

2019

Frequently Asked Questions: World Leprosy Day

Regional Lepra Program

27 January 2019



World Leprosy Day 2019 Questions and answers

What is leprosy?

Leprosy is a transmissible condition that can lead to permanent disabilities if left untreated. It is caused by a bacillus, *Mycobacterium leprae*. The disease primarily affects the skin and peripheral nerves in the face, hands and feet. ¹.

How is leprosy transmitted?

While we know that leprosy is caused by a bacillus, how it is transmitted is less clear, the most accepted explanation is that it is transmitted "via droplets, from the nose and mouth, during close and frequent contacts with untreated cases"

What is the main sign of leprosy?

Early signs may include patches on the skin that are darker or lighter than usual. These patches may also be numb. A trained health professional can easily diagnose the disease.

Why can this disease cause disability in affected people?

PAHO: Leprosy

WHO: Leprosy

ILEP Federation: International Federation of Anti-Leprosy Associations

 $^{^{1}}$ For more information about this disease and actions to celebrate World Leprosy Day, it is possible to access the following sites:



Late diagnosis can lead to disability in eyes, hands or feet. Timely detection and treatment is vital to avoid disability.

Classification of disability due to leprosy. World Health Organization.

In order to standardize and monitor the actions of prevention and care of disability related to leprosy, the World Health Organization generated a classification to examine disability in eyes, hands and feet:

Hands and feet.

- Grade O. No decrease in sensitivity, no visible deformity or damage.
- Grade 1. Decreased sensitivity, but no deformity or visible damage.
- Grade 2. Visible deformity or present damage.

Eyes

- Grade O. There are no eye problems due to leprosy.
- Grade 1. Eye problems due to the presence of leprosy, but vision is not seriously affected.
- Grade 2. Severe visual disability.

Source: World Health Organization. Global leprosy strategy 2016–2020: accelerating towards a leprosy-free world – 2017 Monitoring and Evaluation Guide. Nueva Delhi: SEARO-OMS, 2017.

Do fingers and toes fall off to people affected by leprosy?

No. The disease affects the peripheral nerves, which prevents those affected from feeling pain and injury. If these injuries are not treated, complications and disability may occur. It is important that affected persons receive care to help prevent disability and avoid injuries.

Should people affected by leprosy be isolated in sanatoriums?

No. In the past, leprosy was considered an incurable disease, Due to the high degree of stigmatization, sanitariums were established in many parts of the world to



care for affected persons in isolation. Today, however, leprosy can be cured with modern, multi-drug therapy..

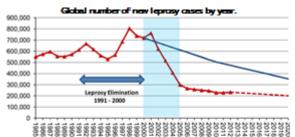
Is leprosy curable?

Yes. Since the introduction of free, multi-drug therapy (MDT), cases of leprosy have reduced from more than 5 million cases in the mid-1980s to less than 200 thousand at present.

What are the main causes of stigma towards people affected by leprosy?

Some people erroneously believe that leprosy is incurable, which leads to fear of the disease and those who suffer from it.

By 2017, the World Health Organization indicated that 210,671 new cases were detected worldwide, most of them in India and Brazil with 126,164 (59.8%) and 26,875 (12.8%) cases respectively. Likewise, the Region of the Americas reported 29,101 new cases, representing about 13% of cases worldwide.



"The red continuous line represents the observed annual new case detection rate between 1985 and 2012, with extrapolation to 2020 based on the trend after 2005 (red dotted line). The blue continuous line is the predicted new case detection rate based on modeling with the SIMLBP model, applying an intermediate scenario in the presence of an infant BCG vaccination programme"

Smith WC, van Brakel W, Gillis T, Saunderson P, Richardus JH (2015) The Missing Millions: A Threat to the Elimination of Leprosy. PLOS Neglected Tropical Diseases 9(4): e0003658. https://doi.org/10.1371/journal.pntd.0003658 https://journals.plos.org/plosntds/article?id=10.1371/journal.pntd.00 03658



On the other hand, 12,189 cases with visible or severe ² disability were diagnosed (5.8% of the total number of new cases detected in 2017), of which 2,149 were detected with this condition in the Americas.

Table. Summary of the main statistical data worldwide and in the Region of the Americas. 2017

	World	Américas
Number of new cases detected	210 671	29 101
Number of new cases of MB leprosy	125 983	21 646
Number of females among new cases	82 922	12 813
Number of children among new cases	16 979	1 766
Number of new cases with visible or severe disability (grade 2 according to the classification of the World Health Organization)	12 189	2 149
Number of new child cases with visible or severe disability (grade 2 according to the classification of the World Health Organization)	238	57

Source: World Health Organization. The Weekly Epidemiological Record – WER. 31 August 2018, 93th year. No 35, 2018, 93, 445–456

Global Health Observatory (GHO) leprosy data are available via the following link: https://www.who.int/gho/neglected_diseases/leprosy/en/

Are children currently affected by leprosy in the world?

Yes. Everyday more than 40 cases of leprosy are diagnosed in children worldwide. Timely detection and treatment of this disease in children is vital to avoid disability. Also, the presence of cases in children is an indication that the disease is still transmitted in the community. In 2016, the Region of the Americas reported 1,766 cases of leprosy in children. Of these, 57 were diagnosed with visible or severe disability (grade 2 according to the classification of the World Health Organization).

The focus of World Leprosy Day 2018 was preventing disability in children. Find out more about leprosy in children here: English | Español | Português | Français

² Grade 2 according to the classification of the World Health Organization



What is the situation of stigma and discrimination against people affected by leprosy and their family members globally?

According to data from the *International Federation of Anti-Leprosy Associations* (ILEP) worldwide there are 157 laws that generate discrimination. These types of laws are present in more than 20 countries of the world and impact migration, use of public transportation, employment, education, property ownership, and marriage of those affected by leprosy. Historical stigmatization and discrimination also means that those affected by leprosy also experience prejudice even in countries where there are no laws or regulations that formally promote discrimination.

Leprosy in the Region of the Americas

In the Region of the Americas, new cases have decreased more than 30% over the last 18 years. Currently, there are around 30,000 reported cases each year and the Region has maintained compliance with the goal ³ of elimination as a public health problem ⁴. Argentina, Brazil, Colombia, Cuba, Mexico, Paraguay, Dominican Republic and Venezuela are countries that experience a high proportion of new cases in the Region (more than 100 cases per year). Brazil, one of the three countries with the highest number of reported cases worldwide, recorded 26,875 new cases in 2017 (contributing more than 90% of the disease burden in the Americas).

³ Prevalence rate of less than one case per 10,000 inhabitants.

⁴ Achieving the goal of elimination as a public health problem does not imply the elimination of the problem.



Map. New cases of leprosy in the Region of the Americas. 2017



Source: Pan American Health Organization (PAHO / WHO)

Regionally, 7% of new cases report visible or severe disability (grade 2 according to the classification of the World Health Organization) at the time of diagnosis.

Historically, what kind of violation of human rights has generated abuses against people affected by leprosy and their families?

The protection of human rights is universal, and the people affected by leprosy and their family members have the same rights as any other person.

Certainly, people affected by leprosy have had their civic, political, economic, social and cultural rights affected for centuries. Even this violation of their rights has transcended the members of their families and subsequent generations.

More specifically, historically, affected people have been subject to separation from their families and denial of care services, education, to have their own properties, to free movement, among many other actions that significantly affected their lives.



What effects do stigma and discrimination have on affected people and their family members in relation to social determinants of health?

According to the Special Rapporteur of the United Nations for the Elimination of Discrimination against Persons Affected by Leprosy and their Families, "stigma is a social determinant of health and disease", because it causes direct effects in the following aspects:

- Delays in the diagnosis and compliance with the treatment regimen.
- Accessibility of housing, work and education sources.
- Social relationships and the non-recognition of affected people of support and assistance options.

Is there currently a formal commitment at the world level to fight against discrimination against people affected by leprosy and their families?

The Human Rights Council of the United Nations, through the mandate enshrined in Resolution 65/215 (2010), has urged all States to stop any type of discrimination towards affected persons and their families. In November 2017, the UN appointed a Special Rapporteur since November 2017 ⁵ to examine and report on progress in this area. For more information visit: www.ohchr.org.

The World Health Organization's Global Leprosy Program is implementing the Global Leprosy Strategy 2016-2020. This is based on three pillars:

- 1. Strengthen government ownership, coordination and partnership.
- 2. Stop leprosy and its complications
- 3. Stop discrimination and promote inclusion. This has been the first time that the World Health Organization has established a parameter to measure the reduction of discrimination).

⁵ Resolución 35/9 (2017). Consejo de Derechos Humanos de las Naciones Unidas.



Vision, objectives and goals of the Global Leprosy Strategy 2016-2020

Vision	Zero disease
	Zero transmission of leprosy infection
	Zero disability due to leprosy
	Zero stigma and discrimination
Goal	Further reduce the global and local leprosy burden
Target	Zero children diagnosed with leprosy and visible deformities
	 <1 per million (Rate of newly diagnosed leprosy patients with visible deformities)
	No country with legislation allowing discrimination on basis of leprosy

Source: World Health Organization. Global leprosy strategy 2016–2020: accelerating to-wards a leprosy-free world – 2016 operational manual. Nueva Delhi: SEARO-OMS, 2016.

The Regional Leprosy Program

The Regional Program recommends the following actions:

- Promote the adoption and implementation of inclusion policies.
- Intervene in all forms of stigmatization and abolish laws that allow discrimination.
- Encourage the participation of affected people in care and treatment services
- Involve the community and promote the coalition of affected people.
- Generate access to socio-economic support services.
- Community-based rehabilitation.

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