### WHO GOODWILL AMBASSADOR'S NEWSLETTER

# Elimination of Leprosy

### April 2013 • Number 61

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



The Goodwill Ambassador is surrounded by residents of Indira Nagar colony in Jharkhand, India, when he visited on April 6. (Photo: Tsuyoshi Ota)

### MESSAGE

## **Tracking Down New Cases**

Efforts to tackle leprosy have been slowing of late. It may be that many people who embarked on the journey to achieve a leprosy-free world began to ease up once the disease was eliminated as a public health problem at the national level. As I have said in the past, however, on a journey of 100 miles the 99th mile is only the halfway point. Having one more mile to go is the same as having 50 more miles.

In the fight against leprosy, eliminating the disease as a public health problem is just a milestone on the road to its eventual eradication. We must do whatever we can to get as close as possible to our ultimate goal of reducing the number of new cases to zero.

In recent years, the number of new cases reported annually has hovered around the 200,000 mark. Allied to the fact that our antileprosy activities appear to be stagnating, this is cause for concern.

Dr. C.M. Agrawal, the Deputy Director General (Leprosy) at India's Ministry of Health and Family Welfare, has mobilized community health workers to search actively for new patients in 209 high-endemic districts as the first step in a strategy for early detection and complete treatment of new leprosy cases. As a result — and this is only to be expected — the number of new cases is showing a tendency to increase.

This is an encouraging sign, Dr. Agrawal says. The most important thing is to reach out to every corner, grasp the actual situation and manage the cases detected. One should not be afraid of reporting an increased number of cases due to active search.

I am a strong supporter of this stance. Once again we need to do our utmost to detect and treat new cases, be they in remote rural areas or in sprawling urban slums. Is this not our duty? Our fight against leprosy is only at the halfway point.

— Yohei Sasakawa, WHO Goodwill Ambassador

### CONTENTS

### Message 1 Human Rights

Perspectives from Japan 2

Interview Javed Abidi, Chairperson, Disabled People's International **3** 

#### Column

Reflections on ENAPAL By Menberu Adane Yihunie

**Report** "Weaving Hope" photo exhibition in Indonesia **5** 

Ambassador's Journal India 6

**News** Dr. Etsuko Kita takes over at SMHF

From the Editors 8

8

### **Perspectives from Japan**

Experts brief IWG members on Japan's approach to resolving leprosy issues.



The International Working Group (IWG) to formulate action plans and monitoring mechanisms for the implementation of Principles and Guidelines on ending discrimination against people affected by leprosy met in Tokyo for its second meeting on March 15. A day earlier, five Japanese experts representing the government, the legal profession, the media, civil society and people affected by leprosy gave visiting IWG members their views on Japan's experiences with leprosy and human rights.

Koji Abe, who directs the Ministry of Foreign Affairs' Human Rights and Humanitarian Division, described how the Japanese government "took the initiative" to fight leprosy-related discrimination internationally from 2007. Working through the Human Rights Council, it tabled resolutions that led to the historic resolution adopted by the UN General Assembly in December 2010.

The government has pursued the issue in other human-rights arenas, too, such as the International Covenant on Civil and Human Rights. It will continue to provide "vigorous support" for efforts to tackle discrimination, Abe said.

### **BYSTANDERS' CULPABILITY**

Michihiro Ko, who heads Zenryokyo, the national association of sanatoria residents, provided the perspective of people forcibly confined to sanatoria under the Leprosy Prevention Law. Over the decades his organization fought to have the law abolished, to improve the quality of residents' lives and to restore their dignity in the face of stigma and prejudice that saw many of them disowned even by their own families.

Analyzing the history of discrimination in Japan, Ko said there were perpetrators, victims, and bystanders. It was the attitude of the bystanders — "citizens blindly accepting the government stance" on leprosy — that was the "main reason for the problems we faced."

Yasuyuki Tokuda, a lawyer, regretted that lawyers did not become actively involved in the issue until the Leprosy Prevention Law was repealed in 1996. "This is a blemish on our profession," he said. In an effort to "make up for the mistakes of the past," Tokuda has pursued compensation for those who were isolated in sanatoria under the law. He has also worked to ensure that people who suffered a similar fate when Taiwan and Korea were under Japanese rule are compensated. "Over the years, I have keenly felt that the role of lawyers is to work alongside people like Mr. Ko," Tokuda said. Nevertheless, he concluded, "I don't think we have ever been able to atone for our sin."

#### **MEDIA 'SHAME'**

Another profession that came in for self-criticism was journalism. Masayoshi Esashi is a member of the editorial board of the *Mainichi Shimbun* newspaper company. In the past, he said, papers overlooked "the incessant struggle taking place behind the walls of the sanatoria — the forced abortions, the sterilizations. That is the shame of the media."

Today, one of the critical issues facing sanatoria residents is the declining quality of services and reduced staffing. But without better media coverage of their plight, gaining public understanding is difficult. "At one point, the elderly residents proposed going on hunger strike in protest. I was shocked. I covered this story, but it was not widely reported," he said. "Everyone needs to know that past policies violated their Constitutional rights."

Generating greater public awareness is the role of a citizens' study group headed by Professor Takahisa Endoh. Among its objectives are to find a way to have the public embrace leprosy as an issue than concerns everyone, to complete the work of the verification committee into the problems concerning leprosy\*, and to take over the activities of Zenryokyo as its aging members pass away. "Leprosy is an interdisciplinary issue. Crosscutting is needed," Professor Endoh said. "We want to involve all people.

IWG members appreciated the opportunity to learn more about Japan's experiences, with some aspects of what they had heard coming as a surprise. Said Ethiopia's Menberu Adane Yihunie, "Even in Japan, there are still people longing to drink tea with their relatives." IWG members and colleagues, photographed in Tokyo on March 15.

#### FOOTNOTE

\* The Japan Law Foundation Verification Committee Concerning the Hansen's Disease Problem issued a report in 2005 to verify the reason why the segregation policy was implemented for so long, the reality of the human rights violations caused and to make recommendations and proposals to prevent a recurrence.

### **Straight Talking**

We have neglected leprosy, but people affected must speak out, says Javed Abidi.

#### PROFILE: Javed Abidi

Javed Abidi is Chairperson of Disabled People's International (DPI) and a member of the International Working Group (IWG) to monitor the implementation of Principles and Guidelines to end discrimination against people affected by leprosy and their families.

### Tell us about DPI.

As the only global cross-disability, disabled people's organization (DPO), DPI is unique. All other global disability organizations are single-disability organizations. DPI also has an unparalleled grassroots reach, especially in countries of the Global South. It has members in 130 nations in five regions across the world. It was the first successful cross-disability endeavor to translate talk about full and equal participation for people with disabilities into action.

### When and why was it established?

DPI was set up in 1981, the International Year of Disabled Persons. It was the culmination of efforts by people with disabilities to take control of their own destinies. Leaders from that era said, 'We are tired of our lives being controlled by parents and professionals. While we respect and value them, we should be in charge of our own lives and be able to take our own decisions.' That's when the world-famous slogan "Nothing

about us without us" was born. The idea was so powerful that in a very short space of time it had spread across the globe.

### What is DPI's mission?

To advocate for the rights of persons with disabilities — for *all* rights of *all* people with disabilities.

### "I firmly believe that people affected by leprosy are part of the disabled community."

### FOOTNOTE

\* The body of independent experts that monitors the implementation of the Convention on the Rights of Persons with Disabilities by the States Parties. All States Parties are obliged to submit regular reports to the Committee on how the rights are being implemented.

### One of your concerns is the North-South divide. Please explain.

There are said to be more than 1 billion disabled people on Earth. Eighty percent are in what is called the Global South, the poor countries of Africa, Asia, and Latin America. Yet the management of disability is in the hands of the people in the Global North. That's something that has begun bothering people in the South. They feel that others are speaking for them and presuming what they feel or want or need. I want to give a voice to the Global South and ensure that their voices are heard.

### Where does leprosy fit into the disability movement?

I firmly believe that people affected by leprosy are part of the disability community. In my eyes, there is no difference between a blind person, a deaf person, a wheelchair user, and a person affected by leprosy, Down's syndrome, autism or any other disability. But I find that the disability movement at large has neglected the cause of people affected by leprosy. Their concerns don't feature much in the mainstream disability-rights



discourse. But having said that, why hasn't the leprosy community come knocking on the door, as have people with psychosocial or intellectual disabilities or autism? You have to be vocal; you have to fight for your own rights.

### What can DPI do for leprosy?

One thing I have promised to do is to survey our Member National Assemblies and see whether people affected by leprosy are part of the movement and whether our members are aware of the

issues. From the leprosy side, I will solicit a list of all leprosy organizations in each country and forward it to our members. Somebody will be made aware, somebody will be embarrassed, somebody will make a phone call, and some kind of discourse will start.

### What suggestions do you have for the International Working Group?

I have not heard much mention of the Convention on the Rights of Persons with Disabilities in our discussions. If you look at the Convention carefully, it contains everything that the Principles and Guidelines do; it's just that the Principles and Guidelines are focused specifically on leprosy. The Committee on the Rights of Persons with Disabilities (CRPD)\* needs to be sensitized about leprosy. The nations that go before it need to be questioned on issues relating to people affected by leprosy. At last year's Conference of States Parties there were side events on different disabilities. There was not a single person speaking for leprosy there. Where are the people who will go and talk with members of the CRPD? There should also be a strategy to ensure that a person with leprosy makes it to the CRPD. What a great day that would be!

### **Onward and Upward**

Ethiopia's organization of people affected by leprosy has come a long way.

I was born and raised in Addis Ababa at a settlement of people affected by leprosy. It is located next to ALERT, Africa's biggest medical facility for leprosy. My father, like many other people in the settlement, had been severely disabled by the disease.

I didn't truly understand how bad things could be for people affected by leprosy until I was employed by the Ethiopian National Association of Persons Affected by Leprosy (ENAPAL). To help it develop into a nationwide organization, I accompanied its leaders all over the country. We visited remote settlements in the grip of every kind of misfortune. Seeing the abject poverty and the daily struggle to survive, and hearing the stories of rejection and exclusion, I realized my family were relatively fortunate by comparison.

#### **COMMON VOICE**

COLUMN

ENAPAL was the last of the major disability organizations in Ethiopia to be founded. It came into being in 1996 on the initiative of some 30 people affected by leprosy who lived in the settlement where I grew up. Following the integration of the leprosy program into the general health service, they had gathered to discuss the decline in services offered by ALERT and the change in the mode of delivery and management. The need for a common voice to address these issues led to the emergence of ENAPAL.

In the beginning there were 17 local branches. Now there are more than 63 branch associations in seven administrative regions, and over 15,000 feepaying members.

Today, one of ENAPAL's important tasks is to network with leprosy control bodies at all levels of federal and regional government to press for early detection of new cases, treatment of leprosy reaction and physical rehabilitation. Why? Because for over two decades Ethiopia has continued to report the second-highest number of leprosy cases in Africa — around 5,000 annually. Of these, over 1,000 have visible disability and sensory loss, with profound consequences for their quality of life.



Making a difference: ENAPAL toilet project in Ambo

In addition to medical issues, there are many other challenges, as I have seen on my travels. These include poverty, illiteracy, low self-esteem, limited or non-existent social services, lack of work, derelict housing and little or no social participation.

Since many of these problems stem from deeprooted misconceptions about leprosy, working to eliminate stigma is a priority. ENAPAL is committed to awareness raising and reaching out to different sectors of society, making use of print and electronic media and events such as World Leprosy Day to challenge old stereotypes.

Community development and socio-economic rehabilitation are other key tasks. Self-help groups, income-generation activities, savings and credit cooperatives, skills training and educational support are all part of ENAPAL's strategies. Housing projects too are important for building dignity and promoting social integration.

By working with local governments, NGOs and others, ENAPAL is able to get things done. For example, it networked with Ethiopian Electric Power Corp., arranging for it to supply electricity for a water pump for irrigation in a settlement called Addis Hiwot. Elsewhere, in settlements such as Hawasa and Shashemene, where residents had lived in fear of eviction, it reached agreements with the local authorities under which the land was transferred free of charge to the residents. Living conditions have since been transformed.

### Although a late starter, ENAPAL is now the strongest of Ethiopia's disability groups.

### SOLID BASE

ENAPAL is now the strongest of Ethiopia's disability groups. It has built a solid base and has a committed leadership. Other groups have seen the potential of people affected by leprosy and acceptance has increased.

As it grows, ENAPAL has to work on issues such as human resources development, leadership training and other capacity-building skills. It also needs to maintain and strengthen its relationships with government and other partners.

What ENAPAL has achieved is still small compared to the vastness of the problems, but it is making a difference. After serving the organization for more than 10 of its 16 years, I left ENAPAL in January. I did so confident that its leaders and members have the vision to build on what has been achieved so far.

#### AUTHOR: Menberu Adane Yihunie



Menberu Adane Yihunie was a social worker with the Ethiopian National Association of Persons Affected by Leprosy (ENAPAL) from 1999 to 2001 and served as its managing director between 2004 and January 2013.

### Say It with Pictures

A photo exhibition in Indonesia seeks to change perceptions about leprosy.

#### AUTHOR: PerMaTa

PerMaTa is an organization of people affected by leprosy in Indonesia. It marked its sixth anniversary earlier this year.



"Weaving Hope": The organizers were particularly keen to reach out to the younger generation.

Indonesia annually reports the third largest number of cases of leprosy in the world, after India and Brazil. The disease remains feared by the public and even by some health officials. This fear, which is based on a lack of knowledge and understanding of leprosy, results in the stigma and social discrimination that people affected by the disease face.

A diagnosis of leprosy can cause problems at home, at the workplace or in school. It puts a strain on a marriage and makes it hard to get or retain a job or stay in class. It can lead to marginalization and social exclusion.

Dissemination of accurate information about leprosy is thus vital for reducing the stigma. As an NGO working to uphold the dignity and rights of people affected by leprosy, PerMaTa has held workshops, distributed leaflets and taken part in World Leprosy Day activities to promote greater awareness of leprosy. Last November we decided to try something different and hosted a photo exhibition.

### **'WEAVING HOPE'**

"Merajut Harapan" (Weaving Hope) was held at a shopping mall called Royal Plaza in Surabaya, East Java. It featured photos of people affected by leprosy going about their daily lives in the community. The images were taken by Budi Yuwono, one of our members, who came up with the idea.

Most of the people in the photos had been diagnosed and treated in a timely manner and do not suffer from disability. Our objective was to trigger a shift in public perceptions so that people no longer become scared at the very mention of the disease or automatically associate it with disability or disfigurement.

One of the reasons for choosing Royal Plaza as the venue is that people of all ages and from all walks of life go there every day, including students who hang out there after school. We felt it would be a good place to share information with them and get them to start thinking differently about the disease. Given that students represent the next generation, we felt it was especially important to target them to help shape future perceptions of leprosy.

Captions accompanied the photos and we also distributed leaflets with detailed information about leprosy. In addition, PerMaTa members were on hand to answer questions, as was a representative of the provincial health office. The many questions we received indicated the concerns people still have about the disease.

#### **POSITIVE RESPONSE**

Encouraged by the level of interest, including positive media coverage, we organized a second exhibition at the Royal Plaza in February. This time, we kept count of all the people who stopped by, logging more 3,000 visitors over a five-day period.

We also left it to visitors to pick up a leaflet if they wanted further information, rather than giving them to everyone who came, after we noticed how many leaflets end up being discarded the first time. Based on our calculations, some 14 percent of visitors picked up a leaflet.

Overall, we were very pleased with how the two exhibitions went. Looking at the expressions on the faces of visitors as they studied the photos, it was apparent that this was a better way to engage with the public and share information about leprosy than through a brochure alone. As the saying goes, a picture is worth a thousand words.

The exhibitions conveyed the message that with early diagnosis and treatment, the disability that people associate with leprosy can be avoided. Moreover, by showing that people who have been treated and cured are perfectly able to live and work in society, we are dispelling the notion that they should be "exiled". We hope to organize more exhibitions in other parts of Indonesia in future.

### Four Days in Jharkhand

The Goodwill Ambassador returns to the Indian state of Jharkhand to bring himself up to date on the lives of people affected by leprosy there.

#### INDIA (APRIL 4-8)

In April I traveled to Jharkhand. It was my third visit to this eastern Indian state, following trips there in 2003 and 2006. Together with representatives of people affected by leprosy, I met with state government officials to request that they strengthen anti-leprosy activities and take steps to improve the lives of people affected by the disease.

Jharkhand was formed from part of Bihar state in 2000. It has a population of around 27 million, with many tribes and hard-to-reach areas. When I first visited 10 years earlier, there were some 35,000 registered cases of leprosy, making for an extremely high prevalence rate (PR) of 13 per 10,000 people.

The rallying cry I used at the time seems to have been heeded: "Reach the unreached — detect patients and deliver medicine to those who aren't getting it." Ten years on, despite many ongoing challenges, the PR is now down to 0.7 per 10,000 and the number of registered cases has been reduced to 3,317.

There were plenty of restrictions in place at the time of my visit. On March 28, just a week before my arrival, 10 Maoists rebels had been killed in a deadly clash. In response, Maoists shot dead five policemen on April 4, called a two-day strike for April 6 and 7, and blew up railway tracks. This complicated my plans, but I was determined to accomplish as much as I could. I was joined by Mr. Vagavathali Narsappa, the chairman of National Forum India (NFI) — the organization of people affected by leprosy formed in 2006 and Mr. Mohammad Jainuddin, NFI's state leader representing Jharkhand's 58 leprosy colonies.

On arrival at Ranchi airport on April 5 after an overnight stay in Delhi, I travelled for an hour by



An ASHA in action at Murhu Community Health Center

road to Khunti district. My destination was Murhu Community Health Center. There I met eight people affected by leprosy — including a 10-yearold girl and several people with disabilities of the hands and feet — and 10 female health workers, or ASHA (accredited social health activists.) Medical officers and ASHAs train people affected by leprosy on how to prevent further disabilities. Learning self-care is a key to reducing the possible economic or social consequences of leprosy and also to maintaining one's dignity.

After leaving the health center, I travelled into Ranchi. I accompanied Mr. Narsappa and Mr. Jainuddin to meetings with L. Khiangte, the principal secretary of the welfare department, and K. Vidyasagar, the principal secretary of the health department. The mandate of Mr. Khiangte's department covers Scheduled Tribes and Scheduled Castes only, although he said he would consider what could be done for people affected by leprosy. For his part, Mr. Vidyasagar noted that the number of cases of leprosy had come down significantly over the past decade and said he wanted to continue to give leprosy a high priority.

In the evening I attended a gathering of some dozen members of National Forum India's Jharkhand branch. They told me they had started their activities in the state in 2007, focusing on skills training and reducing the number of children who dropped out of school. A capacitybuilding workshop for youth was conducted in 2012, aiming to motivate young people to get involved in NFI activities. It was encouraging to see Mr Sailendra Prasad, a member of the State Committee, give his activity report in fluent English. He is employed in the administrative section of the local college and is the kind of role model that will motivate other young people to step into the social mainstream and succeed.

On April 6, Mr. Ram Sevak Sharma, Chief Secretary of Jharkhand, took time from his busy schedule to meet us. We discussed the situation of people living in leprosy colonies, where many do not have proper housing, basic infrastructure or land ownership, and must rely on begging. The current disability pension of Rs. 400 is not enough, and Mr. Jainuddin submitted a petition for the amount to be increased to Rs. 1,500. The chief secretary said he would look into the matter.

Based on the experience of Bihar, where the state government has finally announced the



Talking with residents of Indira Nagar colony

> welcome news that it is raising the pension for people affected from Rs. 200 to Rs 1,800, I do not expect the pension in Jharkhand to rise overnight; however, it is important for the people to negotiate directly with the officials concerned and to persevere. I am prepared to come from Japan to assist their challenge as often as needed.

> Following a courtesy call on Justice Narayan Roy, the head of the State Human Rights Commission, I visited Indira Nagar colony, which has a population of 550. I was looking forward to seeing the tree I had planted there a decade earlier, but the colony has developed to such an extent that the tree was nowhere to be seen. While housing conditions had much improved, I noted here and



(Top photo) With nursing students Sikha Mahato, left, and Sonali Mahato; (above) view of Nirmala colony in Ranchi

there the presence of the wooden carts used by the severely disabled and the elderly when they go begging. Some things, it seemed, had not changed.

A sustainable livelihood generation project was started at this colony with the support of Sasakawa-India Leprosy Foundation (SILF), but this was cancelled due to a number of obstacles. I hope a new group of residents will consider taking up the challenge. When I asked the children if they liked studying, they all replied "Yes!" Among them was a girl who said she was going to study very hard to become a doctor.

On April 7 I met Sonali Mahato and Sikha Mahato, recipients of SILF scholarships to study at a four-year nursing college. Now in their first year, they are practicing how to give injections and take blood pressure. "We never imagined we would go on to higher education," they told me, eyes shining. "We are so thankful to God and to everyone. In the future, we want to work for the elderly and the disabled in the colonies."

Following a press conference I visited Nirmala colony in Ranchi. It is home to 150 people and is located next to a dirty river below a trunk road. According to the residents, the huts they occupy used to suffer damage when the river flooded, but now there is a concrete wall to keep back the water, built with support from Sasakawa Memorial Health Foundation. What hasn't changed, however, is the stench from the garbage clogging the waterway, and the clouds of mosquitoes and flies. It is not a healthy environment.

While this visit did not produce immediate and visible results, I believe it was another step in the long process of improving the lives of people affected by leprosy and achieving a world in which they can live in dignity. I intend to be alongside them every step of the way.

# Introducing Dr. Etsuko Kita

International health expert assumes chair of Sasakawa Memorial Health Foundation.



NEWS

"No nonsense" is the description of Dr. Etsuko Kita that springs to mind after a few minutes in her company. Dr. Kita, who assumed the chair of the board of Sasakawa Memorial Health Foundation on April 1, brings

with her a wealth of experience in international health and humanitarian aid activities and a stern disapproval of slackers.

Trained as a pediatrician, Dr. Kita has spent time with Japan's health ministry, working on overseas development assistance. Her resume includes spells with UNICEF at its Afghan Program Office in Peshawar and with the WHO at its Department of Emergency and Humanitarian Action. For the last eight years, she served as president of the Japanese Red Cross Kyushu International College of Nursing in Japan.

She credits her interest in becoming a doctor — and working with developing countries — to reading in the Japanese edition of *Reader's Digest* about the activities of a U.S. Navy physician, Thomas Dooley, in Laos and Vietnam in the 1950s. Later, in Afghanistan, she turned her attention to public health after seeing a young girl die of pneumonia and examining the factors that led to her death.

Based on her experiences, one of the lessons Dr. Kita drummed into her nursing students was the importance of critical thinking. "University is not just about learning what your professors know and what's written in textbooks. It's about acquiring the ability to think for yourselves and learning to deal with the problems you encounter that you don't know about."

She admits to having a short temper, but says her ire is directed at those who don't try hard enough. "I would often get mad at students and younger faculty members, telling them they could achieve so much more if only they applied themselves."

Taking over from Professor Kenzo Kiikuni, who has become president of SMHF, Dr. Kita oversees an organization with a focus on leprosy, palliative care and public health. "The foundation has a history and tradition of nearly 40 years," says Dr. Kita. "I am not about to make changes." But she does intend to explore "the balance between physical, mental and social health."

Regarding leprosy, Dr. Kita says, "While the disease physically affects a relatively small number of people today, especially here in Japan, its social dimension — the discrimination and the prejudice — is something that involves everyone. Dealing with that is a very difficult challenge."

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# FROM THE EDITORS

People affected by leprosy are often described as "voiceless," having been left out of official histories. Anwei Skinsnes Law, the International Coordinator of IDEA, begs to differ. In a speech at National Sanatorium Tama Zenshoen during a recent visit to Japan, she cited letters, books, poetry and artwork, not to mention the venerable *Star* newspaper started by Stanley Stein at Carville Leprosarium, as evidence to the contrary.

IDEA, the International Association for Integration, Dignity and Economic

Advancement, is also making sure that voices get heard through its oral history project. To date, IDEA has recorded the stories of around 200 individuals in 35 countries in 20 languages, she said.

IDEA is particularly concerned with the older generation of people affected by leprosy and ensuring they earn their rightful place in history. "I believe there is so much to learn from the older generation," Law told her audience. "Their wisdom and friendship are a blessing for us all."

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