

# FOR THE Elimination OF Leprosy

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



Yohei Sasakawa (center) with delegates to India's first-ever national conference of persons affected by leprosy held last December in Delhi.

## A MESSAGE FROM THE GOODWILL AMBASSADOR

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# Moving against Discrimination

On January 29, 2006, I was in India to launch a global appeal endorsed by a group of world leaders. The next day, India announced the elimination of leprosy as a public health problem. I was delighted that these two historic events came at the same time, and offer India my warm congratulations on its tremendous achievement.

The global appeal is intended to draw attention to stigma and discrimination against persons affected by leprosy, and generate momentum to resolve this problem once and for all.

Medical people often talk about leprosy as a "neglected (tropical) disease." I find this description inappropriate. To me it sounds disrespectful to all those patients who've suffered from the disease, those who've been cured yet still faced discrimination and those at the front line who have devoted themselves to leprosy work since the days before an effective treatment became available.

That said, it is unfortunately true that when it comes to tackling stigma and discrimination, we all of us have been neglectful. Given how many diseases there are in the world, and despite the

progress made by modern medicine, no other disease has been quite as misunderstood or stigmatized as leprosy. We must not forget the tragic fate of so many throughout its long history.

To truly win the fight against leprosy, we need to move forward simultaneously on both the medical and social fronts, as if they are two sets of wheels on the same car.

It is apparent there will continue to be a fair number of new patients for the time being. These new cases must not be neglected. Important tasks will be to ensure that early detection and prompt treatment occur within the context of an integrated health service environment.

At the same time, we must cure society of the disease of discrimination, and enable leprosy patients, those cured of the disease, and their families to live with dignity.

So let us make this a year when we move forward with increasing momentum in our fight for a world without leprosy.

— Yohei Sasakawa, WHO Goodwill Ambassador

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# Putting Empowerment on the Agenda

Groundbreaking meeting issues 'Delhi Declaration' affirming dignity and rights of persons affected by leprosy.

India's first ever national conference of persons affected by leprosy was held in New Delhi on December 19, 2005.

Under the theme of "Integration and Empowerment," the landmark conference drew some 600 delegates — among them representatives from India's nearly 700 leprosy colonies — as well as senior government ministers, health workers and activists.

More than 11 million Indians have been cured of leprosy since the mid 1980s, and while less than 60,000 people are believed to live in these self-settled colonies, social integration and economic advancement remain far off for many.

"We have won the medical battle against leprosy thanks to multidrug therapy, but the war against social stigma and irrational discrimination is still to be won," said WHO Goodwill Ambassador Yohei Sasakawa at the opening of the conference.

Chaired by IDEA India President Dr. P.K. Gopal, who described the gathering as "a historic day for persons affected by leprosy," the conference heard speeches from Union Minister for Justice and Social Empowerment Meira Kumar, Union Minister for Policy Implementation Oscar Fernandes, Leprosy Elimination Alliance President Dr. S.K. Noordeen, International Leprosy Union Chairman Dr. S.D. Gokhale, and Federation of Leprosy Organizations President Dr. Brahm

Dutt, among others.

For many of the colony representatives, it was their first experience to participate in a national conference. It provided them with the opportunity to link up with other persons affected by leprosy from all over India, and inspired the hope that by joining forces they could work together to build a better future. The bursts of applause that regularly punctuated the Federation of Indian Chambers of Commerce and Industry Golden Jubilee Hall were testimony to the feelings of empowerment



Delegates came from all over India for the landmark meeting.

## DELHI DECLARATION OF DIGNITY New Delhi, India, December 19, 2005

Whereas, the preamble to the Universal Declaration of Human Rights, adopted in 1948, recognizes "the inherent dignity" and "the equal and inalienable rights of all members of the human family" as the foundation for freedom, justice and peace in the world;

We, the participants in the National Conference on Integration and Empowerment of Persons Affected by Leprosy, held in Delhi, India, on December 19, 2005, do hereby join together to affirm our dignity and our right to be involved in decisions that affect our lives and our future.

Therefore, as partners working together to eliminate the stigma associated with leprosy and the destructive effects that it has on people's right to live their lives with dignity, we, the participants in this National

Conference, do hereby resolve that the following recommendations be adopted in order to promote quality of life, freedom from degrading treatment, and each individual's most basic human rights.

1. Every effort should be made by government agencies, non-governmental organizations and the people themselves to ensure that individuals affected by leprosy are not discriminated against in any way in their daily life, including the areas of education, employment, housing, public transportation, and the availability of medical services.
2. The government should be encouraged to actively promote the human rights of individuals affected by leprosy, and actively prevent violations of these most basic rights.
3. All discriminatory laws, including the law that facilitates divorce due to leprosy, should be repealed.
4. The use of dignified terminology is essential to eliminating the stigma and appropriate language should be used to address people affected by leprosy. Derogatory terms such as "leper," "maharogi," "kodi," etc., should never be used.
5. Opportunities should be provided for individuals and organizations made up of persons affected by leprosy to work in partnership with government agencies and non-governmental organizations to develop activities and programs.
6. Individuals affected by leprosy should be nominated in the State and National Commissions as members under the Persons with

the occasion aroused.

Commented Anjan Dey, who overcame leprosy to qualify as a physiotherapist at the hospital near Pune where he once swept floors as a patient, such an event would have been “unthinkable” just a few years ago. “I am really happy to note that for the first time hundreds of people affected by leprosy have come to the national capital, are staying in good hotels, organizing their own conference and interacting in the best tradition of a national meet,” he said.

**‘An event like this would have been unthinkable just a few years ago.’**

During an “empowerment session,” delegates highlighted their concerns and hopes, and urged that the momentum begun by the conference not be allowed to taper off.

“The gains of this historic conference should not be lost after the program is over,” said delegate M. Gurappa from Haryana, adding that there should be a national body, headquartered in Delhi, where persons affected by leprosy could come together and “present a united face in front of the government, business and other sections of society.”

Echoing his comment, Bhimarao Madhale from Maharashtra said, “A very important thing for us is to be united, because without unity we cannot achieve anything substantial, in spite of the good wishes of many others.”

From West Bengal, Swapan Kumar Bannerjee called for “a strong democratic movement among cured people to create their leadership and make society at large take cognizance of our rightful needs.”

During the day, the newly-created National Forum for the Empowerment of People Affected by Leprosy met to discuss its future agenda. The 17-member forum, including 9 persons affected by leprosy, agreed to complete an ongoing survey of the nation’s self-settled colonies and draw up a list of their needs.

A key document to emerge from the conference was the Delhi Declaration of Dignity (see below), listing 14 recommendations to promote quality of life, freedom from degrading treatment and each individual’s most basic human rights.

It is now up to those who took part to build on the foundations the conference created, but what it already achieved was summed up by an elderly woman from Haryana, who said, “I did not get the bag and shawl that were given to all delegates as I was late arriving, but what I got today was something I never got in the last 30 years since I had leprosy: respect and dignity.” ■

Disabilities Act.

7. Every effort should be made to encourage support and inclusion of the person affected by leprosy within their family.
8. Individuals affected by leprosy and organizations representing these individuals should be supported in efforts to develop productive networks that will ensure that the voice of the persons affected by leprosy continues to be heard.
9. Every effort should be made to ensure that children of persons affected by leprosy receive equal opportunities for education and employment.
10. A national effort should be made to ensure that all types of media, including newspapers, films and television, portray individuals affected by leprosy with dignity.

The media should be encouraged to become part of the effort to eliminate the stigma by promoting modern, current information about the disease and those affected by it.

11. Proper housing and care should be given to elderly persons affected by leprosy. A reasonable amount not less than Rs. 500/- as pension should be given to the leprosy-disabled persons.
12. Networks to ensure the prevention and treatment of disabilities should be strengthened, especially among hospitals and private health centers.
13. Sustained training programs for government medical staff should be implemented to ensure the ongoing, comprehensive treatment of persons affected by leprosy.
14. Persons affected by leprosy should be afforded their rightful place in the

history of leprosy worldwide. Persons affected by leprosy pledge their support to governments and NGOs to eradicate leprosy from the country and to improve the quality of the lives of the persons affected by leprosy.

In conclusion, we strongly affirm that the final victory in the fight against leprosy should only be declared when there are no more persons to be cured, no more disabilities to treat, no more discrimination and human rights violations to overcome, and when persons once affected by the disease can lead normal, integrated and empowered lives with the same opportunities, rights and duties as their fellow citizens.

Persons affected by leprosy

# Beating Leprosy in Bangladesh

Strong political commitment has played a key role in success.

Having achieved leprosy elimination at the national level two years ahead of WHO's original target of 2000, Bangladesh is today hopeful of achieving elimination at the sub-national level, too.

At the time of the original World Health Assembly Resolution in 1991, the country's estimated PR was about 13.6/10,000 population. By December 31, 1998, it had fallen to 0.87, going below 1 for the first time.

Although leprosy was eliminated as a public health problem at the national level, there remained 15 districts/areas where it was endemic. Consequently, the National Leprosy Elimination Program (NLEP) of Bangladesh set a new target of achieving sub-national (district/area) elimination by the year 2005. It also aimed to reduce the grade II deformity rate among newly-detected cases to less than 5%. This had stood at 21.40% in 1991, dropping to 8.98% at the end of 1998.

With the passage of time, registered prevalence is gradually coming down, and at the end of the second quarter of 2005 had fallen to 0.51/10,000. Leprosy remained endemic in six districts and two cities, compared to 15 districts/areas in 1998. However, the rate of grade II deformity remains more or less static among newly detected cases, showing a slight decline to 8.01%.

The NLEP has thus allocated a further two years to achieve its goals.



Leprosy awareness training for religious leaders

## FACTORS FOR SUCCESS

The factors that contributed to achieving elimination as a public health problem are as follows:

- Strong political commitment with allocation of adequate resources as well as administrative support;
- Technical assistance and critical funding by the WHO, World Bank/International Development Association co-financiers;
- Efficient health infrastructure in rural settings;
- Integration of leprosy services with general health

- services for sustainability;
- Partnership with NGOs based on mutual trust and respect;
- Emphasis on specificity and reliability of diagnosis of leprosy cases;
- Strengthening of IEC activities;
- Alliance with some key groups such as the Bangladesh Scouts, general medical practitioners, traditional healers, religious leaders, karbari (village chiefs) and headmen in hill districts, academic (medical) institutes and dermatologists, etc;
- Successful implementation of special initiatives such as LECs, NLECs, skin camps and SAPEL

## 2006-07

On the basis of lessons learnt, the NLEP has formulated the following plan for 2006-07 and beyond, along with routine activities such as case-finding and case-holding.

### 1. Program management capacity

- a. Program monitoring by holding review meetings with upazila (sub-district) health administration and NGO representatives;
- b. Strengthening of training facilities at the central level;
- c. On-the-job training of a core group of leprosy workers to improve quality of service;
- d. Refresher training on leprosy for doctors;
- e. Refresher training for program organizers and TB-leprosy control assistants;
- f. Overseas training for health managers.

### 2. Raising community awareness

- a. Orientation on leprosy for Scouts, traditional healers, religious leaders, etc.;
- b. Development, preparation and dissemination of IEC materials;
- c. Development and preparation of TV spots on leprosy and telecasting;
- d. Organization of skin camps;
- e. Installation of billboards containing basic facts of leprosy at health institutes.

### 3. Prevention of displacement of deformed persons affected by leprosy

- a. Vocational training for self-reliance;
- b. Community-based rehabilitation to reduce stigma and prevention of displacement from the mainstream population.

Bangladesh has made commendable progress, but further consolidation of government and NGO efforts, and continued technical assistance by WHO and other partners, will be needed. ■

## AUTHOR:

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Dr. Maksuda is Bangladesh's National Program Manager (Leprosy).

# Monitoring Progress in Southeast Asia

A journey to Malaysia and Indonesia to see how they are faring post-elimination, followed by a trip to India to visit colonies and attend a historic conference.

## MALAYSIA, INDONESIA (NOVEMBER 28-DECEMBER 5)

In many countries that have achieved the WHO's target for eliminating leprosy as a public health problem, it is perhaps inevitable that leprosy is slipping down the list of government and health ministry priorities. Yet sustainability requires continued political commitment, otherwise there is a real risk of undoing the good work that has been achieved to date.

Toward the end of last year I visited Malaysia and Indonesia — two countries that achieved elimination at the national level some years ago — to observe the current state of leprosy countermeasures and urge those concerned to continue fighting the disease.

In Malaysia, I visited the province of Sabah, which has a population of 2.86 million, or 11% of Malaysia's total. Nationwide, the leprosy prevalence rate is around 0.3 per 10,000, but in Sabah it is rather higher at 0.44, and there are several areas within the province where much more work needs to be done.

Sabah also has a large floating population of migrant workers from neighboring Indonesia and the Philippines, and in fact some 60% of the leprosy cases in the province are foreigners.

Local health officials I spoke with stressed the importance of early detection and treatment, but said it was even more important to educate the general public about leprosy. I understand there are plans to conduct IEC activities and home visits, and there is talk of giving healthcare workers periodic training about leprosy.

Further, Sabah also has various programs for the distribution and management of MDT supplies, the monitoring of treatment and follow-up, and prevention of subsequent complications. Pursuing these strategies, regions such as Sabah, which have achieved elimination, will be able to sustain the achievement and further decrease the number of patients.

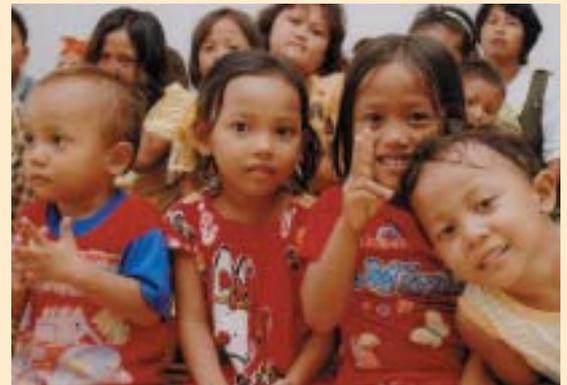
Indonesia achieved elimination in 2000. Since MDT was introduced in the 1980s, some 300,000 people have been cured of leprosy. The current prevalence rate is just under 1 per 10,000. But with a population exceeding 200 million, every year some 20,000 new patients are registered. This means that after India and Brazil, Indonesia has the third-highest number

of patients in the world.

However, in Indonesia, the priority diseases are malaria, TB, dengue fever and more recently avian flu. On arrival in Jakarta, I first paid a call on Health Minister Siti Fadillah Supari and Vice President Jusuf Kalla, outlining the world situation of leprosy and seeking from them an ongoing commitment to tackling the disease.

Some 30% of Indonesia's leprosy cases are to be found in East Java, where I visited Surabaya and Sulawesi. Located approximately in the middle of the Indonesian archipelago, Sulawesi was once home to a large number of leprosy patients,

In Surabaya, I visited the 93 families living in Babat Jerawat leprosy settlement. The people I met seemed in good heart, and the children ran about wearing big smiles. There might be discrimination outside the settlement, but within it there was a positive spirit and a sense of community. Yet I can't help thinking that had there been an effective IEC strategy in place, there would have been no need for a separate village of persons affected by leprosy at all.



Children at the Babat Jewarat colony in Surubaya

This contrasted with the situation on Bunaken, a beautiful coral island about 45 minutes by boat from Manado in North Sulawesi, where I was encouraged to find persons affected by leprosy living in the community. In a population of some 1,500, 11 people are being treated for leprosy, and 12 have been cured. There is no discrimination shown them, and they live and work alongside everyone else. It's an example that I hope will be emulated in other parts of the country

In Makassar, Sulawesi, I visited two

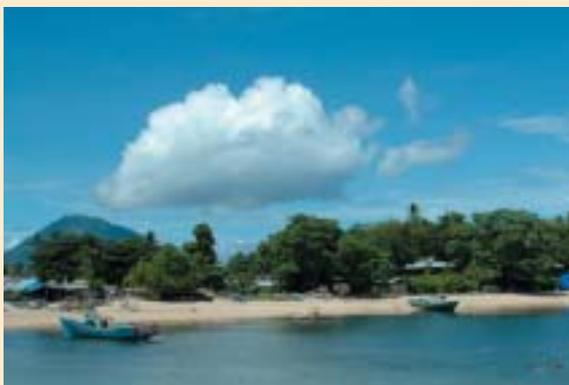
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Vice President Jusuf Kalla



Health Minister Siti Fadillah Supari



Bunaken Island, North Sulawesi (left); Bharat Mata Kusht Ashram, Haryana State (middle, right), where an old dwelling reminds of times past

institutions that seemed to symbolize different phases of the fight against leprosy. The Daya Leprosy Hospital has 220 beds but almost three-quarters of them are empty. Now that MDT is readily available, I feel there is no longer a need for a specialist hospital such as this today.

The National Leprosy Training Center, by contrast, has an important role to play in improving the quality of services. To date, some 3,000 leprosy officers, 1,500 doctors and 1,000 medical students have received training here. By nurturing human resources and acting as a national knowledge base on leprosy, I'm sure it has a key role to play in sustaining Indonesia's fight against the disease.

#### INDIA (DECEMBER 14-19)

According to 2004 statistics published by the WHO, 64% of the world's leprosy patients are to be found in India. While the actual number of cases has come down dramatically, those affected by the disease still face severe social discrimination, and might be considered a "leprosy caste." For at least some of these people, shunned by family and friends, their home becomes a self-settled colony.

At the start of 2005 I proposed that a survey be carried out of all such colonies, and that a conference of colony leaders be held. By the time this conference took place in December, the results indicated there were 630 colonies across the 23 states and union provinces surveyed so far. While many residents survive by begging, some are engaged in enterprises such as weaving, carpentry and small-scale manufacturing as a means to make a living.

I visited several such colonies, in the Delhi area and in the state of Rajasthan, during my

seventh and final visit of 2005 to India last December.

I went first to Satya Jeevan leprosy colony located at Lajput Nagar in Delhi. Once it consisted of tents pitched along the side of the road, but now the colony residents live in brick buildings. Eighty households made up of 230 people live here. While the majority of them survive on begging, in recent times the number of people making a living by selling water to passers-by or working as rickshaw drivers has been increasing.

It was here I met a 14-year-old girl, both of whose parents once had leprosy. Previously she had attended school in the area, but when it came out that her parents had had leprosy, she was bullied by her classmates and eventually had to leave. She hasn't been to school for more than a year, but fervently wishes to return to her studies. There were other children in a similar situation, and I promised to assist in building a school at the colony.

Next I visited another colony, Bharat Mata Kusht Ashram, in Haryana state. Established in 1973, it is home to some 300 people today. What is special about this colony is that the residents have formed a cooperative association and have built the economic foundations of a community that doesn't rest on begging.

Over 120 residents are engaged in weaving and other occupations, and donate a portion of the profits to the cooperative. This money is used to purchase feed for the chickens and cows the colony keeps; to pay for doctors to come and visit; and to help support those with severe disabilities.

The following day I flew to Jaipur in Rajasthan. Jaipur is the founding place of the NGO known as Sarthak Manav Kushthashram

#### Leprosy LEXICON

##### ● Treatment completion rate (cure rate)

Ensuring that all new patients who start multidrug therapy complete the full course of treatment within a reasonable period of time is an important component of leprosy control. Treatment completion means that a patient with paucibacillary leprosy completes 6 monthly doses within a 9-month period, and a patient with multibacillary leprosy completes 12 doses within 18 months. Treatment completion rate can be used in the field as a proxy for cure rate, which require an additional examination.

(SMK), an organization set up by well-to-do ladies some 30 years ago to help persons affected by leprosy achieve self-reliance.

The colony that is the focal point of their activities is located near a Hindu temple and is home to 30 families totaling 80 persons who once had leprosy, and their children. Many colonies in India are located close to temples, and residents look to receive alms from worshippers, although they are not allowed into the temple themselves.

At this particular colony, the residents make a living from weaving and making hand-printed cloths. They also manufacture order-made shoes free of charge for people cured of diseases coming from many parts of the state.

The colony has established good connections with a European NGO, which directly purchases large quantities of the woven products it makes. As with Bharat Mata Kusht Ashram, a portion of the sales price goes toward food, electricity, medicine and other necessities for the community, and supports those who are unable to work. What is left over counts as each individual's income, and I heard that some of them are remitting money to help far-off family members.

The next day, I drove three hours south of Jaipur to Ajmer, a popular pilgrimage center for both Hindus and Muslims. Halfway along the pilgrimage route is a deprived area with a history of more than 100 years. Here some 3,000 people live, of whom approximately 2% have leprosy or once had the disease.



Residents of a Delhi colony gather for a meeting.

Many people move here in order to solicit alms from pilgrims. In contrast to the two colonies I visited earlier on this trip, here most of the residents survive by begging. Although there have been a number of projects designed to help them become economically independent, these have mostly ended in failure because the idea of living on handouts is firmly entrenched.

On the other hand, the colony is progressive in the sense that persons affected by leprosy live alongside other members, their children go to local schools and there is no discrimination in marriage.

**Any success will ultimately depend on the outlook of persons affected themselves.**

Although the prevalence rate of Rajasthan is 0.31 per 10,000 population, the problem of discrimination remains, and further efforts will be needed to sustain what has been achieved. Ensuring that correct information about leprosy is properly disseminated is an important part of these efforts.

Further, while there are colony residents that are becoming economically self-reliant, there are others for whom begging remains the routine form of survival. And even those who are successful are often successful only within the confines of a colony.

To change the situation, I will continue to work with governments, the WHO, NGOs, the media, and business organizations to inform, educate and communicate with people about leprosy.

But any success ultimately will depend on the efforts and outlook of persons affected by leprosy themselves. Hence the most important event of this visit was the first-ever national conference of persons affected by leprosy, held in Delhi on December 19, and reported in more detail elsewhere on these pages. The conference was a great success, and issued the Delhi Declaration of Dignity, which will serve as a blueprint for the way ahead for a society without discrimination against persons affected by leprosy. I intend to give this movement my full support. ■

# Global Appeal Launched

World leaders endorse call for end to stigma against persons affected by leprosy.

A Global Appeal to End Stigma and Discrimination against People Affected by Leprosy was announced in New Delhi, India, on January 29, 2006.

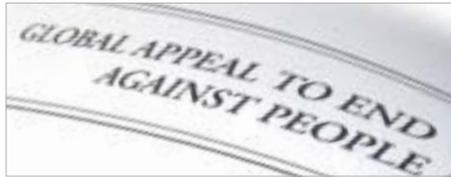
The appeal calls on the UN Commission on Human Rights to take up the issue of discrimination against persons affected by leprosy as an item on its agenda, and requests that it issue principles and guidelines for governments to follow.

It also calls on people all over the world to change their perception of leprosy and help foster an environment in which people with leprosy, those who once had the disease and their families can lead normal lives free from stigma and discrimination.

An initiative of The Nippon Foundation Chairman Yohei Sasakawa, who also serves as WHO Goodwill Ambassador for the Elimination of

Leprosy, the Global Appeal has been signed by a dozen current or former world leaders and luminaries, including former President of the United States Jimmy Carter, The Dalai Lama and former President of Costa Rica Oscar Arias.

The appeal was launched at a ceremony attended by former Chief Justice of India Y.V. Chandrachud and other dignitaries, and in the afternoon was followed by a two-part seminar on "Law, Human Rights and Leprosy."



India was chosen as the venue as it has the most number of leprosy cases of any country in the world. January 29, 2006, was World Leprosy Day, which falls on the last Sunday in January.

For more information and to see the full text of the appeal, visit <http://www.nippon-foundation.or.jp> ■

## Leprosy FACT

● India announced on January 30, 2006, that it has achieved the elimination of leprosy as a public health problem.

## FROM THE EDITORS

### HISTORY IN THE MAKING

Few who were there will forget the sense of history being made when the first national conference of persons affected by leprosy was held last December in New Delhi, India. Titled an "integration and empowerment" conference, it more than lived up to its name. Delegates from all over India — many representing leprosy colonies — came together in a collective show of solidarity, determined to work together to remove the stigma associated with leprosy. For many, traveling to the capital, checking into their hotels and registering for the conference was part of the empowering experience.

The aspirations of these conference delegates were summed up in the 14-point Delhi Declaration (see pages 2-3), a blueprint for action that calls for everything from the repeal of discriminatory laws to the dignified portrayal of persons affected by leprosy in the media.

Some six weeks later, another document was issued — the Global Appeal. As reported on this page, it calls on the UN Commission on Human Rights to take up the issue of stigma and discrimination against people affected by leprosy and has been endorsed by an influential list of world leaders and Nobel laureates.

The fact that in quick succession two initiatives have been launched that put human rights at the top of the agenda should not obscure the fact that the medical side of the disease still requires vigilance.

For years to come, new cases of leprosy will continue to be diagnosed, and the needs of these patients must be addressed. The new WHO strategy focuses on further reducing the leprosy burden and sustaining leprosy control activities as the way forward in 2006 and beyond.

Plus, there is some "unfinished business" left over from last year. A handful of countries have yet to eliminate leprosy as a public health problem. They should be given encouragement to complete the task they have been working toward these past few years, so that they can join other countries in the post-elimination phase.

Some countries, such as Bangladesh (see page 4), which achieved elimination several years ago, have made elimination at the sub-national level next goal as a means to further reduce their leprosy burden.

While this will not be the appropriate strategy in every case, countries need leeway to choose what works best for them.

## FOR THE ELIMINATION OF LEPROSY

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