

FOR THE Elimination OF Leprosy

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



Timor-Leste Health Minister Dr. Rui Maria de Araujo presents certificates to recovered persons at Oecusse Enclave in September.

A MESSAGE FROM THE GOODWILL AMBASSADOR

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Countdown to Elimination

Two months remain until we reach the deadline set by WHO for eliminating leprosy as a public health problem at the national level.

To fulfill my responsibilities as goodwill ambassador, for the last three years I have spent a third of each year traveling to endemic countries and meeting with political leaders, journalists, health ministry officials, field workers, NGO representatives and persons affected by leprosy.

Everywhere I go, I deliver the three messages that leprosy is curable, treatment is free and social discrimination has no place. In some ways, I feel like a politician on the campaign trail.

Come the end of the year, we shall discover what WHO has to report about the success of the elimination strategy. Whatever the final outcome, all countries concerned deserve praise for doing their utmost to achieve elimination, often in the face of great obstacles.

Regarding the use of numerical targets, I am aware of the various criticisms raised. For myself, I believe that setting a target of less than 1 person per 10,000 has been extremely effective in maintaining the motivation of those involved.

For political leaders especially, being able to cite a numerical target has been a very useful way of getting parliamentarians and the media to cooperate.

I have said repeatedly that elimination of leprosy as a public health problem is a milestone along the way to fundamentally eradicating both the disease and the social stigma that for so long has accompanied it.

With that in mind, I intend to become more, not less, active after 2005.

The Nippon Foundation, of which I am chairman, will continue to work through WHO. The Novartis Foundation for Sustainable Development has indicated that it will be making available free supplies of MDT through 2010. Measures against leprosy will be strengthened through a reinforced partnership between concerned stakeholders.

There are still many people who need our help. With that thought to motivate us, let aim for a world without leprosy.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Good News on Human Rights

UN Sub-Commission calls for a comprehensive study of discrimination against persons affected by leprosy.

*My name is Gopal from India...I am Kofi from Ghana...
I am Lourdes Nevis Mary...I am Amar.*

With these words, four leprosy-affected persons from India, Ghana and Nepal introduced themselves as part of the oral statement issued in Geneva by The Nippon Foundation (TNF) at the 57th session of the UN Sub-Commission on the Promotion and Protection of Human Rights on August 5, 2005.

Preceding them was Goodwill Ambassador Yohei Sasakawa, who told the session, "Leprosy has long been associated with stigma and discrimination. People affected by the disease have been marginalized. They have been invisible. They have had no voice. But today I would like to introduce some cured persons who have found the courage to speak out. They speak to you on behalf of millions of leprosy-affected people in the world today."

Dr. P.K. Gopal mentioned how leprosy affected his education. Kofi Nyarko recalled the humiliation and suffering he experienced. Nevis Mary told of her continuing fear of discrimination and social isolation. Amar Timalisina revealed that leprosy forced him into a divorce.

With their brief comments — later expanded upon at a parallel session organized by TNF — on how leprosy blighted their lives, these four people personified the issues addressed earlier in the session when Professor Yozo Yokota presented a working paper on "Discrimination against leprosy victims and their families" as requested by the Sub-Commission last year under the agenda item "Prevention of discrimination and protection of minorities."

In his report, Professor Yokota ran through the long history of discrimination against persons affected by leprosy, highlighting "ignorance, indifference and irresponsible attitudes" as the reasons for continuing discrimination, and called on governments to abolish all remaining discriminatory legislation and prohibit all forms of discrimination against persons with leprosy and their families.

In response, several members of the Sub-Commission offered their comments, notably Francoise Hampson, who while welcoming the paper suggested that it was "invidious" for the Sub-Commission to single out one disease and give the impression that discrimination does not apply to other diseases, such as TB or mental illness. She urged Professor Yokota to prepare an expanded paper on discrimination based on medical illnesses and conditions.

On the other hand, Lee Casey remarked that few people had been regarded for so long, or so universally, as suffering from a divine punishment,



After beating the disease, these cured persons are courageously speaking out

and that "leprosy was in a category by itself." Adul Sattar also spoke of leprosy as a disease that merits "special emphasis."

In the end, these latter views held sway. On August 11, the Sub-Commission adopted, without a vote, a historic resolution on discrimination against persons affected by leprosy and their families, and prepared a draft decision to this effect.

KEY POINTS

The Sub-Commission requests or encourages governments to

- abolish legislation requiring the forced hospitalization of leprosy patients and provide prompt and effective treatment on an outpatient basis
- provide appropriate remedies to former patients forcibly hospitalized
- prohibit discrimination against those with leprosy and their families
- include education about leprosy in school curricula

In addition, the Sub-Commission

- appointed Professor Yokota to prepare a comprehensive study on the issue on the basis of his preliminary working paper
- requested that he enter into dialogue with the WHO, UNESCO and other relevant entities
- called on the UN secretary general and UN High Commissioner for Human Rights to provide him with all necessary assistance
- endorsed (subject to the availability of funding) a proposal to organize regional seminars to hear directly from former patients and their families as well as doctors, social workers, experts, NGOs and government officials. ■

Leprosy LEXICON

● Accompanied MDT

This addresses the problem of patients who cannot make regular visits to their nearest health center to receive supplies of multidrug therapy — or who live in areas without adequate health coverage. Accompanied MDT allows them to collect their entire course of drugs when they are diagnosed, accompanied by someone close to them who will follow them throughout their course of treatment.

Documenting Leprosy's Human Face

Filmmakers examine the leprosy experience in Brazil and India.

When Brazilian filmmaker Andrea Pasquini went in search of a location for a fictional movie she was planning to make on the “deplorable state” of public hospitals in Brazil, she encountered something even more shocking: Santo Angelo, one of Brazil’s 33 colony hospitals for persons affected by leprosy and home to several people for over 60 years.

“I had no idea places like that existed in Brazil, and that Brazil was at the top of the list [sic] of countries with the most cases of leprosy,” she told a workshop on the sidelines of the 57th session of the UN human rights Sub-Commission in Geneva.

She immediately remembered her childhood in Casa Branco, a small town in the interior of the state of Sao Paulo, where terrifying stories involving “lepers” were commonly told.

“My grandmother, to whom my film is dedicated, used to warn me that, if ever I met a group of people dressed in rags and asking for food, I should run away as fast as possible, because those people had a highly contagious disease that would cripple anyone who they had contact with.

in the face of adversity.

“Meeting the people portrayed in the movie was one of the best gifts I have received in my entire life,” said Pasquini. “Despite all the suffering engraved in their memories and in their bodies, the wish to live a full life led those people to weave personal stories full of emotion, conquest, faith, love, creation, courage and humility.”

MEDIA INDIFFERENCE

Like Pasquini, Indian journalist Ujjwal K. Chowdhury grew up with the notion that leprosy-affected persons were beggars. “I never considered that ‘leper’ was a derogatory term to identify a particular community as distinct and inferior from the rest of the community — even as a working journalist,” he told the workshop.

Indeed, the Indian media have largely been indifferent to this issue, he said, “and even where there have been stories, they have been misleading stories, which have served to reinforce prejudice.”

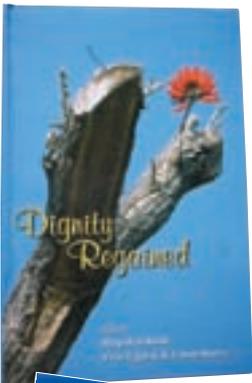
It was exposure to the work of the International Leprosy Union and the activities of the Goodwill Ambassador for the Elimination of Leprosy that opened Chowdhury’s eyes. “When I saw Mr. Sasakawa embracing people affected by leprosy in the dingy lanes of Kolkata, I was astounded, because I had never done that in all my 38 years,” he said. “I realized that the image we had [of persons affected by leprosy] was totally wrong with respect to their treatment, rehabilitation and rightful position in society, which is how I and my team became involved in the

movement for the regaining of dignity.

The resulting documentary — *Leprosy, Stigma, Suffering — What Next?* — depicts the exclusion from Indian society of those affected by the disease and the denial of their basic civil rights. A follow-up film *From Dignity Lost to Dignity Regained** covers their struggle for social acceptance and rehabilitation. A related book, *Dignity Regained*, is a compilation of inspiring stories of 12 men and women who overcame stigma and prejudice to find personal and professional fulfillment.

“Leprosy is the story of 11 million Indians,” said Chowdhury, pointing out that more than 1% of India’s population has the disease or has been treated for it. It was a story he himself only recently took note of, but one he now wants everyone to hear. ■

Cover of *Dignity Regained* (top), flyer for *The Best Years of Our Lives*



Pasquini (left) and Chowdhury take questions in Geneva.

“My grandmother is one of the most generous people I have ever known. However, a lack of information made her the bearer of terrible prejudice. Like her, millions of people around the world continue to disseminate completely unfounded ideas about this disease.”

The Best Years of Our Lives was Pasquini’s way of fighting against the frightening images of leprosy that filled her childhood by showing “the dignity, the everyday life, the dreams and achievements” of those touched by the disease.

The film, which won first prize at the prestigious It’s All True documentary film festival in 2003, consists of testimonies from the remaining residents of Santo Angelo, recalling the days when hospitalization of those affected by leprosy was compulsory. It’s a tale of aching sadness and despair, but also of the triumph of the human spirit

Reference

* *From Dignity Lost to Dignity Regained* will be shown on Indian television in January 2006.

South-East Asia Nears Elimination Goal

India's progress has had a huge impact on efforts to eliminate leprosy in the region.

The leprosy elimination program spearheaded by WHO is one of the success stories in the global health field. WHO-recommended multi-drug therapy (MDT) has brought about a dramatic decline of prevalence and new case detection worldwide, but especially in WHO's South-East Asian Region (SEAR).

SEAR traditionally bore the highest burden of leprosy, with India being the country with the highest disease burden. But now the region is steadily moving toward achieving the goal of eliminating leprosy as a public health problem, i.e. prevalence of less than 1 case per 10,000 population.

The regional leprosy prevalence rate has declined from 4.6/10,000 in 1996 to 1.05/10,000 as of June 2005. Regional new case detection has declined from a peak of 47.76/100,000 in 1998 to 17.94/100,000 as of March 2005.

The decline in prevalence and new case detection has been most dramatic in India during the last three years, where 24 out of the country's 35 states/Union Territories have now achieved the elimination goal. Prevalence declined from 4.2/10,000 in 2002 to 1.23/10,000 as of June 2005. New case detection declined from 57.5/100,000 population in 2002 to 23.40/100,000 as of March 2005. These reductions are mainly due to:

- minimization of 'operational factors' such as wrong diagnosis, re-registration of cases, delayed treatment completion, over-treatment etc;
- better treatment compliance rates;
- regular updating of registers.

As for the region as a whole, the salient contributions of SEAR to the leprosy elimination goal have been:

- more than 90% of the approximately 14.2 million cases cured globally are from SEAR;
- 8 of the 11 countries of SEAR have attained and

sustained the elimination goal at the national level; Bangladesh and Myanmar have achieved elimination at the second, sub-national level, i.e. in all 6 divisions in Bangladesh and all 17 states/divisions in Myanmar; and Thailand has achieved elimination in 75 of the 76 provinces, Sri Lanka in 21 of the 25 districts and Indonesia in 20 of the 33 provinces;

- The three remaining countries — India, Nepal and Timor-Leste — have substantially reduced the burden and are making concerted efforts to reach the goal by December 2005.
- PR has declined by 92% over a 18-year period from 1985, when MDT was first introduced.

More than 90% of the approximately 14.2 million cases cured globally are from SEAR.

EFFORTS CONTINUE

The political commitment continues to be sustained in all countries and all countries are implementing critical and focused activities to further reduce the disease burden.

Given the high priority accorded to leprosy elimination, the WHO regional director for South-East Asia appointed a regional adviser for leprosy elimination and established a 10-member Regional Technical Advisory Group (RTAG) to advise WHO on all aspects of leprosy elimination. The director-general of WHO took the decision to relocate the global leprosy unit from Geneva to the South-East Asia Regional Office, effective March 1, 2005.

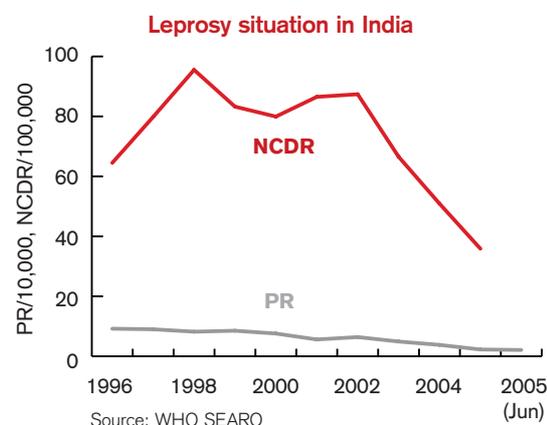
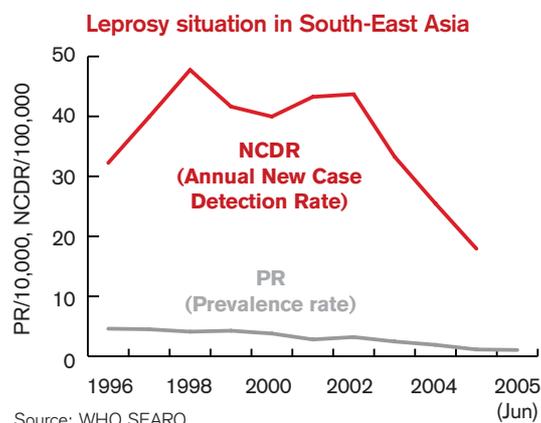
With improved attention to quality of diagnosis and minimization of 'operational factors', particularly in India, WHO is hopeful that SEAR, including India, can achieve the elimination goal by December 2005.* ■

AUTHOR:

Dr. Derek Lobo



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Reference

* WHO will continue to provide technical support to member countries to achieve national and sub-national elimination, carry on the free supply of MDT and assist countries in mobilizing the required resources and strengthening partnerships.

ENAELP Makes Its Mark

An association of ex-leprosy patients in Ethiopia goes from strength to strength.

Showing what can be achieved when a group of motivated people organize themselves for a cause they believe in, the Ethiopian National Association of Ex-Leprosy Patients has established itself as a respected and influential body representing the interests of persons affected by leprosy in Ethiopia.

The origins of ENAELP trace back to 1992, when 30 people held a meeting in a field to discuss the decline in leprosy services offered by the ALERT hospital in Addis Ababa. Out of those discussions came the decision to form an association to lobby for the human rights of leprosy-affected persons. Within two years, the concept of a nationwide association had taken shape, and in 1996 ENAELP was officially registered by Ethiopia's justice ministry as an indigenous NGO.

Today ENAELP consists of a national association and 54 branch organizations. It is run by a nine-member executive committee elected by a general assembly composed of two members from each branch. The national association coordinates capacity-building among the branch associations, which are expected to network, lobby and generate their own funds.

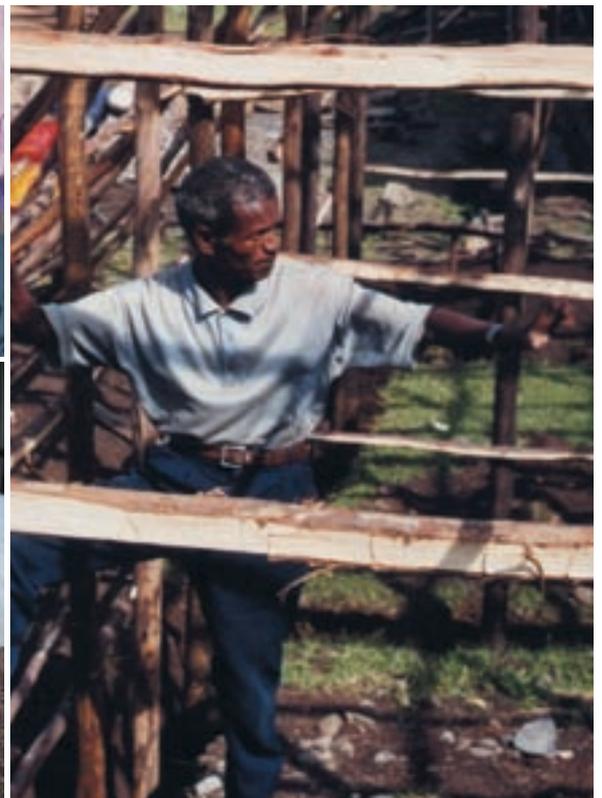
In recent years, ENAELP has enjoyed growing success in terms of its advocacy, awareness and empowerment activities. Every year it marks World Leprosy Day, producing brochures and posters, publishing an annual magazine (*The Truth*) and

airing a two-hour radio program. It is a founding member of the Ethiopian Federation of Persons with Disabilities, and with the help of committed partners is engaged in providing educational opportunities, creating income-generating projects and extending revolving loans to persons affected by leprosy and their families.

The advantages of speaking with a collective voice can be seen in the efforts of ENAELP branches: liaising with local authorities to obtain water and electricity for a settlement in Awassa; convincing Habitat for Humanity to allow the participation of leprosy-affected persons in a new housing development in Dessie; and securing greater recognition for leprosy-affected persons in Gulele, a suburb of Addis Ababa.

Some 5,000 people are diagnosed with leprosy each year, 14% of whom are already suffering from disability. They are usually from the poorest sectors of society and even after they are cured, the stigma of leprosy exacerbates their socio-economic plight.

ENAELP's vision is of a society free of poverty and discrimination, where persons affected by leprosy can participate fully in the economic, social and political life of the country. But realizing that vision in one of Africa's poorest countries represents an enormous challenge. In the words of chairperson Birke Nigatu, "Deep-rooted misperceptions about leprosy remain. This is what we are here to fight." ■



(Clockwise from top left) How ENAELP helps: a loan beneficiary stands in front of his clothing stall; a home owner works on his Habitat for Humanity house; a women's group earns a living from embroidery.

Progress and Challenges

Yohei Sasakawa witnesses the UN human rights Sub-Commission pass a historic resolution on leprosy in Geneva, then visits the Democratic Republic of Congo and Timor-Leste to assess their efforts to achieve the elimination goal.

SWITZERLAND (August 3-5)

There are an estimated 20 million people in the world today who have recovered from leprosy. Including family members, there may be as many as 100 million people who have been affected directly or indirectly by the disease. Despite the fact that leprosy is now completely curable, it still stigmatizes people. Too often, education, job and marriage prospects suffer.

Because of this deep-rooted prejudice and discrimination, in recent years I have made tackling the social aspects of the disease as important as addressing the medical aspects.

In 2003, I had my first opportunity to brief members of the UN Sub-Commission on the Promotion and Protection of Human Rights on leprosy. It was the first time the subject had been brought before them. The following year, the Sub-Commission called for a preliminary investigation into leprosy as a human rights issue, appointing Professor Yozo Yokota to prepare a report on "Discrimination against Leprosy Victims and Their Families." This August, I was present in Geneva when Professor Yokota presented his initial findings and recommendations at the 57th session of the Sub-Commission.

Although leprosy is completely curable, it still stigmatizes people.

I had the opportunity to address the session myself but after some brief remarks gave the microphone to four recovered persons (see page 2). It was the first time recovered persons had addressed a full session of the Sub-Commission, so it was a momentous occasion. They spoke from personal experience, and their words carried more weight than anything I could say.

I am happy to record that the Sub-Commission passed a resolution endorsing the conclusions and recommendations contained in Professor Yokota's report, and he will now begin work on a detailed version.

DEMOCRATIC REPUBLIC OF CONGO (August 6-11)

The Democratic Republic of Congo is one of several African states yet to achieve elimination,

so I was keen to make my first visit there ahead of the December 2005 target set by WHO.

Formerly the Belgian Congo, and for a time known as Zaire, the DR Congo is today ruled by an interim government that is planning to hold democratic elections sometime in 2006.

Beset by infrastructure difficulties as a result of long years of war, instability and mismanagement, but also due to its sheer size, the DR Congo faces many hurdles in the fight against leprosy. In recent years, the prevalence rate and detection rate have been rising, but this reflects concerted efforts by the authorities to track down hidden cases and reach more people. At the time of my visit, the prevalence rate stood at 1.91/10,000.

On August 7, I traveled by road from the capital, Kinshasa, to Bas Congo Province, where I visited Kivuvu Hospital. Once a leprosarium, it is now leprosy referral center.

After spending some time talking with the patients, I visited a village of recovered persons who make a modest living from agriculture and needlework. Children gathered round me, all smiles, and I asked one of them what he wanted to be when he grew up. "A doctor," he replied. I truly hope this boy will go on to fulfill his dream; there is no reason why a healthy child should be denied a bright future, just because a parent has had leprosy.

The next day I visited the WHO Office in Kinshasa for a briefing. Dr. Simon Van Nieuwenhove put matters in perspective when he said that the DR Congo is not so much a country but a continent, with all the



Greeting staff at the Kapolowe leprosy hospital in Katagana Province



Vice-President Zahidi
Ngoma



Health Minister Dr. Emile
Bongeli Yeikelo Ya Ato

implications that has for the logistics of leprosy elimination. Unfortunately, the areas where there are the most cases of leprosy are also those affected by the ongoing militia violence and unrest, making it harder to achieve effective health coverage.

Although it won't be possible for the DR Congo to achieve elimination this year, Dr. J.N. Mputu Luengu B, the national leprosy program manager, told me that the country intends to reach the target by the end of 2007. With the support of WHO and other partners, as well as political commitment at the highest levels, I have every hope it will achieve this goal.

I was fortunate to be able to spend some time with Health Minister Dr. Emile Bongeli Yeikelo Ya Ato and also called on Vice-President Zahidi Ngoma as well as the chief cabinet secretary. All voiced their support for elimination and promised to work for an end to discrimination. In particular, the health minister said he wanted to sit down with health officials, the WHO, and NGOs and map out a strategy for making more effective use of NGO support.

For the second half of my stay, I traveled to Katanga Province in the southeast of the country. At 3.94/10,000, Katanga has the highest PR of any of the DR Congo's 11 provinces, and contributes one-third of the country's leprosy cases.

After calling on the provincial governor in the capital, Lubumbashi, I took part in a press conference attended by some 50 local journalists. Speaking before the media, the health minister said that two of his relatives once had leprosy, which I felt was a brave admission, given the level of stigma that still exists.

From Lubumbashi we drove north about 120 kilometers to Kapolowe, where there is a leprosy hospital, rehabilitation center and a village of recovered persons. What with patients, cured persons, hospital staff, dignitaries and area residents, there must have been several hundred people gathered for the occasion.

I was taken on a tour of the wards and of the settlement, where I saw recovered persons engaged in making sandals and baskets. The patients each make three or four baskets a day, for which they earn the equivalent of \$1. Given that average annual income in the DR Congo is about \$100, this struck me as a good wage.

I was told that there is a region of the DR Congo called Sasakawa. It is also a person's name meaning "one who gives light." It's a name I want to live up to as I encourage all concerned in their efforts to help the DR Congo see its way to achieving elimination.

TIMOR-LESTE (September 4-7)

At the beginning of September I made a brief visit to Timor-Leste. The country gained its independence from Indonesia in 2002. With outside help, especially from the UN, East Timor is slowly finding its feet, but faces many challenges.

The insurgency that preceded its secession from Indonesia completely destroyed its infrastructure, and the health sector was no exception. Public health services are gradually being rebuilt, with the health ministry at the center of these efforts.

At present, for a population of some 1 million people, there are only about 30 doctors. There is also a dearth of hospitals and health centers.

Against this backdrop, leprosy elimination has made remarkable progress, thanks to the tremendous efforts of the WHO country representative, Dr. Alex Andjaparidze.

According to the most up to date figures, 625 new patients have been registered in the past two years, and the current prevalence rate is 3.9/10,000. Over half — or 388 — live in an enclave called Oecusse.



Recovered persons in Oecusse enjoy festivities to celebrate successful completion of their treatment.

Traveling by UN helicopter, I flew one-and-a-half hours from the capital, Dili, to Oecusse. There, I took part in a ceremony to congratulate more than 200 people on the successful completion of their treatment. They ranged in age from children not yet in their teens to the elderly. I was delighted to see there was little evidence of deformity among them.

Both President Kay Rala Xanana Gusmao and Health Minister Dr. Rui Maria de Araujo are committed to elimination. Given the small number of patients, and the fact they occupy one designated area, I believe a concentrated effort will see the elimination target achieved in due course. ■

ILEP Looks to the Future

New general secretary takes up post at turning point for the organization

Douglas Soutar became ILEP's new general secretary in September, with a track record of 25 years in overseas development work — the last 10 as LEFRA's programs director.

He joins ILEP at a challenging time in its history, with members increasingly involved in a broad range of health issues as the context of leprosy control in many countries changes.

It is also a time of renewed collaboration with the World Health Organization, marked by the publication earlier this year of WHO's new global strategy, which ILEP has endorsed.

"I think the shift in thinking toward the sustainability of leprosy activities is very positive," said Soutar. "But it will have to be encouraged and developed, which is where ILEP members have a key role to play."

"What we bring to an important new strategic document is a vast range of operational experience," he said. "Our members have lots of people in the field who know what the realities are for patients. For years ahead, there will still be people affected by leprosy and they will need input from ILEP members."



Douglas Soutar: members have "key role to play"

NATIONAL NETWORK IN INDIA

A survey of leprosy colonies is being undertaken across India in preparation for a national forum of leprosy-affected persons scheduled for December in New Delhi.

At the forum, colony representatives and other cured persons will discuss the possibility of forming a national network.

Organizations of recovered persons already exist in a number of Indian states/union territories, but this would be a national network for improving quality of life and facilitating social integration. ■

FROM THE EDITORS

BUILDING RESPECT

On the outskirts of Dessie, a city some 400 kilometers northeast of Addis Ababa, Habitat for Humanity is constructing a community of 150 new homes. A small number of these have been earmarked for persons affected by leprosy — but only after the local branch of the Ethiopian National Association of Ex-Leprosy Patients (see page 5) successfully lobbied Habitat for Humanity to be included.

Housing is the biggest issue facing the leprosy-affected community in Dessie, where some members squat in makeshift accommodation on a hillside, and others occupy a plot of land next to an unkempt graveyard. Yet the initial objective of taking part in the Habitat for Humanity project was not the chance of a proper home but to prove a point.

"There was a perception that leprosy-affected persons are good-for-nothing and would be unable to afford the down payment required or pay back the loan," said Sisay, ENAELP's Dessie branch chairman "The first goal of participation, therefore, was to 'break the stigma' by showing

that we could."

One of the lucky home-builders is the branch secretary, Liben. He arrived in the area in 1966 to receive treatment for leprosy and has remained ever since. For more than 30 years, he supported himself and his family by begging. But when the Dessie branch of ENAELP was formed in 1995, membership provided him with the incentive to change his life.

"I thought I should set an example and stop begging," he said. "And I didn't want to be seen as a beggar when I represented our association."

Now he rears sheep, which he sells to hotels and restaurants, and it was the sale of a couple of sheep that secured the down payment on his new house.

Making the transition from begging to sheep-rearing took courage but it pleases his children and his friends look at him with new respect.

Like anyone who has taken out a mortgage, he worries about being able to pay it off; but if he wants to set an example and help "break the stigma," there is no better way.

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