

FOR THE Elimination OF Leprosy

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



Student volunteer and villager at a JIA-run work camp in a leprosy-affected village in southern China (see pages 4-6) Photo credit: JIA/FIWC

MESSAGE

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Leprosy and Human Rights

When explaining the issue of leprosy and human rights to UN bodies and human rights organizations, there is always likely to be a problem of interpretation. People unfamiliar with the realities of the disease tend to construe this as a “right-to-health” issue.

However, given that leprosy services are being integrated into the general health-care system and treatment is available free of charge, it is necessary to study the bigger picture. We must look beyond the issue of access to health care, and the fundamental right to health that underpins this, and focus specifically on the scourge of discrimination.

Even after people with leprosy have been treated and cured, the stigma of the disease can undermine their basic human rights, in particular, the right to work, to marry and to receive an education. This discrimination is most apparent among those in a vulnerable position — women, children, persons with disabilities and the elderly.

Since the introduction of multidrug therapy in the 1980s, some 15 million people around the world have been cured of leprosy. However, they

are not the only potential targets of discrimination. Tens of millions of their family members and relatives also face social ostracization. This is all the more reason why any consideration of leprosy and human rights must go beyond a right-to-health definition.

When the UN Human Rights Council (UNHRC) classifies the problem of discrimination, it divides it into different categories, including discrimination against women, children, the disabled and the poor. Leprosy-based discrimination comes under all these headings. It is social discrimination writ large, and universal in nature.

I should therefore like to propose to the newly constituted UNHRC that it take up the human rights aspect of leprosy as an issue of discrimination, and examine this deep-rooted problem from every angle.

This is a subject about which I feel strongly, and I hope that we can move toward together to rid the world of leprosy-based discrimination forever.

— Yohei Sasakawa, WHO Goodwill Ambassador

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End Discrimination Now

Professor Yozo Yokota discusses the issue of leprosy and human rights.

Japan's Yozo Yokota served as a member of the UN Sub-Commission on the Promotion and Protection of Human Rights from 2000 until its final session in June 2007. In 2003 he was asked to prepare a preliminary report on discrimination against persons affected by leprosy and their families. Subsequently he was appointed special rapporteur and commissioned to produce a comprehensive study on the topic. The report is now in its final stages, but in the meantime the sub-commission has been voted out of existence. With the fate of his report now hanging in the balance, we asked Professor Yokota for his views on leprosy as a human rights issue.

How much did you know about leprosy before you undertook this assignment?

When I was very small my mother, who was a devout Christian, took me to Tama-Zenshoen [a leprosy sanatorium in a suburb of Tokyo]. I think she felt it was her duty to visit people in hospital and offer them encouragement. Through my mother's introduction I got to know about leprosy and the importance of treating people with the disease as human beings. But only much later did I become familiar with the extent of discrimination, as a result of the Kumamoto court case in Japan.*

When the sub-commission asked you to prepare a preliminary report on discrimination against people affected by leprosy, it was the first time it had considered the issue. How did this come about?

In 2003, Mr. Sasakawa made a presentation over lunch in Geneva to members of the sub-commission. Members were curious to know what the problem was, and were very surprised to learn of its scale and gravity. They were ready to take up the issue as soon as possible.

How big an issue is leprosy-based discrimination?

First, it is a big issue in terms of the number of people affected, certainly in the order of millions; Mr. Sasakawa says tens of millions. The number is so great that we cannot put it aside. Second, the issue of discrimination against people affected by leprosy has elements in common with other discrimination issues, such as discrimination against people suffering from poverty, caste-based discrimination, and discrimination against minorities.

At the same time, discrimination against leprosy-affected people has certain distinctive features — the misunderstanding of the nature of the disease or the psychological, emotional

responses toward it that are often described as stigma, and which result in discrimination. Interestingly, even people who are strongly motivated to do something about human rights abuses, and who feel that we should strive to eliminate discrimination, exhibit discriminatory attitudes toward people affected by leprosy mainly due to lack of knowledge about the disease.

Even people motivated to act against human rights abuses discriminate.

What explains this, do you think?

Many people still think that leprosy is a disease easily transmitted through touching; that if you are affected, the treatment is not perfect and that deformities will follow. This image of leprosy has been around for centuries, and it persists today, even among well-educated people. So they discriminate, if only for the simple reason that they are afraid, or they want to protect their children. Unfortunately, this kind of misconception persists, and is different from other kinds of discrimination that I know of.

How does discrimination manifest itself?

The most obvious instance which I personally saw was that in some cases hotels were not willing to allow leprosy-affected people to stay. Usually they had signed up to attend a conference on discrimination, and hotels were afraid that other patrons would be unhappy. This happened when we were organizing seminars in India and Brazil.

Have you found different attitudes toward leprosy on your travels?

In some countries, once a family member is affected by leprosy, the family abandons that person. But in other countries, families come together and take care of them. Maybe in some societies the name of the family is more important, so they try to get rid of whoever has been affected before rumors start. In other societies, family unity still exists but is based on love and affection, not honor or reputation.

What stories stay with you in particular?

One gentleman about my age told me that he had been born into a reasonably wealthy family living in a big house. But when he was young he came down with leprosy and was forcibly taken to hospital and kept there for decades. He had always

PROFILE:

Yozo Yokota

Yozo Yokota is a Professor of Law in the Faculty of Law at Chuo University, Tokyo, and Special Adviser to the Rector of United Nations University. He gained his Doctorate in Law from the University of Tokyo in 1969. Until recently he served as a member of the UN Sub-Commission on the Promotion and Protection of Human Rights.

Reference

* In 2001, the Kumamoto District Court in western Japan ruled in favor of the plaintiffs in a lawsuit filed by residents of leprosy sanatoriums. The court found that the government had infringed on their human rights as provided under the Japanese Constitution through the policy of isolation it imposed under Japan's Leprosy Prevention Law. The law, introduced in 1907 and reinforced in 1953, was not repealed until 1996.



dreamed of returning home, so when the law was changed and he was free to leave, he went back. When he knocked on the door, a window in the door opened and a man's face appeared. He suspected the man was his father. "I am your son," he said. The window slid shut. He banged on the door, but there was no response. As he was telling me this, the man started to cry and couldn't continue. What suffering he had endured: his dream was to be reunited with his family, yet they rejected him completely.

In the course of your interviews, did you find that people affected by leprosy had specific demands?

Many do not have big demands or requests. Mostly they want the United Nations to be aware of the problem, to be aware that they exist, and not to forget them. People affected by leprosy have been abandoned by family, friends and the community. They congregate with other affected persons, but as a group they feel isolated from the rest of society. So when somebody from the UN or an NGO comes to talk to them, they are very happy. My feeling is that they want to be treated as fellow human beings, with dignity.

What is the status of your study?

I am putting the final touches to it. In my report I include principles and guidelines to end discrimination against leprosy-affected people. The major principles are that leprosy is not easily transmittable, it is a curable disease, many people have been cured in the past two decades, and in most countries it is no longer a public health problem. Nonetheless, discrimination continues to exist and this is a serious human rights violation that should be stopped immediately. In the

guidelines, we give specific recommendations to governments, media organizations, schools and hospitals about what to do and what not to do. That's the main part of the report. I also recommend that the Human Rights Council continues to study the human rights implications of leprosy and also that UN bodies and agencies endeavor to address the issue of discrimination along the lines of the principles and guidelines included in this report, through education and public awareness campaigns.

Do you see some pressing concerns?

In countries where patients were once forcibly hospitalized, the laws have since changed and sanatorium residents are free to leave. But that doesn't mean they are able to do so, nor should they be made to without their consent. Finding a place to live, and a way to make a living, are not easy for them. In a number of countries, governments are looking to sell or redevelop the land that sanatoriums stand on as urbanization encroaches and sanatorium populations dwindle.

What should humankind learn from the way people affected by leprosy have been treated?

Discrimination, and in particular discrimination against a particular category of person, is the worst kind of human rights violation. Such categorizations are a creation of the human mind. They have nothing to do with the objective character of a person. Disease is a condition of being human. It could happen to anyone. Simply because some people have suffered from leprosy, they are put in a certain category and treated miserably. This is totally against the concept of human rights that should be enjoyed by all human beings, whatever their situation and wherever they are. ■

Living the Work Camp Life

Ryotaro Harada's calling is organizing work camps in leprosy-affected villages in China.

In my third year at university, when I should have been job-hunting, I joined Korean and Japanese volunteers at a work camp at a Chinese leprosy village. It was February 2002.

As a boy I had been bullied at school, and determined to become a journalist so that I could tackle the issue of discrimination. I thought the work camp experience would be a useful talking point at job interviews.

At the same time, I was beginning to wonder if I really understood what discrimination meant. Maybe I was guilty of it, too. With these thoughts in mind, I decided to take part in the camp, because I knew that people affected by leprosy were among the most discriminated against of all.

Yankeng village in Guangdong was established in 1957. At the time, about 300-400 people diagnosed with leprosy were forcibly isolated there. To get to the village we drove for miles along a dirt track through the mountains. On arrival, volunteers who had been there before got out and shook hands with the villagers, some of whom appeared to have no fingers. When I alighted, saying "Hello" was all I could manage to do. I felt it would have been insincere of me to shake hands.

After dinner that evening, I had a 'conversation' with one of the villagers, Mr. Ou. Over 15 minutes of written exchanges using Chinese characters, it seemed like we were communicating surprisingly well. In truth, however, I was concerned, because I was touching his ballpoint pen and notebook. With a gesture, he invited me to his house. I grew more nervous.

Inside, the air was chilly, and slightly damp. Now I was scared. Although I knew that I wouldn't catch leprosy, I was still afraid to breathe in the air in the room. I hesitated to sit

down. When he handed me a monkey banana, I didn't know what to do. I couldn't refuse it, so I just stuffed it in my mouth and swallowed

Mr. Ou showed me a photo. It was taken during an international leprosy conference on an outing to the Great Wall. He also showed me a postcard from a Japanese friend. He looked so pleased, and I realized he was just a normal person. Indeed, he might have been my grandfather. As he was telling me about the photo, I sat down. I began breathing normally and even laughed. When it was time to leave, Mr. Ou saw me to my accommodation. "See you again tomorrow," I wrote, and held out my hand.

Grandma Lin lived a couple of doors down from where the work volunteers stayed. Her fingers were stumps, and her left leg was made of tin. Every morning when I left my room, Grandma Lin would be sitting in front of her door on a wooden chair.

"Morning!" I would call out. Grandma Lin couldn't talk, but would flash me a smile. Is this the smile of someone who has been oppressed for long years, I thought? I held her in great respect.

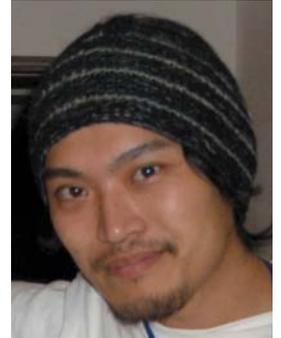
RETURN TO CHINA

In June 2002, I became involved in preparations for another work camp in Linghou village in Guangdong, and went there in September to conduct a survey. Compared to Yangkeng, living conditions were much worse, and people had glum expressions. Back home, my job-hunting had not been going well, and as I looked around Linghou, I became increasingly depressed. I didn't want to have to come back for the work camp in November, as I promised I would.

But I did, and through the experience I came to know the villagers better and appreciate what work camps could achieve. This was also the first work camp in which Chinese students participated, although they didn't stay at the camp overnight.

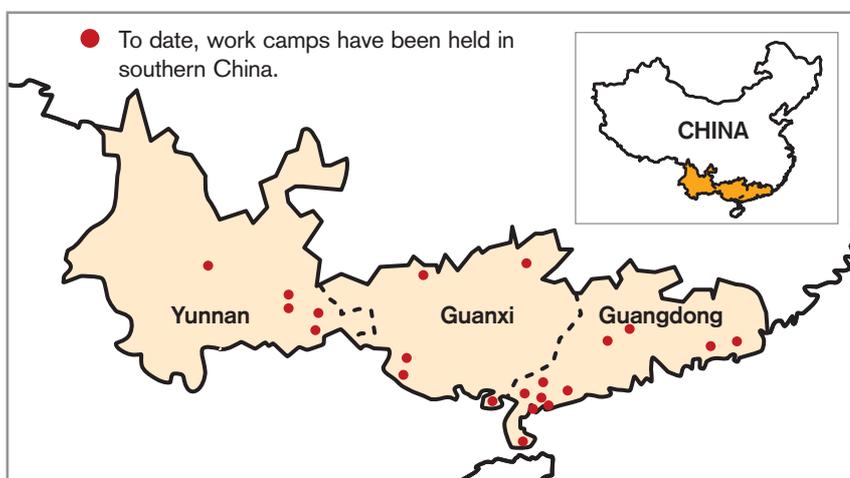
In April 2003, immediately after graduating, I went to live in Linghou. From there I traveled around persuading local students to get involved. Up to that point, the volunteers had mostly come from overseas, but from August, Chinese

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Ryotaro Harada



Ryotaro Harada is General Manager of JIA — Work Camp Coordination Center, an NGO based in China.

JIA Activity Map



students became full and enthusiastic participants in work camp activities.

Since then, the work camp program has expanded rapidly, leading to the establishment of JIA — Work Camp Coordination Center to put the program on a solid footing organization and build a global network (see Partners).

BUILDING BONDS

Work camps are all about creating bonds between people — between villagers and volunteers, between volunteers themselves, and between villagers and neighboring communities.

I tell potential recruits not to approach a work camp with the idea of “ending discrimination against people affected by leprosy,” “offering a hand of love to the suffering” or “participating as a volunteer.” Instead, they should ask fundamental questions, such as “what is leprosy,” “what is love?” and “what is being a volunteer?” Their answers are likely to be, “I don’t really know, but I’d like to find out.” That is the first step.



Harada with Linghou villager Cai Wanqing

Volunteers arrive, picturing the degree to which the villagers must be suffering. Some of them are fearful when they see what the disease has done to hands and feet. However, the most frequent impression they have is: “The villagers have a far more positive outlook than we imagined; they’ve accepted the fact of leprosy and are getting on with their lives.”

PARTNERS

JIA — WORK CAMP COORDINATION CENTER



JIA was founded in 2004 in Guangdong, China, as a non-profit NGO to coordinate community service work camps to help Chinese villages of people affected by leprosy. There are some 600 such villages in China, dating back to the 1950s and 1960s when persons diagnosed with the disease were relocated to remote mountain areas. Many of these villages are extremely poor, lack access to adequate medical care and have been cut off from the outside world for decades. Because of stigma, their aging residents have never been able to return home.

Work camps generally last between one week to 10 days, during which time volunteers work on projects to improve residents’ living conditions — including building toilets, repairing roofs, constructing roads and digging drainage ditches.

JIA has its roots in Friends International Work Camp, an NGO set up in Japan in the early 1950s. The first work camps in China pre-date JIA, which was set up to provide a sound organizational structure as the concept took hold. Initially the work camps were largely supervised by foreign volunteers, but today the majority of



staff running the organization are Chinese.

An important part of JIA’s work is to carry out needs-assessments to clarify the general situation in the villages and identify specific projects to be undertaken by volunteers. Other key functions are to promote work camps among potential volunteers, host fund-raising events and run training workshops.

Between 2001 and 2006, 1,200 people from 15 countries and regions participated in 64 work camps, touching the lives of 1,000 people affected by leprosy in 24 villages in China.

As JIA grows, it plans to broaden its social commitment beyond leprosy to include the elderly, the orphaned and rural areas suffering from extreme poverty. It has established a JIA Global Network, and is currently looking at the possibility of holding work camps in Vietnam. ■



Residents of Teng-Qiao village in Guangdong Province bid farewell to volunteers at the end of a JIA work camp.

Photo credit

All photos on pages 4-6 courtesy of JIA/FIWC

This in turn causes volunteers to reflect on their own lives, and see their day-to-day concerns in a fresh light. Little by little, bonds develop between the villagers and the volunteers, and they become like family. (Indeed, that is what “jia” means in Chinese.) When the work camp comes to an end, the volunteers return home, revitalized.

As for the villagers, the benefits of the work camps go beyond paved roads and new toilets. Isolated, abandoned and disdained for long years, they have an opportunity to interact with people who take a straightforward and genuine interest in them. The results are heartwarming on both sides.

In addition, seeing the student volunteers mix easily with the villagers sends a message to people living nearby. In Pingshan village, where many camps have been held since February 2004, there is today almost no discrimination toward villagers in surrounding communities.

Pingshan has also hosted a reunion between one of the villagers, Uncle Tao, and his cousin, who were reunited after 53 years through the efforts of volunteers. In the second half of July, Uncle Tao made a successful visit to his hometown in the company of volunteers. Such home visits are being

organized at other villages too.

On a personal note, I married Cai Jieshan, a Chinese volunteer, in October 2005. In the days before Chinese volunteers became regular participants in the camps, Jieshan often came to visit Linghou, and soon the villagers were asking, “When are you two getting married?” One villager more than most eagerly anticipated the announcement. Her name was Cai Wanqing. On October 11, 2005, the day after we registered our marriage, I went to Linghou with the happy news. But when I told Cai Wanqing, she just said, “Oh, I see.” It was as if all the enthusiasm had drained from her. A couple of weeks later, she was dead. I was told that her last words were, “I’ll never see Ryotaro and Jieshan again.”

JIA work camps are putting down roots and over time I hope to see them spread to other parts of the world. At first, I think the focus should be on leprosy, but there is no reason why they should not eventually concentrate on helping other disadvantaged communities. JIA’s motto is “World as One Family by Work Camp.” It may be a dream, but it is one I hope to see realized in my lifetime. ■

Leprosy FACTS

The global registered prevalence of leprosy at the beginning of 2007 was 224,717 cases; the number of new cases detected during 2006 was 259,017. Four countries (Brazil, DR Congo, Mozambique and Nepal) have yet to eliminate leprosy as a public health problem. Together they accounted for about 23% of all new cases detected in 2006 and 34% of all cases registered at the beginning of 2007. (Source: WHO)

Looking In on Myanmar

Leprosy is well under control, but stigma and discrimination remain.

MYANMAR (MAY 20-23)

At the end of May I visited Myanmar in connection with a project supported by The Nippon Foundation to build and renovate schools in Shan State. But I also took the opportunity to bring myself up to date on the leprosy situation.

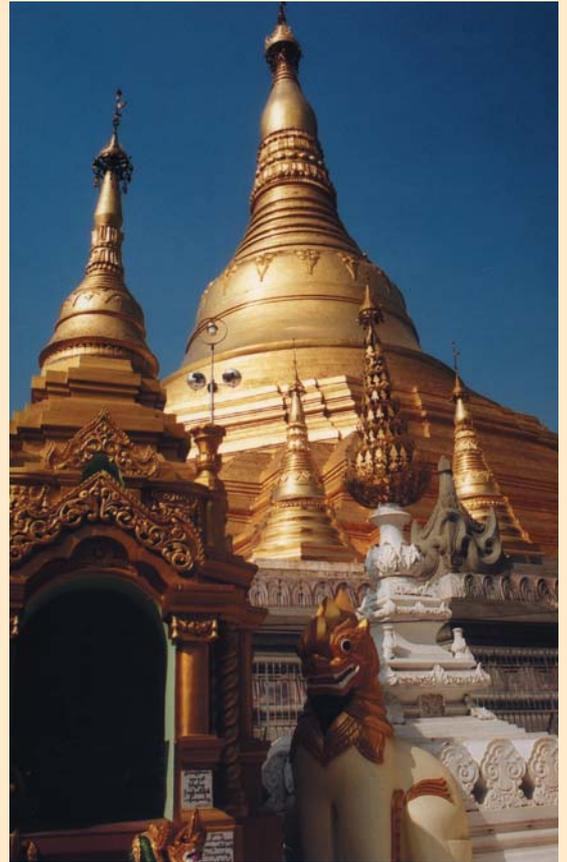
In 1988, Myanmar's leprosy prevalence rate was 39.9 per 10,000 persons at the national level. Thanks to the efforts of all concerned, the prevalence rate dropped dramatically in the years following, and in January 2003 Myanmar announced that it has achieved the WHO target of eliminating leprosy as a public health problem. The achievement has been sustained under the leadership of Health Minister Dr. Kyaw Myint.

There are about 350,000 people in Myanmar today who have been cured of leprosy. Of these, between 2,500 and 3,000 live in some 50 colonies around the country. As is found elsewhere, discrimination against people affected by leprosy exists, and there are many cases of persons unable to marry or attend school because someone in their family has been affected by the disease.

To address such issues, an organization for people affected by leprosy called Myitta Arr Marn ("Strength of Well Wishes") was founded two years ago. It aims to promote dignity and respect for those affected by the disease, provide them with a common platform to voice their concerns, and promote their social and economic rehabilitation. Currently run by professionals, the plan is to turn over control of the organization to people affected by leprosy in due course. Last year MAM held its first empowerment workshop and there are plans to set up a number of local branches in leprosy-endemic areas.

In the former capital, Yangon, there is a breathtaking Buddhist structure called the Shwedagon Pagoda. For the 90 percent of Myanmar's population who are Buddhists, this is the most important symbol of their religion in the country, and paying homage there is a blissful experience. But people affected by leprosy hesitate to go to the pagoda because of the stigma and discrimination they face.

During my stay, I met with nine people affected by leprosy who live in a colony in the suburbs of Yangon. Not one had visited the



People affected by leprosy hesitate to visit the pagoda for fear of discrimination.



Meeting with colony residents on May 20 in Yangon

pagoda, despite its proximity. Creating a society in which people affected by leprosy can go to Shwedagon without fear of discrimination is a big challenge, and I would like to do what I can to help. ■

Sungai Buloh to Become Heritage Site?

Malaysia's health ministry announces plans to preserve leprosy center's rich history



Disused building at Sungai Buloh

Plans announced by the Malaysian health ministry on July 20 to build an infectious disease control center in Sungai Buloh also call for turning part of the existing leprosy center there into a heritage site and tourist attraction.

Located outside Kuala Lumpur, the 500-acre plot of land owned by the ministry currently houses the Sungai Buloh hospital and leprosy center, as well as numerous landscape garden businesses, many of them operating illegally.

The leprosy center, which will remain open, dates back to 1930. It is currently home to 340 residents, the majority of whom have lived there for decades.

DR. P.L. JOSHI

Dr. P.L. Joshi is the new Deputy Director-General of Health Services (Leprosy) at India's Ministry of Health and Family Welfare. He succeeds Dr. G.P.S. Dhillon, now in charge of the National Vector Borne Disease Control Program.

BBC WORLD DOCUMENTARY

The Outsiders — Leprosy in the 21st Century, a documentary in two parts, will be broadcast on BBC World on August 18 and 19 (Part 1) and August 25 and 26 (Part 2). Filmed in Brazil, Ethiopia, India and the Philippines, it focuses on the lives of people affected by leprosy as well as efforts being made to eliminate stigma and discrimination.

SURVEY OF INDIA'S COLONIES

An ongoing survey begun in 2005 to determine the number and socio-economic status of self-settled leprosy colonies in India has so far collected data in 23 of India's 35 states and union territories. Of 55,244 people affected by leprosy living in 630 colonies (which are also home to non-affected persons), about half make a living from begging, the survey has found. ■

FROM THE EDITORS

FROM GENEVA TO GUANGDONG

Bringing leprosy to the notice of the UN sub-commission on human rights in 2003 was an important and overdue step in focusing minds on the human rights dimension of this oldest of diseases. But placing the issue on the agenda of the new UN Human Rights Council will not be easy when so many other issues clamor for its attention.

However, as former sub-commission special rapporteur Yozo Yokota tells us in an interview, he is recommending that the Council continue to study the human rights implications of leprosy and that other UN bodies and agencies endeavor to address the issue. In terms of the number of people affected, leprosy-based discrimination is too big an issue to push aside, says Professor Yokota; moreover, it has elements in common with other forms of discrimination, such as that relating to poverty, caste and minorities. We hope, therefore, that the Council will follow his recommendation and treat the matter with the urgency it

deserves.

Meanwhile, at the grass-roots level, efforts to break down barriers between people affected by leprosy and mainstream society are continuing in different countries. In this issue, we feature the work of Joy In Action, an NGO established in 2004 to organize work camps to improve living conditions in leprosy-affected villages in China.

Initially, only student volunteers from abroad, such as Ryotaro Harada, took part in the camps, as the isolated villages with their neglected inhabitants were off the radar of Chinese students. Now all that has changed, and the work camp ethic is spreading fast.

Not only do the work camps result in physical improvements to the villages, but they also enrich the lives of the inhabitants in other ways through the relationships they develop with the young volunteers. For both villagers and volunteers alike, it is a heartwarming experience, as our cover photo clearly shows.

FOR THE ELIMINATION OF LEPROSY

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