

# FOR THE Elimination OF Leprosy

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



Delegates to the second national conference of people affected by leprosy held in New Delhi, India, on October 4, 2006

**A MESSAGE FROM THE GOODWILL AMBASSADOR** **CONTENTS**

## Two Wheels

Ridding the world of leprosy requires that both the medical and social aspects of the disease be addressed. They are two wheels of the same cart. Thanks to the efforts of all concerned on the medical front, the dramatic drop in the number of leprosy cases represents a public health success story. Unfortunately, however, stigma and discrimination remain deep-rooted.

Until recently, no one had aggressively tackled the social aspects of leprosy. For this, I approached what is now the UN Human Rights Council, and later launched a Global Appeal, which 11 world leaders joined me in signing.

In India, I suggested conducting a thorough survey of all the country's leprosy colonies and forming a national network of leprosy-affected persons. I also called for a national conference. The second such conference took place this October in New Delhi. Colony leaders and others made their voices heard as the vice president of India and the chief minister of Delhi listened.

There was one regrettable occurrence. Rooms had been reserved for delegates at a hotel in Delhi,

but the hotel summarily canceled the reservation after learning that its guests would be "Lepers." Needless to say, this event caused great dismay among delegates.

Thanks to the presence of the vice president, the conference was held at Vigyan Bhawan, India's national conference facility. The venue thrilled delegates, who said that "To be part of a meeting there — and one we are leading — is nothing short of a dream."

But this dream is becoming reality. Indians affected by leprosy are getting organized. It is a joy to see them become a body that can put their case to society. They have made many requests to the government, but their basic stance is one of self-help, and I greatly respect them for this.

My goal is to help leprosy-affected people everywhere become more powerfully organized and run their own campaigns. The cooperation of many different organizations will be needed, so I ask for your support.

— Yohei Sasakawa, WHO Goodwill Ambassador

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# Quest for Empowerment Gathers Pace

India's vice president addresses second national conference of affected persons

On October 4, India's vice president told a national gathering of people affected by leprosy in Delhi that there is a need to make a sustained effort to change the social image of leprosy. While praising India's achievement of leprosy elimination, he said, "We cannot remain oblivious to the problems of social stigma and discrimination, which force the leprosy-cured persons to spend their lives in exclusion, loneliness and ignominy."

"With a view to sensitize people to treat cured persons with love, dignity and empathy, we need to educate people that leprosy is not an easily communicable disease and clear their misgivings," Vice President Bhairon Singh Shekhawat told the 2nd National Conference on Integration & Empowerment of People Affected by Leprosy.

Organized by the National Forum of People Affected by Leprosy, the conference brought together 700 delegates from 14 different Indian states to discuss key issues such as housing, education and employment.

India's constitution, the vice president reminded delegates, "provided us not only a right to live but a right to live with dignity," and he expressed concern that even the healthy children of people affected by leprosy face difficulty in getting educated and finding employment. To bring about change, he said, "it may be necessary to frame legislation and adopt policies and strategies that, by providing leprosy-affected persons with their basic needs, will enable them to attain their fundamental right to live with dignity." He also appealed to companies and NGOs to create more job opportunities for affected persons.

Another senior government official, Delhi's Chief Minister Sheila Dikshit, received an ovation from delegates when she announced that she would be raising the monthly allowance for persons affected by leprosy from Rs. 850 to Rs. 1,000. She also said that she would be considering other measures to improve the lives of those living in the capital district.

## EMPOWERMENT SESSIONS

The core of the conference was devoted to the voices of people affected by leprosy. The day's two "empowerment sessions" gave colony representatives from around India a platform to talk about the everyday problems and hardships they and their communities face, and suggest solutions.

Girdhari Lal (Delhi), called for children of people affected by leprosy to receive a proper education, which would help them to achieve self-sufficiency. He also sought property rights for affected people and said they should have their own representative in the nation's Parliament.



Vice President Bhairon Singh Shekhawat

Zainuddin (Jharkand) talked about how affected people are pushed away from their land and property and made to live far from cities in leprosy colonies where they cannot find appropriate sources of livelihood. "Where should I go? I am a citizen of this country, a son of this land. Then why is there no place for me?"

C. L. Mishra (Punjab) also brought up the lack of employment opportunities. "People affected by leprosy don't want to be beggars by choice," he said. "They want to work and earn a living. But they do not get any work."

"People affected by leprosy don't want to be beggars by choice"

In one of the most powerful testimonies, Maya, a wife and mother from Delhi, described her experiences married to a person affected by leprosy. The couple have two sons, but it was difficult to find a school that would take them. Finally, after many requests, the boys were accepted, on condition that they sit apart from their classmates. "I just want to say that I and my sons have been living with my leprosy-affected husband for so many years and are perfectly healthy. There is no need to discriminate," she said.

The day following the conference, there was a meeting of the National Forum, which is made up of colony representatives from around India. Members agreed that the Forum will be established as a trust with two chapters — one for the northeast of India, and one for the rest of the country — and confirmed that it would be an organization composed of, and for, people affected by leprosy. Efforts by India's leprosy affected to help themselves are thus gathering pace. ■

# Laying the Groundwork for Change

Socio-economic empowerment workshops serve as catalyst for action

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V. S. Upadhyay



V. S. Upadhyay is a retired Professor of Anthropology from Ranchi University who has been engaged in research on socio-economic aspects of leprosy-affected persons for the last two and a half decades. Currently he is Program Coordinator (Eastern India) for IDEA India, and an Advisory Board Member of the National Forum of Persons Affected by Leprosy. He also runs a school for children of 190 leprosy-affected families in Ranchi.

It was in 2005 that WHO Goodwill Ambassador Yohei Sasakawa suggested to IDEA India President Dr. P. K. Gopal that he conduct a survey of leprosy colonies in India. To date, the survey has yielded a list of about 700 colonies in different states.

This led to a chain of socio-economic empowerment workshops across India, attended by representatives of various colonies in each state. It was the first opportunity for persons affected by leprosy to meet their brothers and sisters. This motivated them to unite and coordinate their efforts to better the quality of their lives.

To borrow the words of Jawaharlal Nehru, India's first prime minister, it represented "an awakening," stimulating persons affected by leprosy to unite and fight for their human rights. Goodwill Ambassador Sasakawa addressed many such meetings.

In his speeches, Mr. Sasakawa always encouraged participants to develop a network and work together for their rights as citizens of the country. At each workshop, participants chose their own leaders, and nominated one from their number to be the state representative to the National Forum of People Affected by Leprosy, inaugurated last year as an all-India network.

The workshops proved an encouraging experience for all concerned as they spoke their mind about discrimination, the sad compulsion of begging, the lack of employment opportunities for the leprosy disabled and even their educated children, and government apathy in the face of demands for basic civic amenities.

In short, the workshops put the following points before society and the government.

1. Persons affected by leprosy should be brought under the wing of the Ministry of Social Justice and Empowerment at the central level as well as in all states, as they now need social and economic rehabilitation.
2. Persons affected by leprosy have been treated as social rejects (suffering more rejection than



Participants at recent SEE workshop in Raipur

scheduled castes, or SCs) from time immemorial, and so the constitutional provisions for SCs should be extended to them and their children (especially those living in leprosy colonies).

3. The social justice ministry should establish a special commission for persons affected by leprosy, to be headed by such a person.
4. The National Human Rights Commission of India should have a special unit for persons affected by leprosy at both central and state levels to deal with cases of human rights violations.
5. Persons affected by leprosy should not have to pay court fees when filing a case, at any level.
6. Of the 3% of jobs reserved for disabled persons, 1% should be reserved for persons affected by leprosy. Training centers for the disabled should admit persons affected by leprosy, too.
7. All families of persons affected by leprosy should be given Below Poverty Line (BPL) status automatically, and all provisions should be extended to them.
8. A uniform pension scheme for persons affected by leprosy should be declared nationwide by the central government (currently pensions vary from Rs. 200 in Bihar to Rs. 1,000 in Delhi) to check migration to greener pastures.
9. Persons affected by leprosy and their families, who are presently occupying governmental or semi-governmental land or housing, should be given title to it. In cases where eviction is unavoidable, they should be given alternative accommodation, free of charge.
10. The majority of persons affected by leprosy live in dilapidated housing. They should be given houses under an appropriate housing scheme, such as the Indira Awas Yojna, away from established colonies, if possible.
11. Under Sarva Shiksha Abhiyan, a program for the universalization of elementary education, the government should give directives to establish in each colony a school and a center for Integrated Child Development Services (ICDS).
12. There should be free education for children of persons affected by leprosy at all levels.
13. The majority of disabled persons affected by leprosy are now elderly. The social justice ministry should allot special funds for NGOs that are ready to establish old-age homes for them.
14. Municipal boards or corporations should provide urban-based leprosy colonies with all civic amenities, including electricity, water supply, roads and public toilets. ■

# Toward Consensus on POD

Conference draws up answers to five key questions about prevention of disability

Over 100 experts from 30 countries gathered in the Philippines recently to discuss techniques for preventing disability in people with leprosy and other chronically disabling conditions.

Co-sponsored by the American Leprosy Missions (ALM), the WHO and ILEP, the Consensus Development Conference on the Prevention of Disability (POD), held September 13-16, 2006 in Cebu City, sought to find ways of making POD activities an integral part of case management of chronic diseases such as leprosy, lymphatic filariasis, Buruli ulcer and diabetes.

Following the conference, a Consensus Statement on Prevention of Disability was issued. The key conclusions are summarized here.

## How can we make sure people with reactions and neuritis are treated as early as possible?

Reasonably effective treatment for reactions and neuritis exists, and the current priority is to expand coverage so that all patients have access to it. Patients should be made aware of the problem through health education at diagnosis and upon treatment completion, to promote self-reporting. Those at higher risk should have monthly nerve function assessments. An effective referral system should be available for patients who have complaints indicative of neuritis or have demonstrable new nerve function impairment.

## What simple approaches can be developed to promote home-based self-care?

Self-care is a key strategy in the prevention of disabilities and is a vital component of leprosy control, but the extent of its coverage is very limited. Full participation by those affected is

essential in any self-care program. Development of facilitation and counseling skills within existing local structures is necessary to achieve adequate coverage and sustainability of self-care in the prevention of disability.

## What are the prerequisites for an effective footwear program?

The routine use of appropriate footwear is one of the most important POD interventions in leprosy, as loss of sensation in the sole of the foot and plantar ulceration are so common. Anyone with Grade 1 disability should be helped to obtain the right footwear, either by purchasing appropriate, commercially available shoes or through an organized program.

## For effective POD, what are the essential recording and reporting requirements?

A simple recording and reporting system is vital for the management of POD. Data collection should be dictated by its use for both clinical and managerial purposes. Measuring and recording Grade 1 disability is necessary for defining the need for protective footwear. Visual acuity and the absence of wounds/ulcers are key indicators for evaluating the efficacy of POD activities.

## What are the priorities for research in POD?

Research to address issues of coverage and access should now be the priority, firstly in the area of self-care and footwear provision, and secondly in the area of treatment for reactions and neuritis. Research aimed at improving the efficacy of specific POD interventions is still needed, but it should be seen as a lower priority. ■

## PARTNERS

### AMERICAN LEPROSY MISSIONS



ALM is America's leading leprosy organization and is celebrating its 100th anniversary in 2006.

Headquartered in

Greenville, South Carolina, its mission is "To serve as a channel of Christ's love to persons affected by leprosy and related conditions, helping them to be healed in body and spirit and restored to lives of dignity and hope."

As a non-denominational Christian ministry, ALM provides care to people around the world with leprosy, Buruli ulcer and

related diseases. It supports projects in approximately 15 countries and works with health organizations, other non-profits and governments worldwide.

As the nature of leprosy work changes, ALM has been broadening its focus under an agenda it calls Leprosy Plus. Included is a greater emphasis on provision of services such as Prevention of Disability (POD).

As part of its centennial celebrations, it has been engaged in a campaign to finance research to find a vaccine for leprosy. It has also published *Contagious Compassion*, an insightful 256-page book about ALM's history.

# Overcoming Stigma

Once a monk with leprosy, Leng Sophea is now a happily married teacher

**AUTHOR:**  
Leng Sophea



Leng Sophea works as a Khmer teacher and support worker at the Kien Khleang national leprosy rehabilitation unit in Cambodia.

I was born in 1984 and grew up in a poor family in Cambodia's Kandal Province. I lived in a village with my parents Cheng Peng Leng and Youen Yen and my two sisters and three brothers.

In 1997, I left home to go and live for one year with relatives. In 1998, I moved into a pagoda. I studied Khmer, Cambodia's national language, for one year with a monk. I became a monk the following year, when I was 15.

In 2000, I realized that something was the matter with my health because I was developing symptoms such as a puffy face, claw-finger, drop-foot and the inability to close my eye. I found a Khmer doctor to examine me. He did not know what was wrong but he treated me with traditional medicine for one year.

I was getting better. From 2000, I also began studying the Baley language in addition to Khmer. These studies took me to Phnom Penh.

Then my condition began to take a turn for the worse. I went to another Khmer doctor who examined me and told me I needed to go to a health center.

At that point, I decided that I didn't want to see another doctor because I didn't have any money. Also, I was in the middle of my studies, which I loved, and I didn't want to stop.

But my illness was progressing. My claw-hand and drop-foot were becoming worse. So I thought about it again and decided I should go and see a doctor. I didn't know what was going to happen to me.

In 2003, a doctor in Phnom Penh told me that I had leprosy. "What is leprosy?" I asked him.

As he explained the disease, he told me that I could be cured. But he also said leprosy stigmatizes those who have it, and many people are afraid of it.

When I heard this, it made me very sad. I didn't want to live in this world anymore. I wanted to die.

I didn't tell my family about leprosy. I kept my condition to myself and lived alone with my worries, which were so big. I stayed in my room in the pagoda for one year. I didn't want to go out and meet people.

"I didn't want to live in this world any more. I wanted to die."

Between 2003 and 2004 I was treated with MDT at a health center in Kandal Province. At the end of 2004, I had reconstructive surgery on my hands and feet.

After that, I got a job with CIOMAL at the Kien Khleang national leprosy rehabilitation unit. I now work as a Khmer language teacher and support worker. I stopped being a monk in 2005.

In July 2006, I got married to Van Tavy and have found happiness in my life.

I have had leprosy, but I will not let the disease stigmatize me. As to the future, I hope to study at university one day.

In the meantime, my message to everyone is: if you have any problem, please hurry and see a doctor or go to a health center. ■



Leng Sophea gives a Khmer lesson to young women who have had reconstructive hand surgery.

# Visits to India Continue

Ensuring ongoing political commitment to tackle leprosy and attending a national conference of affected persons saw the Goodwill Ambassador return to India twice in recent months.

## CHHATTISSGARH (SEPTEMBER 12-14)

India announced that it had achieved the WHO's goal of eliminating leprosy as a public health problem in January of this year. However, of the country's 28 states and six union territories, five have yet to reach a prevalence rate of less than 1 case per 10,000 population. In September, I visited one of these states — Chhattisgarh — to enlist further political, administrative and media support in tackling the disease.

On my arrival in Raipur, the state capital, I went straight to an Empowerment Workshop attended by spokespersons from 32 colonies in Chhattisgarh, which identified representatives for the newly created National Forum of People Affected by Leprosy. This was followed by a workshop titled *Nayi Disha: Commitment to Elimination and Beyond* (*Nayi Disha* means 'New Direction'). Some 80 people were taking part, including the state governor, chief minister, health minister and health secretary.

As of June, Chhattisgarh had 4,612 registered cases of leprosy, and a PR of 1.99. Compared to my last visit in January 2004, when the PR stood at 13, this is a huge improvement. Health Minister Dr. Krishnamurthy Bandhi said that just as regional cooperation and social awareness helped to defeat polio, the same would be true of leprosy.

During the workshop, I talked about the Global Appeal to end stigma and discrimination that 11 world leaders joined me in signing at the start of this year. I also talked about my efforts to get the United Nations to pass a resolution on leprosy and human rights and issue guidelines to each country. I was pleased to learn that 1,000 copies of the Global Appeal, translated into Hindi, had been distributed to health centers around the state.

I saw one posted on the wall of the health



A foot-care camp at Durg

center I visited later in Durg, 30 kilometers from Raipur, where I spent time with around 20 people who were participating in a foot-care camp being conducted by health workers assisted by volunteers from the Lions Club.

Next I visited a nearby community to watch a puppet play designed to spread correct information about leprosy. As the puppets danced, they asked the audience questions about leprosy. Those who answered correctly received a present.

Back in Raipur, I called on the office of Chief Minister Dr. Raman Singh. He told me that my three messages — leprosy is curable, treatment is free, social discrimination has no place — are being taken to every district and every block and that children are being taught about leprosy at school. He also said that the media have been mobilized and that these efforts to educate the public would continue.

My final appointment of the day saw me go to the health minister's official residence where I had a chance for further discussions with the minister and health secretary. Dr. Bandhi told me that from the government's perspective, the contribution made by NGOs was vital. Meanwhile, Health Secretary B. L. Agrawal spoke of the practical difficulties involved in socially and economically rehabilitating the state's 50,000 people affected by leprosy, many of whom live in colonies. There are limits to what the government can do, he said, so it is important for the government and NGOs to work closely together, and for NGOs to show the way.

## ORISSA (SEPTEMBER 16-18)

On September 16 I flew to Bhubaneswar, the capital of Orissa state, where I attended another *Nayi Disha* workshop. In states which have already achieved elimination, the focus of these workshops is "commitment beyond elimination."

This was my second visit to Orissa since 2004, and I was particularly satisfied that this once highly endemic state, with its many tribal peoples, has been able to achieve elimination. Good coordination between the state leprosy officer, the WHO coordinator and NGO-funded technical support teams undoubtedly played a key role.

Over 200 people took part in the workshop, including Health Minister Shri Duryodhan Majhi, Principal Secretary Shri Chinmoy Basu, and Women and Child Development Minister Smt. Pramila Mallik. Many of those attending worked

## Leprosy LEXICON

### ● Quality Leprosy Services

The new Global Strategy emphasizes quality leprosy services as an essential component of an effective program. Quality leprosy services are: accessible to all who need them; patient-centered and observe patients' rights (including the right to timely and appropriate treatment, and confidentiality); and address each aspect of case management (including diagnosis, treatment, POD interventions and referral for complications).



The Delhi conference: the voice of people affected by leprosy

at district health centers, and there were also media and NGO representatives present.

Health Minister Majhi said, “Eliminating leprosy is the biggest success since smallpox. But building on this represents a new challenge. What can we do to help persons affected by leprosy achieve economic independence?”

On my previous visit, Orissa’s PR was 6.4/10,000. Today it is 0.94. However, State Leprosy Officer Dr. P.K.B. Pattanaik said he was not satisfied and is now pursuing elimination at district level. He also said he was cooperating closely with local officials in the social rehabilitation of affected persons.

#### DELHI (OCTOBER 4)

The following month I returned to India to attend the 2nd National Conference on the Integration & Empowerment People Affected by Leprosy in New Delhi on October 4. This conference is designed to be the voice of people affected by leprosy, both patients and those who have recovered from the disease. The first ever conference was held in Delhi in December 2005.



Speaking in Delhi

I see these events as a way for people affected by leprosy to make themselves heard and claim their basic rights through their own efforts. Bringing

them together in a national network and giving them a forum where they can exchange ideas and opinions will bring pressure to bear on government and society to tackle stigma and discrimination.

This second conference was inaugurated by the Vice President of India Shri Bhairon Singhji Sekhawat and attended by Delhi’s Chief Minister Smt. Sheila Dikshit as well as many experts in the field of social work and rehabilitation.

The vice president is very knowledgeable about leprosy, and stressed the need to integrate people affected by leprosy into society’s mainstream while making sustained efforts to change the social image of leprosy. Because he was taking part, the conference was held at the Vigyan Bhawan, Delhi’s premier conference facility — a fact that was not lost on delegates, for whom the venue was of enormous symbolic importance as a mark of the progress their movement is making.

In the more than 20 journeys I have made to India over the last three years, the changes I have witnessed have been nothing short of miraculous: India’s achievement of elimination and its ongoing commitment to fighting leprosy; the first ever survey of the nation’s colonies; a national conference to empower affected persons; and the creation of a national forum. All have been made possible by the determined efforts of everyone concerned.

Over the course of these visits, I feel India has become my second home. To see the dawn of hope on the faces of people affected by leprosy is what keeps me going and I can truly say that this has become my life’s work. ■

# Delhi 'Y' Cancels Booking

Conference delegates told to make other arrangements

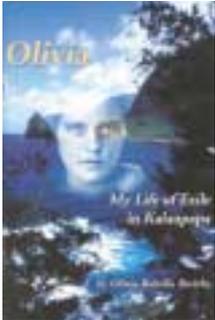
When the Delhi YMCA Tourist Hostel canceled the booking for a group of delegates to the recent national conference of people affected by leprosy held in India's capital in October, its action made clear just how much more work needs to be done to overcome the stigma and discrimination surrounding the disease.

In a letter to IDEA India President Dr. P.K Gopal dated September 9, the hostel manager wrote that the room reservations were cancelled "as we were not aware that the group consists of lepers." The letter said that other guests may object "as it has happened in the past when the

same group stayed last year."

The incident sparked strong protests from IDEA India, The Leprosy Mission Trust, India, and from the American Leprosy Missions (ALM), among others. ALM President Christopher J. Doyle wrote, "I find it hard to believe that a Christian agency would deny access or accommodation to people just because they are affected by leprosy. Did not Jesus himself reach out and touch people with leprosy? ... You need to reexamine your policy and position."

The YMCA has since apologized.



## OLIVIA ROBELLO BREITHA

Olivia Robello Breitha, who was diagnosed with leprosy in 1934 and spent the rest of her life at the Kalaupapa settlement on Molokai in Hawaii, died in September at the age of 90. She published her autobiography, *Olivia: My Life of Exile in Kalaupapa*, in 1998.

Breitha once wrote: "My name is Olivia, not L-E-P-E-R. ... I wrote a book because I wanted people to know what I feel, what I felt, how much I struggled, fighting the disease, fighting ignorance, fighting bureaucrats, fighting that awful hurtful word. ... Trying not to be a statistic — trying to be a person." ■

## FROM THE EDITORS

### FOREVER YOUNG

On October 4, Dr. Shigeaki Hinohara celebrated his 95th birthday. In a newspaper column to mark the occasion, the much-published author and president of the Sasakawa Memorial Health Foundation recalled having pneumonia as a young man. "Left weakened by the disease, I felt I would be satisfied if I could work up until I was 60. Instead, here I am at 95, still in good shape, working harder than I did when I was young and delighted by the fact."

By comparison, Dr. Hinohara's fellow countryman Yoshimi Komaki is a relative youngster at 76. But he too fell victim to disease when he was young. In 1947, at the age of 17, Komaki was diagnosed with leprosy. As a result, he was sent to the Hoshizuka-Keiaien leprosy sanatorium in Kagoshima, southwestern Japan, where he spent the next 58 years.

In January 2003, Komaki took a trip to southern China to see the lives of people

affected by leprosy in that country. What he saw shocked him. Living in isolated, impoverished communities, the inhabitants of the villages he visited had little access to medical care and many were suffering from wounds.

Spurred by the desire to help, Komaki the following year donated ¥5 million of his own money. This was used to build a road to connect a village he had visited with the outside world, and also a school. Wanting to do more, in 2006 he took part in a work camp organized by student volunteers. He has since moved to China. Working with the NGO Joy in Action (JIA), he now visits some 20 villages in southern China, distributing bandages and medicine, and teaching the student volunteers how to clean and care for wounds. By sharing his own experiences, he is helping the villagers believe they can change their lives.

For both Dr. Hinohara and Mr. Komaki, old is not a word in their vocabulary.

## FOR THE ELIMINATION OF LEPROSY

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