

# FOR THE Elimination OF Leprosy

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



Working to ensure that those cured of leprosy can lead normal lives free of stigma must be part of the elimination process.

## A MESSAGE FROM THE GOODWILL AMBASSADOR

### You Are the Main Actors

My life's work is to realize a world without leprosy and rid society of the disease called discrimination. My activities are focused on attaining these objectives.

As a big first step, I am appealing for the cooperation of governments, healthcare providers and NGOs in endemic nations in bringing the number of patients in their countries to below 1 per 10,000 population by the end of 2005 (the goal set by the World Health Organization). Major countries that have yet to do so include India, Brazil, Nepal, Madagascar, Mozambique and Angola.

To achieve elimination, it is necessary to conduct educational and information campaigns that spell out the true facts about leprosy. Specifically, society needs to be told that leprosy is curable, treatment is free and discrimination has no place.

I ask those who have recovered from leprosy to become involved in this effort. You who have suffered the tyranny of social discrimination are in the best position to correct misconceptions.

What you say carries the power of conviction. I know it may be hard to go public because of what you have been through, but the daily discrimination you face as a result of social prejudice is not your fault. It is a disease that afflicts society.

We must fight for the elimination of leprosy, but we must also fight for the human rights of those affected by it. Following my appeal to the UN Sub-Commission on Human Rights, it agreed to investigate leprosy as a human rights issue. By its next meeting in August 2005, a preliminary working paper on discrimination against those affected by leprosy will be published.

All of you are needed in this effort. Be courageous and become involved. You are the main actors; I undertake to give you my support.

Let us work together to go from elimination to eradication, and ensure that everyone touched by leprosy can take his or her rightful place in society.

— Yohei Sasakawa, WHO Goodwill Ambassador

<b>Message</b>	<b>1</b>
<b>India Report</b>	
Health secretaries meet in Goa	<b>2</b>
<b>Human Stories</b>	
Bernard K. Punikai's quest for dignity	<b>3</b>
<b>Interview</b>	
Dr. Jo Robertson on leprosy history	<b>4</b>
<b>Ambassador's Journal</b>	
Visits to Bihar, Goa	<b>6</b>
<b>News</b>	
UN High Commissioner for Human Rights; Yomiuri Prize	<b>8</b>
<b>Letter</b>	<b>8</b>
<b>From the Editors</b>	<b>8</b>

# Operational Factors Targeted

India on course to achieve elimination, with many states also going for goal.

Up to one-third of reported cases of leprosy in India may be invalid, putting the country closer to the elimination goal than published figures suggest, a meeting of Indian health secretaries heard recently.

The review meeting of health secretaries from 11 endemic states was held in Goa from September 30 to October 1 to go over the progress of leprosy elimination in India and discuss priority action needed to achieve the target by the end of December 2005.

India had a prevalence rate of 2.4 per 10,000 as of March 2004, but if the figure is adjusted to take account of operational factors such as over-reporting, wrong diagnosis, re-registration and delayed release from treatment, the PR is closer to 1.4, said Dr. Derek Lobo, Regional Advisor, Leprosy, WHO.

Dr. A.K. Sood, National Institute of Health & Family Welfare, presented the results of Leprosy Elimination Monitoring and Case Validation Studies in India for 2003 and 2004, which indicated that reported prevalence and detection rates were inflated in most states. Wrong diagnosis varied from 3.7% in Chhattisgarh to 19.0% in Madhya Pradesh, re-registered cases were high in Tamilnadu (45.5%), Delhi (36.2%) and Orissa (32.6%) and wrong grouping was high in West Bengal (40.6%) and Madhya Pradesh (39.4%).

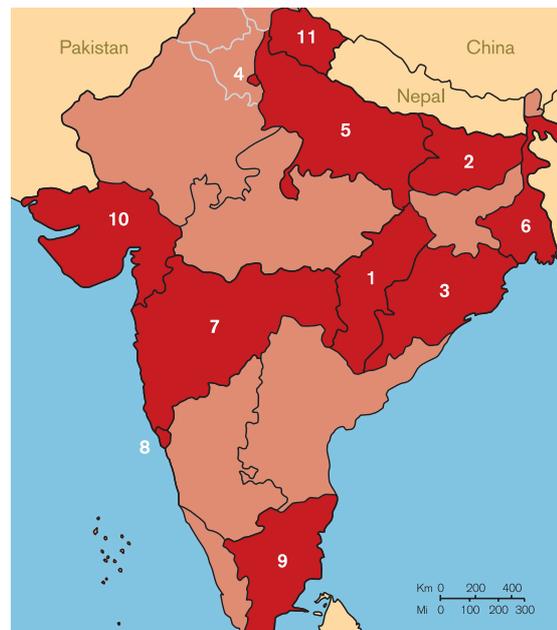
Noted Dr. G.P.S. Dhillon, Deputy Director General (Leprosy), Government of India, "We are carrying excess baggage. Why?"

As of March 2004, 17 states/Union Territories had achieved elimination status, with another seven states/UTs very near with a PR of between 1 and 2 per 10,000 population. Nine states have a PR between 2 and 5 and only two states now have a PR of over 5. Seven endemic states contributed 75% of the country's leprosy case load. According to Dr. Dhillon, if these seven states achieved a 25% reduction in cases by the end of 2005, then elimination would be achieved.

Looking at epidemiological factors state by state, an interesting picture emerged. For example, Bihar (which contributes 17% of India's leprosy case load) was among the states complimented for the progress it has made to bring down its PR, despite infrastructure difficulties.

By contrast, apparently better-off states such as Karnataka (PR of 1.52 on December 2003) and Madhya Pradesh (1.65) were a source of worry because their PR has been hovering at the same level for three or four years.

On the drug management side, Dr. Serge Manoncourt, WHO, raised concerns about the ability to provide an uninterrupted supply of drugs to patients by maintaining a three-month buffer



stock of MDT at state, district and block levels. Although there is an adequate supply of MDT in the country, he said, the lack of an adequate distribution system was resulting in excesses, shortages and expired supplies at primary and community health centers and at district stores.

In the last 20 years, India has made massive strides in reducing its leprosy burden, with more than 10 million cases cured. Nonetheless, it contributed about 68% of global prevalence and about 80% of new cases worldwide in 2003.

Clearly, there is still work to be done, and it is important to "finish the agenda."

Attention is now focusing on the district and block level. Ms. Rita Teotia, Joint Secretary (Health), Government of India, said that 174 districts (88 high priority and 86 medium priority) in 14 states/Union Territories, and 836 high endemic blocks (with a PR above 5 per 10,000) had been identified as priority areas and said special initiatives would be taken to address their needs.

Shri J.V.R. Prasada Rao, Secretary (Health), GOI, reasserted the government's full commitment to the National Leprosy Elimination Program, and emphasized the need for intensified supervision, regular monitoring and timely evaluation of each activity until elimination is achieved.

In particular, he stressed that district authorities such as chief medical officers and health officers must be fully involved in the leprosy program in their districts, especially at the block level.

He announced that the government would continue NLEP activities at least until March 2007, even if national elimination is achieved by the end of next year, so as to support states with high case loads in their ongoing elimination efforts. ■

## Prevalence Rates

1. Chhattisgarh	
2000 Mar.	14
2004 Mar.	6.01

2. Bihar	
2000 Mar.	14.7
2004 Jun.	4.5

3. Orissa	
2000 Mar.	11.5
2004 Aug.	4.5

4. Delhi	
2000 Mar.	3.5
2004 Mar.	3.9

5. Uttar Pradesh	
2000 Mar.	6
2004 Mar.	3.5

6. West Bengal	
2000 Mar.	5.2
2004 Mar.	3.02

7. Maharashtra	
2000 Mar.	3.7
2004 Mar.	2.97

8. Goa	
2000 Mar.	3.3
2004 Jun.	1.75

9. Tamilnadu	
2000 Mar.	5
2004 Mar.	1.4

10. Gujarat	
2000 Mar.	1.8
2004 Aug.	1.25

11. Uttaranchal	
2001 Mar.	1.8
2004 Jun.	1.22

Note: Partial map of India indicating states represented at the Goa meeting. PR data shown above given by states at the time of the meeting.

# A Quest for Dignity

Bernard K. Punikai'a has spent a lifetime fighting for human rights.

## QUOTE:

**Bernard K. Punikai'a**

"We want to be part of the process.... To be in a position to help others as well as ourselves."  
*Quest for Dignity*

Bernard K. Punikai'a was born in Honolulu, Hawaii. He was diagnosed with leprosy at the age of six, taken from his mother, and later forcibly isolated on the remote Kalaupapa peninsula, island of Molokai, in 1942.

From an early age, he was involved with politics at Kalaupapa and was a member of the Citizen's Committee that abolished Hawaii's outdated isolation law in 1969. He was a leader in the battle to prevent the state government from closing down Hale Mohalu, the residential treatment facility near Honolulu that had provided an alternative to living at Kalaupapa since 1949.

When Hale Mohalu was ultimately bulldozed in 1978, Bernard was a leader in creating the Coalition for Specialized Housing, which developed affordable housing on the Hale Mohalu site for senior citizens and persons with disabilities.

Bernard gave the keynote address at the Opening Dinner Reception for the *Quest for Dignity* Exhibit, when it was launched at the United Nations in 1997.

It was Bernard who coined the phrase "Quest for Dignity", which has come to symbolize worldwide efforts aimed at reaffirming the human rights and humanity of all those who have had leprosy.

An accomplished composer and musician, Bernard has written many songs including "Out of the Darkness", which was composed

specifically for the Opening of the *Quest for Dignity* exhibit at the UN.

In 2000, Bernard was elected as IDEA's President for International Advocacy\*, a position he still holds. In 2002, Hawaii Governor Ben Cayetano declared August 29 — Bernard's birthday — as "Bernard K. Punikai'a Day" in honor of his lifetime of achievements and contributions to society.

Speaking up has been a way of life for me. To be silent is to be part of the oppression.

"When I reflect back on my early life, going back to age four or five, I can see that a pattern had been established whereby some people would describe me as being a renegade. One of the things that really gets to me is fairness and fairness in how you treat people. I have always been concerned about fairness, rights, civil rights, human rights, how people treat other human beings. I like to think that whenever I notice any kind of injustice or unfairness, that I will not be silent. Speaking up has been a way of life for me. To be silent is to be part of the oppression.

"Anytime anyone is diagnosed with this disease, they are traumatized because they are burdened with 3,000 years of stigma, fear and rejection. Your belief is your reality and all too often, your beliefs about the disease stem from what you've heard about the stigma, fear and rejection. We can no longer sit by and watch people's identities and people's lives be destroyed by the stigma associated with this disease. We are your sons, daughters, fathers, mothers, brothers, sisters, grandparents. We are truck drivers, poets, teachers, politicians, musicians, artists and so much more. We refuse to allow people to define ourselves, our humanity, by a disease."

— Bernard K. Punikai'a ■

## Leprosy LEXICON

### ● Disability

Leprosy impairs the body's peripheral nerves, and can lead to disability if not treated. WHO uses a grading system to measure levels of disability (0 to 2) at six sites (eyes, hands, and feet). These are used to assess a patient's overall disability grade. Disability in new patients is normally only reported at Grade 2 levels. Lower rates of disability are a sign of early detection.



Bernard outside the Honolulu Academy of Arts.  
Photo by Pamela Parlapiano

\* *The International Association for Dignity, Integration and Economic Advancement (IDEA) is the first organization whose leadership is largely made up of people who have been affected by leprosy.*

# Preserving the History of Leprosy

Eliminating leprosy is an important goal, but so is ensuring that records survive.

*Dr. Jo Robertson is Research Officer for the Global Project on the History of Leprosy, an initiative of the International Leprosy Association, funded by The Nippon Foundation. The project, which began in October 2004, is developing a database of locations where leprosy archives can be found in order to facilitate historical research into leprosy in the period after 1800. It is based at the Wellcome Unit for the History of Medicine at the University of Oxford.*

## What is the purpose of the project?

This project is dedicated to ensuring that the history of the work done against leprosy is not forgotten and that the voice of the person affected by leprosy is heard. The strategy is to create and develop a database of references to historical documents; build an infrastructure for future research that will attract and encourage researchers across the world to undertake work on the modern history of leprosy; and include references to existing collections of audio and video interviews relating to leprosy so that pathways will be created for researchers interested in the personal voice.

Anwei Law from IDEA is working on the oral history side of the project, where the strategy is to develop advice to assist others to undertake oral history work; instigate networking among oral historians interested in leprosy; and give some initial assistance in cases where valuable particular individual histories are in danger of being lost due to age or illness.

## How did you become involved?

My doctorate *In a State of Corruption: Loathsome Disease and the Body Politic* is on the representation of leprosy in colonial Queensland. I started my doctorate as a result of the documents that I saw in the Queensland State Archives. The correspondence and reports about people who had been isolated on islands off the coast of Queensland were extremely moving, and I could not understand why I could not find any voices that objected to the isolation of these people.

## Why is this work important?

As the campaign to eliminate leprosy moves toward achieving its goal, leprosy work is being integrated into general health services. As this happens, the concerted and specific work that has been developed and spans more than two centuries will move into a different phase.

Time will only tell if leprosy will ever disappear, but if the transition into the general medical health service is not successful, it is not inconceivable that the skills and knowledge

gained against the disease may some day need to be revived. Without careful management, however, this knowledge is in danger of being lost.

Even though published research work is easy to access, the records that provide a more detailed picture of that research may not be available to future researchers because the copious data that has been compiled will have been discarded.

Independently of medical research priorities, leprosy also provokes many questions of political, social, cultural, national, and international interest, making the preservation of records an imperative if these issues are to be explored.

Above all, this is a disease that has caused misery for 3,000 years. As it fades away, we mustn't allow a record of that human suffering to be lost, so that future historians can interpret the significance of this milestone for mankind.

There are many impressive collections of records and it is hard to single out any one.

## Do many historical records exist, and which in particular stand out?

So far our database has over 200 sites where substantial repositories of historical records can be located, and there are many more that have been identified, but not yet added to the database. There are many really impressive collections of records, and it is getting extremely difficult to single out any one collection.

What is interesting is how it is possible to see a "story" — one facet of the leprosy story — emerge out of a simple list of documents that are held in a single collection. In addition, when the collections are put together, it is also becoming possible to trace the larger story of leprosy in single countries and also internationally.

One of most exciting finds has been the wonderful collection at the Gandhi Memorial Leprosy Foundation in Wardha, Maharashtra, India. The foundation was established in 1951 and prided itself on taking an "entirely different approach to the problem of leprosy."

The plan was to select a small area for control and eradication work; to examine every individual and put all leprosy patients on oral DDS; to follow their contacts; to undertake repeated surveys for finding out new cases; and to segregate infectious cases wherever and

## LEPROSY FACTS

- The modern history of leprosy studies began in 1847 with the publication in Norway of *Om Spedalskhed (About Leprosy)* by Daniel Cornelius Danielssen and Carl Wilhelm Boek. In the early 19th century, Norway had the most leprosy patients of anywhere in Europe.



Dr. Jo Robertson: dedicated researcher

whenever possible either in villages, homes or colonies.

The records from this collection tell an amazing story of Indian responsibility for leprosy work and there are so many facets of this story that need to be told, not least of all the stories of the paramedical workers who went out into the villages to administer medication and also the stories of the people in the villages who were both involved in this work and were also recipients of treatment. As far as I'm concerned the paramedical workers were heroes at the "cutting face" of leprosy.

In this instance, the compound at GMLF, Wardha, and most of all, the people who have been associated with this work, provide indispensable insights into that story. In this case, the archive is much more than documents — it is a living one.

#### **What impact is the project having?**

Although there is much more to find and add, the database has attracted a good deal of attention and has begun to stimulate historical research.

The website itself has already attracted many visitors, some of whom have made contact with the project and indicated that they have embarked on history projects. These include academic researchers in countries as diverse as Colombia and Taiwan. Some are

established scholars while others are post-graduate students looking for projects to research for doctoral and masters dissertations.

The website is also increasingly attracting requests from the general public for information about leprosy in addition to offers of assistance from those who have direct experience of leprosy work in many different parts of the world. Offers from China, Japan, the Philippines, and from Yemen (for the Arab and Islamic countries) are some of the most recent.

#### **Do you notice many differences from country to country in the way people with leprosy were treated by society?**

Not really. Isolation of people with leprosy seems to have been widespread, with similar effects, worldwide. As a result of my work for the project, I've had the opportunity of visiting some of the places where people with leprosy have been isolated. People still live in these places, their lives and those of their descendants irrevocably affected by the leprosy control policies of the past. Cuttack in Orissa, India, for example, has well-established communities of second and third generation people.

#### **What advice do you have for people who may have access to records or be in a position to contribute to the project?**

It is vitally important for people who have worked in the field to preserve the documents that have resulted from that work so that its existence can be documented on our database. Those who have been involved in leprosy research and leprosy control, may have compiled material of importance for the writing of a history of the disease. Primary documents such as organizational, policy, scientific and medical reports, photographs, film, and correspondence are all of great value to history researchers. I hope people who have had experience of leprosy will take this opportunity to put their experiences on record. ■

*Anyone who would like to make a contribution to the work of the project should contact Dr. Jo Robertson (Research Officer) at the following address:*

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# India's Progress

Meetings in Bihar and Goa confirm the headway that India is making in its efforts to eliminate leprosy and tackle discrimination but also the challenges that still lie ahead.

## BIHAR (AUGUST 26-29)

At the end of August I visited Bihar in northeast India. It was my second visit to this populous state, one of several where much work remains to be done if India is to achieve the goal of elimination by the end of 2005.

I used to be pessimistic about Bihar's prospects. When I first visited in December 2002, the prevalence rate was 11 per 10,000 population. This time, according to Bihar's health ministry, it was down to 4.5/10,000. I am encouraged to see that the efforts of those who have been working hard for leprosy elimination in Bihar now appear to be bearing fruit.

In total, I spent three days in Patna, Bihar's capital, and one day in Gaya. In Patna, I attended two meetings. The first was a workshop to discuss the role of medical professionals, the media and NGOs in leprosy elimination. The second was on how to involve non-leprosy organizations.

The workshop, which was organized by Dr. S.D. Gokhale, Chairman, International Leprosy Union, and chaired by Dr. P.K. Gopal, President, IDEA India, also focused on the role of cured persons. In particular, it looked at the part they can play in educational campaigns to neutralize discrimination and so make it easier for people to come forward for treatment.

## We must do everything to enable all cured persons to be accepted by society.

On the opening day, about 30 recovered persons each gave a self introduction. They included an MBA student, a housewife, a construction worker, a stationer, a shopkeeper, a milkman, a barber, a bicycle repair man and a computer technician. They all appeared to be leading normal lives. But encouraging as this was, such people are the exception, not the rule, and I believe we must do everything possible to enable all cured persons to be accepted by society.

The second meeting I took part in was on the role of social organizations and was attended by about 60 representatives of companies, banks, industry organizations and other groups. Representing the Bihar government was Health Commissioner Dr. A.K. Choudhary; attending from WHO were Dr. S.J. Habayeb and Dr. Derek



Lobo, and from the government of India, Dr. G.P.S. Dhillon, DDG (Leprosy).

Dr. Choudhary said that while Bihar is making progress in reducing the number of patients, work still needs to be done to restore the dignity of cured persons. Dr. Lobo said it was important to move beyond the current situation where cured persons tend to find work only within the leprosy community; they must be given support in finding work outside work.

I used the opportunity to appeal for the support of all sections of society, stressing the three messages that leprosy is curable, treatment is free, and social discrimination has no place. I emphasized that if every Indian was to have a proper understanding of leprosy, it was vitally important to start a huge social movement.

While in Patna, I gave a speech at Patna Women's College. I told my audience of 500 students that leprosy wasn't just a medical disease, but was a social problem with a long history of human discriminating against fellow human. Each student, I said, should consider leprosy elimination and the restoration of the human rights of those

Speaking out: people recovered from leprosy address the Bihar workshop



Patna Women's College: students learn what they can do for elimination

affected by the disease as her problem. I urged them to put Bihar at the head of the movement to eliminate leprosy from India.

For the second half of my stay I visited Patna District and Gaya District. In both, the PR has dropped to 4-5/10,000 but elimination activities are still needed. First I visited the Masaurhi primary health center, which serves a population of 200,000. Under it are two more health centers and 26 sub-centers. Health workers and community health workers (anganwadi workers) who discover new patients refer them to the primary health center. Each sub-center sees about 10-15 new patients a month. Thanks to early diagnosis and prompt commencement of treatment, there are almost no cases of deformity.

Next I went to Gaya to visit the regional hospital. Here I met the district magistrate, the head of the hospital and about 30 front-line health personnel. I thanked them for their efforts and promised to come and celebrate their success when elimination was achieved.

I also visited Bodh Gaya primary health center. There are 21 sub-centers, and a total of 95 leprosy patients registered. Here, too, I was told there were no cases of deformity.

I concluded my stay in Bihar by calling on Chief Minister Rabri Devi, and her husband Laloo Prasad, the former chief minister and now Union railways minister. Both showed keen commitment toward elimination and promised me their continued support.

### GOA (SEPTEMBER 29-OCTOBER 2)

At the end of September I visited the Indian state of Goa to attend a two-day India Health Secretaries Meeting for Leprosy Elimination sponsored by the World Health Organization. The conference discussed strategies to achieve elimination by the end of 2005, and was attended by officials of 11 out of 15 high endemic states.

The occasion was significant because of the senior level of the Indian government representatives attending — Shri J.V.R. Prasada Rao, Secretary (Health), Ministry of Health & Family Welfare; Dr. S.P. Agarwal, Director-General of Health Services; and Ms. Rita Teotia, Joint Secretary (Health).

With just over a year to go, it was important to have these top officials convey the government's determination to eliminate leprosy in front of the representatives of the endemic states. Further, it was an opportunity for government and state officials spend time together, affirm their common resolve and discuss concrete strategies.

I am also hopeful that state health secretaries and their representatives will have been inspired by the example of other states and gone away

with a renewed sense of purpose to bring down the prevalence rate in their own states.

For my part, I said that I was prepared to travel to India as often as necessary until elimination was achieved, and stressed that I stood shoulder to shoulder with the Indian people. For the first time, I wore Indian national costume.

While in Goa, I visited two teenage boys currently being treated with MDT. One was diagnosed early because his mother had some knowledge of leprosy symptoms and had him checked when she discovered a patch. Later his cousin was also found to have leprosy.

One boy doesn't mind taking MDT but the other is reluctant because he's afraid it will make his skin turn dark. I told him this would only be temporary and encouraged him to take his MDT like his cousin. I was reminded how important it is to explain treatment and reaction to patients.

I also visited a state-run leprosarium established in 1934 by Dr. Froilano de Melo when Goa was a Portuguese colony. Set in some 60 acres amidst coconut palms, jackfruit trees and mango trees, it has plentiful greenery. At one time it had as many as 280 occupants but today has only 18 (11 women and 7 men), whose average age is between 70-80. It stopped accepting patients two years ago, and there is talk of eventually turning the complex into a hospital for HIV/AIDS or other diseases.



Visiting the Leprosaria Central in Goa

Nowadays, many of its buildings have fallen into disrepair, but the wards in use appeared clean and well-run by the staff of seven nurses. The residents all wore uniforms and engaged in a variety of pursuits including electrical repairs, carpentry and painting. I was told they are content, but I sensed the loneliness of their isolated existence in their faces. One elderly lady has been living there since the age of 12. In beautiful Goa, it was all the more painful to encounter people long recovered from the disease but unable to return to society, and I renewed my determination to end the discrimination that permits this to happen. ■



Shri J.V.R. Prasada Rao, Secretary (Health), GOI

# UN High Commissioner, Sasakawa Meet

Arbour says education key to eliminating discrimination

Ambassador Yohei Sasakawa met with newly appointed UN High Commissioner for Human Rights, Ms. Louise Arbour, in Tokyo on November 9, 2004.

Ms. Arbour had served as a member of the Supreme Court of Canada and as chief prosecutor for the International Criminal Tribunal for the former Yugoslavia and Rwanda. She assumed her duties as high commissioner in July 2004, replacing Sergio de Viera Mello, killed in the bombing of UN headquarters in Baghdad in 2003.

In her meeting with Ambassador Sasakawa Ms. Arbour expressed her deep concern over



the issue of leprosy and human rights. She said discrimination is caused by ignorance and fear and that education and information would be the key to eliminating the problem.

## 11TH YOMIURI INTERNATIONAL PRIZE

Japan's best-selling daily awarded its 11th Yomiuri International Cooperation Prize to WHO Goodwill Ambassador Yohei Sasakawa in October for his decades of work toward eliminating leprosy around the world and the discrimination it causes. The

award was presented by Yomiuri Shimbun President Takuo Takihana. Previous recipients include Sadako Ogata, former UN High Commissioner for Refugees. The prize marks the newspaper's 120th anniversary. ■

### LETTER

#### ANOTHER VIEW OF BRAZIL

It is nice to read that the role of NGOs is very important (Issue No. 10, From the Editors). From my point of view not necessarily in picking up the slack when government priorities waver, but in collaboration with government services and treading where government is not yet reaching in terms of new initiatives and research.

You mentioned that time was lost in the battle to eliminate leprosy in Brazil. If you took some time looking at the annual statistics, especially, for example, at detection rates or at rates of Grade 2 disability among new patients, you would realize that much has been achieved over the past years. If you were to analyze the situation state by state you would find out that some states have had excellent results and high cure rates.

It is sad to observe that the good efforts of the thousands of dedicated government leprosy workers in Brazil have not been mentioned.

*Pieter A.M. Schreuder*

### FROM THE EDITORS

#### LEPROSY'S LEGACY

Preserving the history of leprosy is the subject of our interview with Dr. Jo Robertson on pages 4-5. While the archive material that her project focuses on dates from 1800 onward, the first records of a leprosy-like disease trace back to 1400 BC. This is a disease that has given rise to human misery for over 3,000 years. Now, thanks to MDT and the concerted efforts that have been made around the world, leprosy is close to being eliminated as a public health problem in every country.

The suffering and despair caused by leprosy, and what the disease tells us about man's inhumanity to man, should never be forgotten. But neither should the inspiring stories it has produced, not least of the individuals who have borne their affliction with courage and dignity in the face of despair.

Then, too, there are the thousands who have worked hard and selflessly to care for and treat patients, as Pieter A.M. Schreuder reminds us in his letter. We must not forget.

### FOR THE ELIMINATION OF LEPROSY

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