

FOR THE Elimination OF Leprosy

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



WHO Goodwill Ambassador Yohei Sasakawa meets Indian Prime Minister Dr. Manmohan Singh in New Delhi.

A MESSAGE FROM THE GOODWILL AMBASSADOR

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The Start of a New Movement

On March 21, I met Indian Prime Minister Manmohan Singh in New Delhi. The security at the Prime Minister's Residence was tighter than at the White House, but the atmosphere in his office was surprisingly relaxed. The prime minister was very well informed about the leprosy situation in India, and also about elimination activities. "Mr. Sasakawa," he was gracious enough to say. "You have been an inspiration to India. You are doing noble work."

When I conveyed to Dr. Singh my three messages — "Leprosy is curable; treatment is free; social discrimination has no place" — the prime minister repeated them several times. Concerning the last of the three, he had a clear message of his own. "I am doing my utmost for the elimination of this disease, and am making efforts to redress the human rights problem faced by patients, recovered persons and their families."

I have heard Dr. P.K. Gopal, president of IDEA India, say, "Until now, patients and recovered persons didn't regard the discrimination they faced as a violation of their human rights. They simply resigned themselves to their fate." There are others

who have said, "When I came down with leprosy, it was as if I left the caste I belonged to and joined the leprosy caste." Now, after so long, recovered persons are breaking their silence and forcefully expressing their views.

In February and March, workshops were held in Brazil and India on leprosy and human rights. Concurrently, a member of the UN human rights sub-commission conducted a fact-finding mission on discrimination. At both workshops, the main actors were recovered persons, who stated frankly that their lives were a history of being discriminated against as human beings. My wish to see them lead the fight is starting to be realized. When they speak out, they are the most persuasive campaigners for bringing about proper understanding of the disease.

At last, the medical and social aspects of the fight against leprosy are in alignment. I sense the beginning of a new movement. Let's seek the involvement of a wide cross-section of society, with recovered persons leading the way.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Taking Note of Discrimination

Workshops in Brazil and India lay groundwork for report to UN sub-commission.

At last year's session of the UN Sub-Commission for the Promotion and Protection of Human Rights, members agreed to investigate discrimination against persons affected by leprosy, appointing fellow member Yozo Yokota* as special rapporteur.

Prof. Yokota will present his findings at the sub-commission's 57th session this August. To assist him in preparing his report, earlier this year The Nippon Foundation organized seminars in Brazil and India on leprosy and human rights.

The seminars provided Prof. Yokota with an opportunity to hear directly from patients and recovered persons and visit leprosy settlements and hospitals to investigate social discrimination.

Earlier in the year, Prof. Yokota attended the African Leprosy Congress, where he also interviewed people affected by leprosy.



Yozo Yokota interviews a person affected by leprosy.

BRAZIL

The Brazil seminar (February 27-28) was held in Rio de Janeiro with the cooperation of Sao Paulo University, the health ministry and MORHAN. In addition to Prof. Yokota, fellow sub-commission members Jose Bengoa (Chile), Iulia-Antoanella Motoc (Romania) and El-Hadji Guissé (Senegal) also attended. From Brazil, there were participants from the health ministry, the government special secretariat of human rights, legal circles and NGOs as well as recovered persons.

Sessions included testimony by leprosy-affected persons; the results of a fact-finding survey on Brazil's 33 leprosy colonies; and a report by government agencies tackling human rights issues. By the end of the two-day seminar, a number of proposals addressed to the UN Commission on Human Rights (UNCHR) had been drawn up:

1. The UN should foster and support research, campaigns and public policies that deal with the cure, treatment and elimination of leprosy;
2. Discrimination and stigmatization should be regarded a problem as relevant as other issues that impair elimination of leprosy;

3. Hold more such seminars around the world;
4. Prepare a resolution dealing with the issue of leprosy in vulnerable and marginalized groups;
5. Prepare a resolution condemning the utilization of negative images of people with leprosy;
6. Include information about leprosy in elementary and secondary school teaching materials;
7. The UN should provide resources for the creation of a fund that would enable persons affected by leprosy to go to Geneva to address members of the sub-commission.

INDIA

The following month, a second workshop was held in Pune, India (March 18-19) with the cooperation of the International Leprosy Union and IDEA India. It focused on discrimination in specific areas such as health services, education, housing, marriage, inheritance and disability prevention and also tackled broader social issues involving isolation, stigma and the law.

Attended by leprosy specialists, legal experts, representatives of NGOs, human rights organizations and others, the workshop heard accounts of discrimination experienced by the many recovered persons present, for whom this was an important opportunity to speak out.

During the workshop, the result of a recent survey commissioned by an Indian human rights committee on social discrimination against leprosy-affected people in four states was announced. It showed the severe discrimination faced by patients and recovered persons in their daily lives.

NEXT STEPS

Prof. Yokota stressed the importance of incorporating the voices of the leprosy-affected in his report, which he said is taking shape as a result of his participation in these seminars. "Normally, it's a three-year process involving a preliminary report, an interim report and a final report. But to speed things up, I am positioning the report I shall be submitting in August as a final report, so that the sub-commission may act on it swiftly.

"Following on from that, I am hoping that the UNCHR will promptly issue a resolution and that governments in each country will take all necessary measures so that as quickly as possible we can achieve a society in which persons affected by leprosy are accorded equal treatment."

Adding a further proposal to those made at the Brazil conference, Prof. Yokota suggested that on World Leprosy Day each year, the UN secretary general, the high commissioner for human rights and political leaders from different countries invite persons affected by leprosy to hear their views. ■

Reference

* Professor of International Law at Chuo University, Tokyo

The Real Work Is Just Beginning

In our last issue, we reported that Brazil aims to achieve elimination this year. Dr. Rosa Castalia, leprosy program coordinator for the Ministry of Health, explains.

When were you appointed to this post?

In June 2004.

Brazil has made much progress since then.

We observed that the prevalence rate had remained the same since 1998 — at around 5/10,000. With the help of PAHO* and WHO, we began to clean the database. As a result, we found in 2004 that we had 30,000 patients under treatment, and not 90,000, as previously thought. We also started using the method of calculation that WHO uses around the world.

What is the PR now?

Nationwide, our PR is 1.7/10,000 [as of February 2005]. Of Brazil's 27 states, the states in the south and southeast have a very low PR, with most having already achieved elimination. The majority of patients are concentrated in the northeast and central regions, which account for about 70% of all patients. Our expectation is that at the end of 2005 — in fact, in January 2006, when we have all the data — we will declare elimination at the national level.

It's excellent to hear you aim to reach the elimination goal by the end of 2005.

Achieving the elimination goal at the national level is not the end of the work, it is the beginning of the more difficult part of the work — to achieve elimination levels where the disease cannot be reproduced, and achieve very low rates of disability,

in each state and then each city. We are designing a five-year plan for 2006-2010 to achieve this and one of the big challenges is to eliminate cases among children. In Brazil, about 8% to 10% of cases occur in children less than 15 years old with about 4% of them having disabilities.

Why such a high rate of new cases among children?

It points to shortcomings in epidemiological surveillance. It is very important to examine contacts. If there are adult family members who are not being treated, this is something that contributes to the high prevalence among children.

What is the situation at the city level?

Brazil has 5,500 cities, with cases of leprosy reported in 2,254 of them. Of these cities, we have identified 206 as priority cities, the criteria being that they have more than 50 new cases every year, more than 20% of the cases involve children, and the majority of cases are multibacillary leprosy.

All the things we do now, we will have to do more of and better after elimination.

There seems to be close collaboration between the government and NGOs such as MORHAN.

Social movements such as MORHAN and other NGOs such as ILEP each have their own specialties. MORHAN works on human rights questions and ILEP is very good on rehabilitation and prevention of disability. Meanwhile, PAHO supports us in epidemiological analysis and training. The important thing in this process is that the government has to be the leader and coordinate everything. At first, it wasn't so easy for some partners to understand this. But now everybody understands that we all need each other. This is a big country with big problems!

Once you succeed in achieving elimination, there is the challenge of sustainability.

All the things we do now, we will have to do more of and better after elimination. Elimination at the national level is a political achievement. But it's not enough. I am afraid of a situation in which we declare elimination, but lots of patients we are treating say, 'How can this be so? I am here, I am sick!' It must be very, very well explained. ■

Leprosy FACT

- Statistics compiled by Brazil's Ministry of Health in 2004 showed that only 27% of healthcare units in the country have facilities for diagnosing and treating leprosy. The ministry is now working to support training for all nurses, doctors and healthcare services personnel.



Dr. Castalia: cases among children pose challenge

Reference

- * Pan American Health Organization

Moving Forward on Human Rights

Visits to Brazil and India focus attention on discrimination, while a trip to Cambodia shows that persons with leprosy still try to hide the disease.

BRAZIL (FEBRUARY 27-MARCH 1)

In late February I was in Brazil for a workshop in Rio de Janeiro on Human Rights and Leprosy (see page 2). When I visited Brazil in June last year, a health ministry spokesman said, in relation to leprosy strategy, "We were asleep." Since then, the ministry has begun to move quickly, and is pursuing some forward-looking policies.

Most importantly, it is overhauling its approach to treating leprosy and incorporating it into the public health services, as has been done elsewhere in the world.

The ministry is now moving quickly and is pursuing some forward-looking policies.

In connection with this, it is conducting an ongoing survey of Brazil's 33 former colonies carried out by the health ministry with the cooperation of MORHAN with a view to ensuring the civil rights of people affected by leprosy, improving conditions for them and assisting with their rehabilitation and return to normal life.

An initial survey, conducted last November, found that facilities were poor, staff were in short supply and their level of quality variable. Basic health information is also lacking.

Further, colony residents with nowhere else to go and few links to society and family live in fear of what will happen if ever the colonies are closed. This, in turn, relates to unresolved issues concerning residence rights, property rights and the transfer of these rights to their children.

Among those who spoke at the workshop, Cristiano Torres left the deepest impression on me. The head of a leprosy colony committee and the chairman of a leprosy soccer association, he was one of the Olympic torch bearers when the Olympic flame passed through Brazil in 2004. Mr. Torres stressed the importance of distinguishing between "leprosy" and "Hansen's disease." Although in English it is common to refer to leprosy, in Brazil it is mandatory to use the latter term. As Mr. Torres explains it, leprosy is synonymous with suffering, Hansen's disease is not.

By the end of the two-day conference, a number of concrete proposals had emerged from the discussions. Where pertinent, these will be included in the report being prepared by Prof. Yozo Yokota for the UN Sub-Commission on the Promotion and Protection of Human Rights.

On March 1, I went to Nova Iguaçu district on the outskirts of Rio de Janeiro to visit a regional health center and the Crurupatiti colony. Nova Iguaçu has the highest prevalence rate in Rio state, at 5/10,000. Between 1997 and 1999, the health center was shut for renovations, as a result of which 40% of registered leprosy patients stopped receiving treatment. Now the center is conducting active follow-up and treatment.

The colony, situated in a mountainous area, is spread out like a large village. In addition to a hospital, there are five residential districts that are home to around 1,400 people — both recovered persons and their families as well as others. The facility is more than 50 years old, and those living there appeared to be contented and self-sufficient. However, as the workshop made clear, for Brazil's Hansen's patients, many issues remain unresolved



Telling it like it is: Cristiano Torres speaks out



"Treatment for Hansen's disease here"

with regard to residential rights, property rights and what the future holds.

INDIA (MARCH 17-21)

On March 18-19, I took part in another workshop on leprosy and human rights in Pune, Maharashtra State. In my opening remarks, I cited Raoul Follereau, who in letters and speeches half a century ago talked about leprosy as a curable disease and one that was difficult to catch. Appealing for an end to discrimination, he asked what it meant to be cured if after the fact a person was still called a “leper.”

Only recently is society waking up to the magnitude of this problem and starting to do something about it. Prof. Yokota, who took part in this workshop as well, said it was shameful that the UN was only now taking up the issue.

The keynote address was given by Chandrashekhar Dharmadhikari, a retired judge, who cited the need to change popular thinking if persons affected by leprosy are to be treated equitably by society.

Following the opening ceremony, International Leprosy Union Chairman Dr. S.D. Gokhale presented the findings of a survey on leprosy and human rights in four states: Bihar, Uttar Pradesh, Orissa and Maharashtra. The survey showed how disability is the starting point of discrimination and prejudice; that disability is a major cause of inequitable treatment in the job market; and that disability and poverty are deeply intertwined.

On a positive note, self-help movements of the disabled are beginning. Further, in various parts of India, it is now a legal requirement that disabled



A recovered person making car parts near Pune

persons have a say in making policies and laws.

Concerning legislation, academics and lawyers pointed out that most people were unaware that leprosy-affected persons are covered by the disabilities act, although they acknowledged that in reality the act does not adequately recognize disability due to leprosy. They also highlighted the fact that leprosy remains grounds for divorce under India’s marriage laws. For various forms of discrimination to be removed, they said, legislation must serve as an instrument of social change and laws must be “internalized” if they are going to have any effect.

There was also a session at which

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Workshops such as this one in India are turning the spotlight on stigma and discrimination.

recovered persons recounted their experiences. A book of these accounts will be published this year.

Following the conference, on March 20 I visited a well-maintained colony on the outskirts of Pune. Four women were waiting at the entrance to greet me. Each of them held a silver tray containing a small silver dish. The woman nearest me opened my mouth, and filled it with sugar. My mouth was so full I didn't know what to do. At the sight, they all burst out laughing. It was a very strange greeting!

Government Bandorawalla Leprosy Hospital, Kondhawa, is a five-minute walk from the colony. It consists of a men's ward, women's ward, workshops and a surgery. All together, 150 leprosy-affected people live there, including those who require surgery or ulcer care, and others who have nowhere else to go.

Sad to relate, they include a 13-year-old girl. She exhibits no deformity but had to come to the hospital because there was no MDT available at the health post near her village. It pained me to think that because she had spent time in this facility, she was going to suffer discrimination even after she was cured.

I was heartened to meet Mr. Anjan Dey. Although he lost the use of his right hand to leprosy, after treatment he began working at the hospital as a physiotherapy attendant and later received certification from Christian Medical



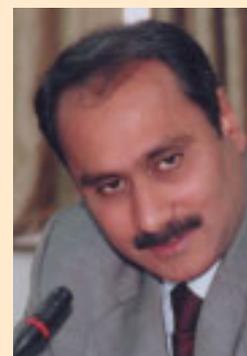
Anjan Dey: from patient to therapist

College in Vellore. Once he was a patient who slept on the hospital floor. Now he is in charge of the physiotherapy department, and is well respected beyond the hospital for his knowledge and experience. He has also raised a family.

Nearby the colony is a factory employing 106 people, including 90 recovered persons. It makes engines parts and bumpers under contract to India's largest motor manufacturer, Tata Motors. Until the factory began receiving orders from the car maker, it went through some difficult times and even faced bankruptcy. But the employees all returned their salaries to raise capital, and were able to turn the factory into a going concern.

Running a commercial operation in a competitive market is no easy matter, and the factory still faces various challenges. But for now the wages it pays are overtaking those of the average Indian worker. I told the employees that as news of this success spreads, it will give encouragement to recovered persons everywhere.

On this visit to India, I also had the opportunity to meet with Prime Minister Manmohan Singh and Health Minister Dr. Anbumani Ramadoss. The prime minister gave his unequivocal commitment to eliminating leprosy and redressing the human rights issue (see page 1). The health minister told me, "We have almost achieved elimination. I believe we will be able to make an announcement to the world by the end of this year. We are also doing our utmost on the issue of human rights, because this was a movement begun by Mahatma Gandhi."



India's health minister, Dr. Anbumani Ramadoss

CAMBODIA (MARCH 23-25)

After India, I went to Cambodia, where I visited a leprosy colony in the village of Treung in Kampong Cham Province. The journey from the capital Phnom Penh was along an excellent asphalt road, and the colony was set in beautiful green surroundings. The village is said to have a population of 1,107, of whom seven are leprosy patients and 95 are recovered persons.

When we arrived, about 50 leprosy-affected persons and 50 villagers gathered to greet us.

I was shocked to see that a young boy who had contracted leprosy from his mother was missing part of his toes. Nowadays, when drugs are widely available, it is extremely rare to see a young patient with such severe deformity.

Apparently, it is still customary in some areas to conceal leprosy, making case detection difficult. Not knowing that drugs are available and a complete cure is possible, there are patients who wait until the symptoms become pronounced and deformity occurs. This situation is extremely unfortunate, and needs to be corrected. ■

Making Something of ‘Nothing’

Nevis Mary finds a new role in life after leprosy threatened everything.

Nevis Mary, 46, was born in Madurai, India. Her father was a cotton worker and her mother a school teacher. She grew up in a happy home, and won a place at university as a merit scholar. She was 20, and a college student, when leprosy began to affect her. From that point on, she said, “My life was nothing.”

She developed a fever, couldn’t move her body, was treated with traditional medicine and spent three years in bed. But far from improving, her hands and feet began to suffer from deformity. Still unaware of the nature of her disease, it was over three years before she was diagnosed with leprosy. Thereafter, she spent two years in hospital being treated.

During that time, her father died of shock that his beloved daughter had leprosy, and her mother followed him to the grave two years later.

In order to support herself and her three younger brothers, Nevis became an assistant in a college. But she didn’t last long in the job once her colleagues found out she was a person affected by leprosy. She contemplated suicide on a number of occasions, but things began to look up when she enrolled in a distance learning program to qualify as a teacher. Subsequently, she taught at public school for three years.

Having been through so much, Nevis has clearly emerged a new person.

Leprosy LEXICON

● POID

Prevention of impairment and disability is an integral part of leprosy control. While early detection and treatment with MDT is key, nerve impairment leading to disability can occur even after a patient has been cured. Left unchecked, disability results in handicaps that prevent full social participation, leading to marginalization and isolation. POID is thus not merely a medical/technical issue, but a social one for every leprosy-affected person.

But eventually the staff at this school, too, began to make an issue of her leprosy. It was at this point that she met Dr. P.K. Gopal, president of IDEA India, an association of and for leprosy-affected persons. Meeting a person who was speaking up on behalf of individuals with leprosy was a life-transforming experience for Nevis. At his suggestion, she applied for a government job as a person with disability, and at the age of 33 became a clerical worker with the Indian Railways.

Her older brothers and sisters had made no effort to help her, other than recommending she enter a sanatorium. But Nevis was determined to survive by herself. In Indian society, however, it is not possible for a woman to live alone. To have a husband is essential, so she looked to get married — no easy task for a woman affected by leprosy.

Thanks to an introduction from a friend who understood her situation, she was married in 1993. She was 33, and her new husband, who taught German at high school, was 40. At the



Nevis Mary: a mission to encourage others

time, she told him that she had undergone various treatments for disability, including treatment for leprosy, but without clearly stating she had once had the disease. Her husband simply told her not to worry.

Although her in-laws proved far less understanding, her husband is now fully aware that she is a recovered person and backs her completely.

Fearful of losing her new job, at first she hid the true nature of her condition from colleagues. But as she became more involved in the activities of recovered persons, a coworker asked her what kept her so busy. “Actually, I’m someone who has recovered from leprosy,” she replied. After this, word spread and her close friends at work no longer ate lunch with her. But eventually, once Nevis had explained the disease to them, they realized there was nothing to fear, and now they are eating together as before.

Having been through so much, Nevis has clearly emerged a new person — self confident, self-respecting and truly understanding of the anguish suffered by those with the disease. She stands firmly by them, encouraging them, speaking out boldly on their behalf at conferences and offering them a friendly ear.

As for leprosy, she is now able to say, “It’s nothing.” ■

Health Ministers Pledge Support

Yohei Sasakawa visits two African nations moving toward elimination.



On a visit to Africa in April, Yohei Sasakawa met with the health ministers of Mozambique and Tanzania, who pledged their determination to see their countries achieve the elimination target. Mozambique currently has a PR of 2.5, while Tanzania's stands at 1.3.

Dr. Ivo Garrido, Mozambique's minister of health, said that the country's new government was fully committed to achieving the goal.

"For us in Mozambique, the fight against leprosy is not an issue of numbers. Fighting against leprosy is fighting for human dignity. That is why it is one of the top priorities of this government. We want to be able to tell the world that we, too, have won the fight."

He added that Mozambique intended to give leprosy the same priority as malaria, TB and HIV/AIDS.



PROBLEM OF STIGMA

In Tanzania, Health Minister Anna Abdullah said that the biggest problem in combating leprosy was stigma. Stigma means delays in seeking treatment, which results in disability.

"Up to 10% of new cases in Tanzania are diagnosed with grade II disability, which is a sign that people are hiding cases," she said. "We have to treat the minds of Tanzanians that leprosy is a disease like any other."

The country is now in the process of promoting community awareness and integrating leprosy treatment into the primary healthcare system.

"We hope to achieve the target, if not this year, then next," Health Minister Abdullah said, adding, "There should be no leprosy in the country. We shouldn't be content with a PR of less than 1 per 10,000." ■

(Top) Dr. Ivo Garrido,
(above) Mrs. Anna
Abdullah

FROM THE EDITORS

PEOPLE, NOT NUMBERS

In countries that have yet to achieve elimination, leprosy pales in comparison to the challenge posed by malaria, TB and HIV/AIDS. This reflects the enormous strides that have been made in the past two decades to bring leprosy under control, but also indicates the scale of the public health problem in these other areas.

But whether the leprosy caseload is large or small, every case represents a human life, an individual affected physically, emotionally and psychologically by the disease and with a knock-on effect on their families as well. As Mozambique's new health minister is quoted on this page as saying, "it's not an issue of numbers."

Dr. Rosa Castalia reminds us of this too when she comments on page 3 that the issue of elimination must be handled very sensitively. Many Brazilians affected by leprosy who will hear the government announce this year or next that the country has achieved elimination will think, "What about me?! I still have the disease."

The elimination target is a milestone along the

way to achieving a world without leprosy. Now that we are nearing the target in every country, it is more important than ever to see the individuals behind the statistics, and hear their voices. Just because the numbers are getting smaller, doesn't mean the problem is any less for the persons concerned.

Article 25 of the Universal Declaration of Human Rights states: "*Everyone* [italics added] has the right to a standard of living adequate for the health and well-being of himself and his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control."

As we consider not only leprosy but other diseases — and also poverty and malnutrition — that are causing misery, claiming lives and imposing strains on the healthcare systems of countries concerned, we still have a long way to go.

FOR THE ELIMINATION OF LEPROSY

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