WHO GOODWILL AMBASSADOR'S NEWSLETTER

FOR THE Elimination OF Leprosy

December 2010 • Number 47

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

Yohei Sasakawa listens to community leaders at Sungai Buloh leprosy treatment center in Malaysia, when he visited in November.

MESSAGE

Preserving Our Heritage

In the previous issue, I wrote of my visit to Bergen in Norway, where I visited Dr. Hansen's study, the leprosy museum and the national archives. I told of how carefully the history of leprosy, and the memories of those affected by the disease, have been preserved.

Now that leprosy is a receding threat, I believe we have an important responsibility to preserve the history of a disease that blighted so many lives and pass on this memory to future generations. Today, in the name of development, hospitals, sanatoriums, homes and other buildings related to leprosy are being torn down. Long-term residents are being given no option but to move. This is happening in Taiwan, in Brazil, in Malaysia — all over the world, in fact — and concerns me greatly.

In the Principles and Guidelines recently endorsed by the UN Human Rights Council — a long-held dream of mine — there is a clause which states that governments should allow people to continue to live in the leprosariums and sanatoriums that have become their homes, if they so desire. I hope all governments will come to respect this point.

The history of this disease is also the history of an assault on human dignity and human rights resulting from discrimination. People with leprosy were targeted for exclusion, and forced to live an isolated existence. Countless millions, guilty of no crime, were shunned by society. This is an enormous negative legacy.

This discrimination is not a thing of the past. It is part of our history, which we are creating day by day. It is an error that we must strive to ensure that future generations do not forget. That is why we must pass on the memory of what people affected by leprosy endured, as well as their courageous struggle against stigma and exclusion.

I believe the historical heritage of leprosy is on a par with UNESCO world heritage. Therefore, I appeal to all concerned not to allow this important heritage to be lost.

— *Yohei Sasakawa*, WHO Goodwill Ambassador

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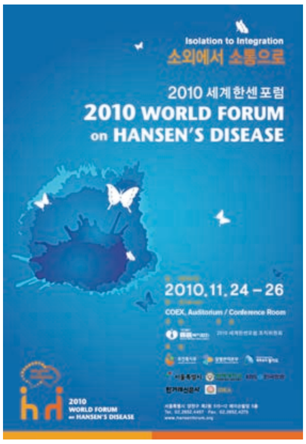
From Seoul to the World

International gathering showcases Korea’s experience of Hansen’s disease.



“Isolation to Integration” was the theme of an international forum on Hansen’s disease held in Seoul, South Korea, from November 24 to 26, 2010. Over 1,000 delegates from 17 countries took part in the event, which issued the 12-point *Seoul Declaration* calling for an end to all forms of discrimination against people affected by leprosy.

The opening ceremony, which included a video message from UN Secretary General Ki-Moon Ban, was held against the backdrop of an artillery attack by North Korea on a South Korean island the previous day. Notwithstanding this national emergency, eight National Assembly members, a provincial governor and a former prime minister were in attendance. Their presence underlined the political support the issue of Hansen’s disease now receives in Korea.

Minister of Health and Welfare Soo-Hee Chin noted that people affected by leprosy in Korea had suffered not only from the disease itself but also from social prejudice, discrimination, segregation and violence. Thanks to the enactment of a special law on Hansen’s disease and improved welfare policies, prejudice and discrimination were diminishing, she said, but much work still needed to be done.

South Korea ended the compulsory segregation of people affected by leprosy in 1963, setting up “resettlement villages” around the country for people to move into. Many of these were in remote locations and met with opposition from surrounding communities. There are 89 recovery villages today, and 13,734 people affected by Hansen’s disease are said to be living in South Korea.

Organized by the Hanvit Welfare Organization, a nonprofit corporation dedicated to promoting the rehabilitation of persons affected by leprosy and raising societal awareness of the disease, the forum was an opportunity to showcase the progress South Korea has made in these areas, particularly in the last decade. But it also aired some of the outstanding issues that remain — issues that resonate not only in South Korea but also in other countries with a history of the disease.


People affected by Hansen’s disease at the World Forum

Accordingly, plenary sessions covered topics ranging from health-related human rights, Hansen’s disease and rehabilitation strategies, the role of media, and history and memory.

National Assembly Member Choon-Jin Kim noted that the government has an obligation to protect the health of its citizens but that it fails to do so in some cases. When that happens, people must demand this as a fundamental human right. “This is a role for people affected by Hansen’s disease,” he said.

ROLE MODEL

Sang-Kwon Jung, president of IDEA International, spoke on the movement for economic advancement within Korea’s resettlement villages, offering this as a model for other countries to follow. From raising pigs and poultry, residents advanced to factory ownership. Through economic self-independence comes greater social participation, he said.

Dr. Kyu-Ok Kim of Ajou University’s Lifelong Learning Center described an educational project to turn a resettlement village into “a place of happiness and hope.” One of the outcomes was the confidence to call for better public transport. “We are citizens. We demand a bus stop,” she quoted residents as saying. “They found their human rights.”

Yoon-Hyung Gil, a reporter for *Hankyoreh* newspaper, noted that while coverage of Hansen’s disease in the Korean media has improved, there was a tendency for articles to treat persons affected by the disease as secondary to the story of who was visiting them or doing something for them. “You are the minority of minorities,” he told people affected by Hansen’s disease in the audience. “You have to speak out.”

Interviewed later, Gil-Yong Lee, the president of Hanvit Welfare Association, said that one of the goals of holding the World Forum had been to show the Korean public and the world at large that people affected by Hansen’s disease are capable of organizing a major conference such as this. “In Korea, we have achieved a degree of self-reliance by dint of our own efforts and some outside help,” he said. “We want to export this ‘can-do’ spirit to the world.” ■

The Old and the New

Korea's Sorokdo National Hospital gets a facelift, but preserves its historical sites

It's a six-hour drive to reach Sorokdo National Hospital from Seoul, but no longer does the last leg of the journey involve a boat ride. Three years ago, a bridge linking Sorok Island with the mainland was completed, ending the physical and symbolic isolation of this one-time leprosy colony off the southwest corner of the Korean Peninsula. The bridge is just one of the signs of change taking place on the island, as the hospital moves ahead with a program of rebuilding and renewal ahead of its 100th anniversary in 2016.

The island's association with leprosy dates back to the Japanese occupation of the Korean Peninsula (1910-1945), when the authorities set up a leprosy clinic on Sorok in 1916. During the 1930s, facilities were expanded and Sorok Island became the destination for every individual on the peninsula diagnosed with leprosy. The segregation policy remained in place beyond the end of Japanese colonial rule, coming to an end only in 1963.

At its peak, the island was home to as many as 6,000 persons affected by Hansen's disease. Today that population numbers a little over 600, some bedridden and permanently hospitalized, and others living in one of seven small villages on the island. The average age of residents is 73.

On a recent visit, around 30 delegates to the World Hansen's Disease Forum toured the main hospital and some of the island's historical landmarks. Those with previous experience of Sorok were visibly surprised at the extent of the changes they saw. As outlined at the forum by the hospital's director, Dr. Hyung-Cheol Park, Sorokdo National Hospital's vision is of a bright future in which all the needs of people affected by Hansen's disease under its care are fully taken care of so that they can spend the rest of their lives in comfort.

WRITTEN IN BLOOD

Older buildings recall a different era, when the attitude toward the colony's inmates was in marked contrast to today. There is the former prison, where those who disobeyed the rules were sent as punishment. Using his own blood, a detainee wrote on the wall lamenting his fate.

The barred windows of Sorokdo's former prison

There is also the old operating theatre, where experimental autopsies were carried out on the patients, and where men were forced to undergo vasectomies. Another message written in blood expressed sorrow at being unable to have children.

Apparently, Sorok's residents used to pray they would die on a Sunday — the only day that autopsies were not performed — so that their bodies would spared this final indignity and be taken straight to the crematorium. Such autopsies continued to be performed up until the 1980s.

In a landscaped garden, a stone monument marks the spot where in 1940 a notorious Japanese hospital director erected a statue of himself. A photograph shows patients being forced to bow before it. Two years later, the director was stabbed to death by a disgruntled patient.

Dr. Oh stands next to the autopsy table.

Dr. Dong-Chan Oh, the hospital dentist who accompanied the visitors on their tour, has worked at Sorokdo National Hospital for 16 years. "When I first arrived, the conditions were poor," he says. "The patients' wounds were festering, and flies covered their food. Things have really changed for the better."

He said that the bridge has helped to open up Sorok to the outside world. Many people have visited and this has helped to break down their prejudice. Yet discrimination remains strongest in communities closest to the island, he believes. "There is a Korean saying that your enemies are those who live nearest you. I think that still applies." ■

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Three Decades of Struggle

Artur Custodio M. de Sousa reflects on MORHAN's efforts to promote the reintegration of persons affected by Hansen's disease into Brazilian society.

When was MORHAN established?
MORHAN was established at the beginning of the 1980s. This was a time when several social groups in Brazil gathered to fight for citizenship rights and economic, social and democratic advancement. This was also a time when public policies on Hansen's disease in Brazil were changing from compulsory segregation toward outpatient treatment with multidrug therapy. There was a need to lessen social prejudice against people affected by Hansen's disease, as well as to make progress toward eradicating the disease itself.

Does MORHAN's mission remain the same, or has it changed?
Our mission remains unchanged, but our strategies and networks have evolved. We've also developed a broader, intersectoral approach. We've added new fields of action, including education, culture, and the environment, and developed different strategies for different groups, such as children or the elderly.

Why does Brazil still have so many cases of Hansen's disease?
Hansen's disease has always been associated with excluded social groups who lack the power to speak out and influence public policies. Furthermore, Hansen's disease requires continuous action, and it takes a long time for the effects of that action to be seen. Most officials at the federal, regional and municipal levels neglected long-term actions that should have been implemented in the 1980s and 1990s.

What are the main issues facing people affected by Hansen's disease in Brazil?
There are two key issues. The first concerns the former colonies. Residents need access to high-quality medical care for non-Hansen's disease-related health problems. Plus, there are issues involving citizenship, quality of life, and use of existing infrastructures to be addressed. The second key issue concerns the persistence of Hansen's disease in Brazil. Among other things, we need a sustainable policy of continuous action; easy access to medication and treatment; a strengthening and broadening of information, education and communication activities; and the involvement of all of society in the struggle against the disease.

What have been some of MORHAN's most successful achievements?
MORHAN's accomplishments are achieved daily through our continuous social struggle. In the 1990s, our efforts led to the abolition of discriminatory laws and the official prohibition of the use of the term "leprosy." More recently, we have invested heavily in media campaigns to inform the public about the disease, as well as strengthened our participation in several official bodies with deliberative powers, such as national, regional, state and municipal health councils. In 2007, we succeeded in sensitizing President Lula da Silva to sign a provisional measure, which subsequently became law, to compensate persons who were forcibly segregated. To date, more than 5,500 applications for compensation have been approved.

How closely does MORHAN work with the government?
Alice de Tibiriçá, a social activist in the 1930s, said, "With the government, if required; without the government, if possible; and against the government, if necessary." Most of the time, MORHAN works closely with the government, but there are also times when we represent society's dissatisfaction.

The WHO is exploring ways of strengthening the participation of people affected by Hansen's disease in leprosy services. What are your views?
Without a doubt, people affected by Hansen's disease have much to contribute to public policies. In Brazil, MORHAN finds inspiration in the teachings of Paulo Freire, who says, "There isn't greater or lesser knowledge, only different kinds of knowledge." Based on this, we believe that the knowledge of those who have experienced the disease and who belong to the community must be respected and heard. But this role must be an active one, not a mere concession. It must have an impact; that's an essential feature of any participatory process. People affected by leprosy must be included in both the design and execution of public policies. Otherwise, it's just an empty gesture.

What has MORHAN taught you?
I've been with MORHAN since I was 16. I've learned that people are not and should not be treated as commodities, and that respect for all forms of life is fundamental. I've learned that we should be less competitive and "Darwinist" in the organization of our societies, and that we should cooperate more. Today, I am passing on to my children much of what I've learned. It fills me with pride to see them engage in social struggles and activism, and I give thanks to the likes of Bacurau and many others from MORHAN who have shaped my outlook. ■

PROFILE:
Artur Custodio M. de Sousa

Artur Custodio M. de Sousa is national coordinator for MORHAN, the Movement for the Reintegration of Persons Affected by Hansen's Disease.

Acknowledgment
Thanks to Alice Cruz for her assistance with translation.

Leprosy in the News

Could we be doing a better job of working with the media?

AUTHOR:
Jonathan Lloyd-Owen
Jonathan Lloyd-Owen is editor of the WHO Goodwill Ambassador's Newsletter.

People working in leprosy often talk about the need to make better use of the mass media. But what do we mean by this?

The media perform a number functions that can all play an important role in increasing awareness. These include informing the public about the basic facts of leprosy, especially that it is curable; monitoring the effectiveness of measures to diagnose, treat, and rehabilitate people; exposing examples of discrimination, such as outdated legislation; influencing policymakers by sensitizing them to the issues; and championing the cause of individuals and communities seeking to overcome social prejudice and make their way in the world.

In such ways, the media can be extremely influential, by virtue of their enormous reach. But not everything that happens in the world gets into the media. News organizations have criteria for deciding whether to run a story: Is it newsworthy? Is it timely? Is it relevant to a lot of people? Does it have emotional impact? And, given the fact that most news outlets are commercial enterprises, will it sell more newspapers or attract more viewers?

> "Sometimes a good article about leprosy will be undone by a thoughtless headline."

Leprosy is not a big news story for the media, so they have a tendency to ignore the issue. Worse, when they do turn their gaze on leprosy, in their choice of terminology, images and storyline, they often stereotype and stigmatize.

Anyone who uses Google Alerts can see how often the word "leper" crops up in English-language media — both in stories about the disease, and in stories that trade on the word's pejorative connotations to make a point about an individual or group perceived as socially or morally unacceptable.

Sometimes, an otherwise good article about leprosy will be undone by a thoughtless headline. The online edition of *The Guardian* newspaper ran a piece in October titled "Egypt's last leper colony broaches time of integration." It later changed the wording to "leprosy colony" and included a note to the effect that the original headline was in breach of the paper's style guide, which deems the term "inappropriate and stigmatizing."

In addition to the style manuals of individual news organizations, in the UK there is also an industry-wide Editors' Code of Practice drawn up by editors themselves under the auspices of the UK Press Complaints Commission. On discrimination, the code states: "The press must avoid prejudicial or pejorative reference to an individual's race, colour, religion, gender, sexual orientation or to any physical or mental illness or disability." It continues, "Details of an individual's...physical or mental illness or disability must be avoided unless genuinely relevant to the story."

TESTIMONIALS

While style guides and codes of practice can be used to hold media organizations to account over use of the "L" word, I wonder if guidelines alone are enough. The word is so deeply engrained that it is used unthinkingly, as if the thought has never occurred that it may be inappropriate. Perhaps editors need to be given compelling reasons why the term offends — and who better to tell them than people affected by leprosy themselves.

To sensitize the public, we have to sensitize the mass media. That's why media workshops on leprosy have been held in India and elsewhere for this purpose. Yet is there not also a need for workshops to help those working in leprosy to make better use of the media?

Long-established NGOs all have dealings with the media. The Leprosy Mission successfully approached the BBC over its use of terminology. LEPRA and ILEP contacted *The Guardian* over the article mentioned above.

Leprosy stakeholders in different countries all have stories they want to share with the media. Maybe they should be sharing with each other their experiences, both good and bad, of using the media.

What approaches work and what don't. How to interest journalists in a story and frame the issues in a way that meets their criteria for what's newsworthy. How to be interviewed when reporters come calling. How to write a press release. How to organize a media event.

Beyond leprosy, there are plenty of other sectors working to see that they are fairly represented in the media — HIV/AIDS, disability, mental health, to name but some. Let's draw on their experiences, too, as well as those of different stakeholders within leprosy, and compile a manual of best practices. It should benefit coverage of leprosy, and in the process, reflect well on the media too. ■

Searching for the Past

The Goodwill Ambassador visits a couple of islands with a past linked to leprosy, and meets with people affected by leprosy in Vietnam, Palau and Malaysia,

VIETNAM (OCTOBER 31)

During a visit to Vietnam in October, I took the opportunity to go to the Ba Sao Leprosy Treatment Center in Ha Nam Province, about 100 kilometers south of the capital, Hanoi. Vietnam eliminated leprosy as a public health problem in 1995, but continues to see new cases of the disease, including 400 so far this year.

The Ministry of Health and the National Institute of Dermatology and Venereology run 20 leprosy sanatoriums nationwide; Ba Sao is one of these. It is home to about 50 persons affected by leprosy, ranging in age from their 50s to their 90s. Nearby is a small hamlet that is home to more people affected by leprosy and their family members.

On arrival I first visited the wards. Among the residents I met was Dao, 61, who has lived at Ba Sao for more than 30 years. Although cured, she is suffering from various chronic ailments. Now that her husband is dead, she has no family.

As I toured the center, I saw from the window a brand new building. This turned out to be a bathroom and shower unit that had been built over the summer by volunteers. They included students from Waseda University in Japan, one of whom is now working part-time at my office in Tokyo.

Moving on to the hamlet, I passed the time of day with a number of the residents. They included Be, a woman in her 80s, and Qvet, who lives next door to her daughter and family, who are building a new house. The government provides a monthly allowance to those living in the hamlet, as well as two meals a day. To supplement this, many of the residents raise chickens, pigs and cows.


Saying hello to a resident of Ba Sao treatment center

Although living conditions were comparatively good, the community is isolated. Stigma remains an issue, it seems, and must be addressed.

PALAU (NOVEMBER 11)


Raibyo-shima, where people with leprosy were sent during the era of Japanese rule

On November 11 I traveled to Palau in Micronesia. My destination was Koror Island, seat of Palau's capital until 2006.

Palau has a population of around 20,000. Currently it has 6 registered leprosy patients. Although my stay was brief, I arranged to meet with some of those undergoing treatment. They included a 17-year-old girl whose mother took her to hospital when they realized she had no sensation on a patch on her leg. Another man told me his uncle also had the disease. I spoke with a nurse, who said she pays a visit to each household to make sure the patients are following their treatment.

I was interested to discover that near Koror was an island once known as Raibyo-shima, or leprosy island. The name comes from the old Japanese term for leprosy, and dates back to when Palau was under Japanese rule. Keen to pay a visit, I traveled the 1.6 kilometers in a small motor boat. I was told it would not be possible to land, but I was able to wade ashore.

Once on land, I was confronted by a jungle-covered hill. I discovered a small wooden staircase in the undergrowth and cautiously proceeded to climb. The steps soon petered out, but I continued anyway. I searched for signs of where people might once have lived, but wasn't able to find any evidence. On the way back to the boat, one of my traveling companions inadvertently broke one of the wooden steps. Thus is history obliterated, I thought.

Visiting Pulau Jerejak in Malaysia, where few traces of its association with leprosy remain

The real name of Raibyo-shima is Ngerur Island. Only later would I learn that the remains of some buildings as well as some graves were to be found on the other side of the island. I learned also of the existence a man in his 80s who had been sent at the age of 10 to Raibyo-shima, where he had remained for several years. A doctor brought medicine once a month, and rice and tinned foods were also delivered. The islanders cultivated taro potato, sago and sweet potato. I understand the man, who later worked as a construction worker on Guam, is in good health.

MALAYSIA (NOVEMBER 20-22)

On a visit to Malaysia in late November, I made a point of visiting Pulau Jerejak, a small island lying off Penang. Now home to a resort, Jerejak's past includes spells as a quarantine station for immigrant workers, a hospital for tuberculosis patients, a prison and a leprosarium.

It was in 1871 that Jerejak was selected by the Straits Settlements, the British territories consisting of Singapore, Penang and Malacca, as a place to isolate leprosy patients. It fulfilled this function until 1969, when all remaining patients were transferred to Sungai Buloh leprosarium near Kuala Lumpur. Between 1969 and 1993, when it served as a prison, the island was dubbed the Alcatraz of Malaysia, after the infamous prison in San Francisco Bay.

As with Sungai Buloh, Jerejak has an important place in the history of leprosy in Malaysia, yet its past function as a place of isolation for those with the disease is not widely known. My guide to the island, 29-year-old Faisal Omar, who was born and raised on Penang, was taught nothing of this aspect of the island's history when at school. In fact, he first heard about its leprosy connection when he accompanied an Indian visitor to the island, who told him he had once worked there as a doctor.

There is mention of Jerejak in a book published in Japan in 1942 by a Japanese leprologist. When he visited in 1933, there were 765 patients, among them 601 Chinese and 128 Indians. The sanatorium was apparently divided into different sections based on factors such as race and the degree of disease severity. The only form of treatment was chaulmoogra oil.

Today, little remains of the island's leprosy past. One can only conclude that these historical sites have been obliterated. By whom, and for what reason? It is hard to fathom. Some reports suggest that the buildings were demolished and sold off as scrap.

It is also a struggle to preserve the history of another important site near Kuala Lumpur, Sungai Buloh, which I visited on this trip. To expand a university that has already been built on part of the site, the authorities are asking about 300 people to move to separate accommodation.

Sungai Buloh was once a self-contained community with its own schools, hospitals, cinema, fire department and local government. At the time of my visit, the population numbered 232 persons. Of these, 113 occupied some of the 409 chalets still standing, while the remaining 119 were hospitalized with various ailments. Many of the remaining residents are elderly and disabled. Those that are able to work grow plants and cultivate trees for sale, an activity for which Sungai Buloh is famous.

I met with five male residents of Sungai Buloh. They had been requested to vacate their homes to make room for the expansion of the university. They told me that the eastern section of Sungai Buloh had already been destroyed, but that they were keen to see the remaining buildings preserved. "We just want to be allowed to live in peace."

There are conflicting forces at work here: to preserve the site for its historical significance and allow the residents to remain where they choose, versus redeveloping the land in the interests of the population at large. It was society that forced these people to live here in the past; I feel they should not now be forced anywhere against their wishes. ■

Leprosy and Human Dignity

Southeast Asian networking project gathers momentum

A program on leprosy and human dignity launched in June 2009 in cooperation with the Association of Southeast Asian Nations Secretariat (ASEC) is proceeding with the support of The Nippon Foundation.

Renamed the "Leprosy and Human Dignity Program — South East Asia," the program has two key objectives. First, to help build and empower domestic and regional networks of people affected by leprosy in order to promote communication and cooperation between them; and second, to foster partnerships with non-leprosy-affected communities and organizations, such as human rights groups, community development NGOs and the media, for the purpose of sensitizing society to leprosy issues.

Grants are being offered to organizations that submit proposals for projects that fulfill the goals of the program. For more information, contact program director, Adi Yosep (adyose@yahoo.com).

HANDA WINS ONE FOUNDATION AWARD

HANDA Rehabilitation and Welfare Association was one of six NGOs selected as Philanthropy Stars when The One Foundation announced its 2010 philanthropy grants in Beijing in November. Founded by actor and maritial arts expert Jet Li, the foundation selects award winners on the basis of credibility, execution, sustainability and professionalism.

HANDA's efforts over the preceeding 14 years to reduce stigma and discrimation against people affected by leprosy in China were unanimously acknowledged by the panel of judges. HANDA also polled top in online voting.

Said HANDA's secretary general, Dr. Michael Chen, "This achievement would not have been possible without the support of our partners and the work of our volunteers. We will regard this as another starting point in our effort to make a better world and build a better future for people affected by leprosy and others in need."

GLOBAL APPEAL 2011

Global Appeal 2011 to end stigma and discrimination against persons affected by leprosy will be launched at Peking University in Beijing, China, on 25 January, 2011.

The annual appeal, the sixth to date, is being endorsed by the heads of approximately 100 universities from around the world. See our next issue for a full report. ■

FROM THE EDITORS

THINKING BIG

At the recent World Forum on Hansen's Disease in Seoul, READ Nepal's Raj Kumar Shah took the opportunity to remind delegates that he has a very ambitious plan: to put a person affected by leprosy on top of Mt. Everest. Sitting in the audience was his partner in this venture, Brian Smith, a mountaineer and founder of the NGO, HAND (Helping Assist Nepal's Disabled).

Candidates for the Everest expedition have already been selected, and earlier this year they completed a 5,500-meter training climb up Yala Peak. Smith, who led the way, said that while he had plenty to teach them about mountaineering technique, he had nothing to teach them about "heart." "They really want to make it to the top," he said. "They're raring to go."

The ambitious endeavor also has an ambitious timetable — 2011 — but overriding that will be ensuring the chosen climbers are properly prepared for the challenge. There is too the question of funding, and efforts to gain financial backing are ongoing.

In his remarks, Shah also mentioned a sponsored radio program about leprosy that was responsible for saving a marriage. A man who was going to divorce his wife because she had leprosy changed his mind after listening to the broadcast, which dispelled the misconceptions he had about her disease.

Raj looks forward to the day when the media can report that a person affected by leprosy has conquered the world's highest peak, so dispelling many more notions about leprosy.

NEWS EXTRA

A resolution on elimination of discrimination against persons affected by leprosy and their family members was adopted at the Third Committee of the 65th Session of the UN General Assembly in November.

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