WHO GOODWILL AMBASSADOR'S NEWSLETTER

FOR THE

Elimination OF Leprosy

October 2011 • Number 52

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

A young girl at Ashadeep Leprosy Colony in Chhattisgarh, India, handles yarn used in handloom weaving (September 2011)

MESSAGE

Further Steps on Human Rights

In December 2010, the UN General Assembly approved a resolution on ending discrimination against persons affected by leprosy and their family members. This was the result of a process that began when I approached the Office of the UN High Commissioner for Human Rights in 2003 — a process sustained by the efforts of many, including NGOs, organizations of people affected by leprosy and the Japanese government. The resolution's accompanying principles and guidelines clearly outline the rights to which people affected by leprosy and their families are entitled. They also indicate the responsibility of governments and civil society to restore and protect those rights.

Yet nothing will change without further action on the part of all stakeholders. We must take every opportunity to bring the resolution to the attention of the relevant authorities. We must encourage them to act on its words. For my part, I am planning to hold a seminar on human rights in each of the world's five main continents, starting next year. The purpose is to raise awareness of the resolution among political leaders, international bodies, NGOs, media and the general public and ensure that the resolution is properly implemented.

How to reduce stigma and discrimination was the subject of the first session of the recent global leprosy program managers' meeting held in New Delhi. Invited to give a keynote address, I outlined the three strategies I follow. The first is to focus the international community's attention on leprosy as a human rights issue. The second is to build awareness and transform social perceptions through initiatives such as an annual Global Appeal. The third is to empower people affected by leprosy.

While the WHO's primary responsibility is to further reduce the incidence of the disease, I welcome the fact it has also taken up the disease's social consequences. I look forward to joining all stakeholders in a renewed effort to combat both leprosy and the discrimination that it causes.

— *Yohei Sasakawa*, WHO Goodwill Ambassador

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Implementing the Enhanced Strategy

Program managers' meeting focuses on stigma, disability and other challenges.

Participants at the recent program managers' meeting in New Delhi

At the recent meeting of global leprosy program managers held at the WHO's Southeast Asian Regional Office on September 28-29, one country report stood out. Morocco's Dr. Abdellatif Idrissi Azzouzi chose to title his presentation "Fatima or the Hard Reality of Leprosy". He showed a photograph of a severely disfigured woman and later explained that she was one of three new cases with Grade II disability that Morocco registered in the first half of this year.

It was a reminder that even as the number of new cases continues to fall globally, leprosy still takes its toll on the individuals affected. Fatima's example also drew attention to one of the goals of the Enhanced Global Strategy* that the program managers had come to discuss: reducing the occurrence of Grade II impairments and disabilities in new cases.

Welcoming the nearly 100 program managers, technical experts and partners to the meeting, Dr. Samlee Plianbangchang, the WHO's regional director, acknowledged the progress made by the global leprosy program in recent years, but said that "as the disease burden declines, we can expect more challenges." Among these are the need to improve case-finding activities and also to intensify efforts to overcome the stigma and discrimination that people affected by leprosy face.

SOCIAL DIMENSION

In a sign of the increasing importance the WHO attaches to addressing the social aspects of the disease, the first session was devoted to "Reducing Stigma and Discrimination."

Said Dr. Wim van Brakel (NLR Technical Advisor): "One reason why it has been so hard to do something about stigma is that it has been poorly understood until now. We've had a much too simplistic picture of what stigma and discrimination are." He outlined a comprehensive stigma reduction model and drew attention to new stigma guidelines published recently by the International Federation of Anti-Leprosy Associations (see sidebar). "The consensus is that we can't just use one particular strategy."

Underlining the need for a holistic approach to treating leprosy and its consequences, an approach that extends beyond medical care,

LEPROSY WISH LIST

Maryse Legault
Director, Leprosy Relief Canada

AN INCREASE IN EARLY DETECTION TO AVOID DISABILITIES.
In programs Leprosy Relief Canada funds, we emphasize increasing early diagnosis, especially in cases involving children.

THE RIGHT OF EVERY PERSON AFFECTED BY LEPROSY TO EQUITY, SOCIAL JUSTICE AND HUMAN RIGHTS.
Leprosy Relief Canada strongly believes in the necessity of the UN Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members. We support initiatives ensuring the full realization of all human rights for persons affected by leprosy.

GREATER PUBLIC AWARENESS OF THE NEEDS OF INDIVIDUALS AFFECTED BY LEPROSY.
This year, Leprosy Relief Canada is celebrating its 50th anniversary. Today, too many Canadians believe leprosy is a disease of the past. We need to change that perception.

Do you have a leprosy wish list? Please write in and let us know: smhf_an@tnfb.jp

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FOOTNOTE

* Enhanced Global Strategy for Further Reducing the Disease Burden Due to Leprosy (2011–15).

was Dr. P.K. Gopal (National Forum). “The cure remains incomplete until persons affected by leprosy regain the social and economic status that allows a dignified life,” he said.

On the subject of reducing Grade II disability in new cases, Professor W.C.S. Smith (University of Aberdeen) listed three approaches: preventing leprosy, early diagnosis and treatment, and prevention-of-disability activities. Should a new case with Grade II disability appear, he urged program managers to find out the reason why the patient was diagnosed too late. “Trace your way back through the patient journey,” he said. “Use this as an opportunity to investigate and develop solutions.”

LACK OF COMMITMENT

Many of the presentations by the national program managers pointed to a lack of political commitment as one of the challenges they faced. But the meeting also raised the issue of keeping program managers and health workers motivated as leprosy becomes less of a problem. Said Dr. V. Pannikar, former team leader of the Global Leprosy Program, “The graphs are getting flat. It is a challenge to keep enthusiasm up. But if we don’t do what we are supposed to do, leprosy will come back. We have to make small, small interventions; cumulatively, they add up.”

One of these small interventions is examining contacts, including household contacts, of a person diagnosed with leprosy. This was described as a cost-effective way of detecting new cases in individuals with increased risk of developing the disease, and was one of the recommendations to come out of the meeting. Discussion also focused on chemoprophylaxis and the operational conditions under which it might be used successfully.

While commending the goal to reduce disability in new cases, several participants expressed concern over whether enough was being done for persons who are already disabled. Furthermore, “does the idea of rehabilitation extend to social and economic rehabilitation?” asked Menberu Adane (Ethiopian National Association of Persons Affected by Leprosy), one of several affected persons’ representatives invited to attend.

> “The graphs are getting flat. It is a challenge to keep enthusiasm up.”

Goodwill Ambassador Yohei Sasakawa delivered the keynote address and the meeting was ably chaired by Dr. Joseph Kawuma (German Leprosy and TB Relief Association). Among Dr. Kawuma’s exhortations to program managers was to remind them of their responsibility to ensure there was a correct interpretation of the trends being seen in leprosy: “We mustn’t tell the world that there is a diminishing number of cases when there is diminishing case-finding,” he said.

Asked for a program manager’s perspective on the proceedings, Dr. Salah Mohamed Abdel Nabi of Egypt, speaking on the sidelines, said: “It is very useful to meet colleagues from all over the world and hear new things. I think it is the same for all of us.” ■

GUIDELINES

ALL ABOUT STIGMA

Health workers and social workers who encounter stigma in leprosy and other health conditions now have a handy new tool to help them understand and deal with it better.

Guidelines to reduce stigma is a four-part series released earlier this year by the International Federation of Anti-Leprosy Associations (ILEP). The guidelines are the outcome of several years of study, culminating in a major stigma research workshop held in Amsterdam in 2010.

“What is health-related stigma?” provides basic information on stigma, its causes, manifestations and effects. “How to assess health-related stigma” describes ways to assess stigma using quantitative instruments and measurements. “A roadmap to stigma reduction: an empowerment intervention” offers recommendations on how to develop an approach for reducing stigma. Last but not least, “Counseling to reduce stigma” explains the use of counseling at a basic level in dealing with stigma.

“We made sure that people affected by leprosy were well represented and well consulted with regard to the content of the guidelines,” said Dr. Wim van Brakel, one of the main contributors.

The guidelines are electronic publications that can be downloaded from the ILEP website (www.ilep.org.uk). A template is available to facilitate translation into other languages.

Non-Stop Activist

Andhra Pradesh-born Vagavathali Narsappa's work is never done.

SLAP President V. Narsappa: "Everyone must be a leader."

It may not have the most felicitous acronym, but the Society of Leprosy Affected Persons, or SLAP, doesn't mind one bit if it gets your attention. Founder and President Vagavathali Narsappa set up the organization in 2006 to promote a better quality of life for people affected by leprosy in the Indian state of Andhra Pradesh. It is the umbrella group for the state's 101 leprosy colonies and is affiliated with the National Forum, the nationwide networking organization of people affected by leprosy that Narsappa serves as trustee.

Narsappa was 10 years old when he was diagnosed with leprosy. His village wanted him gone, so his father took him to Victoria Hospital in Nizamabad and left him there. "Can you conceive what it was like for a young child to be abandoned by his family?" he asks.

Leprosy marked him out. He describes taking the school exam for Class 7. "A government official dropped the exam paper in front of me and wouldn't let me in the building. I had to do the test sitting in the hot sun. But I passed and got good marks." Subsequently, when he failed the exam for Class 10, his formal education came to an end.

'WHY NOT US?'

Finding it difficult to work because his fingers were reduced to stumps, Narsappa was forced to beg. This humiliation, along with everything else he had experienced, forged him into an activist. "I looked around and saw that other sectors of society had organizations, and thought, 'Why not us?'"

He started his first group in a few districts of Hyderabad, where he was now living. One of his early actions was to organize a rally in February 2004 seeking an increase in the disability pension the state paid persons affected by leprosy. This was duly achieved when the amount was raised from 200 to 500 rupees. However, like all the struggles Narsappa engages in, it took time — four years — and the pension is still not enough, he says.

"The problems we face will not all be fixed in a day or two. Solve one, and another takes its place. We are constantly fighting the government for our basic rights," he says. For a while, when the government wouldn't listen, SLAP began presenting its demands to a government-funded statue of Mahatma Gandhi — a media-savvy way to draw attention to the impasse.

SLAP's demands cover the spectrum — from basic amenities for colonies and better leprosy services to educational opportunities for children from affected families. Narsappa, aware of the shortcomings in his own education, attaches particular importance to seeing that the next generation receives a proper schooling.

"Education plays a pivotal role in the growth and development of society and (the) nation," he wrote in a letter he presented to the Governor of Andhra Pradesh recently. Healthy children should not suffer just because their parents are affected by leprosy. They should not become a burden on the community because they did not receive educational support.

> Narsappa says that watching an account of his life makes him cry.

Social integration is the goal, but it will take time, he believes. "Our children are healthy, but society does not accept them. People say it's nice that leprosy is curable, but they are not ready to integrate with people who have had the disease."

One way forward will be economic success. "When people see a big building, a car, a good suit, there is no stigma," he says. "But if they see someone who is poor, there is stigma."

DIARY OF ACTIVITIES

Narsappa keeps a diary of his activities, meticulously recording who he met and what was discussed. In his correspondence with government officials, LEPRA India plays a supportive but unobtrusive role.

"I have no job," Narsappa says. "I only have the work of an activist. I am always thinking, 'What must we do to achieve success?'" His answer is that everyone must get involved. "Everyone must be a leader," he says.

Featured in a British television documentary earlier this year, SLAP's president says that watching an account of his life makes him cry. "I have been through so much." But it's those experiences that motivate him to keep on doing what he does best: not literally "slapping" people in the face, but making sure they sit up and take notice when he talks about the struggles borne by people affected by leprosy and demands recognition of their needs and rights. ■

On the Road in India

The Goodwill Ambassador visits Chhattisgarh and Andhra Pradesh, and attends a global leprosy program managers' meeting in New Delhi.

CHHATTISGARH (SEPTEMBER 22–24)

Chhattisgarh is one of India's newest states and primarily rural in character. Along with Bihar, it is one of the two remaining states where the prevalence rate of leprosy remains above the threshold of 1 case per 10,000 people. Its task is to "reach the unreached."

A four-hour drive from Raipur airport brought me to the town of Bilaspur. My destination was Bramba Vihar Leprosy Colony. Formed in 1979, it is home to 46 residents. Heavy rains had left parts of the colony waterlogged. Appeals to the authorities for infrastructure improvements — including better drainage — have so far fallen on deaf ears.

Three self-help groups operate in the colony. Facilitators from The Leprosy Mission India (TLMI) are teaching savings and book-keeping and have helped the groups to open bank accounts. They generate income from buying and selling wood.

Although living conditions were not the best, I had the impression the colony is well organized under its leader, Mr. Chitra Singh. I urged him to work closely with Mr. Ghasiram Bhoi, the president of the State Leprosy Rehabilitation Committee of Chhattisgarh, an organization of people affected by leprosy. That way, I said, the voices of the state's scattered colonies would be heard.

To coincide with my visit to Bilaspur, Chhattisgarh's state leprosy officer had organized a meeting of district leprosy officers. In his presentation, Dr. D. Bhatpahare explained that the leprosy prevalence rate had fallen from 11 cases per 10,000 people in 2001 to 1.46 in 2006; since then it has remained above the 2.0 mark. "We are progressing slowly, but well," said Dr. Bhatpahare. The state still faces difficulties — including hard-to-reach districts, a lack of personnel, and the low priority of the leprosy program — but Dr. Bhatpahare was clearly intent on overcoming them.

Self-help group members with TLMI facilitator at Bramba Vihar colony.

Earlier in the day, at his suggestion, I had called at a shop in Bilaspur to meet a man who had undergone reconstructive hand surgery. With the 5,000 rupees he received from the government for undergoing the procedure, he started a business making and selling earthenware pots. Seeing Mr. Kumhar's confident demeanor and the family he was supporting underscored for me the importance of this aspect of leprosy services.

Artisan Harilal Kumhar with wife Sarojani and daughter Chandani. He successfully underwent reconstructive surgery and now runs his own business.

Recent heavy rains had left parts of the colony waterlogged.

My final appointment in Bilaspur was with the state health minister, Shri Amar Agrawal. It was his birthday and well-wishers thronged his residence. He told me he wanted to make the state a model for leprosy policy. Mr. Bhoi told him about conditions at the colonies and the minister agreed to keep in touch on the issues.

The next day I visited Ashadeep Leprosy Colony in Bhilai, about an hour's drive from Raipur. As I relate elsewhere on these pages, it was one of the most impressive colonies I can

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recall visiting. This was in contrast to Santvinoda Leprosy Colony in Rajim, which I visited 24 hours later. Located near a famous temple, its principal source of income is begging. I did not witness the spirit of endeavor I saw in Ashadeep.

While in Chhattisgarh I also met representatives of the Human Rights Commission and took part in an NGO workshop. The latter was hosted jointly by TLMI and the State Leprosy Rehabilitation Committee. Mr. Bhoi showed why he is a leader, saying: "At the same time that we continue our appeals to the government, we can't rely on assistance alone. We need to make our way in life by dint of our own efforts." This is the right attitude and, with the right opportunities, it can be done.

ANDHRA PRADESH (SEPTEMBER 25–27)

Whereas Chhattisgarh is still grappling with leprosy as a public health problem, Andhra Pradesh has been far more successful in controlling the disease. On the other hand, it has more leprosy colonies than any other state and people affected by the disease still contend with many issues.

Following a media briefing at Hyderabad Press Club, I set out on a three-hour drive to Devanagar Leprosy Colony in Nizamabad. I had feared that demonstrations in support of independence for the Telengana region of Andhra Pradesh would lead my journey to be cancelled. But my acquaintance and friend Mr. Madhu Goud Yaskhi, Member of Parliament for Nizamabad, who had requested that I visit this colony in his constituency, assured me all would be well.

Arriving at Devanagar colony, I found a crowd of some 200 people waiting. There was a heavy police presence and a large number of journalists.

Mr. Madhu Goud Yaskhi, MP, greets residents at Devanagar Leprosy Colony.

Mr. Yaskhi arrived soon afterward, and together we made our way to meet some of the residents.

The colony has a population of 815, including 460 persons affected by leprosy. Some work in agriculture, some run their own businesses and a portion make a living from begging. The Sasakawa-India Leprosy Foundation has recently decided to provide microfinancing for a beauty salon, digital photo shop, laundry and general store, as well as for a buffalo-rearing enterprise.

I first met Mr. Yaskhi in 2006. A lawyer by profession, he lived in the United States for 14 years before returning to India to enter politics. He credits me with opening his eyes to leprosy after learning about my work. At a breakfast he hosted the next morning at his home in Hyderabad, he said he had come to know the Devanagar colony while commuting between Nizamabad and Hyderabad. Every year, he celebrates his birthday at the colony.

In the afternoon, we took part in a seminar on laws that discriminate against persons with leprosy. Mr. Yaskhi said he would create a bipartisan

ASHADEEP: A WORKING COLONY

I have been traveling to India for some 40 years and must have visited over 100 leprosy colonies, but Ashadeep Colony in Bhilai, Durg District, Chhattisgarh State stands out. If there is a role model for a well-run colony, then this may be it.

Ashadeep is home to 246 residents, of whom 150 are affected by leprosy. One of their main sources of income is weaving and the colony has 16 handlooms. Three were purchased with a grant from the Sasakawa-India Leprosy Foundation, which also arranged further skills training for the weavers.

Floor mats are among their staple products, as well as floor coverings made from recycled saris. The state government provides the raw materials and pays each weaver a minimum 200 rupees a day for their labor.

During my visit, I saw several weavers at work and also met a basket seller and a broom salesman. I watched

committee on leprosy and take up the issue with the Supreme Court. “What we need are not laws but a warm heart,” he declared.

While in Hyderabad, my schedule included meetings with Andhra Pradesh Governor E.S.L. Narasimhan, the CEO of the Society for the Elimination of Rural Poverty, Mr. B. Rajsekhar, and Minister for Social Welfare Shri Pithani Satyanarayana. On each occasion, I was accompanied by Mr. V. Narsappa, the determined and hardworking president of the Society of Leprosy Affected Persons.

Mr. Narsappa had arranged for me to meet around 50 representatives from a dozen or so colonies. After listening to the different problems they raised, I urged them to get behind Mr. Narsappa. “If all Andhra Pradesh’s 101 colonies form a cohesive unit, you will become a powerful force,” I told them. “You will be heard.”

Separately, I also met with some 20 educated youngsters from nearby colonies at a gathering hosted by LEPRA India. These youth can help change society. I believe they will play their part.

An interaction with youth from Hyderabad colonies

NEW DELHI (SEP 28–29)

With Justice Minister Salman Khurshid in New Delhi

From Hyderabad I moved on to New Delhi, where I had been invited to give a keynote address at the WHO’s Global Leprosy Program Managers’ Meeting. I commended program managers on their achievements to date, but urged them not to grow complacent. Many challenges remain and it is important that we all work together closely. I also hoped they would act on the WHO guidelines for greater participation of persons affected by leprosy in leprosy services.

My appointments in Delhi included a meeting with Minister of Law and Justice Shri Salman Khurshid, at which I raised the issue of discriminatory laws. I also visited a leprosy colony, Anand Gram, in east Delhi, where leaders from 15 colonies in the surrounding Tahirpur district had gathered to describe the difficulties their communities face. Their problems, like those of their counterparts in Chhattisgarh and Andhra Pradesh, have solutions. But they will take time to achieve, and more efforts are needed. ■

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a woman show me how she makes a broom using her hands and feet. I was impressed to see children helping out with weaving chores after returning from school. All seemed to be going about their tasks with a sense of purpose and a smile.

The founder of the colony is Mr. Vishwanath Ingale. Now in his seventies, he is not in the best of health. However, it was clear to me that his imprint was stamped on the colony.

I learned that he started Ashadeep in 1965 on the grounds of a cemetery. He proved himself to be a real fighter, agitating on behalf of colony residents to provide for their needs and to better their prospects. Over the years, he has been arrested 19 times for his activism and spent time in prison. He has paid particular attention to the education of children, the empowerment of women and vocational training. The Leprosy Mission India has support him in his efforts.

Mr. Uday Thakar of Hind Kusht Nivaran Sangh, who has spoken with Mr. Ingale extensively about his life, said the colony has been a success because of its founder’s philosophy, business acumen and his willingness to seek cooperation from all quarters. In establishing rules for the colony, he stopped the sale of illegal liquor, promoted legitimate forms of work and saw that everyone had a role. “People trusted him when they saw that he delivered on what he said,” said Mr. Thakar. “A good leader can effect change.”

I was impressed to learn that some doctors and engineers have emerged from among the colony’s younger generation. Not only that: people from the surrounding community have sought marriages for their daughters with young men from the colony.

Ashadeep colony shows the world that people affected by leprosy can work for a living and lead dignified lives free from begging. As I told residents as I was leaving. “It has been a pleasure to visit with you. All colonies in India should be like this.”

NEWS

100 Years and Counting

The remarkable Dr. Shigeaki Hinohara keeps on keeping on

Indulge us as we mark the 100th birthday of Dr. Shigeaki Hinohara, the president of the Sasakawa Memorial Health Foundation (SMHF)*. Well-known in Japan as a poster boy for "*Living Long, Living Well*" (the title of one of his best-selling books), Dr. Hinohara was instrumental in the foundation's establishment in 1974.

He had been approached to see if his Life Planning Center, formed in 1973 to promote lifelong health, could play a part in a new initiative to tackle leprosy being mulled by The Nippon Foundation in conjunction with leading Japanese chemotherapist, Professor Morizo Ishidate. Since the Life Planning Center already had its own agenda, Dr. Hinohara suggested forming a separate organization, pledging his full cooperation. The idea received the backing of The Nippon Foundation and thus was SMHF born.

Recalls Dr. Hinohara: "Professor Ishidate's idea was to suppress the development of leprosy. By cutting off the source of infection, he wanted to ensure that the next generation didn't get the disease. In other words, his approach to curing leprosy was to prevent the disease occurring. At the time, this was a very new idea."

The Life Planning Center was also based on the idea of prevention. "For more people to enjoy good health, not only doctors and health professionals but also the general public need to learn the science of health and conduct themselves on the basis of that knowledge," says Dr. Hinohara. "Such an attitude, we felt, could contribute to preventing disease or its reoccurrence. So I was happy to support the work of the new foundation."

Preventing the occurrence of leprosy remains one of the outstanding challenges some 37 years after SMHF was founded. But thanks to treatment with multidrug therapy and the work of many partners, the global leprosy situation has vastly improved in the intervening decades.

As for Dr. Hinohara, who celebrated his 100th birthday on October 4, he continues to lead a full and active life. His 10-year diary is filled with appointments for the next nine years, and keeping busy is one of the secrets to his longevity. Among the others? Eating 90 grams of steak twice a week and taking care over his appearance. As the dapper Dr. Hinohara told a newspaper reporter recently, "If you want to stay young, the ace up your sleeve is to be a snappy dresser."

Happy birthday, Dr. Hinohara. ■

FROM THE EDITORS

COUNSELING IN CAMBODIA

Sophea Leng loves his job. He counsels people affected by leprosy at Kien Khleang Leprosy Rehabilitation Center (CIOMAL) in Cambodia. Empathy and tissues are the tools of his trade. Sophea got his start when doctors asked him to find out why patients weren't taking their medicine, or were refusing to eat, and he grew into the role.

He spoke about his work at the recent global leprosy program managers' meeting in Delhi. During a coffee break, he added more details. "It's very important to listen and let people talk about what they want," he said. "I tell them it's OK to shout, get angry, or cry" — hence those tissues.

Although he once had leprosy himself, he does not mention this to the person he is counseling. Nor does he offer advice. "It is not my place to make decisions for them. I can only ask how something makes them feel, or what they want to do about it. The idea is to help them find a way to solve their problems themselves."

The work is not without its pitfalls. On one occasion, after Sophea comforted a weeping client, offering her tissues and a consoling word, she went to his superiors and accused him of "falling in love with me."

Called upon to explain himself, Sophea told his boss he had just been doing his job — the job he loves and is learning more about each day.

FOOTNOTE

* Dr. Hinohara is chairman of the board of trustees of St. Luke's International Hospital in Tokyo and is a board member of over 80 different organizations.

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