From Manila to the World

Nepal’s peace process is making headway, with elections scheduled for June. With a return of law and order, a WHO-sponsored seminar last November held out the hope that eliminating leprosy as a public health problem within this year is a possibility. Along with the people of Nepal, I yearn for lasting peace in their country.

Elsewhere, I understand that Brazil is proceeding smoothly toward the elimination milestone. Meanwhile, when Mozambique’s President Guebuza visited Japan in January, I lobbied him to make further efforts for leprosy elimination, and promised that I would make my fourth visit to his country in May. I am also planning trips to Tanzania and the D.R. Congo.

The WHO, through its Regional Director for Africa Dr. Sambo, is working hard to help the remaining African countries move beyond elimination. For my part, I am prepared to go to Africa any number of times to ensure that they succeed. The day when every country on earth passes the elimination landmark will represent a major step toward a leprosy-free world.

In the meantime, we must also tackle the issue of discrimination, which continues to blight the lives of people affected by leprosy and their families. Last year, former US President Jimmy Carter, the Dalai Lama and other world leaders joined me in issuing a Global Appeal to end stigma and discrimination. That appeal has been translated into many languages and is displayed at venues all over the world.

At my initiative, a second Global Appeal was launched on January 29 in Manila. This time, my fellow signatories were people affected by leprosy who joined me in issuing a powerful call to end disease-based discrimination. I believe their involvement will have an enormous impact and I commend them for speaking out.

In the words of Global Appeal 2007 that I signed together with these courageous men and women: “Silence on this issue is not acceptable. We urge you to join us in the fight to end this social injustice.”

— Yohei Sasakawa, WHO Goodwill Ambassador

Some 300 people gathered at the Philippine International Convention Center in Manila on January 29 for a morning of speeches, songs and messages of endorsement for the Global Appeal 2007 to end stigma and discrimination against people affected by leprosy.

The appeal, signed by 16 people affected by leprosy from 13 countries together with WHO Goodwill Ambassador Yohei Sasakawa, follows a first Global Appeal launched a year earlier in New Delhi and endorsed by world leaders including former US President Jimmy Carter and the Dalai Lama.

As Goodwill Ambassador Sasakawa stood at her side, 11-year-old Ma. Kristina Sacdalan read out the manifesto, which includes the words: “Denying the inherent human rights of anyone on the basis of disease is indefensible. Discrimination can never be justified.” Ma. Kristina once had leprosy but was cured with multidrug therapy.

The appeal is designed to raise awareness of the discrimination still faced by people affected by leprosy and their families and the devastating consequences for those thus stigmatized.

“Leprosy is not like other diseases,” Sasakawa told the gathering. “People can be completely cured, yet society does not accept them. This is a result of misunderstandings about the disease and wrong knowledge. Society is at fault.” He went on to praise his co-signatories for confronting the discrimination they have faced and joining him in putting their names to the appeal.

Dr. P.K. Gopal, a leader of the National Forum of People Affected by Leprosy in India and president of IDEA International, who was one of several signatories present, said it was “a great day for all of us” and felt that Global Appeal 2007 was “even more important” than last year’s event given the presence of so many stakeholders and the involvement of leprosy-affected persons on an equal footing.

Karen S. Gomes-Dumpit, director of the National Commission on Human Rights of the Philippines, said the appeal would play an indispensable role in advocacy and policy-making. “People affected by leprosy do not ask for more rights, they only ask for equal rights,” she said.

“He are not asking for more rights, they are asking for equal rights.”

**NATIONAL FORUM**

The previous day, policy makers, partners and persons affected by leprosy came together for a one-day national forum to draft a Philippine Declaration in support of the Global Appeal.

Groups representing three different regions of the Philippines discussed their experiences relating to stigma and discrimination, formulated a consensus on the issues they wished to see addressed, and identified the interventions they wanted to pursue to reduce stigma and discrimination.

The forum also heard reports from affected persons from India, Indonesia and China on the situation in those countries and efforts at empowerment through networking.

Among the demands contained in the declaration are “access to all public establishments and facilities and equal opportunities to utilize services necessary to sustain the basic needs of life” and “to be treated and identified as normal individuals.”

Health Secretary Francisco Duque III presented a copy of the Philippine Declaration to Goodwill Ambassador Sasakawa at the Global Appeal 2007 launch ceremony the following day.

**PIONEERING ROLE**

Chosen by Sasakawa as the host country for the Global Appeal event, the Philippines has a long association with efforts to control leprosy. The country successfully piloted the use of multidrug therapy, eliminating the disease as a public health problem in 1998, and was once home to the world’s largest leprosy colony, Culion, which marked its transformation from an island of despair to an island of hope during its centennial celebrations in 2006.

Currently the Philippines sees around 3,000 new cases a year, and leprosy is a priority disease in the health ministry’s disease-free zone initiative.

“How we respond to leprosy tells us a lot about who we are and the society we now live in,” Health Secretary Duque said.
Not enough people affected by leprosy who would benefit from surgery are receiving it, said Dr. Tim Lewis, the Medical Superintendent of Anandaban Hospital in Nepal.

Speaking at a WHO seminar in Kathmandu last November, Dr. Lewis said that increased awareness of both the benefits and availability of surgery was necessary so as to increase the number of referrals. “When we do disability camps, the majority of patients we come across who are surgically correctible are not aware that surgery is an option,” he said.

Run by The Leprosy Mission International, Anandaban Hospital is the only medical facility in Nepal offering leprosy surgery on a regular basis. Of the 200-250 procedures performed at the hospital each year, about half are leprosy related.

Surgery in leprosy has three aims, Dr. Lewis said: to prevent disability, to improve function and to reduce stigma. “I sometimes get young female patients with minor clawing of the hand that doesn’t impair function. They tell me they don’t want people to know they have had leprosy, but they also want a straight hand for cosmetic purposes. This can help eliminate stigma and integrate them fully into society.”

The people who profit from surgery are those who are motivated to look after themselves, said Dr. Lewis. This is important because reconstructive surgery involves “vigorous pre- and post-operative physiotherapy, and unless the patient is going to cooperate with this regime, he is unlikely to gain much benefit.”

Patients also need a reasonable expectation about the outcome, he said. An operation will improve but not necessarily completely correct a condition, and will not address the underlying problem of nerve damage. Consequently, it will do nothing to restore sensation. “They will need lifelong self care and regular care of the foot or hand,” he said.

Surgery is not for everyone. Those unlikely to benefit are elderly patients with long-standing deformity, patients who have adapted well to deformity and those whose deformity is complicated, he said.

**NOT JUST SURGERY**

Disability management is far more than surgery, stressed Dr. Lewis. “Probably the most important department in our hospital for the prevention of disability is our footwear department and yet it tends to get a lot less recognition than our surgeons and physiotherapists.”

He said it was regrettable that he was still operating on patients in their twenties and even in their teens. “If you go into their history, you will find that they have taken a course of MDT and have developed disability during their treatment. This has not been recognized and now three or four years down the line they have come looking for surgery,” he said. “We have missed the boat and prevention is far better than what I am talking about today.”

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**ADVERTORIAL CONDEMNS YMCA**

Following last year’s refusal by the Delhi branch of the YMCA to allow delegates to a national forum of persons affected by leprosy to stay there (see Issue #23), the International Leprosy Union took out an advertorial in the *Indian Express* newspaper on January 18 criticizing the decision.

Titled “An Appeal to the Conscience of Society” and signed by ILU Chairman Dr. S.D. Gokhale, the advertorial described as “outrageous” the letter sent to conference organizers canceling the group booking and called it “an affront to not just the leprosy-affected people but to also the governments, the organizations and individuals working for the cause of leprosy.”

“This just shows how difficult it is to change the hard attitudes and mindsets of the community,” added the appeal, which also ran in a local-language Maharashtra state newspaper.

ILU, a non-governmental organization based in Pune, India, promotes the social, physical, financial and emotional rehabilitation of people affected by leprosy. “Let us work together to give them not just economic security, but empower them with their basic human rights which all of us, as human beings, are entitled to,” the appeal concluded.

After the advertorial appeared, Dr. Gokhale received a letter from Dr. S.C. Gupta, Joint Director, Health Services (Leprosy), Government of Maharashtra, which said that the state government was working to eliminate leprosy and raise awareness of health issues, and praised the advertorial’s “highly constructive” contribution.
Valley of Hope
The Sungai Buloh National Leprosy Control Centre
Phang Siew Sia, Wong Chau Yin
MCA Subang Division (May 2006)

In 1930, a lush valley 25 kilometers from Kuala Lumpur became the largest leprosy colony in the British Commonwealth. Sungai Buloh Settlement (later Leprosarium and now the National Leprosy Control Centre) would eventually be home to as many as 2,400 people affected by the disease. For almost four decades, through World War II and the birth of an independent Malaysia, the occupants lived in virtual isolation from the outside world. Managed by a medical superintendent and his staff, with its operations supported by the able-bodied among the residents, the leprosarium had its own rules and regulations, its own currency, school, places of worship, social clubs, fire brigade, police force and even a prison.

Over time, Sungai Buloh has been transformed. With the implementation of the national leprosy control program in 1969, the emergence of an effective cure for leprosy in the 1980s and the graying of the resident population, a way of life known only to a few is gradually being obliterated. For many outsiders, the name Sungai Buloh has become synonymous with flowers and plants rather than with leprosy, as commercial nurseries thrive there. A general hospital complex serving the surrounding area has also recently opened.

Valley of Hope sets out to record the story of the settlement while there are still those alive to tell the tale. Its enterprising authors (see below) make clear that this is a story about the leprosarium and its people, not a disease, and their research is largely based on interviews with surviving residents. The book’s title is how Sungai Buloh was once known — as a place where people lived in hope of a cure.

Sungai Buloh was constructed in the wake of it’s a repository of stories of patients who have struggled to live through both the physical and psychological sufferings caused by leprosy. As such, it is a very important part of the history of leprosy in this country as well as the world.

What did you know about leprosy as a child?
I didn’t know much since my parents hardly told us anything about it and didn’t want us to talk about it in public. It wasn’t until I started to go to school that I realized how different the outside world was from the place that I grew up. Then I started to hear from classmates and teachers that leprosy was a dreadful disease and that patients were kept isolated for fear of infection. But I knew it wasn’t infectious as I used to hang around the leprosarium and never heard of any cases of healthy people or children getting the disease from another patient. I also knew it can cause

Co-author Joyce Wong describes how writing Valley of Hope enriched her life.

How did you become interested in Sungai Buloh?
I was born there and brought up nearby. My parents had been patients and moved out after my birth as they were not allowed to raise children within the compound. As I grew older, I came to understand more about the leprosarium and appreciate its unique story.

Why write a book?
I brought Siew Sia, my co-author, to the leprosarium in 2002 and briefed her on its past. She was fascinated by the beauty of the place and impressed by the history, and suggested we start a project to preserve its story. At first, we just planned to do a brief write-up and collect some photos. As we worked on, the materials as well as our sentimental attachment to the leprosarium grew and we decided to do a book.

How did you go about your research?
Since we could find very little documentation on the leprosarium’s history, most of our research was based on interviews with residents, ex-residents and their families, observing the daily routine and studying old photos. We had a lot of interaction with the residents. In fact, most of our weekends during the two years of our research were spent in Sungai Buloh.

What makes Sungai Buloh special?
Sungai Buloh is a one-of-a-kind place, probably in the whole world. Very seldom can we find such a well-organized, self-sufficient community that has been isolated from the outside world for several decades. The institutionalized lifestyle has had such a strong influence on the community’s culture and habits.
the 1926 Leper Enactment Act, which required the segregation and treatment of those with the disease. Given the dire conditions in existing facilities, the idea behind Sungai Buloh was to create a self-contained community where patients could live in humane surroundings while under medical supervision.

Brought together by a common disease, this community was “a melting pot of different races, cultures, backgrounds, histories, nationalities.” In fact, the population of the leprosarium was dominated by ethnic Chinese, who far outnumbered Malays and Indians, and in pre-independence days there was also a handful of Japanese, Eurasians and Gurkha soldiers under treatment.

In chapters covering everything from medical care and living arrangements to schooling and social clubs, the authors recount what life was like for young and old, single and married in Sungai Buloh. One of the central figures in the book is a lady they call Saw Cheng, whose life they follow from the time she was admitted as a girl of 14 to when she has become a woman of 82 with failing eyesight and a missing leg.

Through Saw Cheng, readers are introduced to the admissions procedure, the loneliness and dislocation experienced by new arrivals, the gradual adjustment to Sungai Buloh’s routine, the rigors of treatment with dapsone injections, annual tea parties and costume competitions, and the strength of spirit of the now mostly elderly residents. “I have served my time longer than any convict sentenced to life imprisonment,” Saw Cheng tells the authors with no apparent trace of rancor.

Today there are under 400 inhabitants of Sungai Buloh, ranging in age from their 40s to their 90s. Many are too old or infirm to live elsewhere. Every inch of spare land, it seems, is given over to cultivating flowers, trees and turf. Commercial gardening — a rehabilitation program suggested by a past medical superintendent — has become big business, and is attracting an influx of outsiders and immigrants.

Fearing that the unique history of Sungai Buloh was disappearing without a proper accounting of it, the authors set about their work. In writing this book, they have constructed an affectionate monument to the people who spent their lives there, even as the buildings they once lived in are slowly crumbling away.

Has the experience of writing this book changed you?
The most precious thing Siew Sia and I gained from writing Valley of Hope is our friendship with a group of elderly residents. Through them, we learned to count our blessings. By helping them out in small ways, such as making phone calls and writing letters, we experienced the joy of giving and how lucky it is to be the giver. In fact, we still visit them very often and take other friends with us. Personally, I found my life became much more meaningful during the three years spent on the research and writing, even though I had to sacrifice a lot of my time and energy. I look at life from a different perspective now. This project has also opened the door for me to explore more of myself and to embark on activities that are spiritually fulfilling. I think I can say the same for Siew Sia, too.

What should the legacy of Sungai Buloh be?
The story of its people. There is a lot to be learned from them. It still amazes me to see how strong some of the older residents are, how they are able to live independently in spite of their physical condition. Some of them are without hands and legs, some are blind. They have been deprived of the basics in life that we take for granted and yet they live their lives with dignity, without complaining.

But it’s sad to note how tremendously this place has changed. The older generation that is the “trademark” of Sungai Buloh is slowly fading away. There is an influx of outsiders. Some of them have created a lot of social problems. The older residents who are so defenseless are left at the mercy of these people. We hope that more care and attention can be given to these old folks.
Visits to Laos and Nepal

Calling at a leprosy village north of Vientiane; attending a conference in Kathmandu

**LAOS (NOVEMBER 23)**

On a recent visit to Laos, I had the opportunity to visit Ban Somsanouk, a village about 130 kilometers north of the capital, Vientiane. It is one of several villages in Laos where people affected by leprosy live, but the only one where they are drawn from different ethnic groups. Ban Somsanouk has a population of 1,136. Of these, 165 are affected persons, of whom 109 have disabilities.

While I got the impression that the affected persons live among the rest of the villagers, I understand the community is not entirely free from stigma. From what I was told, some people still think that leprosy is divine retribution and that the disease originates from within. Also, many of the leprosy-affected persons are severely disabled, and clearly at a disadvantage compared to their able-bodied neighbors.

When I arrived, people turned out to give me a warm welcome. I told them that leprosy is curable, it is not God’s punishment and that discrimination is fundamentally wrong. I also urged them to spread correct knowledge about the disease. Leprosy may no longer be a public health problem in Laos, but from a human rights perspective, it is clear that more needs to be done.

**NEPAL (NOVEMBER 26-DECEMBER 2)**

My visit to Nepal took place against the backdrop of momentous political developments following the signing of a peace accord between the government and Maoist rebels signaling an end to a decade of conflict. Not unrelated, perhaps, Nepal is one of five major countries that have yet to pass the WHO’s elimination milestone of reducing prevalence of leprosy to less than 1 case per 10,000 population at the national level.

At present, PR stands at 1.65 and officials estimate that elimination could be achieved this year. One of my reasons for visiting at this time was to attend a WHO regional seminar on leprosy elimination designed to review progress and encourage greater efforts.

The day before, I traveled south of the capital to Anandaban Leprosy Hospital. Founded in 1957 by The Leprosy Mission International, it is the biggest leprosy hospital in the country and the main leprosy referral hospital for Nepal’s Central Development Region. Over the years, the hospital has helped thousands of people affected by leprosy and more recently has also been providing primary health care services to the local community as the number of leprosy cases lessens.

The hospital’s reputation for treating people with leprosy extends far and wide, and patients come from India, Tibet and Bhutan, as well as from Nepal. Sometimes they are referred to Anandaban at the border. On the day I visited, there were 69 leprosy in-patients, 9 general patients and 4 children or relatives accompanying the in-patients.

Through offering outpatient services and operating a general ward, Anandaban Hospital is also helping to lessen stigma. Over time, it seems, the surrounding population is coming to see leprosy as just another disease.

Another reason for visiting Anandaban was to attend the opening ceremony of the IDEA Nepal 4th General Assembly, which was being held in a packed meeting hall in the hospital grounds.

IDEA, which stands for Integration, Dignity and Economic Advancement, has chapters in many countries, and is a self-help organization working for the social empowerment of people affected by leprosy. Dr. P.K. Gopal, the president of IDEA...
International, recalled how he had been present a few years earlier when IDEA Nepal was established. “There were just a handful of leprosy-affected persons and some medical staff. What a change!” he said.

For my part, I told the assembled audience that there are two approaches to dealing with the issue of stigma and discrimination — a top-down approach and a bottom-up one. The top-down approach involves initiatives such as issuing last year’s Global Appeal signed by world dignitaries, and seeking to have the United Nations issue guidelines to member nations.

The bottom-up approach is a grass-roots effort. Some 135,000 people have been cured of leprosy in Nepal. I urged IDEA to encourage as many of them as possible to become members in order to mobilize support and help the organization grow. While self-help is the key, I also said there will be times when government assistance is required. For that partnership to be effective, the government must be fully informed about the situation of affected persons. Overall, I was very encouraged by what I saw and returned to Kathmandu with the feeling that IDEA Nepal is moving in the right direction.

Leprosy FACTS
Of Nepal’s 75 districts, 44 have a leprosy prevalence rate of less than 1 per 10,000 population.

Organized by the WHO’s South-East Asian Regional Office, the two-day seminar on leprosy elimination took stock of Nepal’s position and the challenges it faces. A major barrier remains the health consequences of poverty. Nonetheless, Nepal is making progress in reaching out to people with leprosy, and I hope this conference will spur it closer to the elimination milestone. Lending their support and experience were several representatives from India’s health ministry, and I understand they had productive discussions with their Nepali counterparts on how to deal more effectively with leprosy cases in their common border areas.

For the last part of my visit to Nepal, I flew to Pokhara, where Dr. Iain Craighead took me around Green Pastures Hospital and Rehabilitation Center, a well-run facility in a lovely location set up in 1957 by the International Nepal Fellowship, a Christian mission. INF focuses on health and development in the West and Mid-West regions of Nepal for poor and marginalized peoples. Leprosy is one of INF’s six core areas, among the others being TB and HIV/AIDS.

Green Pastures was established as a leprosy hospital, but with the improvement in leprosy control services and the introduction of MDT, patient numbers have fallen so it has broadened its scope to help people with all kinds of disabilities.

The hospital was once far from the town, but as Pokhara has expanded, Green Pastures is no longer the remote location it was, and this has helped to familiarize people with its work and reduce stigma toward those with the disease. In more remote areas, however, I understand that many still think of the disease as a curse and some people come directly to Green Pastures rather than to their local health center, because they don’t want people in their area to know that they have leprosy.

During my tour of the grounds I saw a safe-cooking class, visited a vocational training workshop where the emphasis is on making local products and includes three months in the local bazaar learning how to sell, and saw a training farm where patients learn how to grow food in a kitchen garden and raise animals including goats and rabbits. A total of 60 to 80 people train at the farm a year, usually in small groups.

Green Pastures aims to get patients back living with their own families in their own communities, and does not encourage people to live in the residential unit. The community rehabilitation program is extremely successful, Dr. Craighead told me, and there has not been a new admission to the residential unit for over 10 years.

While in Nepal, I had the opportunity to call on King Gyanendra at the royal palace. I explained my role as goodwill ambassador and my concerns about discrimination against people with the disease. I also called on Prime Minister Koirala and outlined my mission. Both expressed their support for the efforts being made to tackle leprosy and I am hopeful that we shall see further progress in due course.
Full Text of Global Appeal 2007

Issued in Manila, the Philippines on January 29, 2007

“Every person is born free and equal in dignity and human rights.” *

Many people think that leprosy no longer exists. But it does — and also the stigma and discrimination it causes.

Discrimination against persons affected by leprosy is one of the oldest and most pervasive examples of social injustice in the history of the human race.

Even today, millions of men, women and children continue to suffer social, economic and legal discrimination, simply because they or a family member have had leprosy.

Leprosy is curable disease. Yet misguided notions about leprosy persist, with devastating consequences for those thus stigmatized.

Denying the inherent human rights of anyone on the basis of disease is indefensible. Discrimination can never be justified.

Silence on this issue is not acceptable. We urge you to join us in the fight to end this social injustice.

Together, let us create a society in which every individual is free and equal in dignity and human rights.

SIGNATORIES

The appeal was signed by 16 people affected by leprosy from 13 countries, and by Goodwill Ambassador Yohei Sasakawa.

Present at the launch ceremony at the Philippine International Convention Center in Manila were Adi Yosep (Indonesia), Hilarion M. Guia (the Philippines), Sarat Kumar Dutta (India), P.K. Gopal (India), and Zhuo You (China).

The other signatories are Shehu Abdullah S/Fada (Nigeria), Birke Nigatu (Ethiopia), Cristiano Claudio Torres (Brazil), José Ramirez, Jr. (USA), Kof Nyarko (Ghana), Lak Kiri (Cambodia), Michihiro Koh (Japan), Natália Isabel da Graça Marçal (Angola), Nicole H. Holmes (USA), Parawati Oli (Nepal) and Vadenora da Cruz Rodrigues (Brazil).

The appeal can also be found online at the website listed on this page.

FROM THE EDITORS

POLITICAL AND PERSONAL

Dr. Antonio G.M. La Vina, the dean of the Ateneo School of Government, said it best. The global appeal launched in Manila on January 29 is in many ways a political event, directed at all governments and all peoples. But because the appeal is signed by people affected by leprosy, this political event is truly a personal one, too, he said.

The dean had his own personal memories. He recalled as a small boy growing close to a young man who lived in the family home. One day, the man mysteriously disappeared and they later learned he had died in a leprosy sanitarium. The young man had often painted landscapes and loved nature, and although the family only spoke of him in whispers, his memory was everywhere in the pictures he had left behind. “This political event is also personal for me,” the dean said.

The previous day, participants at a one-day National Forum were treated to a similar blend of the political and the personal. The forum produced a Philippine Declaration, a political document demanding respect for the human rights of people affected by leprosy and making a number of specific demands. Yet it was forged on the personal testimonies of people such as Zalika G. Dimalenda, once a promising student and now a volunteer health worker and day-care assistant; in between, a diagnosis of leprosy had brought discrimination and despair and led her to attempt suicide on more than one occasion.

As in many countries, there is still stigma and discrimination in the Philippines toward people affected by leprosy. But the inherent warmth of its people, the sense of mission possessed by many committed individuals and their enthusiastic participation in the events of January 28-29 lead us to hope that this political-personal appeal from Manila will strike a chord near and far.

Reference

* From the First Article of the Universal Declaration of Human Rights (1948)

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Publisher
Yohei Sasakawa

Executive Editor
Tatsuya Tanami

Editor
Jonathan Lloyd-Owen

Associate Editors
Akiko Nozawa,
James Huffman

Layout
Eiko Nishida

Photographer
Natsuko Tominaga

Editorial Office
5th Floor, Nippon Foundation Building,
1-2-2 Akasaka, Minato-ku,
Tokyo 107-8404
Tel: +81-3-6229-5601
Fax: +81-3-6229-5602
smhf_an@tnfb.jp

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