

FOR THE Elimination OF Leprosy

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



Prize-winners at the 61st World Health Assembly included MORHAN, represented by Cristiano Torres and Artur de Sousa (4th and 5th from right)

MESSAGE

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Good News from Geneva

While in Geneva to attend the 61st World Health Assembly, I spoke with health ministers of the remaining countries still passing through the leprosy elimination stage. Mozambique's minister of health told me that his country had eliminated leprosy as a public health problem at the end of last year, and that it had asked a WHO-ILEP team to verify the data, which it duly did. He said the government remains fully committed to further reducing the disease burden.

From the DR Congo's health minister I was delighted to learn that his country is also at this important milestone, while from Nepal, recent developments give rise to cautious optimism. Following the general election there, I was told that the new cabinet has the elimination goal in its sights. Brazil is the only other country yet to clear the elimination phase, so I urged the health minister to redouble efforts to this end. He assured me of Brazil's commitment, and accepted my offer to visit in November.

This month, the Japanese government is submitting a resolution to the 8th session of the

UN Human Rights Council calling for an end to discrimination against people affected by leprosy and their families. This initiative received strong backing from the health ministers I met, and I also sought cooperation from nine ambassadors of HRC member states. On my return home, I secured the support of the presidents of Madagascar, Mali and Mozambique, and the prime ministers of Ethiopia and Niger, who were visiting Japan for an international conference on African aid and development.

Should the resolution pass, it will represent a significant breakthrough for all of us involved in this fight, not least for people affected by leprosy themselves. But like the goal of leprosy elimination, it is not the end of the story. In order to create a truly leprosy-free world, we must not only wipe out the disease but also ensure that people affected by leprosy and their families enjoy full participation in society. This is the challenging goal that remains; let us move steadily toward it.

— Yohei Sasakawa, WHO Goodwill Ambassador

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DR Congo Makes Headway

Data shows country passed the elimination milestone at the end of 2007.

Since 2005, the DR Congo (DRC) has been classified as one of the countries yet to achieve the WHO-set target of eliminating leprosy as a public health problem, attained when the disease prevalence rate falls below 1 case per 10,000 population.

Following a visit by Goodwill Ambassador Yohei Sasakawa in 2005, the DRC undertook to reach the elimination goal by December 31, 2007. With the data now available to us, we can confirm that this goal was achieved at the end of last year. At time of writing, the prevalence rate of the disease at the national level stands at 0.97/10,000.

LONG ROAD AHEAD

But eliminating the disease as a public health problem does not mean an end to the fight against leprosy in the DRC. We still have a long road ahead of us. That is why, under the current WHO global strategy for 2006-2010, we are working to further reduce the leprosy burden in our country. This is also in accord with our health minister's vision to eliminate leprosy at the provincial level and to strengthen the quality of services for preventing leprosy-related disability and for rehabilitating those affected by the disease.

With a total of 8,820 new cases of leprosy reported in 2007, the DRC is one of the biggest sources of leprosy cases in Africa. The provinces that give the most cause for concern are: Katanga, Equateur, Orientale and Bandundu.

The rise in new cases reported in 2007 is due, among other things, to the increase in the geographic coverage of the national leprosy elimination program thanks to the return of peace and to the implementation of mini-elimination campaigns in the health zones of Moba (Katanga), Ango (Orientale) and Kiri



Map of the DR Congo showing high-endemic provinces

(Bandundu).

The small proportion of new cases with Grade II disability (8.42%) is testament to early detection of patients, as a result of improved case detection, due to greater community awareness and participation in leprosy control activities.

LEPROSY HOTSPOT

Tanganika, in Katanga Province, remains one of the most leprosy-endemic districts in the entire country, with the problem centered on the health zones of Moba, Nyunzu, Kalemie and Kansimba.

In Orientale, the problems are in the health zones of Ango, Ubundu, Doruma, Wamba, Bafwabaka, Bafwasende and Banalia. In Equateur, the focus is Tshuapa district, with the health zones of Bokungu, Mondombe, Wema, Yalifafu and Ikela. And in Bandundu, the problem is concentrated in the district of Maindombe, with the health zones of Kiri, Pendjwa, Inongo and Banzow.

We recognize that the leprosy elimination program has made great efforts in the detection of cases, and especially in taking responsibility for patients. This translates into a prevalence/detection ratio of 0.74, due mainly to the improvement in cure rates in almost all provinces.

We are now focusing mainly on reducing the leprosy caseload in the DRC, and at the same time on strengthening the strategy for preventing disability and rehabilitating people affected by the disease. ■

AUTHOR:

Dr. J.N. Mputuluengu – B

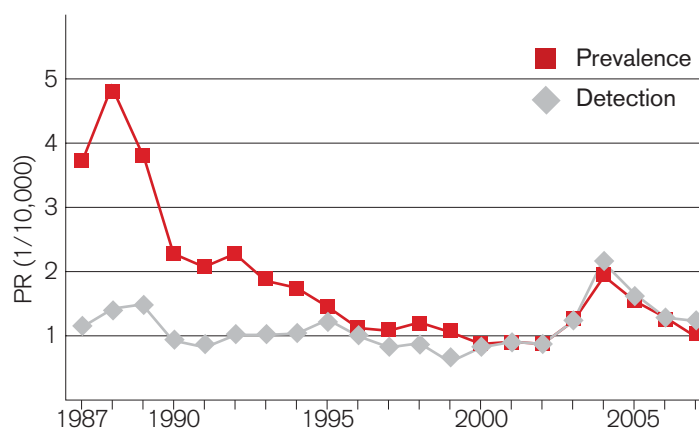


Dr. Mputuluengu – B is director of the Democratic Republic of Congo's national leprosy elimination program.



Children in Kivuvu, Bas-Congo Province

Decline in Leprosy in the DRC (1987-2007)



A Trinidadian Tale

Documenting a family's odyssey with leprosy.

AUTHOR:
Rudy Hypolite

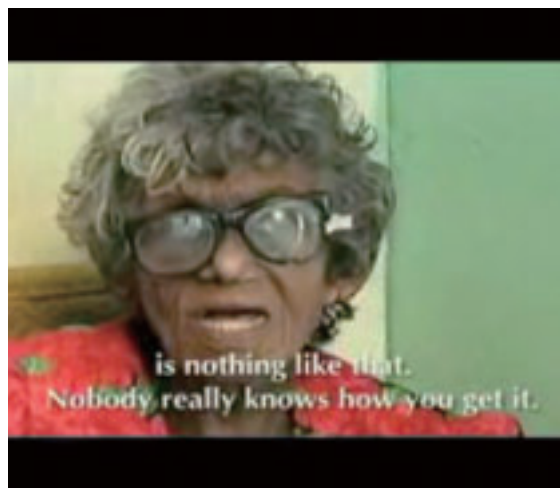


Rudy Hypolite works as a producer, director, and editor of content produced for Harvard University's multi-media website.

As a filmmaker working in the United States, I've mainly been interested in creating documentaries that give voice to the underserved, misunderstood or marginalized members of society. This has led me to produce films on the migration of young, poor, black women from the rural South to Northern cities during the turbulent 1960s, the role of racism in the strained relationship between black males and the police, and the challenges that face inner-city youth in high schools today.

I've come to realize that my biggest inspiration and influence in choosing this path has been my aunt Virginia, a person affected by leprosy, and thus the reason for my most recent undertaking, titled "Hansen's Disease: A Family's Odyssey." This work-in-progress chronicles a family's struggle to deal with the misconceptions and stigma associated with the disease, from the perspectives of my aunt and family members, with additional insights from two other persons affected by leprosy.

I grew up in Trinidad. It was there that Aunt Virginia, my mother's sister, was diagnosed with leprosy as a teenager and sent to a leprosarium on the island of Chacachacare (pronounced "shack-a-shah-carry"), an hour-and-a-half boat ride away.



Virginia Samuel being interviewed by her nephew Rudy. See a clip on www.youtube.com/watch?v=SyFCZq821RE

From childhood through my teens, I visited Aunt Virginia and Uncle Shurali, who also had leprosy, on the secluded island off the coast of Venezuela. My brothers and I would go on weekends, and also spent the summers there. I have happy memories of swimming, eating, fishing, daydreaming, playing billiards and interacting with my aunt, uncle and the other patients. We didn't see them as being any different from the folks in our neighborhood back home.

My aunt and uncle had four daughters, and I wondered why my cousins didn't live with their

parents. Later, I found that all four babies had been taken away at birth and given to my grandmother to raise. This was just one example of the injustices and indignities suffered by people affected by leprosy during this time, and one that sowed the seeds of subsequent family divisions.

"We are blessed to have someone like my aunt who can teach us life lessons."

Like many people with the disease that I've come to know, love and respect, my aunt and uncle never exuded any bitterness or self-pity. Rather, they had sunny dispositions and always sought to help others in need. They both maintained a strong belief in God and the Catholic Church, even though the church contributed to some of the misconceptions about the disease. In Sunday school and the regular Sunday services my family attended, it was brought up on occasion that persons afflicted with leprosy were sinful and unclean, and were being punished by God.

In the late 1960s, the government started mainstreaming people affected by leprosy into the general population in Trinidad, and gave my aunt and uncle a home. But the stigma surrounding leprosy remained, and was something I witnessed first-hand. Going anywhere with my aunt, I saw the scorn and contempt in people's eyes, and had a hard time understanding why they didn't see the beautiful, caring person that I knew and loved. Even her own mother and sister were ashamed of what people thought, although they loved her dearly.

Although my family subsequently migrated to the U.S., these experiences have always stayed with me. In making this documentary, therefore, I wanted to give a voice to my aunt and others like her. And through her story, I also wanted to address how leprosy affected my family, in particular the difficulties Aunt Virginia faced reestablishing relationships with her children. For my part, I believe we are blessed to have someone like my aunt who can teach us life lessons about the resilience of the human spirit, and should thus make a conscious effort to offer our understanding, support and compassion.

Finally, I hope the film will put to rest misperceptions about this completely curable, mildly infectious disease that unfortunately persist. As Aunt Virginia says, "It's time people realize and don't treat people who suffer with this disease as if they're cast out. It's not like Biblical days." ■

LEPROSY FACTS

A leprosy colony existed on Chacachacare, an island that belongs to Trinidad and Tobago, between 1921 and 1984. Patients were cared for by the Dominican Sisters, and later by the U.S. Sisters of Mercy.

Students and Skin Health

Pilot project in the Philippines shows the important role schoolchildren can play.

The Philippine Leprosy Mission is running a three-year pilot project called PILA to identify approaches for screening, detecting and diagnosing skin diseases, including leprosy. Dra. Ma. Gemma C. Cabanos, PLM's executive director, explains how it works.

What is PILA and why was it started?

PLM-Initiated Leprosy Activities, or PILA, was one of the Philippine Leprosy Mission's initial responses to the WHO's global strategy for 2006-2010. It is designed to implement strategies that have proven effective in improving the coverage of immunization and nutrition programs in the Philippines.

How does the project work?

The PILA project works in partnership with two institutions that are basic to every community: schools and health care units. Elementary and high school students campaign for skin health and pre-screen their respective household members, using an observation guide and reporting sheets. School authorities collect the data and submit it to health authorities. These reports are supplemented by the skin survey or preliminary screening for skin problems undertaken by barangay* health workers among households with no elementary or high schoolchildren, and also among institutions. People found to have skin lesions are then advised to visit the local government unit-run rural health unit or health center, where schedules of screening for common skin diseases by trained medical officers have been pre-arranged. This is when suspect or clinically-diagnosed leprosy lesions can be identified and confirmed.

Where is PILA being carried out?

In Ilocos Norte, in the northern tip of the country, where relatively high case-detection and prevalence rates are reported. Currently, eight cities and municipalities are implementing PILA,

and projects will be implemented in four more municipalities in Ilocos Norte this year. The goal is to cover all 23 municipalities and use the lessons learnt to motivate other provinces to apply the strategies.

Are you pleased with the results to date?

Using dermatology as the entry point for finding all kinds of skin problems is a very effective way of finding hidden cases of leprosy. The community develops a heightened awareness of skin problems, which increases voluntary reporting. Community members are now regularly seeking consultation at rural health units, even on days that were not scheduled for PILA activities.

What lessons does the PILA project have for other countries?

The control of leprosy is not the sole responsibility of health ministries or departments. The public and private sector must participate in increasing the awareness of skin health and services. The PILA project has also demonstrated that schoolchildren and volunteer health workers are effective in pre-screening of household members and community members with skin problems.

What is the level of awareness of leprosy in the Philippines today?

Awareness is low and a great majority of the population is misinformed about the disease. IEC for leprosy needs to be stepped up to educate the people in order to improve their attitudes and behavior toward persons affected by leprosy. People who are ignorant of the disease generally avoid persons with leprosy, especially those with deformities, for fear that they will get the disease themselves. This is also observed among health workers because many lack the knowledge and skills to recognize the signs and symptoms and manage the disease and its complications. ■

INTERVIEWEE:

Dra. Ma. Gemma C. Cabanos



Dra. Ma. Gemma C. Cabanos is executive director of the Philippine Leprosy Mission.



School for skincare: boy with observation guide (left), hands-on instruction (right)

Reference

* The smallest political unit into which cities and municipalities in the Philippines are divided.

Culion — The Evolution Continues

New website boosts island's profile as 'normal community,' while memorializing its past.

AUTHOR:
Dr. Arturo Cunanan



Dr. Arturo Cunanan is head of the Culion Museum and Archives Project, Culion Leprosy Control and Rehabilitation Program.

Two years ago, the municipality of Culion in the Philippines marked the 100th anniversary of the founding of what would become the world's largest leprosy colony. The centennial was attended by high-ranking government officials and dignitaries, including WHO Goodwill Ambassador Yohei Sasakawa. But the most important guests were former residents of Culion, who returned in their thousands to see for themselves how the island they once called home had evolved from a "leper colony" into a normal community.

Looking back on the celebrations of May 2006, it is impossible to overestimate their symbolic

importance to Culion. For me, the key word is "transformation." By this I mean the transformation of the old Culion "Leper Colony" into a general hospital, of the Culion Reservation into a new political unit — a municipality — and above all, the transformation that took place within each and every resident of Culion, modifying their belief in themselves, in their fellow residents and in Culion itself. The result was Culion's full emancipation from the bondage of ostracism and ridicule that

stemmed from the social stigma attached to leprosy. At last, we were no longer different.

A SPECIAL PLACE

But no longer being different does not change the fact that Culion remains a very special place. Its history ensures this, as does the beauty of its largely unspoiled scenery.

Located some 200 nautical miles southwest of Manila at the northern tip of Palawan, its relative isolation meant that Culion was deemed the ideal site for a leprosy colony when the authorities' solution to the problem of leprosy in the Philippines at the start of the 20th century was to remove people with the disease from the general population.

By its 25th year, over 16,000 leprosy patients had been brought to Culion*. At the same time, there was also a dedicated community of doctors, nurses and researchers, who carried out some of

the most important work in the history of this disease.

For many of us, the Culion centennial was about remembering not only the suffering and the sacrifice, but also the contributions of so many people to increasing our knowledge about leprosy, and ultimately, to overcoming the disease despite many setbacks along the way. The remarkable story of the island, its inhabitants, and Culion's contribution to leprosy research can be found in the Culion Museum and Archive, which was re-launched at the time of the centennial and now attracts a steady stream of tourists and researchers.

NEW CHALLENGE

Because of the spotlight it shone on the island, the centennial helped to open the gates to people interested in experiencing the beauty of Culion's white sand beaches, bountiful forests and pristine environment. This increased attention comes at a price, however, as the once silent and empty streets now teem with motorbikes and tricycles. New businesses are opening, the population is increasing and the



Nature and history are captured in this screen shot from Culion's new website, launched in April (www.culion.net)

demand for more and better amenities grows. Today, therefore, we find Culion adjusting to the challenge of being a "normal" community.

One noteworthy development since the centennial has been the launch this spring of a new website devoted to Culion. An initiative of the Culion Leprosy Control and Rehabilitation Program, it is a gateway to Culion's history, museum and archives, the Culion Sanitarium and General Hospital, and the Culion Local Government Unit. It reveals the riches that social scientists and historians will find when they visit, and showcases the stunning views with which the island is blessed. The response from former residents of Culion, especially those who have emigrated to Europe or North America, or are working abroad, has been particularly encouraging.

Culion, we like to say, is truly a "paradise regained." Please come and see for yourself. ■

Reference

* For the last eight years, no new cases of leprosy have been detected on Culion. The number of people affected by the disease is less than 1% of the island's population today. Suffering from complications and disabilities, they are either confined to hospital or living with relatives.

'There Is Still Work to Be Done'

Health ministers pledge ongoing commitment to tackling leprosy.

Goodwill Ambassador Sasakawa met with ministers of health from seven countries on the sidelines of the 61st World Health Assembly in Geneva in May for an update on leprosy and leprosy control activities in their countries.

Brazil Mr. J. Gomes *Temporao* expressed his delight that MORHAN was chosen as this year's recipient of the Sasakawa Health Prize. He stated that the government of Brazil and MORHAN have been cooperating with each other on the social rehabilitation of people affected by leprosy, and that President Lula is especially committed to this cause. He also gave assurances that the Brazilian government is doing all it can to achieve the goal of eliminating leprosy as a public health problem.



Nepal Mr. G. *Pokharel* said that health features significantly in plans to transform the nation, now that peace and stability have returned following the recent general election. He said the government will focus on a community approach to primary health care, and that leprosy is one of the important issues to be tackled. With the strengthening of democracy in the country, he said, Nepal looks forward to fulfilling its commitment to leprosy elimination.



Madagascar Dr. Jean Louis Robinson reported that following the achievement of leprosy elimination, efforts at leprosy control are ongoing and much progress has been made in terms of reducing the proportion of multibacillary and child cases. He said that complacency would not be tolerated and that the government was committed to the goal of eradicating leprosy altogether. What is important now and for the future, he said, is quality of service. More needs to be done to improve quality, to boost efforts at early detection and completion of cure, and to ensure the social rehabilitation of people affected by the disease.



Mozambique Dr. P. I. Garrido said that according to Mozambique's own evaluation of the data, it achieved leprosy elimination in December 2007. However, because this was a sensitive issue, it wanted external confirmation. This was duly forthcoming following evaluation by a joint national-WHO-ILEP team over a three-week period in April. The minister said Mozambique was proud to have achieved elimination a year ahead of its goal, but said there was still much work to be done and that the government remained as committed as ever to fighting leprosy.



DR Congo Dr. V. Makwenge Kaput pointed to the progress the DR Congo has made, while noting there are still some problems at the provincial level. The country as a whole has achieved the elimination goal, and he said he hoped to mark the achievement when the goodwill ambassador next visits the DRC this August.



Indonesia Dr. S. F. Supari said that while her country has passed the elimination milestone, leprosy still remains a problem in some provinces. In addition, the human rights dimension of the disease also needs to be addressed, she said. A particular issue is the lack of job opportunities for people affected by leprosy, and the government is providing food assistance in certain cases.



Philippines Dr. Francisco Duque gave an assurance that the government of the Philippines is committed to sustaining leprosy elimination and to promoting the socio-economic rehabilitation of people affected by the disease. ■

Testing the Waters

The Goodwill Ambassador spends a productive three days in Geneva during the 61st World Health Assembly.

SWITZERLAND (MAY 21-23)

There were three items on my agenda when I traveled to Geneva this May: first, to attend the presentation of the Sasakawa Health Prize; second, to liaise with health ministers on the sidelines of the 61st World Health Assembly; and third, to meet with a number of ambassadors representing member countries of the UN Human Rights Council.

The Sasakawa Health Prize was established 24 years ago in response to the WHO's "Health for All" initiative, and recognizes outstanding contributions by individuals or organizations in the field of primary health care. This year's winner is MORHAN, a Brazilian NGO dedicated to fighting leprosy and rehabilitating those with the disease.

I was delighted that the selection committee saw fit to honor a close partner in the fight against leprosy in this way. Only when we embrace the problems faced by others as our own will "Health for All" prevail, and MORHAN, through the involvement of thousands of volunteers, is an example of how this can be achieved.



Torres (third from left) with the Sasakawa Prize. WHO Director-General Dr. Margaret Chan is at far left.

Cristiano Torres gave a speech of acceptance on behalf of MORHAN, and in so doing became the first person affected by leprosy to address the World Health Assembly. He received long and sustained applause.

I sought support for a draft resolution calling for an end to discrimination.

It was also gratifying to see what a source of pleasure this award was to the Brazilian government. MORHAN and the authorities have not always seen eye to eye in the past, but they enjoy a constructive relationship today and this can only be beneficial for improving the situation for people affected by leprosy. I wish MORHAN well with its work.

In my meetings with health ministers from various countries (see facing page), I stressed the importance of continuing to provide leprosy services in order to control the disease in countries where it has already been eliminated as a public health problem. I also urged the ministers of Brazil and Nepal, the two countries yet to reach the goal, to redouble their efforts.

The third reason for my presence in Geneva was to seek the understanding and support of ambassadors of member states of the UN Human Rights Council for a draft resolution to end discrimination against people affected by leprosy and their families, which is to be proposed by the Japanese government at the 8th session of the Council scheduled for June 2-18.

I met a total of nine ambassadors (from the Philippines, Russia, Romania, Pakistan, the UK, Brazil, France, Madagascar and India), who all expressed interest in the issue and promised their support, subject to further consultations with their respective governments.

These were constructive exchanges, not least because I realized there is a clear need for much more awareness-building if society is to fully grasp the issues surrounding leprosy and the scale of the problems people affected by the disease face.

At time of writing, the draft resolution had received favorable responses from about one third of the 47 member states on the Council, so there is still much work to be done. ■

Sasakawa Reappointed Goodwill Ambassador

New term runs from June 2008 to May 2010.

The World Health Organization has extended Yohei Sasakawa's term as Goodwill Ambassador for a further two years. His reappointment was announced on May 22 in Geneva.

In this role, Sasakawa will continue to promote and strengthen efforts to eliminate leprosy as a public health problem in the few countries

where it remains one, work to reduce stigma and discrimination suffered by persons affected by leprosy and enhance public awareness of WHO's global strategy.

Ambassador Sasakawa assured WHO Director-General Dr. Margaret Chan that he would do his utmost to help achieve a leprosy-free world.

HOTEL MANAGERS LEARN ABOUT LEPROSY

Following an incident last November in which participants in a leadership workshop for people affected by leprosy were evicted from a hotel in Indonesia, the groups that organized the seminar held a leprosy awareness workshop in May for hotel managers in Makassar, the city in South Sulawesi Province where the incident occurred.

About 50 managers attended the YTLI-PerMaTa

workshop, designed to sensitize them to leprosy and leprosy-related issues.

Describing the event as a success, one of the organizers, PerMaTa's Adi Yosep, said, "All who attended expressed their commitment to stopping discrimination toward people affected by leprosy, and their willingness to disseminate information about leprosy to other hotels."

MORHAN WINS HEALTH PRIZE

The Movement for the Reintegration of People Affected by Leprosy (MORHAN), an NGO founded in Brazil in 1981, has won the 24th Sasakawa Health Prize.

Accepting the award from WHO Director

General Margaret Chan and President of the 61st World Health Assembly Dr. Leslie Ramsammy in Geneva, MORHAN Vice National Coordinator Cristiano Torres said, "In our 27 years, MORHAN has never received such an important award." ■

FOR THE ELIMINATION OF LEPROSY

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FROM THE EDITORS

FIGHTING FOR SOCIAL JUSTICE

Addressing the World Health Assembly in Geneva last month, WHO Director-General Emeritus Dr. Halfdan Mahler spoke of "the transcendental beauty and significance" of the WHO Constitution's definition of health, and the vision of "Health for All" embodied in the 1978 Alma-Ata Declaration. As conceived, this was a level of health that would permit people to live socially and economically productive lives. "The Health Assembly did not consider health as an end in itself, but rather as a means to an end," he said. He warned, however, that without "renewed local and global battles for social and economic equity in the spirit of distributive justice, we shall indeed betray the future of our children and grandchildren."

Later, at a dinner honoring Yohei Sasakawa's



reappointment as Goodwill Ambassador, Mahler pursued the same theme. "Mark Twain said, 'When you part with your illusions you may still exist, but you have ceased to live.' My personal problem with today's cruel social and economic world, where the few have far too much and the many, many, many more have far too little, is that I increasingly see and feel my illusions becoming mere hallucinations.

"We live, in my opinion, in a socially and economically unjust world and a politically dubious world to put it mildly. But, of course, the brave fight for equitable social justice in health must continue everywhere, and not least in the struggle for the global elimination of leprosy.

"Ambassador Sasakawa is a shining example of a brave and successful fighter for justice for all human beings affected by leprosy with all its moral, social and economic discriminations. I express once more my admiration of Ambassador Sasakawa for his bravery and above all his persistence."