WHO GOODWILL AMBASSADOR'S NEWSLETTER
FOR THE
Elimination of Leprosy

August 2010 • Number 45

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


Residents of a leprosy colony located next to the regional hospital in Abéché in Chad's Ouaddai Region, photographed in July.

MESSAGE

Primary Stakeholders

It was in India in 2004 that I first used the expression, "You are the main actors." I was talking with people affected by leprosy, and voicing my belief that they themselves have a vital role to play in eliminating leprosy and its accompanying stigma. After long years engaged in the fight against the disease on both the medical and social fronts, I am convinced of this.

At different meetings and press conferences, and also at the UN Human Rights Council, I make a point of inviting people affected by leprosy to come to the fore where they can be seen, heard and acknowledged. In India, I assisted with the formation of the National Forum, the increasingly influential network of people affected by leprosy. Recently, in that country, in Bihar State, representatives of Bihar Kushth Kalyan Mahasangh, a leprosy welfare society, sat directly opposite the state health minister to discuss housing, land ownership, pensions and other pressing issues. As a result, the state authorities are now in the process of reviewing their policies.

I was delighted when the WHO organized a meeting in Manila recently to draw up guidelines for strengthening the participation of people affected by leprosy in leprosy services. The WHO is at last recognizing what people affected can contribute to national programs. No longer being cast exclusively in the role of recipients of services, they are being invited to speak out and work alongside other stakeholders. This is an epoch-making development. It is a path to restoring dignity.

Among people affected by leprosy there will be those who hold back because of their lack of experience. I say to them: "Fear not. You have enormous potential and ability. Embrace the WHO's shift in thinking. Your input as the primary stakeholders in leprosy will go a long way toward eliminating the disease and bringing an end to stigma and discrimination as we strive for our goal of a leprosy-free world."

— *Yohei Sasakawa*, WHO Goodwill Ambassador

CONTENTS

From ‘Clients’ to ‘Partners’

A new era of involvement beckons for people affected by leprosy in leprosy services.

“Unique and important,” “a milestone,” “historic” were just some of the descriptions applied to a two-day meeting on June 9-10 to develop guidelines to strengthen the participation of people affected by leprosy in leprosy services.

Hosted by the WHO at its Western Pacific Regional Office in Manila, the meeting reviewed draft guidelines prepared by a WHO-appointed task force on identifying ways that people affected by leprosy can be involved as partners in leprosy services: not merely as patients.

Some 50 national program managers, representatives of people affected by leprosy and other experts took part in the discussions, which took their cue from the WHO’s Enhanced Global Strategy for Further Reducing the Disease Burden Due to Leprosy (2011-2015). In that document, for the first time, people affected by leprosy were acknowledged to have a major role to play in leprosy services, “especially in the area of advocacy, awareness and rehabilitation.”

How to realize this was the task undertaken in Manila. Chair Jose Ramirez, Jr. (USA Coordinator for IDEA) commented, “The end result of our deliberations will result in more inclusive practices.”

Delegates are all smiles at the end of the Manila meeting.

AREAS OF PARTNERSHIP

Using the Enhanced Global Strategy as a framework, the draft guidelines indicated 14 areas of potential partnership, including planning and management of services, training and capacity building, stigma and discrimination, prevention of disability, and research. Task force member Dr. Wim van Brakel (Royal Tropical Institute) talked the meeting through some of these. “We need to make an inventory of where we are now. It is not as if we are starting from zero,” he said.

Subsequent presentations showed that the involvement of persons affected by leprosy in leprosy services is already happening at various levels. Speakers including Sophea Leng of Cambodia and Maria Graciela Baez of Paraguay spoke of their experiences working, respectively, in rehabilitation and counseling. Baez, who herself received psychological help from another person affected by leprosy, said, “People affected by leprosy can be good counselors because they have important experience and can help others to recover their dignity, security and self-belief.”

CHALLENGES

With the draft guidelines being the work of several different contributors, there was a consensus on the need to simplify objectives, be consistent in the language used and ensure that guidelines would be of assistance to the people they were intended to serve — namely, national program managers — who needed to be persuaded that participation by people affected can benefit their work.

One program manager who sounded a positive note was Dr. Alcino Ndeve (Mozambique). He said that he had a health minister who was committed to leprosy and who chaired an annual meeting of leprosy stakeholders. Mozambique was putting in place the “humanization of health care” and he would be incorporating the points raised into his country’s national program. “They cannot be treated as projects, they must be part of the program,” he said.

Representing a group of people affected by leprosy from Mali, Coulibaly Oumar (AMHL) addressed the national program managers in the room when he said, “This is a complex, diverse topic. It is not easy to find a common formula that may be applied to all the countries in all the contexts. I think all program managers should be creative, given the context and the realities you are facing.”

Concerning resource mobilization, Dr. Joseph S. Kawuma (GLRA) saw a role for people affected by leprosy, especially in the context of leprosy control programs that are facing situations of diminishing resources. “I am asking to hear in clear terms whether organizations of people affected by leprosy indeed have a clear role to play in mobilizing resources — financial and human — to supplement the more or less desperate situation for leprosy control in some settings.”

‘A KIND OF EMPOWERMENT’

In his closing remarks, Dr P.K. Gopal (IDEA India), a member of the task force, spoke of his satisfaction that such a meeting had taken place. “This is a historic event…a kind of empowerment, enabling people to work with the government. This is a beginning.”

How the guidelines are accepted by governments will be the test of their effectiveness. The task force is now working on revising them, with a view to issuing them early next year. ■

Don't Forget Us

Michihiro Ko wants all 13 of Japan's leprosy sanatoria preserved for posterity.

Michihiro Ko stands in front of the charnel house at Tama Zenshoen in Tokyo.

Michihiro Ko, the president of Zen Ryo Kyo*, the National Hansen's Disease Sanatoria Residents' Association, worries about the future of Japan's 13 national leprosy sanatoria, home to a dwindling population of some 2,400 residents with an average age of almost 81. For the better part of a century, people with leprosy were forcibly isolated in these facilities. However, under the 2009 Law on Promotion of Issues Related to Hansen's Disease, the question of what is to become of the sanatoria is to be addressed. But Ko, 76, who lives in Tama Zenshoen Sanatorium, is not convinced that the government is taking the matter seriously.

What do you want for the sanatoria?
I see them as having several uses. First, my wish is for each sanatoria, or at least part of it, to be preserved as a museum of human rights and place of reflection, serving as a reminder that the mistakes of the past should never be repeated — just as the former Auschwitz concentration camp in Poland is a very important museum and learning center today.

> "I believe that the government is simply waiting for us to die off."

Japan's past policy toward people with Hansen's disease was accepted completely by the public. No one questioned what the government said. Society didn't think about the consequences for people who were forcibly quarantined under this policy. Later, when a cure was discovered and those isolated in the sanatoria began to get better, there was no call for their release because the government made no attempt to inform the public. Nor was there an official effort at social reintegration, because the leprosy prevention law remained in effect.

Over 25,000 people have died in the sanatoria. Their bones are interred at charnel houses there. I want a law that requires the government to maintain the charnel houses for all time. For its part, I believe the government is simply waiting for us to die off, when it can close down the sanatoria. But if the sanatoria are closed, then our sacrifices will be forgotten.

You also see the sanatoria as capable of meeting various social needs.
The country needs more daycare centers for children of working parents, for example, and the sanatoria could be used for this purpose. Also, in Japan's aging society, there are not enough facilities providing care for the elderly. It should be possible to adapt sanatoriums as places where old people can live out their final days. Sanatoria have built up knowledge and expertise in nursing and elderly care. They are very appropriate for this.

What changes have you seen since the 2009 law came into effect?
The health ministry hasn't begun anything new as a result of the law, which was passed in a very short time with the signatures of 930,000 petitioners. The public doesn't know this; Parliamentarians don't know this. Therefore, our job is to tell everyone — Parliament, the public — that the law we passed together is not functioning, but is just gathering dust.

You are very insistent on this, aren't you?
It is vital that the public is made aware of the situation. Everything starts from that point. It was the public that in the past allowed the government to isolate us. Thereafter society completely forgot about us and took no interest in the matter. It was because no-one raised their voices that we remained in isolation for so long. ■

Footnote

* Zen Ryo Kyo dates back to 1951, when its forerunner, Zen Kan Kyo, an association of sanatoria patients, was established as the earliest example of a national-level association of persons with leprosy. In 1996, the year Japan's Leprosy Prevention Law was abolished, it changed its name to Zen Ryo Kyo.

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Questionable Questions

A potentially damaging survey on leprosy is modified after concerned parties intervene.

AUTHOR:
Dr. Padebattu Krishnamurthy

Dr. Padebattu Krishnamurthy is Secretary, Damien Foundation India Trust, and Coordinator for India, International Federation of Anti-Leprosy Associations (ILEP)

Geared toward a medical agenda, leprosy control programs find it difficult to manage social issues related to the disease. But for individuals with leprosy or its aftermath, social, economic and psychological needs often take precedence over medical needs.

Stigma and discrimination are important consequences of leprosy. They exist in the context of a public that is ill-informed and programs that are ill-prepared.

Today there are increasing efforts by well-meaning, socially-minded medical experts to study and understand stigma and its ramifications. Protocols and questionnaires have been developed even though their internal validity remains unclear. Sociologists wonder whether questionnaires for assessing stigma hurriedly prepared and hastily introduced might not have a negative impact.

The fact is, people are always eager to measure something or other. Stigma is no exception. But nothing can be more harmful than an amateurish, makeshift attempt to do so. When such an attempt is made, prompt intervention by informed individuals is required before the damage is done. Nothing exemplifies this better than an episode that occurred recently in India.

NATIONAL SAMPLE SURVEY

It all started when people affected by leprosy petitioned Parliament in 2008 to make an assessment of their living conditions, especially the conditions of those living in self-settled colonies. A Parliamentary sub-committee was formed that visited colonies in different states, observed conditions and interacted with the people there.

Based on the report of the committee, Parliament asked the health ministry to undertake an exercise to assess the leprosy burden in the country. An autonomous governmental body was given the responsibility of designing the protocol. It was pilot-tested in one of the North Indian states and the final protocol, including methodology, was prepared.

The whole exercise was called the National Sample Survey. Under this, house-to-house surveys would be carried out in randomly selected districts and blocks in 33 states to identify new leprosy cases.

The survey protocol also included four questionnaires to assess stigma and discrimination. These had been prepared by medical experts who perhaps had less insight into sociological issues. Moreover, it was doubtful whether persons affected by leprosy had been consulted, even though they were the reason why the whole exercise had been planned.

The questionnaires were meant to be applied to new cases detected during the National Sample Survey, as well as their neighbors, prominent elders from their communities, and other randomly selected community members.

However, several questions could be regarded as stigmatizing, and would be bound to encourage negative attitudes and undermine the spirits of people affected by the disease.

A few voices were raised in protest. As the coordinator for India of the International Federation of Anti-Leprosy Associations (ILEP), I appealed to the government to have a discussion with a few experts in sociology and also with Dr. P.K. Gopal, the president of the National Forum (a nationwide network of people affected by leprosy) who had experience of using standard questions to solicit information on stigma from the general community.

The government also became convinced of the need for a critical review of the questionnaires and invited Dr. Gopal and me, along with the director of the government agency responsible for the protocol and its implementation, for talks.

Open and frank discussion led to the firm conviction that the questionnaires deserved a thorough overhaul. It was decided to discard two of the questionnaires and retain two: one for persons affected by leprosy (but for use on patients under treatment, not new cases detected during the survey, as envisaged earlier) and randomly selected persons from the community.

All present realized the naivety of asking someone newly detected with leprosy about relations with their spouse, problems they experience in society and difficulties in marrying off their children. Similarly, questions for neighbors about their readiness to live next to someone affected by leprosy, or for village leaders as to whether a leprosy-affected person should be isolated, or whether a leprosy-affected woman should breastfeed her baby, reflected profound ignorance and indifference. As a result, the questionnaires were radically altered. All questions with negative connotations were removed or modified.

The modified questionnaires were sent to all states concerned, accompanied by detailed guidelines on how they were to be used. Even though some people still expressed unhappiness with them, they were at least satisfied that the offensive elements in the original questionnaires had been removed.

Change is possible, if the informed also act. ■

Man with a Message

People affected by leprosy don't want pity, they want understanding and support.

Mark Anthony Bengan: positive role model

Mark Anthony Bengan earned a diploma in computer accounting in May. The 26-year-old Manila resident with a bright smile and a taste for alternative rock enters the job market confident his qualification will stand him in good stead. But 10 years ago, back in his home province of Capiz in the central Philippines, the future looked far less rosy.

Mark was 17 when he first noticed patches appearing on his skin. His grandmother urged him to visit a folk healer, who concluded that Mark was possessed. Two years later, the patches were still there, so he went to see a dermatologist, who diagnosed him with leprosy.

By then, Mark already suspected he had the disease, based on TV programs he had seen that described symptoms similar to his own. His immediate response to the diagnosis was a feeling of self-loathing, and the question, "Why me?"

His spirits rose when the dermatologist assured him that leprosy was curable and he was started on a course of multidrug therapy. But after a year he did not feel well because of leprosy reaction (when the body reacts to the dead bacteria killed off by the medication), so the whole family relocated to Manila in 2003 to enable Mark to receive treatment at the Philippine General Hospital.

By now, Mark had already experienced the stigma and discrimination that accompany leprosy. In Roxas City, Capiz, friends shunned him when they found out he had the disease. In Manila, the family had to move house after their landlady learned of Mark's condition.

"Because of this discrimination, I learned to be a loner. For two years, I hardly left home," he recalls.

But two things saw Mark's life take a turn for the better. In 2004, he joined the Hansen's Club, a support group for people affected by leprosy at the Philippine General Hospital. And he came into contact with the Philippine Leprosy Mission (PLM), which encouraged him to pursue his studies and awarded him a two-year scholarship to study computer accounting.*

The Hansen's Club meets on the second and fourth Wednesdays of every month. It has about 15 regular attendees, and the number is growing. "We help each other and offer advice to new members. I tell them that they have to fight the disease, that leprosy is curable, and that with the help of doctors and the PLM, it is possible to return to society."

Only his studies stopped Mark from attending the meetings. Now he has graduated, he is once more a Hansen's Club regular, because he wants to be there for people who need the kind of encouragement he received when he needed it most.

> "I learned to be a loner. For two years, I hardly left home," he recalls.

TV APPEAL

Mark's message to the general public, which he relayed on national television for World Leprosy Day, is straightforward: "People affected by leprosy don't want pity, they want understanding and support."

One problem is that people don't know enough about leprosy, he says, and what they do know is often ill-informed. "If people learn you have Hansen's disease, they turn away before you can tell them about it. But I will always talk about the disease to those who want to know more."

While acknowledging the important role of support groups such as the Hansen's Club, and NGOs such as the Philippine Leprosy Mission, he says the government also has a vital part to play. "I think they need to make more commercials to educate people about leprosy."

Mark is one of seven siblings. Today they all live together with their parents, with the exception of two older brothers who now have families of their own.

"When I was first diagnosed with leprosy, my mother was very sad and hurt. This was not what they had planned for me. But my family stood by me and never rejected me. Now I want to do my best for them, because of what they have done for me." ■

Footnote

* For the 2010-2011 school year, the Philippine Leprosy Mission's Educational Assistance Program funded a total of 267 students across prep school, elementary, high school, vocational and college levels. The Sasakawa Memorial Health Foundation supported a further 135 students at elementary level and above.

African Sojourn

The Goodwill Ambassador visits Ethiopia and makes his first visit to Chad.

ETHIOPIA (JULY 12-17)

In July I traveled to Ethiopia. The main purpose of my visit was to speak at a symposium to commemorate the work of the late Nobel Prize-winning agronomist Dr. Norman Borlaug. However, I also made time to update myself on the leprosy situation.

On July 13, I went to the WHO office in Addis Ababa, where I was briefed by Dr. Fatoumata Nafo-Traoré, the country representative. She pointed out that the annual number of new cases has remained constant at around 4,000 for more than 10 years, an indication that transmission is ongoing. Of new cases, around 7% have grade 2 disability.

The next day, I called on Health Minister Dr. Tewodros Adhano. Accompanying me were Leulseged Berhane, the president of ENAPAL (Ethiopia National Association of People Affected by Leprosy), and Menberu Adane Yihune, ENAPAL's managing director. The minister told me that leprosy remains a priority and stressed his commitment to raising awareness and promoting social rehabilitation. The ministry is working closely with ENAPAL on such issues as housing and microfinance.

From the health ministry I travelled to ALERT, the All-Africa Leprosy, Tuberculosis and Rehabilitation Center in the suburbs of Addis Ababa. Established in 1965, ALERT has played a major role as a training center for leprosy personnel and as a specialist facility for diagnosis, treatment, surgery, ophthalmology and rehabilitation. Today the hospital and its training functions are overseen by the Ethiopian government.

ENAPAL's headquarters are located in the compound of ALERT. Formed in 1966 to protect the rights of people affected by leprosy, promote awareness about the disease, and support economic and social self-reliance, ENAPAL now has a presence in eight out of Ethiopia's nine regional states and has 63 branches nationwide.

ENAPAL has started a number of income-generating projects in the vicinity of the hospital, where a large self-settled colony of people affected by leprosy and others has formed. I visited some of these projects, which include weaving, embroidery and edible oil milling, and was impressed by what I saw.

Leprosy was once a serious problem in Ethiopia. Today the situation is much improved. The commitment of the health minister, the important contribution of key partners such as the German Leprosy Relief & TB Association, and the positive work being done by ENAPAL, lead me to think that the country is moving in the right direction.

CHAD (JULY 18-21)

Embroidery worker at an ENALAP project in Addis Ababa

After Ethiopia, I made my first ever visit to Chad. Chad eliminated leprosy as a public health problem in 1997. However, in parts of the country, the prevalence rate of the disease remains high, especially near the border with Sudan.

Dr. Toupta Boguena, Chad's health minister

I arrived in the capital, N'Djamena, on July 18, where I was met at the airport by Health Minister Dr. Toupta Boguena, WHO country representative Dr. Saidou P. Barry, and Dr. Landrey Bide, the WHO's leprosy point man in Africa. Paying a call on the health minister the next day, I learned that she had experience of the disease in her family. She told me that her father had been orphaned as a young child, and was raised by an aunt who had leprosy.

Next I went to a meeting with Assaid Gamar Sileck, the vice-president of National Assembly. In response to my request for his support in tackling the disease, he promised he would look into setting up a committee on leprosy. I was also fortunate to be able to meet Prime Minister Nadingar, who was busy preparing for an important regional summit.

Back at the health ministry, I was briefed by Dr. Moussa Djibrine Mihimit, the national coordinator for leprosy. He told me that in 2009, the number of new cases reported dropped to 484, or a prevalence rate of just 0.54 per 10,000 population. However, in the east and south of the country, there are still four regions where the prevalence rate remains between 1 and 2.75. Of concern are the high percentage of new cases with

The Goodwill Ambassador meets with residents of a colony by the regional hospital in Abéché.

grade 2 disability (17%) and the high proportion of children among new cases (9%). Other challenges include political instability in some regions, the difficulty of monitoring nomadic tribes, and a lack of resources. (Indeed, 90% of the operating costs of the health ministry's leprosy program are borne by the Fondation Raoul Follereau.)

On July 20 I flew to Abéché, Ouaddai Region, about 700 km to the east of N'Djamena. Around 300,000 refugees have fled here from Darfur in neighboring Sudan. They include a large number of people affected by leprosy. In addition, people with leprosy cross over from Sudan to seek treatment.

After paying a courtesy call on the governor, I visited the regional hospital. In the grounds, people affected by leprosy and their families have formed a colony totaling 436 people. They live in simple huts made of mud walls with thatched roofs like pointed hats, clustered together in a narrow area. There is a plan to relocate them to an area 7 kilometers away. There is no water at the site, so a proposal to drill a well is now under consideration. Another drawback is its distance from the market. I had an opportunity to see the site afterward, and it seemed to be in the middle of nowhere. It appeared unsuited to its intended purpose and I rather felt it would result in the community's isolation.

Back in N'Djamena, I visited Habbéna district. About 30 years ago, a health center specializing in leprosy was set up here, and a colony of people affected by the disease formed. Habbéna means "abandoned land," but as the community becomes increasingly mixed, I was told it has also come to mean "we love them" when the word is pronounced differently. Today the population of 980 people includes 89 people affected by leprosy.

After Habbéna, my next stop was CARK (Centre d'Appareillage et de Rehabilitation de Kabalaye) in N'Djamena. This is a facility run by a Catholic NGO that manufactures artificial limbs, crutches and other aids for victims of war, accident and disease, and also offers physical rehabilitation. CARK works in association with the government's national leprosy program.

In the afternoon I visited Koundoul, about 20 kilometers south of N'Djamena. This is the site of a local NGO called ASALT, set up with support from the Fondation Raoul Follereau. ASALT helps people recovered from leprosy to become self-reliant. People living in Habbéna district come here by bus and farm 20 hectares of land and raise sheep. They consume for themselves nearly everything they produce and sell the rest. In the future, I understand ASALT would like to establish an agricultural study center here.

Artificial limbs on display at CARK.

My time in Chad reminded me that the road to achieving a world without leprosy is a long one, and that to achieve this goal requires continued application and perseverance. The elimination of leprosy as a public health problem is only a milestone. Sustaining this achievement, further reducing the number of new cases, diagnosing them before disability occurs and ensuring that those who are cured can take their place in society are the challenges that Chad and all endemic countries face. ■

Japan's Leprosy Literature

Tokyo publisher completes 8-year project to compile writing from sanatoria.

Tokyo-based publishing house Koseisha has issued the final volumes of a 10-volume set of essays, poetry, fiction and children's writing by residents of Japan's leprosy sanatoria*.

Work on the project known as the *Hansenbyo bungaku zenshu* (Collected Works of Hansen's Disease Literature) began in 2002 and was completed in July. The books represent a remarkable compendium of writing dating back to the 1920s produced by those confined for life under the government's past policy of isolating people with the disease.

An interview with publisher Shuichi Fujimaki will appear in an upcoming issue of the newsletter.

Footnote

* The full set costs ¥48,000 (US$550). Contact the publisher for details: info@libro-koseisha.co.jp

PERRY ENRIQUEZ

Perry Enriquez, a long-time resident of Carville, Louisiana, died on July 22 at the age of 102. He first arrived at Carville, then the national leprosarium for the continental United States, in 1936. Goodwill Ambassador Yohei Sasakawa had the pleasure of meeting Perry when he visited Carville in October last year. When asked what the secret to a long life was, Perry told Sasakawa that it was singing and playing the guitar, and not drinking or smoking.

UNHRC

The Human Rights Council Advisory Committee was due to meet in early August to review the revised draft set of principles and guidelines for ending stigma and discrimination against people affected by leprosy and their family members.

If adopted, the text will be submitted to the Council's 15th session in September. ■

FROM THE EDITORS

TERMINOLOGY

Many would doubtless agree that "a person affected by leprosy" is an unwieldy term; however, it does not carry the stigma of the "L" word. Yet when it is shortened to PAL, or even LAP (a "leprosy-affected person"), the descent into acronyms is a slippery slope to more labeling.

At a recent meeting in Manila, Dr. Vijaykumar Pannikar, the former team leader of the WHO's global leprosy program, argued that we are all persons affected by leprosy. He made the comment in an exchange with Coulibaly Oumar, a delegate from Mali, who had been talking about "my people". Dr. Pannikar argued that anyone who has an interest in seeing an end to leprosy and its related discrimination is a person affected by leprosy.

Recently, the expression "primary stakeholder in leprosy" has been gaining currency. In draft guidelines for the participation of persons affected by leprosy in leprosy services, the term was defined as "the persons, families and communities affected by leprosy." It is not necessary to rigidly identify those who are medically affected and those who are not, the definition went on. "The persons and groups, who have experienced certain consequences of the disease, whether it is physical, social or psychological, are the primary stakeholders."

"Primary stakeholder in leprosy" may be no shorter than "a person affected by leprosy," but arguably it represents a shift from a passive to an active mindset. Primary stakeholders have a "stake" in wanting an end to leprosy and leprosy-related discrimination. They are now being actively courted to contribute their expertise to make that a reality.

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