



Making leprosy history

As we commemorate World Leprosy Day on 31 January 2010, we can look back at one of the biggest public health successes. A biblical disease has been brought down to a very small number of patients. Since 1980, more than 14 million people have been cured of leprosy, shrinking the worldwide burden to fewer than 250,000 cases per year.



Watch our new video on leprosy in India on www.youtube.com

Novartis and the Novartis Foundation for Sustainable Development have contributed significantly to these results. Since 2000, Novartis has donated multi-drug therapy (MDT), the treatment recommended by the World Health Organization, and helped to cure approximately 5 million patients worldwide. The foundation participates in the fight against leprosy since 1985. By introducing special social marketing campaigns, the foundation has played a major role in reducing the stigma attached to leprosy and helping patients reintegrate into society.

But resting on past accomplishments is not a legitimate option. We have not yet broken the vicious circle of transmissions and there are still too many new leprosy cases every year. The "last mile" in fighting leprosy proves to be a very difficult one. As in the past, we need a well-coordinated multi-stakeholder commitment to pursue the fight and make leprosy history.

I hope you enjoy reading the newsletter and thank you for your continued support.

Klaus M. Leisinger

Leprosy – a public health success story

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 patients in segregated villages for fear of the disease spreading. The poorest of the poor were the most affected by leprosy and its related stigma. They were left without means to support themselves and forced to live in underfinanced and understaffed leprosy colonies.

¹ As a strategic goal, WHO defined leprosy elimination as reaching a prevalence of less than 1 leprosy case per a 10,000-population.

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%. Today, worldwide prevalence is estimated at approximately 250,000 cases and leprosy is eliminated in all but three countries (Brazil, Nepal and Timor-Leste).¹

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 for Sustainable Development made a key contribution 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.

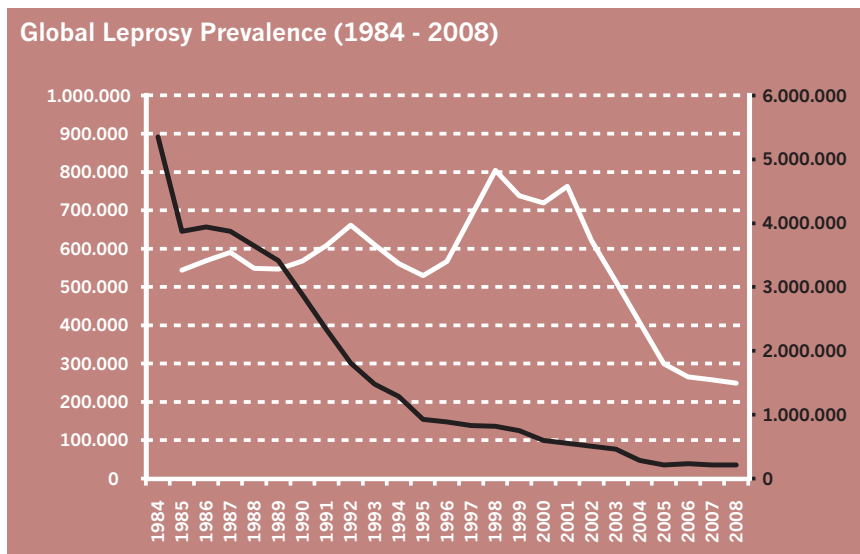
Novartis and the Novartis Foundation have significantly contributed to the reduction of leprosy prevalence and the change in perception related to the disease. Since 1986, the foundation has been active in the fight against leprosy. And since 2000, Novartis – the only supplier of quality MDT – has donated treatments, helping to cure approximately 5 million patients by the end of 2009. In addition to pioneering innovative approaches to provide comprehensive care to patients, the Novartis Foundation supports the WHO in the distribution of MDT, and fosters dialog among stakeholders engaged in leprosy control.



The „old face“ of leprosy



If treated early, leprosy only leaves spots on the skin



Source: WHO

□ new cases
■ registered patients at end of year

Empowering patients in India

The foundation's leprosy project in India, designed to prevent disabilities and rehabilitate patients, is still active today. 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% 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. 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
- Provision of instant grip aids to enable people with advanced deformities to perform daily tasks without assistance



Early detection of leprosy



Hand splint to correct disabilities



Grip aids help patients to perform daily tasks



Patients learn how to treat ulcers and wounds

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 provide equipment and training to support income generation or offer reconstructive surgery for functional improvement. From 1999 to 2003, four “mega-camps” 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 1000 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.

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 chart on page 2), a stagnation has occurred from 2005 onwards caused by several factors. These include:

- Difficulty to maintain or even increase knowledge about leprosy among health workers given the small number of patients.
- Shift in priorities of national health authorities to diseases with a larger patient burden, especially when countries have reached elimination status (less than 1 leprosy case per a 10,000-population).
- Relatively slow development of the disease due to the long incubation period (up to several years). Many of today’s leprosy patients are likely to have been infected when the prevalence rate was much higher.
- While a rough search campaign was sufficient to find numerous leprosy cases in times of high burden, 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. So, the key is still to detect – inter alia through the systematic examination of household contacts surrounding new patients – and treat patients early on. 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). This target focuses attention on the disability and disfigurement which result from nerve function impairment and thus stresses the importance of early detection.

In an effort to contribute to the last mile by disseminating knowledge about leprosy among health workers, the Novartis Foundation has recently published the eighth edition of *Leprosy* – for medical practitioners and paramedical workers, a book available free of charge (see www.novartisfoundation.org). In yet another initiative, the foundation has launched an online space meant to facilitate dialog between all interested players who wish to contribute to innovative studies to improve the efficacy of leprosy control worldwide (see www.leprosy-control-studies.net).

Novartis is committed to the free provision of MDT treatments until leprosy is eradicated. Yet, more than ever, “going the last mile” requires to strengthen the engagement of all stakeholders. Working together, we can achieve our shared goal of making leprosy history.



Voices from the field

Kamala*: “Due to the lack of sensation in my feet, I developed an ulcer”

“I was about 13 when I noticed a slightly discolored patch on my left thigh. I was at boarding school and informed my warden. At the dispensary, the doctor told me it was leprosy. I knew about leprosy as my mother had also been affected. The thought immediately crossed my mind that I would end up like her: disfigured and deformed. This prompted me to seek immediate treatment. My parents brought me back to boarding school but I stopped studying when I failed the examination. Soon afterwards, it was arranged that I would marry a local boy residing in the same area. I did not want to keep it a secret and told my fiancé that I had had leprosy and as a consequence had lost some sensation in my feet. He reacted very kindly and told me his father also had been treated for leprosy and had learned to live with it. He asked me whether I would look after his father should he develop complications, which of course I accepted.

My husband was working as a rickshaw driver and we had no financial problems. But then, two years ago, he had an accident and our entire life was disrupted. A one-month

stay in hospital, followed by two months of convalescence, left us in financial hardship; I had to ask my brother to help us out. Yet, it was not enough and I started making snacks at home to sell as a hawker. This work involved a lot of walking and due to the loss of sensation in my feet, I developed an ulcer on my foot, which restricted my travel and earnings. I spoke of my difficulties to a government health worker, who took me to a camp where many leprosy patients were given free aids and appliances.

At the camp, a lady taught me how to clean my foot and dress the wound. After using two kits in two months, the ulcer had almost healed. The people from the camp also provided me with special footwear to protect my feet and a handcart to sell snacks. I quickly started making money again and today my monthly earning has increased five-fold from 1000 Rupees (~ CHF 22) as helper to almost 5000 Rupees (~ CHF 110). Sometimes, my father-in-law also comes to help us on busy Sunday mornings. My husband has recovered and is looking for a suitable job as he can no longer drive a rickshaw. My children are studying at school and I am free of debt!”

*(*name changed on request)*

