

FOR THE Elimination OF Leprosy

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



President Ramos-Horta signs the official declaration that leprosy is no longer a public health problem in Timor-Leste on 23 March 2011.

MESSAGE

Timor-Leste's Achievement

In terms of area and population, Timor-Leste and India are polar opposites. But one thing they now have in common is a notable public health achievement: the elimination of leprosy as a public health problem. Timor-Leste became the latest country to reach this milestone, which was officially recognized at a ceremony in Dili in March. India attained this landmark at the end of 2005.

Although I have made far fewer visits to Timor-Leste than I have to India, I have felt equally supportive of its efforts to tackle the disease. For such a young nation, formed only in 2002, this is a proud achievement. To my regret, I could not be present for the ceremony as I was supervising emergency relief efforts for survivors of the earthquake and tsunami that hit Japan on March 11. However, I understand it was a wonderful occasion and that President Jose Ramos-Horta himself attended.

For India, bringing the prevalence of the disease down below one case per 10,000 population was similarly a historic moment. Given the millions of cases the country used to account for, this once

seemed an impossible dream.

There is a I reason why I bring together Timor-Leste and India. I want to recognize Timor-Leste and all who made this achievement possible, but I also want to draw attention to the experience of India since 2005. There are still areas of the country where the disease is a serious problem. It is evident too that the political commitment that made elimination possible is weakening.

As I have always emphasized, and as the case of India shows, elimination is not the end of the road; there is still much work to do. I am confident, however, that India will not let its progress falter, while I am sure Timor-Leste will heed the lessons that India can teach.

Now only Brazil has yet to pass this milestone. Under a new president and new health minister, I am hopeful Brazil will redouble its efforts. I will be following its progress closely. Should it require any assistance, let us give it every support.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Good News from Dili

Timor-Leste officially declares leprosy eliminated as a public health problem.



On March 23, 2011, President Jose Ramos-Horta of the Democratic Republic of Timor-Leste officially announced that his nation had eliminated leprosy as a public health problem at a ceremony that took place in the

capital, Dili, in front of health workers, people affected by leprosy and assembled dignitaries.

PRESIDENT'S PLEDGE

A small country of about one million people, Timor-Leste achieved independence from Indonesia in 2002. Since then, it has had to grapple with political unrest, security concerns and geographical constraints, all of which have created serious barriers to the delivery of health services to its people.

In spite of these challenges, the health ministry, working in close cooperation with the WHO and other key partners including The Leprosy Mission International, has had a leprosy elimination program in place since 2003. The national program has focused primarily on training health staff in the detection and treatment of leprosy, actively looking for cases, and ensuring all patients have uninterrupted access to multidrug therapy (MDT). Just one year ago, in fact, the ministry and its partners held a workshop on

leprosy, underlining their commitment to see Timor-Leste make progress on this issue.

As a result of these efforts, the country saw the prevalence rate of leprosy fall from 5.18 per 10,000 people in 2004 to 0.73 by the end of December last year, when there were 73 cases under treatment. The WHO considers leprosy is no longer a public health problem when prevalence drops below one case per 10,000 people.

In his address, President Ramos-Horta told people affected by leprosy in the audience, "You have suffered for a long time. This government will do its utmost to see that people affected by leprosy, including family members and those who have been cured, can achieve normal lives."

Among those attending the ceremony were National Parliament President Fernando Rasama, Health Minister Dr. Nelson Martins and the Deputy Regional Director of the WHO's Southeast Asia Region Office, Dr. Poonam Khetrupal Singh.

Dr Singh stated, "This is an important milestone. With Timor-Leste achieving this goal, all countries in Asia have now eliminated leprosy as a public health problem." She added, "WHO is committed to continuing the program with the same intensity to further reduce the disease burden, especially in the three remaining endemic districts, i.e. Oecusse, Baucau and Viqueque."

One of the three, Oecusse, is cut off from the rest of Timor-Leste by the Savu Sea. It is thought to have served as a leprosy colony in times past, helping to explain why it contributes so many cases.

'STAY FOCUSED'

Because of his involvement in emergency relief aid work related to the earthquake and tsunami in Japan, Goodwill Ambassador Yohei Sasakawa was unable to attend. He was represented by The Nippon Foundation's Executive Director Tatsuya Tanami.

In remarks delivered on his behalf, the Goodwill Ambassador warned Timor-Leste against complacency. "I hope you will stay focused on leprosy, continue to look for new cases and help those who have recovered from the disease to help themselves."

But he also expressed his happiness at the outcome, saying, "Above all, I congratulate Timor-Leste on its achievement of elimination. And I thank you all for your dedication and hard work, which made this possible." ■



People affected by leprosy at the March 23 ceremony marking a public health milestone for Timor-Leste

Going Places

Rambarai Sah has come a long way from a lonely hut by a river.



June 2010 edition of the Goodwill Ambassador's Newsletter

On the wall of Rambarai Sah's mother's house hangs the cover of the June 2010 edition of the Goodwill Ambassador's Newsletter. It features a photo of her son and two other activists presenting a petition to the deputy chief minister of India's Bihar state. Neighbors stop by to admire the picture and comment that her son is going places.

There was a time when it seemed like Rambarai wouldn't be going very far at all. At age 10 he became aware of a patch on his leg. He applied ointments and bandages to cover it up, but it wouldn't go away. People began to talk and he went to a nearby hospital to be examined. The doctor diagnosed leprosy and said there was no cure.

Once his schoolmates got to hear of this, they refused to sit next him and he was consigned to the back of the classroom. "Everyone avoided me," he recalled. Unable to focus on his studies, he dropped out. The head teacher told him not to return, and took the books and stationery he had paid for. "Nobody talked to me. Nobody played with me. My days were filled with tears."

A month later, the village head came to his house, telling his parents that unless they sent their son away, the whole family would be ostracized. There was little choice. His father built him a hut about 1 kilometer away, by a river. For two years he lived there alone, begging by day and crying at night, fearful of ghosts.

One day a person affected by leprosy who had passed through the village begging for food came to the river to eat. He saw Rambarai's leg and asked if he was receiving multidrug therapy. "But there is no cure!" the boy replied. His new acquaintance set him straight. Rambarai ran home to tell his parents, and the next day set off for the hospital he had been told about: Little Flower, in Raxaul, by the border with Nepal.

A NEW LIFE BEGINS

Rambarai stayed on in Raxaul, joining a colony of people affected by the disease. At first he continued to subsist on begging; then he got work at Little Flower assisting in the construction of a new building. It was at Little Flower that he met his wife, the daughter of leprosy-affected parents, marrying her at 19. A hospital job followed, and he studied English in his spare time.

Thanks to money he made working as a guide in Nepal, he and his wife were able to open a shop. More recently, Rambarai has been supplementing this income by working as an insurance agent. The couple have two sons, and



Rambarai Sah: people have set ideas about leprosy

Rambarai attaches great importance to their education. One is at college in New Delhi, and the other is aiming to follow in his brother's footsteps.

Rambarai's experiences have helped others. "I think I was the first man in my village to have leprosy," he says. "Later there were two more, but they continue to live at home. Now everyone in my village knows there is a cure for leprosy and that there is no need to send people away."

Yet stigma remains the great enemy. "There are parts of Bihar where we won't be served tea — even our children, which is the real problem." But stigma, he acknowledges, is an issue the world over. "People have very set ideas about leprosy. Educated people know better, but here in Bihar, many people are not educated. Sometimes it is very hard to reason with them."

Rambarai is increasingly involved in organized efforts to empower people affected by leprosy and break down social barriers. A chance encounter led to an introduction to the National Forum, the countrywide platform of people affected by leprosy, and the opportunity to attend a conference in Mumbai. Connecting with the forum, he says, opened up new horizons.

He also became one of the founding members of the Bihar Kustha Kalyan Mahasangh (BKKM), which has been playing an active role lobbying for improved pensions for people affected by leprosy in the state. Last year, he and fellow members conducted a survey of all 63 self-settled colonies in Bihar to present to state authorities.

Now he has assumed his biggest role yet: becoming one of the first nine trustees of the National Forum and helping to shape the future for people affected by leprosy. "It's an amazing opportunity," he says.

Rambarai Sah's journey continues. ■

India at the Crossroads

Time to focus on endemic districts, or risk losing gains that have been made.

India declared the elimination of leprosy as a public health problem by the end of 2005, indicating that prevalence of leprosy had been reduced to a national average of less than one case per 10,000 people. This meant that there were still over 100,000 cases in the country, the largest number for any country in the world.

More importantly, these cases were distributed very unevenly among the states and districts. Some areas were left with quite a high number of cases and about one third of the country's 630 districts still had prevalence levels above the elimination cut-off point of one case per 10,000 population.

Currently the leprosy situation is causing considerable concern, to the extent that the Indian Parliament is looking into the issue and has asked for a national sample survey to be undertaken to understand better the problems being faced. The survey is already under way and the results are expected during the latter half of the year. It is possible that the survey will bring out the very difficult situation being faced in certain parts of the country.

POLITICAL COMMITMENT LACKING

The general perception among those interested in the problem of leprosy is that there has been a perceptible decrease in political commitment as well as in the priority given to leprosy at different levels. Leadership at the state and district levels has weakened considerably and in some places it is totally absent. One misses the exemplary vigor and commitment that were very visible and characteristic of the National Leprosy Program of the 1990s and early years of the 2000s.

It is likely that at the decision-making level leprosy is no more considered important as the leprosy prevalence rate has come down to less than one case in 10,000 population, even though this is only a national average. Even worse, at some levels there is a misconception that leprosy is currently only a question of rehabilitating those who have been cured and is no more a medical problem. This can be seen by the fact that many states and a large number of districts have no full-time personnel to provide adequate leadership.

MARGINALIZED POPULATIONS

The currently available information indicates that leprosy continues to cling to certain parts of the country, and to certain population groups, as a result of inadequate attention received and the absence of intensified activities. This

Elimination status: states and districts

	2006 -2007	2007 -2008	2008 -2009	2009 -2010
States	25/29	25/29	27/29	27/29
Union Territories	4/6	4/6	5/6	5/6
Total	29/35	29/35	32/35	32/35
Districts	487/611 (79.7%)	482/614 (78.5%)	510/630 (80.9%)	510/633 (80.5%)

is particularly true in areas where there are significant numbers of marginalized populations, particularly tribal populations

In view of the above, there is a great need to strengthen and invigorate the program to ensure adequate case finding and treatment, failing which there is every chance that the disease problem will increase. This calls for a national dialogue involving all interested parties, so that it becomes possible to have personnel responsible for leprosy at the state level in all states and full-time personnel responsible for leprosy in all districts facing challenges — with the latter provided with sufficient resources, both financial and manpower, in a flexible manner.

There is a great need to strengthen and invigorate the program.

“More of the same” or “one size fits all” approaches are not likely to work. It will be necessary to identify problem areas and communities, analyze the specific challenges that they face and implement locally specific solutions.

The elimination of leprosy from every part of India is an eminently doable job. If anti-leprosy activities are further intensified, new case detection can come down further before it reaches a plateau of 10,000 cases a year, which is equal to a detection rate of less than one case per 100,000. The possibility of such a steep reduction has already been clearly evidenced in countries as varied as China, Vietnam, Thailand and Uganda.

But we need to mobilize all the necessary ingredients, including political commitment. If timely action is not taken now, we may have to face difficult problems in the future. Hence we must act to ensure that the gains made so far are not compromised and a leprosy-free India becomes a reality sooner rather than later. ■

AUTHOR BIO:

Dr. S. K. Noordeen



Dr. S. K. Noordeen is chair of the Technical Resource Group of the National Leprosy Eradication Program of the Ministry of Health & Family Welfare, India.

National Forum Moves Forward

New status as trust strengthens goal to empower people affected by leprosy.

Formed in 2005, the National Forum is a networking organization that draws its membership from approximately 800 self-settled leprosy colonies across India.

On 21 February 2011, it opened a new chapter in its history when it was registered as a trust in Tamil Nadu state. Chaired by Dr. P.K. Gopal, the National Forum has a board of nine trustees, all persons affected by leprosy.

“The National Forum has made great progress since its inception, and has done good work in identifying leaders among people affected by leprosy in each state,” says Dr. Gopal. “The task now is to strengthen the organization at state level.”

Fellow trustee G. Venugopal says the National Forum has helped people affected by leprosy “to think about ourselves in a different way, and to know our rights.” It has also encouraged self-reliance. “The National Forum doesn’t tell people: ‘We will work for you.’ It tells them: ‘You work for yourself. We are with you, in the shape of guidance, cooperation, implementation, and maybe financial support.’”

MAIN OBJECTIVES

The key goals of the National Forum, as laid down in the deed of trust, are as follows:

- Work for the socio-economic empowerment and welfare of persons affected by leprosy and

their families, including the physically disabled.

- Promote respect and dignify the lives of those who have been affected by leprosy, including the physically disabled, and to work in partnership to ensure they live rewarding, dignified lives.
- Associate with the government, non-governmental organizations and international agencies to raise the social and economic conditions of people affected by leprosy, including the physically disabled.
- Educate the community about leprosy.
- Collect information from various sources on the subject of leprosy and physical disability in India, and function as a consultative agency.
- Combat prejudice, discrimination, segregation, social rejection, the use of derogatory terminology and the stigma associated with leprosy through self-support, self-reliance, dignity and public awareness programs.
- Represent people affected by leprosy and, in working for their empowerment, enable people in each state to become autonomous and strong. ■



The nine National Forum trustees and their patron, Yohei Sasakawa, gather for a commemorative photo at the conclusion of their first board meeting on 26 February 2011 in New Delhi. Back row (left to right): Lourdes Nevis Mary, Sarang Sudam Gaidhane, Rambarai Sah, Vagavathali Narasappa, G. Venugopal; Front row: A. Prakkasam, Dr. P.K. Gopal (chairman), Yohei Sasakawa, Bhimrao Madhale, Maya Ranavare.

Back to India

Board meetings in Delhi, lobbying for pensions in Bihar.

INDIA (FEBRUARY 26 – MARCH 3)

India's National Forum of people affected by leprosy is an umbrella organization that represents residents of self-settled leprosy colonies all over India. Founded at my suggestion in 2005, it was officially registered as a trust with the Indian government on February 21 this year*. This is a very important development for improving the lives of colony residents and promoting their social integration.

The aim is to extend the concept of disability to social disability.

For five years, the National Forum has been engaged in building and strengthening its nationwide network. It has held national and regional meetings and conducted a survey of colonies. On February 26, the first meeting of the newly constituted board of trustees was held in New Delhi at the offices of the Sasakawa-India Leprosy Foundation (SILF). Nine trustees, all persons affected by leprosy, took part. Dr. P.K. Gopal was elected chairman of the board and I was honored to be made patron.

In being recognized by the government as a trusted partner in negotiations on matters related to colony residents, the National Forum will, I believe, play a very important role in advancing social reintegration for all persons affected by leprosy in India. In that regard, I stressed the importance of the principles and guidelines that



Jitwarpur colony in Samstipur, Bihar state.

were part of the resolution adopted by the UN General Assembly in December 2010, and urged the board to make full use of them in its activities.

In the evening I flew to Bihar state. This was to follow up on two visits I made in short succession a year earlier. Then, together with National Forum leaders and representatives of Bihar Kushta Kalyan Mahasangh (BKMM), an organization of people affected by leprosy in the state, I had called on Bihar's deputy chief minister and other officials to lobby for pensions for people affected by leprosy. While the authorities responded positively, especially after receiving the baseline data they had requested, subsequent state elections meant the process had to begin afresh.

What the National Forum and BKMM are seeking is a pension for every person affected by leprosy living in Bihar's 63 self-settled colonies, including those with no visible disabilities. Currently, any affected person who has a recognizable physical disability qualifies for a disability pension, although not all are receiving one. The aim is to extend the concept of disability to social disability, on the grounds that stigma and discrimination are also disablers when it comes making a livelihood. Although an Indian government petition committee has recommended that a pension of 2,000 rupees per month be paid to people affected by the disease, because of economic disparities among states Bihar is requesting 1,000 rupees.

Among the state leaders we met with again to press our case were Sanjay Kumar, the National Rural Health Mission's executive director for Bihar, and Bihar's Deputy Chief Minister Sushil Kumar Modi. We also met with the social welfare minister and the health minister. We were fortunate in that Deputy Chief Minister Modi now also doubles as the finance minister, and so has influence over budgetary decisions. From what he said, I am now more confident than ever that the pension will be forthcoming. My hope is that once the issue is settled in Bihar, the state will become a model for others to follow.

While in Bihar, I called on the offices of LEPRO India, where its state coordinator, Rajin Kant Singh, gave me a presentation on LEPRO's activities there. LEPRO operates in nine districts designated by the government.

FOOTNOTE

* The trust deed was registered in Tamil Nadu State as a Public Charitable Trust, in conformity with the provisions of the India Trust Act, 1882.



LEPRA India activities:
(right) prevention of
disabilities camp; (far
right – top) specialized
footwear; (far right –
bottom) self-care kit

I learned that Bihar sees around 20,000 new cases of leprosy a year. The rate of new cases with grade 2 disability is low, which indicates that people are coming in early for treatment. On the other hand, the 16-17% of new cases involving children shows that there is a high rate of infection in the community.

Mr. Singh told me that LEPRA is the only organization in Bihar preparing specialized footwear for people affected by leprosy. I was very impressed by the samples. “No one can tell these are shoes for people affected by leprosy,” he told me. I was particularly intrigued by a foot support to be used inside the house, where shoes are not worn.

Design and supply of protective footwear is one part of LEPRA’s integrated prevention of disability (IPoD) activities, which also include skin care, wound care, exercise, and health education. Afterward, I visited a government health center at Taipur where LEPRA conducts an IPoD camp twice a month. On the expansive roof balcony, I helped out as people cleaned their feet. I was also introduced to a number of patients under treatment and shown the different ways the disease can manifest itself.

My stay in Bihar included a visit to the Jitwarpur leprosy colony in Samstipur. Its residents had once lived alongside the nearby railroad tracks; now they had been given land to one side of a road. As well as people affected by leprosy, there are also persons with disabilities and other of society’s poorer members living there. Conditions were very basic and it brought home to me the extent of the challenges that remain to improve the lives of people in these colonies.

This is one of the goals of the Sasakawa-India Leprosy Foundation. On returning to Delhi, I attended the SILF board meeting on March 2.

The primary objectives of SILF are to assist people affected by leprosy through their own self-help efforts to lead independent lives, and to address the problems of stigma and discrimination.

Five years after SILF was established, it is starting to have an impact through its sustainable livelihood initiatives, designed to facilitate a move away from begging. In 2009-2010, SILF extended its reach to 430 beneficiaries living in 33 colonies across 11 states. But the provision of seed money alone to start income earning activities among peoples with low levels of education and skills is often not enough, so SILF also focuses on skills’ training and capacity building.

SILF has had some success, notably the projects it recognized with its *Rising to Dignity* awards in January, but it has also had some failures, when projects didn’t get off the ground. However, as I told the board meeting, failures are more important than successes, because of the lessons they can teach.

I am particularly pleased by the growing cooperation between SILF and the National Forum. The latter’s nationwide network is crucial for the effective implementation and monitoring of SILF’s projects, as well as the dissemination of information regarding other initiatives. I expect much from this collaboration in the months and years ahead.

While in Delhi I also paid a courtesy call on the offices of Netherlands Leprosy Relief India, where I was warmly welcomed by Dr. M.A. Arif and his team. In addition, I had my first meeting with the new WHO country representative, Dr. Nata Menabde. We agreed on the need to encourage the Indian government to remain focused on leprosy. I look forward to cooperating with her on seeing that our shared objective is realized. ■

Accounts of 'Dignity Regained'

Testimonials challenge negative stereotypes of leprosy



(From left to right) Dignity Regained collections for Cambodia (published in 2010), China (2009) and Indonesia (2011).

Six years ago, a collection of real-life stories about people's experiences with leprosy was published in India under the title *Dignity Regained*. Since then, similar works have been produced in six more countries: Cambodia, China, Ghana, Indonesia, Myanmar and the Philippines.

The books are planned, edited, designed and produced by groups of people affected by leprosy or those close to them, and are published in the local language. As well as serving as a source of encouragement to those in the midst of coping with leprosy, they are also a tool to sensitize the public and challenge widely held perceptions that people affected by leprosy are somehow incapable of leading normal, productive lives.

The accounts do not gloss over the obstacles that society places in the way of a person affected by leprosy, and not all the stories find their subjects in a happy place. From the original volume come these thoughts from Najima Begum: "Leprosy has not only affected me physically. It has left me

mentally wounded and scarred for life."

Others have found a way to cope. Lu Zwen of China says: "Plum blossoms emit sweet scent in the bitter cold. I have experienced so many ups and downs not only of pain from illness and hardship of life, but also pessimism and despair in my heart. Now I have prevailed over all these ordeals."

In the Philippines, Inneng Paderi writes: "At present I am happily married and having a satisfied life. The scars on my skin are just shadows in the past, not the ruins of my life."

And from Ghana, Nana Kwame Osei reflects: "I faced many discriminations and stigma, but I said to myself that maybe it is my crossroad. I learnt how to paint houses from the painter working in my leprosy hospital and became a good painter. Thanks to this skill, many people became my friends. They also come to me when they are facing problems in their lives and I give them advice."

The books are published with support from the Sasakawa Memorial Health Foundation ■

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FROM THE EDITORS

A WORD OF THANKS

The Hindu newspaper reported recently that residents of the Sumanahalli Leprosy Rehabilitation and Training Center had collected money for victims of the earthquake and ensuing tsunami that struck northeast Japan on March 11. The action by the center, in India's Karnataka state, is just one instance of the very many gestures of sympathy, concern

and support that have been transmitted to Japan from the leprosy community around the world. On behalf of Goodwill Ambassador Yohei Sasakawa, this newsletter extends its grateful appreciation to all these individuals and organizations for their thoughts, prayers, encouragement and contributions for the people of Japan's Tohoku region.