

# FOR THE Elimination OF Leprosy

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



An aerial view of Makogai Island, Fiji, which served as a home for leprosy patients from around the South Pacific until 1969.

MESSAGE

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## Speaking Up for Elimination

In 1991, the World Health Assembly set the goal of eliminating leprosy as a public health problem, defining elimination as a prevalence of less than 1 case per 10,000 population. With a goal to aim for, countries achieved elimination one after another, aided by multidrug therapy and sustained support from the WHO and NGOs.

After 2011, Brazil became the only country with a population of over 1 million yet to reach elimination. Now even Brazil is close. This has been possible because WHO set a clear numerical target; without one, results cannot be achieved.

Since 2003, I have visited leprosy-endemic countries 270 times and held 314 meetings with government leaders as Goodwill Ambassador. Being able to explain to them the elimination goal with its numerical objective means they can quickly decide what needs to be done and take action.

Now the elimination target has shifted to the sub-national level. Progressively achieving elimination at state or provincial level and below will eventually lead to a truly leprosy-free world. Numerically targeted elimination is both an

important tactic as well a course of action.

In the decade since India achieved elimination in 2005, however, there has been no significant progress against leprosy. Annual new case numbers worldwide have leveled off. National-level elimination seems to have engendered a sense of complacency. Regrettably, the term has given rise to the misunderstanding that our work is done. Far from it.

Elimination of leprosy at the national level is only a milestone; it is not the end of the road. Does it not clearly state in the Bangkok Declaration, issued at the end of the 2013 International Leprosy Summit, that governments are urged to achieve leprosy elimination at sub-national levels?

As they aim for this, they should not be concerned if case numbers increase. It is only to be expected that strengthening efforts at elimination will lead to more cases being diagnosed. Our fight against leprosy is still only at the midway point.

— Yohei Sasakawa, WHO Goodwill Ambassador

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# Flexibility Is Key

Leprosy workers need to adapt, says new head of WHO's Global Leprosy Program.

## What is your background?

I am a medical doctor. I graduated from the University of Ghent in Belgium and obtained a postgraduate degree in tropical medicine from the University of Liverpool and an MSc in Global Health Policy from the University of London. I have worked in public health my entire career.

## How familiar were you with leprosy before assuming your new role?

I worked for the Damien Foundation in a leprosy and TB control project in the western part of Bangladesh from 1995 to 2000. We reported almost 1,000 leprosy patients a year. During that period, I mostly learned the clinical aspects of leprosy as well as program management, becoming acquainted with the most diverse presentations of leprosy and its complications. Next, I joined WHO as an adviser for leprosy, TB and Buruli ulcer in Papua New Guinea (2000-2004). In my posting to WHO's Southeast Asia Regional Office (2004-2007), I was responsible for TB before moving to the WHO Country Office for Bangladesh to support the national leprosy and TB programs (2007-2011). Prior to joining the Global Leprosy Program (GLP), I was medical officer for TB in Myanmar.

## What attracted you to the position?

There were several reasons. Leprosy remained close to my heart. In primary school, we had to learn about the works of Father Damien, who a few years ago was selected as the greatest Belgian in history. Dr. Frans Hemerijckx, another great name in leprosy, lived in a town close to mine and we even went to the same school.

Although the GLP is a small WHO program, I

felt that any contribution would be more visible. The global leprosy community is rather like a big family. Everyone seems to know everyone.

Leprosy control has come to the stage where it should be possible to significantly reduce the burden in countries with a large burden. I am therefore happy that I have the chance to contribute to ending the leprosy epidemic.

**Leprosy work is not yet finished. But business as usual will also not continue.**

## What do you see as the main challenges facing you as the GLP's new Team Leader?

Reaching elimination of leprosy as a public health problem is not the end of the work. The number of new cases is going down much more slowly. The main challenge will be how to keep leprosy on the agenda in a changing context from vertical programs to those increasingly combined with neglected tropical diseases (NTDs) or fully integrated with general health services. The pool of leprosy experts is ageing, too, and it is a challenge to motivate young doctors to take up leprosy. The more leprosy becomes a rare disease, the more the unit cost for control activities goes up while financial support becomes harder to get due to competing priorities.

## What lessons can you draw on from your previous work and apply in running the GLP?

Having a clear, succinct strategy is a very helpful start. Leprosy, as do other disease control programs,

## PROFILE:

**Dr. Erwin Cooreman**



Dr. Erwin Cooreman is Team Leader of the WHO's Global Leprosy Program, based in New Delhi. He took up his post in November 2015.

## THREE PILLARS OF GLOBAL 2016-2020 STRATEGY

### 1. Strengthen government ownership, coordination and partnerships

Ensure political commitment and adequate resources for leprosy control. Contribute to universal health coverage with a special focus on underserved populations, women and children. Promote partnerships with non-state actors. Conduct basic and operational research and its use for evidence-based policy making. Strengthen surveillance and health information systems for program monitoring and evaluation. Identify and support centers of excellence and promote innovative approaches like e-medicine.

### 2. Stop leprosy and its transmission

Promote early case detection with focus on contact management and active case finding in highly endemic areas. Ensure prompt start and adherence to treatment. Improve disability prevention and care. Strengthen patient and community awareness on leprosy. Improve case management including working toward Uniform MDT.\* Set up a network with laboratory capacity for surveillance of antibiotic resistance. Sustain leprosy knowledge among the health workforce.

\* A shorter, uniform treatment regimen

### 3. Stop discrimination and social suffering

Promote societal inclusion through addressing all forms of discrimination and stigma. Empower communities through active participation in leprosy services. Promote coalition building among persons affected by leprosy. Support community-based rehabilitation for persons affected people with disabilities. Promote access to social and financial support by persons affected by leprosy and their families.

needs direction. There should be a vision — in this case, “a leprosy-free world” — and an ambitious yet realistic goal in the medium term so that we all can work in the same direction.

Partnerships are also very important. Each partner has a distinct advantage, insufficient to make a total change alone, but collectively complementing each other so that all requirements for a successful program can be provided. Such partnerships must be inclusive, with all partners truly involved from the design stage through implementation to evaluation.

It is also important that WHO identifies which role it can and should play, and which it should not. The organization remains in the first place a technical agency. Based on this role, the technical unit should be properly composed and include both medical and technical officers. The GLP does not work in a vacuum but is well connected to the staff in charge of leprosy at regional and country-office levels. This network of actors within WHO is also very important for efficient delivery at a global level.

#### **You have just chaired your first National Programme Managers’ meeting. What did you**

#### **take away from the experience?**

It is important to realize that while there may be agreement on the common goal to pursue, there may be different ways to get there. It is important to accommodate these different perspectives, without diluting the message.

#### **The new global strategy for 2016-2020 will soon be launched. What do you attach most importance to in the document?**

Most important for successful implementation is to take care that all three pillars of the strategy are implemented (*see sidebar*). As all three are mutually reinforcing, the result of their combined application will be more than the sum of their individual applications. The strategy must be considered in its entirety, although some partners may focus on specific areas they are best placed to support.

#### **What is your message for leprosy workers?**

Leprosy work is not yet finished. But business-as-usual will also not continue. People working in leprosy will need to reinvent themselves and adapt to the changing realities. In the future, more than in the past, flexibility will be expected. ■

### **MUSEUM PIECE**

#### **‘WALL CLOCK’**

On January 9, 2011, the 91-year-history of Dajin Leprosy Hospital came to an end when its last residents left their island home off the coast of Jiangmen City in China’s Guangdong Province. All 44 residents, average age 75 and including 30 amputees, were bound for Sian Provincial Leprosy Hospital in Donggan City, Guangdong.

The journey was not an easy one. Since the island lacked a proper wharf, the residents had to stumble down to the stony shore on crutches and artificial limbs. There they boarded a small boat to ferry them to a larger boat for the 90-minute passage to the mainland; from there, it was a further three-hour bus ride to Sian Hospital.

At its peak Dajin housed 600 patients, looked after by a handful of medical personnel. Over the years, a number of attempts had been made by the provincial health bureau to persuade the residents to move to Sian Hospital, but they had always chosen to stay put, since they had made Dajin their home.

Four years on, many now seem at home in Sian, although their number has dropped to 32 out of the original 44. They include Mr. Liu Zhuquan, who is a residents’ leader, and Ms. Huang Shao, affectionately known as “beautiful mother,” who



has found fame in Sian and beyond with the publication of a book about the move from Dajin to Sian in which she features prominently.

On one wall of the Sian Hospital museum is a large representation of a clock, its hands depicted by wooden crutches that once belonged to the Dajin residents. The crutches indicate the exact time that the last resident left the island: 10:35 a.m.

As we focus our attention on the clock, we feel the gaze of 44 people watching Dajin receding into the distance. We also appreciate how the clock symbolizes the passage of time and the long years they spent on the island. But it also marks a break with the past — signifying when their old way of life ended and their new life began.



# Small Islands, Big Challenges

Certain countries face special issues in tackling leprosy.



One of Kiribati's 33 atolls and islands: the country's population of 100,000 is scattered across a vast area of the Pacific.

*Dr. Nobuyuki Nishikiori recently accompanied the Goodwill Ambassador on his mission to Kiribati in the South Pacific. We asked him about the challenges small island states such as Kiribati face in controlling leprosy.*

## 1. Weak health system capacity

Many small island countries face significant challenges in organizing healthcare systems due to a lack of financial and human resources. A population size might be too small to afford an appropriate education system to produce health care professionals, resulting in the necessity to hire doctors, nurses and other health professionals from abroad.

## 2. Scattered population over a wide geographical area

Some island countries consist of many small islands scattered across the ocean. For example, the 33 islands and atolls of Kiribati form a total land area of some 800 square kilometers but extend across 3,900 kilometers of the Pacific. Some outer islands may be accessible via scheduled shipping service only once every six months because of the high cost involved. Ensuring access of island populations to essential health care is extremely challenging under such conditions. Early diagnosis and prompt treatment of leprosy, which is usually a cornerstone of an infectious disease control strategy, is almost impossible to achieve even with a substantial financial investment.

## 3. High cost for all aspects of program operations

Due to seriously limited domestic production capacity, many countries heavily rely on imports for a wide range of commodities. Almost all kinds of goods are hugely expensive, including water, food, gasoline and stationery. In particular, transportation costs can be prohibitive due to the highly scattered population.

## 4. Non-availability of specialist services

Beside essential primary health care services, it is also extremely challenging to secure specialist services. For example, people affected by leprosy with complications may require diagnosis and treatment by a dermatologist experienced in such cases. Rehabilitation and prosthetic services for people with disabilities may also call for specialized care. Normally such services are difficult to secure in small island countries, leaving many people affected by leprosy without optimal quality care.

## 5. Epidemiological transition

Many small island countries are experiencing significant epidemiological transitions. The burden of non-communicable diseases such as hypertension, diabetes, heart disease and strokes is sharply increasing due to lifestyle factors. Scarce health resources need to be diverted, with those for infectious disease control, including leprosy, witnessing significant decline in many countries. ■

### AUTHOR:

**Dr. Nobuyuki Nishikiori**



Dr. Nobuyuki Nishikiori is Coordinator of the Stop TB and Leprosy Elimination Unit, Division of Communicable Diseases, World Health Organization. He is based at the WHO's Regional Office for the Western Pacific.

# Journey to the South Pacific

The Goodwill Ambassador travels to a small island state where leprosy prevalence is still high and steps back in time to visit a former island of isolation.

## KIRIBATI (OCTOBER 19-22)

While the elimination of leprosy as a public health problem has progressed at the national level in countries with populations over 1 million people, in small Pacific island nations such as Kiribati, the Federated States of Micronesia and the Marshall Islands, the prevalence of the disease remains high. In October, I made my first visit to the Republic of Kiribati to see the challenges it faces.

Kiribati is situated more or less in the middle of the Pacific. With a population of around 100,000 people, it consists of 33 coral atolls and islands spread across a vast area of ocean stretching about 3,900 kilometers east to west and around 2,100 kilometers north to south.

Ms. Erei Bonebati Rimon is Kiribati's national leprosy control program manager. She told me that every year the country sees around 100 to 200 new cases of leprosy, giving it a prevalence rate of at least 10 times the WHO target for elimination. By the time of my visit, Kiribati had recorded 121 new patients in 2015. Tawara atoll is the capital and many cases are concentrated in South Tarawa, where about half the nation's population resides.

**A characteristic of leprosy in the Pacific region is the high number of child cases.**

There are only three people in the leprosy program and funding and resources are limited. One of the program's big challenges is accessing Kiribati's small, isolated outer islands that can only be reached by infrequent boat services.



PLF's Wayne Uan

The New Zealand-headquartered Pacific Leprosy Foundation (PLF) is active in Kiribati. I went to visit a skin clinic renovated by PLF in Tungaru Central Hospital in Nawerewere district. There I met an



(Top, above) Skin camps run by the Pacific Leprosy Foundation (PLF) in Kiribati

11-year-old girl who is receiving treatment for leprosy and a 16-year-old boy who is being treated for leprosy reaction.

One of the characteristics of leprosy in the Pacific is the high number of child patients — accounting for around one third of new cases. Ms. Rimon told me that Kiribati is now entering details of new cases on a database and examining the family members of anyone who has been diagnosed.

After calling at the home of a young man who is taking a course of multidrug therapy (MDT), I went to see 62-year-old Kimwaere Mikaere. He is among several dozen people affected by leprosy that PLF has assisted through a welfare program. The program, which is overseen by the capable Wayne Uan, helps them develop income-generating skills ranging from cultivating fruit and drying fish to book-keeping.

With assistance from PLF, Kimwaere has purchased an electric compressor pump. He fills tires and cleans cars for a living. Working 12 hours a day, he makes at least 20 Australian dollars, but sometimes as much as 30 dollars in a country where the average wage is >>



>> much less. Starting the business has given him confidence, he said.

Next I went to see a skin camp run by PLF in North Tarawa. Around 100 people had gathered in the village assembly hall. Blue sheets had been used to partition space into four separate consultation areas. Loud chatter filled the air. PLF calls this activity a skin camp rather than a checkup for leprosy so as not to reinforce stigma. In this way, leprosy is treated as just one disease among many, and this approach seems to be having the intended effect.

North Tarawa is made up of several islets. On my third day in Kiribati I traveled about an hour by boat to Abaokoro Island. Wading ashore, I walked for five minutes along a track to the island's only clinic. There I met with several patients.

One was a 6-year-old boy. White patches had appeared on his arms, legs and back. He had been diagnosed with leprosy and had been taking MDT for three months. I was pleased to hear that he was being treated normally by his classmates. Generally speaking, Ms. Rimon told me, there is less discrimination than in the past because people see fewer advanced cases of leprosy and have a better understanding of the disease.

Also at the clinic was a 16-year-old girl. She had been brought to the clinic by her mother, whose grandmother had been quarantined on Makogai Island in Fiji, where I would be traveling next. This woman knew the importance of early diagnosis, and so had brought her daughter to the clinic when she noticed patches on her skin.

Before I left Kiribati, I met with President

(Left) Kimwaere Mikaere started a business on Kiribati with PLF's help; (above) residents of P.J. Twomey Hospital in Fiji

**'AS LOVING AS PARENTS'**

*Peni Vuniciva was sent to Makogai Island after being diagnosed with leprosy in his youth. On a recent return visit in the company of the Goodwill Ambassador, he recalled some memories of his time there.*

I first came to the island in 1964 when I was 16 years old. The day I arrived was a beautiful day, just like today. I remember it well.

Parting from my parents to come here was hard. I didn't think I would go back alive. I had heard that I would be shot and killed.

But when I got here it was completely different. There were other children my age and the Catholic sisters who worked

as nurses were as loving as parents. I was able to write to my mother and father and tell them that I was being well looked after and doing fine.

When I had first been diagnosed with leprosy, I was told I could no longer go to school; here on Makogai, I was able to.

It was Sister Sheena who taught me how to paint and this would later be my work in life.

I also learned English here and how to play rugby. Being on Makogai gave me the will to live. When it was time to leave, I



Peni Vuniciva with his painting of Makogai

was sad. The sisters and doctors had been so kind.

I never thought I would be visiting here again, so I am grateful for this opportunity to have come back. Thank you.





At the cemetery on Makogai Island, where 1,500 patients and staff are buried.

Anote Tong. I said I appreciated that Kiribati was grappling with many public health issues, but hoped its efforts against leprosy would continue. The health ministry, meanwhile, has set a target of achieving leprosy elimination by 2018. I look forward to the day when Kiribati marks this important milestone.

#### FIJI (OCTOBER 22-24)

From Kiribati I travelled to Fiji. Fiji sees only a handful of new cases of leprosy a year; in recent years almost all new patients have come from outside the country, mostly from Kiribati or Tuvalu. The country eliminated leprosy as a public health problem in 1993.

A century earlier, Fiji — specifically the island of Makogai — was the center of leprosy care in the South Pacific. The government bought the island to use as a leprosy colony and built the Central Leprosy Hospital there.

Makogai operated as a leprosy colony between 1911 and 1969. The hospital was mostly staffed by Roman Catholic sisters, who volunteered to nurse the patients. Over its 58-year history, it saw some 4,500 patients. They came from all over the South Pacific, including New Zealand, Australia, Samoa, Tonga and the Cook Islands.

As the incidence of leprosy declined, the facility was closed in 1969 and the remaining patients either returned home or were transferred to P.J. Twomey Hospital in Tamavua, Suva, which opened the same year and remains the central TB and leprosy hospital in Fiji today.

Before visiting Makogai, I went to Twomey Hospital, where I met with elderly residents who had experienced life on Makogai. They included 66-year-old Peni Vuniciva, who showed

me a painting he had made of the island that he had produced from memory. What struck me in talking with the residents was that they did not have a bad word to say about Makogai, although they remembered how hard it had been hard to part from their families.

Peni accompanied me to Makogai the next day. He was making his first trip back in decades. Leaning on a cane, he was overcome with emotion at times as he recalled the old days. I was particularly struck by his fond memories of those who looked after the patients and how much their kindness had meant to him.

**I was particularly struck by his fond memories of those who looked after the patients.**

I toured the island for a glimpse of its past. I saw the separate wards for men and women, and what remained of the cinema, church and prison — the latter mostly used for locking up drunks, I was told.

I also visited the island's cemetery, where 1,500 people are buried. In some cemeteries I have visited, patients and staff were laid to rest in separate areas, but on Makogai they rest side by side. It seemed to symbolize the good relationship that existed between the patients and those who cared for them.

Makogai is now a marine protected reserve and government research station. It is also an important place in the history of leprosy in the South Pacific. I hope Fiji will play its part in preserving this heritage of humanity. ■

# Leprosy History as Human Heritage

International symposium to look at ways to accelerate history preservation.

The history of leprosy is often portrayed as a negative legacy of humanity because of the severe stigma and discrimination suffered by people affected by leprosy around the world over many centuries. But there is another side to that history, one that has seen people come through the difficulties and find a way to shine in life.

Despite losing their homes, family and friends, and being cut off from society, there have been individuals who have summoned an inner strength and revealed the power and possibilities that human beings are capable of even in the most desperate of circumstances. This too is the history of leprosy — not a negative legacy of humanity but a valuable asset.

An international symposium on leprosy history as the heritage of humanity is being held in Tokyo at the end of January 2016. The three-day symposium will be attended by delegates from Asia, the Americas, Europe, Africa and the Pacific and examine what is being done to preserve the history of leprosy in different countries, who the

key players and agencies are, and how to accelerate these efforts before this history is lost.

Famed Japanese animated film director Hayao Miyazaki will address the symposium on the opening day and the symposium will also unveil the newly re-launched International Leprosy Association – History of Leprosy database.

The January 28-30 symposium is being organized by Sasakawa Memorial Health Foundation with the support of The Nippon Foundation.



## LEPROSY RESEARCH 2017

The Leprosy Research Initiative (LRI) is calling for proposals for funding beginning in 2017. The LRI welcomes proposals for all five of its research priorities.

Among these, research to promote prevention of disabilities in persons affected by leprosy is currently underrepresented and applications addressing this subject will be particularly welcome. Applications from or including African

countries will be given priority.

The LRI is a joint initiative of five NGOs working in leprosy, including Netherlands Leprosy Relief and American Leprosy Missions.

A Letter of Intent outlining the intended research should reach the LRI secretariat by February 28.

For more information, visit the LRI website at [www.leprosyresearch.org](http://www.leprosyresearch.org) ■

## FROM THE EDITORS

### FRESH PERSPECTIVES

*Museum Piece* is an occasional column in this newsletter. The concept is simple: to tell a story through an object on display at a museum that has a connection with leprosy. To date, the pieces we have introduced have included an examination table from the Philippines, a trumpet from Colombia, and a panoramic model, a padlock key and wooden hot spring pipes — all from Japan.

In the current issue, we feature a pair of objects that form the centerpiece of an installation created for a hospital museum in China. Kudos to the Sian Provincial Leprosy Hospital and its residents for

their ingenious use of a pair of crutches and the story they depict.

The recently appointed Team Leader of the Global Leprosy Program, Dr. Erwin Cooreman, learned about Father Damien as a school boy in Belgium. Dr. Cooreman brings a wealth of experience to his new position and shares with us some insights in *Interview*. Partnerships are important, he says, and different perspectives on how to reach a common goal should be respected. But business as usual won't suffice and leprosy workers must adapt to the changing realities.

## FOR THE ELIMINATION OF LEPROSY

### Publisher

Yohei Sasakawa

### Executive Editor

Tatsuya Tanami

### Editor

Jonathan Lloyd-Owen

### Associate Editor

James Huffman

### Layout

Eiko Nishida

### Photographer

Natsuko Tominaga

### Editorial Office

5th Floor, Nippon Foundation Building,  
1-2-2 Akasaka, Minato-ku,  
Tokyo 107-8404  
Tel: +81-3-6229-5601  
Fax: +81-3-6229-5388  
smhf@tnfb.jp

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