

FOR THE Elimination OF Leprosy

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



President of India Dr. APJ Abdul Kalam welcomes Goodwill Ambassador Yohei Sasakawa and his party in New Delhi on September 15, 2006.

A MESSAGE FROM THE GOODWILL AMBASSADOR

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Good Job, Keep It Up

This year, I have been heartened by the progress made by a number of countries in eliminating leprosy as a public health problem.

India, which accounts for 70% of the world's leprosy cases, announced in January that it had achieved the WHO's target, as did Angola. In August, Madagascar declared that it too had reached the threshold. Brazil, which I visited in June, is on track to achieve elimination either at the end of this year or early in 2007. I would like to offer my warm congratulations to all the people involved who have worked so hard to make this possible.

I now look to the remaining countries — Mozambique, Tanzania, the Democratic Republic of Congo and Nepal — to redouble their efforts and follow in the footsteps of India, Angola, Madagascar and the rest. I believe Angola, where I traveled in August, can serve as a good role model. Before I left Luanda, I encouraged officials there to share Angola's strategy for success with others yet to reach the goal.

For those who feared that achieving elimination

would signal the end of a country's commitment to leprosy control, I can say these fears are without foundation. In India and Angola, the authorities view the achievement as a milestone, not the end of the road. They have not slackened in their efforts and remain committed to building on their achievements.

Just last month I had the opportunity to meet with the president of India, His Excellency Dr. APJ Abdul Kalam. In the course of our conversation, Dr. Kalam expressed his concern over the continued existence of leprosy colonies in India — there are over 700 — and spoke also of the need to rehabilitate persons with leprosy-related disabilities.

Breaking down the barriers that separate persons affected by leprosy from mainstream society and caring for those with medical problems related to the disease are important themes. As we push ahead toward a world without leprosy, we must do all we can to help those people whose lives have already been affected.

— Yohei Sasakawa, WHO Goodwill Ambassador

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HANDA's Helping Hand

Over the past decade, a Chinese NGO has transformed the lives of thousands.

HANDA Rehabilitation & Welfare Association turned 10 this year. We asked Zhou You, the organization's president, for his thoughts on HANDA's impact.

How has HANDA* changed your life?

Before I joined HANDA I was a nobody and faced discrimination. Now I feel I can live in society like anyone else. I've also been abroad to exchange views with people affected by leprosy, which has greatly improved my self-confidence. HANDA's greatest achievement has been to help people like me return to society — and even go overseas.

What was your first contact with the organization?

I knew Dr. Yang [the founder of HANDA] before HANDA was set up. At the time, I was working in Mazhou Hospital in Guangdong Province. The hospital was associated with dirt and disorder. To improve its image, I organized people living in and around the hospital to collect money to establish a small garden and add some greenery. We greatly improved our living environment, which made a good impression on visitors. Other hospitals subsequently followed our example. When Dr. Yang was trying hard to set up HANDA, he went to many hospitals and villages seeking activists to work together for people affected by leprosy. He invited me to attend the first HANDA meeting in Guangzhou in 1996. I became involved in HANDA activities from that point.

In what important ways does HANDA assist people?

First, we try to reduce stigma and discrimination. We hold commemorative activities every March 11 — the International Day for Dignity and Respect. We do a lot to educate the public. Lately, we've been going to universities and inviting student volunteers to

get involved. It's having a real impact.

Second, we've begun many programs on behalf of people affected by leprosy, including providing scholarships for more than 800 children of affected persons. We have helped a few of these children go on to college, and one is now studying for a master's degree.

Third, HANDA has changed the attitude of people affected by leprosy from one of self-contempt to one of self-confidence. Before HANDA, we dared not use public transportation, even though people had no idea about our background. We always walked with our heads bowed. Some of our members caught the disease when they were children and were sent to hospitals which they had never left. Thanks to HANDA activities, they can now go out into the world and see how society is developing. They can even stay in a hotel when HANDA organizes some activities.

What challenges does HANDA face from now on?

One of the challenges is to surmount the big gap between our needs and available resources. There are still many people affected by leprosy who face great difficulty and are in need of help. We only get very limited support, mainly from international organizations. We hope we can get more, and also get support from national organizations and enterprises.

Does HANDA's experience hold lessons for persons affected by leprosy in other countries?

HANDA can share its experience in carrying out public education activities to reduce stigma and discrimination. We also feel that providing the opportunity for people to communicate and share their experiences is a very important way to improve their self-confidence and self-respect. ■

Zhou You



Zhou You was first elected HANDA president in 1999. He was reelected in 2004.

* See also Partners on page 5.



Part of the celebrations marking HANDA's 10th anniversary in August

Turning a Lens on Leprosy

A documentary filmmaker talks about the discoveries he made during the filming of *Leprosy in the 21st Century* for BBC World Television.

AUTHOR:
David Notman-Watt

David Notman-Watt is founder of back2back productions, Ltd., an independent television production company based in Brighton, England.

At the start of 2006 I began working on two 30-minute documentary films to be aired on BBC World Television this November. Working closely with the Sasakawa Memorial Health Foundation and The Nippon Foundation, I devised a schedule that included filming trips in Ethiopia, India, Brazil and Culion Island in the Philippines.

As a journalist and filmmaker for over 10 years I have been fortunate to cover numerous stories on diverse subjects. I must confess, however, that I knew very little about leprosy. I am ashamed to say that I blindly believed many of the untruths that I now know surround the disease. Stereotypes and fabrications seem to have become part of its history. Friends jokingly told me to be careful when I prepared to leave for my first filming trip. Many were worried I would be infected. My insurance broker expressed concern.

Once I began to research the topic, I was shocked to discover the culture of folklore that has developed around the disease. The general public seems to have drawn conclusions about leprosy from how it has been portrayed in Hollywood films rather than from any factual knowledge — and I include myself in this shameful ignorance.

Many people I spoke to weren't even aware leprosy still existed today. Where other diseases still grab headlines (and rightly so), leprosy seems to have been banished to the sidelines. As I learned more, opinions expressed in articles or interviews came to seem ill-informed. I began to feel that leprosy had become a forgotten disease.

An islander in Culion, Nestor Lisboa, summed it up quite well one evening as we sat talking

about how those with leprosy have been treated over the years. He said: "Probably because of the stigma of leprosy, they want to separate it, not to contaminate other people, healthy people. At that time, leprosy was treated like AIDS is today — to segregate these people — because they are grotesque, but most of all because of the fear of this disease."

I'm pleased to say my eyes were opened as I began filming. In every country I visited, patients and those cured of the disease could not have been further from the Hollywood myth. Birke Nigatu and the villagers of Denebework in Ethiopia; Francisco da Silva and his wife Maria Soledade deep in the Amazon jungle; Mr. Diwali and the residents of Satya Jeevan Kusht Ashram in New Delhi; the residents of Culion Island with their extraordinary history...

"I did not meet victims. Far from it. I met strong, committed people focused on overcoming stigma."

I did not meet victims. Far from it. I met strong, committed people focused on overcoming the stigma and ignorance that still surrounds leprosy today. Organizations like ENAELP, the Ethiopian National Association of Ex-Leprosy Patients, and communities like Bharat Mata Kusht Ashram in India showed me that people affected by leprosy are now organized. They have created working business models and formed impressive networks that allow them to interact with society on a level playing field. These films are not a depressing tale of broken souls, but rather a positive investigation into individuals around the world taking control of their lives — together.

It is impossible to tell the whole history of leprosy in 60 minutes of television. But what I have tried to do, by recounting some of the remarkable stories I was told this year, is destroy some of the myths surrounding the disease. I sincerely hope I have managed to capture the spirit and bravery of the people I have had the pleasure of meeting in the making of these two films. And I thank them all for making me, and the rest of my team, so welcome.

Leprosy in the 21st Century is a back2back productions ltd. film for BBC World Television, filmed and directed by David Notman-Watt. It airs in November. ■

Interviewing Yohei Sasakawa in Culion in May



Silra Home Revisited

Even with the best of intentions, moving an elderly group of former leprosy patients to a modern facility creates new problems while solving old ones.

On 10 September 2006, I paid a return visit to Singapore Leprosy Relief Association (Silra) Home, exactly one year after it was relocated to new premises in Buangkok Green Medical Park.* Walking through the multi-storied building, I saw many familiar faces, and we nodded and smiled at each other in acknowledgement.

Explaining the reasons behind the move, the authorities said at the time that the old home was run down and the site was needed for a new school. Consequently, the relocation to a brand-new building with modern toilets and elevators in an accessible area was billed as progress. But for the aging residents, whose interests were yet again sacrificed in the name of moving forward, it represented one more act of dislocation in their lives.

In the past, many had lived in Trafalgar Home — formerly the Singapore Leper Asylum — where they had jobs as cooks and cleaners, nursing aides and clerks. When Trafalgar closed in 1993, they were moved to Silra Home, minus their jobs in most cases. Then, last year, came the move to the new Silra Home in Buangkok Green.

The shift to Buangkok Green is probably the final journey for the 60-odd residents, who are in their 60s to 90s, and about half of whom are wheelchair-bound.

They had to exchange their clothes for hospital uniforms, even though they are not ill.

Some welcomed the move. A TV program from 2005 shows them applauding the new premises for being cleaner and free of mosquitoes. The dilapidated buildings at the old Silra Home (constructed in 1971) were a fire hazard. One resident remarked happily that they no longer risked being struck by falling ceiling beams that had been eaten through by termites.

But for others, despite the better, modern living conditions, relocation has brought a fresh set of problems. In building the new facilities, the planners overlooked the basic needs of leprosy-affected persons. There is only one cubicle per toilet with wheelchair access and only three toilets in all for more than 20 male residents on the second level. The cubicle door handles, which conform to building standards, are too short to be gripped by those with hand



The author (left) with Mr. Chan Mun Tuck at Silra Home on 10 September 2006

disabilities. Residents must negotiate a ramp to access the wheelchair toilet. Wheeling up the ramp, residents have slipped and fallen on their heads.

In the old Silra Home, they lived three or four to a room. Now they sleep on hospital beds, more than 20 to a ward. They have had to exchange their own clothes for hospital uniforms, even though, as some protested, they are not ill. Meanwhile, they have been joined by other, non-leprosy affected persons, admitted with skin diseases.

The sleeping arrangements apply to married couples, too: Mr. Chan Mun Tuck and his wife are allocated two beds in one corner of the ward — the nearest thing they have to privacy. Mr. Chan and his wife have repeatedly asked for a partition but so far have received nothing but assurances.

Many residents feel disillusioned and apprehensive and long for the old Silra Home. Mr. Song Kok Huar recognizes the cleanliness and lack of mosquitoes. But he reminds me that the old premises had trees, grass and better ventilation, and says the new home “can’t beat that place.” Another couple, Mr. Kuang Wee Kee and Mdm Ow Ah Mui, decided against moving to the new premises and rented a one-room flat nearby. They disliked the communal living quarters and view the new home as “a camp.”

Those who suffer most are individuals with serious disabilities, such as Mr. Joseph Tan, who is 84, blind, wheelchair-bound, and has hand

AUTHOR:

Loh Kah Seng

Loh Kah Seng is a PhD candidate in History at the Asia Research Centre, Murdoch University. He is working on a social history of the making of modern Singapore.

* ‘The Ambivalence of Relocation: The Experiences of Individuals Affected by Leprosy in Singapore’. The STAR, Carville. 64 (2), July-December 2005: 9-14.

disabilities. Once, he slipped on the toilet ramp and hurt the back of his head. “I’m accustomed to the old place,” he laments. Even after a year, he still can’t find his way to the toilet by himself.

NO PRIVACY

Mr. Lim Kah Lee, a renowned painter and the de facto “voice” of Silra Home, says plainly that nothing has been done to address residents’ complaints. “There is still no privacy and the ward is too open. It is too difficult to go to the bathroom to change our clothes every time, too inconvenient and troublesome.”

Something did change, but only at a high cost. Mr. Lim and Mr. Tan Ah Boon related to me that Mr. Lim Ah Liat, a wheelchair-ridden resident in his 70s, went to the toilet on the second floor at night about two months ago. He fell off his wheelchair on the ramp when leaving the toilet, and died. Staff discovered his body at about 3.30 a.m.

Mr. Lim had been unwell and taking medication, so it is difficult to say how much the fall had to do with his death. Soon after, volunteers staged a skit on how to use the toilet safely. More importantly, the management placed a large aluminium sheet with a patterned surface about four feet long over the ramp in two toilets on the second floor, reducing the angle of the incline and providing a better grip for the wheels.

Mr. Lim Kah Lee tells me the sheets are

being tested for a trial period and there have been no incidents since. The wheels of progress generally turn fast in Singapore but, despite many appeals by residents from the beginning over the toilet ramps, not quickly enough for when it comes to catering to the needs of former leprosy sufferers.

Between those who look back nostalgically to the old home, and the few who reject the present Silra Home premises outright, the majority of residents have come to terms with their new environment, just as they have done repeatedly throughout their lives. The result is a perspective on life that straddles resilience and resignation.

Mr. Lim Ah Hin, a charming man with a small, wiry frame and thick spectacles who plays the harmonica, says he is “simply waiting to die.” Mr. Tan Teow Meng, one of the most vigorous persons in the home, tells me, “I am now so old. The future? I will have no more road to walk. Now, what I wish for most is to simply pass my days, live my life, that’s all.”

At the very least, they deserve to live out their remaining years with all due consideration given to their needs and dignity.

The article is based on interviews with the following residents of Silra Home, Singapore, in September–November 2005, and February and September 2006: Chan Mun Tuck, Kuang Wee Kee, Lim Ah Hin, Lim Kah Lee, Ow Ah Mui, Tan Ah Boon, Joseph Tan, and Tan Teow Meng. ■

PARTNERS

HANDA REHABILITATION AND WELFARE ASSOCIATION (HANDA)



HANDA, which celebrated its 10th anniversary in August, is an organization of people affected by leprosy that was registered as an NGO in Guangdong Province, China, in 1996. It works as a branch of IDEA — the International Association for Integration, Dignity and Economic Advancement — with a mission to promote dignity and respect among all human beings, particularly those affected by leprosy.

Since its founding, HANDA has worked to eliminate social discrimination against affected persons and improve their quality of life through social, psychological, physical and economic rehabilitation. Activities include

organizing skills training workshops; providing small loans to help start income-generating projects that lead to economic independence; running a mobile eye unit and comprehensive foot-care project; helping children of affected persons go to school; and mobilizing social resources to improve the basic living conditions of those with leprosy. It also operates HANDA Quilt, a micro enterprise begun in 1997 that exports handicrafts to several countries.

HANDA is now based in Guangzhou and is active in seven provinces in China. It has made rapid progress in its first decade, and will continue to help persons affected by leprosy as it works toward its goal of a world free of discrimination and full of equality.

Southern African Journey

Following up on previous visits to Africa, the goodwill ambassador visits Lesotho, Angola and Mozambique to check on progress in the fight against leprosy.

LESOTHO (JULY 31 - AUGUST 1)

At the end of July I made my first visit to Lesotho, a landlocked country surrounded by South Africa. Lesotho achieved elimination some years ago, and with just seven new leprosy cases discovered last year, it is close to eradicating the disease altogether.

Arriving in Maseru I headed straight for the office of Minister of Health and Social Welfare Dr. Motloheloa Phooko. The minister briefed me on Lesotho's progress in combating leprosy. He said that political commitment, human resources, free drug supply and community education had all played their part.

Yet there are still areas of concern, including weak surveillance, the existence of social stigma and difficulties in tracing patients due to geographical factors. Speaking of the country's public health situation in general, the minister spoke of a number of challenges hampering health service delivery, especially at the primary healthcare level. He said the country needed to strengthen health centers and train new community health workers.

During my stay, I paid a visit to the Botsabelo Leprosy Hospital. In 1976, there were over 1,000 people hospitalized here. Now there are just seven. I noticed most of the patients under treatment were suffering from disabilities, indicating that stigma may have prevented them from seeking treatment sooner.

It was in Lesotho that I was first asked if I knew the story about the cassava tree: "If your cassava tree grows more than 1 meter tall, then you will get leprosy." Myths about leprosy abound all over the world, and Lesotho is no different. The only way to counter these misconceptions is to inform, educate and communicate.



A well-attended partners meeting in Angola

ANGOLA (AUGUST 2-5)

Angola achieved the elimination target around the same time as India, at the end of December 2005. When I last visited three years ago, there were problems with the distribution of MDT, suggesting elimination could take some time. But thanks to collaboration between the government, the WHO and NGOs, Angola achieved elimination more quickly than I had thought possible. The prevalence rate now stands at 0.93 per 10,000 population.

The main purpose of my visit was to attend a partners' meeting. Chaired by the health ministry, this takes place every year, attended by representatives from ILEP members and other NGOs. Topics ranged from the need to increase the number of health centers where proper diagnosis and treatment are carried out (there are still individual provinces where the PR is in excess of 5) to using books and magazines to spread correct information about leprosy to reinforcing collaboration between the private and public sectors.

Dr. Luis Gomes Sambo, the WHO's regional director for Africa, also attended the meeting. A native of Angola, Dr. Sambo is delighted that his country has achieved elimination, and suggested Angola should serve as a model for other African states that have yet to achieve the goal.

Angola can serve as a model for others yet to achieve elimination.

The next day I visited Funda, a community center for the rehabilitation of leprosy patients about 50 kilometers from the capital, Luanda. Here, residents engage in activities such as shoemaking and wheelchair manufacture, and sell their products to the country's remaining leprosy sanatoria. Today, only six sanatoria are left. The rest have been converted into general hospitals or old people's homes.

Wherever possible, Angola actively encourages the reintegration of persons affected by leprosy into the local community, donating housing and providing assistance so that affected persons can live with their families. I was told that six families from Funda have received assistance and moved to the suburbs of Luanda, and that another five

Leprosy FACT

- The global registered prevalence of leprosy at the beginning of 2006 was 219,826 cases. The number of new cases reported during 2005 was 296,499, a 27% drop compared with 2004. (Source: WHO)



(Left) At Funda, residents make shoes and (right) durable wooden wheelchairs such as this one.

are set to follow.

My field visits in Angola were organized with the help of ARPAL. This local NGO formed by leprosy-affected persons currently has a total of about 300 members in four cities. Not only does it help affected persons build homes, but it also offers them micro credit and campaigns for their human rights. In a show of government support for its activities, ARPAL's headquarters are in a building donated by the health ministry that was once used as a leprosy treatment center.

I agree with Dr. Sambo that Angola can be a model for the rest of Africa. Amid the public health challenges posed by HIV/AIDS, TB, malaria and other diseases, the elimination of leprosy is a success story, and one that should be promoted.

MOZAMBIQUE (AUGUST 6-11)



A health worker in action in Murrupula district

The final stop on my African journey was Mozambique, one of the countries yet to achieve elimination. Mozambique has a leprosy prevalence rate of 2.5 per 10,000 population, and the number of patients is especially high in the three northern provinces. Among these, Nampula Province has a prevalence rate of 6.3. Thus, strengthening elimination activities in the north of the country is an urgent task.

To bring myself up to date, I headed straight to Nampula. The population of some 4 million is spread over a wide area, and over half live below the poverty line. Visiting a health post in Murrupula provided a stark picture of the challenges on the ground. In Mozambique, these health posts are responsible for the distribution of MDT at the local level, yet I learned that only 25% of the surrounding population lives within a 5-kilometer radius of the Murrupula post, so health service delivery is stretched thin.

In the capital Maputo, I had meetings with President Armando Guebuza, Health Minister Ivo Garrido and President of the Assembleia da Republica Dr. Eduardo Mulembwe. I spoke of my visit to Nampula, and asked for their help in ensuring that budgets are approved in a timely fashion and that drug supplies flow smoothly. More work needs to be done on the distribution of MDT in Mozambique, and I hope the situation will have improved by the time of my next visit planned for April 2007.

I thanked the president for giving a 15-minute radio address about leprosy on World Leprosy Day in January, a truly valuable contribution to raising awareness. I was heartened to learn that the national assembly is thinking of forming a task force on leprosy, and encouraged to hear Dr. Mulembwe say that every assembly member has a responsibility to spread correct information about the disease.

Many of Mozambique's problems are caused by poverty, and unless poverty is eliminated, those problems will remain. The government is now focused on job creation and food supply, but I was assured that leprosy remains a public health priority. Health Minister Garrido said that Mozambique aims to achieve elimination by December 2008. However, I hope this will be possible sooner, and will do all I can to help Mozambique pass this milestone. ■

Program Managers Meet in Maputo

African countries makes progress but still have work to do.

Leprosy program managers from 27 African countries gathered in Maputo, Mozambique, August 22-24 for the annual meeting covering countries in the WHO/AFRO region.

The leprosy situation in the region is improving steadily if slowly. Forty-two countries had achieved elimination by the end of 2005, while four — DR Congo, Mozambique, Madagascar and Tanzania — had yet to do so.

The regional prevalence rate at the end of 2005 was 0.63 per 10,000 population, while the new case detection rate was 0.68. The proportion of cases with Grade II disability remained at 10%.

Operational problems identified include incomplete coverage for leprosy services, high staff turnover, inadequacy of trained personnel and a high deformity rate due to late detection.

Among the recommendations adopted at the meeting:

On implementation of new strategies —

Countries will adopt and implement new global and regional strategies to further reduce the leprosy burden and sustain leprosy control activities; those that have not achieved the elimination threshold should continue elimination activities until they do.

On capacity-building — WHO will develop a training strategy and support countries in training health staff and reviewing training modules. Countries will maintain training and refreshment of health staff.

On social mobilization — WHO will update IEC materials. Countries will organize social mobilization activities in order to change the negative image of leprosy in communities.

On drug management — Countries will review drug management practices so as to avoid shortages and expired stocks.

POD CONFERENCE

A Consensus Development Conference on Prevention of Disability was held in Cebu City, the Philippines, September 13-16. A consensus statement was due to be released shortly. See our next issue for full details.

LEPROSY AND HUMAN RIGHTS

On August 24, the UN Sub-Commission on the Promotion and Protection of Human Rights endorsed the recommendations contained in a working paper on discrimination against leprosy-affected persons and their families compiled by Professor Yozo Yokota.

The Sub-Commission has now requested that the Human Rights Council appoint Professor Yokota as Special Rapporteur to undertake a full and comprehensive study of the topic and to produce a draft set of principles and guidelines to end discrimination. ■

FROM THE EDITORS

DESERVING OF RESPECT

For a group of elderly persons affected by leprosy in Singapore, the move to a new residential facility last year has proved something of a mixed blessing. As Loh Kah Seng recounts on page 4, when they traded a dilapidated building for a clean, modern one, they also had to swap their own clothes for a uniform, and the relative privacy of smaller rooms for beds in a large ward.

Catering to the needs of elderly persons affected by leprosy, while preserving their dignity, is a task requiring sensitivity and understanding — and this generation is particularly deserving.

In Japan, the largest concern of the 3,000-plus residents of former sanatoria, whose average age is 78.2, is how they will live out their remaining days. In Brazil, there is now heated debate on the future of “colony hospitals,” as outside populations cast a covetous eye on colony

premises and the privileges afforded those who live there.

In Taiwan, too, the welfare of elderly persons affected by leprosy has become a focal point of human rights activists after the government decided to close down Laosheng Sanatorium to make way for a subway terminal, and move the aging, wheelchair-bound residents to a new facility. Worse, these plans proceeded without the consent of sanatorium residents, making the upheaval in their lives all the more traumatic.

Speaking of affected persons in Japan, Dr. Fujio Ohtani has said: “Our society once dislocated them to where they are today. After they have made these places their homes for so many years, society should not move them once again.”

Let us treat this aging generation with the respect and consideration it is due.

FOR THE ELIMINATION OF LEPROSY

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

With support from:

Sasakawa Memorial

Health Foundation,

The Nippon Foundation

www.nippon-foundation.
or.jp/eng/