

# FOR THE Elimination OF Leprosy

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



C. Pawl (left) and P. Ammu in front of their toy shop in Villivakkam leprosy colony, Chennai, India, in January

## MESSAGE

### Nepal Marks Elimination

On January 19 I had the privilege of attending a ceremony in Kathmandu to hear the announcement that Nepal had officially achieved the goal of eliminating leprosy as a public health problem. Nepal is a country confronting tremendous political and economic challenges as it struggles to find its feet as a republic following years of civil war that brought down the monarchy. With sporadic violence and strikes a common-day occurrence and a new constitution yet to be finalized, the situation in the country is anything but stable.

Under these circumstances, I believe the achievement of elimination is all the more praiseworthy. It shows what can be done when the government, working closely with the WHO and other partners, both local and international, firmly commits to tackling a public health problem. I would also like to note the constructive role played by Nepal's media in the country's elimination activities.

Nepal's health ministry regards leprosy elimination — defined by the WHO as a

prevalence rate of below 1 case per 10,000 people — as a milestone along the road to a leprosy-free world. It has indicated that it plans to bolster measures to further reduce the disease burden and so ensure that the physical and social consequences of the disease continue to decline throughout the country.

Certainly, there is no room for complacency. Nepal must sustain the quality of leprosy services and see to it that all people affected by the disease, wherever they live, have an equal opportunity to receive adequate treatment. Ongoing political commitment is essential, as is close collaboration with partners.

I invite people in countries everywhere engaged in fighting leprosy to join in celebrating Nepal's achievement and in supporting its ongoing efforts to wipe out the disease. Let us strengthen our ties and walk together hand in hand until we reach our final destination, which is a world without leprosy.

— Yohei Sasakawa, WHO Goodwill Ambassador

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# Business Speaks Up

Leaders support principle of social integration and economic empowerment.

Top executives from some of the world's leading corporations have endorsed the fifth in a series of global appeals to end stigma and discrimination against people affected by leprosy, launched in Mumbai, India, by Goodwill Ambassador Yohei Sasakawa on January 25.

Among the 15 corporate signatories from 10 countries were Sir Richard Branson, chairman of Virgin Management, Ratan N. Tata, chairman of Tata Group, and Fujio Cho, chairman of Toyota Motor Corporation.

Held at the Taj Mahal and Tower Hotel, the event was attended by over 100 people, including two of the business leaders who had signed the appeal: Keshub Mahindra, chairman of Mahindra Group, one of India's top industrial houses, and Kan Trakulhoon, president and CEO of SCG, a leading business conglomerate in Thailand and the ASEAN region.

Speaking at the launch ceremony, Keshub Mahindra underlined his support for the appeal, while noting that overcoming the barriers to hiring people affected by leprosy is not easy because of discriminatory attitudes that persist. "I have tried to persuade people in my organization [to hire persons affected by leprosy], but I must say I have not succeeded. There is a built-in prejudice. It is a long learning process," he said.

SCG's Trakulhoon said that his organization believed that people should be treated on an equal, fair and equitable basis. "I am very

pleased to be a part of this program and hope that our intensive efforts today will enable those affected by leprosy to reclaim their dignity and human rights. And in doing so, enable them to live a normal life."

A message from Sir Richard Branson that was read out at the ceremony stated: "As business leaders we have a responsibility to reject discrimination in all forms and encourage equal opportunities for all. I hope the Global Appeal will send out a strong message that prejudice and stigma cannot be tolerated in the workplace."

The appeal 'will be a source of inspiration to a great many people.'

## RESTRICTED OPPORTUNITIES

While significant progress has been made in tackling leprosy as a public health problem over the past two decades, the stigma associated with the disease continues to make life difficult for people affected by leprosy and even their families, restricting opportunities for education, training and employment.

With this in mind, the appeal states in part: "We believe that people affected by leprosy have the same rights as everyone else, and deserve the same opportunities as everyone else.

It continues: "We support the principle of



Yohei Sasakawa addresses the launch ceremony



**List of Signatories for Global Appeal 2010**

- Mr. Roger Agnelli, CEO, Vale
- Mr. Mukesh D. Ambani, Chairman & Managing Director, Reliance Industries Ltd.
- Sir Richard Branson, Chairman, Virgin Management Ltd.
- Mr. Philippe Camus, Co-Managing Partner, Lagardère SCA
- Mr. Chang Zhenming, Vice Chairman & President, CITIC Group
- Mr. Fujio Cho, Chairman, Toyota Motor Corporation
- Mr. Keshub Mahindra, Chairman, Mahindra Group
- Mr. Mikio Sasaki, Chairman, Mitsubishi Corporation
- Mr. Louis Schweitzer, Honorary Chairman and President, Renault
- Mr. Ratan N. Tata, Chairman, Tata Group
- Mr. Kan Trakulhoon, President and CEO, SCG
- Mr. Tsuneji Uchida, President & COO, Canon Inc.
- Dr. Daniel Vasella, Chairman & CEO, Novartis AG
- Mr. William C. Weldon, Chairman & CEO, Johnson & Johnson
- Prof. Muhammad Yunus, Managing Director, Grameen Bank
- Yohei Sasakawa, Chairman, The Nippon Foundation



The reading of the appeal. Front row, left to right: Girish Firdane, Chitra Naikar, Michael Sello, Julie Kamble, Yoges Madhale and Vidhya Naikar. Back row, left to right: Tarun Das, Keshub Mahindra, Yohei Sasakawa, Kan Trakulhoon and Dr. S.K. Noordeen.

social integration and economic empowerment of people affected by leprosy.”

Goodwill Ambassador Sasakawa, whose signature also appears on the document, praised this message from the business community, saying it “will be a source of inspiration to a great many people who want to be part of society and who are beginning to stand up for themselves. It will also help to deter the kind of outrageous discrimination that shuts off opportunities to people with the desire and the ability to work, simply because of a disease they once had.”

In his remarks, the Goodwill Ambassador also singled out a factory in Maharashtra State, affiliated with the Tata Group, that employs people affected by leprosy. He described it as “a great example, and one that needs to be followed in all countries. However, such factories are few and far between.”

A short film on leprosy in India, produced by the Sasakawa-India Leprosy Foundation (SILF) was shown prior to the launch of the appeal. Meanwhile, SILF trustee and president of Aspen India, Tarun Das, raised the possibility of launching a national appeal, and said he would be pursuing the idea with the Indian signatories.

As is the custom with the Global Appeal event, the text was read aloud by people from a leprosy-affected background. The six young people, all living

in the Mumbai area, were Julie Kamble, Yoges Madhale, Chitra Naikar, Vidhya Naikar, Michael Sello and Girish Firdane. All are studying for degrees or are already qualified.

Speaking earlier in the day, they recalled a time when they preferred to conceal where they lived to avoid facing problems at school. But now they said the situation has improved and they do not face such difficulties because people are better informed about the disease and know it is curable. In any case, said Sello, “There are bigger diseases than leprosy now, like HIV/AIDS.”

Global Appeal 2010 follows earlier appeals signed by world leaders (Delhi, 2006), representatives of persons affected by leprosy (Manila, 2007), NGOs active in the field of human rights, and religious leaders (London 2008, 2009). The appeals are launched every year at the end of January, on or near World Leprosy Day. ■

# Southern Pride

India's network of people affected by leprosy holds regional meeting in Chennai.

Chief guest Geetha Jeevan, Tamil Nadu's minister for social welfare, will doubtless have gone away impressed at the packed hall that greeted her at the National Forum southern regional conference held in Chennai on January 24. As a number of speakers emphasized to the crowd of some 350 delegates, the organization is changing the equation for people affected by leprosy and becoming a force to be reckoned with.

Established in 2006, the National Forum is an umbrella organization representing the country's leprosy-affected, particularly those in India's 700-plus self-settled leprosy colonies. It works closely with IDEA India, and shares the same president in Dr. P.K. Gopal. After two national conferences in Delhi and regional conferences in Kolkata and Mumbai, this was the first gathering in the south of the country. Taking part were colony leaders from the states of Tamil Nadu, Kerala, Karnataka and Andhra Pradesh.

After reports on the situation in these states, a succession of guest speakers addressed the meeting. They included Suresh Kaul, president of the voluntary organization SMK in Rajasthan, who said that thanks to the National Forum, colonies in different states now knew what others were doing, and were benefiting from



their knowledge and skills. "The National Forum has brought us together. This is no small thing," he said. "It will be needed until we achieve all our goals and our brothers and sisters are treated like any other citizen in the country."

In the afternoon, representatives of individual colonies approached the podium to list the various problems they faced. Common among them were a lack of jobs, lack of land ownership, and the need for pensions for all leprosy-affected persons.

During the meeting, three people received outstanding achievement awards, presented to them by Goodwill Ambassador Yohei Sasakawa. They included Udaya Kumar, one of the first artists of the Bindu Art School, founded in the Bharatapuram leprosy colony in Tamil Nadu in 2005. ■

## HUMAN STORY

### 'NO TEARS, NO FEARING'



When National Forum President Dr. P.K. Gopal was planning the southern regional conference in Chennai, he turned to an old acquaintance to organize media coverage. Some 30 years ago, K.N. Madhavachari (pictured) was a young man

undergoing treatment at Sacred Heart Leprosy Centre in Kumbakonam, Tamil Nadu, where Gopal was employed as a social worker. Seeing something in Madhavachari, he urged him to get a qualification. Initially reluctant to leave the hospital, Madhavachari had to be pushed to go to Chennai in 1979 to be trained in printing under a rehabilitation program. But once there, he never looked back. "He had an opportunity and he used it well," says Dr. Gopal.

Today, 63-year-old Madhavachari radiates a bullish confidence in himself and his abilities. "I'm a very proud man," he says. "You could say I have

a superiority complex." After studying printing he went on to work for leading publications, also trying his hand at advertising and journalism. Now he runs his own design and printing company, while also free-lancing as a reporter.

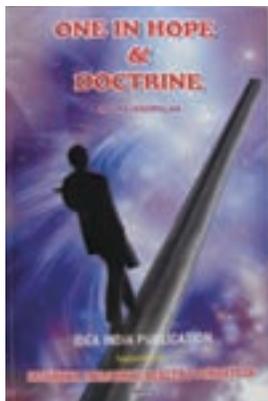
"In the beginning, I would go to people and say, 'I am a person affected by leprosy. I want a job. I don't want help. I am qualified. Are you ready to give me work?'" They would look at me in amazement," he recalls. "If the deadline was the 22nd, I would deliver on the 21st, and do it perfectly. One thing led to another."

Madhavachari has two brothers, one of whom, like him, is a person affected by leprosy. Without children of his own, Madhavachari is supporting his affected brother's five daughters, funding their education, helping find them work and marriage partners.

Based on his own experience, his advice to people who have had leprosy is not to feel sorry for themselves and not to be afraid of what others think. "You can do anything. But you must have confidence — with confidence you can conquer the world," he says. "No tears, no fearing."

## Tamil Tales

Two new books in English offer vivid first-person accounts of coping with leprosy.



*One in Hope & Doctrine*  
M.S. Rajagopalan  
IDEA India Publication,  
supported by Sasakawa  
Memorial Health  
Foundation  
January 2010

The precociously clever son of a school headmaster, M.S. Rajagopalan was set on a high-flying career in banking when a diagnosis of leprosy at the age of 25 “hit me as a bolt from the blue.” At that moment, he writes in *One in Hope & Doctrine*, he saw “the crumbling of all the castles” he had built in his mind.

Forced to quit the bank in Calcutta where he was a trainee, he moved to the Central Leprosy Teaching & Research Institute in Chengalpattu, Tamil Nadu, for treatment. Accompanied by his father on the journey, he was refused entry to a hotel for breakfast because he was a “leper.” The episode came as a rude awakening as it dawned on Rajagopalan that he now had a new identity. But it was also the occasion for some paternal advice that he never forgot: “Remember that you are up against a very cruel ordeal. It is going to be a long, drawn out battle and you better be prepared, both mentally and physically.”

On completing his treatment and being declared free of the disease, he returned to the family home in Calcutta, only to find he was an unwelcome presence. While he had been gone, one of his brothers had married and his new sister-in-law didn’t want a person affected by leprosy in the house. Moving to Madras, he found a job through a friend as an accountant on a building project, only to lose it after a few days when workers refused to have anything to do with him. A second job ended the same way as the wasted muscles and clawed fingers on his right hand betrayed him once more. His sympathetic ex-employer paid for an operation on his hand, but Rajagopalan remained without work and without prospects.

Refusing to contemplate begging, he decided to commit suicide, but not before seeing his parents one last time. En route, he happened to glimpse a

signboard from the train window that would set him on the path to employment, marriage and fatherhood. It was a life-changing moment.

Rajagopalan is a born storyteller. His autobiography is filled with anecdotes and insights that illuminate his tale — from his poignant recollection of being helped by another social outcast — a sex worker — after he suffered a nasty fall to his account of being pursued in marriage by no less than five staff nurses while a patient at a mission hospital.

He emerges as a man of dignity, principle and determination. As the distinguished orthopedic surgeon H. Srinivasan writes about the author, he demonstrates “the importance of preservation of one’s self-esteem against all odds and not allowing self-pity and self-loathing, which many leprosy patients suffer from, to smother one’s efforts to lead a normal and full life and suffocate one’s hopes.” His book deserves a wide audience.

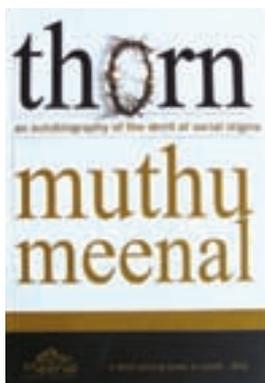
### JOURNEY TO HEALTH

Muthu Meenal was born in a village in Tamil Nadu and diagnosed with leprosy at the age of nine. *Thorn* is the story of her childhood and coming of age, culminating in her marriage.

Once it became apparent that their daughter had leprosy, Muthu’s parents initially put their faith in a medicinal stew of snake meat, hoping it would clear the rash on her face. But when she suffered a leg injury that refused to heal, she was hospitalized — and so began several years of institutionalized living away from her family. Transferred to the Sacred Heart Hospital in Kumbakonam, she was able to resume her schooling — much to her joy — and had an operation to repair her leg. Finally declared free of the disease after six years, she writes, “I felt as if I had been released from a prison.”

Translated from the Tamil by Shubashree Desikan, *Thorn* is not only Muthu’s account of how she coped with her diagnosis and treatment, but also a description of the rural milieu from which she emerged, related in a direct and unaffected style. She is particularly attuned to the suffering of women — the traumatized sex workers she sees while waiting at a bus stop one day, the two friends who commit suicide over thwarted loves, the mistress whose jealous lover savagely attacks her over imagined infidelities.

“I never expected myself to be a writer,” Muthu tells us at the outset. But in laying down “my melancholy, sorrowfulness, and gratitude,” she has certainly succeeded. ■



*Thorn: An autobiography of the devil of social stigma*  
Muthu Meenal  
Meenal Publishing House,  
supported by Sasakawa  
Memorial Health  
Foundation  
December 2009



Yohei Sasakawa (left) greets author Muthu Meenal in Chennai as actor Kamal Haasan looks on.

## Visits to India and Nepal

The Goodwill Ambassador congratulates Nepal on achieving elimination, attends a meeting of the National Forum in Chennai and launches Global Appeal 2010 in Mumbai.



Female community health volunteers in Kavre District, Nepal, in January.

### NEPAL (JANUARY 18-21)

I have been a frequent visitor to Nepal over the years to support that country's efforts to combat leprosy, so it was with real pleasure that my January visit was to commemorate the fact it has eliminated leprosy as a public health problem. The government made an official announcement at a ceremony in Kathmandu on January 19, saying that the prevalence rate of the disease as of December 2009 is 0.89 per 10,000 inhabitants. Currently, 2,445 patients are undergoing treatment nationwide.

In separate meetings with Prime Minister Madhav Kumar Nepal and Minister of Health and Population Uma Kant Chowdry earlier in the day, I congratulated them on this achievement and sought their ongoing commitment to further reducing the disease burden. Health Minister Chowdry acknowledged the work of staff in the field, and the contribution of local and international NGOs, and said it was important to sustain the momentum.

I should also like to acknowledge the role and leadership of the WHO country representative, Dr. Alex Andjaparidze and his team, and also the hard work and dedication of Dr. G. Thakur, the director of the health ministry's epidemiology & disease control division and leprosy control division, and all the staff who work under his direction.

The elimination ceremony was attended by over 100 people, including Mr. Dharmendra Jha, the president of the Federation of Nepali

Journalists. Effective media coverage is an important part of leprosy elimination activities, and the federation has made a constructive contribution.

While most of my visit was confined to meetings in Kathmandu this time, I was able to make one field visit to Kavre District health office, accompanied by Dr. Thakur, who wanted to show me that efforts to inform the public about leprosy continue unabated. The visit coincided with a festival that takes place once every 12 years. I watched a dance performance, and was told that people affected by leprosy were among those participating. Female community volunteers also performed a song about leprosy that is used to raise awareness about the disease. One of the verses translates as, "If you suffer from leprosy, take drugs as prescribed. Do not think you have committed a sin."

Much work remains to be done in Nepal, but all involved are aware of the remaining challenges and know what they have to do.

### INDIA (JANUARY 22-26)

The idea for the National Forum, the increasingly influential network of people affected by leprosy, was first conceived five years ago in Chennai, during a discussion I had with IDEA India President Dr. P.K. Gopal, Dr. S.K. Noordeen, Dr. S.D. Gokhale and others. And it was to Chennai I returned in January for the forum's first ever southern regional conference on January 24 (see page 3). I was pleased to see such an excellent

turnout for the conference, which was held in a 4-star hotel. As Dr. Noordeen, one of the speakers, commented, such a gathering would not have been possible at such a venue a few years ago — indicating the progress being made in breaking down social barriers.

In my remarks to delegates, I said that as individuals, or even individual colonies, their influence was limited, but as the National Forum it was possible to engage with the authorities from a position of strength. Under the umbrella of the National Forum you are united, I told them. “Keep this unity. It is your forum. Therefore it is your responsibility to ensure that it is a success.”

While in Chennai, I attended a cultural event at which children of affected families in Tamil Nadu performed. Later that day, I was invited to the launch of *Thorn*, the English translation of a memoir by Muthu Meenal, a person affected by leprosy. The book was launched in the presence of actor Kamal Haasan, a fan of the book for its simplicity and honesty.

I also visited a couple of leprosy colonies, including Villivakkam, which is led by Mr. A. Prakasam, who is also a National Forum representative for the state of Tamil Nadu.



Visiting a clinic in Hanuman Nagar colony (top); addressing residents of Mahatma Gandhi Kushtvasahat (above)

Nineteen enterprises at the colony are being supported by microloans from the Sasakawa-India leprosy Foundation, including a toy shop in the colony itself and businesses selling shoes, saris, kitchenware and vegetables.

Moving to Mumbai for the launch of Global Appeal 2010 on January 25, my stay included meetings with National Forum representatives from Maharashtra state as well as visits to two colonies on the outskirts of the city. Among those addressing the National Forum gathering was Ram Naik, a former Cabinet minister who was among those who petitioned parliament in 2008 for the empowerment and rehabilitation of people affected by leprosy. Urging greater activism, he told the gathering, “You need a sword in one hand (to fight for your rights) and a pen in the other (to write applications).”

The first colony I visited was Hanuman Nagar in Kalyan, home to about 200 affected families. It recently started a dairy project with a SILF loan and is selling about 70 liters of milk daily to the local market. Like many colonies, it now finds the city encroaching. Next to it on what used to be open land where the boys of the colony once played cricket, two new apartment buildings are being completed. The colony includes a school where children are educated up to 4th standard. There is also a splendid Hindu temple. As there is no other temple nearby, I understand that people outside the colony come to worship there.

The second colony I visited was the Mahatma Gandhi Kushtvasahat in Thane. This too was once an isolated settlement, but it is now part of a larger community. The colony is home to about 185 affected families. I understand that some residents are now renting rooms to people outside the colony as a way of generating income. Certainly this can only help to spur greater social integration.

My main purpose in visiting Mumbai this time was for the launch of Global Appeal 2010. Now in its fifth year, the appeal was signed by representatives of the corporate sector. I am very grateful to two of the signatories, Mr. Keshub Mahindra and Mr. Kan Trakulhoon, for attending the launch ceremony in person. Moreover, I am deeply appreciative of all fifteen business leaders, who felt strongly enough about this issue to put their names to the appeal. I am very hopeful it will have a profound effect. ■

# World Leprosy Day 2010

Calling attention to the rights of people affected by leprosy.



Around the globe, nations marked World Leprosy Day on January 31. In the Philippines, the theme was to empower persons, families and communities toward a leprosy-free Philippines. A Philippine Declaration in Tagalog and English, signed by health officials, NGOs, people's organizations and private groups, was published in an advertisement in the newspaper *Philippine Daily Inquirer* to draw attention to this goal.

## UNHRC ADVISORY COUNCIL MEETS

The Advisory Committee to the UN Human Rights Council met in Geneva on January 26 to discuss draft principles and guidelines on the elimination of discrimination against persons affected by leprosy and their family members. The committee was following up the request made by the Human Rights Council at its 12th session last October, for relevant actors to submit their views on the draft.

Shigeki Sakamoto, the advisory committee expert overseeing the draft, is hoping to circulate a revised version among members as soon as possible, with a view to submitting a finalized draft to the advisory committee in August. Subject to its approval, the draft will be submitted to the 15th session of the Human Rights Council in September 2010. ■

## NEWS EXTRA ACWORTH MUSEUM ONLINE

Those wanting to visit the Acworth Leprosy Museum in Mumbai can now take a closer look at some of the exhibits online. Visit the museum's home page ([www.theacworthleprosymuseum.org](http://www.theacworthleprosymuseum.org)) and click on the Virtual Tour link.

## FOR THE ELIMINATION OF LEPROSY

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## FROM THE EDITORS

### TRAGEDY IN BIHAR

On January 11, 2010, a child burned to death when a land dispute in India's Bihar state turned ugly. Half a dozen roadside huts that were home to families affected by leprosy were torched by a man who owned the adjacent land. The previous week, the landowner had beaten one of the residents and warned the community of serious consequences if they didn't leave. He wanted to sell his property, and the presence of the Pipra leprosy colony was an obstacle. The families, who had been living there for 20 years, refused to budge as their huts stood on government land.

Not so long ago, an incident such as this might well have been shrugged off by the authorities. But now there is an organization that can channel protest in an effective manner, India's National Forum of people affected by leprosy. Colony leaders representing Bihar state had already complained about the beating to local police, who had issued a written instruction to the landowner not to harass the community. Following the arson attack, the leaders swung into action again. They organized

a road block and demanded that the assailant be arrested and that the family of the dead child receive compensation. Mr. S.K. Dutta, who heads the National Forum Northern Region, traveled to Bihar from Delhi and spent four days there working with the community and contacting, among others, the chief minister of the state. Mr. G. Venu Gopal, the forum's general secretary, has also worked tirelessly, communicating the reality on the ground to outside supporters.

Only the previous month, the National Forum, together with IDEA India, had organized a workshop in Patna on social and economic empowerment of people affected by leprosy in Bihar. Now these people were witnessing how the National Forum — their forum — can bring pressure to bear on their behalf. The standing of the National Forum in Bihar has never been higher, but it has taken a tragedy to underline its effectiveness. (At time of writing, the state had agreed to pay the bereaved family Rps. 150,000 and police were hunting for the landowner.)