WHO GOODWILL AMBASSADOR'S NEWSLETTER
FOR THE Elimination OF Leprosy
April 2014 • Number 67

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

The Dalai Lama greets a resident of Kasturba Gram Colony in the Tahirpur Leprosy Complex in New Delhi on March 20.

MESSAGE

Looking to Religious Leaders

On March 20, His Holiness the 14th Dalai Lama paid a visit to the Tahirpur Leprosy Complex in India's capital, New Delhi.

Clasping the hands of those who have endured physical and social suffering as a result of leprosy, His Holiness offered words of comfort and encouragement. "Never give up hope in the face of physical obstacles. Everybody has an equal right to happiness. What is most important is to have self-confidence." There was no doubting that all were heartened by his message. As one who has spent many years working for people affected by leprosy, I was filled with gratitude.

By appealing to our inner selves, religion has the power to bring about social change. On my travels to different countries for leprosy elimination and other humanitarian causes, I have felt the influence that religion has on society. In meeting with many spiritual leaders over the years, I have observed the important role they play in a country or region.

In addition to giving encouragement to people affected by leprosy suffering from stigma and discrimination, religious figures can also change society's perceptions of the disease.

That's why, in 2009, I invited religious leaders representing the world's leading faiths — including Christianity, Islam, Buddhism and Judaism — to endorse my annual Global Appeal for an end to stigma and discrimination against people affected by leprosy.

It will be heartening if all religious leaders encourage people affected by leprosy and their families, just as the Dalai Lama has done by his recent colony visit. Furthermore, if these same leaders could clear up misunderstandings about leprosy in their talks at churches, temples and other places of worship, this would undoubtedly change perceptions about the disease. Should this happen, the walls of discrimination would slowly but surely crumble from both sides.

As I look at the role that religious leaders can play, I would like to call on them to be doing even more.

— *Yohei Sasakawa*, WHO Goodwill Ambassador

CONTENTS

Working for a Living

Livelihood projects in Indian colonies recognized with “Rising to Dignity” Awards.

Members of the successful pig-rearing project (left); harvesting crops (right)

Sasakawa-India Leprosy Foundation used the occasion of India’s Anti-Leprosy Day earlier this year to hand out its fourth annual “Rising to Dignity” Awards at an event in New Delhi. SILF currently supports livelihood projects at self-settled leprosy colonies in 17 states across India, helping to provide colony residents with an alternative to begging. This year’s winners are from colonies in Chhattisgarh, Tamil Nadu and Madhya Pradesh.

PIG-REARING

Chosen as the best enterprise was a pig-rearing operation run by a group of women from Champa in Chhattisgarh. Prior to starting this enterprise the women were dependent on begging and casual labor for their living. Today the project is very successful, resulting not only in increased household income but also making the women more confident and able to deal with outsiders — something they were not able to do before.

At their own initiative they started a self-help group, initially contributing Rs 10 each. With improved earnings this contribution has increased, enabling them to start giving loans to members to meet their contingency financial needs for marriages, deaths, illnesses and their children’s education.

Breeding pigs — and self-confidence too.

Next to be recognized was a group from the New Life Welfare Association, a colony in Tamil Nadu, whose members gave up begging to start a poultry farm. Despite initial setbacks, such as bird flu, within a year they had doubled the capacity of their business. Although most of them are middle aged, they have shown great enthusiasm for the project and have worked very hard for its success.

With success has come increased social acceptance, raising members’ self-esteem and self-confidence. This in turn motivates them to ensure the continued success of the enterprise.

CULTIVATING THE LAND

The third group from Alwasa, Madhya Pradesh, was led by a woman who persuaded colony members to cultivate land that had been allotted to them but was lying vacant for want of funds.

As most members of the colony were middle aged and unable to take on hard physical work due to the effects of leprosy, they decided to invite youths from other colonies to come and settle there. Members were motivated to persist, despite initial hardships such as crop failure and excessive rains.

Today each of the 15 members gets a daily wage. Gradually, they have also dispensed with relying on hired labor for tilling and harvesting, hiring machines instead. They do their own marketing and sell their produce after keeping what they need for themselves. ■

Realize the Potential of the People

If we want sustainable leprosy services, there's a solution staring us in the face.

AUTHOR:
Kay Yamaguchi

Kay Yamaguchi is an advisor of Sasakawa Memorial Health Foundation.

Some years ago I remember Mr. Sasakawa saying that leprosy is different from other diseases because health workers have to go out and search for patients. He was thinking of the stigma attached to leprosy that makes it difficult for those who suspect they have the disease to come forward for treatment.

We need to keep this in mind today as partners gear up their efforts — perhaps for the last time — to seek a leprosy-free world, following commitments made at last July's International Leprosy Summit in Bangkok.

Over the years I have met many people and families impacted by this disease. Some have succumbed to their fate and its socio-economic consequences, but others have resisted. I have watched the growing activism of people affected by leprosy. I have also noted how, once "awakened", they pay close attention to the wellbeing of their family members as well as their own physical care.

Showing me her fingers, Mrs. Hla hla of Myanmar once told me:"I suffered a lot because of these. I don't want my daughter or other young people to end up like me. That's why I am not afraid to speak openly and say, 'Leprosy is curable. Seek treatment without delay.'"

In Tampoi settlement, southern Malaysia, I met a father of two who made a living helping an elderly lady left severely disabled by leprosy. His hands and feet bore witness to his own struggle with the disease. When his daughter was one year old, he had noticed a white spot on her hand. Suspecting leprosy, he took her to a clinic, but it was a false alarm. Several years later, he saw another patch on her body: this time there was no mistake. His daughter was put on treatment but continued going to school as usual.

People affected by leprosy are well placed to recognize the disease in others and the need for prompt treatment.

A WAY FORWARD

I wonder if we have sufficiently appreciated the fact that people affected by leprosy do not want others to undergo the sufferings they themselves have experienced. If we are to reduce the burden of leprosy further, then we must take advantage of this sentiment and encourage it. Individuals and families affected by leprosy need to be invited to take ownership of the diagnosis and the treatment, since they are the ones who benefit most.

Recalling Mr. Sasakawa's comment, it is not feasible today to expect that governments will be able to send out health workers indefinitely to search for every new case. I believe it is those with personal experience of leprosy, their families, and the groups they form, who could play this role.

> We can't expect governments to send health workers looking for every new case indefinitely.

Since the 1980s, some 16 million people have been treated with multidrug therapy. If we include their family members, we are talking of tens of millions of people who have been impacted by leprosy. Empowering just 1 percent of them to look out for their families and neighbors would boost our capabilities tremendously.

Of course, empowerment derives from diverse factors, including the existence of local support groups and associations, and individual attainment of social and economic status. But it also comes from raising people's "leprosy literacy" through various tools, measures and opportunities.

To encourage the greater involvement of people affected by leprosy, Sasakawa Memorial Health Foundation, in collaboration with the International Federation of Anti-Leprosy Associations' Temporary Expert Group, plans to compile successful examples showing how strengthening participation of persons affected by leprosy and their families, or SPP, can have a positive effect on various aspects of leprosy services.

I am not opposed to the idea of having health workers examine household contacts of confirmed cases, nor do I dispute the possibility that preventive treatments may have a positive — if not lifelong — effect. I believe, however, that what is more sustainable over the long-term is empowering families and local communities to recognize the disease and act on that knowledge.

Leprosy has shown it cannot be wiped out in a single campaign. The key to fighting the disease is sustainability of quality leprosy services.

Let us believe in the great potential of the people and groups impacted by leprosy. They should be thought of as a wonderful asset. Surely they underpin the solution to achieving a world free from leprosy and its consequences. ■

Who Do I Tell?

Mathias Duck relates how he came to terms with a diagnosis of leprosy.

In January 2010 I started working as a pastor/chaplain at a leprosy reference hospital. I learned a lot about leprosy. My co-workers explained and taught me many things: leprosy is a relatively simple disease, but also a complex problem.

Although many people believe that it will cause a person's limbs to fall off, leprosy actually manifests itself by patches on the skin with loss of sensitivity. While science says that 95% of people are immune to it, people respond with outrage, shock and fear to someone with the disease.

The WHO distributes effective drugs against leprosy and, once treatment begins, the patient is no longer infectious. Nevertheless, even after completing treatment, people affected by leprosy still have to face rejection, discrimination and stigmatization. Although there can be serious physical consequences for people affected by leprosy (especially those not diagnosed and treated in a timely fashion), the social consequences are often the most devastating.

WHAT IF?

If I had leprosy, I asked myself, whom would I tell, given that most people have horrific notions about the disease. The advice we gave to people affected by leprosy was to share their diagnosis only with those who were going to support them. Some patients told us that none of their family, friends, relatives or neighbors knew that they had the disease. It was their secret and sharing it could mean that they would be rejected, discriminated against and in some cases abandoned by family and friends.

In many cases, religion has perpetuated the stigma of leprosy, mostly because some sacred texts are misinterpreted. At the hospital, we tried to follow the example of Jesus, who touched, healed and empowered people on the margins.

In October 2010 I felt that two fingers of my right hand were asleep. It also felt like the skin was shrinking and I felt slight discomfort stretching those fingers. This continued for two weeks. I knew this could be a symptom of leprosy, though not very common, and I wanted to know the truth. If it was leprosy, I would have to face it.

A church service at the Hospital Mennonita Km 81

I went to the doctors at our hospital. They examined me and found that the ulnar nerve was swollen in my right elbow. They explained that, in their experience, this was related to leprosy. My body had detected leprosy bacilli in the nerve and attacked it. I was put on a six-month course of MDT and a six-week course of corticosteroid treatment.

> I felt that people would judge me and treat me differently if I told them.

The leprosy diagnosis caught me off guard. I did not know whom to tell or how. One of my colleagues told me (I suspect it was intended as comfort) that he was convinced I did not have "that". The medical staff handled my case very professionally. I shared the diagnosis with my wife and my parents and they supported me.

I wanted to share it with more people, with friends and relatives, but I felt that this was a hard thing to do. I felt that I would expose myself and that people would judge me and treat me differently.

FEARS UNFOUNDED

In retrospect, I can say that my fears were unfounded, as I have not perceived that anyone has treated me differently, knowing that I had leprosy. I consider myself fortunate in this regard, compared with most people affected by leprosy that I know. Also, I consider myself lucky that I was working in the right place when the symptoms began and that I suffered no lasting physical consequences.

We always say that leprosy is a normal disease, just like any other. Therefore I felt that I should live the speech and talk about my leprosy just as other people talk about their diabetes or high blood pressure. I must admit that it took me quite a while to get to this point, however.

This experience has helped and enriched my work. I can support patients more empathically and focus efforts to combat stigma and discrimination. I am inspired by Jesus's example and his mandate to "cleanse lepers" (Matthew 10:8). This implies working for the integral wellbeing (physical, emotional, spiritual, economic and social) of all people who are marginalized by society.* ■

AUTHOR:
Mathias Duck
Mathias Duck is a pastor/chaplain at Hospital Mennonita Km 81 in Paraguay. The original version of this article was posted on the author's blog in January.

FOOTNOTE

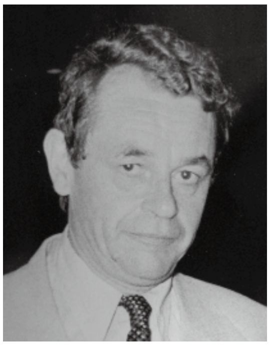
* A practical step you can take to combat discrimination and stigma is to watch your language. The word "leper" is derogatory and discriminatory. No one wants to be labeled only by the illness or condition he or she has. Please note that I use the term leper, only in order to refer to the stigma, but never referring to a particular person.

Remembering Professor Lechat

Dr. Yo Yuasa recalls friend and fellow leprosy worker Professor Michel F. Lechat.

It is sad to note the recent passing of one of the most active and greatest contributors to global leprosy work at the age of 86. When I visited Professor Michel Lechat for the last time in September 2013 in Belgium, accompanied by Dr. S.K. Noordeen, he was immobile and unable to talk, although Mrs. Lechat assured us he was happy to see us.

My first contact with Professor Lechat was in November 1958 at the 7th International Congress on Leprology in Tokyo. He had traveled from the Belgian Congo, where Dr F. Hemerijckx was his mentor and where he worked at the Iyonda Leprosarium. The novelist Graham Greene would write "A Burnt-Out Case" after visiting him there.


Professor Lechat in Tokyo, 1975

Subsequently he gained his doctorate in public health from Johns Hopkins University in Baltimore and later became professor of epidemiology at Catholic University of Louvain's School of Medicine, outside Brussels.

He was a regular member of the WHO's Expert Committee on Leprosy, which he chaired. He also chaired the 1981 meeting of the Chemotherapy Study Group, when the decision was taken to recommend multidrug therapy (MDT) to treat leprosy. More than 30 years later, MDT remains the main tool of leprosy control.

Following the establishment of the Sasakawa Memorial Health Foundation (SMHF) in 1974, he attended the 2nd Seminar on Leprosy Control Cooperation in Asia organized by SMHF in 1975. From that point on, Professor Lechat, together with Dr. Stanley Browne ("Mr. Leprosy"), became an enthusiastic supporter of the foundation.

I became the medical director of SMHF in 1975 and Professor Lechat was to assist me in so many ways — not least at the meetings of the International Federation of Anti-Leprosy Association's Medical Commission, which in those days were conducted in French and not English.

Michel and I became very close friends as well as effective co-workers, traveling together in many leprosy-endemic countries. He enjoyed coming to Tokyo, eating *nigiri-zushi* at Tsukiji fish market and browsing through the second-hand bookshops in the city's Jimbocho district. On one visit he was accompanied by his wife Edith. In Kyoto, they stayed in a Japanese ryokan and toured the city on bicycles.

In spite of his considerable size and loud voice, Michel was a very sensitive, even insecure person. Whenever I was at a conference with him, he would invariably ask me, "How was my presentation?" Needless to say, it was always of the highest order.

Although it is sad to realize that this great leprosy worker is no longer with us, we must be very thankful to Heaven that he was among us when we set out to eliminate leprosy as a public health problem.

Dr. S.K. Noordeen adds: Professor Lechat, with whom I had interacted for over 30 years, played a key role as advisor to the WHO in the development and evolution of WHO policies and strategies in leprosy. His passion for leprosy work, both at the academic and field levels, was unparalleled.

MUSEUM PIECE

FATHER VARIARA'S TRUMPET

In 1894, a 19-year-old Italian missionary arrived at Agua de Dios, a leprosy colony in Colombia. Ordained four years later, Father Luis Variara devoted himself to making Agua de Dios a better place for its inmates, especially its children. In the words of Jaime Molina Garzón, who runs the NGO Corsohansen, Father Variara became one of Agua de Dios's best loved and most memorable characters, offering tremendous support to people whom the government had confined to the colony because of their disease.

The young missionary had a passion for music and one of the first things he did was to start an orchestra. He endeared himself to everyone when he picked up a trumpet used by the patients and put it to his lips, not bothering to wipe the mouthpiece.

The trumpet he used, pictured here, is on display at the convent of the Order of the Daughters of the Sacred Hearts of Jesus and Mary. This was the order that Father Variara founded in Agua de Dios in May 1905 to enable women with leprosy, and the daughters of parents with leprosy, to consecrate their lives to God. The order is active today in a number of countries and is dedicated to the service of the sick and poor.

Father Variara died in 1923. For his service to the suffering of Agua de Dios, he was beatified by Pope John Paul II in 2002.

In Delhi with the Dalai Lama

The Goodwill Ambassador makes a memorable visit to India and returns to Nepal for the first time since 2010.

INDIA (MARCH 18-21)

This was my 50th visit to India, the country that holds the key to reducing the overall burden of leprosy in the world. It was appropriate, therefore, that it should be marked by a very special occasion: the visit by His Holiness the 14th Dalai Lama to a leprosy colony in New Delhi.

The origins of the visit go back to an audience I had with the Dalai Lama at his headquarters in Dharamsala, northern India, in August 2012. During our conversation, I invited him to accompany me to a leprosy colony one day. He readily agreed and I was delighted when he was eventually able to find time in his busy schedule.

Tahirpur in northeast Delhi is a complex of 27 leprosy colonies. Kasturba Gram Colony was selected as the venue for the Dalai Lama's visit on March 20. Some 500 people had gathered to see him and they were not disappointed.

His Holiness's message was unequivocal: "Seven billion human beings are all equal," he said. "People should not look down on others. It is totally wrong. Discrimination is a sin." These words were all the more powerful coming from the Dalai Lama, whose actions in shaking hands with and hugging members of his audience spoke volumes.

Among those present were leaders of the Association of People Affected by Leprosy (APAL), the nationwide network that connects India's 850 self-settled leprosy colonies. Later in the day I attended an APAL meeting, when representatives from 13 states reported on the progress they are making in gaining special pensions for people affected by leprosy. I was pleased to hear of instances where my previous visits to their states had helped to move negotiations forward and said I was prepared to visit as many times as needed to help the colony leaders achieve their goals.

Also attending the APAL meeting was Javed Abidi, the chairperson of Disabled People's International. I believe leprosy groups can learn much from disability leaders and I appreciate Mr. Abidi's efforts to raise the profile of leprosy within the disability movement.

While in New Delhi I called on India's new health secretary, Lov Verma, who was appointed in February. India accounts for over half of all new cases of leprosy in the world and recently decided to increase its budget for leprosy control. I look forward to cooperating closely with the health secretary and his colleagues in doing what I can to help India address the remaining challenges.

NEPAL (MARCH 21-25)

It had been four years since my last visit to Nepal, when I had attended a ceremony in 2010 to mark the country's attainment of the WHO's leprosy elimination target of a disease prevalence rate of below one case per 10,000 population.

Nepal continues to report around 3,500 new cases of leprosy each year. These are mostly found in the Terai plain in the south of the country, bordering India. It is no exaggeration to say that the effectiveness of Nepal's leprosy control program depends on the early detection and treatment of new cases in the Terai.

To reacquaint myself with the situation there, I flew from Kathmandu to Nepalgunj in Banke District in Nepal's Midwestern Development Region. Accompanying me was

A day to remember: sharing a stage with the Dalai Lama at Kasturba Gram

Meeting with self-help group members and health volunteers at Sainguan Village in Nepal's Banke District.

Chudamani Bhandari, director of the health ministry's Leprosy Control Division.

Our first stop was at Saingaun village to meet with a community of people affected by leprosy. This village of some 6,000 inhabitants consists of many low-caste, impoverished people. They include around 50 people affected by leprosy, together with their families.

Twenty-five people affected have formed a self-help group, led by 32-year-old Sahabir Ali Sain. They have started businesses with microloans they have received from the government.

I met with members of the self-help group as well as 18 Female Community Health Volunteers (FCHVs) in a small assembly hall. These volunteers are responsible for everything from maternal and child health to detecting communicable diseases. They perform a vital role in areas where government health services don't always reach.

Prem Kala Dangi

Next I traveled about two hours by road to neighboring Bardiya District, where I visited another community of people affected by leprosy living in Taratal village. The community is supported by International Nepal Fellowship (INF), an NGO established in 1952. At the time of my visit, 63 persons were under treatment with multidrug therapy.

In Taratal I met a community health volunteer who greatly impressed me. A person affected by leprosy, Prem Kala Dangi brimmed with self-confidence and purpose.

The following day, I went to see an INF-run clinic. It was established in 1960 with support from the German Leprosy and TB Relief Association. It serves as a leprosy treatment center for the Midwestern Development Region but also sees its share of patients from the neighboring Indian state of Uttar Pradesh. I also visited the government-run Bheri Zonal Hospital and met with personnel from the Banke District health authority, local NGOs and volunteers. Around 10 local media covered the event.

Returning to Kathmandu, I traveled to Nepal's only leprosy sanatorium. Khokana was established as a national sanatorium in 1857 by the king. Today, around 100 people affected by leprosy and their families live there. As Mr. Bhandari showed me around, I was interested to hear him say he wished to preserve some of the older buildings as a museum of leprosy history.

Afterward I attended a joint meeting with health ministry representatives, WHO officials, people affected by leprosy and NGOs. Health Secretary Dr. Praveen Mishra showed his commitment to leprosy control with a passionate speech.

People's organizations from all over the country had gathered. I was struck by the fact that some 30 percent of their leaders were women, such as Parwati Oli of IDEA Nepal. In India, the majority their counterparts tend to be men.

Also attending this gathering were representatives of disability groups. I understand there is growing participation by people affected by leprosy in the disability movement in Nepal and I welcome this development.

Before leaving Kathmandu I paid courtesy calls on both President Ram Baran Yadev and Prime Minister Sushil Koirala. Keeping a country focused on leprosy requires cooperation from people at every strata of society, from heads of state to the grassroots. Nepal still has much to do, and I hope it will not waver in its efforts to tackle the disease. ■

Uniting Against NTDs

Progress report highlights “new strategies, new drug, new dollars” for leprosy.

Against the backdrop of the WHO’s plan to control, eliminate or eradicate 17 neglected tropical diseases (NTDs) by 2020 announced in January 2012, a group of public and private partners are focusing their efforts on 10 of these diseases, including leprosy, that affect more than 1.4 billion people

Following the London Declaration of 2012, when the partners laid out their plans and launched an informal group called Uniting to Combat NTDs, momentum has been building toward achieving these goals. On April 2, the group issued an update, titled “Delivering on Promises and Driving Progress.”

Concerning leprosy, the report noted that disease transmission is still occurring at a fairly steady rate and that maintaining political interest and NGO support will be necessary to sustain and surpass current achievements. But it drew attention to new initiatives that are being developed — more intensive contract tracing and treating exposed family members with a single dose of rifampicin to reduce the spread of the disease — as well as work on new diagnostic tests and leprosy-specific vaccines. It also noted renewed commitments, both political and financial, made at the International Leprosy Summit in Bangkok last July and at the International Leprosy Congress in Brussels.

In a country profile, the success of Brazil’s school-based outreach strategy to screen 3.7 million children for leprosy and treat 2.9 million for soil-transmitted helminthes in 852 priority municipalities was highlighted.

LIN ZHI MING EXHIBITION

The National Hansen’s Disease Museum in Tokyo is hosting its first-ever exhibition by a foreign artist. Born in China in 1929, Lin Zhi Ming signs his work with the characters meaning “a boat in wind and rain.”

Diagnosed with leprosy at the age of 8, he spent his 20s in a sanatorium before being discharged at the age of 32. A self-taught artist and calligrapher, he survived for some years by selling his works on the street. In 1999 he published “No Misery in the World,” describing his own and others’ experiences as persons affected by leprosy. He is a founding member of the Handa Rehabilitation and Welfare Association, which he now represents as honorary chairman.

Even at 85, Lin is keen to improve his brushwork and has recently been perfecting his life-like depictions of shrimp — works that caught the eye of Goodwill Ambassador Sasakawa. Many of his pieces, however, are of peonies, China’s national flower. “The artist who paints a wonderful picture leaves behind beauty after he has gone,” he says. ■

FROM THE EDITORS

WORKING PARTNERS

Primary stakeholders. Main actors. Working partners. Key collaborators. Allies. Discussions about the status and role of people affected by leprosy in leprosy services continue. The central theme of WHO guidelines published in 2011 on this topic was recognition of the expertise of individuals who have had the disease and, through partnership, enabling them to support in the delivery of leprosy services.

Let us recall the words of the late leprologist Professor Michel Lechat, who died earlier this year and is remembered by his friend and colleague Dr. Yo Yuasa in this issue. It was at the 15th International Leprosy Congress in Beijing in 1998 that Professor Lechat noted the importance of involving people affected by leprosy. It was the first time people affected by the disease had participated fully in an ILA congress and he applauded the fact. “From being victims they have turned into working partners. In the years to come, their collaboration will be essential for ensuring the full success of our common endeavor toward a world without leprosy.” Facilitating this collaboration may not be simple, but it is essential.

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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: +81-3-6229-5388
smhf@tnfb.jp

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