

Comprehensive leprosy care: Empowering patients in India



Since 1986, the Novartis Foundation for Sustainable Development has been active in the fight against leprosy. Spreading the message that 'leprosy can be cured,' the foundation has played a key role in reducing the stigma attached to the disease and helping patients reintegrate into society. A prerequisite for the campaign's major success was the **free provision of multidrug therapy (MDT)** from 2000 onwards by Novartis to all leprosy patients worldwide. The prevalence of leprosy has been reduced dramatically thanks to MDT. Nevertheless, many former leprosy patients suffer from disabilities which continue to impact the quality of life.

The Novartis Comprehensive Leprosy Care Association (NCLCA), supported by the NFSD, aims to **prevent disabilities** beyond early detection of leprosy. The project team helps those with deformities reintegrate into society through **disability care**, including surgeries, grip aids and physiotherapy. By passing knowledge on to local health workers and empowering patients to become autonomous, the project has greatly increased the impact of disability care in India.

Project telegram

Country/region

India, particularly Mumbai area



Project objective

Provide comprehensive care (prevention and treatment of leprosy-related disabilities) for leprosy patients and train health workers and surgeons

Target groups

People affected by leprosy (disabilities), health workers

Partners

State Ministry of Health, aid organizations, JJ Hospital

Project duration

Since 1986



If treated early, leprosy only leaves spots on the skin



The „old face“ of leprosy



Empowering patients in India

Leprosy – a public health success story of a biblical disease

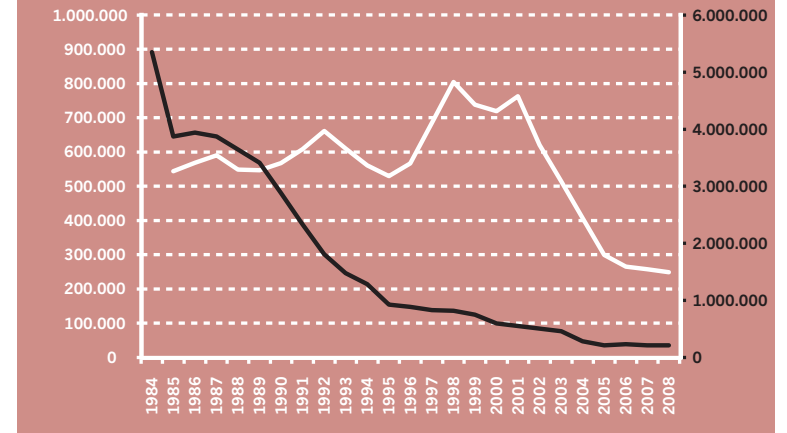
Leprosy has always been more than just an infectious disease. It was considered to be a malady of the whole body and soul, with disastrous consequences for those who became infected. The disease and the deformities it causes were often viewed as a punishment from God and societies dealt with leprosy by isolating the mostly poor patients in leprosy colonies for fear of the disease spreading.

In the early 1980s, the face of leprosy changed dramatically thanks to the development of multi-drug therapy (MDT), an effective treatment against leprosy recommended by the World Health Organization (WHO). MDT cures leprosy patients, interrupts transmission of the disease and prevents disabilities. Even patients with the severest form of leprosy experience improvement within weeks of starting treatment.

Thanks to MDT and an international multi-stakeholder commitment, **more than 14 million people have been cured of leprosy over the past 20 years**, reducing the global burden of the disease by 95% (see figure 1). Today, worldwide prevalence is estimated at approximately 250,000 cases and leprosy is mostly eliminated globally, with some remaining and challenging pockets in several regions.

Novartis and the Novartis Foundation have significantly contributed to the reduction of leprosy prevalence and the change in perception related to the disease. Since 2000, Novartis – the only supplier of quality MDT – has donated treatments, helping to cure approximately 6 million patients by the end of 2010. The Novartis Foundation has been supporting the WHO in the distribution of MDT, and has fostered dialogue among stakeholders engaged in leprosy control.

Figure 1: Global Leprosy Prevalence (1984 - 2008)



Source: WHO

□ new cases
■ registered patients at end of year

Along with the availability of MDT free of cost to patients, an international effort also began to change the image of leprosy and encourage patients to come forward for treatment instead of hiding. With its **social marketing campaigns**, the Novartis Foundation contributed since 1986 to separating leprosy from its horrific image and positioning the disease as any other. In particular, these campaigns ultimately led to the integration of disability prevention and rehabilitation into general healthcare services, effectively reducing the stigma and resulting in earlier and better detection, diagnosis and treatment.

Empowering patients in India

In 1989, the Novartis Foundation started a project in India to provide comprehensive care for people affected by leprosy. Although India has successfully reduced its share of the global disease burden, the country still accounts for the highest absolute number of cases. Despite improved leprosy control – aimed at the early detection of discolored skin patches and subsequent treatment – 3 to 7%

Project description

of cases are detected with irreversible disabilities requiring specific cure, correction and rehabilitation. **Disabilities are secondary injuries which result from the insensitivity (nerve damage) caused by leprosy.** Disabilities such as ulcers or disintegration of bones could therefore be avoided. Patients with severe hand or foot disabilities, which prevent them from living normal lives, are still very often stigmatized and ostracized.

The Novartis Comprehensive Leprosy Care Association in India (NCLCA), founded in 1989, pioneered a **patient-centric approach to disability care, including surgeries, grip aids and physiotherapy** based on simple modalities that can be performed by general healthcare staff. By passing the knowledge on to local health workers and empowering patients to become autonomous, the NCLCA



has greatly increased the impact of disability care in India. At leprosy camps held at health centers or hospitals around Mumbai, NCLCA project representatives teach patients (usually around 50) and healthcare staff how to treat wounds or use physical aid materials.

NCLCA workshops include:

- Early detection of leprosy, mainly among children,
- Health education for patients with insensitive limbs to prevent injury, burns and ulcers (which ultimately cause disabilities),
- Instructions on how to treat wounds and ulcers with a self-care kit,
- Physiotherapy advice to prevent deformities from worsening,
- Provision of physical aids such as hand and foot splints to help correct disabilities, and
- Provision of instant grip aids to enable people with advanced deformities to perform daily tasks without assistance.

Some leprosy camps focus on a specific task like disability care, the selection of cases for reconstructive surgery or the identification of high-risk cases among children to prevent deformities. Others offer reconstructive surgery for functional improvement.

From 1999 to 2003, four “megacamps” were organized with health authorities in the Indian state of Gujarat, performing reconstructive surgery on 5000 patients, and training over 100 surgeons. Through these camps, the **NCLCA reaches 800 to 1,000 patients every year.** The adoption of the NCLCA’s modalities – such as grip aids, self-care kits and health education booklets – by the Indian government has increased impact even beyond these numbers.

Over the past years, **nearly 28,000 self-care kits were distributed** to patients through the Indian National Leprosy Eradication Program. Other countries such as Myanmar, Tanzania and Sri Lanka have also adopted the tools developed by the NCLCA.



NCLCA workshop near Mumbai



Patients treat leprosy-related wounds



NCLCA self-care kits

Contribution to the Millennium Development Goals

1. Eradicate extreme poverty and hunger



Helping people affected by leprosy reintegrate into society through disability care, rehabilitation and reconstructive surgery

2. Achieve universal primary education



3. Promote gender equality and empower women



4. Reduce child mortality



5. Improve maternal health



6. Combat HIV/AIDS, malaria and other diseases



Integrated leprosy care, incl. improvement of access to treatment, disability care, rehabilitation and reconstructive surgery, as well as training of health and social workers

7. Ensure environmental sustainability



8. A global partnership for development



Collaboration with state and district health authorities in India

Challenges in “going the last mile”

Despite these successes, leprosy control is at a critical juncture today. The disease has limited spread and thus the level of international attention and political commitment is declining. Due to the low numbers of leprosy cases, knowledge about diagnosis and treatment is decreasing in many countries.

While leprosy cases have decreased significantly from 1984 to 2004 (see figure 1), a stagnation has occurred from 2005 onwards caused by several factors such as the difficulty to maintain/increase knowledge about leprosy among health workers given the small number of patients or the shift in priorities of national health authorities to diseases with a larger patient burden. In addition, while during times of high prevalence, a rough search was sufficient to find patients, now a more accurate approach involving different actors is required today to find cases in sometimes remote areas.

The good news is that no signs of resistance have emerged so far, meaning that leprosy can be eradicated with the existing medicines. The WHO’s global leprosy strategy for 2011- 2015 continues to focus on disrupting the transmission of the disease but calls for a more detailed geographic approach. While some countries have reached the elimination status on the national level, states, provinces or districts may not have. Further, the strategy now also entails the reduction of new cases with grade-two disabilities per a 100,000-population by at least 35% by the end of 2015 (compared to 2011).

In an effort to contribute to the last mile by disseminating knowledge about leprosy among health workers, the Novartis Foundation published the eighth edition of *Leprosy – for medical practitioners and paramedical workers*. In 2010, Novartis committed to continue providing MDT free of charge to patients worldwide for another five years, sustaining efforts toward final elimination of leprosy in partnership with WHO.

Further information and videos of our projects

www.novartisfoundation.org/projects
www.youtube.com/novartisfoundation

