

# FOR THE Elimination OF Leprosy

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



Prakash Adhikari, editor of Nepal's Rajdhani National Daily, interviews a member of a leprosy self-care group in Mahottari district in April.

**MESSAGE**

## Encouraging Words

In May I went to Geneva for the 62nd World Health Assembly. While there, I had meetings with two top leaders. One was Dr. Margaret Chan, the director-general of the World Health Organization. The other was Dr. Navanethem Pillay, UN High Commissioner for Human Rights, who assumed the post last September.

Since the outbreak of the new strain of influenza, Dr. Chan has had a punishing schedule. Therefore, I much appreciated her presence at a small meeting on leprosy elimination. In response to my remark that the last mile of a 100-mile journey is the hardest, Dr. Chan recalled the lessons of small-pox eradication, when “energy, resources and political commitment” were needed to finish the journey. As for leprosy elimination, the director-general said that the “energetic, persistent and consistent global effort” of the goodwill ambassador would surely ensure the completion of this journey, too.

Dr. Pillay is a South African Tamil. Born in a poor neighborhood, she grew up to be a lawyer, courageously defending opponents of apartheid.

She was elected Judge President of the International Criminal Tribunal for Rwanda and has served as a judge on the International Criminal Court in The Hague. Throughout her career, she has stood up for the rights of the weak and oppressed.

She expressed surprise that leprosy had not been taken up as a human rights concern at the UN until relatively recently, and complimented the Japanese government for bringing the matter before the Human Rights Council. Her office, she assured me, would be following the subject closely.

Between them, Dr. Chan and Dr. Pillay grasp the medical and social issues surrounding leprosy and have demonstrated their unwavering support for eliminating the disease and rooting out stigma and discrimination. Hence I want to share their words of encouragement with national governments, NGOs, health workers, and of course people affected by leprosy and their families. Together let us walk the “final mile” and move nearer to our ultimate goal of a leprosy-free world.

— Yohei Sasakawa, WHO Goodwill Ambassador

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# Enhanced Global Strategy Takes Shape

Program managers, partners meet in India and agree on new target for 2011-2015.

A new global target for leprosy has been agreed following a three-day Global Leprosy Program Managers Meeting in New Delhi to discuss leprosy control strategy for 2011-2015.

The new target is a reduction in the rate of new cases with Grade 2 disabilities per 100,000 population by at least 35% by the end of 2015, compared to the baseline at the beginning of 2011. Such a reduction would indicate that leprosy is being detected early before nerve damage leading to impairments and disabilities.

Making new cases with Grade 2 disabilities the key indicator to monitor progress was one of a number of enhancements to the current leprosy strategy for 2006-2010 that emerged from the April 22-24 discussions at the WHO's South East Asia Regional Office.

Delegates included over 40 National Leprosy Program Managers from around the world as well as members of the WHO Technical Advisory Group (TAG) for Leprosy. Also represented were international NGOs and organizations of persons affected by leprosy, the Novartis Foundation for Sustainable Development, which donates the drugs used to treat leprosy, and The Nippon Foundation, which sponsored the meeting.

Under consideration was the *Enhanced Global Strategy for Further Reducing the Disease Burden Due to Leprosy (2011-2015)*. This is formulated as a natural extension of WHO's earlier strategies and intended, along with the accompanying *Operational Guidelines*, to serve as a basis for each national leprosy program to develop its own country-specific strategy.

## HOUSEHOLD CONTACTS

Another enhancement agreed to at the meeting was to examine all household contacts of newly detected cases, as household contacts of leprosy patients are at significantly greater risk of developing leprosy than contacts that are not living in the same household.

Although this was recommended in June 1997 by the 7th WHO Expert Committee, there has only been limited implementation of this strategy due to concerns over exacerbating stigma and difficulties in implementation. However, the re-introduction of this examination policy is regarded as a positive step that could have the potential to detect cases earlier and prevent disabilities, even though much remains to be discovered about infection and transmission of leprosy.

The *Enhanced Global Strategy* will be further boosted by:

- Reinforcement of the humanitarian issues and rights of people affected by leprosy and absolute assurance of equity and social justice
- Rigorous advocacy of the use of more dignifying terminology whenever talking about or referring to people affected by leprosy
- Stress on the particular needs for improved leprosy control in underserved areas including urban slums and migrant populations
- Highlighting of opportunities to explore public-private partnerships
- Assurance of quality clinical services
- Training of peripheral health workers so they can refer people affected by leprosy to the appropriate

## Leprosy FACT

- At the beginning of 2008, a total of 218,605 leprosy cases were registered for treatment in the world. The number of new cases reported during 2007 was 258,133.



The three-day meeting at WHO SEARO in New Delhi achieved consensus on leprosy control strategy for 2011-2015.



*Left:* National program managers Dr. Jean Norbert L. Mputu (DR Congo) and Dr. Alcino Ndeve (Mozambique); *Right:* Professor Diana Lockwood of the London School of Hygiene & Tropical Medicine is flanked by LEPRAs Terry Vasey and Dr. P V Ranganadha Rao.

- services according to their personal needs
- More holistic assessments of the needs of each person affected by leprosy and provision of appropriate support under community based rehabilitation.
- Promoting further research in the area of chemoprophylaxis for future use as a control measure and in developing better treatment regimens with shorter duration of treatment.

On the question of drug security, the Novartis Foundation reiterated its commitment to providing the drugs used in multidrug therapy (MDT) free of charge.

**GUIDING PRINCIPLES**

Underpinning the *Enhanced Global Strategy* will be a renewed commitment to the main principles of leprosy control outlined in the current strategy, namely, the timely detection of new cases and their treatment with MDT, and quality patient care

that is equitably distributed, affordable and easily accessible. These will continue to form the basis of the strategy for 2011-2015.

Participants had had several opportunities in the months leading up to the meeting to submit their comments and feedback on earlier drafts of the *Enhanced Global Strategy* and the accompanying *Operational Guidelines*. As a result of this consultative process, the meeting was able to concentrate on the enhancements that had been proposed.

In a statement, the WHO said: “A great deal of serious thought and deliberation, considerable time and effort has been dedicated to finalizing this global leprosy strategy. The interest and ideas of those who have contributed to this process is evidence of the clear and continuing commitment to provide quality care for all individuals affected by leprosy wherever they are in the world, and to build on the considerable progress already made in reducing the burden of this disease.” ■

**TARGETING GRADE 2 DISABILITIES**

**INDICATOR IS ‘ROBUST MARKER’**

The rate of new cases with Grade 2 disabilities per 100,000 population was proposed as the new target because it is less influenced by operational factors than other indicators, it focuses attention on impairments that are critical to persons affected by leprosy and it stimulates improvements in case detection.

It is a “robust marker” of the level of occurrence of leprosy in the community and operationally it is easier to recognize compared to the early signs of the disease.

Reported data show a downward trend in new cases with Grade 2 disabilities. A reduction in new cases with Grade 2 disabilities is expected to reflect a reduction in the total number of new cases.

When reviewed together with other indicators,

the indicator of new cases detected with Grade 2 disabilities can be used to estimate under-detection; measure the impact on the need for physical and social rehabilitation; advocate the use of prevention of disabilities activities; and promote collaboration with other sectors.

In addition, the use of this indicator will help to put emphasis on the issues that are important to persons affected by leprosy, governments and non-governmental organizations, donors and other partners.

The new target as initially proposed called for reducing the rate of cases with Grade 2 disabilities by 50%, but this was scaled back to 35% based on the response from national program managers at the April meeting.

# An Uncertain Cure

Medical anthropologist examines the patient experience in Brazil.

In the era of multidrug therapy (MDT), the treatment program that has transformed leprosy from a chronic disease requiring lifelong surveillance into one that can be treated and cured on an outpatient basis, the title of Cassandra White's book catches the eye. Dr. White, an assistant professor in the department of anthropology at Georgia State University, has made a study of how leprosy affects the daily lives of people in Brazil and the ways that economic and social realities constrain their attempts to get well.

She carried out the bulk of her research in 1998 and 1999. During those years, and on subsequent trips, she conducted in-depth interviews with 41 persons diagnosed with leprosy and two more who were being tested, and took field notes on the clinic visits of 144 separate individuals. She also interviewed 14 people who work with leprosy. Most of her research was done in Rio de Janeiro, at a referral center that primarily served patients living in the city's industrial North Zone and in the working-class suburban municipalities to Rio's north.

Dr. White's interviewees were from the *favelas*, or shantytowns, from low-income government housing, or lower middle class neighborhoods. While discarding the stereotypes of all favelas as dangerous, crime-ridden and filthy, she acknowledges problems *favelados* face, including flooding, poor sanitation, prevalence of disease, violence and economic hardship.

Conditions such as these provide a clue as to why leprosy persists in Brazil, Dr. White contends: the disease is a byproduct of structural factors, including an unequal distribution of wealth, power and healthcare services, which have negatively affected the health of the poor in Brazil. Added to that, for the individuals she met in Rio whose health, social life and work situation had changed because of the disease, "leprosy tended to exacerbate the problems of being poor in this Brazilian megacity."

The 'uncertain cure' of the title arises from the difference between how the medical establishment defines the cure for leprosy and

how the patient perceives it. Leprosy is cured with MDT within 6 to 12 months, yet someone who has been technically cured of the disease may continue to suffer from leprosy reaction, or may be permanently impaired because they were late to start treatment. As Dr. White writes of one of her interviewees, who had suffered severe nerve damage to his feet as a result of leprosy, "Celso was skeptical that leprosy was curable; to be cured, for him, would mean a return to the way life was before he began noticing symptoms."

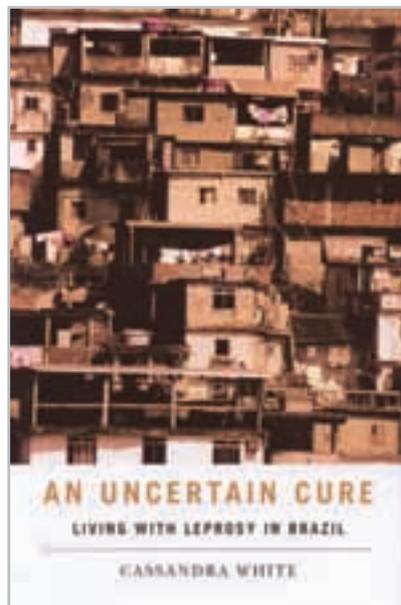
Having observed healthcare workers argue with patients, telling them that they were "cured" and no longer had leprosy, even though they were still experiencing symptoms that were related to the disease, Dr. White suggests healthcare workers should find a way to acknowledge patients' suffering while helping them to understand the process of treatment for leprosy reaction. This is a lesson not to be lost on anyone treating the disease and its aftermath.

A chapter is devoted to the complexities of stigma — on the job, among friends and neighbors, within the family — and the book also addresses the campaign to rename *lepra* (leprosy) as *hanseniasis* (Hansen's disease) as a way to reduce the stigma associated with the disease. Interestingly, among the people Dr. White interviewed, there was a wide range of understanding and interpretation of the two

terms. While many knew *lepra* as a synonym for *hanseniasis*, a few believed it was what they would get if they did not comply with the treatment program for *hanseniasis*, while still others did not associate *hanseniasis* with *lepra* at all.

Some of the individuals featured in *An Uncertain Cure* sail through their treatment with relative ease and only minimum disruption to their lives; others experience a range of physical, social and economic problems as a result of their disease.

All are given a voice in this sensitive and well-documented study of the leprosy experience among low-income and working-class Brazilians which, while firmly rooted in its cultural context, succeeds in conveying what it is like for people to cope with leprosy. ■



## An Uncertain Cure: Living with Leprosy in Brazil

By Cassandra White, Rutgers University Press (February 2009)

# ‘Passion, Persistence, Patience’

No let-up in efforts to control leprosy and reduce the disease burden.

Goodwill Ambassador Yohei Sasakawa traveled to Geneva in May for the 62nd World Health Assembly. On May 21 and 22, on the sidelines of the assembly, he met with representatives of governments and international organizations to discuss leprosy issues.

In a meeting with Francisco T. Duque, Secretary of the Department of Health of the Philippines, he thanked the Philippine government for supporting last June’s Human Rights Council Resolution 8/13 calling for an end to stigma and discrimination against persons affected by leprosy and their families. He also had praise for Dr. Arturo Cunanan, head of the technical division of the Culsion Leprosy and Rehabilitation Program, for his work not only in the Philippines, but also recently in Nepal, where he conducted technical training.

In a meeting with Dr. Suriya Wongkongkathep, Senior Health Supervisor at the Office of Health Inspector General of Thailand’s Ministry of Public Health, he similarly thanked the Thai government for its support of HRC Resolution 8/13. For his part, Dr. Suriya Wongkongkathep said that Thailand had conducted some intensive case-finding activities three years ago and was now focused on assuring quality leprosy services.

In a brief meeting with Zambia’s health minister, Kapemba Simbao, the Goodwill Ambassador said that he looked forward to visiting Zambia over the summer to learn more about that country’s leprosy control program.

## WORKING LUNCH

During a working lunch attended by WHO Director-General Margaret Chan, Dr. Plianbangchang Samlee, WHO Regional Director for South East Asia, and Dr. Mirta Roses, WHO Regional Director for the Americas, and others, Dr. Chan honored the Goodwill Ambassador by saying that she appreciated his “energetic, persistent and consistent global effort” for leprosy.

Dr. Roses underlined the necessity for “passion,

persistence and patience.” With reference to Brazil, which still has to deal with many new cases of leprosy each year, she said the country was using “a different language” in its approach to tackling the disease. However, she stressed that this did not signal a lack of commitment to reducing the leprosy burden, and added that full surveillance of Brazil’s leprosy control activities was being planned.

In a meeting with Dr. Kyaw Myint of Myanmar’s Ministry of Health, Dr. Myint told the Goodwill Ambassador that the leprosy prevalence rate in Myanmar continues to fall. Early detection and treatment are contributing to a decrease in cases with disability, which in turn results in a lessening of stigma. As part of this effort, Myanmar is conducting leprosy awareness campaigns on television.

Professor P. I. Garrido, Mozambique’s Minister of Health, said in a meeting that Mozambique had achieved elimination at the national level at the end of 2007, but that the president waited to make a formal announcement until the following year. By then, Mozambique had achieved elimination at the provincial level too. The country is now focusing on specific districts where the prevalence rate remains high, he said.



Dr. Pillay (left) with Yohei Sasakawa

On May 22, the Goodwill Ambassador met with Dr. Navanethem Pillay, UN High Commissioner for Human Rights, when he explained the background to his efforts to bring leprosy to the attention of UN human rights experts. Dr. Pillay, who was appointed last September, expressed surprise that leprosy had not been taken up as a human rights issue in the past. She commended the Goodwill Ambassador’s continuous efforts to draw attention to the issue and acknowledged the initiative taken by the Japanese government in overseeing the passage of resolution 8/13. She said she looked forward to the report that the HRC Advisory Committee was preparing on leprosy and human rights, and promised that her office would remain fully focused on the issue. ■



Dr. Mirta Roses

Dr. Margaret Chan

# Enlisting the Help of Nepal's Media

Recent visit spent in the company of reporters promotes coverage of leprosy.

## MARCH (APRIL 24-27)

In my role as Goodwill Ambassador, I believe that reaching out to the media is especially important. Drawing the attention of the press to the issues surrounding leprosy and having leprosy covered in an appropriate way leads to the public being better informed. This gives people the knowledge and encouragement to seek treatment and serves to debunk myths about the disease.

Thus I was delighted that my latest visit to Nepal was spent in the company of five local print, radio and television journalists, who would be reporting on my activities during my four-day stay. In addition, I took part in two well-attended interactions with journalists, one in the capital Kathmandu, and the other in Janakpur, Dhanusha district. These were designed to brief media about the disease and to enlist their greater involvement in Nepal's bid to eliminate leprosy as a public health program.

Nepal's health authorities believe that they will be able to reach the elimination milestone of less than one case per 10,000 population by the end of this year. As of mid-March, 3,165 patients were registered for treatment and the prevalence rate stood at 1.16. The burden of the disease is mostly in the Terai belt and some hilly districts in Nepal's Mid-Western and Far-Western regions.

On arrival in Kathmandu, I paid a courtesy call on Minister of Health and Population Girimajrani Pokharel, apologizing for visiting him on a holiday. "This is not a holiday for me," he replied. "We don't take holidays in the midst of this important work."

In the afternoon I attended a workshop at READ-Nepal. Under the leadership of Raj

Kumar Shah, this local NGO's mission is to improve the socio-economic status of people affected by leprosy and other persons with disabilities. It is now working to ensure that their voices are reflected in the new constitution of Nepal that is being written.

READ-Nepal recently completed an eight-bed ward for ulcer care and I was asked to perform a ribbon-cutting ceremony to formally open it. Later I addressed the 50 or so attending the workshop. Among those joining me on the dais were Dr. Garib Das Thakur, director of the health ministry's Leprosy Control Division.

**"As journalists, we must discharge our social responsibilities," Mr. Jha said.**

The tireless Dr. Thakur was one of the main speakers that evening at the first interaction with journalists at a Kathmandu hotel, briefing them on the progress Nepal is making tackling leprosy, and stressing that the leprosy elimination program is a government priority. He also accompanied my party to Danusha and Mahottari districts in the Terai the following day, where a second get-together with local journalists had been arranged in Janakpur.

"This is a poor, impoverished area," Dr. Thakur said to the assembled media. "But with your help we can achieve the elimination goal. Tell people that leprosy is not a curse. Let them know that treatment is free."

Both the Kathmandu and Janakpur events were arranged in cooperation with the president



With Raj Kumar Shah (2nd from left) and Dr. Thakur (2nd from right) at the READ-Nepal workshop



Dhamendra Jha, president of the Federation of Nepali Journalists, speaking in Kathmandu



Devpura subhealth post near Janakpur, Danusha district

of the Federation of Nepali Journalists, Dharmendra Jha. Addressing his colleagues in Janakpur, he said that the goodwill ambassador had come all the way from Japan to fight leprosy, and it would not do for the media to remain silent on such an important issue. “As journalists, we have to discharge our social responsibility,” Mr. Jha said.

Danusha and Mahottari are among two of four districts served by Lalgadh Leprosy Services Center, the NGO run by Nepal Leprosy Trust. LLSC serves a key role as a leprosy treatment and referral center in support of the government’s leprosy control program. Beyond that it performs many other important functions, including capacity building of health workers, building community awareness of leprosy via educational dramas, and organizing community-based empowerment and rehabilitation activities.\*

I was able to see for myself an excellent example of the good work done by LLSC when I was taken to visit Loharpatti Primary Health Center in Mahottari district. The journey took about one hour by car from Janakpur along a dusty, unpaved road busy with carts, bicycles, pedestrians and the occasional bus. Here I met with a self-help group of some 30 persons affected by leprosy that gets together once a week.

This is one of 10 groups started between 2002 and 2004 by LLSC, which gave them training in how to prevent disability and encouraged them to conduct self-care camps for others. From these beginnings, the group has reached out to other disabled and marginalized people. It has embarked on income-generation projects working with loans provided by LLSC, and it has used some of these loans to support a

women’s development group.

In this way, the group members have served as agents of change within their community, and now work along side village committees tackling issues such as hygiene and sanitation.

One of the results has been a reduction in stigma through interaction with other members of the community, who have responded positively to what they are doing. “By helping

the village, we are contributing to society,” says Muslim Momen, the head of the group.

I learned later that when LLSC first approached Mr. Momen to serve as leader, he denied that he had been a leprosy patient. Such was the stigma attached to the



Muslim Momen

disease that it took several attempts before he could be persuaded to get involved.

Shortly after I left Nepal, the prime minister resigned, plunging the country into political chaos. A new cabinet was being selected as this newsletter went to press. Assisted by the WHO and other partners, the health authorities have been taking leprosy very seriously. The strategies and activities of the leprosy elimination program have been strengthened and upgraded. I hope that the work of the leprosy control division will continue unchanged under the new government. In the meantime, I would like to thank the journalists who accompanied me for their coverage of my visit and I hope they will keep leprosy in their sights. ■

**Reference**

\* Sasakawa Memorial Health Foundation has been supporting Nepal Leprosy Trust activities, especially educational street dramas, since 1999.

# ASEC-TNF Project Set to Begin

New initiative on leprosy and human dignity to be launched on June 15.

The ASEC-TNF Project on Leprosy and Human Dignity will be inaugurated this month at a ceremony in Jakarta, Indonesia. A joint initiative of the Association of Southeast Asian Nations Secretariat and The Nippon Foundation, the five-year project aims to address the social and economic consequences of leprosy in Southeast Asia.

The new project will focus on empowerment workshops, the creation of networks of people affected by leprosy, capacity-building programs and the formation of partnerships with different sectors, including the business community, with the goal of achieving a society in which people affected by leprosy can live with dignity.

## PROFESSOR TURKAN SAYLAN



Thousands of people turned out for the funeral of Professor Turkan Saylan in Istanbul on May 19. Professor Saylan, who died of cancer the previous day at the age of 74, gained an international reputation for her leprosy work. She was ahead of her time in appreciating that it was necessary to address patients' social and economic needs as well as treating them with drugs. In recognition of her efforts, she was presented with the International Gandhi Award in 1986.

In Turkey, she was best known as the founder, in 1989, of the Association in Support of Contemporary Living, an organization that built schools and financed the education of poor students, especially girls, from some of Turkey's most impoverished regions.

## HISTORIC DECISION IN DELHI

The Delhi state government has invited the president and secretary of the Delhi Leprosy Patients Union to join the Advisory Board of the Delhi Social Welfare Department. This is the first time that people affected by leprosy have been invited to serve on the board.

Commenting on the groundbreaking decision,

Mr. G. Venu Gopal of the National Forum of people affected by leprosy, said, "It provides us with a chance to throw away the crutches — in the shape of other people — that we have been using for our requirements and to tackle matters by ourselves. We hope the decision of the Delhi government will serve as a model for all other state governments." ■

## FROM THE EDITORS

### UNCHANGING GOAL

When program managers and partners endorsed the *Enhanced Global Strategy* for leprosy 2011-2015 in New Delhi recently, they fixed in place an important next step on the journey to eradicate this age-old disease. The basic principles remain early detection, proper diagnosis, and prompt treatment with MDT, combined with quality patient care available to all who need it on an equitable basis. But for these principles to be uniformly applied, there must be effective and efficient leprosy control activities in all endemic countries. Also essential are awareness campaigns that educate people about the disease and its treatment, and that counter erroneous beliefs that give rise to stigma and discrimination.

Past strategies have brought success, yet

success breeds complacency. As the disease burden declines, much work must be done to reaffirm national and local commitment to tackling leprosy in the face of many other competing demands. Now more than ever, strong partnerships and the prioritizing of resources will be important to ensure that the goals of the enhanced strategy are achieved.

Beyond these goals lies the ultimate vision of a world without leprosy. Based on current knowledge of the disease, the scientific consensus is that complete eradication of leprosy is not feasible. Yet that seems no reason to question, as one delegate did in New Delhi, the inclusion of this vision in the enhanced strategy. As another delegate gently chided, nowhere is it written that we'll never find the answers.

## FOR THE ELIMINATION OF LEPROSY

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With support from:

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Health Foundation,

The Nippon Foundation

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