WHO GOODWILL AMBASSADOR'S NEWSLETTER

FOR THE

Elimination OF Leprosy

February 2014 • Number 66

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

The Goodwill Ambassador visits Jose, Maria and their three children in Brazil's Para State in December 2013.

MESSAGE

Hidden Cases in Brazil and Indonesia

In December 2013 and January this year, I visited Brazil and Indonesia. Brazil sees over 30,000 new cases of leprosy annually and Indonesia around 20,000. In Brazil I traveled to the Amazon basin and in Indonesia to the eastern province of Papua. I toured health facilities and visited communities of people affected by the disease.

In both areas I met people with pronounced disabilities, a sign they were diagnosed late. I also encountered cases of transmission within families. In Brazil's Para State I visited a family where all five members — the mother and father and their two daughters and son — have or once had leprosy. In Papua, I met a four-year-old girl patient.

In Brazil and Indonesia, multidrug therapy is dispensed at health centers. Patients must go there each month for their prescriptions. For many, this can mean long journeys that are costly and inconvenient. Consequently, quite a few never complete their treatment. Is it not possible to prescribe three or six months' worth of MDT at a time, I wonder?

Both countries have made firm commitments to tackle leprosy, but because of the progress of decentralization, the central government's commitment doesn't necessarily filter down to the regions, where budgets and human resources for leprosy control are inadequate and local leaders may not be aware of the leprosy situation.

There must be many hidden cases in difficult-to-reach areas. We need to encourage community health workers, midwives, missionaries, teachers and especially people affected by leprosy to be on the look-out for new cases. Once confirmed, treatment must begin promptly.

Sustaining quality leprosy services requires this. Only this way can we observe the cardinal rule: early detection and prompt treatment. Decentralization notwithstanding, it is my strong wish to see central and local governments in Brazil and Indonesia join forces, raise the priority of leprosy and do their utmost to uncover new cases. I hope the WHO will hold urgent consultations with the governments concerned and find a way forward.

— *Yohei Sasakawa*, WHO Goodwill Ambassador

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Speaking Out from Jakarta

Human rights bodies back latest appeal to end stigma and discrimination.

National human rights institutions from 39 countries and regions became the latest in a growing list of influential individuals and organizations to endorse the annual Global Appeal to End Stigma and Discrimination against People Affected by Leprosy.

Global Appeal 2014, the ninth appeal to date, was launched on January 27 in Jakarta, Indonesia, at a ceremony attended by some 250 people, including Indonesia's Minister of Health, Dr. Nafsiah Mboi, and Coordinating Minister for People's Welfare, Agung Laksono.

Yohei Sasakawa, the WHO's Goodwill Ambassador for Leprosy Elimination, began the appeal in 2006 as a way to draw attention to the issue of leprosy-related discrimination and focus efforts on alleviating it. He told the ceremony in Jakarta: ""It is a sad fact that even today, when leprosy is completely curable, massive walls of stigma and social prejudice still stand between society and those affected by the disease."

Faith leaders, educators, and the medical and legal professions are among those who have supported previous appeals, and the Goodwill Ambassador hoped the backing of human rights organizations would now accelerate efforts to resolve the issue. "They are the very organizations that can investigate the various human rights abuses facing people affected by leprosy and their families and take appropriate measures such as making recommendations to their governments," he said.

Among the signatories represented at the ceremony was Indonesia's National Commission on Human Rights. The commission's Dr. Dianto Bachriadi told the audience that not just the government but the whole country had to be part of the solution, "including religious and public figures." From India, Justice K.G. Balakrishnan, who chairs that country's National Human Rights Commission, spoke of the need for "an overall change in social perception" to motivate respect for the rights of persons affected by the disease.

Providing the perspective of someone who has personally experienced leprosy was Muhammad Amin Rafi, the coordinator in South Sulawesi for PerMaTa, an Indonesian NGO of people affected by the disease. He described being "ostracized, mocked, insulted and humiliated," and said that in the past he had frequently contemplated suicide. "All we want is to be treated as human beings and accepted by the community without distinction," he said.

U.N. RESOLUTION

This year's appeal references the December 2010 U.N. resolution on elimination of discrimination against persons affected by leprosy and their family members, which was adopted in recognition of the disease's devastating social, economic and psychological impact. The resolution reaffirms that people affected by leprosy and their family members should be treated with dignity and are entitled to all human rights and fundamental freedoms under customary international law, relevant conventions and national constitutions and laws.

India, Brazil and Indonesia, which together contribute the most cases of leprosy in the world, were among those countries whose human rights bodies signed Global Appeal 2014 and declared: "As national human rights institutions, we applaud the U.N. resolution and condemn all leprosy-related human rights violations. We uphold the right of people affected by leprosy to live in dignity, free from discrimination. We pledge our support to help to bring down the remaining barriers of stigma and prejudice that stand in their way." ■

Thrown Away Like Garbage

In Indonesia, a man is dumped in a ravine by his family because he had leprosy.

AUTHOR:
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In 2012, 18,994 new cases of leprosy were reported in Indonesia, with those afflicted facing life as outcasts. They are often abandoned by their families, with no prospects of education or jobs.

The story of one leprosy patient has recently shocked authorities, but the fate of 43-year-old Sutarip from Probolinggo Regency in East Java Province resembles that of many. He was literally thrown away like garbage by his own family into a ravine in a forest.

> “(At home) I have a rice field... Why should I have to eat those animals?” he asked.

Prayogo Santoso, who works as a nurse at a local public health center had heard about his case. His village was only a few kilometers away from the forest and he decided to go and look for him.

“I went there and found Sutarip in the forest, 600 meters below a hill,” Prayogo said.

He had been living in the forest for two years — two years since his family dumped him there without any food or water. He survived eating wild animals and drinking rain water.

Prayogo visited him three times before he was finally taken to a hospital, and each time he saw him preparing different animals for his meal, including a snake, a grilled rat and a cat. “I once brought some food for him and was about to throw the grilled rat away when he asked me not to do so,” the nurse said.

“He told me, ‘Today, I can eat your food, but how about tomorrow? What can I eat if you take the rat away?’”


Photo credit: KYODO

UNABLE TO WALK

Sutarip could barely stand up, let alone walk, when Prayogo visited him. His limbs were stiff, as the disease had started to attack his peripheral nerves. He could only lie down in a hole he had dug himself and weighed just 29 kilograms.

Sutarip was eventually brought to a leprosy hospital in the village of Sumberglagah, about 100 kilometers from the forest.

“We gave him a bath after he arrived, because he was very dirty and smelly. We also gave him milk, protein and carbohydrates, which were urgently needed because of the lack of nutrition,” Budiastutik Kusharjuni, director of Sumberglagah Leprosy Hospital, said.

After five days in hospital, Sutarip put on one kilogram. He is now able to sit, stand up and slowly walk when he needs to go to the toilet. But Sutarip is still in a lot of pain and suffers from depression. He spoke little and cried when asked about his diet in the forest.

“(At home) I have a rice field...Why should I have to eat those animals?” he asked with tears streaming down his face.

‘CURSE FROM GOD’

Although Sutarip’s case may sound extreme, it is not uncommon in Indonesia. Most people affected by leprosy live in poverty due to stigmatization and discrimination. Many Indonesians still believe leprosy is a curse from God and a genetic disease. If a family member has leprosy, the relatives have to get rid of him or her, or else the entire family would be cut off by the community.

“And once a person with leprosy is exiled, in many cases, he or she will live alone forever because the family will refuse to take them back,” Teguh Heri, supervisor at Sumberglagah hospital, said.

He said the hospital has had some patients who were hospitalized for more than 40 years. Currently, the eldest patient is a 90-year old woman, who has been in Sumberglagah hospital for 45 years. “Some were here until they passed away and we buried them here as well because their families refused to pick up their bodies,” Teguh said.

As for Sutarip, one of the doctors treating him admits that what comes next is unclear. “We don’t know what the future holds for him once he has recovered and left the hospital,” Edi Cahyono said, adding that Sutarip may be discharged within a month.

Talking about the future, Sutarip, who once worked as a sugar cane farmer, seemed preoccupied with plans of finding a wife. While he was happy about the new shirt and trousers given by Teguh, he was unhappy with his new pair of sandals, which he said were not good enough to attract women.

Divorced twice, Sutarip said his biggest dream is to begin a new life with a beautiful woman, leaving the trauma of the disease behind him. ■

TO OUR READERS

Do you know of stories like Sutarip’s that describe the reality of stigma and discrimination? The Goodwill Ambassador invites you to share them through this newsletter. Please send your stories to smhf@tnfb.jp.

Journeys to Brazil, Colombia and Indonesia

Checking up on Brazil's progress, visiting the history-steeped town of Agua de Dios in Colombia and traveling to Indonesia's Papua Province ahead of the launch of Global Appeal 2014 in Jakarta.

BRAZIL (DECEMBER 18-20)

Brazil is the only country yet to eliminate leprosy as a public health problem. The health ministry has said it aims to do so by 2015, but this looks difficult to achieve. Matters are complicated by Brazil's decentralized system of government, under which a high degree of decision-making authority devolves to the 26 states and more than 5,500 municipalities. For my last mission of 2013, I first traveled to Brazil for an update on the progress it is making against leprosy and the challenges that remain

My visit began in Brasilia, where I had meetings with the health minister, Dr. Alexandre Padilha, and vice health minister, Dr. Jarbas Barbosa. They told me of several initiatives they are taking to strengthen leprosy control measures. For example, the health ministry has conducted a campaign to treat school children for intestinal worms and screen them for leprosy. The campaign covered 2.3 million children and will be repeated this May. The ministry is also planning to give doctors more training on leprosy and they discussed the possibility of having the WHO send a leprosy monitoring team.

Minister Nunes greets her visitors.

On the human rights front, too, Brazil has been active at the federal level. To catch up on the latest developments, I called on Minister Maria do Rosario Nunes of Brazil's Human Rights Secretariat. The meeting was arranged by the Movement for the Reintegration of People Affected by Hansen's Disease (MORHAN). This influential NGO successfully lobbied for compensation for leprosy patients who were forcibly isolated in hospital-colonies under past government policy. Now it is pushing for compensation for the "second generation"—children taken from their parents because their parents had leprosy.

Joining us were some 40 residents of a former hospital-colony in Goiania—both people affected by leprosy as well as children and grandchildren. They had saved money to charter a bus for the six-hour journey so that they could make the case for compensation in person. I was impressed that the minister made a point of shaking hands with each one of them in turn.

Minister Nunes said the government had an obligation to take responsibility for past mistakes and she praised MORHAN for uniting the voices of all those individuals fighting for justice. She pledged to pursue the issue of compensation for the second generation. "We weren't able to debate it in Parliament this year, but it will definitely be realized," she said.

> They told me of several initiatives they are taking to strengthen leprosy control.

I also had my first opportunity to meet with a parliamentarians' group on leprosy that was formed in August 2013. It has 180 members, or about one third of the National Congress. Even though it was the last working day of parliament, some 70 MPs attended the meeting. It was an encouraging turnout.

From Brasilia I flew to Para State in the north of the country. Para alone is three times the size of Japan, giving an idea of just how big Brazil is. My first destination was the state capital, Belem, at the mouth of the Amazon River, where I called on Governor Simao Jatene.

He greeted us warmly, but soon his expression turned serious. Average incomes in the state were half the national average, he said. Primary health services weren't reaching remote parts of the Amazon region. Under the circumstances, controlling leprosy was difficult and he didn't think they had a true grasp of the situation.

Near Belem, in Marituba, is the Dr. Marcello Candia reference unit in sanitary dermatology. It sees 5,500 patients a month and has the huge task of serving as the only leprosy referral center for the whole of Para State. It is has a range of facilities, including a rehabilitation center and a


Speaking with a resident of Santo Antonio do Prata, formerly a leprosy hospital-colony, in Para State, Brazil.

prosthetics workshop. I was pleased to note that it was well stocked with multidrug therapy (MDT). Close by live surviving members of the former Marituba hospital-colony. When I stopped by briefly, I found the elderly residents in good spirits and enjoying a Christmas celebration.

In the afternoon, I traveled by boat to visit an entire family affected by leprosy who live on the banks of the Amazon. Jose, 45, and Maria, 34, live with their three children, who are 18, 12 and 10. Jose began receiving treatment only after he developed disability in his hands and feet. Maria thought that she might have cancer, but at hospital she was diagnosed with leprosy and has since been treated and cured. Their two daughters are currently being treated for leprosy and their son will soon start on MDT.

This family is not so far from Belem and is under the surveillance of the health authorities. But for those living in remoter areas of the state, the situation is rather different. I understand there are many undiagnosed cases in places that are not served by primary health services and cases of patients who give up on treatment because it is too far or inconvenient to make regular trips to a health center to collect their doses of MDT.


The well-stocked MDT dispensary

Santo Antonio do Prata is the location of a former hospital-colony. Still living in the old Prata colony today are 11 residents, the oldest of whom is 97. Nearby are descendants of the current and past occupants and their families.

I attended a meeting of about 40 of these descendants. A woman, one of the “second generation,” took the microphone and told of being sent to an orphanage after being separated from her parents. She had endured a difficult time and the memories were still raw. In addition, there is stigma associated with being from Santo Antonio do Prato, she said.

If Brazil makes good on its intention to compensate this woman and others like her for their trauma and suffering, it will be a first for any country. But there is also an urgent task to reach the unreached. Visiting Para State confirmed for me the extent of the challenge that remains.

COLOMBIA (DECEMBER 21-23)

Several years ago I met Jaime Molina Garzon, the impressive founder of Corsohansen, an NGO of people affected by leprosy in Colombia. Ever since, I had wanted to visit the town of Agua de Dios, where Corsohansen is based.

Agua de Dios is about 110 kilometers from the capital Bogota. It means “water of God” as it was believed that nearby thermal springs were an effective cure for skin complaints. A small group of people with leprosy had been exiled there.

Like many countries, Colombia introduced legislation at some point in its history to isolate people with leprosy. In 1870, the government bought the land at Agua de Dios that people affected by the disease were already living on, creating a colony there. An infrastructure gradually built up—including a hospital that opened in 1880 and three separate sanatoriums whose residents today are all elderly.

On the road to Agua de Dios is a bridge that spans the Bogota River. Built in 1872, it became known as the Bridge of Sighs. For people sent

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(Far left) On the road to Agua de Dios: the Bridge of Sighs; (left) the museum at the Corsohansen office

to the colony, crossing this bridge meant leaving the outside world and loved ones behind forever. Once in Agua de Dios, they lost their rights as Colombian citizens and were issued with identity cards that were valid there and nowhere else.

The law requiring the isolation of leprosy patients wasn't abolished until 1961. Two years later, the town became a municipality. Today it has a population of around 13,000, the majority of whom are people affected by leprosy or their descendants.

There are no less than four separate museums detailing different aspects of its history. One of these is in the well-run offices of Corsohansen. Another is devoted to Luis Antonio Calvo, a famous Colombian composer who was diagnosed with leprosy at the age of 34 and spent the rest of his life in Agua de Dios. The third is the municipal leprosy museum, situated in one of the town's sanatoriums. The fourth, located in a convent, is the Father Louis Variara Museum, which recognizes the work of this Italian priest who did so much for the people of Agua de Dios and was beatified by the Catholic Church in 2002.

The town faces challenges—economically, it lags behind other areas and there is stigma attached to being from Agua de Dios. Jorge Humberto Garcés Betancur, its young mayor, is serving his second term. With parents who are affected by leprosy, he is part of Agua de Dios's past and also part of its future. Like Culion in the Philippines, Agua de Dios deserves to be recognized as a place transformed from a symbol of despair to one with hopes and dreams. It has a history from which the whole world can learn.

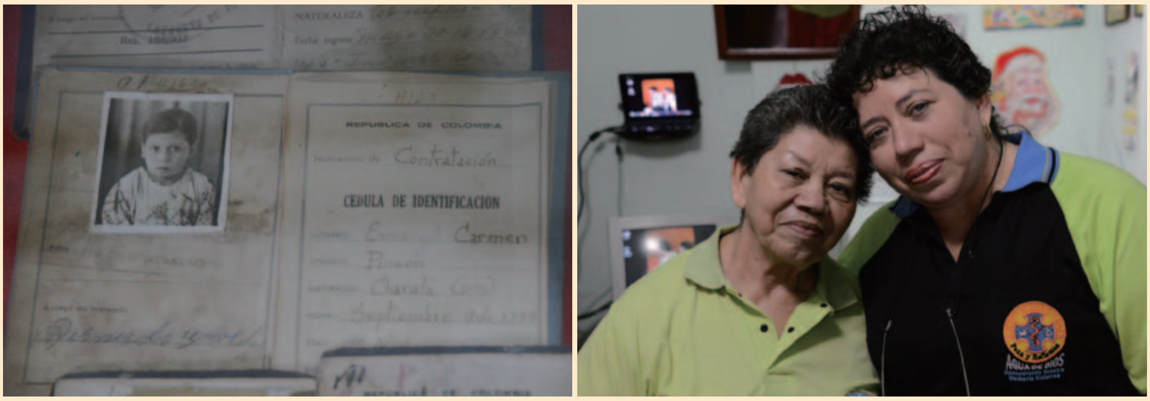
INDONESIA (JANUARY 23-28)

When I spoke with Indonesia's health minister Dr. Nafsiah Mboi in Geneva last May, she told me of a village in Papua Province she visited in January 2013 where half the population was affected by leprosy. To learn more about the situation in Papua, which is Indonesia's largest and easternmost province and forms one half of the island of New Guinea, I traveled there in January.

With dense jungle and mountains rising over 5,000 meters, Papua is a natural wonderland, but also one whose terrain presents particular challenges when it comes to health coverage.

In 2012, Papua recorded 1,384 new cases of leprosy. I was told, however, that of the province's 28 districts and one municipality, only 17 report regularly on leprosy because of difficulty in accessing some highland areas, shortages of trained personnel and budgetary constraints. Dr. Arry Pongtiku, a national consultant for leprosy and yaws in the province, estimates that the actual number of cases is probably double that reported.

When I met with Vice Governor Klemen Tinal, he expressed surprise that his province had so many cases and said it would be necessary to form a special team to look into the situation. Not for



Inmates of Agua de Dios were issued with ID cards such as this one, belonging to Emma, seen here with daughter, Ana.

(Right) Greeting patients at a health center in Biak; (far right) A mother with her daughter, who is being treated for leprosy, in Jayapura

the first time, I felt that my talks with a political leader had helped to generate awareness of this often overlooked disease and I hope that he will act on the concern he expressed.

Jayapura municipality sees around 400 new cases of leprosy each year. Many of these — around 150 in 2013 — are diagnosed at the Hamadi health center, which is located opposite one of the city's main markets. After I was given a traditional welcome of singing and dancing, the clinic's specialist leprosy nurse, Vera Yoku, introduced me to about 20 people who were undergoing treatment for leprosy or already cured of the disease. They ranged in age from four to 72.

I don't think I have seen a patient as young as four before, and she was one of a number of children I met there. In fact, I was told that children account for a troubling 24% of new cases in Papua, while the figure for neighboring West Papua is even more disturbing, at 40%. This suggests there are many infectious cases among the population.

Children account for 24% of new cases in Papua, and for 40% in West Papua.

One of the challenges appears to be convincing people to seek treatment and to complete their courses of MDT. Dr. Pongtiku suggested to me that Papuans have a different concept of sickness. Unless they feel unwell or in pain, the appearance of a patch on their skin is not going to trouble them and they won't do anything about it.

I visited a community called Hamadi Gunung whose residents include 28 people affected by leprosy. Many who attended a ceremony to greet me told of being treated and cured and getting on with their lives. But afterward I spoke with a man who had stayed by his house because he was ashamed of his disease. In another part of the city, I was taken to meet a boy who had given up on his schooling because of the stigma he felt.

Dr. Pongtiku said there is a need for more doctors to work in remote areas of Papua; a need to train health staff to identify cases; and a need for more advocacy. Finding recruits to work in leprosy was also a challenge, he admitted, because there was a certain amount of leprophobia among health staff.

From Jayapura I flew to Biak, a small island off the north coast of New Guinea and part of Papua Province. It was the scene of heavy fighting during the Pacific War. After Jayapura, the district of Biak Numfor reports the highest number of cases in Papua. Here I visited a hospital and a health center, speaking with a dermatologist and talking with outpatients about their experiences. Later I went to visit a former fisherman. He had been treated for leprosy some years earlier but subsequently injured his leg and developed complications that have left him disabled. He lives alone in a small dwelling and his brother brings him food. It was a lonely existence.

From Papua I flew to Jakarta for the launch of this year's Global Appeal to End Stigma and Discrimination against People Affected by Leprosy, which was endorsed by national human rights institutions and is featured on page 2.

I also attended a discussion group involving various stakeholders, among them the chairman of PerMaTa, an organization of people affected leprosy. "Stigma is still a serious issue," Mr. Manek said. "And the worst stigma of all is within the family of the person affected."

My stay concluded with a visit to Sitanala Hospital, a hospital in Jakarta specializing in leprosy. At the time of my visit there were 60 leprosy in-patients, including 11 long-term patients. Adjacent to the hospital is a community where many people affected by leprosy live.

Like Brazil, Indonesia faces many challenges because it is very spread out. But with the right focus, resources and dedication from top to bottom, progress will be made. I will be following its efforts closely and will do all in my power to assist in its work. ■

A Role for Religions in Ending Stigma

Meeting with health minister touches on reach of religious faiths.

Goodwill Ambassador Yohei Sasakawa met with Indonesia's Health Minister Dr. Nafsiah Mboi on January 27 in Jakarta ahead of the launch of Global Appeal 2014 to End Stigma and Discrimination against People Affected by Leprosy. During their meeting they discussed the leprosy situation in the country and the Ministry of Health's focus on 13 provinces where the burden of leprosy remains high.

In the course of their wide-ranging conversation the minister emphasized the importance of using religious leaders as a channel to communicate information about leprosy and reduce discrimination, "because they are close to the people." She cited the role played by church groups in Papua Province in tackling HIV/AIDS. "They have a lot of volunteers and go to remote areas," Dr. Mboi said.

To raise awareness about leprosy, the health ministry will be launching a National Appeal calling for an end to leprosy-related stigma and discrimination endorsed by representatives of Indonesia's six official religions — Islam, Protestantism, Catholicism, Hinduism, Buddhism and Confucianism — together with the Ministry of Religious Affairs and faith-based NGOs.

As part of the campaign, it has prepared booklets about leprosy, including information on symptoms and treatment, tailored to each religion. "We chose religious faiths because they have a network from the top to the grassroots," said the ministry's Dr. Christina Widaningrum, adding that the "follow-up will be very important." ■

FROM THE EDITORS

A NOBLE PRINCIPLE

One of the national human rights institutions to endorse this year's Global Appeal to End Stigma and Discrimination against People Affected by Leprosy is Jordan's National Centre for Human Rights. Jordan is leprosy free, but it decided to support the appeal for two reasons, according its commissioner general, Dr. Mousa Burayzat.

"First, it is consistent with our mandate as a human rights institution to fight discrimination, xenophobia or any form of mistreatment of any person," he said. "And second, it is a noble principle and a humanitarian cause."

Jordan may not have cases of leprosy today, but the disease is recorded in its history and literature and people are aware that leprosy remains a problem in the world, Dr. Burayzat said. No country exists in a vacuum, he added

"Unfortunately, humans live by forms of discrimination, either positive or negative. We discriminate in favor, we discriminate against. It is something ingrained in us," he said. "People discriminate out of fear and ignorance; fear is the cause of a lot of misunderstanding, and even conflict and estrangement, between humans."

But shunning those who are different is self defeating, he believes. "It says in the Koran that we create difference to know each other. Not only to know each other, but so that there would be interaction. It is through interaction that humans achieve progress."

In various parts of the world, people affected by leprosy remain isolated and ignored. It is time for interaction. It is time to achieve progress.

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