

FOR THE Elimination OF Leprosy

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



Pygmies from Wamba district in the DR Congo's Oriental Province. Prevalence of leprosy is quite high among Pygmy communities (see page 6).

MESSAGE

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Motorcycle Maintenance

Forty years have passed since the death of the revolutionary, Che Guevara. As a young medical student, he set off on a motorcycle journey across South America together with a friend who was a biochemist. Passing through Peru, they spent time at a leprosy colony, where they volunteered their services as doctors.

Many people became familiar with this story after it was made into a popular film, *The Motorcycle Diaries*. Doubtless quite a few movie-goers were seeing leprosy depicted for the first time.

As some of you may know, I use the example of a motorcycle when I describe progress in the fight against leprosy. In my analogy, the medical aspect of the disease is represented by the front wheel and the social aspect by the rear wheel. To ensure a smooth journey, both wheels must rotate at the same rate and be the same size. Balance is important.

Concerning the medical aspect, the front wheel has been gathering speed in recent years. Leprosy has been all but eliminated as a public health problem in countries around the world. In

1985, the disease was endemic in 122 nations; today this remains the case in only four.

However, those of us involved in this work have neglected the back wheel. People affected by leprosy still face serious issues with regard to stigma and discrimination. For my own part, it was only a few years ago that I fully came to appreciate the scale of the problem, and began to focus more attention on it.

In other words, though the front wheel has been spinning in the right direction, the back wheel has been holding up progress. The motorcycle needs some fine-tuning.

I am now doing my best to see that initiatives to tackle the social consequences of the disease are brought up to speed with the medical efforts, because they are equally important components of a complete cure. Not until we have adjusted the back wheel will the motorcycle accelerate past the point where everyone is truly free of the disease.

— Yohei Sasakawa, WHO Goodwill Ambassador

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SILF Sets Out Its Stall

New foundation to be a force for empowerment and elimination of stigma

The Sasakawa-India Leprosy Foundation (SILF)*, an initiative of Yohei Sasakawa with generous financial support from The Nippon Foundation, was launched in October 2007 with events in New Delhi and Mumbai. Among the guests of honor were former President of India Dr. A.P.J. Abdul Kalam and Union Finance Minister P. Chidambaram. The new foundation also received encouragement from leading Indian industrialists including Jamshyd Godrej, Mukesh Ambani and Keshub Mahindra.

We are now identifying projects to take forward our mission, which is to eradicate the stigma against leprosy by making sure that people affected by the disease are empowered to live in dignity and are accepted by society.

Empowerment is the first priority. It is clear that education will need special attention. SILF will focus on ensuring that all children from families affected by leprosy have access to education, through scholarships and financial assistance where necessary.

We will try to make sure that, as far as possible, this access is achieved in an integrative manner by encouraging regular schools to accept children who come from leprosy-affected households. Several leprosy colonies run their own schools. These need to be upgraded to provide good quality and inexpensive education, and encouraged to open their doors to children outside the colonies. The fact that there are instances where schools run by a leprosy colony also welcome children from the surrounding community is a source of great encouragement. SILF will work toward replicating this model.

While facilitating pursuit of higher education through scholarships and loans, we will also work to provide opportunities for training and skills development. SILF wants to ensure that skills generation does not take place in a



Former President Dr. A.P.J. Kalam with Sasakawa

vacuum but is linked to the changing employment requirements of a growing economy. We would also like to tie up with several organizations that are providing vocational training to migrant rural youth in deprived areas.

SILF hopes that employers can be persuaded not to discriminate against people who come from leprosy-affected families if they have marketable skills. However, while encouraging employment in the formal sector of the economy, we are acutely aware that this will not be a universal option. Hence we will work toward training and facilitating people for self-employment.

MICRO CREDIT

Access to initial capital is often the debilitating factor that prevents highly marginalized and excluded communities from starting their own businesses. Micro credit can provide the solution, yet for a start-up to be successful and self-sustaining requires prior education along with identification of feasible business options and training in running the business.

SILF will ensure that people affected by leprosy not only have access to start-up capital but are also equipped to manage their businesses in a sustainable and self-reliant manner. We plan to work together to create and assist self-help groups and cooperatives, and the fact that such organizations already exist makes this task easier.

We also propose to work with NGOs that have experience and expertise in the above areas. While many work with marginalized communities, their activities do not extend to self-settled leprosy colonies. SILF has already initiated contacts to apprise them of the prevailing socioeconomic conditions. We are also exploring possibilities for building partnerships with NGOs and CSR divisions of corporate houses.

Every project SILF undertakes will aim to sensitize the wider public to the reality of leprosy. We believe that in changing attitudes and mindsets through widespread awareness of the medical facts — that the disease is difficult to contract, not hereditary and completely curable — the efforts of each and every individual can go a long way. Hence we want to enlist the support and goodwill of different sections of the social spectrum, from politicians and business people to school children and housewives, in what we hope will create a ripple effect that will spread across the country. ■

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Reference

* www.silf.in

Seeking Equal Opportunities for All

For Prof. Dr. Turkan Saylan, leprosy is one piece of a bigger picture.



Dr. Saylan received the International Gandhi Award for Leprosy in 1986

The neatly dressed young woman standing near Prof. Dr. Turkan Saylan could be a research assistant. In fact, she is a bodyguard provided by the Turkish government, who accompanies 72-year-old Dr. Saylan wherever she goes.

Why her country's leading leprologist, now retired and battling cancer, should require a minder is explained by her role as founder and president of one of Turkey's most progressive NGOs, dedicated to keeping the country secular and providing equal educational opportunities for all.

Dr. Saylan first encountered leprosy as a medical student. "It was like the Middle Ages," she recalls. "Doctors didn't treat patients as human beings."

Shocked, she vowed to make a difference. First, though, she had to complete her studies, a process interrupted by marriage, the birth of two children, and two bouts of TB. The second attack kept her flat on her face for more than a year.

Once qualified, Dr. Saylan specialized in venereology and dermatology, "to show up all those who shunned the field." Early in her career, she worked in an insurance hospital, where she was exasperated by her colleagues' discriminatory attitudes toward patients with leprosy.

After she was featured in a TV documentary about leprosy, politicians accused her of talking about a disease that "didn't exist" in Turkey. But at a meeting with the health minister, she persuaded him to let her coordinate the leprosy control program, saying she could do a much better job.

As director of the Istanbul Leprosy Hospital from 1981 to 2002, Dr. Saylan was ahead of her time in appreciating that it wasn't enough just to treat the disease with drugs; it was also necessary to address patients' social and economic needs. Through a group of volunteers, she raised funds to provide scholarships for patients' children and start income-generating projects.

'KEMALIST FEMINIST'

Dr. Saylan describes herself as a "Kemalist feminist" — a reference to Mustafa Kemal Ataturk, the founder of modern Turkey, who based the nation on secular principles. As a woman whose career had benefited from Ataturk's policies, Dr. Saylan and like-minded individuals formed the Association in Support of Contemporary Living (CYDD) in 1989 to safeguard and develop his legacy.

CYDD builds schools and student dormitories, supports the education of girls who would otherwise have no schooling beyond primary level, and provides scholarships to bright students from poor families to see them through university.

In particular, it focuses on addressing the lack of educational opportunities in the poor southeastern parts of the country, where boys continue studying but girls marry young and have large families, perpetuating the poverty in which many live.

Since most of Turkey's leprosy cases originated in these areas, Dr. Saylan was already very familiar with the region and its problems. In furthering the work of CYDD, therefore, she was able to make use of her knowledge and contacts. "Leprosy was a very good calling card," she said.

"People like to applaud me. I say, 'Don't clap. Do as I do. Solve the problems.'"

CYDD now has 95 branches around Turkey. To date, it has helped 25,000 girls go on to secondary education, and provided scholarships to 20,000 university students. Its aim is to build a dormitory in each of Turkey's 850 districts.

To her more extreme opponents, Dr. Saylan is a missionary in disguise. On the basis that her mother was Swiss, they accuse her of recruiting girls to convert to Christianity, a charge she dismisses as absurd. She receives frequent threats, but shrugs, "This is the battle going on in Turkey."

Seated at her desk in CYDD's headquarters in Istanbul, Dr. Saylan works under the watchful gaze of Kemal Ataturk, whose eyes, blown up large, stare out at her from a wall on the other side of the room. "People like to applaud me," says this proud and combative citizen of Turkey. "But I say, 'Don't clap. Do as I do. Solve the problems.'" Her hero Ataturk looks on approvingly. ■

From the Caucasus to the Congo

During a busy two-month period, the goodwill ambassador travels to six countries, including those where leprosy is still a public health problem, and others which see only a handful of cases a year.

INDIA (OCTOBER 9-13)

In October, I traveled to India for the launch of the Sasakawa-India Leprosy Foundation, or SILF (see page 2). SILF's role is to help break down the stigma and discrimination that surround leprosy. Among its tasks will be to assist people affected by leprosy and their families in gaining access to education, skills training and micro-financing. The Nippon Foundation provided an endowment of \$10 million and SILF hopes to supplement this with additional support from the Indian corporate sector. SILF will also act as a catalyst for putting groups of leprosy-affected people in contact with existing self-help programs for disadvantaged communities.

The chief guest at the establishment ceremony in Delhi on October 9 was former President of India Dr. Abdul Kalam, who spoke of the need for "rehabilitation with compassion." One of the key goals is to break down the social and economic barriers that separate self-settled leprosy colonies from wider society. This will take time; the first step is to make the colonies self-sufficient.

A reception attended by Indian Finance Minister P. Chidambaram in the evening was followed 24 hours later by another SILF launch event, this time in Mumbai. While there, I took the opportunity to call on several of India's top industrialists to explain the workings of the new foundation and seek their advice and cooperation.

There was also time for a short field visit, which took me to Trombay, a colony on Mumbai's outskirts. Founded in 1942, it is home to 3,500 people affected by leprosy and their families, including about 1,000 children.

The colony has its own school. Tuition is free, so it also attracts pupils from outside the colony. As a result, it plays an important role in forging ties with the surrounding community and helping to reduce stigma and discrimination.

No one in Trombay begs for a living. But economic self-sufficiency is the major worry. City authorities put a stop to the production of bootleg liquor, which had been an important earner, and the colony is now looking for new ways to generate income.

NEPAL (OCTOBER 13-15)

From India I traveled to Nepal to attend a seminar on leprosy elimination. Nepal is one of the four countries yet to achieve the elimination

goal but is moving in the right direction.

Organized by the government with the help of the WHO, the meeting heard Minister of Health and Population Girirajmani Pokharel say that Nepal hoped to reduce the registered prevalence of leprosy to below 1 case per 10,000 population sometime next year.

Currently, Nepal has 3,700 leprosy cases, and a prevalence rate of 1.45. The elimination goal has already been achieved in 42 out of Nepal's 75 districts, but 20 out of the remaining 33 districts account for 80% of the leprosy caseload. All of these are in the Terai region.

The political and geographical realities of Nepal have made eliminating the disease a challenge, and matters have not been helped by frequent "changes of guard" among those in charge of the effort. In addition, stigma and discrimination remain a problem, and much more must be done in the area of rehabilitation.

However, the central government does recognize the problems and is working to resolve them. It is also able to count on the support of experienced NGOs, both local and international, key representatives of which attended an advocacy workshop the next day.

Because of the situation on the ground, it was unfortunate that people responsible for implementing the strategy at the regional and district level could not attend. They are vital for bringing services into the field, and we need to hear from them about the challenges they face. On my next visit to Nepal, therefore, I plan to visit the front lines, meet them in person, and see the situation for myself.



Kathmandu seminar updates participants on Nepal's progress



Umbaki sanatorium is located in a former oil workers' camp, about 80 kilometers from the Azerbaijan capital.

TURKEY (OCTOBER 16-18)

Leprosy on the Anatolian peninsula has a long history, with leprosaria dating back to Roman times. But not until the advent of the Turkish Republic in 1923 were systematic attempts begun to screen and record cases of leprosy. Turkey has long since eliminated the disease as a public health problem and last year there were just seven new cases.

A remarkable lady who has played a pivotal role in tackling the disease in her country is Professor Dr. Turkan Saylan, whom I had the pleasure of meeting when I called on the Istanbul Leprosy Hospital.

The hospital, which is not far from Istanbul's airport, began functioning as an independent leprosy hospital in 1981. However, the hospital buildings — converted army barracks located on the grounds of a mental hospital — had been used to accommodate leprosy patients since 1927.

Currently the hospital is home to 22 people suffering from leprosy-related disabilities, the youngest of whom is 45. It also offers surgical treatment and rehabilitation, and sees outpatients.

Dr. Saylan served as director of the hospital between 1981 and 2002. Now retired, she remains active in a Turkish NGO focusing on educational projects (see page 3).

One of the admirable things about the approach championed by Dr. Saylan and her colleagues is that they not only attended to patients' medical conditions, but also focused on their social needs. Based on the idea that medical treatment and social support are equally important, patients were properly cared for, provided with

protective shoes and glasses, given assistance for social and economic rehabilitation, and their children provided with scholarship funds. In other words, Dr. Saylan and her team adopted a holistic approach to dealing with leprosy.

I was deeply impressed by Dr. Saylan's methods. At the same time, I was also reminded how implementing such a far-sighted approach to problem-solving requires a person with strong leadership qualities — precisely the qualities that Dr. Saylan so obviously possesses.

AZERBAIJAN (OCTOBER 20-22)

From Turkey, I traveled via a conference in Georgia to Azerbaijan. This was my first visit to this energy-rich nation, which achieved its independence in 1991 with the breakup of the former Soviet Union.

My purpose was to go to the Umbaki leprosy sanatorium, located some 80 kilometers southwest of the capital, Baku. The sanatorium was relocated several times before it took over what had been a temporary camp for oil workers in the Gobistan desert next to Umbaki village in 1957. The camp's out-of-the-way location was doubtless deemed ideal for its purpose.

The route out of Baku follows the coastline of the Caspian Sea, along a good road that leads to the vast Sangachal terminal, one of the largest oil and gas terminals in the world and a symbol of Azerbaijan's mineral wealth.

Turning off at the sign for Umbaki, our party then headed inland along a deeply scarred road in desperate need of repair. It was only a further 25 kilometers to our destination, but took another one



At home with one of Umbaki's 30 residents

and a half hours. The barren landscape and tenuous link with the outside world served to underline the isolation of the sanatorium.

Eventually we reached our goal. Lying just beyond Umbaki village, the sanatorium came into view — a cluster of ageing buildings surrounded by a low wall. In contrast to the stark nature of the surrounding landscape, trees dotted the compound, many of them heavy with pomegranates.

In the days of the Soviet Union, Umbaki was the only leprosy sanatorium in the southern Caucasus, treating cases from Georgia, Armenia and Azerbaijan. At its peak, in the 1960s and 1970s, there were roughly 200 patients. Today it is home to around 30 residents, among them a published poet, Mahmud Mahmudov.

We were taken on a tour of the sanatorium by its director, Dr. Vidadi Aliyev, who makes the punishing journey from Baku to Umbaki several times a week. He first took us to a dilapidated building to show us how residents used to live. Windows were broken or missing, there were holes in the walls and roof, and in general the structure was in a terrible state. "We shared it with frogs and snakes," said Mr. Gasym, one of the former occupants.

The intervention of a charity run by volunteers changed all that. Since 2003, Community Shield Azerbaijan has raised money to completely refurbish two residential blocks, transforming the lives of residents, who now live in draught-free rooms, enjoy hot showers, and heating provided by gas stoves. The charity has also donated several converted shipping containers to serve as a barber shop, laundry room, shower room, restroom and morgue.

As I toured the sanatorium, I was struck by how nicely residents had decorated their rooms, with many of them displaying photographs and other personal effects. I was told that Azeris like to welcome people into their homes, and certainly I shall not forget the warmth with which Umbaki's

residents greeted me as I toured their accommodation — nor the isolation in which they have been forced to spend their lives.

DR CONGO (NOVEMBER 6-10)

I last visited the Democratic Republic of Congo in 2005, when registered prevalence of leprosy was 1.5 per 10,000 population. Since then, the rate has come down to 1.2, notwithstanding the many difficulties the health services face, especially in northern and eastern parts of the country as a result of war, continuing insecurity and lawlessness.

Among the DRC's peoples, the Pygmy population is said to have an especially high rate of leprosy. To learn more about this, I traveled to Oriental Province in the northeast of the country. My destination was Wamba, an administrative district of about 100,000 people of whom some 30,000 are Pygmies.

To reach Wamba, I flew from the provincial capital Kisangani in an 11-seat Cessna belonging to African Inland Mission, accompanied by the DRC health minister and the provincial health minister. Up until the last minute, it was not clear if we would be able to make the journey because of question marks over the state of the Wamba airstrip. Furthermore, the pilot was insistent that he could take no more than nine passengers, so one of our 10-strong party had to stay behind. As it turned out, we would be grateful for this later.

As we approached Wamba, we could see from the air a short, red runway cut into the forest, and



The prevalence of leprosy among pygmies is as high as 57/10,000.

large numbers of people waiting for us. Several days earlier, the local people had cut the grass and trees around the runway in preparation for our visit. But the runway itself was in bad shape, and upon landing the plane was badly jolted before coming to a stop.

After being greeted with music and dancing at the airstrip, we drove for about 30 minutes to the heart of Wamba district. About 500 Pygmies had come in from the surrounding forest to meet us, some having set out three days before.

As we drew near our destination, the route was lined on both sides with Pygmies. Short in stature (averaging 1.5 meters), many had skin patches indicating leprosy, as well as ulcers and sores suggesting other skin diseases. While I saw some people with deformities, there were no cases of severe disability. Later I learned that only those capable of walking through the forest had made the journey.

About 500 Pygmies came in from the surrounding forest to meet us.

Registered prevalence among the Pygmies is said to be 57 cases per 10,000 population, but it is impossible to say how accurate this figure is. Pygmies tend to live deep in the forest, moving from place to place and making it difficult to keep track of cases.

Doctors and nurses visit the jungle on a regular basis to look for leprosy cases, and when they find one they entrust the drugs to the headman and ask him to supervise treatment. But according to one story I heard, the headman distributes medicine to everyone, regardless of whether or not they have leprosy, because all members of the tribe are treated as equals.

As we prepared to leave the village, we were plied with gifts, including a miniature antelope and a myna bird that we had to politely decline. I was also given a lucky cane, which I think I can say had an immediate effect.

On returning to the airstrip, we found the pilot in serious mood. He said he had been assured that the runway was 1,000 meters long, and had approved the flight on that basis. But on measuring it, he found it was only 650 meters: it would be touch and go whether we could take off. Heading down the bumpy runway, it seemed as if we would never become airborne;

but at the last possible moment we did — thankful that we didn't have that tenth passenger to weigh us down.

TANZANIA (NOVEMBER 12-14)



Pupils at a school on Pemba island, Zanzibar

From the DRC I traveled to Tanzania. When I last visited in 2005, I had promised to come back and celebrate when the country passed the elimination milestone. Hence it was with real pleasure that I returned to mark Tanzania's achievement.

I also included a visit to Zanzibar on my itinerary, because I had heard there are still quite a few leprosy cases there. Zanzibar, whose two main islands are Unguja and Pemba, is part of Tanzania, but still enjoys a high degree of autonomy.

In fact, I learned from the health ministry that registered prevalence on Zanzibar is as high as 1.4 per 10,000 population. Although Tanzania may have achieved the elimination goal at the national level, there is clearly no room for complacency.

In my meeting with Zanzibar's President Karume on Unguja, I impressed upon him the need to do more to tackle leprosy. He promised to see that schools would screen for the disease, and that pupils would be taught about it in the classroom. But he also pointed out that in Zanzibar at least, there is little discrimination against people affected by leprosy.

Flying on to Pemba, I traveled to a village where about 30 families affected by leprosy live among the general population. I stopped at a kindergarten, where, just as the president had suggested, there was no stigma and the children studied side by side. Afterward, I had lunch outdoors with members of the leprosy community. As we chatted under a papaya tree about life in the village, I thought of the discrimination that so many others still face, and was happy that here at least they could live together with their families, integrated into the wider community. ■

Thailand — A Model Case?

Why success must not result in a lessening of vigilance

What does Thailand's success in controlling leprosy have to teach other countries? A review of case detection trends between 1965 and 2005 published in the WHO's weekly epidemiological record contains some pointers

Thailand introduced a national leprosy control program in 1955, reducing prevalence of the disease from 50 per 10,000 population in 1953 to 12.42 in 1971. Based on this success, it decided in 1971 to integrate leprosy control activities into the general health care services.

From 1971 to 1975, approximately 1,100 to 1,800 new cases were detected annually (3.2 to 4.1 per 100,000 population). As the pace of activities picked up, the number of new cases detected annually increased, peaking at 4,463 in 1981 (9.5/100,000). Since then, the number has

fallen to 638 cases in 2005 (1.03/100,000).

The review concludes that multiple factors have contributed toward this decline, including improved access to diagnosis and treatment and increased socioeconomic development leading to better living conditions. However, it also illustrates why continued vigilance is required.

While the absolute number of new cases presenting with grade 2 disabilities has declined, the proportion of new cases has fluctuated between 11% and 15%. This suggests that as leprosy becomes less prevalent, awareness among health staff and the general public will likely lessen, which could result in delays in self-reporting. Hence Thailand's success also underscores the importance of maintaining control activities.

Leprosy FACTS

According to World Health Organization figures published in November, registered prevalence of leprosy by WHO region (excluding the European Region) at the beginning of 2007 stood at 231,361 cases. New cases detected during 2006 totaled 265,661.



'NOTHING FOR US WITHOUT US'

A Western Regional Empowerment Workshop was held in Mumbai, India, on November 23. Some 570 delegates, mostly from leprosy colonies in Rajasthan, Gujarat, Maharashtra and Chhattisgarh attended. Organized by the National Forum, the conference also saw the launch of MITRA ("friend"), a newsletter in Hindi and English to reflect the views of people affected by leprosy.

LEPROSY CONTROL IN POST-ELIMINATION ERA INDIA

A group of experts met on November 7 in Chennai to discuss methods for monitoring and evaluation of leprosy control in India in the post-elimination era. The meeting was organized by the Indian government, WHO and Indian Council of Medical Research. Its recommendations will be published shortly. ■

FROM THE EDITORS

ROAD TO UMBAKI

Each shudder and jolt of the four-wheel-drive vehicle on the road to Umbaki leprosarium in Azerbaijan serves to hammer home the physical and psychological isolation of its 30-odd residents from the outside world. In a country with few cases of leprosy, they are very much out of sight, out of mind. But not entirely.

For several years now, a group of expatriate volunteers has helped the leprosarium in various ways, including raising funds to refurbish the residents' living quarters, which had been in a terrible state. Their efforts mean the aging residents now live in dignity and comfort.

Attention of another sort has come with a recent film about an ill-starred romance between a young doctor and a patient, based on a best-selling novel depicting Umbaki. For all its artistic merits, the film perpetuates notions that leprosy is spread by touching, that patients need to be incarcerated in a sanatorium, and, in one of the film's more dramatic scenes, implies that pregnancies must be terminated.

Given that most people know so little about leprosy to begin with, this film will reinforce stereotypes about the disease rather than shed light on the modern-day reality.

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