

FOR THE Elimination OF Leprosy

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



Yohei Sasakawa pictured with WHO Director-General Dr. Margaret Chan in Geneva on May 24 as she extends his term as Goodwill Ambassador.

MESSAGE

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Marching On

In May I attended the World Health Assembly in Geneva. While there, I was honored to have my term as Goodwill Ambassador extended by the WHO's director-general, Dr. Margaret Chan.

I first began my duties as a leprosy elimination ambassador in 2001, which means I have now held this post for over 10 years. In that time I have traveled to 112 countries and had meetings with over 160 current and former political leaders. When I presented Dr. Chan with a list of all the people I have called on, she expressed her delight and shook me firmly by the hand. "That's why I am reappointing you!" she said.

In the past decade, thanks to the efforts of the WHO, governments, NGOs, medical personnel and other stakeholders, the number of countries that have eliminated leprosy as a public health problem has risen to 121. Brazil, the one country yet to pass the elimination milestone, has mapped out a fresh approach under its new president and health minister and has publicly declared it will achieve

elimination by 2015. If all goes well, there is a possibility that every country in the world will have achieved this goal during my tenure.

But as I have repeated many times in these pages, elimination of leprosy is but a global milestone. Achieving it does not mean our fight against the disease is at an end. Moreover, the battle against stigma and discrimination is only now starting to get on track.

In different countries — in certain states, in particular regions — leprosy is still widespread. All stakeholders have a shared understanding that elimination (a prevalence rate of the disease of less than 1 case per 10,000 people) is not, in and of itself, something to be overly celebrated.

When every country has achieved elimination, this will of course mark a public health milestone. But as we move beyond that marker, I promise to strengthen my activities and make further progress together with you all.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Telling It Like It Is

A view from the front line of leprosy control in India.

A District Leprosy Officer (DLO) shoulders a heavy responsibility for carrying out the Indian government's National Leprosy Eradication Program. Dr. Laxman Karmi is DLO of Jharsuguda district in Orissa state. He describes the job, the challenges he faces and what motivates him.

What is the role of a DLO today? Is it changing?

The DLO is the head of leprosy work in his district. But he is hampered by the fact that in many districts he is the only person responsible for the National Leprosy Eradication Program (NLEP), helped by a few paramedical workers and non-medical supervisors. Previously, there were a medical officer and a leprosy eradication unit in addition to a DLO, but that changed with the integration of leprosy services into the general healthcare system.

How much pressure do you feel under to achieve district-level elimination?

Because the vertical structure of the NLEP has been abolished and the program has been integrated into the general healthcare system, there is too much pressure on the DLO to achieve and sustain district-level elimination. Before, NLEP staff were directly accountable for leprosy work; now, the general healthcare system has to carry out this job alongside other huge, priority-based government programs such as JSY*, malaria, TB and HIV/AIDS. This makes it very difficult to get the work done. We have built the capacity of general healthcare staff to carry out case detection and case management, but the problem is sparing the time to do so. In a general sense, leprosy work has been diluted with other programs.

Colonies are like non-healing ulcers in the district. But we cannot simply ignore them.

How do numerical targets, set from above, seem in practice?

A target set by officials at the top, to be executed by field workers, is meaningless and non-practicable. It should be drawn up by the lowest-level workers, in consultation with the community. We should always try and do what the community needs.

What is the picture in your district?

Now almost all people are aware of the symptoms of leprosy, know that treatment is available and that the disease is curable. There may be some

hidden cases, but not that many, I believe. With regard to stigma, I would say it has decreased by 90%. However, it still exists in some locations, and may result in a person diagnosed with leprosy being forced out of his or her village.

In terms of your priorities, where do residents of self-settled leprosy colonies rank?

Colonies are like non-healing ulcers in the district. On the other hand, we cannot simply ignore them. The people living in them are also human beings. We must do what we can to see that the children get educated, that young people find work and that we support the elderly. Looking at the situation from a human rights point of view, there needs to be an integrated approach. All government departments should be involved and the district administration needs to take the lead. It should not be up to the Chief District Medical Officer or the DLO to deal with every problem a colony faces.

One thing you have done for colonies is to set up first-aid centers.

The centers are important because colony residents do not have the time or the inclination to go to government health facilities. Their biggest concern is day-to-day living. Having a first-aid center within the colony means they can get the tablets or dressings they need at any time. What makes these centers distinctive is that they are run by colony residents; health workers only assist them.

Do you think there is a role for people affected by leprosy to improve leprosy services?

Yes. They can be of immense help. The community is more accepting when they hear from someone who has personally experienced the disease. People affected can be involved in different ways — taking part in information, education and communication activities; playing a role in disability prevention and medical rehabilitation clinics held at block community health centers and primary health centers; participating in decision-making meetings at the health department, as stakeholders in the program; and performing services for colony residents, if some way can be found to compensate them for their efforts.

Are there any encounters you will never forget?

The first time I visited a colony, I stood at the entrance to get an overview. A young resident approached me. He was well educated, but had lost his fingers to the disease. He looked at me for some time and then asked, "Sir, why are you a doctor and why am I a leprosy patient staying in

PROFILE:

Dr. Laxman Karmi



Dr. Laxman Karmi joined the Leprosy Eradication Unit of Jharsuguda district, Orissa state, as Medical Officer in 2004. With the subsequent restructuring of Orissa's medical services and the integration of leprosy services into the general healthcare system, his post was upgraded to District Leprosy Officer. A surgeon, Dr. Karmi also carries out reconstructive surgery on people affected by leprosy.

FOOTNOTE

* Janani Suraksha Yojana (JSY) is a safe motherhood intervention under the National Rural Health Mission.

a colony?” His real question was, “Why had God done this? Was it associated with a curse?”

Another time, I had to validate a suspected case at a primary health center. Completing my exam, I told the man that he had leprosy, but that he would be 100% cured in six months with multidrug therapy. For five minutes he remained silent. Two tear drops rolled down his cheek. I could imagine the psychological change taking place in him on hearing he was suffering from leprosy. It was painful to watch.

Visiting a colony one day, I came upon a young woman who had received a marriage proposal. I asked her about the young man and she told me he was from another colony. “Why don’t you marry someone from the mainstream and live in the community?” I asked her. Through tears, she replied, “Who will marry me?” Her words struck home and made me think, “Who would I be able to convince to marry her?”



At a colony first-aid center run by residents

What do you think the future holds for leprosy colonies?

The day will come when there are no more colonies, because the stigma of this disease is gradually disappearing. People now know that if leprosy is treated early, there will be no deformity. Deformity is the only thing that carries stigma, so if there is no deformity there will be no stigma. It is very clear that if the inflow of people into the colonies stops, then colonies will gradually disappear. But it will take time. And we could do more to sensitize the community in the meantime, so as to help stem this inflow.

What about the prospects for leprosy control?

With a reduction in prevalence below 1 case per 10,000 people, we are moving toward an atypical scenario. This will require greater awareness and sensitivity on the part of medical personnel to detect the disease. All should have knowledge of leprosy when examining a patient and keep in mind that he or she might have the disease.

How do you stay motivated?

As mentioned in the great Hindu epics *Ramayana* and *Mahabharata*, after death no material possessions accompany us — only the good works we have done during our tenure on this Earth. I am a believer in this dictum and it keeps me motivated all the time. Unlike other medical jobs, in this sector we are serving those who are truly deprived and upholding their human rights. If a DLO has carried out his duties sincerely, he will definitely feel he has done something for humanity. ■

LEPROSY WISH LIST

Joseph Woo (South Korea)
Hanvit Welfare Association

TO SEE A PERSON AFFECTED BY HANSEN’S DISEASE BECOME THE MINISTER OF HEALTH AND WELFARE

South Korea still has a long way to go to resolve issues relating to the health and welfare of people affected by Hansen’s disease. Considering the sharp decline in their numbers, people affected by the disease count for nothing politically and the South Korean government has little interest in pursuing matters. But if the health minister was a person affected by the disease, he or she would listen carefully to the needs of this underprivileged and

neglected sector of Korean society, and develop programs accordingly.

TO SEE A REVISED HANSEN’S DISEASE WELFARE LAW PASSED

The current Hansen’s disease law is too limited in scope to fully compensate for incidents resulting from past stigma and prejudice and to promote health and welfare now and in the future. The law needs to be amended in a way that meets the needs of those it is intended to help.

TO SEE A PERSON AFFECTED BY HANSEN’S DISEASE BECOME THE DIRECTOR OF SOROKDO NATIONAL HOSPITAL.

Sorok Island was once the destination of every person on the Korean peninsula diagnosed with Hansen’s disease. This policy of segregation began when Korea was under Japanese occupation, and continued after liberation in 1945. Even after a cure was discovered, no real rehabilitation program was put in place. Only when a person affected by Hansen’s disease becomes the director of Sorokdo National Hospital can we say that the needs of island residents have truly been met. That will be a day that goes down in Korean history!

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

Zest for Living

Teacher, poet and activist Nguyen Duc Thin has a love of life that leprosy couldn't dim.

Nguyen Duc Thin says his autobiography runs to 400 pages. That may still not be enough to encompass his seven decades of experiences.

Born in Vietnam's Bac Ninh Province in 1940, Thin grew up to teach history and literature to elementary and middle-school students. While still a boy he was part of a teenage guerilla unit collecting information on the French colonial occupiers. In 1963, as an up-and-coming teacher, he launched the "thousand good things movement" at his school, which spread nationwide, to encourage pupils to do good deeds at school and at home.

Diagnosed with leprosy at the age of 39, he was sent for treatment at Quynh Lap Hospital of Dermatology and Venereology in Nghe An Province. He spent four years there, from January 1979 to January 1983. As he put it in one of the many poems he has written, life did not come to an end in Quynh Lap; Quynh Lap was "a comma to the next page" of life.

'I WILL BE CURED'

Soon after arriving, he met some girls from the nearby village who teased him about his disease. "Yes, I have leprosy," he told them, "but I will be cured." "Stigma," he continued, "is leprosy of the mind and soul." Talking with Thin and listening to his poetry changed the girls' outlook. They started visiting the hospital, became good friends with him and participated in hospital activities.

Thin took his positive message about leprosy to the surrounding community. He convinced local residents with his explanations and his self-confident manner that they had nothing to fear from the disease. Within Quynh Lap, he encouraged his fellow inmates to adhere to their treatment and learn everything they could.

Finding there was no school at the hospital, he helped to start one for the children of patients. He taught them poetry and took them on excursions to show them what life was like outside the



Nguyen Duc Thin (right): a Teacher of the Nation

confines of the hospital compound.

After being discharged, Thin resumed his teaching career at his old school. He was admired and respected for the way he never let the disease get him down.

"Although I contracted leprosy, I still loved life and kept my faith in human beings," he says. "I always acted first to try and erase any feelings of inferiority. I tried my best in having treatment and in practicing to avoid disability."

Although I contracted leprosy, I still loved life and kept my faith in human beings.

As a person affected by leprosy, he realized that if he wanted to be treated fairly and with dignity, "I had to save myself first. That's the reason why I had to lead a good life, study hard, work creatively in every single thing and live with a warm heart."

Thin's achievements are reflected in the recognition he has received from the Vietnamese government: he was designated a Hero of Labor in 1985 and Teacher of the Nation in 1988. He has also been active in diverse organizations including the Red Cross Society, the Study Encouragement Association, the Vietnamese Association of Writers and Artists and the Vietnamese Fatherland Front.

POETRY'S PLACE

Poetry is especially important to him. "It makes me enthusiastic, romantic, eager for life and strong," he says. He identifies with the famous Vietnamese poet Han Mac Tu, who contracted leprosy at the age of 37 and died in 1940.

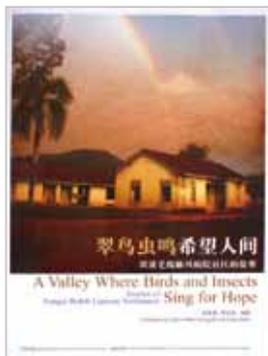
Poems can help people understand leprosy better and inspire those who suffer from it, he believes. "Poetry gains access to our heart. Verses are easy to remember and give us a reason for living."

Now 72, he is retired from teaching and serves as a special tour guide at Do Temple, a famous temple in his home village of Dinh Bang. He writes poetry, using a pen to tap out the words on a keyboard with clawed hands that are a legacy of his disease. And he continues to speak out about leprosy.

"We must eliminate stigma and discrimination as well as the barriers against people affected by leprosy," he says. "We must light the way with science and humanity. We should all join in this work and consider this the reason why we live in the computer science era." ■

Rallying Round the Valley of Hope

A stirring tale of a solidarity group that grew into a social movement.



A Valley Where Birds and Insects Sing for Hope: Stories of Sungai Buloh Leprosy Settlement

Compiled by Chou Wen Loong & Loh Choy Mun
Save Valley of Hope
Solidarity Group
(March 2012)

Established during the British colonial period in Malaysia, the Sungai Buloh Leprosy Settlement* was conceived as an enlightened response to the harsher aspects of the segregation policy then in place for dealing with the disease.

Situated in a tranquil natural environment some 25 kilometers from Kuala Lumpur, Sungai Buloh was a meticulously planned and executed community where people could receive treatment and recuperate, as much as possible while leading a normal life. It also became a world-renowned center for leprosy research.

Lim Yong Long, a researcher on modern architecture in Southeast Asia, came to know of the settlement in 2007. To his dismay, he also learned of plans to bulldoze a 40-acre section to make way for a university medical faculty. Alarmed that a place of such unique cultural heritage was under threat, he initiated a series of actions that led to the formation, the same year, of the Save Valley of Hope Solidarity Group.

Consisting of academics, students, artists, reporters, and more, the group grew into a social movement. Heritage preservation was one motivation, but so was concern for the rights of the remaining 300 residents as members came to know them and their stories. The group's efforts, and some of those stories, are recounted in *A Valley Where Birds and Insects Sing for Hope*.

inmates' ways of life and their social networks are the intangible cultural heritage.”**

GOOD RAPPORT

Both sides appreciated the interaction and a rapport developed between them. The elderly residents, many by now living alone, were very happy to hear the student interviewers addressing them as “Ah Gong” (Grandpa) or “Ah Ma” (Grandma) and looked upon them as their own kith and kin. As for the students, they hoped that by recording the experiences of the elderly inmates “this could inspire us to reexamine the value and meaning of life” while also helping the former to understand and appreciate their unique existence in a positive way.

The book is important because it provides very clear justifications for preserving Sungai Buloh's heritage — among others, its place in the history of leprosy research and as an example of the earliest design of a modern living environment in Malaysia. It also



One of nine oral histories presented in the book, which is a bilingual Chinese- and English-language publication

proposes future uses for the site, such as developing it into a museum or an oral history center and using the natural surroundings as inspiration for creative artists.

If those arguments remain too esoteric for some, then Loh Choy Mun, one of book's compilers, puts it a different way. “If another infectious disease similar to leprosy emerges with no cure, how should we handle it? Should we repeat the mistake in history and accept the policy of segregation that is now bombarded with criticisms? Or do we have better choices? This may eventually boil down to our reflection of history and our respect for patients as living individuals.”

In April 2011, 78 acres of Sungai Buloh were gazetted as a national heritage site. For this, the members of the Save Valley of Hope Solidarity Group must take credit. In championing the cause of Sungai Buloh, they are to be congratulated for underlining the importance of preserving not just historical buildings but also the human dignity of an isolated and largely overlooked community. ■

FOOTNOTES

* Now known as the Sungai Buloh National Leprosy Control Centre, the settlement quickly came to be called the Valley of Hope.

** Support for the oral history research and for the publication of the book was provided by Sasakawa Memorial Health Foundation.

“The inmates' ways of life and social networks are the intangible cultural heritage.”

Under the guidance of Chou Wen Loong, the methods of oral history were used to ensure that the history and cultural values of the settlement were systematically compiled in proper records to be passed on to future generations. “If buildings are seen as tangible cultural relics,” the book notes, “then the

Geneva Days

The Goodwill Ambassador finds plenty to discuss on his recent visit to Switzerland.

SWITZERLAND (MAY 21-25)

In May I visited Geneva to attend the annual World Health Assembly. While there, I was asked by Dr. Margaret Chan, the WHO's director-general, to extend my term as Goodwill Ambassador by a further two years.

I have never accepted an honorary title in name only. Entrusted with the role of Goodwill Ambassador, therefore, I have always devoted myself wholeheartedly to this work. The motto I adhere to is "passion, perseverance and continuity."

Since I was first given a role as a leprosy elimination ambassador more than a decade ago, I have traveled abroad 179 times in that capacity and devoted 1,222 days to my duties. In that time I have met with some 160 presidents, prime ministers, health ministers and other present and former leaders. With the fresh impetus provided by my reappointment, I shall continue to fulfill my responsibilities to the best of my ability.

As Goodwill Ambassador, the motto I adhere to is "passion, perseverance and continuity."

During my stay in Geneva I took the opportunity to hold a number of meetings on the sidelines of the World Health Assembly to discuss leprosy and related issues. Accounts of some of these discussions follow.

It was a pleasure, as always, to meet with Dr. Jarbas Barbosa, Secretary of Health Surveillance at Brazil's Ministry of Health. Brazil is the one country that has yet to eliminate leprosy as a public health problem, but the federal government has made achieving this a high priority — not only at the national level but at

the state level also.

Dr. Barbosa told me that Brazil will launch leprosy screening activities in September in 1,800 priority municipalities that have a higher burden of the disease. Up to 16 million schoolchildren will be screened, with confirmed cases leading to further screening of contacts. "I think we will see a lot of cases that are not now visible," he said, expressing Brazil's determination to make progress on this issue.

Another acquaintance I was able to catch up with was Dr. Enrique T. Ona, Secretary of Health of the Philippines. Dr. Ona told me that his ministry is committed to ending the isolated existence of long-term inhabitants of the country's leprosaria. Integration is very important, he said, although it won't be easy. "We are looking for the active participation of the Department of Social Welfare and Development, especially on behalf of children," he said. The ministry is now collecting data on how many families can be assisted.

From India I met Mr. P.K. Pradhan, Secretary of the Ministry of Health & Family Welfare. Secretary Pradhan told me that although India had eliminated the disease at the national level, there were still many pockets of leprosy in the country and there was no room for complacency. "We are trying to sensitize front-line health workers. Early detection is very important," he said.

From Egypt, meanwhile, I spoke with Dr. Nasr El-Sayed, 1st Under Secretary for Preventive and Endemic Affairs at the Ministry of Health and Population. Egypt has an early detection program for leprosy and offers treatment and social support. "Sometimes the social support is even more important than the medicine," he told me.

I was interested to learn from him that a one-hour documentary about leprosy aired recently on Egyptian television. The program was made



Left to right: Dr. Jarbas Barbosa (Brazil), Dr. Enrique T. Ona (Philippines) and Dr. Nasr El-Sayed (Egypt)



At right: With Novartis CEO Joseph Jimenez; far right: With the Pacific Leprosy Foundation's Jill Tomlinson and Richard Gray.

by one of the country's best-known journalists and was seen by millions. "We are pushing the media to break the silence on leprosy in Egypt," Dr. Nasr said.

Ending the stigma and discrimination that people affected by leprosy face is an important concern of mine, and I had another reason for being in Geneva. I wanted to call on the Office of the UN High Commissioner for Human Rights to discuss the ongoing symposia series on leprosy and human rights that The Nippon Foundation is organizing in five regions of the world. The first of these was held in Brazil in February and the second is slated for India in October.

The five symposia are designed to follow up on the December 2010 UN resolution on eliminating discrimination against people affected by leprosy and their family members. In particular, they seek to find a way to raise awareness of the resolution and implement the principles and guidelines on eliminating discrimination to which the resolution refers.

Therefore, I welcomed the chance to talk with Ms. Marcia V.J. Kran, director of the UNHCHR's Research and Right to Development Division Office and her colleagues to hear their thoughts. Ms. Kran noted that while the principles and guidelines were not legally binding, they were nevertheless "quasi-legal — an agreement that the General Assembly has endorsed — so that they have great persuasive effect ... In a sense, that's



Novartis headquarters in Basel

an achievement, but the real test is in the implementation."

Among the suggestions she and her team made was to make use of provisions in the Convention on the Rights of Persons with Disabilities — for example, measures on awareness-raising

with regard to the media, so as to encourage all organs of the media to portray persons with disabilities in a positive way, in order to address issues of stigma and discrimination.

I had meetings with a number of WHO regional directors. One I had the pleasure of meeting for the first time was Ms. Zsuzsanna Jakab, the WHO Regional Director for Europe. I asked for her cooperation for the visit to Russia and the Ukraine that I am planning to make at the end of June.

During my stay in Switzerland I also traveled to Basel to pay a courtesy call on Novartis and the Novartis Foundation for Sustainable Development. Novartis manufactures the drugs used in multidrug therapy (MDT) — the WHO-approved treatment for leprosy — and the Novartis Foundation has made MDT available free of charge to the WHO since 2000. The provision of this drug security is one of the keys behind the successful elimination of leprosy as a public health problem in virtually every country, and to the ongoing effort to further reduce the burden of the disease in the world.

In a meeting with Novartis CEO Joseph Jimenez and Novartis Foundation Chairman Professor Klaus Leisinger, I thanked them on behalf of people affected by leprosy for the contribution they are making.

Returning to Geneva, I gave a speech at the May 24 awards ceremony when the WHO honors initiatives in public health. One of these awards is the Sasakawa Health Prize, which this year went to Syamsi Dhuha Foundation, an Indonesian foundation that works to improve the quality of life of people living with lupus and poor vision.

At the same ceremony I also had the opportunity to meet Richard Gray, the chairman of the Pacific Leprosy Foundation (PLF) and his colleague Jill Tomlinson. They were collecting the 2012 Dr Lee Jong-wook Memorial Prize for Public Health for PLF's work to eliminate leprosy from the Pacific and New Zealand and mitigate the effects of the disease. I congratulate them on their prize. ■

MORHAN Garner MDG Award

NGO one of 20 winners of Brazil's 4th Millennium Development Goals Award.

MORHAN (the Movement for the Reintegration of People Affected by Hansen's Disease) is one of 20 winners of Brazil's latest Millennium Development Goals (MDG) Award.

The award encourages actions, programs and projects by local government and civil society organizations that help improve the lives of some of the country's most disadvantaged communities, thus making a contribution to achieving the Millennium Development Goals.

MORHAN was recognized for its use of "Telehansen," a free telephone counseling service, as well as mobile health units to assist local municipalities in providing on-the-spot leprosy diagnosis and information to combat the stigma and prejudice that still surrounds the disease.

"Although Hansen's disease has a high cure rate, Brazil ranks first in the world in terms of disease prevalence," says Artur Custodio, MORHAN's national coordinator. "This sad



MORHAN receives an MDG award. Brazilian President Dilma Rousseff is second from left.

reality is strongly influence by stigma, which excludes patients from diagnosis and health facilities. Therefore, information is the best medicine."

The winners of the fourth edition of the award were announced on May 30 at a ceremony in Brasilia attended by Brazilian President Dilma Rousseff.

IDEA HONORED

The International Association for Integration, Dignity, and Economic Advancement (IDEA), has been awarded a 2012 Historic Preservation Media Award for their work on the exhibit "Absolute Faith: Saint Damien, Blessed Marianne and the People of Kalaupapa." Presented annually by Historic Hawai'i Foundation, this

is Hawaii's "highest recognition of projects that perpetuate, rehabilitate, restore or interpret the state's architectural, archaeological, and cultural heritage." This exhibit forms the foundation for the new Damien-Marianne Heritage Center, established in Honolulu by St. Augustine by-the-Sea Catholic Church.

18TH ILA CONGRESS

The 18th International Leprosy Congress will be held in Brussels, Belgium, from September 16 to 20, 2013. The International Leprosy Association (ILA) is organizing a congress program that aims to reflect "the

multidisciplinary character of leprosy and attract scientists and health personnel from a variety of scientific and medical backgrounds." For more information, contact the ILA at ila@ilsil.com. ■

FROM THE EDITORS

'AN IMPORTANT ROLE IN HISTORY'

The Sungai Buloh leprosy settlement in Malaysia has featured in this newsletter on a number of occasions, most recently in the form of a new book introduced on page 5. In addition to oral histories, *A Valley Where Birds and Insects Sing for Hope* contains many photographs. Some were provided by the elderly residents — precious mementos of their earlier selves. Others were taken by photographers

such as locally-born Terry Yan.

Yan admitted that he knew nothing about the settlement until he took up his camera and went in. "Through the lens," he writes, "I began to know the Settlement, and realized it played an important role in history." Thanks to Yan and all who contributed to the book, that history will not be forgotten.

FOR THE ELIMINATION OF LEPROSY

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