

# AMNESTY INTERNATIONAL

## Public Statement

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### **Leprosy: Ancient disease – modern stigma**

#### **Summary**

Leprosy was first recorded thousands of years ago. The disease is caused by the organism *Mycobacterium leprae* (*M. leprae*) and develops slowly due to the slow reproduction rate of the bacillus. Although effective treatment is now freely available, affected individuals still suffer stigma and fear being identified as having the disease. This can impede their access to care. Those who were formerly infected with the leprosy organism continue to suffer discrimination.

To mark World Leprosy Day (27 January 2008) an international human rights appeal was issued on 28 January 2008. Amnesty International joined with other non-governmental human rights organizations to urge an end to stigma and discrimination against people living with or suffering the effects of leprosy.

#### **Background**

Leprosy was recognised in ancient Egypt, China and India and first recorded nearly 3,000 years ago, and continuously since then. As it causes nerve damage in the hands and feet and as well as affecting membranes such as in the eyes and nose, the effect is to numb the sense of touch, leading to vulnerability to injury, scarring and blindness. Lesions can be quite visible and deforming making the infected person liable to stigma and discrimination, even when he or she is completely cured of the disease.

In the 19<sup>th</sup> century, the Norwegian physician, Gerhard Henrik Armauer Hansen, concluded on the basis of epidemiological studies that leprosy was a specific disease and that it was communicable rather than inherited, as was widely thought at the time.

In 1941, a sulfone drug, Promine, was introduced as a treatment for leprosy. It was used successfully though many painful injections were necessary to eliminate the leprosy organism. In the following decade, an oral preparation, Dapsone, was introduced. It, too, was successful but with time, resistant strains of *M. leprae* arose inhibiting the effectiveness of this drug.

In the 1970s, multi-drug formulations started and in the 1980s the World Health Organization recommended treatment with dapsone, rifampicin, and clofazimine. This regime remains the treatment of choice and further efforts are being made to detect leprosy earlier and to develop a vaccine.

### **Stigma and discrimination**

The current stigma and discrimination associated with leprosy can be traced to beliefs and misunderstandings originating in the distant past:

- the disfiguring effects of the disease. (It can cause loss of feeling in the hands and feet and damage to the tissues of the eyes and nose; injuries and mutilations can arise from this lack of sensitivity. If not treated in a timely manner, it can result in progressive deformity and permanent disability.)
- religious interpretations that the disease was a divine curse or punishment
- the belief that there were no means of protection from the disease and the resulting rejection and isolation of those affected
- lack of a cure

These beliefs are factually incorrect and can no longer be accepted as an appropriate reaction to the disease. In the past two decades effective programmes of diagnosis and treatment have led to a significant reduction in the prevalence of leprosy around the world. Currently only four countries have epidemics above the level set by the World Health Organization as representing effective control of the disease -- one case per 100,000 population. This reflects the impact of a free medical treatment programme and the active attempts to identify and treat those with the disease. However, the number of people living with leprosy or its effects is counted in millions and prejudice still remains a burden for those affected. The legacy of social attitudes and discriminatory laws means that people affected by leprosy have yet to see their rights fully respected.

The stigma and discrimination surrounding leprosy can result in physical and social isolation, preventing people from earning a livelihood. The denial of human rights to people living with leprosy and to their families extends also to those who are cured but still bear the signs of the disease and its consequences.

To mark World Leprosy Day, Amnesty International joined with other human rights NGOs and with people affected by leprosy to affirm the right of every human being to live with dignity. It called on the international community to renew its commitment to eliminate the disease and put an end to the associated social discrimination.

Note: The *Global Appeal 2008 to end Stigma and Discrimination against People Affected by Leprosy* was signed by Irene Khan, Secretary General of Amnesty International and the following NGO representatives: Nicholas Howen, Secretary General, International Commission of Jurists; Eugen Brand, Director General International Movement ATD Fourth World; Barry Clarke, Chair, International Save

the Children Alliance; Julio Wilfredo Guzman Jara, Chairperson, Disabled Peoples' International; Richard Blewitt, Chief Executive HelpAge International; Bryan Dutton Director General, Leonard Cheshire Disability; Elly Pradervand, Executive Director, Women's World Summit Foundation; Yohei Sasakawa, Chairperson, The Nippon Foundation.