

LEPROSY BULLETIN

NO. 102 MARCH 2021



Message from the ambassador

The 16th Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy was issued at the end of January. I initiated the Global Appeal in 2006 to promote understanding of leprosy and eliminate the discrimination faced by persons affected by leprosy and their families. It is released each year on or near World Leprosy Day. This year's appeal focuses on the right to work and was endorsed by the International Trade Union Confederation (ITUC).

Because of the coronavirus pandemic, the appeal was launched online for the first time. ITUC General Secretary Sharan Burrow, WHO Director-General Dr. Tedros Adhanom Ghebreyesus, and UN High Commissioner for Human Rights Michelle Bachelet were among those who contributed video messages.

Following the launch of this year's Global Appeal, the WHO is expected to publish its Global Leprosy Strategy 2021-2030. Titled *Towards Zero Leprosy*, the 10-year strategy aims at zero disease, zero disability, and zero discrimination.

I appreciate and support the ambitious goals expressed in "zero leprosy" and believe that as a first step we must redouble our efforts to raise awareness of the disease. This is because I believe the main obstacle in our way is public indifference.

My hope is that the annual Global Appeal will make an important contribution to these awareness-raising efforts. I consider opening people's eyes and engaging their attention as part of my life's work.

Yohei Sasakawa
WHO Goodwill Ambassador for Leprosy Elimination

Contributing to this issue:

Dr. Ren Minghui (WHO)

Dr. Rahat Chowdhury (NLP, Bangladesh)

Sailendra (Atma Swabhimani, India)

Brent Morgan (ILEP)

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

INTERVIEW



Dr. Ren Minghui
 Assistant Director-General
 Universal Health Coverage/Communicable and Noncommunicable Diseases
 World Health Organization (WHO)

Dr. Ren's profile on the WHO's website:
<https://www.who.int/dg/adg/ren-minghui/en/>

Leprosy in the context of the NTD road map

At the end of January, the WHO published its new road map for neglected tropical diseases (NTDs). The road map targets 20 diseases, including leprosy, and features cross-cutting targets aligned with the Sustainable Development Goals (SDGs). In February, the *Leprosy Bulletin* interviewed Dr. Ren Minghui, who has been the WHO's Assistant-Director General for Universal Health Coverage/Communicable and Noncommunicable Diseases since 2017.

LB (*Leprosy Bulletin*): What should people know about neglected tropical diseases?

RM (Ren Minghui): Neglected tropical diseases (NTDs) are a diverse group of conditions of bacterial, viral, parasitic, fungal, and non-communicable origin. Despite their diversity, they share a common geographical and social context and their burden is predominantly located in tropical areas across the globe. Many are vector-borne, have animal reservoirs, and are associated with complex life cycles, making their public-health control quite challenging. They mainly affect poor communities and their correlation with poverty is so close that they are often referred to as diseases of neglected populations. Their entrenchment among disadvantaged population groups with little public voice contributes largely to their neglect.

LB: Are there approaches used for other NTDs that can benefit leprosy and vice-versa?

RM: An approach that can benefit leprosy is involving community health care workers during mass drug administration (MDA) campaigns to detect and refer suspected cases of leprosy, promote contact tracing, health education, and social mobilization. Another opportunity is including leprosy detection and diagnosis in the skin-NTDs approach.

One of the advantages that leprosy can bring is in the field of human rights, stigma, discrimination, and gender where advocacy is particularly strong as compared with other NTDs. Leprosy models can also be used to promote self-care and community-based disability care interventions and the promotion of assistive devices (such as footwear for patients with lymphatic filariasis and mycetoma) or

corrective surgery interventions extended to people affected by Buruli ulcer.

LB: Please tell us about the NTD road map for 2021-2030.

RM: *Ending the neglect to attain the Sustainable Development Goals: A road map for neglected tropical diseases 2021-2030* sets out global targets for 2030 and impact indicators to prevent, control, eliminate, or eradicate 20 diseases and disease groups. Although we made substantial progress over the last decade by prioritizing the public health needs of poor and marginalized populations, many of the targets set in the first road map for 2012-2020 were not met.

The new road map identifies critical gaps and the actions required to reach the new targets. These include working with local governments, local partners, and communities, and fostering their active engagement in NTD programs.

The 2030 global targets are:

- To reduce by 90% the number of people requiring treatment for NTDs
- Get at least 100 countries to have eliminated at least one NTD
- To work with everyone to eradicate two diseases (dracunculiasis and yaws); and
- To reduce by 75% the disability-adjusted life years (DALYs) related to NTDs

For the complete interview, visit
<https://www.shf.or.jp/information/10705?lang=en>



WHO's Global Leprosy Strategy 2021-2030

Following the Global Leprosy Strategy 2016-2020 (*Accelerating towards a leprosy-free world*), the World Health Organization (WHO) plans to release a new global leprosy strategy for the next 10 years.

The new strategy is aligned with the neglected tropical diseases (NTD) roadmap launched at the end of January.

The Global Leprosy Strategy 2021-2030 is expected to be the basis for each country to develop its own national strategy.

Vision

Zero leprosy

Zero infection and disease, zero disability, zero stigma and discrimination

Goal

Elimination of leprosy

Interruption of transmission

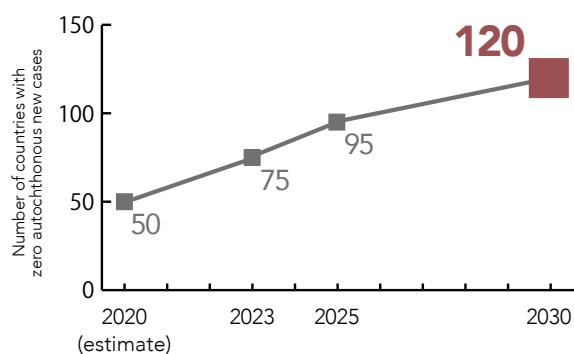
Global targets for 2030

and related impact indicators

According to the WHO's Global Leprosy Programme, achieving the global targets depends upon maximizing usage of existing tools, as well as developing new ones such as diagnostic tests and vaccines.

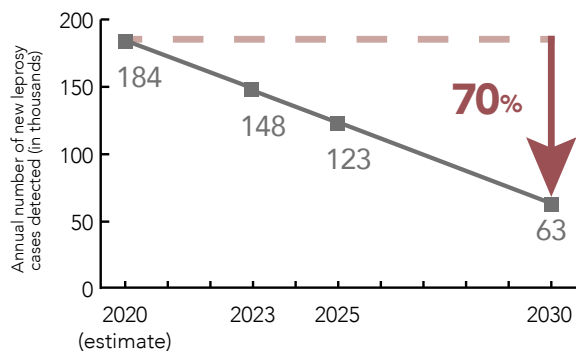
TARGET 1

120 countries reporting zero new autochthonous cases



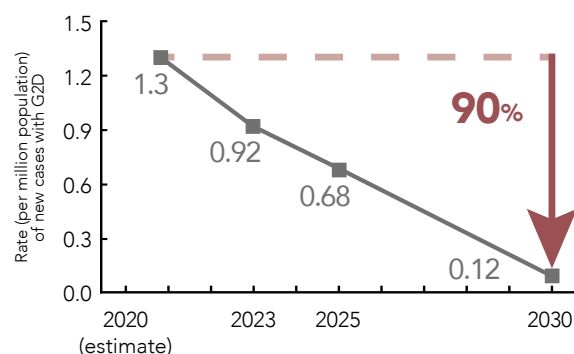
TARGET 2

70% reduction in annual number of new cases detected



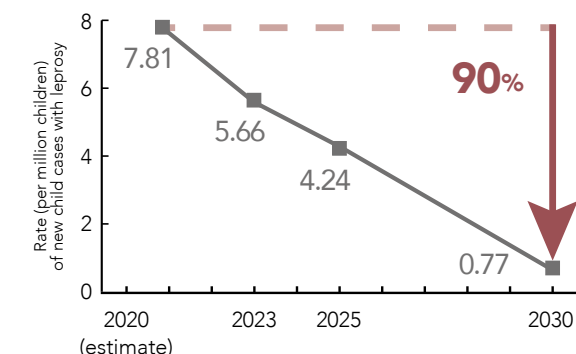
TARGET 3

90% reduction in rate (per million population) of new cases with grade 2 disability (G2D)



TARGET 4

90% reduction in rate (per million children) of new child cases with leprosy



Sources:

- Global Leprosy Strategy 2021–2030 (draft).
- World Health Organization, "Global consultation of National Leprosy Programme managers, partners and affected persons on Global Leprosy Strategy 2021–2030" (Oct. 26-30, 2020), <https://www.who.int/publications/i/item/9789290228226>

LETTER



Dr. Rahat Chowdhury
Deputy Program Manager
National Leprosy Program, Bangladesh

Bangladesh achieved the World Health Organization (WHO) target of elimination of leprosy as a public health problem in 1998. Following that achievement, attention shifted elsewhere and services deteriorated. The goal now is for zero leprosy by 2030.

<http://www.nlp.gov.bd> (accessible from April 2021)

Aiming for zero leprosy in Bangladesh

When I first joined my country's national leprosy program in 2018, I did not have enough knowledge of the disease. In medical school, our textbooks had only one page of clinical description of leprosy. Working in the leprosy program has been life changing for me. I have gained insight, knowledge, and experience from hours of long discussion with leprosy patients and health workers. I have learned about the poor, below-standard lives of leprosy patients, and I know now that there is so much to do for them.

In Bangladesh, more than 21% of people are living below the national poverty line and many people suffer from malnutrition. Traditional ways of life contribute to illiteracy, teenage marriage, and increased maternal and neonatal mortality. Bangladesh achieved the target of elimination of leprosy as a public health problem (less than 1 case per 10,000 population) in 1998, but there are still endemic hotspots where the leprosy new case detection rate is more than 5 per 100,000 population. For various reasons, some people delay seeking treatment, which results in increased disability.

Living with leprosy, especially with disability, has a huge impact on an individual's personal, familial, and social life. In the past, people treated leprosy as a "curse of God" and exiled those with the disease or sent them to a sanatorium. In Bangladesh, the influence of religious beliefs makes people

susceptible to misleading and false information. Persons affected by leprosy may feel embarrassed about seeking treatment, and they often face discrimination. Many of them must quit their jobs, which causes additional social and economic burdens.

Bangladesh's National Leprosy Program, established in 1985, acts as an umbrella body for leprosy activities throughout the country. Since achieving the target of elimination of leprosy as a public health problem, the program has not been receiving adequate attention at the policy level. In 2019, the government allocated only US\$11,000, and support from international donors has been decreasing. Government leprosy hospitals are facing tremendous issues as the government withdraws staff and reassigns them to other health facilities.

Despite this situation, the current government has taken an initiative to achieve zero leprosy status. On Dec. 11, 2019, Prime Minister Hasina announced the "Zero Leprosy Initiative by 2030." This campaign has renewed the motivation and commitment of health workers and sent a clear message at the health policy level about the importance of leprosy elimination. With the prime minister as the torchbearer, there is a bright ray of hope for elimination of leprosy in Bangladesh.



National Leprosy Conference co-hosted by the Ministry of Health and Welfare of Bangladesh, The Nippon Foundation, and Sasakawa Health Foundation in Dhaka, Bangladesh (2019). Nearly 600 health officials from around the country attended and the Prime Minister Hasina announced her commitment to achieve zero leprosy by 2030.

NEXT GENERATION



Sailendra Prasad Shaw
Social Worker
Atma Swabhiman, India

Represented and led by people living in self-settled leprosy colonies, the organization Atma Swabhiman (Self Dignity) is committed to facilitating social inclusion for persons affected by leprosy and their families.

To donate, contact atmaswabhiman@gmail.com.

Twitter: [@atmaswabhiman](https://twitter.com/atmaswabhiman)

Promoting life with dignity and inclusion in mainstream society

Please call me Sailendra. I was born in an isolated leprosy colony on Oct. 2, 1976. I contracted leprosy at the age of seven. My parents have deformities from the disease, but I was able to take multidrug therapy (MDT) medications soon after diagnosis. I was lucky to be cured before deformities could affect me.

In the colony where I grew up, everyone was struggling for survival. People had wounds, sometimes with maggots, and my father would dress these wounds. We had to depend on alms, and I still remember picking through them, trying to find candies and biscuits.

Today, I am educated, independent, and earn sufficient income for my family, but a successful life for myself is joyless when the family and community that raised me are so vulnerable. In 2004, I decided to do what I could to help. I gathered youths from a number of leprosy colonies and together we collected 1 rupee per family per day for colony development. In a year, we raised 150,000 rupees from 20 colonies. This success boosted everyone's morale, and raised hopes for change. Our state was recognized as the first in India to have a group of youth leaders composed of persons affected by leprosy. Later, in 2009, the organization Atma Swabhiman (Self Dignity) was established by and for persons affected by leprosy.

Because of the COVID-19 pandemic, the economic situation of persons affected by leprosy has deteriorated. Alms income from begging has declined and menial work is no longer available. The situation has forced us into asking for support. We are thankful for the individuals and organisations who have generously supported us, including the Jago Foundation and the Sasakawa Health Foundation.

To end discrimination, we need public participation of persons affected by leprosy throughout society, and for some geographical areas in particular, sensitization, education, and awareness-raising at the grassroot level. Equally important is to address and overcome the self-stigma and paranoia prevalent in the minds of persons affected by leprosy. Internalized consequences of discrimination are not given enough attention.

My philosophy of life is to serve humanity by promoting life with dignity and inclusion in mainstream society. Love, affection, trust, and support of fellow persons affected by leprosy—and especially generous responses and support from friends, family, and well-wishers—motivate me to keep going. Every step forward fills me with hope that we will achieve our goals.



World Leprosy Day 2021. People from 20 self-settled colonies marched to raise awareness of issues faced by persons affected by leprosy.

Activities by Sasakawa Leprosy (Hansen's Disease) Initiative for World Leprosy Day 2021

World Leprosy Day at the end of January provides an opportunity for stakeholders to contribute to the goal of a leprosy-free world by reaching out to large numbers of people in a coordinated way. The Sasakawa Leprosy (Hansen's Disease) Initiative contributed through the following activities.

Global Appeal

The Initiative organized this year's Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy. Since 2006, this annual appeal has been promoting a greater understanding of leprosy in collaboration with influential individuals and organizations. The 2021 appeal focuses on the right to work and was endorsed by the International Trade Union Confederation (ITUC). For the first time, the appeal was launched online.



Global Appeal 2021
<https://bit.ly/2PqhybY>



Webinars

The Initiative organized two webinars in the days leading up to World Leprosy Day. "Initiatives for Preservation of Leprosy History in Europe" (Jan. 22) focused on the impressive conservation efforts taking place at Fontilles in Spain and Rovisco Pais in Portugal, and invited discussion about why preserving the history and heritage of leprosy matters. "Zero Leprosy for Whom in a Post-COVID World?" (Jan. 26, 28, 29, 30) offered a platform for 21 organizations of persons affected by leprosy from 17 countries to introduce their activities and the challenges they face. Attendees agreed on the necessity of listening to the voices of persons affected by the disease. Over 400 people participated in the two webinars.



Sasakawa Health Foundation
 webinar series
<https://bit.ly/2NGTPUq>



Flip chart

The Initiative collaborated on a flip chart on leprosy for use by Accredited Social Health Activists (ASHAs) in India to assist in case detection at the grassroots level. The instructional tool was produced jointly with India's Ministry of Health and Family Welfare and WHO India. It features illustrations showing the benefits of being treated for leprosy and the consequences of leaving symptoms unattended. Approximately 310,000 copies are being printed and distributed in six high-endemic states. WHO India produced a companion training video. The Initiative's partner organization, Sasakawa-India Leprosy Foundation (S-ILF), linked the release of the flip charts to World Leprosy Day and secured coverage from more than 120 media outlets nationwide.



Training video (Hindi version)
 for using ASHA flip chart
<https://bit.ly/3uTW9Z2>



Results of social media photo contest

In the run-up to World Leprosy Day and this year's Global Appeal, the Initiative organized a social media photo contest in order to promote the idea that everyone has the right to work. Contest participants shared photographs of persons affected by leprosy and their family members engaged in work as part of everyday life. Here we share five winning photographs from four organizations.

An additional 12 photographs from seven organizations were shared in an online gallery as part of the temporary website for the Global Appeal. We are grateful to the following organizations for their submissions: MORHAN (Brazil), HANDA (China), Raj Pracha Samasai Institute (Thailand), International Nepal Fellowship, IDEA Kenya, FELEHANSEN (Colombia), and Saksham Kushthanteya Swabhimani Sanstha (India).



Tham Bahadur Thapa (far left in photo at left; right in photo above) working as a patient counsellor in Nepal. Photos contributed by International Nepal Fellowship.



Shantabai Sedam working as a basket maker in India. Photo contributed by Saksham Kushthanteya Swabhimani Sanstha.



Lucrecia Vásquez Acevedo working as a clothing operator in Colombia. Photo contributed by FELEHANSEN.



Art Donwichai working as a farmer in Thailand. Photo contributed by Raj Pracha Samasai Institute.

WISH LIST



Brent Morgan
 President, ILEP Federation
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<https://www.leprosymission.org>

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** That the **United Nations (UN) Principles and Guidelines** for the elimination of the discrimination against persons affected by leprosy and their families members be **fully implemented by all UN member countries** to ensure persons with experience of leprosy may fully participate as national and global citizens, and live life in all its fullness.
- 2** For governments, UN agencies, persons with experience of leprosy, civil society, and other partners to work in close coalition with one another so that 10 years from now there can be a **major reduction of new leprosy cases overall** and **no new child cases of leprosy**.
- 3** That new cases of leprosy are diagnosed and treated promptly and, in addition to supporting those affected by the physical consequences, that **all those affected by the psycho-social consequences of leprosy have access to good support services** in their communities.

ANNOUNCEMENT

Museum will open in Portugal's former national leprosarium

At the end of March 2021, a museum will open on the grounds of Portugal's former national leprosarium, Hospital-Colónia Rovisco Pais. The leprosarium accepted its first patients in 1947. In 1996, it was converted into a general physical medicine and rehabilitation center. A small number of former patients continue to live and receive services at the center.

The museum will be housed in a building formerly used as a chapel. Featuring photos, documents, furniture, medical equipment, and other mementos, the displays will share the history of the leprosarium and stories from former patients and staff. The museum is part of a larger project that began in 2016 to preserve the history of Hospital-Colónia Rovisco Pais. The preservation efforts are being supported by Sasakawa Leprosy (Hansen's Disease) Initiative.

<https://www.hansen-stories.pt/en/home/>



**SASAKAWA
 LEPROSY**
 HANSEN'S DISEASE
 INITIATIVE

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