

Making leprosy history

Klaus M. Leisinger*

This is a historic moment: leprosy, a disease already mentioned in texts more than 2000 years ago, is on the brink of elimination. This month the last International Leprosy Congress will be held in Hyderabad. Scientists, politicians, the World Health Organization (WHO), nongovernmental organizations (NGOs) and private-sector foundations have combined their efforts for a final push against the disease. These groups have worked together to make leprosy diagnosis and free treatment available at the village level within primary health facilities in areas where the disease occurs. This approach has proved to be a highly effective way to treat patients, and has led to one of the greatest public health success stories in the world. Today there are only four countries in the world where the prevalence of leprosy exceeds one case per 10 000 inhabitants, compared to 122 countries in 1985.

Globally, we have made tremendous progress, but the battle has not yet been completely won. Tackling residual problems requires learning from past successes and failures, as well as having a clear understanding of the remaining obstacles.

The changing face of leprosy

Leprosy has always been more than just an infectious disease. It was considered to be a malady of the whole body as well as a disease of the soul, with disastrous consequences for those who became infected. It was a shameful affliction, brought about by wrongdoing in a previous life, through a curse of God or witchcraft – in short, a punishment. Sufferers were ashamed of their condition and tried to hide the disease for fear of social repercussions. Lack of treatment or delayed treatment increased the risk of disabilities that, in turn, strengthened and perpetuated the stigma of the disease – a vicious cycle.

Before we developed an effective cure for leprosy, society dealt with the disease by isolating leprosy patients. In virtually every society, those affected by the disease were cast out of their families and communities to live in leprosaria, segregated villages, for fear of the disease spreading. Leprosy affected most often the poorest of the poor, leaving them without means to support themselves and forced to depend on underfinanced and understaffed leprosy colonies for their care.

Since the early 1980s, the face of leprosy has changed dramatically, however, thanks to the development of a curative treatment and its increasing availability, free of charge, to patients. Multi-drug therapy (MDT), the treatment recommended by the WHO, cures leprosy patients, interrupting transmission of the disease after the first dose of medication and preventing disabilities. Even patients with the severest form of the disease experience visible clinical improvement within weeks of starting treatment.

Around the world, various groups have made an effort to change the image of leprosy and encourage patients to seek timely treatment. To remove the stigma associated with deformities, their prevention, correction and rehabilitation are being integrated into general health services. Innovative communication approaches, including mass media, combined with improved access to treatment have both heightened awareness of the free

and effective cure and dispelled some of the disease's stigma. As a result, patients are seeking diagnosis and treatment at an earlier stage. Hopelessness and despair are giving way to the idea that leprosy can be just another chapter in a person's life. As communities witness the impact of MDT, age-old prejudices have begun to change and, with them, societal norms. Discriminating customs are fading in communities that have seen people cured through MDT.

Based on estimates from the WHO, Novartis MDT donation helped cure about 4.5 million patients in the past seven years. Nearly all of the global supply of MDT is provided by a collaboration between the WHO and Novartis, a Swiss healthcare company. Since 2000, Novartis has supplied more than 37 million blister packs at a cost of about USD 64 million. The company has committed to work with the WHO to provide free treatment for all leprosy patients in the world at least through the end of 2010.

Adequate supplies of free, high-quality MDT will help to ensure that the remaining endemic countries reach the elimination target, and that other countries continue their progress. In line with the disease burden, most of the MDT medicines are destined for Asia, with a substantial share for India, which until recently accounted for about two-thirds of new leprosy cases worldwide. While India's outstanding success over the last five years in reducing its share in the global burden of the disease has proven the essential soundness of the elimination strategy, the country still produces a significant number of new leprosy cases each year.

A hopeful new outlook in India

Throughout its involvement in leprosy treatment and control, the Novartis Foundation for Sustainable Development has pioneered unconventional approaches with a profound impact on the way the disease is combated. Many of these approaches are now incorporated into the disability care packages of both the government and NGOs in India.

In addition, the Novartis Comprehensive Leprosy Care Association (NCLCA) pioneered a system of prevention, correction, care and rehabilitation based on simple modalities that can be mastered by general healthcare staff. Since its inception, NCLCA has worked to integrate disability care into mainstream health services. The program provides integrated leprosy care, including improved access to MDT treatment, field-based disability care services and reconstructive surgery and rehabilitation where required. The social and economic reintegration of patients into their communities is also an important objective for the NCLCA.

Disabilities remain the most important factor for social stigmatization of leprosy. By far the best way to prevent these is through early detection of the disease and treatment with MDT. However, because of delays in starting treatment, improper management of leprosy reactions and patients from the pre-MDT period, India is still home to many patients disabled by leprosy. Depending on the nature of the disability, most can be corrected or cared for and any further physical deterioration prevented, but the requirement is substantial as each disabled person may have more than one deformity and may need multiple services.

Training surgeons in reconstructive surgery, conducting camps and workshops, devising simple techniques and transferring technology have all served to bring treatment closer to the leprosy-disabled and have accelerated their integration into the general health services. Services from the NCLCA have benefited thousands of patients who would have developed inoperable deformities and handicaps without help.

The NCLCA's focus on income generation and moral support for economic rehabilitation has transformed the lives of many of the poorest of the poor affected by leprosy. As these patients gain the ability to earn a living and support themselves, social acceptance and integration back into their communities improves drastically.

The work of the NCLCA is far from over but its efforts have ensured that, thanks to comprehensive care, leprosy in India is no longer a life sentence.

Moving toward eradication of leprosy

The progress we have made in curing leprosy and caring for leprosy-affected patients would not have been possible without a team of dedicated, talented people. By bringing such diverse groups together and involving them in the entire process – from drug development to free provision to leprosy patients worldwide – we have transformed leprosy treatment. The teamwork between the WHO, health ministries, NGOs and communities has broken new ground in building public-private partnerships.

Leprosy elimination is indeed a major public health success story. About 20 years ago, fewer than 5% of patients were on treatment with MDT; today, every patient in the world is receiving MDT free of charge through the WHO–Novartis collaboration.

As Mahatma Gandhi recognized, “Leprosy work is not merely medical relief; it is transforming frustration of life into joy of dedication, personal ambition into selfless service.”

We regard it as a privilege to contribute in the effort to realize the vision of a world without leprosy. This will require a continued, concerted effort by all parties to sustain the substantial gains made so far and to take leprosy elimination to the next step and focus on elimination at the sub-national level. We must retain a sense of urgency as we only have a small window of opportunity to do so in view of other pressing health demands.

Leprosy control is at a critical juncture: the disease has a very limited spread, and thus the level of international attention and political commitment tends to be lowering. However, the disease still exists and can resurge. The next step in leprosy control is to move toward eradication. Working together with governments and partners should make it possible to eradicate leprosy and consign the disease to history.

*Klaus M. Leisinger is the President and CEO of the Novartis Foundation for Sustainable Development: www.novartisfoundation.org