

FOR THE Elimination OF Leprosy

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



The Goodwill Ambassador inspects a livelihood project at Jay Durga leprosy colony in Uttar Pradesh, India, on October 22, 2013.

MESSAGE

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Cross-party Cooperation

The recently established Forum of Parliamentarians to Free India of Leprosy is an all-party group consisting of about 50 MPs. The forum is dedicated to defending the human rights of people affected by leprosy and their families, improving their welfare and living conditions, and enabling them to live in dignity. The MPs are undertaking this work in their constituencies as well as through their activities in India's Parliament.

In Japan, an organization of Diet members was set up some decades ago to help people affected by leprosy. It has made efforts to improve the living environment and medical services of those living in sanatoriums.

That such a group should also have been formed in India is very encouraging. What is especially significant is that membership cuts across party lines. When people with political influence and the ability to deliver results put aside party differences, things happen. I very much hope this will spur awareness-building activities to promote a proper understanding of leprosy and that the forum will serve as a catalyst to hasten the resolution of

various legal, social and economic challenges.

One of the central figures in the forum, former Union Minister for Railways Dinesh Trivedi, promised that this would be a sustained commitment that would continue until people no longer face stigma or forfeit their dignity due to leprosy. "These are our own people — our brothers, our sisters, our mothers, our fathers," he said.

In Brazil, too, something similar is happening. Led by the Secretariat of Human Rights, 83 MPs formed a group in August to take further measures against leprosy and other Neglected Tropical Diseases and to promote the elimination of discrimination.

I would like to see parliamentarians form groups in many more countries that are still grappling with leprosy. But for such groups to produce concrete results, our job is to keep them well informed and to cooperate with them very closely. In any event, these recent developments in India and Brazil are to be welcomed.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Back on Their Feet

HANDA's mobile prosthesis workshop provides a timely service in China.



In China, many older persons affected by leprosy are living with disabilities due to late detection and treatment and injuries they exacerbated by working in the fields in their younger days.

Over the years, wounds that did not receive proper treatment developed into ulcers, bone infections and cancer, resulting in amputation. The prostheses that amputees were given were heavy and unsuited to their needs. No one from the manufacturers was willing to enter the leprosy recovery villages where they lived to adjust them. Without suitable prostheses, their amputation stumps continued to develop new ulcers.

To tackle this problem, HANDA Rehabilitation and Welfare Association established a prosthesis workshop in Guangzhou province in 2002. In 2010, it established a mobile prosthesis workshop to expand its area of operations and provide a timely service for people affected by leprosy.* By the end of 2012, it had produced 936 prosthetic limbs for people in 53 leprosy villages in five provinces.

When technicians visit a village, they not only make prostheses but train beneficiaries on how to wear their new limbs as well as how to

care for them. During follow-up visits, they carry out necessary adjustments and maintenance, replacing parts — such as foot plates and ankle joints — as needed.

A NEW LEG FOR MR. ZHOU

Seen here are photos taken when the mobile workshop visited Sian, a leprosy recovery village about one hour from Guangzhou city, in September this year to make a new limb for Mr. Zhou Zaizhao.

In the back of the mobile workshop, HANDA prosthetic technician Yuan Yahua** gets to work making a plaster cast in the shape of Mr. Zhou's leg (1). Next, the prosthetic material is heated and molded in the shape of the cast by assistant technician Wang Dewen (2). The prosthesis is now ready (3), but first Mr. Zhou's leg stump is given a good massage to get the blood flowing (4). The artificial limb is fitted (5), but is a little tight around the knee joint, so technician Yuan makes some on-the-spot adjustments to the prosthesis (6). After further adjustments, this time to the height of the prosthesis (7), Mr. Zhou takes his first steps — and his big smile says it all. (8) ■

FOOTNOTES

* The mobile workshop is currently being funded by The Leprosy Mission New Zealand, Sasakawa Memorial Health Foundation and local donors.

**Yuan Yahua is himself a person affected by leprosy.

Fighting Leprosy with Knowledge

Infolep is the place to go for information on leprosy and related subjects.

Established more than four decades ago by Netherlands Leprosy Relief (NLR), Infolep has become one of the go-to resources for anyone involved in leprosy, from researchers and students to program managers and field workers. Starting out as a library collection in Amsterdam and a literature research and document delivery service, Infolep has grown to include an impressive online portal of all things leprosy.*

Between the library and the portal, users have easy access to more than 23,500 articles, books, WHO reports, training materials and “gray literature” (unpublished documents) — and the list is growing all the time. Over 1,700 can be viewed online in full for free.

For the past 10 years, Infolep has been overseen by Jiske Erlings, NLR’s information officer. Trained as a librarian, Jiske’s initial job with NLR was to look after the library collection, fulfill requests for literature research and mail new articles to subscribers. She was also responsible for maintaining and expanding the Infolep website.

“We used to send out packets of new literature all over the world, which was expensive and time consuming, and the packets didn’t always arrive,” she recalls. “Increasingly, however, we have been able to send out material by email or put it on the website, so that people can just take what they need.”**

GROWING IN SCOPE

In 2012, the International Federation of Anti-Leprosy Associations (ILEP) was invited to participate in and sponsor the project. The support of ILEP and sponsorship provided by NLR’s fellow ILEP members has enabled the upgrade of the Infolep website and the purchase

of new publications.

“The situation is changing very fast,” says Jiske. “Most publications these days are now online. On the other hand, a lot of them are copyright protected and still difficult for people in the field to access. In addition, it is difficult to obtain everything since probably more than 600 articles are published each year.”

Much of Infolep’s collection is in English, so there is further work to be done to broaden its language base. “I’m trying to include more publications in other languages and to expand the collection through cooperation with other organizations,” she says. Another ongoing task is to make links between publications that are interrelated and to draw up a list of key themes that are of particular importance to those working in leprosy, such as stigma and social participation.

“I’m trying to include more publications in other languages and to expand the collection.”

‘KNOWLEDGE CENTER’

As part of its role as an “international knowledge center” for information sources on leprosy, Infolep offers a quick reference service. Questions the information officer has been asked include: “Do you have literature on the link between stigma and Catholicism?”; “Can you find a quote by a famous person on leprosy?”; “Do you have information about self-care in Ethiopia?”; and “Where can I find the latest leprosy statistics?”

Although its online offering is impressive, there are some queries Infolep can’t yet satisfy — such as requests to download the well-known textbook *Leprosy* edited by Robert C. Hastings or other works that are not yet digitized. “I don’t know if dealing with the author copyright and digitizing these books is a task for us, but it would be good to include such works on the website if possible,” Jiske says. Another addition, in due course, will be training videos and other training materials.

As Infolep grows in size and scope, Jiske is clearer than ever about its mission. “I want people to use the website not only to search for documents but also to share publications in order to help fight the disease,” she says. “Especially now there are fewer cases of leprosy, it is important to make knowledge more widely and easily available.” ■



NLR’s information officer Jiske Erlings

FOOTNOTES

* <http://www.leprosy-information.org/>
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**In the first six months of 2013, portal visits were led by those from India, the United States and the Netherlands. The total number of unique visits was 14,328.

A Cruel Disease

Treatment with MDT is not the end of the story for many cured of leprosy.

I often have the privilege of talking about leprosy to audiences in the U.K., based on my 25 years' experience working for The Leprosy Mission in India, Nepal and Bangladesh. One of the points I stress is that leprosy is a cruel disease: your troubles are not necessarily over once you have completed your course of treatment with multidrug therapy (MDT). In fact, they may even seem worse because you are disappointed not to be "back to normal."

A bacterial infection that mainly affects the skin and peripheral nerves, leprosy can result in permanent disability if left untreated. Some people, before they are diagnosed, already have developed irreversible nerve damage, causing muscle weakness or numbness. Perhaps the doctor they first saw did not recognize the disease; or perhaps these individuals genuinely did not notice any problems until impairment set in.

Nowadays, however, many people come early for treatment when they just have changes in their skin. They hope to be cured with no residual problems. Unfortunately, however, this is not always possible.



Practicing self-care in India

DOWNWARD PATH

It seems very unfair — and to some, inexplicable — but the disability associated with leprosy can develop during treatment and escalate after the patient has finished conscientiously taking MDT.

The main cause of this disability is nerve damage caused by leprosy reactions, when the body responds to the infection itself or to the presence of dead bacteria by becoming inflamed.

Take a patient with a single numb patch on his leg who has been diagnosed with paucibacillary (PB) leprosy. Over a six-month course of MDT, any leprosy bacteria he had in his body will certainly die, but debris left from the bacterial cell walls may precipitate an immune response that damages nerves in the leg.

As a result, before completing his MDT, he

develops a condition known as foot-drop and his sole becomes numb. He may then develop an ulcer on his toe where it keeps hitting the ground when he walks. Over time, his foot becomes more scarred and walking more difficult.

If the new muscle weakness and sensory loss are recognized early, treatment with suitable drugs and physiotherapy may reverse the impairment. If the patient is trained and supported in care of the limb, he may be able to prevent ulceration. If muscle weakness does not recover with medication, reconstructive surgery can often restore good function.

To some it seems inexplicable, but the disability associated with leprosy can escalate after cure.

Or take a patient whose skin is shiny and thickened or lumpy because it is packed with leprosy bacteria. He may feel well and have no disability at time of diagnosis. Following a 12-month course of MDT for multibacillary (MB) leprosy, he is declared cured of leprosy and released from treatment.

Subsequently, however, he suffers a fierce immune response to the residual bacterial debris. This may last several years and require months in hospital, where strong drugs are administered to suppress his "lepra reaction." Without proper treatment, this immune response may result in blindness, nerve damage and even infertility, all of which are permanent. With expert medical care, however, the outlook is better.

OTHER DISEASES

Polio is a disease accompanied by pain and fever while the virus circulates in the body. It may cause paralysis, which is devastating and life-long. Decades after the last polio virus in your body has died and you are no longer infectious, you remain lame. Somehow, people understand this more easily than they understand that a person affected by leprosy may be disabled long after his infection is cured.

Pulmonary tuberculosis may scar the lungs, leaving a "shadow" visible on a chest X-ray and perhaps some shortness of breath. But because of all the anti-TB medicine a patient swallows to kill the bacteria, he is no longer infectious and need not worry about passing on the disease to family and friends. Generally, the public accept this.

Sadly, it can be more difficult to convince

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Example of a self-care kit

them that leprosy is cured after a course of MDT, especially if they see that a person has more disability than he had at the time of starting treatment.

KEEPING FAITH WITH MDT

Does MDT work? Yes. We need to exercise faith and believe the evidence produced by scientists and epidemiologists. MDT does kill leprosy bacteria. It does interrupt transmission of the disease. What it cannot do is stop the body’s immune system from overreacting to left-over bits of dead bacteria. For

that, different medicine is needed.

MDT cannot protect unfeeling limbs from injury. For that, teaching self-care techniques (and constant vigilance) are needed. MDT will not restore power to paralyzed muscles, but reconstructive surgery can restore function in appropriate cases.

As well as supplying MDT, every leprosy program must offer these other services. Only then will people obtain the full benefit of their MDT, and the cruel progress of the disease will be fully halted. ■

MUSEUM PIECE

SHARED MARRIED QUARTERS

When Japan opened its first national leprosaria in the early part of the 20th century, marriage between patients was not permitted. Only couples who were already married by the time they entered the sanatorium were allowed to live together.

Quite soon, however, the authorities changed their policy. The idea was to make compulsory institutionalization a less daunting prospect for those diagnosed with leprosy and to make inmates feel more settled in sanatorium life.

But while marriage was permitted, starting a family was not. Husbands had to undergo sterilization and their wives would be forced to have an abortion if they accidentally became pregnant.

Living arrangements were far from satisfactory. As there were no married quarters other than for the small number of couples who had married prior to admission, husbands would visit the female dormitories in the evening to spend the night with their wives, who lived in rooms they shared with seven other women. These “commuter relationships” continued beyond World War II.

Eventually, married quarters were built, but initially this was little improvement on the previous arrangement. Three to four couples had to share a small room of between

10 to 12.5 tatami mats in size, as shown in this model on display at the National Hansen’s Disease Museum in Tokyo.

Those in relatively good health would often be placed with those suffering from disabilities, such as blindness, so they could look after them. At night, couples would stand a low table on its side to partition themselves off from their neighbors and give themselves a modicum of privacy. But it was impossible to forget they were not alone, and living in such close proximity could be a source of stress that eventually led some people to have nervous breakdowns.

As there were not enough rooms to meet the demand for married accommodation, some couples had to continue in “commuter relationships” as they waited for someone to die and a space to open up in the shared marriage quarters. What they really wanted, needless to say, was to have a room of their own.

With patients also pushing for better healthcare and nursing, it was a question of priorities as to when private married quarters were built. While the timing varied from sanatorium to sanatorium, private accommodation was gradually introduced from the 1950s and by end of the 1960s, every married couple had their own quarters.



Pushing for Progress

The Goodwill Ambassador returns to India to attend another leprosy stakeholders' meeting, this time in the high-burden state of Uttar Pradesh.

INDIA (OCTOBER 21-24)

Uttar Pradesh is India's most populous state. Home to some 200 million people, it is bigger than many countries. In the nation that reports the most new cases of leprosy in the world, Uttar Pradesh is the state that contributes the highest number — over 24,000 in the year through March 2013.

I traveled to Uttar Pradesh in October with three main objectives. First, to build political commitment for strengthening leprosy control measures. Second, to accompany leaders of people affected by leprosy in discussions with state officials over their petition for a pension and other living improvements. And third, to see projects funded by the Sasakawa-India Leprosy Foundation that promote the economic self-reliance of people living in leprosy colonies.



The stakeholders' meeting in Uttar Pradesh

Under India's system of federal government, state governments have the main responsibility for implementing measures against leprosy at the field level. The commitment of states to this task is thus essential.

Bolstering that commitment was the purpose of the leprosy stakeholders' meeting I attended in Lucknow on further reducing the burden of leprosy in Uttar Pradesh. Among those taking part were state health officials, the state leprosy officer, district leprosy officers from 37 high-endemic districts, NGO representatives and people affected by leprosy.



Principal Secretary Kumar

The meeting was chaired by Pravir Kumar, principal secretary of health of Uttar Pradesh, who said: "It is most important that we detect cases as early as

possible and start treatment immediately cases are reported. In this, the ministry has very important role." He went on: "One of the reasons why cases are not detected or reported is because of the social stigma attached to the disease. We need to remove such fears from people's minds."

I was gratified to see over 10 local media organizations were covering the meeting.

That is a message that everyone needs to hear, so I was gratified to see there were more than 10 local media organizations covering the meeting. Generating greater public awareness and understanding of leprosy is a key part of tackling the disease and encourages people to come forward for treatment.

The next day, I travelled about 80 kilometers south of Lucknow to Raebareli district, where I visited Jay Durga leprosy colony. Established in 1971, it is home to 40 adults and 31 children.

Jay Durga has several livelihood projects made possible by grants from the Sasakawa-India Leprosy Foundation (SILF). SILF currently supports around 150 livelihood projects in 16 states. The projects at Jay Durga include goat rearing and cycle rickshaws, and benefit 13 people in total.

Members of the SILF livelihood team told me that the success of a project depends on several factors: developing the decision-making capabilities of project members; making use of members' know-how and experience; the existence of a ready market; and the enterprise being attractive enough for the next generation to want to continue it.

Although SILF's successes are still modest in number, the list is growing. As I found in Uttar Pradesh, it is very encouraging to see people who used to rely on begging now running their own enterprises. It gives them confidence and lifts the mood of the community as a whole.

While at Jay Durga I attended a meeting of colony leaders from a dozen of Uttar Pradesh's 68 leprosy colonies. They are all members of the Leprosy Sufferers Welfare Association, a state-wide organization run by Dayalu Prasad and Murari Sinha, the leader and secretary, respectively.

In December 2012, the association submitted



Addressing the colony leaders' meeting at Jay Durga colony

a petition to the Chief Minister seeking improvements in living conditions. The petition contained five requests: 1) a monthly pension of Rs. 2000 for people affected by leprosy; 2) provision of government low-income housing to residents of leprosy colonies; 3) improvements in water, electricity supply and basic sanitation; 4) opportunities for children of people affected by leprosy to receive higher education; and 5) the provision of free medical kits to each colony.

Receiving no reply, the association secretary Mr. Murari resubmitted the petition in September. This time he did so through the media, believing this to be the best way to get the petition noticed. He also delivered copies to all the relevant government agencies. It was to follow up on these efforts that I returned to Lucknow for more meetings.

With Mr. Murari and others, I called on Anil Kumar Sagar, the director of social welfare, requesting his assistance. The following morning, we met with Sunil Kumar, the principal secretary and the key person at the social welfare department. He said it was the first time he had been petitioned about leprosy.

Concerning the pension request, he wanted information on how many people would be eligible and what the situation was in other states.



Murari Sinha hands the petition to Sunil Kumar.

Regarding education, he said the government had a scholarship fund for children of low-income households and recommended that people affected by leprosy apply for this.

The same day I also paid courtesy calls on Governor B.L. Joshi and Health Minister Ahmet Hassan, at which we discussed the petition. My final words before leaving Lucknow were reserved for the Leprosy Sufferers Welfare Association. To move matters forward, I said, they must supply the state government with all the information it had requested.

Less than one week after returning to Tokyo, I received word from Uttar Pradesh. Mr. Murari forwarded a document from Principal Secretary Kumar. It was an instruction to the social welfare officer in each district, attached to which was a list of children of people affected by leprosy that Mr. Murari had supplied. The note read in part: "You are requested to undertake the survey of the listed students. You are further requested to provide them all possible support and take necessary actions to provide secondary and higher secondary scholarships." This is the first time I have seen a state government respond so swiftly.

As I told the colony leaders who had gathered at Jay Durga colony, the power to solve the problems they face lies in their hands. This is true not just in Uttar Pradesh but all over India, led by the activities of the newly renamed Association of People Affected by Leprosy (formerly National Forum India — see page 8). I see my role as lending a hand when needed.

As discussions over a pension in Uttar Pradesh continue, I was very pleased to learn of the recent success of people affected by leprosy in Bihar in securing a monthly livelihood allowance of Rs. 1,800 from the state. I congratulate them on this wonderful news. I trust that before long I will be saying this to my friends in Uttar Pradesh, too. ■

Typhoon Haiyan Hits Culion Hard

Appeal launched to help Philippine island rebuild and recover.



On November 8, large areas of the central Philippines were devastated by Typhoon Haiyan, leaving more than 5,000 dead.

Sasakawa Memorial Health Foundation (SMHF) has a decades-long association with the Philippines through leprosy. It has developed close ties with the island of Culion in northern Palawan

province, which was once the world's largest leprosy colony. Since 2003, SMHF has been providing assistance to the Culion Sanitarium and General Hospital as well as to Culion's association of people affected by leprosy.

While Culion did not suffer the worst of the devastation from the typhoon (known as Yolanda in the Philippines), some 45 percent of the hospital buildings were destroyed, many homes were ruined and 75 percent of the population — some 15,000 people — have been affected.

SMHF has provided emergency reconstruction assistance in cooperation with Dr. Arturo C. Cunanan, Jr., the chief of the Culion Sanitarium and General Hospital.

It has also launched an appeal for donations for Culion's rehabilitation. For further details on how to make a donation, please visit the SMHF website.

Donations are being accepted through February 28, 2014.

NATIONAL FORUM RENAMED

National Forum India (NFI), the nationwide organization of and for people affected by leprosy, especially those living in some 850 leprosy colonies across the country, has a new name. Following the relocation of its headquarters from Tamil Nadu to Andhra Pradesh, necessitating that it reregister, the organization will henceforth be known as the Association of People Affected

by Leprosy (APAL). APAL remains committed to the social and economic empowerment of people affected by leprosy in India, working with its representatives in each state to improve the lives of people affected by leprosy and end the discrimination that they and their families face. The association was originally formed in 2006 as the National Forum. ■

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FROM THE EDITORS

STRENGTH IN UNITY



Congratulations are in order to Bihar Kashta Kalyan Mahasangh (BKKM), an umbrella group of associations of people affected by leprosy in the northern Indian state of Bihar. They recently received the welcome news that the state government

has completed the paperwork to begin dispensing a special pension to be paid to all persons affected by leprosy with Grade II disability. The

monthly pension, to the tune of Rs. 1,800 (including Rs. 300 for skills development), will benefit more than 12,500 people in the state.

BKKM first approached the authorities about a pension in 2010. The government in turn asked them for a list of names of people affected by leprosy and their circumstances. In just two weeks, BKKM visited 997 households in 63 colonies, gathered the information and compiled a report, which they presented to the deputy chief minister (see photo). That hard work was the catalyst for the ultimate success of their campaign three years later. We hope that other states will take note and be guided by Bihar's example.