

# FOR THE Elimination OF Leprosy

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



Nursing aid Valdeci de Lima (right) seen with his mother, Gilda Sabino de Lima, who once had leprosy, in Brazil's Amazonas State.

## A MESSAGE FROM THE GOODWILL AMBASSADOR

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# The Social Aspect of Leprosy

In July I visited Brazil, where the leprosy prevalence rate has dropped to 1.48 and the country expects to achieve elimination either this year or early in 2007. Under the leadership of President Lula, Brazil has set up a special committee to deal with both the medical and social aspects of leprosy. This committee includes representatives from the health ministry, justice ministry, education ministry and the special secretariat for human rights, as well as NGOs, and is working to resolve the outstanding social problems facing affected persons. I was encouraged to learn that in forming this committee the president had taken a cue from the recent Global Appeal.

The problem of discrimination is still deep-rooted in Brazil. Visiting an out-of-the-way location in the Amazon, I met people who had concealed the fact they had leprosy and went elsewhere for treatment to preserve their anonymity. I learned of many examples where leprosy has been an excuse for human rights violations in child custody battles or disputes over property inheritance.

It is my hope that the new UN Human Rights

Council will take up leprosy as a formal item on its agenda at an early date. I want to see it publish a set of effective guidelines for tackling the problem of leprosy-related stigma and discrimination. These should have the goal of dispelling misperceptions about leprosy, assisting people affected by the disease and their families to regain their dignity, and accelerating their reintegration into society.

As I mentioned in the previous issue, my mandate as WHO Goodwill Ambassador includes for the first time the elimination of stigma and discrimination. The significance of this lies in the fact that the WHO is thinking about leprosy not only in a medical context but in a social context, too. At this stage in the fight, it is essential that the two go hand in hand. To engage the Human Rights Council, and to involve society at large, the WHO, governments, NGOs and people affected by leprosy themselves must work together for this purpose. I hope I can count on your support in this critical endeavor.

— Yohei Sasakawa, WHO Goodwill Ambassador

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# Moving in the Right Direction

Leprosy-endemic Nepal still striving to reach the elimination goal.

In recent times, Nepal has witnessed a declining trend in both the leprosy prevalence rate and the new case detection rate. However, this decline was not fast enough to see the disease eliminated as a public health problem by the end of last year. As of 15 April 2006, the PR stood at 1.82.

A small landlocked country of 25 million people, Nepal is divided into five development regions and 75 districts. Nearly half (48.4%) of the population lives in the Terai (plains) region, which makes up 23% of the landmass.

The Eastern Developmental Region (EDR) continues to record the highest PR, and the Central Developmental Region (CDR) the largest number of new case detections. The Western Developmental Region (WDR) has consistently reported the lowest PR in the country.

Table 1 summarizes the disease trend over the last three years using national leprosy elimination program (NLEP) indicators.

Leprosy has remained highly focal, with the Terai region accounting for 82% of the country's caseload. Ten districts alone have half (51%) of the country's registered cases. In none of Nepal's 75 districts is the PR is over 5/10,000. Thirty-five districts have already reached the elimination level.

**Table 1: Disease trend over the last three years**

	2002/03	2003/04	2004/05
NCDR	3.24	2.84	2.4
PR	3.04	2.41	2.02
MB(%)	51.22	50.95	52.3
Child(%)	7.7	6.57	6.78
Grade II DR(%)	3.95	3.48	3.52
Female(%)	29.6	31.8	34.47
Defaulter(%)	5	2.4	0.89

NCDR: New case detection rate per 10,000, PR: Prevalence rate per 10,000, MB (%): Proportion of MB cases among new cases, Child (%): Proportion of children among new cases, Grade II DR (%): Proportion of new cases showing Grade II Disability at detection.

Source: Ministry of Health, Nepal

Treatment compliance has remained consistently good and completion rates reported for the year 2004/05 were 91% for multibacillary cases and 94% for paucibacillary cases.

During the second quarter (16 November 2005 to 15 April 2006) the number of cases under treatment has come down by 5.3%. All the regions have shown a decline. This decline is most marked in the Mid-West Developmental Region (15.8%) and least evident in the CDR (0.05%).

## SERVICE DELIVERY

MDT services are integrated and have been delivered through all the peripheral health facilities of Nepal (188 primary health centers, 697 health posts and 3,129 sub-health posts) since 1987. The participation of hospitals in leprosy service delivery is sporadic and patchy. Referral centers run by international NGOs are providing routine diagnostic as well as referral services.

Outreach clinics — both those of primary health centers and of the expanded program on immunization — are not actively involved in leprosy patient care.

Over the years, the program has created a vast pool of trained manpower and every health facility has more than one trained person. However, most of the human resources developed and deployed are either unutilized or underutilized for want of adequate demand for their services and/or inadequate motivation amongst service providers.

A functioning network of supporting partners exists in Nepal. Periodic review meetings are held regularly at all levels. Supervision has been limited until recently to health facilities that are easily and safely accessible due to the security situation.

## OBSTACLES

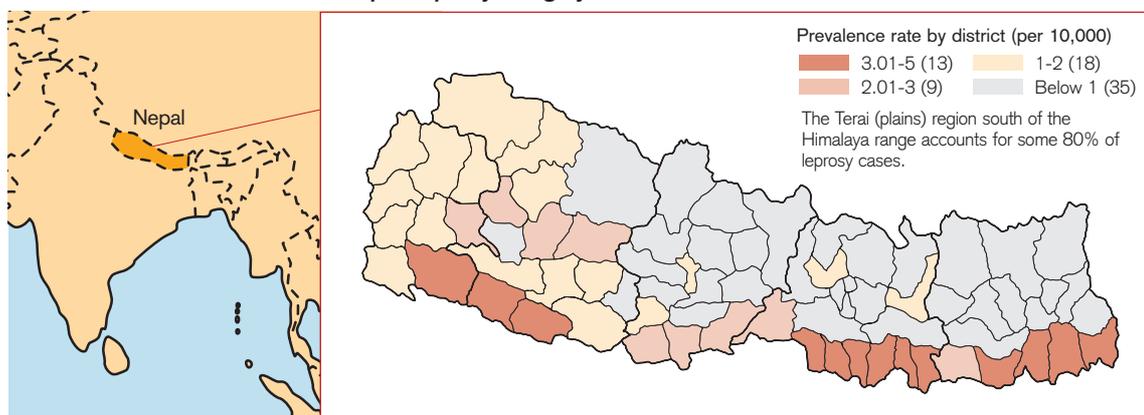
A centralized decision-making process further complicated by an ambiguous line of command is one of the impediments facing the program.

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**Nepal: leprosy is highly focal in its distribution**



## Leprosy FACT

● A 2005 case validation study in Nepal found that one quarter of cases had been improperly diagnosed: wrong diagnosis (9%), re-registration (11%) and non-existent cases (6%).



Nepal: 35 districts have achieved elimination  
Photo by Pamela Parlapiano

Paradoxically, the program is heavily dependent on external support (in terms of money, material and people) from multilateral and bilateral agencies.

The low caseload and low demand for services are rendering integrated service delivery cost ineffective and making it increasingly difficult to sustain skills at the peripheral level. Motivation to do leprosy work among staff in general, and those working in hospitals in particular, is low.

Patient management tasks (including diagnosis and treatment of complications) largely go unsupervised. The quality of laboratory services is not satisfactory. IEC activities are neither needs-based nor area-specific.

**Motivation among staff in general, and those working in hospitals in particular, is low.**

#### **FUTURE PLANS**

The strategy of “early diagnosis and prompt treatment” will remain the same for the foreseeable future, with minor changes in the way that the strategy is being implemented. Perhaps rehabilitation work might be given higher priority in the coming years. Some of the activities under consideration include:

- Strengthen select health centers and hospitals in endemic regions to empower them to provide secondary-level care so that access to secondary-

level care improves;

- Undertake review of cases under treatment and delete all cases inappropriately registered, an exercise expected to bring down PR by 25% to 30% and which will hopefully minimize inappropriate registration in future;
- Evaluate leprosy training — need, suitability of the current curriculum, effectiveness of training process and impact of training — and draw up a plan for future training so as to make it needs-based, task-oriented and cost-effective. Medical colleges and other health-sector training facilities will be progressively involved in leprosy service delivery and training.
- Assess the impact of IEC activities and develop and implement area-specific plans;
- Centralize leprosy diagnosis in low endemic areas and limit this to health centers and hospitals to ensure quality diagnostic services. But health posts and sub-health posts in endemic districts will continue to diagnose cases and initiate treatment, as they do now, for quite some time;
- Promote a more democratic leadership style whereby major stakeholders proactively participate in planning and decision-making.

#### **DUAL CHALLENGES**

In conclusion, the leprosy control program in Nepal faces dual challenges. There is a need to reduce prevalence as early as possible to elimination levels. At the same time, the program has to ensure the availability of quality leprosy services as long as they are needed, and wherever they are needed, at a reasonable cost. ■

# Speakers Vow to Push Ahead

Partners, health ministers pledge their ongoing commitment at Geneva meeting.

A Global Leprosy Forum held on May 26 during the World Health Assembly in Geneva brought together key partners and health ministers from several nations, who all renewed their determination to build on progress in fighting the disease.

The forum was chaired by Dr. S.K. Noordeen of the Leprosy Elimination Alliance, with opening remarks delivered by Dr. Margaret Chan, WHO assistant director-general for communicable diseases and the director-general's representative for pandemic influenza.

Speaking on behalf of the late Dr. J.W. Lee, Dr. Chan noted the success achieved by the elimination strategy, but said this was not a time to relax or be complacent. "As with any control program, the final phase is the most difficult phase. We need to put in that extra effort." She also called for greater attention to be paid to the physical, social and economic rehabilitation of persons affected by leprosy and to human rights violations.

Yohei Sasakawa said he spent a third of each year overseas in his capacity as WHO Goodwill Ambassador for Leprosy Elimination. The three main purposes of his trips were to talk with politicians to make sure that leprosy is a high priority, to solicit the cooperation of mass media and to provide encouragement to those working in the field. In particular, he said, cooperation from mass media is extremely important because it lets the general public know that the disease is curable, free drugs are available and there is no place for discrimination.

Seeking to make clear his stance on the elimination issue, Sasakawa said, "One very important point I would like to stress — the use of the word 'elimination' of leprosy. I regard it as a milestone along the road to eradication. But I am aware that there are some who may misunderstand this and feel that if elimination is achieved, then this movement will have been completed. I will continue to visit various countries, especially those that have yet to

achieve the elimination goal, and I will emphasize that elimination is an important step toward eradication."

Newly reappointed as goodwill ambassador, he noted that his new mandate includes a reference to tackling the social aspects of leprosy, and said this would give a boost to his efforts to get the UN Human Rights Council to adopt a resolution on stigma and discrimination. "I am hopeful that a resolution will be adopted and guidelines issued to each member nation, and that this will lead to an integrated approach covering both medical and social aspects of leprosy."

## INTERMEDIATE GOAL

Addressing his country's recent success in achieving elimination at the national level, India's health minister Dr. Anbumani Ramadoss said this was only an intermediate goal, adding he was confident that India could achieve eradication in the next 10 to 15 years. Dr. Filomeno Fortes of Angola's health ministry said that many challenges remain despite achieving elimination, and that leprosy would continue to be a public health priority for Angola.

Congratulating India and Angola on their success, Dr. Jarbas Barbosa of Brazil's health ministry said Brazil was making up for lost time, and would join in marking the elimination milestone this year or next. Representing the health ministry of Tanzania, a country close to achieving elimination, Dr. Gabriel Upunda admitted that more had to be done to educate not only the general community but health workers too, to ensure that persons with leprosy were accepted and given appropriate support. Meanwhile, Dr. Kyaw Myint, Myanmar's health minister, said his country was emphasizing efforts to sustain elimination and minimize the health, social and economic consequences of the disease.

## NEW STRATEGY

Rigo Peeters, president of the International



Panelists take part in the Global Leprosy Forum in Geneva on May 26.

Federation of Anti-Leprosy Associations (ILEP), said that while the elimination strategy had been effective in reducing prevalence in the short term, “it was based on unsustainable vertical approaches to leprosy control,” and that it was important to move beyond elimination now that a new WHO strategy for reducing the leprosy burden and sustaining leprosy control activities was in place.

Four key elements must be pursued to further reduce the leprosy burden, he said:

- sustaining leprosy services and maintaining diagnostic and treatment skills;
- using new case detection and treatment completion rates as indicators;
- achieving quality targets that reflect the timeliness of detection (new cases with grade II disability) and the quality of patient management (treatment completion rates);
- increasing efforts to prevent disability, assist rehabilitation and fight against stigma

Alluding to efforts by certain countries to achieve elimination at the sub-national level, ILEP’s president said, “The elimination strategy has been extremely successful. But its pursuit at sub-national level risks becoming counter-productive, will disturb field workers, and distort global reporting, making it difficult to interpret current data.”

**Leprosy FACT**

- Novartis has established a plant in India for the production of MDT. The first shipments are expected in the 3rd quarter of 2006.

**DRUG SECURITY**

Drugs used to treat leprosy are being provided free of charge by the Novartis Foundation for Sustainable Development. Dr. Klaus M. Leisinger, the foundation’s president, noted there had been a lot of skepticism initially as to whether the elimination goal was a realistic one.

“My comment four years ago, which is still valid today, was that asking if one can eliminate leprosy is like asking if there is life after death. We will not know until we get there,” he said. “But we do know that the only way to cure leprosy and reduce the disease burden is to detect all patients and treat them with MDT. [T]his is the essence of the elimination strategy.”

Describing leprosy elimination as a major public health success story, he said it proves that “with the necessary political will on all sides, the right strategy and appropriate tools one can move mountains.”

The effort to realize a world without leprosy will require a concerted effort to sustain the gains made so far, he said. “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 problems.”

“Sometimes I worry that we have wasted a lot of time and energy in a rather academic discussions around ‘elimination’. But let us not look back. Diverting energy and time to such discussion would have a high price tag attached — one that is not paid by us — but by the patients and their communities. Irrespective of whether one believes in elimination or not, or whether its focus is at national or sub-national level, the strategy remains the same — to provide patients and communities with easy and uninterrupted access to diagnosis and treatment.”

**“With political will, the right strategy and appropriate tools, one can move mountains.”**

**EMERGING OPPORTUNITIES**

In drawing the meeting to a close, Dr. Noorden directed participants’ attention to a poster on neglected diseases near the WHO library, bearing the words “Hidden successes and emerging opportunities.”

It was particularly appropriate for leprosy, he said, because ‘hidden successes’ suggests how the enormous achievements that have been made sometimes go unrecognized, while ‘emerging opportunities’ reflects the growing numbers of people now talking about moving from elimination to eradication.

He concluded with the following observations:

- all leprosy-endemic countries are strongly committed to the goal of leprosy elimination and would like to proceed to elimination at the local level. There is also a strong urge to move toward leprosy eradication;
- countries are increasing the focus on rehabilitation, and on fighting the social problems of stigma and discrimination;
- the human rights issue is growing in importance, and needs to be addressed more vigorously still;
- the positive aspects of leprosy work — in particular, free drug supply — need to be protected into the future;
- the best tribute to the late Dr. Lee will be to realize his wish to create a world free from leprosy and leprosy-related problems. ■

# From Rio to the Amazon

A recent visit to Brazil confirms that good progress is being made in the fight against leprosy, even in remote parts of the country.

## BRAZIL (JUNE 10-18)

Brazil is one of a handful of countries that have yet to achieve the WHO's goal of eliminating leprosy as a public health problem. However, under the personal direction of President Luiz Inacio Lula Da Silva, the government, the WHO and NGOs are actively working together to reach this milestone.

On my most recent visit to Brazil in June, the prevalence rate stood at 1.48 and I was told there were some 18,000 registered cases. A measure of progress is that in just two years, the reported number of new cases has dropped by 24.27%, down from 49,300 in 2004 to 38,400 in 2005. According to the federal government, Brazil will reach the elimination goal at the national level by the end of the current fiscal year or at the beginning of the next.

The first stop on my journey was Rio de Janeiro, where I visited the Hospital Frei Antonio, the oldest leprosy facility in Brazil. It was originally a monastery founded by the Jesuits in 1752 and was active as a leprosy hospital up until 20 years ago. Today only four elderly residents remain. One of them entered the hospital as a girl of seven and has lived there more than 80 years. When she was admitted, her father planted a sapling in the hospital grounds. Today it has grown into a large tree, and she told me that looking at it is a daily pleasure.

Next I visited the Tavares de Macedo colony in the suburbs of Rio, which was established by the federal government in the 1930s. About 250 people affected by leprosy live here. However, the non-leprosy affected population is much larger, attracted by subsidized rents and utilities.

Most of the arrangements for my visit to Brazil were made by MORHAN, a grassroots movement



A warm Brazilian welcome at Tavares de Macedo

headquartered in Rio for the reintegration of people affected by leprosy. MORHAN has six regional coordinators and 100 centers across 24 of Brazil's 27 states, and works closely with the Brazil government. It sits on the 48-member National Health Council. Half of the council's members are drawn from civic society, and it plays a key role in shaping the federal government's health policies.

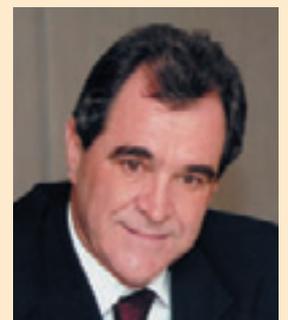
One of MORHAN's major initiatives is a toll-free telephone counseling service called Telehansen. For the past two years, The Nippon Foundation has supported its activities. Staffed by volunteers, including people affected by leprosy, the 12 phone lines Telehansen operates receive an average of 7,000 calls a year related to leprosy. Subjects range from medical questions to queries about human rights and social issues.

**Telehansen receives an average of 7,000 calls a year related to leprosy.**

From Rio de Janeiro I traveled to the capital, Brasilia. Among those I met were Brazil's health minister, Dr. Jose Agenor Alvares da Silva, Dr. Rosa Castalia, in charge of the leprosy control program, Rogerio Sotille, head of the special secretariat for human rights, and Senator Tiao Viana, vice president of Brazil's Senate.

Between them they assured me that the elimination goal would be achieved and that human rights questions were being addressed. Concerning the rehabilitation of people affected by leprosy, the federal government has admitted that the past policy of isolating them was a mistake, and is now working to provide appropriate social support, possibly by offering benefits in the form a pension. This would certainly be a remarkable development if it happened.

Next, I traveled 2,300 kilometers northeast of Brasilia to the town of Fortaleza in Ceara State. There I paid a courtesy call on Dr. Jurandir Frutuoso, the state health secretary. At present, the state PR is 1.76, and Ceara is increasing the number of health personnel as it makes steady progress toward the elimination goal. Dr. Frutuoso also gave me some insights into political



Dr. Jose Agenor



Rogerio Sotille



(left) Exploring the former sanatorium at Iranduba; (right) meeting with Antonio Motelo and Dona Maria

measures being taken for the social rehabilitation of persons affected by leprosy, as well as their integration into general society.

In some countries, the thinking is to close down colonies and have people affected by leprosy find a way to live in the community at large so as to hasten their social reintegration. In Brazil, the government believes it better to encourage family members to go and live in the colonies and achieve social integration that way. It is a very interesting approach.

I visited two colonies that day — Antonio Diogo in Redencao, and Antonio Justa in Maracanau. At the latter, I spoke with 66-year-old Raimundo Martins de Souza (“Severo”), MORHAN’s coordinator in Maracanau. Severo recalled in blunt terms what life had been like in the past, when nuns had been in charge of the colony and ran it on very strict lines. No one was allowed to go out after 10 p.m. regardless of the reason, and they would be attacked by dogs or thrown in the colony jail if they did. The colony was dubbed “the town of the dead” and it was surrounded by barbed wire to prevent escapes. Severo told me that when he entered the colony he was stripped of his citizenship and the word “leper” was inscribed on his identity card.

On leaving Fortaleza, I next headed for Manaus, the capital of Amazonas State. It was in Manaus that I met Dr. Maria da Graca Souza Cunha, head of the Alfredo da Matta Foundation (FUAM), which is making an outstanding contribution to leprosy control in the state, especially in remote, highly endemic areas. She and her staff arranged for me to visit the Paricatuba health center in Iranduba, a jungle town of about 800 people reached by boat along the Rio

Negro, a tributary of the Amazon.

I was pleased to find a good supply of MDT at the health center, despite Iranduba’s isolated location. I was also fascinated to explore the ruins of a leprosy sanatorium. A vast stone complex originally built for immigrant workers, it later became a school, and then a prison, before being turned into a leprosy sanatorium in 1929.

The next day, I went to visit a leprosy-affected family living on the banks of the Rio Negro. To reach them, I traveled by boat for about two hours, passing by isolated dwellings en route.

Antonio Motelo and Dona Maria live together with their son and his family, and make a comfortable living by manufacturing wooden skewers use for cooking fish and meat. Talking with them, I was surprised to learn how deep-rooted the problem of discrimination was.

Antonio was the first to develop leprosy. A paramedic would visit regularly to bring MDT. Next, Dona Maria came down with the disease. Because she didn’t want it to be known locally that she had leprosy, she went to a hospital in Manaus to have the diagnosis confirmed and receive her supply of drugs. Then their daughter contracted the disease. Apparently she too hid the fact and went to Manaus. Even in such a remote location, it seems, people feel it necessary to conceal the disease from others.

I left Brazil confident that the federal government is making strenuous efforts to eliminate leprosy, deliver treatment to all who need it and root out discrimination and prejudice. In addition, it is receiving invaluable support from dedicated organizations such as MORHAN and FUAM. I intend to remain in close contact and do all I can to assist in this progress. ■

# Ambassador Meets Delhi Chief Minister

Discusses urban migration issue, socio-economic empowerment



On July 17, Goodwill Ambassador Yohei Sasakawa paid a courtesy call on Delhi Chief Minister Sheila Dikshit, who expressed an interest in attending the upcoming nationwide conference of persons affected by leprosy on October 2 in New Delhi.

Delhi National Capital Territory currently has a prevalence rate of 2.11 and Chief Minister Dikshit explained that in common with other urban areas, Delhi has to cope with migrants arriving from elsewhere in the country, putting pressure on the services it provides for persons affected by leprosy. "It's a problem," she said. "We would like to offer them more facilities, but the more facilities we provide, the more people come."

For his part, the goodwill ambassador briefed the chief minister on his efforts to get the UN Human Rights Council to pass a resolution on discrimination, and outlined the self-help efforts being made by persons affected by leprosy at the grass-roots level.

In a discussion on socio-economic empowerment, the chief minister noted that needs varied from region to region and said it was vital to take locality into account when teaching income-generating skills.

## HANDA TO MARK 10TH ANNIVERSARY

The HANDA Rehabilitation and Welfare Association (IDEA China) marks its 10th anniversary on August 19. Set up in 1996, its mission is to promote dignity and respect among all human beings — particularly those who have personally faced the challenges of leprosy — and work toward a world without stigma and discrimination.

HANDA has expanded from small beginnings working in a few villages near Guangzhou into a larger organization involving

volunteers in several provinces in southern China. While HANDA has helped many people reintegrate into society, there are many more who continue to face difficulties due to social stigma and economic and physical problems, and HANDA still has much to do.

The anniversary celebrations will mark HANDA's achievements so far, acknowledge the role of its supporters, and mobilize resources for the organization's continued development. ■

## FOR THE ELIMINATION OF LEPROSY

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## FROM THE EDITORS

### BRAZILIAN BEAT

Two countries that feature prominently in this issue are among the handful yet to achieve elimination of leprosy as a public health problem at the national level.

Nepal is a small, landlocked country of 25 million people located in the Himalayas. It has not been helped in recent years by the uncertain security situation, making it difficult to supervise elimination activities. But Nepal has worked hard to tackle its leprosy problem, and has already achieved elimination in almost half of its 75 districts. Coordinating well with NGOs, it is pushing to reach the national goal as soon as it can, while aiming to ensure that quality leprosy services are maintained for all who need them.

On the other side of the world, Brazil is the biggest country in South America. After a period of inertia, leprosy is now a high priority, and federal and local governments are committed to achieving the elimination goal in the near future. Brazil is also active in addressing leprosy's social consequences. The renewed political commitment under President Lula is giving added impetus to the efforts of MORHAN, the grassroots organization that has worked tirelessly for the reintegration of persons affected by leprosy. Often at odds with the government in the past, but today working closely with it, MORHAN takes a refreshingly upbeat approach to its work, and one that bodes well for the future.