

FOR THE Elimination OF Leprosy

August 2004 • Number 9

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



Meeting a girl affected by leprosy at Gidakom Hospital, Bhutan

A MESSAGE FROM THE GOODWILL AMBASSADOR**CONTENTS**

Toward Social Integration

Leprosy has two aspects: medical and social. Thanks to multidrug therapy, we are winning the medical battle, but it will take longer to overcome the social stigma. This battle is just as important, for people will not be free of leprosy until they are free of its associated discrimination.

Knowledge of the true nature of the disease needs to reach every corner of society. In this, the role of the media is important. We also need to mobilize the non-leprosy community.

It goes without saying that the best people to talk about leprosy are those who have had the disease. Too often, though, they have lacked a voice. As we approach elimination, it is more important than ever that they make themselves heard, both to encourage others to seek treatment, and to break down barriers to social acceptance.

For this to happen, they will need to feel comfortable talking about their experiences. However, because of the long history of social discrimination, it will not be easy. We have to create an environment in which the leprosy-

affected can speak out, and in which the wider community is receptive to what they have to say. Their message is that leprosy is just another disease, that it is completely curable, and that there is nothing wrong with those who have been cured.

On the medical side, this message is increasingly understood. The general health services no longer treat leprosy as a special sickness. Treatment can be obtained at any health facility. Medical integration is proceeding well.

But to facilitate the social rehabilitation of those affected by leprosy, to help them regain their dignity, we also need social integration. The efforts of governments, corporations, unions, schools and NGOs must be coordinated to ensure that their human rights are respected.

To help in these efforts, we need to empower those cured of the disease, have them speak out and assume positions of responsibility within influential organizations. We must do all we can to create these opportunities.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Demystifying Leprosy

A workshop explores ways to familiarize people with the true nature of the disease.

Transforming a government program to eliminate leprosy into a people's movement was the goal of the National Consultation Workshop on Advocacy Strategies for the Elimination of Leprosy held in New Delhi June 4-5.

Organized by Dr. S.D. Gokhale (International Leprosy Union), the two-day event brought together an eclectic mix of participants tasked with formulating a strategy for demystifying leprosy and bringing about the social rehabilitation of those affected by the disease.

"Killing the bacillus is not enough. We need to change mindsets," said Dr. Gokhale.

One starting point is people-centered advocacy, defined by Dr. Amitabh Behar (National Centre of Advocacy Studies) as "a set of organized actions aimed at influencing public policies, societal attitudes and socio economic processes that enable and empower the marginalized to speak for themselves."

He outlined several steps for effective advocacy, including identifying and framing the issues, mobilizing interested parties, forming and sustaining networks and alliances, and getting media involved.

For Razia Ismail Abbasi (India Alliance for Child Rights), the issue was why such a workshop was necessary in 2004, 20 years after she had become involved in a similar campaign to change attitudes toward leprosy, and despite the proven effectiveness of multidrug therapy in the interim. The reality, she said, is that leprosy is "not just a bacillus that a combination of drugs can defeat; it is as much a social condition with the power to irrevocably afflict a life."

Where the role of media was concerned, there

was general agreement that the broadest possible definition of the term be used, to allow messages to be targeted and delivered in the most appropriate format.

Shamsher S. Bahadur (The Leprosy Mission Media Center) said that TLM campaigns were coordinated across a whole range of media, and use a "building-block system" in accordance with specific local conditions. The resulting media mix features a combination of mass media (radio and television), interpersonal communications (use of influential community figures), music, theatre, posters, billboards, leaflets, T-shirts, badges and keyrings. In particular, interpersonal communications plays an important role in areas where hardly any mass media are available.

Among the mass media, radio was seen as having the broadest reach, although, as Julian Parr (BBC World Service Trust) pointed out, people only listen to what is local, in their language and has relevance to their lives. Given India's profusion of



Seeking ways to change mindsets

'SOCIALLY RESPONSIBLE' MEDIA

In December 2003, 80,000 copies of a booklet entitled *Together We Can Eliminate Leprosy* were distributed with *The Times of India* in Bihar and Jharkhand. In an area with a high rate of illiteracy, the idea was to target the educated decision-makers who form the paper's readership and who have an influence on society and a positive role to play.

Explains Gautam Chatterjee of Times Response, who worked closely on the project, "First you have to reach the reachable, and then, through them, those who are not easily reached."

Aimed at the lay person, the 16-

page booklet gives an overview of the leprosy situation at the global and national levels, contains messages from the chief ministers of Bihar and Jharkhand, and deals with both the medical and social aspects of the disease. It was produced in conjunction with the WHO, with technical input provided by the National Leprosy Eradication Program (NLEP).

Even among the educated, many



people do not have a clear understanding of the disease, says Chatterjee's colleague, Harnam Shankar. "The upper classes have a perception that leprosy only affects the ignorant, who need to be quarantined. We wanted to generate awareness among them, try and sensitize them, and so influence people down the line."

Although *TOI* was publishing something on leprosy for the first time, it has previously produced booklets on hepatitis B, polio and HIV/AIDS, and also compiled a directory of

tongues, translating a leprosy campaign into different languages is thus time consuming and costly. As for the impact of a campaign, the BBC's research showed that its sustainability directly correlates to the amount of time it runs. "The lesson is that you have to keep hammering away at the message," he said. However, this does not preclude innovative approaches. "Social messaging can be entertaining," he added.

The purpose of the media should be to motivate rather than to educate.

Where the print media are concerned, the workshop heard that a new role for newspapers was evolving in the area of civic journalism, and that this could provide opportunities for coverage of more social issues, such as leprosy. But participants were reminded that newspapers were commercially driven, required articles that bore the stamp of authenticity and that were suitably packaged for the readership.

On the subject of presentation, Dr. Mohan Agashe (actor, theatre director, psychiatrist) said the purpose of the media should be to motivate rather than educate, "to stir curiosity and bring people to the level where they want to be educated." Make leprosy the subtext not the text, he said. "Tell a story while giving an injection."

Group sessions and open debate were also a source of insights and ideas.

In seeking to dispel myths and change mindsets, Dr. H. Srinivasan (Indian Journal on Leprosy) suggested it was sometimes better to

doctors in Bihar and Jharkhand.

"As a media house, we have a social responsibility," says Chatterjee. "Basically, our job is disseminating information. But at the same time, if we are able to disseminate information that society actually needs — about disease, for example — then I think that is also our role."

Reaction has been positive, with a number of people saying they had not been aware that the disease was curable, for example. "It showed that our perception that influential members of society did not know that much about leprosy was correct, and that targeting them was the right thing to do," said Shankar.

One man who was closely involved in the booklet's production, and has made full use of it since, is Dr. Rajan Shukla, NLEP's state coordinator for Bihar.

"The aim of the booklet was not to have people come and join us, but promote attitudinal change," he says. "In the past, it was important to promote awareness generation among patients; today, with the success and availability of MDT, this is less of a priority. Now is the time to focus on members of the general public; their attitudes make or break stigma."

In an illiterate society, every literate person is an influencer, he points out. "When literacy levels are low, people believe what others say, because they

work with deeply entrenched belief systems rather than trying to overturn them. "If somebody tells you he was fated to get leprosy, it's no good telling him it has nothing to do with fate. Why should he believe you? Instead, agree that it probably was fate, but that it was also fate that he came to you to be cured with MDT."



Mahendra Shinde

Another point that the seminar underscored was that in order to reach the broader community, it was necessary to employ the right people for the job. Medical people can't run social programs. These should be left to people who understand the community at large.

The session also emphasized the important role that cured persons can play in speaking out about the disease and assuming a leadership role in NGOs and other organizations. Mahendra Shinde (Bombay Leprosy Project) suggested this was easier said than done, recalling how he had applied for a government position advertised as giving priority to a person affected by leprosy, only to find this was not so.

In closing the conference, Dr. Gokhale pledged various follow-up activities, including creating a resource center on leprosy, identifying spokespersons in hyper-endemic districts, reviewing discriminatory laws, and championing the role of cured persons at the center of any initiative.

"We must recognize this hurts the pride of this country," he said. ■

can't read about it for themselves.

Therefore, the literate have a responsibility to spread awareness."

In addition to the copies distributed with the newspaper in Bihar and Jharkhand, another 10,000 copies were printed, and these have proved very handy as a promotional tool to give to district officials, legislators, industry federations, as well as banks, which have money for social initiatives. It has also been useful to give to other doctors. Dr. Shukla recalls handing the booklet to six or seven heads of department at Patna Medical College. When they started reading, there was a "pin-drop silence," he says. "They found out things about leprosy they never knew."

Health Ministers Give Progress Report

Elimination is getting closer, but a concerted effort is required.

At the annual World Health Assembly in Geneva in May, Goodwill Ambassador Yohei Sasakawa held meetings with health ministers from several African and Asian nations, who updated him on the status of leprosy elimination in their countries. The following is a summary of what they told him.

Dr. Kyaw Myint

*Minister of Health,
Myanmar*

We achieved elimination in February 2003. The key to our success has been to have health workers in the front line who are dedicated to the goal of elimination. In

Myanmar, from midwives on, all our health workers share that goal. However, outside urban areas, challenges remain, and we are making intensive efforts to keep the prevalence rate below 1 case per 10,000.



Professor Andry Rasamindrakotroka*

*Minister of Health and Family Planning,
Madagascar*

Since your visit in 2003, we have formed mobile health teams that are making door-to-door visits in remote areas to reach patients.

Currently there are 13 teams, and this year we hope to increase the number to 23 teams covering 22 regions. The teams help to sensitize and mobilize government and religious leaders to recommend patients to go to hospital and receive free treatment. We are also training people. As a result of these efforts, the prevalence rate has come down from over 4 per 10,000 to 3.34. At this pace, elimination by the end of 2005 is a possibility, but we will need ongoing support if we are going to achieve this goal.



Dr. Mwinyihaji Makame

*Minister of Health & Social Welfare, Zanzibar
(also representing Tanzania on this occasion)*

The number of patients has dropped below 5,000, but we



have yet to see the prevalence rate drop below 1 per 10,000. We are carrying out active search of the entire population, and the fact that IEC activities can be conducted in the same language — Swahili — throughout the country is an advantage. District and regional TB/leprosy coordinators travel to schools and community dispensaries looking for patients and providing information.

Dr. Francisco Songane

*Minister of Health,
Mozambique*



We remain committed to educating schoolchildren to check and see if any of their family members are showing signs of leprosy. We hold meetings with district administrators

in every province to tell them about leprosy and give them literature about it. To achieve elimination by the end of 2005, we will need an extra push not just in the northern part of the country but nationwide.



Dr. Albertina Julia Hamukwaya

*Minister of Health,
Angola*

The lengthy civil war is finally at an end, and as the domestic situation stabilizes, this is a good opportunity to move ahead with leprosy elimination activities.

At present, these cover about 60% of the country. From now on, the urgent task will be to achieve 100% coverage, expand the MDT supply ratio (currently at 30%), and train health workers. An important aspect of this is community involvement. Encouraging early detection of patients, spreading the word that treatment is free, and eliminating stigma are tasks that must be carried out at the community level. ■

LEPROSY LEXICON

• IEC

Information, Education and Communication activities serve several purposes: to raise awareness of signs and symptoms of the disease, encourage self-reporting and bring about an end to stigma. IEC messages are delivered via everything from TV to puppet shows.

* In July, Professor Rasamindrakotroka was replaced as health minister by Jean-Louis Robinson.

Making the Best of Life

Zimbabweans Dan Izzett and his wife Babs have both had leprosy, but they've also had the right attitude to coping with the disease, as Izzet describes.

I grew up with my mother and brother in Harare, my father having died when I was eight. When I was at boarding school in 1962, I kept burning and banging my hands without feeling anything, but thought this was a phase all 14-year-olds went through!

In August 1970, I married Babs and the following November I broke out in a rash. I went to see a dermatologist who diagnosed me as having an STD (Sexually-Transmitted Disease)! I told him that that was impossible but he accused me of lying. Bewildered, I ended up taking three courses of treatment, none of which had any effect.

By this stage my feet and legs had also lost all sensation. Eventually, the dermatologist referred me to another doctor who, after many other tests, took a biopsy and sent it off to the government medical officer in charge of leprosy work. It was only in July 1977 that I was finally diagnosed as having leprosy — a shock, but also a relief after my previous misdiagnosis.

During all this time, Babs, our families and close friends stuck by me. I was aware of the stigma surrounding leprosy and I didn't want to tell anyone except my family.

At work I only told my boss. My mother and I tried to work out how I had caught the disease as a child but we couldn't come up with any answers.

There was no point wallowing in misery, I just had to take hold of the situation.

One morning in 1977, I soaked my feet in a basin while I was shaving. The water, which I'd thought was cool, was extremely hot. After scraping off the dead skin and rubbing in cream, I went to work. That evening when I took my shoes off, my feet were a mass of blisters. An infection started in the little toe of my right foot, which soon spread to the metatarsal bones.

The next few years were incredibly difficult as I was in and out of the hospital as the infection worsened. Added to this, Babs, pregnant with our second son, developed patches on her skin.

The dermatologist told her it was psychological — that she'd broken out in what she thought were insensitive patches in sympathy with me. Not convinced, she decided



Dan Izzett pictured at a Government Rehabilitation Home near Chengalpattu, Tamil Nadu, on a visit to India in September 2003 to participate in an IDEA workshop.

to have a check-up at the tropical disease unit.

Yes, Babs had contracted leprosy as well. She was put on Dapsone, which killed the bacilli before any disabilities developed. However, over the next two years, she suffered severe pain as her body's defenses reacted to the dead bacilli and caused inflammation of the nerves. We had some dreadful days when we were both confined to bed.

On 23 August 1980, surgeons amputated my right leg below the knee as a last resort to stop the infection. There was no point wallowing in misery, I just had to take hold of the situation and plough on through.

And Babs?

Well, I call her the "Iron Lady" for coming through her own illness, all the while supporting me and caring for the children.

Although I've felt frustrated, I've never felt bitter about my illness. I've just kept going, knowing that tomorrow I must provide for my family, tomorrow I've got to get up and make the best of life.

Originally published by The Leprosy Mission Zimbabwe ■

Bhutan's Success

WHO Goodwill Ambassador Yohei Sasakawa's travels take him to Jordan, India and the "land of the thunder dragon," Bhutan, which achieved elimination in 1997.

JORDAN

When I visited Jordan in May, I contacted the local WHO office and the Jordanian Ministry of Health ahead of time, and asked them to look into the leprosy situation for me. I learned from this several things: leprosy was eliminated from the kingdom long ago; there is virtually no evidence that it was endemic; and nobody knows anything about the disease today. There was a hospital on the west bank of the River Jordan, but this was destroyed in 1967 at the time of the Six-Day War. There may be some hidden cases, but since leprosy does not exist in government records, there is no way of finding out. Given that leprosy is described in the Old Testament and Jordan is not far from Christ's birthplace, it's hard to comprehend that no records of the disease exist today.

INDIA

On June 4 and 5, I was in New Delhi to attend a National Consultation Workshop on Advocacy Strategies for the Elimination of Leprosy. Held under the auspices of the India-headquartered International Leprosy Union, the workshop focused particularly on what role the media can play in leprosy elimination, and was attended by government, NGO, and media representatives, as well as people cured of the disease. I used the occasion to suggest to those present that we 1) come up with a concrete plan on how to use the media, 2) consider putting cured persons at the center of elimination activities, and 3) promote not just medical integration but social integration. I urged them to treat discrimination against cured persons and their families as a human rights problem, and reported that I am working to have the UN Commission on Human Rights take up the issue.

As there is a separate report on the Delhi proceedings elsewhere in this issue, let me here just bring up two more important points.

First, I was delighted to hear Dr. G.P. Dhillon, the deputy director general (leprosy) for India's Ministry of Health and Family Welfare, say that the prevalence rate in India as of March 31, 2004, had dropped to 2.44 cases per 10,000 population. Of course, this is at the national level. There are still two states where the prevalence rate is above



Dr. S.D. Gokhale

5 per 10,000, and nine more states where it is between 2 and 5, so the need for still greater efforts at elimination remains unchanged. To make progress toward elimination and remove stigma, widespread PR activities will be required to see that correct information about the disease reaches everyone. This is not just a task for organizations and individuals specializing in leprosy; it needs to involve people and organizations in every sector of society. Again, it is not only a question of medical integration, but social integration as well. The role the media can play in disseminating the right messages about leprosy is enormous — and how to involve the media in doing this was, of course, one of the main themes of this gathering.

In response to my remarks, Dr. S.D. Gokhale, the ILU president, proposed involving cured persons in a systematic and organized way as spokespersons to bring about an attitudinal change regarding the disease and so work toward elimination and the end of discrimination. Nothing carries more weight than the statements of cured persons. Until now, they have led a hidden existence. It is very important that we now ask them to assume a social role in making efforts for elimination and ending discrimination, and I look forward to seeing real progress in this area.

BHUTAN

From India I traveled on to the Kingdom of Bhutan. Bhutan is about the same size as Switzerland, and has a population of about 700,000. A mountainous country, it nestles in the Himalayas between China and India and is known by its people as "the land of the thunder dragon." About 80% of the population work the land. The national religion is Tibetan Buddhism.

Bhutan began fighting leprosy in the 1950s, mainly under the patronage of the royal family, and it wasn't until the 1960s that the government began elimination activities in earnest. In 1962, the royal family invited The Leprosy Mission to Bhutan, following which the government and the NGO joined forces to tackle the disease. Thanks to the effectiveness of MDT, which was introduced to Bhutan in 1982, the country achieved elimination in 1997 and by 2003 the number of cases had dropped from 4,000 in 1966 to just 18.



Health Minister Dr. Jigmi Singay (left) in conversation with Yohei Sasakawa

According to Health Minister Dr. Jigmi Singay, the driving force behind Bhutan's success was the powerful political commitment from the king down and the devoted efforts of health workers.

The role of religious figures has also had a big impact. A Buddhist priest who came down with leprosy meditated, attained enlightenment, was treated and cured, then traveled from village to village telling people about the disease.

Currently, about 10 designated staff work in the leprosy area, but the government program is to integrate treatment into the general healthcare system as the goal shifts from elimination in the direction of eradication.

Bhutan began fighting leprosy in the 1950s, mainly through the efforts of the royal family.



Bhutan: 80% of people work the land

The national hospital at Gidakom, built originally as a leprosy hospital and once the main focus of elimination activities, is now a general hospital. Nearby is a dwelling-cum-workshop for cured persons, where I met a married couple earning a living making handicrafts.

However, stigma is deep-rooted, and there is a widespread fear that those who contract leprosy will suffer deformity. There is also a belief that

"unlucky people get leprosy."

For Bhutan, the challenge will be to sustain its successes. For that, ongoing monitoring and surveys are important, as well as an integrated approach to the rehabilitation of those who have suffered from the disease.

With free healthcare and education for all, Bhutan has a national policy that the king has expressed as Gross National Happiness (GNH). It derives from the belief that the collective happiness of the people is the most important indicator of national well-being, and is based on a set of strategies for creating an environment in which people have the best chance of finding happiness. These involve equitable and sustainable development, conserving the fragile Himalayan environment essential to Bhutan's survival, preserving the best aspects of its culture while carefully choosing what to bring in from the outside, and creating good governance. While it is difficult to put happiness into figures, reducing the infant mortality rate and raising per capita income are two ways that it can be measured. To maintain Bhutan's identity, both men and women are required to wear national dress in public. The role of the extended family, which acts as a social safety net, is also something to which Bhutanese attach much importance.

In Prime Minister Jigme Y. Thinley's words, GNH is a way of developing society that focuses on the human dimension, creating the conditions in which individuals can find happiness, reminding them that material wealth is not everything and that there needs to be a balance between the material and the spiritual. Listening to his explanation, I felt his words served as a warning, and that Bhutan has raised an issue that everyone should consider. But I wonder to what extent those of us who have grown accustomed to affluence will be able to change the way we live, and rethink our values. ■

WHO Shifting Leprosy Program to India

Move will generate momentum at the front-lines of the elimination battle

The World Health Organization is relocating its global leprosy elimination program from Geneva to New Delhi. The move is in line with a proposal by Director-General Jong-wook Lee at the beginning of his mandate.

The idea is to bring WHO staff members most closely associated with leprosy elimination to the area where the highest

disease burden is currently found — India and Southeast Asia — and generate additional momentum toward elimination.

While the program will now be managed from WHO Regional Office for Southeast Asia, New Delhi, it remains an integral part of the Department of Control, Prevention and Eradication at WHO's Geneva headquarters.



SASAKAWA CALLS ON DR. SAMLEE

During his visit to India in June, WHO Goodwill Ambassador Yohei Sasakawa paid a courtesy call on Dr. Samlee Plianbangchang, the recently-appointed regional director for WHO's Southeast Asia Region, in New Delhi.

While the region has achieved much in the area of health development, including higher life expectancy and lower infant mortality, Dr. Samlee noted that many challenges remain. In particular, he singled out polio eradication and leprosy elimination as unfinished items on the health agenda.

For his part, Ambassador Sasakawa welcomed the regional director's commitment and said that he looked forward to seeing leprosy eliminated in the region during Dr. Samlee's term of office. ■

FROM THE EDITORS

CHANGING MINDSETS

A couple of anecdotes related by a participant at the recent New Delhi workshop on advocacy strategies (see pages two and three) revealed the irrational logic of which people are capable. A man with leprosy who went for reconstructive surgery on his hand exhibited rare damage to his index finger, not normally affected by the disease. "Unusual," said the surgeon, "but it can be straightened out." "Oh, you don't have to bother with that finger," said the man, "it wasn't caused by leprosy."

Or there was the man who was more worried about his neighbor finding out that his daughter was being treated for leprosy than he was about whether she would be cured or suffer deformity.

What these stories reveal is how misconceptions can flourish if leprosy is not seen for what it really is — just another disease. But they also show the power of anecdote to convey a point. In seeking a strategy to generate awareness, a well-told story that engages people at an emotional level and sets them thinking about issues can be an extremely effective way to get society at large to consider the topic.

Another approach is to have the subject

taken up by a person of influence. In Bhutan, it was the king, a revered figure, who showed the way by taking a personal interest in leprosy. Once the king and other members of the royal family indicated their concern, this helped to break down barriers and lead the way for Bhutan to achieve elimination in 1997 (pages six and seven).

Ultimately, though, it is the attitude of those affected by leprosy and how they lead their lives that is the starting point for shaping public perceptions. "Stigma begins with me," said Arvin Patel in a memorable phrase from the Delhi workshop, arguing that if a person with the disease treated himself or herself differently, then it was only to be expected that other people would as well.

One man who did not let leprosy get him down was Dan Izzett of Zimbabwe, who recounts his and wife Babs' story of coping with leprosy (page five). While there were times when he felt frustrated about the disease, he writes, he never felt bitter, and has gone on to make the best of life. An example to everyone — and just the sort of inspiring story that can make a difference.

FOR THE ELIMINATION OF LEPROSY

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