

FOR THE Elimination OF Leprosy

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



Residents of Utale 2, a community of people affected by leprosy in Balaka district, Malawi (July 2011)

MESSAGE

The Importance of Research

At a recent meeting in Yangon of national leprosy program managers for the WHO's Southeast Asia region, WHO Regional Director Dr. Samlee Plianbangchang talked about the need for more research into the disease if we are to progressively reduce the burden of leprosy in the world.

This is an important topic. Multidrug therapy is the key to controlling leprosy and to preventing disability. But we must think ahead to the day when resistance to MDT develops. I understand that research into alternative treatment regimens is proceeding. It is a necessary undertaking when considering the long-term future of leprosy control.

The disease has a long incubation period and is slow to develop. Ideally, we need reliable and simple diagnostic tools to confirm diagnosis when the disease is in its early stages, or when there is some doubt over the symptoms. Along with this, let us develop a prophylaxis for individuals at high risk of getting leprosy, such as household members of leprosy patients, so that they can be protected from the disease.

On my travels as Goodwill Ambassador, I have seen many cases of people who suffer from leprosy reaction after they have been cured. Caused by the immune system's response to the presence of dead bacilli, reaction can result in nerve damage and disability if not treated properly. We need to find better ways of dealing with reaction and its debilitating effects.

For now, MDT is our most effective weapon against leprosy. Millions of people have been cured since its introduction. Cases numbers are coming down. But this success is part of the reason why the field seems less attractive to young researchers when they consider what area to specialize in.

Leprosy is still with us. To continue toward our goal of a world without leprosy, we will need to use our existing tools well. But we also need to develop new and improved tools to improve our chances of getting there. For that, we need research.

— Yohei Sasakawa, WHO Goodwill Ambassador

CONTENTS

Message	1
India Report Renewing commitment	2
Interview Muslim Momin	3
Case Study West Bengal housing	4
Obituary Dr. Yang Lihe	5
Leprosy Wish List Dr. Marcos Virmond, ILA	5
Ambassador's Journal Malawi, Central African Republic	6
News	8
From the Editors	8

Renewing Commitment

India health secretaries meeting seeks to put focus back on leprosy

At the end of July, Goodwill Ambassador Yohei Sasakawa traveled to India for a series of meetings with government officials and parliamentarians as part of his efforts to foster ongoing commitment to leprosy control and to generate greater momentum for improving the social and economic status of people affected by the disease.

The main meeting of his visit took place on August 4, when state health secretaries or their representatives from 13 states gathered for a conference in Delhi. Hosted by the Ministry of Health and Family Welfare and WHO India, the conference was called to discuss what needs to be done to further reduce the leprosy burden in India.

The disease remains a public health risk in three states, while 209 out of India's 640 districts have a disease prevalence that exceeds the WHO target of less than 10 cases per 100,000 population. Under 70% of districts are said to have a district leprosy officer.

Addressing participants, Union Health Secretary Dr. K. Chandramouli said the announcement that India had eliminated leprosy as a public health problem at the end of 2005 had led to a certain amount of complacency. "We have to renew the effort we made earlier," he said.

WHO country representative Dr. Nata Menabde highlighted the fact that 10% of leprosy cases in India are children, indicating that the transmission rate is very high. She called for an "innovative approach" to tackle the challenges that remain, noting that different policies were required for rural and urban areas.

The Goodwill Ambassador said that on his visits to India he had noticed a decrease in the number of experienced personnel stationed at state and district leprosy offices. "Further, I get the feeling that there is a general weakening in leprosy control measures," he said. "Now is the time for each of us to renew our resolve and for each state to make a strong commitment to fight leprosy once again."

This point was underlined by Dr. C.M. Agrawal, Deputy Director General (Leprosy), in



Paying a call on Sheila Dikshit, Delhi's chief minister

a separate meeting. If the political will is there at state level, he told Sasakawa, then the leprosy program will receive more priority.

PARLIAMENTARIANS

At a reception in Delhi for Indian parliamentarians with close ties to Japan, Sasakawa took the opportunity to talk about his role as Goodwill Ambassador and sought their support in realizing his dream of seeing an end to leprosy and the discrimination it causes. He talked about the work of the Sasakawa-India Leprosy Foundation and the role of the National Forum of people affected by leprosy, some of whose board members were present.

PENSIONS

In a meeting with Minister for Social Justice & Empowerment Mukul Wasnik, Sasakawa, accompanied by representatives of the National Forum, raised the issue of pensions for elderly and disabled residents of India's 850-plus self-settled leprosy colonies. A parliamentary petition committee has recommended a nationwide pension of 2,000 rupees for colony residents.

The minister acknowledged that existing disability pensions were still insufficient, but said that compared to three years ago there had been a definite improvement. He also drew attention to a number of plans currently under consideration, including the Food Security Bill and the National Rural Health Mission initiative to guarantee basic health for all, that would benefit people affected by leprosy.

Among others, Sasakawa also met with the chairman of the National Human Rights Commission of India, K.G. Balakrishnan, the chairman of the Rajya Sabha Committee on Petitions, Bhagat Singh Koshiyari, and with Sheila Dikshit, the chief minister of Delhi, whom he thanked for raising the pension for people affected by leprosy to 1,800 rupees. ■



Addressing the health secretaries conference on August 4

Born Leader

Muslim Momin draws on his own experiences to help others like him.

Profile:
Muslim Momin



Muslim Momin is facilitator of the Loharpatti Self-Help Group in Mahottari District in southeast Nepal. The group teaches people affected by leprosy self-care techniques to prevent injuries and impairment.



Muslim Momin shares his ideas with members of the Bathanaha self-help group, one of several in Mahottari district.

Why is self-care important?

Self-care is very important to control disabilities and deformities in leprosy. In my experience, people affected by leprosy face hostility and suffer discrimination when they have severe impairments and ulcers, and this restricts their participation in community life. Therefore, I put a huge effort into ensuring that members of my group practice self-care activities properly. I am in regular contact with Lalgadh Leprosy Services Centre* to get shoes and other items that improve members' quality of life and prevent further disability. I also persuaded the Loharpatti Village Development Committee to provide us with land where we can practice self-care regularly. If our bodies are in good shape, then we can think about the future and our well being.

Self-empowerment is another important theme of the group, isn't it?

Members participate in determining their needs and work toward meeting them through income-generation projects supported by loans from the group. Before, it was a struggle to feed their families, educate their children and gain access to health care. Now, through businesses such as selling snacks and raising animals, many have been able to improve their economic circumstances and transform their lives for the better.

What other activities are the group involved in?
My self-help group is now working for equal access

to food, water, housing, education and health care. We also want equal access to government development schemes and to enjoy the same rights as others in the community. I have participated in many meetings with NGOs and government officials, where I speak up for the human rights of people affected by leprosy. Beyond leprosy, I am also working to lift up the socio-economic condition of the poor, widows, women, Dalits (untouchables), children and vulnerable people.

What motivates you?

As a person affected by leprosy, I feel compassion for others like me. I refuse to accept they must suffer the kind of discrimination I suffered at the hands of my family and society. Because of my experiences, I want to raise awareness of leprosy-related disability, the importance of self-care, and also of the networks and resources that are available. Helping to prevent impairment and disability will lead to a reduction in the stigma attached to leprosy within our community.

What are your plans for the future?

To the end of my life, I will fight against leprosy, disability and stigma and help the lives of people through promoting self-care and knowledge about leprosy. Working on behalf of people affected by leprosy, the disabled, the poor, untouchables, widows and vulnerable people gives me happiness and satisfaction. ■

FOOTNOTE

* Lalgadh Leprosy Services Centre is run by the Nepal Leprosy Trust. It is a major leprosy services center in southeast Nepal.

Successful Renovation

A housing project with a happy ending — and some lessons learned.

The plan was to renovate 85 homes for people affected by leprosy in a colony in Durgapur, an industrial city in India's West Bengal state. But the plan hit a snag and the project had to be scaled back. Instead of work on 85 houses that had been budgeted for by the Gandhi Memorial Leprosy Foundation (GMLF) with support from Sasakawa Memorial Health Foundation (SMHF), only 60 could be repaired.

But following a visit to the mayor by a delegation that included colony residents, the city granted 500,000 rupees to cover the remaining renovations. Sudhakar Bandyopadhyay of the German Leprosy and TB Relief Association (India), who played a key role in the project, explains what transpired.

Why did the original budget come up short?

The foundations of the houses at Durgapur Colony were very weak. Continuous heavy rain had caused severe damage. The allocated funds were found to be inadequate. In consultation with the colony committee, it was decided to repair 60 houses on a priority basis and the remaining 25 houses when more funds became available.

How did the mayor become involved?

Since Durgapur is an industrial area, the municipal corporation is comparatively well off. It occurred to me that the mayor, Mr. Rathin Roy, might be able to help. I discussed the idea with the colony leaders Mr. Mukherjee, Mr. Bimal and Mr. Lalan. They knew the mayor to be a good and sympathetic person. They also mentioned local

city councilor and borough chairman, Mr. Shib Shankar Chatterjee. Through Mr. Chatterjee, I fixed an appointment with the mayor and led a delegation of about 10 persons from the colony, along with Mr. Chatterjee, to see him. The mayor gave us enough time, listened to what we had to say and announced that he was immediately allocating 500,000 rupees for repairs.



What arguments did you use?

We explained the housing situation and living conditions of the people and their sufferings. In particular, we emphasized the difficulties faced by the elderly, the disabled and the blind, especially in the heavy rain. We raised the possibility of the houses collapsing and the casualties that might occur. We also noted the economic circumstances of the colony residents and the responsibility of the city to look out for their welfare as part of good governance.

Why do you think the mayor agreed?

I think it was a combination of the above points together with one more. I explained that friends from Japan had extended support for 60 houses and said I hoped that the mayor would kindly provide support for the rest. I think that made an impression and he felt it would be appropriate.

What are the lessons learned?

To generate the necessary political and administrative will to ensure receiving the desired support, it is important that the facilitator and the people in need make a proper presentation of the facts. ■

REBUILDING HOMES, REBUILDING LIVES

The Baba Christo Das Leprosy Colony was established in Bihar, India, many years ago. It gradually fell into disrepair in the absence of regular maintenance work. Leaking roofs, cracked walls, lack of proper drainage and difficult-to-use toilets made life miserable for residents.

Bihar Kustha Kalayan Mahasangha (BKMM), an organization of people affected by leprosy, drew up an initial budget estimate for renovating the colony. Subsequently, it enlisted the help of Vanvasi Seva Kendra (VSK),

a voluntary organization involved in developmental activities. VSK commissioned a survey by a civil engineer. Based on his findings, VSK drew up a revised budget, which it submitted with a funding proposal to SMHF in Japan. SMHF arranged for the necessary monies to be contributed by a motor boat racing charity in Japan.

Renovation work began in October 2010 under the technical supervision of a civil engineer and with the participation of colony

residents. Work was completed in January 2011 and the results go beyond comfortable, hygienic accommodation and better drainage.

Thanks to this project, the local Lions Club started a primary school within the colony and a retired medical doctor now visits regularly to provide free check-ups. Residents have formed a self-help group and the local community has been inspired to collect donations for the colony's maintenance and to support the livelihood activities of its residents.

Remembering Dr. Yang Lihe

Founder of HANDA dedicated his life to people affected by leprosy in China.



Dr. Yang Lihe
(1928 - 2011)

Dr. Yang Lihe, founder and honorary president of HANDA Rehabilitation & Welfare Association, died at his home in Guangzhou, China, on 2 August 2011. He was 82.

Born on 13 August 1928, Dr. Yang was raised in a poor family in Jiangxi province in southeast China. When he grew to realize how many people in China were poor and sick, he decided to devote his life to helping them. He enrolled in Dalian Medical University and graduated as a medical doctor.

He learned about leprosy from Dr. George Hatem (also known as Ma Haide), who worked as a doctor and public health official in China from 1933 until his death in 1989. From what he learned, Dr. Yang decided to make defeating leprosy in China and changing the lives of people affected by the disease his goal in life.

He spent more than 50 years fighting leprosy and was one of the main contributors to leprosy control in China. But he knew this was not the end of his task. People still faced great challenges, even after they were cured.

After participating in the founding meeting of IDEA International, Dr. Yang resolved to establish an organization for people affected by leprosy in China. With support from his family, Dr. Yang, by now retired, used his home as its first office. He covered expenses out of his small pension. After two years of struggle, he was finally able to see the founding of the HANDA Rehabilitation & Welfare Association on 19 August 1996.

To fight against stigma, exclusion and injustice, Dr. Yang proposed carrying out projects

for comprehensive leprosy rehabilitation — physical, social and economic. Thanks to his great leadership and inspiring spirit, HANDA has become one of China’s leading NGOs and has made an enormous difference to the lives of people affected by leprosy in China.

He was one of the main contributors to leprosy control in China.

Dr. Yang enjoyed a long and successful career and was the recipient of numerous official awards. As part of a team of leprosy specialists, he traveled all over the country to see and treat leprosy patients, regardless of how the hot weather or how steep the mountain roads. He regarded people affected by leprosy as members of his own family. His example not only changed the attitude of medical staff but also warmed the hearts of people affected by leprosy. “If you can bring the world happiness and love, and help people escape suffering, that is meaningful,” he said.

Dr. Yang has left us, but his enthusiastic spirit to “pursue the truth and dedicate love” — which have become the core values of HANDA — will live forever.

He is survived by his wife, two children and two grandchildren — as well as by thousands of HANDA members. (Dr. Michael Chen, Secretary General, HANDA) ■

Do you have a leprosy wish list? Please write in and let us know: smhf_an@tnfb.jp

LEPROSY WISH LIST

Dr. Marcos Virmond
President
International Leprosy Association

A NON-TERANOGENIC THALIDOMIDE.

This dreaded drug is a marvellous choice for treating Type 2 leprosy reactions. However, its strong potential to cause deformity in babies makes it a stigmatized drug.

AN EFFECTIVE IMMUNOMODULATOR TO TREAT TYPE 1 AND TYPE 2 LEPROSY REACTIONS.

Leprosy without reaction would be almost a harmless disease.

A POTENT NERVE FIBER REGENERATION INDUCER THROUGH FIBROTIC TISSUE.

Nerves in leprosy retain their potential to regenerate. The problem is to make a path through intense fibrotic areas to reach the end organs (muscle or skin).

A SIMPLE SERUM TEST TO DETECT APPROCHING TYPE 1 AND TYPE 2 LEPROSY REACTIONS.

If you could predict a leprosy reaction ahead of its onset, it would be easier to treat it and prevent deformities.

AN END TO LEPROSY STIGMA.

Stigma is a top reason for delayed diagnosis, maintenance of the infectious chain and onset of disabilities and deformities. I would like to see the elimination of the stigma associated with the disease.

On-the-Ground Realities

The Goodwill Ambassador sees at first hand the difficulties for leprosy control in two African countries.

MALAWI (JULY 13-16)

When I met Malawi's health minister, Dr. David Mphande, in Geneva in May, he told me the country's leprosy control program faced a number of challenges. Many of these can be traced to a shortage of funds, equipment and personnel, which makes monitoring and supervision of the program difficult. Therefore, I traveled to Malawi to help raise awareness of the disease among political leaders and the public.

Malawi, which reported 321 new cases of leprosy in 2010, achieved the WHO's target of eliminating leprosy as a public health problem in 1994. It has maintained a prevalence rate of less than 1 case per 10,000 population since then. However, case numbers at the national level and in some districts have been fluctuating, and four out of its 26 districts have yet to achieve elimination.

During my stay I traveled to Balaka district, about 230 kilometers southeast of the capital Lilongwe. My destination was Utale 2 village, a community of people affected by leprosy. Its origins trace back to 1946, when missionaries established a leprosy sanatorium there. At one time there were five such facilities in the country; now there is only this one, which serves as a health clinic and rehabilitation center.

When I visited, there were 34 persons affected by leprosy living in the rehabilitation center, and 43 more living nearby. They are



Talking with members of the Utale 2 community in Balaka district.

cared for by Father Francis Kachere, who with the support of the Catholic Church looks after their essential needs. The younger people I met showed few signs of disability, but that was not true of the older generation. Among the latter was a lady who told me she had fled from the civil war in Mozambique after being abandoned by her family. With nowhere else to turn, Utale 2 had become her home.

At a joint press conference with the health minister, I said I was visiting because of my concern that leprosy was being neglected. I asked the media to dispel outdated images of the disease and stress that it is curable. Dr. Mphande said he would like bring the number of new cases down to zero. He wanted to strengthen the leprosy program and scale up its capability, emphasizing early diagnosis and treatment. There is work to do.

CENTRAL AFRICAN REPUBLIC (JULY 17-21)

The Central African Republic is another country that has achieved the WHO's interim goal of eliminating leprosy as a public health problem, but where the prevalence rate of the disease is showing a tendency to rise. Given the strains on the health care system imposed by civil war, poverty and other factors over the years, perhaps this should come as no surprise.

In 2010, the Central African Republic reported 235 new cases of leprosy. The prevalence rate of the disease is 0.52 per 10,000 people. Four of

the country's prefectures have yet to achieve elimination — Ombella-M'Poko and Lobaye to the southwest of the capital, and Vakaga and Haute-Kotto to the northeast. FAIRMED, a Swiss-based NGO, plays an important role in supporting the national leprosy program.

Health Minister Jean Michel Mandababa, 41, is enthusiastic and determined. He accompanied me on a field visit to Kaka village in Lobaye Prefecture. The area is home to pygmies, who lead a semi-nomadic existence in the surrounding forests. There are quite a few cases of leprosy among them.



Prime Minister Touadera



Health Minister Mandabada



Pygmies in Lobaye Prefecture. They face many challenges from leprosy.

When I arrived, young and old alike welcomed me with dancing. I met about 50 people affected by leprosy. Many appeared to have disabilities, but few seemed to be taking care of their wounds or injuries. Belgian nuns who began providing medical services to this village about one year ago said that when they first arrived, they were shocked at the conditions they found.

I don't think I have seen a health center without MDT before.

One man I spoke with told me of his sadness at contracting leprosy and how his spirits worsened as disability set in. He requested appropriate footwear. There was certainly a need for it, to prevent further disability, even though it is customary for people to move around barefoot. Life for these people looked very hard indeed.

In the capital, Bangui, I was able to have a number of meetings with key officials to discuss leprosy, including Prime Minister Faustin Archange Touadera, the speaker of parliament, and the social affairs minister. All took a genuine interest in my mission and expressed a desire to tackle issues related to leprosy in their country.

I also visited the offices of the UN and exchanged opinions with Margaret Aderinsola Vogt, a human rights expert. She mentioned the place of sorcery in the Central African Republic and various human rights issues the country was grappling with. People

with leprosy and those with disabilities, for example, are thought to be cursed. In some cases, they have been killed as a result. Having seen media coverage of my visit, she said that images of me mingling with people affected by leprosy would have an impact on helping to reduce stigma.

During my stay I visited a health center in Darama district, about 24 km from the capital. It also serves as one of five leprosy clinics in the country. There were said to be eight outpatients under treatment. However, there appeared to be no MDT and patient records were incomplete as a result of staff fleeing because of civil unrest. I don't think I have seen a health center before without MDT. It seemed to symbolize how this country's health program has become sidelined.

On my last evening I attended a reception at which the prime minister and most of the Cabinet, together with representatives of international organizations, were present. The government presented me with an award for my leprosy work. However, I like to think of it as an award for everyone involved in this effort.

Images of people with disability unchecked and a health center with no MDT denoted for me the fact that health services are not reaching the people and places they need to. At the same time, I was gratified to meet so many of the country's leaders and encouraged to hear their desire to tackle leprosy-related issues. I hope that my visit will prove the catalyst for closer cooperation between the WHO and the health ministry and that the government will press ahead with reducing the prevalence of the disease in the four prefectures where it is endemic. Where there is a will, there is as way. ■

Program Managers Meet in Myanmar

Dr. Samlee cautions against complacency, calls for maintaining awareness.

National leprosy program managers of the WHO's Southeast Asia region met in July in Yangon, Myanmar. In an opening address, Dr. Samlee Plianbangchang, the WHO regional director, acknowledged the successes that had been made against leprosy in the region, but warned against complacency. "We should not be the victims of our own success story," he said, alluding to the region's achievement at eliminating leprosy as a public health problem.

He called for ensuring basic awareness of

leprosy among the population and sustaining the skills of peripheral health workers, since detecting cases early and referring them for prompt treatment can help prevent physical deformity. "Early diagnosis and prompt treatment can significantly contribute to reduce stigma and discrimination," he said, "and the achievement will help facilitate the integration of leprosy services into the general health services."

During 2010, the WHO Southeast Asia Region detected 67% of total new cases of leprosy globally.

LEPROSY IN INDIA

The Technical Resource Group of India's National Leprosy Eradication Program is due to hold a meeting on 18 August 2011 to announce the results of a national sample survey on leprosy commissioned by the Indian Parliament. The survey has been undertaken to give a clearer picture

of the challenges India faces.

The results are expected to highlight the difficult situation in certain parts of the country some six years after India declared it had eliminated leprosy as a public health problem at the end of 2005.

SCIENCE AND DIGNITY



Published by Tokai University Press in Japan in January 2011, *Leprosy: Science working towards dignity* is intended as a definitive summary of scientific knowledge about leprosy. Based on a book first published in Japanese in 1997 and revised in

2007, *Leprosy* includes contributions from overseas experts and is aimed at doctors, researchers and students of the disease.

Edited by Masano Makino, Masnori Matsuoka, Masamichi Goto and Kentaro Hatano, it is a technical work published in the hope that its explication of leprosy will help to hasten the end of prejudice and discrimination toward the disease. ■

FROM THE EDITORS

TWO QUESTIONS

On the Goodwill Ambassador's recent visit to Malawi, a reporter asked why leprosy is still a problem when the drugs to treat it are available free. It's a question that raises some pertinent issues.

The drugs may be free, but they need to reach clinics and health posts where patients can have access to them. Health workers must be able to recognize the disease and initiate the appropriate treatment. Patients placed on MDT need to adhere to their treatment and complete the 6- or 12-month regimen for the cure to be effective. People must be able to come forward for diagnosis and treatment without fear of discrimination because of the stigma leprosy

still attracts in many communities. These are matters that go beyond whether the drugs are free or not.

At a separate press conference, a journalist asked if there were plans to build more rehabilitation centers in Malawi like the one at Utale 2. In reply, the national leprosy program manager explained that Utale 2 was for people with severe disabilities. The program does not intend to wait around for people to become disabled but diagnose them early and treat them promptly. Building more such facilities is not the answer; the answer is ensuring that people are treated and cured and continue to live in the community.

FOR THE ELIMINATION OF LEPROSY

Publisher

Yohei Sasakawa

Executive Editor

Tatsuya Tanami

Editor

Jonathan Lloyd-Owen

Associate Editor

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/