WHO GOODWILL AMBASSADOR'S NEWSLETTER

FOR THE Elimination OF Leprosy

February 2008 • Number 30

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

Sahira Hamadi, 11, and Ame Juma Muhamed, 12, from Tanzania read out Global Appeal 2008 at a ceremony in London on January 28, watched by (from left to right) Sir Edward Clay, Jose Ramirez, Yohei Sasakawa and Dr. Sira Mamboya.

MESSAGE

Forward Momentum

Around 1,500 people attended the recently concluded International Leprosy Congress, which takes place every five years and was held this year in Hyderabad, India. Amid the scientific discussions that are its raison d'etre, noteworthy at this 17th Congress was the fact that about one third of the sessions were devoted to social aspects of leprosy, including stigma and discrimination, empowerment, community-based rehabilitation and human rights. Moreover, among the participants were some 140 people affected by the disease from around the world.

With regard to the social aspects of leprosy, it was in July 2003 that I first approached the Office of the UN High Commissioner for Human Rights to see if it would be possible for the Commission on Human Rights to take up the issue of leprosy. Thereafter, the Sub-Commission passed several non-binding resolutions calling for an end to discrimination. Most recently, I am pleased to see that the Japanese government has been moving in the direction of tabling a motion on the subject at the UN Human Rights Council.

Separately, I have initiated a number of Global Appeals to end stigma and discrimination against people affected by leprosy. The third of these was launched this January at the Royal Society of Medicine in London. This time, I sought the endorsement of leading organizations from the non-leprosy world. Thus I was delighted when nine international bodies, which together represent the interests of children, the elderly, women, persons with disabilities and other vulnerable groups, joined The Nippon Foundation in giving Global Appeal 2008 their wholehearted support.

This offers tremendous encouragement to the movement to end discrimination against people affected by leprosy. Building on this, I believe that we must find common cause with many more such organizations so as to forge a broad coalition of interests to secure our objective. Working together is the best way to overcome stigma in our society.

— *Yohei Sasakawa*, WHO Goodwill Ambassador

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Third Appeal Launched from London

Leading human rights bodies support latest anti-discrimination call

Global Appeal 2008 to end stigma and discrimination against people affected by leprosy was launched at an event held at the Royal Society of Medicine in London on January 28. An initiative of Goodwill Ambassador Yohei Sasakawa, the appeal was endorsed by The Nippon Foundation and nine other international organizations with a focus on human rights. The text was read out by two young people from Tanzania who have been cured of the disease.

This was the third appeal to raise awareness of the problems facing people affected by leprosy, following similar appeals launched in New Delhi in January 2006 and in Manila one year later. "Diagnosed early and treated promptly, leprosy leaves no trace. Far harder to remove is the age-old stigma," the new appeal states. "Defining a person by his or her disease is unacceptable."

Over 100 invited guests listened as Sasakawa explained that repeated appeals were necessary because "the stigma attached to leprosy is deep-rooted" and "is not easily eradicated." He added that people who develop leprosy are sometimes reluctant to seek treatment for fear of social ostracism, with the result that they develop irreversible disability. "This must be prevented," he said.

Sharing the stage with the goodwill ambassador were Barry Clarke, president of the board of International Save the Children Alliance, and Sir Edward Clay, a trustee of Leonard Cheshire Disability. Clarke said his board had no hesitation in supporting the appeal. "Our focus does not prevent us from recognizing calls for action from others who are also working for a better and fairer world," he said.

Best-selling novelist Victoria Hislop (right) with fellow author Tony Gould[2], at the Global Appeal launch.

For his part, Sir Edward noted that some Leonard Cheshire facilities in Asia and Africa had their beginnings as homes for people with leprosy. "Leprosy is one of Cheshire's oldest diseases. Overcoming the stigma and discrimination that people with leprosy suffer is a major objective for us," he said.

'STIGMA HURTS'

Jose Ramirez, one of the signatories of the Manila appeal, then related his experiences as a person affected by leprosy in the United States. These included being taken by hearse from a hospital in his hometown in Texas to the Carville leprosy sanatorium in Louisiana, where he spent the next 3,476 days — "a short time compared to a lifetime of institutionalization for many others." Social worker, managing editor of *The Star*[1], board member of the American Leprosy Missions and advocate for the human rights of people affected by leprosy, Ramirez said, "Stigma hurts," and he challenged the audience to educate others about "the stigma confronting my brothers and sisters throughout the world."

Reading the appeal were Sahira Hamadi, 11, and Ame Juma Muhamed, 12. At their side was Dr. Sira Mamboya, the physician who treated them in Zanzibar. As a doctor she was delighted they had been cured, she said, but the problem is that "the community does not understand" when people have been cured of leprosy — "it still calls them patients." Dr. Sira is now working with the Tanzania Leprosy Association to change social attitudes toward the disease and bring about an end to discrimination (see page 4).

The gathering also heard from Victoria Hislop, whose novel *The Island* featuring the former Greek leprosy colony of Spinalonga has sold nearly 1 million copies worldwide. During her research Hislop made a friend in Athens who was treated for leprosy in the 1960s. She quoted from an email she had received from him the night before. "He said to tell everyone you meet tomorrow at the event that although I am physically cured, every day of my life I fight the stigma."

Global Appeal 2008 was supported by the following organizations: Amnesty International, Disabled Peoples' International, HelpAge International, International Commission of Jurists, International Movement ATD Fourth World, International Save the Children Alliance, Leonard Cheshire Disability, Women's World Summit Foundation, World Council of Churches and The Nippon Foundation. ■

References

1. A newspaper founded by Carville resident Stanley Stein in 1931, *The Star* ("Radiating the Light of Truth on Hansen's Disease") continues to publish to this day.
2. Author of *Don't Fence Me In: From Curse to Cure, Leprosy in Modern Times* (published in the US as *A Disease Apart: Leprosy in the Modern World*)

Hotel Pulls Plug on Workshop

A group of people affected by leprosy forced to hold training event elsewhere.

Posing after a successful workshop — but not at the Valentino. Adi Josep is at top right.

Yayasan Transformasi Lepra Indonesia (YTLI) is a foundation established in August 2007 to serve the needs of individuals and communities in Indonesia disadvantaged by leprosy. It runs various community-based programs, including capacity-building workshops.

In November 2007, YTLI planned a two-day workshop on leadership and management for several advocacy groups in South Sulawesi Province. It chose as a venue the Valentino Hotel in Makassar, the provincial capital.

Because YTLI had never experienced problems when conducting workshops, it did not specify to hotel management that most of the participants would be people affected by leprosy. Booking arrangements went smoothly.

Of the 30 affected persons taking part, all had been cured of leprosy. None suffered from ulcers, and only a handful had visible disabilities.

The group checked into the hotel on November 18 in preparation for the start of workshop the next day. The following morning, just after breakfast, YTLI workshop organizer Adi Yosep was suddenly informed by the hotel manager that the group would have to leave. “The reasons the manager gave me were that many hotel guests had complained they were uncomfortable with, even ‘disgusted by’, the presence of people affected by leprosy in the hotel, reading newspapers, chatting in the lobby, and eating breakfast in the same room as other guests. According to the manager, around 20 guests had checked out.

“I was placed in the difficult position of having to explain this to the participants,” says Adi. “Everyone was very disappointed with the discriminatory attitude of the hotel.”

TEMPORARY RESPITE

As they were checking out, Dr. Andi Asapa, project leader in communicable diseases at the Department of Health in South Sulawesi Province, arrived. Soon afterward, several journalists began showing up. Dr. Andi said that the workshop should be held at the hotel as planned, and discussed this with hotel executives.

Eventually, the hotel relented and agreed to allow the workshop to take place. But it also required YTLI to hold a press conference and explain that it was being allowed to use the premises. Additionally, the hotel said it would prepare a room where participants could take their meals separately from other guests.

While YTLI was not entirely happy with the conditions, it agreed to put the incident behind it and go ahead with the workshop. However, just as participants were checking in again, the owner of the hotel, accompanied by several bodyguards, arrived. According to Adi, the owner was very angry, and used harsh language to order the YTLI group from the hotel.

The manager said other guests were ‘disgusted by’ people affected by leprosy.

“When I tried to explain to him the result of our meeting with the hotel management, one of the bodyguards slapped me in the face. The situation deteriorated and the bodyguards menaced and intimidated us. We were all very shocked.”

When Adi reported what had happened to the police, they called a meeting of everyone involved to find a way to resolve the situation. At that meeting, the hotel agreed to issue a letter of apology, and the bodyguards agreed to guarantee in writing that they would not harass participants further.

Eventually, the workshop went ahead, but not at the hotel. Instead, it was hosted at the health department’s training center in Makassar.

Although traumatized by what took place, Adi’s determination to advocate awareness of the discrimination and stigma that people affected by leprosy face has only been strengthened.

“I believe that we can learn from this experience,” he said. “It will help to unite groups of people affected by leprosy, and will have a positive impact in helping us to move forward.” ■

Reaching Out to the Community

Dr. Sira Mamboya works to transform attitudes via Tanzania Leprosy Association.

I have been involved with leprosy as a medical doctor since 1993. In 2006, the year that Tanzania achieved the WHO goal of reducing the number of cases below 1 per 10,000 population at the national level, I decided to take an unpaid leave of absence from my country's leprosy control program and focus my attention on community work.

With every health facility able to diagnose the disease and prescribe free drugs, I felt there was another challenge we had to address. We were treating patients, declaring them cured and sending them back to the community, yet the community was shunning them as socially unacceptable.

Currently, I am working as general secretary of the Tanzania Leprosy Association (TLA). The association began life in the 1960s as an organization of medical professionals aimed at finding a way to obtain drugs for leprosy patients. Some years later, when the Tanzania national tuberculosis and leprosy program (NTLP) was launched in 1979, TLA and international NGOs worked together to identify and treat all leprosy patients. Initially, NTLP was treating about 35,000 patients a year.

Now that Tanzania has passed the elimination milestone, TLA is transforming itself into an organization to tackle the issue of stigma and discrimination. Its leaders and rank-and-file members consist primarily of people affected by leprosy, whose mission is to take the initiative in changing social attitudes toward the disease.

This is important for a number of reasons. First is the issue of disability. Among new patients today, 12% already have grade II disability, which is irreversible. Persons with the disease are not coming forward for treatment because they fear being rejected by the community.

People affected by leprosy on Penba island, Zanzibar

Second, as I have already mentioned, people affected by leprosy are being excluded from society because the surrounding community is misinformed about the disease. There is a perception that people with leprosy-related disabilities have not been cured and remain infectious. And even when a person shows no outward sign of the disease, the mere mention of the word leprosy stigmatizes.

> There is a perception that people with leprosy-related disabilities have not been cured.

In parts of Tanzania where people are better informed, people affected by leprosy have been accepted. Some become community leaders. But even then, they are still treated differently in certain situations. For example, I know of one village leader who is given his own plate at weddings, rather than being allowed to share the same plate with others as is our custom.

I believe the stigma attached to leprosy and the accompanying social isolation will only be eliminated when those who have personally experienced the disease regain their identity, dignity and self-confidence.

For this, we must empower our members. Part of TLA's role is to instill confidence through leadership training. But confidence can also come from speaking in front of a group for the first time, sitting next to a government official at a workshop, or having one's child attend school.

TLA has identified 39 leprosy settlements in Tanzania and would like to establish a branch in each one. We know of at least 4,000 people affected by leprosy, and if half of them join TLA, that will be a good start. We hope to reach 500 members by the middle of this year.

Athough TLA's raison d'etre is leprosy, I believe it must also play a role in sensitizing its members about other issues such as HIV/AIDS and women's rights. No one else is informing them about these matters because they remain by and large excluded from the community.

The bottom line is: people affected by leprosy are entitled to live with dignity, participate fully in society and enjoy the same rights and opportunities as everyone else. TLA is here to help them achieve that. ■

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Raj Sets Out to Change His World

Young Nepali passionately committed to ending stigma forms his own NGO.

Raj Kumar Shah

Raj Kumar Shah is a young man with a mission. In 2005 he founded READ-Nepal*, an NGO with the goal of transforming public attitudes to leprosy and showing that people with disabilities are able and willing to work.

"In our society, there are still people who think that leprosy is a curse from God and the result of sin," he says.

Born in the Motohari district in Nepal's Terai belt in 1976, he moved to Kathmandu with his family when still young. Diagnosed with leprosy at an early age, he is one of four siblings — three of whom have had the disease.

Raj was first admitted to Anandaban Leprosy Hospital outside Kathmandu in 1984, and was in and out of the hospital numerous times thereafter. At aged 16, he was hospitalized for two years with a condition unrelated to leprosy.

Upon being discharged, he joined a German NGO, where he registered the names of patients and dispensed medicine. Later, he took a job as a clerk at a pharmacy. As a result of these experiences, he decided to study to become a pharmacist.

He approached a local NGO about the possibility of a scholarship but a doctor there discouraged him, telling him that he could not expect to pursue his dream when his hands were so deformed.

The doctor's words stung Raj (as did the fact that he was not invited to sit down while the conversation took place) and he determined that one day he would prove the doctor wrong. Eventually he found another source of sponsorship — the Dutch doctor who had treated him at Anandaban — and went on to qualify as a pharmacist at the end of last year. Armed with his new diploma, he plans to establish his own business one day.

But Raj's consuming passion is READ, which stands for Rehabilitation, Empowerment and Development. Funded by membership fees and donations, its ambitious agenda includes providing free prevention of impairment and disability clinics for people affected by leprosy, organizing health camps, conducting awareness programs about leprosy in communities, and offering skills training in handicrafts.

In the future, Raj would like to open a six-bed ward for in-patient treatment of ulcers. He also wants to launch a radio awareness campaign to sensitize the public to leprosy and work to reduce stigma. Only recently, when paying for some fruit at a street market, he relates how a stallholder refused to place the change his hand when he saw Raj's fingers. Angered, Raj threw the fruit back and retrieved his money.

> The doctor's words stung Raj, and he determined that one day he would prove him wrong.

Some of READ's activities would appear to duplicate the services already provided under the general healthcare system. Put this to Raj, however, and he bristles, "I don't think so." From his perspective, despite the efforts made by the government and other established NGOs, people affected by leprosy still face many problems in Nepal, and much more needs to be done to help them.

"We come into this world with nothing. When we die, we can take nothing with us," he says more than once. "I want people to say that Raj made a contribution during his time on this Earth." ■

READ-Nepal runs a free clinic in Kathmandu (left) and also teaches handicraft skills (center and right)

Reference

* http://read.org.np

Joining Forces to Fight Stigma

Visits to London for the launch of Global Appeal 2008, Hyderabad for the 17th International Leprosy Congress, and Nepal's Terai belt to meet with health workers.

UNITED KINGDOM (JANUARY 26-29)

At the end of January I went to London for the launch of the third Global Appeal to end stigma and discrimination against people affected by leprosy. I began these appeals in 2006 to draw attention to an issue that I feel the world has overlooked. While the wording of the appeals differs slightly from year to year, their intent is always the same: to emphasize the injustice of persistent discrimination toward people affected by the disease and their families, and to call on the public at large to acquaint themselves with the true facts about leprosy as a step toward ending the stigma.

Each year I seek the support of a different set of people or organizations so as to involve a broad coalition of interests from both within and outside the leprosy world. The first appeal, launched from Delhi in 2006, was endorsed by world leaders such as former President Jimmy Carter and Archbishop Desmond Tutu. The second was cosigned by leaders of people affected by leprosy from 13 countries. This year I approached major human rights bodies such as Amnesty International and the International Save the Children Alliance to join me in issuing the appeal, and I was delighted that nine recognized the importance of this issue and lent their valuable support.

This year's appeal was launched from London, since many of the organizations are headquartered in the United Kingdom. As with previous appeals, it was timed to coincide with World Leprosy Day, although for organizational reasons Global Appeal 2008 was issued one day later, on January 28.

I am extremely grateful to the Royal Society of Medicine for allowing us to host the event at at its London headquarters. I would also like to thank Sahira Hamadi and Ame Juma Muhamed, the two young people from Tanzania who read out the appeal, Dr. Sira Mamboya who accompanied them, and Jose Ramirez for recounting his experiences as a person affected by leprosy in the United States.

INDIA (JANUARY 30-FEBRUARY 1) ,

From London I traveled to India to attend the opening of 17th International Leprosy Congress in Hyderabad. This congress, which is organized by the International Leprosy Association, takes place every five years. While the ILA remains a professional body of doctors and scientists concerned with the science of leprosy, it has over time started to give increasing weight to the social aspects of the disease. Hence, I was encouraged to note that speakers at the opening session referred to the human rights of people affected by leprosy and the necessity of ensuring their social and economic integration.

For my part, I said that that we must work harder to counter the ignorance and superstition that still color the way many people regard the disease. We can do this by working closely with the media, spreading correct information about leprosy and condemning the use of stigmatizing terminology.

Ultimately, I believe that people affected by leprosy themselves will be the main actors in a social movement to end discrimination. I look forward to seeing assembly members, government officials, social leaders and industrialists emerge from their ranks. When that happens, they will serve as role models that will help the next generation to develop more quickly.

One such role model is Mr. Md. Salahuddin, the founder of Parvath Nagar, or Rock Land Colony, in Hyderabad. I have met Mr. Salahuddin several times now, and respect him greatly. He established the colony for

Two businesses run by people affected by leprosy in Rock Land Colony

With volunteer health workers at Bakulahar health post in Nepal

people affected by leprosy in 1978 after he came to an arrangement with the city authorities for the use of some 50 acres of rock-strewn land.

Mr. Salahuddin's iron-clad rule was "no begging". People affected by leprosy could have land to live on but only if they agreed to work for a living. This did not happen easily. He fought battles with the authorities over employment rights of residents, and later waged a legal struggle over the title to the land, but in the long run the colony has survived and thrived.

Today there are about 7,500 people living in Rock Land, of whom about 600 are people affected by leprosy. It is an integrated community with many amenities owned and operated by affected persons.

Mr. Salahuddin, who once trained as a bodybuilder and aspired to be "Mr. Hyderabad" before being diagnosed with leprosy, was his usual dapper self and greeted me in his trademark white suit. Now in his sixties, he remains a true leader, and Rock Land is a fitting monument to his achievements.

NEPAL (FEBRUARY 2-5)

A morning mist covers the Rapti river in Chitwan.

After my last visit to Nepal in October 2007, I was determined to return at the next opportunity and see for myself the issues confronting health care workers in the field. With that in mind, I traveled from Hyderabad to Kathmandu, and thence to Nepal's Terai belt, which accounts for about 80% of the country's leprosy cases. My destination was Chitwan District, some 100 kilometers southwest of the capital. The area is famous for the Royal Chitwan National Park, a World Heritage site.

While Nepal's leprosy prevalence rate at the national level has decreased to 1.2 cases per 10,000 people, in Chitwan it lingers at 1.88. Of new cases, 70% are multibacillary. Also worrisome is the high grade II disability rate of 17% among new cases, indicating a pressing need for early detection.

I was encouraged by the number and dedication of the health volunteers I saw.

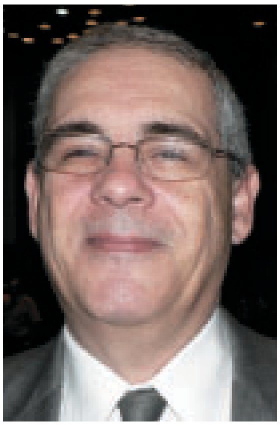
Health officials had told me beforehand that services do not adequately reach some parts of the country because of political problems, although they are hoping for the situation to improve following the election in April. So it was indicative of the challenges that exist that my travel arrangements could not be finalized until almost the last minute; my movements in Chitwan were restricted; and there were reports of explosions while I was there. Nevertheless, I was able to call at a leprosy clinic and several other health facilities.

Although I had been told of the difficulties of motivating local health workers, on this visit at least I was encouraged by the number and dedication of the FCHV (Female Community Health Volunteers) that I encountered. Rooted in the local community, they make an important contribution to the welfare of the populace.

This was a brief but instructive trip. Clearly, Nepal must sustain effort at every level to make further progress against the disease. ■

Virmond Elected New President of ILA

Pledges to breathe fresh life into leprosy's international scientific body.



Brazilian plastic surgeon Dr. Marcos Virmond was elected new president of the International Leprosy Association (ILA) during the recently concluded 17th International Leprosy Congress in Hyderabad.

In an interview on the sidelines of the six-day congress, Virmond said that his goal was to make the ILA a more dynamic organization so as to attract new generations of doctors and scientists and provide them with a place where they can discuss their work. "The ILA is essentially a scientific association for discussing the science of leprosy. It should be the optimum place for them," he said.

Improving communication among members is a key part of these plans. "We are taking measures in the short term to have a very active website, and probably to have a newsletter. In the longer term, we would like to consider reviving the *International Journal of Leprosy*. It is very important for a scientific organization to have an important scientific voice, such as a journal."

While careful to underscore the ILA's scientific credentials, Virmond also welcomed the involvement of people affected by leprosy at the 17th Congress. "Few scientific societies in the world allow the 'users' to take part in their conferences. But I am absolutely in favor of their participation. I do not think you can study the problems of leprosy without the very rich input of those who are suffering from the disease," he said.

Virmond is also a keen student of history, and believes the past has much to teach about leprosy. "As you know, the ILA has had a Global Project on the History of Leprosy, and during my term we are definitely going to try and continue this as a priority."

Regarding prospects of eradicating leprosy, Virmond takes the long view. "This is still a disease we don't know very much about, and we still have patients who suffer from it. In the future, say in 100 years, we may no longer see any patients. But that does not mean the bacteria will have been eradicated. This is why the ILA will continue to exist. As scientists, we would like to understand all the details of this unique pathogen, *M. leprae*," he said. ■

FROM THE EDITORS

FAREWELL, BABA AMTE

Shortly before we went to press, we received news of the passing of Baba Amte. After Mahatma Gandhi himself, there can have been few more remarkable Indians who so devoted their lives to the cause of their nation and to the care of people affected by leprosy. As we related in a past issue of this publication, Amte was born into a wealthy family, but ultimately chose to lead a very different life to the one that his privileged upbringing might otherwise have afforded him.

The ashram for people affected by leprosy that he founded on barren land in 1951 eventually grew to be a model community that provided work and a sense of self-worth to the thousands who came to live there. Among those who made the journey to see for themselves the miracle that Amte had wrought was Goodwill Ambassador Yohei Sasakawa. When Sasakawa visited Anandwan last year, Amte was already in his 90s, and only able to receive visitors while lying on his back as a result of a long-standing spinal injury.

Though brief, it was a memorable encounter that Sasakawa has never forgotten. "It was an honor and a privilege to meet with Baba Amte and I shall always remember the time we spent together," he recalls. "As one who works for the cause of people affected by leprosy, I have the highest regard for what Amte achieved during his remarkable life, and was truly inspired by his deeds. India has lost an outstanding citizen, but Baba Amte's legacy will live forever."

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