

# FOR THE Elimination OF Leprosy

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



Helping a young patient with his dose of MDT at Uppal Public Health Center in Andhra Pradesh, India

## A MESSAGE FROM THE GOODWILL AMBASSADOR

### Let's Pass This Milestone Together

It falls to us to win the fight against leprosy, a disease that has caused human suffering for thousands of years. This year, 2005, is the final year to meet the World Health Organization target of bringing the prevalence rate below 1 case per 10,000 people in every country. Whether or not 2005 will be regarded as a milestone in history depends on how effectively we make use of the remaining months, and how we choose to traverse the final mile of our journey.

Over the past two years, I have used this newsletter to raise a variety of issues. These include integrating treatment of leprosy within the general health services, seeing that MDT reaches everyone who needs it, reexamining statistics, taking up discrimination against people affected by leprosy as a human rights issue, and encouraging recovered persons to become involved in social movements. I have been heartened by the numerous positive responses I have received from you.

I am also gratified that the three messages — leprosy is curable; treatment is free; social discrimination has no place — are being spread

far and wide, again with your help.

However, these messages must be universally acknowledged if we are to cure society of the disease of discrimination even as we eliminate the scourge of leprosy. For that to happen, still greater efforts will be necessary.

Should this year end on a successful note, I pledge to continue my fight against leprosy. Achieving the elimination goal brings with it new challenges to sustain what we have achieved and ensure the dignified reintegration of patients, recovered persons and their families into society.

But unless we first pass the elimination milestone, our activities have no future. It is essential to succeed if we are to move toward the new goals that are forming.

So it is down to us whether or not 2005 will be a year to remember. Please, everyone: let's renew our determination to eliminate leprosy as a public health problem, join together and pass this milestone to the future.

— Yohei Sasakawa, WHO Goodwill Ambassador

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# Moving toward Elimination

This year is the target date to eliminate leprosy as a public health problem in every country. What are the prospects, and what happens post 2005?

Since multidrug therapy (MDT) was introduced on a global scale in 1985, more than 14 million people around the world have been cured of leprosy.

Over the last two decades, the global prevalence of the disease has fallen by almost 90% — from around 5.4 million at the beginning of 1985 to some 0.45 million at the beginning of 2004. (Table 1)

In addition, new case detection has fallen by about 33% since 2001, with approximately 500,000 new cases detected during 2003, down from about 621,000 during 2002 and 763,000 during 2001. (Table 2)

Of 122 countries where leprosy was considered a public health problem in 1985, some 113 had eliminated leprosy at the national level by the end of 2003. Leprosy now remains a public health problem in only nine countries in Africa, Asia and Latin America. (Table 3)

Encouragingly, countries that have reached the goal of elimination have been able to sustain leprosy control activities, and WHO and its partners continue to provide them with critical support in terms of MDT and technical guidelines.

The leprosy elimination strategy is now at a crucial stage, focused on the nine countries where leprosy remains a public health problem, namely Angola, Brazil, Central African Republic, Democratic Republic of Congo, India, Madagascar, Mozambique, Nepal and United Republic of Tanzania.

Together, these countries accounted for 84% of registered cases at the beginning of 2004 and 88% of the new cases detected during 2003.

In some of these countries, the reported data suggest that a significant part of the caseload is artificially inflated due to non-adherence to standard definitions and/or the re-registration of old cases as new, and wrong, diagnoses.

As a priority, regular updating of leprosy registers and strict adherence to standard definitions for case, cure, defaulter and point prevalence will be carried out in identified countries during 2005.

All efforts will be made to ensure that these nine countries reach the elimination target by year's end. For a variety of reasons, however, some may need additional time to reach the defined target of a PR of below one per 10,000 population. Nonetheless, they are showing strong commitment and have been intensifying their efforts in the field.

In most countries where leprosy was a public health problem in 1985, it is now a relatively rare disease.

## THE CHALLENGE OF SUSTAINABILITY

In some countries that have already achieved the goal of elimination at the national level, there is still a significant incidence of the disease in certain provinces or districts. These countries will need sustained efforts to reduce the disease burden in pockets of high endemicity. This is especially true of countries that have reached the elimination goal recently.

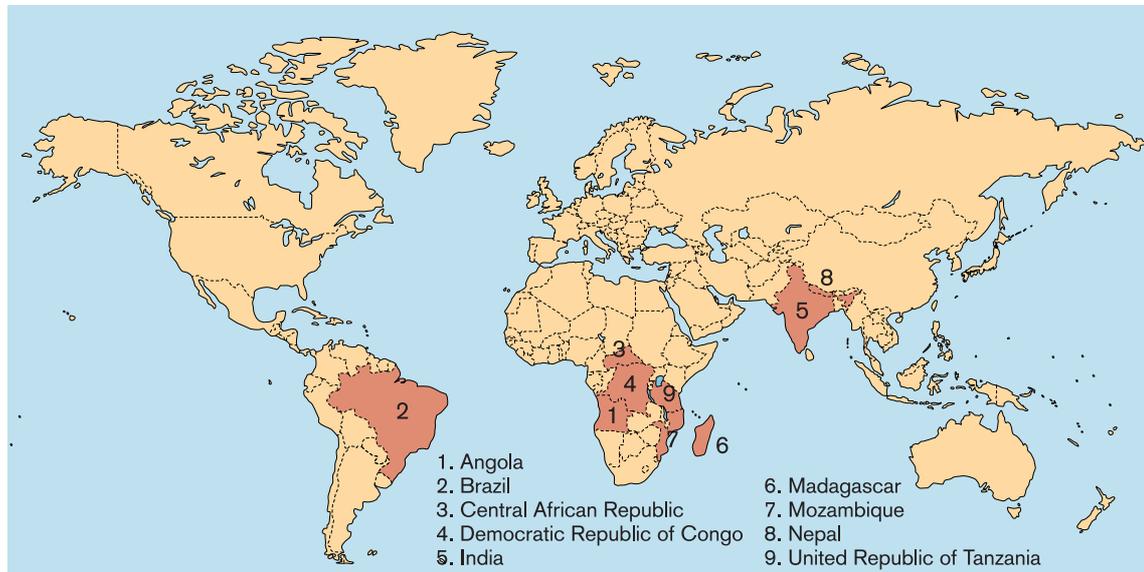
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## Countries Yet to Achieve Elimination as of January 2005

(listed in alphabetical order)



## Leprosy LEXICON

● **Leprosy Defaulter**  
Once diagnosed with leprosy, patients are put on a 6- or 12-month course of multidrug therapy (MDT). A defaulter is a patient who has not collected MDT for at least 12 months consecutively after the start of his or her treatment. A defaulter must be removed from consideration when calculating prevalence rates.

However, in most countries where leprosy was a public health problem in 1985, it is clear that it has become a relatively rare disease. Given such a scenario, maintaining MDT services for leprosy in the context of low prevalence conditions will be a big challenge for a majority of countries in the coming years. This will be necessary if achievements are to be sustained, the disease burden further reduced, and MDT services made easily accessible to communities in which new cases of leprosy will continue to be detected.

Key to this is integrating all essential components of leprosy control within the existing primary health care system. This also includes the development of integrated referral facilities. This will need careful planning and

probably different approaches within each country, depending on the local leprosy burden and the availability of an appropriate health infrastructure or program for integration.

Therefore, in close consultation with member states, regions and local and international partners, efforts are under way to develop a global strategy to sustain leprosy control activities in all endemic countries beyond 2005.

This strategy will assist in sustaining achievements of the elimination strategy to date and in reducing the disease burden further at national and sub-national levels.

It will be presented to the World Health Assembly in 2006 to obtain support and commitment from all the member states. The fight against leprosy continues. ■

**Table 1: Leprosy situation by WHO Region\***

\*excluding Europe

WHO Region	Registered prevalence at beginning of 2004 (Rate/10,000)	Number of cases detected during 2003 (Rate/100,000)
Africa	51,175 (0.81)	46,968 (7.4)
Americas	83,233 (0.99)	51,082 (6.09)
East Mediterranean	5,780 (0.11)	3,944 (0.77)
South-East Asia	302,860 (1.90)	405,609 (25.46)
Western Pacific	10,449 (0.06)	6,190 (0.36)
<b>Total</b>	<b>453,497</b>	<b>513,793</b>

Global annual detection reached a peak of 804,000 in 1998, levelling off at around 750,000 for a number of years but then falling to around 621,000 during 2002 and about 500,000 during 2003, as Table 1 shows.

**Table 2: New cases detected by WHO Region\***

\*excluding Europe

WHO Region	Number of new cases detected		
	2001	2002	2003
Africa	39,612	48,248	46,968
Americas	42,830	39,939	51,082
East Mediterranean	4,758	4,665	3,944
South-East Asia	668,658	520,632	405,609
Western Pacific	7,404	7,154	6,190
<b>Total</b>	<b>763,262</b>	<b>620,638</b>	<b>513,793</b>

The latest available information reveals that about 500,000 new cases of leprosy were detected during 2003, a decrease of about 17% compared with 2002 and about 33% compared to 2001, as indicated in Table 2. There is a decline in the new-case-detection trend in all the WHO Regions, except the Americas.

**Table 3: Countries yet to reach elimination at the beginning of 2004**

Country	Number of cases registered at the beginning of 2004 (Rate/10,000)	Number of cases detected during 2003 (Rate/100,000)
Angola	3,776 (2.8)	2,933 (22.1)
Brazil*	79,908 (4.6)	49,206 (28.6)
Central African Rep.	952 (2.6)	542 (14.7)
D.R. Congo	6,891 (1.3)	7,165 (13.5)
India	265,781 (2.4)	367,143 (34.0)
Madagascar	5,514 (3.4)	5,104 (31.1)
Mozambique	6,810 (3.4)	5,907 (29.4)
Nepal	5,899 (2.4)	6,958 (28.4)
Tanzania	5,420 (1.6)	5,279 (15.4)
<b>Total</b>	<b>380,951</b>	<b>450,237</b>

\* Brazil uses different definitions for a registered case, cure, defaulter and for point prevalence

Table 3 shows the prevalence at the beginning of 2004 and detection during 2003 for the nine countries where leprosy is still a public health problem, according to the latest available information.

# Educating Private Doctors about Leprosy

Recent cases highlight a need to familiarize private practices with early signs of the disease.

In Madagascar, leprosy is not just a disease found in remote areas; it affects people in towns as well.

We recently identified about 20 new cases in the capital, Antananarivo. All were detected by health workers at public health centers. Most cases involved people who had previously been seen by private doctors, but had not been diagnosed with leprosy. By the time they were seen by public health workers, their symptoms were fairly advanced, resulting in a late diagnosis.

Most people living in towns prefer to consult private doctors because they believe the quality of a free consultation at a PHC is not as good as at a private practice, where they have to pay.

It is therefore important to ensure that private doctors are made familiar with the early signs of leprosy, so that they do not mistake them for some other dermatologic condition.

Strengthening collaboration between the public and private health sectors in this way, in addition to the usual detection activities carried out in endemic and remote areas, will help improve case detection and reduce the rate of disabilities.

To this end, we organized a sensitization meeting for private doctors in Antananarivo toward the end of last year, where we showed many slides and photographs of actual leprosy cases and explained the different symptoms.

Doctors were invited to refer suspected cases to a PHC (where MDT and trained health workers are available) for diagnosis and cure. The cooperation

## PREVALENCE RATE TREND IN MADAGASCAR

Provinces	2000	2003	2004*
Antananarivo	0.57	0.53	0.49
Antsiranana	3.74	2.54	2.06
Fianarantsoa	19.12	5.34	4.55
Mahajanga	6.80	4.77	4.08
Toamasina	5.61	4.09	3.98
Toliara	5.67	4.93	4.12
<b>Madagascar</b>	<b>6.90</b>	<b>3.35</b>	<b>2.93</b>

\*Situation at the end of the 1st Semester 2004

of private doctors will ensure that people with leprosy receive proper treatment, since at present only PHCs and some private centers are allowed to register patients and dispense MDT.

Similar meetings to sensitize doctors will be carried out in the provincial capitals of the remaining five out of Madagascar's six provinces during this year.

Overall, the progress made since the implementation of the leprosy elimination program in Madagascar has been encouraging (the country's PR at the end of June 2004 was 2.93/10,000). However, more effort is still required, mostly to improve the quality of diagnosis — we found a 40% error rate during field visits — and to ensure better follow-up of patients during treatment.

In short, we need to address the problem of misdiagnosis, and improve our strategy for following patients on MDT, in order to reach the elimination goal. ■

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## PARTNERS

### INTERNATIONAL LEPROSY UNION



The International Leprosy Union (ILU) was founded in Bombay in 1986 to provide a global forum for bringing together leprosy organizations in developing countries and coordinating their work. While there were already international organizations for donor agencies, there were practically none for recipients, who often found that donors decided the plan of work to be followed without regard to the cultural specificity or ethnic requirements of the local community. One of the goals of the ILU, therefore, was to give developing countries a voice and sensitize donors to their needs.

Initially, the ILU had membership in about 15 countries in Africa and Asia. Its chairman, Dr. S.D. Gokhale, was taken on as a consultant by WHO and traveled to Nepal, Bangladesh, the Philippines and elsewhere to report on the work of NGOs there. In response to evolving needs,

the ILU now concentrates primarily on India.

In supporting the cause of leprosy elimination, the ILU sees leprosy not just as a medical problem but also as a social one, and has always endeavored to give a human face to the elimination strategy. Its vision is of a world free of leprosy and of the socio-economic discrimination it attracts.

To achieve these goals, ILU's priorities today include urging media to play a greater role, encouraging the involvement of the non-leprosy sector, drawing attention to neglected groups such as women and children, and doing a study on assistive devices that help in the rehabilitation of those with disabilities.

In particular, ILU champions the role of cured persons in speaking out, seeing this as a way to help to change the psyche of those affected by leprosy as well the perceptions of the community at large.

# Poetry from the Heart

After being diagnosed with leprosy, Tetsuo Sakurai was forced to leave home at the age of 15. He didn't return for more than 60 years.

Tetsuo Sakurai was born Toshizo Nagamine in 1924 in Myodo-zaki, a small village in Tsugaru in the far north of Japan's main island of Honshu. Toshizo was the seventh son in a wealthy family that owned large apple orchards, and his early life was a comfortable one. A sensitive boy with a good sense of humor, Toshizo entered elementary school in 1931 and was popular with his fellow students.

At 13, he exhibited the first symptoms of leprosy. Two years later, when he was studying for middle school entrance examinations, he was suddenly told by his father that he would have to give up his studies. At that point, he realized he would be leaving home and that life was about to take an altogether different course.



Tetsuo Sakurai pictured at the family orchard in Tsugaru in 2001.

took their own lives. Any attempting to escape were placed in solitary confinement as a warning to others.

To cope with this harsh life, Tetsuo decided to devote himself to study and purchased a collection of Japanese literary classics. He was befriended by the educated daughter of a wealthy Kyoto restaurant owner who became Tetsuo's mentor. Under this erudite teacher, he began studying topics such as theology, European philosophy, Buddhism and literature at the age of 19.

At 21, he "married" a young woman named Masako. This marriage had no legal basis, but was recognized within the sanatorium. In those days, before they entered into such a union, male leprosy patients had to be sterilized. The

procedure was not properly performed on Tetsuo, however. When Masako unexpectedly became pregnant, she was forced to have her baby aborted.

Two years later, Masako died of leukemia. The following year, Tetsuo came down with high fever. By the age of 29, he lost his sight, all his fingers and the use of his vocal cords.

It would be many years before Tetsuo

## Solitary Musings

On a spring evening in the ward,  
I press two seashells against my ears,  
and, closing my eyes, hear  
the roar of the waves in faraway Tsugaru,  
as we heard them then,  
standing shoulder to shoulder,  
atop the dunes of Tsugaru  
in the spring of my seventeenth year.  
And I hear the caw of the gulls  
that skim the waves,  
as, left alone to solitary musings  
on this early evening in spring,  
I feel my heart pounding.

(Translated by Charles De Wolf)

At first, he received treatment in neighboring Hirosaki for 10 months but after he showed no improvement, his parents were obliged to have him quarantined in a sanatorium under Japan's 1907 Leprosy Prevention Law (not repealed until 1996).

They saw him off from Hirosaki Station as he departed for the town of Kusatsu, carrying apples, rice balls and dried squid wrapped in a cloth on his back. Although he felt utterly desolate, Toshizo did not want to upset his parents by crying in front of them over the enforced separation.

In 1941 Toshizo entered Kuryu Rakusen, one of 13 sanatoria established by the Japanese government between 1909 and 1945, and was given the new name, Tetsuo Sakurai.

Although called a sanatorium, those with mild symptoms were put to work on nearby farms, forced to do hard labor and nurse seriously sick patients. Despairing of their future, many patients

adjusted to his condition. Eventually, he joined a group for the blind and developed a passion for Japanese chess. Then, at the recommendation of Shigenobu Kobayashi, the sanatorium's director, Tetsuo joined the poetry group. Listening to poetry turned him back onto to literature, and at the age of 57, he composed his first poem, whispered to a member of staff who wrote it down for him. He also began reading the Bible, and was baptized as a Catholic at the age of 60.

In 1988, *Tsugaru Lullaby*, his first collection of poetry, was published. Two more volumes have followed.

Tetsuo finally returned to his Tsugaru homeland in October 2001 at the invitation of his family. He spent only a few days there, but it was a time of great joy for him. A TV documentary about Tetsuo's return to Tsugaru after 60 years was broadcast by Japan National Broadcasting Corp. in 2002, generating a huge viewer response. ■

# The Fight Continues

Efforts to eliminate leprosy continue to make progress. The battle against social discrimination must do the same.

## THE PHILIPPINES (DECEMBER 1-2, 2004)

In December 2004, I attended WHO's SEARO/WPRO bi-regional meeting in Manila on post-elimination strategies in South East Asia and the Western Pacific. The theme of the meeting was how to sustain elimination once the goal of achieving a prevalence rate of less than 1 per 10,000 population has been achieved. In particular, the strategy focuses on establishing a surveillance system, integrating treatment of leprosy into the general health services and ensuring early detection and treatment.

## INDIA (DECEMBER 3-9)

Eliminating leprosy and rooting out stigma and social discrimination are two sides of the same coin. To win the battle against leprosy, it is necessary to address both. Visiting the Indian states of Madhya Pradesh and Andhra Pradesh only strengthened this conviction.

I have visited India repeatedly in recent years. Of all the countries that have yet to achieve elimination, India has the most cases (266,000 at the end of March 2004). This was my tenth visit since 2003, but my first to these states.

Both states are working toward the elimination goal. As of October 2004, Madhya Pradesh had a PR of 1.28/10,000, and Andhra Pradesh of 1.73/10,000. Elimination is close.

Furthermore, in Madhya Pradesh, there are camps to assist in the process of reintegrating cured persons into society. Known in Hindi as Kushta Kantha Nivaram Karykram (literally, "camps to remove the suffering of recovered persons from within"), they bring together those recovered from the disease as well as community members in a move to tackle stigma and social discrimination.

Meanwhile, in Andhra Pradesh, efforts are being made to integrate leprosy into the general



Malak Singh Shrivastav

health services, where it can be treated as just one more disease.

In Bhopal, I met with Dr. Balram Jakhad, the governor of Madhya Pradesh; Shri Babulal Gaur, the chief minister; Dr. Gaurishankar Shejwar, the health minister; and Dr. M.K. Joshi, the health department director and secretary for state leprosy eradication. In Hyderabad, I called on Shri Sushil Kumar Shinde, the governor of Andhra Pradesh and attended ILEP's India Day meeting and an Advocacy Meet organized by LEPRA where the speakers included Dr. T.V. Venkateswarulu, AP's state leprosy officer.

I also visited with patients, recovered persons and health workers to hear their stories. Of all the people I encountered, I shall not forget Mr. Malak Singh Shrivastav, whom I met in Bhopal. A 56-year-old farmer from the village of Maleh Pipariya, Narsinghpur District, he was diagnosed with leprosy three years ago. Based on the little he knew, he thought this would result in him being shunned by society.

For two days, he couldn't eat, and on the third day, he began to think about killing himself. He told a close friend, and as soon as his family and fellow villagers got to hear of this, they watched over him 24 hours a day for 15 days to make sure he didn't follow through on his suicide plan.

Meanwhile, his wife went to the regional leprosy officer for more information, and convinced her husband that the disease was easily treatable, medicine was available at the primary health center, and that nobody was going to exclude him from society. Thus encouraged, and at the same time moved by the compassion of his family and friends, he began receiving treatment



Shri Babulal Gaur, chief minister, Madhya Pradesh



Shri Sushil Kumar Shinde, governor, Andhra Pradesh

## LEPROSY FACTS

- Each year, the last Sunday in January is set aside as World Leprosy Day, a day to demonstrate support for those with the disease. It was established by French journalist and philosopher Raoul Follereau in 1954. This year, it fell on January 30, the 57th anniversary of the assassination of Mahatma Gandhi.



Care and Concern Camp in Sanchi, Madhya Pradesh

and was completely cured. In all that time, the only stigma he suffered was in his own heart.

As a result of his experiences, Mr. Shrivastav was moved to fund a Kushta Kantha Nivaram Karkyram camp in his district. Known in English as a Care and Concern Camp, it helps to reduce the physical and mental suffering of those with leprosy. Since 2003, he has organized three such camps from his own home, at which those who have lost feeling in their hands and feet receive treatment for injuries, and are given a warm welcome by the local community. He also appears before the media to tell his story.

**Every word uttered by a recovered person is ten times more persuasive than anything I might say.**

I have always felt that the most effective way to rid society of stigma and discrimination is for recovered persons to come together and lead the fight. Every word uttered by a recovered person is ten times more persuasive than anything I might say. In Mr. Shrivastav's case, he is not merely speaking up but extending a hand to patients and recovered persons. I am inspired by his example.

Listening to his story, I was reminded of the words of Mahatma Gandhi: "Leprosy work is not



WHO's Dr. Derek Lobo addresses the Advocacy Meet in Hyderabad.

merely medical relief, it is transforming frustration in life into the joy of dedication, personal ambition into selfless service."

While in Hyderabad, I visited the Uppal Public Health Center in Ranga Reddy District. There I met about 20 leprosy patients as well as some 40 student nurses from the Yashoda School of Nursing and the Kamineni School of Nursing. As the student nurses and PHC workers looked on, I handed out MDT from blister packs to the 20 or so patients — ranging in age from children to adults — who swallowed their dose in front of us as if taking cold medicine. It reinforced the impression that leprosy is just another curable disease, and this is something that I hope will stay in the minds of those student nurses when they have occasion to meet leprosy patients in future.

Elsewhere in Ranga Reddy District, I visited the Sivananda Rehabilitation Home, which proved to be another unforgettable experience. It was started in 1958 as a rehabilitation facility for those with leprosy. At present, it is home to some 500 recovered persons, including some with families.



Scene from Sivananda Rehabilitation Home

The facility includes a school for residents' children, a hospital for basic reconstructive surgery and rehabilitation, and workshops for spinning, weaving and shoe manufacture.

I went from dwelling to dwelling and met about 200 recovered persons, shaking hands with each. The experience brought home the importance of early diagnosis and treatment, since it was apparent that even if social discrimination were to disappear, it would still be difficult for those with severe disabilities to be socially reintegrated. For this to happen, everybody needs to know that leprosy is curable, treatment is free and that they won't face discrimination. At the same time, it is essential that treatment of leprosy is integrated within the general health services.

Even though leprosy is curable, only when people have early access to treatment will it be possible to do away with such colonies. I am resolved to continue the fight so that those who have been treated can live normal lives where they were born, surrounded by friends and family. ■

# WHO SEARO Holds Intercountry Meeting

Meeting tracks progress of elimination program in member countries.

An Intercountry Meeting of National Program Managers for Leprosy Elimination was held in Kathmandu, Nepal from January 6 to 8 to discuss the progress of leprosy elimination in the WHO South-East Asia Region. Forty-five participants from 10 leprosy endemic countries (except DPR Korea) and representatives of NGOs were invited.

For India and Nepal, the two countries yet to achieve elimination, the most critical and priority activities for 2005 are routine case confirmation prior to registration, monthly updating of registers and capacity building of health staff in order to minimize the 'operational factors' influencing prevalence and new case detections. They were also urged to place staff trained and experienced in leprosy in priority and problem pockets.

In order to ensure quality of new case detection, programs should ensure that case finding is mainly focused on promoting self-reporting; strict adherence is maintained to case definitions as per WHO/National guidelines; confirmation of new cases by a competent health staff/MO prior to

registration and initiation of MDT is carried out; and previously treated cases are not registered as new cases, even if they require MDT.

It was also recommended that India and Nepal adopt 'Accompanied MDT' as a policy for certain groups, such as patients from hard-to-reach and distant areas, migrant labor, floating urban population, and nomads.

For countries that have achieved elimination at the national level and are aiming at sub-national elimination, several recommendations were made.

Among them were the suggestions that they consider a shift to 'new case detection' instead of prevalence as the primary indicator once sub-national elimination has been achieved, develop mechanisms for counseling of patients and family members in all aspects of the disease and its treatment, and develop the required organizational set-up to ensure strengthening and sustaining of quality leprosy services within selected facilities in an integrated set-up, in close coordination with all partners. ■

## LETTER

### BUILDING A PLATFORM

As a person affected by leprosy, it has been my experience that not enough has been done to address the social aspects of the disease. I reached the conclusion that the only way to tackle discriminatory talk and behavior is to set up a place where we can bridge the communication gap between people affected by leprosy and the rest of society. We need to build a platform where recovered persons can be counted as normal, healthy individuals and as useful citizens. To this end, I have dedicated my efforts to establishing a community where recovered persons live alongside other members of society, and where there is no fear of the disease, nor discrimination based on caste or creed. "Rock Land Colony" is now home to nearly 2,000 families. Our task is to build up the courage of the cured, and create a social environment for them, as only they can pave the way to a world free from leprosy.

*Md. Sala Huddin*  
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Hyderabad, India

## FROM THE EDITORS

### NEARLY THERE

We are now in the final months of the WHO campaign to eliminate leprosy as a public health problem. Already, thoughts are turning to a post-elimination strategy that focuses on sustaining achievements to date and further reducing the disease burden at the local level.

Creating conditions that enable those touched by the disease to lead normal lives free from discrimination must also be a priority. The best people to bring about change, we believe, are the leprosy-affected themselves. WHO Goodwill Ambassador Sasakawa recently encountered an inspiring example in Malak Singh Shrivastav, whose story he relates in Ambassador's Journal.

The successful farmer from Madhya Pradesh, India, despaired when diagnosed with leprosy and considered taking his own life. But after being cured with MDT, he now extends a helping hand to others and speaks out about his experiences. He has become a committed social advocate, encouraging those affected by the disease to believe in themselves and the possibilities of life after cure.

## FOR THE ELIMINATION OF LEPROSY

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