toward the three targets to be achieved by 2020:

TARGET 1: ZERO G2D AMONG NEW CHILD CASES
As of the end of 2019, 123 countries had reported on G2D cases among children. Of these, 96 (78%) had reached the target. Globally, 370 new child cases with G2D were detected.

TARGET 2: REDUCTION OF THE RATE OF DETECTION OF NEW G2D CASES TO LESS THAN 1 PER MILLION POPULATION
As of the end of 2019, the rate of detection of new G2D cases was 1.36 per million population at the global level. Of the 132 countries that reported, 92 (69.6%) had reached the target.

TARGET 3: ZERO COUNTRIES WITH LEGISLATION ALLOWING DISCRIMINATION ON THE BASIS OF LEPROSY
As of the end of 2019, 127 laws still remained in place in 22 countries.

Source: Weekly epidemiological record issued on Sep. 4, 2020.

WISH LIST

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http://www.nepal-leprosy.com

For each issue, the *Leprosy Bulletin* asks a person affected by leprosy or an individual involved in leprosy-related work for two to three things that they wish could happen. We ask contributors to be bold in order to stimulate thinking and inspire new approaches.

1. A **joyful society** where persons affected by leprosy can **participate freely**; where they are **listened to** when they share their voices; and where they are **respectfully called by their name and profession** instead of by their disease.
2. A **global network** that advocates for **all persons affected by leprosy** to **receive full support** under the **community-based rehabilitation (CBR) matrix** associated with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).
3. A **United Nations convention** that specifically protects and promotes the human rights of persons affected by leprosy and **legally obligates countries to remove all discriminatory laws** related to leprosy.

UPCOMING EVENTS

Webinar series: Issues in leprosy amid the COVID-19 pandemic

In October, Sasakawa Leprosy (Hansen's Disease) Initiative began hosting a webinar series on social, medical, and historical aspects of leprosy in the context of the COVID-19 pandemic. The first webinar focused on contributions being made by organizations of persons affected by leprosy and ways that these organizations can be supported. Video recordings of the content are available at the Sasakawa Health Foundation (SHF) website.

https://www.shf.or.jp/information/9552?lang=en

Future webinars to be held between now and March 2021 are currently being planned.
For up-to-date information, please visit the announcement page on the SHF website.

https://www.shf.or.jp/other_activities/webinars?lang=en

SASAKAWA LEPROSY HANSEN'S DISEASE INITIATIVE

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