

# FOR THE Elimination OF Leprosy

- Leprosy is curable
- Free treatment is available
- Social discrimination has no place



Oda Seleman, 66, and his wife Fatuma Hassan, 60, both recovered persons, outside their home in Morogoro region, Tanzania, in April.

## A MESSAGE FROM THE GOODWILL AMBASSADOR

## CONTENTS

### We Mustn't Give Up

While the elimination strategy has made great strides in recent years, we must be prepared to accept that some countries will not achieve the target by the end of 2005. With hurdles such as poverty, armed conflict and social stigma to surmount, the path to eliminating leprosy as a public health problem has not been easy.

But while I am naturally disappointed at the delay, I am not discouraged. This is only a temporary setback. I take heart from the fact that endemic countries are working to keep leprosy high on the public health agenda, despite the burden posed by other diseases such as TB, malaria and HIV/AIDS. In recent meetings with health ministers in Geneva, I was assured of their commitment; in visits to their countries, I have seen the efforts that are being made.

The countries that have yet to achieve elimination are determined to build on the progress they have made. We must help them maintain the momentum so that they will eventually pass this important milestone.

During the first half of this year, I have traveled once to Brazil, twice to Africa and three times to

India to stand shoulder to shoulder with those working for elimination. India, which has the largest number of leprosy patients in the world, is likely to succeed in realizing what was once a far-off dream. For this, India's central and state governments, the WHO, the media and NGOs deserve much praise for the part they have played.

Other countries, too, have made remarkable advances. Given the situation even five years ago, we have come a long way.

Achieving elimination requires a lot of hard work, but as the countries that have already achieved it have shown, sustained efforts bring results. Today I am more committed than ever to working with the remaining endemic countries — their governments, their media, their frontline health workers — to keep them moving forward.

The WHO elimination strategy has focused attention on tackling leprosy as never before. But it is only an interim goal, which is all the more reason why the remaining countries need to achieve it as soon as they can.

— Yohei Sasakawa, WHO Goodwill Ambassador

<b>Message</b>	<b>1</b>
<b>DR Congo Report</b> The role of community agents	<b>2</b>
<b>Meetings with Ministers</b> 'Our goal is elimination'	<b>3</b>
<b>Ambassador's Journal</b> Travels in Africa and India	<b>4</b>
<b>Column</b> The enemy is stigma	<b>7</b>
<b>News</b> WHO's global strategy for 2006-2010	<b>8</b>
<b>From the Editors</b>	<b>8</b>

# Mobilizing the Community

In the DRC, the work of community agents is leading to a significant improvement in new-case detection.

The Democratic Republic of Congo remains one of the world's most leprosy-endemic countries. The chief obstacles in the way of eliminating leprosy are poor health-services coverage, a situation exacerbated by armed conflict, and the lack of community involvement, especially at village level, in leprosy elimination activities.

In order to speed up the DRC's efforts to achieve the elimination goal, we have adopted some innovative approaches to detect hidden cases in villages and treat them correctly.

Our method has been to intensify elimination efforts in a number of highly endemic districts identified in 2002 by extending the activities of community agents (known as *relais communautaire*) to the village level (and, in cities, to the street level).

**In a shattered country such as DRC, the notion of voluntary service is difficult for many people to comprehend.**

The community agent is a volunteer chosen by villagers (or by the inhabitants of a city street) who agrees to act as a link between the local community and the health services. On average, one community agent serves 200 to 300 people, and there are between one and three community agents per village.

Adopting the community agent approach also helps address another issue — the poor utilization rate of health services. In the DRC, this rate is between 15% and 20%, and represents a significant obstacle in the way of detecting leprosy cases.

The agent's role is to sensitize villagers about leprosy; direct those suspected of having the disease (based on an initial diagnosis involving sensation testing of skin patches) to the nearest

health center; follow the progress of patients taking MDT and make sure they complete their full course of treatment; and look out for leprosy complications or reactions so that the persons affected can receive further treatment at the health center.

Following the implementation of this strategy, we have seen a spectacular improvement in the number of cases detected, especially in the areas covered by the five projects shown (Table 1).

This indicates that we had previously underestimated the scale of the problem, as the strategy has uncovered a large number of hidden cases stemming from the lack of access to healthcare services.

The improvement in case detection (Table 2) has not been without challenges, however. In a shattered country such as DRC, the notion of voluntary service is difficult for many people to comprehend, so it is necessary to provide community volunteers with incentives. These include loincloths, hoes and T-shirts for women, and fishing nets, hatchets, machetes and T-shirts for men.

Also, the increase in case numbers has imposed a strain on MDT stocks, and there have been frequent disruptions in supply that we are working to address.

Turning to community agents has enabled us to tackle a crucial shortcoming of our program, as previously we had not made sufficient use of social mobilization and community involvement at the provincial and peripheral levels.

Integrating the community agent approach into our leprosy control activities gets villagers involved through their interaction with the community agent, which aids in detecting cases at the village level.

In this way, we can reach areas that are without proper health coverage, which is essential if we are to detect and treat all hidden cases. ■

## AUTHOR:

**Dr J. N. Mputu Luengu B.**



Dr J. N. Mputu Luengu B. is National Leprosy Program Manager for the Democratic Republic of Congo.



Map of Africa showing Democratic Republic of Congo (shaded)

**Table 1: Cases Detected in 5 Projects\* (2002-2004)**

Project name	2002	2003	2004
Tanganika	892	1,825	2,310
Haut-Katanga	164	371	403
Tshopo + Kisangani	566	664	1,983
Tshuapa + Equateur	456	612	912
Bas-Fleuve	142	220	264
<b>TOTAL</b>	<b>2,220</b>	<b>3,692</b>	<b>5,872</b>

Source NLP/DRC

\*Note: When the program was drawn up in 2002, eight projects for eight endemic districts were planned, but there was only funding for five projects.

**Table 2: Prevalence and Detection Rates in DRC**

Indicators	2002	2003	2004
Prevalence	4,802	7,173	10,530
Detection	5,027	7,472	11,781
Prevalence rate**	0.91	1.23	1.91
Detection rate***	8.50	12.80	21.40
Children among new cases (%)	11	13	13
Grade II disability among new cases (%)	13	12	11
P/D Ratio	0.95	0.96	0.89

\*\* per 10,000, \*\*\* per 100,000

Source NLP/DRC

# ‘Our Goal Is Elimination’

Endemic countries give their assessment of the tasks that still remain.

*In May, Goodwill Ambassador Yohei Sasakawa attended the World Health Assembly in Geneva, where he met with health ministers and officials from several leprosy-endemic nations who briefed him on the progress of their elimination strategies. The following is a summary of their remarks.*

**Dr. Jarbas Barbosa da Silva Jr.,**  
*Vice Minister for Health Surveillance, Brazil*



We are working very hard for elimination. Our PR is now 1.7. We are confident that the goal of elimination will be achieved this year. The responses from mayors and governors of endemic cities and states as well as of the media have been good. Hansen’s disease has been seen as a disease of poor people, and thus neglected. But President Lula has visited leprosy hospitals three times, and now there is a lot of interest. I hope you will come to Brazil at the end of this year or the beginning of 2006, when we announce we have achieved elimination.

**Lava Kumar Devacota,**  
*Secretary of Health and Population, Nepal*



Our PR has fallen to 1.8. Our goal is to achieve elimination. We are making efforts to achieve this in a clear and transparent manner. Since the new government was formed in February, things have gone well. The Maoist rebels do not target health workers or health facilities, and thus do not have much influence on our activities. There are still misconceptions about leprosy, especially in remote areas, and stigma remains an issue, but we are driving home the message that leprosy is curable and treatment is free.

**Dr. Sebastiao Sapuilo Veloso,**  
*Minister of Health, Angola*



Compared to when you visited two years ago, we are more organized. The people’s satisfaction

level is rising and society is changing. The PR in 2004 was 2.5 and in highly endemic areas, sometimes it is 5 or higher. Access to these areas is a problem. But the area they cover is small and the population density is low. Now, through the national program, we are finally starting to collect data at the municipal level. The PR is coming down, and the gap between the prevalence and detection rates is narrowing. We have a good working relationship with NGOs.

**Dr. Emile Bongeli Yeikelo Ya Ato,**  
*Minister of Health, DR Congo*



Recently, the situation in the country has settled down, and case detection is picking up. We are working for elimination, focusing on 12 areas of the country. Specifically, we are concentrating on eight projects, and making efforts to detect patients at family and village health clinics. Among new cases, children account for 13%, and Grade II disability is between 11% and 13%.

**Fenosoa Ratsimanetrimanana,**  
*Executive Secretary, National Committee on the Fight against AIDS, Madagascar*



In 2004, we discovered over 4,000 new cases. Our PR stands at 2.7. In remote areas, the PR is much higher. We are reviewing our strategy to ensure that all health centers are able to offer leprosy services. What we have learnt from the experience of past years is that by making use of existing resources, such as WHO-AFRO, we can do many things. We are strengthening our operation. Our approach is to keep our strategy simple, but think big. For that, we need strong commitment. We plan on working closely with WHO-AFRO. ■

# Journeys to Africa and India

Poverty and discrimination remain powerful foes, as visits to Mozambique and Tanzania show; while in India, workshops focus on human rights.

## MOZAMBIQUE (APRIL 20-24)

Mozambique has been developing slowly since the end of its 20-year-long civil war in 1992, but it remains one of the world's poorest nations. Over half the 17-million population lives in abject poverty and the country is battling a number of diseases that impact its social and economic development.

Where leprosy is concerned, Mozambique's PR is still rather high (2.5/10,000) compared to other countries, such as Brazil or India, that have yet to achieve elimination.

On arrival in Maputo, I received a briefing from Dr. Bokar Toure, the WHO country representative; Alfredo MacArthur, the health ministry's leprosy and TB countermeasures manager; and Alcino Ndeve, advisor on leprosy to the health ministry. As there had been an election the previous December, they weren't able to give me full details of the new government's public health strategy, as it was still being finalized. But they assured me that leprosy elimination would remain a high priority, as it had been under the previous administration. This was reiterated by the new health minister, Dr. Ivo Garrido, when I met him.

The northern and central parts of Mozambique, home to 60% of the population, are hardest hit by leprosy. There is only 30% health services coverage in these areas, and a

lack of health workers trained in the treatment and diagnosis of leprosy.

When I visited Mozambique in 2002, I traveled to two provinces in the north of the country, Nampula and Cabo Delgado, with the highest PRs, so I was interested to make a return visit to Nampula to see the progress it has been making.

In 2002, there were parts of Nampula where the PR was above 10 and even as high as 20 in some places. Today, the province-wide PR stands at 4.9. Since it is Mozambique's most densely populated province, it needs to make more progress if Mozambique is to achieve elimination.

From Nampula City, the provincial capital, I drove to the village of Namaita, about 40 kilometers away. I attended a festival promoting leprosy awareness; visited an agricultural cooperative jointly supported by ADEMO, an organization for disabled people, and ALEMO, an organization of recovered persons (these groups also run a shoe workshop in Nampula City that I visited later in the day); and donated 150 bicycles to a health center for the use of volunteer leprosy workers. I met a number of the volunteers during this visit, including recovered persons whose blue T-shirts bore the words, "I once had leprosy, but now I'm cured."

Back in Maputo, Dr. Garrido said that



Products grown and produced by recovered persons with the support of ADEMO and ALEMO, self-help organizations for the disabled and those recovered from leprosy.



Festivals such as this one in Namaita offer an opportunity to communicate important messages about leprosy.



Meeting with volunteer leprosy workers

**Reference**

\* WHO grading system to measure levels of disability from 0 to II

unfortunately it would not be possible for Mozambique to achieve elimination by the end of 2005, but said he would be organizing a meeting of governors of the most endemic provinces to work out a strategy for a final push. I understand this strategy will involve not just the health ministry but other ministries, such as the education ministry, as well as the ruling party. I intend to consult with the WHO and other partners to help Mozambique achieve the goal as soon as it can.

**TANZANIA (April 24-28)**

From Mozambique I traveled to Tanzania. With a population of some 36 million, it has a PR of 1.3 and is closing in on elimination. Its TB and leprosy programs have been combined, and it has some of the best geographic coverage and integration in the region.

During a welcome dinner, Health Minister Anna Abdallah told me, “My father had leprosy.” She said that after she mentioned this in public for the first time, she soon received a phone call from her brother. “Is it true that you spoke about this?” he asked. “Yes,” she replied, “Is it not true?”

In a country such as Tanzania, where stigma and discrimination toward those with leprosy remain strong, I believe it was very courageous of the minister to speak out in this manner. Indeed, the minister told me that in eliminating leprosy, she wanted to eliminate “the number one problem associated with it, which is discrimination.” From the standpoint of leprosy elimination, I can’t think of anyone more suited to be health minister than Mrs. Abdallah.

The next day, I visited the WHO office and the health ministry, where I was updated on the progress of elimination. In 1983, Tanzania had 35,000 leprosy cases; in 2004, the number stood

at 5,600. Over the same period, the PR has fallen from 12 to 1.3, due particularly to the concerted work done from 1998. The relationship between the government and NGOs, among them the German Leprosy and TB Relief Association (GLRA), is also very good, and WHO endorses Tanzania’s efforts as an example to all of Africa.

Tasks remain, however. Ten percent of newly detected cases present with Grade II disability\*, indicating that stigma and social discrimination discourage people from seeking treatment. Training of health center staff needs to be strengthened, so all are capable of diagnosing leprosy correctly. In addition, people cured of the disease continue to live in settlements, together with their children, who grow up thinking of themselves as leprosy-affected.

While in Dar Es Salaam, I visited the Mbagala dispensary, where the disability rate among new patients was 13%, and also a long-term care facility for persons affected by leprosy, disabled people and the elderly at Nunge.

Next I traveled to the capital, Dodoma, for a meeting with President Mkapa. He told me that until he received a briefing ahead of my >>



President Benjamin Mkapa of Tanzania

**Leprosy LEXICON**

● **Sustainability**

The capacity of a program to maintain quality and coverage at a level that will provide continuing control and further reduction of a health problem at a cost that is affordable to the program and the community. (WHO *Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities 2006-2010*)



Elderly resident of Nunge settlement, Dar Es Salaam

visit, he never thought of leprosy as a problem he needed to associate himself with as president. “Thanks to your visit, I have come to know my country better,” he said. He remarked that there is an expression in Tanzania, “to be avoided like leprosy,” which is often used by politicians in reference to something they want nothing to do with. In other words, it showed the extent to which the disease was feared and disliked in the country. The president promised that he would help to promote correct information about leprosy.

On the return journey to Dar Es Salaam, I stopped off at a care center in Chazi in the Morogoro region. There are about 40 leprosy-affected persons living in this former sanatorium; others have moved into the local community, with GLRA helping to assist in the transition.

Tanzania still faces challenges, particularly in overcoming discrimination and tackling disability. But given the enthusiasm and determination of the minister and others concerned, I’m sure elimination will not be long in coming.

#### INDIA (May 12-17)



Leaders of Tamil Nadu’s leprosy colonies gather for a monthly meeting at the Villivakkam colony.

In May, I went to Kolkata in West Bengal, and Chennai in Tamil Nadu.

In Kolkata I attended a consultation on Advocacy Strategy and Role of Media in Elimination of Leprosy. Similar meetings have already been held in Delhi, Bihar, Maharashtra, Orissa and Uttar Pradesh. All have been organized by the International Leprosy Union (ILU). The latest meeting was well covered by the media, with some 20 newspapers running stories.

During the conference, I met with West Bengal’s chief minister, Shri Buddhadeb Bhattacharjee, and health and family welfare minister, Dr. Surya Kanta Misra. “I assure you

that we are trying our best to eradicate leprosy from our state,” the chief minister told me.

While in Kolkata, I visited a bloc health center in nearby Howrah, and was impressed by a ventriloquist, who conducted a question-and-answer session on leprosy with a monkey dummy.

In Chennai, I took part in a Regional Conference on Leprosy, co-hosted by IDEA India, the Leprosy Elimination Alliance and Hind Kusht Nivaran Sangh (TN) and involving participants from the four southern Indian states of Kerala, Karnataka, Andhra Pradesh and Tamil Nadu.

At one point, these four states formed the region with the highest PR in India; now all of them have achieved elimination at the state level. Opening the conference, Tamil Nadu’s health minister, Thiru N. Thalavai Sundaram, said the reduction in the number of registered cases in his state from 800,000 to just 5,300 was no reason to relax, and said elimination activities must be sustained.

The second day focused on discrimination. India still has various laws that are problematic from a human rights perspective, often based on the erroneous premise that leprosy is incurable. Most are said to date back to when the country was part of the British Empire.

One presentation showed how an influential medium such as cinema can propagate false notions, using the example of *Blood Tear*, a 1960s hit film re-released last year. At the end of the film, the main character — something of a playboy — contracts leprosy, and this is presented as divine justice. Needless to say, such a scenario has no basis in fact.

During my stay in Chennai, I traveled to nearby Chengalpattu, home of the Central Leprosy Teaching and Research Institute. I also visited the Paranur Government Leprosy Home, formerly the Leprosy Beggars’ Rehabilitation Home. Once, when Mahatma Gandhi alighted at Chengalpattu station to worship at a nearby temple, leprosy patients streamed to the station to catch a glimpse of him. Gandhi would later remark that he had been going to see God, but instead God came to him.

The last place I visited was Villivakkam Leprosy Colony. My visit coincided with a monthly meeting of leaders of 48 leprosy colonies in Tamil Nadu. I told the 200 people attending, “You recovered persons are the main actors in the fight to eliminate leprosy and eradicate discrimination. It is important that you lead from the front!” ■



(Top) West Bengal Chief Minister Bhattacharjee, (above) Health Minister Sundaram of Tamil Nadu

# The Enemy Is Stigma

People affected by leprosy have a fight on their hands. They are fighting for their dignity, and the enemy is stigma.

## AUTHOR:

### Dr. S.D. Gokhale

Dr. S.D. Gokhale is chairman of the International Leprosy Union, India. This column is based on a speech given by Dr. Gokhale on May 16, 2005, in Chennai, India.

Stigma is an expression of a social reaction to anything that is different, unknown or socially unacceptable. Stigma is an attitude of mind born of ignorance or prejudice. Therefore, if stigma is to be abolished, we have to change the mindset of society.

Stigma poisons the psyche of ordinary citizens. It creates fear, from which spring bigotry and violence. Stigma becomes the law. Today, there are many laws in India that place people affected by leprosy at a disadvantage.

Many diseases exist in the world; among them, leprosy causes stigma by the mere mention of its name.

Stigma affects individual relationships. Within society as a whole, it influences social interaction, religious practice and the foundations of marriage.

In the economic realm, it can result in people being unable to make a living. Where the political



Speaking out: A. Prakasan, a Lokdoot (special communicator) addresses a conference on leprosy in Chennai.

process is concerned, it prevents people from voting and taking part in the decision-making process.

Stigma also denies people the opportunity for development. All these things add up to a negation of basic human rights. The result is that people are excluded from society, through no fault of their own.

Many diseases exist in the world; among them, leprosy causes stigma by the mere mention of its name.

But isolating people from society on the basis that they have leprosy is wrong. Defining people by their disease cannot be justified.

## EMPOWER CURED PERSONS

What can be done? The first thing we have to do is to empower cured persons. They must be given the right to decide their own future. They must be given self-confidence. At the society level, policy must be re-thought. All existing programs must be reviewed.

What instruments are available to effect change? Advocacy, for a start. Advocacy is a tool for changing the mindset of society. In this, the role of the media is important. Creating awareness that leads to action is critical. Here, Lokdoots (special communicators) can play a significant part. The example of people who once had leprosy who now fill important social roles such as teachers will help in changing attitudes.

The government can create the social context in which such interaction can occur, but it is up to individuals to make it happen. In the words of one cured person, "If society does not come to us, then we will go to society."

Above all, it should be pointed out that persons affected by leprosy don't want charity; they want their human rights. And increasingly, they are prepared to stand up and fight for them. ■



Making a living: at this auto parts factory in Pune, Maharashtra, most of the workforce consists of recovered persons.

## Leprosy FACTS

- Over the past two decades, the global caseload of leprosy has fallen by almost 90%. At the beginning of 2005, around 0.3 million patients were registered for treatment, and during the year 2004, about 0.4 million new cases were detected globally. (WHO)

# Looking Ahead to the Next Five Years

WHO draws up a global strategy for 2006 and beyond.

The question of how to sustain the progress of the past two decades has been addressed in the recently published WHO *Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities 2006-2010*.

The document, which was drawn up in consultation with ILEP and other global partners, calls for shifting away from “a campaign-like elimination approach” in the direction of “a long-term process of sustaining integrated, high-quality leprosy services.” These services, in addition to case detection and treatment with multi-drug therapy, also include prevention of disability and rehabilitation.

The basic principles of leprosy control — early detection and treatment — remain unchanged.

The main elements of the new strategy are:

- sustain leprosy control activities in all endemic countries;
- use case detection as the main indicator to monitor progress;
- ensure high-quality diagnosis, case management, recording and reporting in all endemic communities;
- strengthen routine and referral services;

- discontinue the campaign approach;
- develop tools and procedures that are home/community based, integrated and locally appropriate for the prevention of disabilities/impairments and for the provision of rehabilitation services;
- promote operational research in order to improve implementation of a sustainable strategy; and
- encourage supportive working arrangements with partners at all levels.

## SOUTHEAST ASIA

WHO's Southeast Asian Region, which accounts for 12 million of the 14.2 million cases cured globally with MDT, outlined its own strategy.

Setting a goal of reducing annual case detection to less than 10/100,000 population for the region and each country by 2010, its key objectives are: sustaining elimination at the national level and achieving it at the sub-national level and below; progressively reducing annual new case detections through timely case detection, prompt treatment and achievement of high cure rates; and ensuring and sustaining quality leprosy services. ■

## FROM THE EDITORS

### NO TIME FOR COMPLACENCY

Five months remain to achieve the shared goal of eliminating leprosy as a public health problem. Of the nine countries still to reach the elimination target, India and Brazil are almost there; the remaining seven are making determined efforts.

While we want to see every country reach the target, a concern arises that some might announce they have succeeded without having any scientific basis for doing so. In the past, over-reporting has been a problem; more recently, underreporting has been emerging as a problem as well.

WHO's director general, Dr. Lee Jong-wook, commented in May that it would be counterproductive to announce that elimination has been successfully achieved by every country unless the evidence backs this up. If we are impatient at this final stage, he said, it will call into question what has been achieved to date.

One of the fruits of the elimination strategy has been the political commitment that has been generated. Leprosy services have reached out to more people, millions have been cured, drugs are

freely available, and diagnosis and treatment are being integrated within general health services.

But the 110-plus countries that have already achieved elimination must guard against complacency. Their work is not yet done. The WHO strategy has always been a milestone, not the final destination.

It is very important that these countries keep moving forward. They owe it to themselves but also to the countries that have yet to achieve the elimination goal. They must show by example how passing the elimination milestone represents a positive achievement that leads to further progress.

Achieving elimination at the sub-national level is a route already being taken by many countries that had a large number of cases. Maintaining the quality of leprosy services is another scenario, one that requires close cooperation with NGOs.

As the final push for elimination continues, it must be accompanied by serious consideration of what comes next.

## FOR THE ELIMINATION OF LEPROSY

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With support from:

Sasakawa Memorial

Health Foundation,

The Nippon Foundation

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