

# FOR THE Elimination OF Leprosy

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



Mrs. Laxmibai Surve, a newly appointed Lokdoot (special communicator) from Maharashtra, addresses a conference in Delhi in January. (see page 4)

## A MESSAGE FROM THE GOODWILL AMBASSADOR

### Overcoming Differences

A mere eight months remain to achieve our common goal of eliminating leprosy as a public health problem.

Regarding the efficacy of the WHO elimination target, I am aware that opinions differ. But because it is an achievable target, and because we are almost there, I believe we should go all out to succeed as it represents an important milestone along the road to our ultimate goal of a world without leprosy.

Those of us working for elimination should think of this common goal as our own, review our activities in this light and plan on walking the final mile together.

It would be unfortunate if at this critical point there were disagreements among the partners that prevented them from cooperating fully. In particular, I would like to see WHO and the International Federation of Anti-Leprosy Associations (ILEP), who both play a central role, collaborate closely together.

In the past, ILEP members were excluded from the Global Alliance for the Elimination of Leprosy.

At the recent African Leprosy Congress, however, I was delighted to see WHO approach ILEP about improving their relationship. I sincerely hope that both sides can now set aside past differences, build a better framework for cooperation and act as one.

We must not forget that those who stand to suffer most from discord among partners are people affected by leprosy.

Further, our efforts alone won't be enough. The active participation of recovered persons is essential. We also need the involvement of organizations, politicians, journalists, administrators, educators, businesspeople and NGOs in spreading awareness about the disease throughout society. This requires a social movement that makes leprosy everybody's issue, not just the specialists' and experts'.

If we can involve the rest of society, starting from a nucleus of committed partners, this will serve us in good stead for the challenges ahead and hasten the arrival of a world without leprosy.

— Yohei Sasakawa, WHO Goodwill Ambassador

<b>Message</b>	<b>1</b>
<b>Conference Report</b>	
Spotlight on Africa	<b>2</b>
<b>Ambassador's Journal</b>	
Visits to India, South Africa and Madagascar	<b>4</b>
<b>News</b>	
Brazil's PR comes down; <i>Don't Fence Me In: From Curse to Cure — Leprosy in Modern Times</i>	<b>8</b>
<b>From the Editors</b>	<b>8</b>

# Spotlight on Africa

Despite many challenges, Africa has made notable progress in the fight against leprosy, as an historic conference in Johannesburg found.

It was with a real sense of occasion that the African Leprosy Congress opened outside Johannesburg on January 31 for four days. Not since Cairo in 1938 had there been an ILA congress on African soil, so there was a lot of catching up to do.

In her speech welcoming delegates, South Africa's health minister, Dr. Manto Tshabalala-Msimang, highlighted the great strides that have been made against leprosy in Africa and the rest of the world since that last meeting, saying, "We are especially proud that African researchers have played a leading role in developing new interventions against the disease."

**The minister highlighted the great strides made against leprosy in Africa.**

Worldwide, some 14 million people have been cured of leprosy over the past two decades and the number of endemic countries reduced from 122 to nine — six of them in Africa. These achievements have come about through collective action, said Dr. Asamoah Baah (Assistant Director-General, WHO) and the key to continued success is partnership, "There is no option but to work together," he said. At the same time, he acknowledged that WHO had not always been a good partner — "we have sometimes been part of the problem, not the solution" — and that the world health body intended to learn from past mistakes.

In a first for an ILA event of this kind, the opening day included a special session devoted to human rights — giving the congress, in the words



Dr. Tshabalala-Msimang, South Africa's health minister

of session chairman Dr. P.K. Gopal (IDEA), "a human face." The session included presentations by persons affected by leprosy from several countries, as well as Prof. Yozo Yokota (Member, UN Sub Commission on the Promotion and Protection of Human Rights). Prof. Yokota said the commission had been "embarrassingly slow" in taking up leprosy as a human rights problem but was now tackling the issue.

Dr. Ji Baohong's state of the art lecture on the Chemotherapy of Leprosy the next day returned the congress to more familiar territory. Dr. Ji (Association Francaise Raoul Follereau) lamented the fact there were so few chemotherapy experts in the field and called for a new generation of MDT regimens to be developed to improve treatment outcomes. "The belief that the current regimen will suffice is short-sighted," he warned, stating that it is not resistance proof and that certain patients require alternatives.

Introducing the subject of community-based rehabilitation, Dr. Wim van Brakel (Royal Tropical Institute of the Netherlands) said there were an estimated 600 million people worldwide suffering from disabilities, of whom approximately 1.5 to 2 million were people with leprosy-related Grade II disability. Only a small percentage of these people have access to rehabilitation, he said.

CBR is a strategy devised to increase that access. It is complementary with institution-based rehabilitation, multidisciplinary ("not medical"), participatory, and empowers people. "There is no one 'method' of 'doing' CBR," said Dr. van Brakel.

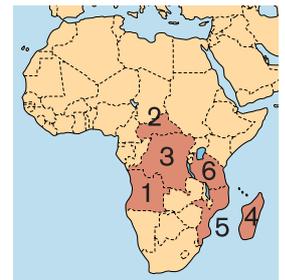
Empowering people was the theme of Jannine Ebenson (The Leprosy Mission, Nigeria) who spoke on the role of self-help groups in Nigeria. "The biggest resource in countries like Nigeria is not oil or money, but people," she said. Small groups can become a powerful voice when confronting officialdom. "People who would have hidden their illness before are now going on national television, talking about the disease, and demanding their human rights," she said.

## ALTERNATIVES TO BEGGING

A panel discussion hosted by IDEA focused on the issue of begging, with participants from several countries offering their views.

In Nigeria, begging is rampant, said Alhaji Shehu Sarkin Fada (IDEA). "If you are found to have a leprosy patch, people believe you have only been created to beg." Your family will isolate you, the government won't allow you to study or work, and people "will stay away from you as they would a lion in the bush," he said. "But if we are given assistance we can change our life. We are human

## AFRICAN COUNTRIES STILL TO ACHIEVE ELIMINATION



(listed in alphabetical order)

1. Angola
2. Central African Republic
3. Democratic Republic of Congo
4. Madagascar
5. Mozambique
6. United Republic of Tanzania

## Leprosy LEXICON

### ● CBR

Community-based rehabilitation is a strategy within community development for the rehabilitation, equalization of opportunities, and social integration of all people with disabilities. It is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health education, vocational and social services.

Source: UN, WHO, and ILO joint position paper (1994)

A choir warms up delegates before the start of the African Leprosy Congress.



beings like anyone else. We are useful to the community.”

Cresenciano T. Rosello (IDEA) recalled how pen-pal letter writing campaigns began on Culion Island in the Philippines after World War II, requesting assistance for the many orphaned children living in what was once the world’s largest leprosy colony. Benefactors were forthcoming and conditions improved, encouraging others with more dubious claims to write as well. “Pen-pal letters became a cottage industry,” he said.

Now a couple of projects are helping prevent a new generation from resorting to begging letters by making them self reliant and self sustaining. “We intend to produce an economic miracle, transforming people from recipients of aid to givers of aid,” he said.

### AFRICA’S PROGRESS

Africa’s remarkable progress, highlighted at the opening of the congress, was dealt with in more detail by Dr. Landry Bide (Regional Advisor, WHO/AFRO) in his state of the art lecture on Leprosy Elimination in Africa. In the 1980s, he said, there were over 1 million cases of leprosy in Africa alone. It was a serious problem, poorly managed. In 1990, 42 out of the 46 states comprising the WHO Africa Region were endemic, and the prevalence rate was above 1% of the population.

All that changed with the introduction of free treatment with MDT and the formation of national programs in every country, giving leprosy a new priority within the health sector. “It ceased to be a charity activity and began to be a policy,” he said.

Africa still grapples with some special problems, including those relating to geographical access (the size of the continent and difficulty of reaching people), cultural access (illiteracy, taboos and poor communication between different groups), financial access (low income levels and largely absent health insurance), and functional access (decrepit health

facilities, lack of trained health workers).

Above all, said Dr. Bide, the main constraint is war, which “destroys health facilities, scares off health workers and displaces populations.”

The symposium on Reaching the Unreached, moderated by Dr. K. Kawuma, noted that the bedrock of the leprosy elimination strategy was early detection and prompt treatment. Nonetheless, each year, new cases are occurring that are not being detected. Why? The answers, he suggested, included ignorance of the disease among both patient and healthcare worker (“some people look and do not see”), problems of distance and cost, and the matter of the diagnosis being “unwelcome.”

Dr. B. F. Njako (GLRA/NTLP) speaking of Tanzania’s experience, said that health workers can’t do everything, especially with the increasing demands made on them by TB and HIV/AIDS, and that it was essential to have greater community involvement in uncovering leprosy cases.

In the Democratic Republic of Congo, war has been a major contributor to poor infrastructure, said Dr. J.N. Mputu (Ministry of Health, DRC). Many health districts are not functional, and there is almost no community involvement, especially at village level, in leprosy detection activities. Volunteers were needed, they needed to be chosen by the local community, and they needed to be remunerated, he said.

In the last state of the art lecture, on Prevention of Disability in Leprosy-Affected Persons, Dr. H. Srinivasan said that while leprosy is no longer a medical problem or (in most countries) a public health problem, the “human problem” of leprosy continues because of impairment, which can lead to marginalization and social isolation.

Disability can occur even after a successful course of MDT, he said, but action can be taken to stop it from happening, and he called on persons affected by leprosy to become the “main actors” in practicing disability prevention. ■

# At the Frontlines of Elimination

India has the most cases of leprosy and Africa has the most endemic nations. Yohei Sasakawa travels to both regions as the elimination deadline nears.

## INDIA (JANUARY 26-29)

In January I was in Delhi to attend a one-day conference on leprosy elimination organized by Dr. S.D. Gokhale, chairman of the International Leprosy Union (ILU). Less a gathering of specialists than a pep rally, it was held with the support of ILU, IDEA, WHO and Gandhi Smitri.

The timing and location of the January 27 conference had special significance. January 30 marks the anniversary of Mahatma Gandhi's assassination. Given Gandhi's association with leprosy work, it is also commemorated as leprosy day in India, and various elimination activities are conducted around this time of year. In addition, the venue for the event was the garden of Gandhi Smitri, formerly Birla House, where Gandhi spent his last days and was assassinated in 1948.

It was Gandhi's dream to see leprosy eliminated from India, and the efforts we make this year will be critical to achieving this. This conference, which drew heavily on Gandhi's memory, was thus important in forging a sense of solidarity as we push toward this goal.

Among those attending were former president of India, Hon. Shri R. Venkataraman; WHO representative to India, Dr. S. J. Habayeb; ILU president, Dr. S. K. Noordeen; and psychologist and actor, Dr. Mohan Agashe.

In my remarks, I repeated the three messages I deliver everywhere I go, that leprosy is curable, treatment is free, and social discrimination has no

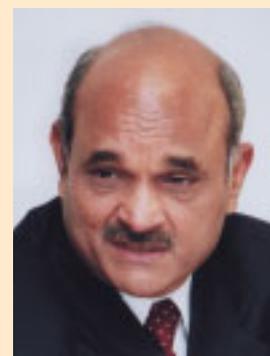
place. According to a recent survey, 50% of Indians polled are now aware of these messages. To ensure 100% awareness will require the cooperation of all sectors of society, including the media and in particular people affected by leprosy themselves. We may be walking the final mile of eliminating leprosy as a medical problem, but we are just taking the first steps toward eliminating the disease of social discrimination.

In that sense, the most important achievement of this conference was to secure the participation of people affected by leprosy from all over India in campaigning to change society's image of the disease and encourage those who need it to seek treatment. In my opinion, there are no more effective spokespersons.

There were nearly 130 persons affected by leprosy at the event. Of these, 32 were selected as Lokdoots, or special communicators, whose mission it will be to tell their countrymen the true facts about leprosy. They were chosen for being financially independent, socially accepted and active in a variety of fields. They show by their own example that people can be cured of leprosy and lead normal, productive lives.

I believe each of them has an enormous contribution to make in eliminating the disease and rooting out discrimination. I look forward to supporting this initiative and seeing it grow.

While in New Delhi, I also paid a courtesy call on the Delhi National Capital Territory health



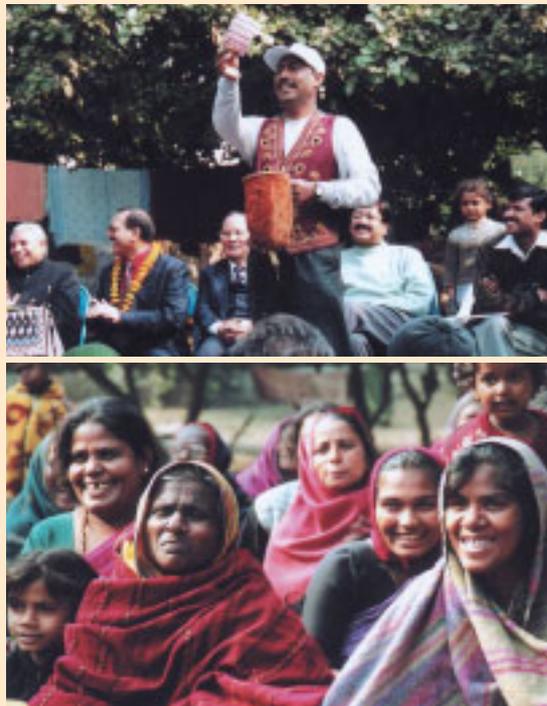
Shri S.P. Aggarwal, health secretary for Delhi NCT



(From left) Dr. S.D. Gokhale, Shri R. Venkataraman and Yohei Sasakawa enjoy a few words with Shakuntala Devi, a newly appointed Lokdoot, or special communicator, from Madhya Pradesh. IDEA's Dr. Gopal is in the background.

secretary, Shri S.P. Aggarwal.

For a big city, Delhi has its share of health problems, battling diseases such as HIV/AIDS, TB and polio, in addition to leprosy. Migratory and floating populations from other states pose a particular challenge. When cases of leprosy are discovered among them, this results in a significant amount of re-registration or duplicate registration of people who have been registered once already and treated. Delhi NCT has a PR of 3.92/10,000, but despite the challenges it faces, Shri Aggarwal assured me Delhi NCT was committed to achieving elimination.



A magician shows how to cure leprosy (top) as an appreciative audience looks on (above).

Just before leaving Delhi I made a brief visit to the Flame of Fire Leprosy Center, a colony largely made up of people from Karnataka State. Established 15 years ago, the colony hopes to set up a rehabilitation program to make residents socially and economically independent without recourse to begging.

Delhi's state leprosy officer had arranged for me to see a performance of a magic show used to educate people about the disease. Using a bag to represent a hospital and a polka dot handkerchief to represent a leprosy patient, the magician placed the handkerchief in the bag along with some MDT. Then, reaching into the bag, he pulled out a white handkerchief, representing a cured patient. Easy to understand and entertaining too, the show impressed me as an effective way to communicate an important message to hidden patients in areas where other media don't reach.

## SOUTH AFRICA (JANUARY 30 - FEBRUARY 4)

From India I traveled to Johannesburg to attend the African Leprosy Congress. The four-day conference was organized by the International Leprosy Association with the support of the South African government, WHO, ILEP, and others.

Great progress has been made in fighting leprosy in Africa, and it was gratifying to see so many nations at the congress. But there's still plenty to be done as Africa is home to most of the world's remaining leprosy-endemic nations.

I told the opening ceremony that I believed this meeting was a truly historic occasion in the long history of leprosy, in that the first session of an ILA congress was to be devoted to the theme of leprosy and human rights. Moreover, of the 273 registered conference participants, 29 were recovered persons attending as part of a 40-strong delegation from IDEA — the International Association for Integration, Dignity and Economic Advancement.

This meeting was a truly historic occasion in the long history of leprosy.

This signals to me that as we draw near the goal of eliminating leprosy as a public health problem, the work of eliminating social discrimination — an initiative in which recovered persons have a central role — is now set to begin in earnest. In that sense, this congress represented a clarion call for ending discrimination.

Prof. Yozo Yokota, the Japanese member of the UN Sub Commission on the Promotion and Protection of Human Rights, was one of the speakers. He briefed the congress on the preliminary report he is preparing on leprosy for the Sub Commission, and later heard testimony from recovered persons about their experiences.

On the sidelines of the conference, I met with a group of health officials coordinating the national elimination programs in the six African countries yet to achieve elimination — Angola, Central African Republic, Democratic Republic of Congo, Madagascar, Mozambique and Tanzania. Listening to their accounts, it became apparent that in addition to operational factors such as re-registration and misdiagnosis common in other endemic countries, in some cases they must also contend with problems beyond their control such as regional disputes, displaced persons and war. Hearing this, I resolved to make more visits to Africa to offer encouragement to these countries for reaching the elimination goal. >>



IDEA Banners of Honor are displayed at a ceremony of remembrance held for persons affected by leprosy at a cemetery on Robben Island.

While in South Africa I also visited Robben Island, used to isolate persons with leprosy from 1846 to 1931, and more recently famous as the place where Nelson Mandela served 18 years of a 27-year prison sentence. IDEA and ILA’s Global Project on the History of Leprosy had organized a workshop on stigma, identity and human rights in association with the Robben Island Museum. The program included a moving ceremony at the so-called “Leper Graveyard” on the island to remember those buried there.

When the Robben Island leprosy asylum was closed down in 1931, patients were transferred to other leprosy sanatoria on the mainland. One of these was Westfort, near the capital, Pretoria, which I had visited a few days earlier.

Westfort Leper Institution opened in 1898 and was one of only two multiracial leprosaria in South Africa. From 1948, under South Africa’s apartheid system, patients who were already isolated from society by their disease were subject to further segregation within the hospital on the basis on their race — giving a special character to the leprosy experience in South Africa.

When it opened, Westfort housed 1,450 patients. But for much of the 20th century it was

home to an average 200 to 300 patients. It was run like a small town, and had a post office, clinic, churches, pharmacy and shop. However, two guards were posted at the entrance, and visits from family members were restricted to once every two weeks, with patients forced to sit behind a glass screen in a prison-like atmosphere when they received visitors.

Hospitalization for leprosy treatment was compulsory in South Africa until 1977, after which specialized institutions for leprosy began to shut down. Westfort, the last of these, closed in 1997.

After visiting Westfort, I called on Johann, 55, a recovered person who lives with his wife, daughter and two granddaughters in the suburbs of Johannesburg. Before being diagnosed with leprosy and sent to Westfort, he was a steel worker. Unfortunately, his MDT treatment was interrupted, as a result of which he suffers disability in his right eye and leg. Without regular work, he receives a disability allowance from the South African government. Although he has the support of his wife and family, he has no contact with the neighbors, and when he goes to hospital once a month for a checkup, he is seen separately from other patients. I was troubled to hear Johann say he feels he has no place in society, and sometimes thinks he was better off in Westfort. But his comments renewed my determination to root out discrimination.

**Leprosy FACT**

● Robben Island became a hospital for people with leprosy, mental illness and chronic diseases in 1846. Initially, many leprosy patients went there voluntarily, but after the 1891 Leprosy Suppression Act, hospitalization was compulsory. Black and white patients had separate wards, with white patients receiving better accommodation, food and medical treatment. The hospital was closed in 1931.

**MADAGASCAR (FEBRUARY 5-9)**

From South Africa I proceeded to Madagascar, where I attended a World Leprosy Day event organized by the Ministry of Health and sponsored by the Association Francaise Raoul Follereau (AFRF). I also met with the prime minister and health minister and visited a number of health facilities.

Lying off the southeast coast of Africa,



Johann and his family in Johannesburg



Yohei Sasakawa speaks at World Leprosy Day as Madagascar's prime minister looks on.

MDT Man makes his presence felt during the World Leprosy Day festivities in Tulear.

Madagascar is the world's fourth largest island, with a population of some 17 million. Seeing it from the air, one can appreciate the physical challenges the terrain presents in the way of reaching remote rural populations. Added to this, heavy rains can cut off communities during the cyclone season. Nonetheless, the WHO, government, NGOs and all concerned are making real efforts to combat the disease. As a measure of progress, when I visited Madagascar in September 2003, the prevalence rate stood at 4 per 10,000. Now it is down to 2.93.

As I learned in Johannesburg, the main challenges facing Madagascar include improving the quality of patient diagnosis by peripheral health workers, improving patient follow-up to make sure that only genuine leprosy patients are on the register, and social mobilization.

Promoting awareness of leprosy is an important part of the strategy, so I was happy to participate in the World Leprosy Day event held in Tulear, a city of 50,00-60,000 in the southwest of the country, where the PR stands at around 4/10,000. Held in a carnival-like atmosphere, the day-long event included music, dance, puppetry and film and was a good platform from which to deliver important messages about the disease.

Both the prime minister and the health minister took part in the ceremony, and their

commitment will certainly be necessary to keep elimination moving in the right direction. I told the people of Madagascar they had my full support, and I would come back and celebrate with them when the country achieved the target.

After Tulear, I visited three towns on the southeast coast of the island, Mananjary, Manakara and Farafangana, all with high prevalence rates, where I met with health workers and visited local hospitals and health facilities.

Basic health centers are at the frontline of the health care system, and each caters for an average 5,000-6,000 people. All told, there are around 2,500 such centers in the country, and the people who work there play a vital role educating about the disease and spotting new cases. But they are not just dealing with leprosy but all health issues, so their job is extremely demanding.

I found that not every health center keeps complete records of patients or MDT. In particular, in some places, MDT isn't getting from the regional hospital to the basic health center, while in others there is a surplus of MDT. Getting this right is essential to the elimination strategy.

Wherever I go, I like to talk with patients, and was able to do so at several locations, including Tulear regional hospital, the Marovhay leprosy and TB center, and St. Vincent Hospital in Farafangana.

Speaking with some of them, I was struck by their solemn expressions. Even though they have been assured that leprosy is curable, they appeared to be suffering the effects of social discrimination.

Madagascar is clearly walking the final mile toward elimination. But the work to eliminate deep-rooted stigma and discrimination is perhaps only just beginning. The three messages I tell to people around the world are all-important, and the third message, that social discrimination has no place, must not be forgotten once elimination is achieved. Driving that message home might be more difficult than treating the disease itself. ■

# Brazil's PR Goes Below 2.0

Ministry announces encouraging progress toward elimination.



On January 28, Brazil's Ministry of Health publically announced that the country's prevalence rate had come down to 1.7 per 10,000, with the number of leprosy patients standing at 30,000. The announcement followed a careful review of the country's statistics.

According to Dr. Rosa Castalia, leprosy program coordinator at the Ministry of Health, Brazil is hoping to achieve elimination by the end of this year in line with the WHO target.

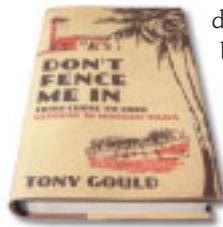
Once the goal has been achieved at the national level, Brazil is aiming to achieve elimination in each city between 2006 and 2010, she said.

## DON'T FENCE ME IN

Tony Gould illuminates the lives of people affected by leprosy and those who made the disease their life's work in his fascinating new book *Don't Fence Me In: From Curse to Cure — Leprosy in Modern Times* (Bloomsbury Publishing).

Through the individual stories of doctors, missionaries and patients, Gould charts evolving attitudes toward the disease and those who contracted it in a compelling narrative that unfolds against the backdrop of Norway, Hawaii, India and elsewhere.

While he doesn't hold back from describing the



desolate existence of people banished to society's margins through no fault of their own, Gould's sympathetic treatment is enriched by his discerning eye for the idiosyncrasies of his often colorful cast of characters.

What emerges is a very human portrait — and for a disease where the humanity of those affected has often been denied, this is a worthy outcome indeed. ■

## FROM THE EDITORS

### THE HEALING PROCESS

Sister Clemence of the Sisters of St. Paul de Chartres works with persons affected by leprosy at Tulear regional hospital in southwest Madagascar. When still a novice, she was inspired by the example of a Father Isidore, who applied makeup to the face of a terminally ill patient so that she could die with dignity.

Today, one of Sister Clemence's activities is to run a beauty clinic at the hospital, where women come to her with their skin complaints.

Sometimes, she uncovers symptoms of leprosy this way. In the week before Goodwill Ambassador Sasakawa visited, Sister Clemence found three new cases.

Often, the best medicine Sister Clemence dispenses is not ointment or advice, but the time she takes to listen to what the women have to say. By sharing details about their lives, they unburden themselves and return home refreshed.

For so long, those with leprosy suffered in silence. It is thus encouraging to see them starting to make their voices heard, and people starting to

listen. At the recent African Leprosy Congress, persons affected by leprosy were a vocal presence, occupying the front rows of the auditorium and playing an active role in some of the sessions.

We also have news of the appointment of Lokdoots, or special communicators, in India — recovered persons who have been selected to dispel myths about leprosy and set society straight about the disease.

In the last two decades, over 14 million people have been cured of leprosy. But as the WHO's Dr. Asamoah Baah commented in Johannesburg, that is not quite true. "They may have been cured physically, but they have not been cured emotionally and mentally" — and they won't be until society is cured of the disease of stigma.

For persons affected by leprosy, an important part of that healing process is being able to talk about their experience. Society at large would do well to take a leaf out of Sister Clemence's book, and lend a sympathetic ear.

## FOR THE ELIMINATION OF LEPROSY

### 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

With support from:

Sasakawa Memorial

Health Foundation,

The Nippon Foundation

www.nippon-foundation.

or.jp/eng/