

FOR THE Elimination OF Leprosy

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



Signatories and their proxies on stage for the reading of Global Appeal 2011 at a ceremony in Beijing on 25 January 2011.

MESSAGE

Resolution for a New Year

A new year has begun, filled with hope. Last December, at the UN General Assembly, a resolution submitted by the Japanese government on ending discrimination against people affected by leprosy and their families, together with principles and guidelines, was adopted by consensus by 192 countries. I am delighted that we begin 2011 armed with this resolution.

This year also sees the start of the WHO's Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy (2011-2015). Great strides have been made to control the disease in recent years and the new strategy builds on this progress. Early detection and treatment with multidrug therapy (MDT) remain the key principles of leprosy control. This requires unwavering political commitment and firm resolve on the part of stakeholders. There must be no let up.

The enhanced strategy focuses not only on the medical aspects of leprosy, but also on the disease's social consequences. It places increased emphasis on the human rights of people affected by leprosy,

as well as outlining for them a participatory role in leprosy services. I welcome these developments.

Familiarizing people with the disease and raising awareness of its human rights dimension are extremely important. On 25 January, I was in Beijing for the launch of the sixth Global Appeal to End Stigma and Discrimination against People Affected by Leprosy. When I initiated the first appeal in 2006, I felt this was one way I could draw attention to the issues. This year's appeal was signed by heads of over 100 of the world's leading universities and focuses on the important role that education plays.

With the set of principles and guidelines adopted as part of the UN resolution, the WHO's new five-year plan, and initiatives such as the Global Appeal, there is potential for progress and change. But in order for these instruments to be effective, they must be understood, implemented and adhered to. That is our mission; I ask for your understanding and support.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Lesson from Beijing

Sixth annual Global Appeal underscores the key role of education in reducing stigma.

Education has an important role to play in contributing to public understanding of leprosy and challenging the stigma attached to the disease. That was the main message of Global Appeal 2011, signed by 110 heads of leading universities in 64 countries and regions, and launched at a ceremony in Beijing on 25 January 2011.

The event was attended by about one hundred people, and was hosted by Peking University. The university's president, Zhou Qifeng, was one of the signatories. Attendees included representatives from the China Society for Human Rights Studies, one of the co-organizers, the WHO, the Ministry of Health, NGOs including HANDA Rehabilitation and Welfare Association, and people affected by leprosy.

In his welcome address, Dr. Min Weifang, chairman of Peking University Council, said that while leprosy was under control in China, "it is undeniable that the public does not know that it is curable. We still need more advocacy to eliminate the disease."

Ye Xiaowen, vice president of the China Society for Human Rights Studies, noted that stigma toward the disease remains strong, and said that his organization will continue to play its part in combating discrimination. "We hope more organizations will join this movement in the future," he said.

Speaking on the behalf of the Ministry of Health, Dr. Hao Yang, deputy director general of the Bureau of Disease Control, said the Chinese government had made enormous strides to reduce the number of cases of the disease, and that as many as 500,000 patients had been cured in the past 60 years. He added: "The government well understands that there are still families suffering from stigma and discrimination; hence it co-sponsored the 2008 resolution [on the elimination of stigma and discrimination] at the Human Rights Council."

'AWARENESS AND EDUCATION'

Leading the recitation of the appeal in Chinese and English, respectively, were Dr. Min Weifang and Professor Paul Webley, director of the School of Oriental and African Studies at the University of London, who was one of the signatories.

"The stigma associated with leprosy is rooted in myths and misconceptions that deserve no place in today's world," the appeal states. "With awareness and education, this stigma can be challenged."

The appeal also highlighted education's role as a tool of empowerment: "With education, people affected by leprosy can be empowered to overcome the social and economic barriers that society has



Scenes from the ceremony: the Goodwill Ambassador delivers an address (top) as the audience (above) listens.

placed in their way."

In an address, Professor Webley said: "I am a psychologist by training, so I know the impact stigma has. But stigma can be tackled. Education and communication are key. Education can give those who are affected by stigma skills, knowledge and confidence to make their way in the world. Communication helps those who are stigmatizing others understand and appreciate why they are wrong to do so."

FROM CEOS TO EDUCATORS

The Global Appeal was first launched in 2006 by Yohei Sasakawa to raise awareness of the discrimination suffered by people affected by leprosy. To date, it has received the endorsements of world leaders, people affected by leprosy, NGOs working in the field of human rights, religious leaders, and CEOs of some of the world's leading companies. In his remarks at the Beijing ceremony, Sasakawa applauded the academic community for endorsing the message of Global Appeal 2011.

"Through education, correct understanding and knowledge can be spread. Through education people become aware of others' suffering. It can instill in us a sense that their pain is a matter for us too," he said.

The Global Appeal launch ceremony was followed by a lively press conference, with the Chinese media asking many questions about leprosy in China. Some 50 articles, mostly in Chinese, were generated by the event. ■



Global Appeal 2011

Leprosy FACT

- There are an estimated 220,000 people affected by leprosy in China, including about 100,000 with visible disabilities. Around 90% of people affected by the disease live in the community, while another 20,000 still live in leprosy "recovery villages" or hospitals. Between 2006 and 2010, 8,000 new cases of leprosy were detected.

Toward an Inclusive Society

Pune workshop seeks roadmap to a discrimination-free future.

What is it about the goal of an inclusive society that has proved so elusive? A recent international workshop in Pune, India, sought to plot a way forward to that dreamed-of objective, buoyed by two key developments that target the obstacles in the way. The first was a UN Human Rights Council resolution that endorses principles and guidelines on the elimination of discrimination against people affected by leprosy. The second was a set of WHO guidelines on strengthening the participation of people affected by leprosy in leprosy services. The guidelines will be published later this year.

In the host country India as well, there had been a significant development: the November recommendations of a Parliamentary Petition Committee on integration and empowerment of persons affected by leprosy. The recommendations include amending discriminatory legislation, and were described by workshop chairman Dr. S.D. Gokhale as “a major step in the history of leprosy in India.”

The workshop, titled “An Inclusive Society: Leprosy and Human Rights,” brought together people affected by leprosy and their supporters from nine countries, including Colombia, Ethiopia, Indonesia and South Korea. The task was to evolve strategies and interventions that would enable the inclusion of people affected by leprosy into mainstream society, as well as to formulate a roadmap for the decade through 2010.

Artur Custodio of MORHAN, Brazil’s Movement for the Reintegration of People Affected by Leprosy, spoke for everyone when he said, “We are here with the intention of changing the world for the better,” adding, “We are also here because the world is changing.”

There was particular interest in one of the potential game-changers, the recently adopted UN principles and guidelines. Following up on remarks by Goodwill Ambassador Yohei Sasakawa, Dr. P.K. Gopal (President,

National Forum, India), said the onus was on people affected by leprosy to demand that the government and civil society implement them. “The ball is in our court,” he said. “If we encounter a violation in any area, we can cite the guidelines.”

REACHING THE GRASSROOTS

Participants repeatedly stressed that new tools such as the principles and guidelines must be made both accessible and usable to those who stand most to benefit from them. “Everything about human rights happens at the national and state level; it doesn’t reach the district or block level,” said a participant from India’s Chhattisgarh state. “How are we going to reach people who don’t even know what human rights are?”



Jaime Molina Garzon

The important role that the media plays in spreading awareness and changing attitudes in a variety of countries was highlighted.

For example, Ethiopia’s ENAPAL has a 15-minute fortnightly radio program titled, “The Voice,” which airs nationwide on a government-

owned station. In Colombia, meanwhile, CORSOHANSEN’s Jaime Molina Garzon writes and edits a bulletin on leprosy that appears once every three months as a newspaper supplement. “It has gone some way toward eliminating people’s ignorance of Hansen’s disease,” he said.

Although Indian government officials had been invited to the workshop, none were represented. However, Ram Naik, former petroleum minister and influential supporter of people affected by leprosy, was present, and underscored his commitment in a rousing speech*. From overseas, both Brazil and Indonesia sent representatives from their national human rights councils.

While the workshop concluded with a number of recommendations for raising awareness, guaranteeing socio-economic security and building independence, what was clear is that the envisioned roadmap will need more specific signposting in order to bring the destination of an inclusive society closer. ■



Input from Ethiopia: ENAPAL’s Leulseged Berhane (left) and Menberu Adane at the Pune workshop.

FOOTNOTE

* It was Ram Naik who submitted the original petition on integration and empowerment of persons affected by leprosy to the Committee on Petitions on December 5, 2007.

A Life Well Lived

Dr. Fujio Otani believed in prioritizing social justice, equity and human rights.

Dr. Fujio Otani was a medical doctor and health ministry bureaucrat who played a pivotal role in addressing the wrongs inflicted by government policy on people in Japan affected by leprosy.

As a ministry official, he oversaw their treatment and care as regulated by the Leprosy Prevention Law, which isolated them for life in state-run sanatoria. Otani used his position to ameliorate their living conditions as best he could.

Once he retired from the ministry, however, he came to realize that merely improving life in the sanatoria had missed the point: Japan's leprosy law was deeply flawed and constituted a violation of human rights by exaggerating the threat and severely restricting individual freedoms. His determined efforts to have the law overturned, coming on top of what he had already done for sanatorium residents, earned him their everlasting gratitude.

A graduate of Kyoto University, Otani joined the Japanese Ministry of Health in 1959 after a long bout with tuberculosis and a spell working at a local health clinic. Some 10 years later, he was placed in charge of the nation's leprosy sanatoria.

His first visit to Tokyo's sanatorium, Tama Zenshoen, was in 1972. Residents had a long list of grievances and were demanding that the ministry send someone to hear them out. They were amazed that it was Otani himself who came, and that he listened until dawn. He was, they would discover, a man who treated them as fellow human beings and empathized with their plight.

Otani was also the first bureaucrat to invite people affected by leprosy inside the health ministry; a colleague recalled how the visitors departed with happy expressions on their faces. This was at a time when officials at the local city office near Tama Zenshoen still received hazard pay for dealing with people from the sanatorium, would serve them tea in disposable cups and would disinfect the chairs they sat in.

From Otani's interaction with people affected by leprosy grew a desire to address the discrimination they faced within the health ministry and in society at large. While in charge of leprosy policy, he saw to it that sanatorium residents' accommodation was

improved and their allowances increased. Even when he became Director General of Health Services (the highest post a technocrat can attain), he kept leprosy close to his heart and maintained the friendships he had formed with sanatoria residents.

However, it was in the years after he retired from the ministry in 1983 that he turned his full attention to revoking the Leprosy Prevention Law. He established what is now the National Hansen's Disease Museum, to raise awareness of the discrimination to which people with the disease had been subjected. He organized seminars on leprosy. Perhaps most importantly, he set up a committee of experts, lawyers, and journalists to study the repeal of the law. The report that the committee submitted to the government paved the way for the law's abolition in 1996.

In 2001, a group of people affected by leprosy sued the government, seeking compensation for their enforced isolation. At the trial, Otani was asked by both sides to testify. For six hours he gave his views on the history and treatment of leprosy, the policy of isolation, and the human rights violations inflicted on the sanatorium residents. He

said he had done his best for them under the policy of the time, but had failed to recognize that their rights were being denied. A person in court that day said it was as if Otani was giving evidence before God.

His testimony helped to bring about a ruling in favor of the plaintiffs, which the government chose not to contest. Among its many ramifications, the decision paved the way for sanatorium residents in Taiwan and Korea, originally confined under Japanese colonial rule, to launch compensation claims of their own.

In an article he wrote a few weeks after the verdict, Otani called on lawmakers, government officials, medical professionals, judicial experts and the media to consider the role they played in the perpetuation of the problem. "Reflecting on my own conduct," he wrote, "I feel that Japanese fail to give serious consideration to human rights problems. ... The problem would never have arisen if Japan were a civilized nation that honored basic human



Dr. Fujio Otani (1924-2010)

A Program Manager's Rallying Cry

Dr. Francesca Gajete of the Philippines calls on her counterparts to get the job done.

AUTHOR BIO:

Dr. Francesca Gajete

Dr. Francesca Gajete is Manager, National Leprosy Control Program, The Philippines. She has been involved with the leprosy program for over three decades.

Three decades ago, creating awareness and translating this into actions taken by the leprosy control program was not as difficult a task for a program manager as it is today. Support from international organizations, the national government and non-governmental agencies was focused on eliminating leprosy as a public health problem, on establishing quality leprosy services in sanatoria, and on implementing manuals of procedure and training modules. Leprosy control was *the* priority program back then.

Program managers now are faced with numerous challenges. Foremost is how to reach out to health workers in the field, who are given so many programs to implement. Program managers need to prioritize their actions according to the funds available from the government, international and local partners, but more importantly, according to what the local chief executives want to see implemented. So it is important for a program manager to collaborate with local government units, in order to ensure that the leprosy program is always included in their year-round plans and programs.

One must also be proactive, always planning and thinking ahead. For the Philippines, it has been a difficult journey and it always will be. The frequent changes of political leaders, government officials and field health workers mean we continually have to conduct training in basic leprosy orientation, case management — particularly on prevention of disability — self-care and psycho-socio-economic rehabilitation.

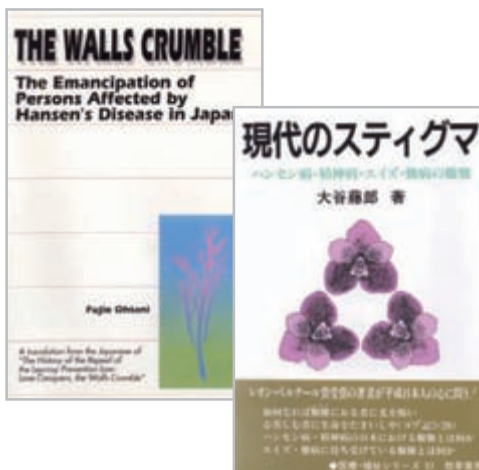
The Philippines' leprosy control program

has proved quite successful, however, in getting national and local government support to enable us to sustain the elimination of leprosy as a public health problem and to provide quality services at all levels of health care. This is not enough, though; we have to be vigilant and constantly aware of the needs of the times so that the program will get the appropriate support at the most opportune time.

We have to be vigilant and constantly aware of the needs of the times.

To beat the odds, a leprosy program manager must possess the virtues of commitment, perseverance and sincerity, as well as a deep concern for persons affected by leprosy — they are, after all, what the program is all about. The Enhanced Global Strategy and Operational Guidelines for 2011-2015 give a more defined role both for program managers and for persons affected by leprosy. They should work hand in hand as partners, and the partnership between them will serve to push forward the human rights dimension to end once and for all the stigma and discrimination that continue to impede our progress.

I issue this call to my fellow national program managers: let us each get our act together so that we hasten the day we attain our common goal of a leprosy-free world. ■



Two of Dr. Otani's books: the work at right is titled "The Current Stigmas: The Hardships of Hansen's Disease, Mental Illness, AIDS and Other Difficult Diseases."

rights and democratic principles. At the root of the Hansen's disease problem are the ills of postwar Japanese society."

In addition to his career with the health ministry, Otani was instrumental in the formation of the Sasakawa Memorial Health Foundation, providing key advice to the small group tasked with its establishment. He went on to serve on the board of trustees, and is remembered with great affection, admiration and respect by all who worked with him.

He also served as the first president of the International University of Health and Welfare and was the author of more than a dozen books that laid out his views on social justice, equity and human rights.

In keeping with his convictions, Otani was firmly opposed to attempts to close down or merge the sanatoria in which people had spent the bulk of their lives. Society excluded people in the past by isolating them in sanatoria, he said; it should not be permitted to move them again for its own convenience.

In a moving tribute at Dr. Otani's funeral, Yasuji Hirasawa, a resident of Tama Zenshoen, described him as "a sun who shined on everyone, nurturing them and helping them grow.... You encouraged us, you gave us a dream. You taught us what it means to live."

Dr. Fujio Otani passed away in December, 2010. He was 86 years old. ■

India and the Middle East

Visits to colonies and a human rights workshop in India, to sanatoria in Egypt, and to a leprosy program managers' meeting in Lebanon.

INDIA (DECEMBER 10-12)

India sees approximately 130,000 new cases of leprosy each year. Nationwide, there are thought to be around 800 self-settled colonies of persons affected by the disease. I am striving to enable the social reintegration of these people, so that they too can lead dignified lives, free from discrimination and prejudice. I was keen, therefore, to attend the *First International Workshop on an Inclusive Society: Leprosy and Human Rights*, in Pune, Maharashtra.

Prior to arriving in Pune, I visited some leprosy colonies in the Mumbai area. The Sanjay Nagar colony in Borivali in the north of the city I have visited previously. It was formed in the 1940s and 50s opposite a cremation ground. Today it is home to approximately 1,500 people.

One of the problems the colony faces is posed by a nearby creek, which floods homes with untreated sewage during the rainy season. The colony's president, Bhimrao Madhale, has raised the issue of flood control with the authorities many times, but to no avail.

Landownership issues are a common concern for colony residents.

Another concern is that of landownership. As Mumbai has expanded, the city now encroaches on what was once wilderness. The colony residents are anxious about the future, but have made no progress with the authorities on the land issue. As they do not legally own the land themselves, they would be in a weak position were they to face eviction. This is a common problem among residents of colonies.

I told them the time had come to join forces with other colonies to address this problem. I believe that if the issue of landownership could be resolved in one state, this would serve as a model for the whole of India.

Next I visited the Panvel Colony about one hour east of Mumbai. It is divided in two by a railway line, and is home to about 28 families, totaling 150 people. A number of small-scale

self-help groups operate there, supported by a Christian NGO. They produce household disinfectant and garments, and provide assistance to elderly and disabled people affected by leprosy.

Some residents beg for a living. I was told of an elderly woman who goes to a nearby temple a couple of times a week, where she makes about 15 rupees, or a third of a US dollar, a day. By contrast, young people I met said they wanted to become schoolteachers, cricketers and the like. One boy told me, "I want to grow up quickly so that I can help my parents." This sentiment was echoed by many others.

In Pune, it was a pleasure to meet up again with Dr. S.D. Gokhale, Honorary President of the International Leprosy Union (ILU), one of the conference organizers. I have known Dr. Gokhale for many years and respect all he has done for people affected by leprosy.

The conference was attended by participants from nine countries, including representatives from MORHAN (Brazil), CORSOHANSEN (Colombia), ENAPAL (Ethiopia) and HANVIT (Korea). It took place against the backdrop of a number of significant developments mentioned on page 2.

In order to pave the way toward an inclusive society, I stressed the significance of the new UN principles and guidelines on ending discrimination. However, I warned participants that the effectiveness of the principles and guidelines depends on how they are used. Each and every individual should familiarize himself with the guidelines, and refer to them in any discussion with the authorities. "You are the main actors," I said, calling on them to strengthen their organizations and solidify their ties with overseas counterparts.

While in Pune, I also visited another colony, named Anandvan, in the Dapodi district. Established in 1952, it is home to about 400 people. Recently a flour-milling operation run by women was established at the colony. There are also plans for a dairy farm nearby.

Compared to when I first began visiting India, it is apparent that the circumstances of people living in the colonies are improving. Nonetheless, there remain many instances of discrimination in society, and much work remains to be done.

With staff of Abu Zaabal leprosy sanatorium in Cairo in December 2010.



EGYPT (DECEMBER 13-14)

From India, I traveled to the Middle East to attend the opening of a regional meeting of leprosy program managers in Lebanon. En route, I stopped in Egypt, where I called on the WHO's Eastern Mediterranean Regional Office (EMRO) and visited two leprosaria.

EMRO is one of the six WHO regional offices, and oversees North Africa, the Middle East and West Africa — representing a total of 22 countries from Morocco to Pakistan. Most of the countries covered by EMRO, including Egypt, are considered low-level endemic countries for leprosy. There are, however, countries such as Afghanistan, Somalia and parts of Sudan where the situation on the ground makes leprosy control extremely challenging.

For its part, Egypt achieved the WHO's interim goal of eliminating leprosy as a public health problem in 1994. In 2009, only 700 new cases of leprosy were discovered. There were 912 registered patients at the end of that year, making for a prevalence rate of 0.13 per 10,000 people. At the provincial level, five of Egypt's 27 provinces have yet to achieve elimination.

Abu Zaabal leprosy sanatorium is in the north of Cairo. When it was founded in 1932, it was some miles from the city; since then, the city has come to its door. At the time of my visit, there were around 700 patients, 35% of them women.



Attending the program managers' meeting in Beirut.

When I arrived, I found plenty of patients in the grounds, enjoying the fine weather. It looked more like an old people's home than it did a sanatorium.

I was particularly impressed by the patients' warmth of feeling toward the medical staff and how pleasant the facilities were. At the same time, I noted how many patients I spoke with felt there was no place for them in society. As I told a television interviewer later, while I admired the set-up at Abu Zaabal, I regretted the fact that many who were being treated there had no homes to return to. Every country must work harder to eradicate the social discrimination that keeps marginalized groups living apart from the mainstream.

The next day I visited Egypt's second city, Alexandria, about 200 kilometers from Cairo. My destination was Amria leprosarium. At its peak, the facility housed around 200-250 persons; today, they number just 20. I was struck by the contrast with Abu Zaabal. Amria is situated in renovated barracks formerly used by British soldiers when Egypt was under occupation. The walls were thick and the atmosphere was heavy.

LEBANON (DECEMBER 15-16)

From Egypt I flew to Lebanon, where I attended a meeting of leprosy program managers from EMRO countries. Representatives from 14 of the 22 countries attended. Invited to say a few words, I stressed the importance of focusing on both on the medical and social aspects of the disease. I used the image I often do of a motorcycle, with the front and back wheels symbolizing the medical cure and social rehabilitation, respectively. The two must turn smoothly together if we are to reach our goal of a leprosy-free world.

I appreciated the opportunity to meet people working in EMRO countries. Over the coming months I would like to get to know the region better, so as to see for myself the challenges these countries face and the lessons that can be learned from their experiences. ■

Micro-enterprises Honored in India

SILF presents first *Rising to Dignity* awards on Anti-Leprosy Day.

World Leprosy Day is celebrated on the last Sunday in January as an important opportunity for governments, NGOs and organizations of people affected by leprosy to raise public awareness of the disease.

In India, where the day is observed each year on January 30 as Anti-Leprosy Day, the Sasakawa India Leprosy Foundation (SILF) presented its first-ever *Rising to Dignity* awards. The awards recognize outstanding examples of successful micro-enterprises that have received loans from SILF under its livelihood funding initiative started in 2008.

The winning projects are all based in self-settled colonies of persons affected by leprosy. They were selected on the basis of the hard work and commitment demonstrated by those running them.

Recognized for their achievements were: Hanuman Nagar Kushth Vasahath's dairy farming project (Kalyan, Maharashtra); Sheetalamata Kushth Dham Sewa Samiti's project to manufacture silver ornaments (Ratlam,



Madhya Pradesh); and Swami Vivekananda Kushth Ashram's project to rent batteries (Bareilly, Uttar Pradesh).

The winners received a cash prize of 100,000 rupees and a trophy at a ceremony held at the residence of Shri Salman Kurshid, Minister for Water Resources and Minority Affairs.

Anti-Leprosy Day in India is celebrated on the anniversary of Mahatma Gandhi's assassination. It commemorates his selfless care of people affected by the disease and the effort he made to combat stigma.

SRI LANKA MUSEUM

The Sri Lanka Ministry of Health has announced that it will create a museum at Hendala leprosy hospital outside the capital, Colombo. The hospital was established by the Dutch in 1708, and a stone plaque engraved with the foundation date can still be seen. Among the buildings on the

hospital grounds is a Dutch-style church.

In times past, people with leprosy were forcibly admitted to Hendala, but the hospital stopped taking new admissions in the early 1980s.

The museum is due to open on World Leprosy Day 2012. ■

FROM THE EDITORS

WORDS INTO DEEDS

The Indian Constitution is a fine document, said a speaker at a workshop in Pune last December, yet a lot of rights "remain on paper." Japan's postwar Constitution is similarly considered by many to be a fine document; yet for decades certain articles were ignored when it came to the rights of persons the state incarcerated in leprosy sanatoria.

Forming another splendid document are the principles and guidelines adopted by the UN General Assembly last December as part of the resolution to end discrimination against people affected by leprosy. The challenge is how to transform these words on paper into

actions by governments and civil society.

This will require actions by those whom the principles and guidelines are designed to benefit; they must take every opportunity to bring the guidelines to the attention of the authorities. "The ball is in our court," Dr. P.K. Gopal of India's National Forum of people affected by leprosy has stated.

The key to change is empowerment. "I have seen the difference when sex workers are empowered," said another participant in Pune, who shared with people affected by leprosy her knowledge of this socially marginalized sector. "When they are empowered," she said, "they can get what they are asking for."

FOR THE ELIMINATION OF LEPROSY

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