

FOR THE Elimination OF Leprosy

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



Yohei Sasakawa and members of his team meet with a group of people affected by leprosy during a visit to Jakarta in February.

MESSAGE

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Partnering for Progress

Recently I was asked to give the keynote address at a conference in Jakarta on neglected tropical diseases, drawing on my experiences as Goodwill Ambassador for leprosy elimination. Let me summarize my main points.

I think the fight against leprosy should be understood as a fight to ensure that everyone has correct public health information about the disease. I myself spend approximately one-third of each year traveling the world on this mission, lobbying political leaders, visiting health workers at the front line, and seeking media cooperation.

I have been helped in these efforts by the coordinating role played by the WHO in forming an effective partnership among governments of leprosy-endemic countries, ILEP members and other NGOs, donor foundations and the pharmaceutical company, Novartis. It was also extremely important that there was a numerical target and a fixed time frame for achieving leprosy elimination as a public health program. The integration of leprosy services into the general health services at the field level has also been a key element for success.

Unfortunately, however, we have not done enough to tackle stigma and discrimination. Through the launch of two separate global appeals, I am asking government leaders and concerned parties to urge the UN Human Rights Council to formally take up this issue. I am also engaging people affected by leprosy in this effort.

In order to cope effectively with these medical and social challenges, I think it will be important to join forces with other agencies such as UNICEF, the UNDP and the World Bank to form a broad international partnership. I would also suggest sensitizing NGOs dealing with social issues about our work. In addition, let us involve the private sector. I believe many companies would be willing to tackle health and stigma issues as part of their Corporate Social Responsibility.

We need to integrate the talents and capacity of many different bodies. Only then can we be confident that information about health and social issues is reaching people everywhere.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Keeping Up Quality

WHO's Dr. Pannikar discusses some of the key issues in leprosy control.

Integrating leprosy services into the general health services has been a necessary step to improve coverage and reduce stigma, but efforts are needed to ensure that the quality of services that was offered under the vertical system is sustained under an integrated system, according to the head of the WHO's Global Leprosy Program.

Interviewed recently, Dr. Vijaykumar Pannikar said integration enables more cases to be reached, and stops leprosy being seen as a special disease. But integration also necessitates simplifying the management of leprosy so that it can be done by the most basic health workers. For that reason, he said, it is important to avoid giving the impression that all there is to leprosy treatment is handing out MDT blister packs.

"Sometimes complacency sets in and people think leprosy is easy to treat. I would like to bring back the focus on the patient and case management besides multidrug therapy," he said. "There is a lot of apprehension that integration will reduce quality of services. We have to keep an eye on this."

"Integration does not mean abolishing special services."

In particular, for dealing with problems such as leprosy reaction and ulcers, he stressed the need to have a good referral system. "Integration does not mean abolishing special services but using them in a different way," said Dr. Pannikar, who argues that existing referral centers should not be closed. "Integration makes



Dr. Pannikar: Team Leader, Global Leprosy Program

INDICATORS FOR MONITORING AND EVALUATION

MAIN

1. New case detection
2. Treatment completion rate

ADDITIONAL

1. % Grade II disability
2. % female
3. % children
4. % multibacillary

QUALITY OF CARE

1. % defaulters
2. Number of relapses
3. % correctly diagnosed cases
4. % with new disabilities

the role of a referral system even more important."

With the WHO's new "Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities" now in its second year, most countries are moving ahead with leprosy control activities. However, a handful of countries have still to achieve elimination of leprosy as a public health problem — the goal established under the previous strategy.

Where these countries are concerned, Dr. Pannikar said, "All remaining countries need to achieve the goal that was set and this will certainly happen within the next few years. At the same time, they need to prepare for sustaining achievements and maintaining quality of services."

As to what "further reducing the leprosy burden" in the current strategy entails, Dr. Pannikar offered this definition:

"The leprosy burden is not about the number of cases, but about the capacity of the local health infrastructure to deal with those cases, and also the effect on the patient, family, and community," he said. "Reducing the burden is also about reducing disability, stigma and children from among new cases."

He pointed out that some countries have a higher burden than others even if the actual numbers are less. "For example, if one country has over 200,000 leprosy cases, of which only 1,000 have disabilities, while another country has only 500 cases, all of which are disabled -- which then has the higher burden?" Dr. Pannikar asked. ■

Leprosy FACT

- India reported that in 2006, a total of 144,633 new cases of leprosy were detected. Of these, 3,041 had Grade II disability, 14,589 were children under 15, and 49,112 were female. As of the end of January 2007, 90,599 leprosy patients were under treatment and the country's prevalence rate stood at 0.79/10,000.

Lessons from Madagascar

The long and bumpy road to leprosy elimination

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Madagascar achieved the goal of eliminating leprosy as a public health problem at the end of 2006. Having worked for the Leprosy Elimination Program since 1997, I would like to share some thoughts on the problems we faced and the lessons we have learned.

Following its inception in 1990, the program went through different stages. It began with the training of health workers and the dispatch of MDT and case-management tools to health centers. From 1997, new case detection/treatment activities were implemented, in the beginning focusing on high endemic areas. These activities started with a leprosy elimination campaign followed by special action projects, and were intensified in subsequent years.

As a result, the detection rate in 1997 was four times what it had been in 1996. Many new cases were detected, and many of them (around 60%) were correctly cured.

But after four or five years we noticed that the prevalence rate (PR) in some districts remained as high as ever. To check on this problem, we visited two remote, high endemic districts that had not been visited in many years. I will never forget one day-long journey of just 43 kilometers, during which we had to cross 84 damaged bridges, three-quarters of which had to be repaired with planks before we could get over them.

Through these two visits, we realized that there was a significant problem regarding the registration of leprosy cases at the peripheral level: cured patients were not being removed from the register, old cases were being registered



Obstacle en route to a remote district

as new cases, and patients were being wrongly diagnosed.

The discovery also suggested that our data was probably flawed at every level, and that the problem needed to be urgently addressed because it might be one of the reasons why Madagascar's prevalence rate remained high.

We determined that the most effective way to resolve the situation was to carry out a diagnosis validation at the peripheral level followed by a register update. As a result of taking these steps, PR began to decrease. We called this period "our final sprint," during which time we expended a lot of hard effort. On one trip to a remote health center to re-examine some leprosy patients, the motorcycles we were riding fell over three times because of the bad road conditions following the previous day's rain.

"On a journey of 43 kilometers, we had to cross 84 bridges, three-quarters needing repairs."

SOME CONCLUSIONS

In the beginning, we didn't give enough training to peripheral health workers before sending them out on active detection, resulting in over or under diagnosis. In addition, we had to cope with staff turnover, although this was unavoidable. We were also too focused on new case detection, neglecting patient follow-up, to ensure that each patient was correctly cured.

Consequently, we had to clarify our epidemiological situation by introducing a new strategy of diagnosis validation followed by register update, something that could have been avoided had we focused on quality of service from the beginning.

Furthermore, by overly concentrating on the elimination goal, we neglected the human side of patient care, such as disability management and rehabilitation.

From these experiences I believe that leprosy control should focus on quality, not quantity. If we respect quality of service, then quantity will follow. Improving quality services is the best way to reach the goal of elimination.

Reaching the goal is not the end of the road, however. Considering the problem of under diagnosis, there are many new hidden cases to be detected and cured. The post-elimination period is even harder, and we must redouble our efforts and apply the lessons learned. ■

Lest We Forget

A new national leprosy museum opens this month in Japan.

On April 1, 2007, the National Hansen's Disease Museum* opens in the western suburbs of Tokyo. Located adjacent to Tama Zenshoen, one of Japan's 13 remaining leprosy sanatoriums, it supersedes the HIH Prince Takamatsu Memorial Hansen's Disease Museum that has stood on the site since 1993. The decision to enlarge and rename the museum was taken following a landmark legal judgment in 2001.

That was the year when the Kumamoto District Court in western Japan ruled in favor of the plaintiffs in a lawsuit filed by residents of leprosy sanatoriums. The court found that the government had infringed on their human rights, as provided under the Japanese Constitution, through the policy of isolation it imposed under Japan's Leprosy Prevention Law. The law, introduced in 1907 and reinforced in 1953, was not repealed until 1996 — four decades after the World Health Organization declared in 1960 that the isolation of leprosy patients was unnecessary.

In its ruling, the court ordered the government to apologize and to pay compensation. As part of its apology, the state undertook to augment the displays at the Tokyo museum as a way to promote public awareness of leprosy and help restore the dignity of people affected by the disease. Work on the project, which included the construction of a new two-storey building, began in October 2005.

HUMAN RIGHTS

The purpose of the newly-launched national museum is to present an accurate history of leprosy so that visitors gain an understanding of all aspects of the disease, and to ensure that memories of the subject do not fade. It is also intended as a venue for thinking about the importance of human rights, and for promoting

an end to prejudice and discrimination against the disabled, the chronically ill and society's most vulnerable members.

Permanent exhibits, situated on the second floor of the new building, include the history of leprosy, sanatorium life (medical treatment, day-to-day living, work, religion, education and recreational pursuits), and the situation in other countries. There are also audiovisual testimonials by current and former sanatorium residents.

The first floor houses a video theatre, offices and meeting rooms, while the original building contains a library and space for special exhibitions.

Written explanations and audio guides for every exhibit are available in Japanese, English, Chinese and Korean.

In its previous incarnation, the museum regularly attracted visits from medical and nursing students, religious organizations, human rights bodies, women's groups, and educators, as well as members of the general public. In recent years, visits by elementary and middle school children taking human rights courses had been on the increase.

We hope that as a national museum it will now attract even more visitors. And when they go home, we trust they will have a better understanding of the history of leprosy in Japan, of why the government maintained a policy of isolating those with the disease decades after similar policies were

abandoned in other countries, of the struggle waged by people affected by leprosy over more than half a century for the restoration of human dignity and what they have been able to achieve.

Above all, if they come away with a new respect for human rights and an awareness of the need for compassion, then the museum will have done its job. ■



An exterior of a museum (above) and an exhibit depicting life in a sanatorium

AUTHOR:
Osamu Sagawa



Osamu Sagawa is a member of the steering committee of the National Hansen's Disease Museum. A person affected by leprosy, he lives in Tama Zenshoen, where he is chairperson of the Residents' Association.

Reference

* The National Hansen's Disease Museum:
www.hansen-dis.or.jp

Breaking Down Barriers

Japanese activist keeps up the fight

When Japan's Leprosy Prevention Law was formally abolished in April 1996, Michihiro Koh claimed back his real name for the first time in 45 years. The second son of a Shinto priest, he was diagnosed with leprosy at the age of 17 and admitted to the Oshima Seishoen leprosarium, located on a small island in Japan's Inland Sea, in 1951. His sudden disappearance caused consternation among his school fellows.

Upon entering the leprosarium, Koh was advised by a member of staff to change his name so as not to "cause problems" for his family. The practice reflected the deep-rooted stigma surrounding the disease, and added to the sense of dislocation felt by patients. "I still remember the shock I felt," he wrote. "It was as if my humanity, my personality, had been obliterated."

Koh was advised to change his name so as not to "cause problems" for his family.

Under the new name of "Masao Kozaki," Koh joined the residents' association of his sanatorium, and became an activist in the movement to seek the restoration of basic human rights for people affected by leprosy in Japan. By 1995, he had risen to the position of general secretary of Zen Ryo Kyo, the National Association of Residents of Hansen's Disease Sanatoriums, a post he holds to this day. It was in that capacity that he announced at a meeting of residents' association representatives on April 3, 1996, that he would start using his real name again.

"We've torn down the legal barriers to our



Koh (center): tireless campaigner for human rights

freedom," he said. "But another wall remains — the wall of prejudice and discrimination. This is not something that can be overcome in a day. It will require ongoing efforts to educate and enlighten people. Only when both these walls have been removed can we say that we have been rehabilitated and had our citizenship restored."

And there was yet another wall that had to come down — the wall within each sanatorium resident. Speaking for himself, Koh said, how could he reasonably expect prejudice to disappear from the world if he couldn't bring himself to use his own name now that the law had been abolished?

Supporting him in this action was his older brother, who understood the reasons behind his decision. But his mother was utterly opposed. The day before an interview with Koh appeared in a nationwide newspaper on May 4, 1996, a month after he had "come out," his mother died of acute heart failure. When the news reached him — on the day the article was published — his first thought was that the shock must have killed her.

PUBLIC SPEAKER

Five years later, when the Kumamoto District Court ruled in 2001 that people who had been incarcerated in sanatoriums should receive a government apology and be paid compensation (see facing page) General Secretary Koh was much in demand as a public speaker, and criss-crossed the country. But when supporters arranged for him to give a speech in his hometown, relatives resisted, in case neighbors discovered the family secret. With only his elder brother to back him, Koh abandoned the plan, but wondered why the one place he couldn't speak was his boyhood home. Eventually, his relatives relented and he returned home for the first time in 50 years.

Today, Koh lives with his wife in Tama Zenshoen in Tokyo, and remains active in the movement to eliminate stigma and discrimination. At the same time, he is at the forefront of efforts to secure the future status of Japan's 13 leprosy sanatoriums, so that the 3,000 or so surviving residents can live out the remainder of their lives with dignity and peace of mind. As their numbers decline, there is growing anxiety among residents that the government will shut down some sanatoriums or merge them with others, and Koh is working with like-minded individuals in government and society to find a solution.

He was one of the 16 people affected by leprosy who together with Goodwill Ambassador Yohei Sasakawa signed Global Appeal 2007 to end stigma and discrimination against people affected by leprosy, launched earlier this year in Manila. ■

No Slowing Down

The Goodwill Ambassador makes an overnight stop in Timor-Leste before heading to Indonesia for a conference on neglected tropical diseases.

TIMOR-LESTE (FEBRUARY 11-12)

I first went to Timor-Leste in 2005 and recently made my second visit. The country, which achieved independence from Indonesia in 2002, faces many challenges in building up the infrastructure of a properly functioning state. Following widespread violence in 2006, the situation is far from stable today. On arrival at Dili Airport I was escorted to my hotel by armed UN security guards, who were to accompany me for the duration of my stay.

My first appointment was with the WHO country representative in Timor-Leste, Dr. Alex Andjaparidze, who brought me up to date on the current leprosy situation in this small nation of 857,000 people. In 2003, the leprosy prevalence rate was 7.5/10,000. It has since dropped to 2.4, a big improvement, but far short of the elimination milestone of less than 1 case per 10,000 at the national level.

Between 2003 and 2006, 1,217 new cases were diagnosed. Of these, 888 (73%) have since completed treatment, while 222 are undergoing treatment. Unfortunately, the remaining 107 didn't finish their course of multidrug therapy. This is largely being blamed on the unstable security situation, which prevented leprosy work from being carried out to the hoped-for extent.

Concerning disability rates, in 2003 15.9% of new cases presented Grade II disability, whereas in 2006, the figure dropped to 8.5%, indicating that new cases are being detected earlier. From what I understand, there is no social stigma attached to leprosy in Timor-Leste culture, so that people with the disease do not suffer discrimination.

In a salutary reminder of the current security situation in the country, the UN vehicle that came to pick me up the next morning arrived with



Inspecting damage to a UN vehicle

cracks in the back window after it had apparently been stoned. My first call of the day was on Vice Prime Minister and Minister for Health Dr. Rui Maria de Araujo, whom I met on my previous visit in 2005. He said that the worsening security situation was a major political problem but that health services were being maintained somehow. On my next visit, he said, we should go back to Oecusse Enclave. Oecusse is a part of Timor-Leste but is actually located in West Timor, which belongs to Indonesia. The PR in Oecusse is 12.7, which compares unfavorably with Timor-Leste's other 12 provinces, where the PR ranges from 0.4 to 4.6. I urged the minister to do all he could to keep leprosy services on track.

I departed from Timor-Leste that evening for Indonesia. Only later did I learn that all roads in Dili were closed, and international flights diverted, shortly after I left. It was another indication, if one was needed, that Timor-Leste's difficulties are unlikely to be resolved any time soon.

INDONESIA (FEBRUARY 13-15)

On February 13, I called on Indonesia's Health Minister Siti Fadilah Supari. Indonesia has already achieved elimination, but it needs to make efforts to sustain the achievement, which I requested of the minister. I also asked that more be done to end discrimination.

Next, I met with Mr. Abdul Hakim Garuda Nusantara, who chairs the Indonesian National Human Rights Commission. The commission, which is independent of the government and parliament, has 20 members. When I talked to him about the social discrimination that people affected by leprosy face, the chairman candidly admitted that the commission had not paid much attention to leprosy before now. He promised that he would promptly launch an investigation and take steps to improve the situation. We also discussed plans to hold a workshop sponsored by the commission. This was a very significant visit because it linked the Indonesian Human Rights Commission to action that can be taken to alleviate discrimination against people affected by leprosy.

In the evening, I met with Indonesia's Coordinating Minister for Social Welfare Aburizal Bakrie. A former businessman who holds a 5th dan in karate, he is an extremely cheerful and dynamic character. He agreed how important it was to have a long-term strategy to



Indonesia's HM
Siti Fadilah Supari



Mr. Abdul Hakim Garuda
Nusantara

Reference

* Neglected tropical diseases affect an estimated 1 billion people, primarily poor populations living in tropical or subtropical climates. NTDs kill, impair or permanently disable millions of people each year, often resulting in life-long physical pain, social stigmatization and abuse. (Source: WHO)



Attending the partners' meeting on neglected tropical diseases in Jakarta

educate people about leprosy through public education, and also emphasized the immediate impact that poster campaigns can have. It transpires that the minister's son owns a television station, and the minister urged me to appear on TV and deliver my message. Arrangements were promptly made for me to record an interview the next day.

February 14 was the opening day of a two-day Meeting of Partners on Tropical Diseases Targeted for Elimination/Eradication* organized by the WHO's Regional Office for South-east Asia. The WHO is currently focusing on 13 neglected tropical diseases — among them leprosy, lymphatic filariasis, onchocerciasis, buruli ulcer and yaws — which are characterized as NTDs because they don't receive the same attention as other diseases like malaria and dengue fever and tend to be neglected by policy makers. This was the second such gathering of experts; the first took place in India in 2005. I was invited to deliver the keynote address and discuss the lessons to be drawn from the global leprosy elimination program.

I said I believed that the success of the elimination campaign was due to cooperation between the WHO, NGOs, pharmaceutical companies and donors; to the setting of a numerical target for elimination (less than 1 case per 10,000 population); and to the setting of a deadline (the end of 2000, later extended to the end of 2005). Speaking as a layman, I also urged that more emphasis be placed on the social aspects of leprosy, namely the stigma and discrimination that surrounds the disease, and that leprosy be seen in a human rights context.

In the afternoon, I recorded the TV interview

that had been arranged the previous day. ANTV, a nationwide commercial network, sent a camera crew to the conference site. I delivered my three simple but extremely important messages, namely, that leprosy is curable, treatment is free, and social discrimination has no place.

Taking advantage of the opportunity, I arranged for Adi Josep, one of the signatories of the Global Appeal 2007 to end stigma and discrimination against people affected by leprosy, to appear with me. They say a picture is worth a thousand words, and had there been more time I would like to have taken Adi with me to call on government figures and have them shake hands on camera. That is often the most effective way to allay people's fears about leprosy.

Late in the afternoon, I met with a group of a dozen people affected by leprosy, who had gathered in Jakarta from around the country for a meeting the next day. Organized by Adi, it was to be the first-ever meeting in Indonesia of persons affected by leprosy. I spent about 30 minutes with the group, who ranged in age from their 20s through their 40s and 50s and were determined to make their voices heard.

In recent years, I have been especially interested in helping such groups in India and elsewhere to get organized and speak out, and I was delighted to see the beginnings of such a movement in Indonesia, too. I told the group that I respected their courage and hoped that their meeting would earn a place in history.

Although my time in Timor-Leste and Indonesia was short, my meetings there reminded me again of my obligations as Goodwill Ambassador, and strengthened my resolve to fight on for a world without leprosy. ■



Mr. Aburizal Bakrie



Mr. Adi Yosep

Activists Meet with India's NHRC

Participants air concerns of people affected by leprosy

The acting head of India's National Human Rights Commission told a meeting of leprosy activists in New Delhi on March 5 that the NHRC would take up with the government the matter of laws which violate the human rights of people affected by leprosy.

Justice Dr. Shivraj Patil said that the human rights of life, liberty, equality and dignity have been enshrined in India's constitution, and that no one can deny or violate them.

Organized by the International Leprosy Union (ILU), the meeting at the NHRC was arranged to enable members of the commission to hear directly from people affected by leprosy and their supporters. Among the requests participants put to the NHRC were for help in ensuring that the basic human rights of the leprosy-affected are respected, support in getting the Law Commission to review discriminatory laws, and efforts to ensure that the legal system is free from discrimination.

One of those taking part, Kamalesh Divyadarshi, pointed out that although leprosy is today a curable disease, there is still mention of it being "incurable" in the law, and he suggested that elected members and representatives should be educated about the disease.

Justice Patil requested that the ILU present a

proposal for a workshop on human rights and leprosy to create awareness about the disease, and the ILU is now following this up.

NATIONAL FORUM WORKSHOP

A capacity-building workshop for state leaders of people affected by leprosy in India was held in Chennai in March. Organized jointly by the National Forum of leprosy-affected persons and IDEA India, the meeting brought together leaders from 10 states in the south, east and west of the country.

The workshop focused on networking, organizing and capacity building so as to enable people affected by leprosy to become agents of change in improving their lives. Some 40 people participated, most of them residents of colonies.

DAY OF DIGNITY AND RESPECT

HANDA Rehabilitation and Welfare Association marked the 9th International Day of Dignity and Respect on March 11 with commemorative events in Guandong, Guangxi and Yunnan provinces of China. The day, which promotes dignity and respect for people affected by leprosy, included performances, tea parties, and visits to leprosy villages, and was well covered in local media. ■

FROM THE EDITORS

PRESERVING HISTORY

A new national leprosy museum opens this month in Japan. As Osamu Sagawa explains on page 4, an important purpose of the museum is to ensure that leprosy, and the many lessons to be drawn from Japan's experience leprosy, are not forgotten.

As such, the museum acts as a monument to all those people whose lives were turned upside down by leprosy and by the legislation adopted to deal with it. It also serves a warning to present and future generations about the need to respect human rights and treat one's fellow human beings with justice and compassion.

Above all, it asks us to ask questions, and consider what is done in the name of society, since for all too long society was content to ignore the basic rights of the people it placed behind sanatorium walls. Don't just look and listen, the museum urges, but stop and think, and ask

yourself 'why?'

As a new museum opens, an old institution is on the verge of closure. The situation involving the Losheng Sanatorium in Taipei (see From the Editors #23) has entered a new phase, with the forcible eviction of the remnants of its elderly population now set for later this month.

Their impending removal has attracted increasingly high-profile demonstrations, but these may have come to late to save the hospital from being leveled and the land used for the construction of part of a mass transit system. Advocates, who would like to see the leprosarium preserved as a historic site, are angered at the disruption to lives of its residents.

The themes of dislocation and upheaval, and the violation of human rights, are dealt with at the Japan's museum, but they are also being played out right now in Taiwan.

FOR THE ELIMINATION OF LEPROSY

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