

# FOR THE Elimination OF Leprosy

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



The Goodwill Ambassador chats with Daw Thida, a resident of Mayanchaung Resettlement Village in Myanmar, on June 29, 2014.

## MESSAGE

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# Compassionate Concern

On July 22, 2014, Japan's Emperor Akihito and Empress Michiko called at National Sanatorium Tohoku Shinseien in Miyagi Prefecture. The couple took the hands of each resident — individuals who have endured years of prejudice and discrimination — and offered words of encouragement. They also conveyed their appreciation to the staff of the facility for their dedication and hard work.

The imperial couple's care and concern for people affected by leprosy has been a long-standing one. Their visits to the leprosy sanatoria began when they were still the crown prince and princess. With this visit in July, Emperor Akihito and Empress Michiko have now met with residents of all 14 leprosy sanatoria (13 national and one private) throughout Japan.

One resident conveyed his deep appreciation to the imperial couple for visiting the sanatoria. He said the visits were not only encouragement for the residents and staff, but also important in raising public awareness

about leprosy and the issues surrounding it. It is my hope that the genuine compassion exhibited by Emperor Akihito and Empress Michiko toward people affected by leprosy will be passed down the imperial line.

As of May 1, 2014, there were a total of 1,840 people living in Japan's national sanatoria, with an average age of 83.6 years. They have led lives of considerable hardship. As their numbers decline, we need to do all we can to preserve their memories and experiences.

I feel it is crucial that we hand on the history of leprosy and the history of these people's sufferings — what I call the negative legacy of humanity — to future generations. They must not be forgotten.

With that in mind, I greatly respect Their Imperial Highnesses for the interest in and concern for people affected by leprosy they have always shown.

— Yohei Sasakawa, WHO Goodwill Ambassador

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# Case-finding in Brazil

Results from targeted leprosy surveillance in the Amazon region indicate the task at hand.



(Left) Drs. Salgado, Barreto and Spencer; (above) Pará State (highlighted) has some of Brazil's highest annual new case detection rates.

Despite worldwide treatment efforts led by the WHO, the rates of transmission of leprosy in Brazil remain largely unaffected. This is evidenced by the relatively stable incidence of the disease over the last decade, with 33,303 new cases detected in 2012, of which 6.7% were children.

Leprosy prevalence in Brazil varies tremendously regionally, with very few cases detected in the southern states (Paraná, Santa Catarina and Rio Grande do Sul) and high new case detection in the central-western regions (Mato Grosso and Goiás), the north (Amazonas, Acre, Rondônia, Tocantins and Pará) and northeast (Maranhão, Piauí, Ceará, Pernambuco and Bahia). Those high-burden states encompass 1,173 municipalities and accounted for 53.5% of all new cases of leprosy in Brazil between 2005 and 2007, although making up just 17% of Brazil's population.

Dr. Claudio Salgado (Federal University of Pará, Belém) and his survey team of experienced leprosy clinicians, physiotherapists, nurses, phlebotomists, field technicians, IT specialists and laboratory technicians have been performing site visits to over 12 hyperendemic communities in the state of Pará in the Amazon region since 2009. With a population of over 7.5 million, the state historically has had some of the highest annual new case detection rates in the country — over 4.0 per 10,000 population, a rate considered hyperendemic by Brazil's Ministry of Health. Based on recent surveys, an estimated 40,000 cases will develop in the next decade in Pará alone.

Dr. Salgado's targeted leprosy surveillance screenings involve clinical and serological examinations of schoolchildren and household

contacts of people affected by leprosy. They are funded by grants from the Brazil Ministry of Health, the National Council for Scientific and Technological Development (CNPq), the Pará Amazon Foundation for Research (FAPESPA) and a grant from the Order of Malta for Leprosy Research (MALTALEP), a French organization that funds leprosy research.

For the first survey in 2009, Dr. Salgado's team consisted of just six people. On a recent screening in the city of Breves on Marajó Island in October 2013, 22 individuals were divided into three teams to maximize the number of schoolchildren and household contacts examined.\*

Breves has some of the highest new-case detection rates in the state. Of the 650 schoolchildren and household contacts that we examined in the week we were there, we diagnosed 7% with leprosy — a disturbingly high percentage that is almost 500 times Brazil's national average of 1.5 new cases per 10,000 population.

Many of the team have been with Dr. Salgado for years, among them Dr. Josafá Barreto, who organizes the surveys. Months before scheduling a visit, he contacts all the schools where we are to perform surveys, making sure that we have permission from the school administrators to visit and providing them with consent forms and information to be distributed to the parents so that they understand what we are doing. He also contacts the local community healthcare agents who have knowledge of people who may have symptoms of leprosy and where they live, as street addresses in some locations are difficult to find without their assistance.

During the week-long surveys, we visit

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Close-up of lesions on shoulder and arm of a child

## FOOTNOTE

\* Two videographers accompanied us and produced a 25-minute video documentary titled "*Hanseníase: Endemia Oculta na Floresta Amazônica*" ("*Leprosy: Hidden Endemic in the Amazon Rain Forest*") with support from the Brazil Ministry of Health. It can be seen on YouTube.



(Left) Assessing muscle strength in the hands of a child diagnosed with leprosy on Mosqueiro Island outside of Belém, Pará; (right, top and bottom) homes on the edge of the Amazon River.

schoolchildren at local schools and household contacts, bleeding and examining between 600 to 1,000 people. The team works up to 14 hours a day or longer, sometimes traveling two hours on rough dirt roads to get to schools and homes in rural areas. For some children, this is the first time they will have seen a doctor in their lives.

The diagnosis of leprosy is based on well-established clinical signs and symptoms. Most of the individuals diagnosed have one or a few hypopigmented anesthetic skin lesions that can be assessed using standard graded monofilament devices to measure the degree of loss of sensation. Areas of skin that have sensory loss on the trunk can be examined for the loss of capacity to produce sweat, another clear indication of nerve damage. Although rare, multibacillary leprosy with symptoms of grade 1 or grade 2 disability can be found, indicating that better surveillance in these areas is necessary to diagnose such cases earlier to prevent lifelong disability.

## LEPROSY IN CHILDREN

In a cross-sectional study of 1,592 schoolchildren and household contacts from eight different cities in Pará between 2009 and 2011, we detected 63 new cases, which is a rate of 4%. The average age of those diagnosed with leprosy was 13 years old.

Leprosy in children is correlated with community-level factors, including the recent presence of disease and multiple active foci

of transmission in the community. Children that we diagnose with leprosy are selected for follow-up visits during the week to examine their household contacts.

Dwellings may consist of between several to more than 15 occupants, most of whom are related. Frequently if a child is diagnosed, we will often find one or more index cases in the household.

Family members who live with an untreated person can become infected, although it is estimated that it takes between three to seven years after repeated infection for an individual to develop clinical signs and symptoms. This is complicated by the fact that about 90% of individuals worldwide are thought to be naturally immune. In these individuals, a single lesion can spontaneously resolve.

The reasons why a minority of those infected develop the disease are complicated and may include genetic traits. Other reasons include poor nutrition that can compromise the proper function of a person's immune system; poverty; living with more than five people in cramped conditions; and poor healthcare delivery in remote areas. (In Pará, only around 40% of the population is covered by the primary health care services.) All these are factors that relate to higher case detection rates.

In many of the cities in Pará where we have done surveys, the number of cases that we detect is much higher than those reported by the healthcare agencies. In one household, >>





(Far left) Dr. Salgado writes up a prescription for MDT for a child diagnosed with leprosy in Oriximiná, Pará; (left) nurses at the local school, where MDT is provided free of charge

we diagnosed five out of six family members with leprosy. This was not only devastating for the family, but also caused great sadness among the doctors and other team members who performed the diagnoses.

### In one household, we diagnosed five out of six family members with leprosy.

“In poor communities, like those settled inside the Amazon forest, there exists a very high hidden endemic population that needs special and urgent intervention,” says Dr. Salgado. “Populations living in remote areas in the Amazon region often completely lack medical care, and these are the people who need to be reached, diagnosed and treated.”

#### BIOMARKERS OF INFECTION

As well as active surveillance for clinical signs of leprosy, we are trying to develop tests to

determine biomarkers of infection and disease progression. We have been testing several protein antigens and also the well-known phenolic glycolipid I (PGL-I) antigen. Individuals with a strong positive response to PGL-I, indicating infection with the bacteria causing leprosy, have been found to have an eight-fold higher risk of succumbing to the disease.

We have coupled the use of detecting PGL-I positive responses with a Geographic Information System (GIS) to locate areas of high and low prevalence and identify “hot pockets” within these hyperendemic settings. The WHO has emphasized the use of GIS as one of the tools for leprosy elimination that can “provide a graphical analysis of epidemiological indicators over time, the spatial distribution and severity of the disease, identify pockets of high endemicity and indicate where there is a need to target extra resources.”

We have been able to map index cases and those with the highest anti-PGL-I titers in schoolchildren and household contacts — in other words, those at greatest risk of developing the disease — and are beginning to understand how leprosy is spread from multiple foci of infection in space and time.

One of our main findings is that children with leprosy or those with subclinical infection were in close proximity to spatial and temporal clusters of leprosy cases. These findings can be applied to better guide leprosy control programs to target intervention to these areas more systematically.

This is something we are actively doing and that, over time, should bring down the number of new cases. In the words of Dr. Salgado, “We are confident that targeted examination of children is the key for early diagnosis, preventing disabilities and breaking the chain of transmission.” ■



Visiting the home of a child diagnosed with leprosy to examine household contacts in Oriximiná, Pará

## Why This Museum Matters

Culion resident underlines why preserving the past is a source of strength for the future.

*On July 26 a ceremony was held on the island of Culion in the Philippines to unveil a historical marker commemorating the island's past history as a leprosy colony (see page 8). As part of the day's events, the Culion Museum & Archives was formally reopened.*

*The museum now has on hand a number of volunteer story-tellers from among residents of the island who are happy to talk about Culion's history and share their experiences.*

*Long-time Culion resident Maxencia Gonzales wrote a speech to mark the occasion, which she delivered on the museum steps against a backdrop of flags bearing the words, “We overcome.” This is a summary of her remarks, which were appreciated by several generations of Culion's population.*

If one bright picture could clearly define the kaleidoscope of our lives as persons affected by leprosy, it is the Culion Museum & Archives.

The Culion Museum & Archives exists because of the unstoppable dream of brilliant, dedicated and committed people, led by Dr. Arturo C. Cunanan, Jr. and with generous funding by the Sasakawa Memorial Health Foundation, to preserve the evidence of our history so that present and future generations can see, understand and internalize the great importance of the life and memories of every patient on Culion.

The museum is one of a kind. It depicts the extraordinary lives of Culion people since 1906. Over 100 years of the history of Culion can be found in the memorabilia carefully stored and preserved here. The exhibits speak of the truths, sufferings, struggles, tears and victories of the patients. They also convey the love, concern, and service of the health workers — people such as Dr. H.W. Wade, Dr. Casimiro B. Lara and Dr. Paul A. Evangelista — many of whom preferred to stay on this beloved island until their deaths.

Old records — papers that once seemed insignificant and not worth keeping — are now the precious proof of our history. Who



Maxencia makes her speech.

can say that Culion's history is just word-of-mouth anecdotes? Who can say that injustice, discrimination and segregation did not happen and were not experienced by people affected by leprosy? The Culion Museum & Archives has the



Maxencia Gonzales stands before a rotating examination table, displayed at the Culion Museum & Archives, that she was examined on as a child.

evidence that this was the reality.

The museum is Culion's identity and pride. It vividly illustrates Culion's dramatic transformation from a place of fear to a promising community of man. It reflects our life's journey, a journey toward victory.

### Papers that once seemed insignificant are now the precious proof of our history.

That is how each life in the present generation should be embraced — with recognition of the past, wrapped in the sad history of leprosy, and with a determination to move forward with our identity and humanity regained. Our trials, sufferings and struggles may be the most painful ingredients of our lives, but they are just parts of the road leading to a fulfilled life. We overcome.

Culion has survived the misery brought by leprosy. The lessons of the past give us strength for the future. In every sacrifice made by the patients we find worth and dignity in today's and future generations. The Culion Museum & Archives will continue to be the flag-bearer of Culion's success — our story, our heritage, our struggle. We overcome! ■



# The Pope and “Leprosy”

Why does this champion of the marginalized favor an unfortunate metaphor?

The spontaneous speech and actions of Pope Francis have revolutionized the image of the papacy and won admiration well beyond the confines of the 1.2 billion members of the Roman Catholic Church. In words and acts the Pope has reached out to those who live on the margins of society, and has encouraged others to do likewise.

While winning many friends, the Pope’s extempore style of communication has also become a matter of concern, particularly to more conservative Catholics. And his repeated use of the term “leprosy” as a metaphor for moral failings has caused dismay among those engaged in the battle for the eradication of the disease.

Last year the WHO Goodwill Ambassador for Leprosy Elimination and other leaders representing leprosy sufferers wrote to the Pope urging him not to use the disease as a metaphor for sin. The Vatican sent them a courteous response, assuring them of the Catholic Church’s commitment to ending discrimination, but Francis has continued to use the metaphor.

## A ‘LEPROSY IN OUR HOUSE’

Having used “leprosy” to decry clerical careerism and the court-like atmosphere prevailing in the Vatican hierarchy, Pope Francis has now used the term to condemn the scandal of priestly pedophilia. In an interview published in the Rome daily *La Repubblica* on July 13, the Pope acknowledged that “even we have this leprosy in our house.”

**“It probably doesn’t cross the Pope’s mind that he’s stepping into a dangerous area.”**

The interview was a good example of the problems sometimes caused by Francis’ free-wheeling approach to communication. It took place with the 90-year-old founder of the newspaper, Eugenio Scalfari, an avowed atheist who is in the habit of reconstructing his conversations with public figures from memory, rather than taking notes or recording them.

The Vatican spokesman, Father Federico Lombardi, warned afterward that not all the statements in the interview could be attributed with certainty to the Pope. Some details were incorrect, he said, though he did not deny use of the word “leprosy.”

A Vatican official, who asked not to be named, said he was not sure whether the letter from the

leprosy campaigners ever actually arrived on the Pope’s desk. The Pope used the term because of its graphic power and because it occurred frequently in the Bible, he said.

“I can understand the concern here, but in countries where leprosy is an issue you will find the Catholic Church in the front line in health care,” the official said. “It probably doesn’t cross the Pope’s mind that he’s stepping into a dangerous area here.”

## COMBATING PREJUDICE

In his actions, Pope Francis has done much to combat prejudice. Last November he publicly embraced Vinicio Riva, an Italian man suffering from disfiguring neurofibromatosis, and he subsequently hugged another middle-aged man with large portions of his facial features missing.

“This Pope’s idealism is so clearly readable in his actions that it is missing the point to call him a clever communicator,” wrote art critic Jonathan Jones in *The Guardian*. But there are some who are beginning to harbor doubts about his “cleverness” in this department.

Giuseppe Rusconi, who reports on the Vatican for a Swiss newspaper, said the Pope’s use of the word “leprosy” was a literary reference based on his reading of the Bible. It was paradoxical that someone who was reaching out to the most marginalized should cite a category of people condemned to live on the fringes of society from biblical times onwards, he said. “Today it’s no longer appropriate.”

Rusconi said the Pope faced a wider problem, however. Speaking mainly in Italian, a language over which he does not have total mastery, he could be drawn into error by the similarities and differences with his mother tongue, Spanish.

“The distinctions are important for a Pope, who is looked to for leadership by hundreds of millions of Catholics,” Rusconi said. “He wants to reach everybody by using simple language, but there is a danger that his message will become imprecise.”

Rusconi said the Pope’s approach to communications, which went down well with non-Catholics, had already caused a degree of confusion and dismay among the practicing faithful. “Everybody knows there’s a problem. Priests, bishops, even cardinals have been talking about it,” he said.

The worry may not have been conveyed to the Pope, because of the reverential fear prevailing in the papal court — condemned by Francis himself — and which may have prevented the leprosy campaigners’ letter from reaching him. ■

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Philip Willan is a Rome-based journalist and author of the book *The Vatican at War: From Blackfriars Bridge to Buenos Aires*.

# Visit to Mayanchaung

The Goodwill Ambassador calls at a leprosy resettlement village in Myanmar.

## MYANMAR (June 29)

Myanmar eliminated leprosy as a public health problem in 2003 but still sees some 3,000 new cases per year. There are said to be around 300,000 people affected by leprosy in the country; of these, 40,000 to 60,000 are living with disabilities.

About 90 minutes by car from Yangon is the Mayanchaung Resettlement Village. The government established a national leprosarium here in 1953 to isolate people with the disease. With social rehabilitation in mind, it closed the leprosarium in 1989 and set up the resettlement village.

I had met some of the residents 10 years ago when they came to see me in Yangon and I had always wanted to pay them a return visit. Now that opportunity had arisen and I headed out of Yangon accompanied by Dr. Min Min Htun of the Department of Social Welfare and Health Planning as well as a contingent of journalists.

As in other countries, people affected by leprosy in Myanmar often find it difficult to reintegrate into society because of social stigma. One way to break down the barrier of discrimination is through informed reporting, which is why I had invited the media to cover my visit.

The village has a population of around 1,600, of whom some 120 are people affected by leprosy. Of these, half live in the Mitta Philanthropic Center, which was my first stop. The center is for people who are unable to live in the village independently and was opened in 1989 by the social welfare ministry.

Residents had gathered in an assembly hall to welcome me. Many were elderly and in wheelchairs, from a generation that contracted leprosy before multidrug therapy became available. I explained why I was accompanied by so many journalists — that it was to help the public gain a better understanding of leprosy through accurate reporting. I was pleased to see plenty of stories in the local press in the days following that shone a light on Mayanchaung and leprosy.

The nursing home is divided into male and female quarters, with residents living in dormitory-type wards. As I toured the facilities, I noticed one or two younger residents, who were evidently disabled. I wondered why they had not received treatment sooner. They each told me a similar story — that they had been too busy making ends meet to spare time to go to a hospital. I couldn’t help wondering, however, if fear of being stigmatized



(Top) Elderly residents of Mitta nursing home in Mayanchaung Resettlement Village; (above) with worshippers at the Baptist church

had held them back until the damage was done.

I also went to a Baptist church in the village. As it was Sunday, a congregation had gathered to worship. They interrupted the service to speak with me. “I came down with leprosy and was abandoned by my family,” a woman told me. “I am saddened by the prejudice I suffered. But thanks to God, I am alive and do not want for food or other necessities.”

Sustained by their faith, they sang a couple of songs for me. As I listened, I found myself moved to tears as I thought about the hardships they must have faced in their lives.

I recalled the first time I visited a leprosarium, in 1965, when I accompanied my father to South Korea. I had been shocked by the effects of the disease on the faces and limbs of those afflicted, and the isolation in which they lived. I felt I had been reminded of this now for a reason.

There are still many people in the world, like the lady I met in the church, who have been separated from their families because of leprosy. For some it is now too late to redress the situation. What we must ensure, however, is that no one who is newly diagnosed with this disease today has their family ties severed because of leprosy. ■

# Culion's Place in History

Philippine island's past as leprosy colony recognized with official historical marker.

The National Historical Commission of the Philippines (NHCP) unveiled a historical marker on the island of Culion in Palawan Province on July 26. The ceremony was led by NHCP Chair Dr. Maria Serena I. Diokno, who formally turned over the administration of the marker to Dr. Arturo C. Cunanan of the Culion Sanitarium and General Hospital.

Beneath the English title "Culion Leper Colony", as the colony was known, the Tagalog inscription records the colony's founding in 1904 by the American military government then running the Philippines, the arrival of the first batch of 365 patients on 27 May 1906 and Culion's growth into the world's largest leprosarium and center of research on the disease in the 1920s. It also notes the deaths of some 2,000 patients due to starvation and illness in World War II during the



Dr. Diokno (left) and Dr. Cunanan (right) flank Culion's historical marker at a ceremony on July 26, 2014.

Japanese occupation, and the subsequent renaming of the old hospital as the Culion Sanitarium and General Hospital in 2009.

## SUNGAI BULOH DVD



*Children of Sungai Buloh* follows the fortunes of two women, Noraeni Mohamed and Faridah Haji Kasim, as they go in search of their roots. Both born to Chinese parents in Malaysia's Sungai Buloh leprosy settlement,

they were sent away for adoption but find themselves returning to Sungai Buloh later in life in a moving effort to restore their lost family ties. Produced by the Sungai Buloh Oral History Team and sponsored by Sasakawa Memorial Health Foundation, the 26-minute documentary is subtitled in Chinese, Bahasa Malaysia and English. For more details, visit [www.thewayhome.my](http://www.thewayhome.my)

## HEALING, INCLUSION, DIGNITY

The Leprosy Mission International and the Leprosy Mission Trust India are co-hosting a two-day forum in Delhi, India on September 29 and 30, 2014, under the banner *Healing, Inclusion, Dignity* — the three issues that people affected by

leprosy say are their main concerns, according to the organizers. Participants from over 30 countries are expected to exchange views from a broad range of perspectives. For further information, visit <http://healinginclusiondignity.org/> ■

## FROM THE EDITORS

### HISTORICAL USAGE

Congratulations to the island of Culion on receiving a historical marker that bears witness to its important history as the "Culion Leper Colony." "Leper," of course, is a word that we have spoken out against many times in these pages as a no-longer-acceptable way to describe a person with the disease of leprosy.

There was a time — as when the leprosy

colony on Culion was established in 1904 — that this word was commonly used. The National Historical Commission of the Philippines, which has used the term in a historical context on the marker, is careful to note on its website that this usage is no longer recommended today. It remains to be seen how many people who look upon the marker will appreciate the distinction.

## FOR THE ELIMINATION OF LEPROSY

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With support from:

Sasakawa Memorial Health Foundation,  
The Nippon Foundation

[www.nippon-foundation.or.jp/en/](http://www.nippon-foundation.or.jp/en/)

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