

# FOR THE Elimination OF Leprosy

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



Dairy entrepreneurs in Chhattisgarh, India: these ladies are among the winners of this year's Rising to Dignity Awards. (See page 3) Photo: S-ILF

## MESSAGE

### The Wheels of a Motorcycle

It was in 2006 in the pages of this newsletter that I first referred to leprosy in terms of a motorcycle. What gave me the idea was seeing the 2004 film *The Motorcycle Diaries* about the travels across South America by Che Guevara, then a young medical student, and his friend Alberto Granado, a biochemist.

While passing through Peru, they volunteered to care for leprosy patients who lived in isolation from society in a colony on the far side of a river. Inspired by their motorcycle journey, I came to think of the disease and the discrimination it causes as the two wheels of a motorcycle.

The front wheel represents our efforts to tackle the disease, and the back wheel our fight against stigma and discrimination. Unless both wheels turn at the same time, it will not be possible to eliminate leprosy from the world. Everywhere I go, I use the image of a motorcycle to urge people to address both the disease and the discrimination.

I was delighted to see that in the WHO's

recently published *Global Leprosy Strategy 2016-2020: Accelerating towards a leprosy-free world*, a bicycle has been used to symbolize this idea. It appears on every page.

According to the explanation in the new strategy, the wheels of the bicycle represent stopping leprosy and its complications, and stopping discrimination and promoting inclusion. But who, I wonder, is riding this bicycle, and where is it heading?

Needless to say, the rider is made up of all the stakeholders in the fight against leprosy — people affected by leprosy included — and their destination is the leprosy-free world that is the long-term vision of the new five-year strategy.

The thrust of the five-year strategy is to accelerate toward that vision. Whether they are traveling by bicycle or motorcycle, I hope all stakeholders move forward with enthusiasm and a sense of responsibility.

— Yohei Sasakawa, WHO Goodwill Ambassador

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# Going Forward Faster

A new five-year strategy aims to increase momentum for a leprosy-free world.

The WHO launched its latest global leprosy strategy in April this year, built around the three main pillars of strengthening government ownership, coordination and partnerships, stopping leprosy and its complications, and ending discrimination and promoting inclusion.

Developed over 18 months in consultation with national leprosy programs, technical agencies and NGOs, as well as patients and communities of people affected by leprosy, *Global Leprosy Strategy 2016-2020: Accelerating towards a leprosy-free world* sets the goal over the next five years of reducing to zero the number of child cases with disabilities related to leprosy, reducing the rate of newly diagnosed leprosy patients with visible disabilities to less than 1 per million, and ensuring that all remaining legislation that permits discrimination on the grounds of leprosy is abolished.

**It is a shame that children are still contracting leprosy and deformities in the 21st century.**

Concerning the strategy's special focus on children as a way to reduce disabilities and transmission, Dr. Erwin Cooreman, team leader of WHO's Global Leprosy Programme, said it was a shame that children were still contracting leprosy and deformities in the 21st century "as it reflects our collective failure not to detect these children early, as most of them are contacts of known leprosy cases."

## CAMPAIGNS MAKE A COMEBACK

Interventions necessary to achieve the strategy's targets include detecting cases early before visible disabilities occur, targeting detection among higher risk groups through campaigns in highly endemic areas or communities, and improving health care coverage and access for marginalized populations.

"While campaigns were organized many years

ago, this had become taboo with the integration of leprosy services into the general health services, since it was assumed that all patients would self-report in a decentralized and integrated setting. This assumption did not come true in many settings. Especially in areas of known high-endemicity, we are again advocating for active case finding," Dr. Cooreman said, while acknowledging that campaigns are labor intensive and costly and so would have to be judiciously designed.

Other strategic interventions that endemic countries are urged to incorporate in their own national plans include screening of all close contacts of persons affected by leprosy, especially household contacts, and — pertaining to the third pillar — incorporating specific interventions against stigma and discrimination.

"This pillar may not be the immediate responsibility of ministries of health and we don't expect ministries to take charge of this. But it is important that national leprosy programs understand the importance of this pillar and play the role of advocate with the relevant ministries as well as with partners who may be better placed to take the lead," Dr. Cooreman said.

The strategy recognizes that the stigma surrounding leprosy and discrimination against persons affected by the disease continues to act as a barrier to better and earlier diagnosis and effective control.

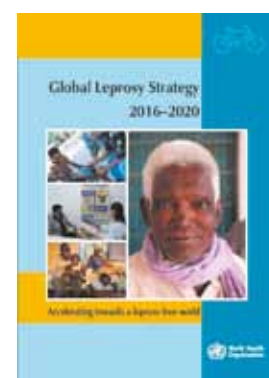
It also notes that many patients experience social exclusion, depression and loss of income as a result of leprosy, and that their families suffer as a result.

Therefore, it goes further than previous strategies in calling for the abolition of all discriminatory laws and promoting policies that facilitate the inclusion of people affected by leprosy in society, positively advancing their role and designed to restore their dignity.

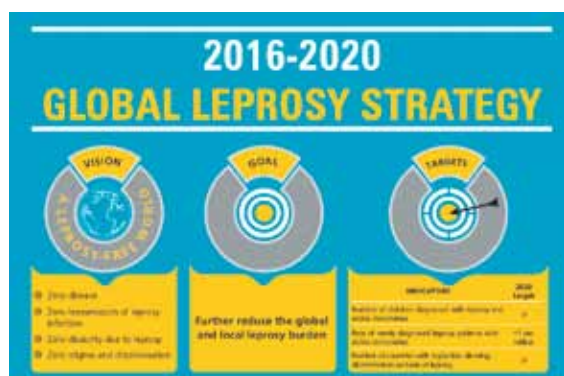
## PRAGMATIC APPROACH

"The vision is a leprosy-free world — a world without Hansen's disease, transmission of infection or disabilities due to leprosy, a world without stigma and discrimination linked to leprosy. Nobody will disagree with these aspirations. While we all would wish this to be realized soon, we all understand that this will happen beyond the life of the current strategy," said Dr. Cooreman.

"Let's be a bit more pragmatic and aim for a realistic goal of further reducing the global as well as local leprosy burden and go for elimination at sub-national levels. In the Operational Guidelines that WHO is developing to accompany this strategy, a list of indicators will further elaborate this goal," he said. ■



The new strategy puts more emphasis on human and social aspects affecting leprosy control.



## LEPROSY FACTS

Of the 213 899 new cases in 2014, 94% were reported from 13 countries — Bangladesh, Brazil, Democratic Republic of Congo, Ethiopia, India, Indonesia, Madagascar, Myanmar, Nepal, Nigeria, the Philippines, Sri Lanka and the United Republic of Tanzania. India, Brazil and Indonesia account for 81% of the newly diagnosed and reported cases globally. (Note: Mozambique, which had over 1,000 cases, did not report in 2014.)



# Getting Down to Business

Stories of Sasakawa-India Leprosy Foundation's "Rising to Dignity" Award winners.

Paan shop owners (right) and sari sales ladies (far right) in Maharashtra; dairy business entrepreneurs in Andhra Pradesh (below)  
Photos: S-ILF



In a small leprosy colony on the outskirts of a town in Chhattisgarh, six middle-aged women took up the challenge of shifting from begging and menial labor to start a dairy business. With financial and technical support from Sasakawa-India Leprosy Foundation (S-ILF) they bought seven Jersey cows. Initially, the women sold their milk through a middleman, who only paid them around half the market rate. Subsequently, four cows died and they found they had been duped by their insurance company.

Faced with these setbacks, Sheela Jaiswal, Tiharin Bai, Dhan Bai, Sulochna Bai, Heera Bai and Bhoori Bai (see cover photo) were ready to give up, but following a series of counseling sessions and training workshops, they resumed work to rebuild their enterprise. The turning point came when the manager of the hotel where the workshops had been held placed an order to supply the hotel with milk. This gave the enterprise much needed stability and restored the women's confidence.

With 22 cows and buffalos, their enterprise is thriving today. They have been able to build better homes and buy sheep, goats and poultry to supplement their income. They are a source of inspiration to other members of their colony and are instrumental in its development.

## BUSINESS ACUMEN



Over the past four years, a group of 10 men with mild to moderate disabilities have transformed their lives by establishing a thriving dairy business in their leprosy colony in Andhra Pradesh. Previously reliant on begging and a small

government pension, B. Satyanarayana, K. Raghava and the eight others — none of whom had previous experience of dairy farming — purchased five buffalos with funding from S-ILF. Since then, they have demonstrated keen business acumen, working cohesively as a group and adhering to their pre-agreed business plan and guidelines provided by S-ILF.

The group is now looking to use part of its income to buy two to three more animals. Their efforts are spreading the message that with hard work and the right motivation, it is possible to live a life of dignity.

## GROWING DEMAND

A group of four women and two men from a leprosy colony in Maharashtra agreed to share assistance from S-ILF to initiate two different projects after attending training programs. The women planned to sell cutlery and the men aspired to sell household items.

The women quickly found there was a larger market for saris and cloth than for cutlery when selling door-to-door. Today, Godavari Parshetti, Shaila Thadkar, Sasikala and Pramila Chinche run a successful sari and cloth material business and have built up an established customer base.

They buy saris and cloth from the local wholesale market, selling door-to-door in nearby villages and receiving customers at their homes. They exude confidence and have shown exemplary resilience for having the courage to step out of their colony to sell in near-by areas.

After a discouraging start selling household items, Mohan Parsuram and Ramarao Ramkrishna decided to revive their ailing paan shop — a stall selling betel leaves — and expand it to sell biscuits and other snacks. They used the funding from S-ILF to invest in a sturdy iron booth and had it painted in bright colors.

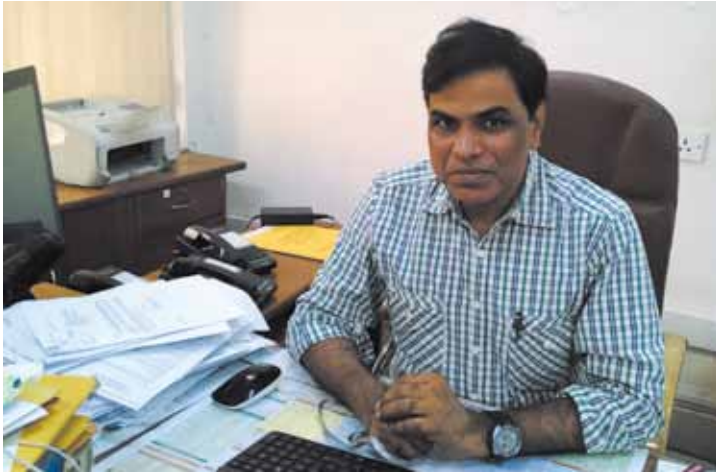
Open from 8 a.m. to 10 p.m. daily, the shop has seen sales pick up. The pair now plan to add stationery products and invest in a photocopier. ■

## FOOTNOTE

The Rising to Dignity Awards are presented each year on Anti-Leprosy Day, January 30.

# Grounds for Optimism

India's point man for leprosy eradication says there is much to be hopeful about.



## What are the key challenges India faces in eradicating leprosy?

Under the National Leprosy Eradication Programme (NLEP), India eliminated leprosy as a public health problem, i.e. less than one case per 10,000 population at the national level in December 2005. However, it remains home to around 60% of the world's leprosy-affected persons. This is because pockets of high endemicity are still present in several states and disease transmission is continuing.

In addition, it is a matter of great concern that the annual new case detection rate (ANCDR) and prevalence rate (PR) are almost static and that the percentage of Grade II disability among new cases has risen from 3.10% (2010-2011) to 4.61% (2014-2015). This clearly indicates that cases are being detected late in the community and there are likely to be hidden cases. A further challenge is to build the capacity of the various human resources categories working for the program.

## What measures is the NLEP adopting to address these various challenges?

We are following a three-pronged strategy for early case detection: 1) Leprosy case detection campaigns (LCDCs) specific to high-endemic districts; 2) Focussed leprosy campaigns (FLCs) in hot spots; and, 3) Case detection in hard-to-reach areas.

In order to reduce stigma, an evidence-based information, education and communication (IEC) plan is being prepared, training is being given to all categories of human resources and they are being assessed through training calendars. In addition, online training software is being developed and online monitoring software called Nikushth will be launched soon to keep track of all the activities being implemented under the NLEP.

## So you see a need for innovative approaches?

Yes. Other approaches being adopted under the

program include the *NLEP Newsletter* and GIS (geographic information system) mapping.

The newsletter is a platform to share guidelines, feedback, best practices, experiences and activities undertaken in the program in coordination with partners, states, NGOs, institutes, medical colleges and associations. It serves as an important communication tool to inform, update and educate our stakeholders as well as target groups.

GIS mapping is at present being followed under the NLEP to segregate districts based on endemicity. In future, it will be used to correlate the distribution of disease with various factors — geographic, socio-economic, operational — and to study and project geographic distribution.

## How big is the gap between the reported number of new cases and the actual number?

In India, cases are being reported passively as well as through active case detection, and around 125,000 new cases are recorded annually. However, the National Sample Survey (2010-11) reported a gap between the number of reported cases and the number of actual cases in the community. To address this, LCDCs have been launched in high-endemic districts, as I mentioned.

## How would you characterize the current attitude toward leprosy control?

Right now, the overall scenario in India favors the program. There is new, strengthened political will to fight against this disease and the government is determined to eliminate leprosy at all levels. It is a positive environment with lots to be hopeful about.

## What is your message for state leprosy officers (SLOs) who actually implement the program?

Ideally, all the guidelines should be followed, but SLOs are at liberty to introduce their own innovative ideas specific to their state's situation.

## Are you optimistic that it will be possible to achieve a leprosy-free India?

Yes. The ultimate vision and mission of the program is to achieve a leprosy-free India one day, which can be achieved by continuous emphasis on early case detection and treatment. There is also a need to pool all available resources from national as well as international partners. If we want to achieve success, we have to work hard until we achieve our vision. There is no room for complacency in the program. ■

## PROFILE:

### Dr. Anil Kumar

Dr. Anil Kumar is Deputy Director General (Leprosy) at India's Ministry of Health & Family Welfare where he is responsible for the National Leprosy Eradication Programme (NLEP).



Communication tool: inaugural issue of the *NLEP Newsletter* (January-March 2016)

# From Spain to the World

The only scientific publication about leprosy in Spanish has a long history.

## AUTHOR:

Dr. Pedro Torres



Dr. Pedro Torres is Editor of *Revista de Leprologia* and Head of Laboratory at Fontilles.

For more than 100 years, the sanatorium of Fontilles\* in Spain has dedicated itself to addressing both the medical and social needs of people affected by leprosy.

As part of its duty of care, Fontilles has always considered relevant the publication of literature covering various aspects of leprosy in order to increase knowledge and understanding of the disease.

Central to this is our flagship journal, *Revista de Leprologia*. It is the only existing Spanish-language publication dedicated to leprosy and in its current form has been published without interruption for 72 years.

It is distributed mainly in Spanish-speaking, low-endemic countries where the disease has not yet been eradicated and new cases continue to be detected. Coming out every four months, it covers topics intended to maintain expertise and knowledge of the disease, including original papers on medical, physical and social aspects of leprosy, and information relevant to leprosy control.

## BEGINNINGS

Five years before Fontilles was officially inaugurated in January 1909 in the wooded hills of Vall de Laguar south of Valencia, a journal called *La Lepra* was launched in 1904. Initiatives had already begun to raise funds and identify a suitable site for a sanatorium, and *La Lepra*'s role was to disseminate up-to-date medical information about leprosy. It also underlined the need to provide adequate assistance to those affected by the disease, who were living in caves or isolated houses far from the nearest village.

In 1910, the journal was renamed *Fontilles*. Under the stewardship of Dr. Mauro Guillen, a dermatologist and first medical director of the sanatorium, it began publishing the latest scientific advances on leprosy. It also included clinical studies carried out at the sanatorium as well as information about the daily needs of the residents. When the sanatorium inaugurated its laboratory in 1922, scientific activity at the sanatorium increased, as did the number of scientific papers published in the journal.

Political changes taking place in the 1930s in Spain and especially the Spanish Civil War

(1936-1939) profoundly affected living conditions at the sanatorium. The last number of *Fontilles* was published in 1931, and the years of severe hardship during and after the civil war made attending to the most basic and essential needs of the residents the main and only priority.

Publishing activities resumed in July 1944 under the newly appointed medical director, Dr. Felix Contreras Dueñas. He gave the new journal the title it bears today: *Revista de Leprologia*.

## 70th ANNIVERSARY

On November 24, 2014, at the Institute of Medical History in Valencia, the Association Fontilles Lucha contra la Lepra (SF) celebrated the 70th anniversary of the journal, which received an award as one of the oldest scientific journals in Valencia.

Over seven decades, the journal has had four different editors and the cover has been redesigned six times. It was the first journal in Spain to publish on the administration of sulfones in the treatment of leprosy, to describe the use of thalidomide for the treatment of leprosy reactions and to promote the implementation of multidrug therapy (MDT) after it was recommended by the WHO in the 1980s.

A total of around 360 copies per issue are distributed to 36 countries. Although there is an annual subscription, free copies are provided to doctors

and health personnel working in leprosy unable to afford the fee, as well as to selected tropical medicine institutes. It can also be accessed on the INFOLEP website.

The journal receives funding support from two members of the International Federation of Anti-leprosy Organizations: The American Leprosy Missions and The German Leprosy and TB Relief Association.

*Revista de Leprologia* has an active, international Editorial Board and has established a collaboration with the *Leprosy Review*, published by LEPROA in the United Kingdom. Any article considered of special interest to our readers is translated into Spanish and published in the journal.

We remain committed to the philosophy the journal has adhered to for more than 70 years, which is contributing to a better understanding of the disease of leprosy. ■



Helping the Spanish-speaking world to a better understanding of leprosy

## FOOTNOTE

\* The official name is Sanatorio San Francisco de Borja. Fontilles is a Spanish NGO founded in 1902.



# Checking on Progress

Meetings in India and Switzerland keep the Goodwill Ambassador busy as he updates himself on the leprosy situation in different parts of the world.

## INDIA (MAY 11-15)

During a visit to India in May, I called on the WHO country representative, the deputy director general (leprosy) of the Ministry of Health & Family Welfare, met with leaders of the Association of People Affected by Leprosy (APAL), visited with members of the Forum of Parliamentarians for a Leprosy-Free India and attended a board meeting of the Sasakawa-India Leprosy Foundation (S-ILF).



With Dr. Henk Bekedam

It was my first meeting with Dr. Henk Bekedam, the WHO representative to India, who told me that the India country office was the biggest in the WHO system, with 1,000 staff in the field. Many of them had been working to eradicate polio,

which India succeeded in doing two years ago. Dr. Bekedam hoped that the lessons learned from this success story could be applied to eradicating leprosy, and that some of the WHO's field staff could now be utilized for this effort.

I was also meeting DDG(L) Dr. Anil Kumar for the first time. He too spoke of using India's success in eradicating polio in the fight against leprosy. He said the budget for his program translated into and he wanted to send teams of men and women working in pairs to visit households and examine families in a bid to promote early detection, even in remote and low-endemic areas. The ministry would

be conducting a major case detection campaign in September and he invited me to witness it.

APAL was founded in 2005, when it was known as the National Forum. It is a nationwide network of people affected by leprosy, primarily those living in the country's 800 or so self-settled leprosy colonies. In the years since, it has worked to promote socio-economic empowerment, improve living conditions, foster dignity and respect, and educate people affected by leprosy about government schemes and benefits that can assist them.

Of current concern at the time of my visit was a shortage of operating funds. This is due to the delay in APAL being granted permission to receive funds from The Nippon Foundation under India's Foreign Contribution Regulation Act. We are all hoping that this can be resolved at the earliest opportunity.

The Forum of Parliamentarians for a Leprosy-Free India is headed by Mr. Dinesh Trivedi, MP. He invited me to his residence where I met with several other members of the forum and thanked them for the work they are doing. Next year, the Global Appeal to end stigma and discrimination against people affected by leprosy will be endorsed by the Inter-Parliamentary Union. It is to be launched in India and I believe the forum will have a valuable role to play.

S-ILF was established in 2006 to support efforts at reintegrating people affected by leprosy through economic and social empowerment; it marks its 10th anniversary this year. S-ILF is active in three main areas — self-reliance, education and awareness training — and I received updates on its recent



Posing for a commemorative photo with APAL leaders — and some of their children and grandchildren — in New Delhi



Greeting Ethiopia's minister of health (top) and attending a meeting with a delegation from Mozambique (above) in Geneva; at a gathering of the Forum of Parliamentarians for a Leprosy-Free India in New Delhi (above right)

projects. It is planning a special anniversary event for 2016 that will be announced in due course.

#### SWITZERLAND (MAY 25-26)

Each year I travel to Geneva to attend the World Health Assembly, where I present the Sasakawa Health Prize, which was won this year by Medicus Mundi Spain (FAMME) for a project on transforming public health systems based on the principles of primary health care. As always, I took the opportunity to meet with health ministers or their representatives on the sidelines of the assembly to hear about the leprosy situation in their country. I have summarized the main points from some of the meetings I had below.

### Brazil is taking its school-based de-worming and leprosy case-finding initiative nationwide.

**Ethiopia** still sees around 4,000 new cases a year and the government wants to move ahead with the mapping of hot spots. There are around 300 high-endemic areas in the country. About 20% of new cases in these areas already have Grade 2 (visible) disability, compared with the national average of 12.5%.

**Indonesia** has increased its budget for leprosy control. It is making concerted efforts to find new cases and is introducing chemoprophylaxis for contacts of confirmed cases. Not all areas of the country are easy to access, and there is a lack of expertise in some places, making it essential to develop the capacity of medical personnel. To eliminate stigma and discrimination, the government is using public broadcasting to disseminate messages about leprosy in an effort to change mindsets.

**Brazil** is redoubling efforts at case detection in high burden states such as Mato Grosso, Pará and Maranhão. It is also taking its school-based

de-worming and leprosy case-finding initiative nationwide. The country is currently in the process of validating data which, if confirmed, would mean Brazil has eliminated leprosy as a public health problem at the national level. This would represent a remarkable achievement, but Brazil will not be resting on its laurels.

In the **Philippines**, local governments earlier this year made a commitment to strengthening anti-leprosy activities. The country aims to have no new cases of leprosy in coming years. In the meantime, there remains a need to promote the reintegration of people affected by leprosy into society.

**Democratic Republic of Congo** is concentrating its efforts on early detection of the disease in order to prevent disability and reduce stigma. It is focusing its activities on high-endemic areas and says that incidence of leprosy is declining in many provinces.

**Mozambique** is tackling leprosy within the context of neglected tropical diseases. The country has achieved elimination of leprosy as a public health problem, but in recent years interest in the disease has waned. In some areas, case numbers are creeping up again and there is a need to reactivate efforts against leprosy.

**Tanzania** sees around 2,000 new cases of leprosy a year. It has a number of disease hot spots where transmission is occurring and children are especially at risk. Since 2007, the country has been conducting awareness-raising campaigns with WHO support and is actively promoting the social reintegration of people affected by the disease. It has begun testing the use of chemoprophylaxis. It has also carried out early case detection in three areas, together with the tuberculosis program, with the support of Novartis.

Several countries are currently undertaking special anti-leprosy initiatives with monies from a fund set up for this purpose after the International Leprosy Summit in Thailand in 2013. I look forward to hearing more about the progress they are making in due course. ■

# Beijing Readies for ILC 2016

ILA president says scientific output vindicates reduced interval between congresses.

As the 19th International Leprosy Congress in Beijing draws closer, the president of the International Leprosy Association (ILA) says the decision to hold the September 18-21 congress only three years after the last congress in Brussels in 2013 was the right one.

"In Brussels, many members of the ILA Council suggested shortening the interval between congresses from five to three years. Now I definitely feel it was a very wise decision," says Dr. Marcos Virmond. "Technology is advancing fast and we are getting results from some studies in a very rapid way."

The organizers have received more than 700 submissions for Beijing, of which they have selected a little over 400 papers for presentation. "That means there is a lot of scientific production every year. People want to have more space to discuss results that are coming out quickly and moving in some new directions," he says.

Among the key topics will be a vaccine for leprosy and the role of chemoprophylaxis. "A vaccine is a welcome topic but it is still something difficult to achieve, not only from a technological point of view, but also because of the need for many and large-scale clinical trials for safety and efficacy," says Dr. Virmond.



"As for chemoprophylaxis, I think this will be a very important item for leprosy control from now on. I don't see anything new in the near future other than chemoprophylaxis. Is it good? Is it the solution? Is it feasible? What are the ethical issues involved? These are definitely issues to be discussed, and the congress is exactly the place to discuss them."

The theme of ILC 2016 is *Unfinished Business: Stopping Transmission, Preventing Disability, Promoting Inclusion*. Dr. Virmond is confident delegates won't be disappointed by what Beijing has to offer them.

"The local organizing committee are quite excited and are doing a very nice job. I am sure we are going to have a very good congress."

## CHURCH APOLOGY



Twenty years after the abolition of Japan's Leprosy Prevention Law, the Synod of the Anglican Church in Japan has apologized for its part in the isolation and inhumane treatment of leprosy patients. Prior to the law's repeal, the Nippon Sei Ko Kai (NSKK) chose not to support sanatoria patients in their efforts to regain their human rights, believing it was not appropriate for a religious organization to become involved in what it saw as a political campaign. It said it should have drawn inspiration from the example of two Anglican missionaries who devoted themselves to the welfare of leprosy patients in the past: Hannah Riddell, who built a hospital in Kumamoto Prefecture, and Mary Helena Cornwall Legh (pictured), who started the St. Barnabas Mission in Gunma Prefecture. ■

## FROM THE EDITORS

### OUR SHARED VISION

As Dr. Marcos Virmond mentions elsewhere on this page, the International Leprosy Congress in Beijing this September will be an opportunity to discuss scientific topics that are key to the future of leprosy control. The timing is also right to review the new *Global Leprosy Strategy: Accelerating towards a leprosy-free world*, with its

commitment to further reducing the burden of leprosy globally and locally. We applaud the strategy for underlining the importance of ending discrimination and promoting inclusion, and trust that along with scientific advances, this focus on the human and social aspects of leprosy control will bring us closer to realizing our shared vision.

## FOR THE ELIMINATION OF LEPROSY

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