

FOR THE Elimination OF Leprosy

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



Yohei Sasakawa poses with IDEA members at the 17th International Leprosy Congress in Hyderabad earlier this year.

MESSAGE

Working Together

The Japanese government has promised me that it will submit a resolution on discrimination against people affected by leprosy and their families at the UN Human Rights Council this summer. (This spring, it has already made a statement on the issue.) As well as being grateful for this strong show of support, it is my deep desire that this resolution passes as soon as possible with the backing of many countries.

The recent International Leprosy Congress, which was successfully held under the leadership of Dr. S.K. Noordeen, was a memorable congress for many reasons — not least because of the number of sessions devoted to the human rights aspects of leprosy, and for the input of people affected by the disease from many different countries.

There were also clear signals that the major partners in the fight against leprosy increasingly recognize that human rights considerations must form a central part of the overall effort to create a leprosy-free world. Hence, although I could not stay for the whole congress, I was

encouraged to note there was a presentation by ILEP General Secretary Doug Soutar on leprosy and human rights. I look forward very much to ILEP's efforts in this area, because I am sure that its involvement will have a profound impact on the situation.

The fight to eliminate leprosy as a disease has naturally centered on doctors and public health experts. But the struggle on the social front requires more broad-based participation. There are many NGOs in what I call the “non-leprosy community” that are active in the human rights field, and we need to sensitize them to the issues and find ways of working together if we are to attain our goals. More than ever, we also need the cooperation of media organizations and the commitment of political leaders.

A resolution passed at the UNHRC would be a tremendous achievement, but it must be accompanied by an unstoppable social movement from the grassroots up.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Looking Back at Hyderabad

Social aspects of leprosy added another dimension to 17th ILC.

The 17th International Leprosy Congress was an important landmark in the history of leprosy and leprosy work as it came at a time of great achievements in conquering the disease as a public health problem.

The Congress attracted over 1,500 delegates from more than 60 countries. The participants included experts from several disciplines ranging from molecular biology at one end to socio-economic rehabilitation at the other. A large number of leprosy-affected people themselves actively participated, allowing their voices to be heard. There were also several pre-Congress workshops that enabled consensus development on several areas of leprosy work.

The Congress benefited from over 600 original papers and about 100 special presentations covering various topics, including clinical aspects, therapy, immunology, microbiology, epidemiology, surgery, rehabilitation and social aspects.

REDUCED DISEASE BURDEN

The Congress reviewed the epidemiological situation of leprosy in the world and the achievements toward elimination of the disease. While it was clear that the disease burden has been hugely reduced, irrespective of some controversies over the reliability of available statistics, the question of dealing with the remaining problems was considered serious enough to merit further intensification of anti-leprosy activities in areas of persisting leprosy endemicity, as well as the



Hyderabad: objectives of the Congress were met

development of newer strategies, aside from investing more in research.

The Hyderabad Congress addressed particularly the issues that directly impact people affected by the disease, including the challenges they face in the areas of stigma, socio-economic rehabilitation, empowerment and human rights. Leprosy-affected persons from several countries contributed to the discussions in a very effective manner.

The Congress also discussed major developments emanating from information on the genome of *M. leprae* and the resulting opportunities for a better understanding of the disease process and possibilities for improved tools for diagnosis and treatment. Overall, the main objectives of the Congress of promoting interaction among leprosy workers and scientists were effectively met.

The Congress was also an important learning opportunity for many young health workers.

It was also a very important learning opportunity for a large number of young health workers who participated in various sessions with great enthusiasm. The facilities at the Congress venue aided the interaction among them, and many of the workers said they would remember the 17th International Leprosy Congress for a long time to come.

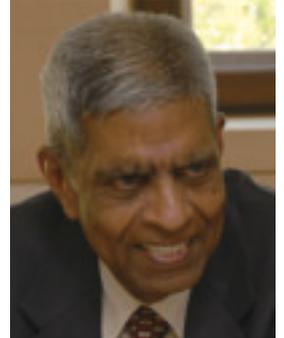
THE CHALLENGES AHEAD

Reflecting on the achievements of the Congress and looking to the future of leprosy work, it is clear that the challenges we face mainly involve further improving our understanding of the disease process and better interventions for management of leprosy and its complications. The public health issues, including leprosy elimination, will have diminished importance in the future in view of the huge reductions already achieved in leprosy prevalence and incidence. However, there will be continuing need for better understanding of the epidemiology of leprosy, particularly in geographic areas where the disease tends to persist.

Meanwhile, as some of the discussions at Hyderabad indicated, an area where the focus is likely to enlarge greatly involves the physical and socio-economic rehabilitation of leprosy-affected persons, including the related issues of social stigma, discrimination, empowerment and human rights. ■

AUTHOR:

Dr. S.K. Noordeen



Dr. S.K. Noordeen was the chairman of the 17th International Leprosy Congress held in Hyderabad, India, from January 30 to February 4.

Sustaining Quality Leprosy Services

In the post-elimination era, guarding against complacency is critical.

The achievements recorded under the WHO's leprosy elimination strategy have been heralded as a public health success story. The challenge now is to ensure that these achievements are not reversed in the "post-elimination" era.

In a presentation at the 17th International Leprosy Congress, Professor Cairns Smith of the University of Aberdeen and a member of the technical commission of the International Federation of Anti-Leprosy Associations (ILEP), compared the WHO strategy that was used to achieve the elimination goal with the current strategy to further reduce the leprosy burden and sustain the quality of leprosy services.

In many ways, he said, the content of the two strategies is the same in terms of their activities, but the current strategy is being delivered in a different context in which the prevalence of the disease is low. "One of the key concepts (of the new strategy) is sustainability."

In the elimination era, the main thrust involved case detection and treatment using multidrug therapy (MDT). To achieve the elimination target of under 1 case per 10,000 population, a number of simplifications were introduced to make the program easier to deliver in the field. In case detection, smears were no longer essential to diagnose the disease, and experts were not necessary to classify leprosy cases as either paucibacillary or multibacillary.

Treatment with MDT evolved, becoming shorter and fixed in duration. The introduction of blister packs made it easy for the drugs to be distributed and easy for patients to take, and MDT was also available free of charge.

The strengths of the elimination strategy were its focus and the fact it was time-bound: there was a specific target, and there was a given period in which to achieve the goal.

LEPROSY FACTS

In 2006, 16 countries accounted for 95% of all new cases of leprosy in the world. The top five were India (138,252 cases), Brazil (44,436), Indonesia (17,682), DR Congo (8,257) and Bangladesh (6,280); the remaining 11 countries each reported between 1,000 and 5,000 new cases. (Source: WHO)

VERTICAL COMPONENTS



But by its very nature, the elimination strategy was unsustainable, he said. It consisted of many vertical components, with dedicated staff at all levels, separate recording and reporting systems, its own drug distribution system and substantial funding devoted to the goal of elimination.

"The issue of sustainability is important," said Professor Smith, "because although the prevalence of leprosy fell dramatically during the elimination strategy, the same did not happen with new case detection, which remained remarkably stable over that period."

CURRENT STRATEGY

The strategy for 2006-2010 is designed to address this issue. It is delivered in an integrated context, is oriented toward continuing to reduce the burden of leprosy, and is no longer time bound.

It is a strategy that emphasizes quality and accessible services at the local and referral level, makes human rights and participation by those affected an essential component, and tackles both the physical and social consequences of the disease. "We are dealing with leprosy not just as a disease that requires MDT," Professor Smith said.

Quality has to be defined by the patient. The program must be patient-centered.

As to just what "quality leprosy services" entail, they comprise services that are accessible to all who need them, with no geographical, economic or gender barriers, he said. "Quality has to be defined by the patient, and hence the program is referred to as patient-centered."

Included are every aspect of case management — diagnosis, treatment, management of reactions, prevention of disability, referral for complications and rehabilitation as well as skill transfer for self-care.

Unfortunately, said Professor Smith, the evidence suggests that accessible and quality leprosy services are not being sustained. Different regions are doing different things. "I think one of the big challenges facing us at the moment is complacency. Having achieved elimination, we are behaving as if we have won a war, when we have only won a battle."

The problem now, and the challenge for the future, is to implement the strategy, he said. To this end, operational guidelines have been produced and a training program for national program managers is now being rolled out. "Partnership is a fundamental focus of the new strategy," he said. "We cannot do this on our own, as one group or sector. WHO, ILEP, patients, families have to come together to address the challenge of making national programs sustainable." ■

Lessons from an HIV/AIDS Activist

Experiences fighting stigma parallel the situation for people affected by leprosy.

Following the death of her husband Christopher from AIDS in January 1987, Ugandan physiotherapist Noerine Kaleeba and 15 other people formed The AIDS Support Organization (TASO) to educate the public about HIV/AIDS and to fight the stigma and prejudice associated with the disease.

From small beginnings, TASO is now the largest indigenous NGO in Africa providing HIV/AIDS services to people on the continent. Its annual budget is close to US\$25 million.

At the recent 17th International Leprosy Congress, Kaleeba shared with delegates some of the strategies that have proved effective in countering negative attitudes toward HIV/AIDS in Africa and how these might help in combating leprosy-related stigma.

“One very important action that we took in the AIDS movement, which has been taken up globally, was to mobilize political leadership. Political leadership is essential, especially when confronting a disease that carries stigma,” she said. “I come from a country that is very lucky in that we had a leader, President Museveni, who took a very early stand in Uganda to be focused about the disease.”

Political leadership is essential, especially when confronting a disease that carries stigma.

Another important step was the involvement of celebrities, which helped to give the movement a higher profile. Among the influential strategic partnerships that TASO struck up was one with Bono, the leader singer of the band U2.

Then there were the “heroic efforts of people with HIV in standing up and giving the disease a human face and voice,” she said. “My husband was on the TV and radio just before he died, sharing his experiences and appealing to others to try and avoid catching HIV.”

This was not without consequences for his family. After Christopher’s illness became public knowledge, there was a period of three months when the couple’s children could not go to school. They were rejected by their peers because their father had AIDS, and endured the taunts of their classmates.

“Although there might be one person in a family affected by HIV, the stigma affects every member,” she said.

Instead of suffering it in silence, Kaleeba’s



TASO co-founder Kaleeba: now an advisor for UNAIDS

family chose to fight stigma out in the open. “We decided to use my husband’s experience to mobilize others, seek out people with similar experiences, and form a support group. This is what led to the formation of TASO,” she said.

She reserves particular praise for her father-in-law. “He was the first man in Uganda to stand up and say (publicly), ‘My son has died of AIDS.’”

SUPPORT SYSTEM

For people affected by the disease who choose to confront stigma, it is essential that they have a support system, said Kaleeba. “No one can challenge and stand up against stigma unless they have support around them. In our experience, this came from families, people you work with, with fellow affected persons challenged by the disease.”

She noted, however, that some families have also been the cause and perpetrators of stigma. She recalled meeting young men and women with HIV who would have liked to join the movement, and use their experiences to help others, but their loved ones said, “Don’t bring shame to our family.”

Other points raised by Kaleeba included the importance of “symbolism in activism.” Hugging and shaking hands have a big impact in influencing public perceptions, she said.

So too does choice of language. “Very early, we rejected the term ‘AIDS victim’, as I am sure you reject the word ‘leper’.”

Language is also crucial in relation to media coverage. “The media has played a key role in addressing stigma in HIV/AIDS. What they promote goes to the public.”

Stigma does not disappear completely, said Kaleeba. “But as long as we remain united, as long as we develop leadership of those affected directly, as long as we strike up meaningful, equal partnerships, we can go forward.” ■

History as Dialogue

Bergen's Lepramuseet plays a key social role in a nation famously linked with leprosy.

AUTHOR:

Sigurd Sverdrup Sandmo



Sigurd Sverdrup Sandmo is the curator of The Leprosy Museum in Bergen, Norway.

Around the second half of the 19th century, Norway, and specifically the city of Bergen, was a world center for leprosy research. It was here that Danielssen and Boeck published the first modern study on leprosy in 1847; that a register of leprosy patients was established in 1856 (the first national register of a disease anywhere in the world); and where in 1873 the bacillus that causes leprosy was discovered by physician Armauer Hansen, after whom the disease has come to be known in many countries.

At one time, Bergen had three leprosy hospitals and the largest concentration of patients with the disease in Europe. The oldest of these hospitals was St. George's. Dating back to 1411, its last two patients died in 1949.

Today, St. George's houses The Leprosy Museum of Bergen. The site consists of 10 buildings that date back to the 18th century, of which the main building and the church are open to the public.

When it was established in 1972, the museum focused on Norway's contribution to leprosy research and the successes of its medical men, with Hansen as its number one artifact. Run by the Faculty of Medicine at the University of Bergen, it presented the expert view of leprosy. Where patients featured at all, they were represented in photographs showing severe cases of the disease, without personal biographies or historical context. The museum was often described as "obscure" or "scary."

In 2003, the museum underwent a transformation. We decided that the "expert monologue" should be replaced by a dialogue with visitors. While it remained important to acknowledge Norway's contribution to leprosy research, it was also important to show the human cost of the disease and to pose questions. In addition, we felt that the exhibitions should

be secondary to the historical nature of the site itself, so we removed all modern fixtures from the central areas and decided to use natural light as much as possible.

In its current form, the museum continues to tell the institutional history of leprosy, and the medical achievements that are so special to Bergen. But this information is now in the background, conveyed in non-expert language.

In the foreground are persons affected by leprosy, individuals who formed the hospital community. In each of the 12 rooms that make up the exhibition space, one person is featured, combined with contemporary sources. No images are presented without some kind of personal context. There is no "curator's voice."

TOUCHY ISSUE

The last people to contract leprosy in Norway were diagnosed in the 1950s. To all intents and purposes, leprosy is a disease that has been eradicated from the country. Nevertheless, leprosy remains a touchy issue. Even if people are no longer infected by the disease, they are still affected by its history, and contact us to find out about topics that have been silenced in their own families.

One of the talking points at the museum is a large plaque with the names of more than 8,000 people who were diagnosed with leprosy in Norway. The names were taken from the national leprosy register. We thought about whether this was the right approach. Were we not perhaps re-victimizing people by listing their names in this way? But it was very important to us not to cite only a number — 8,231 — but to show that these were actual Norwegians.

It is interesting to see what kinds of reactions there are to this exhibit. A lot of people write in our guest book that it is thought-provoking and moving. It has become clear that it triggers discussions among visitors, and between visitors and museum staff, about the disease and the people it infected and affected.

To me, a museum is a function of a democratic society. Bergen's Lepramuseet is part of Norway's history, and people have the right to access their own heritage. We are a social institution and have a role to raise social questions. This is not a place where people are met only with answers. ■



Talking point: the plaque listing names from Norway's leprosy register

Stigma as a Barrier to Employment

Employers sympathetic, but reluctant to hire, Indian survey finds.

To what extent is stigma an obstacle preventing people affected by leprosy from finding jobs? Between July and December 2007, Bino Berry, an occupational therapist at The Leprosy Mission Trust Vocational Training Center in Nashik, Maharashtra, conducted a survey of employers to determine their awareness of and attitude toward leprosy.

A questionnaire consisting of 10 multiple choice questions was administered to 200 randomly selected industrial employers in Nashik, and the responses were obtained in face-to-face interviews.

The survey was prompted in part by concerns that employers were ignorant about leprosy and stigmatized those with the disease.

While the majority of those polled knew that leprosy was caused by a bacteria, answers indicated that some believed the disease was hereditary, was highly infectious, that treatment took at least five years and that deformity was the norm in the long run.

Although they were largely sympathetic to the plight of persons affected by leprosy, few employers were prepared to hire them, the survey found (see right).

What these results underline, Berry said, is the importance of having health education programs for both employers and employees, and he noted that the process of collecting the data had in itself served as an education for those polled. ■

THE PROBLEM EXPOSED

- **Attitude of employers toward people affected by leprosy:**
Sympathy: 61%, Sorrow: 14.5%, Fear: 13.5%, Avoidance: 10.5%
- **Would you accept a person affected by leprosy as an employee?:**
No: 66.5%, Yes: 30%, Can't say: 3.5%
- **Reason for non-acceptance:**
Non-cooperation of employees: 37.5%, Other reasons: 30%, Perception that people affected by leprosy are inefficient workers: 22%, Fear of spreading the disease: 10%.



The Nashik Vocational Training Center teaches skills, but are employers prepared to use them?

PORTRAIT

A PASSION FOR PAINTING

Rintu Karjee likes nothing more than picking up a paint brush and following his muse.

Twenty-nine-year old Rintu Karjee loves to paint. The youngest of nine brothers and sisters, West Bengal-born Rintu first began sketching at the age of six and has not looked back since.

Normally a day doesn't go by without him spending at least some time with his brushes. "It's what I enjoy doing more than anything else," he says. "I don't feel right if I haven't spent time on a painting."

Rintu developed symptoms of leprosy at the

age of 21, but it was several years before he was correctly diagnosed and treated with MDT.

Today he lives with his mother and paints

when the mood takes him. He doesn't set out with a particular theme in mind, but says the images take shape as he works.

Lacking a sales channel, Rintu says he has thousands of pictures piled up at home, and is finding it increasing hard to store them.

But although he can't make a living from his art, he is able to support himself by teaching children how to paint. One way or another, he is never far from doing what he likes best. ■



Rintu (second from right), and some of his work, in Hyderabad

Journeys with a Human Rights Theme

The goodwill ambassador's travels take him to Cambodia, India, and the U.S.

CAMBODIA (FEBRUARY 23-25)

Toward the end of February I journeyed to Cambodia to speak at the opening of an eight-day festival for physically-challenged performing artists. The Spotlight Festival showcases the talents and professionalism of some truly outstanding artists from around Asia, and focuses on their capabilities, not their disabilities.

Although there were no people affected by leprosy taking part, I invited a group of about 40 affected persons to accompany me to the festival's opening night on February 23 so that they could enjoy the performances and draw encouragement from them. Earlier in the day, I had discussed with them the possibility of starting a support network of the kind we now see in India and other countries.

The next day, I traveled to Treung Village in Prey Chhor District, Kampong Cham Province. The village, which was once a leprosy colony, today has a population of 1,243. Of these, 87 are persons affected by leprosy and 125 are children. Once a month, the village receives a visit from a representative of CIOMAL, a Geneva-based NGO and a member of ILEP.

On February 26, I met with Health Minister Nuth Sokhom, and was accompanied by David Awcock, the head of CIOMAL Cambodia, and Dr. Michael O'Leary, the WHO country representative. At this meeting I was told that the national program to control leprosy has been effective and that the number of cases has been coming down. However, stigma and discrimination remain a problem.

Nevertheless, the situation is improving, and people affected by the disease are increasingly accepted. I understand that growing numbers of people showing early signs of leprosy are being referred for treatment by their neighbors, whereas in the past they would have been driven from the village.

INDIA (MARCH 5)

Early in March I traveled to New Delhi as a special invitee to the board meeting of the Sasakawa-India Leprosy Foundation. SILF was established in November 2006 and formally launched in October 2007. It aims to enhance the employability of people affected by leprosy and their families through skills training and education, encourage social responsibility among different sectors of society so as to assist

in job placement and social rehabilitation, create opportunities for affected persons to tap into financial resources for self employment, and build wide-ranging partnerships to achieve these goals.

The meeting was attended by Dr. S.K. Noordeen, immediate past president of the International Leprosy Association and chairman of SILF; Tarun Das, chief mentor of the Confederation of Indian Industry; Syeda Imam, creative director of the Contract Advertising Company, and Dr. Vineeta Shanker, SILF's director.

The board decided that SILF will initially focus on providing assistance for livelihood generation at self-settled colonies and on serving as a catalyst linking the activities of corporates, NGOs, charities and governments with the self-settled colonies.

It also discussed and approved the principles for assistance guidelines. The guidelines will be worked out by a committee to be established within SILF.

UNITED STATES (MARCH 6)



From India I journeyed to the United States, where I had been invited to speak on "Leprosy and Human Rights" at the Woodrow Wilson International Center for Scholars in Washington, D.C. The Wilson Center was established in 1968 as a "neutral forum

for free and informed dialogue."

I said that although the days when people affected by leprosy were forcibly isolated from society were over, invisible barriers still prevent them and their families from full social participation. Ignorance and unwarranted fear of the disease are the culprits, resulting in stigma and discrimination that deny people their basic human rights.

We must treat others as we would hope to be treated ourselves, I said. After all, we each and every one of us have an equal right to live on this Earth. ■

Japan Issues Statement at UNHRC

Raises issue of discrimination as a serious violation of human rights.

On March 13, the Japanese government issued a statement at the 7th Session of the UN Human Rights Council in Geneva to draw the Council's attention to the issue of discrimination against people affected by leprosy and their families.

The statement noted that while leprosy is now curable and the number of cases is in decline, those affected by the disease and their families continue to face prejudice.

"We would like to raise the issue of leprosy

as an issue of discrimination. The international community should recognize that discrimination against leprosy-affected persons is a serious violation of human rights. The stigma of leprosy must be erased," the statement said.

The government of Japan has taken a variety of measures to eliminate discrimination relating to leprosy, including the appointment last September of Yohei Sasakawa as its Goodwill Ambassador for the Human Rights of People Affected by Leprosy.

BANNERS OF HONOR



IDEA members display "banners of honor" in Hyderabad recently. The banners remember the contributions made by individuals with leprosy.

9TH TAG MEETING INCLUDES STIGMA

The 9th Meeting of the WHO Technical Advisory Group on Leprosy Control was held in Cairo on March 6-7. For the first time, a TAG meeting included a session on stigma and discrimination, and invited a person affected by leprosy — Jose Ramirez, Jr. — to address it.

BACURAU VIRTUAL MUSEUM

A museum devoted to the memory of late Brazilian activist Francisco Nunes ("Bacurau") is now online at www.casadebacurau.com.br/en/nav.html

It tells the story of his life and documents his struggle for the human rights and dignity of people affected by leprosy. Bacarau died in 1997. ■

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FROM THE EDITORS

SECOND GENERATION PROBLEM

Research carried out by a young occupational therapist in Maharashtra on employer attitudes toward hiring persons affected by leprosy (p.6) shows that more work needs to be done to educate both employers and employees about the disease. While the majority of employers indicated they were sympathetic toward affected persons, when it came to offering them work, less than a third said they were prepared to do so — mostly citing the problems they could expect from their employees, but also indicating that they didn't feel people affected by the disease would make efficient workers.

A lack of employment opportunities due to the stigma associated with leprosy is not limited to persons directly affected by the disease. As an article in the *Hindustan Times* noted last July

— around the time that occupational therapist Bino Berry was beginning his survey — fear of leprosy remains so strong that even non-affected in a community associated with leprosy suffer from stigma.

The paper quoted a driver called Junan, aged 20, living in an ashram in the north of Delhi, who said, "I'm planning to move out as I don't want the address of a leprosy home on my driver's license. In the past, whenever my employers have discovered where I live, I get the sack."

In parts of India and other countries where leprosy has deep roots, prejudice and discrimination breed poverty. Empowering the "second generation" is surely the way to break this vicious cycle.