

FOR THE Elimination OF Leprosy

October 2004 • Number 10

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



Partners in the fight against leprosy stand shoulder to shoulder at a reception hosted by Yohei Sasakawa in Brasilia in July 2004.

A MESSAGE FROM THE GOODWILL AMBASSADOR

Can Statistics Be Trusted?

In July, I visited Brazil for the first time in two years, and was shocked to discover that elimination activities had made almost no progress. In 2002, when I met then-President Cardozo, he gave his strong commitment to elimination. Unfortunately, I discovered on this visit that administration and health ministry activities have been at a standstill, and official statistics contain errors. For the past six years, the prevalence rate has remained virtually unchanged, and even the health ministry acknowledges that the figures can't be trusted. "We were asleep," a senior health ministry official admitted.

Is this kind of problem limited to Brazil, I wonder? Are the statistics we rely on to be believed? Are there not operational factors such as re-registration and wrong diagnosis that distort the numbers? I'd like to ask other endemic countries to go back and reexamine the figures.

Now, under the firm leadership of President Luis Inacio "Lula" da Silva, who came to power last year, the Brazilian administration, the health ministry, state and municipal officials are united in their efforts to take up the elimination battle

anew. NGOs such as MORHAN, which operates "Telehansen," a nationwide toll-free telephone counseling service, and which uses popular singers and actresses in its campaigns, also play an important role. With the government and NGOs cooperating closely together, I am reassured that elimination activities will now make progress.

When I met him, President Lula expressed his strong determination to "make up for lost time." Indeed, immediately after taking office, he visited leprosy sanatoria, and affirmed his intention to see the disease eliminated.

With only 14 months until the deadline for leprosy elimination, we cannot — must not — waste any time. We need to re-verify the figures, get an accurate picture of the challenge we face, and help those countries that have yet to achieve the target use the remaining time effectively and efficiently.

The battle to eliminate leprosy is turning into a battle against time, and we must not lose.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Brazil Turns Over a New Leaf

The present government is determined to make up for lost time in the battle to eliminate leprosy.

Brazil is second only to India in having the most cases of leprosy in the world.

As of January 1, 2004, Brazil had 79,908 registered cases and a PR of 4.52/10,000 persons, according to official government statistics. Of that number, 49,026 were new cases detected in 2003.

By state, Mato Grosso has the highest PR at 22.11, and five of Brazil's 27 states have a PR of over 10. The northern part of the country has an average PR of over 11.44.

Since 1999, treatment of leprosy has been fully integrated into the general healthcare system. The target for eliminating leprosy has been set at 2005 at the national level, and 2010 at the municipal level, with activities focused on the following seven areas: 1) identifying and treating patients; 2) developing human resources; 3) drawing up an effective elimination strategy; 4) giving complete treatment; 5) reforming the information system on leprosy; 6) updating prevalence rate data; and 7) providing enhanced rehabilitation.

The Brazilian government's active commitment to tackle leprosy elimination has come about since the formation of the present government under President Luis Inacio "Lula" da Silva. Since assuming power in January 2003, President Lula became the first Brazilian president in 100 years to visit hospital-colonies and meet with leprosy-affected persons, visiting facilities in Cruzeiro do Sul, Acre



Dr. Humberto Costa, Brazil's minister of health

State, and Manaus, Amazonas State.

According to Brazil's health minister, Dr. Humberto Costa, many of the country's leprosy patients are to be found among the poor. Since the government is committed to eliminating social injustice and economic disparity, addressing leprosy is included in these goals. Dr. Costa said that the ongoing problem of leprosy has been a blot on the country's healthcare services and a stigma on the country in the international community and the government is determined to correct this.

Dr. Costa said that the ongoing problem of leprosy is a stigma on the country in the international community.

In March 2004, a proposal by Tiao Viana, senator for Acre State, that the last Sunday of every January be made the National Day to Combat and Prevent Hansen's Disease, was voted into law by the Brazilian parliament.

While these and other developments are to be praised, the fact remains that the legacy of problems bequeathed by past administrations represents a formidable challenge. Dr. Rosa Castalia, leprosy program coordinator at the Ministry of Health, frankly admitted that ministry figures published between 1998 and 2003, showing that the prevalence rate remained virtually unchanged during that time, are flawed. She promised that the ministry would be urgently contacting the leprosy coordinator in each state in order to compile accurate statistics. In her words, Brazil did less than it could have done.

DIFFERENT STANDARDS

Another reason why the reliability of the figures coming out of Brazil is open to question is the fact that they are not collected according to international guidelines. For example, in 2002, the difference between the official (Ministry of Health) prevalence rate (4.17) and the standardized WHO rate (2.98) was 1.19, which represents an excess of 27,340 leprosy cases for that year.

According to a report published by WHO based on a Leprosy Elimination Monitoring (LEM) exercise in August 2003, three factors may have contributed to this disparity: 1) interruption of treatment before a definition of clinical status was reached; 2) inclusion of multibacillary patients receiving more than 12 doses of multidrug therapy (MDT) and paucibacillary patients receiving more

Leprosy LEXICON

● Integration

Integrating leprosy within the general health services is generally regarded as the key to elimination. General health services are widely distributed and have close and frequent contact with local communities. This results in better case detection and case-holding, more cost effective treatment, and helps sustain leprosy services. Integration also increases awareness of the disease, helping to reduce stigma.



Brasilia (left), Amazon river scene: After India, Brazil has the most registered cases of leprosy.

than six doses; and 3) inclusion of out-of-date records of cured/released patients.

The 2003 LEM exercise was based on a sample survey conducted in all 27 states covering 153 municipalities, 242 primary health care facilities and 2,189 family health care units. A total of 37,879 cases were examined, of which 11,765 that were newly detected in 2002.

The results show that the PR was 2.2 based on the LEM data from all 27 states.

TOP ENDEMIC COUNTRIES AT START OF 2004

Country	Registered cases (as of Jan. 1)	Rate/ 10,000
India	265,781	2.6
Brazil	79,908	4.6
Nepal	7,549	3.1
Tanzania*	7,063	2.1
Mozambique	6,810	3.4
Dem. Rep. of Congo	6,891	1.3
Madagascar	5,514	3.4
Angola	3,776	2.8
Central African Rep.	952	2.6

*2002 data

(Mid-year Report for 2004, WHO)

In August 2002, overall coverage of MDT services came to just 16%. (At the state level, coverage was less than 50% and in nine states it was less than 10%). While leprosy diagnosis and treatment were available in almost 80% of primary health care units visited, out of 2,189 family health care units, only 485 (22%) of them were capable of carrying out diagnosis and MDT treatment.

Addressing the problem of patient examinations, Dr. Castalia said that doctors were not present at every health unit, and traveled between them. Hence even when patients show up, there are often no doctors available. The problem was especially pronounced in the Amazon region, where doctors were reluctant to go.

But although many problems remain, leprosy elimination is now on the official government agenda. The Ministry of Health has developed a national media campaign and all states are involved in the national elimination plan.

After a long period of confusion and inactivity, it appears that Brazil's elimination campaign is getting back on track, offering genuine hope for the future assuming the new level of commitment is maintained. ■

MORHAN's Vital Contribution

For 23 years, MORHAN has been fighting to eliminate leprosy from Brazil, as National Coordinator Artur Custodio Moreira de Sousa relates.

"Before MORHAN, we walked with our heads bowed. Today, we hold our heads up because we recognize we are part of society." This assertion by Cristiano Torres, MORHAN coordinator for Para State, Brazil, highlights the important role of MORHAN (Reintegration Movement for People Affected by Hansen's Disease) in working to eliminate Hansen's disease and the prejudice that surrounds it.

Established on 6 June 1981 by the charismatic Francisco Nunes "Bacurau," who himself had overcome the disease, MORHAN was part of the explosion in social movements fighting for democracy and human rights that emerged in Brazil in the 1980s. Its history is thus closely bound up with people working to advance the cause of human rights and public health in Brazil.

It was one of the first advocacy groups in the world formed by people affected by Hansen's disease, and its founders believed that only through mobilizing volunteers who had not had the disease could the disease be eliminated and prejudice overcome. Today those volunteers include everyone from ordinary citizens to some of Brazil's best-known celebrities, among them singers Ney Matogrosso and Targino Gondim, actor Ney Latorraca, actresses Solange Couto, Karla Karenina and Elke Maravilha, clothing designer Lino Vilaventura and painter Siron Franco.

Brazil's first cases of Hansen's disease occurred some 500 years ago among Europeans and slaves from Africa. As in other countries, the subsequent history of those affected was marked by pain, suffering, prejudice, isolation, ruined families and shattered lives.

Brazil didn't officially eliminate the practice of isolating patients until 1962 (although not every state followed through). Then, in 1981, the World Health Organization officially recommended that

endemic countries adopt multidrug therapy. This prompted social organizations to begin campaigning against the stigma and prejudice associated with the term leprosy. The health ministry decreed that the term hanseniae (Hansen's disease) be used instead, and eventually this became law after considerable pressure from MORHAN.

Key Objectives

The main goal of MORHAN is to inform society that Hansen's disease can be treated and cured, and, with hard work, completely eliminated. To achieve this, MORHAN has set the following targets:

- Help cure, rehabilitate and socially reintegrate people affected by the disease
- Work to eliminate the prejudice they face at home, at work and in the community
- Ensure that those affected by Hansen's disease can freely exercise their rights as citizens
- Transform old hospital-colonies where patients were isolated from society and their families into places where they are treated with respect, educated about their disease and given access to cultural and recreational facilities that help build up their self-esteem and improve their quality of life.



MORHAN T-shirt:
"Together we can
eliminate Hansen's
disease."

These goals are justified by the high incidence of Hansen's disease in Brazil, where there were 79,908 registered cases at the start of 2004, or a prevalence rate (PR) of 4.52 per 10,000 people. In 2003, 49,026 cases were registered, or a new case detection rate of 2.77/10,000.



(from left) Yohei Sasakawa, singer Ney Matogrosso and MORHAN's Artur Custodio

In the fight to reduce the PR, MORHAN has been campaigning to prevent and control the spread of the disease, both in conjunction with the health ministry and through MORHAN's regional branches. Today MORHAN is represented in 24 of Brazil's 27 states and gives support to more than 100 communities. It also works together

with other social organizations to pressure the authorities to fulfill their social and public obligations with regard to the treatment and cure of Hansen's disease.

The participation of Cristiano Torres in the Olympic Torch Relay was an event of enormous symbolic value.

In 2002, in the run-up to the presidential election, MORHAN started a dialogue with the candidates. Only two — Luis Inacio “Lula” da Silva and Antonio Garotinho — included the elimination as part of their platform. Lula, who is now president, went further and signed a document declaring that if elected he would fight leprosy.

Two years passed, at which point MORHAN publicly aired its dissatisfaction with the government's performance, quoting author Dana Carpender's definition of insanity — “doing the same thing for many years, waiting for different results.” The following month, the health ministry announced changes in the way the leprosy elimination program was to be coordinated and the expansion of the national plan to eliminate Hansen's disease.

Soon after, another event with enormous symbolic value occurred: the participation of Cristiano Torres in the Olympic Torch Relay for the 2004 Athens Olympics. Torres, who publicly

declared he once suffered from Hansen's disease, is perhaps the first person in the world affected by the disease to have taken part in the relay.

Through his participation and statements to the media, Torres demonstrated that fighting for a worthwhile life free of prejudice can produce winners.

More recently, WHO Goodwill Ambassador Yohei Sasakawa visited Brazil. He met with representatives of the health and justice ministries and gave his support to MORHAN's efforts. He urged the authorities to do their best to meet the goal of elimination while reminding them not to overlook the prejudice and stigma people face even after they have been cured of the disease.

Looking ahead, MORHAN will promote the first National Conference of Inhabitants of Old Hospital-Colonies. The purpose is to gather material to include in a report that will serve as a study on what action can be taken at the national level to improve their quality of life. MORHAN is also putting together the first National Exhibition of Cultural Manifestations for the Elimination of Hansen's Disease, which is intended to demonstrate that in order to reduce discrimination, it is necessary to involve all members of society, especially young people.

With the medical progress that has been made, MORHAN believes it is unacceptable to see children affected by Hansen's disease or suffering visible deformity as a result. With the help of our volunteers, we will continue to campaign until we achieve a just society free of Hansen's disease and its accompanying prejudice. ■

ELKE MARAVILHA: ELIMINATION CAMPAIGNER

She's one of the best-known actresses in Brazil through her work in film and television. But there's another side to Elke Maravilha that is less well-known. For the past 15 years, she has been visiting leprosy colonies to spend time with former patients and their families.

Born in the Soviet Union to a Russian father and German mother, Elke went to Brazil right after World War II and struggled for a long time before finally establishing herself as an actress.

Never forgetting the hardships she went through in her own life, Elke now makes time to help leprosy patients, prison inmates and prostitutes, sharing their pain and encouraging them to have hope for the future.

She works closely with MORHAN, a Brazilian NGO fighting leprosy, and is an active participant in campaigns for eliminating the disease and the social stigma attached to it.

“My former husband asked me if I kissed leprosy patients,” the actress told WHO

Goodwill Ambassador Yohei Sasakawa during his recent visit to Brazil. “I said ‘Yes’ and he started hating me. So I divorced him,” she recalls with a laugh. “I'm now happily remarried, and I share my happiness with those who are less fortunate.”

Elke offers a message of hope



A Study in Contrasts

WHO Goodwill Ambassador Yohei Sasakawa's travels take him to South America — to two countries that have had very different experiences of leprosy — and to Switzerland, where the 56th Session of the Sub-Commission on the Promotion and Protection of Human Rights was being held in Geneva.

CHILE

In late June and early July 2004, I visited Chile and Brazil. My visit to Chile was primarily to attend a ceremony in connection with The Nippon Foundation's funding of a scholarship program at the University of Chile, but I also took the opportunity to learn something of the history of leprosy in Chile and the present status of the disease there.

In mainland Chile, there are almost no records of leprosy patients having existed. The only known cases were 4,000 kilometers away on Easter Island, where up until fairly recently there was a leprosy hospital and a small number of patients. Five years ago, a survey of the island's 3,000 inhabitants turned up three patients. They were of Polynesian extraction, and had contracted leprosy in Peru and elsewhere when working as bonded labor.

According to a Chilean dermatologist I met, the reasons why Chile has not suffered from leprosy include: the temperate climate; Chile's distinctive topography — a long, narrow country bordered on one side by the Pacific, and on the other by the Andes, effectively turning it into an island; and an immunity built up through BCG and other vaccination programs. He even suggested that there might be something about the Chilean DNA that kept the country free of leprosy. Based on what I have seen of leprosy, I'm not sure I agree with these reasons. But for now, it remains rather a mystery why Chile has had almost no cases of leprosy.

BRAZIL

I next went to Brazil to update myself on the current leprosy situation and attend a meeting of representatives of WHO, the Brazilian government and others involved in leprosy elimination.

Unlike Chile, Brazil is a leprosy-endemic country that, after India, has the highest number of registered cases in the world. In 2002, of the country's 5,500 municipalities, 3,521, or 60%, have registered leprosy cases. According to the most recent government statistics, there are about 80,000 patients and the PR stands at 4.52/10,000. There is a particularly high incidence of the disease in the Amazon basin and other areas where it is

difficult to provide medical services.

In my capacity as WHO Goodwill Ambassador, I met with President Luis Inacio "Lula" da Silva, and called on his government to make greater efforts for leprosy elimination. He indicated his determination to do so, saying, "We could have solved this problem of leprosy long before, but we did not try hard enough. We need to make up for lost time."

Much work will be needed. Based on what I heard from many people, the efforts of past administrations were sorely lacking. Official figures for the number of patients and the prevalence rate have remained virtually unchanged for six years, up to 2003, and the person now in charge of leprosy at the health ministry admitted that the official figures were not to be trusted.

Since the statistics published by the government fail to reflect the actual situation, this poses a real obstacle to implementing an effective elimination strategy. The present administration has recognized this, and made a number of personnel changes designed to achieve results. "We were asleep," a senior official of the health ministry confessed. Under President Lula and the new health minister,



Yohei Sasakawa meets with President Lula of Brazil (left).

however, a new strategy is taking shape. Elimination at the national level is targeted for 2005, and at the municipal level for 2010, and there is reason for optimism about the future.

If government efforts in the past may have come up short, the same cannot be said of the NGOs and volunteers that have sought to fill the gap. MORHAN (Reintegration Movement for People Affected by Hansen's Disease), an NGO set up 23 years ago by Francisco Nunes "Bacurau," himself a leprosy-affected person, has been operating a nationwide leprosy helpline called Telehansen. The toll-free service answers 18,000 calls a year. Of these, 47% are from people affected by leprosy and are mainly concerned with questions about how to diagnose leprosy and how to obtain MDT.

While Brazil still faces many difficulties, there are grounds for hope that the situation will start to improve.

In the regions, few of Brazil's health centers have resident doctors, and must rely on routine visits. As a result, there are often no doctors present when people with the disease turn up, which means they can't be examined and treated. This helps to explain why Telehansen receives so many calls on these topics.

MORHAN also wields considerable influence over the government in its capacity as a private pressure group and was very critical of the government's performance in the past. But what was apparent on this visit to Brazil was the good and constructive relationship that now exists between MORHAN and the ministry, working together in a powerful partnership toward a common goal.

There is one more aspect of Brazil's involvement with leprosy that I should like to mention: the work of well-known celebrities, two of whom I met on my visit. Actress Elke Malavilha has been meeting with residents of hospital colonies for the past 15 years (see page 5); Ney Matogrosso, one of Brazil's most popular singers, has been taking part in nationwide leprosy elimination campaigns via TV and other media.

What celebrities such as these, and groups such as MORHAN, are doing is admirable. Together with the forward-looking attitude of President Lula's administration, they left me with the impression that while Brazil still faces many difficulties, there are grounds for hope that the situation will start to improve.

Reference

- * The 26-member Sub-Commission on the Promotion and Protection of Human Rights is the main subsidiary body of the U.N. Commission on Human Rights. The 26-member Sub-Commission meets annually in Geneva.

SWITZERLAND

On July 29, I organized a working luncheon in Geneva for the members of the Sub-Commission on the Promotion and Protection of Human Rights*. The 56th Session of the Sub-Commission was being held from July 26 to August 13 and the luncheon was designed to put the problem of leprosy and human rights before members and urge the Sub-Commission to take up the issue in its agenda for discussion.

Prior to this, I had met Deputy High Commissioner for Human Rights Bertrand Ramcharan in July last year. At his suggestion, in August 2003 The Nippon Foundation led the first group of experts including people affected by leprosy to visit the Sub-Commission meeting in Geneva and raise the issue. Then, in March 2004, speaking as an NGO representative, I made the first-ever presentation on leprosy as a human rights problem at the 60th meeting of the United Nations Commission on Human Rights (UNCHR).

At the lunch I organized this summer, 22 out of the Sub-Commission's 26 members attended and heard presentations by Dr. Kenzo

Kikuni, Chair, Sasakawa Memorial Health Foundation, and me on the history and current situation of human rights violations involving leprosy-affected people.

The reaction from those present was quite positive and the chairman of the 56th session,

Mr. Soli Sorabjee, India's representative on the Sub-Commission and his country's attorney general, said on behalf of those attending, "Leprosy is an age-old phenomenon that leads to severe human rights violations. We will be happy to do something to support your movement."

Following this luncheon, the Sub-Commission adopted a unanimous resolution on August 9 to conduct an investigation and produce a working paper on the issue (see page 8 for more details).

I am pleased to note that our efforts are starting to lay the groundwork for an end to human rights violations of those affected by the disease. ■



Mr. Soli Sorabjee

U.N. Sub-Commission Takes Up Leprosy

Working paper on discrimination to be presented at next year's session

This August, at its 56th session, the Sub-Commission on the Promotion and Protection of Human Rights agreed to commission a working paper on "discrimination against leprosy victims and their families."

The Sub-Commission on the Promotion and Protection of Human Rights,

Recalling article 1 of the Universal Declaration of Human Rights, which stipulates that all human beings are born free and equal in dignity and rights,

Recalling also article 2 of the Universal Declaration, which provides that everyone is entitled to all the rights and freedoms set forth therein without distinction of any kind, such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status,

Recalling further article 5 of the Universal Declaration, which provides that no one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment,

Concerned that millions of people suffer from discrimination resulting from physical and mental illness or handicap,

Concerned in particular that tens of millions of people suffer not only from leprosy as a disease, which is scientifically and medically



Scene from last year's Sub-Commission meeting

proven to be curable and manageable, but also from political, legal, economic or social discrimination and isolation as a result of misunderstanding and indifference, and lack of legislative or administrative measures to prohibit such discrimination and to protect and remedy the victims,

Requests Mr. Yozo Yokota to prepare, without financial implications, a preliminary working paper on discrimination against leprosy victims and their families, to be submitted to the fifty-seventh session of the Sub-Commission under the agenda item entitled "Prevention of discrimination and protection of minorities."

www.nippon-foundation.or.jp/eng/leprosy/img/2004666/resolution.pdf ■

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FROM THE EDITORS

PROGRESS AND CHALLENGES

As reported on this page, the Sub-Commission on the Promotion and Protection of Human Rights has agreed to study the issue of leprosy and human rights. Should this lead eventually to the United Nations Commission on Human Rights adopting a resolution on the matter, then an historic landmark will have been achieved.

But even as progress is made on tackling the social aspects of leprosy, there is still much work to be done to eliminate the disease itself. Much of this newsletter is devoted to Brazil, where many challenges remain if the country is to achieve the goal of elimination by the end of 2005. But while Brazil has its own specific problems, as various articles point out, the lessons it offers other countries are there.

For a start, all endemic countries would do well to review their statistics and ask whether

they present an accurate picture of the leprosy situation. Effective elimination strategies and appropriate levels of funding depend on knowing the extent of the problem and what needs to be addressed.

Secondly, unequivocal commitment from the top is essential to provide the momentum necessary to move closer to elimination. President Inacio da Silva's expressed intention to tackle leprosy offers hope that Brazil will make up for lost time and get the job done after several years of government inertia.

And thirdly, the role of NGOs is very important in picking up the slack when government priorities waver, as the efforts of MORHAN have shown over two decades.

A year from now, we hope we can report more good news from Geneva and real progress from Brazil.