WHO GOODWILL AMBASSADOR'S NEWSLETTER
FOR THE
Elimination OF Leprosy
August 2009 • Number 39

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

Yohei Sasakawa meets with Ackim Ntanyela, a resident of the "invalid compound" in Liteta district hospital, Zambia, on July 2.

MESSAGE

Strategic Diplomacy

I spend about one third of the year traveling abroad on leprosy work, spreading the three simple messages that you see in the masthead above. On the ground, my strategy is threefold: to meet with heads of state, to motivate health authorities, and to solicit media coverage.

When visiting a developing country, it is especially important to speak with the head of state and gain his or her commitment to keeping leprosy on the list of health priorities. Doing this helps to make the job of the leprosy program manager easier since so many more people are suffering from HIV/AIDS, malaria and TB.

Tanzania's president once told me that he had read up on leprosy for the first time because of my visit, learning there were many cases in his country. Another president told me flatly, "We don't have leprosy here," and said that as a child he'd heard that everyone with the disease had been sent to an island in the middle of a lake. In fact, unbeknownst to him, there was a major leprosy sanatorium about 40 minutes' drive from his residence.

When I visited Zambia at the end of June, President Banda said with impressive candor that he had always been rather afraid of leprosy. After hearing what I had to say, he said he now knew better, and pledged to redouble Zambia's efforts to eradicate the disease.

When calling on a head of state, I am usually accompanied by the health minister or vice minister. So when a leader pledges his support for leprosy control, his words energize the activities of health authorities.

As we reduce stigma, the role of the media is vital. Wherever possible, therefore, I bring the local media with me when I meet people affected by leprosy. As well as offering each individual my personal encouragement, I want the media to publicly record our handshakes and interaction, as I believe these images help change public attitudes toward the disease.

On visits that I am able to carry out all three parts of my strategy, I feel that my work has been truly meaningful.

— *Yohei Sasakawa*, WHO Goodwill Ambassador

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ASEC-TNF PROJECT

Toward a ‘Caring Community’

Initiative focuses on social reintegration and restoration of dignity.

A new project launched jointly by the Association of Southeast Asian Nations (ASEAN) Secretariat and The Nippon Foundation in Jakarta on June 15 is aimed at empowering people affected by leprosy and building an environment in which they and their families can lead a dignified life. The first phase of the ASEC-TNF Project on Leprosy and Human Dignity focuses on Indonesia. The project will then be expanded to the other nine ASEAN members.

In his keynote address before an audience of about 100 diplomats, dignitaries, journalists and people affected by leprosy, ASEAN Secretary General Dr. Surin Pitsuwan said, “ASEAN aspires to be a caring and a compassionate society … Therefore, we cannot leave any issue of this major proportion undetected.”

Although leprosy is no longer considered a public health problem — as defined by the WHO — in the ASEAN region, there were 25,000 new cases of the disease reported in 2007, with Indonesia contributing the bulk of these. While the disease is curable, the stigma attached to it stops people coming forward for treatment, leading to disability, and many experience social discrimination even after they are cured.

“Societies need to recognize that leprosy is a social problem as much as it is a physical problem,” Dr. Surin told a press conference following the ceremony. “The measure of our success is how well we treat the less fortunate members of our society. We have to treat them with compassion and dignity.”

Initiatives under the project will include capacity-building workshops and seminars by and for people affected by leprosy and family members, and campaigns to make the general public better informed about the disease. ASEC and TNF will work with governments, the private sector and with civil society to implement the project.

Dr. Surin Pitsuwan, ASEAN Secretary General, gives the keynote address.

Project Manager Adi Yosep said that he had experienced both health issues related to leprosy, and also the stigma and discrimination associated with the disease. “As a person affected by leprosy, I am very proud of the project and of its potential.”

In the afternoon, a sensitization workshop heard from Virendra S. Gupte (Tata International Ltd., India) on Partnering with the Business Community, Ryotaro Harada (Joy in Action, China) on Social Changes Related to China in Leprosy, Ujjwal K. Chowdhury (Symbiosis University, India) on the Involvement of the Media in India, and Aco Manafe (Suara Pembaruan Daily, Indonesia) on Breaking the Cycle of Stigmatization through the Media in Indonesia.

The ASEC-TNF Project on Leprosy and Human Dignity is one of several to result from a Memorandum of Agreement signed by ASEC and The Nippon Foundation in 2008*. ■

Footnote

* Beside leprosy, the areas of cooperation between the two parties involve the promotion of traditional medicine in primary health care, programs to empower persons with disabilities, maritime civilian safety and capacity-building within the ASEAN Secretariat.

FROM THE PODIUM

‘LEPROSY IS NOT A CURSE’

Adi Yosep, project manager of the ASEC-TNF initiative on leprosy and human dignity, was diagnosed with leprosy when he was 18. He developed the same symptoms as his mother some years before him, although his parents had kept the true nature of her illness from him.

“When I was first diagnosed with the disease, I was scared and confused,” he said. “I didn’t know much about leprosy. Most of all, I was frightened that my friends would distance themselves from me, that I would not be able to lead a normal life.”

Through a university teacher, he was put in touch with The Leprosy Mission International and began to learn more about the disease. He also took advantage of the free treatment available to persons with leprosy and was completely cured with multidrug therapy.

He was one of a number of people to start PerMaTa, an advocacy group to empower people affected by leprosy, raise awareness of the disease, and tackle the issue of stigmatization. The ASEC-TNF Project will build on these efforts.

“People with leprosy have very low self-esteem. They are stigmatized by their community. We seek to develop their confidence,” he says. “The public needs to know that leprosy is curable and that people with the disease should not be feared. Those with the disease need to know that free treatment is available. And especially, everybody needs to know that leprosy is not a curse.”

The Good, the Bad and the Ugly

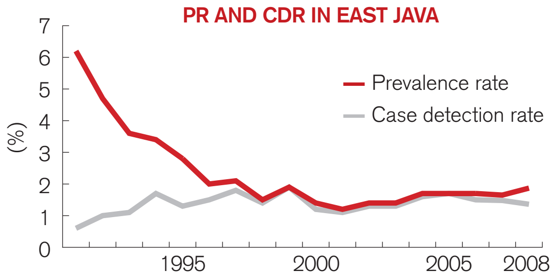
Indonesia has work to do in order to further reduce its leprosy burden.

Clint Eastwood doesn't normally feature in PowerPoint presentations on leprosy, but the director of Indonesia's department of transmissible disease control used the actor's photograph recently to draw attention to the "The Good, the Bad, and the Ugly" in Indonesia's fight against the disease.

Indonesia, a sprawling archipelago of 234 million people, is the fourth largest country in the world in terms of population, and its people are scattered over some 12,000 of the country's more than 17,000 islands. These facts alone indicate the logistical challenges involved in delivering health services to every citizen, and efforts to control leprosy are no exception.

The good news is that Indonesia eliminated leprosy as a public health problem at the national level in 2000, reducing the prevalence of the disease to less than one case per 10,000 people nine years after the World Health Assembly set the target in 1991. But the bad news, said Dr. Iwan M. Muljono, is that the proportion of child cases among new cases stands at 9.6%, that of grade 2 disability at 11.4%, while 82.2% of new cases are multibacilliary (MB).

What makes the situation ugly, he went on, is that the situation has remained static over the past decade, with little change in either the prevalence rate or the new case detection rate. Similarly, there has been no reduction in the ratios of child cases and grade 2 disability cases, while the proportion of MB cases has increased.



After India and Brazil, Indonesia reports the largest number of cases of leprosy annually. In 2008, it detected 17,243 new cases. Of its 33 provinces, 4 had over 1,000 cases each.

Of these, East Java has the highest incidence of the disease, reporting 5,083 new cases last year. In particular, the burden is heaviest in 15 districts/municipalities on the northern coast and on Madura Island. Between 1994 and 2008, a cumulative total of 78,396 people have been cured of leprosy in East Java, of whom 7,641 suffer from permanent disability.

According to the East Java health authorities, the problems the province faces include low-level commitment of policy makers ("leprosy is not interesting for them"), a lack of IEC activities and materials in high-prevalence areas, low involvement of public hospitals in treating leprosy and insufficient community empowerment related to social problems.

"Indonesia faces a number of challenges over leprosy," says Dr. Christina Widaningrum of the health ministry's Directorate General Disease Control and Environmental Health. "Perhaps the biggest is to develop community awareness, so that people come forward and seek treatment." ■

IN THE CLASSROOM

LEARNING ABOUT LEPROSY

At a village in Lamongan, about two hours' drive from East Java's provincial capital Surabaya, around 30 elementary school children are attending a special class on leprosy one Saturday afternoon in June. Their teacher, Ahmad Zainudin, knows the subject well. Some four years ago, after being diagnosed with the disease, the educator found his colleagues giving him a wide berth and his various teaching jobs drying up. It was a bitter time in his life, and the experience led him to help set up PerMaTa, an organization of and for people affected by leprosy, dedicated to fighting for their rights and rooting out stigma.

One school kept faith with Zainudin — the school where he teaches today. A 'natural' in front of a classroom of kids, he has a gift for communicating with his young charges, and on this particular topic he speaks from the heart. As he talks, different images and words are projected onto the classroom wall: the bearded features of G.A. Hansen, the Norwegian physician who identified the bacillus that causes leprosy in 1873; "Mycobaterium leprae," the name of the disease's causative agent; an armadillo, the only significant natural reservoir of leprosy apart from humans.

In the course of the lesson, there seems a lot of information for such a young class to absorb, but Zainudin has no hesitation in laying out all the facts. "It's important to teach children the correct information early in life," he says. "They have good brains. That way, as they get older, they will know not to stigmatize someone just because he or she has leprosy." Having endured the pain and hurt of rejection himself, Zainudin is determined that no one should have to experience the same on account of this disease.

Life at Liteta Hospital

Zambia's former national leprosy center has living reminders of its past role.

Dr. Jombo Namushi

Quiet-spoken Dr. Jombo Namushi, 32, is the medical officer at Liteta Hospital in Chibombo District, about 80 kilometers north of the Zambian capital, Lusaka. The hospital was founded in 1959 as a national tuberculosis center for then-Northern Rhodesia. Four years later, it became the national leprosy hospital and training center, functioning in this capacity until 1993, when it was converted into a district hospital under nationwide health reforms.

The hospital sees an average of two to four new cases of leprosy a year, according to Dr. Namushi. As of the beginning of July, there were seven patients receiving multidrug therapy on an outpatient basis. In addition, there are 13 people affected by leprosy living in the nearby "invalid compound." A further 22 affected persons live in the surrounding villages.

Up until 1993, anyone in Zambia diagnosed with leprosy was sent to Liteta for treatment. Since then, it has been health ministry policy to treat new cases close to their homes to make treatment more accessible and to reduce the stigma attached to the disease. Because the name Liteta remains associated with leprosy, however, some patients still come from other parts of the country to be cured.

> "The health reforms had a positive impact. Patients can now be treated anywhere."

"The health reforms had a positive impact," said Dr. Namushi. "Patients can now receive treatment anywhere. Centralized treatment is what led to the social dislocation of the people you find here." He cites the example of Minison Shamwata, 73, who had to leave behind his family in Southern Province when he came for treatment in 1971 and remains in the invalid compound 38 years later.

Dr. Namushi says that although discrimination still exists, it is nowhere near the level it was at in the past. The integration of leprosy services into the general health services has made a difference, and the public has a better understanding of the disease. "A lot of people today understand that leprosy is a treatable disease and not something you get just from a handshake," he says. For its part, Liteta Hospital places any leprosy-related inpatients together with other patients.

That said, Dr. Namushi admits that he still encounters negative comments from time to time. "People say, 'Oh, you come from Liteta. I hope you won't infect us.' While most don't really mean it, a few probably do," he says. Ignorance is part of the reason, as well as biblical representations of leprosy as an unclean disease. "Zambia is a Christian nation. People read the Bible. In biblical times, a person with leprosy would be abandoned in the bush or the mountains," he says.

LACK OF RESOURCES

In its dealings with leprosy today, most of the challenges the hospital faces are resource-based and relate primarily to the presence of people affected by leprosy living in the invalid compound. Dr. Namushi lists a few of the issues. Water-related infrastructure is inadequate and water must be rationed, making it harder for those with wounds to practice self-care. There is a lack of shoe-making equipment to provide those living in the compound with appropriate footwear, which ideally should be made on site to their specifications. Laundry equipment is old and not functioning. Toilets are some distance from the compound, and the walk there can exacerbate injuries, particularly at night, because there is no electrification. Keeping the toilet area clean is yet another challenge. The residents have taken this task upon themselves, in spite of their disabilities, because the hospital can't afford to pay for a cleaner.

"Developing countries encounter a lot of problems," Dr. Namushi says. "You just try to make do with what you have to sustain the services."

NEW NEIGHBORS

On a positive note, the local community now has a police post. "The police told us that if we wanted a police post, then we would have to provide them with accommodation. As the only houses available were in the invalid compound, in the beginning they didn't like the idea," recalls Dr. Namushi. "Eventually, though, they came to accept it." Now several policemen and various other workers live in the compound among people affected by leprosy — and in this way a few more bricks in the wall of discrimination have been removed. ■

Leprosy FACT

- Among communicable diseases, leprosy is a leading cause of permanent physical disability. Timely diagnosis and treatment of cases, before nerve damage has occurred, is the most effective way of preventing disabilities due to leprosy. The disease and its associated deformities are responsible for social stigma and discrimination against patients and their families in many societies. (From the WHO's *Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy*)

Travels in Asia and Africa

Initiating a new project in Indonesia, encouraging Zambia to keep focused on leprosy, and visiting a home for people affected by the disease in Singapore.

INDONESIA (JUNE 13-15)

In June I traveled to Indonesia. The main purpose of my visit was to attend the official launch of a new project on leprosy and human dignity. This is a joint initiative of the Association of Southeast Asian Nations Secretariat (ASEC) and The Nippon Foundation of which I am chairman. The project is a region-wide movement to restore the dignity and realize the social reintegration of people affected by leprosy. It is one of five projects to be implemented based on a Memorandum of Agreement our organizations signed in June 2008. Never before has a regional body taken up leprosy as a human rights issue, so the ASEC-TNF Project has deep significance. Over time, I am hopeful it can make a real difference to the lives of people affected by leprosy.

With Dr. Surin Pitsuwan, ASEAN Secretary General

The project, which is in its infancy, begins in Indonesia, where ASEC has its headquarters. It is an appropriate starting point, as Indonesia has the highest leprosy burden in ASEAN — 17,000 new cases in 2008 — and stigma remains a deep-seated problem.

For an update on the situation in Indonesia, I arrived in the country a couple of days early, flying into Surabaya, the provincial capital of East Java. East Java has more new cases of leprosy than any other of Indonesia's 33 provinces, newly diagnosing about 5,000 cases annually. Of these, around 600 are children, or a ratio of 12%. Because of the stigma, the disease can affect their education and create problems for them later in life in terms of work and marriage. The proportion of grade 2 disability is similarly high among new cases, at around 11%, placing a burden on families and communities. Indicative of the scale of the problem, I was told that intensive surveys uncover still more new cases, indicating an urgent need for information, education and communication activities at the grassroots level.

Winners of the coloring competition in Surabaya

Following my meeting with health officials, I visited a local convention center where I had been asked to hand out prizes to students in a coloring and writing contest to promote leprosy awareness. I also watched part of a drama about stigma and discrimination performed by high school students.

In the afternoon I traveled to Lamongan, about two hours from Surabaya, where I sat in on a lesson about leprosy being given by Ahmad Zainudin to a class of elementary school children. I first met Ahmad in Manila, when he attended the launch of Global Appeal 2007 to end stigma and discrimination against people affected by leprosy. It was around that time that he and Adi Yosep (see page 2) were in the process of forming PerMaTa, an advocacy organization of and for people affected by leprosy of which Ahmad is now president.

Several members of PerMaTa accompanied me during my stay in East Java. Among them was Farida, who was one of two people affected by leprosy to read out the text of Global Appeal 2009 in London at the start of this year. I was delighted to hear that Farida's visit to London has inspired her to study English and to become more active in PerMaTa as well.

On my last day in East Java, I traveled to Sumber Glagah hospital, about an hour's drive from Surabaya. Established as a leprosy hospital in 1955 by Dutch doctors, the 100-bed hospital today sets aside half its beds for people affected by leprosy. They receive all treatment free of charge, whatever their illness. The hospital

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A patient at Sumber Glagah Hospital practices self-care.

offers reconstructive surgery, has a physiotherapy department, and also makes shoes and artificial limbs for patients. During my tour, I came across a group of patients practicing self-care, so I stopped briefly to chat with them and help them wash their feet. All in all, I found the hospital to be extremely well-run and was very impressed by what I saw.

A few minutes' walk from the hospital is the village of Sumber Glagah. Its population includes about 180 people affected by leprosy. Some run their own small businesses or work as day laborers, and others have land for growing crops, but I understand that many make a living from begging, traveling by motorcycle to nearby towns for that purpose. Just before I left, as I was addressing a group of villagers, one of them loudly announced that he was tired of visits such as mine that never amounted to anything, and demanded work. His anger was understandable. With social reintegration still problematic, I am hopeful that the ASEC-TNF Project will pave the way for more opportunities for this gentleman and others like him by making it easier for people affected by leprosy to find jobs and be accepted by society.

Scene from nearby Sumber Glagah village

ZAMBIA (JUNE 30-JULY 4)

It had been almost 20 years since my last visit to Zambia when I flew into the capital Lusaka at the end of June for an update on that country's leprosy situation. With a population of around 12 million, this southern African nation famous for its copper reserves covers an area of over 750,000 square kilometers and shares borders with eight countries.

Zambia successfully achieved the WHO's goal of eliminating leprosy as a public health problem in the year 2000. However, as in many other countries that have passed this milestone, it is important to ensure that the disease is not forgotten. Thus my visit was intended to remind political leaders that they need to remain aware of leprosy, even though they have other disease priorities such as HIV/AIDS, TB and malaria.

Leprosy control activities in Zambia began in earnest in the 1930s, when the country was known as Northern Rhodesia. Missionaries established leprosaria, and by 1968, four years after Zambia had won its independence from Britain, there were a total of 31 leprosaria in the country.

With the introduction of multidrug therapy to Zambia in 1986 and the implementation of health reforms in the 1990s, there was a change in treatment policy and leprosaria were converted into general hospitals. I visited one of these, Liteta Hospital, during my stay.

But first I called on Health Minister Kapembwa Simbao and his team to learn more about the current leprosy situation. Accompanying me were the WHO's country representative Dr. Olusegun Babaniyi, and Dr. Landry Bide from the WHO Regional Office for Africa.

Zambia currently reports about 300 new cases of leprosy a year. Most are found in Northern Province and Western Province, prompting Dr. Bide to suggest that the health ministry consider

EXCERPT

- "Persons affected by leprosy have a major role to play in leprosy services, especially in the areas of advocacy, awareness and rehabilitation. Organized efforts by persons affected by leprosy are vital to promote a positive perception and attitude about the disease among the public; to bring about essential changes in the legal measures that are discriminatory in nature; and to ensure that leprosy control continues to occupy an important place in the health policy framework of the country." (From the WHO's *Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy*) scaling up activities in these areas.

The health minister said the government was committed to fighting leprosy, despite the heavy demands made by other diseases. However, the ministry's own presentation acknowledged that its efforts were hampered by a number of factors. These included inadequate staffing at provincial and health facility levels, inadequate knowledge and skill among general health staff, inadequate skills and competencies among district coordinators, lack of community awareness and participation, high levels of stigma, and inadequate rehabilitation and care services for people affected by leprosy.

Issues include inadequate human resources and lack of community awareness.

The ministry's presentation also showed there were some gaps in the records. Data for the years 2000 to 2002 was missing and there was low reporting from districts in 2005-2006.

On the subject of data, Dr. Babaniyi encouraged the ministry to implement measures to review data on leprosy control on an annual basis in order to make recommendations on ways to reduce the burden further.

Later the same day, I called on President Rupiah Banda, who kindly made time to meet with me while recuperating from a recent knee operation. I emphasized that although Zambia had achieved the WHO's goal of eliminating leprosy as a public health problem, it should not become complacent, as there was still much to be done, including the work of eliminating stigma and discrimination.

With Zambia's President Rupiah Banda in Lusaka

The president remarked that while he was often called upon to address diseases such as HIV/AIDS and TB, he was never called upon to speak about leprosy. He was interested to learn that I would be visiting Liteta Hospital and said that "in our culture we are afraid to shake hands" with people affected by leprosy and that "there are a lot of diseases we are superstitious about." But after hearing about my work he said he now knew better. He asked the health minister, who was also present, to redouble efforts to eradicate leprosy.

On my visit to Liteta I was accompanied by representatives of the Zambian media, some of whom were learning about leprosy for the first time. After a briefing from hospital staff, I met with some people affected by leprosy who live in a nearby "invalid compound," a legacy of the days when the hospital was a national leprosarium and people who were sent there for treatment were effectively abandoned by their families. I made a point of shaking hands with each person I met, and I hope that these images captured in photographs and broadcast on TV will help to break down lingering discrimination toward people affected by the disease.

In concluding this account, let me mention an anecdote that the health ministry's permanent secretary, Dr.Velepi Mtonga, related. Attending a village function on World Leprosy Day, she heard a child say, "A friend with leprosy is still a friend to me." Remarked the permanent secretary, "It's a cause for hope if a young child says this." I couldn't agree with her more. Reaching children with the right messages is a key aspect of community awareness.

SINGAPORE (JULY 5)

Traveling back to Japan by way of Southeast Asia, I took the opportunity to pay a visit to SILRA Home in Singapore. Founded in 1971, SILRA Home provides accommodation and care for people affected by leprosy. In 2005, it relocated from aging premises to a newly-built facility. Today, 51 residents ranging in age from 59 to 90 live there — a generation with nowhere else to go. Their experiences, and those of their counterparts in the Sungai Buloh Leprosy Sanatorium in Malaysia, are recounted in a new book by Loh Kah Seng (see page 8). I look forward to reading it. ■

‘A Quest for Justice’

Resolution inspired by Father Damien canonization is adopted in Rome.

A resolution promoting the equal and inalienable rights of every human being has been drawn up by three organizations working in the field of leprosy on the occasion of the canonization of Father Damien this October.

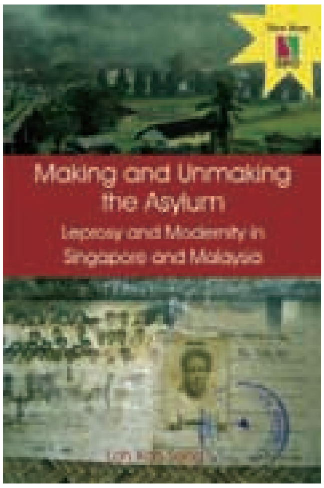
The IDEA, ILEP and AIFO resolution notes that the canonization of Father Damien for his service to people with leprosy “provides … an unprecedented opportunity to focus the world’s attention on the modern-day realities of leprosy … and enables us to promote issues of justice and human rights that were the cornerstone of his work.”

The resolution, which was adopted in Rome at the end of May, stresses that leprosy is curable, that use of the term “leper” is not appropriate in modern times, and that people who have experienced leprosy are equal partners.

To read the full text of the resolution, and to sign it, visit the AIFO website: www.aifo.it/english/

NEWS EXTRA

In June, the Chief Minister of Delhi followed through on her promise and raised the monthly pension of people affected by leprosy in Delhi from Rs. 1000 to Rs. 1800.



LEPROSY HISTORY

A new book on leprosy in colonial and post-colonial Malaysia and Singapore looks at the policies and laws applied to people diagnosed with the disease, and the way patients confined to sanatoria contested the regimes imposed on them, often in ingenious ways.

Author Loh Kah Seng, a visiting research fellow at the Institute of Southeast Asian Studies, conducted extensive interviews with surviving residents of SILRA Home in Singapore and Sungai Buloh National Leprosy Center, Malaysia, for part of his story. Having struggled to make their asylums into homes, many have faced eviction or relocation late in their lives. The book explores their fate, and raises questions about the way they have been treated.

Making and Unmaking the Asylum: Leprosy and Modernity in Singapore and Malaysia, is published by SIRD in Singapore. ■

FROM THE EDITORS

SOCIAL CHANGE IN CHINA

Ryotaro Harada took a message of “joy in action” to Indonesia recently. The Japanese resident of China had been asked to speak at a sensitization workshop in connection with the launch the ASEC-TNF Project on Leprosy and Human Dignity. JIA, of which he is general secretary, organizes volunteer work camps at leprosy villages in southern China. There are about 600 such villages, home to 20,000 people.

Work camps see student volunteers live for one to three weeks in a village, carrying out tasks from building toilets to doing housework. In 2002, JIA organized activities in two villages; last year, it did so in 37. Each village is a stage to change society, Harada said. People from surrounding districts start to lose their fear of the settlement when they see students eating and drinking with the villagers and going hand-in-hand with them to local markets. Villagers start to gain confidence to venture beyond the village.

Strong personal relationships develop between villagers and volunteers, which is why the latter keep coming back. They are not service providers; they are there because they want to be. People think students in China are just interested in getting good jobs, said Harada, but their mindset is changing. They believe the “problem” of the leprosy villages is their problem and they should do something about it. He is also hopeful that the growing network of volunteer alumni will bring further change to society as they come to occupy influential positions in decades to come.

Harada first worked as a volunteer in a village called Linho. Once a symbol of segregation, it is now a symbol of integration. There he met his wife, a fellow volunteer and work camp staff member. They were married in the village, and when their daughter was born they named her Linho.

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Publisher
Yohei Sasakawa
Executive Editor
Tatsuya Tanami
Editor
Jonathan Lloyd-Owen
Associate Editors
Sumiko Okamoto,
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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Sasakawa Memorial
Health Foundation,
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www.nippon-foundation.or.jp/eng/