

FOR THE ELIMINATION OF LEPROSY

A MESSAGE FROM THE SPECIAL AMBASSADOR

Leprosy and Human Rights

We are striving for the elimination of leprosy by the year 2005. "Elimination" here is defined as a prevalence rate of less than one per ten thousand inhabitants of every country in the world.

However, this number really means nothing more than the elimination of leprosy as a *public health* problem — a medical issue. This does not mean that our fight against leprosy ends when we have achieved elimination.

From ancient times, leprosy has been associated with strong social stigma. Leprosy patients have been forced into isolation from the rest of society, and have even been abandoned by their own families — often treated as though they did not even exist. I have long thought that discrimination against those affected with leprosy should be regarded as a human rights issue.

Today there are around 600,000 patients every year in the world who need treatment for leprosy. However, if you include those who have completed medical treatment and their families, there are tens of millions of people who are still suffering from unnecessary discrimination and resulting injustices. They are often denied equal opportunities for education, marriage and employment, which are open to people who have not been touched by the disease.

On July 2nd, I visited Geneva and was able to discuss this issue for the first time with Acting United Nations High Commissioner for Human Rights, Bertrand Ramcharan. Mr. Ramcharan was in full agreement that the discrimination these people have to face is a human rights issue. He then agreed to cooperate with us in an effort to bring about improvement of the situation. I believe that this is a significant and historical event. I am pleased that we have finally been able to make an international appeal for recognition of the pain and suffering felt by the people affected with leprosy and their families. Finally, the world is opening up to this problem as a human rights issue.

Unless this issue is resolved, our fight will never end. Even after we have reached our goal in 2005, our journey will continue until the day that leprosy is completely eliminated, both medically and socially.

佐川 陽子

Yohei Sasakawa
WHO Special Ambassador
President, The Nippon Foundation

Leprosy is Curable.

Free Treatment is Available.

Social Discrimination has no Place.

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SEAR REPORT

Leprosy Elimination Efforts in Southeast Asia

by Dr. Uton Muchtar Rafei, WHO Regional Director for the South East-Asian Region

Although the South-East Asian Region (SEAR) is the only WHO region yet to achieve the elimination of leprosy, it has made noteworthy progress and substantially contributed to the achievement of the leprosy elimination goal globally.

SEAR Achievements

- Over 90% of the approximately 12 million leprosy cases detected and cured globally are from SEAR, including 10.8 million cured cases in India.
- Seven of the eleven member countries of SEAR attained the elimination goal by the original target date of December 2000 and have maintained elimination levels. Myanmar attained the goal in January 2003.
- The three remaining countries — India, Nepal and Timor-Leste are making concerted efforts to reach the goal by December 2005.
- The prevalence of leprosy has declined by 92% over the 17-year period from 1985, when Multi-Drug Therapy (MDT)¹ was introduced in all countries of the Region.

India

In spite of the above achievements, it is a matter of concern that the region accounted for 74% of the globally registered cases and 80% of the new cases detected in 2002. India alone accounts for 90% of the regional and 66% of the global caseload. Therefore, WHO is giving the highest priority to India. I must, however, emphasize that the National Leprosy Elimination Program (NLEP) in India is on the right track and has made notable strides.

Indian Achievements

- Over 90% of the cases detected and cured in the region are from India.
- India has a good health infrastructure. Leprosy services and adequately trained human resources are now integrated into general health services, bringing MDT to the doorstep of the large majority of leprosy patients.
- Comprehensive advocacy and Information, Education and Communication (IEC) activities, as well as many focused activities like Leprosy Elimination Campaigns and Special Action Plans for Elimination of Leprosy are being conducted.
- There is a well-functioning collaboration between NLEP and partners like WHO, the World Bank, and DANIDA² as well as national and international NGOs.

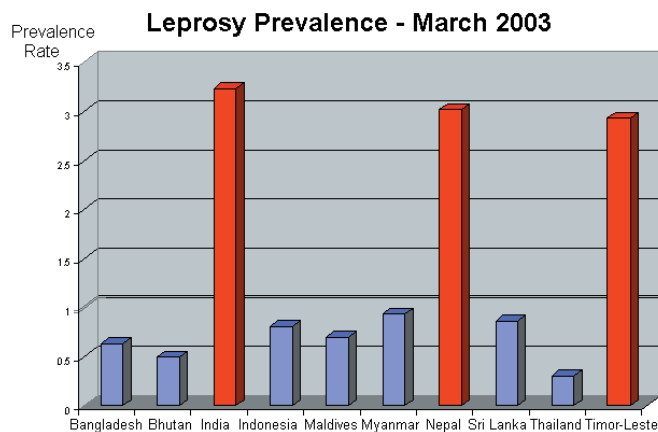
WHO has provided a special package to India for the period 2002-2005. The package has three components.

- a) Strengthening management for improved planning and decision-making, involving the Indian Administrative Service. This includes project directors for the seven highly endemic states, nine state and six zonal coordinators, one national consultant and support staff at the Office of the Deputy Director General for Leprosy. In addition, computer facilities and data entry operators are being provided for thirty-six state leprosy societies.
- b) Capacity Building — the training of 360 district Chief Medical Officers;
- c) Monitoring and Surveillance — Leprosy

¹ MDT — two to three drugs (Clofazimine, Rifampicin and Dapsone), which are used in combination to prevent resistance.

² Danish International Development Assistance

Elimination Monitoring in twelve states and the development of a simplified information system.



In India, as of March 2003, there were 344,003 registered cases: a prevalence of 3.22/10,000 inhabitants. In order to sustain and enhance the political commitment and give a further boost to the program, a joint WHO/NLEP-India meeting was organized on February 5th, 2003 in Yangon, Myanmar, in conjunction with the third meeting of the Global Alliance for the Elimination of Leprosy (GAEL). The meeting was attended by Special Ambassador Sasakawa and by partners like The Nippon Foundation, Sasakawa Memorial Health Foundation and ILEP (International Federation of Anti-Leprosy Associations) agencies. This meeting was useful in determining priorities and concrete steps that need to be taken for leprosy elimination in India by 2005.

Nepal and Timor-Leste

In Nepal, as of January 2003, there were 7,291 cases, giving a prevalence rate of 3.02/10,000 inhabitants. Prevalence is high in the central, eastern and far-western regions of the country. WHO has posted a short-term professional consultant, two national and five regional consultants to support the national program, and is also providing support to intensified leprosy elimination activities.

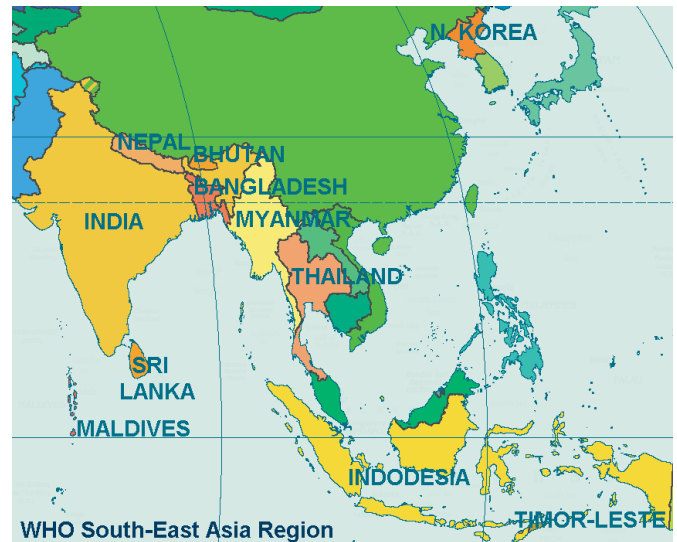
In Timor-Leste, as of March 2003, a total of 249 cases are registered, giving a prevalence of 2.93/10,000 inhabitants. The high prevalence rate has been exacerbated by the pre-independence conflict in the country, which resulted in the severe dislocation of health programs. Of the registered cases, 66% are from the Oecusse district. WHO has assisted the country in the preparation of a strategic plan for the elimination of leprosy and is supporting capacity-building as the first step in strengthening the National Leprosy Program.

With intensified and concerted efforts, we are confident that India, Nepal and Timor-Leste will attain elimination by the year 2005.

Regional Efforts

Bangladesh, Bhutan, North Korea, Indonesia, the

Maldives, Sri Lanka and Thailand achieved the elimination goal by the original target date of December 2000, and Myanmar achieved the goal in January 2003. The national authorities of all these countries deserve congratulations for this success. WHO is now supporting these countries in their progress towards subnational elimination.



To advocate and enhance political commitment towards leprosy elimination in the region, an Inter-country Meeting of National Program Managers for Leprosy Elimination was held in Colombo, Sri Lanka in November 2002. The meeting enabled the sharing of new knowledge and experiences in the march towards the goal of leprosy elimination in the region. Important suggestions were made. The most significant recommendations were to further strengthen the integration of leprosy and phase out vertical structures in a definite time frame, and to undertake measures to prevent operational factors like over-diagnosis and re-registration of cases, leading to a high level of new case detections in some countries.

WHO Recommendations

- Strict adherence to WHO recommended case definitions;
- Validation mechanism to ensure quality of diagnosis;
- Remove setting of case detection targets;
- Periodic register updating to ensure patients who have completed MDT are removed from the active register.

The third GAEL meeting was held in Yangon, Myanmar, in February 2003. All of the partners were well represented, including national delegations from India, Myanmar, Nepal and Indonesia.

All member countries are committed to the Final Push Strategies recommended by WHO and have forged partnerships to further reduce the burden of leprosy.

Leprosy Prevalence in the Southeast Asian Region as of March 2003

Country	Population	Registered leprosy cases	Prevalence rate (x/10 000)	Newly detected cases in 2002	New Case Detection Rate (x/100,000)	People cured with MDT since 1982	Year of reaching elimination target
Bangladesh	129,248,000	8,143	1	9,844	8	140,440	1998
Bhutan	659,000	33	1	13	2	940	1997
India	1,067,482,000	344,377	3	473,658	44	10,383,038	(2005)
Indonesia	207,840,000	16,837	1	12,377	6	257,690	2000
Maldives	270,000	19	1	29	11	1,163	1996
Myanmar	52,827,000	4,965	1	7,386	14	226,698	2003
Nepal	24,154,000	7,291	3	13,830	57	94,448	(2005)
Sri Lanka	19,086,000	1,639	1	2,214	12	34,534	1995
Thailand	61,879,000	1,905	0	1,000	2	56,561	1994
Timor-Leste	849,000	249	3	281	33	N.A.	(2005)
SEA Region	1,564,294,000	385458	2.46	520632	33.28	11195512	Target: 2005

Source: WHO Country Reports

Through improved access to early detection, treatment and intensive education and awareness programs, there has been a perceptible positive change in the public view of leprosy in all countries. There is also a high level of political commitment to reach national and subnational elimination.

I would like to place on record our appreciation and thanks to The Nippon Foundation and Sasakawa Memorial Health Foundation for their consistent support to WHO in its assistance to member countries for leprosy elimination. □

REPORT FROM INDIA

Marching Towards Leprosy Elimination in India

by Dr. Ashok Kumar, Deputy Director-General (Leprosy), Ministry of Health & Family Welfare, Government of India, New Delhi

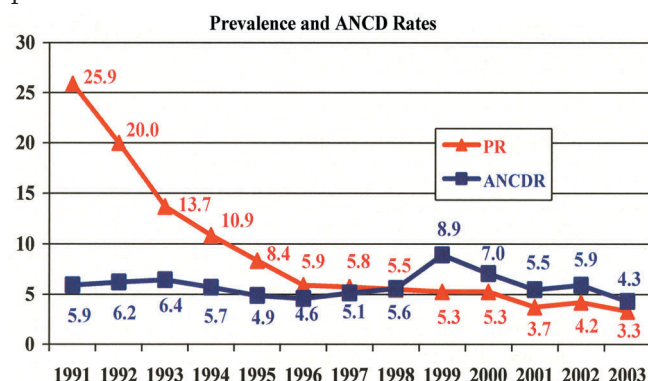
The Current Leprosy Situation in India

Current statistics indicate that India has a prevalence rate of 3.22 per 10,000 inhabitants, with eleven endemic states contributing 92% of the country's leprosy caseload. During the year 2002-03, a total of 476,000 new leprosy cases were detected, of these, 14.9% were child cases, 1.8% were visible deformity cases and 35.2% were multi-bacillary cases. MDT coverage has been extended to all primary health centers and hospitals in all districts of India, and an estimated 10.8 million patients have been cured by MDT through March 2003.

Epidemiological Achievements

With efficient implementation of well-planned efforts since 1954-55, India has substantially succeeded in its fight against leprosy. During 1981, India had a leprosy prevalence rate of 57.6. This has come down to only 3.2 as of March 2003. The Annual New Case Detection (ANCD) rate has also declined.

Elimination has been achieved in fifteen regions, and another six regions are close to leprosy elimination with a prevalence rate of between one and two.



Strategy and Plan of Action for Leprosy Elimination

State-specific action plans for the year 2003-04 have been drawn up by all 35 regions and approved by the Government of India. The main thrust in this third and final year of the second phase of the World Bank-supported National Leprosy Elimination Project can be summarized as follows:

1. Decentralization and Integration of Leprosy Services with General Health Care Services:

This has enabled the General Health Care Services (GHS) to implement integrated leprosy services. Full involvement is ensured at the grassroots level at sub-centers (each covering areas with about 5,000 inhabitants), to deliver the second and subsequent doses of MDT to leprosy patients already diagnosed by Medical Officers at primary health centers.

2. Leprosy Training of General Health Care Staff:

Training was given to Medical Officers, Health Supervisors, Health Workers and village-level functionaries in all districts of all regions during the last four nationwide Modified Leprosy Elimination Campaigns, held between 1998 and 2003.

Similarly, one-day training in Leprosy IEC¹ has been arranged by the states for District Mass Media Officers, Block Extension Educators, Health Educators and Selected Health Supervisors. The district chief medical and health officers of twelve priority-endemic regions have also been oriented through three-day "ILEP Management Courses."

The National Leprosy Eradication Program has also initiated the orientation of General Health Care Staff regarding Prevention of Deformity and Disability Care

1 IEC — Information, Education & Communication



Health Worker
Holding Leprosy
Pamphlet
— Uttar Pradesh,
India

through Block POD² Camps in which patients are taught about self-care.

3. Continued IEC to Facilitate Early Case Detection and Prompt MDT Treatment:

Four nationwide Modified Leprosy Elimination Campaigns (MLEC) have been carried out by all regions since 1997-98. Each time, the number of new cases detected has declined, as follows: 4.63, 2.13, 1.65 and 1.02 lakhs³. The positive benefits of community education, detecting hidden leprosy cases and prompt application of MDT treatment are clearly apparent.

Each State has been encouraged to draw up district- and urban-specific plans for IEC for the year 2003-04.

4. SAPEL⁴ / LEC⁵:

The Special Action Plan for Elimination of Leprosy in rural areas and the Leprosy Elimination Campaign in urban areas are covering identified groups that are normally inaccessible due to location or other complicating circumstances.

5. Prevention of Disability (POD) & Care:

The training of General Health Services staff for POD, education of patients for self-care, and reconstructive surgical services for patients with deformities are all being continued. This is being carried out through specialized NGO institutions, district hospitals and tertiary referral centers.

6. Monitoring and Evaluation:

The Government of India has recently developed a Simplified Information System under the National Leprosy Eradication Programme. This has been implemented in the country since October 2002. With the Simplified Information System, the country is now equipped with an inbuilt information system for monthly monitoring, feedback and timely corrective actions at various levels.

Involvement of Partners for Elimination in India

India's Programme for Leprosy Elimination continues to be a combined effort of all the regions of India and the various organizations involved, e.g. the World Bank,

WHO and DANLEP. Support received from the Novartis, The Nippon Foundation, and Sasakawa Memorial Health Foundation have been of tremendous help.

NGOs have been involved in the cause of leprosy elimination for many decades and their contributions have had a strong, positive impact. More than 290 NGOs are working in the field of leprosy throughout the country. The roles and responsibilities of the NGOs have recently been redefined, with a new focus on the integration of leprosy services into General Health Care Services.



Efforts have also been made to invite NGOs from different health fields to take appropriate actions towards leprosy elimination.

The International Federation of Anti-Leprosy Associations is actively involved as an NLEP partner and supports 145 District Technical Support Teams around the country. These are assisting in the integration of leprosy services into General Health Care Services. In addition, the International Leprosy Association, in collaboration with Sasakawa Memorial Health Foundation and other NLEP India Partners, is organizing National Conference on the Elimination of Leprosy — India, planned for December 19th - 22nd, 2003, in Raipur, Chhattisgarh. Active participation of a large number of regional level NLEP managers will further enhance their involvement and commitment towards achieving the national goal of leprosy elimination in India. □

2 POD — Prevention of Disability

3 One lakh = 100,000

4 SAPEL — Special Action Plan for Elimination of Leprosy

5 LEC — Leprosy Elimination Campaign

THE SPECIAL AMBASSADOR'S JOURNAL, 2002

In December 2002, I visited several areas in India and Bangladesh. During my travels, I became aware that the media's grasp of leprosy is surprisingly limited. It was news to many of those I talked to that India has the largest number of patients in the world. This reinforced my conviction that education is absolutely vital.

Uttar Pradesh, India

Uttar Pradesh is one of the most highly endemic states of Northeastern India, as well as the state with the largest population — 166 million. Elimination

activities here are being promoted spiritedly with the dedicated efforts and energetic leadership of people in the government, private organizations and a wide variety of NGOs. This system is coordinated by Leena Nandan, the newly assigned project director. I visited the Unnao district (population 2.7 million), where I went to community health centers, as well as villages where health workers are conducting detection campaigns. In these villages, I met with several patients receiving MDT. I also met several eminent political leaders, including Chief Minister Mayawati, who all showed a keen interest in the leprosy problem and promised their commitment to the elimination effort. At a press conference attended by some sixty journalists from local newspapers, TV and radio stations, I explained the current state of leprosy elimination around the world, in India and, most specifically, in Uttar Pradesh. As a result, articles appeared the next day in twelve newspapers (three English and nine Hindi).

I discussed several issues with the Project Director Leena Nandan, including the need to come up with a simple way to reach schools, thus enabling students to find early signs of the disease simply by checking the skin of family members. Later, I learned from Ms. Nandan that leprosy elimination was being given top priority by the state. Following this, the project people immediately designed an illustrated chart of the human body in order to facilitate detection. The chart is distributed to primary school children. Children take the sheets home, bring them back the next day, and the data is then evaluated at a Primary Health Center.



Yohei Sasakawa and Chief Minister Mayawati

Bangladesh

In Bangladesh, I met with the Minister of Health and observed leprosy elimination activities in Dhaka. This work is being jointly conducted by the government and The Leprosy Mission, Bangladesh. They are making continuous efforts toward the early detection of leprosy in women and children. Even though the target has been met, the need for vigilance never ceases.

Bihar, India



Anganwadi Workers in Bihar

In Patna, the capital city of Bihar, I attended a briefing lead by a state leprosy officer and WHO state coordinator. It was reported that, though the leprosy elimination activities in Bihar had a late start, the number of patients is markedly fewer than it was in 2001.

There was also a report on the Communication for Behavioral Impact, or COMBI, program, which was conducted in three districts of Bihar on an experimental basis. I next went to the district of Jahanabard, one of the districts where COMBI is being conducted, where I had a meeting with the district magistrate and an all-female group of social workers known as Anganwadi Workers. They are cooperating with COMBI and promoting awareness at local levels. In general, the reports and our own observations indicate that the elimination efforts in Bihar are gradually getting on track, although there still exist numerous problems to be overcome. In fact, the very possibility of elimination by 2005 was questioned by reporters. Nevertheless, the firm commitment expressed by top political leaders and others in the government is cause for a certain amount of optimism. □



UNITED NATIONS

Press Release

3 July 2003

Acting High Commissioner and Head of Nippon Foundation Discuss Discrimination against People with Leprosy

Acting United Nations High Commissioner for Human Rights Bertrand Ramcharan met on 2 July with the Nippon Foundation to discuss the problem of discrimination against people with leprosy and their families.

Mr. Ramcharan and Nippon Foundation President Yohei Sasakawa concurred that the problem of discrimination and social stigmatization suffered by those affected by leprosy should be addressed from a human rights perspective. The acting High Commissioner said it would be important to bring the issue to the attention of the UN Special Rapporteur on the right to health and to other relevant UN human rights organs.

Mr. Ramcharan and Mr. Sasakawa both expressed interest in a continuing dialogue and cooperation and agreed on the need to increase awareness of issues related to discrimination against people affected by leprosy. Mr. Ramcharan further suggested that the Sub-Commission on the Protection and Promotion of Human Rights, which will meet from 28 July to 15 August in Geneva, could provide an opportunity to organize a briefing on the human rights issues faced by those affected by leprosy. The Nippon Foundation and the Office of the High Commissioner for Human Rights agreed on their interest in collaborating — along with the World Health Organization — in such awareness-raising and advocacy efforts.

Newly Appointed WHO Director General — “Within My Tenure”

On July 1st, Yohei Sasakawa, President of The Nippon Foundation and WHO Special Ambassador for Elimination of Leprosy met with newly appointed WHO Director General Dr. J.W. Lee to discuss ongoing work towards the elimination of leprosy. They reiterated their commitment to the goal of eliminating leprosy by the year 2005 and discussed the importance of India — stating that success in India is vital to the overall effort.

“Although increased anti-leprosy activity there has been discouraging to some, who ask ‘With so many new cases, how can we achieve elimination by 2005?’ we must not hesitate in our activities, but rather push on towards the goal,” stated Dr. Lee.

Mr. Sasakawa stressed the importance of being actively involved “on-site,” stating plans to visit India, Nepal, Madagascar, and Angola, and emphasizing the importance of India and of tackling the issue in India state by state rather than viewing India as simply one area.

Dr. Lee mentioned plans to refocus the program closer to the areas most affected, and stressed the importance of working together to successfully meet the goal of leprosy elimination by 2005.



Dr. J.W. Lee and
Yohei Sasakawa (right)

| HUMAN STORIES |

Modifying Ancient Lore

Legends and beliefs from ancient times have a tendency to perpetuate themselves. In the case of leprosy, overcoming the beliefs of centuries requires our best efforts in both education and treatment. Even today, living in the 21st century, we still have many battles ahead of us. We now focus on detecting the first signs of the disease and then treating it with MDT to stop the disease at a very early stage. Nevertheless, we must not forget those with more advanced cases in order to fully grasp the scope of the task that lies before us. With this in mind, the following story from India is worth reading and empathizing with. From unfortunate endings to happy beginnings, the story illustrates the vital role education plays in combating the disease.

— Editor

The Asra village council was meeting yet again. Council members sat on either side of the headman. Across from them stood Dhelabai and her family. The village watchman began the meeting stating that Dhelabai had leprosy. Neither she nor her family denied this. The headman ordered her out of the village, her husband acquiesced, and in ten minutes the meeting was over.

Thus expelled, the woman next sought refuge in her parents' village, but her deformities brought on abuse there too. She tried to beg, but people ignored her.

Deprived of her family and rejected by both villages, Dhelabai hanged herself from a babool tree.

(Continued on Page 8)

Another Asra woman named Baisantin worked with her husband in the headman's house but, when she contracted the disease and her fingers began to twist, she was told that there was no place for her in the village. She took her baby and went home to her parents, who had her admitted to a leprosy hospital. At the hospital though, she was told to stop breastfeeding her child. This broke her spirit and she threw herself in front of a train.

Asra has many such stories to tell. And the introduction of MDT in the late 1980s had distressingly little effect. Patients continued to hide the disease and the community ignored the efforts of district leprosy workers. As a result, in Asra, the largest village in its district, only two leprosy-affected people had been registered. The rest hid their symptoms and grew progressively worse.

One major reason for this problem was that the headman, Vyas Narain, who had been trained in Ayurvedic medicine, believed that leprosy patients would infect those around them and that they must be cast out of the community.

However, in 1991, regional leprosy workers organized a six-day treatment camp in the village. The workers' preparatory efforts focused on the headman and his wife — without their support, the patients in the village would not likely have had the courage to come for treatment. The headman was initially afraid that the leprosy patients from the countryside would cause a village-wide epidemic, but the workers explained that if people became aware of the cure, the root of the disease would be eliminated.

The headman eventually gave in, reluctantly. On the first day, he watched from a distance. The second day found him sitting near people with leprosy. By the third day, he was touching patients and helping to clean their wounds. On that day, he also began allowing patients to bathe in the large communal pond. He later said, "The camp changed my perception. I realized that my interpretation of the Ayurvedic books was not correct regarding leprosy."

Since the workers had focused on his wife as well, by the last day, many women were attending, and the village itself wore a festive look, complete with rangoli and kalash decorations.

The final day was a celebration. Women sang songs,

put on a play, and there was a common lunch, attended by the headman.

Perhaps the most symbolic gesture of the day came from the wealthy village grocer, who

announced that he had the disease and there received his first MDT treatment.

The celebrations not only exorcised the collective guilt of the village; they were an indication of a general welcome for the cure and promised social acceptance of those affected by leprosy.

Thanks to the efforts of the health workers and the resulting revelation of the headman, the people of the village are no longer fearful of leprosy and leprosy-related suicides are a thing of the past. □

Extracts from "Combating Leprosy"
— by DANLEP-Madhya Pradesh



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