

FOR THE Elimination OF Leprosy

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



The Goodwill Ambassador visits with residents and staff of Hospital Gonzalo Gonzales in Quito, Ecuador in October 2016.

MESSAGE

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Toward an Inclusive Society

I seek to realize an inclusive society in which people affected by leprosy can fully participate without fear of discrimination. To this end, I have worked with governments and supported organizations of people affected by the disease in different parts of the world.

To make an inclusive society a reality, however, it is necessary to strengthen the voices of those concerned. In June 2015, I cooperated with Disabled Peoples' International (DPI) in organizing a side event at the annual conference of states parties to the Convention on the Rights of Persons with Disabilities held at UN headquarters in New York.

The side event was titled "Voices of People Affected by Leprosy" and was made possible through the efforts of DPI Chairperson Javed Abidi, who reached out to organizations of people affected by leprosy in several countries and developed close ties with them. This was the first time in the history of the conference that leprosy had been featured.

As a result of this event, both people affected by leprosy and those otherwise disabled agreed to seek ways to deepen their cooperation, no matter what the cause of their disability.

This was an example of persons from different backgrounds who had never collaborated before coming together to create the foundations on which to build an inclusive society in the future.

For such to be realized, it is very important that their voices reach the rest of society and that they participate in any decision-making process that affects their quality of life.

This November, at the initiative of the DPI, a conference was held in India designed to promote the integration of leprosy into the disability movement worldwide. Delegates from the host country, Nepal and Indonesia engaged in productive discussions.

It is my belief that when people affected by leprosy link up with other groups and organizations, find common cause and together make their voices heard, this benefits both parties by boosting their influence.

This represents a big step toward an inclusive society.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Beyond Borders

Seoul forum shows that Hansen's disease heritage resonates around the world.



Consensus-building: the 2016 World Forum on Hansen's Disease

The 2016 World Forum on Hansen's Disease—Shaping (a) Better Future: Historic Significance of Hansen's Disease Cultural Heritage was held in Seoul, South Korea from November 1 to 3.

Organized by the Korean Federation of Hansen's Disease Associations (KFHA), the forum had the goal of forming a consensus on the preservation of tangible and intangible Hansen's disease cultural heritage, fostering international cooperation on alternative uses of former Hansen's disease facilities, and disseminating a positive message about people affected by the disease.

In 2010, the first World Forum on Hansen's Disease hosted in the same city traced the journey from isolation to inclusion of persons affected by leprosy. As the current forum revealed, that journey is by no means at an end, but promoting an appreciation of what Hansen's disease cultural heritage has to offer the world can accelerate progress toward understanding and acceptance.

MILESTONE YEAR

For South Korea, the year 2016 represented a significant historical milestone in Hansen's disease history as it marked the centennial of the founding of the Sorokdo National Hospital on May 17, 1916. As part of events to observe this anniversary, a Hansen's disease museum was inaugurated on Sorokdo, designed to preserve a record of the island's role as a leprosy colony, as well as to serve as a venue for human rights education.

On human rights, the conference heard from representatives of a Korean lawyers' group, who reviewed the status of lawsuits and legal appeals against the Korean government concerning compensation for those segregated on Sorokdo in the past. Their conclusion: human rights are not totally restored and people affected by the disease still suffer prejudice and discrimination.

Delegates were also treated to a roundtable discussion involving Korean academics, heritage experts

and others. Among the topics they examined were what aspects of Hansen's disease heritage would have value for future generations and how these assets should be utilized. For Professor Donjin Kang of Kyungsoong University, the answer was clear: "To prevent repeating a painful history."

STORIES ARE KEY

From overseas, delegates from 16 countries gave presentations on museums,

places of cultural significance in the history of Hansen's disease, and efforts to promote these as World Heritage Sites. A number of speakers emphasized that heritage preservation was about more than just objects and buildings.

Huang Yen Hong, curator of the Si'an Hospital Museum of Hansen's Disease, a small but innovative museum in China, said: "Stories are the soul of the museum. They are the spirits of the objects on display. They make them meaningful and vivid."

Echoing this was Yasunori Fukuoka, a professor emeritus at Japan's Saitama University, who has conducted numerous interviews with persons affected by the disease in Japan as part of his research. Over time, he said, he came to the realization that "only the voices and narratives of people affected by Hansen's disease can give the buildings and properties real meaning as intangible cultural heritage."

Stories were also woven into the presentations of Valerie Monson, who described the work of an organization that helps descendants of persons affected by Hansen's disease learn about their ancestors buried at Kalaupapa in Hawaii, and of Kofi Nyarko of IDEA Ghana, who has paved the way for persons living in Hansen's disease communities to return to their hometowns.

In addition to Korea's Sorokdo, other important locations in leprosy history were spotlighted during the course of the three days. These included St. George's Hospital in Bergen, Norway; Spinalonga, the former fortress in Greece that once served as a Hansen's disease colony; Nagashima Aiseien sanatorium in Japan's Inland Sea; and Agua de Dios, a former colony in Colombia.

Delegates endorsed the Seoul Declaration, an ambitious document focusing on upholding human rights, eliminating discrimination, and preserving the history of Hansen's disease—in particular so that those affected are afforded their "rightful place in history." This forum was evidence that progress is being made, but that there is still much work to be done. ■



Hansen's Disease as Cultural Heritage

Time to challenge traditional preservation discourses and shine a light on leprosy history.



AUTHOR:

Shu-yi Wang, PhD

Dr. Wang is an assistant professor adjunct of the Department of Landscape Architecture, Chinese Culture University, Taiwan.

It was my great honor to attend the 2016 World Forum on Hansen's Disease hosted by the Korean Federation of Hansen's Disease Associations. Over three days, speakers elaborated on Hansen's disease and its historical, social and cultural significance, addressing topics ranging from oral history and human rights to historic preservation and social stigma. It provided a venue for people who care about these issues to engage in some profound conversations.

Given my background in heritage studies, I was particularly interested in the discussions on the future of Hansen's disease as cultural heritage in human history. Among the issues raised at the conference, historic preservation of Hansen's disease and the nomination of World Heritage Sites were at the forefront of various exchanges.

While Hansen's disease museums in Japan, South Korea, Norway and elsewhere provide the public with opportunities to learn about the disease's history, the nomination as World Heritage sites of the physical environments where people affected by leprosy lived brings international recognition of a difficult past.

The traditional definition of heritage does not fit the history of a marginalized people.

This represents a change in what is considered worthy of preservation, as the traditional definition of heritage does not fit the history of a marginalized people. Places such as leprosy colonies were never a priority in historic preservation due to their lesser architectural value and subordinate importance in nation building. Plus, the relationship between society at large and those affected by leprosy was considered painful.

GOVERNMENT'S ROLE

For me, the highlight of the conference was the session focusing on the preservation of the cultural heritage of Hansen's disease in South Korea. Over more than a decade, the government has expended efforts on preserving the history of Hansen's disease, including the designation of the Sorokdo National Hospital as "Registered Cultural Heritage" in 2004 and the establishment of the Sorokdo National Museum in 2016.

During a roundtable session, expert panelists discussed museum displays, preservation of existing buildings on Sorokdo and the possibility of World Heritage Site nomination. Those taking



The author (2nd from L) with fellow delegates in Seoul.

part included hospital administrators, people affected by leprosy, sociologists, architectural historians and conservationists.

Hansen's disease heritage can be considered a living heritage. Therefore, the participation of leprosy-affected people and their family members in the conference was meaningful and significant, especially when we consider the critical question frequently raised in the domain of heritage preservation: "Preservation of what, and for whom?"

The preservation of the history of Hansen's disease raises some complicated issues, especially when it involves sites that still function as home to people affected by the disease and their families, who continue to be stigmatized and marginalized. There is a probability that nomination as a World Heritage Site, in the hope of preserving the history and physical environment of a leprosy settlement, might expose current inhabitants and make them more vulnerable.

On the other hand, leprosy settlements have much to offer the general population in terms of history, social commentary and public policy, and moves to preserve them reflect an awareness of the value in acknowledging a painful past.

The conference in Tokyo on Leprosy/Hansen's Disease History as Heritage of Humanity hosted by the Sasakawa Memorial Health Foundation in early 2016 made a case for the importance of the history of Hansen's disease to the world, and called for international collaboration on preserving this history. Now, strategies for achieving this are needed.

The open conversation regarding the history and historic preservation of Hansen's disease in South Korea at the recent World Forum set a good example for other countries to follow. Some of the issues raised with regard to Korea, such as strategies of historic preservation and adaptive reuse of historic buildings on Sorokdo, may be facing other countries, too. It's time to challenge traditional preservation discourses and envisage one that illuminates the history of Hansen's disease. ■

Meeting Nepal's Challenges

New strategic plan aims to address issue of stagnant epidemiological indicators.



Man with a strategic national plan: Dr. Pandey at his office in Kathmandu

What is the leprosy situation in Nepal today?

Nepal eliminated leprosy as a public health problem nationally in 2010, but new case numbers have remained the same and the prevalence rate of the disease has increased from 0.79/10,000 at the time of elimination to 0.89/10,000 in 2015.

Among new cases, there are a significant number of child cases (7.73%) and those with Grade II disability (4.42%), while the number of females cases detected (36%) is disproportionately low. Active transmission of the disease is ongoing, and we know there are hidden cases in the community.

How are you addressing these issues?

In line with the WHO Global Leprosy Strategy 2016-2020, we have adopted a strategic national plan with a vision of a leprosy-free Nepal. Our targets are zero children with visible deformity at time of diagnosis; less than 1 case per million population of newly diagnosed cases with visible deformity; and zero stigma and discrimination toward persons affected by leprosy. We also aim to eliminate leprosy as a public health problem at the district level.

What are your strategies for achieving these targets?

We are adopting a number of different approaches. These include expediting early case detection through "mini leprosy campaigns" in endemic districts, active case-finding in disease pockets within those districts, and an initiative to declare "leprosy-free villages."

The latter involves everything from advocacy and community awareness to going house to house to detect and treat cases in a designated village until we are able to declare that village free of leprosy. This initiative started in three village development committees (VDCs) in Saptari District in the eastern part of Nepal and will expand to other VDCs.

We are also looking to mobilize female health

workers and female community health volunteers for early detection of leprosy, especially among women and children, and to involve people affected by leprosy in early case detection, advocacy and planning.

Nepal sees a high proportion of new cases from India. What are your thoughts on this?

We share a long, open border with India and there is a free exchange of people between the two countries. Out of Nepal's 75 districts, 20 districts in the lowland Terai region bordering India account for more than 80% of all new cases. At present, there are

some 700 new cases from India receiving treatment in Nepal; I believe there are also some cases from Nepal being treated in India. To achieve a leprosy-free Nepal, we need to work together with India.

To achieve a leprosy-free Nepal, we need to work together with India.

What do you make of the recent leprosy case detection campaigns in India?

We have been closely observing India's two recent leprosy case detection campaigns and learning a great deal. As we prepare to launch our own mini leprosy campaigns in high-endemic districts, I have been in close contact with Dr. Anil Kumar, India's national program manager, and we have been exchanging views on the importance of political advocacy and involving community health volunteers and people affected by leprosy.

Are you optimistic that Nepal will be free of leprosy one day?

Based on our strategic plan, yes. But we will also need new tools and approaches to interrupt transmission and prevent disability. In this regard there are several promising developments in the areas of diagnostic tests, preventive chemoprophylaxis and immunoprophylaxis. Mapping of cases to set up targets for leprosy campaigns will also be vital. I must also mention collaboration with our international and national partners, including Sasakawa Memorial Health Foundation, which is crucial to accelerating our progress. I am confident that with our partners' strong support we will achieve and sustain our goal of a leprosy-free Nepal. ■

PROFILE:

Dr. Basu Dev Pandey
Dr. Basu Dev Pandey, MD, PhD is Deputy Director General, Department of Health Services at the Ministry of Health of Nepal.

Reflections on S-ILF's First Decade

Going forward, there is a need to reach out to more colonies and households.



AUTHOR:

Dr. Vineeta Shanker
Dr. Vineeta Shanker is Executive Director of Sasakawa-India Leprosy Foundation.

Sasakawa-India Leprosy Foundation (S-ILF) was established in 2006 to assist people affected by leprosy to regain their dignity as productive and accepted members of mainstream society. With a focus on economic and social empowerment and ending reliance on begging, it supports the goal of sustainable transformation in the lives of those affected by the disease and the lives of their children.

Looking back over our first decade, I take satisfaction in the hope and confidence in the future that we have been able to nurture. Through small grants and assistance in setting up micro-enterprises, we have supported people in their quest for dignity and sustainable livelihoods.

But more than that, we have helped to reduce self-stigma and given people the confidence to create a better life. This has come about through opportunities for interactions with different groups outside communities of the leprosy affected, be it at capacity-building workshops or in business transactions.

In addition, both our scholarship programs for higher education and our skills training workshops leading to employment have helped to assuage anxieties of parents about their children's future and, at the same time, have motivated young people to dream of a brighter tomorrow.

NEEDS-BASED DEVELOPMENT

From the outset we had a mandate, but no preconceived notions about how to fulfill it. Our program focus was derived in consultation with the Association of People Affected by Leprosy, or APAL (originally known as the National Forum) and evolved with the needs and demands of the situation on the ground. We could have started with a geographical focus or by taking up more than one project per leprosy colony, as this would have been easier for us. However, this would have meant covering less colonies, which would have led some states or colonies to feel left out and made the convergence to a partnership with S-ILF more difficult.

With the benefit of hindsight, perhaps we could have begun the process of scaling up our work a couple of years earlier. To date we have been able to reach



Dinesh Trivedi, MP (2nd from L) speaks at S-ILF's 10th anniversary.

out to only a third of the 800 or so self-settled leprosy colonies that exist in India. Meanwhile, our outreach to people affected by leprosy living in the wider community is minimal: we need to do more to step into the advocacy arena to ensure their participation in government welfare schemes, thereby facilitating their social and economic integration into the mainstream.

Going forward, S-ILF is looking to reach more households in more colonies in more states. We also want to bring more children into our scholarship schemes or into those of the government, to ensure that no child is deprived of an opportunity to pursue higher studies or learn skills that will help in breaking out of the cycle of poverty and stigma that his or her parents have been through.

In addition, we want to push for better policies through the Forum of Parliamentarians to Free India of Leprosy, whose cross-party members are committed to using their good office and influence to raise awareness about leprosy and bring about positive change for people affected by the disease. This they do by facilitating access to government schemes, pushing for change in the legal/policy framework that still discriminates on the basis of leprosy and by publicly supporting people's efforts to live with dignity.

I am happy that we have been able to win the trust and confidence of people affected by leprosy and their leaders as a credible partner in their efforts to improve their lives. We now aim to further strengthen those ties as we work together for an India free of leprosy and the discrimination associated with it. ■

MUSEUM PIECE

NOY LABOD'S BANJO

Teodorico Cañete was a patient at the Eversley Childs Sanitarium in Cebu, the Philippines. A talented musician, Mr. Cañete or 'Noy Labod' as he was fondly known, would strum his banjo to the delight of patients and visitors alike. He also gave lessons, teaching youngsters how to play the banjo, guitar and the ukulele too. Noy Labod carried this banjo wherever he went, relieving himself and other

patients of the sadness and pain of separation from family that sanitarium life imposed.

Noy Labod's banjo is a 12-stringed instrument. It was donated to the Eversley Childs Sanitarium Museum & Archives with what was left of its 12 strings. The museum intends to replace the strings and restore the banjo to full working order. (Nancy Sabuero, ECS Museum & Archives)



Flying Visits

The Goodwill Ambassador tours a hospital in Ecuador, hosts a lunch meeting in Switzerland and attends an anniversary in India.

ECUADOR (October 15-18)

In October I traveled to Ecuador for the 3rd UN Conference on Housing and Sustainable Urban Development (Habitat III). While there, I took the opportunity to visit the Hospital Gonzalo Gonzalez, which was established almost 90 years ago to treat leprosy. Today it is home to around 20 persons affected by the disease, who live in a residential area within the hospital compound.

Over the years, as the incidence of leprosy has declined and the approach to treatment has evolved, the hospital has been put to other uses. It also now serves as an in-patient facility for treating drug and alcohol abuse.

To my surprise, the hospital was only 10 minutes' drive from my hotel in the capital, Quito; in my experience, such facilities are often in out-of-the-way locations. Quito is a small city, however, and by the time we reached our destination we had traversed several hills and found ourselves at the foot of a mountain. In that sense, the hospital was indeed set apart from the rest of the city, an impression emphasized by the sturdy gates at the entrance and the wall surrounding the compound.

In 2009, the government constructed 23 residences within the grounds where the 20 remaining residents now live. Their average age is 65, and the oldest resident is 84. There are 80 beds for in-patients but almost none of them are in use today.



Yolanda Toro with examples of her wonderful handicrafts

I was invited by Yolanda Toro, the unofficial leader of the residents, to visit her home. She has lived at the hospital for 25 years. She likes to sew and make baskets as part of her rehabilitation.

Her accommodation was neat and tidy, and there were examples of her work everywhere.

Yolanda, whose father also had leprosy, was originally from southern Peru. She entered the hospital at the age of 30. Her treatment began early, so she exhibits few after-effects of the disease. Before she entered hospital, however, her marriage broke up and she has had no contact with her family since.

After touring the grounds, I met all the residents for a chat. They gave me copies of a magazine that used



Greeting a resident at Hospital Gonzalo Gonzales

to be published by the hospital. The first issue came out in 1961 and was aimed at persons affected by leprosy throughout the country. As well as information about the disease, it included articles on romance, daily living and also featured poetry and tributes to those who had died. The content was written by patients and an association of female volunteers.

Talking with the residents, I learned that their most pressing concern is the government's desire to redevelop the hospital now that cases of leprosy are few and far between. Were this plan to be realized, it would mean that the residents would have to leave the



Copies of the magazine the hospital once published



Scenes from the hospital grounds



Attending the S-ILF anniversary celebrations in Delhi

place that has become their home. Understandably, the thought of being relocated is hard for them to accept and I hope an equitable solution is found.

SWITZERLAND (October 25-27)

In October I travelled to Geneva for the 135th assembly of the Inter-Parliamentary Union (IPU). I was seeking the formal endorsement of this body—the world organization of national parliaments—for next year’s Global Appeal to end stigma and discrimination against persons affected by leprosy. I was delighted, therefore, when the IPU agreed to support Global Appeal 2017 at its executive board meeting.

Afterward, I hosted a lunch for IPU delegates to provide them with an opportunity to learn more about leprosy. Over 40 legislators from 23 countries attended. Among those I had the pleasure of meeting was the speaker of India’s Lok Sabha (lower house of Parliament), Ms. Sumitra Mahajan.

The event concluded with remarks from IPU



Hosting a luncheon for the IPU in Geneva

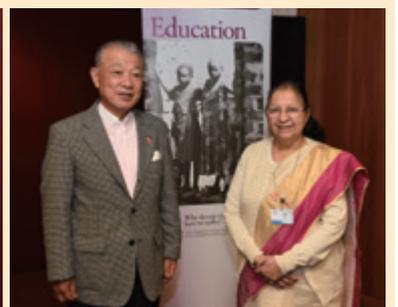
chairman, Mr. Saber Hossain Chowdhury of Bangladesh, a man I hold in high regard for his contribution to abolishing his country’s outdated and discriminatory 1898 Lepers Act. I look forward to the IPU’s involvement in Global Appeal 2017 and to the impact its support for ending discrimination will have.

INDIA (November 19-21)

The Sasakawa-India Leprosy Foundation (S-ILF) was established in 2006 to support in the reintegration of people affected by leprosy into society. It celebrated its 10th anniversary in November. I flew to Delhi for the reception, which was hosted by Executive Director Vineeta Shanker (see page 5).

Over these ten years, as the most important pillar of its work, S-ILF has been expanding its activities to help residents of self-settled colonies to become economically independent through skills training and the provision of microloans for enterprises. It has also placed emphasis on education and vocational training of children growing up in these colonies. S-ILF has come a long way since its founding, but there is still much to be done. I am confident it will tackle the issues in close cooperation with people affected by leprosy.

The day after the reception, I attended the S-ILF board meeting. Mr. Tarun Das, who has served on the board since S-ILF’s inception, was elected chairman after Dr. S.K. Noordeen had indicated earlier in the year that he would be standing down for reasons of health. I would like to record my heartfelt thanks to Dr. Noordeen for his decade of service, and welcome Mr. Das to his new position. ■



With (from L to R) WHO Director General Dr. Margaret Chan, IPU President Saber Chowdhury and Lok Sabha Speaker Sumitra Mahjan, in Geneva

Vatican Conference on NTDs

Meeting follows conference in June that focused on care of persons with leprosy.

A Vatican conference on neglected tropical diseases (NTDs) and rare pathologies was held November 10-12, 2016, hosted by the Pontifical Council for Health Care Workers.

NTDs, which include leprosy, are among the most common diseases of the poor, with one in six people around the world said to have at least one NTD.

Representing the Goodwill Ambassador, Nippon Foundation Executive Director Tatsuya Tanami spoke

about the foundation's work against leprosy, its support for the WHO's Global Leprosy Programme and the role of the Goodwill Ambassador in raising awareness of leprosy and advocating for an end to the stigma and discrimination that people affected by the disease still face.

"Leprosy is not only a medical issue, but a social issue. Unless both are tackled at the same time, it will not be possible to achieve a truly leprosy-free world," he said.

LEPROSY RESEARCH INITIATIVE

The Leprosy Research Initiative (LRI) invites proposals for funding beginning 2018 for research projects on leprosy. Preference is given to research applications combining leprosy with other NTDs or other diseases that share cross-cutting issues with leprosy.

Examples include combined self-care/wound care of leprosy and other diseases affecting the foot

or lower limb; combined approaches for skin-related NTDs; combination of prevention/treatment of NTDs; and combination of preventive chemotherapy for leprosy and other NTDs.

A Letter of Intent outlining the intended research should reach the LRI secretariat by February 28. For more details, visit www.leprosyresearch.org ■



www.leprosyresearch.org

FROM THE EDITORS

INDIA'S MASSIVE EFFORT

The leprosy case detection campaign undertaken by India recently was on a scale that boggles the mind. Some 320 million people across 19 states were screened by 300,000 health teams. The results indicate that when new case numbers for 2016 are announced, they will considerably exceed the 127,000 reported in 2015.

A campaign of this size requires careful planning and execution. The revised operational guidelines issued by India's National Leprosy Eradication Programme lay out how it is done and the challenges to be overcome.

Committees were formed at every level—national, state, district and block—for planning and implementation. Before and during the campaign, intensive information, education and communication activities were carried out to create community awareness and acceptance. Pamphlets, posters, folk plays, puppet theatre, wall painting, drum beating and "miking" were among the tactics, depending on the area and literacy levels. Teams of health functionaries were trained from district to village level in how to suspect cases of leprosy through physical examination of each and every person in every house visited. Micro-plans were drawn up for high-

risk areas and underserved populations. Supervisors mapped out the areas they were supervising in advance. The help of "local influencers" was enlisted.

As for the challenges, these included reaching nomadic tribes, boat people, urban slum dwellers and those in remote, sparsely populated areas. There was also the possibility of non-cooperation, because people had lost faith in the health program due to the poor quality of services they receive, were suspicious, poorly informed or because they were of high socio-economic status and "assume that leprosy cannot occur to them."

Great emphasis was placed on the teams behaving politely and explaining the purpose of their visit clearly. Accredited social health activists and field-level workers were reminded they were not to make diagnoses but only to note suspected cases and refrain from making negative comments. Accurate data collection was paramount.

One piece of advice catches the eye. "This activity is going to benefit your own people," the local volunteers were told. By extension, the whole country benefits. This, surely, is the message at the core of this massive campaign to detect hidden cases in the community and interrupt transmission of the disease.

FOR THE ELIMINATION OF LEPROSY

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