

FOR THE Elimination OF Leprosy

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



Heather and her grandson Jonathan at an event bringing together family members of people affected by Hansen's disease in Brazil.

MESSAGE

Brazil's Commitment

As a previous issue of this newsletter already reported, Brazil, the only country yet to achieve the elimination of leprosy as a public health problem, gave a firm undertaking to do so at the World Health Assembly in Geneva in May this year. Under Brazil's new president, Ms. Dilma Rousseff, this effort is being overseen by Minister of Health Dr. Alexandre Padilha, and by an old friend and colleague, Dr. Jarbas Barbosa da Silva, secretary (vice minister) for health surveillance.

On November 28, during a visit to Brasilia, I had an opportunity to meet with Dr. Padilha and Dr. Barbosa to discuss their plans. Dr. Padilha told me that Brazil had made its intentions clear: eliminating Hansen's disease was at the top of the government's list of health priorities and that a budget for this had already been allocated for the next fiscal year. He assured me of the health ministry's strong commitment and said that Brazilians are united in wanting to address the issue.

A few days earlier, at the opening ceremony

of the 12th Brazilian Leprosy Congress and International Leprosy Association Regional Congress of the Americas, Dr. Barbosa stated in a video message that the country is already close to achieving a prevalence rate of less than 1 case per 10,000 population at the national level. However, this was not sufficient, he said: Brazil aimed to eliminate the disease as a public health problem at the state and city level also.

To hear confirmation from the ministry of health's top officials of Brazil's resolve to tackle leprosy in this determined and ambitious manner was a major highlight of my visit.

I welcome Brazil's renewed commitment to take up leprosy elimination as a matter of urgency. Brazil has the resources and the personnel to go about this task, but all of us must be willing to offer whatever support and help is necessary. I sincerely desire to see Brazil succeed in this effort.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Leprologists Meet in Maceio

ILA president stresses role of science in supporting the front line.



The International Leprosy Association (ILA) Regional Congress of the Americas and the 12th Brazilian Leprosy Congress were held concurrently in the city of Maceio from November 23 to 26.

The ILA and the Brazilian Society of Hansenology (SBH), the organizers, are among the oldest scientific societies devoted to leprosy in the world, and the event drew experts from as far afield as India and Japan for presentations covering everything from molecular biology and genetics to history and human rights.

Dr. Marcos Virmond, president of both the ILA and SBH, welcomed delegates at a packed opening ceremony on November 23. He told them it was the purpose of the congress to provide those on the frontlines of leprosy with better tools, and that it was the responsibility of scientists to come up with them. "I believe that the fight against leprosy will be won by those working in basic health services in the community. Keep this in mind during your daily work in the laboratory," he said.

From the health ministry, Dr. Jarbas Barbosa underscored in a video message Brazil's commitment to eliminating leprosy as a public health problem. "This is our obligation to the

health of Brazilians," he said. For his part, WHO Goodwill Ambassador Yohei Sasakawa said that the medical and social challenges of the disease go hand in hand and must both be addressed if leprosy is to be overcome. He also noted that next year's Global Appeal to end stigma and discrimination against people affected by leprosy would be launched from Brazil.

'VERY ACTIVE'

Among those attending from overseas was Dr. Yo Yuasa, a past president of the ILA. Commenting on his stay in Maceio, he said: "The thing that struck me most is that the Brazilian Society of Hansenology is very active and its members are very committed. While the increasing lack of leprologists in other countries is a big problem, my feeling is that for the next 10 or 20 years at least, this will not be the case for Brazil."

Pointing out that most of those attending the conference were researchers rather than field workers, he added: "There's a question as to how much of what was discussed and debated at the conference will translate into activities in the field. That remains to be seen." ■

LEPROSY WISH LIST

Dr. Sunil Deepak

Amici di Raoul Follereau (AIFO)

NATIONAL REFERRAL CENTERS

In so many countries that have reached the goal of eliminating leprosy as a public health problem, the focus on diagnosing and treating new cases of the disease has disappeared. To visit these countries and find so many new cases with advanced disabilities is very discouraging.

I feel that along with integration of leprosy services into primary health care, there is a need to have national referral centers. In line with an integrated approach and for issues of sustainability as well as for creating synergies, these

referral centers should provide leprosy expertise but also look at other neglected infectious diseases present in their countries. I wish to see more attention given to identifying strategies for creating such centers.

SELF-ADVOCACY BY PERSONS AFFECTED BY LEPROSY

After the approval of the UN Convention on the Rights of Persons with Disabilities (CRPD) and after the resolution by the UN Human Rights Council (and subsequently the UN General Assembly) on eliminating stigma and discrimination against persons affected by leprosy, I was hoping to see and hear more from organizations of

persons affected by leprosy; so far, this has not happened.

I would like to see more people with leadership qualities emerge from among people affected by leprosy; people with vision and ideas who will speak out and promote a debate on a future plan of action. Identifying them and supporting them to become stronger leaders is needed. For example, many countries are framing or modifying national disability laws and policies to comply with the CRPD and setting up monitoring mechanisms to verify that the convention is implemented properly. However, I have not heard anywhere of persons with disabilities due to leprosy

A Good Man Passes

Founder of Hyderabad colony came from a privileged background

Mohammed Salahuddin, who died in September aged 80, was the founder of Parvath Nagar, or Rock Land Colony, Hyderabad, in the Indian state of Andhra Pradesh. Born into a wealthy family, Salahuddin once trained as a body builder and aspired to be “Mr. Hyderabad” before being diagnosed with leprosy in his teens. He established the colony in 1978 after he came to an arrangement with the city authorities for the use of some 50 acres of rock-strewn land.

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 grown and prospered.

“He wanted to do something for others. That was his nature.”

Recalls Dr. J. Subbanna of LEPRO India, who worked with Salahuddin on a number of projects: “He was an activist among people affected by leprosy who wanted to secure their basic amenities so they could live with dignity. He tried to generate political will and momentum. Although his vision was blurred,

he had a very sharp mind; he remembered everything. The main thing about him was his passion for doing something; it was very touching. Until he died, he was on the job.”

Another who knew Salahuddin well was V. Narsappa, president of the Society of Leprosy Affected Persons, who says that unlike others with his resources and family background who found themselves in a similar situation, Salahuddin chose not to remain at home. “Salahuddin was not like that. He wanted to do something for others. That was his nature. He was a Muslim and a good person. He came out and lived in leprosy colonies.”

In an account he wrote of his life, Salahuddin described his motivation in wanting to establish Rock Land Colony. “What we wanted was to build a colony where normal healthy people and cured individuals would live side by side, leaving aside any fear of disease and differences of caste and creed...

“I realized that the first step would be to counsel the people living in the surrounding area about our objective. We began by speaking to them, and trying to make them understand that leprosy was not a punishment for one’s sins; neither was it a contagious disease. We tried to emphasize the point that those who were fully cured had every right to lead a normal, healthy life with other normal, healthy people.”

Today Rock Island Colony is an integrated community with many amenities owned and operated by people who once had leprosy. It stands as a monument to its founder’s vision. ■

and their organizations playing a role in this, even though CRPD implementation will influence their lives as well.

DIALOGUE BETWEEN PERSONS AFFECTED BY LEPROSY AND DPOS

I would like to see greater dialogue between persons affected by leprosy and disabled people’s organizations (DPOs). I feel it is important for them to share their own distinctive needs as persons affected by leprosy as well as to reaffirm that they are equally members of DPOs. For example, when Disabled Peoples’ International (DPI) has its annual assembly, I would like to see some capable leaders of organizations of

persons affected by leprosy participate, speak out and become more visible. Only when they are visible can they raise their legitimate issues.

DIALOGUE BETWEEN PERSONS AFFECTED BY LEPROSY AND CBR PROGRAMS

I would also like to see greater dialogue between persons affected by leprosy and community-based rehabilitation (CBR) programs. Both ILEP and WHO have taken up this issue and one important result of their advocacy has been the inclusion of leprosy as a specific issue in the supplementary module of CBR Guidelines. Yet in the field, where CBR

programs are implemented, there are huge gaps where people affected by leprosy are not included.

Once again, I would like to see greater visibility and dialogue on this, led not by organizations such as ILEP or by persons working in leprosy programs, but by persons affected by leprosy themselves. For example, in November 2012, when the 1st CBR World Congress is held in New Delhi, I wish to see a dialogue between representatives of persons affected by leprosy from different countries and CBR implementers.

Do you have a leprosy wish list? Please write in and let us know: smhf_an@tnfb.jp

Brushing Away the Pain

Self-taught Brazilian artist believes in painting's capacity to heal and to help others.

Every morning José Tadeu Bezerra de Oliveira comes back to the former hospital colony where he was confined at the age of 12 with Hansen's disease and teaches art to all those who still make their life there. It was here in Santa Marta* that Tadeu developed a love of painting; through painting, he hopes to help others experience the contentment he has found.

Santa Marta and its environs have been Tadeu's home for the past 30 years. Now 42, he was diagnosed with leprosy in 1983 after a stone became lodged in his foot when he was playing football. His mother found it strange that it didn't bother him, so took him to their local health center in the north of Brazil's Goiás state. He was referred to Santa Marta hospital colony in Goiania, the state capital, for a "routine examination" following which he thought he would be free to go home.

Instead, Santa Marta became his home. Although the policy of compulsory segregation of persons with Hansen's disease had already been abolished by law, it was still being applied in Goiás state and Tadeu became another of its

victims. He was unfortunate also in that he would eventually lose part of his right leg to complications arising from the disease.

Without art I probably would have been one more person who self-destructed.

RENAISSANCE ARTISTS

Tadeu took up painting, using materials provided by charity groups. He identified himself with the Renaissance artists. "Perhaps I was one in a previous life," he muses. Around him, he watched fellow inmates turn to drink and end up in the colony jail for infringing its rules against consuming alcohol and spending time with the opposite sex. There were many suicides.

"Without art, I probably would have been just one more person who self-destructed. Art

provided a bridge between suffering and the life I now enjoy outside [the former colony], where I feel at ease and fulfilled," he says.

Not everyone found that bridge or was able to cross it. "Lack of proper medical care can be a form of imprisonment," he says. "If you develop disabilities there is a tendency not to want to live on the outside, because you are psychologically damaged as a result of your experiences. That is why people killed themselves or never left, even though they were entitled to in later years."

Tadeu's experiences have convinced him that to treat someone with Hansen's disease, you have to know the whole person. "For me, Hansen's disease is not only a physical condition. There are psychological factors at work that can cause the lesions and after effects to become more severe," he says. "You need to take a person's psyche into account as well. That way, you can lessen the toll the disease takes."

ACTIVIST

In addition to pursuing his art, Tadeu has also pursued

compensation from the authorities for the way he and others like him were segregated in hospital colonies. As the government didn't accept claims from those who were forcibly confined after the official end of that policy, he had to make many trips to the capital Brasilia to press their case — including one just four days after his leg was amputated. He is also supporting the compensation claims of children taken at birth from parents who had Hansen's disease.

A father of two who is married to the sister of a former patient, Tadeu offers his services to Santa Marta on a volunteer basis. There is an arts and crafts house where he works with long-time hospital residents with physical and mental disabilities, as well as doing his own work, which he sells around town. He looks and sounds a man at peace with himself.

"I think of this place as my atelier," he says with a smile. "Although I have a disability, good things have happened to me. I want to give something back." ■

Profile:

José Tadeu Bezerra de Oliveira



José Tadeu Bezerra de Oliveira teaches art at the former hospital colony in Brazil's Goiás state where he was sent at the age of 12.



Tadeu: "Good things have happened to me. I want to give something back."

FOOTNOTE

* Now known as Santa Marta Hospital of Sanitary Dermatology and Rehabilitation

To Africa and Brazil

The Goodwill Ambassador travels to Mali, Burkina Faso and Brazil.

MALI (NOVEMBER 1-4)

Mali achieved the WHO's goal of eliminating leprosy as a public health problem in 2001. At the start of 2011, it had 373 registered cases of leprosy. Among the 363 new cases of the disease reported in 2010, the rates of child cases and of cases with Grade II disability stood at around 5% each. This is comparatively low compared with other African countries.

According to the health ministry, doctors, nurses and health care workers in Mali receive regular education about leprosy and each health district has at least one person with knowledge of the disease. This is one reason why the country has been able to sustain its elimination status.

In the suburbs of Bamako, the capital, I visited a health center where nine people are currently being treated for leprosy. Diagnosis and treatment are available at all of Mali's health centers, but physical and social rehabilitation remain a challenge.

Next I visited the Center for Vaccine Development - Mali (CVD-Mali). This has its origins in an institute established in 1931 by Dr. Emile Marchoux (1862-1943) as a center for leprosy research, treatment and training in francophone Africa. Dr. Marchoux was a researcher in tropical diseases who advocated a humanitarian approach to leprosy.

Today the center conducts research into several diseases. I was given a tour by Dr. Samba Sow, who heads the center. There were 10 patients in the leprosy ward. Commenting on one young man's case, he said, "Just by looking, it is hard for a general doctor to determine that this is leprosy, but actually the disease is quite far advanced." Dr. Sow continued: "Although the number of cases of leprosy is falling, that should not mean we ease up on the education of medical personnel. That would be dangerous."

In addition to wards for leprosy and Buruli ulcer, I saw a laboratory with 2,000 mice used for research into leprosy and other diseases, facilities for making artificial limbs, and a vaccine laboratory. Given that this is the only place in Africa where full-fledged research into leprosy takes place, it is an important facility.

Next I went to see a project supported by the Fondation Raoul Follereau to help people affected by leprosy raise their living standards by rearing and selling goats and cows. As we approached, I



Dr. Sow examines a young patient (top); a goat-rearing project (above).

was astonished at the number of goats I could see; there must have been thousands. Some 140 people affected by leprosy are among the 200 people working on the project. They each sell an average of 50-60 goats a month.

I met several of the people involved, who live together in a colony. Their spokesman, Mr. Goulou Traore, told me, "I think you have seen the smiles on our faces and how we are living with dignity. There are 1,472 people in this community. We want to expand the project so that everyone benefits."

BURKINA FASO (NOVEMBER 4-6)

Among African countries, Burkina Faso achieved the WHO's elimination goal relatively early in 1992. In the past, it saw as many as 8,000 new cases annually; in 2010, the number was just 320.

But as patient numbers have fallen, so has government interest. Of concern is that fact that among new cases of leprosy in 2010, some 20% presented with Grade II disability. This suggests that health staff require more training, and that the public need to be better informed about leprosy and the importance of seeking medical advice when symptoms appear. >>



Addressing a meeting at Tavares de Macedo

At the health ministry I met with health minister Adama Traore. He assured me he was committed to eradicating the disease and the discrimination that it causes. Following our meeting, we attended a press conference together. Although my visit coincided with a major Islamic festival, and it was a Saturday, about 15 media organizations showed up. As always, I asked for the media's cooperation in raising awareness of leprosy and spreading correct understanding so as to reduce stigma.

On November 6, I drove for a couple of hours to see a project in Koudougou. Together with Dedougou further to the west, it sees a large number of leprosy cases. Supported by the Fondation Raoul Follereau, around 70 people affected by leprosy are cultivating millet, corn and rice on their own parcels of land. However, they must travel some distance to get there, there are no agricultural experts on site, and this year there has been a shortage of water.

One man I met told me they weren't earning enough money from their efforts, but that it was important for them to be doing something. That's the right attitude for living with dignity. But it will not be easy to make a living from agriculture when one is not blessed with good weather and the soil is poorly nourished. Passion, perseverance and effort will be required.

BRAZIL (NOVEMBER 23-29)

In November I flew to Brazil to attend the opening of the 12th Brazilian Leprosy Congress and to lay the groundwork for the launch of Global Appeal 2012 to end stigma and discrimination against people affected by leprosy as well as for a conference on human rights. I also attended an event organized by MORHAN, the influential NGO working for the reintegration of people affected by Hansen's disease, and called on government officials in Brasilia.

Held concurrently with a regional meeting of the International Leprosy Association, the Brazilian Leprosy Congress in the coastal resort city of Maceio took place against the backdrop of Brazil's renewed commitment to pursue the elimination of leprosy as a matter of urgency. This was underlined in a video address from Vice Minister of Health Dr. Jarbas Barbosa.

While in Maceio, I visited a hospital that helps to rehabilitate persons affected by leprosy. This rehabilitation is not only physical but social, and includes skills-training with the goal of having people affected by leprosy find jobs and support themselves without having to rely on the state.

In Sao Paulo, I met with the president of the Brazilian Medical Association, José Luiz Gomes do Amaral who is also the newly elected

Telling their stories; and being encouraged by Elke Maravilha (far left)





A MORHAN mobile clinic in Rio Bonito



With Health Minister Padilha in Brasilia

president of the World Medical Association. The WMA and representative members are endorsing next year's Global Appeal. A strong message from the association will go a long way toward reducing the stigma and discrimination that people affected by leprosy still face — even at the hands of medical professionals.

Next I flew to Rio de Janeiro, the headquarters of MORHAN. At a nearby former hospital colony, Tavares de Macedo, MORHAN had organized a major event to focus attention on the issue of children who were separated from their parents at birth and placed in institutions or put up for adoption because their parents had Hansen's disease.

The Brazilian government is already paying a pension to people who were forcibly isolated in hospital colonies as a result of past policy. Now MORHAN is seeking financial compensation for the children who were also victims of this policy.

At times, my interpreter was reduced to tears as she relayed these stories.

During this event, which was attended by around 500 people, including government officials and media, I heard some searing testimony. There were accounts of physical and sexual abuse at the hands of foster families, as well as other cruelties. A woman recalled being forced to wash in alcohol and having her clothes burnt when as a young girl she went to live with her new family. Another recalled being given a doll with its fingers cut off, to represent a person with Hansen's disease, after telling her foster family how she missed her birth mother. Others spoke of being treated like slaves. At times, my interpreter was reduced to tears as she relayed these stories.

There was also an appearance by the irrepressible, irreverent Elke Maravilha. The popular Russian-born entertainer is a long-time supporter of MORHAN's work and of

people affected by Hansen's disease in Brazil. Shedding a few tears of her own, she said to all those who had spoken, "I'm not crying for you — you are all wonderful. I'm crying for the people who did this to you"

MORHAN is helping to reunite children with their parents and siblings, through the creation of a DNA database and by painstakingly sifting through other records. They have had a number of successes, and some cases have received tremendous media coverage.

As part of its activities, MORHAN currently operates two mobile clinics offering free diagnosis for leprosy. I had a chance to see one in action. Typically, a week before the truck reaches its destination, local MORHAN volunteers hand out information and let people know the clinic is coming. Then the truck sets up shop for a week, employing a local health professional to examine patients. In the week following its departure, MORHAN volunteers carry out follow-up advocacy. On the day I visited the mobile clinic, three new cases of leprosy had been diagnosed.

In Brasilia I had meetings scheduled with the health ministry and the special secretariat for human rights. Prior to these, I called on the WHO country representative. His office confirmed that leprosy is an important priority for the current Brazilian government, underscored by the fact that it is allocating more resources to tackle the disease. Furthermore, Brazil is also attacking the problem of poverty, and this will have a positive impact on controlling leprosy.

In my meeting with Health Minister Dr. Alexandre Padilha, I praised the stance of the health ministry in declaring it was going to eliminate leprosy as a public health problem at an early date. The minister told me that Brazilians are united in their desire to tackle Hansen's disease. A member of the health ministry team drew my attention to next year's desk diary, which features a different disease or health topic each month. Symbolic of the fact that "Hansen's disease" is at the forefront of Brazil's to-do list, it was the first of two topics for January. I took this as another sign that Brazil is serious about tackling the disease. ■

Bangladesh Repeals 'Lepers Act'

Century-old act stigmatized people affected by leprosy

A long campaign to have a discriminatory piece of legislation scrapped finally bore fruit on November 24 when Bangladesh's Parliament repealed the 1898 Lepers Act. The law, which dated back to the days when there was no cure for the disease, enabled the forcible seclusion of people affected by leprosy in government-run institutions.

The campaign to have it repealed was spearheaded by Saber Hossain Chowdhury, a member of Parliament from the ruling Awami League, with support from The Leprosy Mission International-Bangladesh and other organizations.

"We consider this as a big milestone in our journey towards 'A Bangladesh without leprosy'

and as a definite dynamic motivation for all our efforts at the promotion and protection of the human rights of the people affected by leprosy, which are so often violated, and grossly violated, because of this disease," said Martin Adhikary, director of advocacy and promotion for TLMI-B.

Speaking on the BBC World Service, Saber Hossain Chowdhury said: "We are sending the message that people, regardless of what their medical conditions are, are entitled to the same rights and privileges as we who are not afflicted with the disease expect to have. It's about human rights. It's about upholding the dignity of all people."

TOKYO VISIT



Dr. Shin (left) and Dr. Samlee (right) with the Goodwill Ambassador

being made against leprosy in their regions and underscored the importance of focusing on the social as well as the medical aspects of the disease.

The regional directors of the WHO's Southeast Asia and Western Pacific regions met with Goodwill Ambassador Yohei Sasakawa in Tokyo at the end of November. Dr. Samlee Plianbangchang (SEARO) and Dr Shin Young-soo (WPRO) discussed the progress

HUMAN RIGHTS SYMPOSIUM

The Nippon Foundation, together with partners, is holding the first of five regional seminars on human rights on February 1, 2012, in Brazil. The purpose is to promote awareness and implementation of last year's UN resolution to end discrimination against persons affected by leprosy and their family members. ■

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FROM THE EDITORS

WHITHER THE ILA?

The International Leprosy Association is a venerable institution ably led by its current President Dr. Marcos Virmond, who presided over the recent ILA Regional Congress of the Americas and 12th Brazilian Leprosy Congress. But as leprosy declines, the ILA faces an uncertain future. Its membership has dwindled to around 130 and it has not been able to publish a scientific journal for several years.

In many parts of the world, leprosy does not suggest itself as an attractive career option to young researchers (although Brazil, which sees the second highest number of new cases each year

after India, may be an exception). There aren't the big scientific themes to prick their interest, nor the abundant research grants to draw them in.

The next international congress of the ILA will take place in Belgium in September 2013. In times gone by, ILA congresses attracted between 1,000 to 1,500 delegates, but Dr. Yo Yuasa, a past president of the organization, expects only a few hundred to attend due to fewer field workers being present. "Doubtless the future of the ILA will be debated in Brussels," he says. "But from my perspective, so long as leprosy exists in the world there is a need for the ILA."