

LEPROSY BULLETIN

NO. 103 MAY 2021



From elimination as a public health problem to zero leprosy

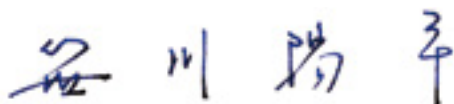
Message from the ambassador

Thirty years ago, in 1991, the 44th World Health Assembly adopted a resolution to eliminate leprosy as a public health problem at the global level by the year 2000. Since then, most of the world's countries have attained elimination as it was then defined: reduction of prevalence to a level below one case per 10,000 population.

Unfortunately, this accomplishment has not resulted in the disappearance of leprosy from the world. In many countries, the attainment of elimination was followed by budget and staff reductions. As a result, some countries are still dotted with "hotspots" where leprosy is endemic and "silent areas" where cases are not being reported but there may be many persons who have the disease. Prejudice and discrimination against persons affected by leprosy and their families remain deeply rooted.

In the most recent Global Leprosy Strategy, WHO set ambitious targets to be achieved by 2030. These include reducing the annual number of new cases detected by 70% and increasing the number of countries reporting zero new autochthonous cases to 120 countries. I would like to propose here that we establish similarly specific targets for implementing the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members.

When I think back to the energy that was generated 30 years ago when countries decided to unite in a fight against leprosy, I feel a renewed commitment to fulfilling my role as the WHO Goodwill Ambassador for Leprosy Elimination. I want to work with you to achieve WHO's 2030 targets and realize a leprosy-free world.



Yohei Sasakawa

WHO Goodwill Ambassador for Leprosy Elimination

Contributing to this issue:

Dr. Marcos Virmond
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APAL, India

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

VIEWPOINT



Dr. Marcos Virmond

former President, International Leprosy Association (ILA)
<https://www.leprosy-ila.org/do.php/Home>

retired Director, Instituto Lauro de Souza Lima, Brazil
<http://ilsl.br/instituicao.php>

Reflections on 30 years of the elimination strategy

The resolution by the World Health Organization (WHO) to “eliminate leprosy as a public health problem by the year 2000,” adopted by the World Health Assembly in 1991, was instrumental in changing the face of leprosy as we entered the 21st century. The elimination strategy involved worldwide implementation of multidrug therapy (MDT) and complementary strategies that evolved as more patients were cured.

MDT

WHO started promoting implementation of MDT in 1982, but the treatment did not immediately reach all patients. The adoption of the resolution helped to generate increased political commitment and interest in making resources available.

From an operational perspective, essential changes that took place included a simplified two-type classification for clinical diagnosis — multibacillary (MB) or paucibacillary (PB) — introduced in 1993. The drugs started to be packaged in calendar blister packs, improving delivery and compliance. Then, in 2018, it was decided that the same three-drug regimen could be used for all leprosy patients, with only the duration changing according to the diagnosis (six months for PB and 12 months for MB).

Drug resistance, while considered to be very low for MDT, is always a concern and a comprehensive monitoring system was established by WHO and major endemic countries. For a three-drug regimen, the side-effects reported are mild and serious adverse events are rare. MDT has proven to be robust and safe when its worldwide implementation within the elimination strategy is considered. While continually discussed and debated, the fact that MDT has cured more than 16 million leprosy patients deserves recognition.

Complementary strategies

Despite the enormous success of MDT as a chemotherapy for leprosy, its implementation did not result in notable

interruption in the transmission of leprosy. To overcome the stagnation of leprosy control in some countries and further reduce the disease burden, complementary strategies have been launched. “Leprosy services” include not only provision of medication, but also creation of a positive environment in which leprosy is discussed in the same light as any other curable disease; comprehensive treatment is made available as part of general health services; and the needs of persons affected by leprosy are considered holistically. Even as we make use of new tools like post-exposure prophylaxis (PEP), the quality and availability of leprosy services continue to be an essential part of interrupting transmission.

Public information campaigns helped to change traditionally negative perceptions of leprosy to acceptance based on knowledge. As attitudes changed, health personnel felt more able to address the issues of stigma and discrimination. Discriminatory laws were amended, and employment and opportunities for persons affected by leprosy became a reality.

The participation of non-governmental organizations (NGOs) has been a notable aspect of the elimination strategy. Managers and scientists have the capacity and creativity to develop strategies, but who puts them into action? Who makes the drugs available to patients? NGOs have had a central role in the success of the elimination strategy as providers of necessary funds, technical leadership, and humanitarian comfort to all persons involved in the fight against leprosy.

We should be proud of what we have accomplished in the elimination strategy of the past 30 years. We can expect that leprosy will become a rare disease everywhere in the world within a few decades. At the same time, there is still much that we do not know about *Mycobacterium leprae* and the disease that it causes. Successes like the genome sequence of *M. leprae* in 2001 remind us of the value of continued funding for research.

REPORT



Dr. Wim van Brakel

Chair, WHO Task Force on Criteria for Elimination of Leprosy (TFCEL)

Medical Director, NLR, The Netherlands

<https://nlrinternational.org/about-nlr/>

Task Force on Criteria for Elimination of Leprosy (TFCEL) and Its Outcomes

The new WHO Global Leprosy Strategy 2021-2030 “Towards zero leprosy” has recently been published.¹ Now that we have a tool in hand to prevent leprosy — post-exposure (chemo) prophylaxis (PEP) with single-dose rifampicin (SDR) — it is appropriate to set our sights on interrupting transmission of *M. leprae* and on achieving zero incidence of new cases of leprosy in endemic countries. Accordingly, the goal of the new Global Leprosy Strategy is “elimination of leprosy (defined as interruption of transmission/absence of disease).”

Whether or not a country has achieved elimination (defined as interruption of transmission/absence of disease) must be confirmed through a verification process. Evidence collected in a “Dossier for Elimination of Leprosy”² will allow WHO to verify that a country a) has an adequate surveillance system; b) has met the criteria for elimination of leprosy; c) has ongoing services for detection, treatment and management of sporadic cases that may occur even after elimination has been achieved; and d) has continued services for care for and inclusion of persons with leprosy-related disabilities in place. To develop concepts, criteria, indicators, and milestones for the Dossier, the WHO Global Leprosy Programme set up a Task Force on Criteria for Elimination of Leprosy (TFCEL) in March 2020, following an initial workshop on the topic in Mexico City in February 2020. TFCEL met monthly in 2020 and concluded with a workshop in Chengalpattu, India, in March 2021.

One outcome of TFCEL’s work was to make a conceptual distinction between “interruption of transmission” and “elimination of leprosy disease.”³ The time span between infection with *M. leprae* and appearance of signs and symptoms of leprosy can be very long (average five years but up to 20 years or more). Consequently, after transmission of leprosy bacilli has been stopped in a country or area, we can still expect new cases to develop for quite a number of years.

TFCEL has therefore defined “interruption of transmission” and “zero leprosy disease” as separate milestones. Because PEP regimens can prevent development of the disease in persons who have been infected, PEP implementation is one way to bring the achievement of zero leprosy disease closer to the time of interruption of transmission.

TFCEL outcomes included emphasis on the importance of the term “autochthonous” in relation to new cases of leprosy. Autochthonous means that people have acquired an infection locally. Quite a few countries that used to be endemic for leprosy, including Japan, still report new leprosy cases every year, but in many instances these new cases are not autochthonous; they are the result of leprosy bacilli acquired in another country. In order for a country to apply for WHO verification that leprosy has been eliminated as an endemic disease, one criterion is that no new autochthonous cases have been detected for a number of years.⁴

In summary, TFCEL achieved the following outcomes:

- Definitions for all key concepts related to interruption of transmission and elimination of leprosy disease
- A new four-category classification system for endemicity of leprosy (High, Moderate, Low, Non-endemic)
- An operational framework of Phases of Elimination with milestones for moving from one phase to the next
- Indicators for monitoring interruption of transmission and elimination of leprosy disease
- A matrix with criteria for essential and good quality leprosy services in the various stages of elimination
- A prototype Leprosy Transmission Assessment Survey
- A prototype Dossier for Elimination of Leprosy

¹ <https://apps.who.int/iris/handle/10665/340774>

² The formal name of the Dossier is still to be agreed.

³ The operational definitions adopted by TFCEL are as follows: **Interruption of transmission** is “an epidemiological state in a previously leprosy-endemic country or area where there is no more local

transmission of *M. leprae*, evidenced by zero new autochthonous cases among children <15 for at least five years.” **Elimination of leprosy disease** is “zero new autochthonous leprosy cases in the past three years.”

⁴ Technical note: the criteria for verification will allow for sporadic autochthonous cases to appear for some time after verification, since some cases may have very long incubation periods.

LETTER



Dr. Radhiah Mustafar
Deputy Director, National Leprosy Control Centre, Malaysia

Tan Ean Nee
Council Member, Sungai Buloh Settlement Council, Malaysia

Sungai Buloh Leprosarium on the UNESCO World Heritage Centre's Tentative List:
<https://whc.unesco.org/en/tentativelists/6388/>

Sungai Buloh entry in the International Leprosy Association's History of Leprosy website:
https://leprosyhistory.org/geographical_region/site/sungai-buloh

Seeking international recognition for Sungai Buloh

Ninety years ago in Selangor, Malaysia, a lush valley known as Sungai Buloh was transformed into a home for leprosy patients. Covering an area of 562 acres, the Valley of Hope, as it is sometimes called, was the largest leprosy settlement in the British Empire and the second largest in the world. The settlement was planned without fences and leprosy patients were given the opportunity to live normally and independently. They were provided opportunities in education, training, employment, and hobbies.

Leprosy patients in Malaysia gained access to a cure for the disease with the introduction of dapsone in 1948, and when the government launched a leprosy control program in 1969, compulsory isolation of leprosy patients was stopped and the treatment of leprosy was decentralized. Once treatment for leprosy improved further with the implementation of multidrug therapy (MDT) in the 1980s, many patients were discharged.

Today there are only 118 residents left at the Sungai Buloh settlement. These residents are no longer under threat of the disease and most of them are in their golden years. They are the last batch of people remaining before the leprosarium becomes history. They are well taken care of by the government, with free accommodation and a daily food allowance worth 21 Malaysian ringgit. Those who are unable to take care of themselves are admitted into the wards and taken care of till their last breath. For residents who are looking for their missing descendants, the government provides DNA tests to assist the search process.

Before the COVID-19 pandemic, various activities were organized to eliminate public fear and discrimination against leprosy. During guided heritage tours, we would encourage the public to visit the recovered patients in the ward in order to interact with them and listen to their stories. We also encouraged the recovered patients to continue learning by offering classes in painting, pottery, and English. We have taken them out for day trips to a concert, a bird park, and the beach. We hope that, after many years of living in an isolated community, they can re-integrate into mainstream society.

Although the pandemic has caused all activities to come to a standstill, we still encourage them to continue painting. Through their paintings they express their blessings and gratitude to all frontline medical staff and all heroes that help to fight COVID-19. We hope to build up their confidence and dignity.

Their learning spirit and positive energy radiated to society are great inspirations to us all! They have proven that everyone can have a complete, healthy inner self despite any physical constraints. We envision that their spirit will inspire younger generations to face challenges in life with resilience, perseverance, and endurance.

The Sungai Buloh Leprosarium is now on the UNESCO World Heritage Centre's Tentative List. We hope that the settlement can receive recognition while our residents are still alive. World Heritage status would help our efforts to preserve the essence of this unique place and its community for posterity.



Preserving the Sungai Buloh settlement and its residents is a way of paying tribute to leprosy survivors.



Visits to the wards from young people brought joy and happiness to the residents.



"A Blessing In Disguise" contains paintings produced by seven resident artists during the COVID-19 pandemic.

REPORT



Dr. Vivek Lal
Chief Executive Officer, Sasakawa-India Leprosy Foundation (S-ILF)

India achieved elimination of leprosy as a public health problem at the national level in 2005. S-ILF was founded one year later with assistance from The Nippon Foundation. The organization's mission is to end discrimination and ensure equal social, economic, and cultural opportunities for persons affected by leprosy and their families. From a base in New Delhi, S-ILF works with people living in self-settled colonies nationwide.

<https://silf.in>

COVID-19 relief efforts for India's self-settled leprosy colonies

The COVID-19 pandemic has left us in the face of an unprecedented crisis. The most severely impacted have been the poor and marginalized population, including persons affected by leprosy residing in self-settled leprosy colonies. In the wake of a country-wide lockdown last year, the priority of Sasakawa-India Leprosy Foundation (S-ILF) was to ensure food and necessary household supplies so that “no one should remain hungry” in the colonies.

With the help of the colony leaders of more than 380 colonies, we conducted an assessment in order to prioritize our support according to need. S-ILF and Association of Persons Affected by Leprosy (APAL) worked together closely to facilitate distribution of dry ration kits, and we reached out to more than 7,000 households across 134 leprosy colonies in 12 states of India. We partnered with state governments and local administration, civil society organizations, and volunteers to support logistics for an efficient, non-duplicative effort. The large-scale relief response was possible through generous support from donors, both institutional and individual. Great efforts were put in by staff and partners in enabling timely support and the challenges were mostly operational burdens imposed by the lockdown.

Unfortunately, India has been hit with a second wave of COVID-19, which is proving to be even more devastating in its impact. Apart from suffering and loss of lives, it has impacted adversely in terms of loss of livelihoods and educational opportunities.

We are interacting regularly with members of APAL at the state level and with colony residents to assess needs on the ground. We are aiming for a properly planned approach that incorporates mid-term restorative and long-term preparedness measures in addition to short-term relief. We have begun to address the immediate requirements of food and essential supplies, and we are enabling access to vaccination through provision of accurate information. At the same time, we are addressing the need for uninterrupted education for children in the colonies through the efforts of our learning centers' teachers. S-ILF is also supporting residents to choose alternative livelihood options that can be profitable during the pandemic and that minimize the need for movement outside of their neighborhoods. As the number of people adversely affected by the pandemic is increasing every day, we are staying mindful of the need to increase our support as well. Above all, those residing in leprosy colonies must not suffer further neglect.



Ration distribution in a leprosy colony in Amravati, Maharashtra (June 2020).



Ration distribution in a leprosy colony in Sundargarh, Odisha (February 2021).

INITIATIVE NEWS



Establishment of rapid diagnostic method to detect rifampicin resistance

Sasakawa Health Foundation is supporting research being conducted by Koichi Suzuki, professor of medical technology at Teikyo University, and Kei Mikita, assistant professor of infectious disease medicine at Keio University School of Medicine, which aims to develop a rapid diagnostic method for detecting rifampicin-resistant *Mycobacterium leprae* that can be easily performed anywhere without the need to transport specimens to a specialized laboratory and that can provide results on site by the following morning.

The research addresses concerns that Single-Dose Rifampicin Post-Exposure Prophylaxis (SDR-PEP), which involves the administration of the single antibiotic drug rifampicin, could result in microbial substitution and

the spread of rifampicin-resistant bacteria. A method to detect rifampicin-resistant bacteria in patients prior to SDR-PEP will ensure the efficiency of disease control efforts. Evaluation of the method is scheduled to conclude in March 2022.

Project title: "Establishment and evaluation of rapid diagnostic method to detect rifampicin-resistant *Mycobacterium leprae* for efficient SDR-PEP"

Principal investigator: Professor Koichi Suzuki, Department of Clinical Laboratory Science, Faculty of Medical Technology, Teikyo University, Japan

Co-investigator: Assistant Professor Kei Mikita, Department of Infectious Diseases, Keio University School of Medicine, Japan

New website for Sasakawa Leprosy (Hansen's Disease) Initiative



The Sasakawa Leprosy (Hansen's Disease) Initiative has launched a new English language website. With colors representing the strategic alliance of the WHO Goodwill Ambassador for Leprosy Elimination (red), Sasakawa Health Foundation (teal), and The Nippon Foundation (green), the website offers the full story of each member's past accomplishments and the Initiative's future goals. The updated graphic summary of our vision, mission, goals, and strategies shown above can be downloaded through the site. We hope that you will visit and feel inspired to work with us to achieve a leprosy-free world.

Sasakawa Leprosy (Hansen's Disease) Initiative website
<https://sasakawaleprosyinitiative.org>



WISHLIST



Eduardo de Miguel Selma
Head of Fontilles International Projects Department

Currently working on preservation of the historical heritage of Fontilles:
<https://fundacionfontilles.org/the-foundation/historical-heritage/?lang=en>

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 tool to fight stigma and social exclusion** around the world so that dignity can be restored to all persons who died in oblivion and marginalization and fundamental rights can be secured for all persons affected by leprosy living today.
- 2 A Global Leprosy History Digital Archive** that will make testimonies and stories of lived experiences available to future generations as they face new challenges.

ANNOUNCEMENT

Remembering Dr. P.K. Gopal



Dr. P.K. Gopal passed away on March 18, 2021. Born in Tamil Nadu, India, Dr. Gopal was diagnosed with leprosy at the age of 12. After being cured, he devoted his life to helping others affected by the disease. In 2005, he founded the National Forum, the first organization in India formed by and for persons affected by leprosy. May his soul rest in peace.

2015 interview

A precious video of WHO Goodwill Ambassador Yohei Sasakawa interviewing Dr. Gopal in 2015 can be viewed on The Nippon Foundation's Leprosy Today website.



<https://bit.ly/leprosy-today-special-interview>

Letter for a mentor

The National Forum is known today as APAL. The current president of APAL, V. Narsappa, shared his memories of Dr. Gopal with the *Leprosy Bulletin* in a letter (shown at right).



<http://bit.ly/leprosy-bulletin-gopal-memory>



Association of People Affected by Leprosy
Equity and Inclusion

Memories of Dr. Gopal

I am Narsappa, president of APAL. I had a good relationship with Dr. Gopal, and I have great memories of him starting from 2004. I especially remember his work for the national survey of leprosy colonies in India.

He was a very kind-hearted person who always worked for the good of everyone. He was an ardent social worker who became known both nationally and internationally as a great social activist. He received the Padma Shri award, one of the highest civilian awards in India, in recognition for his distinguished contributions to social service. He received many other awards as well.

I am grateful to him for connecting leprosy colonies around the country and forming a network. He conducted meetings, found the main common problems at the grassroot level, and worked for the elimination of leprosy-related stigma. He supported socio-economic empowerment, education for children, and infrastructure such as street lights and cement concrete roads for people living in leprosy colonies. He made me and many others into leprosy champions and national leaders through his motivational words. He taught me how to take on the problems of persons affected by leprosy as if they were my own problems and to work with perseverance to solve them.

His sincerity and dedication to his work will forever be appreciated, and his relationship with APAL is everlasting. There is a vacant place now that was once filled by his vigor. All of us at APAL deeply mourn his passing.

We pray for Dr. P. K. Gopal's soul to rest in peace. May God keep his soul with Him in Heaven.

Vagavathali Narsappa, President of APAL

SASAKAWA
LEPROSY
HANSEN'S DISEASE
INITIATIVE

WHO Goodwill Ambassador's Leprosy Bulletin No.103

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The *Leprosy Bulletin's* content is posted online at
<https://sasakawaleprosyinitiative.org/latest-updates/initiative-news/>



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