

FOR THE Elimination OF Leprosy

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



ALERT Hospital in Addis Abba, Ethiopia, offers outpatient services, reaction treatment and surgery to patients young and old.

A MESSAGE FROM THE GOODWILL AMBASSADOR

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'No Place for Complacency'

In the previous issue, I used this space to congratulate India on eliminating leprosy as a public health problem. I'd like to extend my congratulations to Angola as well and express my sincere gratitude to the people in both countries who made these achievements possible.

In making the announcement, India declared that it would continue to press for elimination at the subnational level. I am deeply appreciative of India's commitment, especially given that several Indian states have populations larger than many of the world's countries.

Its resolve to keep moving forward dispels the misgivings of those who feared that once the WHO goal had been achieved, the government would lose interest. But as I have repeatedly stated, achieving the elimination goal is only a milestone along the path to truly eradicating the disease, and India's commitment reassures me that we are all thinking along the same lines.

"There is no place for complacency at any level" is the clear-cut message coming from the Indian government.

In Myanmar, every February 6 is observed as Leprosy Elimination Day. In times past, Myanmar had a serious leprosy problem. In 1973, its estimated prevalence rate was around 240. Nonetheless, it achieved elimination in 2003.

But as Myanmar's health minister was quick to point out at this year's event, the achievement needs to be sustained. There are still neglected populations to reach, and interest in leprosy control must be maintained even as the disease burden is further reduced.

In Ethiopia, another country that achieved elimination some years back, the disability rate among new cases is extremely troubling, pointing to the need to make adjustments to the leprosy control program. Meanwhile, stigma and discrimination persist.

All this should keep us mindful of the fact that the elimination of leprosy as a public health problem is not the end of our struggle, and that we still have much to do.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Progress Continues

Countries look beyond national-level elimination to new priorities

INDIA

“India has achieved elimination of leprosy as a public health problem as of December 2005. We thank all those who joined hands to make this possible.”

So announced an ad sponsored by the Ministry of Health and Family Welfare that appeared in *The Times of India* on January 30, 2006.

As of the end of 2005, India’s prevalence rate at the national level stood at 0.95/10,000, a remarkable achievement for the country given the situation only a few years ago.

Work now continues at the subnational level, where the Indian government is looking to achieve leprosy elimination through existing MDT services in the remaining states and districts under its National Leprosy Eradication Program.

In particular, it is focusing on endemic districts and urban localities, districts showing high disability rates and states with a high proportion of children among new cases.

The program also aims to:

- increase institutions for providing reconstructive surgery services to leprosy-disabled persons
- continue capacity-building efforts among all categories of staff whose involvement in the program is essential.
- continue to increase awareness about leprosy among the general public with the aim of bringing about attitudinal change and removing stigma against the disease.

The eradication program is set to continue for some years, in order to reduce prevalence in the remaining endemic areas and avoid a recurrence of the disease in areas where success has already been achieved.

As the newspaper ad also said, “Together, we will continue to fight leprosy.”



It's official: India achieves the elimination goal.

MYANMAR

In a speech in Yangon on February 6 marking the third anniversary of leprosy elimination in Myanmar, Health Minister Dr. Kyaw Myint said that the country’s achievements to date needed to be sustained, and that it would take a few more years to consolidate elimination status.

At the same time, as the disease burden continues to drop, he cautioned that it may not be easy to maintain interest in leprosy control at current levels in the face of competing demands from other more serious diseases.

“Myanmar must make efforts to sustain the elimination of leprosy.”

Myanmar introduced a leprosy control program soon after independence in 1948. Although the program was well organized and technically sound, the limitations of dapsone therapy in the treatment of leprosy presented problems for reducing the disease burden. By 1973, Myanmar had an estimated 700,000 cases of leprosy.

However, the implementation of multidrug therapy (MDT) in 1986 at the recommendation of the WHO paved the way for elimination. Under the guidance of the National Health Committee and the Ministry of Health, and with technical support from WHO and other partners, elimination activities were carried out at the grassroots level in collaboration with local authorities and organizations.

As a result, the prevalence rate fell from 39.9 per 10,000 population in 1988 to less than 1 in January 2003, achieving the elimination goal at the national level. Since then, PR has continued to decline and was reported to be 0.44 at the end of December 2005.

In his remarks, Dr. Kyaw Myint stressed the importance of maintaining the quality of leprosy services within the integrated health system; strengthening the capacity of health staff; expanding coverage to underserved communities and urban districts; and reaching out to migrant and floating populations and people living in border areas.

“Myanmar must make efforts to sustain the elimination of leprosy it achieved in 2003, and work to establish a network to care for those disabled by leprosy in order to minimize the health, social and economic consequences of the disease,” he said. ■

ANGOLA

● Health Minister Dr. Sebastio S. Veloso informed Goodwill Ambassador Yohei Sasakawa in a letter dated January 29, 2006, that Angola had achieved the goal of leprosy elimination at the national level. He said Angola’s prevalence rate currently stood at 0.94 and that the country would continue to fight the disease until it had been eradicated.

No More Stigma

Eminent world figures issue call

GLOBAL APPEAL TO END STIGMA AND DISCRIMINATION AGAINST PEOPLE AFFECTED BY LEPROSY

Leprosy is among the world's oldest and most dreaded diseases. Without an effective remedy for much of its long history, it often resulted in terrible deformity. It was also thought to be extremely communicable. Patients were abandoned, forced to live in isolation and discriminated against as social outcasts.

In the early 1980s, an effective cure for leprosy became available. Multidrug therapy has successfully treated over 14 million people to date. Contrary to popular belief, leprosy is extremely difficult to contract. With prompt diagnosis and treatment, it can be medically cured within 6 to 12 months without risk of deformity.

Yet fear of leprosy remains deep-rooted. Misguided notions endure — that it is “highly contagious,” “incurable” and “hereditary.” Some even regard it as “a divine punishment.”

Ignorance and misunderstanding result in prejudice and discriminatory attitudes that remain firmly implanted as custom and tradition.

Consequently, patients, cured persons and their entire families suffer stigma and discrimination. This limits their opportunities for education, employment and marriage, and restricts their access to public services.

Fearful that by speaking out they will invite further discrimination, for long years people affected by leprosy, including their families, have been cowed into silence. Such silence reinforces the stigma that surrounds them.

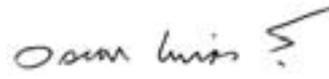
The world has remained indifferent to their plight for too long.

Article 1 of the Universal Declaration of Human Rights states that “All human beings are born free and equal in dignity and human rights.” This article, however, is meaningless to people affected by leprosy, who continue to suffer discrimination.

We appeal to the UN Commission on Human Rights to take up this matter as an item on its agenda, and request that it issue principles and guidelines for governments to follow in eliminating all discrimination against people affected by leprosy.

We further urge governments themselves to seriously consider this issue and act to improve the present situation with a sense of urgency.

Finally, we call on people all over the world to change their perception and foster an environment in which leprosy patients, cured persons and their families can lead normal lives free from stigma and discrimination.



Oscar Arias*
Former President of Costa Rica



Jimmy Carter*
Former President of the United States of America



The Dalai Lama*



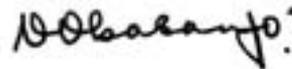
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Prince of the Hashemite Kingdom of Jordan



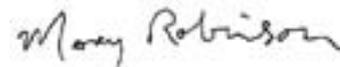
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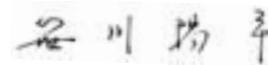
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President of the Federative Republic of Brazil



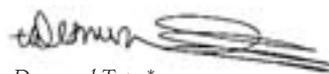
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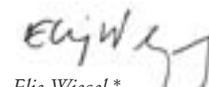
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January 29, 2006

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Trading for Rehabilitation

Delhi-based MESH helps traditional crafts artisans with disabilities to a better life



Executive Secretary Jacqueline Bonney at MESH's Delhi headquarters.

Jacqueline J. Bonney MBE sits behind her desk in a showroom piled high with beautifully made bedspreads, cushion covers, tablecloths and papier-mâché products, and launches into an enthusiastic description of the work of MESH.

Started 25 years ago in Delhi by a group of North American expatriate wives, MESH — or Maximizing Employment to Serve the Handicapped — provides opportunities for disabled people and their dependents, especially those affected by leprosy, to be rehabilitated in order to become self-sufficient.

“The fact is that there are a huge number of people in India affected by leprosy who don’t need treatment anymore but whose lives have been turned completely upside down by the disease,” says Bonney, MESH’s executive secretary for the past 10 years. “It is necessary to find ways of helping them.”

MESH’s founders focused their initial efforts on a leprosy colony north of Delhi, where they encouraged men to weave and to raise poultry. Today, MESH buys and sells handicrafts and poultry from some 45 autonomous groups of disabled and leprosy-affected persons all over the country.

All products are purchased at prices suppliers set. MESH then adds transport costs and a 15% service charge to come up with its selling price.

Nearly 80% of MESH’s handicraft business is export, with products shipped to wholesalers in the United Kingdom, Sweden, Canada, the United States, Australia and elsewhere. Its main customers are U.K.-based TLM Trading, the trading arm of The Leprosy Mission, and IM Soir Sweden, an

organization working to change attitudes toward persons with mental and physical disabilities.

PRODUCT DEVELOPMENT

As MESH has become more attuned to keeping its overseas customers happy with well designed and marketable products, business has grown. Sales topped 10 million rupees for the first time in fiscal 2004-05 and are expected to grow 10% this year.

Gone are the days when clients would take whatever MESH had to offer, only to end up with piles of tablecloths they couldn’t sell. Now MESH is increasingly buying to order

— and buying products that have benefited from professional design input from the customer.

In a project begun two years ago, funded by the Swedish Mission Council through IM Soir Sweden, two designers have been working with a number of MESH suppliers. As well as coming up with designs, they help local artisans develop new techniques that will increase their product range, teach them about making swatches and about systematic labeling and coding of products to help them operate on a more business-like footing.

“Indians love bright colors but these just don’t work in places like Sweden.”



Simultaneously, TLM Trading decided to design its own products and work with MESH to identify the groups best suited to make them.

“It’s the way the commercial world does it,” says Bonney. “Benetton doesn’t go to its seamstresses and say, ‘Design us a T-shirt.’ They give them a design and have them make it.”

For suppliers that continue to develop products by themselves, MESH evaluates their marketability and makes suggestions for improving them.

“There’s a real issue with color,” Bonney says. “Indians love bright colors, but these just don’t work in places like Sweden where the light is so different. So we try to teach them what works and what doesn’t.”

Reference

To see an online catalog of products handled by MESH, visit www.mesh-crafts.com



A weaver at work at Bharat Mata Kusht Ashram, a MESH supplier in Haryana State, adjacent to Delhi.

JOB SATISFACTION

A nurse by profession, Bonney left her native Britain in 1978 to work at a leprosy hospital in Andhra Pradesh. After two and a half years, she moved to a self-settled colony near the hospital where she spent the next 15 years.

There she became involved in all aspects of colony life, including rehabilitation efforts. At her suggestion, women weavers who had been making bed webbing stitched the strips of cloth together to make bags, which Bonney arranged to be sold through a fair trade organization. In due course she came into contact with MESH, where she is now happily ensconced.

“Seeing people who didn’t have much do a little better” is how she describes the job satisfaction that MESH provides. She cites the example of a man who makes ceramic piggy banks. He used to be a burden on his family after leprosy left him with bent fingers, but a combination of reconstructive surgery and the development of a new product line for export to TLM Trading has given him a good living. “It’s changed his life,” said Bonney.

The piggy-bank maker was helped by a TLM project, one that closely involves MESH, to seek out disabled artisans in traditional crafts communities and bring them back into the workforce. “This is quite different from what we did before, when we looked for disabled people who were already in

hospitals or colonies, and who had learned a craft,” says Bonney.

MESH also encourages groups working with marginalized people to include the disabled and the leprosy affected. Bonney once turned down an approach by a group working with HIV/AIDS widows and poor rural women to sell its products because it didn’t include any people with disabilities. “But I told them, ‘Since you are working with marginalized people, why not take the most marginalized, who are the disabled?’” She is pleased to report that they now make up 30% of the group’s workforce.

If there’s a downside to MESH’s growing success, it’s that the standards it has put in place for exports make its products more expensive on the domestic market, where the “fair trade” tag is not a selling point. “We face a dilemma,” admits Bonney, who says MESH will have to come up with a strategy to make people with disposable income aware of what it does. “We clearly cannot compete with sweatshops and the influx of Chinese-made goods because our concern is fair income for the artisans with whom we work.”

But in a sign that MESH is doing lots of things right, the colony to which it traces back its beginnings no longer has need of the support MESH provided for so long. For Bonney, it’s the best endorsement MESH can have. “That’s our dream,” she says. “Real rehabilitation.” ■

GLRA KOLKATA

SEWING FOR EMPOWERMENT



At the Kolkata branch of the German Leprosy and TB Relief Association (GLRA), women affected by leprosy are being taught sewing and knitting skills with a view to securing them a source of income.

Since the program began last year, the GLRA has trained some 220 women — both those who have had leprosy and others who come from a leprosy-affected household.

The GLRA pays for their bus fare and lunch for the duration of their training, then loans them a small amount of capital to help them go into business. Many use this to buy a sewing machine, which the GLRA sells them at a discounted price by buying in bulk from the manufacturer.

Taught in groups of between 10 and 22, the women train for a minimum of three months, or longer if other skills such as stitching and craft-making are involved. Priority is given to the disabled and the poor.

Although men are also admitted, there are more places for women because they are in “double jeopardy,” explains GLRA’s Sudhakar Bandyopadhyay. “If a husband gets leprosy, his wife must look after him. If a wife gets leprosy, the

husband looks for a new wife.”

“Our goal is to help these women make a financial contribution if they are still living with the family, or to enable them to stand on their own two feet.”

The GLRA buys the raw materials the trainees work with from a person affected by leprosy, a cloth wholesaler who buys scraps from a garment factory. These are fashioned into baby clothes, bags and other items, which are sold to shopkeepers who sell them at the local market.

One of the most satisfying aspects of the program is seeing the change that comes over the women as they gain in confidence, says Sudhakar. “They arrive with pale, drawn expressions. But then they are inspired and start smiling. They regain their dignity.”

Journeys to India and Ethiopia

Visits to Delhi and Kolkata launch a Global Appeal; travels to Addis Ababa and Shashamane gauge progress in the fight against the disease

INDIA (JANUARY 28-FEBRUARY 3)



Launching the Global Appeal on World Leprosy Day

On January 29 I was in Delhi to launch the Global Appeal to Eliminate Stigma and Discrimination against Persons Affected by Leprosy (full text on page 3).

Nearly a dozen world leaders and Nobel Laureates had joined me in putting their names to the appeal, which is designed to draw the world's attention to the ongoing problems faced by those affected by the disease.

Among the dignitaries in attendance was the former chief justice of India's Supreme Court, Y.V. Chandrachud, who was one of several distinguished speakers at a symposium on "Law and Leprosy" later in the day.

I also used the occasion to announce that I was establishing a new fund to help empower persons affected by leprosy in India and increase their chances of social and economic integration.

The fund has three goals: to provide persons affected by leprosy with vocational training and job opportunities; to establish micro-credit schemes; and to provide educational opportunities for children living in colonies, using education to break the cycle of stigma and poverty.

On January 30, I moved to Kolkata to announce the Global Appeal to media representatives in West Bengal. Among those joining me on the platform was the state minister for law and justice, who said that there are a number of laws that could help the leprosy-affected but which are not working properly because there is no social awareness of the issues they address. "The law is a cart," he said, "and awareness is the horse. The cart

cannot move without the horse."

The state of Jharkhand, which has a prevalence rate of 1.4, was the last stop on my journey. In the capital, Ranchi, I participated in a media workshop and a state/district level consultation. I also traveled to Jamshedpur, the home of Tata Steel, India's largest private-sector steel company, to attend a human rights seminar and visit a couple of colonies. One of these is supported by Bharat Sevashram Sangha, a Hindu charitable organization that has worked tirelessly to promote leprosy elimination in India. I saw new houses being built and the site was being attractively landscaped.

"The law is a cart, and awareness is the horse. The cart cannot move without the horse."

On my travels I was accompanied by persons affected by leprosy from Nepal, Indonesia and the Philippines. I want to thank them for speaking at the different venues we visited together and for sharing their insights. As Adi Yosep of Indonesia reminded us in Kolkata, we must listen and learn from persons affected by leprosy, respect their voices and not make assumptions on their behalf.



Oli Parwati (far right), a leprosy-affected person from Nepal, chats with residents of a colony during a visit to Jamshedpur, Jharkhand State, in January.

ETHIOPIA (FEBRUARY 24-MARCH 2)

At the end of February I paid my first visit to Ethiopia in about 10 years. Although only a short stay, it was extremely rewarding.

Ethiopia achieved elimination in 1999 and registers only about 5,000 new cases annually. Unfortunately, over 40% of these involve disabilities. To tackle this problem, efforts to ensure early detection need to be stepped up.

Fighting against discrimination and working to restore the dignity of those affected by the disease is the Ethiopian National Association of Ex-Leprosy Patients (ENAELP). Established in 1996, it now has 54 branches around the country.



Sasakawa, Birke and Prime Minister Meles Zenawi

Birke Nigatu, ENAELP's charismatic chairperson, joined me in paying a courtesy call on Prime Minister Meles Zenawi. I limited my remarks to allow her to speak at length with the prime minister. She also joined me at a press conference, where she described her experiences as a person affected by leprosy. The resulting media coverage was excellent.

On February 28, I drove to Shashamane, about 250 kilometers south of Addis Ababa. Shashamane is composed of about 15 villages totaling 60,000 people. About 12 kilometers from the center is a general hospital. Established as a leprosy hospital in 1951, but today treating TB, AIDS and other illnesses, it accounts for the large number of leprosy-affected persons living nearby.

One of the villages I stopped at was Kuyera, which is home to about 7,000 recovered persons and their families. In a joint initiative of ENAELP and the GLRA, self-help groups of 10-15 people meet once a week. With practiced eyes, recovered persons inspect each other's old injuries. Those whose hands and feet are well looked after are rewarded



Checking for ulcers at Kuyera village in Shashamane

with a round of applause, while those found to have ulcers are told to be careful, and some are even fined for not taking better care of themselves.

Some 60% of leprosy-affected persons living in Shashamane are said to have serious disability, and 99% live below the poverty line. According to locals, it is hard for such people to find work because of the social stigma. For those who want to go into business, the lack of startup capital is an insurmountable obstacle, so many resort to begging to make a living. Quite a few are involved in agriculture, but yield is poor and they are hard-pressed to grow enough for their own needs.

On the way back to Addis Ababa, I stopped to inspect an initiative of The Sasakawa Global 2000 Agricultural Program. Here a farm was trying out a new type of irrigation system.

Ethiopians are normally only able to work the land for a couple of months of the year during the rainy season. However, by installing this simple system, the farm I visited has extended the cultivation period by two months, enabling it to grow better quality vegetables and raise dairy cows. The farmer's wife told me the results were marvelous.

It occurred to me that this irrigation system should be taught to persons affected by leprosy living in rural settlements. Giving them access to the latest agricultural techniques will not only greatly improve their lives, but will, I hope, encourage neighboring farmers to come and learn from them and so break down the barriers of discrimination.

There is no reason why this can't be tried in other countries, too. My trip to Ethiopia provided me with a very important insight, and I am excited about the possibilities. ■

Leprosy LEXICON

● Leprosy Control Activities

Continued intervention is required to keep leprosy under control and reduce the incidence and prevalence of the disease. As defined by the WHO Global Strategy for 2006-2010, leprosy control activities delivered by the health system include diagnosis, MDT, patient and family counseling, community education, prevention of disabilities/impairments, rehabilitation and referral for complications.

India's Scouts Spread the Word

Movement communicates information about leprosy at the grassroots level



14-year-old Khusbu Kumari took time out from her studies recently to attend a leprosy workshop in India's Jharkhand State.

In addition to being a student, Khusbu is also a lokdoot (communicator)

involved in the Indian scout and guide movement's effort to raise awareness about leprosy dating back to 1984.

Since 1999, the scouts have enlisted the help of persons affected by leprosy such as Khusbu, who participates in the movement's "Leprosy-free Schools" initiative by accompanying scout leaders to different schools in her home state and talking to her peers about the disease.

She says the students relate to her because she is one of them and describes herself as "very happy" doing what she does.

Scouts also go from door to door in villages,

counseling families as part of a "Leprosy Elimination Active Doorsteps" program. In addition, they take part in mass awareness campaigns, and operate mobile exhibitions at temples, bazaars and other venues.

"Scouts are trusted," says M.A. Mecci, National Joint Secretary, Scout and Guide Fellowship. "When government officials visit, people shut their doors. But when we go, they respond."

CULION CENTENARY

The Culion Sanitarium in the Philippines, formerly known as the Culion Leper Colony and now as the Culion Municipality, is preparing to observe its 100th anniversary this May.

The event, which marks the metamorphosis of Culion and its people into a thriving municipality, celebrates the community's triumph over adversity and recalls its 100-year journey toward healing.

Founded in 1906, the Culion Leper Colony was once the world's largest leprosy colony. ■

FROM THE EDITORS

IDEAS HAVE WINGS

When a good idea comes along, it's worth grabbing. The expatriate ladies who founded MESH, the Delhi-based organization that works to Maximize Employment to Serve the Handicapped (see page 4-5), started by introducing two income-generating projects to a leprosy colony north of Delhi; weaving was one, raising poultry the other. The birds came into the picture at the suggestion of a spouse, who had gone to India with the Food and Agriculture Organization to promote broiler chickens as a source of protein. The plan worked well. Chickens were raised by leprosy-affected persons, dressed and sold. The tasty meat found a ready market.

Those working in leprosy often focus on the medical or para-medical areas, but drawing on skills from other fields — agriculture, for example — in the rehabilitation of those affected by the disease is surely worth exploring further.

On a recent visit to Ethiopia, Goodwill Ambassador Sasakawa called on a farm where a new type of irrigation system is enabling farmers to spend more time working the land, yielding impressive results.

Having just visited an area of rural settlements

where persons affected by leprosy were struggling to make ends meet, it suddenly made perfect sense that the same technology should be made available to these people as well, to assist them in bettering their livelihoods.

ENAELP — the Ethiopian National Association of Ex-Leprosy Patients — is already embarked on a number of income-generating projects, including oil processing and flour milling, to increase the income of rural households. With further guidance and access to improved technologies — perhaps with the help of an outside partner — they could doubtless do even more.

In overcoming stigma and discrimination, nothing succeeds like success. When people are able to make a living, and their standard of living improves, they start to grow more self-confident and gain the strength to deal with the attitudes of the uninformed.

To help in the socio-economic rehabilitation of persons affected by leprosy, let's look for hints wherever they are to be found, and create new synergies between the leprosy and non-leprosy communities, so as to open the eyes of all parties to the possibilities of creative collaboration.

FOR THE ELIMINATION OF LEPROSY

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