

FOR THE Elimination OF Leprosy

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



Two area residents who came to meet Yohei Sasakawa when he visited a district hospital in Moramanga, Madagascar, in May.

MESSAGE

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Earning Trust and Respect

Last month I visited Madagascar to congratulate it on eliminating leprosy as a public health problem and to seek its ongoing commitment to tackling the disease. Over a year earlier, India and Angola also achieved elimination. That leaves just five countries that have yet to attain the WHO goal: Brazil, Nepal, Tanzania, Mozambique and the DR Congo.

India, Angola and Madagascar were all at one time countries for which elimination seemed an impossible dream. But thanks to the dedicated efforts of everyone from political leaders to health workers in the field, these countries were able to pass this milestone—and more quickly than anyone dared hope.

Today leprosy is a relatively small problem alongside the many public health challenges the world faces. But accomplishing elimination based on an internationally recognized numerical target after surmounting many difficulties is no small achievement. It attests to the character of a country and its people, and earns for them the trust and respect of the international community. This breeds confidence, which can serve as a galvanizing force

for tackling other issues.

Starting with the president, all the people I met in Madagascar on my visit expressed their joy and satisfaction. The speaker of Madagascar's Senate told me that it was the first time in the history of his nation that it had been internationally recognized for solving a problem and had someone come specially to congratulate it.

It is my impression that the five countries yet to achieve elimination are steadily moving in the right direction. In Mozambique, which I visited after Madagascar, eliminating leprosy is now a national goal designated by the president and by the Cabinet. I would like to urge all the remaining countries to treat this as a national goal.

But achieving leprosy elimination is not just about reaching a target; and it is not an end in itself. For countries that have achieved elimination, and those still striving for it, the tasks remain the same: to reach out to committed partners, work closely with them and ensure that progress is sustained.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Sasakawa Receives Int'l Gandhi Award

Honor recognizes decades of service to fighting leprosy

WHO Goodwill Ambassador Yohei Sasakawa was recently presented with the 2006 International Gandhi Award at a ceremony in Wardha, India, spiritual home of India's "father of the nation" Mahatma Gandhi.

The award is made every three years by the Gandhi Memorial Leprosy Foundation, which was established in 1951 to perpetuate the memory of Gandhi and his life-long interest in leprosy.

First issued in 1986, the award goes to an individual or institution that has made a significant contribution to improving the quality of life of leprosy-affected persons and helping them to lead normal lives in society.

Indian Vice-President Shri Bairon Singh Shekhawat, who chairs the award committee, presented the award at a ceremony on April 12.

In his speech of acceptance, Sasakawa said that "from eliminating leprosy as a public health problem, we are moving toward eradicating the disease altogether. But leprosy has another aspect; a social aspect. We still have a long way to go before the stigma and discrimination associated with the disease have been banished. Until then, people affected by leprosy will not truly be free of it."

The vice-president described Sasakawa as an "exceptional man of our times in the field of leprosy eradication." He continued: "Today, the biggest challenge we face is the integration of the leprosy-cured persons into society's mainstream. A large number of leprosy-affected people, after they are cured, remain poor and below the poverty line... they are denied their

fundamental right of life with dignity."

Sasakawa has spent the past three decades supporting efforts to eliminate leprosy from the world, and in 2001 was appointed WHO Goodwill Ambassador for Leprosy Elimination. In recent years, he has increasingly focused his attention on tackling the social aspects of the disease.

"We still have a long way to go before stigma and discrimination are banished."

On World Leprosy Day 2006, in New Delhi, he led 11 world leaders including former US President Jimmy Carter, the Dalai Lama and former President Venkataraman of India, in issuing a Global Appeal to end stigma and discrimination against persons affected by leprosy and their families.

On 29 January this year, in Manila, he joined 16 representatives of people affected by leprosy from around the world in issuing a second Global Appeal, calling for the restoration of the dignity and recognition of the human rights of leprosy-affected persons. In the words of Global Appeal 2007: "Denying the inherent human rights of anyone on the basis of disease is indefensible. Discrimination can never be justified. Silence on this issue is not acceptable."

Sasakawa donated his cash prize of 200,000 Rupees to the newly formed Sasakawa-India Leprosy Foundation (see page 8). ■



Past Winners of International Gandhi Award

- 1986: Dr. Dharmendra (India) and Dr. Turkan Saylan (Turkey)
- 1988: Dr. Ma Hai De (China) and Professor T. N. Jagadisan (India)
- 1990: Dr. R. V. Wardekar (India) and Dr. M. F. Lechat (Belgium)
- 1992: Dato E. J. Lawrence (Kuala Lumpur) and Late Cardinal P E Léger (Quebec)
- 1994: Dr. Joon Lew (South Korea) and Dr. V. Ekambaram (India)
- 1996: Ms. Jean Watson (United Kingdom) and Dr. S. K. Noordeen (India)
- 1998: Mrs. Mathilde Gruner (Germany) and Dr. S. D. Gokhale (India)
- 2000: ALERT (Ethiopia) and Dr. K. V. Desikan (India)
- 2003: Dr. H. Srinivasan (India)

‘Good Progress Is Being Made’

Health officials provide updates on road to leprosy elimination and beyond

In May, Goodwill Ambassador Yohei Sasakawa attended the World Health Assembly in Geneva. While there, he met with several health ministers and officials who briefed him on the progress of leprosy activities in their countries. In addition to these meetings (summarized below), he also met with health ministry officials from Indonesia, Myanmar and Mongolia, as well as with Dr. Luis Gomes Sambo, WHO regional director for Africa, and Dr. Samlee Plianbangchang, WHO regional director for Southeast Asia, and asked for their continued support for leprosy works in the countries and regions concerned.

Dr. José Gomes Temporão
Minister of Health, Brazil



The Brazilian government strongly supports the fight against leprosy. A recent evaluation shows good progress is being made. There is also an important social movement for the defense of patients’ rights with which the government is working closely. *Secretary of Health Surveillance Gerson Oliveira Penna adds:* President Lula initiated a law providing all people affected by leprosy with a pension for life. There is also a presidential order that people affected by leprosy be accepted as part of society.

Prof. David H. Mwakiyusa
Minister of Health and Social Welfare, United Republic of Tanzania



We have detected a large number of patients in border areas between Tanzania and Mozambique, especially since we abolished visas for travel between the two countries. We are now integrating leprosy and TB programs. Personnel are being trained to cover these two diseases. We have closed many leprosariums because we want to remove stigma; those that remain are for people who have nowhere to go. Community-level rehabilitation must be promoted, and we need a good referral system.

Mr. Girirajmani Pokharel
Minister of Health and Population, Nepal

Nepal is in the process of political transition. Health is an important issue. The recent interim constitution states that free access to health services is an indigenous right of the people. We

are committed to achieving the leprosy elimination goal. *Dr. Mahesh Maskey, chairman of the Nepal Health Research Council, adds:* Leprosy is closely associated with poverty. The social stigma attached to the disease is also a big issue. Nepal is economically backward and faces many problems. However, the health indicators are improving, and the commitment of health workers and volunteers is quite high. We are not certain about the current leprosy prevalence rate (PR) but believe it must be improving.

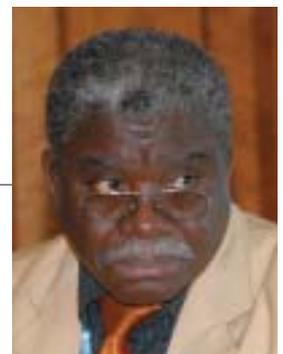


Dr. Anastácio Ruben Sicato
Minister of Health, Republic of Angola



Although leprosy is no longer a critical problem, we are keeping up our leprosy activities and hope leprosy will eventually disappear. The PR now is 0.84. In 2005 it was 0.77 but it went up to 1.21 in 2006 because of active detection. Now it is on the decline again.

Dr. Benoit Kebela Ilunga
Secretary General, Ministry of Public Health, DR Congo



We have achieved elimination in several provinces but we still have a few provinces where PR is high. We have a national strategic plan for elimination and are making our utmost efforts. Country-level PR is 1.55. ■

Breaking Down Barriers

UN convention on disability offers hope for future

WHO estimates that up to 10% of the total global population is disabled, with most belonging to the poorest and most marginalized sectors of society. This translates to about 650 million persons with disabilities worldwide. Most persons with disabilities lack access to opportunities for basic education, and 98% of children with disabilities in developing countries are unable to go to school. Acting as a barrier to employment, this condemns them to a vicious cycle of poverty. According to the International Labor Organization as of 2003, 80% of persons with disabilities in Third World Countries remained unemployed.

But the situation is not as bleak as it seems. There is hope on the horizon, particularly with the passage of the UN Convention on the Rights of Persons with Disabilities last December 2006.

The UN Convention is an international agreement among states on how to treat persons with disabilities. It declares that persons with disabilities have and should enjoy the same fundamental human rights as everyone else.

Persons affected by leprosy are among those whose human rights are upheld by the convention. Just as with other persons with disabilities, they are rendered disabled more as a result of society's negative attitudes than by their own physical limitations. But they suffer additional stigma from the way their disease is perceived.

“They are rendered disabled more by society’s attitudes than by their own limitations.”

This was brought home to me during my stint as Commissioner of the National Anti-Poverty Commission (representing the Disability Sector) in the Philippines. One of my council members was an 82-year-old person affected by leprosy named Cresencia Loredo. Though cured of the disease, she had been left disabled. I was surprised that in spite of her age she was still so active. During our council meetings, she consistently demonstrated her concern for people affected by leprosy and helped me to understand their situation.

I began to feel quite ashamed as the picture became clear. Although I grew up, and still live, in Camarin, Caloocan City, near the Dr. Jose Rodriquez Sr. Hospital in Tala, I had no knowledge of the difficulties faced by the patients who were cared for there. Through Mrs. Loredo, I was able to meet with them. I also had in-depth discussions with the head of the hospital on how they could be



Acquiring skills at the Livelihood, Education and Rehabilitation Center in Metro Manila

empowered, proposing that they be given an opportunity to earn their living.

In 2003, I signed an agreement with the Department of Health and the National Housing Authority to convert the old Malaria Research and Eradication Center into the Livelihood, Education and Rehabilitation Center (LERC) for persons with disabilities, including those affected by leprosy. Now the center is being used by various disabled persons' organizations, parents of children with disabilities, and a group of persons affected by leprosy headed by Mrs. Loredo. They engage in community-based activities such as early education of children with disabilities, rehabilitation and health care, vocational training for out-of-school youth and livelihood enterprises for persons with disabilities.

My desire to alleviate the plight of persons affected by leprosy has been strengthened by my work with the Philippine Council of Cheshire Homes for the Disabled. We have established the Inclusive Youth Center (IYC), which brings together disabled and non-disabled young people. We have initiated the IYC project in Quezon City and Caloocan City, the two largest cities in Metro Manila in terms of land area and population.

IYC regularly conducts seminars and workshops among the non-disabled to raise awareness of the plight of young people with disabilities. Through the IYC, we also hope to educate society to change its negative attitudes toward persons affected by leprosy. IYC welcomes young persons affected by leprosy, and also families affected by the disease. In fact, we are going to organize an IYC chapter in Tala. I hope that this will help to reduce, if not totally eradicate, discrimination against them.

I am convinced there are many persons affected by leprosy in the world who just need an equal opportunity to share their skills and experiences. Let us take full advantage of the UN Convention to make this happen. ■

AUTHOR:

Richard D. Arceno



Richard D. Arceno is a person with severe disability. During his stint as Commissioner of the National Anti-Poverty Commission, Philippines, he authored several policies that improved the plight of marginalized sectors in the Philippines. Mr. Arceno also became Senior Adviser to the 1st and 8th Ad Hoc meetings on the UN Convention on the Rights of Persons with Disabilities held at UN headquarters in New York. He can be contacted at richardarceno@yahoo.com

Baba Amte: Man with a Mission

An Indian social activist who has been an inspiration to millions

AUTHOR:
Anita Kainthla



Anita Kainthla is a writer and poet, and author of *Baba Amte—A Biography* Viva Books Private Limited (2005)

I first came upon the story of Murlidhar Devidas Amte in a newspaper article. Intrigued, I wanted to find out more, and went to visit him several times at his “Garden of Joy” in the state of Maharashtra. The more I learned, the more I was filled with wonder and amazement at his achievements and decided to write a book.

Born in 1914, Murlidhar grew up in an affluent household and became a lawyer. As a young man, he had a taste for good clothes, movies and fast cars; but he also had a social conscience, which caused him misgivings about India’s caste-ridden society and the state of poverty and oppression in which so many lived. However, attempts to reach out to his fellow man met with stiff resistance from his father and the high-caste circles in which he moved.

Influenced by the likes of Mahatma Gandhi, with whom he spent some time, and by Vinoba Bhave, Gandhi’s spiritual successor, Murlidhar eventually turned his back on the comfortable life and began organizing the downtrodden into unions and fighting for their rights. He even lived and worked among them to experience their plight.

One day, while working as a scavenger, he stumbled upon a man so terribly afflicted with leprosy that what little remained of his body barely suggested he was once human. At first, Murlidhar fled in fear; later, he returned, realizing that the only way to mitigate the fear he felt was to replace it with love. It was a turning point in his life. Aged 34, he decided to devote himself to the care and rehabilitation of leprosy patients.



Baba as a young man (top), and today

‘GARDEN OF JOY’

After spending some time acquainting himself with leprosy and its treatment, he set out with a young wife, two infants, a lame cow, four stray dogs, six people affected by leprosy and a handful of Rupees for 50 acres of scrubland donated by the Maharashtra government. Amte, who was now called ‘Baba’ (father), named the place Anandwan, or Garden of Joy, which he described as “an outcast land for outcast people.” Together, they turned these barren acres into a successful example of rural development and community living.

Baba’s wife, Sadhna Tai, deserves special mention. Raised in an orthodox Hindu tradition by a family of Sanskrit scholars, she relinquished all caste prejudices upon her marriage to Amte, and worked alongside him in even the most difficult circumstances. In 1949, their untiring efforts led to the foundation of Maharogi Sewa Samiti (MSS), an organization for curing and rehabilitating the leprosy affected. It was registered in 1951.

This was also the year that Vinoba Bhave inaugurated Anandwan. Bhave noted: “Its name ‘Anandwan’ is most appropriate... This is not a lepers’ colony, not a home or settlement for leprosy patients. Here a new epic of service and labor is being written.” More patients began to arrive, medical services were started, and within a couple of years it was self-sufficient in everything.

Today, Anandwan has grown to 450 acres, and is a thriving community of people affected by leprosy as well as others with disabilities. It is testament to the power of Amte’s motto, “Charity Destroys, Work Builds.”

Baba did not rest with Anandwan. In addition to establishing two more rehabilitation centers for leprosy-affected persons—Ashokwan in 1955, and Somnath in 1967—he also diversified into other areas, beginning projects for tribal peoples and persons with disabilities. He also became actively involved in the protest movement against the construction of big dams in India.

Now 92 and bed-ridden as a result of a degenerative spinal injury, Baba Amte continues to welcome visitors and draw accolades. He numbers among his friends the Dalai Lama, who wrote in the Foreword to my book: “In creating Anandwan, (Amte) provided a practical opportunity for people even with crucial disadvantages to show that they could regain dignity and come to be recognized as productive members of society.”

In the Dalai Lama’s words, Amte is a man “who has consistently put others before himself; a living example of true compassion in action.” I could not agree more. ■

From Mumbai to Maputo

The goodwill ambassador's travels take him to India, Madagascar and Mozambique.

INDIA (APRIL 11-15)

In April, I made my second visit of the year to India, traveling to Wardha in Maharashtra State. This holds a special place in the hearts of Indians. About eight kilometers from the center of the town is the Sevagram Ashram, where Mahatma Gandhi lived from 1936 to 1948, the year of his assassination. Here he meditated, cared for persons affected by leprosy, and oversaw India's independence movement.

The reason for my journey was to accept the 2006 International Gandhi Award from the Gandhi Memorial Leprosy Foundation at a ceremony held on April 12. After receiving this great honor from India's vice president, I called at the ashram, now a place of historic interest. I spent a few moments in the shade of a tree, reflecting on all that has been achieved since Gandhi's day, but also on how pervasive stigma and discrimination remain.

On April 13, I traveled to Warora. This is the home of one of India's most celebrated social activists, Baba Amte. In 1949, he established a community for people affected by leprosy that he called Anandwan, or Garden of Joy.

After a memorable meeting with Baba Amte, who is now confined to bed, his son, Dr. Vikas Amte, took me on a tour. The land covers some 450 acres and is home to some 5,000 people affected by leprosy and persons with disabilities from all over India. They don't receive handouts but are employed in a variety of occupations — including agriculture, sewing, printing, carpet-making, and brick-making — to enable them to become self-sufficient. There is a bank, post office, shops, hospital and university and a famous band. It's just like a small town.

According to Vikas, "our mission is to close down Anandwan" — to change society so that places like Anandwan are no longer needed. Truly impressed by what I saw, I feel Anandwan has much to teach.

On April 14, I flew to Mumbai, where I visited the Sanjay Nagar



At work in Anandwan



leprosy colony in Borivali, north of the city. This colony is led by Mr. Bhimrao Madhale, who is also the leader of Maharashtra's 37 self-settled colonies. It is located alongside a creek and is home to 5,000 persons affected by leprosy and their family members. In 2005, 30 homes were destroyed by flooding and hundreds more were damaged. But in a demonstration of unity and mutual assistance involving neighboring communities, area residents have done a wonderful job of rebuilding.

Next I visited the Acworth Leprosy Hospital. Founded in 1890, the hospital two years ago established a small museum in what used to be Ward No. 1. The museum recently copied all the historical documents related to leprosy for the past 100 years in the Maharashtra state archives. This will benefit students and researchers and the museum has already started to collaborate with the University of Mumbai's history department.

MADAGASCAR (MAY 2-4)

On my last visit to Madagascar in 2005, I promised that I would return to congratulate the country when it eliminated leprosy as a public health problem. It was thus with great pleasure that I flew to Madagascar in May. Although only a short visit, it was very productive. I met with the president, health minister, foreign minister and the speaker of the Senate, and also had the honor of addressing the chamber.

In my address, I asked parliamentarians to publicize my three messages: leprosy is curable;

Visiting Sanjay Nagar leprosy colony north of Mumbai

treatment is free; discrimination has no place. My words met with a good response, and promises from them to spread the word in their electoral districts.

For Madagascar to have passed the elimination milestone required enormous effort, hard work, and resources. But to sustain the achievement is going to require more of the same. In addition, there is much still to be done to address leprosy's social aspect — the stigma and discrimination associated with the disease. Even as I congratulated Madagascar's leaders, I urged them to redouble their efforts to maintain progress.

During my stay, I traveled to a hospital in Moramanga, a town 120 kilometers southeast of the capital Antananarivo. In the ward I toured, 26 of the occupants were people affected by leprosy. Most had been hospitalized at the first signs of the disease and included a woman who had since given birth and was living there with her husband and child. Some said that they were unable to go home despite being cured, while others had never received a visit from their families in more than 25 years. I later met with a representative of the country's human rights commission to enlist his support in tackling leprosy-related discrimination.

I also participated in a partners' meeting involving officials from the health ministry, WHO and the Association Francaise Raoul Follereau (AFRF). The meeting outlined a three-year program to achieve elimination at state level, to improve access to health care, to promote social reintegration and to provide care for persons with disabilities. To facilitate these activities, the Sasakawa Memorial Health Foundation and AFRF each presented the government with 10 motorcycles.



Addressing Madagascar's parliament



With Madagascar President Marc Ravalomanana

MOZAMBIQUE (MAY 5-8)

Mozambique is one of three African countries yet to achieve the WHO elimination target. On my last visit in August 2006, I discovered that because of problems of budget allocation, drug insecurity and shortage of trained personnel in rural areas, elimination activities were not proceeding as hoped. I was greatly encouraged to learn that these problems have largely been addressed. Without doubt, this turnaround is due to the commitment of President Armando Guebuza.

Lately, the president has been getting the health minister to brief the entire Cabinet about leprosy activities, and has put the government's support behind elimination. Passing this milestone is now a national policy for the year 2007 to 2008.

When I met with Prime Minister Luisa Dias Diogo, she told me that Mozambique would continue to work in partnership with the WHO for elimination. She also promised that she would tell the national assembly to spread my three messages throughout the northern part of the country, where leprosy is more of a problem.

Looking at the progress that has been made in the past year, I would say that Mozambique has every chance of achieving the elimination goal by the end of 2008. Health Minister Paulo Ivo Garrido said every province now has personal computers, making it possible to manage medical data. Further, a leprosy database has been set up in Cabo Delgado province and is being made available to other provinces.

The ministry and WHO are placing volunteer staff at the town and village level. Further, with the permission of the government, the WHO has decided to install a leprosy officer in the north of the country. Minister Garrido also said he plans to ask experts to evaluate the country's elimination activities and analyze its statistics. This suggests to me that Mozambique is confident that it is moving in the right direction, and I shall follow its progress with interest. ■

New Foundation Established in India

Delhi-based NGO to promote economic advancement, social reintegration

The Sasakawa-India Leprosy Foundation (SILF) has been established in New Delhi, India.

The new public charity, an initiative of Goodwill Ambassador Yohei Sasakawa, will work to facilitate the empowerment and economic advancement of people affected by leprosy and their families and promote their integration into mainstream society.

The official launch of SILF is scheduled for October 2007.



Yohei Sasakawa presents SILF Executive Director Dr. Vineeta Shanker with the cheque he received for winning the International Gandhi Award.

PRECAUTIONARY STEP

An informal consultation was held in India late last year to look at rifampicin resistance in the treatment of leprosy. Rifampicin is a core component of multidrug therapy, which has been key to the dramatic decline in the prevalence of the

disease over the past two decades.

Organized by the WHO, the meeting concluded that surveillance of rifampicin resistance should be established immediately to ensure that the success of the MDT program is not threatened. ■

FROM THE EDITORS

NO ROOM FOR COMPLACENCY

Success breeds success, but success also breeds complacency. Ensuring that the will to tackle leprosy remains firm even as prevalence of the disease declines is essential in order to sustain the progress that has been made over the past two decades.

A combination of factors has been responsible for the dramatic improvement in the world leprosy situation, which has seen over 15 million people cured of the disease since the 1980s and the number of patients brought down to less than 300,000 worldwide. These factors include the guidance of the WHO, the political commitment of leaders who when called upon have risen to the elimination challenge, vastly experienced NGOs with long years of working in the field who have contributed their knowledge and input, and the countless dedicated health workers who operate at the frontlines of primary health care.

But above all it has been the existence of an effective cure — multidrug therapy — made available free of charge around the world, that has been the backbone of the worldwide

program to eliminate leprosy. MDT, consisting of three drugs — rifampicin, clofazimine, and dapsone — has been used to treat leprosy for 25 years. But its main component, rifampicin, has been in use for some 40 years in the treatment of TB and other conditions.

It is logical to expect that over time drug resistance will develop, and there are already reported cases of *M. leprae* resistance to rifampicin in several countries. Hence the recent Informal Consultation on Rifampicin Resistance in Leprosy held late last year in India to initiate drug resistance surveillance is timely indeed. In the words of the report: "For leprosy, a chronic disease with social stigma, drug resistance poses a serious impediment at a stage when there is a dramatic decline in prevalence due to intensive and concerted chemotherapy intervention made by the global community. To effectively meet the challenge of containing the disease and sustaining the declining leprosy trend, it is essential to keep a vigil on the drug resistance scenario at many vulnerable settings." The message is clear: no room for complacency.

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