WHO GOODWILL AMBASSADOR'S NEWSLETTER
FOR THE
Elimination OF Leprosy

December 2008 • Number 35

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

President Lula of Brazil with MORHAN members Erica Mattos (left) and Silvia Daflon (right), at a meeting on November 18.

MESSAGE

Come On, Brazil

On November 18 I had a meeting with President Lula of Brazil. I sought his renewed commitment to eliminating leprosy.

I know President Lula takes a deep interest in leprosy and people affected by the disease. Soon after assuming office, he visited one of the country's former leprosy hospital-colonies. He also signed legislation to compensate those who suffered under Brazil's past policy of isolating leprosy patients.

Therefore, it is hard to accept that Brazil, along with Nepal, is one of only two countries still to achieve the WHO's interim goal of eliminating leprosy as a public health problem. The way things are going, it will soon be the only country — a situation I made clear to the president while requesting that he take corrective action.

On hearing that Brazil was lagging behind in achieving the elimination goal, a goal agreed at the 44th World Health Assembly in May 1991, he promised to do something. Later that night, I understand that the president, the health minister and other officials got together and decided to ask heads of municipalities around the country to make leprosy a priority, along with dengue fever.

One can't hope for progress without the momentum generated by strong leadership. In many countries, actual responsibility for dealing with the issues devolves to the municipalities, so it is imperative that this momentum carries all the way from the top to the front-line health workers.

Elimination of leprosy as a public health problem is a milestone, a strategy on the way to the ultimate goal of eradicating the disease altogether. Countries that have already achieved elimination are committed to the current WHO strategy of further reducing the number of new cases by sustaining quality services.

Therefore, let's encourage Brazil to move past the elimination milestone. It must not be left behind.

— *Yohei Sasakawa*, WHO Goodwill Ambassador

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Enhancing the Global Strategy

Informal consultation recommends innovative approaches for post-2010

Exploring ways of making the global strategy for dealing with leprosy more strategic and innovative in addressing the remaining and emerging challenges was the subject of an informal consultation organized by the WHO's Global Leprosy Program among a small group of experts on September 17–18 in New Delhi.

Chaired by Dr. S.K. Noordeen, president of the Leprosy Elimination Alliance, the meeting resulted in a number of recommendations on key technical, operational and strategic areas that will be taken into account as the WHO develops its "Enhanced Strategy for Reducing the Leprosy Burden in Endemic Countries: 2011–2015."

As a next step, a working group is being established to draw up the first draft of the "Enhanced Strategy," which will be shared with all partners and experts to get their comments and suggestions. There will also be a meeting of selected national program managers from all WHO regions, members of the International Federation of Anti-Leprosy Associations (ILEP) and other partners on April 20-22, 2009, in New Delhi.

RECOMMENDATIONS

- TARGETS. After in-depth discussion on the merits and demerits of setting numerical targets and time frames, the group recommended that the enhanced strategy for reducing the leprosy burden should include the setting of realistic numerical targets based on grade 2 disabilities among new cases, since this is likely to have an impact on reducing the occurrence of new cases in the population. The benefits of using this indicator include promoting early case detection, reducing delays in diagnosis leading to transmission, reducing stigma and discrimination, reducing costs on disability care and promoting collaboration with other partners.

- HOUSEHOLD CONTACTS. In most countries where leprosy was once highly endemic, the current leprosy profile shows a relatively low endemicity, while in others it is reaching the profile of a rare disease. Under these circumstances, the risk of leprosy among household contacts becomes significant. In areas where a high proportion of new cases are being detected among contacts, examining household contacts at the time a new case is diagnosed and providing a single dose of rifampicin to household members as a prophylaxis would be a useful measure to reduce the occurrence of leprosy in the community.

- ALTERNATIVE TREATMENT REGIMENS. The current treatment of leprosy based on WHO recommended multidrug therapy for MB and PB leprosy is unlikely to see any major changes over the next 10 years. However, the situation may be threatened by two very likely scenarios: question marks over the continuing availability of clofazimine due to pressure on the manufacturing industry, and the emergence of rifampicin resistance, which may reverse the hard-fought achievements of leprosy control. Recognizing the long duration and relatively complex studies needed for testing the efficacy and safety of newer drug regimens for anti-leprosy chemotherapy, it will be important to start testing alternative treatment regimens.

- RESEARCH. It is important to continue research, particularly in key areas of disease prevention, drug development and operational research for improving tools and methods for disease control and improving quality of clinical services, including referral services.

- CAPACITY BUILDING. Capacity building of general health services personnel is important for providing adequate services for leprosy. However, capacity-building programs should carefully assess needs and direct efforts only to areas where leprosy occurs in order that programs are efficient and cost-effective.

- ENHANCED SUPERVISION. Supervision over many programs remains weak — something seen even during the era of specialized national leprosy control programs. In the current integrated leprosy control era, there is a need for enhanced supervisory support, particularly at the field level. Appropriate resources should be made available to strengthen effective supervision at all levels.

- SPECIALIZED SERVICES. With the decreasing occurrence of leprosy, the issue of integration should be carefully reassessed so that specialized services are available where necessary and at the appropriate level.

- UNDERSERVED POPULATIONS. There is a need to focus on underserved populations so that the magnitude of leprosy among them can be assessed and locally-specific sustainable anti-leprosy activities developed with inter-sectoral collaboration. Although the current global strategy says that leprosy services should be based on the principles of equity and social justice, and accessible to all who need them, leprosy services are still not adequately available. ■

Emphasizing a 'Social Approach'

Shigeki Sakamoto lays out his ideas on anti-discrimination guidelines.

INTERVIEWEE:
Prof. Shigeki Sakamoto

In June 2009, the UN Human Rights Council unanimously adopted a groundbreaking resolution on the elimination of discrimination against persons affected by leprosy. As a follow-up, the Human Rights Council Advisory Committee has been asked to draft a set of principles and guidelines by September 2009 for the Council's consideration. The task of compiling these falls to Shigeki Sakamoto, a professor of international law at Kobe University in Japan, president of the Japanese Association of International Human Rights Law and a member of the Human Rights Council Advisory Committee. The Goodwill Ambassador's Newsletter caught up with him one afternoon in late autumn at the National Sanatorium Tama Zenshoen on the outskirts of Tokyo, which he was visiting to learn more about the issues facing people affected by leprosy.

What is your task?

On January 15, 2009, there is to be a meeting in Geneva on leprosy sponsored by the Office of the UN High Commissioner for Human Rights (OHCHR). The following day, The Nippon Foundation is organizing a separate meeting of leprosy-related NGOs to get their opinions. Based on these, I shall be drawing up principles and guidelines for the elimination of discrimination against people affected by leprosy and their family members. I want to reflect what patients, people recovered from the disease and their families really think in these guidelines.

Have you had dealings with the leprosy issue in the past?

No, this is my first experience. Following the resolution on leprosy initiated by the Japanese government and unanimously adopted by the Human Rights Council, the Human Rights Council Advisory Committee was requested to look into the issue. At the inaugural meeting of the 18-member Advisory Committee in August, I was given the responsibility of researching the issue and putting together the principles and guidelines. Now I'm learning all I can about the subject.

From your perspective, what are the main issues?

There has been a focus up to now on the care of patients and people affected by the disease, but I think the focus should be rather more on their rights. The UN Convention on the Rights of Persons with Disabilities embodies this idea. In the past, the emphasis was on a medical approach to the issue of disability, but the convention recognized the need for a social approach to address the way people with disabilities have been excluded from society. That's the way I think about leprosy also. We have to adopt a social approach.

What are you hoping to achieve?

Patients and affected persons exist around the world. Discrimination toward them has yet to be eliminated. When we think about what is necessary in order to end such discrimination, legislation is one approach. But even if you have a law that bans discrimination, discriminative social customs will remain. So in the principles and guidelines I want to include measures that can be taken to eliminate this kind of discrimination in each country. These would include stressing the importance of human rights education, and addressing mistaken ideas such as that leprosy is incurable, or that it's highly contagious. This is necessary, so that discriminatory attitudes toward people affected by leprosy do not continue into the next generation. These are the kind of guidelines I hope to produce.

Realistically, what can you get out of just two days of meetings in January?

It's true that the hearings are short, but I am already collecting the voices and opinions of people affected by leprosy, so it's not just about those two days in Geneva. I'm gathering as much information as I can in advance, and will do my best to reflect all these viewpoints. Meanwhile, the OHCHR has been collecting information about [anti-discrimination] measures taken in individual countries. I will be drawing on all this information as I compile the guidelines.

You have a lot of work to do in a limited amount of time.

Fortunately, Professor Yozo Yokota [the Special Rapporteur on leprosy discrimination for the Sub-Commission on the Promotion and Protection of Human Rights] produced reports in the past, which I intend to use. So in that sense we are not starting from zero, which is a great help.

For the January 15 meeting, the OHCHR has asked you to include discussion of the broader issue of health and human rights.

Yes, there is also a requirement to address the issue of health and human rights, so I will be adding a new section to the principles and guidelines. There are many infectious diseases apart from leprosy, and some have questioned why leprosy should be singled out. Therefore, I want to draw up the principles and guidelines in a way that will benefit the human rights of people suffering from other diseases as well. I see this as a starting point. ■

Parliament Committee Backs Petition

Report could have profound impact on status of people affected by leprosy.

In a major breakthrough for Indians affected by leprosy, a Parliamentary committee issued a report in October giving its wholesale backing to a petition calling for the integration and empowerment of people affected by leprosy.

The report of the Rajya Sabha (Upper House) Committee of Petitions comes on the heels of a controversial Supreme Court decision in September upholding a 1950 Orissa state law ruling that a leprosy patient cannot contest a civic election or hold municipal office.

The petition was submitted to Parliament through Vice President of India Shri. Hamid Ansari and signed by Mr. Ram Naik, former Union Minister of Petroleum and Natural Gas, Dr. P.K. Gopal, president of IDEA India and the National Forum, and four others.

It drew attention to the social stigma that continues to surround leprosy and the difficulties affected persons face as a result, despite the "spectacular success" medical science has had in combating the disease. It also highlighted discriminatory provisions in a total of 16 Acts, including the Hindu Marriage Act.

After hearing the petition in June, the 10-person committee undertook to visit Hyderabad, Tirupathi, Nellore, Chengalpattu, Chennai and Mumbai to see for itself self-settled leprosy colonies, rehabilitation homes, and leprosy hospitals, interacting with residents, NGOs, representatives of state governments and ministries on issues raised in the petition.

Based on its findings, the committee compiled a report containing the following observations and recommendations:

1. It called for a new survey of people affected by leprosy in India in order to help in planning and strengthening services to them and formulating any policy for their rehabilitation;

2. It recognized the need for a well-defined national policy, and stated that the government should involve people affected by leprosy in formulating it;

3. It hoped that the relevant ministries and state governments would urgently consider amendments to anachronistic and discriminatory provisions in Acts that "have hampered the empowerment of this marginalized section of society;"

4. It strongly recommended that the criteria for issuing a disability certificate for the purpose of getting a government job be wavered in the case of people affected by leprosy, and that they should be issued with a disability certificate irrespective of the degree of disability;

5. It noted that public misconceptions about the disease have resulted in people affected by leprosy being discriminated against, segregated and isolated from the community, and recommended that the health and information ministries and state governments launch a nationwide campaign to address this;

6. It strongly recommended that in all states people affected by leprosy who are unable to earn their livelihood be given a monthly allowance of 2,000 rupees;

7. It desired that the government consider enhancing the budget for special footwear;

8. It recommended that products made by people affected by leprosy be exempted from VAT;

9. It recommended that medical officers from the nearest primary health center or doctors from the nearest government hospital visit colonies at least once a week to attend to their needs;

10. It requested that the central government advise state governments to provide civic amenities in all self-settled colonies free of charge;

11. It recommended that the government ensure education up to higher secondary level, free of charge, for dependent children of people affected by leprosy;

12. It recommended that people affected by leprosy who are eligible for a driving license be provided with loans at affordable interest rates for the purchase of auto rickshaws;

13. It requested the finance ministry to advise banks to grant loans under affordable rates of interest to people affected by leprosy engaged in employment-generation programs;

14. It strongly endorsed the use of positive terminology for people affected by leprosy; and

15. It urged that the government take up its recommendations "in a time-bound manner," that all sections of society play their part in facilitating social integration, and that the media highlight issues of people affected by leprosy and give due coverage to advocacy programs. ■

QUOTE
Dr. P.K. Gopal

"It was a great achievement that the Parliamentary committee of the Upper House accepted our petition. It has created an awareness of the problems and needs of people affected by leprosy. I am sure this will help to mitigate the sufferings of the people to some extent, and also help to remove the stigma and discrimination."

Agent of Change

G. Venu Gopal is part of the National Forum's push for social integration.

G. Venu Gopal, 56, sits at his desk in the North India office of the National Forum of people affected by leprosy and reflects on the progress the organization has made in its first three years. As branch general secretary, Venu Gopal oversees a 17-strong committee that represents the interests of some 250 self-settled leprosy colonies in 10 of India's northern states.

"Now all the leprosy-affected persons of India are on one platform. We are united. We have the chance to know about each other, even though we are living in different states. We feel it is a great achievement for us. Without such unity, it would not be possible to reach the goal of socio-economic empowerment."

For Venu Gopal, it is also a great personal achievement. "I had been working in a small circle before the establishment of this National Forum office. Now I have the chance to serve many people in a broad way," he says.

> "Now I have the chance to serve many people in a broad way."

Originally from Andhra Pradesh, Venu Gopal was diagnosed with leprosy during his second year in college, leaving him unable to complete his degree. After seeing the social stigma that attached itself to his family when he was hospitalized for treatment, he decided to leave home.

Concealing his condition, he worked for a year as the assistant to the Norwegian chief engineer of a steel plant construction project. On the job, Venu Gopal picked up basic accounting and other office skills. Then he moved to Delhi after a person affected by leprosy told him there was less discrimination in the north. "You are educated," the man told him. "Come with me. You can do something."

His new acquaintance helped him to join a colony and Venu Gopal became involved in a number of different organizations. "I learned more, and asked people to show me when I didn't understand things," he says. Over time, he gained the skills and experience that he now puts to good use as National Forum branch general secretary and as a community worker for Help Age and Help Age International, for whom he monitors the welfare of 300 elderly leprosy-affected people. "It took me 10 years to learn to handle all these things. Now I am capable. I can speak six languages," he says proudly.

Venu Gopal recalls his first visit home, following his marriage to the daughter of a person affected by leprosy with whom he has three children. "When they saw I was established, some people treated me well," he says. "Gradually, things are changing. Now among our circle, nobody hates me." But facing society is still very hard, he admits. "I don't know, when I am with 100 people, if there is one person who might hate a leprosy-affected person. If there is, then I will be insulted. I am not thinking about the 99 others, I am thinking about that one person."

In their drive to empower people affected by leprosy, Venu Gopal and his National Forum colleagues are visiting every colony in every state, encouraging them to stand on their own feet and urging them to turn their back on begging. In the process, he is telling them to make income-generating projects a priority, and instructing them in how to draw up proposals for funding that can be submitted to the Sasakawa-India Leprosy Foundation (SILF), with which the Forum expects to work closely.

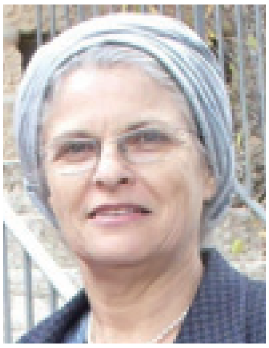
Moving forward with such applications is important, he says, because expectations among people affected by leprosy are rising. "If we only organize workshops and conferences, we won't fulfill our aims."

Venu Gopal is confident that the pace of social integration will quicken when SILF is ready to start issuing grants, but he is realistic enough to know that change won't occur overnight. "We are talking about 1 crore 20 lakhs (12 million) people affected by leprosy," he says. "There are crowds of people out there, in so many different places. They are still living in small huts; they are begging. You can imagine: is it possible to see changes in a couple of years? It is a crusade. I think it is a crusade. And I am proud that I am part of this crusade." ■

Echoes from the Past

Jerusalem's Hansen Hospital is a museum in the making

AUTHOR:
Ruth Wexler RN, MPA



Ruth Wexler is nursing director at the Israel Hansen's Disease Center. She has been working at the Hansen Hospital in Jerusalem since 1988.

The early days of the asylum (Hospital photos courtesy of Ruth Wexler)

In what today is one of Jerusalem's most affluent neighborhoods stands an impressive but nearly vacant building: the Hansen Hospital.

Established in 1887 by the city's Protestant community as the *Jesus Hilfe Asyl* (Jesus Help Asylum), it was designed by Conrad Shick, a German missionary and self-taught architect. The spacious two-story building was set in a large, walled compound containing four water cisterns, a vegetable garden, fruit trees and livestock, and was designed to be self-sufficient. Each floor had access to its own toilet via a bridge.

Built to accommodate 60 leprosy patients, the asylum was soon known as "The Leper House." It was thought of as a closed institution, but in fact patients were free to leave, and family members could come and visit.

The Herrenhut Brotherhood of the Moravian Church ran the facility between 1887 and 1950. Staff came from Europe to care for the patients, who were mostly Muslims, although there were some Christians and a few Jews. Since an effective cure did not exist, care was based on the accepted principles of hygiene, fresh air, proper nourishment, physical activity and spiritual support.

In 1948, following the establishment of the State of Israel and the division of Jerusalem, the asylum found itself on the Israeli side of the city. Some of the patients and staff left, moving to an asylum in the village of Silwan, east of the city.

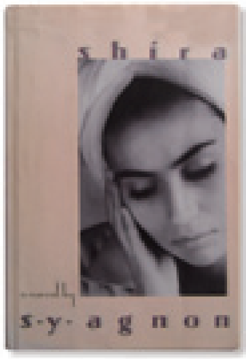
In 1950, the Moravian Church sold the entire compound to the Jewish National Fund, following which the Israeli Ministry of Health took over the running of the asylum and renamed it the Hansen Government Hospital.

With the development of multidrug therapy, patients were gradually rehabilitated and discharged. The last in-patients left the hospital in 2000.

While much of the compound has fallen into disuse, parts are still used on an outpatient basis by two units of the health ministry: the Israel Hansen's Disease Center, and the Infant Mental Health Unit.

The hospital was the subject of a two-year photo project by Yuval Yairi, whose work was exhibited in New York and Tel Aviv in 2005. It was also used as the backdrop for Israeli Nobel laureate S. Y. Agnon's novel, *Shira.*

Work is now under way to turn part of hospital into a museum focusing on its human and cultural story. ■



The building as it looks today (left), *Shira* (above)

Acknowledgment
Professor Mark N. Lowenthal
MB BCh (WWRand) FRCPE

A Meeting with President Lula

The Goodwill Ambassador travels to Brazil to get the latest on leprosy control activities there, and to offer his encouragement and support.

BRAZIL (NOVEMBER 17–19)

In November I visited Brazil for a meeting with President Luiz Inacio Lula da Silva. I have been concerned about Brazil, where the leprosy prevalence rate remains quite high at 2.8 per 10,000 population. Along with Nepal, it is one of only two countries that have yet to advance beyond the WHO's interim goal of eliminating leprosy as a public health problem. Therefore, I wanted to learn more about the nation's current situation, and what can be done to help it pass the elimination milestone.

First I met with Dr. Maria Leide de Oliveira, coordinator of the National Program for Leprosy Control at the Ministry of Health. She reminded me that multidrug therapy was introduced to Brazil in 1986, and that the federal government has made leprosy a priority. She said that it is doing its utmost to achieve elimination.

However, she pointed out that Brazil is divided into 27 states and some 5,800 municipalities, and the high level of regional and local autonomy restricts the efficacy of central policy. Consequently, the strategy for leprosy is not being applied in a uniform way across the country.

As an example of the challenges the program faces, she mentioned that in 2007, 15,000 health centers nationwide (or just 34% of all health facilities existing) were diagnosing and treating leprosy. Ideally, that number should be 20,000 to 30,000, said Dr. Leide. Another problem stems from frequent changes in health personnel at the municipal level resulting from local elections, which disrupt relationship-building efforts between the federal and municipal authorities.

Brazil detected some 40,000 new cases of leprosy in 2007, of which 7.5% were children, and 6% presented grade 2 disability. The ministry has identified 1,173 municipalities, mainly in the Amazon region, that together form 10 leprosy hot spots. These clusters account for about 50 percent of new cases nationwide.

Dr. Leide stressed that one of the national program's priorities is to reduce the detection rate of new cases in children under 15. The goal is a 10% reduction by the year 2011. She said firmly that municipalities where child cases exist ought to be ashamed.

With President Lula (left) in Brasilia on November 18

Later the same day I met with President Lula. Also present were Minster of Health Jose Gomes Temporao, Special Secretary for Human Rights Paulo de Tarso Vannuchi, Health Surveillance Secretary Dr Gerson de Oliveira Penna, Dr. Leide, and representatives of MORHAN, the influential support group for people affected by leprosy. For the outcome of this meeting see my message on page one. What emerged was President Lula's keen commitment to solving the problem of leprosy in Brazil. He made it very clear to all present that he wants to see progress made on this issue.

During my stay in the capital, Brasilia, I also called on the offices of GAMAH, an NGO supporting women affected by leprosy, and met with Mrs. Marly Araujo, the organization's president. She is a nurse, and is herself a person affected by leprosy.

Following my time in the capital, I visited Sao Paolo, where I went to the Padre Bento Hospital and the Sao Francisco de Assis Home. The latter was built in 1973, on land donated by the city. It houses the former occupants of the leprosy isolation facility that was converted into the Padre Bento Hospital after the nation's policy of isolating people with the disease was scrapped in the 1960s. Of the 80 residents, 42 are affected by leprosy; the remainder are rent-paying senior citizens.

Brazil remains a concern, but I am hopeful that my visit has spurred political efforts to renew attention on the country's leprosy burden. I shall be following its progress closely. ■

TNF, SMHF Receive Damien-Dutton Award

Foundations recognized for effective long-term concern and contributions.

Dr. Walsh (center) with Yohei Sasakawa (left) and Professor Kenzo Kiikuni

The Nippon Foundation (TNF) and the Sasakawa Memorial Health Foundation (SMHF) were jointly presented with the 2008 Damien-Dutton Award at a ceremony in Tokyo on October 10.

Named after Father Damien, the Belgian priest who cared for people with leprosy on the island of Molokai, Hawaii, and Brother Dutton, his American helper, the award is considered the most prestigious in the field of leprosy.

Making the presentation on behalf of the Damien-Dutton Society for Leprosy Aid was Board Member Dr. Douglas Walsh who said, "As many of us are well aware, these two related foundations have played and continue to play a significant role in improvements in the care and management of the worldwide leprosy problem."

Between 1995 and 1999, The Nippon Foundation funded the worldwide distribution of multidrug therapy, and the two foundations are committed to improving the dignity and self-respect of people affected by leprosy. Accepting the award on behalf of their organizations were Yohei Sasakawa, chairman of The Nippon Foundation, and Professor Kenzo Kiikuni, chair of the Sasakawa Memorial Health Foundation.

The Damien-Dutton Award was established in 1953 to honor an individual or group who has contributed significantly toward the conquest of leprosy through medical care, scientific research, rehabilitation, education, social welfare or philanthropy. The first winner was Stanley Stein, a crusading patient at the National Leprosarium in Carville, Louisiana, and founder of The Star newspaper. Other winners include Mother Theresa, John F. Kennedy, the Catholic Medical Mission Board, and the American Leprosy Missions. ■

FROM THE EDITORS

OUT OF INDIA

In September, India's Supreme Court upheld an Orissa state law declaring that a person with leprosy cannot stand for elected municipal positions. The top court was ruling on the case of a man who was disbarred from office in 2003 a few days after he was elected on the grounds that he had leprosy. The ruling came as a blow to all those campaigning for the social integration of people affected by leprosy, but served to highlight the existence of discriminatory statutes such as Orissa's.

The following month, however, there was a very positive development in India. A parliamentary committee issued a landmark report in response to a petition calling for the integration and empowerment of people affected by leprosy. Chaired by Shri M. Venkaiah Naidu, the former president of the Bharatiya Janata Party (BJP), this influential committee endorsed the petition and compiled a list of observations and recommendations to improve the lives of people affected by leprosy (see page 4).

Among these is the report's hope that the relevant ministries and state governments will urgently consider amendments to "anachronistic and discriminatory provisions in existing legislation." Given the subject of the recent Supreme Court decision, it would be heartening if Orissa became one of the first states to heed this call.

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