

# FOR THE Elimination OF Leprosy

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



Yohei Sasakawa (right) at Kokhana leprosy village, Nepal, in 2004: field visits are an important aspect of the goodwill ambassador's mission.

## A MESSAGE FROM THE GOODWILL AMBASSADOR

## CONTENTS

### Beyond 2005

Ever since I was appointed WHO goodwill ambassador for leprosy elimination, I have given this role my highest priority. I do not regard it as an honorary title but one I must earn every day.

For me, the most important part of the job has been going out into the field. This means visiting countries that have yet to achieve elimination; gaining the understanding of political leaders; encouraging health workers, NGOs and others at the front line; and enlisting media support. Above all, it means getting to know persons affected by the disease personally, and helping to rally everyone around our common goal of elimination.

My father was deeply touched by the miserable medical and social predicament of patients and cured persons, and made it his mission to do everything he could to help them. Until his death at the age of 96, he worked tirelessly on their behalf. In fact, from the age of 80 until the end of his life, he made more than 100 trips abroad for this and other purposes.

In the 10 years since his death, much progress has been made. But we are by no

means near the end of the fight, even though we are in the process of passing the elimination milestone, with all but a few countries having already reached the WHO goal.

Given the nature of the disease, the annual number of new cases will continue to top the 100,000-mark for the foreseeable future. Nor must we neglect the needs of those recovered persons who are prone to ulcers and other ailments as a result of nerve damage sustained before they were treated.

Meanwhile, the battle to restore the dignity of leprosy-affected persons and enable them to participate fully in society is really just beginning, after centuries of discrimination and neglect.

As the end of 2005 draws near, I am calmly awaiting the outcome of the elimination strategy and thinking about the next step. Whatever the result, there is plenty still to do. I intend to work for the day when leprosy is no more, and I look forward to your continued support.

— Yohei Sasakawa, WHO Goodwill Ambassador

<b>Message</b>	<b>1</b>
<b>Media Workshops</b> Showing leprosy in a new light	<b>2</b>
<b>Special Report</b> Success brings new challenges	<b>4</b>
<b>Ambassador's Journal</b> Two visits to India	<b>5</b>
<b>Human Story</b> A tale from Tanzania	<b>7</b>
<b>News</b> Meeting on "neglected" diseases	<b>8</b>
<b>From the Editors</b>	<b>8</b>

# Cultivating the Press

Media Partner Workshops are designed to show the Indian media that there is another way to portray leprosy — not as a dreaded disease but as a source of inspiring stories.

In India, the need to sensitize the press on the subject of leprosy has been felt for some time. Participants at several workshops on “Advocacy Strategies and the Role of Media for the Elimination of Leprosy,” held in the high endemic states in 2004 and 2005, all urged that this be done.

As a result, a number of Media Partnership Workshops have been held across India in the latter part of 2005, organized by communications consultancy ICONS Media in association with the International Leprosy Union (ILU) and IDEA India, and with support from the Sasakawa Memorial Health Foundation (SMHF) and The Nippon Foundation (TNF).

## OBJECTIVES

The workshops have several objectives, among the most important being to familiarize the media with leprosy, raise awareness of the movement to attain the dignity and socio-economic integration of cured persons, discuss ways of fighting social stigma and discrimination, and discourage sensationalist coverage and the use of derogatory terms such as “leper.”

They are also an opportunity for leprosy activists to network with journalists covering health, development and social issues; to create a support base within the mainstream media; and to put leprosy into the national “mind-space” via newspaper and television coverage.

A short-term goal is to build up a groundswell of media interest in leprosy in the run-up to the first ever national forum of leprosy-affected persons scheduled for Delhi on December 19, where cured persons and colony representatives will discuss the possibility of forming a national network.

## FORMAT

The media partnership workshops are typically divided into three parts. First, a documentary film is shown that gives a general introduction to the disease. This is followed by an inaugural session featuring the WHO goodwill ambassador, the state governor and the state health minister, accompanied by leading leprosy activists who address participants about the disease, stigma and the role that the media can play. Finally, doctors, cured persons and social activists address the audience on specific issues related to the medical and social aspects of the disease.

## AUTHOR:

**Professor Ujjwal K. Chowdhury**



Professor Chowdhury is a director of ICONS Media and a media advisor to the government of India (Ministry of Textiles).



Media workshops generate good coverage.

## UNDERLYING MESSAGES

Underpinning the workshops are the three messages championed by the WHO goodwill ambassador — that leprosy is curable, treatment is free and readily available, and that there is no place for discrimination.

The workshops also take aim at myths and prejudices surrounding the disease, emphasizing that leprosy is very hard to transmit — it can't be caught by touching or shaking hands — and is not the result of a person's transgressions in a past life.

The medical discussions include information about what leprosy is; signs and symptoms; treatment; the importance of early detection; self-care; prevention of disabilities; and reconstructive surgery.

The discussions on the social aspects of the disease focus on both social and economic rehabilitation and ways of empowering persons affected by leprosy. Examples are drawn from the work of NGOs and experts in the field.

In particular, the workshops stress the role the media can play in combating the stigma surrounding leprosy by creating positive, humanistic portraits of people affected by the disease.

Backing this up are the personal testimonies of

cured persons, giving participating media the opportunity to get to know first-hand the stories of those whose lives have been affected by the disease, the struggles they have faced and how they have coped.

At time of writing, sessions have been held in Kolkata (110 participants); Patna (120); Guwahati (75); and Lucknow (170), with more sessions planned for Chennai, Jaipur, Ranchi, Ahmedabad, and Pune.

Among those taking part have been government health department officials, representatives of WHO, ILU, IDEA India, local NGOs and ILEP agencies, cured persons, local representatives from most major newspapers and television stations, and contingents from the leading media schools in the state.

Coverage of the workshops has generally been good, often featuring interviews with the WHO goodwill ambassador as well as leprosy activists such as Dr P. K. Gopal (IDEA India) and Dr S. D. Gokhale (ILU).



The goodwill ambassador (right) meets the Indian media

### REACTIONS OF PARTICIPANTS

Archiman Bhaduri, a senior journalist with *The Times of India* in Kolkata, said that until he attended the Kolkata workshop, stories about leprosy had never been a topic of interest because they don't sell the next day's newspapers. "But the workshop opened my eyes to some harsh facts about our society. It also made me realize there are some very positive stories out there."

He said he appreciated the opportunity to speak both with cured persons and those working closely with them, and said that the workshop brought home to him the truth of the statement: "Half the world doesn't know how the other half lives."

Aneeta Tewari, senior sub-editor of the *Hindustan Times* Lucknow edition, was assigned to cover the workshop held in that city. "Initially it

seemed like a routine assignment," she said, "but the workshop provided me with a new insight and objective in life."

Exposure to the work of the WHO goodwill ambassador "shook my conscience as an educated journalist," she said. Hearing of the way patients can be disowned by their own family members "made me to decide to contribute my own resources toward eradication of the disease and its associated social stigma."

**"The workshop opened my eyes to some harsh facts about our society."**

She was also inspired by the "shining example" of Dr. Gopal, whose struggle with the disease as a young man interrupted his studies but who went on to become an activist in the worldwide fight against leprosy and discrimination.

From starting out as a routine assignment, Tewari's report grew to fill over one page of her newspaper. "The story aimed at clearing myths about leprosy, providing confidence to affected persons in their fight against the disease and increasing social awareness to dispel the stigma associated with it," she said.

Hitendra K. Patel, a senior lecturer in the Department of History at Rabindra Bharati University, Kolkata, and executive editor of *The Last Mile* (a magazine to bring awareness of leprosy to India) admits he was not very interested when first introduced to efforts to improve the situation of persons affected by leprosy.

But while acquainting himself with the literature on the subject he came to realize that the equivalent of 1% of India's population has been treated and cured of leprosy over the past two decades. Many of these recovered persons have led a marginalized existence on the fringes of society for no fault of their own, he said, and must be given "all possible help" to lead normal lives.

In that regard, the Kolkata workshop was "a big help for me in understanding different aspects of leprosy stigma," he said, and a meeting with Yohei Sasakawa was "particularly rewarding."

"I am a teacher, and the next time a student affected by leprosy comes to my class, I would treat him as any other student who is affected by a disease. Before attending this workshop I would not have dared to do so," he said. "I think this sums up what I have gained personally from this workshop." ■

# Success Brings New Challenges

Dr S.K. Noordeen, the architect of WHO's elimination strategy, looks at what has been achieved and the work that remains to be done.

In the history of public health there are not many achievements as gratifying as the elimination of leprosy. But while leprosy is a relatively small problem today in public health terms, it continues to pose important challenges in terms of physical and social rehabilitation.

The idea that leprosy could be addressed from the public health perspective developed in the wake of the introduction of the first effective anti-leprosy drug, Dapsone, back in the 1950s. As leprosy patients were the only source of infection, it was quite conceivable that by treating all patients in the community, leprosy transmission in time could be arrested and thus leprosy controlled. However, the results with Dapsone were generally disappointing due to the slow cure effected by the drug and the development of drug resistance over a period of time.

The 1970s saw renewed interest in leprosy control largely due to the identification of newer drugs such as Rifampicin and Clofazimine as highly effective in the treatment of leprosy. However, the way the drugs were administered to patients by different health workers varied widely. Therefore, it was only natural for WHO to embark on an initiative to develop a consensus on treatment of leprosy for control programs through the establishment of a study group on the subject.



**Early results of MDT as observed in the field were so encouraging that the initial reservations died out.**

The WHO Study Group which met in 1981 had a judicious combination of microbiologists, chemotherapy experts, leprologists and leprosy control program managers. The recommendation on multidrug therapy (MDT) made by the group was the result of intense analysis of all available scientific evidence, on-the-ground realities of implementing public health programs and a strong desire to bring about a major impact on the leprosy situation in endemic countries — even if this meant compromising on some less critical scientific requirements.

The report of the WHO Study Group on *Chemotherapy of Leprosy for Control Programs*, which

was published in 1982, is considered today as a historic document that enabled patients to receive standard, highly effective and acceptable treatment for their disease through MDT.

The initial reaction of leprosy workers to the WHO-recommended MDT varied widely as it had introduced some revolutionary changes such as treating patients for finite periods of time and simplifying classification of the disease. However, the early results of MDT as observed in the field were so highly encouraging that the initial reservations and criticisms died out over a period of time. MDT was accepted in all countries and programs, and leprosy workers everywhere received it with great enthusiasm, leading to renewed motivation to control the disease.

## HISTORIC OPPORTUNITY

The phenomenal reduction in the prevalence of leprosy seen even within five years of the introduction of MDT resulted in further intensification of leprosy control activities everywhere. This led WHO to recognize there was a historic opportunity

to aim at the elimination of leprosy as a public health problem with a deadline of the year 2000.

WHO defined elimination as reducing prevalence of the disease to less than one case per 10,000 population. This is not to be confused with eradication of the disease — aiming at reaching zero prevalence and zero transmission, which is not possible. The idea was that when leprosy prevalence reached a level below one case per 10,000 population, the disease would die out over a period of time, provided anti-leprosy measures, including MDT, continued to be available.

It may be argued that the definition of leprosy elimination, the target figure of one in 10,000 and the deadline of the year 2000 were arbitrary, and not open to strict scientific “proof.” Nonetheless, the goal set by WHO enabled development of strong political commitment everywhere and effective and widespread leprosy control programs in all endemic countries.

With regard to the deadline itself, the year 2000 was essentially an aspirational goal. When progress proved insufficient, the goal was moved to the year 2005. It may be necessary to push the goal back further in a very small number of countries.

The progress so far indicates that leprosy

## AUTHOR:

**Dr. S.K. Noordeen**

From 1979 to 1984, Dr. Noordeen coordinated WHO's leprosy research program, which eventually led to the development of multidrug therapy. From 1984 to 1988, he led the WHO global program on leprosy, and spearheaded the drive to eliminate leprosy as a public health problem. He is currently chair of the WHO South-East Asia Region's Regional Technical Advisory Group for the Elimination of Leprosy.



Dr. Noordeen: issue of disability will persist

prevalence globally has been reduced by over 94%. At the country level it is expected that all but five or six countries will have reached leprosy elimination by the end of 2005.

However, while prevalence measures the current disease burden, it does not fully reflect the rate of occurrence of new cases. Globally, the reduction in new case detection is only 32%. This is mainly due to the nature of the disease: a good proportion of currently occurring new cases are probably due to infections acquired several years earlier, and even prior to the introduction of MDT. Therefore, reductions in new case detection will be relatively slower, but the declining trend is clearly visible in most parts of the world.

#### PROBLEMS OF SUCCESS

Leprosy programs in most countries today are facing the problems associated with their success. With steep reductions in the disease burden, the question that governments, the NGO community, leprosy workers and donor agencies must now address is how to formulate a suitable and viable strategy to deal with residual leprosy, which will be a relatively small health problem.

For any disease, fulfilling the needs of a very small number of patients will always be a challenge unless health care systems are very well developed and have a good referral network. Where leprosy is concerned, the enormous amount of capacity-building undertaken in the past to deal with the disease is not going to disappear overnight, so in one form or the other this is likely to benefit patients at least for the next five to ten years. At the same time, the strongly committed constituency of leprosy interest groups that exists

has an important role to play in ensuring that the essential needs of leprosy patients are not ignored.

On the question of sustainability of leprosy services, there is a general consensus that only through integrated services will sustainability be possible. That said, it is important to define what services will be provided and at which level.

Sustainability will to a large extent depend upon two factors: first, capacity-building at the peripheral level, and establishment of referral services at the appropriate level (which in turn requires networking); and second, appropriate infrastructure.

Depending upon the country and the development of its health infrastructure, as well as the size of the remaining leprosy problem it faces, these services will have to be adjusted so that they not only meet the needs of the leprosy patients but also remain cost effective.

#### QUALITY OF SERVICE

Another oft-mentioned issue is the importance of maintaining quality services in the post-elimination period. Here we face a dilemma in terms of accommodating quality services within integrated health services, where it would be unrealistic to expect leprosy patients to receive a superior quality of service to patients suffering from other health problems.

If the leprosy interest groups want to maintain their strong support to leprosy sufferers, the only alternative is to build up a good referral network where, at least at that level, leprosy patients would receive quality services. However, accessibility to such referral services will remain problematic.

Even as the number of patients needing medical attention diminishes steeply, the issue of disabled leprosy patients needing rehabilitation — whether physical, social or economic — will persist for several years. Currently, rehabilitation programs for persons suffering from other disabilities in most developing countries, whether institution-based or community-based, are quite limited and even rudimentary. It is difficult for such programs to accommodate the requirements of leprosy-affected persons in the near future. As such, special initiatives for them will remain important for now.

To sum up, elimination of leprosy as a public health problem has been quite a success story, notwithstanding the need to deal with the small number of new cases that will continue to occur. In addition, rehabilitation issues will be in the forefront of leprosy activities in the future.

Let us not hesitate to celebrate our success so far; at the same time, we must not ignore the remaining challenges. ■

#### Leprosy FACT

- At the beginning of 2005, the global registered prevalence of leprosy was 286,063 cases, with 407,791 new cases detected in 2004. The number of new cases was about 107,000 less than in 2003, or a 21% decrease. During the past three years, the number of new cases detected globally has decreased at the rate of about 20% per year. (Source: WHO)

# Spreading the Word

Media workshops in India generate interest, but there needs to be a way to sustain coverage once they are over.

## INDIA (September 18-24)

During September and October I visited India twice to take part in a number of media workshops. On arrival, though, my first task was to give a lecture at Jadavpur University in Kolkata. I spoke on Leprosy and Human Rights before around 200 faculty and students. The chancellor of the university is West Bengal's governor, Shri Gopal Krishna Gandhi: Mahatma Gandhi's youngest grandson.

Prior to our meeting, the governor had visited Premananda Memorial Leprosy Hospital, where he spoke with a number of patients. Impressed by their self-confidence, the governor appeared committed to eliminating leprosy and supporting the rehabilitation of those affected by the disease. He recalled his grandfather's response to being invited to attend the opening of a leprosy hospital in Tamil Nadu, saying: "I will come to lock the door when it is over."

We met again on September 20 at the first of the media workshops. This was also attended by West Bengal's health minister, who said that the number of leprosy cases in the state had come down from 150,000 to 16,000 and that elimination was just a matter of time. (The state's PR is currently 1.88.) The minister said that from now on it was important to make efforts to rehabilitate cured people "economically, socially and psychologically" and that the media have an important role to play.

While in Kolkata, I visited the Gandhiji Prem Nivas Leprosy Center in Titagarh on the outskirts of the city. Founded by Mother Teresa in 1958, it currently sees about 400 patients a month who come for multidrug therapy. About 200 recovered

persons and their families live at the center, which has facilities for weaving, shoemaking and carpentry.

The second media workshop I took part in was in Patna, which Bihar's governor, Sardar Buta Singh, also attended. Bihar accounts for 23% of India's leprosy cases, but has been making great progress. Three years ago when I visited, the PR was 8.7; today it is 1.8. This is thanks to the efforts of the state government, WHO, NGOs and other partners. Among the latter is *The Times of India*, which a couple of years ago collaborated on producing an informative booklet entitled *Together We Can Eliminate Leprosy*. This has been widely distributed and has helped to set the record straight about the disease.

For the next workshop I made my first visit to Assam, famous the world over for its tea. Unfortunately, due to the insurgency, my movements were restricted. Nonetheless, I was able to meet many people, including representatives of the North East Chamber of Commerce, who invited me to dinner. I took the opportunity to stress to them what an important role industry has to play in the rehabilitation of the leprosy-affected, and urged them to take this on as part of their corporate social responsibility.

## (October 18-20)

I returned to India in October for another media workshop, this time in Uttar Pradesh, the country's most populous state. Since my last visit three years before, the PR had fallen from 4 to 1.6. I learned that schoolchildren are now obliged to perform skin checks on their family members as part of their homework. This is something I first saw in Mozambique, and which I spoke about on my last visit to UP. I was thus delighted to see that this idea has been taken up and is proving helpful in discovering new cases.

My overall impression from these workshops is that the media still have a lot to learn about leprosy — which is of course why such events are being held. Coverage has been very positive, but the next task is finding a way to provide the media with a steady flow of information to ensure that interest is maintained. ■



West Bengal Governor Gopal Krishna Gandhi (left) and State Health Minister Surjya Kanta Mishra confer at the media workshop in Kolkata.

# Isa's Bright Future

Treated and cured of leprosy, a Tanzanian boy has his life ahead of him.

## AUTHOR:

### Uwe H. Preuss

Uwe H. Preuss is Tanzania Country Representative for the German Leprosy and TB Relief Association (GLRA)

Photos by Uwe H. Preuss



(Counterclockwise from top left) Isa in September 2001, holding a photo of himself before he began treatment; Isa in May 2005; and seen with Sister Maria Paula, also in May 2005.

In September 2000, Isa Chonde was brought by his sister Aziza to Sister Maria Paula at the Nazareti Leprosy Care Center in Ifakara, a town about 400 kilometers southwest of Dar es Salaam, the business capital of Tanzania. He was nine years old and suffering from severe leprosy.

Thanks to the treatment he received, Isa was cured and released one year later. Fortunately, he didn't develop any permanent disabilities.

Sadly, though, Isa's mother wants nothing to do with him because of the disease. Today he lives with his sister Aziza, her five children and a niece of his other sister. Aziza's husband died some years earlier.

Together with three of her children, who have finished primary school, Aziza cultivates ten acres of sugar cane, which she sells to a nearby sugar factory.

She also tends some five acres of rice fields, producing three crops every two years. What she doesn't need to feed the family is sold on the local market.

Now 14, Isa is an alert boy who enjoys going to

school. His favorite subjects are English, Kiswahili, science and mathematics. What he likes most, however, is playing football.

Isa's teachers and all his schoolmates know that he once had leprosy; that he is now cured; and that he can't pass the disease on to others. He is fully accepted by everyone.

**Isa's teachers and all his schoolmates know that he once had leprosy. He is fully accepted by everyone.**

During his one-year stay in Nazareti, Isa learned to recognize the symptoms of leprosy. When you ask him, "What do you do if you see someone with skin patches?" he replies, "Send that person to Sister Maria Paula in Nazareti, where you will be cured and well looked after!" ■

## Leprosy LEXICON

### ● PB, MB

Leprosy is an infectious disease caused by the bacillus *Mycobacterium leprae*. Depending on the bacillary load, leprosy is classified as either paucibacillary or multibacillary. PB leprosy, a milder form of the disease, is characterized by up to five skin patches with definite sensory loss; MB leprosy is associated with more than five such patches. In most cases, the diagnosis is straightforward.

# Partners Discuss 'Neglected' Diseases

Successful intervention in leprosy shows what can be done with donated drugs.



At a meeting of Partners on Tropical Diseases Targeted for Elimination/Eradiation that took place in Bangalore, India, on November 17-18, leprosy was held up as an example of what can be achieved using donated drugs to provide drug security and full coverage.

Organized by the WHO Regional Office for South-East Asia (SEARO), the meeting was called to urge policy makers, the donor community and other stakeholders to make concerted efforts to tackle five so-called neglected tropical diseases:

leprosy, lymphatic filariasis, leishmaniasis, soil-transmitted helminthiasis, and yaws.

Following the successful intervention in leprosy thanks to drugs donated by The Nippon Foundation and Novartis (with the goal of achieving under one case per 10,000 population by the end of 2005), GlaxoSmithKline has agreed to donate albendazole until lymphatic filariasis is eliminated by the goal of 2020.

For the other three diseases, tools are available and pharmaceutical companies are coming forward to offer drugs, but as yet there is a lack of commitment by the affected countries.

Analyzing the global health funding situation, Professor David Molyneux (Liverpool School of Tropical Medicine) noted that resources are being transferred to the 'big three' diseases — HIV/AIDS, TB and malaria — but with only a limited chance of achieving results because the policies pursued are reactive and do not control transmission, a prerequisite for any public health impact. ■

## FROM THE EDITORS

### MOVING AHEAD

When the first issue of this newsletter was published in April 2003, the global leprosy prevalence rate stood at 524,311. Twelve countries (down from 24 in 2000) had yet to achieve the WHO goal of elimination.

In the two and a half years since, Yohei Sasakawa has traveled far and wide in his capacity as goodwill ambassador for leprosy elimination. The country he has visited most in that time has been India, whose progress has been crucial to the overall success of the global elimination strategy.

Of the nine remaining countries that have yet to achieve elimination as we approach the end of 2005, Mr. Sasakawa has visited all but the Central African Republic. In addition to his regular trips to India, he has visited several of these countries more than once.

An important purpose of these visits has been to secure the commitment of political leaders and urge them to seize the opportunity presented by the WHO's elimination strategy to remove this age-old disease as a public health problem.

Also on the itinerary has been Geneva, to

draw the attention of the UN Sub-Commission on the Promotion and Protection of Human Rights to the socio-economic alienation of persons affected by leprosy, even after they have been medically cured of the disease.

As the elimination strategy runs its course, Mr. Sasakawa has placed increasing emphasis on reaching out to the non-leprosy community, with hopes of instigating a broad-based social movement to redress the disadvantages that persons affected by leprosy face.

As of December 2005, progress is being made on both the medical and social fronts. Elimination as defined by the WHO has been achieved in all but a handful of countries and a post-elimination strategy has been drawn up by the WHO in consultation with partners. Meanwhile, leprosy has been taken up as a human rights issue at the UN sub-commission and is to be studied further.

Promoting awareness of the needs of those affected by leprosy remains an ongoing challenge, and one that will be addressed by the goodwill ambassador with renewed vigor in 2006.

## FOR THE ELIMINATION OF LEPROSY

### Publisher

Yohei Sasakawa

### Executive Editor

Tatsuya Tanami

### Editor

Jonathan Lloyd-Owen

### Associate Editors

Akiko Nozawa,

James Huffman

### Layout

Eiko Nishida

### Photographer

Natsuko Tominaga

### Editorial Office

5th Floor, Nippon

Foundation Building,

1-2-2 Akasaka, Minato-ku,

Tokyo 107-8404

Tel: +81-3-6229-5601

Fax: +81-3-6229-5602

smhf\_an@tnfb.jp

With support from:

Sasakawa Memorial

Health Foundation,

The Nippon Foundation

www.nippon-foundation.

or.jp/eng/