

FOR THE Elimination OF Leprosy

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



India's president, Dr. A.P.J. Abdul Kalam (center) flanked by Chhattisgarh state's chief minister, Dr. Raman Singh (left) and governor, Lt. Gen. K.M. Seth (right) at the opening of the National Conference on Elimination of Leprosy in Raipur.

A MESSAGE FROM THE GOODWILL AMBASSADOR

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The Need to Communicate

As the deadline for elimination approaches, it is apparent that three simple messages have still to reach everyone: leprosy is curable, treatment is free, social discrimination has no place. This knowledge is essential to encourage self-reporting, which has a key role to play in bringing to light new cases as the push for elimination accelerates; it is also vital to breaking down the stigma still associated with the disease, especially in a country such as India.

Why aren't these simple messages better known? We can blame ignorance, prejudice, the presence of the disfigured still among us. We can also, if we choose, blame the media.

I know from personal experience as WHO Ambassador that the media's grasp of leprosy issues is not what those of us working to eliminate the disease would hope. On the other hand, it is a question of priorities. There are many more pressing public health issues in the world today; leprosy is not at the top of the list, even in endemic nations. By extension, it is not at the top of the newsroom agenda, either. After all, leprosy has been around since the dawn of recorded time. It is not a new disease, and "new" is short for "news."

But that is no excuse for ignoring leprosy, or worse, peddling old prejudices or misrepresenting the facts when it is taken up as an issue.

The fact is, there is a story to tell, and a very good story: leprosy elimination is one of the great successes in the health field globally. Some 12.5 million people have been cured, 10 million in India alone. But the other "good" story is that a disease dating back to biblical times has yet to be eliminated, even though a cure exists. Why not?

For this to happen, we need political leaders to maintain their commitment, we need the public to be aware of the symptoms and the cure, we need social awareness that there is nothing to fear from the disease. In short, we need the media.

But rather than expecting the media to be our advocate, we have to make our case to the media. I feel the leprosy community should be doing much more in this respect. If there are times when the media neglects leprosy, or gets the story wrong, we shouldn't blame the media but regard it as our failure and ask what we could be doing better.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Raipur Conference Issues Rallying Cry As Deadline for Elimination Approaches

'We've never had a better opportunity. Let's not waste it' was the clear message to emerge from a major conference in India that gave fresh impetus to elimination.

With less than two years to go before the WHO target date for the elimination of leprosy as a public health problem, the National Conference on the Elimination of Leprosy held recently in India was particularly timely.

India accounts for two-thirds of the world's leprosy cases (and nine-tenths of South East Asia's), so the January 27-30 conference in Raipur, the capital of Chhasttishgarh, focused attention on the country where the most work remains to be done.

India has made great strides in recent years to reduce the burden of the disease through the widespread application of multidrug therapy (MDT), and the conference duly noted this impressive progress. But it also sounded a warning about "a general tendency toward complacency as a result of initial successes" and urged all concerned to redouble their efforts to achieve the elimination goal by the end of 2005.

The conference served to remind that India is a big country — too big to talk meaningfully of national averages — and highlighted the differences that exist from state to state, and district to district, where highly endemic pockets can exist. In particular, it expressed concern over a number of states, especially Bihar, Jharkhand, Orissa, Uttar Pradesh, West Bengal and the host state of Chhattisgarh, with regard to prevalence rates and case detection levels.

It also identified specific population groups where sustained efforts will have to be made to ensure that cases are uncovered and treated in timely fashion, namely tribal populations, border populations, and urban slum populations, which are either difficult to reach or difficult to keep track of — or both.

The contribution made by MDT in controlling leprosy was reviewed in "MDT and Management of Leprosy in the Field," with speaker Dr. Raja Rao, LEPROA India, stressing that its effectiveness was based on punctuality of treatment, regularity of treatment and completion of treatment. "Elimination is within our reach. We have never been as close as we are today," he told delegates. "This success is our success: the success of workers in the field." But he added that there was still a long way to go before "every patient in every village" was reached, and that further efforts were vital.

To this end, the conference urged that IEC (Information, Education and Communication) campaigns about symptoms and the availability of a free cure be strengthened to encourage self-reporting, and that the integration of leprosy within the general health services be accelerated so that more people can be reached.

Operational factors came under particular scrutiny, with a number of problems highlighted, among them delayed diagnosis, over diagnosis, re-registration of cases and inadequate training of general health services workers. Dr. Derek Lobo, WHO/SEARO, drew attention to the phenomenon



The well-attended conference came at a critical juncture in India's fight against leprosy.

of "survival case detection," or uncovering new cases — whether genuine or not — as a way for leprosy workers to justify their existence. "We are extremely good at reaching the reached — again, and again, and again, he said."

Conference chairman Dr. S.K. Noordeen, Leprosy Elimination Alliance, alluded to this same issue when he reminded delegates that the future was about "the sustainability of leprosy treatment" not "the sustainability of leprosy workers."

Outlining a vision beyond 2005, Dr. Noodeen said services to every leprosy patient must be sustained, leprosy's continued decline must be monitored, those with disabilities must continue to be rehabilitated, and there must be complete acceptance of leprosy-affected persons within the community. The goal in all cases was integration within the general health services, he added.

Dr. Abraham Joseph, Schieffelin Leprosy Research & Training Centre, meanwhile, painted some possible scenarios from a public health perspective: will we see a further decline in incidence and prevalence, leading to total eradication; are we going to see a static state of

LEPROSY LEXICON

● Elimination

Elimination in the leprosy context refers to the "elimination of leprosy as a public health problem," which the World Health Organization defines as less than one case per 10,000 population. It is different from **eradication**, which is the permanent reduction to zero of incidence of infection.

incidence and prevalence if complacency creeps in; or even worse, will there be an initial decline followed by a subsequent increase, as has been the case with malaria? Let us learn the lessons from other eradication and elimination programs, he said.

A much applauded initiative on the sidelines of the conference was a workshop on the role of the media. Leprosy has not always been written up in the way the leprosy community would like, and has been a subject “enveloped in mystery, prejudice, misconception and stigma,” in the words of Dr. S.D. Gokhale, International Leprosy Union, who chaired the session.

Elimination is within our reach. We have never been as close as we are today.

As an example, a member of the audience cited an item in a Tamil daily that sensationalized the fact a restaurant was found to be employing three people affected by leprosy, leading to a public outcry and closure of the restaurant.

But despite this uneasy relationship with the media, participants recognized that in order to achieve the goal of elimination, the media has a vital role to play by keeping the topic in front of political leaders, raising awareness of the symptoms of leprosy, reinforcing the message that leprosy can be cured, and reducing stigma.

“We need to reframe the agenda of elimination to include rehabilitation and the role of the media,” said Dr. Gokhale. “Media action has to be strengthened.”



After elimination, rehabilitation was a key word at the conference, or “rehabilitation with compassion” in the words of India’s president, Dr. A.P.J. Abdul Kalam.

Dr. Kalam spoke at the opening ceremony of the need to make treated leprosy patients feel able to function normally in society, and to find a way for them to be rehabilitated with their families. “Each of us must ask, ‘What can I do to eliminate leprosy?’ We all of us have an important mission, and if we all join together, we can achieve it,” the president said. “The ignited mind is very powerful.”

The issue of discrimination was a recurring theme at the conference, with responses to leprosy patients said to range from total acceptance to total rejection. Although much work still needs to be done to reduce prejudice (and particularly among the better educated members of society, it seems), there was a sense that incidence of discrimination is lessening, as awareness improves and the proportion of patients with deformities declines. As a poster presentation concerning leprosy activities in Udupi, in the state of Karnataka, reported, “People are aware that leprosy is a curable disease and there are drugs available free of cost and the treatment is for short duration...The social stigma attached to the disease is being fully removed from the minds of the people.”

Various leprosy-related organizations had stands at the conference, including The Leprosy Mission Trust India, MESH (Maximizing Employment to Serve the Handicapped), and IDEA India. Among the IDEA delegates were more than 30 people from leprosy colonies, for whom the conference provided a confidence-building opportunity “to travel for the first time out of their states, stay at hotels, and interact as equals with other participants in the conference from all over India,” said IDEA India President Dr. P.K. Gopal.

If delegates were left with one message, it was to seize the opportunity India has to eliminate leprosy while a cure exists, free treatment is available and national commitment is there. In a country facing other more serious health problems, it’s an opportunity that may not last forever.

RAIPUR PLEDGE

On this Martyr’s Day, with what I have learned, I consider it my privilege to solemnly pledge to renew my commitment and strength to wage a renewed war against leprosy to ensure our national goal of the elimination of leprosy is reached everywhere, and to touch people with care and compassion to dispel the social evils of leprosy, to build the capacities of those affected by leprosy, and to integrate them into the mainstream of society.
(Read out by Dr. Noorden, Conference Chairman, on January 30, 2004, the 56th anniversary of Mahatma Gandhi’s assassination) ■

Advocacy and Empowerment: Putting A Human Face on Leprosy Elimination

In the drive to eliminate leprosy, have we focused unduly on statistics, and neglected the individuals we are trying to help?

When people in India discuss the role of media in the campaign to eliminate leprosy, they highlight the need for advocacy.

But in discussing advocacy, we need to be clear about what we mean; otherwise, our efforts will be channeled into traditional pursuits such as brochures and posters that fail to achieve our goal.

Advocacy is a process of communication and persuasion in support of a cause; a well-thought out, professional strategy to influence change.

Where elimination is concerned, the goal of advocacy should be to bring about a change in mindsets — of governments, agencies, NGOs, the leprosy-affected and society at large.

Include former patients when planning any policy or strategy. Ultimately they are the masters of their own destiny.

The public need to be told that leprosy is a disease like any other, that it can be cured, and that there is no reason to shun those affected by leprosy. Those of us working to eliminate leprosy need to be reminded it has a human face. And the leprosy-affected need to be empowered.

It seems to me that through a massive elimination campaign based on the distribution of MDT to achieve WHO and government targets, we have lost sight of the individual leprosy sufferer and his dignity as a human being.

Because of the system of free delivery of drugs, free housing, and free clothing we have made leprosy patients chronically dependent upon either the state or on the hospitals that are supported by voluntary donations, mostly from abroad.

If a person becomes a parasite, how can we expect him to be self-confident and be accepted in normal society? In the process of receiving free delivery of services, leprosy patients have lost not only their dignity, they have lost their souls.

This donor-recipient approach has de-humanized leprosy work. Because its focus is on statistical targets, leprosy workers concentrate entirely on numbers and not on individual sufferers or their rehabilitation. Joseph Stalin said: "The death of one man is a tragedy. The death of millions is a statistic." Are we going to de-humanize leprosy by only talking about statistics?

My experience of working with WHO missions in Nepal, the Philippines and Bangladesh, and of

work in China and Korea as ILU chairperson, tells me of the need to reorganize our approach.

In this, the media has an important role to play, as the recent advocacy workshop in Raipur made clear. I include some of the suggestions put forward there in the following list of prerequisites of a successful elimination campaign.

1. Empower cured persons and involve them in communicating to the community that leprosy is curable and treatment is free, and make use of them in media campaigns.
2. Create a resource center where photographs, human-interest stories and basic news items are available to any media organization in India, in order to get the media more interested and involved in the elimination campaign.
3. Develop a district-specific media strategy, including organizing field trips for journalists to see the situation at first hand.
4. Include former patients when planning any policy or strategy. Ultimately they are the masters of their own destiny. Our job is to help them help themselves.
5. Involve all NGOs and community-based organizations in leprosy work. Until now, it has been the monopoly of leprosy agencies or at most NGOs working in the health area.
6. Employ more women to deal with female leprosy cases, in order to give a human face to leprosy. There is also a need to recognize people who have been totally rehabilitated with an award of some kind — and also the dedicated workers who made this possible.
7. Place more emphasis on reconstructive surgery, rehabilitation and issues regarding children and women living in the shadow of leprosy. All our claims about elimination are not going to be trustworthy as long as people see disabled and disfigured persons around them, and women and children who are stigmatized.
8. Have leprosy-disabled persons join the movement of all disabled persons to see that the Persons with Disability Act, which contains provisions for prosthetic appliances, seed money for vocational rehabilitation and other initiatives, is effectively implemented. ■

AUTHOR:
Dr. S.D. Gokhale



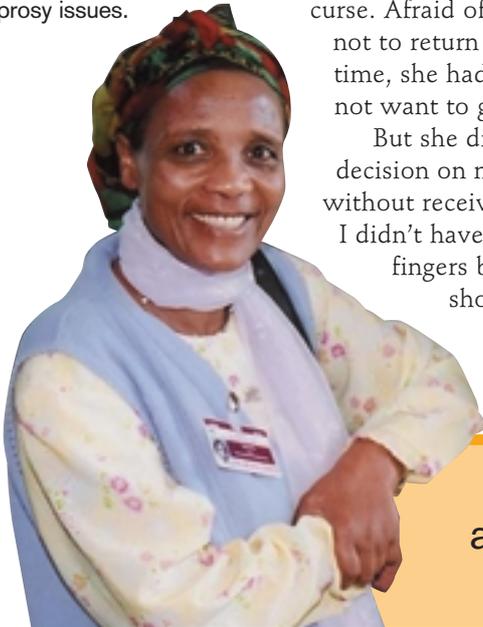
Dr. S.D. Gokhale is chairperson of the International Leprosy Union, a non-governmental development organization that supports the cause of leprosy elimination leading to total eradication and solicits support by building political will and awareness in the print and electronic media.

Learning a Skill Restored My Dignity

Her situation got worse before it became better, but in the end, as Birke Nigatu relates, her story has a happy ending.

AUTHOR:
Birke Nigatu

Birke Nigatu is chair of the Ethiopian National Association of Ex-Leprosy Patients, an organization established to help former patients, advocate on their behalf and raise awareness of leprosy issues.



I developed leprosy when I was only six years old. At that time, I was living with my grandmother as my parents had divorced. When the symptoms of leprosy first appeared on my face, my relatives took me to a traditional healer, health centers and hospitals; they even tried witchcraft, but all to no avail. Surprisingly, neither the health centers nor the hospitals identified the disease. But the last hospital I visited referred me to an Alert Hospital (which specializes in leprosy) and I went there with my mother.

When the doctor said I was affected by the disease, my mother cried and said it was a curse. Afraid of the stigma, she warned me not to return to the hospital again. By this time, she had started a new life, and did not want to go through another divorce.

But she didn't realize the impact of her decision on my life. I spent four years without receiving treatment, simply because I didn't have access to it. Gradually, my fingers became clawed. When I showed my mother, she just told me to rub them, saying we had no history of such a thing in our family.

Leprosy is like any other disease. It is curable.

By now I decided to seek treatment by myself. I borrowed the bus fare and went back to the Alert Hospital, where the doctor told me I should be admitted.

Thanks to the treatment I received, I was cured, although I was left with small disability in my fingers and toes. Rather than return home, where my presence would have humiliated my mother, I decided to lead my own life. Not only had leprosy left me disabled, it had also isolated me from my parents and relatives. Increasingly, I cut myself off from people.

But then I learned how to embroider using my disabled fingers, and this skill is what restored my dignity. I said to myself that with God the Almighty, nothing is impossible. Today I am married with four daughters, and lead a contented life as a person without leprosy. I even became a pioneer for many people affected by leprosy, encouraging them to walk away from begging and take up embroidery.

For me, leprosy is like any other disease. It is curable. Besides, disability is not an inevitable consequence of leprosy. Even those of us with disabilities can participate in productive activities according to our ability.

I believe that the disabled should not be dependents; they should not be beggars. I acknowledge, though, that the disabled, especially those disabled by leprosy, face many problems that sometimes seem overwhelming. In that situation, integrated effort is called for, and we must do all we can to help them. ■

PARTNERS

LEPRA MARKS 80TH ANNIVERSARY



LEPRA, the U.K.-based medical development charity, is celebrating its 80th anniversary this year. Founded as the British Empire Leprosy Relief Association on 31 January 1924, LEPRA works actively in a number of countries to restore health, hope and

dignity to people affected by leprosy.

From the outset, LEPRA operated as a medical organization to spearhead outpatient work and foster research into all aspects of the disease.

It pioneered the use of chaulmoogra oil in treatment of leprosy in its early years, and was recognized as the first "leprosy prevention organization" in 1931.

Later it conducted field research into the use of Dapsone as a more effective treatment for leprosy and in 1974 became one of first associations to introduce multidrug therapy (MDT) at field level following drug trials that showed MDT resulted in a total cure.

As well as providing medical treatment, an important aspect of LEPRA's work is education to combat the social stigma often experienced by those with the disease. It also provides economic and social rehabilitation programs, including teaching people affected by leprosy new work skills and providing loans to help them start their own businesses.

While LEPRA's main objective remains the eradication of leprosy, it will increasingly draw on its experience of leprosy work to tackle other diseases such as tuberculosis, HIV/AIDS and malaria in order to benefit entire communities.

Return to India

If the goal of leprosy elimination is to be achieved, then what happens in 2004 will be crucial. Yohei Sasakawa returned to the country with the biggest caseload to attend a key conference designed to accelerate momentum toward this goal. He considers it very significant that it was inaugurated by the president of India.

RAIPUR

My first trip of 2004 was to India, where I attended the National Conference on the Elimination of Leprosy from January 27 to 30. Held in Raipur, state capital of Chhattisgarh, it was sponsored by the International Leprosy Association, the Indian government, the government of Chhattisgarh and major partners in the fight against leprosy.

Speaking at the opening ceremony, India's president, Dr. A.P.J. Abdul Kalam, said that concerted action would be necessary to achieve elimination by the end of 2005, and demonstrated his clear commitment to this goal. He also stressed the importance of rehabilitating people affected by leprosy, using the term "rehabilitation with compassion." An essential part of this process, he said, would be to promote health education to raise awareness of leprosy and eliminate the stigma associated with the disease. Dr. Kalam left delegates with the thought, "Let my brain remove the pain of the suffering community." With this powerful endorsement from the nation's top leader, I have strong hopes that elimination

activities in India will make rapid progress.

In my own remarks at the opening ceremony, I said that on a journey of 100 miles, after 99 miles we are only half way. This year and 2005 represent the last mile of our journey to achieve elimination. We must proceed with a sense of urgency if we are to complete this journey successfully.

During the conference I had an opportunity to meet with two senior representatives of India's Ministry of Health and Family Welfare: Mrs. Rita Teatota, joint secretary, and Dr. G.P.S. Dhillon, the newly appointed deputy director general (leprosy) for General Health Services. I asked them for even more effort from the Indian government, and they told me that a focused action plan for elimination activities in the years 2004 and 2005 was currently being finalized and would be announced very shortly. With India preparing for a general election in April, I imagine there will be some political changes, but I am hoping these won't disrupt the final push for elimination.

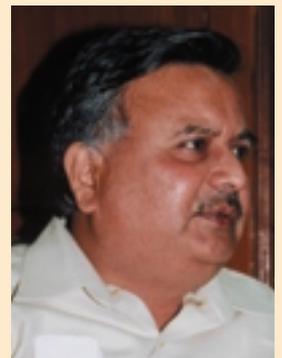
I also gave a keynote address offering my thoughts on the situation in India based on several



Mrs. Rita Teatota



Dr. G.P.S. Dhillon



Dr. Raman Singh



Dr. Krishnamurthy Bandhi

Ambassador Sasakawa walks at the head of an elimination parade passing through the center of Raipur, accompanied by State Health Minister Bandhi at left.



Multipurpose health workers respond to a quiz about leprosy elimination (right); children at an elimination rally



visits I had made in the past year.

Firstly, I reported on my meetings with the political leaders of several Indian states and the various activities initiated as a result of securing their commitment to elimination.

Secondly, I talked about my encounters with the media in the places I visited, which confirmed my impression that journalists still have a poor grasp of leprosy elimination. How to build a relationship with the media was one of the themes taken up by this conference at a workshop chaired by Dr. S.D. Gokhale, chairman of the International Leprosy Union. For my part, I suggested that we need to come up with a strategy that interests the media in what we are doing and results in active coverage of elimination activities.

Even in a hierarchical society such as India's, disease does not discriminate — and neither does the cure.

Thirdly, I talked about the need for a social movement to enhance leprosy elimination, which I called “broadening the scope of integration: reaching out beyond the leprosy community.” So long as responsibility for tackling leprosy remains in the hands of specialist government agencies, medical institutions and NGOs in a vertical setup, this won't be possible. We need to involve different bodies in the non-leprosy community if we want society to gain a proper awareness.

I also had the opportunity for discussions with Chhattisgarh's chief minister, Dr. Raman Singh, and the state health minister, Dr. Krishnamurthy Bandhi. Chhattisgarh has the third highest prevalence rate among India's states at 5.08 cases per 10,000 population. In common with other states, Chhattisgarh has a significant tribal population (over 34%), and faces a number of challenges in tackling leprosy, including large numbers of people living in remote areas, poor levels of hygiene and nutrition because of widespread poverty, and a high level of social discrimination. Consequently, much effort needs

to be put into case discovery and treatment, awareness-building and rehabilitation. But both Chief Minister Singh and Health Minister Bandhi fully understand the issues and showed me they are on top of the situation.

On January 29, I visited a primary health center in a village about 30 kilometers from Raipur, where I met about 20 multipurpose health workers who deal with a wide range of health issues, including maternity care, child care and tuberculosis prevention, not just leprosy.

I was told that these health workers are each responsible for about 5,000 people and do their rounds by motorcycle or bicycle. Many of the homes they visit are far apart, and some can only be reached on foot. When I heard this, I felt quite humble and grateful to them for their dedication.

On this occasion, they had gathered to prepare for a Modified Leprosy Elimination Campaign that was due to begin the next day. I was impressed by their knowledge of leprosy, their grasp of the leprosy situation in Chhattisgarh, and their determination to see the prevalence rate reduced to less than one case in 10,000 by the end of 2005.

A number of them related their experiences of elimination activities, and one account in particular stays with me. It concerned a member of the Brahmin caste, occupying a high position in the community, who discovered he had leprosy. His fingers began to twist out of shape, but he was cured thanks to MDT, and expressed his heartfelt gratitude to health workers. The moral of the story is that even in a hierarchical society such as India's, disease does not discriminate — and neither does the cure.

January 30 is Martyr's Day in India, marking the anniversary of the assassination of Mahatma Gandhi. That morning, several thousand children gathered in a square in Raipur to rally for leprosy elimination. I marched alongside the state health minister at the head of a long procession of political leaders, government workers and boys and girls as it passed through the center of the city, where the marchers handed out pamphlets promoting elimination. While I am confident that these children will grow up to know a world without leprosy, I am keenly aware that we must work even harder if that is to happen. ■

LEPROSY FACTS

- India's prevalence rate has gone down from 57.6 per 10,000 people in 1981 to 3.2 per 10,000 in March 2003

Ambassador Receives Update On Situation in Western Pacific

The region as a whole has entered the post-elimination stage, but Micronesia and the Marshall Islands have yet to reach the elimination goal.

On November 5, 2003, Ambassador Yohei Sasakawa met Dr. Shigeru Omi, Regional Director, WHO-Western Pacific Regional Office.

Dr. Omi stated that the goal of leprosy elimination (a prevalence rate of less than one case per 10,000 population) had been achieved at the regional level in the year 1991. At the national level, 35 of the 37 countries and areas had achieved the goal by the end of 2000 covering more than 99.9% of the regional population. However, he added that the prevalence rate remains higher than the elimination goal in the Federated States of Micronesia and the Marshall Islands.

In these Pacific island countries and areas, WHO has supported nationwide leprosy awareness campaigns involving the mass media,

ministries of education and other relevant agencies. Similar campaigns have also been conducted in highly endemic pockets in a number of the large countries that have already reached elimination at the national level.

Nevertheless, the region as a whole has entered the post-elimination phase and is in the process of development of regional post-elimination strategies that will be introduced during a bi-regional meeting with the South East Asia Region in the fourth quarter of 2004 to share the experiences of the countries that have reached elimination.

Dr. Omi said WHO greatly appreciated the recent visit of Mr. Sasakawa to Papua New Guinea and the Philippines. ■



Dr. Shigeru Omi

FROM THE EDITORS

COMPASSION IS KEY

In his speech to open India's national conference on leprosy elimination, Dr. A.P.J. Abdul Kalam (pictured on our cover) spoke of the importance of rehabilitating cured patients with their families.

As one of the delegates who listened to the speech said afterward, India's president went to the heart of the matter: if your family won't accept you, then nothing else matters.

Sometimes a family shuns one of its own for purely economic reasons. For a household living on the poverty line, accepting back a family member affected by leprosy means another mouth to feed. If that person cannot contribute to the family's income — through disability or lack of employment opportunities — then he or she becomes a burden.

But often the reason is something far more insidious — social stigma. As Birke Nigatu recounts in her moving story on page five, though cured of leprosy she felt unable to return home because of the "humiliation" it would have brought upon her mother. Fortunately, Birke's story has a happy end, as she learned a skill, regained her self-esteem and has proved an

inspiration to others.

Helping those affected by leprosy to help themselves is a message included by Dr. Gokhale in his thought-provoking piece on page four. If rejecting a family member affected by leprosy is heartless, making a leprosy patient chronically dependent upon the state or on hospitals is equally heartless — it turns him into a "parasite" and erodes his dignity. "How can we expect him to be self-confident and be accepted in normal society?" Dr. Gokhale asks.

It seems we need to remind ourselves that those affected by leprosy are fellow members of the human race and deserve to be treated with compassion: "rehabilitation with compassion," in the president's well-chosen words.

With this issue, our newsletter enters its second year of publication, and takes on a new look. We hope it will become even more of a forum for two-way communication — a place to raise issues, identify injustices, encourage progress and point the way to a world without leprosy and its associated discrimination. We look forward to your comments and contributions.

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Publisher

Yohei Sasakawa

Executive Editor

Tatsuya Tanami

Editor

Jonathan Lloyd-Owen

Associate Editors

Akiko Nozawa,

James Huffman

Layout

Eiko Nishida

Photographer

Natsuko Tominaga

Editorial Office

5th Floor, Nippon

Foundation Building,

1-2-2 Akasaka, Minato-ku,

Tokyo 107-8404

Tel: +81-3-6229-5601

Fax: +81-3-6229-5602

smhf_an@tnfb.jp

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Sasakawa Memorial

Health Foundation,

The Nippon Foundation

www.nippon-foundation.
or.jp/eng/